Understanding and defining people's body image experiences after a stroke

by

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ABSTRACT

When someone has a stroke, it can cause bodily changes which may lead to an altered body image experience. What this experience is like, and how it impacts wellbeing and recovery, is not fully understood. We need to understand this to identify whether support for body image experience is required post-stroke. This thesis involves three studies which aimed to build the evidence base and allow deeper insight into post-stroke body image experiences. If these experiences impacted wellbeing and recovery, the aim would also be to recommend how body image could be assessed and supported post-stroke.

A systematic review, which identified 61 relevant papers, enabled a summary of existing evidence. Findings showed that people experience a changed body image post-stroke, which impacted their everyday lives. Methods for assessing body image within these studies were not specifically validated for stroke. Semi-structured interviews with 22 people with stroke confirmed this changed experience, its impacts, and enhanced our understanding by providing additional nuanced detail. From this, a stroke-specific definition of body image to support patient, family, carer and clinician understanding was developed. Feedback from clinicians, participants, and public advisors described this as being clear, relevant and comprehensive.

An expert panel of clinicians reviewed my interpretation of the findings and found them to be clinically relevant. They recommended practical, and psychological, methods whereby body image experience could be supported. They also considered how post-stroke body image and any benefits of support could be assessed.

Recommendations for clinical practice and future research have been made. The stroke-specific summary and definition of body image will facilitate a more consistent understanding around, and identification of, people who might be struggling with their post-stroke body image experience. Initial recommendations for post-stroke body image support and methods of assessing any benefits of this support provide direction for future research.

TABLE OF CONTENTS

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II LIST OF TABLES AND FIGURES

Figures

Tables

III GLOSSARY OF TERMS, ABBREVIATIONS, LIST OF SYMBOLS

Glossary of Terms

Term	Definition
Referring to the people involved in the thesis	
Person/People with Stroke	A person who has experienced a stroke or strokes.
Participant	A person who has taken part in research as part of the thesis
Clinical Expert	A healthcare professional with experience or qualifications relevant to stroke or body image
Carer	A person who looks after someone who has had a stroke
Body image related terminology	
Body Image (general definition used throughout the thesis)	An individual's subjective perceptions, thoughts and cognitions, feelings and affect, and behaviour in relation to the body's appearance, functions and capabilities (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b).
Body Schema	The non-conscious process (Gallagher, 1986a; Stott, 2019) in charge of regulating body posture and movement (Gallagher, 1986a, 2005)
Body Perception	The experience of the lived body, where the body is viewed as being a vehicle for being in the lived world (Merleau-Ponty & Landes, 2014; Stott, 2019)
Body Esteem	An evaluative term, typically referring to self-concept and usually linked to weight, and as such, a person's attitudes, evaluations and feelings about their body (Williams et al., 2013)
Body Dissatisfaction	Negative thoughts and feelings towards one's physical appearance or body (Burrowes, 2013; Cash, 1990; Grogan, 2016; Heider et al., 2018)
Embodiment	"embodiment includes (but is not limited to) recognition of the actual impairments of strength, coordination, and sensation that arise from lesions to physical parts of the brain that usually control these functions. Embodiment also includes a person's subjective experience of these impairments and how he or she

	make sense of or interpret them. Furthermore, it recognizes the influence of social structures and constructions on these interpretations. For instance, embodiment includes recognition of how society classifies a hemiplegic arm with soft tissue contractures at the elbow, wrist, and hand as being a “deformity” and the impact of the social responses (both desirable and undesirable) that arise from others as a result of this classification.” (Timothy et al., 2016)
Methods or research related terminology	
Deductive Content Analysis	An analysis method involving coding data into pre-decided categories based on the research objectives (Elo & Kyngäs, 2008)
Epistemological perspective	Knowledge of the world (Ahmed, 2008)
Inductive Content Analysis	An analysis method where data is openly coded and can be used to create post-hoc concepts (Elo & Kyngäs, 2008)
Interpretative Phenomenological Analysis	An approach to qualitative inquiry used to examine how people make sense of life experiences (Smith et al., 2009d)
Manifest Content Analysis	A form of content analysis where the data is the surface structure of what participants say (Bengtsson, 2016)
Microsoft Teams (MSTeams) (Microsoft, 2022)	A video call application. It can be used as a desktop application, or on a smartphone or tablet application.
NVivo (NVivo, 2022)	Qualitative data analysis software
Ontology	The reality of the world (Jackson, 2013)
Stroke related terminology	
Aphasia	Difficulty with communication (language or speech), including reading, listening, speaking or typing/writing. Intelligence is not affected (National Health Service (NHS), 2021a)
Bodily changes	A term used to refer to any changes people with stroke experience in relation to their body

Stroke	“rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (Aho et al., 1980)
Systematic Review	A form of evidence synthesis which “attempts to identify, appraise and synthesise all the empirical evidence that meets pre-specified eligibility criteria to answer a specific research question.” (Cochrane, 2022a)
Transient Ischaemic Attack	“a seemingly temporary disruption of blood supply where symptoms last less than 24 hours” (Albers et al., 2002; National Institute for Health and Care Excellence (NICE), 2022).

Abbreviations List

Abbreviation	Definition
AACODS Checklist	Authority, Accuracy, Coverage, Objectivity, Date and Significance Checklist
ABI	Acquired Brain Injury
ACT	Acceptance and Commitment Therapy
ADL	Activities of Daily Living
AP	Assistant and Trainee Assistant Practitioners
ASI	Appearance Schemas Inventory
ASI-R	Appearance Schemas Inventory-Revised
Barthel	The Barthel Index
BICSI	Body Image Coping Strategies Inventory
BIR	Body Image Researcher
BIQ	Body-image Ideals Questionnaire
BBPDS	Bath Body Perception Disturbance Scale©
BCS	Body Cathexis Scale
BES	Body Esteem Scale
BIDQ	The Body Image Disturbance Questionnaire
BIQLI	The Body Image Quality of Life Inventory
BMI	Body Mass Index
BSQ	Body Shape Questionnaire
BPT	Body Perception Tool
CARSAL	The Centre for Appearance Research Salience scale
CARVAL	The Centre for Appearance Research Valence Scale
CaSM	Confidence after Stroke Measure
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CI	Chief Investigator
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COREQ	Consolidated Criteria for Reporting Qualitative Research
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
COVID-19	Coronavirus Disease
CRN	Clinical Research Nurses
CT	Computerized Tomography
CVA	Cerebrovascular Accident
DAS-24	Derriford Appearance Scale
DoS	Director of Studies

DSM-IV	Diagnostic and Statistical Manual of Mental Disorders-IV
ELHT	East Lancashire Hospitals Trust
EMBASE	Excerpta Medica dataBASE
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
EThOS	E-Theses Online Service
GAD-7	Generalized Anxiety Disorder-7
GDPR	General Data Protection Regulation
GOHAI	The General Oral Health Assessment Index
GP	General Practitioner
GQOLI	General Quality of Life Inventory
HRA	Health Research Authority
IAPT	Improving Access to Psychological Therapies
IMD	Index of Multiple Deprivation
IPA	Interpretative Phenomenological Analysis
IQR	Interquartile Range
IRAS	Integrated Research Application System
ISRCTN	International Standard Registered Clinical/soCial sTudy Number
LTHTR	Lancashire Teaching Hospitals Trust
MBI	Modified Barthel Index
MBSRQ	Multidimensional Body-Self Relations Questionnaire
MECIR	Methodological Expectations of Cochrane Intervention Reviews
MeSH	Medical Subject Headings
mRS	modified Rankin Scale
MSEI	The Multidimensional Self-Esteem Inventory
MSTeams	Microsoft Teams
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
NR	Not reported
OSF	Centre for Open Science
OTSeeker	Occupational Therapy Systematic Evaluation of Evidence
PCPI	Patient, Carer and Public Involvement
PHQ-9	Patient Health Questionnaire-9
PI	Principal Investigator

PICO	Population/Patient/Problem, Intervention, Comparison and Outcome
PIS	Participant Information Sheet
PRESS	Peer Review of Electronic Search Strategies
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses-P
QoL	Quality of life
REC	Research Ethics Committee
SALT	Speech and Language Therapist
SD	Standard Deviation
SIBID	Situational Inventory of Body-Image Dysphoria
SMBIQ	Swansea Male Body Image Questionnaire
SSNAP	Sentinel Stroke National Audit Programme
TBI	Traumatic Brain Injury
TIA	Transient Ischaemic Attack
TSCS	Tennessee Self Concept Scale
TSCS:2	Tennessee Self-concept Scale—Second Edition
UCLan	University of Central Lancashire
UK	United Kingdom
UL	Upper Limb
USA	United States of America
VAS	Visual Analogue Scale
VDRS	Visual Discomfort Rating Scale

List of symbols

Symbol	Meaning
✓	Yes/Agree; Strength/Benefit
✘ or ×	No/Disagree; Disadvantage/Limitation
-	Unidentifiable, undetermined, unclear, unsure, neutral

1. CHAPTER 1: INTRODUCTION

In this chapter I will broadly outline the global burden of stroke, the burden of stroke in the United Kingdom (UK), and for individual stroke survivors. The concept of body image will be introduced, initially focusing on the general population, before focussing on what we know specifically about how people with stroke experience their body image (body image experience), and any health policies that incorporate body image. I will highlight gaps in our knowledge about post-stroke body image experience and the importance of addressing these gaps. Finally, I will describe how the thesis and its structure will bridge these gaps.

1.1. WHAT IS A STROKE?

A stroke is a sudden and unexpected health event (Kuluski et al., 2014). It occurs when a blood clot blocks blood supply to the brain (ischaemic stroke) or when a blood vessel supplying (external to or within) the brain bursts (haemorrhage) (National Health Service (NHS), 2019c). The lack of blood supply stops oxygen and nutrients reaching the brain and brain cells begin to die. The World Health Organization (Aho et al., 1980) defines stroke as:

> “rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin”. (p.114)

Some people may experience a ‘mini-stroke’ or Transient Ischaemic Attack (TIA). This is traditionally considered as a temporary disruption of blood supply where symptoms (see section 1.2.2) last less than 24 hours (Albers et al., 2002; National Institute for Health and Care Excellence (NICE), 2022). However, this is an arbitrary cut-off point as there have been people diagnosed with a TIA who still have symptoms after this point (Albers et al., 2002). In contrast, other people will have symptoms lasting less than 60 minutes (Levy, 1988). Some researchers argue that TIA and minor stroke diagnoses are a continuum of each other (Albers et al., 2002; Turner et al., 2018), meaning that these events may be difficult to differentiate. Therefore, the distinction between stroke and TIA has become somewhat arbitrary and suspected stroke warrants immediate treatment for those who are suitable. Like stroke, TIA is also highly predictive of a subsequent stroke (Hill & Coutts, 2011; Johnston et al., 2000; Wu et al., 2007). Consequently, when someone has a TIA, they must cope with the impact of the TIA and the additional impact of increased risk of stroke. Therefore, within this thesis, the impact of stroke and TIA will not be differentiated between and when stroke is referred to, it will include TIA unless stated otherwise.

1.2. WHAT IS THE BURDEN OF STROKE?

1.2.1 How many people are affected?

In 2019, there were 101 million people with stroke globally, with 12.2 million new cases each year (The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2019 Stroke Collaborators, 2021). As of 2021, there were approximately 1.3 million people with stroke in England, Wales and Northern Ireland (Sentinel Stroke National Audit Programme (SSNAP) & King's College London, 2021), with data from 2019 showing that 100,000 people have a stroke across these three UK nations each year (Sentinel Stroke National Audit Programme (SSNAP), 2019). In Scotland, data from 2021/2022 shows that 176 people per 100,000 will have a stroke each year (Public Health Scotland, 2023). Globally, 1 in 4 people aged over 25 years will have a stroke in their lifetime (The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2016 Lifetime Risk of Stroke Collaborators, 2018).

Stroke is a leading cause of death and disability, globally (Public Health England & Brine, 2018; The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2015 Neurological Disorders Collaborator Group, 2017). In 2019, annual global deaths from stroke surpassed 6.5 million, and in 2016, there were 48,628 deaths from stroke in the UK (The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2016 Stroke Collaborators, 2019; The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2019 Stroke Collaborators, 2021).

In England, the age at which people have a stroke is falling. The mean age of onset was 70.6 years in 2016, down from 72.4 in 2007. In 2016, 38.2% of strokes occurred in people aged 40 to 69 (Public Health England, 2018). Despite this, most services are designed for older or retired people (Kersten et al., 2002).

Stroke mortality rates are decreasing substantially worldwide (The Global Burden of Diseases Injuries and Risk Factors Study (GBD) 2015 Neurological Disorders Collaborator Group, 2017) and have more than halved in England over the last two decades (Seminog et al., 2019). This means that more people are living with the effects of stroke.

1.2.2 How are people affected?

The possible bodily changes that can be caused by stroke are wide-ranging and can lead to difficulties with every aspect of daily living (Adamson et al., 2004; Chohan et al., 2019; Stroke Association, 2019). This includes but is not limited to, needing help with activities of daily living (Sturm et al., 2002) and reducing quality of life, with the latter being increasingly more negatively impacted with increasing stroke severity (Haley et al., 2011; Tengs & Lin, 2003). In a recent UK survey, 98% of people with stroke reported that their lives had been impacted in some way by their stroke (Stroke Association, 2019). Some of these impacts are physical and observable with 65% of people reporting severe physical disability after stroke (Adamson et al., 2004). Other changes, such as psychological or emotional, cognitive or perceptual changes, are less obvious to those other than the person with stroke. Stroke-related changes can be grouped as followed:

- **Body changes affecting muscles or movement**: (Stott, 2019) hemiplegia (paralysis on one side of the body (National Health Service (NHS), 2020c), commonly face, arm and leg), hemiparesis (weakness in one side of the body (Stoykov & Corcos, 2009)), muscle weakness, spasticity (muscle overactivity (Sheean, 2010)), balance, difficulties in processing bodily movements, fatigue, urinary incontinence, dysarthria (difficulty speaking (National Health Service (NHS), 2019a)) and dysphagia (swallowing difficulties (National Health Service (NHS), 2021b))
- **Common psychological or emotional changes affecting 75% of people with stroke include but are not limited to:** anxiety, depression, lack of confidence and emotional changes including loss of control over emotions or feeling lonely, nervous, frustrated or angry (Chohan et al., 2019; Stroke Association, 2019). These latter changes could be due to the changes that the stroke has made to the brain, or could be a reaction to the challenges and fears associated with surviving a life-threatening event or dealing with the effects of the stroke (Chohan et al., 2019; Stroke Association, 2019).
- **Increased risk of cognitive decline** (Tang et al., 2018): problems with attention, memory, language (reading, writing), executive function (decision-making, problem-solving, multi-tasking) orientation, fatigue and seizures (Al-Qazzaz et al., 2014; Chohan et al., 2019; Stroke Association, 2019)
- **Behavioural disability:** difficulties with awareness and ability to conduct self in everyday activities and towards others, and ability to learn (Adamson et al., 2004; World Health Organization (WHO), 1980)
- **Changes to perception of sensation (Stott, 2019)**: impairments to somatosensory (including sensations such as touch, pressure, temperature, and pain) perception (Connell et al., 2008; Guy-Evans, 2021)). For example, difficulties in being able to feel light touch or temperature changes (Connell et al., 2008)
- **Changes to perception of body awareness** (Stott, 2019): neglect or inattention (seemingly ignoring a part of the body); anosognosia (reduced

awareness of impairments (Prigatano, 2010)), asomatognosia (being unaware or confused about the ownership of a limb (Feinberg et al., 2010)); and somatoparaphrenia (a subtype of asomatognosia where people also show delusional misidentification and confabulation (Feinberg et al., 2010)), phantom limb sensations (sensations in a limb that does not exist (Nikolajsen & Jensen, 2001)), alien hand syndrome (involuntary or non-purposeful limb movements with a sense of loss of ownership or control of the limb (Hassan & Josephs, 2016)), supernumerary phantom limb (sensation of having additional limbs that do not actually exist) and allochiria (confusion of bodily sides, including but not limited to, which side of the body has been touched (Obersteiner, n.d.))

- **Changes to other sense perceptions** (Stott, 2019): including changes to smell and taste, including flavour perception (Dutta et al., 2013; Green et al., 2008), visual problems, including changes to the visual field and reduced visual acuity (Naeem, 2012) and hearing impairments (Koohi et al., 2017)

Specifically, physical and psychological symptoms of stroke can affect balance, mobility, movement, sleeping, speech/communication, toileting, sight, dressing, personal care, feeding, swallowing, hearing and fatigue (Stroke Association, 2019). People might feel apprehensive about physical problems, such as worrying about falling or stair-climbing, anxiety around post-stroke changes or fear of stroke recurrence (Mukherjee et al., 2006). Cognitive changes may cause people to be concerned about behaving inappropriately in social settings, affect interpersonal relationships or cause confusion or worry if something happens that they cannot remember (Mukherjee et al., 2006). People might have difficulty in returning to paid work (Lawrence, 2010) and they may feel abandoned by loved ones (Mukherjee et al., 2006).

Global evidence shows that physical and communication disability, fatigue, internal barriers and stigma from others impact involvement in social activities. While many impacts of stroke are less obvious to other people, they can impact on relationships and wider social participation, including working and social lives (Lawrence, 2010). This is harmful, as reduced social contact and poor functional support is associated with depression (Northcott et al., 2016). Overall, these wide-ranging impacts on physical, psychological and cognitive functioning could impact people's views of themselves and their body image, which may need addressing as part of stroke rehabilitation.

1.2.3 Stroke Policy

The importance of comprehensive stroke rehabilitation is recognised globally (Stroke Unit Trialists' Collaboration, 1997). The World Stroke Organization aims to reduce the global burden of stroke through prevention, treatment and long-term care (Lindsay et al., 2014). A Global Stroke Services Action Plan, developed by a Global Stroke Guidelines and Quality Committee has been produced to support global care and outcome improvement after stroke. This action plan was the first global stroke guidance published and includes recognition of the need for developing and improving long-term support for people with stroke and their families (Lindsay et al., 2014). Globally, the quality and quantity of stroke rehabilitation is lower in low-income countries than in high-income countries. Rehabilitation services are reported to be best in Hong Kong, Honduras and Thailand, and worse or lacking official guidance in Aruba, Armenia, Burkina Faso, Uganda and Kenya (Owolabi et al., 2021). This is important for this thesis, as it highlights the need to be aware of health inequalities in stroke rehabilitation. The importance of ensuring that any suggestions made for improving stroke rehabilitation guidelines are accessible to and implemented in all countries cannot be over emphasised.

Rehabilitation services tend to be rated as acceptable across Europe and the UK (Owolabi et al., 2021). The European Stroke Action Plan for 2018 to 2029, alongside the Stroke Alliance for Europe, recognises that for people with stroke, there is a wide range of issues to consider that vary in importance. Relevant to body image, this includes but is not limited to adjustment and wellbeing, including emotional, behavioural, and psychosocial aspects (Norrving et al., 2018). In the UK, the National Health Service (NHS) is responsible for providing healthcare services and support to patients and carers (National Health Service (NHS), 2022a). In England, the NHS has produced a long-term plan which outlines its ambitions for improving health care over the ten years beginning January 2019 (National Health Service (NHS), 2019b). In the plan are aims to implement more out of hospital, integrated and higher intensity rehabilitation during stroke recovery. This is to improve outcomes for people with stroke to six months and beyond and is in partnership with the Stroke Association (National Health Service (NHS), 2019b). People who have disability following their stroke should also receive specialist rehabilitation in hospital and in the community (National Institute for Health and Care Excellence (NICE), 2013). There is limited evidence surrounding altered body image experience following a stroke. So, it needs to be considered as part of their overall psychological adjustment following a stroke (Morris, 2011). Helping people to adjust to the long-term consequences of their stroke is a recognised research priority by the James Lind Alliance and the NHS (James Lind Alliance Priority Setting Partnerships, 2022; National Health Service (NHS), 2022b).

The 2016 National Clinical Guidelines from the Royal College of Physicians focuses on a person-centred approach to recovery and rehabilitation. This includes shifting the emphasis of rehabilitation towards using evidence to help people with stroke solve their problems from a more individualised perspective (personalised medicine), as opposed to suggesting that individuals fit in with existing, less personalised interventions (Intercollegiate Stroke Working Party, 2016).

Therefore, there is a recognised need for improved rehabilitation post-stroke. However, body image issues and their impacts post-stroke have not yet been fully explored. Research is needed to identify if, how, when, and how often body image should be addressed post-stroke.

1.3. INTRODUCING THE CONTEXT OF BODY IMAGE

Bodily changes caused by stroke, whether temporary or permanent, may change how body image is experienced (Pruzinsky, 2004). Body image has previously been defined as the cognitive attention placed on the appearance, or image, held of the body (McBride, 2018). However, it is more complex and multidimensional than this, comprising perceptual, cognitive (or attitudinal), affective and behavioural dimensions (Gardner, 2012). These components are defined in greater detail in Chapter 2, but are briefly summarised here:

- **Perceptual:** mental image of body or body parts (Delinsky, 2012)
- **Cognitive/attitudinal:** beliefs, thoughts, interpretations, and attributions held about the body and bodily appearance, and the meaning of them in relation to self-evaluation (Delinsky, 2012; Menzel et al., 2012)
- **Affective/emotional:** perceived satisfaction or dissatisfaction with the body or parts of the body, and associated feelings such as anxiety or distress (Delinsky, 2012; Menzel et al., 2012)
- **Behavioural:** behavioural response, including avoiding mirrors or public situations (Bailey et al., 2017; Delinsky, 2012; Menzel et al., 2012)

1.4. BODY IMAGE EXPERIENCES IN THE GENERAL POPULATION

Research has overwhelmingly focussed on negative aspects of body image experience due to trying to identify ways to intervene or reduce them (Tylka, 2012). Having a negative or poor image of one's body can lead to low self-esteem (Tiwari, 2014). Having a better or more positive body image experience, sometimes known as body satisfaction, is linked to benefits including but not limited to having fewer depressive symptoms and higher self-esteem (Gillen, 2015). This section will outline factors that can influence body image experience, and the impacts of a disturbance to body image experience.

1.4.1 Factors that can influence body image experience

Body image experience is influenced by various biological, individual, historical, and cultural and social factors (Slade, 1994). An insight into some of these factors is provided here, with a focus on age, sex, body mass index (BMI), media exposure and sexuality. The term ‘sex’ is used to refer to males and females because there is little or no data on non-binary/gender fluid identification and how that relates to body image after stroke.

Satisfaction with different bodily aspects fluctuates over the age span, with people becoming more and less satisfied with different parts of their body as they get older (Ålgars et al., 2009; Burrowes, 2013). For example, while ageing is typically associated with decreased body satisfaction, both men and women become less likely to agree that there are parts of their body that they do not like at all (Ålgars et al., 2009). This means that different considerations or approaches towards understanding body image experience are likely needed for people across different age groups.

Body ideals seem to remain important for females across the lifespan, with evidence of age-related bodily dissatisfaction and desire to remain looking youthful (Cameron et al., 2019) or to be thinner (Ålgars et al., 2009; Radwan et al., 2019). Females are traditionally less satisfied with their appearance than males (Abbott & Barber, 2010; Burrowes, 2013) and are more likely to struggle with their body image experience**,** regardless of age or ethnicity (Burrowes, 2013; Robertson et al., 2021). This may explain why most research into body image dissatisfaction has focussed on females (Ålgars et al., 2009; McCabe & Ricciardelli, 2004).

There is a perception that with age, women become further removed from traditional beauty standards of youthfulness, and therefore experience age-related bodily dissatisfaction (Cameron et al., 2019). Comparatively, males tend to show dissatisfaction with their physical shape and condition or want to be heavier (e.g., muscularity) (Ålgars et al., 2009; Radwan et al., 2019). Younger males tend to want to increase muscle size, while older males seem to focus on losing weight and increasing tone (McCabe & Ricciardelli, 2004). However, the nature of ageing and body image for men is less understood.

Having a high BMI or being overweight can also contribute towards experiencing dissatisfaction with body image (Ålgars et al., 2009; Burrowes, 2013), with the effect stronger for females (Ålgars et al., 2009). Generally, body dissatisfaction increases as people become more overweight (Schwartz & Brownell, 2004). Conversely, when people who are obese or overweight lose weight, they appear to experience an improved body image (Chao, 2015). This could be compounded by the stigma and discrimination of being overweight that is perpetuated by society (Schwartz & Brownell, 2004).

Exposure to and reinforcement of thinner, idealised bodies in the media is associated with experiencing body image issues (Bakhshi, 2011; Burrowes, 2013) for everybody across cultures and ethnicities (Burrowes, 2013; Thomas & Kleyman, 2020). The images used in advertisements affect perception of product/brand, but also of the viewer’s body image. Women are often represented by thin body ideals (Sohn & Youn, 2013). Viewing these images compared to average or plus size models or pictures without people has been found to result in a more negative body image experience for females (Groesz et al., 2002a). For males, muscularity seems important (McCabe & Ricciardelli, 2004), perpetuated by increased exposure to ideal muscular male bodies (Blond, 2008). Exposure to muscular media images is associated with negative self-image for males (Barlett et al., 2008). Sexuality also seems important in body image experience, with gay men reporting greater body dissatisfaction than heterosexual men (Jankowski et al., 2014).

Generally, the use of muscular male models and slim female models in the mass media is damaging (Barlett et al., 2008), although, men do seem to attribute less importance to their bodily appearance than women (McCabe & Ricciardelli, 2004). However, this needs to be considered in the context of limited research on the impacts of sociocultural messages around ideal male body on body dissatisfaction. Additionally, most research has been conducted on college-aged samples (McCabe & Ricciardelli, 2004).

Generally, these concepts do support the idea that people who do not fit the societal ‘stereotypes’ are more prone to experiencing difficulties with their body image experience. Therefore, body image experience can be impacted and perpetuated by a variety of factors, which appear to interact with each other. The above examples represent a snapshot of the complex factors and considerations which can negatively affect body image experience, in addition to stroke. Theoretical perspectives that describe how body image experiences are influenced and perpetuated in the general population are provided in Chapter 2.

Overall, the complexities and individualised nature of body image make it difficult to draw generalised conclusions for specific groups. So, experience of body image should be considered in relation to these factors.

1.4.2 Body image disturbance

To acknowledge the impact of body image issues in the general population, the English government launched the ‘body confidence campaign’. This was after concerns that people suffer from negative feelings about their body image, which can impact their wellbeing, self-esteem and subsequently their physical and mental health. To inform policy, the government wants to understand the causes of negative body image, its impacts and potential interventions (Burrowes, 2013).

While many people’s perception of their own body has little impact on their day-to-day lives, for others, very negative (or disordered) perceptions of their own body may result in harmful behaviour changes for example, those with eating disorders (Tylka, 2012). At the more extreme end of the spectrum, people may experience body dysmorphic disorder. This is classified as an obsessive-compulsive/related disorder, characterised by cognitive symptoms such as perceived defects or flaws in physical appearance. People with this disorder may show a preoccupation with these perceived defects, which are not observable or may only appear slight to others. Muscle dysmorphia is a form of body dysmorphic disorder, characterised by a belief that body build is too small or is insufficiently muscular (American Psychiatric Association (APA), 2013). Most people tend to reside somewhere near the middle of that spectrum where they experience some dissatisfaction or concern about their body, which is not related to a more serious condition (Tylka, 2012). However, people who experience changes in bodily functioning or appearance as a result of acute illness or living with chronic health problems may consider a disturbance in body image experience as being a normal response to their illness (Piotrowski, 1982). This includes feeling physically inadequate and unattractive (Taleporos & McCabe, 2002). Despite evidence showing that body image can impact negatively on people’s daily lives and although body image is modifiable (e.g., through intervention (Lewis-Smith et al.)), it is under-researched and often neglected (Cash & Smolak, 2012a).

1.5. BODY IMAGE EXPERIENCE IN POPULATIONS WITH A DISABILITY OR CHRONIC ILLNESS

Body image experience is mediated by factors including the nature of disability and the degree of deviation from the social ideal (Taleporos & McCabe, 2002). People with more severe physical disabilities usually feel worse about their body compared to those with mild or no physical disabilities (Taleporos & McCabe, 2005). Women who have a physical disability are prone to experiencing a more negative body image perception than women without disability, with differences larger among younger women (Moin et al., 2009; Nosek et al., 2003).

To take examples from specific appearance-altering conditions, breast cancer treatment can result in sudden bodily changes such as lumpectomy or mastectomy, which can lead to body image concerns and reduce sexuality and intimacy (Paterson et al., 2016). People with colorectal cancer who require a stoma (an opening made in the tummy to divert part of the bowel outside of the body (National Health Service (NHS), 2020a)) as part of their treatment are more likely to report body image issues than those who do not (Sharpe et al., 2011). They might feel able to accept and normalize these changes, or feel they want to hide it (Hueso-Montoro et al., 2016). For the latter, this could be because negative social attitudes towards physical difference seem to become internalised (Taleporos & McCabe, 2002).

However, people may also have conditions where an impairment is not visible to others, such as mental illness. This can also negatively impact body image experience, possibly due to the distress and emotional burden of trying to hide their illness from other people (Pachankis, 2007; Shpigelman & HaGani, 2019). Therefore, visible and less externally visible bodily changes can affect body image experience for people with disability or long-term illness.

1.6. BODY IMAGE EXPERIENCE AFTER STROKE

Stroke can lead to visible and less externally visible bodily changes (see section 1.2.2.), which may impact body image experience.

1.6.1 Acknowledging the role of perceptual factors in post-stroke body image experience

People experiencing motor, sensory, proprioceptive (neurological ability of the body to sense movement and position (Collins English Dictionary, 2022)) or attentional issues from their stroke (Stott, 2019; Stott et al., 2021) are a sub-group who will have a different body image experience from people without these issues (Doyle et al., 2014; Gandevia, 1982; Stott, 2019; Stott et al., 2021; Tham et al., 2000). Section 1.2.2 outlines the nature of post-stroke attentional changes. It evidences why it could be challenging to gauge an accurate self-appraisal of body image from people who have perceptual changes. Body image experience in this sub-group has already been explored through in-depth and peer-reviewed research (Stott, 2019; Stott et al., 2021). For these reasons, this sub-group of people with stroke are not included in this thesis.

1.6.2 Factors that influence body image experience after stroke

A stroke may result in long-term physical and psychological changes for survivors. Therefore, it is not surprising that body image may be negatively affected after a stroke. For people with stroke, body image has been described as a complex issue which can be difficult to describe and explain (Lawrence & Kinn, 2012). Female stroke survivors have reported feeling less attractive due to a changed appearance (Kitzmuller et al., 2013) and attempting to hide bodily impairments post-stroke due to stigma (Leahy et al., 2016). Body image concerns also appear more pertinent in younger survivors (Ch'ng et al., 2008). In those aged under 60 years, body image has been shown to affect self-esteem and lead to feelings of poor self-worth and depressive symptoms after stroke (Keppel & Crowe, 2000). However, it is unclear what influences peoples' experiences of body image after a stroke. There is only limited evidence surrounding body image experience following a stroke.

Therefore, the aims of this thesis are to broadly describe the body image experiences of a generalised stroke population, and how these experiences impact on their everyday lives. As such, a broader definition of body image will be used for this thesis. Body image will be defined as encompassing an individual's subjective perceptions; thoughts and cognitions; feelings and affect; and behaviour in relation to the body's appearance, functions and capabilities (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b). Greater detail regarding the definition is provided in Chapter 2.

1.6.3 Why does body image after stroke need clinical attention?

Issues with body image in medical conditions including stroke are often neglected (Pruzinsky, 2004). This is a problem, because post-stroke body image changes can be linked to depression (Keppel & Crowe, 2000) and can lead to embarrassment, reduced self-confidence, worries and fears about the opinions of others, and social withdrawal (Lawrence & Kinn, 2012). This could have implications on recovery and life after stroke, such as limiting important activities including attendance at rehabilitation appointments (National Institute for Health and Care Excellence (NICE), 2013), engagement with social relationships and return to paid work and caregiving (Lawrence & Kinn, 2012). Therefore, experiencing a negative body image post-stroke may require long-term psychological support (Lawrence & Kinn, 2012).

1.6.4 Summary of English stroke policy

Although the English government acknowledges the potential impacts of body image on wellbeing through its 'body confidence campaign' (Burrowes, 2013), stroke policy does not provide guidance for supporting post-stroke body image experience. Therefore, there is no guidance on if, how and when to assess and try to improve body image experience if it becomes an issue for a person with stroke. Body image may require long-term consideration and psychological support, or risk having negative implications for healthcare outcomes and costs, social withdrawal and stroke recovery (Keppel & Crowe, 2000; Lawrence & Kinn, 2012). However, not enough is currently known about body image to inform policy, prevention or potential treatment.

1.6.5 The need for future research: what we do not know

Stroke has many long-lasting effects on physical and psychological recovery. Some research has described changes to body image after stroke, but this is limited to women of a certain age and we do not know if there are similar experiences for others. Body image changes might further compound stroke-related difficulties, with reduced participation in activities of daily living, alongside slow recovery, poorer wellbeing and not living well with stroke. Research is needed to better understand post-stroke body image experience to facilitate intervention strategies to reduce any negative impact. Research is also needed to identify how and when to assess body image, measure changes over time, and identify whether any support or intervention can improve it. There is no reliable or consistent method for exploring or measuring the experience of body image post-stroke, so there is limited knowledge and understanding about how common or disabling body image issues are for people with stroke. There is also no recognised advice for clinicians providing this support, or accessible self-help materials available for people with stroke. This thesis aims to bridge some of these gaps in evidence through exploring post-stroke body image and methods of assessing it, including justifying if and how body image should be included in policy.

1.7. PHD OVERVIEW

1.7.1 Aims

I will explore the body image experience of people with stroke by:

- Systematically reviewing the literature concerning body image experiences post-stroke, and methods of assessment, as a first step towards building an evidence base; and
- Interviewing a broad range of people with stroke to explore and understand their experience of body image and its impact on wellbeing and recovery; and
- Triangulating the information from the systematic review and interviews to summarise and describe post-stroke body image experiences; and
- Making recommendations for strategies that may support the assessment of and improve outcomes for people with stroke with negative body image experiences

The secondary aims are to:

1. Explore commonly repeated themes in the experiences of body image for people with stroke across factors including but not limited to age and sex

2. Develop a summary, including definition, of body image experiences and issues following stroke: this will describe body image experience in a clear, succinct, and visual way to aid communication with people with stroke, and facilitate its assessment and measurement
3. Discuss key findings with people who have clinical expertise in stroke and psychology to explore possible methods of support for post-stroke body image issues and to explore whether any of the existing and identified body image assessment methods would be appropriate to use with people with stroke

Not enough is known about the changes in body image experiences to narrow down focus to specific bodily changes or demographic characteristics such as particular age groups or one sex. Therefore, the aims are to describe the body image experiences of anyone who has had a stroke as long as they are able to express their thoughts and feelings regarding their post stroke body. This is to remain as inclusive as possible given the exploratory nature of this thesis. It will focus on exploring how the common physical and psychological changes after stroke impact body image experience and subsequent wellbeing and recovery. To understand these impacts, the ‘lived experience’ of body image will be concentrated on; namely the conscious thoughts and opinions held about the body after stroke. In this way focus will be on the subjective experience of body image post-stroke, rather than focussing on whether body image changes are a reaction to the stroke, or an effect of the stroke.

1.7.2 Thesis Structure

To address and present the aims and findings of the thesis, the following structure will be used:

CHAPTER 1: INTRODUCTION, provides an overview of stroke and body image experiences, highlighting the gaps in knowledge and how they will be addressed through this thesis.

CHAPTER 2: BODY IMAGE, provides greater detail around how body image will be defined within the thesis and relevant considerations for how body image is experienced in the general population.

CHAPTER 3: EPISTEMOLOGICAL PERSPECTIVES, shows my worldview and philosophical perspectives that form the perspective from which I have conducted this research

CHAPTER 4: METHODS FOR A MIXED METHODS SYSTEMATIC REVIEW EXPLORING POST-STROKE BODY IMAGE EXPERIENCE AND METHODS OF ASSESSING IT, describes the methods of a systematic review exploring post-stroke body image experience, including any tools, measures or methods used to assess these experiences.

CHAPTER 5: RESULTS OF A MIXED METHODS SYSTEMATIC REVIEW EXPLORING POST-STROKE BODY IMAGE EXPERIENCE AND METHODS OF ASSESSING IT, describes the results of the systematic review. Results will be narratively synthesised.

CHAPTER 6: EXPLORING POST-STROKE BODY IMAGE EXPERIENCES USING AN INTERPRETATIVE PHENOMENOLOGICAL APPROACH, describes a set of one-to-one interviews with people who have had a stroke to explore their experiences of their body image post-stroke. Interviews were recorded and transcribed for qualitative analysis. This will generate a series of themes and subthemes describing lived experiences and impacts of body image post-stroke and will form the basis of a stroke-specific summary and definition of body image experience. The summary will describe body image experience in a clear, succinct, and visual way to aid communication.

CHAPTER 7: EXPLORING POST-STROKE BODY IMAGE EXPERIENCES IN EXPERT PANEL SESSIONS*,* describes discussion groups with people who have clinical expertise in stroke and psychology. Attendees were asked to discuss key findings from the review and interviews and to suggest how body image issues could be addressed after stroke. Attendees were also asked to discuss the body image measurement methods, including those found through the systematic review and identify if any are appropriate for use post-stroke to explore body image changes post-stroke.

CHAPTER 8: PERSONAL REFLECTION, provides reflections from throughout the process of conducting this research, including what was originally planned compared to what actually happened, and reflection and reflexivity on what could have been done differently.

CHAPTER 9: OVERALL DISCUSSION, CONCLUSIONS AND IMPLICATIONS FOR FUTURE CLINICAL PRACTICE, RESEARCH AND POLICY, provides an overall summary of the research in this thesis, including critique, and will outline implications for clinical practice, future research and policy.

2. CHAPTER 2: BODY IMAGE

In this chapter, I will provide greater detail around how body image is defined within the thesis, outlining frequently used terminology from the literature. This will lead into a description of how body image is assessed in the general population and what research evidence tells us about how body image changes or which concerns should be supported post-stroke. This will provide the information to justify the work presented in Chapter 4 onwards.

2.1. HOW BODY IMAGE WILL BE DEFINED IN THIS THESIS

In one of the earliest (1950) definitions, body image was described as a perceptual construct that reflected social attitudes and interactions (Grogan, 2016; Schilder, 1950). Since then, the concept of body image has been expanded to include bodily satisfaction, appearance evaluations, body esteem and body schema (Grogan, 2021; Schilder, 1950). This terminology will be described in greater detail in section 2.1.2.

The general understanding of body image ranges from stereotypical assumptions about it being related to weight, always being negative, or being a 'women's' issue, to more complex and multidimensional interpretations, including perceptual and affective (feelings, emotions) components (Bailey et al., 2017). The definition of body image used within research also tends to vary depending on the study (Bailey et al., 2017). It is frequently defined as how people view their body in terms of physical appearance (Keppel & Crowe, 2000; Reber, 1985; Roid & Fitts, 1994). In line with this definition, it has been argued that despite body image actually being complex and multidimensional (Cash & Smolak, 2012a), Western society definitions focus mostly on appearance (Tiggemann, 2004). This is emphasised by the factors that affect body image in the general population, as outlined in section 1.4. For example, Western society perpetuates pressures to conform to stereotypical body shapes and to focus on appearance by using idealised images of people to sell products in advertising (e.g., (Blond, 2008; Groesz et al., 2002a)). Comparatively, in clinical contexts (Pruzinsky, 2004) body image includes positive or negative perceptions (Grogan, 2016) about bodily function, bodily abilities (competence) and bodily sensation (Pruzinsky, 2004). This likely reflects the traditional use of the biomedical model within the NHS (Singh, 2016). This model has focussed on illness as having a purely biological basis, while not considering social, psychological and behavioural factors and components of illness (Engel, 1977).

More recently, and to try and develop a more holistic understanding of body image, Grogan (2016) defined body image as relating to a person's perceptions, thoughts and feelings about their body (Grogan, 2016).

This wider definition includes psychological aspects of perceptions and attitudes towards the body, and experiences of embodiment (Grogan, 2016). This will be further outlined later in this section.

These examples highlight the lack of consensus on defining body image. This could be due to its subjective nature and the different ways that it is experienced by different people. However, without defining the term ‘body image’, this makes it difficult to understand or to fully capture its associated evidence base. Pragmatically, there was therefore a need to decide on a definition of body image which could be used throughout the thesis to ensure that findings remained specific to body image. This emphasises the importance of clearly defining body image in this thesis and justifying its use.

To reflect the ‘complex and multidimensional nature of body image’ (Cash & Smolak, 2012a), and the research in this thesis is exploratory in nature, a broad definition of body image will be used (Gallagher, 2005; Grogan, 2016). It will be defined using the Cash (2002; 2012) definition as ‘encompassing an individual’s subjective perceptions, thoughts and cognitions, feelings and affect, and behaviour in relation to the body’s appearance, functions and capabilities’ (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b), where these constructs are defined as follows:

- **Perceptions:** the mental image a person has of their body or bodily parts. It includes the sensations associated with ‘living in’ their body, such as perception of muscularity or flabbiness, shape of body parts, and whether body parts are perceived as individual components, or as being connected (Delinsky, 2012; Kilteni et al., 2015)
- **Thoughts and cognitions:** the beliefs, thoughts, interpretations, and attributions a person holds about their body and bodily appearance, and the meaning and importance of these aspects in relation to how they evaluate themselves, including how they contribute to their self-worth. This could include beliefs about appearance or appearance ideals (Adams et al., 2017; Delinsky, 2012; Menzel et al., 2012)
- **Feelings and affect:** perceived satisfaction or dissatisfaction with the body or bodily parts, and associated feelings such as anxiety or distress. These feelings can be contextual or situational, such as only becoming self-conscious about appearance in front of others, or in public places (Connolly & Mahoney, 2018; Haimovitz et al., 1993; Moorley & Cahill, 2018). Shame is also salient to body image experience and can occur when people feel that they are not meeting

perceived cultural ideals of appearance (Delinsky, 2012; Menzel et al., 2012; Rumsey et al., 2004; Wang et al., 2021)

- **Behaviour:** a behavioural response, such as avoiding mirrors or public situations (Bailey et al., 2017; Delinsky, 2012; Menzel et al., 2012). These behavioural manifestations could indicate anxiety surrounding appearance. Excessive checking of bodily factors, such as weighing oneself more frequently, checking appearance or skin pinching (to check for fat) could indicate investment or over-evaluation of appearance (Menzel et al., 2012; Mitchison et al., 2013)
- **Appearance**: the manner or style in which a person appears (Dictionary.com, 2022)
- **Functions:** how the body works, including but not limited to, hearing, eating, seeing, washing, reading, communicating, walking, drinking, sitting, sleeping, dressing or undressing, using the toilet, shaving, shampooing and help with medication (Disability Rights UK, 2022)
- **Capabilities:** the functional capability of the body, including but not limited to physical capability (grip, standing, balance, walking speed), cognitive capability and sensory capability, including visual and auditory acuity (Kuh & The New Dynamics of Ageing Preparatory Network, 2007)

When people perceive their body image negatively, this can be due to damage to an area of the brain which affects attention; physical bodily changes; or psychosocial disturbances (Gainotti, 1993; Hosseini & Padhy, 2022; Keppel & Crowe, 2000; Rubio & Van Deusen, 1995). Changes to perceptions may present as a disturbance of one, or more perceptions, thoughts, feelings and behaviours in relation to body image (Gardner, 2012). Critically, the stance taken within this thesis is the importance of subjective views of body image. It is the *subjective* changes that represent an individual's reality (Keppel & Crowe, 2000; Tyerman & Humphrey, 1984).

2.1.1 Body image and embodiment

Sometimes, body image and embodiment are differentiated between, whereby body image can be defined as the human experience of embodiment (Cash & Smolak, 2012a). There are different theories of embodiment (e.g., as described by Krieger (2005)). One example by McBride (2018) is where embodiment is conceptualised as a whole bodily experience, related to the self and how it is experienced through the body. The body is an engaged being within the world and embodiment is a person's experience of the lived body; namely, the experience of living as a body (McBride, 2018). As described by Merleau-Ponty, the lived body is the subjective experience of the body (Gallagher, 1986b). This includes the feeling of inhabiting the body and feeling it from the inside, which includes being aware of bodily position and movement of body parts (Khatchatourov & Stewart, 2007).

In this respect, embodiment and the lived body can be viewed differently to body image. Whereas the lived body is about the broader concept of the subjective experience of inhabiting a body (Gallagher, 1986b), body image is more specifically related to opinions, thoughts, perceptions and behaviours relating to the body (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b). Where the term ‘lived body image experience’ is used within the thesis, this is to encompass a person’s subjective experiences of living with their body image experience. Embodiment can also be considered as a broader concept than body image. However, sometimes, body image and embodiment show greater overlap. Specific to stroke, embodiment has been described by Timothy et al. (2016) in a way which more aligns with body image:

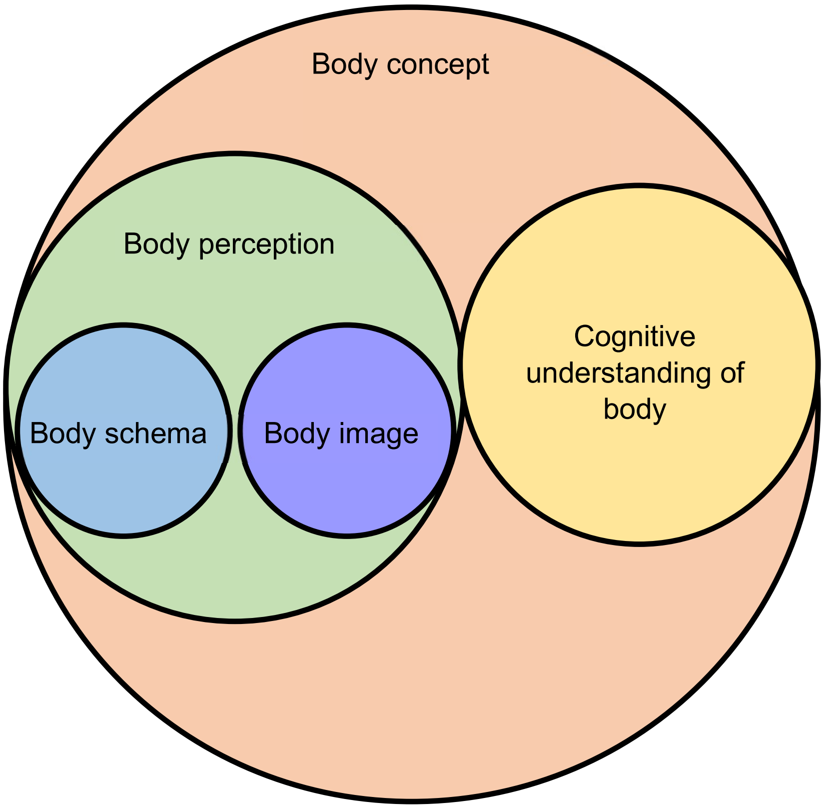
> “embodiment includes (but is not limited to) recognition of the actual impairments of strength, coordination, and sensation that arise from lesions to physical parts of the brain that usually control these functions. Embodiment also includes a person’s subjective experience of these impairments and how he or she make sense of or interpret them. Furthermore, it recognizes the influence of social structures and constructions on these interpretations. For instance, embodiment includes recognition of how society classifies a hemiplegic arm with soft tissue contractures at the elbow, wrist, and hand as being a “deformity” and the impact of the social responses (both desirable and undesirable) that arise from others as a result of this classification.” (p.1566)

This description more aligns with the way in which body image is defined; by taking into account functionality, subjective experience and interpretation of stroke-related changes, but also the influence of social factors. It also highlights the potential for confusion between different terminologies which seem to describe similar concepts. For the purpose of this thesis and to provide clarity around terminology, embodiment will be considered a whole body experience, in line with McBride’s definition as outlined above.

2.1.2 Body image and associated terms

Alongside considering the context of embodiment in relation to body image, it is also beneficial to expand upon the different terms used to define body image. This is due to the similarities and differences between body image and associated bodily terms. There are a variety of associated terms, so only those most similar or often used interchangeably with body image will be outlined here. Figure 2.1 is used to exemplify the relationship between these most typically used terms.

Figure 2.1 *Diagram to Show the Relationship Between the Most Typically Used Terms Associated With Body Image*



Body image fits under the overarching term of body perception (Gallagher, 1986a; Klinke et al., 2014; Stott, 2019). Body perception sits alongside the way an individual cognitively understands their body, to form the term body concept (Gallagher, 1986a). Body perception refers to the experience of the lived body, where the body is viewed as being a vehicle for being in the lived world (Merleau-Ponty & Landes, 2014; Stott, 2019). This is an overarching term for perceptions and thoughts about the body as a whole.

Body schema is a subset of body perception, (Gallagher, 1986a; Klinke et al., 2014; Stott, 2019), which is often confused with body image (Gallagher, 2005; Stott, 2019). While body image is a conscious experience of the body (Gallagher, 1986a, 2005; Stott, 2019), an individual's body schema represents the non-conscious process

(Gallagher, 1986a; Stott, 2019) in charge of regulating body posture and movement (Gallagher, 1986a, 2005). This often does not capture the conscious lived experiences of body image, but instead the non-conscious bodily processes that regulate posture and movement (Gallagher, 1986a, 2005). Therefore, while linked to body image, the term body schema on its own does not capture the essence of the conscious and lived experience of body image, which is the focus of this thesis. The term body perception remains useful as long as it relates to conscious experiences of the body, and because in some of the literature, body image is used interchangeably with body perception (Burrowes, 2013).

Body satisfaction and dissatisfaction are also used in relation to body image, typically as evaluative terms. For example, body dissatisfaction represents negative thoughts and feelings towards one’s physical appearance or body (Burrowes, 2013; Cash, 1990; Grogan, 2016; Heider et al., 2018). Body esteem is a similar evaluative term, although it refers to self-concept and is usually linked to weight, and as such, a person’s attitudes, evaluations and feelings about their body (Williams et al., 2013).

Constructs within body image must also be used with caution. Perceptual body image typically relates to the accuracy with which a person can judge the physical dimensions of their body (Cash & Deagle III, 1997; Cornelissen et al., 2019; Grogan, 2016). Attitudinal body image relates to the feelings that a person has about their body, particularly its size and shape (Cornelissen et al., 2019; Grogan, 2016). Given the focus on lived experience and impacts of body image within this thesis, attitudinal body image is a better fit within the aims of this thesis should differentiation be required. The use of attitudinal body image also demonstrates another way in which body image and its associated terminology differ from embodiment from a conceptual perspective. While embodiment focuses more on interpretation of whole-body experiences (McBride, 2018; Timothy et al., 2016), attitudinal body image focuses more on how someone feels about their body (Cornelissen et al., 2019; Grogan, 2016).

In some literature the term attitudinal body image describes a dispositional factor, namely that it is experienced as a personal trait (Menzel et al., 2012). A trait is a relatively constant aspect of personality that directs or motivates responses to a situation. While traits are universal and identifiable across different people, uniqueness of traits to a person are derived from their role in making up an individual’s personality (Allport, 1929). For research purposes, traits and states are often differentiated between as they capture different experiences (Cash, 2012b). State-level body image refers to body image experiences as being transient and momentary (Cash, 2012b). It is beyond the scope of the thesis to discern these terms further, but should differentiation appear relevant for people with stroke, it will be explored.

2.1.3 Theoretical perspectives describing development and perpetuation of body image experiences

In order to understand and offer greater insight into the different factors that can influence body image (Grogan, 2016) and by which mechanisms (Cash & Smolak, 2012b), there are multiple theoretical perspectives to consider.

a. Sociocultural Perspectives

The sociocultural model of body image emphasises that ideals of beauty and appearance become internalized. This results in satisfaction or dissatisfaction with appearance based upon whether an individual feels that they meet those ideals (Tiggemann, 2012). In Western society, people are thought to learn about these ideals through their parents, peers and the media's strong emphasis on appearance as portrayed in movies, television programmes, advertisements and conversations, resulting in time, money and effort invested in pursuit of ideal beauty, through dieting, hair and cosmetic procedures (Tiggemann, 2012). These three groups of influence have been referred to as the Tripartite Influence model (van den Berg et al., 2002):

1) Parents represent strong communicators of sociocultural pressure, mostly through family attitudes and direct verbal messages around body shape and eating habits (Rodgers & Chabrol, 2009)
2) Peer influence typically begins in adolescence and has largely negatively impacts on body image experience through pressure to conform to appearance expectations. Deviations from these expectations can lead to negative peer experiences (Kenny et al., 2017)
3) Use of social media has risen rapidly over the past decade, with a positive relationship between the amount of social media use and body image disturbance (Saiphoo & Vahedi, 2019). Comparing one's appearance to that portrayed as 'more attractive' in social media can lead to increased body image concerns (Hogue & Mills, 2019).

The Tripartite Influence model accounts for a large proportion of negative body image experiences in the general population (Burrowes, 2013).

b. Evolutionary Perspectives

Evolutionary perspectives of body image relate to the characteristics that people consider to be attractive in a partner. Various aspects of 'attractiveness', such as symmetrical facial features and ideal waist-to-hip ratios, are used to assess the likelihood of reproductive success, and hence, the desirability and quality of a partner (Ålgars et al., 2009; Swami, 2012). Body image issues then occur due to competition between sexes for partners (Swami, 2012). Research suggests that body image and perceived attractiveness do have evolutionary underpinnings, but, sociocultural perspectives must be taken into account to understand the complicated interactions between age, gender, BMI and body image (Ålgars et al., 2009).

c. Genetic Perspectives

Genetic perspectives acknowledge the importance of psychosocial factors but argue that they do not explain all the individual differences across body image experiences. Some people are more susceptible to experiencing body image issues due to genetic or biological factors (Suisman & Klump, 2012). These include thin-internalization, as identified through research with twins (Suisman et al., 2012; VanHuysse et al., 2016), and higher body mass (Stice & Whitenton, 2002).

d. Feminist/Objectification Theory

Feminist theory proposes that today's culture objectifies the female body, meaning that women are likely to experience self-objectification. This is linked to the body as a locus of control for women (McKinley, 2012). When women have an external locus of control, it relates to the idea that they are not responsible for their body image experience. Instead, it is affected by societal pressures (Fredrickson & Roberts, 1997; Furnham & Greaves, 1994; Grogan, 2016; Grogan, 2021; McKinley, 2012), namely placing greater importance on achieving the idealised body image as perpetuated by society (Furnham & Greaves, 1994). Attention is drawn to how the female body looks or works and can lead to feelings of being judged and learning to become 'objects' to be watched and evaluated (Fredrickson & Roberts, 1997; Grogan, 2016; Grogan, 2021; McKinley, 2012). Society normalizes gender inequalities and causes women to be socialised to focus and place importance on their appearance (McKinley, 2012). Emphasis placed on female sexual attractiveness means that body satisfaction is considered more important for women than for men (Furnham & Greaves, 1994). Comparatively, women who have an internal locus of control, such as those who believe that they are in control of their own body shape are less likely to experience dissatisfaction than those with an external locus (Furnham & Greaves, 1994).

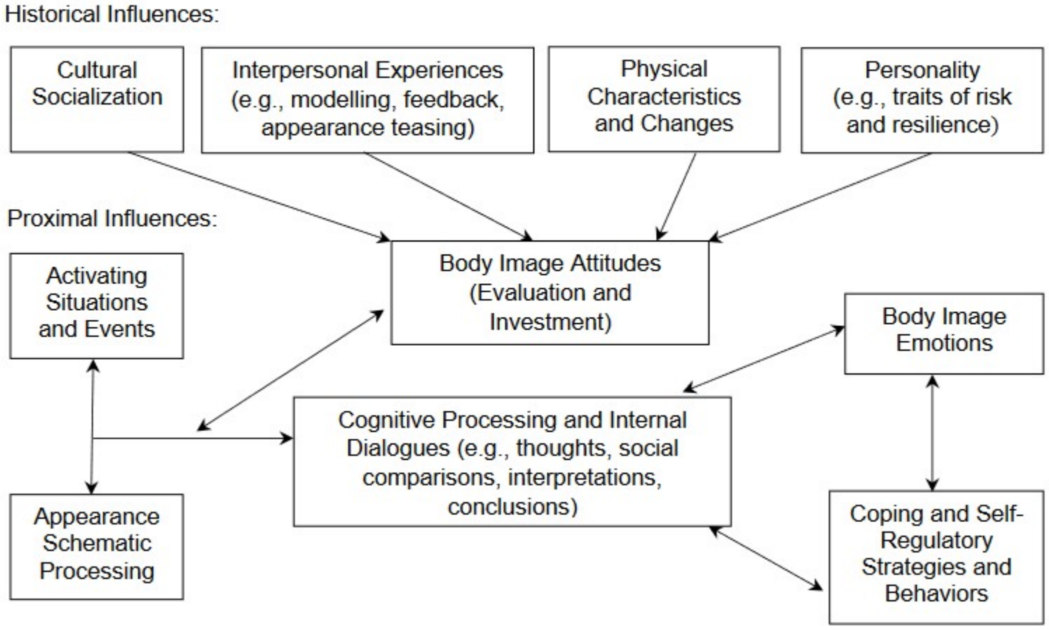
e. Positive Psychology

Despite the multidimensional nature of body image, most research has focussed on negative aspects of body image (Tylka, 2012). Positive psychology is an emerging perspective, which attempts to focus on the positive aspects of body image (Grogan, 2016; Grogan, 2021; Tylka, 2012). Where body image interventions attempt to ameliorate 'negative' body image experiences, but do not try to build a positive body image, this may only result in a tolerance of the body. Taking a positive psychology approach encourages appreciation, respect, celebration and honouring the body which could make benefits of intervention more effective and lasting (Tylka, 2012; Tylka & Wood-Barcalow, 2015b).

f. Cognitive-Behavioural Perspectives

One of the most influential theoretical explanations of body image is the cognitive-behavioural perspective (Grogan, 2016) relating to social learning and conditioning, and cognitive mediation of behaviours and emotions (see Figure 2.2). Historical factors of culture, interpersonal experiences, physical characteristics and changes, alongside personality, are responsible for the fundamental body image perspectives that a person has. These attitudes are based on self-evaluation of body image (e.g., satisfaction, dissatisfaction) and investment, namely how important the body is in that self-evaluation. Cognitive processing mediates emotions and coping related to body image. Being in different environments or situations, and appearance processing, impact cognitive processing and body image attitudes directly (Cash, 2012a). These personal psychological characteristics are the main factors associated with causing negative experiences of body image (Burrowes, 2013).

Figure 2.2 *Cash's Cognitive-Behavioural Model of Body Image (Cash, 2012a; Lewis-Smith et al., 2019)*



How is body image assessed in the general population?

The most commonly used body image measures are those assessing how someone evaluates their physical appearance (Kling et al., 2019; Krawczyk et al., 2012). This is because for the general public, the most common concept of body image is the evaluative component (Kling et al., 2019). The main assessment tool formats include self-report questionnaires (Kling et al., 2019), and figure drawing or pictorial scales (Gardner & Brown, 2010). For self-report questionnaires (e.g., the Body Appreciation Scale (Avalos et al., 2005; Tylka & Wood-Barcalow, 2015a), Body Shape questionnaire (Cooper et al., 1987), Body Esteem Scale (Franzoi & Shields, 1984) and Body Shape Satisfaction Scale (Burrowes, 2013; Slade et al., 1990)), a low score would suggest inaccurate body perception or low body satisfaction. These are well established in the general population (Burrowes, 2013).

Figure drawings are where people are presented with a series of drawings representing different body shapes and asked to select their 'ideal' and 'perceived' body shape (e.g., (Gardner et al., 2009)). Low scores would indicate inaccurate body perception or low body satisfaction (Burrowes, 2013). Another method relates to actual body weight and shape measures, where data are gathered by trained professionals or by self-report in relation to weight and shape (Burrowes, 2013; Rastmanesh et al., 2009).

In 2019, a systematic review was conducted to explore the scales/subscales available in English for measuring body image in adults. The authors identified 58 measures which met their appearance-focussed definitions of body image. Over 150 additional measures which assessed body image more broadly were also identified (Kling et al., 2019). The authors of another systematic review of figure drawing scales for assessing body image identified nine methods for use with adults, comprising figure, silhouette, semi-silhouette and pictorial scale methods (Gardner & Brown, 2010). These two reviews alone demonstrate the number of tools available for assessing body image. Using different scales can make it difficult to compare data across participants, studies and settings, and to and succinctly review the totality of the available research (Burrowes, 2013).

It is important to note that research on body image has tended to focus on younger people, meaning tools will likely be more appropriate for younger populations. (Cameron et al., 2019). Additionally, some groups, including non-white men and older adults, have received little research attention (Burrowes, 2013). Future research should evaluate and create measures to capture the body image experiences of older people (Cameron et al., 2019) and people of different ethnicities and abilities.

2.1.4 Body image intervention

When Google is searched for body image self-help, a plethora of options are available. Most appear to be designed for adolescents (e.g., (Young Minds, 2022)), but material is available for other ages from The Mental Health Foundation (Mental Health Foundation, 2022). The methods with the strongest evidence around improving negative body image experiences are exercise-based interventions, media literacy education (as opposed to health-based education) and psychotherapeutic based programmes (Burrowes, 2013). The most effective intervention formats are multisession, group-based, and with a facilitator (Alleva et al., 2015b). General cognitive-behavioural techniques, which include discussing cognitions and their role in body image, teaching self-monitoring and restructuring of cognitions, changing negative body language, conducting exposure exercises, providing relapse-prevention strategies and providing stress management training, are common and one of the most effective ways to elicit improvements in body image. However, existing interventions typically only result in small improvements to body image, with greater improvements seen in participants selected due to having ‘negative’ body image, as opposed to participants who had not been screened (Alleva et al., 2015b). This suggests that a larger improvement could be expected in people experiencing greater difficulties with their body image experience. This strengthens the importance of having accurate ways to assess body image to facilitate the possibility of targeted interventions for people with the most to gain from support.

Some interventions specifically target promoting positive body image. In a meta-analysis of thirteen interventions (Guest et al., 2019), only three studies using the same intervention (online functionality-based, structured writing intervention (Alleva et al., 2015a; Alleva et al., 2018a; Alleva et al., 2018b)) were found to be of high methodological quality. Only two identified studies (Jankowski et al., 2017; Mellor et al., 2017) were used to evaluate interventions specifically aimed at increasing positive body image in men, with neither showing effectiveness (Guest et al., 2019). In summary, current interventions typically only result in small improvements in body image experiences and are more focussed towards younger people and females.

2.2. SUMMARY

In summary, body image is a broad and multidimensional concept. To be able to explore body image experience through this thesis, a clear definition was needed. When trying to define body image, terminology is often used interchangeably, demonstrating a need for clarity around the way in which research studies define body image. There are also a variety of factors that can affect body image experience, and different theories as to how these factors are perpetuated across society and ultimately impact different people. While there is evidence suggesting how best to support those who struggle with body image issues, there is no consensus on the most effective way to do this. The definitions of and methods to assess and support body image experience, are complex. These complexities, combined with the lack of stroke-specific guidance for supporting body image for those who need it, emphasise the need for clear and focused research to enable better definitions and understanding of and support for people after stroke.

3. CHAPTER 3: EPISTEMOLOGICAL PERSPECTIVES

3.1. INTRODUCTION

In this chapter, I will outline the conceptual background of this thesis. To do this, I will first describe my position, placing my worldview into context. I will briefly outline the impacts of Coronavirus Disease (COVID-19) on my thesis to provide historical context. Then, I will describe my ontological and epistemological perspectives (see section 3.4 for definitions of these terms). Keeping these perspectives in mind, I will then provide theoretical and practical justifications for using interpretative phenomenological analysis as my chosen method.

3.2. RESEARCHER POSITIONALITY AND WORLDVIEW

It is important that I outline my position to facilitate understanding of the research decisions that I have made within my thesis (Jackson, 2013; Sikes, 2004). This is because my position may influence the way I think about and carry out my research, especially when I interpret my qualitative interviews (Sikes, 2004).

I am a White British, middle-class female and have been aged between 23-26 years whilst completing this thesis. I was born in Northwest England, speak English, and am an only child. I studied Psychology, beginning at A-Level through to Master’s level, for ten years before beginning this PhD. During this time, I developed a particular interest in how psychosocial and other external factors influence thoughts and behaviours. Specifically, I became interested in how social comparison to others, particularly through social media, could impact mood and wellbeing. This led me to my Master’s degree research topic of whether the body satisfaction of young women could be impacted by viewing Instagram profiles of ‘attractive’ and ‘less attractive’ young women. Whilst exploring the literature around body satisfaction and dissatisfaction, I gained knowledge around social, historical and cultural influences which could affect how different people think about their body. This is how I developed a personal interest in body image research and highlights my personal assumptions that external factors can influence people’s perceptions of their body.

Then, towards the end of my Master's degree, my Grandma, with whom I was very close, experienced multiple transient ischaemic attacks. This was my first experience of being close to someone who had any type of stroke and seeing how it impacted my Grandma led to my interest in stroke and its consequences for wellbeing and everyday life. Combining this with studying stroke as part of exploring long-term health conditions in my Master's degree programme, drew me to my current research assistant position on the Stroke Research Team at the University of Central Lancashire. Whilst working on the Stroke Research Team and learning more about stroke and the breadth of research in the area, the opportunity arose to apply for a PhD studying body image after stroke. This represented the perfect opportunity to combine my keen interest in people's opinions and thoughts about their body, with how the potentially life-changing impact of stroke affected such thoughts and opinions.

Over the last decade, my career has progressed from student to early career researcher. I do not have a clinical background and glean any clinical knowledge of stroke from the expertise of my supervisory team and from reading relevant literature.

I have an intrinsic interest in why people behave or act in certain ways, and in how experiences shape who we are. I am aware that these interests and influences will likely impact on how I interact with the various parts of participants' experiences and stories, and the aspects of their stories that I will be drawn to, and think it is important to acknowledge this.

Therefore, the positionality of this thesis, based upon my worldview, includes the assumption that how we experience our body image is heavily influenced by, and also influences, our interactions with external factors including other people and the media.

3.3. IMPACTS OF COVID-19

An unexpected event which impacted my research plans was the COVID-19 pandemic. The UK lockdowns were launched when I was 6 months into the thesis (March 2020). I had begun developing the protocol during the early months of the pandemic, so had to consider the effects of the pandemic on my research plans. Initially, there was minimal guidance regarding research activities during COVID-19 and only virtual participant work was permitted. So, I amended the protocol to include the same research phases but with virtual and telephone alternatives and adapted all project materials to reflect this. I provide a reflection of the impacts of COVID-19 in sections 8.2.1 and 8.2.2.

3.4. ONTOLOGICAL AND EPISTEMOLOGICAL PERSPECTIVES

From an ontological perspective, where ontology is the reality of the world (Jackson, 2013), the focus of this thesis is not on the objective medical nature of stroke. Instead, the focus is on people's subjective experiences and relationships with their post-stroke body, and if and how this impacts their lives. These experiences and relationships must be understood and interpreted for individual contexts, as every individual has unique thoughts, interpretations and ascribes meaning to them (Ahmed, 2008). This aligns with a phenomenological perspective, through which attempts are made to explore individual perspectives (Dabengwa et al., 2023). Within phenomenology are two main perspectives: Husserl's descriptive phenomenology and Heidegger's interpretative/hermeneutic phenomenology. Descriptive phenomenologists aim to find the 'essence' of an experience which represents a snapshot of reality to be able to consider the findings in a wider context (Dabengwa et al., 2023; Vagle, 2016). Interpretative phenomenologists explore people’s narratives about an experience (Smith & Osborn, 2007) by ‘mediating’ the meaning from participants to develop a hermeneutic interpretation (see section 3.5.1 for further detail) (Creswell & Poth, 2016) and which applies only to local and more individualised contexts (Dabengwa et al., 2023). I was not aiming to capture the essence of experience, but to explore and understand the meaning of body image experience after stroke. Therefore, I felt that Heidegger’s approach best aligned with my perspectives.

I also do not believe that it is possible to completely bracket personal thoughts and perspectives when completing research. Accordingly, interpretative phenomenology explores narratives about experiences using extant literature, researcher’s pre-suppositions and theory (Smith & Osborn, 2007). Therefore, I identified interpretative phenomenology (referred to throughout as phenomenology) as being an approach which best aligned with my views around the individual experiences of body image, and which would best help me to explore these through my methodology.

Alongside recognising the important of individual difference, I also believe that people’s individual contexts are largely influenced by external social factors, such as culture, upbringing, and media. Due to this, body image experiences must also be understood within the wider social contexts in which they occur. I believe that while body image is something that is experienced by an individual, it is also influenced by the world around us and how we relate to it. In this case, body image is based on the relationship between the stroke survivor (experiencer) and their lived world (experience) (Jackson, 2013).

This ontological perspective of body image experience being subjective and largely influenced by social aspects supports the epistemological perspective (knowledge of the world) (Ahmed, 2008) of social constructionism (Gergen, 1985). This approach is less about the cognitive processes behind knowledge and more about suggesting that knowledge is shared and co-created through social processes. Namely, social factors can shape or even construct people’s interpretations and their social world (Young & Collin, 2004). Social constructionists believe that knowledge is created and perpetuated by social exchanges (Gergen, 1985). As such, social constructionists argue that we should be aware that our knowledge of the world is not necessarily based upon objective, unbiased observations, but instead is influenced by socially developed norms, such as gender. It argues that how we understand the world is often based on our specific history and culture. Knowledge is then sustained and shaped through daily social interactions within these specific contexts. Knowledge is also linked to social action, such as the ways of treating people that are considered acceptable

(Burr, 2015). Therefore, the social world has a significant role to play in how we develop and sustain knowledge. In summary, I think that social constructionism aligns with the idea that we must consider the different views and perspectives that people might have of their post-stroke body image due to their unique life experiences and social environments.

Therefore, I feel that my conscious views best align with phenomenology (which recognises the importance of individual perspectives) within the context of social constructionism, whereby body image experience influences and is influenced by other people in society.

Identifying and outlining this epistemological perspective has been important, as it will have impacted how I decided to collect and analyse data (Jackson, 2013).

3.5. CHOOSING THE APPROPRIATE METHODS

I have used a hybrid mixture of perspectives throughout my thesis. To summarise the existing evidence around post-stroke body image experiences and maximise the findings by using different sources of evidence, I used a mixed methods systematic review (see Chapters 4 and 5). Systematic review methods are often aligned with positivist perspectives (Furunes, 2019). However, the mixed method approach aims to identify key concepts and how they are translated within and across studies, producinga synthesisis which is a new interpretation of the evidence. Then, I conducted interviews with people who had experienced a stroke. I used an IPA approach (Smith et al., 2009d), and drew on influences from phenomenology as part of a hybrid approach (see section 3.5.1). Finally, I used qualitative content analysis as part of my expert panel groups to categorise opinions of clinical experts. This approach also veers towards positivism by categorising data as opposed to attempting to interpret it beyond description. I reflect upon the epistemological perspectives within each respective chapter.

3.5.1 IPA approach

Aligning with my epistemological perspectives (see section 3.4) and to capture subjective, in-depth and individualised accounts of post-stroke body image experiences, a phenomenological and interpretative qualitative approach is required. This allows me to focus on the study of participant's experiences (phenomenology) whilst acknowledging my own role in understanding participants' understanding of the experience (interpretation). Initial reading and exploration of different methods led me to interpretative phenomenological analysis (IPA) as described by Smith et al. (2009d), which can be used to examine how people make sense of major life experiences (Smith et al., 2009d). There are theoretical, philosophical and practical justifications which provide a strong rationale for using the IPA approach from Smith et al. (2009d) in this thesis. These are outlined below.

a. Theoretical and philosophical justifications for using IPA

IPA is comprised of three theoretical perspectives: phenomenology, idiography and hermeneutics. Through the lens of psychology (relevant to my positionality), phenomenological philosophy provides a rich source of ideas for how to examine and understand lived experience. To expand on section 3.4, a core interest shared by phenomenological philosophers is thinking about what the ‘experience of being human’ is like, with particular focus on the things that are important to us and that make up our lived world (Smith et al., 2009d).

There are four main phenomenological philosophers: Edmund Husserl, Martin Heidegger, Jean-Paul Sartre and Maurice Merleau-Ponty (Smith et al., 2009d). Husserl is regarded as the founder of twentieth-century phenomenological philosophy (Macann, 1993). He has informed IPA through his focus on researcher reflection, namely that researchers should ‘bracket’ their lived experiences to be able to understand another person’s lived experience (Finlay, 2011; Smith et al., 2009d; Tuffour, 2017). This allows descriptions of experiences to be anchored to the data, without being subjected to outside influence (Tuffour, 2017). Husserl believed that if we could understand how someone comes to accurately know their own experiences, it might allow them to identify the essential qualities of that experience. These essential features of experience would then ‘transcend’, or go beyond, the circumstances and illuminate the experience for others too (Smith et al., 2009d). Husserl was focused on finding the essence of experience, but modern IPA attempts to capture particular experiences as experienced by particular people (Smith et al., 2009d).

Since Husserl introduced his theory, each subsequent phenomenological philosopher has added something to his ideas (Smith et al., 2009d). Where Husserl attempted to explore a person’s experience as separate from the world in which they live, Heidegger introduced the concept that people cannot be separated from their own personal world, establishing the term ‘Dasein’. In other words, people as ‘living beings’ cannot be separated from their experiences nor their activity of ‘being in the world’ (worldliness) (Cerbone, 2009; Heidegger, 1962; Horrigan-Kelly et al., 2016; Smith et al., 2009d). Therefore, people *exist* within their social context and experience shared interactions with the world, which must be understood (Heidegger, 1962; Horrigan-Kelly et al., 2016).

Sartre and Merleau-Ponty built upon these ideas and focused on understanding existence itself through ‘existential’ phenomenology (Langdridge, 2007). Sartre expanded on the concept of ‘worldliness’ by describing how human perceptions and experiences of the world are shaped by their relationships with others (Sartre, 1956; Smith et al., 2009d). Merleau-Ponty moved away from the concept of worldliness to instead describe how humans have an *embodied* relationship with the world and see themselves as different from everything else in it (Merleau-Ponty & Landes, 2014; Smith et al., 2009d). Collectively, the views of Heidegger, Sartre and Merleau-Ponty have culminated in a holistic phenomenology which informs IPA (Smith et al., 2009d; Tuffour, 2017).

However, the viewpoint of Merleau-Ponty best aligns with this thesis (Merleau-Ponty, 2010). Merleau-Ponty suggested that we do not simply perceive our body as an object in the world, but as our means of communicating with the world (Merleau-Ponty, 1962; Smith et al., 2009d). This idea has been expanded upon more recently to describe how the body is not just an object in the world that we see, touch and smell. Instead, it is viewed as a principle of experience that *allows* us to see, touch and smell. Our body is deeply involved in how we relate to the world, to others and to ourselves. Accordingly, the ideas underlying phenomenological theory describe how analysing the body is crucial for understanding the relationship between our minds and the world, between ourselves and others, and between our mind and body (Gallagher & Zahavi, 2008). Using phenomenology will therefore facilitate my attempts to understand how the post-stroke body is experienced and how it affects experiences. This aligns with the concept of exploring lived experience, or our lifeworld, that was emphasised by Merleau-Ponty (Langdridge, 2007).

Merleau-Ponty also described how we see ourselves as different from everything else in the world, which means how we relate to others begins from a position of difference. Therefore, we can never entirely share another person's experience as their experience belongs to their individual and personal *embodied* position in the world (Smith et al., 2009d). Merleau-Ponty is the best-known philosopher on embodiment (Gallagher & Zahavi, 2008), referring to the idea that our mind and body work in unity to express our intentions and give meaning to our behaviours (Merleau-Ponty, 2012; Moya, 2014; Smith et al., 2009c). In this way, the body adapts to our intended meaning and gives itself a type of embodied consciousness (Merleau-Ponty, 2012; Moya, 2014).

Aligning with the concept that we can never entirely share another person's experience (Smith et al., 2009d), IPA also relates to the ideas of Heidegger (see section 3.4) in that phenomenological inquiry is an interpretative process with importance placed on individual contexts and experiences (idiographic). By using IPA, the researcher gathers data on and makes sense of how a phenomenon appears (Heidegger, 1962; Smith et al., 2009d). Through IPA interviewing, we do not receive objective accounts of experiences from participants. Instead, we receive an experience that has been subjectively interpreted by the participant and which is affected by their personal perspectives, meanings, experiences, and values. The researcher must then try to interpret and make sense of these experiences to understand them. The participant's experience is considered as 'first-order', while the researcher's experience is 'second-order'. This leads into hermeneutics, which is the theory of interpretation (Smith et al., 2009d). My perspectives will be inherently involved in interpreting the phenomena and I acknowledge this as opposed to trying to bracket or side-line it (Heidegger, 1962; Smith et al., 2009d). In line with IPA, I will also need to be mindful of 'the hermeneutic circle'. Namely, to understand the part, you look to the whole and to understand the whole, you look to the parts. This will be relevant when iteratively analysing each interview; and when analysing all interviews together (Smith et al., 2009d).

Overall, Merleau-Ponty's view that the body shapes our knowing about the world is critical in IPA; the body and mind must be considered a central element of our experience (Gallagher & Zahavi, 2008; Smith et al., 2009d). This is my view too; that we cannot separate our body from our life experiences. This also reinforces the importance of understanding how people experience their body after a stroke, as their body or how they think about it may be altered. I want to explore individual experiences of post-stroke body image experiences whilst acknowledging that these experiences are shaped in the context of social constructionism. As a methodology, IPA, in the context of individual experiences aligns with phenomenology (Dabengwa et al., 2023). However, IPA does not fully align with phenomenology. Therefore, phenomenology has not been used in its strictest form but as a touchstone that has influenced my interpretation. This is further expanded upon in section 6.15.2.

b. Practical justifications

IPA also has practical strengths as a method. I drew from the stages of IPA that are outlined by Smith et al. (2009d), as they offer clear guidance on the different components and stages of analysis to facilitate thorough analysis of the data. However, and although critiqued by other phenomenologists such is Giorgi, the guidelines for this IPA approach are flexible and it can be considered as a craft or technique as opposed to a stringent method (Gill, 2020).

Using IPA facilitates development of themes and subthemes from the data (Smith et al., 2009d). This is important as it will provide the structure for my summary of post-stroke body image experiences.

Before deciding upon IPA, I considered different methodological approaches, the limitations of which provide further rationale for using IPA. Initially, I explored thematic analysis as it provided stages for data analysis, culminating in themes and subthemes from collected data (Braun & Clarke, 2006). Reflexive approaches to thematic analysis, such as those by Braun and Clarke (2006) would have most aligned with the exploratory nature of this thesis (Braun & Clarke, 2021). Similar to IPA, this approach recognises analysis as a subjective process requiring a researcher who reflects on their assumptions and their role in the analysis (Braun & Clarke, 2021). Therefore, reflexive thematic analysis can be used to explore experiences of a phenomena. It would share alignment with my epistemological perspective, through supporting exploration of how personal experiences (phenomenological aspects) are located in wider socio-cultural contexts (aligning with socio-cultural perspectives) (Braun & Clarke, 2021). In thematic analysis, themes are developed across cases after coding the full data set (Braun & Clarke, 2021). However, the strength of IPA lies in the fact that it can be used to place greater emphasis on individual experiences, as it involves detailed focus on each participant before developing themes across participants (Braun & Clarke, 2006).

Additionally, while reflexive thematic analysis would have facilitated development of my summary of post-stroke body image experience, thematic analysis is also typically viewed as a more simplistic form of analysis. It is not associated with any pre-existing theoretical frameworks within which to anchor analytic claims. This means that it risks having limited interpretative power beyond description (Braun & Clarke, 2006). This does not match the level of depth and detail required for the aims of my thesis.

Comparatively, Grounded Theory is an approach which uses existing theoretical frameworks (e.g. see Glaser and Strauss (2017) methods) and can be used to inductively produce a theory (Glaser & Holton, 2004). While this would support creation of my summary of post-stroke body image experience, a core principle of traditional grounded theory requires the researcher to keep their knowledge of the literature separate from data collection and the analysis, so that it does not influence interpretation of the data (Glaser, 1992; Timonen et al., 2018). This situates the researcher and the participants as separate from existing knowledge (Mills et al., 2006) I intend to use knowledge gained from my systematic review to help me to understand post-stroke experiences and iteratively inform my interview schedule. This conflicts with the principles of Grounded Theory.

The most common approach to Grounded Theory used in Psychology (aligning with my background in Psychology) is that by Charmaz (2000) (Smith et al., 2009g) and is constructivist Grounded Theory. It involves co-construction of data between participant and researcher, whereby the researcher has a role in understanding the participant’s experience and the meaning of the data collected (Charmaz, 2000). It would have facilitated the development of an explanatory level account of post-stroke body image experiences across participants, including its impacts and experiences (Smith et al., 2009f). However, IPA was chosen as it focusses on exploring personal meaning and sense-making for people who share a particular experience (e.g., exploring experience of body image in people with stroke) (Smith et al., 2009f). This felt more suited to the exploratory nature of the thesis and for carrying out initial explorations of post-stroke body image experiences. Future research could take a Constructivist Grounded Theory approach to build the evidence base now that this thesis presents the initial evidence.

Finally, I considered using hermeneutic phenomenology as outlined by van Manen (1990). This is because hermeneutic phenomenology focuses on understanding the structure of meanings in human experiences (Ho et al., 2017; van Manen, 2007), making it relevant to the aims of this thesis. The focus for researchers using hermeneutic phenomenology is to reach an in-depth level of co-construction of meaning with participants. This is achieved by focussing on the hermeneutic circle of understanding (Laverty, 2003). Rather than achieving this level of co-participation, I intend to acknowledge the inevitable influence that my views and opinions will have on my interviews and their analysis, without seeking to achieve this level of joint meaning-making. This is because I feel that this may detract from the views of stroke survivors, which are central to my thesis. However, IPA does recognise the importance of hermeneutics (as outlined earlier), so this concept is not lost completely.

In terms of the practical undertaking of hermeneutic phenomenology, van Manen provides an outline approach for interview analysis (Mitchell-Levy, 2018). However, this is less structured than the outline provided for IPA by Smith et al. (Smith et al., 2009d). From my perspective as a novice researcher, only a series of analysis activities are outlined in hermeneutic phenomenology, compared to the set structure provided by IPA (Smith et al., 2009d; van Manen, 1990). Therefore, I was unsure whether hermeneutic phenomenology would provide any methodological advantage over IPA. It has been argued that the focus of IPA is on encouraging participants to make sense of their life experiences, which is more akin to therapy than to phenomenology (van Manen, 2017). Smith's ideas of IPA have been criticised as being more appropriately viewed as 'Interpretative *Psychological* Analysis'. This is due to him appearing to interpret phenomenological terms such as 'lived experience' in a psychological manner; focussing on the person, their views and understanding, and their personal experience rather than the phenomenon under investigation (van Manen, 2017). However, this is the purpose of this thesis; to understand personal experiences of body image post-stroke. Therefore, while this concept of 'psychologising' IPA may be viewed as a disadvantage by some researchers, it aligns with my worldview and the aims of this thesis and may be advantageous in this work. Therefore, while hermeneutic phenomenology shares commonalities with the aims of the thesis in terms of exploring experience, and also with my epistemological perspectives, I believe that IPA represents a better fit with my personal worldview.

As a method, IPA has been criticised for giving insufficient recognition to the role of language; the same event could be described in multiple different ways by different people. This means that an interview and subsequent analysis could actually be telling us more about the way an individual talks about an experience as opposed to the *actual* experience (Tuffour, 2017; Willig, 2008). However, Smith argues that experience is intertwined with language (Smith et al., 2009d; Tuffour, 2017). Throughout this thesis, it is the subjective nature of body image that is important. Therefore, in my opinion, while we should recognise that language use contributes to the uniqueness of how an experience is recounted, it also adds depth to our understanding of each experience as unique to that individual.

Overall, using IPA encourages detailed analysis of qualitative data to examine participants' unique experiences, whilst facilitating development of themes and sub-themes displaying commonalities across participants. I have drawn upon the IPA approach outlined by Smith et al. (2009d) to carry out and analyse my interview study.

3.6. RIGOUR

Rigour and truth are crucial in all aspects of research (Houser, 2013). Trustworthiness is a central concept for rigour (Cypress, 2017; Lincoln & Guba, 1991). Considerations of the quality of the research undertaken will be addressed in more detail in the individual study chapters. In some cases, the approaches used to address rigour may seem at odds with phenomenology and/or social constructionism, but this will be discussed in the individual chapters.

3.7. SUMMARY

In this chapter, I have presented my researcher positionality, worldview and my ontological and epistemological perspectives. This is to provide transparency around factors which may influence my research and choice of data collection methods. As such, I then discussed why IPA was the most appropriate method of data collection and analysis for the thesis. Ultimately, evaluating the strengths and limitations of and exploring alternative methods to my approaches have supported my reasoning for using them.

Overall, I have taken a blended and hybrid approach in relation to the epistemological perspectives throughout the thesis. I will explore the tensions of this within Chapter 8 (section 8.4) when I reflect upon the process of completing my thesis.

4. CHAPTER 4: METHODS FOR A MIXED METHODS SYSTEMATIC REVIEW EXPLORING POST-STROKE BODY IMAGE EXPERIENCE AND METHODS OF ASSESSING IT

4.1. INTRODUCTION

In the previous chapter, I presented my worldview and perspectives to facilitate transparency of the methods used throughout this thesis. In this chapter, I present the methods for a mixed methods systematic review of published and grey literature on post-stroke body image experiences. This will be followed by the results, which follow a narrative synthesis approach (Popay et al., 2006) in Chapter 5. This Chapter and Chapter 5 have been written with consideration of the systematic review reporting guidelines in the Cochrane handbook for Systematic Reviews of Interventions (Cumpston et al., 2022) (with additional information from the Methodological Expectations of Cochrane Intervention Reviews (MECIR) manual (Churchill et al., 2022)), the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines (Tong et al., 2012) and to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses-P (PRISMA) statement (Page et al., 2021). Reflections on the quality of the methods used and their alignment with my epistemological perspectives are presented in section 5.8.5.

4.2. RATIONALE FOR CONDUCTING A MIXED METHODS SYSTEMATIC REVIEW

While the literature specifically exploring post-stroke body image experience is sparse, findings do show that body image can be impacted after a stroke (e.g., (Keppel & Crowe, 2000; Stott, 2019). However, what is unclear is:

- How is body image experienced after stroke and what is its impact on wellbeing and recovery?
- How to appropriately assess any benefits of body image intervention post-stroke?

We also know that the existing evidence around body image experience after stroke comprises both qualitative and quantitative studies. Therefore, to capture all relevant findings, a mixed methods approach was adopted (Sandelowski, 2000). A mixed methods systematic review can be defined as:

> “combining the findings of qualitative and quantitative studies within a single systematic review to address the same overlapping or complementary review questions.” (Harden, 2010, p.7)

The use of mixed-methods research has been advocated as a versatile design Sandeldowski (2000). Therefore, based on methods described by (Harden, 2010) and (Harden & Thomas, 2005), the approach taken was to integrate the quantitative findings with a more qualitative understanding of people's lives. This is further outlined in section 4.5.5.

4.2.1 Theoretical and philosophical justifications

Whilst a mixed methods systematic review does not adhere to phenomenology or social constructionism, as quantitative evidence is underpinned by positivism (Furunes, 2019), given the sparse evidence base, exploring all available evidence seemed appropriate despite a tension between my Epistemological perspectives . I will further explore this tension in my reflective chapter (see section 8.4).

4.2.2 Practical justifications

From a practical perspective and to fill the identified gaps in knowledge, a systematic approach, as opposed to a scoping review, was identified as the most appropriate method. Scoping reviews are typically used to identify areas for a future systematic review (Lockwood et al., 2019). They allow mapping of the existing literature (Daudt et al., 2013; Munn et al., 2018) and use a less stringent and specific protocol than systematic reviews, permitting a more flexible approach to exploring the literature that already exists in an area (Lockwood et al., 2019). However, scoping reviews do not necessarily facilitate a detailed description of the findings due to being broad (Arksey & O'Malley, 2005) and not attempting to answer a specific research question (Munn et al., 2018). A scoping review would be a more appropriate method to use if it was unclear where the research gaps were, what the typical sources of evidence were for this topic (Daudt et al., 2013), or whether there was sufficient literature to conduct a systematic review (Arksey & O'Malley, 2005). A scoping review also does not usually involve assessing the quality of the evidence (Arksey & O'Malley, 2005; Munn et al., 2018), which was important for considering the existing evidence (see section 1.6).

In contrast, Cochrane provides the following definition of a systematic review:

> "A systematic review attempts to identify, appraise and synthesise all the empirical evidence that meets pre-specified eligibility criteria to answer a specific research question." (Cochrane, 2022a)

Explicit and systematic methods are used to minimise bias and produce more reliable findings to inform decision-making (Cochrane, 2022a). This will create a picture of the existing evidence in relation to the research questions and will have value in informing decision-making by also considering the quality of evidence.

Cochrane is ‘internationally recognized as the benchmark for high-quality information about the effectiveness of health care’, with focus on providing trusted and accessible synthesised evidence (Cochrane, 2022b). The PRISMA reporting guidelines are advocated by Cochrane to ensure that each aspect of the review is clearly documented and reproducible (Cochrane, 2021). The Cochrane recommendations mostly relate to reviews of the effectiveness of interventions (Chandler et al., 2022). However, because the methods are considered gold standard, with minor modification, these will be followed for the observational studies included in this review. Accordingly, the review questions have been developed using the Population/Patient/Problem, Intervention, Comparison and Outcome (PICO) model (see Table 4.1) to ensure that they are well-formulated and clear (Cochrane Library, 2022; Medical College of Wisconsin Libraries, 2022).

An existing scoping review exploring current knowledge and understanding of changes to body perception experiences after stroke is available in thesis format (Stott, 2019). However, whereas my thesis focuses on psychosocial factors involved in body image experience, the authors of the scoping review *excluded* studies which focussed on psychosocial factors, instead focussing on bodily experiences (Stott, 2019). The current review will focus on body image as opposed to body perception (see section 2.1.2 for description of terminology).

4.3. OBJECTIVES

The original systematic review objectives were to identify for adults after stroke:

1. What is the frequency of negative body image perception?
2. What are their lived body image experiences and what is the impact of negative body image perception on stroke recovery?
3. What tools are available or have been validated to assess body image?

However, as the review progressed, it became clear that particularly for the qualitative papers being identified, data were not reported specifically around ‘negative’ body image. Therefore, the review questions were iteratively updated to the following:

For adults with stroke:

1. How is body image experienced?
2. How does body image impact recovery?

3. What methods and/or tools are available, have been used or have been validated to assess body image experiences and/or perceptions specifically for this population?

The review protocol was published online for transparency through the Centre for Open Science (OSF) (Centre for Open Science, 2022). It was split across two smaller protocols; one representing lived experiences of body image experience (Davidson et al., 2020b) (OSF identification number: fejvq) and one representing identification of methods of assessing post-stroke body image experience (Davidson et al., 2020a) (OSF identification number: b43um). The published protocols also reflect the changes made to the review process.

Table 4.1 presents the PICO (Oregon Health & Science University, 2022) for each question. There was no 'Comparator' for any of the review questions.

Table 4.1. *Population/Patient/Problem, Intervention, Comparison and Outcome (PICO) model (Oregon Health & Science University, 2022) for Each Review Question*

Review question	Population/ Patient/ Problem	Intervention (or cause or prognosis)	Outcome
1	In adults with stroke…	…how has their stroke…	…impacted on their body image experiences?
2	In adults with stroke…	…how has their body image experience…	…impacted on their recovery?
3	In adults with stroke…	…what methods and/or tools are available, been used, or been validated…	… to assess body image experiences and/or perceptions specifically for this population

4.4. METHODS

4.4.1 Criteria for considering studies for inclusion in the review

a. Condition or domain being studied

Stroke and body image were the focus of this review. As described in section 1.1, stroke is usually defined as "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" (Aho et al., 1980) with imaging that is compatible with ischaemic stroke or intracerebral haemorrhage (including those with normal CT scans). For the purpose of this review, the study authors' definition of stroke was accepted. Transient Ischaemic Attack (TIA) or 'mini-stroke', was also included and is defined as neurological dysfunction and stroke-like symptoms, lasting less than 24 hours and caused by focal brain ischemia (National Health Service (NHS), 2020b; National Institute for Health and Care Excellence (NICE), 2021). Justification for including TIA within the thesis is described in section 1.1.

As outlined in section 2.1 body image is a multidimensional construct encompassing perceptions, thoughts, feelings, and behaviours, in relation to the body's appearance, functions, and capabilities (Cash & Pruzinsky, 2002; Grogan, 2016; Grogan, 2021). Crucially, to be included, a study had to provide data which related to how the body or bodily changes were impacting someone in terms of their body image. For example, evidence which was only related to function, and which did not provide data on how function impacted upon perceptions, thoughts, feelings or behaviours would not be eligible. Detail around how each aspect of body image is defined is provided in section 2.1 and is adhered to in this review.

Where study authors defined body image, their definition was accepted if it at least partially aligned with this thesis definition and was related to lived experience of body image. Studies were also reviewed for eligibility where authors did not define body image, but the results were relevant to the thesis definition. This is because there is sometimes ambiguity around terms related to body image as outlined in section 2.1.2. Studies which did not explore lived body image experience, such as where only neurological aspects of body image or body schema were explored, were excluded.

b. Types of studies

Primary research (use or collection of original data) using qualitative, quantitative, or mixed methods to explore body image perception after a stroke was eligible for inclusion. Research included may have been conducted in any setting (e.g., hospitals, community, or rehabilitation) where participant recruitment was prospective, consecutive, or used convenience sampling. There were no restrictions on country, language, or year, as long as papers (e.g., journal articles, reports, and evaluations) were published. Case studies with four participants or fewer (Schoch, 2020), audits, opinion/commentary or discussion papers, protocols, reviews, letters, books and editorials were ineligible, although the reference list of relevant articles (see section 4.4.3.b) were searched. Research that only explored carer, relative, friend or NHS staff perspectives and did not consider stroke survivor perspectives was excluded.

c. Types of participants

Research was included if participants were adults aged 18 years or over who had experienced a stroke. Their stroke could have occurred within any time frame and be their first or subsequent stroke. To be able to understand and explain how their bodily changes had affected them and their perception of their body image, they needed to be aware of the changes experienced. Therefore, studies whose primary focus was on the experiences of those whose accurate self-appraisal had been impacted e.g., due to anosognosia, were excluded.

Studies involving only people with subarachnoid haemorrhage were excluded, due to subarachnoid haemorrhage having a different aetiology, prognosis and management to other types of stroke (National Health Service (NHS), 2018). There were no restrictions based on sex or other characteristics. Studies of mixed populations, such as stroke and acquired brain injury or subarachnoid haemorrhage, required results for participants with stroke to be available separately. Where the data were not presented separately, the author was contacted. If the data for stroke could not be extracted separately, the study was excluded.

d. Types of outcome measures

Study data needed to include one or more of the primary outcomes.

Primary outcomes

For adults after stroke:

- Identification and description of how body image is experienced
- A summary of lived experiences of body image and their impacts on recovery
- Identification of any tools, measures, or methods (referred to as assessment methods), including individual sections, domains or questions, that have been used to collect data with the purpose of exploring body image experiences or perceptions after stroke

The primary outcomes initially aligned with the original review questions. After updating the review questions, the primary outcomes (as presented above) were also updated to reflect the changes made.

Outcomes were kept broad due to the exploratory nature of the review. To address the review questions, outcomes were derived from studies which considered the lived experiences of body image in stroke survivors. Lived experience refers to how people's unique perspectives and experiences are shaped by subjective aspects of their identity, such as gender and race, which affects how they live their daily lives (SAGE Research Methods, 2008).

Secondary outcomes

The following outcomes in relation to exploring or describing post-stroke body image were also of interest in case they related to body image experiences:

- Psychological wellbeing
- Function
- Quality of life

4.4.2 Search methods for identification of studies

The search methods for this review, including a comprehensive search strategy, were developed and reviewed with support from a Faculty Information Specialist[A]. The supervisory team approved the final strategy and the Faculty Information Specialist assessed the strategy using the PRESS Peer Review of Electronic Search Strategies assessment (McGowan et al., 2016) (see Appendix 1). To develop the search strategy, the Cochrane terms for ‘body image’ and those most relevant to ‘stroke’ were used. Acquired brain injury, broadly defined as any injury caused to the brain since birth, was added as a search term as there is wider research that explores body image perception in individuals who have an acquired brain injury which includes people with stroke (e.g., (Headway, 2020; Howes et al., 2005a; Howes et al., 2005b)). Further terms were added based on additional reading and the MeSH terms and keywords identified from some of the most relevant papers already identified (e.g., (Keppel & Crowe, 2000)).

The search strategy for all databases was modelled on the strategy designed for MEDLINE Ovid (see Appendix 2). A combination of syntax methods were used in the search to reduce the likelihood that word variances were missed (see Appendix 3). All stroke-related terms were combined with ‘OR’, as were all body image terms. The final strategy then identified studies with any of the terms related to stroke ‘AND’ body image.

a. Electronic searches

The Cochrane guidelines (Higgins et al., 2019), Joanna Briggs Manual for Evidence Synthesis (Aromataris & Munn, 2020) and other methodological guidelines were followed where possible. The following electronic databases were searched from inception:

[A] Mrs Catherine Harris, Information Specialist, UCLan

- MEDLINE (Ovid) (last searched 02/09/2020)
- EMBASE (Ovid) (last searched 02/09/2020)
- CINAHL (EBSCO) (last searched 02/09/2020)
- PsycINFO (EBSCO) (last searched 02/09/2020)
- The Cochrane Library (last searched 02/09/2020)

Searches were originally run in April 2020 and were updated on the above dates before screening. Appendix 2 shows all search strategies, including the original number of hits and the number identified by the re-run searches. No limits or filters were placed on the searches.

4.4.3 Searching other resources

a. Grey literature

To make the search as comprehensive as possible and to try and reduce the effects of publication bias on the results (Song et al., 2013), grey literature was searched in a systematic way for relevant findings. Grey literature refers to documents other than published primary research papers, such as but not limited to, theses and conference proceedings (Alberani et al., 1990). Grey literature was identified using the same methods as in the main searches, but with simplified search terms, across: Ask Doris, EThOS, Google (first 100 search results), NICE (NHS) Evidence Search, OpenAccess theses and dissertations, OpenGrey, OTSeeker Database for Occupational Therapy Research and The King's Fund. This strategy (see Appendix 4) was approved by the supervisory team and the Faculty Information Specialist.

b. Reference lists

The reference lists of all included studies, and also articles which met all aspects of the inclusion criteria except for not being primary research (e.g., opinion articles, reviews), were searched for additional papers that may have met the inclusion criteria.

4.5. DATA COLLECTION AND ANALYSIS

4.5.1 Selection of studies

All research articles (titles and abstracts) identified from the search were imported into EndNote (or Microsoft Excel for grey literature articles where citations were not readily available for download), and duplicates removed. Titles and abstracts were screened by one author (CD) according to the eligibility criteria and those which were irrelevant were excluded. Full text articles were retrieved for those which appeared relevant and examined for compliance with the eligibility criteria. If there was uncertainty over eligibility, advice was sought from a second reviewer (e.g., DoS) and/or members of the supervisory team as required (e.g., if there were disagreements). We wrote to authors of studies where more information was required to confirm eligibility (e.g., if a full text could not be located). Translation of potentially eligible articles was performed, where necessary, by people fluent in the respective language[B]. Where not possible Google Translate was used. Only research with a publication, report or evaluation was included in the review.

a. Multiple publications

Where potentially eligible abstracts or papers appeared to correspond with other eligible papers, they were cross-referenced to identify if they reported data from the same cohort. Where this was the case, one ‘name’ was used for the study, but study data may have been extracted from multiple sources.

b. Documenting excluded studies

The main reasons for studies being excluded are documented in the PRISMA diagram (see section 5.3).

4.5.2 Data collection and management

Data extraction and quality assessment (see section 4.5.3) were completed simultaneously by one author (CD[C]). Data relevant to the review questions were extracted using review-specific extraction forms. One form was developed for qualitative research and another for quantitative research. For mixed methods research, the extraction form for the methods that most aligned with the review questions was used. The forms were piloted and updated accordingly. Then, second reviewers (EJH[D] & NL[E]) completed independent data extraction of two qualitative and two quantitative papers using the forms. Each extraction was discussed and compared iteratively. Working with second reviewers allowed improvements to be made to the data extraction forms. After these two independent extractions, agreement was reached that the extractions were similar, so the second reviewers (NL, CG[F] & LL[G]) then verified all subsequent data extractions. Disagreements were discussed and any that could not be resolved were taken to a member of the supervisory team.

[B] Translators: Dr Robert Kasza, Senior Lecturer in Japanese, UCLan; Dr Svetlana Tishkovskaya, Senior Lecturer in Health Statistics and Statistician at Lancashire Clinical Trials Unit

[C] Miss Catherine Emma Davidson, PhD Student, UCLan

[D] Dr Emma-Joy Holland, Research Associate, UCLan

[E] Miss Naomi Lynden, Research Assistant, UCLan

[F] Dr Clare Gordon, Senior Research Fellow, UCLan

[G] Professor Liz Lightbody, Professor of Stroke Care and Improvement, UCLan

Qualitative and quantitative data extraction forms included information about:

- The report: full reference, publication type
- The study: purpose, country
- The participants: sample characteristics e.g., demographics, inclusion/exclusion criteria, sample size
- The research design and features: methods, sampling, analysis methods
- Stroke information: type of stroke, time since stroke, stroke sequence (first ever vs recurrent), stroke-related impairments
- Study outcomes
- Body image information: how was it assessed?
- Results relating to post-stroke body image experiences
- Study strengths, limitations, and conclusions as expressed by the study authors

Where a body image tool was used in a research project, information was extracted on:

- The full and abbreviated names of the body image tool
- Format of tool e.g., scale questions, drawing
- Number of items in the tool, including names of any domains or sections
- Which items from the tool are used to assess body image perception?
- Timeframe for tool e.g., looks at body image over the last [x number of] weeks
- Has the tool been validated for use in/by people with stroke or any other population?
- Strengths and limitations of the tool identified by the study author

If no information around validation was reported in the paper, it was assumed that the tool had not been tested for validity in a stroke population because the systematic review searches should have retrieved the paper. However, a Google search for each tool was conducted alongside ‘stroke’ and ‘body image’ to ensure a paper testing validity in stroke had not been missed.

If several articles had reported outcomes from the same study population, data would have been taken from the first publication that referred to each follow-up period. If multiple measures had been used to assess any of the outcomes at the same time-point in the same sample, data would have been included from the sample with the largest denominator. If the denominator had been the same for both measures, data from the assessment with the highest proportion of participants experiencing the outcome of interest would have been included.

Multiple papers pertaining to one study were classed as one study, and data extracted from the richest source, with additional relevant information extracted from the other sources where appropriate. For example, where an abstract related to a published paper, they were classed as one study and data extracted from the paper. Where an abstract and/or paper were based on a thesis/dissertation, they were classed as one study and data extracted from the thesis/dissertation. This was to collect as much detail as possible in relation the included evidence.

4.5.3 Assessment of risk of bias and quality assessment in included studies

Quality assessment was implemented based on the guidance provided by Popay et al. (2006) to assess the robustness of the review synthesis . Robustness refers to:

> "the methodological quality of the primary studies included in the review and/or the trustworthiness of the product of the synthesis process" (Popay et al, 2006, p.15)

Quality assessment was important, if studies were included that were of poor quality and this not critiqued, it would affect the trustworthiness of the synthesis. To follow recommendations made by Popay et al. (2006), three areas of robustness were considered:

- The quality and quantity of the evidence base that it is built on (see section 5.7 for quality assessment)
- Methods used to minimise bias (see section 5.7 for quality assessment)
- The extent of the detail provided by reviewers as to why individual studies meet the inclusion criteria (see Appendix 6)

Addressing these elements allows assessment of whether robust conclusions can be drawn from the results, and whether, where applicable, results can be generalised to different population groups and/or contexts (Popay et al., 2006).

Therefore, the risk of bias and quality of studies meeting the inclusion criteria was assessed using forms relevant for the research method (qualitative, quantitative or mixed). Where study authors used multiple research methods, the assessment method used depended on the method most aligned with the aim of the paper. These were; the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (CASP, 2018b) or the CASP Cohort Study Checklist (CASP, 2018a). Where appropriate, risk of bias was graded and is reported in 'risk of bias' tables. Grey literature was quality assessed using the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist (Tyndall, 2010).

Each paper was assessed, with a second reviewer (LL, CG or NL) checking the decisions. If a consensus was not reached, input was sought from a third reviewer. Quality and risk of bias for all included research are reported in tables and figures and are summarised in section 5.7. To support the trustworthiness and robustness of the conclusions drawn from the review, the implications of the quality of included studies are discussed in section 5.7.2. No research was excluded based on quality. If any studies had been identified which determined the validity of body image tools for use with people after stroke, they were assessed using the COSMIN checklist (Mokkink et al., 2018).

4.5.4 Dealing with missing data

Where a full paper could not be located for a study (e.g., where a relevant title or abstract was identified but not a corresponding paper, or where only a conference abstract had been found), or where a full paper had data missing, author contact was attempted. This was initially with first authors or the author whose details were provided on the paper for correspondence. If these details were unavailable, contact was attempted with the next author for whom contact details could be found. Contact was attempted up to three times by email, or via ResearchGate, for each paper. Where papers did not report the mean or range for required descriptive statistics (e.g., age, time since stroke), these were calculated where possible from data presented in the paper.

a. Assessment ongoing tables

Appendix 5 summarises (Lefebvre et al., 2021):

- Studies for which missing data could not be obtained
- Ongoing trials where results were not yet available
- Studies that seemed to meet the eligibility criteria, but for which data were incomplete or the related record could not be obtained

These are classed as papers that are awaiting assessment. The information that could be located about each paper (e.g., title, abstract and/or full-text) was screened to see if the paper could be eligible. However, eligibility could not be confirmed for one or more of the following reasons:

- Full-text could not be located and eligibility unclear from abstract; or results/data not presented in abstract
- Access to results specific to stroke was required (e.g., study included a mixed sample)
- Access to results specific to body image experience was required

Therefore, these papers could not definitively be excluded, but not enough information was available.

Missing data were not imputed.

4.5.5 Data synthesis

To draw conclusions from the evidence, quantitative data was synthesised using a combined statistical pooling approach and narrative approach was planned for qualitative data (Popay et al., 2006). There is a lack of clarity around integrating qualitative and quantitative methods within a systematic review (Thomas et al., 2004). However, the Evidence for Policy and Practice Information and Co-ordinating Centre, which is committed to informing policy and professional practice with sound evidence, propose the following stages (Evidence for Policy & Practice Information Centre, 2019; Thomas et al., 2004):

a. Meta-analysis of quantitative data
b. Synthesis of qualitative studies
c. Bringing the two sets of studies together

To follow these stages, qualitative and quantitative findings were extracted, quality assessed and synthesised separately. The synthesis plan is presented below.

a. Quantitative Data: Meta-analysis

The intention for the quantitative results was to conduct subgroup analyses and to meta-analyse the data using random effects to pool point estimates and present them with 95% confidence intervals.

b. Qualitative Data: Thematic Synthesis

For the qualitative data, a narrative approach, drawing from Popay et al. (2006)'s guidance of conducting narrative synthesis was used (Ryan et al., 2018). Narrative synthesis involves:

1) developing a theory of how the intervention works, why and for whom

2) developing a preliminary synthesis of findings for included studies
3) exploring relationships in the data and;
4) assessing the robustness of the data.

Stage 1 was not followed as it did not relate to the aims of this review (Popay et al., 2006). Stages 2-3 were addressed using a thematic analysis approach (thematic synthesis) and Stage 4 is addressed in section 5.7. Thematic synthesis is a method of thematic analysis specifically for using in a review when the research question relates to experiences. It has three stages (Ryan et al., 2018; Thomas & Harden, 2008):

1) Free line-by-line coding of the findings of primary studies
2) Organisation of these 'free codes' into related areas to construct 'descriptive' themes (completed in NVivo and discussed with Director of Studies)
3) Development of 'analytical' themes.

Therefore, under the umbrella of the narrative synthesis approach outlined by Popay, a thematic synthesis was used to produce a summary of findings through identifying and bringing together the main themes arising from the literature (Mays et al., 2005; Thomas & Harden, 2008).

Stages 1 and 2 of the thematic synthesis involved staying close to the data from the original findings of the included studies in order to create a list of themes that described experiences of body image post-stroke. This was done by adding descriptive codes to the extracted findings across each primary study in NVivo and then grouping the codes from across studies into themes.

For stage 3, the themes were explored and honed to make sure that they told an analytical story of the data to present existing findings of experiences and impacts of post-stroke body image. This was a cyclical process that was repeated until a list of final themes had been developed which described the initial descriptive themes (Thomas & Harden, 2008). The DoS and supervisory team agreed the final themes were sufficiently representative of the data.

c. Combining the quantitative and qualitative data

In line with the mixed methods synthesis approach, the plan for the quantitative and qualitative data was to combine them into a narrative description. Using this approach, the quantitative findings would structure the summary, and qualitative views be weaved through as appropriate to demonstrate explanatory and analytical themes (Harden & Thomas, 2005).

d. Summary of findings

A summary of the results is presented. Within this, the qualitative results are presented as themes to tell the story of the data. Study data are also summarised in the following tables:

- Records awaiting assessment (Appendix 5)
- Tables of all records (including body image terminology and inclusion rationale) (Appendix 6)
- Main results summary tables (Appendix 7)
- Summary of bodily changes reported (Appendix 8)
- Methods of assessing post-stroke body image experience identified from the systematic review (Table 5.2)
- Quality assessments of included papers (Tables 5.3-5.5 & Figures 5.3-5.4)

4.5.6 Rigour

Although there is no commonly implemented way of assessing the quality of the thematic synthesis , a 15-point quality checklist by Braun and Clarke (2006) for use with thematic analysis was adhered to. Depending on the studies identified, the rigour of any quantitative synthesis would be assessed using the Meta-analysis Of Observational Studies in Epidemiology (MOOSE) guidelines (Stroup et al., 2000). Reflection on rigour is presented in section 5.8.5.e.

4.6. SUMMARY

In this chapter, I have presented the methods for a systematic review to explore published and grey literature on post-stroke body image experiences. In the next chapter, I will present the results of this mixed methods systematic review.

5. CHAPTER 5: RESULTS OF A MIXED METHODS SYSTEMATIC REVIEW EXPLORING POST-STROKE BODY IMAGE EXPERIENCE AND METHODS OF ASSESSING IT

5.1. INTRODUCTION

In Chapter 4, I presented the methods for a systematic review exploring post-stroke body image experience and methods of measuring it. In this chapter, I present the results of the review. They are presented as narrative syntheses to provide an overall summary of the literature, as the data did not lend themselves to meta-analysis. I also provide a summary of body image tools, measures or methods used (directly or indirectly) to assess body image post-stroke. Then, I will present quality assessments for each paper to contextualise the findings in light of study quality and strength of evidence.

5.2. PRESENTING THE QUALITATIVE AND QUANTITATIVE RESULTS SEPARATELY

As outlined in section 4.5.5, the plan was to separately analyse the qualitative and quantitative results before combining them. However, during the analysis process, it became clear that the quantitative and qualitative findings addressed different concepts. The views and experiences expressed by participants in the qualitative studies did not align with the more discrete scale scores collected through the quantitative studies. Therefore, it did not make sense to try and combine them as there was no overlap in the data. So, the qualitative and quantitative findings have been summarised separately (see sections 5.4 and 5.5).

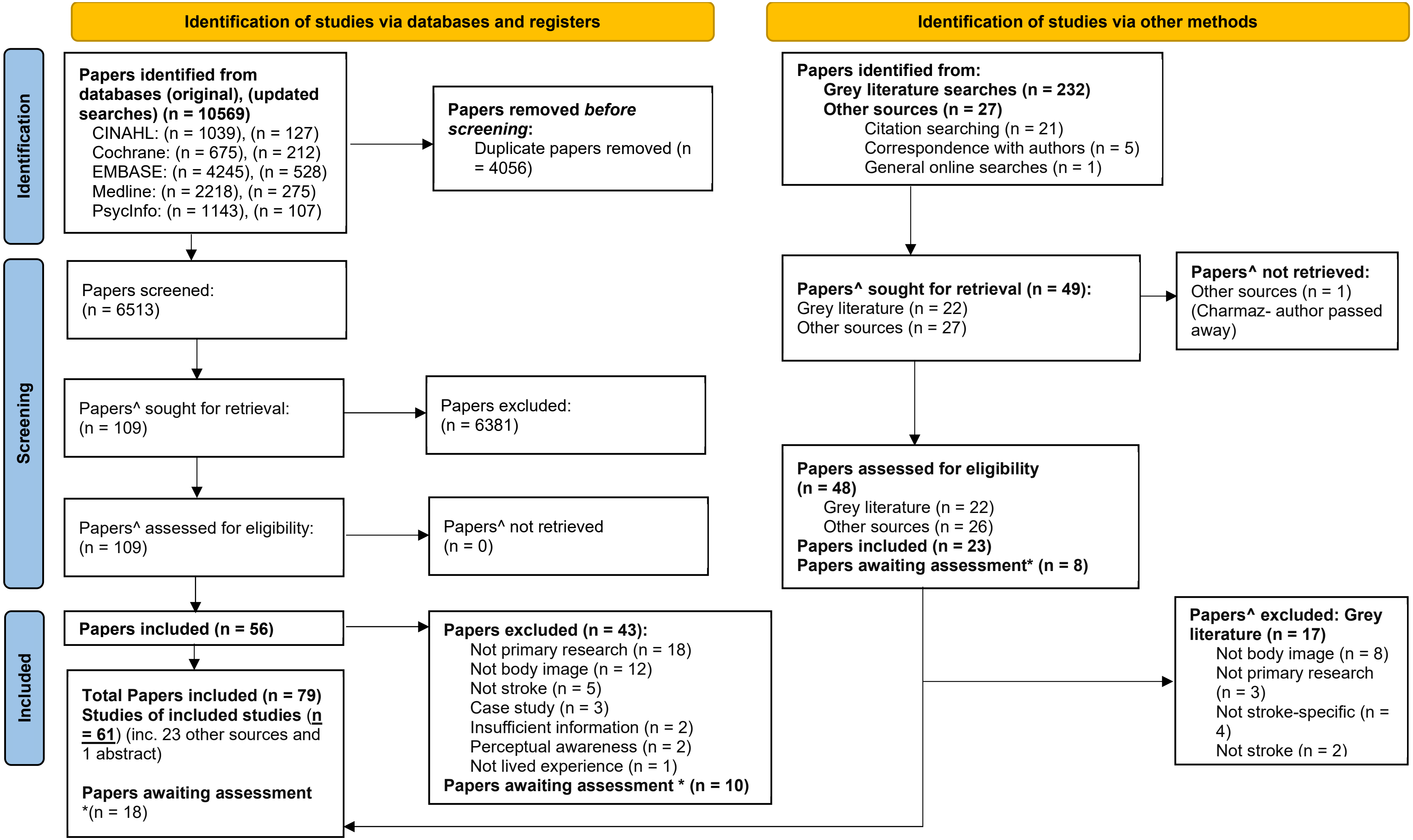
Also, in relation to the quantitative data, there was variability between the measures and scales used and what they were measuring. Therefore, it was not appropriate to combine the numerical results or to use a detailed statistical approach. Instead, findings are presented in narrative summaries. These findings were developed using a thematic synthesis approach as used for the qualitative data (see section 4.5.5.b). Data from different variables were extracted as 'themes' in the same way as conceptual themes were created from the qualitative synthesis (Mays et al., 2005; Popay et al., 2006). Although typically associated with qualitative data, thematic synthesis is particularly useful for quantitative data where there is heterogeneity in outcome variables and measurements, as is the case for the quantitative data from the current review (Ryan et al., 2018).

5.3. DESCRIPTIVE SUMMARIES OF INCLUDED STUDIES

Overall, 10569 papers were identified, and 4056 duplicates removed. The remaining 6513 papers were screened on title and abstract and 6381 were excluded. One hundred and nine full texts were sought for retrieval. An additional 23 papers of interest were identified through the grey literature searches and 27 through other sources (citation searching, author correspondence, general online searches).

Twenty-one authors were contacted to request additional information. Fifteen either did not respond or information received led to exclusion. Six studies were included and one author (Soumya et al., 2019) suggested an alternative paper published after the search dates which was subsequently deemed eligible (Sadanandan et al., 2020). Papers which could not be located and are awaiting assessment to determine eligibility or are where required data could not be obtained (n= 18) are presented in Appendix 5. In total, 157 papers were screened. The PRISMA diagram (see Figure 5.1) presents the numbers of papers excluded at each stage of the review, with justifications. Multiple papers pertaining to one study were classed as one paper. Across study types (qualitative, quantitative, and mixed methods), where a paper represents multiple studies, the largest sample size presented from those studies has been used in calculating total participant numbers. In total, 79 studies relating to 61 papers were included. Forty-seven were qualitative involving 864 participants, ten were quantitative involving 585 participants and four were mixed methods and included 79 participants (see Appendix 7). The number of participants in each study ranged from 5 to 151, age ranged from 14 to 93 years, and time since stroke ranged from 0 days to 25 years. Participants were recruited from hospital or rehabilitation units (n= 30 papers), the community (n= 21 papers), or a combination of the two (n= 4 papers). For six papers, recruitment setting was unclear or not reported.

Figure 5.1 *PRISMA Diagram to Show Flow of Study Exclusion and Final Numbers of Included Papers*



Key: *detail regarding papers awaiting assessment is provided in section 4.5.4.a

Of the mixed methods studies, two had only qualitative results relevant to the review, one had only relevant quantitative results and one had relevant mixed methods results. Appendix 7 shows summaries of the qualitative, quantitative and mixed methods papers.

Despite 61 studies meeting the inclusion criteria, only 7 (11%) used the term ‘body image’ in their primary aim and only 17 (28%) used it elsewhere. This means that only 24 (39%) used it anywhere in the paper. Half of these (n= 12) did not define it (see Appendix 6). Therefore, 12 papers contained a definition of body image which are presented in Table 5.1 mapped against the thesis definition of body image.

Table 5.1. *Mapping the Definitions of Body Image from Included Studies Against the Cash Definition of Body Image (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b)*

Study (first author(s) et al., year)	Dimension of project definition of body image						
	Thoughts	Feelings	Behaviours	Perceptions	Appearance	Functions	Capability
Barak et al. (1999)	✓			✓	✓		
Braga (2012)	✓	✓		✓	✓		
Brinkmann and Hoskins (1979)	✓	✓		✓	✓	✓	
Goodyear (1978)		✓			✓	✓	
Howes (**2004**; 2005b)	✓	✓		✓	✓	✓	✓
Keppel and Crowe (2000)	✓	✓		✓	✓		
Kinoda (2008)	✓			✓	✓	✓	✓
Nasr et al. (2016)	✓		✓			✓	✓
Picado (**2018**; 2019)	✓			✓	✓	✓	✓
Sadanandan et al. (2020)		✓			✓	✓	✓
Stott (**2019**; 2021)	✓	✓		✓	✓	✓	✓
Lourenço (2012)	*‘Body image’ used in title, but translation meant in-text definition was too ambiguous to decipher.*						

Key:

✓ = Yes

Bold = main source of data extraction for the study

Most papers considered appearance, thoughts, perceptions, and functions. Only one paper used a definition of body image which incorporated behaviours, meaning this has not often been addressed as part of body image in the stroke-specific literature. Given the high proportion of included papers which do not use the term ‘body image’, the inclusion rationale for each report is also shown in Appendix 6.

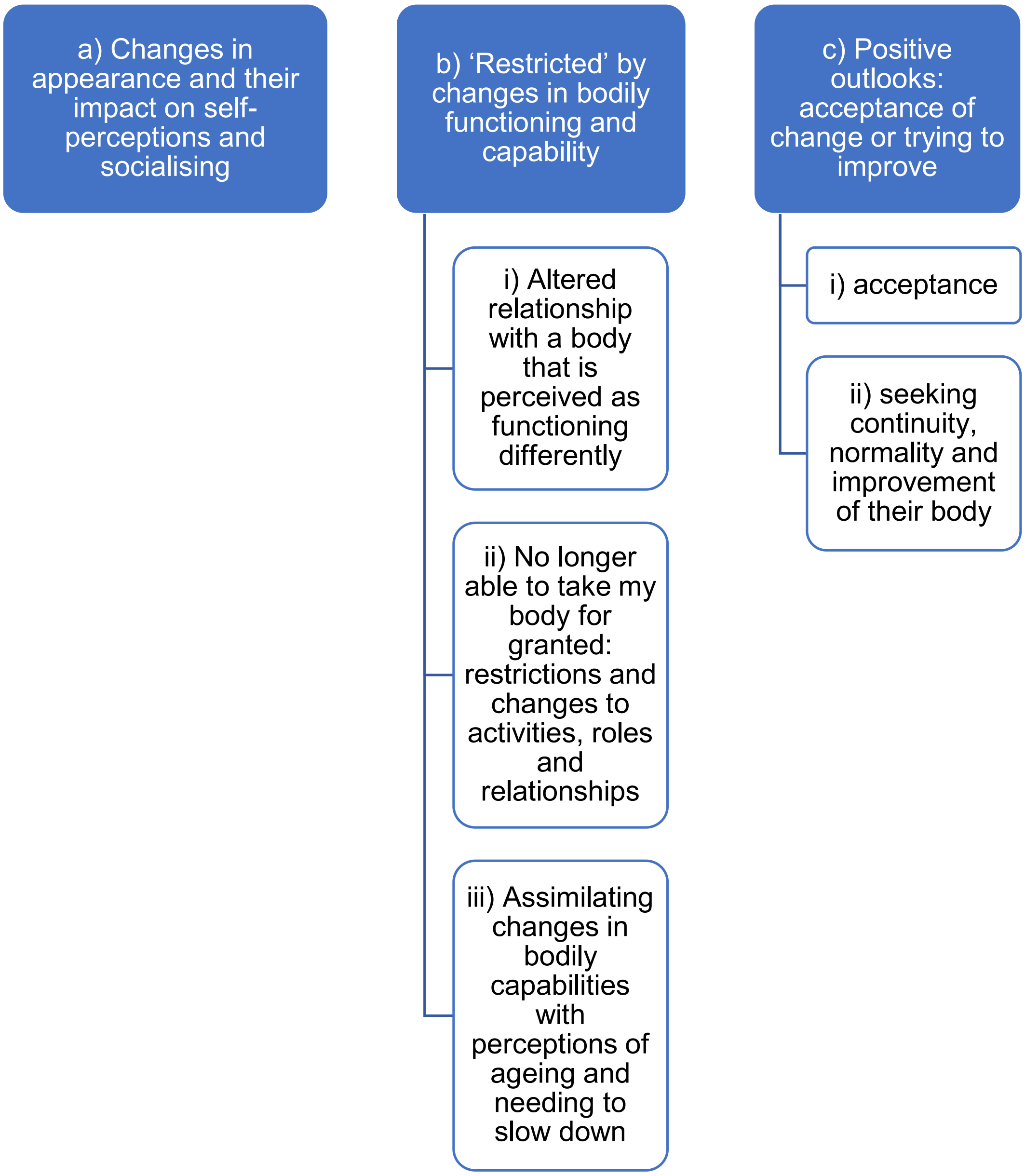
5.4. QUALITATIVE RESULTS: NARRATIVE SUMMARY OF THE EXPERIENCES AND IMPACTS ON WELLBEING AND RECOVERY OF BODY IMAGE POST-STROKE

As outlined in Chapter 1, the broad definition of body image used throughout the thesis and for synthesising the results is; people’s perceptions, thoughts, feelings and behaviours in relation to their body’s appearance, functions, and capabilities (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b). Papers were included because they aligned or partially aligned with the thesis definition of body image. For example, they may have provided data on how a person felt about their appearance after their stroke, but not about their functioning. Crucially, they had to include data which fitted my definition, even though the authors may not have used the term ‘body image’ or used the same language as in this definition.

Within the qualitative summary are themes and subthemes that have been derived from the thematic synthesis of the data. Given that all papers had to align with the definition in some way to be included, the terminology of the definition (e.g., functioning, capability) was used to word the final theme titles. Therefore, the title of each theme describes the essence of the category, while demonstrating its relation to body image as per the thesis definition.

Subgroup analyses would have been conducted (e.g., across different ages, sexes), but there were insufficient data to group the results in this way. Across the qualitative papers, samples ranged from 5 to 125 participants, aged between 18 and 93 years and between 0 days to 25 years post-stroke. The main/overarching theme was that people experience changes to their body after a stroke which impact their lived experience of body image and subsequently their daily lives. This is further categorised into three main themes; a) Changes in appearance and their impact on self-perceptions and socialising; b) ‘Restricted’ by changes in bodily functioning and capability and; c) Positive outlooks: acceptance of change or trying to improve. The structure of the themes and subthemes are presented in Figure 5.2. Each is described in more detail, with exemplar quotations provided from the data. Before the themes are presented, a brief summary of the bodily changes described by participants is presented to help contextualize the results.

Figure 5.2 *Diagram to Show the Themes and Subthemes Derived from the Synthesis of the Qualitative Systematic Review Results*



5.4.1 Brief summary of bodily changes

In the qualitative studies, participants reported a wide range of bodily changes (Wyller & Kirkevold, 1999) which may be consistent or vary based on time and situation (Taule & Råheim, 2014; Taule et al., 2013). These included physical and observable (physical and/or functional), less objectively evident (cognitive; psychological, mood or emotion; sensations and; thoughts about the body) and combination (communication, symptoms specifically in relation to spasticity) (Stott, 2019). These experiences have been summarised in Appendix 8. Physical functional changes, which could affect specific body parts or the whole body, often impacted on people's lives (Wyller & Kirkevold, 1999), as people realised their physical limitations (Ch'ng et al., 2008). Different emotions and feelings towards the body, such as frustration with lack of movement, or difficulty controlling emotions were prevalent.

5.4.2 Themes and subthemes

a. Changes in appearance and their impact on self-perceptions and socialising

Participants perceived negative changes to their appearance. This included feeling "lopsided" due to a sunken shoulder, which made them look "terrible" (Lever & Pryor, 2015, 2017) or being "stooped over shrivelling," (Rittman et al., 2007). Muscle contractures made hands look like a "claw" and facial paralysis was perceived as making the face look "abnormal" and causing drooling (Kvigne & Kirkevold, 2003). Participants expressed concern over what others might think if they perceived that their bodily changes were noticeable by others (e.g., (Barker et al., 2013; Girardon-Perlini et al., 2007; Kinoda, 2008; Lawrence & Kinn, 2012; Taule & Råheim, 2014)). Negative descriptors were used for how they felt others might perceive them now that they had a changed body. These included being "irregular", "stupid" (Kvigne & Kirkevold, 2003), "handicapped" (Rittman et al., 2007) "incompetent", "drunk", "childish" (Bronken et al., 2012), "disgusting" or a "dummy" (Boylstein, 2002) or "not being as fun" (Kuluski et al., 2014). Appearance seemed to be linked to self-worth and perception of social-standing:

> "… I used to look as though I was a first-class person; now I'm sort of like a second-class citizen. It downgrades you." (Purton, Sim & Hunter, 2020, pg. 5)

Some studies reported that this was more pertinent for women:

> "I don't feel beautiful or attractive any longer. I feel that my body has, that I have become uglier. My self image is not so good…. In front I see my ''hanging'' eyelid… I thought nobody cared about me any more when I look like that… so I try at least to look as good as possible." (Kitzmüller & Asplund, 2013, pg. 25)

In terms of appearance, some participants described feeling "ill" when they looked in the mirror (Immenschuh, 2003). Negative perceptions caused people to feel uncomfortable in relation to socialising, including being "ashamed" (Immenschuh, 2003; Kvigne & Kirkevold, 2003; Kvigne et al., 2004) and "embarrassed" (Bronken et al., 2012; Moorley & Cahill, 2018; Purton et al., 2020; Rittman et al., 2007). Others potentially felt more visible to others and described feeling “self-conscious” (Ellis-Hill, 1998; Purton et al., 2020), “conspicuous” (Gorst et al., 2016; Kvigne & Kirkevold, 2003; Purton et al., 2020), or “exposed” (Kvigne et al., 2004), which reduced confidence (Gorst et al., 2016). Confidence and self-image were also sometimes impacted when people gained weight (Lever & Pryor, 2015, 2017; Nasr et al., 2016).

Some people felt uncomfortable about their own perceptions and also the perceptions of others. The body became an uncomfortable focus in social situations (Ellis-Hill, 1998; Stott et al., 2021). Some people were happy to socialise but felt that others found it “difficult” to meet with them (Kvigne & Kirkevold, 2003), possibly because they felt that others did not know how to deal with their stroke (Murray & Harrison, 2004). Conversely, other people had a reduced desire to socialise and withdrew from social situations (Boylstein, 2002; Nanninga et al., 2015; Taule & Råheim, 2014).

When around others, people with stroke felt “constantly watched or evaluated” (Carlsson et al., 2004; Purton et al., 2020), with some experiencing deterioration in their functional ability when they saw people that they knew in public (Ellis-Hill et al., 2000):

> “I still feel like a freak. I just don’t like going anywhere where I’m well known and I feel now I’m not walking properly” (Ellis-Hill et al., 2000, pg. 731)

For younger people specifically, they reported “feeling unattractive and self-conscious about visible disabilities”, which impacted “self-concept and ability to enjoy social interactions” (Ch'ng et al., 2008). People wanted to fit in and be “normal”, as they now perceived abnormalities in their appearance (Gorst et al., 2016). It was considered important to control movement and appearance in public (Ellis-Hill, 1998) and it was difficult when they felt that they were not in line with social conventions (Arntzen & Elstad, 2013). This included when they felt they could not do things in the same way as others could, such as eating with a knife and fork (Carlsson et al., 2018). As such, some people attempted to hide or minimise perceived conspicuousness of their bodily changes (Carlsson et al., 2004; Gorst et al., 2016; Leahy et al., 2010; Leahy et al., 2016; Purton et al., 2020; Yuki, 2008). This included avoiding talking if they felt like their speech was affected (Bronken et al., 2012) and adapting eating habits or stopping eating in public altogether (Purton et al., 2020):

> “But I remember one self-conscious thing where my arm was out of control. I couldn’t put it anywhere […] I was with a friend walking publicly […]. I said, oh, can you put my hand in my pocket to feel a bit more normal, because it sort of felt like it was this appendage that wasn’t quite right. […] She didn’t say anything.

> But it was sort of upsetting. I wasn't at ease and I wasn't as poised as I normally would be." (Lever & Pryor, 2017, pg. 2015)

Women tried to "keep up their appearances" and "compensate" for visible bodily changes with "attractive clothes and hairstyles" (Kitzmuller et al., 2013), or risk feeling less "pretty" (Lever & Pryor, 2015, 2017). In this respect, people could influence their external presentation, even if they could not improve its physical state (Lever & Pryor, 2015, 2017). Body image experience was impacted if people could not physically present their body in their preferred way. This emphasises the idea that people feel conspicuous when they perceive that they do not fit with social conventions.

Self-presentation in relation to personal care, including showering, applying makeup, cutting nails, blow-drying hair and brushing teeth was now a challenge (Carlsson et al., 2018). This affected the younger image that people wanted to present to others, leaving them feeling like a "mess" (Purton et al., 2020). This included not being able to wear their preferred clothes due to difficulties dressing, including manipulating fastenings and zips (Purton et al., 2020):

> "Sometimes I feel scruffy when I go out… seeing everybody else smartly dressed and I'm sort of there in a pair of tracksuit bottoms… not wearing proper trousers… I feel out of place a bit." (Purton et al., 2020, pg. 6)

Walking aids or wheelchairs were used to compensate for bodily changes. They became absorbed into perception of body image and magnified the focus and attention of others onto the changed body (Boylstein, 2002; Murray & Harrison, 2004). For some, this was perceived as reducing the chances of finding a partner because "they see the walking stick and that is all they are interested in and not the real person me." (Murray & Harrison, 2004). Visible changes sometimes elicited help from others which impeded progression of recovery and independence (Arntzen et al., 2015b). Conversely, some people struggled with lack of acknowledgement from others of hidden aspects of stroke, for example perceptions of their body as being different due to emotional or memory problems (Immenschuh, 2003; Murray & Harrison, 2004), but their outward appearance did not portray these to others. So, while they perceived that their body was now different, other people did not. This created tension surrounding stroke-related impairments not being acknowledged or validated by other people (Carlsson et al., 2004; Crowfoot, 2016a; Ellis-Hill, 1998; Ellis-Hill et al., 2000; Immenschuh, 2003; Kvigne & Kirkevold, 2003; Leahy et al., 2010; Leahy et al., 2016; Meijering et al., 2016; Murray & Harrison, 2004; Nasr et al., 2016) and elicited negative feelings for participants including "hypochondria" (Kvigne & Kirkevold, 2003) and annoyance (Ellis-Hill, 1998). Many felt it would have been easier to have some visible signs of stroke, to allow others to recognise their experiences (Kitzmuller et al., 2013; Murray & Harrison, 2004; Purton et al., 2020; Taule & Råheim, 2014; Taule et al., 2013).

b. ‘Restricted’ by changes in bodily functioning and capability

People experienced a changed relationship with their body, that was now perceived as functioning differently. When the body did not function as expected, people had to consider it more during daily activities. Changed perceptions of bodily capability could impact interests and relationships with others. Some people attributed such impacts to ageing. These impacts and attributions are described across three subthemes: i) Altered relationship with a body that is perceived as functioning differently, ii) No longer able to take my body for granted: restrictions and changes to activities, roles and relationships and; iii) Assimilating changes in bodily capabilities with perceptions of ageing and needing to slow down.

i) Altered relationship with a body that is perceived as functioning differently

Alongside perceiving negative changes to their appearance, people also perceived that their body was now different in the way it worked (Lawrence & Kinn, 2012). People felt that their post-stroke body was restricting (Timothy et al., 2016). They experienced anxiety and mourned the loss of their pre-stroke selves, identities, aspirations, plans and abilities and even questioned their worth (Backe et al., 1996; Girardon-Perlini et al., 2007; Kuluski et al., 2014; Leahy et al., 2010; Leahy et al., 2016). Due to this, they experienced a changed relationship with it, which could lead to them using negative, third-person or objectifying language when describing it (Ellis-Hill, 1998; Ellis-Hill et al., 2000; Kitzmuller et al., 2013; Yamauchi, 2007), for example:

> “That side...feels bigger…monster-ish [laughs]…[pause] it’s like a marshmallowey, come sort of like bloated… not human…[laughs]” (Stott, et al., 2021, pg. 7)

Examples of the negative, third-person or objectifying language used were evident throughout the findings. Exemplifying negative language used to describe the body, it was now perceived as being “overshadowing”, “ambiguous” “elusive” (Arntzen et al., 2015b) and “scary” (Nanninga et al., 2015). This made it seem as if the body was now unknown. It was now something that was “dependent” (Nanninga et al., 2015), which may have been experienced in contrast to a pre-stroke body which was a facilitator of everyday activities. Post-stroke impairments were spoken about negatively (Immenschuh, 2003; Stott et al., 2021) and people felt “anger”, “alienation” and “irritation” (Arntzen & Elstad, 2013; Eilertsen, 2005; Eilertsen et al., 2010; Erikson et al., 2016; Lever & Pryor, 2015, 2017; Nanninga et al., 2015) towards it. They experienced “despair”, “frustration”, “vulnerability”, (Doyle et al., 2014) “insecurity” (Carlsson et al.,

2004) and being “overwhelmed” by how to cope with new everyday challenges (Arntzen et al., 2015b). In this sense, it seemed that their body had let them down and perpetuates the ideas of the body now being an unknown. This is confirmed by limbs or bodily functions that did not work as expected being experienced as “strange” or “unfamiliar” (Gorst et al., 2016).

The use of third person language to describe bodily changes can also be exemplified (Boylstein, 2002; Stott et al., 2021; Taule & Råheim, 2014; Taule et al., 2013; Timothy et al., 2016):

> “…rather than dragging this foot along after me…” (Gorst et al., 2016, pg. 593)
>
> “putting up with the useless thing its so tiring.” (Barker et al., 2013, pg. 487)

Then, linked to this, limbs or bodies were described as objects (Arntzen et al., 2015a; Arntzen et al., 2015b; Doolittle, 1991; Faircloth et al., 2004; Timothy et al., 2016) or as if they had a mind of their own (e.g., (Arntzen & Elstad, 2013; Stott, 2019; Stott et al., 2021)), and were no longer under the control the person (Doolittle, 1990, 1991, 1992; Gorst et al., 2016; Nanninga et al., 2015; Timothy et al., 2016), which was “frustrating” (Stott et al., 2021):

> “It doesn’t feel part of me, I’ve got to tell it what to do, I get cross with it and sometimes hit it”. (Stott, 2019, pg. 209)

These changed perceptions of functioning meant that the body now conflicted with sense of self-concept, often disrupting future plans (e.g., (Atkinson et al., 2012; Ch'ng et al., 2008; Stott et al., 2021; Timothy et al., 2016)). People questioned how reliable their body was (Eilertsen, 2005; Eilertsen et al., 2010; Moorley & Cahill, 2018; Pallesen, 2012, 2014), perceiving it as “useless” (Barker et al., 2013; Kitzmuller et al., 2013; Nanninga et al., 2015; Rittman et al., 2007), “unfamiliar” (Taule & Råheim, 2014; Taule et al., 2013) “untrustworthy” (Crowfoot, 2016a; Kvigne & Kirkevold, 2003; Moorley & Cahill, 2018), “unpredictable”, (Arntzen & Elstad, 2013; Eilertsen, 2005; Eilertsen et al., 2010; Nanninga et al., 2015; Pallesen, 2012, 2014), “betraying” (Moorley & Cahill, 2018), “peculiar” (Arntzen & Elstad, 2013), “disrupted” (Crowfoot, 2016a), “puzzling” and “perplexing” (Ellis-Hill, 1998).

Powerful metaphors were sometimes used to describe bodily impairments (e.g., (Rittman et al., 2007)). Limbs with changed function or capability were described as being, “dead” (Doyle et al., 2014; Kitzmuller et al., 2013; Lever & Pryor, 2015, 2017) or likened to “a pig’s arm” (Kitzmuller et al., 2013) a parasite (Stott et al., 2021), as being in “plaster” (Stott, 2019) or in a “cast” (Kinoda, 2008). There was a sense that the body was perceived as being slower, through joints being described as having “rusted up” (Gorst et al., 2016), and the body described as being “clogged up” (Norris et al., 2010) or “stuck” (Stott et al., 2021). New sensations were “annoying” or could not be described fully (Stott, 2019). Overall, people no longer trusted themselves (Erikson et al., 2016) or their body (Timothy et al., 2016; Wyller & Kirkevold, 1999), or had lost confidence in the functional ability of their body (Arntzen & Elstad, 2013). Reduced confidence in the body led to feelings of grief, loneliness, isolation, fear, confinement and reduced engagement (Arntzen & Elstad, 2013):

> “I feel like I am in a prison, there is no freedom”. (Arntzen & Elstad, 2013, pg. 70)

Some people showed a heightened vigilance and monitored their bodily functions in case they were early indicators of stroke recurrence. This fear sometimes led to behavioural change based on presumed stroke risk, factors such as altering diet and exercise habits (Crowfoot, 2016a; Immenschuh, 2003).

ii) No longer able to take my bodily functions and capabilities for granted: restrictions and changes to activities, roles, and relationships

People sometimes experienced sudden reminders of their bodily changes. For example, sudden difficulties in thinking, talking, new bodily sensations, or limbs that did not function as expected (Bergström et al., 2014; Bergström et al., 2015; Stott, 2019). Their unanticipated or unwanted onset made these changes more noticeable when they came to the fore (Stott, 2019; Stott et al., 2021).

> “Sometimes I feel when walking… I can’t take my right side with me…because of heavy and I can’t walk”. (Stott, 2019, pg. 210)

These sudden reminders (e.g., memory loss or speech problems) were experienced as being “repulsive”, due to contrasting with their pre-stroke image (Pedersen et al., 2019b). A change from normal caused people to be more aware of their body due to its unfamiliarity (Arntzen & Elstad, 2013; Pedersen et al., 2019b; Stott et al., 2021; Timothy et al., 2016) and perceived pre-stroke differences (Stott et al., 2021).

> “I see myself as different because of the way I walk and the way I act. I can’t go anywhere like a normal person.” (Rittman et al., 2007, pg. 24)

People had to think about their impairment before embarking on activities previously done automatically, such as disembarking public transport (e.g., (Kuluski et al., 2014)). In this way, stroke disrupts the previously taken-for-granted body (Bergström et al., 2014; Bergström et al., 2015; Kvigne & Kirkevold, 2003; Meijering et al., 2016; Rittman et al., 2007; Timothy et al., 2016; Yamauchi, 2007) and means that bodily functions and capabilities are perceived as more noticeable. For the minority, attending and listening more to their body led to a closer relationship with and understanding of their body. This was through a renegotiation of relationship with their bodily changes (Crowfoot, 2016a). However, for most, this was a negative experience:

> “… and to wash your hair and to put on mascara! Things I never considered before! I got shaky; I did not have the strength to hold the mascara brush that weighed absolutely nothing! Those are the things you don’t think about, those girly things!” (Arntzen et al., 2015b pg. 315).

Daily lives had to be altered to accommodate bodily changes, (Arntzen et al., 2015a; Backe et al., 1996; Meijering et al., 2016; Rittman et al., 2007; Rittman et al., 2004; Stott et al., 2021), impairments or sensations (Stott et al., 2021) (e.g., pain, (Gorst et al., 2016)), which could affect self-perception (Pedersen et al., 2019b):

> “Everything stops, everything you used to do you can’t do… you’ve even someone to wash yourself… It changes everything, changes your whole way of life, and it’s very difficult.” (Purton et al., 2020, pg.4).

Having to think and do things differently than before their stroke made people feel “sad” (Girardon-Perlini et al., 2007; Pedersen et al., 2019b) and meant that bodily functions, such as walking and activities of daily living, including getting ready in a morning now took more concentration, energy (Arntzen & Elstad, 2013; Carlsson et al., 2018; Gorst et al., 2016; Kitzmuller et al., 2013; Meijering et al., 2016) and time (Doolittle, 1991; Kvigne et al., 2004; Moorley & Cahill, 2018) which was tiring (Arntzen & Elstad, 2013; Arntzen et al., 2015b; Barker et al., 2013; Carlsson et al., 2018; Erikson et al., 2016; Kvigne et al., 2004; Pedersen et al., 2019b; Rittman et al., 2007; Timothy et al., 2016; Wyller & Kirkevold, 1999). People perceived that they had slowed down to accommodate bodily changes (Stott et al., 2021). Tiredness and a sense of the body slowing down impacted functional ability, including work (Backe et al., 1996; Kitzmuller et al., 2013; Kvigne & Kirkevold, 2003; Nasr et al., 2016; Norris et al., 2010; Taule & Råheim, 2014; Taule et al., 2013; Yuki, 2008). They sometimes became more cautious due to not being able to predict how their bodies would respond (Timothy et al., 2016) or due to the practicalities of having an impairment (Gorst et al., 2016). In turn, people were wary of leaving the house due to feeling unsafe or worrying about falling, which impacted on outside and community activities (Rittman et al., 2007; Stott et al., 2021).

> “. . .I have to be careful where I’m walking . . . because if it’s uneven or you know rough or anything like that. I’m conscious that I’m likely to sort of trip on things because this wretched foot doesn’t lift up, very often it doesn’t lift. It flops and it drags . . . “ (Gorst et al., 2016, pg. 592)

This contributed to a perception of reduced capacity impacted quality of life (Pedersen et al., 2019b). In contrast to reluctance to socialise due to changes in appearance (see section 5.3.2.a) the extra time, attention and concentration now needed to think about functioning and essential activities left less time and energy for engaging in enjoyed activities, such as socialising (Kuluski et al., 2014; Stott et al., 2021). People protected themselves from energy-consuming activities (Pedersen et al., 2019b). Spontaneous social plans were less frequent due to being perceived as “stressful” and “confusing” (Nanninga et al., 2018; Nanninga et al., 2015; Pallesen, 2012, 2014). This could lead to alienation and a limited social world (Bronken et al., 2012; Erikson et al., 2016; Rittman et al., 2007; Stott et al., 2021) or feeling trapped (Rittman et al., 2007). People perceived that they “could not” function as desired (Pedersen et al., 2019b). Previously enjoyed activities, which were important to people’s identity (Kuluski et al., 2014) such as walking, had to be adapted to match the new abilities of the changed body, or pre-planned to include breaks and account for tiredness (Boylstein, 2002; Ch'ng et al., 2008; Doyle et al., 2014; Nanninga et al., 2015). Some activities had to be stopped altogether due to physical or cognitive limitations (Backe et al., 1996; Carlsson et al., 2004; Kuluski et al., 2014; Rittman et al., 2007; Stott et al., 2021). A loss of valued activities or skills due to bodily changes, which were connected to identity, contributed to a sense of feeling “lost”, upset (Purton et al., 2020), unhappy (Rittman et al., 2007) and “angry” (Rittman et al., 2004). Multi-tasking was no longer perceived as being possible, which impacted on perception of identity (Kuluski et al., 2014).

In general, a loss of valued activities impacted upon independence, autonomy, identity and self-esteem (Girardon-Perlini et al., 2007).

> “[I’m] not a whole person. I feel half a person because I can only do half the things I used to do. I can’t do what I used to do.” (Purton et al., 2020, pg.5)

When people no longer trusted their body’s capability, it affected their confidence and hobbies that relied on the body, such as cycling (Kvigne & Kirkevold, 2003) and swimming (Purton et al., 2020). There was a sense that people’s minds would tell them that they could do something, or wanted to do it, but that their body would hold them back (Faircloth et al., 2004; Immenschuh, 2003; Purton et al., 2020), leading to a cognitive dissonance between beliefs and behaviours (Lawrence & Kinn, 2012; Purton et al., 2020).

> “[I’m] a vegetable. A very annoyed vegetable. I don’t like it at all…I’m a vegetable because I just can’t seem to, somebody’s got to accompany me, whether it’s in the car, if I go for a walk, and, anyway, I can’t walk very far. That makes me feel more like something that’s planted than a person. I’m stuck at the moment.” (Timothy et al., 2016, pg. 1571).

Some people now had to rely on support from other people to return to a sense of their normality or as part of their improvement. Due to this, bodily changes, such as reduced independence or emotional/behavioural instability impacted their ‘normal’ relationships (Girardon-Perlini et al., 2007; Nanninga et al., 2018; Stott et al., 2021). As a way of trying to maintain a sense of normality, people oversaw others doing jobs for them (Bergström et al., 2014; Bergström et al., 2015). They also received support from others in areas which they now struggled with, such as constructive thinking (Erikson et al., 2016). In this way, it was as if other people helped to extend the abilities of the body and brain (Erikson et al., 2016). For some, this was a negative and restricting experience. People felt dependent on others (Carlsson et al., 2004), that others lacked allowances for their new impairments (Leahy et al., 2010; Leahy et al., 2016). Some even said that they felt “worthless” if they required constant assistance (Rittman et al., 2007). If they had no-one to support them, they felt “alone” (Rittman et al., 2007):

> “I have family but they all have their own things to do...except one of my sisters who comes from [mentions the city] to bring me something to eat, like a dog” (Rittman et al., 2007, pg. 26)

When people were forced to rely on others for additional support, it felt restricting (Crowfoot, 2016a; Kvigne et al., 2004). They felt vulnerable and at the mercy of others (Purton et al., 2020). Social interactions were restricted to family and friends who visited them (Girardon-Perlini et al., 2007). Self-perception was no longer that of a competent adult, but of a “toddler” (Backe et al., 1996), or “a baby”; and they were now “treated like a child” when they needed help with self-care (Purton et al., 2020). This was an intrusion into their private space and they felt exposed and embarrassed (Purton et al., 2020). Conversely, some people felt lucky to have family who helped (Nasr et al., 2016) and being around family and friends who were aware of the their changed situation meant that the body was not a social focus, reducing feelings of stigma (Ellis-Hill, 1998; Ellis-Hill et al., 2000; Immenschuh, 2003).

However, some experienced guilt and insecurity from having to rely on others (Girardon-Perlini et al., 2007). They felt like a burden which contributed to feelings of isolation, depression and feeling useless (Rittman et al., 2007). When younger people required support, they became frustrated if they felt they were being “wrapped in cotton wool”, which was disempowering, prolonged their view of themselves as a patient (Leahy et al., 2010; Leahy et al., 2016). Some distanced themselves from relationships due to them being a reminder of their former self (Kuluski et al., 2014) or of continued restrictions (Erikson et al., 2016).

Restrictions on socialising due to how people appear is already presented in section 5.3.2.a. But change in function and ability to perform and fulfil social roles such as being a grandparent, also restricted social activity (Arntzen et al., 2015a; Carlsson et al., 2004; Ch'ng et al., 2008; Girardon-Perlini et al., 2007; Kuluski et al., 2014; Kvigne et al., 2004; Nasr et al., 2016; Purton et al., 2020).

> *Talking about involuntary hand spasms*: “If she puts her little hand in mine and mine grips hold of it, well I could really hurt her” (Purton et al., 2020, pg.5)

This contributed further to people perceiving themselves differently (Kuluski et al., 2014). People with partners perceived imbalances in traditional relationship roles including needing help with self-care, or not being able to drive, complete heavier tasks due to functional changes (Purton et al., 2020). Intimacy was impeded by physical difficulties (Lever & Pryor, 2015, 2017).

iii) Assimilating changes in bodily capabilities with their own perceptions of ageing and needing to slow down

The impacts of stroke caused people to feel more aware of their age and assimilate bodily changes with their personal perceptions of getting older. Age was perceived as being linked to stroke diagnosis, lasting impairments, and taking medication (Leahy et al., 2010; Leahy et al., 2016). The perception of ageing may be different for different people. Most people accepted what they considered to be normal, age-related changes caused by their stroke, which provoked for them a sense of needing to slow down and reduce daily activities (Boylstein, 2002; Eilertsen, 2005; Eilertsen et al., 2010). For some, this was perceived as aligning with their life trajectory (Meijering et al., 2016) and normalized the impacts of stroke, such as reduced energy, as part of the ageing process (Rittman et al., 2007). Others perceived assimilation with ageing as being negative (Leahy et al., 2010; Leahy et al., 2016) and that they were “old before their time” (Leahy et al., 2010; Leahy et al., 2016). This premature perception of ageing was linked to “isolation”; and they felt as if it portrayed them “as old and less intelligent” (Nasr et al., 2016).

c. Positive outlooks: acceptance of change or trying to improve

Some people reported positive outlooks or optimism after their stroke. This was mostly through expressing or describing an i) acceptance of their post stroke body, or through ii) seeking continuity, normality and improvement of their body.

i. Acceptance

Some people learned to live with their bodily changes through adjustment, adaptation or accommodation (Boylstein, 2002; Carlsson et al., 2004; Ch'ng et al., 2008; de Guzman et al., 2012; Moorley & Cahill, 2018; Nanninga et al., 2015; Pedersen et al., 2019b; Rittman et al., 2007; Stott et al., 2021). It was important to look for positives

(Lawrence & Kinn, 2012) which helped people to tolerate their new body (Timothy et al., 2016). This was the case despite significant body changes impacting function and capability and participants made the best of their situation (Crowfoot, 2016a; de Guzman et al., 2012; Eilertsen, 2005; Eilertsen et al., 2010; Ellis-Hill, 1998; Ellis-Hill et al., 2000; Gorst et al., 2016; Immenschuh, 2003; Kvigne et al., 2004; Moorley & Cahill, 2018; Rittman et al., 2007; Timothy et al., 2016).

However, some people continued to struggle with acceptance (Bronken et al., 2012; Nanninga et al., 2018; Nanninga et al., 2015; Nasr et al., 2016). This included feeling resentment towards limiting bodily changes (Leahy et al., 2010; Leahy et al., 2016). Despite attempts to come to terms with a new self, negative language was still used to the self in relation to being disabled:

> "I had long hair [. . .] I had all my hair cut off. […]The hairdresser said, ‘‘Are you sure about this?’’, but it was because in a way I thought, ‘‘Well, this hair is the hair of her, it's the hair of the woman, that could, that walked and was well and wasn't, you know, and, wasn't disabled and I don't want her hair anymore because I'm not her now. I'm somebody new.’’" (Kuluski et al., 2014, pg. 7)

However, people felt lucky or grateful to have survived their stroke without having to live with major impairments (Arntzen et al., 2015a; Immenschuh, 2003; Kuluski et al., 2014; Taule & Råheim, 2014; Taule et al., 2013), some used their faith to frame their acceptance, such as accepting their stroke as part of God's plan (Rittman et al., 2007) or as strengthening their dependence on God (Timothy et al., 2016).

ii. Seeking continuity, normality and improvement

Generally, people felt better when they could maintain a sense of continuity in over-riding bodily changes between pre- and post-stroke (Boylstein, 2002; Timothy et al., 2016). This helped to reduce emotional impacts caused by their body (Stott et al., 2021) and reduced impacts on self-image, self-esteem or overall self-perspective (Rittman et al., 2007). For those who maintained their sense of continuity, they felt like "the same person" or that nothing had really changed since before their stroke (Boylstein, 2002; Rittman et al., 2007).

People sought out activities to try and re-gain their perception of themselves that they held before the stroke (Faircloth et al., 2004). Continuity was sought through engaging in behaviours to improve overall body image perceptions. Most people expressed a desire for their body to return to pre-stroke 'normal', or at least to improve (e.g., (Arntzen et al., 2015a; Bergström et al., 2014; Bergström et al., 2015; Boylstein, 2002; Doyle et al., 2014; Kuluski et al., 2014; Lawrence & Kinn, 2012; Lever & Pryor, 2015, 2017; Nanninga et al., 2015; Norris et al., 2010; Taule & Råheim, 2014; Taule et al., 2013; Timothy et al., 2016; Yamauchi, 2007; Yuki, 2008)). People were motivated to improve by thinking about their desired body (Yuki, 2008), to improve function (Bergström et al., 2014; Bergström et al., 2015; Kvigne et al., 2004) or by hoping to return to their social lives (Taule & Råheim, 2014; Taule et al., 2013).

Some expected that their body would return to normal on its own, heal itself, or conversely, some felt there was nothing they could do about it (Arntzen et al., 2015a; Boylstein, 2002; Nanninga et al., 2015) apart from taking their medication which they hoped would help them to improve enough to return to valued activities (Rittman et al., 2007). However, most who sought bodily improvement did so demonstrated through active determination and changed behaviours. They took care of their self-presentation (Kvigne & Kirkevold, 2003), developed techniques to adapt to bodily changes (Arntzen & Elstad, 2013; Boylstein, 2002; Doyle et al., 2014; Kvigne & Kirkevold, 2003; Kvigne et al., 2004) exercised (Bergström et al., 2014; Bergström et al., 2015; Kitzmuller et al., 2013; Kuluski et al., 2014; Rittman et al., 2007) and helped at home (Kuluski et al., 2014). Engaging with rehabilitation helped people to cope and maintain hope of improvement (Rittman et al., 2007; Stott et al., 2021).

People also listened to (Carlsson et al., 2004) and tested their bodies and engaged in problem solving, such as trying out different tasks to see what they could achieve and ways to achieve it (Boylstein, 2002; Ch'ng et al., 2008; Crowfoot, 2016a; Yamauchi, 2007) or to learn new skills (Arntzen et al., 2015a). Positivity and relief were experienced when improvements were made (Arntzen et al., 2015b; Kitzmuller et al., 2013; Nanninga et al., 2015; Raghavan et al., 2016; Yuki, 2008) or when people noticed occasions where their body was ‘normal’ again, such as when they walked with an improved gait (Yamauchi, 2007). If they worked physically, such as going to the gym, to achieve a breakthrough:

> “when I get up one morning…and this leg doesn’t feel heavy and I can…walk smoothly” (Stott et al., 2021, pg. 9)

People who were more physically impaired used tools or equipment to improve their bodily functions or capabilities and used them to enable participation in everyday tasks. For some, not being able to use different types of equipment, such as a coffee maker, emphasised their changed body (Arntzen & Elstad, 2013). But for most, people found supportive tools, such as aids (Timothy et al., 2016) or assistive devices (Rittman et al., 2007) useful. This included but was not limited to using a tray to carry things around the house (Nasr et al., 2016), a string to help in pulling up a jacket zip (Carlsson et al., 2004) a mobility scooter to enable shopping and engagement in community life (Nanninga et al., 2018). One lady now perceived her wheelchair as her “feet” (Kvigne & Kirkevold, 2003). These helped to minimise the impacts on bodily perceptions due to being a way to achieve previous functions and capabilities (Rittman et al., 2007; Stott, 2019).

People found continuation of normality through support from others, such as family (e.g., (Carlsson et al., 2004; Nasr et al., 2016)) or a spouse (e.g., (Carlsson et al., 2004)) to be a positive experience. It enabled them to maintain some enjoyed activities including going out, or gardening and helped maintain optimism for the future (Rittman et al., 2007). Family members sometimes took over previous responsibilities, such as shopping or banking, enabling people with stroke to enjoy pleasurable tasks, such as gardening and ultimately to stay living at home (Rittman et al., 2007). People felt "comfortable" and "better" being supported by a spouse compared to a physical therapist, as this was a more familiar, and ultimately normal, experience (Timothy et al., 2016). For some, a new social role strengthened relationships (e.g., (Leahy et al., 2010; Leahy et al., 2016)). Existing ones were enhanced through support and affection (Murray & Harrison, 2004) and new ones established (Kitzmuller et al., 2013; Kvigne et al., 2004).

Some people went beyond desire for normality and viewed their post-stroke lives as an opportunity for change (Taule & Råheim, 2014; Taule et al., 2013) or saw themselves as a new person. Generally, they wanted to continue to move forward with their lives. This included monitoring their weight, maintaining their personal standards and (Lever & Pryor, 2015, 2017), taking better care of their appearance (Immenschuh, 2003) and health than they had before their stroke (Boylstein, 2002; Pallesen, 2012, 2014) and looking for opportunities for self-development (Pallesen, 2012, 2014).

5.5. QUANTITATIVE RESULTS

Across the 10 quantitative studies, samples ranged from 7 to 48 participants, aged between 14 and 88 years and within 20 days to 20 years post stroke. The quantitative results were grouped into themes using a thematic synthesis approach (see section 4.5.5.b) to describe the data. The desriptive themes are presented in this section.

5.5.1 Brief summary of bodily changes: quantitative studies

The focus of the quantitative papers was varied. The majority (n= 3 papers) compared body image, body cathexis or quality of life scores of people with and without stroke. In two papers, the focus was on people with stroke rating their pre- and post-stroke body image to identify any changes. In one of these papers and a further two papers, body image, body esteem or body cathexis was correlated against factors including sex, site of stroke, time since stroke and/or severity of stroke-related impairments. One study evaluated the effects of rehabilitation on oral health and quality of life, another explored the relationships between anxiety, depression, self-esteem and body-esteem and the final one evaluated the effect of a physical conditioning intervention on fitness, function and self-concept.

Overall, stroke negatively impacted body image experience. People with stroke perceived their body image as being better before their stroke (Goodyear, 1978; Keppel & Crowe, 2000). Similarly in studies that compared those with stroke to those who hadn’t had a stroke, those without a stroke perceived their body image as being better (Braga, 2012; Li et al., 2001; Picado et al., 2019; Picado, 2018).

The quantitative studies mostly provide insight into the areas of the body most liked or disliked by people after stroke or impacting on psychological wellbeing. Studies used a variety of assessment methods to explore satisfaction with various body parts in terms of appearance and function post stroke with unsurprisingly wide variation in terms of what people reported being most dissatisfied with. In contrast to people without stroke who attributed more importance to appearance-related aspects of body image, people with stroke were most dissatisfied with body parts related to function/activities of daily living (Picado et al., 2019; Picado, 2018). This was highlighted by the results due to the majority of measures assessing satisfaction with body parts and functions. They were more satisfied with those not directly involved in activities of daily living such as their face, skin, height and age (Sadanandan et al., 2020). This suggests the heightened importance of functionality in body image for people with stroke and corresponds with heightened awareness of bodily functionality.

Stroke-related issues can also have very broad impacts. For example, a study into oral health following a stroke found that most of the sample felt that their appearance was worse or were not pleased with how their teeth looked. They felt self-conscious, limited their contact with people, and were uncomfortable eating in front of people (McMillan et al., 2005). This demonstrates how specific impacts of stroke can cause unique and broad issues and impacts.

5.5.2 Individual factors affecting post-stroke body image experience

The summary of quantitative findings must be understood in the context that there appears to be a complex and interacting relationship between factors that may influence body image experiences post-stroke. These encompass personal characteristics and stroke-related characteristics (type of stroke, side of stroke, time since stroke). Gender is an inter-weaved factor which will be discussed for each characteristic where it has been studied.

a. Personal characteristics

Personal characteristics encompassed age and BMI. Age was not found to significantly affect body image perception (Goodyear, 1978). However, higher BMI post-stroke was linked to greater dissatisfaction with body image (Braga, 2012). People who felt that they had a higher BMI judged their BMI as being higher than it actually was and wanted a smaller one (Braga, 2012). People with a higher BMI judged their current body image as being overweight. Women wanted a thinner and more ‘normal’ weight image, and men wanted a larger image (Braga, 2012). However overall, weight seemed less valued than other aspects of body image experience (Lourenço, 2012).

b. Gender

As mentioned previously with regards to weight, there was disparity in the role of gender after stroke in the studies reviewed. Some studies found no significant role of gender in terms of satisfaction with the body, body cathexis or body image after stroke (Braga, 2012; Keppel & Crowe, 2000; Sadanandan et al., 2020), whereas, other studies found differences in experiences (Barak et al., 1999; Goodyear, 1978; Lourenço, 2012) or explored one gender (Howes, 2004). One study found that for males, there was a link between depression and concern about their weight; and between depression and lower satisfaction with their sex organ. After a year, they were more concerned with being thinner (Howes, 2004). Another study found that females had better body image scores pre- and post-stroke compared to males, although this was not statistically significant (Goodyear, 1978).

There could be different brain mechanisms for some of the subdimensions of body image for men and women (Barak et al., 1999). One study found that women most valued aspects of function related to physical attractiveness and appearance, which was linked to higher self-esteem. For women who were worried about their weight, this was linked to greater concern around endurance, strength and agility and reduced self-esteem. Men most valued their physical and facial attractiveness, with greater esteem around physical attraction being linked to feeling better about muscular strength. Perception of muscle strength influences perception of physical condition. Comparatively, having less esteem about muscle strength was associated with more depressive symptoms (Lourenço, 2012).

c. Stroke

In one paper, a mixed sample of men with stroke and traumatic brain injury were more dissatisfied with physical and sexual functioning than matched controls (matched on age, education levels, pre-injury socio-economic status and BMI). Compared to people with stroke, people with traumatic brain injury were more satisfied with aspects related to physical functioning (appetite, reflexes, muscular strength, energy levels and chest), and weight gain (hips and thighs). This shows that even similar conditions can result in different body image experiences. Although, there were no differences between the groups in terms of psychosocial functioning (Howes et al., 2005b).

Type of stroke (ischaemic or haemorrhagic) was not found to affect body esteem (Lourenço, 2012) or body image scores (Keppel & Crowe, 2000). There were contradictory findings around lesion location and body image. Some findings suggested that specific lesion location within the brain did not affect body image (Picado, 2018; Sadanandan et al., 2020) whereas others reported that that impaired body image or body esteem were correlated or more prominent for left-sided lesions (Barak et al., 1999; Keppel & Crowe, 2000). For the studies which found that left-sided lesions were linked to body image or esteem, they reported that patients had only had one stroke and were between 1-36 months post-stroke (Barak et al., 1999; Keppel & Crowe, 2000). For the studies which reported no affect, first or recurrent stroke was not reported.

Two studies (Keppel & Crowe, 2000; Sadanandan et al., 2020) used the same tool yet found differences in relation to lesion side. This could be due to one exploring body cathexis (Sadanandan et al., 2020) and the other, body image (Keppel & Crowe, 2000). Therefore, an explanation for the differences in findings could be due to what is being measured. Body cathexis is only one aspect of body image, which could explain the differences in findings; namely that different constructs are being measured and compared here.

All had relatively even spread of sexes. Time since stroke was similar across studies, ranging between less than 3 weeks to 36 months, except for one study where time ranged from 4 months-240 months (Picado et al., 2019; Picado, 2018). Specific duration of time since stroke does not appear to influence the experience of body image (Keppel & Crowe, 2000; Lourenço, 2012; Picado et al., 2019; Picado, 2018) or body cathexis (Sadanandan et al., 2020). Instead, people seem to have different experiences at varied timepoints. Men who were less than 6 months post-stroke felt better about their physical attraction than men more than 6 months post-stroke (Lourenço, 2012). Accordingly, for upper body strength, body esteem was correlated to time since stroke (Barak et al., 1999). Even at one-year post-stroke, people still experienced issues relating to body image that are impacting their QoL. People with stroke compared to healthy controls had lower self-esteem and body image scores at one year, despite experiencing improvements in physical function and being similar at baseline (Li et al., 2001). Issues in relation to level of activeness prevented people from fulfilling their desired ‘social-selves’ (Ellis-Hill, 1998; Ellis-Hill et al., 2000). People with stroke also rated their current self significantly more negatively compared to their past-self and still expected to improve (Ellis-Hill, 1998; Ellis-Hill et al., 2000).

5.5.3 Psychological impacts

a. Self-esteem and depression

The relationship between body image, body esteem and depression is complex and not yet fully understood. While some studies have found a positive correlation between body image and self-esteem, others have found no relationship. A poor body image is linked to having worse self-esteem (Keppel & Crowe, 2000). The direction of the association is unclear; either feeling good about one's body makes people feel good about themselves or feeling good generally improves the way people feel about aspects of their body (Keppel & Crowe, 2000). Mood was related to perceived self-difference, regardless of physical and self-care abilities (Ellis-Hill, 1998; Ellis-Hill et al., 2000).

Similar conflicting findings have been found when exploring the relationship between better body esteem and depression. One author reported that having better body esteem was associated with fewer depressive symptoms, and that feeling more sexually attractive was associated with having fewer anxious and depressive symptoms (Lourenço, 2012). However, another author described a lack of correlation between depression and anxiety, and changes in body esteem, particularly for people with left cortical infarct (Barak et al., 1999).

b. Summary of quantitative findings

Although findings suggest that experiences of body image tend to be negatively impacted by stroke, there is no clear direction for the factors that consistently impact on post-stroke body image experience. Findings suggest that BMI and gender do affect body image experience, but exact impact and relationship is unclear. Stroke related variables, such as lesion location and effects of time post-stroke are even less clear. Therefore, the quantitative evidence is largely inconclusive in relation to specific factors that impact body image experience. This could be due to the large individual differences between people after stroke given the uniqueness of each person's experience. Or it could be because this area has been insufficiently studied. There are only a limited number of studies and the studies that have been undertaken have small samples and are likely to be underpowered especially for the number of variables under study. Different methods have been utilised to measure the variables under study including body image. This emphasizes the need for a more consistent way to assess body image experience post-stroke to better understand it.

5.6. NARRATIVE SUMMARY OF IDENTIFIED METHODS FOR BODY IMAGE ASSESSMENT

This section presents a summary of post-stroke body image assessment methods identified through the review. Across the included studies, 15 methods were used and are presented in Table 5.2. Thirteen methods were only used in one study. The most popular method was the Body-Cathexis Scale (BCS) (Secord & Jourard, 1953) which was used across four papers. Eight papers purposefully measured body image and utilised the entire assessment. Another eight only used part of the scale. Only the oral health transition scale (Locker, 1998; McMillan et al., 2005) was designed purposefully for using in the study after being adapted from an existing approach (Locker, 1998). Two methods were modified for use with people with stroke (Ellis-Hill, 1998; Ellis-Hill et al., 2000; Goodyear, 1978). None of the papers reported psychometric testing or validation for stroke. The Google searches confirmed that no studies had taken place to test the validity of the methods for assessing post-stroke body image experience. Therefore, it was assumed that none of the tools had been validated for this purpose.

Table 5.2. *Methods of Assessing Post-Stroke Body Image Experience Identified from The Systematic Review*

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
Bath Body Perception Disturbance Scale© (BBPDS) (Lewis & McCabe, 2010)	1: (Stott, 2019)	✗	To capture body perception changes (e.g., size, pressure & sense of limb ownership)	7 questions: VAS capturing body changes & interviewer drawing based on participant description of their body image. Severity of distortions rated and quantified.	Whole	Higher score = greater disturbance (maximum score = 57) (Lewis & McCabe, 2010; Stott, 2019)
The Body-Cathexis Scale (BCS) (Secord & Jourard, 1953)	4: (Howes, 2004; Howes et al., 2005b) (Keppel & Crowe, 2000)	✓	To capture positive (satisfaction) or negative (dissatisfaction) feelings about different body parts	46 body parts rated on a 5-point scale: (1= strong negative feelings; 5 = strong positive feelings).	Whole: (Keppel & Crowe, 2000; Sadanandan et al., 2020) Partial:	Higher score = greater satisfaction with body parts (maximum score = 230)

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
	(Sadanandan et al., 2020); (Goodyear, 1978)				(Goodyear, 1978; Howes, 2004; Howes et al., 2005b)	
Body Esteem Scale (BES) (Franzoi & Shields, 1984)	2: (Barak et al., 1999) (Lourenço, 2012)	✗	To evaluate changes in body esteem (Franzoi & Herzog, 1986)	35 items; 5-point Likert scale (1 = strong negative feelings; 5 = strong positive feelings); 6 dimensions, with 3 subscales for each sex. Females: physical condition, weight concern & sexual attractiveness. Males: physical attractiveness, physical condition & upper body strength.	Whole	Scores = "low" if 2 SD< from means for general population (Barak, 1994)
Body Perception Tool (BPT)	1: (Stott, 2019)	✗	Patients visualise their altered body	Three-dimensional digital avatar, altered to describe body changes. Severity captured by	Whole	0 (no discomfort)-10 (highest

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
(Turton et al., 2013) & Visual Discomfort Rating Scale (VDRS)			perceptions on an avatar	the VDRS (VAS to capture perceived discomfort).		possible discomfort)
Body Shape Questionnaire (BSQ) (Cooper et al., 1987; Cordas & Neves, 1999; Stott, 2019)	1: (Braga, 2012)	✓	To measure concerns about body shape	34-item questionnaire.	Whole	Sum score of 80< = no body image disorder; 81-110 = mild disorder; 111- 140 = moderate disorder; & > 140 = severe disorder (Di Pietro, 2002)

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
General Quality of Life Inventory (GQOLI) (Li et al., 1995; Li et al., 1997)	1: (Li et al., 2001)	×	Assesses physical health, psychological health, social functioning, & living condition dimensions	64-item self-administered scale across 4 dimensions; rated on 5-point scale. Psychological health dimension contains 4 items, one of which is 'self-esteem & body image. 4 dimensions, further divided into 16 factors. Each item rated on a 5-point scale.	Partial	Higher scores = better QoL
GOHAI (The General Oral Health Assessment Index) (Atchison & Dolan, 1990)	1: (McMillan et al., 2005)	×	To assess self-reported oral health status & oral health related-QoL in the elderly	12-item self-administered 5-point Likert scale (1 = always; 5 = never). Three dimensions (each with ≥1 aspect linked to body image): Physical functioning; Pain &	Partial	Higher summed score = better reported oral health status

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
				discomfort; Psychosocial functioning.		
Image Itself Scale (Paula, 2010)	1: (Braga, 2012)	✓	To assess body dissatisfaction when people see images of their body distorted using real BMI values	7 distorted images of participant; they choose: which one looks like them, which they currently feel like, & which they would like.	Whole	Assesses value of dissatisfaction due to having actual BMI values for reference.
Male body image questionnaire- Swansea Male Body Image Questionnaire (SMBIQ)	1: (Howes, 2004; Howes et al., 2005b)	✓	Investigates male body image concerns	18 statements across: desire to lose weight (fat concern), desire to gain a bigger build (thin concern) & gender stereotypes (gender stereotyping). 7-point scale (1 = definitely disagree; 7 = definitely agree).	Whole	Higher score = stronger agreement with that factor (maximum score = 42)

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
(Edwards et al., In preparation)						
"My body image" (Lovo, 2001)	1: (Picado et al., 2019; Picado, 2018)	✓	To assess how the participant sees & feels their body	Questionnaire with 6 categories: physical condition, body ability, health, appearance; question where people mark body parts which mean more & list 3 aspects that they would change Categories 1-4: scored on 6-point Likert scale, where scores represent frequencies (0 = Never, 5 =Always) (Lovo, 2001). Categories 5-6 not scored.	Whole	Categories 1, 2 & 4: maximum score = 20. Category 3: maximum score = 40. Maximum possible score: 100 (Lovo, 2001)

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
An oral health transition scale (Locker, 1998; McMillan et al., 2005)	1: (McMillan et al., 2005)	×	To assess general oral health	Scale with 7 questions. General appearance, ability to chew, speech, ability to swallow, comfort of the mouth, & ability to use a toothbrush. 5-point Likert scale (1 = very much better; 5 = very much worse).	Partial	NR
The PainQuILT™ (Lalloo et al., 2014; Lalloo et al., 2013)	1: (Stott, 2019)	×	Body map & visual icons which describe different pain perceptions	Body area selected on two-dimensional body map. Pain perception is selected & rated. Participants consider impact on QoL over last 24 hours & are asked 7 'impact' questions to rate from 1-10 the effect of the pain on day-to-day experiences.	Whole	Visual summary of the body map areas selected, the pain icons, severity rating (out of 10), any comments made & a visual impact

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
Semantic Differential self-concept scale (Osgood et al., 1967; Warr & Knapper, 1968)	1: (Ellis-Hill, 1998; Ellis-Hill et al., 2000)	×	Measurement technique to examine the meaning of concepts from a list of polarised adjectives (Osgood et al., 1967; Warr & Knapper, 1968)	20 adjective pair scales at each end of a score range (1-7). 3 appear relevant to body image: unattractive-attractive; dependent-independent; inactive-active.	Partial	Maximum score= 140
Tennessee Self Concept Scale (TSCS) (Fitts, 1965)	1: (Brinkmann & Hoskins, 1979)	×	To assess self-concept by self-descriptive statements used to portray picture of oneself	Written instrument. Scores compared to normative group. ‘Physical self’ provides an indication of a person's view of their body.	Partial	Lower score = worse

Assessment method	Papers where method used	Used explicitly to assess body image?	Purpose in papers	Number of items & type (scale)	Whole or partial tool?	Possible scores and cut-off points
Tennessee Self-concept Scale—Second Edition (TSCS: 2) (Fitts et al., 1996)	1: (Keppel & Crowe, 2000)	✗	For people to portray a picture of themselves	82 self-descriptive statements across 3 self-concept scales; completed twice (as felt within 2 weeks pre-stroke, & over the last 2 weeks). The PHY scale reflects personal view of body, health, physical appearance, skills & sexuality.	Partial	NR

Key:

VAS = visual analogue scale

NR = not reported

✗ = No; ✓ = Yes

5.7. QUALITY ASSESSMENTS

The results of the quality assessment for each study are presented in Tables 5.3-5.5 and Figures 5.3-5.4. Robustness of the qualitative, quantitative and grey literature studies is summarised within each respective section.

The CASP checklist does not offer a weighting system or guidance on how to operationalise and report the overall quality of a study. Instead, it offers three options for each question when considering whether the study addressed that aspect of quality: ‘Yes’, ‘Cannot Tell’, or ‘No’. In an attempt to operationalise and summarise study quality, Tables 5.3-5.5 have been used. To reflect study ratings, where a question received a ‘Yes’, it is shown as green; ‘Cannot tell’ (further operationalised to included ‘Neutral’) is shown as orange; and ‘No’ shown as red. The ‘Modal rating’ column has then been used to show which rating was most common for each study in an attempt to indicate overall study quality. Where a study has received a mixture of colour ratings for its ‘Modal rating’, this is where the most frequent scores were split between two ratings. No weighting was used for the questions; instead the purpose was to provide an indication of quality across the CASP checklist for the included studies.

5.7.1 Qualitative studies

The qualitative studies received mostly positive or neutral ratings (see Table 5.3 and Figure 5.3).

Table 5.3. *Qualitative Study Quality Assessment: CASP Qualitative Checklist (CASP, 2018b) Results*

Study (first author(s) et al., year)	Question Number										Modal rating
	1	2	3	4	5	6	7	8	9	10*	
Arntzen and Elstad (2013)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟧	🟩
Arntzen et al. (2015a)	🟩	🟩	🟩	🟧	🟩	🟥	🟩	🟩	🟩	🟧	🟩
Arntzen et al. (2015b)	🟩	🟩	🟩	🟧	🟩	🟧	🟩	🟩	🟩	🟧	🟩
Atkinson et al. (2012)	*Abstract only*										
Backe et al. (1996)	🟩	🟩	🟩	🟧	🟩	🟥	🟩	🟥	🟩	🟧	🟩
Barker et al. (2013)	🟩	🟩	🟩	🟧	🟧	🟥	🟥	🟥	🟧	🟧	🟧

Bergström et al. (2014); Bergström et al. (2015)	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟨	🟨	🟩	🟩	🟩
Bronken et al. (2012)	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟨	🟩	🟩
Carlsson et al. (2004)	🟩	🟩	🟩	🟥	🟩	🟥	🟩	🟥	🟩	🟥	🟩	🟩
Carlsson et al. (2018)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟥	🟥	🟨	🟩	🟩
Ch'ng et al. (2008)	🟩	🟩	🟨	🟨	🟩	🟥	🟥	🟥	🟩	🟩	🟩	🟩
de Guzman et al. (2012)	🟩	🟩	🟩	🟨	🟥	🟥	🟩	🟥	🟨	🟥	🟩	🟥
Doolittle (1991)	🟩	🟩	🟩	🟨	🟩	🟥	🟥	🟥	🟨	🟨	🟩	🟩
Doyle et al. (2014)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩
Eilertsen (2005); Eilertsen et al. (2010)	🟩	🟩	🟩	🟨	🟩	🟨	🟩	🟩	🟨	🟨	🟩	🟩
Ellis-Hill et al. (2000)	🟩	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟨	🟨	🟩	🟩
Erikson et al. (2016)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟨	🟩	🟩
Faircloth et al. (2004)	🟩	🟩	🟩	🟥	🟨	🟥	🟥	🟥	🟨	🟥	🟥	🟥
Girardon-Perlini et al. (2007)	🟩	🟩	🟩	🟥	🟩	🟥	🟨	🟥	🟥	🟨	🟩	🟥
Gorst et al. (2016)	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩
Kinoda (2008)	🟩	🟩	🟩	🟨	🟩	🟥	🟨	🟩	🟩	🟥	🟩	🟩
Kitzmuller et al. (2013)	🟩	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩
Kuluski et al. (2014)	🟩	🟩	🟩	🟨	🟨	🟩	🟩	🟩	🟩	🟨	🟩	🟩
Kvigne and Kirkevold (2003)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟨	🟩	🟩	🟩
Kvigne et al. (2004)	🟩	🟩	🟩	🟨	🟩	🟥	🟩	🟩	🟨	🟨	🟩	🟩
Lawrence and Kinn (2012)	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟨	🟩	🟩
Leahy et al. (2010); Leahy et al. (2016)	🟩	🟩	🟩	🟨	🟩	🟥	🟩	🟥	🟨	🟨	🟩	🟩
Lever and Pryor (2015, 2017)	🟩	🟩	🟩	🟥	🟩	🟥	🟩	🟨	🟩	🟨	🟩	🟩

Meijering et al. (2016)	🟩	🟩	🟩	🟥	🟩	🟥	🟧	🟧	🟩	🟧	🟩	
Moorley and Cahill (2018)	🟩	🟩	🟩	🟧	🟧	🟥	🟩	🟥	🟧	🟧	🟩	🟧
Murray and Harrison (2004)	🟩	🟩	🟩	🟩	🟩	🟧	🟥	🟥	🟩	🟧	🟩	
Nanninga et al. (2015)	🟩	🟩	🟩	🟧	🟩	🟥	🟩	🟧	🟩	🟧	🟩	
Nanninga et al. (2018)	🟩	🟩	🟩	🟧	🟩	🟥	🟧	🟧	🟩	🟧	🟩	🟧
Nasr et al. (2016)	🟩	🟩	🟩	🟧	🟩	🟧	🟩	🟧	🟧	🟧	🟧	
Norris et al. (2010)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟥	🟩	🟧	🟩	
Pallesen (2012, 2014)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟧	🟧	🟩	
Pedersen et al. (2019a); Pedersen et al. (2019b)	🟩	🟩	🟩	🟧	🟩	🟥	🟩	🟩	🟩	🟧	🟩	
Purton et al. (2015); Purton et al. (2020)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟩	
Raghavan et al. (2016)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟥	🟧	🟧	🟩	
Rittman et al. (2004)	🟩	🟩	🟩	🟧	🟧	🟥	🟩	🟥	🟧	🟧	🟩	🟧
Rittman et al. (2007)	🟩	🟩	🟩	🟧	🟧	🟥	🟩	🟧	🟧	🟧	🟧	
Stott et al. (2021)	🟩	🟩	🟩	🟩	🟩	🟧	🟩	🟩	🟩	🟧	🟩	
Taule and Råheim (2014); Taule et al. (2013)	🟩	🟩	🟩	🟩	🟩	🟧	🟩	🟩	🟩	🟧	🟩	
Timothy et al. (2014); Timothy et al. (2016)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟩	
Wyller and Kirkevold (1999)	🟩	🟩	🟩	🟩	🟩	🟧	🟧	🟥	🟩	🟧	🟩	
Yamauchi (2007)	🟩	🟩	🟧	🟧	🟧	🟩	🟩	🟩	🟩	🟥	🟩	
Yuki (2008)	🟩	🟩	🟩	🟧	🟩	🟥	🟧	🟩	🟧	🟧	🟩	
Modal rating	🟩	🟩	🟩	🟧	🟩	🟥	🟩	🟩	🟩	🟧	🟩	

Key:

Yes	Cannot tell/ Neutral	No

Q1. Was there a clear statement of the aims of the research?

Q2. Is a qualitative methodology appropriate?

Q3. Was the research design appropriate to address the aims of the research?

Q4. Was the recruitment strategy appropriate to the aims of the research?

Q5. Was the data collected in a way that addressed the research issue?

Q6. Has the relationship between researcher and participants been adequately considered?

Q7. Have ethical issues been taken into consideration?

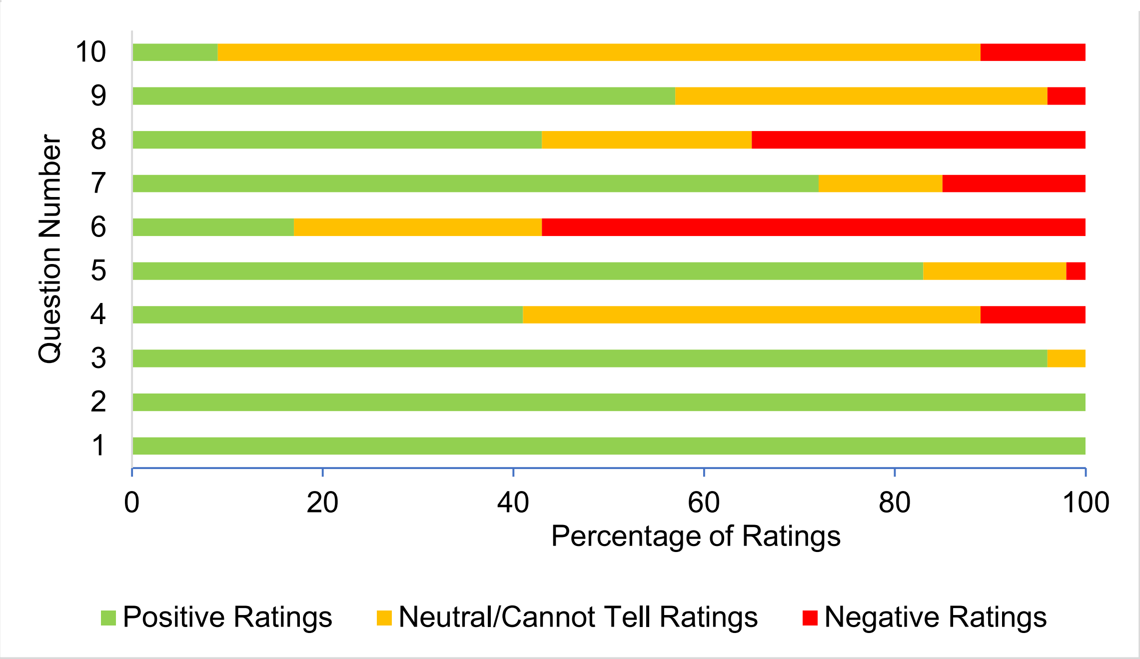
Q8. Was the data analysis sufficiently rigorous?

Q9. Is there a clear statement of findings?

Q10*. How valuable is the research?

*No rating system provided, so judgement made by researcher.

Figure 5.3 *Ratings Spread (%) of CASP Ratings for the Qualitative Papers*

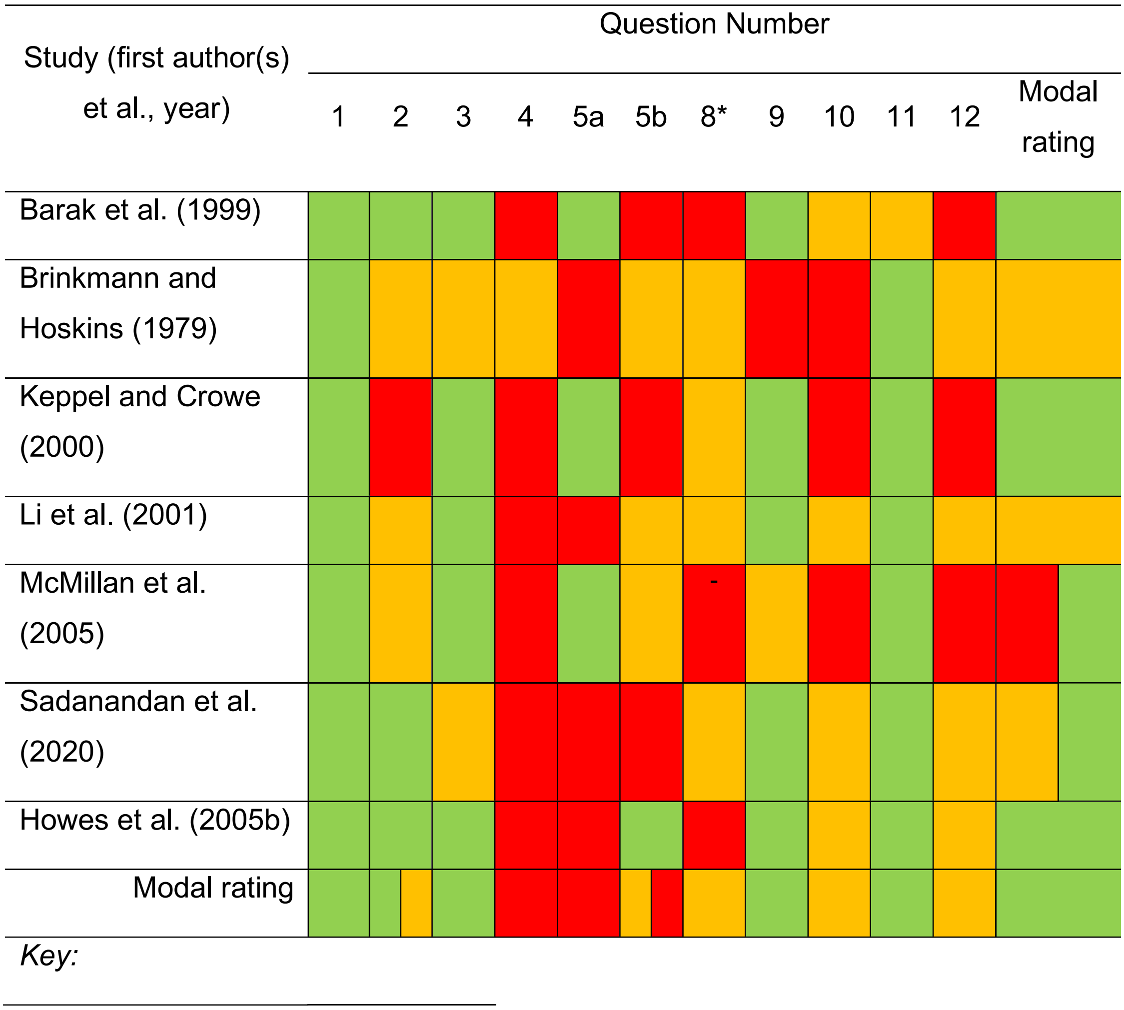


To summarise the results shown in Table 5.3 and Figure 5.3 in terms of robustness (methodological quality) (Popay et al., 2006), the relationship between researcher and participant was often inadequately reported, meaning bias could not be fully evaluated because researcher reflexivity nor researcher role in the creation of data was fully acknowledged (Berger, 2015; Dodgson, 2019). Rigour of data analysis was typically difficult to identify or not reported. The value of the research could not be fully evaluated for most of the papers. This was predominantly due to the nature of qualitative research and the homogenous or specific samples that make it difficult to transfer or generalise findings to other populations or sub-samples.

5.7.2 Quantitative studies

The quality of quantitative studies is presented in Table 5.4 and Figure 5.4.

Table 5.4 *Quantitative Study Quality Assessment: CASP Cohort Study Checklist (CASP, 2018a) Results*



Study (first author(s) et al., year)	Question Number											
	1	2	3	4	5a	5b	8*	9	10	11	12	Modal rating
Barak et al. (1999)	🟩	🟩	🟩	🟥	🟩	🟥	🟥	🟩	🟧	🟧	🟥	🟩
Brinkmann and Hoskins (1979)	🟩	🟧	🟧	🟧	🟥	🟧	🟧	🟥	🟥	🟩	🟧	🟧
Keppel and Crowe (2000)	🟩	🟥	🟩	🟥	🟩	🟥	🟧	🟩	🟥	🟩	🟥	🟩
Li et al. (2001)	🟩	🟧	🟩	🟥	🟥	🟧	🟧	🟩	🟧	🟩	🟧	🟧
McMillan et al. (2005)	🟩	🟧	🟩	🟥	🟩	🟧	- 🟥	🟧	🟥	🟩	🟥	🟥🟩
Sadanandan et al. (2020)	🟩	🟩	🟧	🟥	🟥	🟥	🟧	🟩	🟧	🟩	🟧	🟧🟩
Howes et al. (2005b)	🟩	🟩	🟩	🟥	🟥	🟩	🟥	🟩	🟧	🟩	🟧	🟩
Modal rating	🟩	🟩🟧	🟩	🟥	🟥	🟧🟥	🟧	🟩	🟧	🟩	🟧	🟩

Key:

Yes	Cannot tell/ Neutral	No

Q1. Did the study address a clearly focused issue?

Q2. Was the cohort recruited in an acceptable way?

Q3. Was the exposure accurately measured to minimise bias?

Q4. Was the outcome accurately measured to minimise bias?

Q5a. Have the authors identified all important confounding factors?

Q5b. Have they taken account of the confounding factors in the design and/or analysis?

Q8. How precise are the results? *No yes/no answer

Q9. Do you believe the results?

Q10. Can the results be applied to the local population?

Q11. Do the results of this study fit with other available evidence?

Q12. What are the implications of this study for practice?

- = not reported

Footnote: Only one report (Li et al., 2001) was relevant to Q6a (Was the follow up of subjects complete enough?) & Q6b (Was the follow up of subjects long enough?),

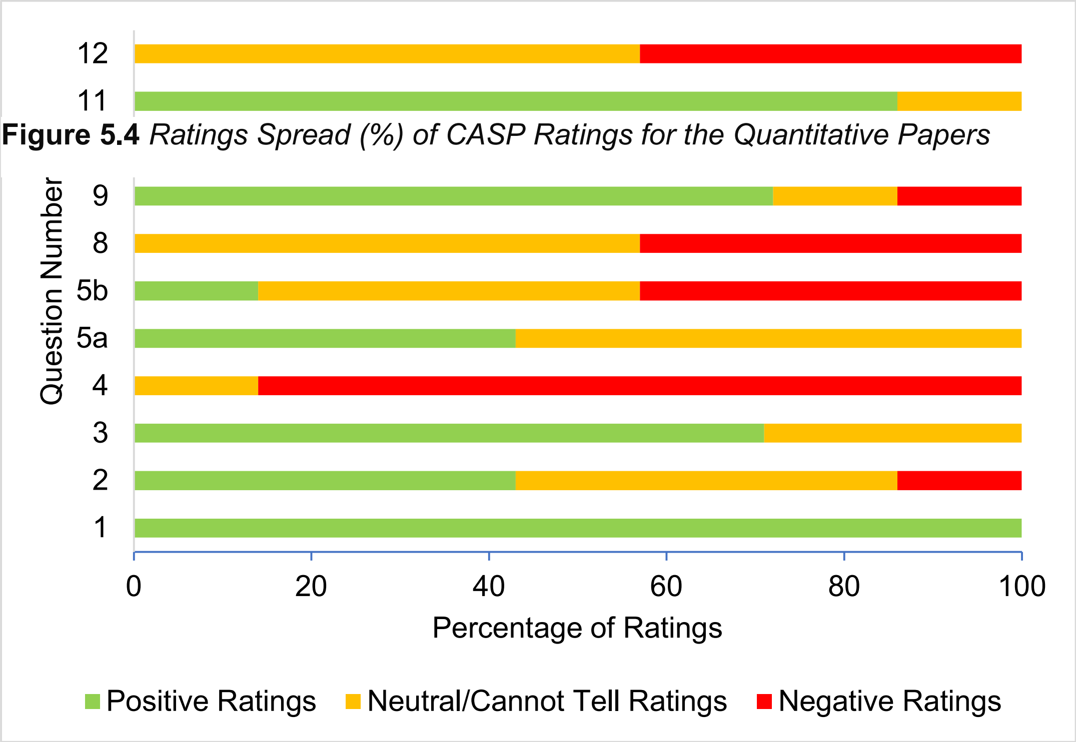


Figure 5.4 *Ratings Spread (%) of CASP Ratings for the Quantitative Papers*

so they were omitted from the table. Li et al. (2001) scored positively for both of these questions.

To summarise the results shown in Table 5.4 and Figure 5.4 regarding methodological robustness, there was lack of detail surrounding sampling type and justifications of eligibility criteria and recruitment setting. This caused difficulties in identifying selection bias and judging the quality of sampling methods. Confounding factors were often not clearly identified or accounted for, meaning potential bias in results. No studies fully addressed issues around biased measures of outcome (namely that no measures of body image were validated in stroke); precision of results (confidence intervals did not tend to be reported); application of results and implications for practice (samples were often not applicable due to smaller sample sizes and lack of inclusion of people with certain difficulties e.g., aphasia (difficulties with communication (National Health Service (NHS), 2021a)), more severe stroke).

5.7.3 Grey literature

The quality of the grey literature is presented in Table 5.5.

Table 5.5 *Grey Literature Quality Assessment: Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) Checklist (Tyndall, 2010) Results*

Study (first author(s) et al., year)	Authority	Accuracy	Coverage	Objectivity	Date	Significance	Modal rating
				Qualitative			
Boylstein (2002)	🟩	🟧	🟧	🟩	🟧	🟩	🟩🟧
Crowfoot (2016a); Crowfoot (2016b)	🟧	🟩	🟩	🟩	🟩	🟩	🟩
Immenschuh (2003)	🟧	🟩	🟩	🟩	🟧	🟩	🟩
Stott (2019); Stott et al.	🟧	🟧	🟩	🟩	🟩	🟩	🟩

(2018a, 2018b)	🟧	🟧	🟩	🟩	🟩	🟩	🟩
Quantitative							
Howes (2004): study 3	🟧	🟧	🟩	🟩	🟩	🟩	🟩
Braga (2012)	🟧	🟩	🟩	🟩	🟧	🟧	🟩🟧
Goodyear (1978)	🟧	🟧	🟧	🟩	🟩	🟩	🟩🟧
Lourenço (2012)	🟧	🟧	🟩	🟩	🟩	🟩	🟩
Picado et al. (2019); Picado (2018)	🟧	🟧	🟩	🟧	🟧	🟧	🟧
Mixed Methods							
Ellis-Hill (1998)	🟩	🟧	🟩	🟩	🟩	🟩	🟩
Modal rating	🟧	🟧	🟩	🟩	🟩	🟩	🟩

Key:

🟩 Yes	🟧 Cannot tell/ Neutral	🟥 No

Authority	Identifying who is responsible for the intellectual content
Accuracy	Aim or brief; methodology; peer-reviewed; supported; representative; explicit & appropriate data collection; accurate, unbiased?
Coverage	Are any limits clearly stated?
Objectivity	Identifying bias, particularly if it is unstated or unacknowledged.
Date	Date that confirms relevance?

Significance	Value judgment, in the context of the relevant research area

To summarise the results shown in Table 5.5 in terms of robustness, unlike the peer-reviewed qualitative literature (see section 5.3), the authors of the grey literature tended to make their research perspectives clear. This allowed better understanding of their potential influence over the data. Generally, the grey literature could be considered as meaningful, including having feasibility, utility and relevance. However, studies were not necessarily representative as sample sizes were small and included specific eligibility criteria, leading to issues of generalisability.

5.7.4 Summary of quality assessments

Although the existing evidence has shed light on post-stroke body image experience, the quality of evidence is variable. This is mostly due to a lack of transparency around researcher-participant relationships, sampling, and rigour. This raises uncertainties about the trustworthiness of the conclusions drawn from the results. This shows a need for high quality and transparent research to enable clear assessment of quality and contribution to knowledge.

5.8. DISCUSSION

This systematic review has explored the lived experiences of body image for people after stroke to enhance understanding of how post-stroke body image impacts on wellbeing and recovery. As part of this, any methods, measures or tools used to assess body image after stroke have been identified. In this section, the findings regarding body image experiences and impacts will be discussed in relation to existing literature before the findings related to identified body image assessment methods are discussed.

This is one of only two reviews to focus on body image after a stroke. The previous review (Stott, 2019) focused on a narrower subsample of the stroke population, only including people who had somatosensory or perceptual bodily changes post-stroke. It also looked more at the broader concept of body perception. This review took a psychosocial perspective, including a generalised stroke population and a focus specifically on body image. However, the inclusion of some participants with somatosensory or perceptual bodily changes could not be avoided where samples were mixed (e.g., (Stott et al., 2021)). The similarities and differences between the reviews will be elucidated in the following sections.

5.8.1 Body image experiences and impacts

Body image after stroke has been explored both directly (e.g., explicitly as part of the aims) and indirectly (e.g., a concept has been identified within a study that relates to body image although not explicitly stated) in existing research. Themes derived from this review provide knowledge around the importance of perceived continuity and normality of body image after stroke. When people experience a change from their pre-stroke normality due to their stroke, they usually experience their body image as being worse. The qualitative findings show that negative perceptions of their body and self-presentation, including appearance, functions and capabilities, caused people to think that others would also have negative perceptions of them. This seemed to affect self-confidence, and could lead to social withdrawal, resulting in isolation or reduced social activities.

Previously valued activities were affected by a changed perception of bodily appearance, functioning and capability. People were now more aware of what other people thought of them. Everyday activities needed to be adjusted to accommodate the changed body, including slowing down, adapting tasks, or reducing frequency of activities and socialising. Changes to these valued or everyday activities could affect sense of identity. In this way people experienced a changed relationship with their body, which was now perceived as being untrustworthy. Some people struggled to accept or adapt to their changed body image. Others were more optimistic and accepting or worked to return their body image to its pre-stroke ‘normal’. When people felt greater continuity with their pre-stroke body image, the stroke seemed to exert less of an impact on their body image. Other people saw their stroke as an opportunity for improvement and to take better care of themselves and their body.

No specific individual factors were identified that could explain the negative impact that stroke has on body image. Instead, it seems to be a complex contribution of the interplay of several mediators and moderators from the general population that might impact post-stroke body experience. For example, there is some indication that gender may influence body image experience. Women seem more concerned with appearance while men seem more concerned with physical function. But the findings are not consistent across studies and further research is required.

Aspects of this review corroborated the findings from previous (Stott, 2019) review. There is overlap in the papers identified for inclusion. For example, in ‘altered perceptions as a holistic or embodied experience’. There are additional similarities in the findings between the two reviews which will be acknowledged throughout this discussion. The two reviews in conjunction could arguably be considered to broaden the picture of bodily experience post-stroke.

There was wide variation in the participants recruited following a stroke (between zero days and 25 years post-stroke). This makes it difficult to assimilate the results, but perhaps indicates that the changes to body image experience, for some, can be prolonged. Further research is required to determine the proportion of people following a stroke who have an altered body image experience following a stroke.

The body was now central to lived experience, aligning with the concept of body centrality outlined by Merleau-Ponty (Merleau-Ponty, 1962; Smith et al., 2009d) (see section 3.5.1). Now that peoples' body (as the vehicle through which the world is perceived) had changed, so had their experiences of the world (Merleau-Ponty, 1962; Smith et al., 2009d). People described a multi-faceted negative experience of their body image after stroke. Part of this negative perspective was evident through negative language and objectification, a sense of bodily unfamiliarity and a disconnect between mind and body. Objectification is evident across research into stroke populations without perceptual awareness difficulties (e.g., (Doolittle, 1990, 1991, 1992)), as well as those with perceptual awareness difficulties and were described as impacting on sense of bodily ownership (Stott, 2019).

People with different perceptual changes after stroke will feel differently about how in control of their body they are after stroke (Stott, 2019). In this review, people with stroke perceived that their body had changed. It was now untrustworthy when it would not function how they wanted it to. Loss of bodily control is linked with emotional challenges including self-consciousness, self-esteem and reduced confidence (Walsh et al., 2015). Their previously taken for granted body now had to be considered during or prior to daily tasks. This experience is evident in the existing wider literature about bodily experiences (e.g., (Leder, 1990)). The adapting or abandoning of valued activities seemed to impact identity, perhaps due to no longer fitting with pre-stroke 'normality'. In an attempt to be perceived as 'normal', people tried to hide or minimise the appearance of visible bodily impairments. There was a sense that a return to 'normal' would mean a return to valued activities, socialising and social roles. This desire to portray a 'normal' body image to the external world links to social pressures and conformity to cultural 'body ideals (e.g., (Taleporos & McCabe, 2005)). A body ideal is defined by the American Psychological Association as:

> “the body type promoted within a culture and its media as most attractive or most appropriate to a person’s age, gender, and race. This is variously internalized, imposed, and resisted by individuals and groups.” (American Psychological Association, 2022)

People in the general population who cannot reach perceived societal standards of the ideal body image may feel negatively toward impaired aspects of their body (Shpigelman & HaGani, 2019; Taleporos & McCabe, 2005). Those with more severe disabilities have lower body esteem than those with milder or no physical disability (Taleporos & McCabe, 2005). This corresponds with the high levels of sociocultural pressures and sociocultural explanations of body image within Western society to conform to the ideal of the ‘body beautiful’ (Groesz et al., 2002b; Lawrence, 1991; McCabe & Ricciardelli, 2001; Ricciardelli & McCabe, 2001; Stone, 1995; Taleporos & McCabe, 2005; Thompson & Stice, 2001). Therefore, the meaning of the body after stroke seems to be socially defined, reflecting body image as a whole in the general population (Boylstein, 2002; Ellis-Hill et al., 2000).

An alternative explanation for a desire to return to ‘normal’ after stroke links to the life-thread model of stroke recovery (Ellis-Hill et al., 2008). This is a metaphor for the threads or strands which represent our life stories. They represent past memories and future plans. Some strands remain constant throughout life, such as a role as a parent or child, and some will change, such as hair length. People’s life threads overlap and converge with the threads of others through shared social experiences. Through personal narrative, people create links between their known past and unknown future, which helps to provide confidence in a future which is presumed to continue as normal. When a stroke happens, the life threads are suddenly broken and frayed, and continuity is impacted. People must now try and manage their threads to either join them up and regain a sense of continuity, or tie them off (Ellis-Hill et al., 2008). In this respect, a desire for continuity could be seen as an attempt to join up pre- and post-stroke body image and perceptions.

An approach which appears to link both of these explanations (societal standards and life threads) is Cash’s cognitive-behavioural model of body image (Cash, 2012a; Lewis-Smith et al., 2019) (see section 2.1.3.f). The concept of body image being internalized before stroke and being based upon ‘historical influences’ creates a sense of ‘normal’ body image, which could be represented as part of the life thread. People then try and return to this ‘normal’ and ‘tie-up’ the thread after stroke as suggested by the life thread model. Societal pressures may then emphasise the perceived importance of appearing ‘normal’ to the outside world. People then adjust or respond differently to changes in their body image experiences. This reflects the diversity in influences on body image in the general population (Crowfoot, 2016a). This diversity is likely further compounded by the plethora of possible bodily impacts that can be caused by stroke, which may be coped with and experienced differently by different people depending on their own unique contexts. Considering Cash's cognitive-behavioural model of body image (Cash, 2012a; Lewis-Smith et al., 2019) through the stroke-specific lens of or in conjunction with the life-thread model of stroke recovery (Ellis-Hill et al., 2008) could therefore offer initial conceptual perspective to enhance understanding of post-stroke body image experience.

Equipment or walking aids were absorbed into body image experience as part of bodily functioning. Reliance on aids or equipment made people feel conspicuous or that others only saw their aid (e.g., walking stick). Use of a walking aid or having a disability can influence other people's reactions and lead to either positive or negative feelings or thoughts (Shpigelman & HaGani, 2019). For other people with stroke, equipment was viewed as enabling activities. Alongside reliance on aids or equipment, some people now had to rely on support from other people. This affected body image experience by conflicting with traditional gender roles, again linking into sociocultural pressures. For men, requiring assistance can be experienced as being further from traditional masculine body image expectations leading to a lower body esteem than for women, for whom reliance still means that conformity to the feminine ideal can be maintained (McCabe & Ricciardelli, 2001; McCabe & Ricciardelli, 2003, 2004; Murnen & Don, 2012; Taleporos & McCabe, 2005). In terms of other people, those who cannot hide their impairment must learn to actively cope with the reaction of others (Pachankis, 2007; Pahwa et al., 2017; Shpigelman & HaGani, 2019).

There is also a hidden side of stroke for people who do not have an obvious disability, but still feel different. The current findings showed that they face not having their impairments or changes acknowledged or validated by other people, leading to annoyance or feelings that others perceived them differently to how they perceived themselves. People with mental illnesses that are not obvious to others experience worse body image and self-concept compared to people with physical, observable changes (Shpigelman & HaGani, 2019). They face the issue of whether or not to disclose their impairment to others, which could impact psychological wellbeing (Pachankis, 2007; Pahwa et al., 2017; Shpigelman & HaGani, 2019). In this respect, following a stroke, people may feel that the body image that other people see does not reflect how they actually feel, and lead to a disconnect between their mind and body. This also means they must cope with people not reacting to their changed body, which could lead to feelings of conflict as part of adjustment.

People assimilated their stroke and bodily changes to ageing. This could impact body image experience due to Western society having a negative view of ageing, particularly for women (Clarke & Korotchenko, 2011; Hofmeier et al., 2017) and linking to societal pressures. With age, women typically become less interested in adhering to social expectations. However, they remain expected by society to adhere to them. Priorities shift towards bodily functioning, but appearance remains important. The ageing process seems linked to experiencing a decline in perceived societal value (Hofmeier et al., 2017), which was evident in the current findings where people perceived feeling “older” as being linked to “less intelligent” (Nasr et al., 2016). This supports the current findings as the women in the studies were more likely to express desire to keep up their appearance for social reasons. Contrastingly, older men express less concern about appearance and age-related bodily changes than women and have higher self-esteem (Clarke & Korotchenko, 2011).

These negative associations with ageing could explain why after a stroke when people felt or likened themselves to an ‘older’ person, they also experienced issues with their body image. Perceptions of ageing are different across cultures. For example, people from Asian cultures hold more positive societal views of ageing compared to Western cultures (Löckenhoff et al., 2009). Future research should explore the perceptions of people from different cultural backgrounds to see whether different societal views of ageing influence post-stroke body image experiences.

People coped differently with the impacts of a changed body image. Coping and self-regulatory strategies and behaviours are acknowledged as part of body image experience by cognitive behavioural explanations of body image (Cash, 2012a; Lewis-Smith et al., 2019).

Perceived ability to cope is built upon confidence in personal ability to cope with a situation based on available resources e.g., physical, social, psychological or material. Then a coping strategy is used (emotion, problem or meaning focussed). Through emotion-focussed strategies, people regulate the emotions or distress caused by the situation, compared to problem-focussed coping where the problem that caused the stress is directly addressed (Berjot & Gillet, 2011; Lazarus &

Folkman, 1984). Meaning-focused coping, which is most evident across the current results includes five typical responses: 1) realisation that the situation will not be resolved, leading to a re-ordering of priorities to deal with the altered reality; 2) pursuit of realistic goals to resolve a stressful situation; 3) finding benefits in the situation; 4) reminding self of benefits already found and 5) finding meaning in ordinary events (Hewstone et al., 2007). These individual differences in coping mechanisms may explain the different attitudes expressed towards how post-stroke body image is experienced and how it is perceived as impacting on everyday life. For example, some participants turned to their faith to frame their acceptance of their stroke and its impacts, which is also evident across existing research into post-stroke adjustment (Sarre et al., 2014).

While it is important to understand factors which predispose people to negative psychological outcomes post-stroke, it is also important to understand mechanisms which promote psychological well-being. Understanding which factors influence both positive and negative outcomes will allow the development of better interventions to support mental health post-stroke. In relation to coping, findings indicate evidence of post-traumatic growth after stroke. Post-traumatic growth relates to increased appreciation and an increased sense of personal strength (Tedeschi & Calhoun, 2004). This was evident in relation to seeing life post-stroke as an opportunity for change, to take better care of themselves and their body and expressing optimism or positive outlooks. Research shows how people with stroke can show post-traumatic growth compared to healthy controls (Kuenemund et al., 2016). This should be promoted via active coping and cognitive processing of the impacts of their stroke (Kelly et al., 2018). Evidence could also be drawn from post-traumatic stress disorders after stroke (e.g., (Perkins et al., 2021)) to provide comprehensive support. For example, helping patients to understand how stroke risk factors and post-traumatic stress disorders are linked, to support both emotional reaction to the stroke and physical behavioural responses e.g., improving lifestyle factors to prevent stroke recurrence (Perkins et al., 2021).

5.8.2 Body image terminology

Limited use of the term ‘body image’ across included studies shows that body image has rarely been specifically studied after stroke. Only a third of the studies included used the term ‘body image’, meaning that even where results could be related to the definition of body image used within this thesis, this was not identified or acknowledged. Of the studies which did use the term, only 50% provided a definition, all of which varied significantly. This means there is not a clear understanding of the concept of body image in the stroke literature. The lack of a clear definition makes assimilation and interpretation of the results difficult.

Some but not all of the components of the thesis definition were seen across the included studies. The most consistently used definitions included thoughts, feelings and perceptions around appearance, which aligns more with the lay and commonly recognised definitions of body image (Bailey et al., 2017). Function and capability are also acknowledged, but to a lesser degree. This could be because these aspects are not traditionally labelled as body image in the general population (Bailey et al., 2017). Behaviours were rarely identified in relation to body image, yet the current results show how people’s everyday behaviours, including socialising and activities, were being affected by perceptions of their changed body image. This means that studies investigating body image terminology may only actually be exploring partial domains of it, and therefore not providing the whole picture. This is problematic given the multi-dimensional and complex nature of body image.

The implications of lack of use and consistency of the term ‘body image’ means it may be difficult to identify as a concept both in research and clinically after stroke. It also means it may be inappropriately used or used when a different related term may be more applicable. Pragmatically, it was useful to have a pre-decided and broad definition of body image experience to use when identifying relevant studies for inclusion. However, this would have been easier if there was a clear and consistently used definition to provide clarity both in terms of research and clinical practice.

5.8.3 Body image assessment methods

Out of the 15 assessment methods identified by the review that had been used to directly or indirectly assess body image experience post-stroke, none were validated for use with people after stroke. The most commonly used tool (the Body Cathexis scale (Secord & Jourard, 1953)) was only implemented in four studies.

This lack of consistency over tools not only exists in stroke but also the general body image literature. Previous systematic reviews into different populations have identified some of these methods (e.g., (Gardner & Brown, 2010; Kling et al., 2019)). The most recent review only identified one of the methods identified by the current review (the BSQ) as meeting their definition of body image and being of acceptable quality. The lack of overlap in tools identified may not be surprising given the focus on body image. One focussed on body image disturbance only (Gardner & Brown, 2010), while the other focussed only on appearance (Kling et al., 2019). This emphasises the lack of consistency in body image terminology alongside a lack of quality.

The lack of stroke-specific body image assessment methods identified from this review supports the need for a consistently used, appropriate, acceptable and clinically feasible method for assessing post-stroke body image experience. This needs to be easily understood, valid, sensitive and capture all aspects of body image. Crucially, it should be implementable both in research and clinical practice. The lack of consensus around tools also makes it difficult to compare findings between studies, adding to the lack of clear understanding of post-stroke body image experiences. Given the array of available body image assessment methods, there is a need for further research to identify which method is most acceptable and meaningful for people with stroke. This would help in assessing the effectiveness of any body image support that is provided to patients, but also in quantifying the frequency and scale of body image issues experience by people with stroke.

The body image assessment methods identified from this review will be further discussed in section 7.3.4 in preparation for evaluation as part of the expert panel groups.

5.8.4 Rationale for a narrative synthesis approach

a. Narrative synthesis approach

Narrative synthesis is sometimes considered as a ‘second best’ approach to synthesising review findings, that should only be used when statistical meta-analysis or specialist synthesis (e.g., meta-ethnography for qualitative studies) is not appropriate (Popay et al., 2006). Based on the review questions and the aim of summarising the existing evidence, there was no requirement for a specialist theory-driven synthesis, nor a focus on producing a theory from the results. Arguably, methods including but not limited to, grounded theory, meta-ethnography or realist synthesis approaches would have been appropriate if more of an interpretation or focus on theory was required (Dixon-Woods et al., 2005; Dixon-Woods et al., 2004).

Instead, the narrative synthesis approach used allowed a descriptive summary of the data to be created which tells the story of the findings (Popay et al., 2006). The intention was that the quantitative and qualitative findings would be synthesised separately and then brought together into a narrative synthesis of the results. As outlined in section 5.2, this was not appropriate. This meant that the synthesis was not fully in line with the guidance outlined in section 4.5.5. Researchers considering completing reviews in this area in the future should think about conducting separate reviews for quantitative and qualitative methods.

b. Thematic synthesis

Within narrative synthesis, a thematic analysis approach is a way of synthesising the data through translation (exploring similarities and/or differences across studies) (Pawson, 2002; Popay et al., 2006). The thematic synthesis approach allowed the main ideas from the studies to be reflected in the results (Popay et al., 2006). It also allowed an organised and structured approach to describing the data (Dixon-Woods et al., 2005; Dixon-Woods et al., 2004) and was adaptable for the heterogenous quantitative data (Ryan et al., 2018). This structured approach was beneficial given the large amount of data identified through the review which needed to be synthesised. Having the data synthesised into themes would support easier comparison of key findings with subsequent key findings from the interview study (see sections 5.4.2 and 5.5).

An alternative and similar method considered was content analysis. Taken in its traditional form, this method usually involves converting qualitative data into quantitative form. This may have been useful in terms of coding findings into a framework to produce a summary of findings mapped against the thesis definition of body image. However, content analysis can be reductive, and complexity and context can be lost. This would not have been useful for the current study given the complexity of body image (Dixon-Woods et al., 2005; Dixon-Woods et al., 2004).

5.8.5 Study Limitations

a. Quality and certainty of evidence

Before commenting on the quality and certainty of evidence, the appropriateness of the CASP checklist in evaluating study quality should be considered. The CASP offers effective assessment of the transparency of research studies and of their reporting standards. However, it is not as effective at capturing the quality of the design and conduct of studies (Long et al., 2020). When compared to other quality assessment tools, such as the evaluation tool for qualitative studies and the Joanna Briggs Institute tool, the CASP checklist is the least sensitive to validity and methodological quality (Hannes, 2010). Additionally, the lack of guidance or weighting of questions provided by the CASP checklist must be taken into consideration. It means that the quality assessments provide only an insight into study quality and subsequently robustness and trustworthiness of conclusions, as opposed to a rigorous assessment of weighted study quality. However, pragmatically, this aligns with the purpose of the current study in presenting a broad idea of the quality of the large number of included papers, including key areas where quality should be addressed in future study. Additionally, the quality rating assigned to each CASP question for each study (as shown in Tables 5.3-5.5 and Figures 5.3-5.4) allows the reader insight into areas of strengths and weakness for each study and thus the opportunity to make specific judgements for each area of quality presented.

In general, the quality of the qualitative studies was acceptable, based on studies mostly receiving positive or neutral CASP ratings. However, there were limitations in terms of reporting on rigour of data analysis and consideration of the relationship between researcher and participants. This is important, as for qualitative research, the researcher is the primary instrument for data collection (Johnson et al., 2020). This means that they play a crucial role in the data collection and that the data is inherently reliant on them and how they collect and analyse it (Patton, 1999). Without showing that they have thought about considering the ways that the researcher might have influenced the data, it means they at the researcher may have biased the results and their interpretation.

The quantitative studies had more risk of bias with only slightly more positive ratings than negative or neutral. The biggest issues were around lack of reporting detail, smaller sample sizes and use of unvalidated tools. For both the qualitative and quantitative studies, there was lack of detail around recruitment. This makes it difficult to judge the quality of sampling methods and presence of bias. This affects the value and transferability of the findings. Overall, implications for practice were minimal due to studies being small and not providing robust enough evidence to inform policy.

Therefore, the robustness of the conclusions that can be drawn from the existing evidence base are limited. Conclusions must be considered in light of the methodological and reporting limitations of the included studies.

b. Identifying all relevant studies

The lack of use of the term ‘body image’ across studies which were ultimately eligible represents a limitation in the process of identifying relevant studies. It was evident during construction of the eligibility criteria and piloting the searches and screening processes that even studies which did not refer explicitly to ‘body image’ in their title or abstract could still contain results relevant to post-stroke body image experience. Therefore, care was taken during screening to identify papers whose abstracts gave an indication that results may link to lived experiences of body image, including general bodily experiences, body cathexis, embodied experiences and terminology outlined in section 2.1.2. This enhanced the thoroughness of the review process and the likelihood of relevant papers being identified. However, it posed the issue of when a concept stopped being body image and would fit better under the remit of rehabilitation or functional adaptation. This is because the definition could arguably be applied to a vast quantity of papers surrounding post-stroke experiences and rehabilitation. Care was taken to exclude papers that would not answer the review questions (e.g., where body image was discussed from a neurological perspective, e.g., (Connell & Adams, 2011)) and to include papers which were relevant even if they used different terminology. Body image is also sometimes described as a perceptual concept or an attitudinal concept (see section 2.1.2). Perceptual body image relates to the accuracy with which a person can judge the physical dimensions of their body (Cash & Deagle III, 1997; Cornelissen et al., 2019). Attitudinal perspectives focus on feelings about the body (Cornelissen et al., 2019). Attitudinal body image aligns with the lived experience focus of the thesis, so care was taken when screening that exploration of body image was more related to attitudinal perspectives.

c. Mixed samples of awareness disorders

Despite excluding studies that only included participants with perceptual awareness disorders, some studies included mixed samples of people with different restrictions or changes to their bodily awareness that may impact recognition of bodily changes (e.g., (Stott et al., 2021)). Some studies also did not measure it in participants. Therefore, it was difficult to tease out the experiences of people with and without these awareness disorders. However, there were sufficient patterns across the studies to suggest commonalities for patients after stroke in terms of their body image experiences.

d. Reflections on epistemological perspectives

As outlined in section 3.5, the use of a mixed methods systematic review aligns more with positivism than the phenomenological and social constructionism perspectives described in section 3.4 (Furunes, 2019). This is compounded by inclusion of quantitative data. However, given the limited data in this area, it was important to include all available evidence to be able to understand and build the evidence base in this topic area.

Body image means different things to different people and can be considered a fluid concept. This made it challenging to identify literature and meant it needed to be clearly defined. The use of a definition within the review contrasts with phenomenological and social constructionist perspectives. It does not align with the concept of body image being a fluid and potentially socially constructed term. It also algins more with the structured approach more akin to positivism (Lit & Shek, 2002; Zaborek, 2009). However, the definition was needed to provide some boundary on what would and would not be considered body image as part of the systematic review. Therefore, it was a pragmatic decision to define body image experience to enable completion of the systematic review and to make it manageable within the limited resources of a PhD. Additionally, the use of the thematic analysis quality checklist could be considered as aligning more with positivism due to its structured and linear nature. However, it was important to identify a method to reflect upon the quality of the review synthesis.

e. Reflections on rigour

The PRISMA checklist has been adhered to throughout completion of the review and a PRISMA flow diagram presented. PRISMA does not increase the quality of the review, but instead shows transparency of methods (Page et al., 2021).

To reflect on quality, a 15-point checklist by Braun and Clarke (2006) was adhered to. The criteria are presented in Table 5.6. Each process of the quality assessment is reflected upon in the table, apart from ‘Transcription’ which was not relevant to the thematic synthesis of data from primary studies.

Table 5.6. *Reflection on Addressing the 15-point Checklist of Criteria for Good Thematic Analysis (Braun & Clarke, 2006)*

Process	Number	Criteria	Reflection on addressing criteria
Transcription	1	Data transcribed to an appropriate level of detail, and transcripts checked against the tapes for ‘accuracy’	Not applicable
Coding	2	Each data item given equal attention in the coding process	Addressed during NVivo coding process: all relevant data extracted

	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	from the primary studies were coded in detail Iterative process to ensure that data and themes representative of primary data
	4	All relevant extracts for each theme have been collated	DoS and supervisory team supported process by reading iterations of the quotations and themes and providing feedback on whether the themes felt representative of the codes, and were distinct, coherent and answered research questions
	5	Themes checked against each other and back to the original data set	
	6	Themes are internally coherent, consistent, and distinctive	
Analysis	7	Data have been analysed (interpreted, made sense of) rather than just paraphrased or described	Purpose of review was not to interpret the data, but to make sense of and summarise it
	8	Analysis and data match each other- the extracts illustrate the analytic claims	Extracts were narrowed down from list of supporting quotations for each theme. This helped to achieve balance between narrative and extracts
	9	Analysis tells convincing and well-organized story about the data and topic	
	10	Good balance between analytic narrative and illustrative extracts is provided	DoS and supervisory team provided feedback to help in ensuring that extracts matched themes

			and narrative, and that the narrative told the story of the data in relation to post-stroke body image experience
Overall	11	Enough time allocated to complete all phases of analysis adequately, without rushing a phase or giving it a once-over-lightly	Analysis process was conducted over multiple months and was not considered complete until all data was felt by the researcher and DoS to represent the data from the included primary studies
Written Report	12	Assumptions about, and specific approach to, thematic analysis are clearly explicated	Approach to thematic analysis reported in section 4.5.5
	13	Good fit between what you claim you do, and what you show you have done- i.e., described method and reported analysis are consistent	Methods reported in section 4.5.5 and match analysis reported in sections 5.4 and 5.5
	14	Language and concepts used in the report are consistent with the epistemological position of the analysis	The language and concepts used reflect the hybrid approach of the epistemological perspectives taken
	15	The researcher is positioned as active in the research process;	The role of the researcher is described through the methods and their influence over the data

		themes do not just ‘emerge’	collection and analysis process is acknowledged in section 5.8

Overall, each point within the checklist has been addressed, suggesting that the analysis of the review was rigorous. The use of a checklist for rigour for the systematic review reflects the hybrid approach of epistemological perspectives used throughout the thesis. A checklist might seem slightly at odds with the overall phenomenological perspectives outlined in Chapter 3, but this thematic analysis checklist suits the chosen approach taken for synthesising the results of the systematic review.

5.8.6 Study strengths

a. Data extraction forms, extraction process and synthesis

The involvement of multiple researchers in developing and trialling the data extraction form contributed to its quality and utility. Methods were employed to increase trustworthiness and reduce bias. Any papers where eligibility was unclear were discussed with the supervisory team and all extractions and quality assessments were verified. Initial ideas around the qualitative narrative synthesis and the deduced themes were discussed with the supervisory team to collate perspectives and ensure that ideas were logical and representative of the synthesised data.

b. Non-English language papers

Studies did not have to be written in English language to be included in the review. This enhanced its inclusivity, and its relevance and application globally. However, it is also possible that body image concepts could have been understood differently across cultures, so care needs to be taken when interpreting what ‘body image’ means in different cultures.

5.8.7 Implications of the results for practice, policy, and future research

a. Implications for future research

It is difficult to extrapolate findings from the studies in this review to the wider stroke population due to the large number of qualitative methods, small sample sizes, wide timeframes, and specific sub-samples of people with stroke. Research is needed to explore the stroke population more generally and at specific times post-stroke to improve understanding of post-stroke body image experiences. As part of improving this understanding, there is a need for a clear outline of what this experience might be like and its impacts on everyday lives. This would help people with stroke to better understand their bodily changes and facilitate health care professionals, families and carers in supporting the experiences of people with stroke.

Results indicate that there might be a role for psychological support for body image after stroke. Further research is needed to understand how to better support people if they struggle with their post-stroke body image experiences.

5.9. CONCLUSION

This review provides a foundation for building the evidence base around post-stroke body image experiences and impacts. In doing so, it has highlighted gaps in the knowledge and understanding. It reflects the hybrid approach of epistemological perspectives rather than the overall stance of phenomenology and social constructionism taken within the thesis. This was necessary to be able to coherently summarise the existing evidence. Results show that after stroke, people must adjust to a changed body image. This process seems to be different for different people. It is important to acknowledge the uniqueness of not only post-stroke adjustment, but also perceived body image experience. However, the themes identified from this review suggest that there are patterns across different peoples’ experiences. Additionally, most studies did not have a clear definition of body image and body image was not the main research focus. Body image as a specific outcome is under-researched. Despite studies exploring aspects of post-stroke body image experience, there has been no exploration of what the term ‘body image’ means to people with stroke and studies have not specifically addressed how recovery or rehabilitation was affected by body image experience. Although numerous assessment tools have been used to explore post-stroke body image, none have been validated for people with stroke.

Overall, research is needed to clarify and build upon this review to create a clear picture of how body image is experienced after stroke. This needs to be in-depth to provide clarity around the nuanced experiences of body image post-stroke. Then, attempts can be made to recommend effective and appropriate support and assessment methods.

The results of the review will inform the subsequent phases in this thesis. The findings have enhanced understanding around experiencing a changed body image post-stroke and have helped to identify it as a broad and potentially impactful concept. This will inform the probing questions used in the interviews to help in gathering a broad picture of body image experience (see section 6.5.2). A summary of the findings and the assessment methods identified will also be taken to the expert panel group for evaluation (see section 7.3.4).

6. CHAPTER 6: EXPLORING POST-STROKE BODY IMAGE EXPERIENCES USING AN INTERPRETATIVE PHENOMENOLOGICAL APPROACH

6.1. CHAPTER INTRODUCTION

In Chapter 5 I have shown that people experience altered thoughts, feelings, perceptions and behaviours in relation to their body after stroke. However, findings that are related to body image experience are often combined with other findings and are not explored in detail. The literature does not tend to categorise these experiences as related to ‘body image’. This means that we do not have a clear understanding of post-stroke body image experiences and impacts. In this chapter, I present the methods and results of a study to specifically explore, in-depth, body image experiences after stroke. I will also reflect on rigour and quality, and alignment of the methods with my epistemological perspectives.

6.2. AIMS AND OBJECTIVES

To understand the experience of body image post-stroke by:

1. Exploring its impact on stroke recovery
2. Identifying common body image concerns post-stroke and exploring the impact of factors including but not limited to age or sex
3. Developing a summary of body image experience and its impact following stroke to aid communication about body image with stroke survivors, and provide the theoretical basis for the development of support and/or methods to assess and measure body image after stroke

6.3. METHODS

6.3.1 Study design

A cross-sectional qualitative design using semi-structured interviews.

6.3.2 Setting

Three trusts were approached about recruitment: Blackpool Teaching Hospitals NHS Foundation Trust, East Lancashire Hospitals Trust (ELHT) and Lancashire Teaching Hospitals Trust (LTHTR). Two Trusts (ELHT and LTHTR) were involved in recruitment.

6.3.3 Participants

Participants were patients who had been admitted with an acute stroke and were being followed up after discharge in the stroke review or outpatient clinics.

6.3.4 Sampling

Aligning with IPA, the aim was not to create generalisable results, but results which represented a variety of perspectives (Smith et al., 2009f) to try and reflect real-world variation in the stroke population. The sample characteristics were frequently reviewed during recruitment and the recruiters asked to approach different groups to facilitate recruitment of a diverse sample. This was in line with a purposive sampling strategy, which involved monitoring the demographic and stroke-related characteristics of participants and identifying characteristics which were under-represented.

a. Inclusion criteria

Participants had to meet the following criteria:

- Adults (aged 18 years or older)
- Stroke (first or recurrent) around 6 months before recruitment
- Able to communicate by any means to convey their experiences of body image
- Able to provide informed consent, either written or with a witness
- Capacity to consent

b. Exclusion criteria

- Subarachnoid haemorrhage as their most recent stroke (see section 4.4.1.c for justification of exclusion)
- A life-threatening/terminal illness as confirmed by a member of their Direct Care Team

6.3.5 Consent

Informed consent was taken in line with the Health Research Authority (HRA) Principles of Consent and participants voluntarily provided consent after being adequately informed and having a fair choice of whether to take part (Ursin, 2008). Re-iterated consent was audio recorded before they completed demographic data collection. For one participant with communication difficulties, signed paper aphasia-friendly consent, witnessed by a member of the ELHT community team was re-done before participation.

Participants were reminded that they could withdraw at any point and could have a break if needed. They were reminded that their interview recordings would be kept confidential and that they would be anonymous in the study write-up. Re-iterated consent was informally confirmed throughout participation.

When a participant’s spouse or relative was present during the interview, their input was transcribed to contextualise the conversation but was not included in the analysis. This is because although permission was sought from the spouse/ relative to record them, consent was not taken from them to be able to include their data in the analysis. Details about ethical standards can be found in section 6.6.

6.3.6 Data saturation

Data saturation was considered across the sample and on an individual basis (Saunders et al., 2018). In relation to the sample, no further participants were recruited once data saturation had been reached. This was deemed to be when interview content showed evidence of becoming repetitive and that similar views were being expressed (Saunders et al., 2018) across a sample of participants comprising different sexes, ages, stroke severity and ethnicities. This would indicate that additional interviews were not generating any new significant information and that the majority of post-stroke body image experiences had been captured for the sample. On an individual level and to align with the ideographic aspects of IPA, saturation was also considered as being achieved at a participant level when probing questions made the researcher feel as though they had a full understanding of the participant’s perspectives (Legard et al., 2003).

While IPA focuses on individual accounts, data saturation requires the researcher to be aware of the experiences of multiple participants (Hale et al., 2008). Consideration of ‘data adequacy’ (the appropriateness of sample *composition* and *size*) could have been more applicable when thinking about the sufficiency of the sample size (Vasileiou et al., 2018). Regardless of approach, transparency of how sample size adequacy was reached is important (Saunders et al., 2018; Vasileiou et al., 2018). For this study, data saturation offered a practical way of conducting each interview ideographically, and then reflecting after each whether any similar views had been expressed in previous interviews. This is important, as thinking about the amount of useful information collected from new participants and identifying when enough data has been collected is an indicator of high-quality research (Morse, 2015; Stenfors et al., 2020).

6.3.7 Method of approach

At ELHT, participants were screened for eligibility and then recruited during or in proximity to community stroke review appointments by Assistant and Trainee Assistant Practitioners (APs). At LTHTR, recruitment was conducted by Clinical Research Nurses (CRNs), who screened lists of stroke follow-up clinics and historical stroke ward admission logs to identify those meeting the eligibility criteria.

Across both Trusts, eligible patients were approached in-person or via telephone. Recruiters asked eligible patients if they would like more information about the study. Those who did were provided a brief outline of the study. Those interested in taking part were provided with a participant pack containing an information sheet, consent form and contact details form, available in standard, witnessed consent and aphasia-friendly formats (see Appendices 9-14). The aphasia-friendly information and consent forms were reviewed for acceptability by two patient, public and carer involvement (PCPI) members who had experienced a stroke (PCPI1 & PCPI2). One (PCPI2) had communication difficulties. This made sure that the materials were appropriate for use.

Patients wanting to participate could complete and return the contact details and consent forms. The researcher then contacted patients via phone, email or post. A mutually convenient time was arranged to complete the pre-interview baseline data collection and interview via telephone or Microsoft Teams (MSTeams) (Microsoft, 2022), depending on their preference. Verbal consent was also recorded at the beginning of participation (see section 6.6 for additional detail about ethical standards).

6.3.8 Sample size

Sample sizes vary greatly in IPA, with three to six participants being suggested for student projects and up to 35 participants being considered a larger sample (Brocki & Wearden, 2006; Cassidy et al., 2011; Smith et al., 2009f). Therefore, recruitment was capped at 23-24 participants across the two participating sites.

The final sample needed to be large enough to develop meaningful points of similarity and difference between participants, but to not risk becoming overwhelmed by large amounts of data (Smith et al., 2009f). Given the exploratory nature of this thesis, a recruitment cap was set. This allowed flexibility in the identification of when enough participants had been interviewed to allow detailed exploration of post-stroke body image concepts and commonalities across participants (Hale et al., 2008). One example of this would be when recurrent themes could be identified (Smith et al., 2009a).

6.4. NON-PARTICIPATION

Sites were asked to complete screening logs to ascertain how many people met the eligibility criteria but did not wish to participate. This provided data on what factors made participants ineligible and the number who declined to consent.

6.5. DATA COLLECTION

Data was collected either by telephone, through MSTeams video calls, or both depending on patient choice. This ensured the safety of the participants and researcher given the COVID-19 pandemic. For those using MSTeams, they had the choice to use the camera during the interview in case they preferred not to see themselves given the sensitive topic of body image. Those with communication difficulties had the choice of being seen face-to-face. Interviews took place in a comfortably familiar setting for them (Smith et al., 2009c). The intention was to speak to all participants individually to facilitate honesty and openness. However, participants were offered to have someone with them if they preferred. Where a significant other was present during the interviews, their contributions to the conversation were acknowledged in the transcripts.

Participant characteristics, stroke-related information and outlines of stroke-related impairments were captured before the interview in a baseline questionnaire (see Appendix 15). Body image experience was captured during one-to-one, semi-structured interview (see Appendix 16 for interview schedule) by video or audio recording. Data were collected directly from participants and not from clinical notes to gain subjective insights into how participants viewed their current health. This subjective approach aligns with existing research exploring body image post-stroke, where the information of interest is the subjective experience of participants (Bergström et al., 2015; Keppel & Crowe, 2000; Tyerman & Humphrey, 1984). Participants who took part through MSTeams were offered an introductory session to ensure that they were happy with using the software. They were also asked if there were any alternative or creative methods that they would like to use during the interview, such as showing photographs, drawing, or use of an online creative platform (e.g., Padlet (2022)). This was provided as an option to allow participants to use visual as opposed to verbal methods as a means to further understand their experience. Offering this option enriched the narrative account and thus could provide greater insights into their thoughts, perceptions, and experiences (e.g. (Rainford, 2020)).

6.5.1 Pre-interview baseline data collection (see Appendix 15)

This was designed to capture information to describe the sample in terms of demographic information, function and current mood. The questions were read out and/or shown to participants and responses recorded directly onto an electronic copy of the data collection form. For the interview completed face-to-face, responses were recorded onto a paper copy and transferred into an electronic format after the session. Crucially, data were related to what participants could remember and therefore, their own awareness of the signs and symptoms of the stroke, aligning with the subjective nature of the thesis. The baseline data collection was used to describe participant characteristics and not used as outcome measures. It comprised of:

- **Demographic information:** date of birth, gender, ethnicity, postcode (to determine index of multiple deprivation (IMD)), marital status, education level, occupation/previous occupation (to determine if impacted by stroke), weight and height (to determine BMI) of all participants. This was to facilitate an in-depth description of the sample and allow a broad range of options for disaggregating interview findings. Participants were asked if they had any other significant illnesses to determine whether they might impact on body image experience.
- **Self-reported pre- and post-stroke stroke cognitive information:** impact and severity of stroke on cognition.
- **Self-reported stroke-related information:** most recent stroke; if it was their first or subsequent stroke (with dates) its type (clot, bleed or unknown); its severity; the side of their body it affected; and any symptoms (with severities) that the stroke had caused.
- **Disability (modified Rankin Scale (mRs)) (Farrell et al., 1991; van Swieten et al., 1988):** a 6-point ordinal, hierarchical scale ranging from ‘0: no symptoms at all’, through to ‘5: severe disability’, and later added (although not relevant to this thesis), ‘6: Dead’ (Broderick et al., 2017; Harrison et al., 2013; van Swieten et al., 1988). It is a valid and clinically relevant interviewer-administered tool for assessing stroke recovery in relation to disability, mobility or handicap (Banks & Marotta, 2007; Harrison et al., 2013; van Swieten et al., 1988). The mRS was administered twice and

participants were asked to rate it pre-stroke and currently. This was to allow subjective comparison of perceived disability before and after stroke and relates to the ways in which participants perceived their body. The mRS has excellent ceiling effects and limited floor effects (Dromerick et al., 2003; Marvin & Zeltzer, 2015) suggesting that it accurately reflects true disability (2010). It also correlates highly with other measures of function or disability (Zeltzer, 2008), including the Barthel index and Frenchay Activities Index (Cup et al., 2003). This demonstrates the validity of the mRS in assessing disability after stroke. It has been criticised for significant interobserver variability (Harrison et al., 2013; Wilson et al., 2005), however only one person (CD) administered it in the current study. A single-point change on the scale is relevant, meaningful (Harrison et al., 2013) and easily identifiable meaning perceived changed in disability pre- and post-stroke could be captured where relevant.

- **Function (Modified Barthel Index (MBI)) (Mahoney & Barthel, 1965):** The Barthel index (Barthel) is a measure used to assess functional ability in relation to how well patients can manage ten everyday tasks without a caregiver: feeding, bathing, grooming, dressing, bowel and bladder continence, toileting, transfers, mobility and stair use (Mahoney & Barthel, 1965; Williams, 2011). Multiple versions of the Barthel exist under its one name, making synthesis of its measurement properties difficult (Quinn et al., 2011). The version used here was a modified and more concise version (MBI), with a total score of 20 (Collin et al., 1988a; Collin et al., 1988b; Mahoney & Barthel, 1965; Wade & Collin, 1988), selected for ease of completion. Higher scores indicate more independence (Williams, 2011). It is not stroke-specific but is prevalently used with people with stroke to measure functional independence and has validity and reliability in stroke (Mahoney & Barthel, 1965; Quinn et al., 2011; Williams, 2011). It also has floor and ceiling effects for people with minor and severe stroke (Quinn et al., 2011). However, the purpose for this thesis is to provide sample description as opposed to measuring function or functional changes.
- **Depression (Patient Health Questionnaire (PHQ-9)) (de Man-van Ginkel et al., 2012; Kroenke et al., 2001):** The Patient Health Questionnaire-9 (PHQ-9) is a brief, self-administered (Kroenke et al., 2001) and easy-to-use instrument (de Man-van Ginkel et al., 2012) to identify depression (Kroenke et al., 2001). There are nine questions representing the Diagnostic and

Statistical Manual of Mental Disorders (DSM-IV) criteria for depression, answered by people in relation to how often (on a scale of 0; ‘not at all’ to 3; ‘nearly every day’) they have been bothered by that problem in the last two weeks (Kroenke et al., 2001). Scores of 5, 10, 15 and 20 represent mild, moderate, moderately severe and severe depression respectively (Kroenke et al., 2001). The PHQ-9 demonstrates reliability, validity and clinical utility with stroke patients who can communicate adequately (de Man-van Ginkel et al., 2012; Gilbody et al., 2007; Kroenke et al., 2001). The researcher read aloud each question and the response options so that the participant could select their response.

- **Anxiety: (Generalised Anxiety Disorder (GAD-7)) (Spitzer et al., 2006):** The Generalized Anxiety Disorder-7 (GAD-7) is a seven item scale that assesses anxiety within the last two weeks (Spitzer et al., 2006). The questions are answered on a 4-point Likert scale (0 = not at all, 3= nearly every day) based on how frequently symptoms have been experienced (Rutter & Brown, 2017). Higher scores indicate more GAD symptoms (Spitzer et al., 2006). The GAD-7 provides an indication that someone is experiencing GAD (Spitzer et al., 2006). Scores of 5, 10 and 15 represent mild, moderate and severe levels respectively (Spitzer et al., 2006). The GAD-7 is considered a valid tool for identifying generalised anxiety and its severity in both clinical practice and research (Spitzer et al., 2006) and ceiling effects are minimal (Alghadir et al., 2020; Manzar et al., 2021).

6.5.2 Interview schedule

The interview schedule was iteratively developed with support from the supervisory team, PCPI feedback and the systematic review. To make sure that the schedule was acceptable and appropriate for use, feedback was first sought from a clinician[8] with an interest in post-stroke body image. It was then piloted with members of the Stroke Research Team at UCLan, which the DoS provided feedback on. Finally, it was piloted during a mock interview with PCPI1. This developed the interview skills of the researcher and allowed a check of the flow and content of the schedule (see Chapter 8).

To follow the interpretative phenomenological approach, the schedule was semi-structured. However, it was also important for the interview to be led by the participant’s concerns to help the researcher to come closer to understanding each

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[8] Penny Doward

participant’s experience. To facilitate this, open-ended questions to encourage lengthy, in-depth responses with minimal verbal input from the researcher were used. The structure helped in guiding the interview, while allowing flexibility to explore different areas of participants’ experiences when they arose (Smith et al., 2009c). This helped to keep the interview on topic but allowed the researcher the flexibility to ask additional questions on relevant topics brought up by participants, which helped in the collection of patient-driven data. It allowed participants to take the lead where appropriate and encouraged discussions around information and experiences that were significant to them.

At the beginning of the interview, participants were informed that that there were no right or wrong answers, and that the interview was about their experiences. The first questions were broad and facilitated details accounts of participant’s interpretation of body image, and then of their stroke. Participants were asked what they understood by the term ‘body image. This was based on the results of the review, which emphasised that body image is understood in different ways by different people. It would also help with the development of the stroke-specific definition of body image.

The use of broad questions at the beginning helped participants to become comfortable in talking and encouraged introduction of more personal, detailed questions later in the interview through building rapport. Prompts were prepared in case participants had difficulty in responding to offer a route for their response (Smith et al., 2009c).

As part of the IPA approach to help the researcher to focus on the idiographic aspects of participant’s individual experiences, the researcher engaged deeply with each participant, listened attentively and probed to learn more (Smith et al., 2009c). Probing questions were mostly specific and individualised to each participant’s responses. However, the schedule contained more general probing questions for use if needed to facilitate the flow of the interview (see Appendix 16).The findings from the systematic review helped to iteratively inform these probing questions, as they showed that body image was a broad and potentially impactful concept. As such, the probing questions were also kept purposefully broad, including: ‘how did that make you feel?’ and ‘how did that impact you?’. Where participants were in full flow answering a question, the researcher noted any additional points of interest and followed them up when participants reached a natural end in their speech (Smith et al., 2009c). The results of the review also shaped the content of the schedule. For example, questions were added which asked about both positive and negative experiences of body image. This is because the results of the review showed that people can have positive outlooks of their post-stroke body image (see section 5.4.2.c).

If participants opted to use any creative methods during their interview, they were asked to elaborate, and to describe what their creations showed and what they meant.

As part of the IPA approach to help the researcher to focus on the idiographic aspects of participant's individual experiences, the researcher engaged deeply with each participant, listened attentively and probed to learn more (Smith et al., 2009c).

At the end of the interview, participants were shown a copy of an existing diagram of post-stroke body image perceptions that had been developed based on research with people who experienced functional restrictions and restricted body awareness after a stroke (Stott et al., 2021). People who took part through MSTeams saw the whole diagram and read it with the researcher. For people who took part via telephone, the researcher read out the themes and subthemes from the diagram. Participants were asked whether it resonated with their experiences, whether they understood it and if anything needed adding or taking away to make it representative of their experiences.

After each interview, the researcher reflected upon their interview techniques to identify areas for improvement and to increase rigour (see section 6.5.4).

6.5.3 Audio/visual recording

All interviews were audio recorded using an encrypted DS-9000 Dictaphone. Participants who took part via MSTeams consented to the interview being video recorded through the software. The video recording supported transcription by allowing detail to be added around body language cues or written descriptions of creative aspects presented (e.g., photographs).

6.5.4 Field notes

After each interview, a reflections form was completed by the researcher to detail immediate thoughts and feelings about the interview. This supported understanding of the interview during analysis and enhanced reflexivity around improving interview techniques.

6.6. ETHICAL ISSUES PERTAINING TO HUMAN SUBJECTS

6.6.1 Documentation of approval by an appropriate ethics review board

Ethical approval was granted by the Wales Research Ethics Committee 4 Wrexham on 30th November 2020 (REC Reference: 20/WA/0305). A substantial amendment was approved on 23rd July 2021. This included two amendments; the removal of the requirement for people with stroke to be recruited only at 6-month review appointments and; to permit other UCLan staff members to transcribe interviews.

6.6.2 Participant safety

Participants' GPs were informed by letter that they were taking part in the study (see Appendix 17). If participants scored 15 or above on the PHQ-9 (Kroenke et al., 2001) or 10 or above on the GAD-7 (Spitzer et al., 2006), a cause for concern letter (see Appendix 18) was sent to their GP and confirmation of receipt of this letter sought. Active listening was used during all sessions to monitor any discomfort in the participant. If participants became upset, the researcher cautiously and sensitively asked if they would like to talk about it. If the topic was causing undue distress, it was changed (Smith et al., 2009c). At the end of the interview, participants were debriefed and directed to additional support helplines and reminded to contact their GP if they needed additional support.

6.7. DATA PROCESSING

Under normal circumstances where COVID-19 did not pose a risk, questionnaires would have been completed on paper and stored securely in a filing cabinet until transferral into an electronic version. Instead, questionnaires were completed directly into an electronic version. This was beneficial as it reduced the amount of confidential data handling. For in-person interviews, a paper copy was completed with the participant, before being transferred into an electronic version and the paper copy destroyed.

All questionnaire responses were imported into a password-protected excel spreadsheet in preparation for analysis in SPSS (Version: 28.0.0.0). All interviews were transcribed verbatim. Participants were assigned a participant number and any details which could identify them were omitted from the transcript to ensure anonymity.

6.8. DATA ANALYSIS

6.8.1 Transcript return

A summary interpretation of any creations produced by participants was sent to them for clarification to ensure researcher understanding of their meaning. A copy of the body image definition derived from the interviews was sent to PCPI members and participants for comment to ensure that the definition made sense, that it was acceptable and to enhance trustworthiness of the findings and interpretation (see section 6.12.2).

6.8.2 The analytic process

After conducting each interview, the author listened back to the recording before conducting the next interview. This was so that the researcher could try and bracket each individual interview to allow understanding of each participant's unique perspective, in line with the theoretical basis of idiography within IPA (Heidegger, 1962; Smith et al., 2009d). It also facilitated iterative updating of the interview schedule to facilitate collection of relevant, high-quality data (Smith et al., 2009c). Table 6.1 demonstrates the analysis process and how it was applied. All coding was completed by the author and themes were derived from the data. A combination of hand-coding and NVivo (version 1.5.1) (NVivo, 2022) was utilised. Where participants used created methods (e.g., Padlet, photographs), the researcher summarised the discussion around what the participant had presented and sent the summary to them to clarify (see section 6.10.1). The descriptions were then coded where applicable as part of the transcript.

Table 6.1 *Stages of Analysis, Based on Smith et al. (2009a)*

	Stage	Description	Application
1	Reading and re-reading	Recording reflections from the interview; Listening to the interview recording; Repeated reading of the transcript	Reflections recorded after each interview. Interview recording listened to before the next interview to identify areas of improvement for the interviewer. Repeated listening and reading of each transcript

2	Initial noting	Descriptions of participant experiences and initial researcher interpretations	Initial thoughts (descriptive and interpretive) coded in NVivo for each transcript
3	Developing emergent themes	Working with notes as opposed to transcripts; Breaking up the narrative flow of transcripts to form categories	Initial codes grouped into categories for each transcript
4	Searching for connections across emergent themes	Charting or mapping of how themes link together	Groups of codes printed out and organised until they represented the researcher's interpretation of each participant's individual experiences
5	Moving to the next case	Moving to the next participant's transcript and repeating stages 1-4, while bracketing where possible the ideas emerging from the previous case	Stages 1-4 repeated for each transcript individually
6	Looking for patterns across cases	Looking for connections across cases, which themes are most potent? Labelling and re-labelling of themes and identifying main and super-ordinate themes; Maintaining unique idiosyncrasies	All grouped codes for each transcript from stage 4 merged together in NVivo, printed, cut out, and moved around until the most potent higher order themes and relevant subthemes could be identified for the data as a whole. Categories from

	while showing shared higher order qualities	hand-coding were then reflected into NVivo

Also, in an attempt to bracket and maintain the unique stories of each participant, each transcript was analysed individually, before the codes for all transcripts were merged for final analysis in stage six. To generate categories for codes both in stages four and six, a variety of strategies were used. These included: abstraction (putting like with like), subsumption (similar to abstraction, but where an emergent theme becomes a main theme to bring together subthemes), polarization (looking for differences rather than similarities), contextualization (considering the temporal moment of an experience), numeration (considering the frequency of experiences) (Smith et al., 2009a). To enhance rigour through transparency, examples of these processes are shown in Appendix 19.

Participant responses regarding what they thought the term ‘body image’ meant were grouped and synthesised as part of developing the project-specific definition of body image after stroke. Participant evaluations of the existing Stott summary of body image (Stott et al., 2021) were categorised and are presented Table 6.4 to show whether and how different aspects resonated with them.

6.8.3 Rigour and quality

Rigour was enhanced through transparency (e.g., exemplifying aspects of the analysis process in Appendix 19) and establishing trustworthiness by considering researcher reflexivity (see section 6.5.4) and checking participant opinions on researcher interpretation of findings (see section 6.8.1). To further enhance the rigour, credibility, and trustworthiness of results, once a first iteration of themes and subthemes had been developed, a second researcher (DoS) individually interpreted the data. This was to ensure that the developed themes and subthemes were clearly rooted in and were deducible from the data. Codes and themes/subthemes were discussed and modified until the researcher and second researcher reached agreement.

The data presented within the themes and subthemes were identified by the researcher and second researcher as being pertinent illustrations of the concept of each theme. To reach this decision, the more exemplary quotations for each subtheme were identified and read, until the most appropriate one was identified for use within the resultant synthesis.

To demonstrate rigour and quality, the methods of the IPA approach were assessed against quality criteria as outlined by Yardley (2000) and suggested by Smith et al. (2009b). Given the importance of rigour in qualitative research, rigour was further assessed using criteria outlined by Dabengwa et al. (2023). Reflections on quality and rigour are presented in section 6.15.7.

6.9. RESULTS: RECRUITMENT AND DATA COLLECTION

Patients who met the inclusion criteria (and subsequently, specific sampling characteristics as per section 6.3.4) were approached by recruiters between May 2021-February 2022 either ahead of, during, or after their clinical appointment. A total of 22 participants were recruited as detailed below. Data collection took place between the 9thJune 2021 and 1st March 2022.

6.9.1 ELHT recruitment summary

Recruitment commenced at ELHT on 10th May 2021. Screening logs were incomplete although the data provided permitted a snapshot of 83 of the patients screened for participation. Twenty-nine packs were recorded as being distributed. Reasons for declining to participate included having too much going on, too many health issues, or not being interested in participation. Fourteen people returned completed consent forms, of which the researcher was unable to contact five and one person completed the questionnaire but not the interview so was considered as being lost to follow-up. Eight people completed the study.

6.9.2 LTHTR recruitment summary

Recruitment commenced at LTHTR on 26th August 2021 using specific requests for people who met under-represented aspects of the sampling plan. Stroke patient lists were screened from March-December 2021 to identify eligible patients. Screening logs were maintained except for June and August, which were manually screened on paper and where the CRNs provided estimates (n= 140). Of these patients, an estimated 129 were ineligible or decline to participate. Of the additional 620 patients confirmed on the screening log, 598 were ineligible and 13 were eligible but declined to take part.

Thirty-one patients were eligible and 15 did not participate either without providing a reason, not being contactable, having a change in circumstances, having too many commitments, feeling that it wasn’t suitable for them, or re-admittance to hospital due to another health condition. Sixteen provided informed consent, with 14 participating. The two people lost to follow-up did not provide a reason for withdrawing.

6.9.3 Interview setting

Twelve participants took part via telephone and eight through MSTeams video calls, with their cameras turned on. One participant who had communication difficulties was seen in her home in line with COVID-19 safety guidelines and permissions. The first three participants were offered the choice of completing both the questionnaire and interview in one session, or separately. All opted to complete them in one session. However, following feedback from a recruiter regarding their opinion that the length of time was too long for someone with stroke, subsequent participants were encouraged to complete the questionnaire and interview across two sessions. Participants who took part through MSTeams were offered an introductory session to ensure that they were happy with using the software.

One participant wanted his wife present during the sessions so that she could help him with understanding the questions; one wanted his daughter present to facilitate translation if required as his first language was not English; and one could be heard clarifying details of his experience with his wife during the call.

6.9.4 Duration

The questionnaire took between 10-30 minutes to complete, depending on how much participants elaborated on responses. Interview durations ranged between 0:27:09 and 2:14:35 (the longest was split across two sessions), with a median time of 01:11:35.

6.10. RESULTS: SUMMARY OF PARTICIPANTS

The 22 participants recruited (55% male) were aged between 48-83 years (median = 66.2). Demographic and stroke-related information is presented across the sample in Table 6.2 and individually for each participant in Table 6.3. One participant reported having cognitive problems before their stroke (mild memory difficulties) and 14 (64%) reported having other significant illnesses. Fourteen participants reported having co- or multi-morbidities. The most common were hypertension (n = 6), cardiac conditions (n = 5), diabetes (n = 4) and arthritis (n = 3). Seven participants (32%) had a healthy BMI, seven were overweight (32%) and the rest were obese.

Most participants perceived that their stroke had been mild (68%) or severe (18%). For most, it was their first stroke (64%) and the most common type of stroke reported was ischaemic (55%). Time since ranged between 5.0-9.9 months (median = 5.9). Lasting symptoms caused by the stroke are reported in a table in the results.

At the time of assessment, participants reported low severity of disability, mobility or handicap (mRs median = 2, IQR = 1- 2.3), and were physically able to manage everyday tasks (MBI median = 20, IQR = 19- 20). Median depression (2.5, IQR = 1-6) and anxiety (2, IQR= 0- 5.3) scores as measured by the PHQ-9 and GAD-7 respectively indicated low levels of depression and anxiety. Three people met the threshold for anxiety so a cause for concern letter was sent to their GPs (Spitzer et al., 2006).

For seven of the ten participants (70%) who worked, their occupation had been affected by their stroke. Three were in the process of a phased or trial period of return to work, three had stopped working altogether and it was unclear if they would be able to return and one person had agreed to take redundancy.

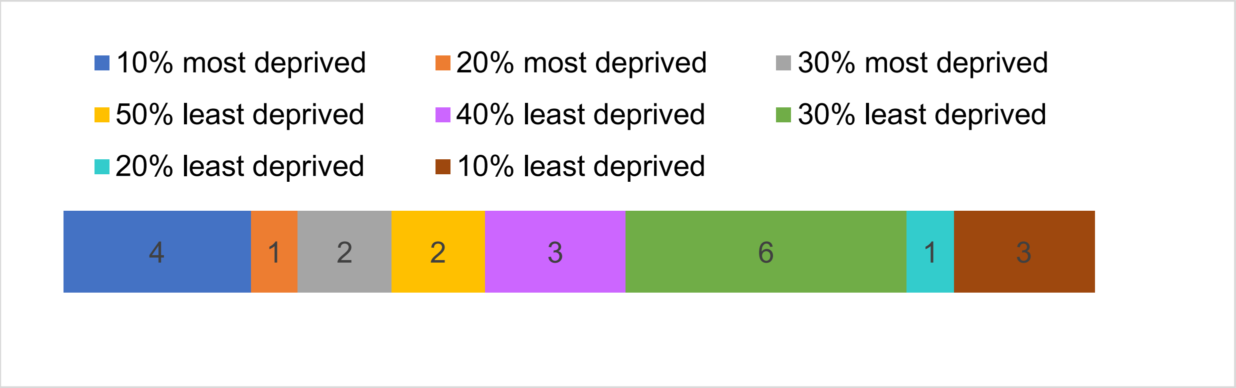
Table 6.2 *Demographic and Pre-Stroke Information Across the Whole Sample*

Characteristic		Frequency	Proportion
Marital Status	Single or divorced	2	9.1
	Married or long-term partner	15	68.2
	Widowed	5	22.7
Highest Level of Education	Apprenticeship	1	4.5
	High school	6	27.3
	Higher education	9	40.9
	Vocational qualification	6	27.3
Occupation Category	Blue collar	8	36.4
	Retired	11	50.0
	Unemployed	1	4.5
	White collar	2	9.1
Ethnic Group	Indian	1	4.5
	Indian British	1	4.5

	Pakistani British	1	4.5
	White British	18	82.0
	White European	1	4.5
IMD Category of Deprivation	10% most deprived	4	18.2
	20% most deprived	1	4.5
	30% most deprived	2	9.1
	50% least deprived	2	9.1
	40% least deprived	3	13.6
	30% least deprived	6	27.3
	20% least deprived	1	4.5
	10% least deprived	3	13.6

Figure 6.1 shows a spread of IMD categories, with representation from each category.

Figure 6.1 *Spread of IMD Deprivation Categories*



In line with reviewing the sample during recruitment and to increase the likelihood of a sample representative of the stroke population, the researcher identified that there was little to no representation of people from non-White ethnicities or severe stroke. There were also more males than females, and the average age of participants was below that for stroke. Accordingly, towards the middle of recruitment the researcher asked recruiters to focus on identifying more females, more older people, people with more severe stroke and people from different ethnic backgrounds.

6.10.1 Creative materials

Three participants presented photographs during their interview, with one using Padlet (2022) for this. Two of them used photos to facilitate descriptions of themselves in relation to identity or functionality and not in relation to body image. The third participant presented photographs that he had purposely taken to show his body image experience and analysis of these are incorporated into the narrative summary of findings. A summary interpretation was sent to him to clarify researcher understanding and meaning.

Table 6.3 *Demographic and Stroke-Related Information for Each Participant*

ID	Age (years)	Gender (F or M)	Ethnic Group	Marital Status	Category of highest level of education	Pre-stroke occupation category*	Self-reported stroke severity	Time since stroke (months)	MBI score
2	59	M	WB	Married	HE	White	Severe	9.6	20
4	59	M	WB	Married	HE	Retired	Mild	6.1	20
6	76	M	WB	Widowed	HE	Retired	Mild	5.3	19
8	82	F	WB	Widowed	VQ	Retired	Mild	6.9	19
10	66	M	WB	Married	VQ	Blue	Severe	9.9	10
11	48	M	Indian	Married	HE	White	Severe	6.0	20
12	69	M	WB	Married	HE	Retired	Mild	6.1	20
13	64	F	WB	Divorced	HE	Retired	Mild	5.2	19
15	67	M	WB	Married	HE	Blue	Mild	5.1	20
16	74	F	WB	Married	A	Retired	Mild	5.7	20
17	80	M	WB	Married	VQ	Retired	Mild	8.8	20

14	55	F	WB	Single	HS	Blue	Mild	6.6	20
18	70	M	WB	Married	VQ	Retired	Mild	5.4	20
21	60	M	Pakistani British	Married	HS	Blue	Mild	7.3	20
23	56	F	Indian British	Married	HS	Unemployed	Mild	5.2	20
24	79	M	WB	Married	VQ	Blue	Moderate	6.4	20
22	66	F	White European	Partner	HE	Blue	Mild	5.4	20
30	78	F	WB	Widowed	HS	Retired	Mild	5.7	19
27	75	F	WB	Widowed	VQ	Retired	Mild	5.0	14
25	83	F	WB	Married	HS	Retired	Moderate	5.5	19
29	57	M	WB	Married	HE	Blue	Moderate	5.6	18
31	63	F	WB	Widowed	HS	Blue	Severe	6.2	18

Key:

WB = White British

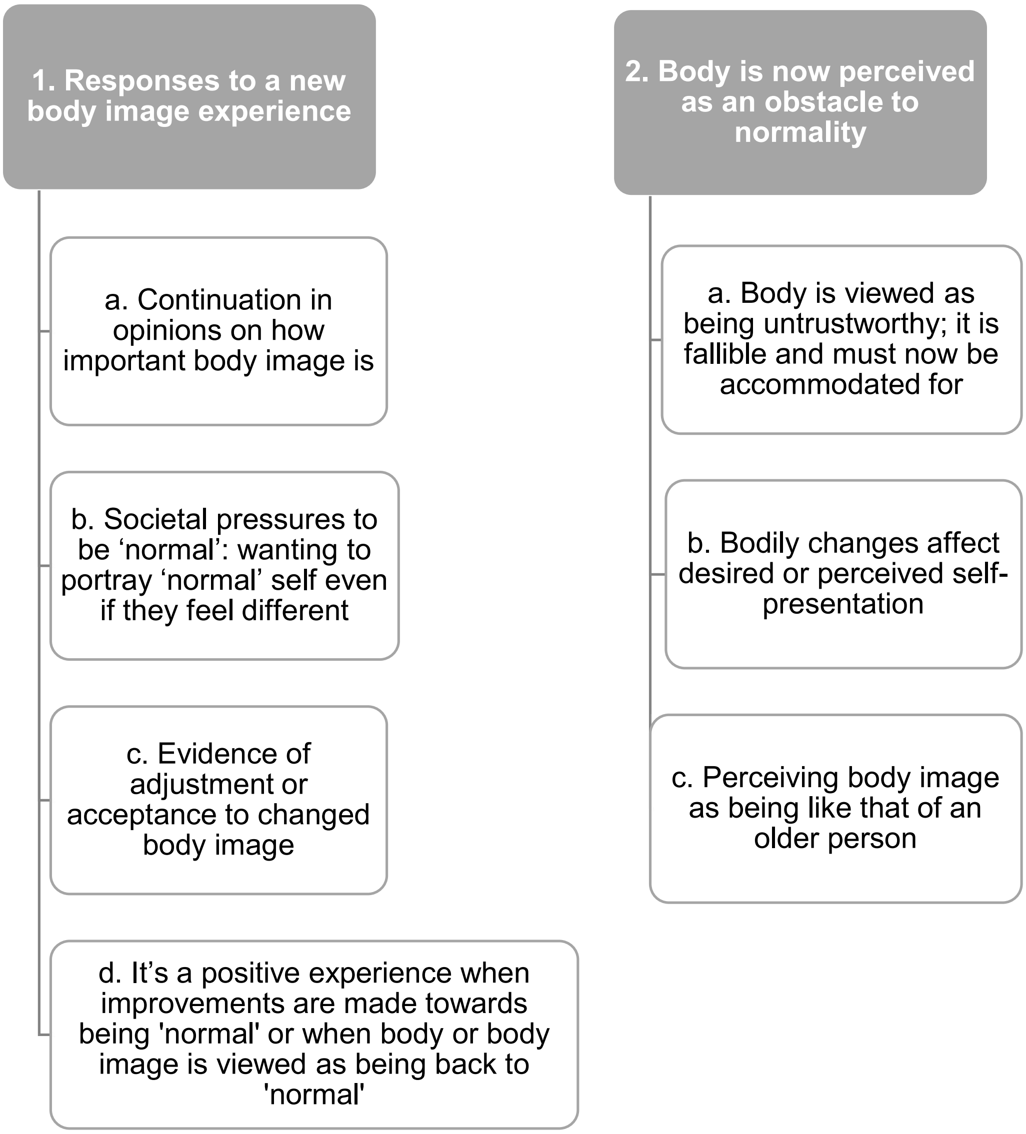
HE = Higher education; HS = High school; VQ = Vocational qualification; A = Apprenticeship

*Blue or white collar, retired or unemployed

6.11. THEMES AND SUBTHEMES

Two main themes were identified from the data: 1) Responses to a new body image experience and 2) Body is now perceived as an obstacle to normality, which are subdivided into seven subthemes. They are presented in Figure 6.2 with their subsequent subthemes. Some aspects arose during the interview that did not relate to body image, such as general adjustment to stroke, importance of family and/or spouses in recovery and general functional recovery. Only body image is described in the results. A key thread relevant across the themes and subthemes is the importance of context in body image experience. Namely, the sense of a changed relationship with the body being dependent on the context in which it was experienced. Each theme and subtheme are described in more detail, with

Figure 6.2 *Diagram to Present the Themes and Subthemes Derived from the Interviews*



1. Responses to a new body image experience

a. Continuation in opinions on how important body image is

b. Societal pressures to be ‘normal’: wanting to portray ‘normal’ self even if they feel different

c. Evidence of adjustment or acceptance to changed body image

d. It’s a positive experience when improvements are made towards being 'normal' or when body or body image is viewed as being back to 'normal'

2. Body is now perceived as an obstacle to normality

a. Body is viewed as being untrustworthy; it is fallible and must now be accommodated for

b. Bodily changes affect desired or perceived self-presentation

c. Perceiving body image as being like that of an older person exemplar quotations provided from the data and additional relevant quotations presented in Appendix 20.

6.11.1 Theme 1: Responses to a new body image experience

Participants responded in different ways to a changed body image after stroke, which seemed dependent on (a) pre-stroke body image opinions. There was evidence of (b) societal pressures to be ‘normal’ and wanting to portray a ‘normal’ self even if they felt different. As a whole, participants demonstrated (c) evidence of adjustment or acceptance to a changed body image. It was also (d) a positive experience when improvements were made towards being 'normal' or when body or body image was viewed as being back to ‘normal’.

a. Continuation in opinions on how important body image is

After their stroke, participants seemed to maintain their pre-stroke views on the importance of body image. Some were not worried about their body image, they just looked after their body by keeping clean, neat and tidy and eating healthily (P06, P29). However, even for those people who were not particularly concerned about their external presentation or what other people thought of them, context was important, and body image gained greater importance when in social situations:

> “If there are other people around then I want to look, erm, acceptable […] I prefer to be tidy so that I erm, would not put people off by my appearance. However, I’m me erm, I don’t have to be determined by what I think other people would view me like” (P29)

Conversely, other people explicitly described how their self-presentation was important to them. They felt better when they got dressed up and described how people might notice or even think that they were ill if they let themselves go (P16, P23, P30). For the people for whom body image seemed important, it appeared to be a part of their identity and the person that they wanted to present to others:

> “It’s, image. Int’it; she’s a nice lady (laughs) she’s got nice clothes on …I wonder where she goes to the shops. (laughs)” (P30)

Body image gained greater importance post-stroke for people to whom it was important pre-stroke, evident through descriptions of paying greater attention to self-presentation and to projecting a positive body image:

> “I think I pay more attention to that because before stroke, it was just normal life […] I just pay extra attention to that to be this positive person to project those positive vibes and just fit in” (P22)

Values fostered during upbringing and passed on from parents affected opinions of body image and self. Attributions to taking care of their appearance (e.g., P22) or of body image and self-presentation not being important (e.g., P29) were made by parents as role models. This shows the role of family in fostering general values placed on body image, which seem to be continued post-stroke. Additionally, some of the male participants commented on how body image is more prominent for females (P06, P12), supporting the notion of perceived gender differences.

b. Societal pressures to be 'normal': wanting to portray 'normal' self even if they feel different

During adjustment to their changed body, participants wanted to be 'normal', where normal was who they were and what they were able to do pre-stroke:

> "Eh, normal, what's, what's normal to me? P-somebody who walks at a regular speed, sss-who is smooth with their walking, who doesn't catch their feet on the ground […] 'n-normal' is a very weird word now; it never used to be weird. […] But that, it's, it's being able to do what I used to be able to do" (P02)

A motivation to be normal was social pressure (e.g., P02). Additional nuanced examples of this desire to present a 'normal' body image were also evident:

> "When my Mum says, "You're tired, your speech is going". So, I cut down walking. I used to walk all the day," (P23)

Another participant described practising his walking before letting his wife see so that she did not see him struggling (P02). These examples suggest attempts to preserve other people's perception of participants' pre-stroke body image. The influence of other people on body image experience seemed to become important after hospital discharge. In hospital, participants were surrounded by other people in a similar situation and aspects of personal care support were viewed as normal as part of the rehabilitation process. It was only when they left hospital that they started to "feel really conscious" (P02) of how they looked to others. This was due to greater exposure to people and feeling like people were viewing them differently (P02). This was compounded by minimal exposure to others during COVID-19 lockdowns, subsequently followed by increased exposure. Exposure to others made people feel more conscious of their body or more aware that they were not 'normal' (P02):

> "the more you sort of interact with different people, uh, the more conscious

> you are…...that erm, you, you, you want to be able to move in the same way that they move. it was probably three weeks before I went out err, just in the street and that was a walk with the physios (smiles) and I really did feel conscious about it then […] and you just get ev-you think every eye is watchin' ya (laughs)" (P02)

People also felt self-conscious when they perceived that an aspect of their body looked different after their stroke (P02, P13, P14), even if it was something not perceived as noticeable to others (P02), evident in this example where one lady did not want her photograph to be taken:

> "And I kept sort of just, "I'll just nip to the loo.", or (Laughing). But in the end, I just gave in and let them take one. And actually, looking at it, was really good for me because I realised that it wasn't that noticeable […] But it was good for this self-consciousness 'cause it made me feel a lot better about it." (P13)

Participants were most concerned with presenting a 'normal' appearance when they were going to be seen by others (e.g., P08, P27). They felt embarrassed when out in public and their body would not function how they wanted it to, linking to feelings of the body being out of their control (e.g., P02). Feeling social pressure to be normal made participants feel like they had to explain to people why they were functioning differently, for example, that the impacts of their stroke meant that they were now slower paying at the checkout (P14). Social pressure also seemed to make participants feel that they had to show other people that they were still 'normal' despite the stroke:

> "after one month I went out, so people saw me outside and "oh, you're just normal". I say "yeah, it wasn't that bad". You know, you just have to say that." (P23)

c. Evidence of adjustment or acceptance to changed body image

Some participants were adjusting to or accepting the way that their body was now. This could be due to a general positive approach to their body image coupled with minimal stroke impacts (P15). For others with more stroke impacts, they reasoned that they could not change anything so there was "no point in getting worked up over it" and to just "get on with it" (P14) and compensate with other parts of their body, such as their other functioning hand (P31). Bodily changes were difficult to cope with, but people tried not to let it affect them:

> “CD: How does that make you feel when you can’t get your words out? [..]
>
> P31: Horrible. I’m not bothered anymore.”

Social context was important, with most participants referencing the adjustment or acceptance of other people when reasoning their own personal adjustment or acceptance:

> “you get a bit conscious knowing that you’ve had a stroke, so that what you think people look at, look at you and think, might not be correct. Erm, but do you know what, this is how I am and, and if people don’t like it then they can…know what they can do (laughing)” (P14)

However, this could be difficult, and it was still hard to not think about what other people thought (e.g., P02). Changes visible to other people seemed more difficult to adjust to. There was a sense that less obvious or visible changes could be adapted into pre-stroke bodily image more easily (P23).

> “So, the second one wasn’t really bad because it was my hand. Because my face, because I knew the second one, right I’ve had a stroke again, so, ya’know, I could take it. But, the first time was really bad, it took me like three months, you know. So, s-second one was alright” (P23)

Worries about other people’s thoughts seemed to decrease with time (P02), although this could also be due to functional improvement and fewer personal body image concerns. For some people, the impact of their stroke on their body image was minimal. They were managing and trying to adapt. Part of this coping was a sense of feeling lucky when thinking about how much worse the impacts of their stroke could have been on their body, and subsequently their body image:

> “Erm, I know I’ve been very lucky in the way that I look and the way that I think and, and do and what have you” (P14)

Comparatively, other people were not and had not been concerned about what other people thought at all (P24). These different outlooks to the perspectives of other people emphasises the role of individual differences in body image experience.

d. It’s a positive experience when improvements are made towards being 'normal' or when body or body image is viewed as being back to ‘normal’

Participants seemed to feel better about and feel more like themselves when they perceived that their body image was similar or the same as before their stroke. This included when they saw improvements in themselves or when their functioning returned to normal:

> "But and I put some make-up on, and I did my hair and then I looked at myself in the mirror and I thought, "Hmm, yeah. I can still, I can still look decent when I, when I go out like that."" (P13)

Participants felt good when other people did not recognise that they had experienced a stroke (e.g., P08). When they still perceived that they had improvements to make towards being 'normal', participants seemed to view their 6-month post-stroke state as temporary. Their goal was still to improve or to return to 'normal' (P29).

6.11.2 Theme 2: Body now perceived as an obstacle to normality

After their stroke, participants viewed their body as an obstacle that prevented them from experiencing their pre-stroke normality. It was now (a) untrustworthy, fallible and needed accommodating for and (b) bodily changes affected desired or perceived self-presentation. The body and its perceived improvement seemed to be viewed as the key to returning to 'normal'. The body was a vehicle, and if it worked better, then life would improve (e.g., P29). However, some participants did not expect to return to normality, with pre-stroke life being like an "old life" (e.g., P13). Body image was now (c) perceived as being like that of an older person. Generally, there was now a sense of disconnect between desired body image or bodily intentions and actual body image and capabilities.

a. Body is viewed as being untrustworthy; it is fallible and must now be accommodated for

After their stroke, participants viewed their body as something which could not be trusted to work as autonomously as it had before. In this respect, the function and capability aspects of body image experience became magnified by their stroke. The physical aspects of their body which had been impaired by the stroke stood out to them as being untrustworthy, which resulted in a lack of confidence in their own body:

> "we're not toddlers anymore who are every bouncy ya'know, toddler falls over; it tends to bounce back up… We, we are, well I am, um, I'm an old guy you know, you fall and it can be quite a struggle. But when you're unbalanced bet-and certainly on your legs that you, you don't, you get very

> uncertain about walking, so you, you lose the confidence about walking…you're much more likely to fall." (P02)

Distrust and doubt in their body was also experienced in relation to fear of stroke recurrence. People completed 'stroke tests' (e.g., touching their nose and touching the wall) to make sure that changes in bodily sensations were not because of another stroke. This fear of recurrence affected daily activities, with tasks that were perceived as being too strenuous often being stopped or people feeling reluctant to go out and feeling more content to stay at home. Reflecting on early impacts of the stroke that had been recovered from compounded this fear. Even when people did not perceive that their stroke had resulted in obvious bodily changes, having the stroke had affected their outlook and body image experience:

> "Don't see myself as different but I'm probably not quite the same. Because it, erm… I think it's such a s-it's a shocking experience and you, it's always at the back of your mind that it might happen again you know" (P25)

It was clear that participants now felt a disconnect between their current perception of their body image and the body image they desired. This was mostly in relation to wanting to be able to complete certain activities, but not physically being able to. This was frustrating and restricting:

> "I can't do the things that I want to do, and I should be able to do because my body won't let me…. Your mind still wants to do, but your body won't do it." (P13)

Negativity and anger were displayed towards impairments when they affected the ability of the body to work autonomously. People felt cross with their body because they had experienced a stroke (e.g., P02, P29). Affected and unaffected bodily parts which did not work as well as before their stroke felt "disproportionate" (P02) and out of control, even being likened to "[having] somebody else's leg" (P24). The body now necessitated more thought to function and participants were suddenly more aware of bodily functionality than ever before (P04, P29). Chores took longer, which was "annoying" and people ran out of time to complete tasks in the same way that they had pre-stroke (P25). It felt "pathetic" when they could not complete something that was previously "just normal, natural" (P13):

> "Everybody says yeah babies learn to walk and it's perfectly natural and everybody does it; no, it's not natural, not when you've gotta think about it. Not when you've gotta think about every movement that your body's gotta make, that's not natural (chuckle/deep breaths). The brain has let me down here

> (chuckle/deep breaths). It’s forgot.” (P02)

Having to re-learn or adapt previously autonomous bodily functions caused people to liken themselves, their body or their functioning, such as walking (e.g., P02), to that of a toddler. Having stress urinary incontinence, typically associated with getting older, was juxtaposed with viewing and treating the self like a toddler and making sure to always go to the toilet before going out (P13). Some impairments, such as walking difficulties, also only came into thought when their functionality was required. Fatigue or tiredness meant that participants had to “constantly think and plan” (P13) to make sure that they did not do too many daily tasks or activities which would leave them tired. This left them with more time “sitting around”, leaving “more time to think” and leading to feelings of being “quite depressed” (P13). This new sense of tiredness or fatigue was experienced as their body letting them down. Context was also important, and experiences of body image became more pronounced during social situations:

> “I hadn’t realised until I did it, but I haven’t eaten in public since my stroke. And there was a long phase where I couldn’t cut my food up or I’d pick something up and then drop it because my left hand didn’t work. And I’m still slower because I’m, I have to be more, how to describe it, I suppose you have to be more thoughtful. So, when you go to cut something up, it actually requires thought, whereas you do it almost without thought. And I’m having a conversation at the same time, so your brain is doing…[…]More than one thing at a time.” (P13)

Having a stroke also made people aware of the “mortality” or their body (P12) and to “enjoy [life] while you can” (P18). There was also evidence of post-traumatic growth using the following imagery:

> “P15: I think a big blue balloon. […] With, [reaches up with hand and gestures across the screen] “It’s a boy,” written on it. (smiling) […] like a, a rebirth image.” (P15)

This caused the body to be viewed as something to look after more, by avoiding “undue risk” and valuing health, including watching their weight (P04). This had the “unintended consequences” of weight loss through diet and/or exercise (P04, P14), which was a positive body image experience and felt good. Overall, it was evident that the body and its change in perceived trustworthiness was experienced as being central to daily experiences.

b. Bodily changes affect desired or perceived self-presentation

Participants explained that it was their own personal perceptions and internal thoughts about their appearance which were the most salient to how they felt, even if other people did not notice any changes (e.g., P04):

> "No, because even going back to the face thing [*facial droop*] […] It didn't matter what people said to me, it's what's you feel in here that, that affects what you think isn't it?" (P13)

This feeling was strong enough to affect perceived ability to look in the mirror to complete physiotherapy exercises and therefore affected rehabilitation. Conversely, perceiving even small differences from before the stroke, such as a reduced muscle mass on one side which was not obvious to other people, could be a motivator to complete exercises or to try and return to perceived normal (e.g., P02). Responses to bodily changes therefore seem linked to both the location and type of bodily changes, and how important different bodily aspects were to that person in terms of their pre-stroke body image. In contrast, other participants were more concerned or aware of what other people thought of them. For example, when other people could not understand the participant with speech difficulties, they were perceived as looking 'stunned' and 'confused', as they could not understand her (P31).

Bodily changes affected ability to self-present as desired. Eyesight difficulties meant problems with dressing correctly or in hair being "not as tidy as it used to be" (P08). For some, this was linked to not being able to manage a hair dryer and brush to be able to create their desired hairstyle (e.g., P13). Others said that they sometimes neglected how they looked, including sitting at home with "3 sizes too big trousers" looking like a "tramp" (P22). Social support from family encouraged and supported people to take better care of and look after themselves (e.g., P08, P22). Overall, it took more effort to present a 'normal' body image after stroke:

> "And after stroke, it definitely takes like more focus, more devotion, more determination to do everything to get back to normal and sometimes it's hard" (P22)

c. Perceiving body image as being like that of an older person

Participants commonly referenced their age, ageing, or getting older when discussing their body image or bodily perceptions. For some, particularly where perceived stroke-related impacts had been minimal, ageing was their biggest concern with their body image, and not their stroke-related impacts (P04, P17). For those who linked having a stroke with ageing, they made references to it in different nuanced ways. For some, having a stroke emphasised their age and made them more aware of it (e.g., P04). In this respect, they likened their body image to that of an older person, which they sometimes wanted to marginalise. This included in relation to taking medication:

> "I don't want to be reminded that (pause) I'm now old [amused face]. Or I'm now got drugs for the rest of me life, which I only associated with me grandmother and me grandfather ya'know, bein' on drugs (P04)

It also related to physical bodily changes. One lady who experienced a one-sided mouth droop likened her situation to that of her mother, who had a "lopsided" mouth due to a health condition. These examples also demonstrate the complex relationship between personal life experiences such as social relationships and role models before stroke and experiences of body image:

> "when she was quite old, she was late 80s, […] her mouth was lopsided and ironically it was the same side [smiling while talking]. And, and somehow, I think I thought I, I kind of looked like that. [slight laughter in voice] I mean mine was nowhere near as bad, but because it reminded me so strongly and funnily enough, I look very like my mother, so perhaps that emphasised it even more [quizzical look towards screen]." (P13)

Descriptions were used that were associated with being older, including describing walking as "old man shuffles" (P06), or having a "slightly quavery voice" as seen in older people (P13). Linking to the 'what others think' aspect of the stroke-specific definition of body image and highlighting a difference between self and others' perceptions, people felt that others saw them differently, including as being "slightly more frail" that they felt (P12). Emphasising this disconnect between what other people think and how internal body image is perceived, people perceived their 'self' as being the same, despite the body physically ageing:

> "My body might be getting older, but, but I don't think I've changed an iota." (P15)

Gender was also referenced as playing a role in post-stroke body image experiences:

> "if a man is old, he's silver fox. If female is old, she is perceived differently than a, than a man and I don't want to be received like I'm old bag or something, no." (P22)

This also taps into societal influences of how men and women are perceived differently with age. These examples also demonstrate the complex relationship between personal life experiences such as social relationships and role models before stroke and experiences of body image. Other people associated stroke as being an older person’s disease, now classifying themselves as being part of that “age group that has them [strokes]” (P15).

6.12. RESULTS: STROKE-SPECIFIC DEFINITION OF BODY IMAGE EXPERIENCE

This section provides a definition of body image after stroke, synthesised from participant responses to being asked what they thought the term ‘body image’ meant, alongside evidence from the themes described in section 6.11.

6.12.1 Definition

Body image as perceived by the participants in this study appears to have three main components. People hold **internal thoughts** about how they think that they look, move and function. This translates into a view of their body which they self-present to the outside world (**external presentation**). They then hold perceptions of how they think other people view them (**what others think**).

Elaboration:

For some participants, body image was described as how they thought that they looked (**internal thoughts**) or presented themselves (**external presentation**). For others it was a physical concept, mostly relating to function. Although less often, some people also related body image to the common media-portrayed ideals of weight, diet or height.

For some participants, there was focus on how they felt they were seen by others (**what others think**). They sought to self-present to others in the same way that they had before their stroke. They were striving to achieve their perceived ‘normal’ pre-stroke body image.

In relation to social roles and relationships, participants described that different people they knew held different images of them, depending on shared history and relationship roles. For example, grandchildren might view them as an older person, whereas a partner still remembers them as they were when they were younger.

Figure 6.4 represents the new, stroke-specific project-derived definition of body image. It is important to recognise the variability in the way that different people will recognise and identify with the term ‘body image’. They may identify with the whole definition or only associate with parts of it. Participants also suggested a variety of factors which had the potential to impact body image perception. These included external/social factors such as upbringing and parental influence and media stereotypes; and psychological, internal factors such as confidence.

6.12.2 PCPI and participant feedback on definition

a. Initial PCPI feedback

Before being sent to participants for feedback, email feedback on the definition was sought from two PCPI members with stroke to ensure its readability and that it was accessible. They were asked to consider the following about the definition:

1. Did it make sense?
2. Format, including how it could be adapted for people who might have aphasia or communication difficulties?
3. Any other comments or suggestions on how it could be improved?

One PCPI member (PCPI1) reviewed a standard version of the definition (see Appendix 21) and the other (who had communication difficulties) (PCPI2) reviewed both the standard version and an aphasia-friendly version (see Appendix 22). To be responsive to feedback, the aphasia-friendly version was only sent to PCPI2 after initial feedback had been received from PCPI1 so that adaptations based on feedback could be made.

Regarding the standard definition, both the text and diagram were described as looking good and making sense. To be adapted for people with aphasia, PCPI1 suggested adding small icons at the beginning of the paragraphs to help to get the message across or to introduce the paragraph theme. This feedback was acted upon during development of the aphasia-friendly definition.

PCPI2 felt that the aphasia-friendly definition was alright, including the font size and text. However, given that people have different types of aphasia, its layout might not work for everyone. For example, while some people may be able to read the document in its current format, it may need adjusting or to be read out to some people. This feedback will be considered when developing different formats of the definition. It could be adapted based on people’s needs, including an audio recorded version, or images and text of different sizes and colour contrasts.

b. Participant feedback

At the end of their interviews, 21 participants agreed to receive a summary for feedback. When the summary was circulated, 13 (62%) provided telephone (n= 8) or email (n =5) feedback. Of those who did not provide feedback, seven did not respond to contact attempts by the researcher and one participant's wife said that he did not have any feedback to add.

Feedback showed that participants who perceived that their body image was not affected, or who did not worry or think about their body, felt that the definition was not particularly relevant to them. Although, they could generally understand it and/or see why it might be useful to people for whom body image was an issue following a stroke. Participants who had experienced body image changes felt that it resonated with them. They could pick out different aspects of their body image experiences and how they defined body image within it. People mostly commented that the diagram made sense, was simple and easy to understand. For example, P04 commented that the definition summary:

> "Managed to encapsulate such a large, multi dimensional topic in a brief, short summary document and diagram." (P04)

For some people, the text was a little more difficult to grasp. One lady who did not like to read, did not like it nor did she understand it. This emphasises the importance of ensuring that different formats of the definition are available for people e.g., audio versions. However, generally, people said that once they had read and absorbed it, then it made sense.

c. Additional PCPI feedback

Additional PCPI feedback was sought from an Applied Research Collaboration public advisor (PCPI3) when the researcher was gathering feedback for later aspects of the thesis (see section 7.9.3.c). She offered a different and important perspective as a South Asian lady without stroke, but who had four family members/friends who had experienced a stroke. She was asked about the relevance of the definition to people with stroke and whether it made sense.

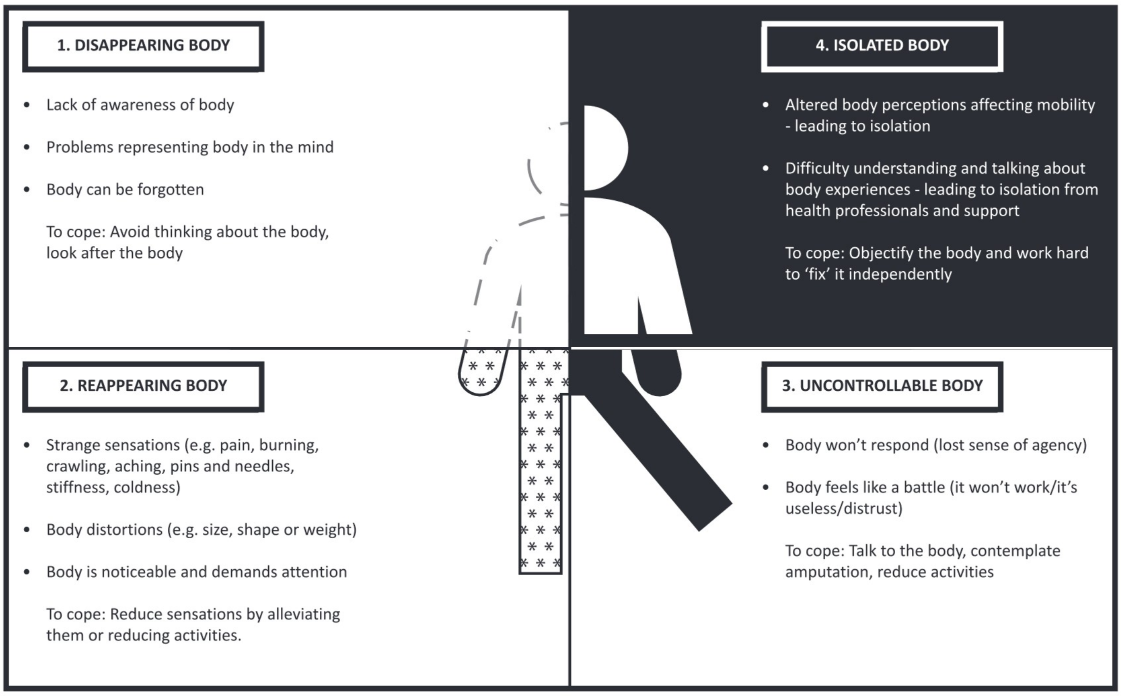
In terms of the definition, she described how people from her culture are much more focused on what other people think of them rather than internal thoughts. This could have implications after stroke, as she felt that the effects of stroke-related visible changes had particularly large impacts on people's mental health. She described personal experiences of knowing people with stroke who were distressed about or tried to hide visible bodily changes. This was described as being largely due to social pressure and subsequently caused distress.

Regarding the definition text, PCPI3 felt that for people whose first language was not English, it was too much to read. So, it should be broken down into bullet points to make it simpler. She also felt that it was important to add examples to emphasise the points being made and to make it interesting. She felt that the diagram made sense, was easy to understand, memorable, and supported the text. She also suggested it should contain more colours to divide the sections more clearly. Red should be used to make things stand out, with bold headings. She felt this would also make it easier for a person whose first language was not English to understand.

6.13. RESULTS: EVALUATION OF STOTT DIAGRAM OF BODY EXPERIENCES AFTER STROKE (Stott et al., 2021)

Figure 6.3 shows the existing diagram of bodily experiences post-stroke.

Figure 6.3 *Diagram Taken from Stott et al. (2021) to Demonstrate Body Perception Experiences of People with Stroke*



1. DISAPPEARING BODY

- Lack of awareness of body
- Problems representing body in the mind
- Body can be forgotten

To cope: Avoid thinking about the body, look after the body

4. ISOLATED BODY

- Altered body perceptions affecting mobility - leading to isolation
- Difficulty understanding and talking about body experiences - leading to isolation from health professionals and support

To cope: Objectify the body and work hard to 'fix' it independently

2. REAPPEARING BODY

- Strange sensations (e.g. pain, burning, crawling, aching, pins and needles, stiffness, coldness)
- Body distortions (e.g. size, shape or weight)
- Body is noticeable and demands attention

To cope: Reduce sensations by alleviating them or reducing activities.

3. UNCONTROLLABLE BODY

- Body won't respond (lost sense of agency)
- Body feels like a battle (it won't work/it's useless/distrust)

To cope: Talk to the body, contemplate amputation, reduce activities

Participant responses and general evaluation of whether this diagram resonated with them are presented in Table 6.4. For most people, the diagram either did not resonate with them, or only parts resonated with them. Some participants felt that aspects were relevant at the time of their stroke or initially afterwards, but not anymore. The section that currently resonated with over half (n= 13) of the participants was section 2 (reappearing body). This was followed by section 4 (isolated body) (n = 9), section 3 (uncontrollable body) (n = 7) and section 1 (disappearing body) (n = 5). Overall, the diagram was felt to better represent people with more severe stroke, limb impairments or weakness. The modal scenarios were that people perceived mild impacts and described the diagram as not being relevant; or that people perceived moderate impacts and described the diagram as being relevant. Overall, there was variability in the way that people related to it.

Of those who commented on the figure of the person in the centre of the diagram (n = 4), there were mixed opinions:

- P14 (video call interview): Unclear what the different sections of the body signify; “pointless”
- P15 (video call interview): Not sure why leg is sticking out at an angle. Tingly and fuzzy are well-represented. Graphically, do suggest what the feelings might be.
- P29 (video call interview): Covers areas not personally experienced although has seen due to profession. Stars represent sensations. Understands dotted lines for disappearing body.
- P31 (in-person interview): Recognises self in diagram: leg sticking out is equated with her leg not working

Where participants suggested what needed adding to the summary, it typically related to individual impacts of stroke. This included physical weakness, balance difficulties (P02), that the body has got bigger (i.e., weight gain due to reduced activity) (P08), loss of independence (P13) and linguistic retrieval problems (P15). Within ‘uncontrollable body’, two participants commented how for “body feels like a battle”; the word “battle” was wrong, being too extreme (P11) and suggesting that the body is an opponent (P29).

The diagram was less likely to resonate with people who had minimal impact from their stroke, but these participants often reflected or agreed that it might be better suited to people with worse impacts. However, someone with mild stroke did relate to it. Therefore, there is no clear pattern as to whom the diagram might resonate best with. Overall, there was a sense that while potentially useful for people with more severe stroke or impacts, the diagram did not capture the range of body image issues experienced by participants in the current study. There is a need for expansion, simplification or clarification for this particular participant pool.

Figure 6.4 *Current Stroke-Specific Definition of Body Image Experience*

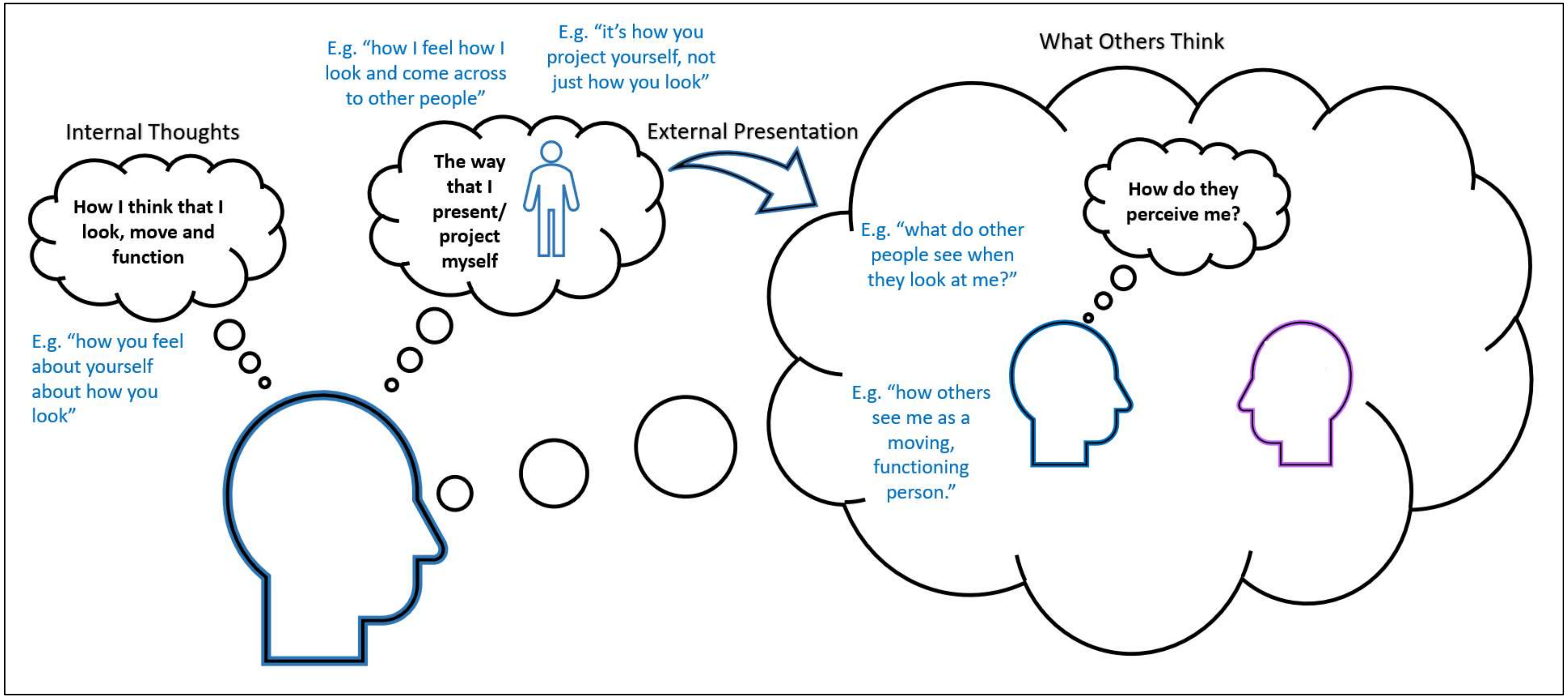


Table 6.4 *Participant Evaluation of Whether They Currently Related to the Stott et al. (2021) Summary Diagram*

P# & Call Type*	Section of Stott summary diagram				Additional comments
	Disappearing body	Reappearing body	Uncontrollable body	Isolated body	
02, V	✗	✓	✓	✓	-
04, V	✗	✓	✗	✗	-
06, T	✗	✓	✗	✗	Comments related to weight & diet
08, T	✗	✓	✗	✗	Difficult to understand
10, V	✓	✓	✓	✓	-
11, V	✓	✗	✗	✓	Language too extreme e.g., “battle”
12, V	✗	✓	✗	✗	-
13, V	✗	✗	✓	✓	-
14, V	✓	✓	✗	✓	Not helpful & difficult to understand
15, V	✗	✗	✗	✗	-
16, T	✗	✗	✗	✗	-
17, T	✗	✗	✗	✗	-
18, T	✗	✗	✗	✗	-

P# & Call Type*	Section of Stott summary diagram				Additional comments
	Disappearing body	Reappearing body	Uncontrollable body	Isolated body	
21, T	×	✓	×	×	-
22, T	×	✓	×	✓	Overall: very good
23, T	×	×	×	✓	-
24, T	×	×	×	×	-
25, T	×	✓	✓	×	-
27, T	✓	✓	✓	✓	-
29, V	×	✓	✓	✓	Good & comprehensive
30, T	×	✓	×	×	Bit muddled up
31, P	✓	✓	✓	×	-

Key:

V = video call; T = telephone; P = in-person

✓ = related to; × = did not relate to

Stroke severity:	Mild	Moderate	Severe

6.14. RESULTS: IDEAS FOR SUPPORT

Of the participants who suggested ways through which their bodily experiences or others' bodily experiences post-stroke could be or could have been better supported, the majority described the desire for opportunities to talk about their feelings (P02, P04, P12, P15, P22). This could be by someone else who has had a stroke (P13), and therefore lived experience or through healthcare professionals affording them the time to express their concerns so that they could be better understood (P14, P25). Following medical advice was described as important in reducing chance of recurrent stroke (P04). Increased or timelier practical and medical support was also described as important in recovery from bodily changes, including home aids, financial support and the opportunity to discuss impairments with a GP (P17, P29). Charting the journey (e.g., through videos) was described as something which could be done to be able to look back on progress and enhance views of their body image and bodily achievements (P02).

One participant explicitly described how people cannot be made to feel any different; some people can be helped but some will be impacted psychologically by bodily changes and cannot be helped (P17).

6.15. DISCUSSION

6.15.1 Summary of results

This study sought to explore in-depth the body image experiences of adults with stroke and its impacts on wellbeing and recovery. People responded differently to experiencing changes to their body image. Crucially, participants wanted to return to their pre-stroke 'normal'. This became most evident in social contexts, where body image seemed to take on heightened importance. Due to social pressures, people wanted to portray their 'normal' self even if they felt different. In this respect, less visible changes seemed easier to adjust to. Bodily changes meant that participants could no longer present themselves in their preferred way, or they perceived that they now self-presented differently. Some now perceived their body image as being more like that of an 'older' person.

Overall, the body was perceived as an obstacle to being 'normal'. From a functional and capability perspective, having a stroke and the consequent bodily changes, meant that the body was viewed as being untrustworthy, fallible and requiring accommodation. Contrastingly, some people were adjusting to their changed body or had accepted their bodily changes. Positivity was experienced when people felt as if their body or body image was returning to its pre-stroke 'normal'. There seemed to be a pre- to post-stroke continuation in how important body image was to each participant. People who thought that body image was important pre-stroke maintained these views post-stroke, and vice versa for people who did not think it was important.

For people with stroke, the term ‘body image’ was reflected by three main components. These were: **internal thoughts**, about how they thought that the looked moved and functioned, which translated into how they felt that they **externally self-presented** to the outside world, and subsequently perceptions of **what other people must think of them**.

The data from the in-depth interviews builds on the data from the systematic review. Whilst there was significant overlap there were also novel findings. New findings revealed by the interviews relate to the stroke-specific definition of body image, and the relevance of context and pre-stroke body image experience in post-stroke body image experience. These findings will be discussed in the context of existing literature, after the transferability of the results has been outlined.

6.15.2 Reflections on Epistemological perspectives

The ethos of the thesis was to evidence post-stroke body image and impacts, through exploring similarities and differences across the sample as a whole. An IPA approach allows detailed exploration of an individuals’ lived experience (Smith et al., 2009d). Although allowing this detailed exploration, using purely phenomenological methods (i.e., focusing only on individual experiences) did not fit with the ethos of the thesis. Phenomenology was used as the lens through which to explore the lived experiences of each person before using cross-participant analysis to derive the themes and subthemes from the data. In this respect, phenomenology was used as a touchstone; influencing the interpretation of the data, but I was not wedded to it as an approach. Arguably, the concept of cross-participant analysis is more aligned to my perspectives of social constructionism, whereby considering the views across participants helps to socially construct the themes and co-construct a definition.

Deciding to co-construct a definition of body image, may have veered more towards positivism, but on reflection is linked to my need for structure in terms of the way that I work (this is further explored in section 8.4). I have reflected on alignment with my epistemological perspectives as relevant throughout the discussion section.

6.15.3 Transferability

In the sample, there was a relatively equal spread of males and females, but the median age (66.2 years) was considerably younger than the median age for stroke in the UK (77 years, IQR= 67-85) (National Institute for Health and Care Excellence (NICE), 2019). Additionally, most of the participants had experienced a mild stroke. Eighty-two percent were White British, which is comparable with the English and Welsh population (86%) (Office for National Statistics, 2012). For Northwest England specifically, there was greater ethnic variation in the sample compared to its 90.2% white population. Despite using the sampling frame to try and increase the number of non-white participants, the most common ethnic groups in the UK (Black, Asian, Mixed or Other) were not fully represented by the sample. This means care should be taken when interpreting the results and if they represent the ethnic diversity within particular communities. However, participants were from a spread of IMD categories, indicating representativeness in terms of socio-economic status. This score should be used to compare areas and not to directly identify deprivation of individual people (Office for National Statistics, 2019).

In summary, the sample is likely to skewed towards younger people, those with mild stroke and people not from ethnic minority backgrounds. However, it still represents the percentage of White British people in the English population. Additional research including older people and those with more severe stroke is required to be able to improve the transferability of findings.

6.15.4 Stroke-specific definition of body image

a. Rationale for defining stroke-specific body image

The findings show how body image is something that impacts and is impacted by social experiences. It seems to be a fluid experience, with the potential to be understood and interpreted in different ways by different people across different social contexts. This brings forward the argument of whether labelling ‘body image’ is arbitrary, and whether it is actually a broad, complex and unique experience that is socially constructed. Additionally, the idea of a labelled ‘definition’ of body image does not align with phenomenological and social constructionist views, and attempting to define body image, as with defining body image as part of the review, can be regarded as veering towards positivism.

However, having a stroke-specific definition of body image could have practical benefits. The purpose of deriving this definition was more to allow clinicians to think about aspects of care when helping people to adjust to life post-stroke. The purpose was to give people a focus or starting point in order to be able to discuss body image. In practice, it could act more as a conversational tool. This draws into social constructionism, whereby knowledge is transferred through communication. Additionally, a phenomenology lens was used in co-constructing the definition, through asking each individual what body image meant to them, thus capturing individual perspectives and opinions.

Therefore, while co-constructing a definition or conversational tools does not strictly adhere to phenomenology or social constructionism, aspects of these perspectives can be identified within the methods and thinking behind its development.

There is only one other existing summary of post-stroke bodily experiences (Stott summary (Stott et al., 2021)) (see Figure 6.3). In this section, this existing summary will be compared to the current stroke-specific definition to explore similarities and differences.

b. Comparison of Stott summary to the new stroke-specific definition of body image

The Stott summary of shared body experiences post-stroke (Figure 6.3) and the new, current definition from this thesis (see Figure 6.4) share some overlap. *Internal thoughts* from the new definition are partially represented by the Stott summary, as it relates largely to personal or internal perspectives of bodily experiences. However, for the most part, the two definitions are distinct. Core aspects that are represented in the new definition, including *external presentation* and *what others think*, are not reflected in the Stott summary. This could be explained by the fact that the Stott research and current research take different research perspectives. The aim of the Stott research was to explore experiences of altered body perceptions after stroke, and to understand how this affects experiences of patient comfort. In contrast, this thesis used a broader psychosocial perspective as an exploratory method to widely understand body image experiences. As such, the Stott summary does not include the importance of social context in bodily experiences, nor reference pre-stroke bodily opinions.

There are also some key differences between the samples which informed the Stott summary and new definition. In the Stott research, eligible participants had to be experiencing motor, sensory, proprioceptive or attentional issues due to their stroke. Comparatively, people with perceptual awareness difficulties were not specifically sought for the current study. This could explain why Figure 6.3 did not resonate very well with participants in this study, as they were less likely to feel as if part of their body was missing or not there, or less likely be aware that they were neglecting a part of their body. This is reflected by only 23% of the sample identifying with ‘Disappearing body’ from the Stott summary.

Additional differences between the summary and definition could be due to recruitment setting and sample characteristics. Participants with significant communication problems were excluded from the Stott research, whereas they were sought out for this thesis. The 16 participants in the Stott research, recruited from community stroke charities, were an average of 59 years old and five years post-stroke. Therefore, participants were younger and further into stroke recovery than the current sample. A notable finding was that participants felt that aspects of the Stott summary were more relevant earlier in their stroke trajectory as they experienced more stroke-related impacts at that time. This juxtaposes the fact that participants from the Stott research were actually later in their stroke recovery. This buffers the notion that the diagram better reflects people who are experiencing more severe stroke-related impacts and provides support for the intended purpose of the Stott summary. Without being informed that the summary was designed based on the experiences of people with awareness deficits and/or limb impairment, participants thought it would be better suited to people with more severe stroke or with limb impairments and awareness deficits. A key example is for one lady with aphasia for whom the diagram really resonated; she liked it because the leg impairment in the diagram mirrored her impairment. For people with aphasia, it seems important to ensure that a diagram, model or explanation would contain clear visual elements. Overall, these sample differences could explain some of the differences in findings, given the array of individual differences that can affect body image experience. The diversity of experiences and the differences may reflect the challenges in trying to form an over-arching model for post-stroke body image experience.

Participants were asked how well the current definition of body image resonated with their experiences. Feedback was positive, with participants generally resonating with the definition and summary. Improvements were suggested around improving the formatting for people with different impairments (e.g., visual or hearing difficulties), which can be used in the future to improve the accessibility of the findings. To further understand the utility of the definition and summary, further samples of people with stroke who were not involved in the current research should be asked if it resonates with them.

c. Comparison of general body image definitions to thesis definition of body image

Until development of the new stroke-specific definition of body image, the definition used throughout the thesis was that by Cash and Pruzinsky (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b) (see section 2.1). Table 6.5 shows the overlap in the dimensions of the Cash & Pruzinsky definition of body image and the new definition.

Table 6.5 *Domains of Cash & Pruzinsky (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b) Definition of Body Image Compared with the New Stroke-Specific Current Definition of Body Image*

Domains of general definition of body image (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b)	Definition synthesised from interviews		
	People hold internal thoughts about how they think that they look, move and function	View of their body which is self-presented to the outside world (external presentation)	Perceptions of how they think other people view them (what others think)
Perceptions	✓	✓	✓
Thoughts/Cognitions	✓	✓	✓
Feelings/Affect	✓	✓	✓
Behaviour	✓		✓
Appearance	✓	✓	✓
Function	✓		✓
Capabilities	✓		✓

There is clear overlap between the two definitions of body image. The way that Cash and Pruzinsky consider perception as part of their definition of body image parallels with the current findings. For example, in the way that participants felt a sense of their body parts, connectedness of their body, and the mental image they held of themselves. However, there are also distinct differences for body image experiences of people with stroke. Thoughts/ cognitions, particularly around appearance and its meaning to people, are defined in a similar way by Cash and

Pruzinsky. But, for people with stroke, this meaning was more linked to ageing or a sense of change. Feelings/affect for the current participants included being self-conscious and disliking parts of the body. This aligns with the Cash and Pruzinsky definition, but for people with stroke, this was more focussed on parts of the body changed by their stroke. Behaviours as described by Cash and Pruzinsky were also identifiable in the current findings. People avoided or prevented exposure to the way they looked. But, specifically for people with stroke, this had a large social element, incorporating perceptions, thoughts and feelings about how other people saw them, which influenced their behaviours. These similarities show that while the new definition overlaps with the Cash and Pruzinsky definition, the current findings expand on this and highlight that particular attention should be paid by clinicians to those bodily aspects changed by stroke, and to how people feel and respond to social situations. The overlap supports the validity of the new definition as a definition of body image.

While it is important to acknowledge the unavoidable influence that the Cash and Prusinsky definition had on findings, the new definition was derived only from the interview findings and its meaningfulness and relevance was confirmed by participants who sent feedback. The validity of the definition is also supported by aspects presented within the main themes and subthemes (see section 6.11).

6.15.5 Theme Findings

a. Desire to return to ‘normal’

In terms of bodily experiences after a stroke, the body is experienced in a social world and needing to feel ‘normal’ in social settings is reinforced by social factors (Moorley & Cahill, 2018). This aligns with sociocultural perspectives of body image, whereby perceived norms are perpetuated by society (Tiggemann, 2012) (see section 2.1.3.a). However, for people with stroke, body image experience seems to be much more complex. This need to feel ‘normal’ is compounded by possible visible differences experienced as a result of stroke, causing people to feel further away from ‘expected’ societal and functional norms. Namely, as explained within Cash’s cognitive behavioural explanation of body image (see section 2.1.3.f), both cultural socialisation and physical characteristics and changes impact body image experience.

In the general population, appearance is the most important aspect of body image experience (Picado et al., 2019; Picado, 2018). Appearance and self-presentation were identified as important to participants in this study. However, because a stroke causes changes to bodily functions, function subsequently appears to take on a magnified role within body image (Alleva & Tylka, 2021; Lourenço, 2012; Picado et al., 2019; Picado, 2018). This likely reflects sustained stroke-related impacts to bodily movements or because after their stroke, some people had to think consciously when and how they wanted to move their body – something that was previously intuitive (Stott, 2019; Stott et al., 2021). This can lead to the body being perceived as an obstacle to 'normality', aligning with the concept of the body being central to experience as outlined by Merleau-Ponty (Merleau-Ponty & Landes, 2014; Stott, 2019).

Changes in function are linked to a sense of disconnect between mind and body, which affects confidence. Confidence for people with stroke is defined in relation to gradually re-building skills and activities and re-engaging with life roles, which establishes positive self-belief and motivation. Friends and family re-enforce these beliefs. Conversely, fear is linked to avoidance of activities, particularly social activities (Horne et al., 2014). Therefore, confidence could play a key role in motivation or perceived 'ability' to return to 'normal', particularly where confidence was an important part of identity pre-stroke (see section 7.10.1.a for discussion of the utility of motivation as a possible method of supporting adjustment and acceptance of post-stroke body image issues). If people believe that they can rebuild their skills and life roles, then this may support their return to their perceived 'normal'. As such, recovery milestones should be subjective, and should depend on what it is important to different people in order to have a life with meaningful values and activities (Ellis-Hill et al., 2008).

Achieving or aiming for previously enjoyed ('normal', pre-stroke) activities could act as motivation. This could then snowball when improvements are made and when re-enforcements are received from significant others, therapists, or through intervention. In this respect, people with stroke may use their pre-stroke 'normal' as a comparator for their desired body image. However, this contrasts with the general population, where comparators are typically based on 'idealised' bodies due to sociocultural influences (Bakhshi, 2011; Burrowes, 2013; Thomas & Kleyman, 2020). Instead, participants used their pre-stroke body image as their comparator. This again ties in with the importance of historical factors (e.g., pre-stroke physical characteristics) as recognised by cognitive-behavioural perspectives of body image (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019) and the role of these changes in body image experience.

For participants who viewed their body as being the same or similar to their pre-stroke ‘normal’, they seemed to give minimal thought to their current body image experiences. However, if their pre-stroke body image was perceived as a ‘better’ version of themselves, then they may have compared their new body image to their pre-stroke body image. This idea is supported by the notion that when people compare their appearance unfavourably to that of others’, it can lead to personal dissatisfaction with appearance (Myers & Crowther, 2009). In this case, post-stroke appearance is perceived unfavourably compared to pre-stroke. This is reflected by self-evaluations (e.g., satisfaction or dissatisfaction) of body image as outlined by cognitive-behavioural perspectives (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019).

In comparison to the general population, participants did not show evidence of comparing themselves to the media or consider their body image to be worse than other people’s. This could be because their main focus is to regain ‘normality’. Or, it could be because the sample was comprised of older people, and it is typically younger people who are more exposed to idealised image and more likely to engage in comparisons (Barnhart, 2022; Lee et al., 2014). Overall, this has implications for post-stroke support, as a self-acceptance or self-compassion therapy could facilitate a more positive view of their current body and prevent negative feelings from making comparisons to the previous self or others. This approach aligns with positive psychology perspectives in terms of encouraging bodily appreciation as part of supporting body image experience (Tylka, 2012; Tylka & Wood-Barcalow, 2015b). Fostering positive perspectives of body image is supported by research from the general population, whereby self-compassion has been found to enhance well-being (Zessin et al., 2015). For women in particular, self-compassion can enhance body appreciation, by reducing the impact of body comparison and appearance-based self-worth on body appreciation (Homan & Tylka, 2015). This concept is supported by feminist/objectification theory, which poses that women in particular are susceptible to negative feelings due to societal pressures and expectations around appearance (Furnham & Greaves, 1994).

Individual differences in experiences are therefore exacerbated by the variety of possible stroke severities, initial symptoms and lasting effects of stroke.

b. Importance of pre-stroke body image to post-stroke body image experience

The importance placed on body image before and after stroke is similar. This is reflected by cognitive-behavioural perspectives of body image through acknowledgement of the role of how important body image is in self-evaluation (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019). However, it is not represented by existing summaries of post-stroke experiences. People who were not concerned about their body image pre-stroke, remained less concerned about body image post-stroke. If they showed concern, it tended to relate to functional aspects. People who were concerned with or aware of their body image pre-stroke and who experienced bodily changes were more aware or distressed about bodily changes and consequent body image. Therefore, perceived pre-stroke levels of body image importance contribute to post-stroke body image experience.

This concept of maintained importance of body image relates to body image as a 'trait' or characteristic of personality, which remains the same across different contexts (Cash, 2012b; Cash, 1990; Cash et al., 2002; Tiggemann, 2001). The role of personality in body image experience is partially represented by genetic perspectives which argue that susceptibly to body image struggles are based on genetic or biological factors (Suisman & Klump, 2012). However, they do not explain all individual differences and are better explained by the broader cognitive-behavioural perspectives of body image which acknowledge that personality is one of the many factors influencing body image experience (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019). However, the role of personality also links to the life-thread perspective (Ellis-Hill et al., 2008) (see section 5.7.1), whereby post-stroke experiences are made sense of by people combining their personal stories of their past, present and future (Moorley & Cahill, 2018). This represents an example of where cognitive behavioural explanations of body image and the life thread model of stroke recovery could be considered in conjunction to support understanding.

In the general population, personality traits may buffer against experiencing body image related distress. Out of the five main personality traits (neuroticism, extraversion, openness, agreeableness, conscientiousness), higher levels of neuroticism (emotional instability) and lower levels of extraversion (quantity and intensity of interpersonal relationships) and conscientiousness (organisation and goal-directed behaviour) are linked to body image struggles (Allen & Walter, 2016; Friedman & Kern, 2014; John et al., 2008; McCrae & Costa Jr, 2008; Ozer & Benet-Martınez, 2006). However, body image and its relation to personality traits is not fully understood after stroke. In the current study, participants who showed lower levels of emotional instability through tending not to worry or having a positive outlook on life were less likely to be concerned about their body image. Linking to interpersonal relationships, those who were immobile or experiencing fewer social interactions seemed to struggle more with their body image. This could be associated with various factors, including mood or stroke severity. These are confounding variables to consider in future larger studies into post-stroke body image experience.

Participants who were less focussed on recovery and rehabilitation (i.e., goal-directed behaviour) or who were experiencing delays in recovery were more concerned about their current body image and its impacts on their future. Therefore, personality traits seem to play a role in post-stroke body image experience.

However, explaining body image experience through personality variables alone could be considered deterministic. Research can only suggest associations between personality traits and body image (Allen & Walter, 2016), which means that other factors may have influence. Accordingly, as identified by the current findings, across existing research, and reflected by cognitive behavioural perspectives (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019) body image experience also fluctuates depending on different situational contexts and times (state body image) (Cash, 2012b; Taule & Råheim, 2014; Tiggemann, 2001). This can include being around different people, how exposed or ‘on show’ the body is, paired with individual cognitive, emotional and behavioural variables (Haimovitz et al., 1993).

The current findings are therefore best explained by satisfaction with body image being comprised of both trait (stable) and state (situational) components (Haimovitz et al., 1993; Tiggemann, 2001). If appearance as part of body image is highly valued as part of self-worth (trait), it can lead to risk of reduced appearance self-esteem (Noser & Zeigler-Hill, 2014). If the body takes on greater volume post-stroke (state), this could explain how body image could contribute to reduced self-esteem post-stroke (Keppel & Crowe, 2000). This perspective acknowledges the contribution of the person, the situation, and then the person experiencing that situation, which interact to result in different ways that body image could be experienced (Tiggemann, 2001). This is less deterministic and accounts for the variety of factors that likely explain and impact on body image experience post-stroke. It also aligns with the broad ideas of cognitive-behavioural perspectives, where a variety of personal and situational factors influence body image experience (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019).

c. Importance of context in body image experience

Further supporting the role of state body image, context is important in how body image is experienced post-stroke. It is not reflected within the Stott summary, but it is identifiable in body image research in the general population (Haimovitz et al., 1993), in cognitive behavioural perspectives of body image (Cash, 2012a; Grogan, 2016; Lewis-Smith et al., 2019) and in people with stroke. In relation to the influence of context on rehabilitation and recovery, some participants actively spoke about ways through which their body image had influenced their recovery (e.g., not wanting to look in a mirror to practice exercises, feeling self-conscious about walking outside in a street where they felt the neighbours were watching). Whilst in hospital, participants felt shielded from the gaze of people who did not understand their new bodily situation. When leaving hospital to return home and to their normal context after a stroke, aspects of body image become magnified (e.g., (Connolly & Mahoney, 2018; Eilertsen et al., 2010)). However, existing research in relation to this transition has focussed on broader aspects of recovery such as symptom management and sense of self, and not specifically on body image. It has also tended to only include specific subsamples of people with stroke, including but not limited to women or people with ischaemic stroke (Connolly & Mahoney, 2018; Eilertsen et al., 2010). Therefore, the current findings have provided specific insight into the effects of moving between contexts on body image experience.

In relation to social context, participants expressed empathy towards people who had experienced more severe impacts from their stroke. They commented that seeing or knowing these people made them feel grateful or lucky that they were experiencing perceived lesser impacts. This feeling could be explained through downwards comparison theory. Drawing from research with people who have not had a stroke, when a person’s subjective wellbeing is compromised after a stroke, comparing themselves to another person who is perceived to be worse off could result in feeling better about their situation (Wills, 1981). It also links to cognitive-behavioural explanations whereby social comparisons are made as part of body image experience (Cash, 2012a; Lewis-Smith et al., 2019). This emphasises the social impacts and influences on body image experience.

In relation to the different theoretical perspectives of body image (see section 2.1.3), all except evolutionary perspectives can be identified within or explain aspects of the findings. However, it can be seen that cognitive-behavioural perspectives are the broadest and most applicable to the current findings.

6.15.6 Strengths and limitations

a. Sample

Firstly, it should be acknowledged that the use of descriptive statistics to describe the sample in section 6.10 contrasts with the principles of phenomenology. However, the aim was purely to describe the characteristics of the sample and therefore to help other researchers to be able to evaluate the transferability of the research. The stroke population is varied, affecting people of all ages and sexes (Sentinel Stroke National Audit Programme (SSNAP), 2020). In contrast to this, the analysis method of IPA usually involves a homogenous, or similar, sample to allow specific similarities and differences to be examined across participants (Smith et al., 2009e, 2009f). For such a diverse population, it therefore might be expected that a specific sub-sample be selected for exploration via IPA (Smith et al., 2009f), bringing into question the appropriateness of IPA for this study. However, the focus of this thesis is broad. The evidence base for body image is still in its infancy, so there was insufficient justification for narrowing down the sample of interest based on socio-demographic factors.

To broadly explore the similarities and differences of body image experiences after stroke, minimal sampling criteria were implemented. People had to have experienced their stroke around 6 months ago, have been hospitalised for their stroke, and subsequently attended a review appointment. Therefore, the trajectory of recovery and adjustment for people with stroke was explored without implementing arbitrary constraints when choosing the sample. Six months was chosen as the post-stroke time scale to allow time for people with stroke to reflect on their bodily changes. A limitation of focussing on people only at 6-months post-stroke is that it does not provide a full picture of how body image experience might change with time. However, this is the time where the most change and spontaneous recovery occurs post-stroke and then becomes stable (Bernhardt et al., 2017; Grefkes & Fink, 2020). Pragmatically, 6-month review appointments are recommended by clinical guidelines (National Institute for Health and Care Excellence (NICE), 2010) and were anticipated to provide practical opportunity for recruitment and future intervention.

People were eligible to participate if they could communicate by any means to convey their experiences of body image perceptions. This was to avoid excluding people with more severe communication or cognitive difficulties. This is important, as existing research often excludes those with cognitive and communication problems, which means the results of that research cannot be applied to that population. In reality, it was difficult to recruit these people. This could be because the nurses or APs were protective of their patients. However, in doing so, this potentially reduced the transferability of results.

Nevertheless, the current study has demonstrated the importance of including people with communication difficulties in future research, as participants who had communication difficulties expressed distress around other people's reactions to them. Further research is needed to better understand both the body image experiences of people with communication difficulties, and how to make recommendations for support in the future.

b. Recruitment

Participants were recruited based on stroke characteristics as opposed to body image experience. This is not wholly reflective of IPA, as the phenomenon of interest was post-stroke body image experience. The decision to recruit based on stroke was a pragmatic one, reflecting the likely challenges of understanding what the term 'body image' actually means. My personal reflections from during the interview process provide support for this decision, as people were experiencing body image changes without defining it as such:

> "Participant was happy to talk, although interview was challenging as has almost pre-decided no body image issues and didn't think he would be useful." (Researcher's Interview Reflections from P15)

Recruiting to body image may therefore have resulted in missing people who were experiencing body image changes but who had just not labelled it as such.

Sampling sites and requests for participants with specific demographic or stroke-related characteristics were identified and provided by the researcher. But the researcher was not directly involved in recruiting participants, reducing their influence over the sampling process.

At sites, not all patients were being systematically screened and so screening logs (designed to show how many people were screened, how many were eligible, and how many refused participation) did not reflect actual patient numbers. This means that there may have been selection bias. The possibility of a skewed sample was addressed through using the sampling frame. However, recruiting people from ethnic minorities was challenging. A recruiter described how this was due to language barriers, cultural differences and greater focus in certain backgrounds on physical than psychological care post-stroke.

c. Virtual and telephone methods

There were limitations to having to use virtual and telephone methods due to COVID-19. One of the recruiters verbally reported that people were put off from taking part due to needing to use virtual or telephone methods. Participants unfamiliar with using MSTeams may have felt participation was daunting or complicated. People mostly declined to use MSTeams, preferring to talk over the telephone; possibly because this was more familiar to them. For those who used MSTeams, they were either confident enough using technology or already familiar with it.

During sessions, body language and non-verbal cues could not be identified as easily as the researcher could not fully see the participants. People who took part via telephone did not visually see the Stott summary, so feedback was based on the researcher reading it out. This could have impeded participants' understanding of it. To counteract this, visible and meaningful body language and non-verbal cues were added to the transcripts of participants who took part through MSTeams. The thoughts of telephone participants around the Stott summary were also corroborated by people who did see the diagram.

However, there were benefits to using telephone and virtual methods. It meant that both the researcher and participants were in comfortable and familiar settings, which promoted a more relaxed atmosphere and hopefully encouraged people to speak more openly about their experiences. Participants who took part through MSTeams were offered an introductory session to ensure that they were happy with using the software, and, on reflection, had the added benefit of helping to build rapport with the researcher.

For three of the interviews, a significant other was present which could have led to response bias or discouraged participant openness. However, significant others did facilitate the interviews by confirming details or helping communication.

d. Data collection methods: questionnaire

The main aim of the questionnaire was to describe the population. Before taking part, participants were aware that the topic of study was body image. The baseline questionnaire could therefore have influenced participant perceptions of what body image was. One participant commented that she thought that body image was related to appearance but going through the questionnaire and being asked about function, had made her think it might be something else. This was evident from my personal reflections after her interview:

> "she'd reflected on questionnaire questions and despite originally thinking body image was looks, now thought it must be wider based on what I'd asked" (Researcher reflections, P13)

However, completing the questionnaire post-interview could have meant that the interview impacted on the questionnaire responses. It likely would not have been possible to ameliorate these effects altogether. To counteract bias, consistency was maintained with the questionnaire being completed before the interview. However, this shows how the use of questionnaires to describe the population could have impacted participant responses. Participants who took part through MSTeams could see the questionnaire through screen-sharing. This could mean bias in responses, as there was variability in whether participants responded independently to the questions, or whether they needed probing questions. However, the purpose of the questionnaire was not to collect outcome data, but to allow description of the sample. In line with the nature of the thesis, what was important is the subjective thoughts and opinions of the participant, which was facilitated through allowing them to choose which option they felt best suited them.

e. Data collection methods: interview schedule

The use of a semi-structured as opposed to an open interview schedule contrasts with a truly phenomenological approach. However, research with people who have experienced a brain injury shows that a completely unstructured approach could be inappropriate due to their cognitive, perceptual, sensation and emotional changes (Paterson & Scott-Findlay, 2002). This approach may have placed too much cognitive load on participants who had experienced a stroke, who could potentially have had difficulties with recall and focus. Therefore a more structured approach, which included prompts, was likely more appropriate (Paterson & Scott-Findlay, 2002). Although the use of a structure means that I had more influence over the data collected, I also felt that the quality of my data collection was enhanced by having a structure to give me confidence during the interviews.

f. Analysis

No pre-defined model of body image was used during data collection or analysis. This was to ensure that concepts arose organically and were not forced to fit around existing theory which may not have fully explained post-stroke body image experience. However, this could have made findings and data collection more prone to researcher bias, as there was no pre-defined framework. This means that the researcher had a greater role in developing the structure of findings. Bracketing of the researcher's personal perspectives was not attempted during the analysis process, as the researcher should be considered as the data collection tool (Johnson et al., 2020). As such it was not possible to separate the lifeworld of the researcher from the analysis process. This is fully acknowledged for transparency.

6.15.7 Reflection on quality and rigour

Indicators of high quality qualitative research outlined by Yardley (2000) are presented in Table 6.6, alongside reflection on how the criteria has been addressed across the study. Additional considerations for rigour (shown in the table in bold italics) have been made based on components of rigour identified from a scoping review of approaches to rigour specific to phenomenological and phenomenographic orientations (Dabengwa et al., 2023).

Table 6.6*. Descriptions of How The Quality Indicators by Yardley (2000) and Dabengwa et al. (2023) Have Been Addressed* Throughout the Interview and Analysis Process

Essential quality of good qualitative research	Description	Reflection on how quality has been addressed
Sensitivity to context	Theoretical	Consideration of different theoretical and methodological approaches that could have been used for the study, taking into account my epistemological perspectives and ***positionality of author*** (see Chapter 3). This justified the need for a method with idiographic focus. Existing literature in the topic area explored through systematic review (see Chapter 5) demonstrates awareness of wider research context.

	Relevant literature	Results discussed within context of relevant (***extant***) literature (see section 6.15) to help orient the study (Smith et al., 2009b).
	Empirical data	Gathered following an IPA approach as outlined in Table 6.1, with strengths and limitations discussed in section 6.15.
	Sociocultural setting	Demographic characteristics of sample taken into consideration and described (see section 6.10, and transferability discussed in section 6.15.3.
	Participants' perspectives	See section 6.15.7.a for reflection on participants' perspectives of the researcher. ***Sensitivity to context:*** Interview schedule piloted with other academic staff with experience of working in stroke and with people who have had a stroke to make sure that it was sensitive and appropriate for use (see section 6.5.2). Considerable number of verbatim extracts to support the arguments being made and thus giving participants a voice (see section 6.11) and allowing the reader to check the interpretations made (Smith et al., 2009b).
	Ethical issues (***and use of ethics boards***)	Ethical issues considered in section 6.6. Researcher-participant relationships addressed in sections 6.15.7.a and 8.4.3.

Commitment and rigour	In-depth engagement with topic	***Commitment: carefully reading the transcripts***: Followed in stage 1 of IPA approach (see Table 6.1). ***Prolonged engagement:*** Interviews allowed time to address interview schedule. Reflective notes made after each session. General engagement with topic demonstrated through rationale for why thesis topic chosen (see section 3.2) and completion of systematic review (see Chapter 5).
	Methodological competence/skill	I had never used an IPA approach before but have previously used thematic analysis. Before beginning my interviews, I spent considerable time learning about IPA and following the guidance outlined by Smith et al. (2009d) to increase my competence in using this approach. To ensure the participant was comfortable, I was attentive and used active listening (Smith et al., 2009b).
	Thorough data collection	***Data saturation*** discussed (see section 6.3.6). Reflexive notes collected for each participant (see sections 6.5.4 and 6.15.6). ***Rigorous designing:*** See strengths and limitations of sample, recruitment, questionnaire and interview schedule in section 6.15.6.

	Depth/breadth of analysis	Stages of data analysis outlined (see Table 6.1). ***Triangulation*** (see section 6.15.7.b): feedback sought from participants to make sure that the derived body image definition was relevant and meaningful.
Transparency and coherence	Clarity and power of description/argument	Results presented in themes to tell a story to enhance the clarity and power of the description of results (see section 6.11).
	Transparent methods and data presentation	Methods and data collection detailed in sections 6.3 and 6.5, including quotations from the data to support analytic claims (see section 6.11). ***Thick description:*** Detailed description of researcher positionality (see section 3.2), methods (see section 6.3), sample (see section 6.10), analysis (see section 6.8) and results (see sections 6.10- 6.14). Limitations in relation to generalizability also discussed. ***Use of research protocol***, which was adhered to throughout
	Fit between theory and method (***use of theoretical framework***)	Reflection on IPA methods used and coherence with philosophical perspectives taken (see section 6.15.2).
	Reflexivity	Reflections throughout section 6.15 to show considerations of my influence over the data collection and analysis.

Impact and importance	Theoretical (enriching understanding)	Empirical data collected from interviews to create new insights into topic. Possible theoretical contributions discussed in section 6.15.5.b, where links to cognitive-behavioural perspectives of body image and the life thread model are postulated.
	Socio-cultural	Findings discussed in sociocultural contexts (see section 6.15.5) to demonstrate perceptions of society and their possible influences on body image experience. ***Adequately describing participants to account for whether they fit into study criteria:*** participants described in section 6.10 and justification for sampling and recruitment methods in section 6.15.6.
	Practical (for community, policy makers, health workers)	Practical implications, including those for future research are outlined in section 6.15.9.

Key: ***bold italics*** = component of rigour described by Dabengwa et al. (2013)

Where not already discussed within the thesis, aspects of quality and rigour are described within this section.

a. Positionality of author

It is likely that researcher awareness of the Cash and Pruzinsky (2012) definition, amongst other theories (e.g., those presented in section 2.1.3) influenced the analysis process and some of the interview prompts used. It is important to acknowledge this influence and highlight that it cannot be untwined from the new stroke-specific definition. However, the Cash and Pruzinsky (2012) definition is broad and encompassing and knowledge of it may have facilitated the breadth of the new definition.

It is also important to acknowledge the researcher’s personal characteristics and their possible influences over data collection and analysis for transparency. Several participants showed their awareness of researcher characteristics by referencing the researcher being younger than them or being female. Responses may have been different if they were speaking to a peer or someone of a similar age or same sex.

b. Triangulation

To enhance trustworthiness and credibility of the data analysis, two researchers independently interpreted the data within the themes and subthemes. This reduced the bias of interpreting results from only one person’s perspective. Additionally, member checking was carried out with the new definition of post-stroke body image. This was to explore whether it reflected participant experiences and whether it made sense. Participants were not sent out themes and subthemes as some of their individual experiences may not have been reflected in such general summaries.

6.15.8 Importance of PCPI feedback

To increase the likelihood of its real-world relevance, the stroke-specific definition was reviewed by three PCPI members. PCPI1 and PCPI2 have experienced a stroke and PCPI3 had familial and friend experience of stroke and was from a different cultural background. Feedback gathered from these different perspectives showed how the definition should be adapted for different patient groups and different backgrounds (e.g., people whose first language is not English). This feedback is important as it can be used to modify the definition to make it accessible for different people as part of dissemination and future research and therefore have greater utility for people with stroke.

6.15.9 Implications & Future Research

This section will outline the key implications from this study and make suggestions for future research. A key finding is the stroke-specific definition of body image. This, along with the key study findings, should be explored with stroke populations different from the one it has been developed from, including people from different ethnic backgrounds, age groups and stroke severities. This would ensure relevance for the wider stroke population, and allow future suggestions for support to be inclusive, or to be tailored to different groups. Although Stott (Stott, 2019; Stott et al., 2021) has explored bodily experiences with people after stroke who have perceptual awareness disorders, these could also be explored specifically in relation to body image experience.

Findings show that the importance placed on body image pre-stroke is maintained after stroke. Methods for screening people with stroke to identify whether they need support with body image should take into account thoughts and opinions of pre-stroke body image. Therefore, research is needed to systematically identify risk factors for body image issues post-stroke, and impact.

As part of identifying people who might struggle with their body image post-stroke, participants highlighted how it would be useful to be able to talk about their body image after stroke. This is also evident in existing literature (Stott, 2019; Stott et al., 2021). Clinicians could be supported in how to have these conversations and in understanding what body image means to people after stroke and its potential impacts, for example, through motivational interviewing (see section 7.10.1.a). This includes changing how people think about their perceptions that other people have negative opinions of them, to subsequently reduce the distress this can cause (Gorst et al., 2016). Providing guidance for clinicians in having these conversations aligns with the NHS long-term plan which outlines a need for enhanced support provision for people with stroke (see section 1.6.4) (National Health Service (NHS), 2019b).

This study also provides evidence around the mental and emotional impacts of post-stroke body image experience on everyday life. As outlined by the Stroke Priority Partnership a top priority for stroke care is addressing the mental and emotional (psychological) problems caused by stroke (Stroke Association, 2021). This includes understanding the impacts of these problems on life; interventions which could prevent psychological difficulties support adjustment and improve wellbeing; and how they could be made accessible to people with stroke. This research provides evidence around the mental and emotional impacts of stroke caused by altered body image and its impacts on daily life. Additional priorities include understanding the long-term impacts of stroke on abilities necessary for daily life, including what support could be provided to facilitate these abilities (Stroke Association, 2021). The current research highlights the impact of a changed body on valued activities, which appears to be linked to sense of purpose and wellbeing. Future research into body image after stroke needs to explore in an objective way, how altered body image impacts activities. To determine the effectiveness of support, stroke specific measurement tools are required. This should account for the importance of context and pre-stroke body image opinions in body image experience.

In summary, the implications from this research show need for stroke-specific body image support. To ensure that recommendations for support are as inclusive as possible, further research is required to explore whether findings resonate for people with different demographic backgrounds and stroke impacts. This is particularly relevant due to the assimilation between stroke and ageing evident in the data. The impacts on body image with younger people has previously been explored quantitatively (Keppel & Crowe, 2000). However, sample sizes have been small and measures used have not been stroke-specific. This work should be replicated with larger sample sizes and stroke-specific assessment tools, and experiences of different age groups should be explored qualitatively to understand nuanced experiences. Further research is also required to explore how body image could be supported after stroke, including who could provide the support, at what time point and at what clinical level.

7. CHAPTER 7: EXPLORING POST-STROKE BODY IMAGE EXPERIENCES IN EXPERT PANEL SESSIONS

7.1. INTRODUCTION

In Chapters 4 to 6, I have presented evidence surrounding the body image experiences of people with stroke, the impacts of these on wellbeing and recovery, and methods of assessing body image post-stroke that have been used in existing research. In this chapter, I present the methods and results of gathering the opinions of people with expertise in stroke, psychology and body image. This is to collect initial evidence around the relevance of the findings, including the new stroke-specific co-constructed definition of body image, make informed and preliminary suggestions of how people with stroke could be supported with their body image experiences, and explore how any benefits of support could be assessed. To enhance the quality of this chapter, the methods and results have been reported with consideration for the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007). Reflections on quality and rigour and alignment with the epistemological perspectives within the thesis are also discussed.

7.2. AIMS AND OBJECTIVES

To conduct an expert discussion group to:

- Gather feedback on the clinical relevance of the key findings from the systematic review and interviews (including the stroke-specific co-constructed definition of body image), and subsequently;
- Provide informed and meaningful recommendations based on the key findings and the experiences of clinical experts for supporting and assessing body image post-stroke.

This was achieved by asking group members for their opinions on:

1. The key findings from the systematic review and interviews
2. Possible ways of supporting people with their body image post-stroke, based on the presented findings and their own experiences
3. Possible methods of assessing or identifying any benefits of support, which would be acceptable and meaningful for people after stroke

7.3. METHODS

7.3.1 Study design

A cross-sectional qualitative design was used, comprising expert panel discussion groups and one-to-one discussions.

7.3.2 Setting

Clinical experts were recruited via email from their respective Trusts and Universities.

7.3.3 Participants

Participants were known contacts of the researcher, supervisory team or of the other participants. They had varied and relevant expertise, as decided by the researcher and supervisory team, to be able to consider the key findings in relation to their clinical experiences, and/or advise on possible psychological support approaches in relation to the body image experiences and issues.

a. Sampling

Participants met the following eligibility criteria:

Inclusion Criteria

- Adults (aged 18 years or older)
- A healthcare professional with relevant experience or qualifications to be able to consider the key findings in relation to stroke and/or advise on psychological support options. This would likely include, but was not limited to nurses, occupational therapists and Clinical Psychologists
- Provided informed consent

Exclusion Criteria

- There were no applicable exclusion criteria

b. Method of approach

Purposive sampling for healthcare professionals meeting the above eligibility criteria was conducted by the researcher. Two identified people suggested either another person in lieu of (n= 2) or as well as (n= 1) themselves. Potential participants were contacted by the researcher, or through an introductory email from the person who recommended them. They received an email with a brief introduction, PhD outline, group purpose, and information sheet (see Appendix 23).

The researcher identified a mutually acceptable time and date for the group and sent out a calendar invitation for group members. Invitees were informed that accepting this invitation represented permission for their contact details to be securely stored for the purpose of contact about the study.

c. Sample size

Nine people were originally approached.

d. Consent

Attendance at the session was considered as implied informed consent to participate, as outlined by the information sheet (see Appendix 23). Participants were reminded of this at the beginning of the session. Consent was taken in line with the HRA Principles of Consent and was voluntarily provided after being adequately informed and having a fair choice of whether to take part (Ursin, 2008).

7.3.4 Preparation for the group

Before participating, all members were sent four documents via email (see Appendix 24):

- A summary and background to the thesis
- A summary of the key findings from the systematic review and interviews, including the stroke-specific co-constructed definition of body image
- The Body image assessment methods identified as being most relevant (based upon findings of Chapters 5 and 6 and as presented in Table 7.1) (see ‘Body Image Assessment Methods’ slides from Appendix 25)
- An agenda for the session

They were asked to read the documents in preparation for discussion during the session.

a. Summarising the key findings from the systematic review and interviews

The key findings from the review and interviews were condensed into summary spider diagrams, to include key quotations from the review and interviews. This was to provide an outline summary of the findings so that clinical experts could compare the findings to their clinical experiences and to provide a foundation for discussing the stroke-specific co-constructed definition of body image, support and assessment methods during the sessions.

The summaries provided an overall picture of the findings based on the themes from the review and interviews, with pertinent quotations added as examples:

- Body image is experienced more negatively after a stroke, compared to pre-stroke experiences & the general population: although need to be aware of individual differences in experiences
- Body image experience is contextual and can change across different situations
- Body image is less impacted when people feel a sense of continuity with their pre-stroke ‘normal’ self and body image
- Concern around what other people think of them and how they are seen, which affects relationships and socialising
- Changed relationship with or perception of the body due to bodily changes

They were also sent an agenda showing the planned structure for the session.

b. Identifying and shortlisting all possible assessment methods for consideration

Alongside the body image assessment methods identified from the systematic review (see section 5.5), additional sources were searched for other possible methods of assessing body image. These comprised reviews of pictorial and non-pictorial body image tools for use in the general population (Gardner & Brown, 2010; Kling et al., 2019), exploring links to additional papers identified from wider reading and a Google search for body image assessment methods.

All identified methods were filtered based on findings from the systematic review and interviews to exclude those which:

- Focussed only on body size, shape, weight, BMI, appearance, muscularity, eating disorders or sexual activities and which were therefore considered as not being broad enough to address the multi-dimensional nature of body image experience

- Used an avatar as a measurement method: more focussed on appearance and not internalisation of how people perceive their personal body image. Does not capture the way that people may feel differently about their body image across different contexts

- Only used a rating scale of body parts or functions: too functional, and would not help in understanding the issues at the forefront of people's mind if all body parts were being explored
- Did not include ratings of the importance of the perspectives of others, which was identified in the findings as being relevant to post-stroke body image experience

Overall shortlisting was discussed with the supervisory team to sense-check exclusion categories and reasons. None of the pictorial scales identified from the review of pictorial scales (Gardner & Brown, 2010) were deemed eligible for consideration for this thesis, because they all focussed only on body size, shape, weight or BMI or appearance. All other identified methods and their sources are presented in Appendix 26.

After initial shortlisting, a more detailed mapping of identified and included tools was completed to provide rationale for their presentation to the clinical experts. As presented in Table 7.1, the assessment method content was mapped against the project and stroke-specific definition of body image and the broad, overall definition of body image used throughout the thesis.

Table 7.1 *Mapping of Assessment Methods to Current Definitions and Cash and Pruzinsky (Cash & Pruzinsky, 2002; Cash & Smolak, 2012b) Definition of Body Image*

	Domains of current definition		Thoughts, feelings, behaviours or perceptions about bodily:				Modal rating
Assessment method	Internal thoughts	External presentation	What others think	Function	Capability	Appearance	
"My body image" (Lovo, 2001)	✓	✓	U	✓	✓	✓	✓
Appearance Schemas Inventory (ASI) (Cash & Labarge, 1996)	✓	✓	✓	✗	✗	✓	✓
Appearance Schemas Inventory-Revised (ASI-R) (Cash et al., 2004a)	✓	✓	✓	-	-	✓	✓
Body Image Coping Strategies Inventory (BICSI) (Cash et al., 2005)	✓	✓	U	U	U	✓	?
Body-image Ideals Questionnaire (BIQ) (Cash & Szymanski, 1995)	✓	✓	*	✓	✓	✓	✓
Derriford Appearance Scale (DAS-24) (Carr et al., 2005)	✓	✓	✓	✗	✗	✓	✓
General Quality of Life Inventory (GQOLI) (Li et al., 1995; Li et al., 1997)	U $^{\$}$	-	-	-	-	-	/

	Domains of current definition		Thoughts, feelings, behaviours or perceptions about bodily:				Modal rating
Assessment method	Internal thoughts	External presentation	What others think	Function	Capability	Appearance	
Multidimensional Body-Self Relations Questionnaire (MBSRQ) (Brown et al., 1990)	✓	✓	U	✓	✓	✓	✓
Semantic Differential Self-Concept Scale (Ellis-Hill, 1998)	✓	✓	*	✓	✓	✓	✓
Situational Inventory of Body-Image Dysphoria (SIBID) (Cash, 2002)	✓	✓	✓	✓	✓	✓	✓
Tennessee Self Concept Scale (TSCS) (Fitts, 1965)	✓	U[£]	-	-	-	-	/
The Body Image Disturbance Questionnaire (BIDQ) (Cash et al., 2004b)	✓	Partially	✓	-	-	✓	✓
The Body Image Quality of Life Inventory (BIQLI) (Cash & Fleming, 2002)	U[+]	-	-	-	-	-	-
The Centre for Appearance Research Salience scale (CARSAL) (Moss & Rosser, 2012)	✓	✓	✓	×	×	✓	✓

	Domains of current definition		Thoughts, feelings, behaviours or perceptions about bodily:				
Assessment method	Internal thoughts	External presentation	What others think	Function	Capability	Appearance	Modal rating
The Centre for Appearance Research Valence Scale (CARVAL) (Moss & Rosser, 2012)	✓	✓	^	✗	✗	✓	✓
The General Oral Health Assessment Index (GOHAI) (Atchison & Dolan, 1990)	✓	✓	✓	✓	✓	✓	✓
The Multidimensional Self-Esteem Inventory (MSEI) (O'Brien & Epstein, 2022)	U @	-	-	✓	-	✓	/
The Tennessee Self-concept Scale—Second Edition (TSCS: 2) (Fitts et al., 1996)	✓	✓	U	✓	✓	✓	✓

Key:

Yes	Partially	No	Undeterminable

✓ = maps to domain; ✗ = does not map to domain; - = not applicable; ? = unsure;

U = undeterminable; insufficient descriptions of method available to make a decision;

* Potentially- included as could be adapted for purpose;

^ included as could be used alongside CARSAL;

/ Insufficient detail to exclude;

[$] but has 4 items related to ‘self-esteem and body image’;

[£] but purpose is to explore self-descriptive statements used to portray his own picture of himself;

[+] explores effects of body image on life domains;

[@] measures global self-esteem which includes body appearance and functioning

c. Body image assessment methods that were presented to group

Five full examples or sections of assessment methods were located by the researcher. An additional 12 methods, which were inaccessible or needed to be purchased for access, were tabulated to show a description of the items and/or a description of the scale. Before participating, all panel members received a Microsoft Word document containing the five full examples/sections of assessment methods and the additional 12 tabulated descriptions of methods (see section 7.3.5.a). During the group, the same methods were presented as part of a Microsoft PowerPoint presentation (see Appendix 25). An additional two methods (suggested by participants and discussed during the group session) were presented during the individual sessions as additional PowerPoint slides (see Appendix 27).

Methods where full tool or preview was identified by researcher and presented:

- Appearance Schemas Inventory (ASI) (Cash & Labarge, 1996)
- Body-image Ideals Questionnaire (BIQ) (Cash & Szymanski, 1995)
- Derriford Appearance Scale (DAS-24) (Carr et al., 2005)
- Semantic Differential Self-Concept Scale (Ellis-Hill, 1998)
- The Centre for Appearance Research Salience scale (CARSAL) & The Centre for Appearance Research Valence Scale (CARVAL) (Moss & Rosser, 2012)

Methods identified from the systematic review where only a description was available, and which were therefore only presented in tables:

- "My body image" (Lovo, 2001)
- General Quality of Life Inventory (GQOLI) (Li et al., 1995; Li et al., 1997)
- Tennessee Self Concept Scale (TSCS) (Fitts, 1965)
- Tennessee Self-concept Scale—Second Edition (TSCS:2) (Fitts et al., 1996)
- The General Oral Health Assessment Index (GOHAI) (Atchison & Dolan, 1990)

Methods identified from other reviews or from the internet where only a description was available and which were therefore only presented in tables:

- Appearance Schemas Inventory-Revised (ASI-R) (Cash et al., 2004a)
- Body Image Coping Strategies Inventory (BICSI) (Cash et al., 2005)
- Multidimensional Body-Self Relations Questionnaire (MBSRQ) (Brown et al., 1990)
- Situational Inventory of Body-Image Dysphoria (SIBID) (Cash, 2002)
- The Body Image Disturbance Questionnaire (BIDQ) (Cash et al., 2004b)
- The Body Image Quality of Life Inventory (BIQLI) (Cash & Fleming, 2002)
- The Multidimensional Self-Esteem Inventory (MSEI) (O'Brien & Epstein, 2022)

Additional tools presented during individual discussions that were suggested during group:

- Nottingham Activities of Daily Living (ADL) Scale (Barer, 1989)/Nottingham Extended ADL Scale (Nouri & Lincoln, 1987)
- Confidence After Stroke Measure (CaSM) (Horne et al., 2017)

7.3.5 Data collection

a. Discussion group guide

A topic guide was developed by the researcher and approved by the supervisory team to address the main aims of the sessions (see Appendix 28). Screen-sharing was used during the sessions to show a Microsoft PowerPoint presentation. This began with participant introductions, a brief background of the thesis and a reminder of the key findings, including the stroke-specific co-constructed definition of body image. In line with the three objectives, there were three main discussion points:

i. Experiences where stroke patients had exhibited body image issues to understand the real-world relevance of the findings and new definition
ii. How body image difficulties could be supported after stroke
iii. Evaluation of the presented body image assessment methods

Each point was addressed separately. After discussion points (i) and (ii), there was a break, after which the researcher summarised the discussions from the first half. Then, the shortlisted assessment methods were presented one-by-one in the PowerPoint slides and (iii) was discussed in relation to appropriateness for use in stroke and relation to body image. Assessment methods that were presented in tables (see section 7.3.4.c) were only discussed when they were brought up by participants.

A subsequent follow-up email was sent to participants to ask them whether findings resonated with them on a more general level as part of question (i), as the majority of examples provided for this discussion during sessions were about specific patients.

b. Recording the sessions

Sessions were screen captured through MSTeams and audio-recorded on an encrypted Dictaphone. The researcher made brief notes during the sessions of immediate key points, such as suggestions of additional assessment methods to facilitate prompt follow-up. These were reflected upon to support understanding of findings.

c. Seeking PCPI feedback

PCPI feedback was sought on the shortlisted body image assessment tools to consider their meaningfulness and relevance for people with stroke.

7.4. ETHICAL ISSUES PERTAINING TO HUMAN SUBJECTS

7.4.1 Documentation of approval by an appropriate ethics review board

Ethical approval for the programme of research is outlined in section 6.6. Specific approval for the panel group as part of a substantial amendment was received from the same ethics committee on 4th February 2022, followed by HRA and HCRW approval on 7th February 2022.

7.5. DATA PROCESSING

Sessions were transcribed verbatim in preparation for analysis. Participants were assigned a pseudonym based on their role (e.g., for an occupational therapist; OT1) and any details which could identify them were omitted from the transcript to ensure anonymity. Any meaningful gestures or relevant non-verbal cues were added into the transcript based on the MSTeams screen capture of the sessions. Transcripts were uploaded into and coded using NVivo (version 1.5.1).

7.6. DATA ANALYSIS

7.6.1 The analytic process

Qualitative content analysis, defined as: “a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use.” (Krippendorff, 2019), was used to organise findings from each discussion point into a summary of key results and thus provide a structure for analysis (Elo et al., 2014; Elo & Kyngäs, 2008; Erlingsson & Brysiewicz, 2017) surrounding:

i) thoughts and opinions on the review and interview findings, including the new stroke-specific co-constructed definition of body image, in the context of their experiences of working with patients who they perceived as having body image issues post-stroke

ii) suggestions for support for people with body image issues post-stroke

iii) opinions on whether the identified methods of assessing post-stroke body image had the potential to detect potential benefits of support around post-stroke body image

To address the objectives, a manifest form of content analysis was used, where only the surface structure of what participants said was used as the data. This is in comparison to ‘latent’ analysis, where deeper structure of responses is explored through the idea of ‘what was intended to be said?’ (Bengtsson, 2016), which is not necessary in addressing the current research objectives. Deductive content analysis was used to code findings to pre-selected categories (Bingham & Witkowsky, 2022). Deductive content analysis involves coding data to a categorisation matrix based on the research objectives (Elo & Kyngäs, 2008). It can also include aspects of inductive content analysis where data can be openly coded and grouped into categories where appropriate. This means that important data that does not fit into the categorisation matrix can be used to create additional post-hoc concepts (Elo & Kyngäs, 2008). Overall, this approach was identified as allowing the objectives to be met in a concise and meaningful way.

a. Rationale for using content analysis

This section will provide an outline of why qualitative content analysis was identified as the most appropriate analysis method for the expert panel sessions. Firstly, its applicability in answering the research objectives will be outlined. Then, comparison to alternative methods of analysis will be used to further justify its use as the most appropriate method.

Applicability in answering the research questions

The purpose of analysis was not to seek meaning or to interpret participant responses, but to organise qualitative data into categories that aligned with the research questions and describe what was said in response to each discussion point. This included a flexible approach to analyse clinician descriptions of patient experiences, relevant to the key findings, alongside a structured, deductive and pre-planned approach for describing types of support based on the stepped care model of stroke (NHS Improvement- Stroke, 2011) and positive and negative evaluations of body image assessment methods. As such, predetermined codes based on the research questions were applied to the data.

Based on the purpose of the sessions, an in-depth, interpretative approach such as IPA was not appropriate. Instead, a more surface-level, descriptive approach was needed. Qualitative content analysis was identified as a method which could support this requirement. Many standardized procedures are available to inform quantitative content analysis, but there is less consensus for qualitative content analysis (Baxter, 2009). Each qualitative content analysis is unique due to the distinct nature of qualitative research and researcher experience and characteristics (Hoskins & Mariano, 2004). This is compounded by a lack of set guidelines for undertaking qualitative content analysis. Instead, the approach is flexible and there is no simple correct way to undertake it. It therefore relies on researcher judgement to decide the variations most appropriate for their research questions (Elo & Kyngäs, 2008; Weber, 1990). This makes the analysis challenging (Elo & Kyngäs, 2008) and necessitates a transparent approach to permit quality and rigour to be elucidated. To enhance the trustworthiness of the analysis, a checklist designed to improve the trustworthiness of content analysis has been implemented at each stage of analysis (Elo et al., 2014). This is reflected upon in relation to rigour in section 7.10.4.c.

Comparison to alternative methods

Before settling upon content analysis, alternative methods of analysis were considered. Initially, framework analysis was considered. Framework analysis is a flexible method, independent of theoretical underpinning and adaptable across different research questions. However, it has been described as most suited to analysing interview data where themes are generated by making comparisons within and between participants (Gale et al., 2013). This was not the aim of analysis for the expert panel groups, which instead aimed to categorise suggestions of body image support and opinions of body image assessment methods into positives and negatives. Although framework analysis could be used for this kind of deductive analysis, compared to content analysis, framework analysis is less suited to a simple deductive approach as is necessitated here (Gale et al., 2013).

Thematic analysis was also considered. This is because thematic analysis is also independent of theoretical underpinning, being less focused on interpretation, and more focussed on the descriptive themes derived from data (Braun & Clarke, 2006). It would facilitate production of data summaries (Braun & Clarke, 2006). As with framework analysis, it is also often used to show similarities and differences across the data (Braun & Clarke, 2006). Thematic analysis and content analysis are similar methods (Vaismoradi et al., 2013). However, the main benefit that content analysis offers for this study is quantification of data by means of the frequency of different categories or themes (Vaismoradi et al., 2013). This could be applied to the expert panel data as a means of identifying the frequencies with which different positive or negative evaluation points were suggested across different discussion points.

A key difference is that where thematic analysis is considered theoretically flexible, qualitative content analysis is typically considered atheoretical (Braun & Clarke, 2021; Forman & Damschroder, 2007). Qualitative content analysis is considered the least interpretative of the qualitative analysis methods, and is often considered as being a method purely for description (Braun & Clarke, 2021; Cho & Lee, 2014; Vaismoradi et al., 2013). This meets the aims of the expert panel group. Therefore, despite sharing similarities with thematic analysis and framework analysis, content analysis has advantages when applied specifically to the current objectives.

7.6.2 Derivation of themes

Subsequently derived themes for categorisation were:

1) Feedback on the relevance of the key findings: experiences of perceived body image issues in stroke patients
2) Ideas for how support could be provided for body image issues after stroke
3) Ideas for methods of assessing any benefits of body image support provision post-stroke

Category 1 was represented by an inductive approach and categories 2 and 3 by a deductive approach.

7.6.3 Stages of the content analysis

The general principles for the deductive qualitative content analysis follow three stages (Elo et al., 2014; Elo & Kyngäs, 2008):

1. Preparation phase: data collection and sampling (see section 7.3); selecting the unit of analysis, making sense of the data and whole (Elo et al., 2014; Elo & Kyngäs, 2008) (see sections 7.5 & 7.6.1)
2. Organising phase: developing a categorisation matrix; coding the data into the categories. Choosing data that fits matrix and adding data, to create additional concepts based on principles of inductive content analysis (where important) (Elo et al., 2014; Elo & Kyngäs, 2008; Patton, 1990; Sandelowski, 1993, 1995) (see sections 7.6.1 & 7.6.2)
3. Reporting phase: analysis, conceptual map or categories (Elo et al., 2014; Elo & Kyngäs, 2008) (see section 7.8)

7.6.4 Number of data coders

The researcher coded all transcripts. Key findings for each sub-category were discussed with the DoS, who attended the group session and so had knowledge of the key ideas generated by the group.

7.7. TECHNIQUES TO ENHANCE TRUSTWORTHINESS

7.7.1 Rigour and quality

A checklist designed specifically to improve the trustworthiness of content analysis was adhered to throughout (Elo et al., 2014). The checklist contains different questions for thinking about the different stages of the content analysis. Specifically in relation to trustworthiness, it provides prompts for helping the researcher report results fully, clearly and transparently, including how well a reader would be able to judge transferability of results.

7.7.2 Transcript return

Transcripts were not returned to participants for comment nor were participants asked to provide feedback on the data. However, during the group session, the researcher summarised their understanding of the discussion so far, which was agreed by participants.

7.8. RESULTS: SUMMARY

Nine people were originally approached, and all responded. One declined participation but suggested two people in lieu, of whom one agreed. One person who agreed to take part did not participate due to time constraints. Ultimately, six people and the DoS attended the group, which was run by the researcher via MSTeams on 11th May 2022. Two people who could not attend the group later took part in individual sessions (13th May and 8th June 2022). The group session lasted 2:00:54 and the individual sessions 01:21:09 and 0:45:25. Table 7.2 presents the pseudonym, role description and attendance length for each participant.

Table 7.2 *Summary of Expert Panel Group Participants, Including Assigned Pseudonym, Role Description, Whether They Attended the Group or Individual Session, and Whether They Attended the Full or Part of the Session*

Pseudonym	Role description	Attendance (and whether full or partial)
AP1	Assistant practitioner in stroke team	Group (full)
BIR	Body image researcher	Individual
CL1	Clinical lead in community stroke and neuro-rehab	Group (partial)
CP1	Clinical psychologist & works in community stroke services	Group (partial)
CP2	Clinical psychologist working in stroke & senior research fellow	Individual
OT1	Occupational therapist, researcher & previously a practicing clinician in stroke & traumatic brain injury	Group (full)
OT2	Occupational therapist in stroke team	Group (partial)
SR1	Stroke researcher & previously stroke specialist nurse	Group (full)

Participants were from across three universities and three hospital trusts. Seven had backgrounds in or currently worked in stroke care and/or research and one had a background in body image research.

7.9. RESULTS: THEME CATEGORIES

This section first presents participant opinions on the stroke-specific co-constructed definition of body image, which naturally arose during the sessions in conversations about the findings. Then, the three results categories are presented: 1) Feedback on the relevance of the key findings: experiences of patients with perceived body image issues; 2) Ideas for support and 3) Discussion of body image assessment methods. Where applicability to people with stroke is discussed, this is based on the study findings and expertise and experiences of participants.

7.9.1 Feedback on the relevance of the key findings: experiences of patients with body image issues

This section will describe participants' feedback on the relevance of the key findings, including the novel stroke-specific co-constructed definition of body image, in the context of their experiences of working with patients whom they perceived as showing post-stroke body image changes. Where relevant, discussions around findings have been organised based on the summary of results sent to and presented to participants (see Appendix 24) to demonstrate how the clinicians related to the findings.

a. Body image is experienced more negatively after a stroke, compared to pre-stroke experiences & the general population

The stroke-specific co-constructed definition was described as being:

> " a really great representation and just yes just really crosses over with so much, so much other research out there." (BIR)

This also shows that the definition was considered to show similarities with findings from research into different health conditions, buffering its trustworthiness and meaningfulness as a definition of body image in the context of a long-term illness. Within the definition and summary of key findings, participants agreed that they could recognise different aspects of the findings in their clinical practice. These will now be described in sections b-e.

b. Body image is less impacted when people feel a sense of continuity with their pre-stroke 'normal' self and body image

Clinicians felt that this resonated with their experiences, and that it was important to consider how people conceptualised body image pre-stroke, as this could be important in post-stroke experience.

> “that is why I brought the issue of some people with their body, they are bodily conscious from before the stroke it comes up more readily for them.” (CP2)

This also ties into the definition, whereby people hold internal thoughts about the way that they look, move and function.

c. Concern around what other people think of them and how they are seen, which affects relationships and socialising

Opinions around these findings can be linked to the stroke-specific definition in relation to ‘external presentation’ and ‘what others think’ and could impact everyday activities. Body image issues were described as arising on different occasions, including but not limited to, self-care activities and exposure of private bodily areas, or not wanting to engage with previously enjoyed social activities due to bodily changes.

> “You know, halitosis believe it or not which is invisible, talking with their hands over their mouths, not wanting visitors to come near them, so actually affected relationships.” (SR1)
>
> “I think at that initial stage it comes up a lot with kind of private aspects of body parts as well kind of in terms of, what it means for others erm… to help me to self-care erm… kind of what it means for others to see maybe parts of my body that otherwise would be private.” (CP2)

Crucially, whatever patients perceive to be ‘body image’ is true and valid for them:

> “for the person who is living with that condition and they might see that as body image but someone else might not. But I suppose if they see it as body image, then it is true for them.” (SR1)

Body image seems inextricably linked to confidence, although the direction of the relationship is not clear. In relation to clinical practice, if confidence was affected by body image, this could lead to patient disengagement with previously enjoyed activities:

> “he just will not leave the house at all and he doesn’t want people to see him like that because that is not him. So we are doing a lot of work around building his confidence and getting over some of these hurdles really.” (AP1)

This could contribute towards loneliness, which can have additional negative impacts on wellbeing.

d. Body image experience is contextual and can change across different situations

Linking in with the different situations described in section 7.9.1.c (e.g., socialising, self care) there was consensus that body image is more noticeable after hospital discharge and social exposure, including effects of societal perceptions of visible disability and ageing. Through additional email feedback (from OT1), it was suggested that societal perceptions of people with stroke need to be considered as part of the definition, to reflect how society perceives people who have a disability or who are older.

Accordingly, and further supporting the thesis findings, clinicians provided examples of patients viewing themselves as being older since their stroke:

> "he just said, he was saying to me oh well I have aged, you know it is like you were saying before, I have aged. He said I looked in the mirror and I thought that's my dad looking back at me" (CP1)

This also links in with the 'internal thoughts' aspects of the stroke-specific definition.

Clinicians also felt that body image experience was linked to perceptions of disability post-stroke:

> "I just it's the invisible disabilities that have always caused, that tend to cause most problems. You know we have had somebody who was, had slight balance problems, so she chose to use a stick even though she didn't need it just because she wanted people to keep away from her but I think what you are saying is also getting mixed up with the sort of, it is not so much their body image, it is their perception as a disabled people, person they don't want to be seen as being disabled and I just don't know how we, you know and that is part of it, isn't it just to realise you don't have to conform to your pre-self." (OT1)

Overall body image was perceived by clinicians as being linked with perceptions of disability, particularly in a social context:

> "There is still quite a negative view of being disabled and what, and what I am not sure is I think it is addressing not just body image because there is all that sort of Instagram, Tik Tok and all that looking beautiful and conforming to society, which has actually got worse, I think over the last 20 years because of social media, plus the negative view of disability, so it is a

> very big topic not just body image but disability and what we want as a society.” (OT1)
>
> “So when we look at that, it is, the sense of disability and the sense of how this body image can also vary or be dictated to by the surrounding people in their environment on how they are being influenced around that.” (CL1)

Bodily changes were described as being linked to shame, and as impacting mood and relationships. Participants recognised that patients spoke about impaired body parts in third person as opposed to ‘belonging’ to them. This was explained as a method of not having to acknowledge the changes, but could also help in building a ‘relationship’ with impaired body parts:

> “she keeps saying that [name of arm] is going to have to get on the page and do what it really needs to do, he is not going to sit there and be lazy and she talked about the arm in quite a positive way and that it had to joint the party, she said it has to join the party” (SR1)
>
> “almost kind of made friends I suppose with her arm. So it certainly helped with everything, it helped with her psychological acceptance of having a stroke, erm… yes it just became it went from something that was extremely negative, and quite frightening to something that was okay and she was accepting of really.” (OT2)

They also recognised patients comparing themselves to others perceived ‘worse-off’ after stroke.

Generally, Overall, participants agreed with findings and felt they resonated with them. They could identify examples from their clinical practice where body image experiences were evident. Crucially, the social connotations surrounding body image were recognised as being important in post-stroke body image experience, particularly around societal perceptions of disability and ageing.

7.9.2 Ideas for support

Ideas for support were discussed in relation to the Stepped Care Model for Psychological Interventions After Stroke (NHS Improvement- Stroke, 2011) and were categorised as such during the analysis:

- Level 1: Initial questions, leading to screening for patients who need support
- Level 2: Early support if something to be addressed
- Level 3: Additional support as required

They are summarised in Figure 7.1 and subsequently narratively summarised.

Figure 7.1 *Summary of Suggestions for Support, in Line with the Stepped Care Model for Psychological Interventions After Stroke*

Equivalent level on Stepped Care Model for Psychological Interventions After Stroke	Support level	Description of suggested levels of support
Level 3: Severe and persistent disorders of mood and/or cognition	Additional support as required	Additional support: psychological help focussed around acceptance and self-worth: psychological therapy, one-to-one sessions or peer-led stroke-specific support group intervention
Level 2: Mild/moderate symptoms of impaired mood and/or cognition	Early support if something to be addressed	Opening a conversation and helping people feel like they can discuss their body image without feeling vain. Normalising bodily changes caused by stroke as part of normalising views of disability. Practical help
Level 1: ‘Sub-threshold problems’ at a level common to many or most people with stroke	Initial questions	Brief, simple, early assessment to start a conversation and lead to areas to be addressed or more detailed assessment as required

a. Level 1: Initial questions: screening for patients who need support

There is a need for a simple screening tool which could be used at six-month stroke review appointments to identify people who might need body image support post-stroke. Considerations should also be made for whether the Sentinel Stroke National Audit Programme (SSNAP) database (King's College London, 2021) could be updated to address body image experience as an unmet need. These ideas are further explored.

Need for a simple screening tool

Before considering ideas for support, participants agreed a need for a brief and simple method of assessment or screening to identify whether people with stroke are experiencing issues with their body image. Then, if necessary, they could be directed to appropriate support or complete a more detailed assessment which asks short and direct questions about body image. If someone was struggling, screening could progress onto a more in-depth assessment. Crucially, there must be a referral-type route to follow or support that can be offered. It needs to be clear to patients that clinicians are happy to discuss body image. This could include the opportunity to discuss experiences and validation of feelings without causing patients to feel like they are being vain.

Currently, body image issues may not be identified because health professionals do not specifically ask about it. Patients may also not name ‘body image’ and it may present in different ways that need unpicking and exploring by health professionals:

> “…so people talk about how the changes in the body relate to their mood rather than actually I have got difficulties with body image so I think it comes up but it comes up in other ways, disguised and you have to almost unpick what is it that makes people feel depressed and some people would say I just don’t look the same when I walk kind of thing. But they don’t really name it, as body image interestingly, yes.” (CP2)

Discussions around body image might arise more readily for people more conscious of their body pre-stroke. Additionally, body image as part of self-concept was described as being difficult for health professionals to discuss with patients, indicating a need for support around talking about post-stroke self-concept. Overall, this suggests a need for greater awareness and conversation about body image experience after stroke in clinical environments.

Six-month review appointments

Initial questions should be asked early after stroke to identify people at risk from experiencing more serious mental health issues in relation to their body image further into their recovery. This is particularly true when those issues and experiences risk being missed due to being labelled as ‘adjustment’. Pragmatically, this assessment could be part of the 6-month review process. Six months was considered a short timeframe in the context of potentially lifelong stroke-related impacts, as adjustment could take much longer than this. However, six months was argued as being the time when people realise that they need to get on with their 'changed' life. Within this time, some risk factors for body image struggles may present themselves, and people's pre-existing attitudes to body image could indicate propensity for future problems.

After these initial questions, and if the patient indicates that they are struggling with their body image, it should be determined whether the issues are functional or psychological (e.g., confidence), if they can be fixed, and who health professionals can alert that body image is going to cause problems if left unexplored. Ideally, issues with body image experience would be identified early in the rehabilitation process. However, patients should be able to seek support at any time.

Utilising SSNAP

Care should be taken to avoid increasing the burden of the already numerous screening assessments used with patients following a stroke. It should be considered if there is an existing tool routinely used which could be applicable to body image, or at least provide initial insight. However, there are not typically any direct questions about body image nor anything consistent on SSNAP to assess body image. Additionally, there is lack of consistency across stroke units regarding which tools are used for identifying psychological difficulties. A starting point could be to add a question to SSNAP as part of the 6-month stroke review appointments to highlight body image experience as an unmet need.

b. Level 2: Early support if something to be addressed

Early support should involve normalising disability or bodily changes and providing practical solutions to improve body image experience.

Normalising disability or bodily changes

People with stroke should be supported to help them to normalise the concept of disability and bodily changes. Disability or physical impairment is common in society. Patients could also be shown that they do not have to conform to their pre-stroke self, which was likely influenced by societal perceptions of disability. Instead, patients should be supported to develop a new 'normal' to adjust to.

Practical solutions

Patients should be offered practical solutions to support them in adjusting to their changed body after stroke. This should involve identifying any changes that could be made to support them in coping with or overcoming bodily impacts from the stroke which are affecting their everyday lives. One example could be to take patients to different towns or locations to practise walking if they felt self-conscious in places where they might be recognised.

c. Level 3: Additional support as required

If practical adjustments do not work, there could be a need for additional psychological services. This would be particularly important for people whose body image experiences are hindering their rehabilitation. Social skills training could be provided to help people with visible changes to easily explain their changed appearance to others and reduce discomfort around being in public. People should be encouraged to reflect on their progress, and to focus on self-compassion, positive body image and fostering a positive relationship with their body. This relates to encouraging a better view of their self-worth. Psychological support could be provided through one-to-one methods including cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), compassion-focussed therapy or narrative therapy, or through group sessions. Group sessions should be led by someone with lived experience of stroke and a psychologist and be focussed on encouraging acceptance and decreasing the important of appearance in self-worth. Education should be provided around acknowledging the influences of socio-cultural ideals and ideal bodies. There are existing interventions for different conditions, (e.g., breast cancer (Lewis-Smith et al., 2018)) which could be adapted to be stroke-specific.

7.9.3 Discussion of body image assessment methods

Two categories were identified as being important for analysing the discussions related to methods of assessing post-stroke body image: i) Evaluation of presented methods; and ii) Key aspects regarding preferred format of assessment methods. The results of (i) are presented in Table 7.3 and the results of ii) are narratively summarised.

a. Evaluation of presented methods

Table 7.3 shows evaluation of whether any of the tools presented could be suitable in identifying benefits of body image support. The consensus was that no single assessment method would fully capture post-stroke body image experiences and impacts, nor be appropriate or useful within stroke. While some of the methods had useful elements, all would need adapting to be considered appropriate for use. The ones most preferred were the DAS-24 (Carr et al., 2005) (identified by the researcher) due to addressing various aspects of body image and asking practical questions; and CaSM (Horne et al., 2017) (suggested by participants during the group session) due to being broad, easy to use and validated in stroke. Paid scales are less useful given the costs that would be involved if adopted by services.

Next steps for the discussed tools were either that no further evaluation was required as the method was deemed inappropriate or not useful; that in order to establish utility, the author of the method needs contacting to obtain a full copy or, that the method should be taken forward for further evaluation (e.g., PCPI feedback or future study in people with stroke).

b. Key aspects regarding format of assessment method

The body image researcher (BIR) described the importance of differentiating between a screening tool and a method of assessing the effectiveness of intervention. This was difficult to tease apart during sessions, however, was attempted during the analysis process. Crucially, a method of assessing the effectiveness of support should involve multiple scales; to include a body appreciation scale alongside one of the tools presented to the expert group. Body image screening tools and methods used to explore the effectiveness of support need to be visual with few words, and as short as possible. They should be inclusive and easily converted for patients with aphasia or people with functional difficulties. Health literacy and complexity must be considered, including thinking about language and cognitive load. This will avoid alienating people with language or cognitive impairments. One suggestion to achieve this was to use a distress thermometer as a response option, with scale points that are meaningful and that can prompt further discussion. Assessment methods need to have an evaluative aspect. For example, if a question relates to function, it should also ask about the impacts of that function. Methods also need to specify what time point patients are being asked about e.g., if it is about post-stroke or pre-stroke experiences. Wording should ensure that people are not made to feel vain if they talk about their body image or appearance (as opposed to more functional or objectively ‘severe’ impacts).

c. PCPI feedback on the most preferred tools

The CaSM (Horne et al., 2017) and the DAS-24 (Carr et al., 2005) were sent to PCPI3 for feedback regarding whether they made sense and whether they were relevant to people with stroke in relation to their body image experience. PCPI3 preferred the CaSM, as it was easy to understand and complete, requiring people to just tick a response. They liked the use of the thumb images as part of the response options but did not feel they were necessary. The CaSM was perceived as being relevant and accurate for people with stroke in relation to their body image, with applicability to everyone. They suggested that a question was needed to assess how people feel across different social contexts, given the importance of socialising (e.g., within and outside of the community, and around different family members, as this could change).

In relation to DAS-24, they did not like the use of scale numbers as they could be difficult to interpret. Instead, it would be easier to use ‘agree’ and ‘disagree’ to facilitate understanding. All statements were applicable, but ‘distressed at beach’ was felt to be ambiguous. This aligned with the thoughts of the expert panel members. PCPI3 suggested that questions were needed around financial and mental health, sex life and how people feel when they go to work, and across different social contexts.

Therefore, overall, while PCPI3 felt that both measures were applicable, the CaSM would be easier to complete and more relevant for people with stroke.

7.9.4 Summary

The results show that the review and interview findings, incorporating the stroke-specific co-constructed definition of body image, were perceived as relevant and meaningful to healthcare professionals in relation to their clinical experiences. Subsequently, the clinical experts outlined that there is a need for a simple screening method to detect any body image issues that people might experience after a stroke. This could be incorporated into the Stepped Care Model for Psychological Interventions After Stroke (NHS Improvement- Stroke, 2011) as part of NHS stroke services. This will help in directing people with stroke to further assessment and appropriate support if necessary. Support could initially include open conversations about body image experience, or suggestions of practical support to help in coping with bodily changes and their impacts on body image. If additional support is required or if issues are more long-term, psychological support focussed on improving self-worth and reducing importance of appearance perceptions to self-value should be provided. Support should be available even after patients have been discharged as not all body image issues will emerge within 6 months post-stroke. None of the body image tools identified thus far are suitable for screening or measuring the effectiveness of support. The ones rated most highly by participants were the DAS-24 (Carr et al., 2005) and CaSM (Horne et al., 2017), with the latter most preferred by PCPI3 due to it being perceived as more relevant and easier to complete. Either of these measures would need adapting either for people who have had a stroke (DAS-24) or for specific aspects of body image (CaSM).

Table 7.3 *Evaluation Points from the Expert Panel Sessions Surrounding Body Image Assessment Methods, Including Summary and Next Steps*

Assessment Method		Evaluation Points	Summary & Next Steps
ASI (Cash & Labarge, 1996)	–	Content covered in other scales	Questions may not be appropriate. Does not address all aspects of body image.
	×	Dislike some of the questions e.g., Q4: 'If I could look just as I wish, my life would be much happier' and Q9: 'Aging will make me less attractive'	
	×	Reinforces gender binary e.g., Q10: To be feminine, a woman must be as pretty as possible' or 'To be masculine, a man must be as handsome as possible'	
	×	Questions could cause distress which wasn't there before	
	×	Very related to physical appearance	
	×	Possibility of skewed answers: long-standing body image versus current time	
BIDQ (Cash et al., 2004b)	✓	Some useful elements e.g., how body image affects life	Some useful elements.
	✓	Could be used to measure intervention impact	
	×	Less useful as need to pay to access	
	×	Scale as a whole is not useful	
BIQ (Cash & Szymanski, 1995)	✓	More straightforward than the similar 'semantic differential self-concept scale' (Ellis-Hill, 1998)	Adjective pairs are vague.
	×	Just a long list of different adjectives; would not know what adjectives referring to	

Assessment Method	Evaluation Points	Summary & Next Steps
	× Not great even as an evaluative measure × Would not resonate with patients after stroke nor with study findings × Cognitively complex to complete	Would not resonate with people after stroke. Too complex.
CARSAL & CARVAL (Moss & Rosser, 2012)	✓ Contextualised in sentences brief, simple & could adapt response options for people ✓ Good for assessing appearance concerns in those with visible difference ✓ Straight forward & to the point ✓ Taps into appearance investment, which is different for different people, & we are not necessarily aware of how important it is to our self-worth – Would need to specify whether questions refer to now – Would assess level of severity, but tricky to notice progress in interventions, so combine with BIDQ e.g., how issues affect function & how distressed it makes people × Does not tap into broader body image e.g., functional aspects × Wording: could put ideas in people's heads e.g., if they weren't feeling bad before, it might make them feel bad	Simple, but only tap into appearance aspects of body image.

Assessment Method	Evaluation Points	Summary & Next Steps
	× Wordy	
CaSM (Horne et al., 2017)	✓ Taps into aesthetic and physical aspects, which other tools did not have ✓ Easy to use, validated in stroke, aphasia version & good for screening ✓ Could intersect with body image: broad and also taps into identity ✓ Useful in bringing up conversations about body image e.g., being body conscious	Liked by experts: broad, validated in stroke, easy to use & aphasia-friendly version available.
DAS-24 (Carr et al., 2005)	✓ Some appropriate & specific items e.g., 'Distress at reflection', clothing limitations ✓ Taps into different areas & has practical questions that can be worked on with patient e.g., if they avoid undressing with partner, misjudged about appearance – Would have to specify that the question refers to the stroke – 'Distress'; instead, could say self-conscious × Might be emotional or not valid depending on experiences since the stroke e.g., 'distressed at beach' × Some important concepts are not captured & not enough about mind body connections × Explores symptoms i.e., if someone needs help, but needs to look at impacts of support	Most appropriate tool introduced by CD: addresses various aspects of body image & has practical questions; although some might not be relevant & would need adapting.

Assessment Method		Evaluation Points	Summary & Next Steps
Nottingham ADL Scale (Barer, 1989) & Extended Scale (Nouri & Lincoln, 1987)	× × ×	Does not reflect on how people feel about appearance Reductionistic: does not assess how much people care or are distressed by those aspects and how this impacts their life Not very relevant in initiating conversations about body image more aspects of function	Reductionist & not tapping into body image, only function.
Semantic Differential Self-Concept Scale (Ellis-Hill, 1998)	✓ – – × × × ×	Includes mood & capabilities which links into body image Designed for head injury Could do against carer completion too to compare self & others' perceptions Could be interpreted in different ways: needs discussion with patient = time consuming Not sure how much of it is touching on body image Presentation: too many items, too broad long & complex, quite abstract Difficult to conceptualise the present moment especially early in recovery or for someone with memory difficulties: answers might depend on the moment and location	Ambiguous to interpret by people with stroke & researcher. Unsure how much it relates to body image. Presentation is complex.

Key:

Assessment Method	Evaluation Points	Summary & Next Steps

Take forward for further evaluation	Contact author to obtain a full copy & then possible further evaluation	No further evaluation required

✓= Strength; - = Neutral; × = Limitation

7.10. DISCUSSION

The aim of this study was to discuss with clinical experts the relevance of the key findings from the review and interviews (including the new stroke-specific co-constructed definition of body image) and subsequently how post-stroke body image experiences could be supported and how any benefits of support could be evaluated. This was to make recommendations for future methods of supporting post-stroke body image issues. Participants liked the new definition of body image and felt it was relevant for people with stroke. Coupled with the summary of findings, they could liken the results to examples from their clinical practice. Based on the thesis findings and their clinical experiences, they provided suggestions for supporting post-stroke body image experiences using the Stepped Care Model for Psychological Interventions After Stroke (NHS Improvement- Stroke, 2011). These included initial questions to identify patients who need further assessment or support, leading to practical or psychological support as required. None of the presented body image assessment methods were considered usable on their own for assessing benefits of post-stroke body image support. Participants suggested how an assessment method should be formatted, including being visual, inclusive and accessible.

The findings will now be discussed in relation to existing literature and the strengths and weakness of the current methods will be described. Then, implications and suggestions for future research will be outlined.

7.10.1 Considering feedback on the key findings and new definition

Participants agreed with and emphasised the importance of social pressures and contexts in the way that body image is experienced, particularly in relation to disability. They felt that society has negative views of visible differences and disability. Societal attitudes impact how people with disability experience their everyday lives, social participation and integration into the community (Wang et al., 2021). These societal views may contribute to body image post-stroke being experienced negatively. People with a difference that they feel is visible to others are likely to experience psychosocial problems. This includes concerns around interacting with other people, exposing their changed body to others and negativity or ignorance from other people in relation to their bodily changes (Rumsey et al., 2004). This societal stigma is then further compounded by having to cope with their own personal thoughts and experiences of disability. As in previous chapters, the cognitive-behavioural model also ties in with the discussion and feedback provided from the expert sessions. For example, it shows the perceived relevance of the effects of cultural socialisation and bodily changes on body image experience (Cash & Smolak, 2012a).

Participants also felt that confidence was particularly relevant in patients' body image experience and if impacted could lead to disengagement with previously enjoyed activities. This could lead to loneliness and isolation. Self-confidence is a broad term which relates to personal beliefs about whether a specific activity can be successfully completed (National Research Council, 1994). Confidence is important in stroke recovery and rehabilitation regardless of stroke severity (Horne et al., 2014). Loss of confidence is common after stroke (Stone et al., 2004) and is linked to avoidance of activities and social activities (Horne et al., 2014). So, if linked to body image experience, this is an area which could be relevant to further explore in terms of support provision.

Therefore, after reviewing the results and reflecting on their own clinical experiences, the areas considered most pertinent to body image experience post-stroke were views of disability (both individual and societal), and confidence. Individual views of disability link through to the 'internal thoughts' aspects of the new stroke-specific definition of body image, while societal views are related to external presentation and what others think (see Figure 6.4). This shows how the attendees could relate their clinical experiences to the new definition.

7.10.2 Considering methods to support body image experience post-stroke

Participant suggestions of how to support body image post-stroke ranged from initial conversations and practical help; to more in-depth conversations and normalising bodily changes; through to intensive psychological support. Crucially, individualised strategies for patients were considered important. Targeting the meaning of stroke for individual people and addressing the activities and personal concerns most important to them is crucial in helping with their post-stroke progress (Ellis-Hill et al., 2008; Ellis-Hill, 1998; Ellis-Hill & Horn, 2000; Ellis-Hill et al., 2000). The suggestions made for supporting body image post-stroke, which focussed on normalising bodily changes and disability after stroke, will now be discussed.

Participants suggested that there is a need to change both individual and societal opinions around disability and visible difference. A rapid evidence assessment of the body image literature synthesised three main ways to reduce negative body image experiences in the general population. These are protection (increasing individual resilience around individual factors to protect them from experiencing negative body image); prevention (addressing societal or environmental factors to prevent negative body image e.g. changing the types of image portrayed in the media), and;

improvement (intervention to improve negative body image) (Burrowes, 2013). These concepts are identifiable throughout suggestions made by participants and will be highlighted as such.

a. Protection and Intervention

In terms of changing individual opinions around disability and visible difference, it could be emphasised to patients that disability is not uncommon. As of 2020, one in five people in the UK had a disability (Department for Work and Pensions, 2022). Additionally, participants agreed that patients use third-person vocabulary to describe affected body parts as a way of not having to acknowledge bodily changes. For people with stroke, using third-person language is a mechanism of objectification to create separation between sense of identity and bodily changes (Stott et al., 2021; Tham et al., 2000). It was therefore considered important to encourage people with stroke to adjust to and accept their 'new normal', as opposed to trying to seek out their pre-stroke body image.

One suggestion for a therapeutical approach to this was ACT, which is a mindfulness-based behavioural therapy that focuses on forgiveness, compassion and living in the present moment (Harris, 2006). ACT could offer a low-intensity psychological support option for people with stroke by reducing anxiety (Majumdar & Morris, 2019; Sianturi et al., 2018). For people in the general population with body image dissatisfaction, it can increase flexible thinking and ultimately reduce this dissatisfaction (Griffiths et al., 2018). So, ACT could have utility in supporting a new and more flexible way of thinking about bodily changes post-stroke.

Linked to this, self-compassion related interventions can improve self-compassion, depression and anxiety across people with mental health problems (Wilson et al., 2019). They can also protect against body image issues in the general population and for people with eating disorders (Braun et al., 2016; Rahimi-Ardabili et al., 2018). For people with stroke, psychological distress can be caused by a loss of self and lack of self-compassion. Targeting these aspects may reduce distress (Crowe et al., 2016).

Narrative therapy was also suggested. This focuses on the socio-cultural and political contexts of people's problems, with the main idea being that people hold different stories of their lives. These stories can be 're-authored' as part of the therapeutic process (Wallis et al., 2011). This could be useful in helping people to change their perspective on post-stroke bodily changes and 'normalise' their post-stroke body. In relation to self-understanding and self-acceptance, another suggestion for individual support was CBT. CBT teaches people to understand and change their unhelpful or damaging thought patterns and behaviours (Fenn & Byrne, 2013). For people with body image disturbance, CBT improves body image experience (Jarry & Ip, 2005). Although there is mixed evidence for CBT in stroke, it has been found to have positive effects on depressive symptoms (Wang et al., 2018). Therefore, it is plausible that if people experience depressive symptoms after their stroke in relation to body image, CBT may help.

An alternative approach, known as motivational interviewing (MI), may also have utility in addressing adjustment and acceptance to body image changes post-stroke. After a stroke, depression could result from failure to adjust (Gracey et al., 2009; Watkins et al., 2011). This could include failure to adjust to a changed body image experience. MI is a person-centred, talking based therapy where the therapist works with the patient to increase awareness and importance of change. This helps them to change how they think about life after stroke. This is done through the therapist sensitively encouraging amplification of the discrepancy between current issues (e.g., stroke-related bodily changes) and a person's goals or values (e.g., desired pre-stroke or 'normal' body image) (Patel et al., 2018). MI helps people to develop cognitive strategies to help them in working on these issues (Auton et al., 2016; Watkins et al., 2007; Watkins et al., 2011).

The concept of addressing discrepancy is supported by Gracey's "Y-Shaped" process model of rehabilitation (Gracey et al., 2009). Through this approach, continued behavioural experimentation or learning supports the process of resolving the discrepancy. This ultimately helps the patient to develop their identity and encourages psychological growth (Gracey et al., 2009). Confidence is built through encouraging self-efficacy, which subsequently enhances motivation and readiness to change (Patel et al., 2018). For people with stroke, MI has been found as having the potential to help them adjust to and accommodate concerns most important to them (Auton et al., 2016; Watkins et al., 2007; Watkins et al., 2011). Therefore, this approach has potential applicability in helping people to accommodate body image issues.

The therapeutic approaches that result in the most sustained improvement to body image experience in non-clinical samples are CBT or ACT (Lewis-Smith et al., 2015; Lewis-Smith et al., 2018). However, MI has utility for people with stroke (Auton et al., 2016; Watkins et al., 2007; Watkins et al., 2011). Therefore, these approaches may represent the starting point for future research exploring the acceptability and utility of different support methods for people after stroke.

In terms of specific support to target body image, solid conclusions cannot be drawn about the most effective types of body image intervention. In terms of self-help, a plethora of options are available online. Most appear to be designed for adolescents (e.g., from YoungMinds (Young Minds, 2022)) but material is available for other ages from The Mental Health Foundation (Mental Health Foundation, 2022). In terms of more formal intervention for the general population, improvements are usually minimal, with only small effects on internalisation of beauty ideals and social comparisons (Alleva et al., 2015b). Group therapy approaches were recommended by the BIR as being the most effective in improving body image across different populations. Evidence supports this, with the most effective approaches being delivered in groups face-to-face across multiple sessions (Lewis-Smith et al., 2015; Lewis-Smith et al., 2018). There is a need for further research to explore which components of body image support would be more beneficial for people with stroke, including therapeutic approach and format of support. It is also important to ensure that any support considers both males and females, as evidence around body image interventions for males is lacking (Guest et al., 2019).

b. Prevention

In terms of addressing societal opinions around disability and visible difference, a broader approach could be taken to normalise disability. This could include media and disability promotion and working with stroke-specific charities. Reducing the anxiety that is sometimes experienced when people who do and do not have a disability meet could reduce prejudice and promote positive interactions (Wang et al., 2021). Increased positive exposure to people with disability improves public attitude towards disability (Wang et al., 2021). So, ensuring that disabled people are better represented in the media could help to normalise disability.

c. Confidence and disengagement with services

Finding ways to improve confidence post-stroke has been identified as a research priority by people with stroke (Pollock et al., 2012). This can be done by progressing skills and successfully engaging in activities, which help to establish a positive self-belief and significant others can help to reinforce these positive beliefs (Horne et al., 2014). Therefore, improving confidence represents an area for consideration in improving engagement with rehabilitation and post-stroke body image experience. This is an area which could be addressed through MI (Patel et al., 2018) (see section 7.10.1.a).

7.10.3 Enhancing understanding around the impacts or prevalence of post-stroke body image experience

a. SSNAP Database

Participants described that there needs to be greater understanding around the impacts and prevalence of post-stroke body image difficulties. They suggested that a question could be added to the SSNAP database in order to highlight it as an unmet need and gather data. Data gathered by the SSNAP database helps in describing the quality of care provided (National Health Service (NHS), 2019b). The NHS Long-Term plan acknowledges that updating SSNAP can increase the comprehensiveness of data gathered to make sure that it meets the needs of clinicians, commissioners and patients. To effectively gather this data for post-stroke body image experience, an appropriate question or questions would need identifying. Although the purpose of the current study was not to identify a body image screening tool, participants described what would be needed from such a tool (see section 7.9.2.a). Although they described what could be added, how effective the tool would be in identifying patients with body image issues remains unknown. So, this would need to be tested prior to being added into SSNAP.

b. Format and timing of assessment method

Whether body image assessment methods are used as screening tools or to explore the effectiveness of support, they need to be visual, simple, and as short as possible. This is supported by existing research by Stott (2019), which explored the feasibility of three body perception assessment tools in people with stroke who had communication difficulties. Mirroring the thoughts of clinicians in the current study, participants expressed a preference for a visual, simple and accessible tools (Stott, 2019). Drawing from evidence from the general population, tools also need to account for experiences across different contexts, which is supported by evidence from the general population (e.g., (Cash et al., 2002)). However, the tools identified by Stott (2019) research were avatar-based, which are identified within section 7.3.4.b as not fully reflecting the stroke-specific definition of body image derived from the current thesis and furthermore, they do not account for the importance of context.

Participants queried the appropriateness of exploring body image experiences at 6-months post-stroke. Pragmatic and recovery-related reasons for this are discussed in section 6.15.5.a. The risk of missing people who need support was ultimately perceived as justification for opening up body image conversations with patients at 6 months post-stroke.

7.10.4 Strengths and limitations

This section will outline the strengths and limitations of the study methods.

a. Sample

Most participants were known to the researcher or supervisory team. This could have led to social desirability bias in responses if participants felt they had to answer questions in a certain way. However, discussions were varied, and participants offered both positive and constructive criticism. Also, the supervisory team, apart from the

DoS, were not present during the sessions. In relation to the characteristics of the sample, despite attempting to recruit male clinicians, all participants were female. To be considered more representative of clinician views, further research is needed with male clinicians. This is because they may express different viewpoints or have different experiences of body image communication with patients. For example, in general patient populations, opposite sex patient-clinician communication has different characteristics than same-sex communications, with the latter typically feeling easier and more equal. Patients also seem more willing to discuss emotional aspects with female clinicians (Sandhu et al., 2009). This should therefore be taken into account when considering who should be discussing body image experiences with people who have had a stroke.

b. Data collection

The group format facilitated conversation and discussion between participants until consensus was reached. The subsequent individual sessions allowed in-depth opinions to be gathered from another clinical psychologist and the only body image researcher involved. This increased applicability of results to the research questions through addressing psychological and body image support recommendations. Participants in the individual sessions were asked for their opinions on the assessment methods suggested by the group, allowing more detailed evaluation of preferred methods.

There was a lot of content to address within a two-hour session. Two longer sessions would have enabled greater detail to be collected for each discussion point. For example, participants spoke in-depth about how they could relate their clinical experiences with the findings. Additional time would also have been useful given the large number of body image assessment methods presented. This was necessitated by the difficulties in identifying their full versions and not wanting to discount them altogether simply because they could not be located. Not having these full versions made shortlisting and evaluation more difficult, meaning they were not assessed to the same extent as the full copies of methods presented. Best efforts were made to describe the key aspects of each tool that was unavailable, but ideally full versions would have been located to allow a more accurate and complete appraisal of tools.

During the group, when discussing possible approaches for support post-stroke body image experiences, the conversation seemed to naturally gravitate towards methods of screening for body image issues. This may reflect the current focus of rehabilitation practice around assessment, as opposed to rehabilitation. This is useful for future reference and in considering early methods of identifying whether someone needs body image support after their stroke. However, the intention of reviewing methods was to measure the effectiveness of support in the future. This could have been lack of clarity or distinction between screening or evaluation methods by the researcher. Or it may suggest that a screening tool or an ability to have open discussions with patients is what feels most pertinent or relevant to clinicians in real-world, everyday clinical practice.

c. Reflection on quality and rigour

The quality checklist implemented throughout this study is presented in Table 7.4, with reflections on how or where within this chapter each question has been considered.

Table 7.4. *Quality Checklist from Elo et al. (2014) with Reflections on How Each Question Has Been Considered or Addressed Throughout the Methods and Analysis of the Expert Panel Sessions*

Phase of content analysis	Questions to consider	Reflection
Preparation	Data collection method: 1. How do I collect the most suitable data for my content analysis? 2. Is this method the best available to answer the target research question? 3. Should I use either descriptive or semi-structured questions? 4. Self-awareness: what are my skills as a researcher? 5. How do I pre-test my data collection method?	1 & 2. Rationale and comparison to alternative possible methods provided in section 7.6.1 3. Group discussion guide developed to address key questions for group (see section 7.3.5.a) 4. Researcher positionality outlined in section 3.2 5. Discussion guide finalised with supervisory team section 7.3.5.a
	Sampling strategy: 1. What is the best sampling method for my study? 2. Who are the best informants for my study? 3. What criteria should be used to select the participants? 4. Is my sample appropriate? 5. Is my data well saturated?	1. Strengths and limitations of sampling strategy used outlined in section 7.10.4.a. 2 & 3. Discussed with supervisory team who have extensive experience of working in stroke, and based upon my knowledge of body image

		4. Sample strengths and limitations considered in section 7.10.4.a 5. Saturation was not considered, as the sample size was based upon availability to attend the sessions and known contacts of the supervisory team. Instead of saturation being important, the aim was to collect data from different perspectives. Although there were limitations of sample variability e.g., gender (see section 7.10.4.a), a variety of healthcare professional roles were included in the analysis
	Selecting the unit of analysis: 1. What is the unit of analysis? 2. Is the unit of analysis too narrow or too broad?	1.The perspectives of the clinical experts involved 2. As outlined in section 7.10.4.a, the sample is likely too narrow as it does not include the perspectives of male clinicians
Organisation	Categorization and abstraction: 1. How should the concepts or categories be created? 2. Is there still too many concepts? 3. Is there any overlap between categories?	1. Categories were organised based on pre-defined research objectives (see sections 7.2 and 7.9) 2. Number of concepts links to number of research objectives. More time for the sessions would have been beneficial to consider the concepts in more detail (see section 7.10.4.b) 3. The categories were designed to be distinct: clinical relevance, support, assessment. Discussion and

		reflection on the findings presented came up naturally in conversation throughout the sessions, so could be considered as showing overlap
	Interpretation 1. What is the degree of interpretation in the analysis? 2. How do I ensure that the data accurately represent the information that the participants provided?	1. Interpretation was avoided as the purpose was to describe and summarise the data. Although, my personal views undoubtedly impacted my summaries as described in section 3.2 2. Descriptive analysis was used, so the findings reflect the information provided by participants. DoS attended the group and agreed with categorisation and presentation of data (see section 7.6.4)
	Representativeness 1. How to I check the trustworthiness of the analysis process? 2. How do I check the representativeness of the data as a whole?	1. This checklist was used throughout the analysis process, and has been completed to show trustworthiness 2. There was general agreement within the group, suggesting consensus was reached and that the data was representative of participant perspectives.
Reporting	Reporting results: 1. Are the results reported systematically and logically? 2. How are connections between the data and results reported?	1. Results are presented in categories structured around the objectives of the group and the questions asked 2. Exemplary quotations are presented to show how the data informs the results

	3. Is the content and structure of concepts presented in a clear and understandable way? 4. Can the reader evaluate the transferability of the results (are the data, sampling method, and participants described in a detailed manner)? 5. Are quotations used systematically? 6. How well do the categories cover the data? 7. Are there similarities within and differences between categories? 8. Is scientific language used to convey the results?	3. Concepts presented in categories, and suggestions for support are structured around the Stepped Care Model for Psychological Interventions After Stroke 4. Data, participants (see sections 7.8 and 7.9) and sampling (see section 7.3.3) described in detail 5. They are not used systematically, but key quotations are used within the results to exemplify points 6. Categories were based on questions which were used for data collection, therefore categories cover data well 7. Yes: as categories were based on the distinct research questions 8. Scientific language is used where appropriate e.g., when describing methods of possible support (see section 7.9.2)
	Reporting analysis process: 1. Is there a full description of the analysis process? 2. Is the trustworthiness of the content analysis discussed based on some criteria?	1. Analysis process reported in section 7.6 2. Yes: it is based on these criteria

As outlined in section 5.8.5.e, using a checklist to address rigour reflects the hybrid approach to epistemology used throughout the thesis. Although this might seem at odds with the qualitative approach to analysis, the use of this quality checklist suits the approach taken within this chapter.

d. Data collection method

Pilot testing the data categorisation methods is recommended with deductive content analysis to ensure utility and appropriateness categories (Schreier, 2012). However, this is more important if there are multiple coders, and the categorisation of themes was not discussed with a second researcher. Although, the categories of questions to be discussed with the group were approved by the DoS and supervisory team.

e. Reflections on epistemological approaches

The purpose of the panel groups was for the attendees to suggest and/or reach consensus around whether the findings were identifiable in their clinical practice, how post-stroke body image experiences could be supported and how benefits of this support could be assessed. So, the individual perspectives of clinicians and their experience of treated and supporting people after a stroke were explored as well as societal perspectives. The aim was around reaching practical conclusions to ultimately determine how results could be applied to clinical practice. This, again, relates more to positivism and was due to pragmatic reasons. However, exploring individual perspectives of clinicals and their experiences of treating and supporting individuals does link through to phenomenology and exploring individual experiences.

Content analysis (and thematic analysis) have developed from quantitative content analysis. Due to this, qualitative content analysis can be considered as leaning towards positivism (Braun & Clarke, 2021). Therefore, although qualitative content analysis was my preferred method for analysing the expert panel groups, I also acknowledge how it does not align with my Epistemological perspective and was instead chosen for pragmatic reasons.

7.10.5 Implications & Future Research

This section will outline the key implications from this study and make suggestions for future research. The first key finding relates to support for the real-world relevance of the results of the thesis. Stroke clinicians could relate their clinical experiences to the new definition and finding. This provides support for moving forward in the future to develop and hone the new definition with different groups of people with stroke. Also, because stroke clinicians can identify the relevance of the findings, this has implications in supporting future research and improvement of stroke rehabilitation services around body image after stroke.

Secondly, stroke-specific body image support was identified as necessary across multiple levels of the stepped-care model (NHS Improvement- Stroke, 2011). Participants suggested that stroke therapists could be offered training to support even the earliest conversations about body image to prevent it going unrecognised. This could be incorporated into wider discussions around adjustment. To facilitate this, research is needed to understand the key components for a brief education package for healthcare staff so that they can feel more confident in identifying and supporting any initial body image issues. To avoid patients feeling concerned about being vain while discussing body image, it is important for healthcare staff to understand the breadth of body image and its possible impacts. Clinicians need to be equipped with some brief questions that they can ask which are not too onerous or time-consuming and that can be easily implemented in existing stroke care structures (e.g., 6-month review). Further research is required to explore the most succinct but inclusive questions that could be asked to achieve this.

Finally, discussions around the body image assessment methods elucidated the core aspects required for a method that is acceptable and relevant for people with stroke, from the perspective of clinicians. This has also shown which methods clinicians think would be feasible within clinical practice. Next, feedback should be sought from people with stroke to explore their opinions of these most feasible tools, and to explore whether existing tools can be adapted for the purpose, combined, or whether a new assessment method is required. Identification or development of an assessment method could have utility in screening people who might need support with their body image post-stroke, and in exploring benefits of an intervention. To facilitate development of this method, further evidence is needed from people with stroke who have different impairments, disabilities, ethnicities and of different ages.

7.10.6 Summary

This study has provided novel insight into the opinions and expertise of healthcare professionals regarding their experiences of working with stroke patients who they perceive to have body image issues. It has corroborated and exemplified the real-world applicability of the study findings, which will be further explored in Chapter 9. Using the Stepped Care Model for Psychological Interventions After Stroke (NHS Improvement-Stroke, 2011), suggestions have been made across different levels of support for how patients might be helped with their body image where required. It has also shown that there is no method of assessing body image that would be acceptable in its current state for people with stroke.

8. CHAPTER 8: PERSONAL REFLECTION

8.1. INTRODUCTION

In this chapter, I present a personal reflection of my thesis and research process. Writing Chapter 3 encouraged me to think about my own personal and academic background and how this might have affected my research decisions. In this reflective chapter, and to enhance methodological quality, I will present my personal reflections from throughout the process of completing the thesis. This will include reflexive considerations of how my personal and researcher characteristics and values may have affected the results. I acknowledge them in this chapter for transparency. I will also outline the research skills that I have learnt.

8.2. INITIAL EXPECTATIONS COMPARED TO REALITY

Before beginning the thesis, I knew that it would develop my skills as an independent researcher. As such, I have learnt skills to cope with and overcome various practical and personal obstacles. This section will outline examples of unanticipated events or changes that occurred during my thesis and will incorporate examples of what I wanted or planned to do, compared to what I actually did. By doing this, I will also demonstrate how I responded to events that happened in order to consider the subsequent implications.

8.2.1 Impacts of COVID-19: Disadvantages

As outlined in section 3.3, COVID-19 impacted on the research process, including development of the research protocol. It also had practical implications during completion of the thesis. One of these implications was restrictions to campus access. This meant that I was initially reliant on the support of admin staff at UCLan who generously agreed to print, organise and send my first site file and first batch of participant-facing materials. When restrictions loosened in Spring 2021, I was able to visit campus to collect and process returned participant consent forms.

It also had implications for recruitment. Before COVID-19, I had planned to recruit participants in-person at hospital sites. Due to COVID-19 guidelines and being unable to visit sites, I relied on NHS staff who were already extremely busy due to COVID-19 pressures, to identify participants as per section 6.9. Recruitment was minimal during the first three months of opening due to these impacts of COVID-19 and staffing pressures. This slowed interview progress and resulted in an extended recruitment period. These COVID-19 related pressures also made it difficult for detailed screening logs to be maintained, which meant that staff sometimes had to retrospectively estimate some of the recruitment figures (see sections 6.9.1 & 6.9.2). Relying solely on virtual, telephone or email communication was less personal than working in-person with recruiters. This could have impacted on my opportunity to have nuanced communication with staff and potential participants, and this likely affected recruitment.

I had also planned for all research participation to be face-to-face in acknowledgement of stroke-related difficulties that might hinder telephone/online communication (e.g., eyesight, hearing, concentration or speech issues). Staff also reported that some patients were reluctant to participate due to sessions not taking place in-person. Using virtual or telephone methods may also have hindered participants' desire to use creative methods during the interviews. If in-person, then having materials directly available may have encouraged their use. Some participants shared photographs with me through MSTeams, which I described in the transcripts. However, this was not possible during telephone interviews meaning data collection may not have been as rich for those participants.

8.2.2 Impacts of COVID-19: Advantages

A benefit of virtual and/or telephone work with participants was that travel to and from participants' homes was not required and there was a faster turnaround time between securely storing original copies of interview recordings. Virtual methods allowed interviews to be video captured so that details could be added to transcripts of nuanced movements, which is data that I would not have otherwise had access to with in person methods. One site reported that a participant who had previously been reluctant to use virtual methods to access post-stroke support had subsequently shown an interest in seeking such support, due to using MSTeams during the study.

Switching to virtual working to protect a potentially vulnerable population during the COVID-19 pandemic could be an experience relevant for future research. I noticed it was more difficult to identify non-verbal cues and body language than in-person interviews. This includes cues from participants and the researcher (e.g., eye contact and nodding to demonstrate active listening). This affected aspects such as knowing when a participant was taking a pause in their speech or had finished talking. To address this, I let participants know that I would try and stay quiet to let them elaborate and used verbal cues so participants could hear me encouraging them and to show them that I was listening. Rapport could have been impacted by the less personal approach of telephone/MSTeams. However, to counteract this, I took extra time to introduce myself to participants when I first contacted them. For those who used MSTeams, we had a 15-minute introductory session where we made sure that MSTeams worked properly and that they were happy with the interview setup. While telephone calls felt less personal than MSTeams sessions, they potentially afforded participants additional anonymity, which could have encouraged them to open up more.

Generally, completing my thesis during the pandemic has taught me skills in reacting to and working flexibly around unexpected circumstances.

8.2.3 Ethics submissions

Applying for ethical approval for the thesis helped me to visualise my desired outcomes and the ways that each phase would fit together and answer the objectives. It also helped me to think about new skills that I wanted to learn, including using IPA and discussion groups. After gaining ethical approval, I expected to complete each phase in succession. In practice, the phases overlapped, requiring significant organisation, prioritisation and compartmentalising for my research to remain on target and focussed. This taught me that despite having a precisely planned project, research happens in the context of an unpredictable real-world.

8.2.4 Scoping to systematic review

I changed the design from a scoping to systematic review because, upon reflection with my supervisory team, the methods I was using were more akin to a systematic and rigorous review. I subsequently updated my searches and screened the new results. Making this decision later in the research process was time consuming but meant that my search results were more up to date and my design more rigorous. Once it became a systematic review, I made sure to follow the PRISMA guidelines and used the CASP tools for quality assessment.

8.2.5 Deciding on the final definition of body image to use in the systematic review

I gave a lot of thought to how I would define body image throughout the thesis. This originally had implications for my systematic review. Initially, I screened papers using a more lay and appearance-focussed definition of body image. However, after team discussion, deeper understanding of body image theories, and exploring the papers being excluded by this definition, we decided to expand to the current broader definition. So, I re-screened my systematic review search results in line with this wider definition. Although this enhanced the reliability of my screening due to assessing records twice, it was time-consuming and added complexities around recording new search results and tracking reference list screening. I would now feel more confident in screening and would use more simplified spreadsheets to record inclusion/exclusion decisions.

8.2.6 Cyber attack

During final preparations for the first site file to be sent to my first recruitment site, UCLan experienced a cyber-attack, and all shared system networks were offline for around a month. This delayed progress as most of my thesis documents were stored on the University Network as per university guidelines. It also delayed recruitment by about a month, as I had to wait for the central storage drives to be fully re-instated because all confidential and participant-related data would be stored there.

8.2.7 Changes to supervisory team

I had two changes to my supervisory team during my candidature; one supervisor left the team and two joined. The knowledge of my supervisors and our shared understanding of my thesis meant that when my new supervisors joined the team, they brought new skills and expertise which have undoubtedly enhanced the design and quality of my thesis. It has really made me appreciate the value of being able to discuss ideas with people who have specific expertise in different areas. I will be able to apply this experience to future work in research teams.

8.2.8 Recruitment

Staff were initially reluctant to purposively recruit people (e.g., different ethnicities) due to a desire to be inclusive. I learnt through discussing this with my supervisory team that by not purposively recruiting these people, the recruitment was less inclusive. By understanding this and then emphasising to staff the importance of the spread of participant experiences, this helped to encourage staff to focus on recruiting those not reflected by the sample. I learnt a lot from my first site opening and experiences of recruiting, taking those learning experiences meant that recruitment at my second site was much more efficient. For example, I knew the recruitment details to emphasise at site set-up (e.g., keeping screening logs) and we had weekly meetings to aid communication These practical experiences have helped me learn about the processes of doing clinical research in the NHS and will be invaluable in future research.

8.2.9 Interview experiences

Towards the end of recruitment, I gained approval to complete an in-person interview with a participant who had communication difficulties. This was daunting as it was my first home-visit and my first opportunity to work with someone who had difficulty communicating. This experience helped me to appreciate the differences between in-person and virtual work. Namely, that in-person, nuanced body language is much easier to identify (see section 8.2.2).

8.2.10 Focus groups to expert panel groups

Although I had initially planned to run focus groups with people with stroke, their relatives/carers and healthcare professionals to gather their opinions on my findings, time constraints and re-consideration of how this would enhance the project outcomes lead to a design change. Instead, I submitted an ethics amendment to complete the expert panel group discussions. This allowed me to think about different ways that people might be supported with their body image post-stroke, as opposed to honing my research findings, which was really important to understand the clinical implications of my project. This validated that considering post-stroke body image experience was an important aspect of care and allowed me to begin to identify potential ways in which to screen and support people following a stroke. This is the first step in terms of taking my research forward into clinical practice and added real-world practical perspectives to my findings.

8.2.11 NIHR and implementation of the Health Inequalities Assessment Toolkit

Within the last year of my thesis, I was introduced to the Health Inequalities Assessment Toolkit, developed by the NIHR School for Public Health Research and NIHR Applied Research Collaboration North West Coast (2022). I used this tool to reflect upon my work and consider how it has addressed health inequalities and how they could be considered going forward. The Toolkit also provided an extra dimension around individual differences. For example, to consider how people of different genders, ages, socio-economic status and ethnicities may experience different interactions between these factors which all have the potential to influence post-stroke body image experience.

8.3. DEVELOPING A RESEARCHER IDENTITY

In this section, I will reflect upon how completing the thesis has impacted my researcher identity. The development of my skills during my thesis in parallel to my career on the Stroke Research Team have complemented each other. They have built my identity as an independent researcher and increased my time management skills and abilities to effectively prioritise tasks.Completing this thesis has allowed me to develop my identity as a stroke researcher. Writing Chapter 3 helped me to understand my world perspective as being psychosocial. My background is in Psychology, which initially drew me towards ideas that were not fully inclusive of the medical complexities of post-stroke experiences. This was evident in my initial selection of an appearance-focussed definition of body image which was the perspective of body image that I had used in my work with young women and the influences of social media (Davidson, 2018). I realised that my perspective needed to be broadened to ensure that I addressed the complexities associated with post-stroke experiences. Then, I became aware of the importance of applying a ‘stroke’ lens to my work, to include unique stroke-related impairments. This helped me to develop my researcher identity from a purely psychological one, into having a more stroke-specific psychological and psychosocial identity as a researcher.

Completing this thesis has also allowed me to develop my identity as a qualitative researcher. I feel more confident in discussing and interpreting my findings and in making research decisions as my skills in postulating ideas more independently have expanded. I have always enjoyed being organised, however completing the thesis required me to not think ahead too much and to focus on daily prioritised tasks. Without doing this, it could have been overwhelming. I learnt not to underestimate the power of changing tasks or direction or taking a short break from work to help me to return to a task feeling more capable of completing it.

I have also learnt to be more aware of my strengths and weaknesses as a researcher. I tend to be over-inclusive or cautious, evidenced through extracting too much data during my systematic review. This added unnecessary time to tasks and overcomplicated some aspects of my review. Therefore, this was something that I consistently tried to be aware of. Another weakness is preferring to be regimented in my workflow. I usually prefer having a to-do list and working through it. I soon learnt that this was not possible while completing the thesis, particularly in relation to writing lengthy chapters that require frequent re-visiting.

I developed my writing style throughout the thesis, through a combination of trying to focus on writing more concisely and avoiding unnecessary detail, using an active voice and through invaluable feedback from my supervisory team.

8.4. CRITICAL REFLECTION ON THE DATA COLLECTION AND ANALYSIS PROCESS

In this section, I will draw from the CASP qualitative checklist (Critical Appraisal Skills Programme (CASP), 2018) to reflect upon how I think my personal and research characteristics may have impacted the data collection process. This includes my researcher role, personal biases and influence during data collection, acknowledging my prior knowledge and the utility of keeping a reflective journal.

8.4.1 Reflection on my researcher positionality and the requirements of PhD scholarship

As part of completing the thesis, I knew it was important for my research to make an original contribution to knowledge and to have potential to impact for stroke care. I wanted my results had to include something practical, to be able to take forward for future study and ultimately impact care. This is part of the reason why I decided to take a systematic approach to my review, why I felt it was important to create a stroke-specific definition of body image to support clinician understanding of what body image experience might look or feel like after stroke, and also why I wanted to make initial practical recommendations for how body image might be supported and assessed in the future. These aspects all veer towards positivism, contrasting with social constructionism and phenomenology. Therefore, I experienced tensions between my worldview and the requirements of PhD scholarship and in building the evidence base to make practical impacts in the future. While acknowledging the individual experience of body image from a phenomenological perspective, rooted in the context of social constructionism, I also acknowledge the use of methods which conflict with this perspective in order to fulfil the PhD scholarship and increase the likelihood of having practical clinical impact in the future by developing recommendations (definition, support, assessment methods) which could be taken forward and potentially tested empirically.

8.4.2 Reflecting on the interviews

To help me to remain grounded in each interview and during the analysis process, I completed a reflective sheet after each interview. In it I noted my gut instincts and initial thoughts, leading into whether I felt that the participants had considered what body image was before the interview. I added additional thoughts during analysis. These reflections allowed me to acknowledge the things that I felt that I did well and those that I wanted to improve on. So, I used my reflections to help in developing my interview style and subsequently enhance rigour. I also included a ‘researcher comments’ section with each questionnaire so that I could immediately note down any initial thoughts about and reactions to the participant’s responses. Overall, my reflections allowed me to highlight any assumptions that I felt I might have made during the interview or about the participant. This helped me to better understand my personal influences over the research process and therefore increase transparency.

8.4.3 Data collection

As the data collector for this thesis, I had inherent influence over the data collection process (Johnson et al., 2020). I chose this topic area due to personal interests in body image and stroke as outlined in Chapter 3. It is imperative to acknowledge my personal biases in terms of the importance of this area of research. A key area where I had influence over the research was around body image terminology. As discussed earlier (see section 5.8.5.d), for pragmatic reasons I had to identify a definition for the fluid concept of body image for the review. I then identified research which I considered partially or fully met this definition. Given the overlap between body image terminology and its fluid nature as a term, I therefore acknowledge my potential influence of which papers were included. However, the broad nature of the definition means that the review is likely to be thorough and inclusive as opposed to being too narrow.

In relation to the interviews and given the inherent power dynamic between researcher and participant, I tried make participants feel relaxed by building rapport. Different levels of rapport were built with different participants based on individual differences in the amount of colloquial conversation. Level of rapport likely influenced how willing participants were to open-up and provide more in-depth responses. Interviewees would sometimes reference something that we had spoken briefly about before the interview recording started or during completion of the baseline questionnaire. Participants also tended to talk in detail about symptoms experienced post-stroke whilst completing the questionnaire. I tried to capture this within the questionnaire notes. If participants began talking about something which I felt answered a question I might ask during the interview, I would use prompts such as “it would be great to talk about that in more detail next time”. This acknowledged the validity of what they were saying and avoided them having to repeat themselves for the purpose of the recording. My outlook was if that discussion point was important and at the forefront of participants’ experiences, it would then organically arise in the interviews.

I felt nervous for the first few interviews, but this reduced with time as I relaxed into conducting them. I gradually became more confident that I was able to come across professionally and get the best from each session. My confidence in my interviewing abilities also increased after feedback on a transcript from my supervisory team which helped me to reflect upon and consider the strengths and weaknesses in my interview questions and to update the interview schedule accordingly. I noticed my interest in emotional factors emerging via the probing questions that I was initially asking, such as “how does that make you feel?”. After identifying this and the potential for this question to drive the results towards emotionality and body image, I made conscious efforts to ask broader questions, such as “how does that impact you?”.

Participants knew the topic of the research and that I worked on the Stroke Research Team, and I only told them more if they asked as I did not want my background in psychology to affect their response. For those few who asked, knowing my research background could have made them reflect more on the psychological impact of their experiences and thus affect how they responded to me. Other people brought up clinical queries, at which point I would explain that I did not have a clinical background but that they could talk to their GP. Some participants referred to me being younger and/or female, indicating awareness of these factors. This likely impacted some of their responses to my questions.

As the data collector for the interviews, I acknowledge my influence over how they were conducted. This is expanded upon in the following section.

a. Prior knowledge

Overall, given the subjective nature of body image, but also the lack of consensus over what body image means, I had to take extra care over which aspects of the research I attempted to bracket, and which aspects of my existing knowledge were useful.

It is likely that my prior knowledge around potential stroke-related bodily changes impacted my thoughts during the interviews and their analysis. An assumption that I noticed myself making during the interviews was in relation to those participants who would tell me that no-one else would notice that they'd had a stroke. My go-to question was “how does that make you feel/affect you?”. A turning point for me was when one lady jokingly asked whether she should have a “sign on” saying that she'd had a stroke. This made me realise how my broad perception of stroke through a lens of research, literature and speaking to other people, was very different when seen through the lens of someone who has experienced a stroke. It was a useful and personal reflective point for me.

It is also important to acknowledge that my prior knowledge of the definition of body image likely affected my interview style and the probing questions I asked. For example, if a participant mentioned a functional experience, I explored this further and asked about impact, which aligns with the broad project definition. This means that the definition undoubtedly impacted data collection and analysis. However, this is buffered by it being a broad definition.

I experienced tensions when trying to bracket my personal views for the interviews. I did not try to bracket my existing knowledge when completing interviews, but I also did not want to influence participants' responses. From completing my systematic review, I was aware of the depth and scope of possible body image experiences that people might have after a stroke. This knowledge helped me to better identify possible discussion of body image during the interviews and therefore helped me to ask more effective probing questions. This is evident from my following post-interview reflection:

> “[Participant was] not overtly concerned about body image but some nuanced conversation shed light on aspects relating to body image” (My post-interview reflections for P04)

However, body image is also personal and subjective. It was a balancing act between ensuring that whatever participants felt was their experience of body image was true and valid for them, but also pulling out additional aspects of body image which, due to its broad definitions and interpretations, may not have been explicitly identified by participants as being body image. An example from my personal reflections shows my thoughts on this after completing an interview:

> “[I] could have picked up on […] juxtaposition of [participant describing] having no impacts [of stroke], but eyesight being annoying and needing adapting to” (My post-interview reflections for P18)

This demonstrates trying to achieve the balance between what participants perceived as an impact, compared to an objectively observable impact, and also of myself as a researcher reflecting upon additional ways to explore these areas of juxtaposition.
I also tried to reflect upon whether I though participants had prior knowledge or had given thought to what ‘body image’ meant before their interview:

> “Felt as if P02 had given thought to how they understood body image ahead of the interview and had thought about how body image had affected them” (My post-interview reflections for P02)

In this respect, I was not only reflecting upon my influence over the data, but also trying to understand any pre-conceived ideas brought to the interview by participants. This was important because there was also a challenge of exploring body image experiences with participants who said that they had no changes to their body image, based on their perceptions of what body image was, but did describe changes to their body image based on the thesis definition:

> “Participant was happy to talk, although interview was challenging as has almost pre-decided no body image issues and didn’t think he would be useful. Although, […] he was concerned about cause of stroke, and participant did bring up lifestyle changes as a result of stroke” (My post-interview reflections for P15)

This supports the use of a broad definition of body image to help in teasing out experiences of body image post-stroke due to challenges around terminology, although not typically expected from phenomenology.

I acknowledge my influence over the body image assessment methods that were presented for feedback to the expert panel group. In line with positivism, I tried to provide logical reasoning for the different methods presented (see section 7.3.4.b) in an attempt to bracket my subjective opinions and to make the process more objective. However, the methods identified based on this hinged on my chosen definitions of body image. Also, the feedback provided were based on results that I had gathered, meaning that suggestions for support were based on work inevitably influenced by me. I acknowledge my influence as a researcher and data collection tool throughout the thesis.

Therefore, it is clear from my personal reflections that positivistic approaches were present in my methods and thought processes. However, this was mostly from a practical perspective and in ensuring rigour of processes within the remit of the thesis.

8.4.4 Data analysis

Throughout completing this thesis, I learnt a lot about my desire for organisation and to follow structured and linear processes. This need for structure arguably lends itself more to positivism as opposed to constructionism and alongside the requirements of a PhD scholarship, could explain why some aspects of the thesis veer towards positivism. For the qualitative analysis aspects of the review and for the interviews, I had to push back my desire for linearity of the research process and immerse myself into working back and forth within the data to allow me to complete detailed analysis.

From my personal reflections, even for a lady who defined body image in a similar way to the way I did in the thesis in terms of it being broad, I noted the complexities around analysing body image experiences:

> “Complicated to analyse- lots of intermingled ideas but seems largely focussed around using motivation and distraction to avoid the fact she’s had a stroke; wants to be normal; draws upon background to cope” (My post-interview reflections for P22)

I think this was due to the complex and fluid nature of body image and demonstrates the tensions I experienced in teasing out body image experiences and impacts. This also reflects the tensions between letting go of a structured and linear process for defining and analysis body image experiences and embracing the iterative analysis process.

One area where I acknowledge that I did bracket, was not my knowledge per se, but was when interviewing and subsequently analysing each participant's individual transcript. I analysed each transcript individually, before analysing across participants at the end. To do this, I became fully emersed in each participant's transcript and coded only their interview. Once I had completed this, I moved onto the next interview and immersed myself in their transcript, and so on. This was to help me to capture the individual aspects important to each participant.

I also gave thought to bracketing when it came to analysing the interviews. It was important to acknowledge each person's subjective opinion of what body image was, and this is reflected in the creation of the stroke-specific definition of body image. However, to paint the full picture of body image, I had to go above and beyond participant definitions and use the broader thesis definition of body image experience to make sure that I considered the many shapes that body image experience can take and which may not have been acknowledged by participants.

8.4.5 Reflection on approaches rigour

Reflecting the hybrid epistemological approach taken throughout the thesis, the approach to rigour has also been mixed and has comprised of checklists specific to the methods used for each study, with an additional consideration for phenomenology for the interviews. While the approaches to rigour may not entirely align with phenomenology, they were each appropriate for the methods used. The reflection tables used to summarise approaches to rigour have been important in demonstrating and signposting how rigour has been considered throughout the thesis for each respective study. This has enhanced the trustworthiness, transparency and openness of the methods used.

8.5. SUMMARY

My personal and researcher characteristics cannot be disentangled from the research process and must be understood as part of contextualising and interpreting the results of this thesis. Acknowledging these influences is an important part of the reflective process and in this chapter, I have suggested ways through which I may have inherently influenced the results.

9. CHAPTER 9: OVERALL DISCUSSION, CONCLUSIONS AND IMPLICATIONS FOR FUTURE CLINICAL PRACTICE, RESEARCH AND POLICY

9.1. INTRODUCTION

In this chapter, I will briefly summarise the main findings including the strengths and limitations of the original research and discuss implications for clinical practice, policy, and research.

9.2. SUMMARY OF FINDINGS

Prior to this thesis, there was limited evidence around how people with stroke experience their body image, and its impacts on wellbeing and recovery. It was important to understand this, as evidence from the general population showed that body image can negatively impact psychological wellbeing and everyday activities. Further evidence from different clinical populations (e.g., cancer) showed that bodily changes can negatively impact on body image experience. Given that stroke can lead to a variety of bodily changes, it represents an area where changes to body image experience are likely.

Therefore, the main aim of this thesis was to build the foundations for the evidence base around post-stroke body image experience to enhance our understanding. To begin with, existing published and grey literature was systematically reviewed. The review identified 79 studies which showed that people have different experiences of adjusting to a changed body image after stroke. However, most of these studies used convenience samples and did not clearly define body image, nor what it meant for people with stroke. Where tools or scales were used to assess body image experience, they had not been validated for use with people with stroke.

Findings showed that people wanted to return to their perceived ‘normal’ pre-stroke body image, with the most negative experiences had by those people who perceived that they were further from their desired pre-stroke ‘normal’. After a stroke, the body was perceived as an obstacle to ‘normality’. It impacted on desired or perceived self-presentation, with perceived changes to appearance impacting on self-perceptions and socialising. Societal pressures to be ‘normal’ made people want to portray their ‘normal’ self even if they felt different. Also linked to the body being perceived as an obstacle to normality, the body was now experienced as being restricting and untrustworthy. Consequently, people experienced a changed relationship with their body. They could no longer take it for granted and they experienced changes to their activities, roles and relationships. Due to a sense of changed bodily capabilities and a sense of needing to slow down, people assimilated their post-stroke body image with their personal perceptions of ageing or being older.

Conversely, some people demonstrated positive outlooks of their post-stroke body image. This included acceptance of their bodily changes, or determination or desire to improve their body image. Generally, people sought continuity and normality, and experienced positivity when they perceived that their body image was getting closer to their perceived pre-stroke ‘normal’. The interviews added new detail around the changeability of body image experiences across different social contexts. Results emphasised the importance of feeling or perceiving the self as ‘normal’ in post-stroke body image experience and added nuanced detail around how post-stroke body image was likened to ageing. They provided new insights into the continuation of opinions in how important body image was pre and post stroke, and how this sense of importance impacted post-stroke body image experience. Existing research has used wide timeframes in relation to post-stroke body image experience. Through this thesis, the timeframe post-stroke has been limited to one where people start to make adjustments. This will also pick up longer-term issues that may affect life after stroke.

Crucially, the interviews also provided enough data to be able to develop a stroke-specific definition of body image. This is particularly important given the lack of the use of body image terminology across stroke research and the lack of consistent use of definitions. The experts also described the results as being identifiable in real-world clinical practice, supporting their real world application.

Clinical experts felt that none of the existing presented body image assessment methods would fully evaluate body image experience in people with stroke. The methods had not been validated in stroke, nor did they include all of the elements that seemed relevant to people with stroke.

The limitations of this research should be acknowledged when considering the contributions to knowledge of the findings. For example, in terms of transferability, the sample from which the definition of post-stroke body image experience was derived comprised people at 6-months post-stroke with mostly mild or moderate stroke, only one person with aphasia, and did not fully reflect the ethnic diversity of England. Body image issues could be different based on different stroke severities, impairments, and at different time points post-stroke. People from different ethnic backgrounds may also have different experiences. Therefore, future research should focus on exploring body image experience with specific subsamples of the stroke population to ensure that the definition is as transferable and meaningful as possible. Additionally, the expert panel group was comprised only of women, therefore possible different perspectives from men could have been missed. To enhance transferability and relevance of findings, future research should seek out the opinions and expertise of male clinicians to determine if their experiences around body image in stroke patients is different than for women.

However, the findings have multiple contributions to this research field. The stroke-specific summary and definition of body image provide a foundation for enhancing understanding of post-stroke body image experience. They show that it is an area of post-stroke experience that requires both research and clinical attention. The summary and definition need to be validated in other sub-samples of the stroke population, upon which an assessment method can be identified which seems to reflect the elements important to people with stroke. Suggestions have been made through this thesis for how body image experience could be evaluated post-stroke. Therefore, an evidence base has been developed through which future research can be built.

From a conceptual viewpoint, results contribute to knowledge by showing how the cognitive-behavioural model of body image experience (Cash, 2012a; Lewis-Smith et al., 2019) appears the most effective and relevant in explaining post-stroke body image experience. This is largely due to its consideration for the roles of both historical (e.g., pre-stroke), and proximal (e.g., current, post-stroke) factors in body image experience. However, considerations should also be made for the life-thread model of stroke recovery (Ellis-Hill et al., 2008), which could be viewed in conjunction with the cognitive-behavioural model to allow a better understanding through a stroke-related lens. Namely, it is important to understand the depth of how people's pre-stroke body image experiences relate to their experiences of, and the importance placed on their post-stroke body image.

Recommendations for support based on this evidence summary and the knowledge of clinical experts provide initial ideas for considering how this clinical attention could be considered. Implications for clinical practice and policy, and for the future research required to inform it will now be outlined.

9.3. IMPLICATIONS FOR CLINICAL PRACTICE AND POLICY

The findings of this thesis show that body image experience can have long-standing and wide-ranging impacts on wellbeing post-stroke. Some participants reported positive effects. This included viewing life post-stroke as an opportunity for change or improvement, and to take better care of themselves. However, the impacts were often prolonged and overall were typically perceived and experienced negatively. They included impacts on self-esteem, confidence, socialisation and relationship roles, everyday activities, and consequently identity and sense of normality. This supports the idea that body image experience should be recognised as part of stroke rehabilitation guidelines. This is important given the global recognition of the need for long-term, comprehensive stroke rehabilitation (Lindsay et al., 2014) and has implications for the need for body image experience to be given attention after stroke.

Body image experience was highlighted during the expert panel groups as being an unmet need in stroke care. For body image to be addressed in stroke care guidance, there needs to be a better evidence base. How common body image issues are post-stroke, who is most at risk, what impact they have on recovery, QoL and wellbeing, and how best to support them is unknown. There is lack of consistent, evidence-based guidance available for clinicians to systematically identify people with stroke who have body image issues. This means that the extent of distress experienced is unknown, and that people with stroke, who are struggling with their body image experience, may not be receiving adequate or appropriate support. To address this, data should be collected to identify how many people struggle with their body image experience post-stroke, and the nature and severity of its impacts. As suggested by clinical experts, this could be addressed through short, focussed questions via the SSNAP database.

There are additional challenges in identifying people who might be struggling with their body image experience post-stroke. Body image as a discussion topic may arise more readily for people more concerned about it pre-stroke, and generally may not always be labelled as ‘body image’ by patients. So, to be able to identify patients struggling with their body image experience, healthcare professionals need to be aware of body image, including what it is, how it may present itself as an issue, and its possible impacts on patient health and wellbeing. Healthcare professionals should also be aware of the subjective impacts of body image experience on wellbeing, as opposed to more objective and identifiable effects, as the most impactful aspects will be personal to each patient. Therefore, there is a need for training or guidance for healthcare professionals in screening for body image issues in people with stroke.

Identifying and exploring with patients whether they are struggling with their body image experience could be supported using the stroke-specific body image summary and definition developed from this thesis. It could be used to enhance understanding and communication of the wide-ranging impacts of post-stroke body image experience. This emphasises the importance of continued research around this summary and definition to hone and adapt it for different subsamples of people with stroke.

After identifying people who are experiencing distress due to their body image, it is important that healthcare staff have options available for signposting them to appropriate support. The findings of the thesis show that part of the process of adjusting to changed body image post-stroke seems to relate to a perceived return to pre-stroke normal, or acceptance of a new post-stroke normal. Potentially numerous forms of support could help this (see section 7.10.1.b). However, there is limited data to inform guidance or training for healthcare staff in supporting patients, nor what support should look like, or how it should be provided for people with stroke. Different approaches to support need to be tested in a systematic way. The current findings also show that social support, family and community seem to buffer the impacts of a changed body image experience, suggesting possible benefits of involving family, friends and carers with possible body image experiences.

The evidence from this thesis has shown that a changed body image experience can be an issue after stroke. But, how much of an issue it is remains unclear. There is no one body image assessment method which would reliably and acceptably measure body image post-stroke. This could be due to a lack of attention in this area, but it could also be due to the difficulties presented by the uniqueness of both stroke-related impacts and body image experience. To be able to better identify and support people with post-stroke body image issues, there needs to be a method of screening that could be used across all patients. The accuracy, sensitivity and specificity of this needs to be tested. Then, to address the uniqueness of different peoples' body image issues, additional assessment should then be personalised and holistic.

A lack of suitable method for assessing any benefits of support represents another gap in the data to inform policy and guidance around stroke rehabilitation. To begin to address this gap, the findings of this thesis show that identification and support for body image issues should be as early as possible to avoid body image issues snowballing and impacting on self-esteem and depression. Patients and their families should be made aware that different feelings could arise around their bodily changes at any time. They should be advised to seek support even after they have been discharged from stroke services. They should be made aware of where and how they can access body image support should they need it. This is particularly important if body image changes begin to impact previously valued activities to the point that they affect mood, or if socialising becomes significantly reduced, and people start to feel lonely or isolated.

Whatever format body image support takes, the financial implications must be considered. This is particularly important for lower income countries that have reduced quality and quantity of stroke rehabilitation (Owolabi et al., 2021). For post-stroke body image support, financial implications could include psychological therapies, but also practical help such as tools or aids. This has implications for costs and emphasises the importance for recognition within policy and resource funding decisions.

Crucially, findings were reviewed by people with stroke and clinicians with relevant expertise in stroke. This gives the results real-world application and provides meaningful and novel insight into the opinions of people affected by stroke. This enhances the trustworthiness of the findings and means that the implications for clinical practice and policy described here are relevant as they have been informed by key stakeholders.

9.4. IMPLICATIONS FOR RESEARCH

Throughout completion of the thesis and after discussing the results with clinical experts, multiple gaps were identified in the evidence base which warrant further research. For adults with stroke, there is insufficient evidence from high quality, large scale and robust studies to:

- Understand body image experiences for people with different types of stroke-related impairments (e.g., people with aphasia and more severe impacts of stroke) and from different demographics (e.g., people from ethnic minority backgrounds)
- Identify people who are at a higher risk of struggling with their body image experience (e.g., those for whom body image experience was particularly important pre-stroke)
- Determining factors for which people with stroke could be screened for to identify increased propensity for body image issues, including pre-stroke body image attitudes
- Determine how best to support people who are struggling with their body image experience (e.g., of the recommendations made by the expert panel group, which would be most effective in ameliorating or preventing negative impacts?), including how to assess any benefits of support
- Understand the effectiveness of different methods to support body image experience
- Estimate the number of people struggling with their body image experience to understand whether it a widespread issue

This evidence for people with stroke is needed to allow clearer understanding of their body image experiences, to identify risk factors for body image issues and to inform body image support approaches. These approaches will also need testing to ensure that they are effective and meaningful for people with stroke and are feasible. Generally, research needs to show greater consideration of transferability and applicability of findings. Qualitative and quantitative studies are required as part of this. Qualitative studies should focus on the following:

- Exploring body image experiences in different subsamples of people with stroke to identify patterns and commonalities across experiences; hone suggestions for support across different groups; and to identify whether any part of the stroke population warrants specific focus in terms of body image experience

- Checking whether people with stroke not involved in developing the current stroke-specific definition of post-stroke body image can relate to it
- Honing and building upon the current stroke-specific summary and definition across different subsamples to enable its use as a method of clearly communicating possible post-stroke body image experiences for people with stroke, their families, carers and healthcare professionals
- Co-developing suggestions with people who had had a stroke for post-stroke body image support and methods of assessing them, which are acceptable for people with stroke

Crucially, qualitative studies need to use rigorous and transparent methods to ensure their quality. They need to report greater detail about the research and analysis undertaken, to include acknowledgement of possible researcher influences and researcher-participant relationships.

Quantitative studies with large sample sizes should be used for the following:

- Validating methods of assessing body image for people with stroke
- Testing the feasibility of different assessment methods for: screening for people with body image issues post-stroke; identifying those at greater risk of having issues; the effectiveness of potential methods to support body image experience; and implementation, including whether these methods could be effectively implemented within the NHS

Greater detail needs to be provided around sampling and confounding factors. Validated measures of body image post-stroke are also required to reduce bias and ensure that findings reflect body image experiences.

9.5. CONCLUSION

This thesis is the first primary research with a sole focus on lived body image experience post-stroke. It has begun the development of evidence to show that people experience a change in their body image after stroke. This changed experience is complex and varies depending on how the stroke has changed the body, individuals' perception of how their body has changed and how this leads to changes in self-identity, including how they are perceived by others and in society. This is largely due to a perceived deviation of their body image from their pre-stroke normal, compounded by societal pressures to be 'normal'.

The clinical experts involved in this thesis identified the key findings and stroke-specific definition as being relevant and meaningful. Subsequently, discussions then supported a need for a method of identifying people with stroke who are struggling with their post-stroke body image experience. They also pointed out that body image is not considered as part of stroke rehabilitation, which is emphasised by its lack of consideration in stroke clinical guidelines. This has utility for highlighting body image experience as an unmet need within stroke rehabilitation, improving provision of support and to prevent issues becoming more serious and impacting recovery. This links to key concepts in post-stroke recovery, including practical support provision; and in psychology, including possible psychological support options. Health and social care professionals require training to be able to identify, signpost and support post-stroke body image changes.

Ultimately, post-stroke body image experience is an important and impactful aspect of post-stroke recovery and wellbeing. The evidence presented through this thesis contributes towards understanding post-stroke body image experience, how body image issues could be identified post-stroke, and how any identified issues might be supported.

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V APPENDICES

Appendix 1: PRESS Peer Review Assessment of the Systematic Review Strategy

PRESS – Search submission & Peer Review Assessment (McGowan et al., 2016)

SEARCH SUBMISSION: THIS SECTION TO BE FILLED IN BY THE SEARCHER

Name of searcher: Catherine Davidson	**E-mail: cdavidson4@uclan.ac.uk**
Date submitted: 08.09.20	**Date needed by: ASAP**

Note to peer reviewers – please enter your information in the Peer Review Assessment area

Systematic review title:

Body image perception in adults who have had a stroke

This search strategy is …

X	My PRIMARY (core) database strategy – First time submitting a strategy for search question and database
	My PRIMARY (core) strategy– Follow-up Review NOT the first time submitting a strategy for search question and database. If this is a response to peer review, itemize the changes made to
	SECONDARY search strategy – First time submitting a strategy for search question and database
	SECONDARY search strategy – NOT the first time submitting a strategy for search question and database. If this is a response to peer review, itemize the changes made to the review suggestions.

Database & Interface

(i.e. Ovid MEDLINE, EBSCO CINAHL…): *[mandatory]*

Ovid Medline, EMBASE, EBSCO CINAHL, EBSCO PsycInfo, and the Cochrane Library

Research question

(Describe the purpose of the search) *[mandatory]*

The search will address the following research questions:

1. What is the frequency of negative body image perception after stroke?
2. How do adults who have had a stroke perceive their body image after their stroke and what is the impact of negative body image perceptions on stroke recovery?
3. What tools are available or have been validated to assess body image in adults who have had a stroke?

PICOS format

Research Question 1

(Outline the PICOS for your question, i.e., Patient, Intervention, Comparison, Outcome, and Study Design, as applicable)

P	Adults who have had a stroke

I	N/A
C	N/A
O	Frequency of negative body image perception after stroke
S	Any study design using qualitative, quantitative or mixed methods

Research Question 2

(Outline the PICOS for your question, i.e., Patient, Intervention, Comparison, Outcome, and Study Design, as applicable)

P	Adults who have had a stroke
I	N/A
C	N/A
O	Body image perceptions and their impact on stroke recovery
S	Any study design using qualitative, quantitative or mixed methods

Research Question 3

(Outline the PICOS for your question, i.e., Patient, Intervention, Comparison, Outcome, and Study Design, as applicable)

P	Adults who have had a stroke
I	N/A
C	N/A
O	Tools for assessing body image
S	Any study design using qualitative, quantitative or mixed methods

Inclusion criteria

(List criteria such as age groups, study designs, etc. to be included) *[optional]*

- One of the aims or objectives, methods, results, or conclusions of the paper relates to body image
- Clinical diagnosis of stroke as defined by the author of the paper
- Participants aged 18 years of age or older
- Primary research
- Quantitative or qualitative methods
- Any study setting/context
- Any timeframe since stroke
- Any publication year
- Any language
- Published paper

Exclusion criteria

(List criteria such as study designs, date limits, etc. to be excluded *[optional]*

- Subarachnoid haemorrhage
- Grey Literature
- Reviews
- Commentaries
- Discussion papers
- Study protocols

Was a search filter applied?

☒ ☐

NO YES

If YES, which one(s)? (e.g., Cochrane RCT filter, PubMed Clinical Queries filter) Provide the source if this is a published filter *[mandatory if YES to previous question]*

Other notes or comments (that might be useful for the peer reviewer)? *[optional]*

I have attached the Medline version of my search strategy.

Since running my searches in in April 2020, I have run updated searches using the same strategy, but with limits on publication dates to capture only the most recent publications. I then combined these updated results with my EndNote file of results from April in preparation for screening.

Please 'copy and paste' your search strategy below
(exactly as run, including the number of hits per line) *[mandatory]*

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to April 13, 2020>
Search Strategy:
----
1 stroke/ (99193)
2 stroke.mp. (286695)
3 cerebrovascular accident*.mp. (6957)
4 cva*.mp. (4536)
5 acquired brain injur*.mp. (2149)
6 abi.mp. (6707)
7 Cerebrovascular Disorders/ (46241)
8 (stroke or cerebrovasc* or brain vasc* or cerebral vasc* or cva* or apoplex*).tw. (286428)
9 ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal gangli*) adj5 (isch?emi* or infarct* or thrombo* or emboli*)).tw. (102386)
10 ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli*) adj5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)).tw. (56257)
11 (poststroke or post stroke).mp. (13944)
12 body image/ (17215)
13 bod* imag*.af. (30047)
14 self imag*.mp. (3858)
15 self concept*.mp. (57898)
16 (self adj3 perce*).mp. (20798)
17 (bod* adj4 satisf*).mp. (1928)
18 (bod* adj4 dissatisf*).mp. (3422)
19 self understanding.mp. (399)
20 (bod* adj4 experience*).mp. (3738)
21 bod* awareness.mp. (679)
22 bod* appraisal.mp. (5)
23 bod* representation.mp. (617)
24 identity.ab,ti. (134797)
25 dysmorph*.mp. (15043)
26 bod* schem*.mp. (647)
27 bod* scheduling.mp. (0)
28 (Self esteem and (bod* or imag* or appearance* or looks or attractive*)).mp. (4476)
29 (bod* adj4 positiv*).mp. (8782)
30 (bod* adj4 negativ*).mp. (7270)

31 self representation.mp. (389)
32 (bod* adj4 concept*).mp. (1616)
33 sense of self.mp. (2550)
34 (bod* adj4 perce*).mp. (22794)
35 (lived adj4 bod*).mp. (311)
36 embod*.mp. (11674)
37 disembod*.mp. (280)
38 misembod*.mp. (1)
39 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (455766)
40 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (295690)
41 39 and 40 (2441)

****

PEER REVIEW ASSESSMENT: THIS SECTION TO BE FILLED IN BY THE REVIEWER

Statement of Confidentiality

I agree to hold all information contained in this worksheet and submission form as confidential and understand that materials may not be shared outside PRESSforum or used for any competing purpose without the written permission of the librarian who submitted the search for peer review.

Type “yes” to indicate agreement): _______yes__

Peer reviewer’s name: Cath Harris

E-mail: charris10@uclan.ac.uk

Date completed: 08/09/2020

1.1 Please select the one most appropriate answer for each element

	No revisions	**Revision(s) suggested**	**Revision(s) required**
1. Translation of research question	x		
2. Boolean & proximity operators		x	
3. Subject headings	x		
4. Text word searching	x		
5. Spelling, syntax & line numbers	x		
6. Limits and filters	x		
Overall evaluation*	x		

** If one or more “revision(s) required” is noted above, overall evaluation must be “revision(s) required”*

2. My understanding is the stroke part of the strategy has been derived from the Cochrane Stroke Strategy. There is a new Cochrane stroke strategy which has just been published in 2020 – this uses the proximity operators with adj3 instead of adj5 as was used previously. Therefore, in lines 9 and 10 **adj3** may make the search more precise.

Additional comments:

If the terms for ‘stroke’ were adapted from the Cochrane Stroke Strategy, it is probably necessary to cite it in the write-up.

Translation of the research question

- Does the search strategy match the research question/PICO? – *yes. The search is formatted according to the PICO*
- Are the search concepts clear? – *yes*

• Are there too many or too few PICO elements included? *No, given there are three questions to be answered the right number of elements have been included to retrieve relevant papers.*

• Are the search concepts too narrow or too broad? *No, the concepts in the search are accurate and reflect the research question. Both the concepts of 'stroke' and 'body image' are well-defined/clear.*

• Does the search retrieve too many or too few records? (Please show number of hits per line.) *No*

• Are unconventional or complex strategies explained? – *the strategy is straightforward using a balance of MesH terms and free text searches.*

Boolean and proximity operators (these vary based on search service)

• Are Boolean or proximity operators used correctly? *Yes*

• Is the use of nesting with brackets appropriate and effective for the search? *Yes*

• If NOT is used, is this likely to result in any unintended exclusions? *N/A*

• Could precision be improved by using proximity operators (eg, adjacent, near, within) or phrase searching instead of AND? *no*

• Is the width of proximity operators suitable (eg, might adj5 pick up more variants than adj2)? *My understanding is the stroke part of the strategy has been derived from the Cochrane Stroke Strategy. There is a new Cochrane stroke strategy which has just been published in 2020 – this uses the proximity operators with adj3 instead of adj5 as was used previously. Therefore, in lines 9 and 10 adj3 may make the search more precise.*

Subject headings (database specific)

• Are the subject headings relevant? *Yes*

• Are any relevant subject headings missing; for example, previous index terms? *No*

• Are any subject headings too broad or too narrow? *No*

• Are subject headings exploded where necessary and vice versa? *Subject headings are used appropriately*

• Are major headings ("starring" or restrict to focus) used? If so, is there adequate justification? *Not used*

• Are subheadings missing? *No*

• Are subheadings attached to subject headings? (Floating subheadings may be preferred.) *Not used*

• Are floating subheadings relevant and used appropriately? *Not used*

• Are both subject headings and terms in free text (see the following) used for each concept? *Yes*

Text word searching (free text)

• Does the search include all spelling variants in free text (eg, UK vs. US spelling)? *Yes*

- Does the search include all synonyms or antonyms (eg, opposites)? *Yes*

- Does the search capture relevant truncation (ie, is truncation at the correct place)? *Yes*

- Is the truncation too broad or too narrow? *It is possible that bod* might be too broad and may pick up irrelevant terms. However, given the context and use with proximity operators this is maybe unlikely. If a lot of irrelevant results are returned it could be worth testing (body or bodi*) instead to see if this helps make the search more precise?*

- Are acronyms or abbreviations used appropriately? Do they capture irrelevant material? Are the full terms also included? *They are used appropriately, and the full terms are also included.*

- Are the keywords specific enough or too broad? Are too many or too few keywords used? Are stop words used? *'Of' is a stop word and has been used in line 33 – however, I do not think this will affect the search.*

- Have the appropriate fields been searched; for example, is the choice of the text word fields (.tw.) or all fields (.af.) appropriate? Are there any other fields to be included or excluded (database specific)? *Fields have been searched appropriately*

- Should any long strings be broken into several shorter search statements? *No*

Spelling, syntax, and line numbers

- Are there any spelling errors? *No*

- Are there any errors in system syntax; for example, the use of a truncation symbol from a different search interface? *No*

- Are there incorrect line combinations or orphan lines (ie, lines that are not referred to in the final summation that could indicate an error in an AND or OR statement)? *No*

Limits and filters

- Are all limits and filters used appropriately and are they relevant given the research question? *No limits or filters are used*

- Are all limits and filters used appropriately and are they relevant for the database? *N/A*

- Are any potentially helpful limits or filters missing? Are the limits or filters too broad or too narrow? Can any limits or filters be added or taken away? *No*

- Are sources cited for the filters used? *N/A- but may need to cite the Cochrane Stroke Strategy if used.*

Appendix 2: Systematic Review Search Strategies

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to September 01, 2020>
Search Strategy:
----
1 stroke/ (102374)
2 stroke.mp. (295621)
3 cerebrovascular accident*.mp. (7116)
4 cva*.mp. (4699)
5 acquired brain injur*.mp. (2251)
6 abi.mp. (6919)
7 Cerebrovascular Disorders/ (46443)
8 (stroke or cerebrovasc* or brain vasc* or cerebral vasc* or cva* or apoplex*).tw. (295080)
9 ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal gangli*) adj5 (isch?emi* or infarct* or thrombo* or emboli*)).tw. (104542)
10 ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli*) adj5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)).tw. (57713)
11 (poststroke or post stroke).mp. (14554)
12 body image/ (17410)
13 bod* imag*.af. (30845)
14 self imag*.mp. (3946)
15 self concept*.mp. (58696)
16 (self adj3 perce*).mp. (21649)
17 (bod* adj4 satisf*).mp. (1990)
18 (bod* adj4 dissatisf*).mp. (3527)
19 self understanding.mp. (409)
20 (bod* adj4 experience*).mp. (3850)
21 bod* awareness.mp. (713)
22 bod* appraisal.mp. (5)
23 bod* representation.mp. (640)
24 identity.ab,ti. (138099)
25 dysmorph*.mp. (15396)
26 bod* schem*.mp. (655)
27 bod* scheduling.mp. (0)
28 (Self esteem and (bod* or imag* or appearance* or looks or attractive*)).mp. (4609)
29 (bod* adj4 positiv*).mp. (9019)
30 (bod* adj4 negativ*).mp. (7420)
31 self representation.mp. (400)
32 (bod* adj4 concept*).mp. (1652)
33 sense of self.mp. (2633)
34 (bod* adj4 perce*).mp. (23420)
35 (lived adj4 bod*).mp. (323)
36 embod*.mp. (12144)
37 disembod*.mp. (297)
38 misembod*.mp. (1)
39 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (467829)
40 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (302996)
41 39 and 40 (2510)
42 limit 41 to yr="2019 - 2020" (276)

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Database: Embase <1974 to 2020 September 01>
Search Strategy:
--------------------------------------------------------------------------------
1     stroke/ (145454)
2     stroke.mp. (450006)
3     cerebrovascular accident*.mp. (212667)
4     cva*.mp. (9704)
5     acquired brain injur*.mp. (3972)
6     abi.mp. (15604)
7     Cerebrovascular Disorders/ (29373)
8     (stroke or cerebrovasc* or brain vasc* or cerebral vasc* or cva* or apoplex*).tw. (460857)
9     ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or
infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal gangli*)
adj5 (isch?emi* or infarct* or thrombo* or emboli*)).tw. (148192)
10     ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or
infratentorial or supratentorial or basal gangli*) adj5 (haemorrhage* or hemorrhage* or haematoma*
or hematoma* or bleed*)).tw. (84794)
11     (poststroke or post stroke).mp. (24382)
12     body image/ (22152)
13     bod* imag*.af. (31536)
14     self imag*.mp. (5019)
15     self concept*.mp. (91776)
16     (self adj3 perce*).mp. (26631)
17     (bod* adj4 satisf*).mp. (2562)
18     (bod* adj4 dissatisf*).mp. (4334)
19     self understanding.mp. (498)
20     (bod* adj4 experience*).mp. (5088)
21     bod* awareness.mp. (1039)
22     bod* appraisal.mp. (6)
23     bod* representation.mp. (778)
24     identity.ab,ti. (152603)
25     dysmorph*.mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate
term word] (26252)
26     bod* schem*.mp. (943)
27     bod* scheduling.mp. (0)
28     (Self esteem and (bod* or imag* or appearance* or looks or attractive*)).mp. (8124)
29     (bod* adj4 positiv*).mp. (11480)
30     (bod* adj4 negativ*).mp. (9492)
31     self representation.mp. (493)
32     (bod* adj4 concept*).mp. (2036)
33     sense of self.mp. (3359)
34     (bod* adj4 perce*).mp. (30995)
35     (lived adj4 bod*).mp. (390)
36     embod*.mp. (13685)
37     disembod*.mp. (353)
38     misembod*.mp. (1)
39     1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (714857)
40     12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (379213)
41     39 and 40 (4604)
42     limit 41 to yr="2019 - 2020" (529)

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Database: CINAHL <2020 September 02>
Search strategy:

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1. (MH “Stroke”) (69,717)
2. Stroke (120,074)
3. “cerebrovascular accident*” (1,710)
4. cva* (1,315)
5. “acquired brain injur*” (1,957)
6. abi (2,046)
7. (MH “Cerebrovascular Disorders”) (7,043)
8. cerebrovasc* or “brain vasc*” or “cerebral vasc*” or apoplex* (24,747)
9. ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or “anterior circulation” or “posterior circulation” or “basal gangli*”) N5 (isch?emi* or infarct* or thrombo* or emboli*)). (14,175)
10. ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial lor supratentorial or “basal gangli*”) N5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)) (18,240)
11. “poststroke” or “post stroke” (7,571)
12. (MH “Body Image”) (11,477)
13. “bod* imag*” (13,698)
14. “self imag*” (1,740)
15. “self concept*” (33,003)
16. (self N3 perce*) (14,005)
17. (bod* N4 satisf*) (1,137)
18. (bod* N4 dissatisf*) (2,256)
19. “self understanding” (292)
20. (bod* N4 experience*) (2,167)
21. “bod* awareness” (472)
22. “bod* appraisal” (2)
23. “bod* representation” (63)
24. AB (identity) or TI (identity) (27,404)
25. dysmorph* (2,126)
26. “bod* schem*” (166)
27. “bod* scheduling” (0)
28. “self esteem” and (bod* or imag* or appearance* or looks or attractive*) (2, 808)
29. (bod* N4 positiv*) (2,515)
30. (bod* N4 negativ*) (2,034)
31. “self representation” (105)
32. (bod* N4 concept*) (809)
33. “sense of self” (1,812)
34. (bod* N4 perce*) (9,307)
35. (lived N4 bod*) (223)
36. embod* (4,314)
37. disembod* (114)
38. misembod* (1)
39. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 (155,209)
40. 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 (99,325)
41. 39 AND 40 *(limited to: 01/01/2019-31/09/2020)* (134)

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Database: PsycINFO <2020 September 02>
Search strategy:
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1 (DE “Cerebrovascular Accidents”) (21,054)
2 Stroke (39,804)
3 “cerebrovascular accident*” (21,370)
4 cva* (913)
5 “acquired brain injur*” (2,242)
6 abi (1,679)
7 (DE “Cerebrovascular Disorders”) (4,774)
8 cerebrovasc* or “brain vasc*” or “cerebral vasc*” or apoplex* (33,251)
9 ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or “anterior circulation” or “posterior circulation” or “basal gangli*”) N5 (isch?emi* or infarct* or thrombo* or emboli*)) (8,272)
10 ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial lor supratentorial or “basal gangli*”) N5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)) (5,626)
11 “poststroke” or “post stroke” (4,976)
12 DE “Body Image” (16,345)
13 DE “Body Image Disturbances” (1,848)
14 “bod* imag*” (21,831)
15 “self imag*” (6,507)
16 “self concept*” (79,600)
17 (self N3 perce*) (50,518)
18 (bod* N4 satisf*) (2,587)
19 (bod* N4 dissatisf*) (5,040)
20 “self understanding” (2,012)
21 (bod* N4 experience*) (5,771)
22 “bod* awareness” (2,474)
23 “bod* appraisal” (7)
24 “bod* representation” (605)
25 AB (identity) or TI (identity) (120,635)
26 dysmorph* (2,992)
27 “bod* schem*” (762)
28 “bod* scheduling” (0)
29 “Self esteem” and (bod* or imag* or appearance* or looks or attractive*) (7,912)
30 (bod* N4 positiv*) (2,752)
31 (bod* N4 negativ*) (2,840)
32 “self representation” (1,281)
33 (bod* N4 concept*) (2,687)
34 “sense of self” (7,858)
35 (bod* N4 perce*) (8,505)
36 (lived N4 bod*) (500)
37 embod* (22,812)
38 disembod* (735)
39 misembod* (1)
40 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 (60,179)
41 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 (283,818)
42 40 AND 41 *(limited to: 01/01/2019-31/09/2020)* (108)

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Database: Cochrane <2020 September 02> (Limits: Jan 2019- Sep 2020)
Search strategy:

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1 MeSH descriptor. [Stroke] explode all trees (9629)
2 (stoke) (68100)
3 (cerebrovascular NEXT accident*) (12652)
4 (cva*) (1136)
5 ((“acquired brain”) NEXT injur*) (505)
6 (abi) (1451)
7 MeSH descriptor. [Cerebrovascular Disorders] explode all trees (15003)
8 (cerebrovasc* or (brain NEXT vasc*) or (cerebral NEXT vasc*) or apoplex*) (23589)
9 ((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher * or intracran* or intracerebral or infratentorial or supratentorial or MCA or “anterior circulation” or “posterior circulation” or (basal NEXT gangli*)) near/5 (isch?emi* or infarct* or thrombo* or emboli*)) (15031)
10 ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or (basal NEXT gangli*)) near/5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)) (10965)
11 (“poststroke” or “post stroke”) (5744)
12 MeSH descriptor. [Body Image] explode all trees (675)
13 (bod* NEXT imag*) (2158)
14 (self NEXT imag*) (333)
15 (self NEXT concept*) (6740)
16 (self near/3 perce*) (3484)
17 (bod* near/4 satisf*) (372)
18 (bod* near/4 dissatisf*) (435)
19 (“self understanding”) (27)
20 (bod* near/4 experience*) (348)
21 (bod* NEXT awareness) (274)
22 (bod* NEXT appraisal) (1)
23 (bod* NEXT representation) (21)
24 (identity:ab,ti) (1819)
25 (dysmorph*) (341)
26 (bod* NEXT schem*) (25)
27 (bod* NEXT scheduling) (0)
28 (“self esteem” and (bod* or imag*or appearance* or looks or attractive*)) (1226)
29 (bod* near/4 positiv*) (848)
30 (bod* near/4 negativ*) (797)
31 (“self representation”) (10)
32 (bod* near/4 concept*) (168)
33 (”sense of self”) (187)
34 (bod* near/4 perce*) (4280)
35 (lived near/4 bod*) (5)
36 (embod*) (282)
37 (disembod*) (10)
38 (misembod*) (0)
39 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR9 OR 10 OR 11 (85267)
40 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 (20320)
41 39 AND 40 (220)

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Appendix 3: Syntax Terms Used in Final Search Strategy of the Systematic Review, With Rationale

Syntax (Cochrane Effective Practice and Organisation of Care (EPOC), 2017)	Rationale (Cochrane Effective Practice and Organisation of Care (EPOC), 2017)
/	Subject heading; used for the overarching terms of ‘stroke’, ‘cerebrovascular disorders’ and ‘body image’
.mp	Title, abstract and subject heading; used for the majority of relevant additional terms to identify studies
*	Truncation to add more characters; e.g. bod* imag* would identify body image/s, bodily image etc.
.tw OR .ab, ti	Word in title or abstract; a focussed search for the word as a pertinent term in the paper
adj*n*	A word with n words inbetween; to capture versions of relevant terms that may be otherwise missed e.g., ‘bod* adj4 satisf*’ would allow for ‘satisfaction with the body’
?	Wildcard (to be any letter); to allow for variances in spelling e.g., ‘isch?emi*’ would identify: ischaemic, ischemic
.af (National Library of Medicine, 2022)	All searchable fields (National Library of Medicine, 2022); used as a broad search for body image

Appendix 4: Grey Literature Search Strategy, Search Dates and Number of Hits

Platform	Search Strategies	Last Searched	Number of Hits
Ask Doris	1. "stroke" and "body image" 2. "abi" and "body image" 3. "acquired brain injury" and "body image” 4. "cerebrovascular" and "body image"	13/01/2021	3
Ethos		13/01/2021	4
Google		12/04/2021 & 12/05/2021	First 100 search results
NICE (NHS) Evidence Search		13/01/2021	121
OpenAccess theses and dissertations		13/01/2021	15
OpenGrey		13/01/2021	1
OTSeeker Database for Occupational Therapy Research		13/01/2021	1
The King’s Fund		13/01/2021	0
ProQuest Dissertation & Theses Global	1. “stroke” in the document title and “body image” anywhere* 2. “abi” in the document title and “body image” anywhere 3. “acquired brain injury” in the document title and “body image” anywhere	13/01/2021	90

4. “cerebrovascular” in the document title and
“body image” anywhere

Appendix 5: Papers where Assessment is Ongoing

First Author(s) & Year	Title	Reason for assessment ongoing
Author contact attempted & response received from author(s)		
Soumya et al. (2019)	Effectiveness of Graded Motor Imagery (GMI) on upper limb motor function in patients with subacute stroke	Full-text unavailable: findings not available from abstract, therefore data could not be extracted
Turton (2014)	Body perception after stroke and its impact on everyday living.	Full-text unavailable: insufficient information in abstract to determine inclusion
Author contact attempted & no response received from author(s)		
Howes et al. (2005b)	Female body image following acquired brain injury.	Full-text screened: need results specific to stroke to consider inclusion
Kuvalekar et al. (2015)	Quality of Life among Persons with Physical Disability in Udupi Taluk: A Cross Sectional Study.	Full-text screened: need results specific to stroke to consider inclusion
Langer (1994)	Depression in disabling illness: severity and patterns of self-reported symptoms in three groups.	Full-text screened: need results specific to body image to consider inclusion
Lovo (2001)	*Adaptação e aplicação de questionários de imagem corporal em portadores de hemiplegia* [Adaptation and application of image questionnaires body in patients with hemiplegia]	Full-text nor abstract could not be located: could not be screened

Medvedev (2018a, 2018b)	The image of the physical "I" in people with disabilities with hemi paresis as a result of hemorrhagic stroke Correction of the image of the physical "I" in people with disabilities with hemiparesis who underwent a hemorrhagic stroke	Full-text screened: need results specific to body image and how it was measured to consider inclusion
Nasr et al. (2015)	The experience of living with stroke to inform self-management interventions: A qualitative study.	Full-text could not be located: findings unavailable from abstract, therefore data could not be extracted
Riani et al. (2015)	Imagem e esquema corporal de hemiparéticos por lesão encefálica direita devido a acidente vascular encefálico e traumatismo crânio-encefálico [Image and body scheme of hemiparetics due to right brain injury due to accident and traumatic brain injury]. HU Revista, 41 (1 and 2), 33-40.	Full-text screened: need results specific to stroke to consider inclusion
Rintala et al. (1997)	Dating issues for women with physical disabilities	Full-text screened: need results specific to stroke to consider inclusion
Santos et al. (2013)	Functional capacity and quality of life of elderly people with a history of stroke. [Capacidade funcional e qualidade de vida de idosos com historico de acidente vascular encefalico.]	Full-text screened: need results specific to body image to consider inclusion

Author contact not possible		
Kuswanto et al. (NR)	Enhancement of body image through guided imagery in stroke patients	Contact, abstract nor full-text could be located: could not be screened for eligibility
Leal and Knopp (2010)	*Um olhar à esquerda: análise da perceção da imagem e do esquema corporal em indivíduos com lesão hemisférica direita* [A left look :analysis of the perception of body image and scheme in individuals with hemispherical lesion right]	Contact, abstract nor full-text could be located: could not be screened for eligibility
Schwab and Harmeling (1968)	Body image and medical illness.	Contact could not be located. Full-text screened: need results specific to stroke to consider inclusion
Soumya et al. (2016)	Lived experiences of cerebro vascular accident (CVA) patients from selected physiotherapy units of Calicut, Kerala.	Contact nor full-text could be located. Abstract located but insufficient detail to determine eligibility.
Sousa et al. (2012)	Post-stroke abnormal eating behaviors.	Contact nor paper could be located. Abstract located but insufficient detail to determine eligibility.
矢野昌子 (2007)	脳血管障害患者のボディィイメージの表現に関する文献研究[Expression of body image in patients with cerebrovascular disorders Literature research.]	Contact, abstract nor full-text could be located: could not be screened for eligibility

Appendix 6: Table of All Included Papers from the Systematic Review, Whether the Term 'Body Image' Is Used and Defined, and Rationale for Inclusion

References: First author(s) (year)	Title	Term 'body image' used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
	Qualitative		
Arntzen and Elstad (2013)	The bodily experience of apraxia in everyday activities: a phenomenological study	☹	Lived experiences
Arntzen et al. (2015a)	Long-term recovery trajectory after stroke: an ongoing negotiation between body, participation and self	☹	Impacts
Arntzen et al. (2015b)	Body, participation and self transformations during and after inpatient stroke rehabilitation	☹	Impacts
Atkinson et al. (2012) (Abstract)	A comparison of clinician and patient views on symptoms and impact of post-stroke spasticity	☹	Impacts
Backe et al. (1996)	Patients' conceptions of their life situation within the first week after a stroke event: a qualitative analysis	😐: NR	Lived experiences
Bergström et al. (2014); Bergström et al. (2015)	Complex negotiations: The lived experience of enacting agency after a stroke	☹	Lived experiences
Boylstein (2002)	Medical knowledge and functional assessment in the everyday lives of stroke survivors	😐: NR	Lived experiences

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Carlsson et al. (2004)	A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in person < 75 years	☹	Impacts
Carlsson et al. (2018)	Upper-limb sensory impairments after stroke: self-reported experiences of daily life and rehabilitation	☹	Impacts
Ch'ng et al. (2008)	Coping with the Challenges of Recovery from Stroke: Long Term Perspectives of Stroke Support Group Members	😐: NR	Lived experiences
Crowfoot (2016a); Crowfoot (2016b)	Unlocking the puzzle: a narrative inquiry into the experiences of people with transient ischaemic attack or minor stroke	☹	Lived experiences
de Guzman et al. (2012)	Self-Concept, Disposition, and Resilience of Poststroke Filipino Elderly with Residual Paralysis	😐: NR	Lived experiences
Doolittle (1990, 1991, 1992)	Clinical ethnography of lacunar stroke: implications for acute care	☹	Lived experiences
Doyle et al. (2014)	Upper limb post-stroke sensory impairments: the survivor’s experience	☹	Impacts
Eilertsen (2005); Eilertsen et al. (2010)	Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women	☹	Lived experiences

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Erikson et al. (2016)	Living with the long-term consequences 11-13 years after stroke: A phenomenological study	☹	Lived experiences
Faircloth et al. (2004)	Disrupted Bodies: Experiencing the Newly Limited Body in Stroke	☹	Impacts
Girardon-Perlini et al. (2007)	Dealing with losses: the perception of disabled patients after stroke	☹	Lived experiences
Gorst et al. (2016)	Foot and ankle impairments affect balance and mobility in stroke (FAiMiS): the views and experiences of people with stroke	☹	Impacts
Immenschuh (2003)	“My arm and leg- they are just sleeping” Perspectives of younger people on their experience of having a stroke	☹	Impacts
Kinoda (2008), Translated by RK from Japanese	Qualitative Research into the Body Image of Hemiplegic Stroke Patients	☺: “Conscious representation of the body" (Henry Head, adopts the concept proposed by Gordon Holmes (references not provided) (Kinoda, 2008, pg. 98)	Specifies body image & definition aligns with thesis definition: impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Kitzmuller et al. (2013)	Living an unfamiliar body: The significance of the long-term influence of bodily changes on the perception of self after stroke	😐: NR	Impacts
Kuluski et al. (2014)	Life interrupted and life regained? Coping with stroke at a young age	☹	Impacts
Kvigne and Kirkevold (2003)	Living with bodily strangeness: Women's experiences of their changing and unpredictable body following a stroke.	☹	Lived experiences
Kvigne et al. (2004)	Fighting back- struggling to continue life and preserve the self following a stroke	☹	Lived experiences
Lawrence and Kinn (2012)	Determining the Needs, Priorities, and Desired Rehabilitation Outcomes of Young Adults Who Have Had a Stroke	😐: NR	Lived experiences
Leahy et al. (2010); Leahy et al. (2016)	Stroke in young women: An interpretative phenomenological analysis	😐: NR	Lived experiences
Lever and Pryor (2015, 2017)	The impact of stroke on female sexuality	☹	Impacts
Meijering et al. (2016)	Home-making after stroke. A qualitative study among Dutch stroke survivors	☹	Impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Moorley and Cahill (2018)	Experiences of African-Caribbean women of their body after stroke	☹	Impacts
Murray and Harrison (2004)	The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis	☹	Impacts
Nanninga et al. (2015)	Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine	☹	Lived experiences
Nanninga et al. (2018)	Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors	☹	Impacts
Nasr et al. (2016)	Exploring the Experiences of Living With Stroke Through Narrative: Stroke Survivors' Perspectives	😐: “Body image is the core aspect of identity and “acts as a standard that influences not only the way we think of ourselves, but also our ability to perform various activities and the goals we set for the future”	Impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
		(Chrisler & Ghiz, 1993, p. 68) (Chrisler & Ghiz, 1993)”	
Norris et al. (2010)	"I feel like half my body is clogged up": Lay models of stroke in Central Aceh, Indonesia	☹	Lived experiences
Pallesen (2012, 2014)	Body, coping and self-identity. A qualitative 5-year follow-up study of stroke	☹	Impacts
Pedersen et al. (2019a); Pedersen et al. (2019b)	Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis	☹	Impacts
Purton et al. (2015); Purton et al. (2020)	The experience of upper-limb dysfunction after stroke: a phenomenological study	☹	Impacts
Raghavan et al. (2016)	Music Upper Limb Therapy—Integrated: An enriched collaborative approach for stroke rehabilitation	☹	Impacts
Rittman et al. (2004)	The experience of time in the transition from hospital to home following stroke	☹	Impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Rittman et al. (2007)	Transition Experiences of Stroke Survivors Following Discharge Home	😐: NR	Impacts
Stott (2019); Stott et al. (2018a, 2018b, 2021) (Dissertation: 2019)	2019: Embodiment, altered perception and comfort after stroke 2021: ‘Somebody stuck me in a bag of sand’: Lived experiences of the altered and uncomfortable body after stroke	😐: 2019: the beliefs and attitudes held about the body, comprised of perceptual experience, conceptual understanding & emotional attitude towards the body (Gallagher & Zahavi, 2008) 2021: thoughts about the body (Stott, 2019)	Impacts
Taule and Råheim (2014); Taule et al. (2013)	Life changed existentially: a qualitative study of experiences at 6–8 months after mild stroke	☹	Impacts
Timothy et al. (2014); Timothy et al. (2016)	Transitions in the Embodied Experience After Stroke: Grounded Theory Study	☹	Lived experiences

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Wyller and Kirkevold (1999)	How does a cerebral stroke affect quality of life? Towards an adequate theoretical account	☹	Impacts
Yamauchi (2007)	Bodily Experiences of Patients with Stroke complicating Unilateral Limb Weakness as Viewed through Nursing -Focusing on the 6 Weeks Since Symptoms Onset	😐: NR	Lived experiences
Yuki (2008)	The building of future self-body image by stroke survivors	☺: NR	Specifies body image: lived experiences
Quantitative			
Barak et al. (1999)	Perception of Body Esteem Following Stroke	😐$^{\sim}$: “…the picture of our body that we form in our mind. It represents the way in which the body appears to us” (Barak, 1999, p.1) (Barak et al., 1999; Barak, 1994)	Specifies body esteem: impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Braga (2012) (Dissertation)	Percepção da imagem corporal de adultos após acidente Vascular encefálico: uma abordagem psicofísica *[Translation from Portuguese:* Perception of adult body image after stroke: a psychophysical approach]	☺: The body has two dimensions: - Perceptual: recognition of body shape & size - Attitudinal: feelings & beliefs about the body Body dissatisfaction: negative feelings around appearance & the body) (Cash, 2002a) & greatly affects body image (Braga, 2012)	Specifies body image: lived experiences
Brinkmann and Hoskins (1979) (Journal article)	Physical conditioning and altered self-concept in rehabilitated hemiplegic patients	😐: “… a person's concept of his physical being, or body.” (no reference provided), (Brinkmann & Hoskins, p. 859)	Lived experiences

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
		(Brinkmann & Hoskins, 1979)	
Goodyear (1978) (Dissertation)	The measurement of body image in stroke patients	☺: Self-reported positive & negative feelings towards body parts & functions (not referenced) (Goodyear, 1978, pg. 5) (Goodyear, 1978)	Specifies body image: lived experiences
Keppel and Crowe (2000)	Changes to Body Image and Self-esteem following Stroke in Young Adults	☺: Subjective view held of the body in terms of physical appearance (Reber, 1985; Roid & Fitts, 1994)	Specifies body image: impacts
Li et al. (2001)	Longitudinal Study of Quality of Life Following Stroke	😐: NR	Impacts
Lourenço (2012) (Dissertation)	Impacto da percepção daimagem corporal após acidente vascular cerebral no desenvolvimento de depressão	😐^**:** Translated: a multidimensional construct resulting from a continuous	Specifies body image: impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
	[*Translation from Portuguese*: Impact of body image perception after stroke on the development of depression]	and dynamic process throughout peoples’ lives. (Alves & Duarte, 2010; Barros, 2005; Furnham et al., 2002; Morgado et al., 2009)	
McMillan et al. (2005)	Oral health-related quality of life of stroke survivors on discharge from hospital after rehabilitation	☹	Impacts
Picado et al. (2019); Picado (2018) (Dissertation) Translated via Google translate from Portugese	Perceção da Imagem Corporal e Esquema Corporal em pacientes pós-Acidente Vascular Cerebral [*Translation:* Perception of body image and body schema in patients after stroke]	☺: *Translated*: a person’s view of themselves in identifying the characteristics of their body, which is influenced by life history, cultural & psychosocial factors” (Riani et al., 2015)	Specifies body image: impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Sadanandan et al. (2020)	Body Cathexis among Stroke Survivors: A Cross-Sectional Study	😐*: Body cathexis (degree of satisfaction or dissatisfaction felt towards parts & aspects of the body) (Jourard & Secord, 1955) is a measure of perceived body image & a component of self-concept (Sadanandan et al., 2020)	Specifies body cathexis: lived experiences
		Mixed methods	
Barker (2013)	Development of a self-report scale of spasticity	☹	Impacts
Bronken et al. (2012)	Psychosocial well-being in persons with aphasia participating in a nursing intervention after stroke	☹	Impacts
Ellis-Hill (1998); Ellis-Hill et al. (2000) (Dissertation: 1998)	1998: New world, new rules; life narratives and changes in self-concept in the first year after stroke 2000: Self-body split: issues of identity in physical recovery following a stroke	😐: NR	Impacts

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title
Howes (2004); Howes et al. (2005a)	2004: The body and the self following acquired brain injury 2005: Male body image following acquired brain injury	☺: 2004: the picture held of the size, shape & form of our bodies & our feelings about them (Slade, 1994) 2005: the subjective view of the body, state of health, physical appearance, skills or sexuality (Roid & Fitts, 1994). Part of self-concept.	Impacts

Key:

^ referred to as body esteem; ~ talks about body esteem as an important component of body image; * Looks at body cathexis, as a concept of body satisfaction and a measure of perceived body image

☺ = term ‘body image’ used in primary aim; 😐 = term ‘body image’ used somewhere in report, but not in primary aim; ☹ = term ‘body image’ not used

References: First author(s) (year)	Title	Term ‘body image’ used? (Definition if ☺ or 😐)	Rationale for inclusion based on abstract/title

Lived experiences= lived experiences of a changed body: evidence of data describing people’s experiences of living with or adapting to a changed body or perceptions of it due to their stroke

Impacts= impacts of changed bodily experiences: evidence of data specifically exemplifying ways in which a changed body or perception of it has impacted people’s lives

NR= not reported

Appendix 7: Summary Tables for the Papers Included in the Systematic Review

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\#}$ †	Main strengths & limitations
Arntzen and Elstad (2013), Norway	To explore apraxia through Merleau-Ponty's concept of bodily intentionality; observation, open-ended interviews & videotaped interactions & ADL	×	Rehabilitation units; occupational therapists selected participants; N= 6; F= 50%. Age: M= *68.3*, range= 60-80. Time:1 week- 3 months.	✓ Transparency of author perspectives × Smaller sample size than planned × Philosophical perspective may limit focus & results
Arntzen et al. (2015a), Norway	To explore stroke survivors' long-term (1–13 years) experiences; longitudinal, in-depth interviews	×	Rehabilitation unit & group-based education programmes; N= 9; F= 33.3%. Age: M= *56.5*, range= 39-72. Time: 6 months-12 years.	✓ Range of time since stroke = insights into recovery process ✓ Analysis & interpretation discussed × Limited information about repeat interviews

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\#\,\dagger}$	Main strengths & limitations
				× No major cognitive or communication difficulties & only mild to moderate disability
Arntzen et al. (2015b), Norway	To understand how body, participation & self, interrelate & change across contexts post-stroke & what it means for process of change & well-being; repeated, retrospective, in-depth, open-ended interviews	Partially: bodily relationships	Rehabilitation unit & group-based education programmes; convenience sample; N= 9; F= 33.3%. Age: M= *56.5*, range= 39-72. Time: 6 months- 12 years.	✓ Analytical distance & different author perspectives considered ✓ Research question further developed based on issues emerging from analysis × Findings sometimes difficult to separate from discussion × All moderate stroke
Atkinson et al. (2012), USA Abstract only	To compare clinician & patient views of post-stroke spasticity & their impact on health-related quality of life; clinician	✘	N= 59.	✓ Large sample size for qualitative study (6 focus groups with 59 patients)

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
	interviews & emergent themes taken to patient focus groups			
Backe et al. (1996), Sweden	To find out how life is conceived within a week of acute post-stroke care (*as seen from nurses' viewpoint*); open-ended, semi-structured interviews	✘	Hospital medical clinic; N= 6; F= *33.3%.* Age: range= 50-66. First stroke: 100%. Time: within 3 weeks from stroke.	✓ Sample reached saturation ✓ Well-prepared & engaged interviewers & pilot interviews to check questions × Some sample parameters not justified e.g., age, hemiplegia, first stroke, no aphasia
Bergström et al. (2015), Sweden	To understand the lived experience & meaning of agency during the first-year post-stroke; longitudinal, descriptive & interpretive interviews	✘	Larger multi-centre study of stroke rehabilitation services; participants suggested by occupational therapists from larger study; N= 6; F= 50%. Age: M= *73.8,* range= 64-89. Time: up to 12 months post-stroke.	✓ Justified why people had to be able to communicate ✓ Longitudinal design = depth into experiences × Living situations of participants were different e.g., different care contexts, living alone

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
Boylstein (2002), USA	What insight do the Functional Independence Measure & Frenchay Activities Index provide into functional status post-stroke across home & public settings & are they valid? Do people with in the same recovery category have similar recovery experiences?; comparative case study interviews.	✗	Veterans' Health Centres; purposeful sample of participants from larger study; N= 31; F= 0%. Age: M= 63.7 (SD= 11.3), range= 40-84. Time: recently hospitalized with diagnosis of acute stroke & discharged home.	✓ Structured interviews enhanced continuity across interviewers × Mostly high functioning male veterans × Structured interviews may have meant participant responses did not guide interview
Carlsson et al. (2004), Sweden	To explore how people 1-year post-stroke with astheno-emotional	Partially: Questions about	Strategic sampling of 53 people with astheno-emotional syndrome	✓ Justification & discussions about interview procedures & grounded theory methods used

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
	syndrome experienced changes in everyday life; semi-structured interviews with observations & questions about ADL to allow triangulation	perceptions, thinking & feelings, & handling the difficulties caused by AE	from existing research group; N= 15; F= 46.7%. Age: M= *50.1*, range= 30-69. First stroke: 100%. Time: 1 year.	× Limited sample: only mild stroke, no aphasia × Reader referred to another study for sampling information
Carlsson et al. (2018), Sweden	To describe experiences of sensory impairment in the upper limb post-stroke, its influence on daily life, coping strategies, & sensory training; individual interviews & inductive content analysis	✘	Hospital department of Neurology & Rehabilitation & a daycare; purposive sample; N= 15; F= 46.7%. Age: range= 35-78. Time: 6 months- 11 years.	✓ Discussion of codes between authors until consensus reached × Mild to moderate sensorimotor impairment & younger than mean age of stroke × First author had previously had professional contact with participants, but was reported as not affecting results- why?

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
Ch'ng et al. (2008), Australia	To explore long term perspectives (including challenges) on coping with stroke recovery to inform the design of psychological interventions; focus group	✘	Community stroke support group; purposeful sampling; N= 26; F= 53.8%. Age: M= 60.88 (SD= 15.78), range= 22-79. First stroke= 88.5%. Time: 6 months- 12 years.	✓ Coder agreement reported & accuracy confirmed through member checking ✓ One group specific to younger people might draw attention to needs of younger people × No mild stroke × Relationships between researcher & participants not reported
Crowfoot (2016a); Crowfoot (2016b), Australia	What are the experiences of people with TIA or minor stroke & how are they shaped by different healthcare pathways; narrative inquiry: one, face-to-face, semi-structured interview	✘	General practices; recruited as follow-up from existing study; N= 12; F= 25%. Age: M= *73.4*, range= 63-87. Time: 3-12 months.	✓ Population demographic similar to New South Wales & Australia × Only one interview timepoint = limitation given narrative inquiry design & interview process condensed from 3 to 1 in a previously unused extension to narrative inquiry

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
				× Unintentional over-recruitment of males; gender-related influences on experiences could have been missed
de Guzman et al. (2012), Philippines	To describe the self-concept, disposition, & resilience of poststroke Filipino elderly with residual paralysis through the lens of mask-painting; interviews & mask-painting	✘	Religious care home; purposive sampling; N= 9; F= 33.3%. Age: range= 60-70. Time: 66.7% within 2 years.	✓ Mask-painting did not require fine motor skills that would be difficult for people with residual paralysis (de Guzman et al., 2012) × Unclear why people with communication difficulties excluded × No interview recordings & analysis methods unclear
Doolittle (1990, 1991, 1992), USA	How is the habitual body experienced post-stroke & how is bodily integrity regained?; Longitudinal, clinical ethnography interviews (9/person)	Partially: Body experiences	3 urban hospitals; N= 13; F= 38.5%. Age: M= 67, range= 50-88. Type: Lacunar= 100%. Time: recruited within 72 hours.	✓ Design provides insight over time × Generalisability issues: what about more severely impaired people? × Unclear from outset that only lacunar stroke included

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
Doyle et al. (2014), USA	To describe the experience of sensory impairments, their impact, & sensory rehabilitation & recovery; qualitative descriptive semi-structured interviews; & focus groups for member checking	✘	Stroke support groups & assisted living facilities; purposeful sampling through advertising; N= 15; F= 20%. Age: M= 55.5 (SD= 15.7), range= 30-78. Time: 6 months- 16 years. 8/15 also took part in focus group.	✓ Broad criteria to facilitate varied sample ✓ Member-checking × Volunteer bias from support groups: could be more in pursuit of improvement
Eilertsen (2005); Eilertsen et al. (2010), Norway	To examine older women's experiences of recovery during the first 2 years post-stroke; prospective, longitudinal, case-study interviews (12-14/participant)	✘	Stroke units; consecutive recruitment by stroke nurses; N= 6, F= 100%. Age: M= *74.3*, range= 68-83. Type: cerebral infarction= 100%. First stroke = 100%.	✓ Under-studied population ✓ Participants encouraged to make their own themes to increase help researcher understanding × Sample skewed towards less disabled × Themes felt pre-decided

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
Erikson et al. (2016), Sweden	To describe & understand the impact of stroke on everyday life 11–13 years after stroke; longitudinal, qualitative, descriptive & interpretive interview study	✘	Rehabilitation clinic; purposively selected from a sample of people with ABI who had participated in a previous interview study; N= 11; F = 45.5%. Age: range= 50-67. Time: 11-13 years.	✓ Member checking × 11/12 people agreed to take part, showing motivation to share experiences & rich data × Lack of people of different ages & with cognitive impairments
Faircloth et al. (2004), USA & Puerto Rico	To explore how bodily experience informs stroke patients' understandings & recovery & how they give meaning to the disrupted body; qualitative interviews & observations	Partially: bodily experiences	Stroke survivors discharged from hospital to homes; purposive sampling; N= 51.	✓ Results also align with those from different groups × Veterans & mostly male × Unclear where observations came into results & lack of justification of methods × Findings difficult to extract

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
Girardon-Perlini et al. (2007), Brazil. *Google translated from Portugese*	To understand how people with stroke see themselves; semi-structured interviews	Partially: How people see selves	Community; snowball; N=6; F= 33.3%. Age: M= 66, range= 62-71. Time: 2 months- 12 years.	✓ Community setting matches aim of exploring living with disability × Findings not clearly presented as subthemes & difficult to tease apart results & discussion × Response bias: family members allowed to stay for interview × Recruitment bias: snowball sample
Gorst et al. (2016), England	To explore the views of people with stroke & the nature of their foot & ankle impairments & whether & how they impact on their life; face to face semi-structured, audio recorded interviews	✘	Stroke Groups & Stroke Research Network Database; purposive sampling; N= 13; F= 46.2%. Age: M= 66.5 (SD= 12.2), range= 38-78. Time: 4 months- 20 years.	✓ Mentions saturation ✓ Audit trail ✓ Meetings between researchers ✓ Pilot interviews analysed & discussed × Response bias: interviewer was physiotherapist

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\#\dagger}$	Main strengths & limitations
Immenschuh (2003), Germany	To understand the experience of ischemic stroke from the perspective of people under 55 years of age; interviews	✘	University hospital stroke unit; identified by ward physician; N= 11; F= 45.5%. Age= M= *35*, range= 18-51. First stroke= 100%. Time: 3- 12 months.	✓ Focus group informed interview schedule & inclusion criteria ✓ Longitudinal: highlights changes & emotional struggles over time × Unclear why haemorrhagic stroke excluded × Impacts of visible & invisible impairments could not be compared
Kinoda (2008), Japan. *Translated using Google by CD; Tables & Figures Translated by RK from Japanese*	To find out what kind of body image hemiplegic stroke patients have; semi-structured interviews	✓	Rehabilitation ward; N= 7; F= 42.9%. Age: M= 53.7, range= 30-63. Type: Infarction= 57.1, Haemorrhage= 42.9. Time = 57-139 days.	✓ Considered opposite examples within data to minimise bias in interpretation ✓ Interviews short to account for participant concentration & fatigue × Interviews might be too short to capture depth

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
				× To be judged valid: concept had to have multiple examples: could mean nuanced examples are lost
Kitzmuller et al. (2013), Norway	To illuminate the significance of the long-term influence of bodily changes on the perception of self after stroke; narrative interviews	Partially: Bodily changes & perception of self	Stroke Association & home nursing services; recruited by local leaders of Stroke Association & home services; N= 23; F= 39.1%. Age: M= 51, range= 32-68. Time: 3-25 years.	✓ Inclusion criteria: broad with variety of stroke-related impairments × Young age range × Inclusion criteria could exclude those with bodily changes who did not have disabling stroke × Response bias: where spouses present
Kuluski et al. (2014), UK	To understand the experience of stroke as a disabling life situation among young people & the strategies used to	✗	Interviews taken from database of interviews where participants recruited from the community using maximum variation sampling technique; N= 17; F= 64.7%.	✓ Author code comparisons & theme verifications × Participants had to contact researcher = skewed towards higher functioning people

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]		Main strengths & limitations
	recover & cope; individual interviews		Age: M= 46.5, range= 23-55. Time: 1- 12 years.	× ×	Interviews = semi-structured prompting around anticipated themes-– what were these? 3 interviewers = variation in interview content/findings
Kvigne and Kirkevold (2003), Norway	To present & discuss from a phenomenological & feminist perspective, findings of how females with stroke experience their body & life after stroke & how it can influence the lived body in women's life world; series of qualitative interviews.	Partially: Experience of body, lived body	3 rural hospitals; recruited as assessed by head nurse & physician; N= 20; F= 100%. Age: range= 37-78. First stroke: 100%. Time: during first 6 weeks- 1 year after return home.	✓ ✓ ×	Interviews were started by asking participants to describe their stroke: opened way for dialogue Interview = access to body language- facilitates understanding Large age span but no consideration of differences across ages

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
Kvigne et al. (2004), Norway	To explore how females with stroke experienced & managed their life post-stroke; longitudinal phenomenological semi-structured interview study	✘	3 rural hospitals; invited women meeting inclusion criteria; N= 20; F= 100%. Age: range= 37-78. First stroke: 100%. Time: during first 6 weeks- 1 year after return home.	✓ Longitudinal design provides insight over time × Not representative of stroke population: no serious mental &/or linguistic disorder; all female but title does not specify this
Lawrence and Kinn (2012), UK	To understand young adults' experience of stroke over an extended time period to inform patient-centred interventions & outcomes for young adults with stroke; longitudinal design	✘	NHS Health boards via stroke nurse specialists & consultant physician; purposive sampling with sampling frame; N= 10 (32 interviews); F =50%. Age: *M= 45.4*, range= 37-54. Time: 3-22 months.	✓ Involvement of patient advisory group in research decisions ✓ "Phenomenological stance": participants spoke about topics important to them as opposed to researcher's agenda × Only 1 participant with severe stroke; majority had few 'visible' impacts; all Caucasian

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
	using unstructured interviews			
Leahy et al. (2010); Leahy et al. (2016), Ireland	To capture the lived experience of stroke from the perspectives of young stroke patients; IPA, face-to-face interviews	Partially: Lived experience	Hospital stroke service; eligible participants issued information sheet; N= 12; F= 100%. Age: range= 20-48. Time: 10-29 months.	✓ Interviews guided by participants × People with difficulties that would make participation difficult were excluded × Only mild to moderate stroke & excludes dysphagia × 1 interview with a male but excluded from analysis: research question did not specify females & only males declined to participate
Lever and Pryor (2015, 2017), Australia	To explore the impact of stroke on female sexuality in women with stroke; descriptive individual semi-	Partially: Bodily impacts in	Direct & indirect advertisements to stroke groups, committees & foundations; convenience; N= 12; F= 100%.	✓ Iterative dialogue between researchers ✓ Researcher characteristics similar to participants: facilitated collection of personal data

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\#\dagger}$	Main strengths & limitations
	structured conversational interviews	relation to sexuality	Age: M= 52, range= 31-70. Type: haemorrhagic = 44%, ischaemic = 33%, unsure = 22%. Time= 1.17- 15.75 years.	× Recruitment more difficult than anticipated × Volunteer bias: likely more comfortable discussing sexuality concerns × Excluded those with communication impairment
Meijering et al. (2016), Netherlands	To examine in-depth the experiences of home for people with stroke (& their family caregivers); 1- 2 semi-structured in-depth interviews	✘	Stroke rehabilitation unit; N= 31; F= *38.8%.* *Age: M= 58.3,* range= 31-81. Time: 7 months- 6.5 years.	✓ Contradictions in participants' experiences acknowledged within themes ✓ Coding & analysis by multiple authors ✓ Repeat interviews continuously refined × No mild stroke × Response bias: significant other present in most interviews

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
Moorley and Cahill (2018), UK	To understand the lived experience of life after stroke among African-Caribbean women in the East End of London; semi-structured in-depth interviews & phenomenological approach	✘	Local day centres, community halls, hospital outpatient clinics & sheltered accommodation. N= 6. F= 100%. Age: range= 47-85 years. Time since stroke: ≥6 months.	✓ Facilitates understanding of how stroke affects African-Caribbean women & influence of culture & gender × No detail around interview questions or content
Murray and Harrison (2004), UK	To explore the concerns, perspectives & experiences of people after stroke; in-depth semi-structured email & face to face interviews	Partially: Experiences	National Stroke Network & email discussion group for stroke survivors; N= 10; F= 60%. Age: M= 48.8, range= 38-81. Time: 4-20 years.	✓ Author agreement over interpretations ✓ Email methods: good for those self-conscious about appearance or disability & elicited detailed responses until all issues exhausted ✓ Topic areas broad to enable participants to raise important issues vs researcher's agenda

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
				× Email methods: no non-verbal communication
Nanninga et al. (2015), Netherlands	To increase understanding of the support that people with stroke & their families need to renegotiate their attachment to meaningful places in the rehabilitation clinic & their own living environments; semi-structured in-depth interviews using contrasts between different rehabilitation phases	✘	Stroke survivors with multifaceted problems receiving or received multidisciplinary treatment in a rehabilitation stroke unit & additional 9 participants in the clinical & post discharge; N= 33; F= *39.4%.* Age: *M= 57.2, range*= 31-81. Type: I*schaemic= 25%, Haemorrhagic= 8%.*	✓ Iterative learning between interviews = improved interviews ✓ Multiple coders & analysers × All severely affected stroke patients × Recall bias in recollecting experiences, so broadened to prospective interviews × Themes organised by previously deduced codes from existing literature × Response bias: all interviews included a significant other

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
Nanninga et al. (2018), Netherlands	To enrich the discussion on mobility in stroke rehabilitation by translating theory of mobility from the context of geography to rehabilitation; in-depth interviews (primary & secondary evidence)	✘	Rehabilitation stroke unit after discharge from an acute hospital stroke unit; secondary qualitative analysis of existing data. N= 33. F= *39.4%.* Age: M= *57.2,* range= 31-81. Type: I*schaemic= 25%, Haemorrhagic= 8%.* Time: 6 months- 6.5 years.	✓ Analysis guided by data ✓ Multiple coders × Unclear if people with communication difficulties included × Secondary analysis of data collected for different purpose = different focus & key ideas could have been omitted
Nasr et al. (2016), UK	To explore how people with stroke perceive their experiences of living with stroke & how context-dependent components of human experience can be	✘	Local stroke clubs, community & day rehabilitation centres, & outpatient rehabilitation units; approached by managers of stroke centres. N= 5.	✓ Stories not treated as representative nor used to reach saturation ✓ Narrative inquiry supports storytelling × Lacks critical examination of author's own role around bias × Small sample

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
	understood; narrative, open interviews			
Norris et al. (2010), Indonesia	To explore the lay understanding of stroke in Central Aceh, Indonesia; interviews	✘	2 districts of Indonesia; purposive sampling frame; N= 11; F= 63.6%. Age: M= *52.1* years, range= 32-69.	✓ Region included had highest rate of stoke in the country ✓ Participant-selected photographs as mechanism of exploring experiences × Need extra sensitivity around ethical approvals made in the UK but for other countries/cultures
Pallesen (2012, 2014), Denmark	To identify how people with stroke view themselves, perceive any associated disability & how they manage their lives from a long-term perspective; phenomenological	Partially: Main focus of patient experiences involves the body, coping & self-identity	People who previously participated in questionnaire study about stroke population characteristics; N= 15; F= 33.3%. Age: *M= 61.9*, range= 42-84. First stroke: 100%. Time since stroke= 5 years	✓ Inclusive to those with communication difficulties ✓ Family members helped with narrative but could have influenced responses ✓ Interviews supplemented by telephone calls, emails & post = greater depth

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#][†]	Main strengths & limitations
	narrative & semi-structured interview study			× Recall bias/inaccuracies, exacerbated by cognitive problems or aphasia
Pedersen et al. (2019a); Pedersen et al. (2019b), Norway & Denmark	To explore the QoL of stroke survivors during the first year of recovery in North Norway & Central Denmark; interpretative, inductive study; individual semi-structured in-depth interviews	✘	Hospitals; recruited by health personnel. N= 11; F=36.4%. Age: range= 35-66. Time: 1 year.	✓ Interviewers & participants had previously met = strengthened relationships facilitating openness & honesty ✓ Multiple interdisciplinary authors ✓ Participants encouraged to lead conversation & open questions × Stroke survivors with cognitive/ communication difficulties not represented & mostly younger × Recall bias when family present
Purton et al. (2015); Purton	To explore the experiences of UL dysfunction in people	Partially:	Stroke rehabilitation unit; purposeful sampling, recruited by	✓ Interview guide developed with stroke support group

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
et al. (2020), UK	with stroke, the meanings ascribed to these experiences over time & effects on sense of self; longitudinal interviews	Experiences of bodily dysfunction	senior physiotherapist on unit. N= 13; F= *61.5%.* Age: M= *73.7*, range= 62-86. Time: within previous 2 months.	× Not considered influences of recruitment by senior physiotherapist i.e., pressure to participate × All participants recruited from 1 stroke unit & excluded people with dysphasia or cognitive problems
Raghavan et al. (2016), USA	To explore whether an intervention could be designed to address physical, psychological & social domains of rehabilitation simultaneously to support long-term post-stroke UL recovery; quasi-experimental mixed-method pre-test post- test design with 1-	✘	Rehabilitation centres & hospital; referred by physicians & therapists; N= 13; F= 30.8%. Age: M= 52 (SD= 14), range= 21-68. Type: Ischaemic = 5%, Haemorrhagic = 5%; Time: 8-144 months.	✓ Group discussion encouraged intervention participation & feedback × Insufficient detail around focus groups compared to quantitative aspects × No elaboration of themes presented, only quotations

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
	year follow up; 45- min intervention twice a week for 12 sessions; each included a focus group about the experience of living with stroke.			
Rittman et al. (2004), USA	To describe the experience of time during the transition from hospital to home; in depth, semi-structured interviews & field observations during home visits	✘	Invited to participate while hospitalised; N= 51; F= 0%. Age: M= 64.7, range= 46-84. Type: acute but ill-defined CVA = 49%, cerebral infarctions= 33%, cerebral occlusions= 8%, intracerebral haemorrhages= 4%, ill-defined CVD= 6%.	✓ Multiple experienced researchers coded interview data × Unclear why only male veterans × Geriatric Depression Scale (GDS) recorded but not reported × No topic guide

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
Rittman et al. (2007), USA	To describe psychosocial experiences during the first month of transition from hospital to home, including changes in sense of self & bodily experiences, connectedness & community integration; semi-structured interviews, field notes, & quantitative data to describe characteristics & functional changes	Partially: Psychosocial bodily experiences	Data derived from a longitudinal multisite study to develop culturally sensitive models of stroke; participants invited while hospitalized for acute stroke. N= 125; F= 1.6%. Age: M= 66, range= 40-93. Type: Ischaemic= 53%, CVD= 42%, Haemorrhagic= 4%. Time: 0-129 days.	✓ Spread of ethnicities: African American, Puerto Rican & non-Hispanic White × Unclear if findings discussed in relation to body or general experience × Extraction of findings difficult as results & discussion interweaved
Stott (2019); Stott et al.	To explore the experiences that people with stroke have of their	Partially: Experiences of body	2021: Stroke support groups & charity for South Asian women;	✓ Patient partners helped during interviews

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †	Main strengths & limitations
(2018a, 2018b, 2021), UK	body & determine whether their altered body caused discomfort in physical, psychological & social terms, how they coped & whether they felt their discomfort warranted clinical intervention; phenomenological interview study		purposive sample; N= 16; F= 37.5%. Time: 8 months- 23 years. 2019: Previous study, stroke café & stroke support groups; N= 10; *F= 30%.* Age: *M= 58.5*, range= 43-81. Time: 11 months-22 years.	✓ Researchers discussed themes together ✓ Most participants known to the researcher: good for rapport ✓ Order in which tools presented was rotated to reduce bias ✓ Interviews tailored to meet participants' comprehension & communication issues × Participants were from stroke support groups, so may have already discussed stroke-related body changes × Few severe stroke or people from different ethnic backgrounds

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported$^{\# \dagger}$	Main strengths & limitations
				✓ Unclear why participants had to have motor, sensory, or spatial attention impairments
Taule and Råheim (2014); Taule et al. (2013), Norway	To explore the experiences of living with mild stroke in the context of early supported discharge & continued home rehabilitation, with focus on patient-attributed meanings of activity & participation in the home recovery process; interpretative face-to-face interview design	✘	Recruited from home rehabilitation group of larger randomised controlled trials to compare conventional treatment with early supported discharge models; purposive sample; N= 8; F= 50%. Age: M= *60.8,* range= 45-80. Type: Haemorrhagic= 12.5%; 7 x ischaemic= 87.5%. Time: 6-8 months.	✓ Variation: gender, age, civil status ✓ Participants shared previously unshared thoughts ✓ Multiple authors reflecting on presuppositions × Limited knowledge of participants' possible cognitive impairments or fatigue × All mild stroke × Response bias: partner helped expression of story, but could lead to withholding information

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported[#] [†]	Main strengths & limitations
Timothy et al. (2014); Timothy et al. (2016), New Zealand	To explore embodiment & stroke through understanding bodily experiences & its relation to their lived experience during the first month at home after discharge from hospital-based rehabilitation after stroke; 3 telephone calls & 1 interview	Partially: Bodily experiences, lived experience	Physical therapy clients in >65s' stroke rehabilitation ward; purposeful sampling & iterative theoretical sampling, identified by physical therapists; N= 7; F= 28.6%. Age: M= *77.7,* range= 66-89. Type: circulatory infarct = 100%. First stroke: 100%. Time: participation within 1 month after discharge.	✓ Saturation reported as being reached × Given small sample size, unclear how authors can be sure of reaching saturation × Other factors not identified due to small sample may have influenced themes e.g., culture, age, & sex
Wyller and Kirkevold (1999), Norway	To explore whether QoL is a meaningful concept for people with stroke & how a stroke impacts QoL; longitudinal interviews	×	Strategic subsample of stroke patients admitted to hospital during a 6-month period; N= 6; F= 33.3%. Age: M= *73.8,* range= 65-85. Time: 3 years.	✓ Checked for disproving data across transcripts ✓ 2 analysts = increased trustworthiness × Participants knew interviewer was a physician & felt he could relate to their experiences; but haven't considered

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †		Main strengths & limitations
					how this might have affected participant responses
Yamauchi (2007), Japan	To understand what kind of bodily experiences people with post-stroke hemiplegia have during recovery & its significance; inductive hospital observations & post-hospital interviews	Partially: Bodily experiences	Neurosurgery hospital ward; patients selected as participants; N= 5; F= 20%. Age: range= 30-70. Type: cerebral infarction= 60%, intra-cerebral haemorrhage= 40%. Time: within 6 weeks.	✓ × × ×	Respondent validation of summaries Unclear why observations & interviews used & does not state form of interview data No accommodation of communication difficulties For one participant, only notes were treated as data: possible
Yuki (2008), Japan	To examine the building of future self-body image (possible body self) at different stages of recovery post-stroke; semi-structured interviews	✓	2 hospitals & 2 health facilities for the elderly; selected from stroke patients; N= 15; F= 26.7%. Age: M= 64 (SD= 9), range= 52-80. Type: cerebral haemorrhage= 60%, cerebral infarction= 40%.	✓ × ×	Compared opposite examples in the data Unclear why recruited from settings for the elderly Some aspects of eligibility criteria not justified

Qualitative Papers

Study: first author(s) (year), country	Purpose; design & method of assessing body image	Specific to body image? ^	Sample information where reported# †		Main strengths & limitations
			First stroke: 100%. Time: 2.5-7.6 years.	×	Time is a focus of results, but not referenced in original aims

Key:

^: ✓= Yes, ✗= No

#: Setting; Sampling; Sample size (N); % of females (F). Age (years). Type (of stroke) & first or recurrent? (occurrence) (%). Time (since stroke): range;

†All percentages rounded to the nearest whole number

M = mean; SD= standard deviation;

Italicised= researcher calculated the figure presented.

Quantitative Papers

Study$^{£}$, country, method of assessing body image	Purpose; design & design related to assessing body image	Specific to body image?^	Sample information where reported$^{\# \dagger}$	Key findings	Main strengths & limitations
Barak et al. (1999), Israel, Body Esteem Scale (BES) (Franzoi & Shields, 1984)	To evaluate body esteem after stroke & make correlations to the site of the stroke, sex, time since onset, & severity of physical impairment; cross-sectional questionnaire study	Partially: "Body esteem, an important component of body image…"	Consecutive group of patients admitted with acute stroke; N= 101; F= *49%.* Age: M= 58.9 (SD= 8.92). First stroke: *100%.* Time: 6 months.	• Differences in body esteem score subscales between sexes • Lower body esteem correlated with left cortical lesions • Males: lower physical attractiveness perception in right cortical lesions vs subcortical • No correlation between body esteem & lesion size or disability	✓ Stroke clinically confirmed × No justifications for measures or inclusion criteria × Lack of correlations attributed to small sample size
Braga (2012), Brazil, Body Shape Questionnaire (BSQ) (Cooper et	To identify perceptual & affective aspects in adults with hemiplegia or	✓	People with stroke recruited through volunteer sampling via support group &	• No significant difference between sexes in terms of body image dissatisfaction • Greater BMI linked to higher body image dissatisfaction	× Relatively young age for stroke × Cannot determine stroke severity$^{\$}$

al., 1987; Cordas & Neves, 1999; Stott, 2019), Image Itself Scale (Paula, 2010)	hemiparesis after stroke vs control group in terms of psychophysical tasks of estimation & choice of body dimensions; image & questionnaire study		university; N= 15; F= *26.7%.* Age: female: M= 57 (SD= 18.77), men: M= 50.90 (SD= 3.39).	• Participants with higher BMI judged selves as having higher BMI than they actually had & wanted a smaller BMI • Women wanted thinness & men wanted to be heavier	
Brinkmann and Hoskins (1979), USA, Tennessee Self Concept Scale (TSCS) (Fitts, 1965)	To determine the effect of a physical conditioning program on fitness, function & self-concept in hemiplegic patients; longitudinal evaluation of	P: “Self-concept includes various components such as self-esteem, which refers to degree of positive self-	Community; people with CVA; N= 6; F= *71%.* Age: M= 43.7, range= 22-59. Type: Thrombus: *57%;* Aneurysm: *14%;* Postoperative embolus: *14%;* Blood disorder: *14%.*	• Baseline: scored lower than normative group on 4/14, including Physical Self score (indication of a person’s view of his body) • Physical self-score improved but stayed lower than normative group • Diminished view of body, health, physical appearance, skills & sexuality	× Lack of correlations could be due to inadequate measurement methods × 'Normative' sample taken from unpublished study & cannot assess quality/details

	exercise intervention	attitudes & body image”			
Goodyear (1978), USA, Body Cathexis Scale (Secord & Jourard, 1953)	To ascertain body image perceptions of people with stroke, whether they think their body image has changed since before their stroke & whether the areas perceived to have changed are different based on age or sex; descriptive survey	✓	Recruited from acute care facilities; N= 22; F= 45.5. Age: M= *73.18*, range= 58-85. Type: Brain stem CVA= 4.5% Basilar CVA= 4.5% Cerebellar infarct= 4.5% CVA= 86.4%. First stroke: 100%. Time: Hospitalised for less than 3 weeks.	• Body image perceived more positively pre-stroke • Age did not affect body image, although younger people (56-70 years) had lower body image scores • 22/35 body parts & functions assessed were rated as significantly different post-stroke • Females: higher body image scores before & after stroke	✓ Researcher acknowledges the assumptions made throughout the study ✓ Using written questionnaire may have excluded people with eyesight, comprehension or dexterity difficulties
Keppel and Crowe (2000), Australia, The	Within-subjects, cross-sectional questionnaire	✓	People with stroke recruited from hospital	• Body image negatively affected after stroke with reductions in self-esteem	✓ Stroke clinically confirmed

Body-Cathexis/Self-Cathexis Scale (BC-SC) (Secord & Jourard, 1953) & TCSC-2 (Fitts et al., 1996)	study; to examine the perceived effect of stroke on body image & self-esteem in young adults to better understand the effects of stroke on body image & self-esteem		rehabilitation; N=33; F= *61%.* Age: M= 36.73 (SD= 12.79), range= 14–57*.* Type: Infarction= 42%, Vascular haemorrhages= 27%, Subarachnoid haemorrhage= 21% Aneurysmal ruptures= 9%. First stroke: 100% Time: 1–36 months.	• Effects more marked in left hemisphere lesions; although no significant effects of lesion location or type of vascular event • Pre-stroke, only self-reported physical self-esteem & body image were strongly correlated. After stroke, all measures of self-esteem & body image were strongly associated • No significant influences of gender or time since stroke	✓ Subjective experience important: highlights what’s pertinent for participants ✓ Data mostly normally distributed × Small sample size: limiting scope & generalisability of findings × All participants had adequate language functions & no less severe stroke
Li et al. (2001), China, General Quality of Life Inventory (GQOLI) (Li et al.,	To compare the QoL of stroke patients with healthy controls & prospectively	✘	People with stroke; N= 121; F= *48%.* Age: M= 60.4 (SD= 8.1), range= 35- 85. Type:	• People with stroke: lower self-esteem & body image than controls after 1-year, but not at baseline	✓ Stroke clinically confirmed ✓ Significant effects apparent after 1

1995; Li et al., 1997)	examine QoL across 12-months after hospital discharge using a multidimensional measure; longitudinal cohort study with control group		Infarction= 54% Haemorrhagic= 46%. First stroke: 100%.	• No significant difference between QoL at baseline between haemorrhage & infarction • Body image & self-esteem scores paralleled by scores for social support & communication, & marriage & family relationship factors	year: follow up was long enough × Unclear whether provision made for people with cognitive/language difficulties
Lourenço (2012), Portugal, Body Esteem Scale (BES) (Franzoi & Shields, 1984)	To investigate anxiety, depression, self-esteem & body-esteem in people with CVA; questionnaire & interview study	P: Due to link between body esteem & body image	Rehabilitation Medicine Centre of Alcohol; N= 62; F= *50%*. Age: males: M= 55.84, (SD= 10.80), females: M= 55.29 (SD= 13.71), 25-81 years. Type: ischaemic: males: 71, females: 74.2 ischaemic. Occurrence: NR. Time: 7< months (N = 35;	Women: • Sexual attraction (physical appearance) most highly valued & feeling more physically attractive linked to higher self-esteem • Feeling more sexually attractive linked to fewer anxious & depressive symptoms • Concern with weight positively associated with self-esteem	✓ Author standpoint clear × Men & women cannot be directly compared because of sex-specific measures

			56.5%) & ≥6 months (N = 27; 43.5%); NR.	• No effects of time since stroke Men: • Most highly valued physical attraction • Less esteem about muscle strength associated with more depressive symptoms • People with stroke less than 6 months ago had more esteem for physical attraction Women & Men: • No effects of stroke type • Greater body esteem = fewer depressive symptoms		
McMillan et al. (2005), China, The General Oral Health Assessment	To investigate oral health-related quality of life in elderly stroke survivors	✘	Elderly stroke inpatients about to be discharged from a Stroke Rehabilitation Unit & community dwelling	GOHAI: • More people with stroke had problems with speaking • 63% of people with stroke not pleased with the look of their	✓	Stroke & control group comparable, including on dental condition: could explain lack of

Index (GOHAI) (Atchison & Dolan, 1990); Oral health transition scale (Locker, 1998; McMillan et al., 2005)	after rehabilitation; cross-sectional questionnaire study		comparison group; N=43; F= *39.5%.* Age: M= 73.9 (SD= 6.1). First stroke: 100%. Time: *Approximately within the previous 32 days*	teeth, 2% were uncomfortable eating in front of people, 2% felt self-conscious of teeth problems, 9% limited contact with people, 14% were worried about teeth problems. 23% limited food intake/choice of food & 42% were unable to speak clearly Oral health transition scale: For people with stroke, compared to pre-stroke: • 75% considered appearance to be worse • 50% felt speech was worse	difference between groups × Excluded people with serious stroke & aphasia/ dysphasia × Recruited from social centre: if people visit the centre, are they less concerned with social appearances?
Picado et al. (2019); Picado (2018), Portugal, "My body image"	To characterise & compare perception of body image & body schema in adults with &	P: Title includes body image	Stroke participants recruited from nursing homes & continuing care units & comparison group of community residents without stroke;	People with stroke: • Gave more importance to functional body aspects vs people without stroke who gave more importance to	✓ Mean age of sample consistent with population ✓ % with ischaemic stroke

questionnaire (Lovo, 2001)	without stroke; observational-descriptive & cross-sectional		representative non-probabilistic sampling; N= 31; F= 58.1%. Age: M= 78 (SD= 7.8). Type: Ischemic= 83.9%, Haemorrhagic: 16.1%. Time: 4-240 months.	appearance-related body aspects • Had less confidence & less positive attitude towards body • Time since stroke & stroke hemisphere did not influence body image perception • Degree of dependence explained variation in body image perception	representative in stroke population × Tools not validated for Portuguese population
Sadanandan et al. (2020), India, Body Cathexis Scale (Secord & Jourard, 1953)	To explore body cathexis of stroke patients; cross-sectional descriptive survey	✓ Body cathexis is described as a measure of perceived body image	Purposive sample of people with stroke from 2 rural areas; N= 151; F= 46.4%. Age: M= 64.58 (SD= 10.33), range= 28-80. Type: Ischemic= 76.2%, Haemorrhagic: 23.8%. Time: majority within last 6 months: 52%; > 6 months: 48%.	• All participants satisfied with body parts not directly involved in ADL For people with stroke: • No significant differences in body cathexis based on lesion side, gender or time since stroke • Top 5 areas of dissatisfaction: energy level (98%), wrist (88.1%), elimination (86.1%),	✓ Clarity of sample helps transferability decisions × No discussion of how people with communication difficulties were supported × Does not describe all of areas assessed by BC scale

	fingers (76.2%), & arms (73.5%)

Key:

£: first author (year)

^: ✓= Yes, ✗= No

#: Setting; Sampling; Sample size (N); % of females (F). Age (years). Type (of stroke) & first or recurrent? (occurrence) (%). Time (since stroke): range

M = mean; SD= standard deviation

Italicised= researcher calculated the figure presented

$= difficult overall to determine strengths & limitations from translation

Mixed Methods Papers

Study, Country, Method of assessing body image	Purpose; design for assessing body image	Specific to body image?^	Sample information$^{\#}$	Key Findings	Main Strengths (✓) & Limitations (✗)
Barker et al. (2013), UK, Interviews (Qualitative)	To design a screening questionnaire to indicate presence & extent of spasticity; interviews to determine content & confirmed quantitatively through Rasch analysis	✗	Spasticity clinic & stroke clubs; purposive; N= 48. Time: 50% >2 years.	Reported as part of narrative synthesis (see section 5.3)	✓ Stroke clinically confirmed for 50% of sample ✓ Qualitative findings confirmed by quantitative methods × Limited information about qualitative study
Bronken et al. (2012), Norway, Interviews (Qualitative)	To explore how people with aphasia experienced the intervention & its impact on their recovery & psychosocial well-being	✗	Hospital-based acute stroke or rehabilitation units*; purposive; N= 7; F=*14.3%.* Age: M= *54*, range= 33-72.	Reported as part of narrative synthesis (see section 5.3)	✓ Enhanced validity & understanding from triangulation of data ✓ Instruments acceptable for people with aphasia × Younger than average

			Type: haemorrhagic: *28.6%*, ischaemic: *71.4%.* First stroke: 100%. Time: 4-12 weeks		× Participation difficult for people with communication difficulties
Ellis-Hill (1998); Ellis-Hill et al. (2000), UK, Interviews (Qualitative), Questionnaires (Quantitative) 1998 = quantitative & qualitative; 2000 = qualitative, where 2000 is a subsample	Qualitative: • To explore the life narratives of people with stroke to understand how meaning of stroke constructed within life story & to identify the main issues faced • To explore a measure which could be used to assess identity change.	✘	Qualitative, 1998: Hospital; identified by occupational therapists; N= 10; F= 40%. Age: M= 72, range= 46-82. First stroke: 100%. Time: 6-12 months. Qualitative, 2000: Hospital; identified from 1998 paper; N= 8; F= *37.5%*. Age: M= 67,	Qualitative results reported as part of narrative synthesis (see section 5.3) Quantitative results: • At baseline, people felt they were as attractive as pre-stroke • Participants perceived selves more negatively vs past self & expected improvement. Pattern maintained at follow-ups • At 1 year: participants described themselves as inactive & dependent.	Qualitative (1998): ✓ Biographical, narrative approach facilitated people to talk about things important to them ✓ Pilot studies helped to improve data collection × People with severe speech problems excluded × People may have only participated because author was a health professional

of the 1998 cohort	Quantitative (1998): To explore self-concept after stroke using Semantic Differential self-concept scale Completed concurrently with the interviews to determine if mood is associated with self-concept, activity levels or physical ability		range= 56-82. First stroke: 100%. Time: *0 days-16 months.* Quantitative: Hospital; identified by occupational therapists; N= 30-38 across timepoints; Baseline: F= 53%, 1-year: F= 47%. Age: M= 72, range= 46-88. First stroke: 100%.	Despite physical improvements, it was issues related to their ‘active-selves’ which prevented them from being able to make the most of their ‘social-selves’	Qualitative (2000): ✓ Themes agreed between authors × Could not complete life narrative interviews with people with speech or memory difficulties Quantitative (1998): ✓ Longitudinal & prospective × All first stroke, no severe communication problems × Attrition due to longitudinal design ✓ Matched statistical analysis: so not all available data was used
Howes (2004), UK,	To explore whether the overall structure of	✓	Howes (2004) overall:	Howes (2004):	Howes (2004):

Questionnaires (Quantitative). Longitudinal repeated measures design: baseline & 1 year. Baseline represented by Howes et al. (2005a); Howes et al. (2005b)	psychological distress & body image concerns, (observed in Howes 2004 thesis; studies 1 & 2) Study 2 (Howes, 2005) (Howes et al., 2005a): to examine the perceived effect of acquired brain injury (ABI) on body image & psycho-emotional functioning to better understand how ABI affects male body image; between subjects questionnaire		Hospital; referred by clinical neuropsychologist; N= 14; F= 28.6%. Age for males: M= 41.80 (SD= 15.10). Howes (2005): General hospital & Headway group; referred by Clinical Neuropsychologist; N= 10; F= 0%, & matched control groups from general public. Age: M= 40.5 (SD= 15.01).	• Overall, for stroke & TBI: poor body image linked to depression after ABI • For males with stroke & traumatic brain injury (TBI): ➢ Self-esteem decreased with time ➢ Sexual functioning important for psycho-emotional health across timepoints • Males with stroke: thin concern increased with time • All males: at 1-year, there was a relationship between depression & fat concern	✓ Sex-specific measures could capture nuanced issues unique to sexes × Female group (Howes et al., 2005b): small sample was not large enough to split according to aetiology of injury (TBI vs stroke) × Unclear why only acute stroke included Howes (2005): ✓ Each clinical group well-matched to control group e.g., no significant differences in time since injury between stroke & TBI groups × Some measures not used with controls

Howes (2005): - Compared to controls, males with ABI (TBI & stroke) were more dissatisfied with physical & sexual functioning - TBI group: more satisfied with physical functioning & areas related to weight gain	because equivalents unavailable

Key:

^: ✓= Yes, ✗= No

#: Setting; Sampling; Sample size (N); % of females (F). Age (years). Type (of stroke) & first or recurrent? (occurrence) (%). Time (since stroke): range

†All percentages rounded to the nearest whole number

M = mean; SD= standard deviation

Italicised= researcher calculated the figure presented

*Information sought from another paper which describes a larger study from which the sample was drawn (Kirkevold et al., 2018)

Appendix 8: Summary of Post-Stroke Bodily Changes Identified from the Systematic Review

Physical and observable: Physical and/or functional

- Aged in functioning (Pallesen, 2012, 2014)
- Appetite (Boylstein, 2002)
- Arms (Raghavan et al., 2016)
- Balance (Boylstein, 2002)
- Sleep (Taule & Råheim, 2014; Taule et al., 2013)
- Constipation (Eilertsen, 2005; Eilertsen et al., 2010)
- Debility (Taule & Råheim, 2014; Taule et al., 2013)
- Difficulties with dressing if upper limb problems (Arntzen et al., 2015a)
- Dribbling (Kvigne et al., 2004; Lever & Pryor, 2015, 2017)
- Fatigue and exhaustion (Carlsson et al., 2004; Kvigne & Kirkevold, 2003)
- Functioning slowly (Kvigne et al., 2004)
- Incontinence (Kvigne & Kirkevold, 2003), urinary (Lever & Pryor, 2015, 2017)
- Inflammation (Kvigne & Kirkevold, 2003)
- Limping (Boylstein, 2002)
- Loss of control (Nanninga et al., 2015) or uncontrollable movements (Lever & Pryor, 2015, 2017)
- Not obeying signals (Backe et al., 1996)
- Paralysis (Immenschuh, 2003)
- Physical vulnerability (Kvigne & Kirkevold, 2003)
- Swallowing (Lever & Pryor, 2015, 2017)
- Unable to control natural/physical functions (Kvigne et al., 2004) such as arm movement (Taule & Råheim, 2014; Taule et al., 2013)
- Unsteady (Eilertsen, 2005; Eilertsen et al., 2010)
- Upper and lower limb difficulties, including altered tone, circulation, movement limitations (Lever & Pryor, 2015, 2017)
- Weight gain (Immenschuh, 2003; Lever & Pryor, 2015, 2017)

Less objectively evident

Cognitive

- Altered cognition (Lever & Pryor, 2015, 2017)
- Loss of control over cognitive functions (Kitzmuller et al., 2013)

- Reduced mental capacity, such as memory loss or concentration problems (Taule & Råheim, 2014; Taule et al., 2013)
- Sensitive to environmental factors (Carlsson et al., 2004)

Psychological, mood or emotion

- Anger, loss, and suicidal ideation (Ch'ng et al., 2008)
- Depression (Ch'ng et al., 2008; Kvigne et al., 2004)
- Distress (Kvigne & Kirkevold, 2003)
- Expression of and changes in emotions (Kvigne & Kirkevold, 2003; Taule & Råheim, 2014; Taule et al., 2013)
- Frustration (Kvigne et al., 2004)
- Loss of control over mood or emotions (Kitzmuller et al., 2013)
- Mental vulnerabilities (Kvigne & Kirkevold, 2003)

Sensations

- Burning (Carlsson et al., 2004; Stott, 2019)
- Coldness (Doyle et al., 2014; Stott, 2019)
- Heaviness (Carlsson et al., 2004; Doyle et al., 2014; Eilertsen, 2005; Eilertsen et al., 2010; Stott, 2019; Yamauchi, 2007)
- Hypersensitivity (Doyle et al., 2014)
- Like body/limb/fingers asleep (Carlsson et al., 2004; Doyle et al., 2014)
- Numbness (Carlsson et al., 2004; Doyle et al., 2014; Yamauchi, 2007)
- Pain (Boylstein, 2002; Kvigne & Kirkevold, 2003; Yamauchi, 2007) and pain sensations: aching, pinching, electric shock, throbbing, shooting, sharp or pounding pain (Stott, 2019)
- Other sensations: tingling, sensitive to temperature, cramps, increased sensitivity to touch or texture (Carlsson et al., 2004)
- Perceptual loss (although not pertinent for the thesis) (Stott, 2019)
- Pins and needles (Stott, 2019)
- Sensation (Lever & Pryor, 2015, 2017)
- Stiffness (Carlsson et al., 2004; Stott, 2019)
- Weight of paralysed limbs (Yamauchi, 2007)

Thoughts about body

- Body-based restrictions related to confidence (Taule & Råheim, 2014; Taule et al., 2013)

- Changed (Backe et al., 1996; Taule & Råheim, 2014; Taule et al., 2013)
- Forcible presence (Pallesen, 2012, 2014)
- Inconvenient (Pallesen, 2012, 2014)
- Odd (Doyle et al., 2014)
- Out of control (Arntzen & Elstad, 2013)
- Trust in ability reduced (Pallesen, 2012, 2014)
- Unfamiliar (Taule & Råheim, 2014; Taule et al., 2013)
- Unpredictable (Carlsson et al., 2004; Kvigne & Kirkevold, 2003)
- Unreliable (Arntzen & Elstad, 2013; Pallesen, 2012, 2014)
- Varying and fluctuating (Carlsson et al., 2004)
- Vulnerable (Pallesen, 2012, 2014)

Combination

Communication changes

- Communication difficulties (Lever & Pryor, 2015, 2017)
- Control of physical functions in formulating a word (Taule & Råheim, 2014; Taule et al., 2013)
- Language (Bronken et al., 2012)
- Not being able to find the right words (Kvigne et al., 2004)
- Voice sounding different (Raghavan et al., 2016)

Spasticity

- In terms of specific symptoms of stroke, spasticity was associated with pain, spasms, fatigue, restricted movement, loss of balance, and altered (Barker et al., 2013). Post-stroke spasticity was represented by ten health-related QoL domains in terms of effects on individual wellbeing: symptom impact, physical function, activities of daily living, ambulation and mobility, ambulation risk, social function, social support, loss of role function, appearance, and adaptive resiliency (Atkinson et al., 2012).

Appendix 9: Example of the Standard Information Sheet for the Interviews

Developing a Model of Post-Stroke Body Image Perception, V1.1
Phase 2: Interviews, Participant Information Sheet, 30/06/2021
IRAS ID: 280678

Hospital logo

PARTICIPANT INFORMATION SHEET: STROKE SURVIVORS INTERVIEWS

1. Title of Study

Developing a Model of Post-Stroke Body Image Perception

2. Version Number and Date

V1.1, 30/06/2021

3. Invitation to Participate

We would like to invite you to take part in a research study which is part of a PhD project at the University of Central Lancashire (UCLan). It is being conducted by a PhD student (the researcher) and a team of experienced researchers. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask questions. Talk to others about the study if you wish. Thank you for reading this information sheet.

4. What do we want from the study?

After someone has had a stroke, they might feel as if their body image has changed. We want to explore how people experience any changes that might happen to their body after having a stroke. We also want to look at how those changes might affect them, and how best to measure them.

5. Why have I been invited to take part?

You have been invited to take part because you have experienced a stroke.

6. Do I have to take part?

Taking part is voluntary. If you do not wish to take part, your care will not be affected in any way. If you would like to take part, then we will ask you to sign a consent form. If you have difficulty with writing or your eyesight, a witness will listen to your responses in relation to the information sheet/questions and attest to your verbal consent to participate. The witness may be your relative/friend, or a member of staff, it is your choice.

7. What will happen to me if I take part?

If you agree to take part, you will be invited to a one-to-one interview with the researcher. Before the interview begins, the researcher will check that you are still happy to participate. You may also be contacted between 6-12 months later to take part in another interview so that we can see how body image perceptions change over time.

The researcher will ask you some questions about yourself, your stroke and how you are feeling. Then, you will be asked some questions about the way you feel about your body since your stroke. You can talk about your experiences, and use creative materials such as pictures, paints, and pens to help you answer the questions if you prefer. We may also talk about ways to assess body image after stroke.

The interview will take place in a mutually convenient location e.g. at your home, or in a private room at UCLan or hospital. We anticipate that it will last about 1-1.5 hours. After the interview, you will have chance to ask questions. You may stop participating at any time without giving a reason or abstain from answering any questions that you don't want to talk about.

1. Are there any special arrangements being made because of COVID-19?

For your safety, if COVID-19 is still an issue at the time when we arrange the interview, we won't meet face-to-face. Instead, we can use virtual conferencing software, such as Microsoft Teams, or telephone. If this is the case, we will support you in participating, including setting up and using the software.

2. How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The University privacy notice for research participants can be found on the attached link https://www.uclan.ac.uk/data_protection/privacy-notice-research-participants.php

No personal data will be transferred outside the European Union.

We will only use information from you that we need for the research study. This information will include:

- **Your name and contact details**- so that we can contact you and send out study materials
- **Information about your GP**- to inform your GP, with your consent, of your participation and as an emergency contact should we be concerned about your welfare
- **Audio and/or screen capture recordings of the interview** – we will type these out (transcribe them) and use them to help understand your experience of body image.
- **Creations that you might make during the group**- the researcher with your permission, will scan or photograph these and use them to help explain the results of the study. They may also be shown to participants in a later part of the project but will be anonymised first.

3. How will my data be stored?

We will keep all information about you safe and secure in line with the University Data Protection Code of Practice. All data that we collect will be transferred onto and stored on a secure UCLan drive. Physical copies of information, including paper copies of consent forms, will be stored in locked filing cabinets in locked UCLan rooms only accessible by project and research staff.

National laws may require us to show information to university or government officials (or sponsors), who are responsible for monitoring the safety of this project. In this situation, directly identifying information (e.g. names, addresses) would be safeguarded and maintained under controlled conditions.

It is possible in some circumstances, (where there is a risk to your safety or that of others) that the researcher may be concerned about some of the issues that you have raised. If this happens, the researcher may wish to discuss what you have said with a member of staff responsible for your clinical care, or your GP as appropriate. However, if the researcher does have to discuss any issues that you have raised, they will also discuss it with you.

4. Will my data be anonymised?

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a unique code number instead. We will write our reports in a way that no one can work out that you took part in the study.

5. How long will my data be stored for?

Your data will be stored securely at UCLan for the duration of the PhD project and an additional 5 years. Then, it will be fully anonymised and added to the UCLan data repository for future use in accordance with the Research Data Management Policy. At this time, all data that could identify you will be deleted or shredded. Anonymised data will be made open access as appropriate. Your contact details will be destroyed once we no longer need to contact you.

6. What are my choices about how my information is used?

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. You can stop being part of the study at any time, without giving a reason, but with your permission we will keep information about you that we already have.

7. Are there any possible disadvantages or risks in taking part?

You may find that just talking about some issues can be upsetting or make you feel emotional. In these circumstances, the researcher can discuss these issues further and provide suggestions of people to talk, for example, helplines or your GP.

8. Are there any benefits from taking part?

There is no intended benefit to you from taking part, other than being able to talk about your body image experiences after stroke. You may find participation in the research rewarding on a personal level. It is hoped the information we get from this study will help provide information to inform psychological and emotional care in the future.

9. What will happen if I want to stop taking part?

You are free to withdraw at any time during the study without giving any reasons or explanation, and without incurring a disadvantage. You have until your data begins analysis to withdraw it.

10. Expenses and / or payments

Travel expenses will be reimbursed at the rate of public transport or local taxi fare.

11. What will happen to the results of the study?

Findings will be shared widely using a range of methods, these will include:

a) Written feedback provided to study participants
b) Presentations at a range of conferences
c) Publication in a PhD thesis and journals

12. Who has reviewed the study?

The study has been reviewed and given a favourable opinion by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing, and dignity.

13. Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- Leaflet available from www.hra.nhs.uk/patientdataandresearch or a copy from the research team
- By asking one of the research team
- By contacting the researcher through email (cdavidson4@uclan.ac.uk) or telephone (01772 895537)

You may keep this information sheet and you will also be given a copy of the signed consent form.

14. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the Chief Investigator for the project, Professor Liz Lightbody on 01772 893648 or celightbody@uclan.ac.uk and we will try to help. If you remain unhappy or would like to speak to someone external to the project, or have a complaint which you feel you cannot come to us with, then please contact the Research Governance Unit at OfficerForEthics@uclan.ac.uk.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

15. Who can I contact if I have further questions?

If you have any further questions, you can contact the researcher (PhD student) or the Chief Investigator for this project. Contact details are below.

16. Contact details of investigatory team

Researcher/PhD Student:
Name: Catherine Davidson
Contact number: 01772 895537
Email address: cdavidson4@uclan.ac.uk
Mailing address: BB444, Brook Building, University of Central Lancashire, Preston, PR1 2HE

Chief Investigator:
Name: Professor Liz Lightbody
Contact number: 01772 893648
Email address: celightbody@uclan.ac.uk.
Mailing address: BB415, Brook Building, University of Central Lancashire, Preston, PR1 2HE

If you have any concerns about the study before, during or after participating you can contact your local Patient Advice and Liaison Service:

Name	Address	Telephone Number
HOSPITAL NAME	*HOSPITAL ADDRESS*	*PALS NUMBER*

17. Support Contact Details

Stroke Association: 0303 3033 100
Headway: 0808 800 2244
Mind: 0300 123 3393

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 10: Example of the Standard Consent Form for the Interviews

University of Central Lancashire
UCLan

Developing a Model of Post-Stroke Body Image Perception, V1.1
Phase 2: Interviews, Consent Form, 30/06/2021
IRAS ID: 280678

Hospital logo

PARTICIPANT CONSENT FORM: PHASE 2 INTERVIEWS

TITLE: Developing a Model of Post-Stroke Body Image Perception

Name of Chief Investigator: Professor Liz Lightbody

Version Number:

Please <u>initial</u> the box if you agree

1. I confirm that I have read and understood the information sheet dated [**DATE & VERSION NUMBER**] for the above study. I have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary. I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected. ☐

3. I understand and consent that if I withdraw during the interview, data collected before my withdrawal will be kept with my permission, but no further data will be collected from me. After the interview, I understand that I have until data analysis begins to withdraw my data. ☐

4. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Central Lancashire. ☐

5. I understand that relevant sections of my data collected during the study may be looked at by individuals from the UCLan Research Team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my information. ☐

6. I understand that the information and transcribed data collected about me, and anything that I create during the interview, will be anonymised and used to support other research in the future. It will ☐

not be possible for any participant to be identified from this anonymised data.

7. I agree to my General Practitioner being informed of my participation in the study. ☐

8. I understand that if I record or say anything that may lead the researchers to have concerns for my safety (or the safety of others) that they will have a duty of care to report this information to the relevant regulatory person/organisation. ☐

9. I agree to:

    a. Participate in an interview with the researcher taking consent ☐

    b. Allow the sessions to be audio-recorded and transcribed. *(This is a requirement to enable analysis of your data).* ☐

    c. Also allow the session to be screen-captured (video-recorded) if virtual. ☐

    d. Being contacted in the future by the researcher taking consent and asked to provide my opinions on a summary of the data ☐

    e. Potentially being contacted in the future by the researcher taking consent and invited to take part in a second interview in around 6-12 months ☐

10. The transcribed and anonymised data, including any drawings or creations that you produce during or for the interview, will be used for a number of purposes. Key themes will be drawn from the data analysis, and where relevant, quotes taken from the data may be used. Your creations may be used to help explain some of the themes. This data will be anonymised and therefore cannot be traced back to any individual:

    a. I agree for my data to be used in reports or publications, and to be used for future teaching and training purposes. ☐

    b. I agree that any drawings or creations that I produce can be anonymised and shown to participants in a different part of the study ☐

c. I agree for my data to be shared within the same research theme. ☐

11. I would like to receive a summary of the study results when it is completed and therefore consent to my contact details being securely stored separately from the consent form for this purpose, and then destroyed. ☐

12. I agree to take part in the above study. ☐

Participant name	Date	Signature
Name of person taking consent	Date	Signature

Chief Investigator
Professor Liz Lightbody
BB415, Brook Building, UCLan
01772 893648
celightbody@uclan.ac.uk

Student Investigator
Catherine Davidson
BB444, Brook Building, UCLan
01772 895537
cdavidson4@uclan.ac.uk

Appendix 11: Contact Details Form for the Interviews

University of
Central Lancashire
UCLan

Hospital logo

Name: ___________________________

Telephone: ___________________________

Email address:

____

Postal address:

____

____

____

____

Appendix 12: Example of the Witnessed Consent Form for the Interviews

University of Central Lancashire
UCLan

Developing a Model of Post-Stroke Body Image Perception, V1.1
Phase 2: Interviews, Witnessed Consent Form, 30/06/2021
IRAS ID: 280678

Hospital logo

WITNESSED CONSENT FORM: PHASE 2 INTERVIEWS

THIS FORM IS TO BE USED ONLY FOR PARTICIPANTS WHO HAVE VISUAL IMPAIRMENT OR DIFFICULTIES WITH WRITING

TITLE: Developing a Model of Post-Stroke Body Image Perception

Name of Chief Investigator: Professor Liz Lightbody

Participant Name: ___________________

Version Number:

Please <u>initial</u> the box if you agree

1. I confirm that the participant named above has read and understood the information sheet dated [**DATE AND VERSION**] for the above study. They have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily. ☐

2. The participant named above understands that their participation is voluntary and that they are free to withdraw at any time without giving any reason and without their medical care or legal rights being affected. ☐

3. The participant named above understands and consents that if they withdraw during the interview, data collected before their withdrawal will be kept with their permission, but no further data will be collected from them. After the interview, they understand that they have until data analysis begins to be able to withdraw it. ☐

4. The participant named above understands that the information they provide will be held securely and in line with data protection requirements at the University of Central Lancashire. ☐

5. The participant named above understands that relevant sections of their data collected during the study may be looked at by individuals from the UCLan Research Team, from regulatory authorities or ☐

from the NHS Trust, where it is relevant to them taking part in this research. They give permission for these individuals to have access to their information.

6. The participant named above understands that the information and transcribed data collected about them, and anything that they create during the interview, will be anonymised and used to support other research in the future. It will not be possible for any participant to be identified from this anonymised data. ☐

7. The participant named above agrees to their General Practitioner being informed of their participation in the study. ☐

8. The participant named above understands that if they record or say anything that may lead the researchers to have concerns for their safety (or the safety of others) that they will have a duty of care to report this information to the relevant regulatory person/organisation. ☐

9. The participant named above agrees to:

    a. Participate in an interview with the researcher taking consent. ☐

    b. Allow the sessions to be audio-recorded and transcribed. *(This is a requirement to enable analysis of their data).* ☐

    c. Also allow the session to be screen-captured (video-recorded) if virtual. ☐

    d. Being contacted in the future by the researcher taking consent and asked to provide their opinions on a summary of the data ☐

    e. Potentially being contacted in the future by the researcher taking consent and invited to take part in a second interview in around 6-12 months ☐

10. The transcribed and anonymised data, including any drawings or creations that participants produce during or for the interview, will be used for a number of purposes. Key themes will be drawn from the data analysis, and where relevant, quotes taken from the data may be used. Their creations may be used to help explain some of the themes. This data will be anonymised and therefore cannot be traced back to any individual:

a. The participant named above agrees for their data to be used in reports or publications, and to be used for future teaching and training purposes. ☐

b. The participant named above agrees that any drawings or creations that they produce can be anonymised and shown to participants in a different part of the study ☐

c. The participant named above agrees for their data to be shared within the same research theme. ☐

11. The participant named above would like to receive a summary of the study results when it is completed and they therefore consent to their contact details being securely stored separately from the consent form for this purpose, and then destroyed. ☐

12. The participant named above agrees to take part in the above study. ☐

13. I confirm that I have acted as witness to this consent procedure (witness to initial box). ☐

Relationship or professional to the patient who witnessed the consent

____

Name of witness	Date	Signature
Name of person taking consent	Date	Signature

Chief Investigator
Professor Liz Lightbody
BB415, Brook Building, UCLan
01772 893648
celightbody@uclan.ac.uk

Student Investigator
Catherine Davidson
BB444, Brook Building, UCLan
01772 895537
cdavidson4@uclan.ac.uk

Appendix 13: Example of the Aphasia-Friendly Information Sheet for the Interviews

Hospital logo

Phase 2: Interviews

PARTICIPANT INFORMATION SHEET

Developing a Model of Post-Stroke Body Image Perception

Information sheet

We would like to ask you to take part in some research.

We are doing some **research.**

Would you like to **take part** in the **research**?

It's up to **you** to **decide**.

But first, you need to **understand** the research.

Please **read this information** carefully.

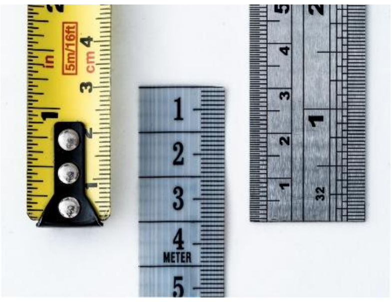
You can **talk to your friends or family or your GP** about the research.

What is the study about?

Stroke can **change the way people think about their body.**

We want to know **how** people **experience these changes** to their body and **how** these changes might **affect them.**

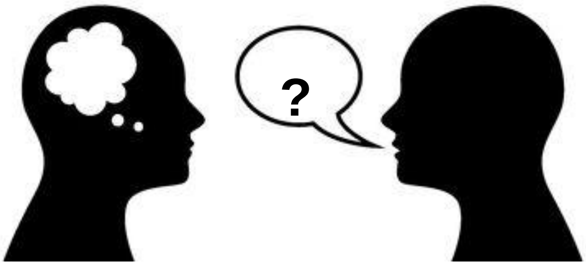
We also want to think about how to **measure these changes**.



Do I have to take part?

You are **free** to **decide** whether or not to **take part**.

We will give you **all** the **information** about the study and answer all your **questions**.



We will ask you to **sign a consent form**.

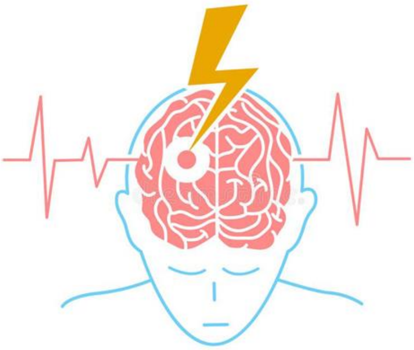
You are **free** to **stop** the research at any time and you **do not** have to give a **reason**.

Information we have collected from you up to the point of stopping, will be **kept** with your permission, and used in the research.

Why have I been asked to take part?

You are **over 18 years** old.

You have had a **stroke**.



Do I have to take part?

No, you do not.

How can I take part?

You can take part in a **one-to-one interview** with a researcher.

We think it will take about **1-1.5 hours.**

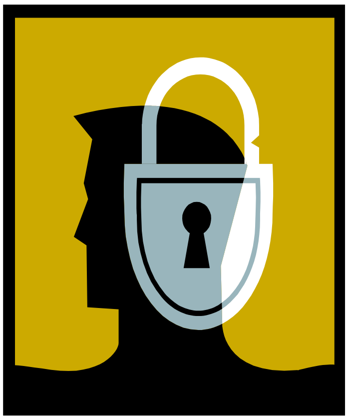
We will hopefully **meet in person**. If this is **not possible because of the Coronavirus,** we will talk through **video call or telephone.**

We can **make sure** you have the **right equipment** for this.

The interview will take place in a **private place**.

The interview will be **audio-recorded.** If the interview is a **video call, the screen will be recorded.** This means the recording would show your face.

The recordings will be **typed out** and **your name** will **not be used**.



All **information** will be **locked away**.

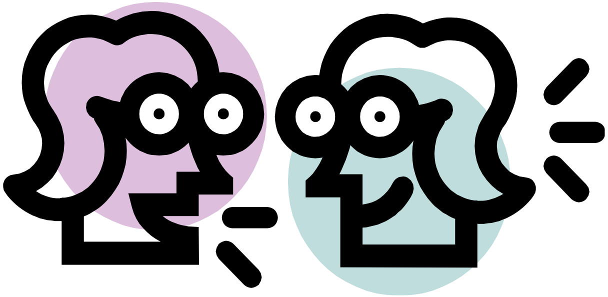
The researcher will make sure that you have some **creative materials** available, like pens or paper, to help you **express yourself** during the interview.

The researcher, with your permission, may **show other participants** your **creations** in a later part of the study.

 	We will tell **your GP** that you are taking part.

What are the possible **good things** about taking part?

You might **enjoy talking** about it**.**



You can **help develop research** that may **help patients following a stroke.**

What are the possible bad things about taking part?

It is **very unlikely** that taking part will **cause you harm**.

You **might** find it **upsetting** to talk about how you **feel about your body** after stroke**.**

What if I want to stop taking part?

You can **stop** taking part at **any time**.

You **do not have to give a reason** for this.

Will I be **paid** for taking part?

No, you will not be paid.

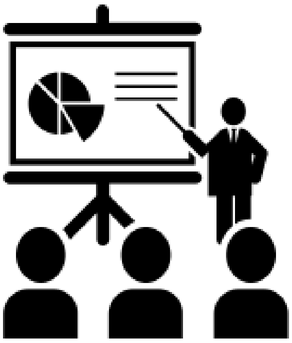
If you have to travel, **we can pay** for **public transport or local taxi** and **provide refreshments.**

Will taking part be confidential?

Yes.

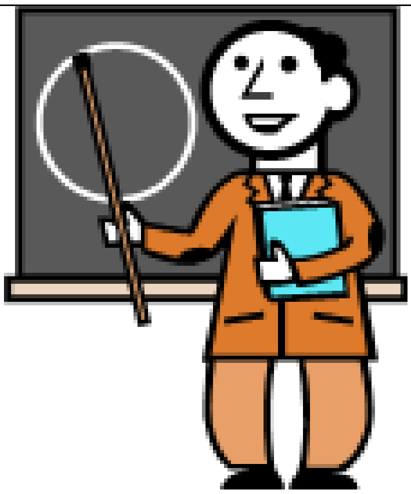
What will happen when the research finishes?

We will **present results at conferences.**



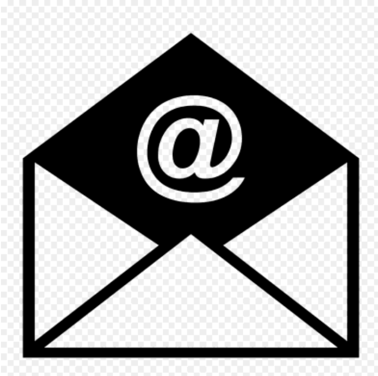
We will try to **publish results in journals**.

It may be used for teaching purposes and to contribute to **other projects** within the **same research theme.**



If you would like to know the **outcome** of the study, we can send you a **summary** of the **results** on completion.

We will **check** whether **you are happy** for us to **keep your contact details** for this.



Who is **organising** the research?

The **University of Central Lancashire** is paying for this study.

1828
University of
Central Lancashire
UCLan

Who has **reviewed** the research?

The **NHS Research Ethics Committee** have **approved** the study**.**

You may **keep this information** and a copy of the **signed consent form**.

Who do I **contact** if I have any questions?

Contact **Catherine Davidson,** who is the **student doing the research:**

☎ **01772 895537**

✉ **cdavidson4@uclan.ac.uk**

Contact **Professor Liz Lightbody,** who is the **Chief Investigator** for the research**:**

☎ **01772 893648**

✉ **celightbody@uclan.ac.uk**

What if there is a problem?

Contact **Professor Liz Lightbody (see above)** ↑

You can also contact the **University Research Governance Unit**:

☎ **01772 892728**

✉ **OfficerForEthics@uclan.ac.uk**

How can I complain?

To **complain formally**, follow the **NHS Complaints Procedure**.

Ask your hospital about this.

You can access independent information and advice about research, or regarding NHS complaints procedure, by contacting the **Patient Advice & Liaison Service**:

[INSERT LOCAL PALS INFORMATION SPECIFIC TO NHS TRUST]

☎

You can contact the following **charities** if you need any **support** or someone to talk to:

☎

Stroke Association: 0303 3033 100
Headway: 0808 800 2244
Mind: 0300 123 3393

Appendix 14: Example of the Aphasia-Friendly Consent Form

University of Central Lancashire
UCLan

Hospital logo

Phase 2: Interviews

PARTICIPANT CONSENT FORM

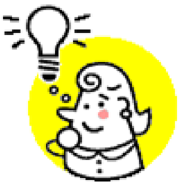
Developing a Model of Post-Stroke Body Image Perception

Chief Investigator: Professor Liz Lightbody

Participant ID: ____________________

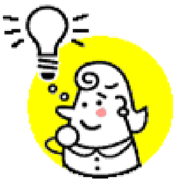
Version Number:

Please circle the appropriate box

 	I have **read** and **understood** the **information sheet.**	

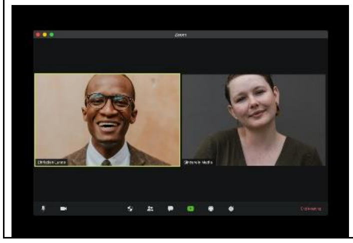
 	I have had **time to think** about the **information** and ask **questions**.	👍 yes no 👎

☺	I am **happy** with the answers.	👍 yes no 👎

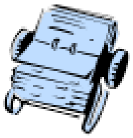
 	I **understand** that I can **stop** at **any time;** I do **not** have to **give a reason.** If I	👍 yes no 👎

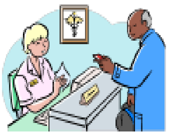
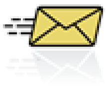
	stop, **I agree that information** about me **up to** that point can be **kept.**	

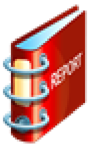
 	I agree to be **interviewed** about **how I feel** about **my body** since my stroke.	

 	I am happy for the **interview** to be **audio** and/or the **screen**	

	recorded if the interview is through video call.	

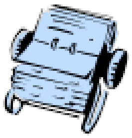
 	I agree that researchers may have my **contact details** so they can **ask my opinions** on the findings and **might invite** me for **another interview.**	

 	I agree to my **GP** **being informed** of my participation in the study.	yes no

  	I understand that **information** collected about me will be **anonymised** and used in **reports and conferences,** and for **teaching purposes.**	yes no yes no yes no

 	I agree that anything **creative** that **I produce** may be **shown to participants** in a later part of the study, after it has been **anonymised**.	

 	I agree that my **anonymised information** may contribute to **other projects** in the **same research theme**.	

 	I would like to receive **a summary of the results** and agree that researchers may keep my **contact details** for this purpose.	

---------------------------------	-----------------	-----------------------------------
Name of participant	Date	Signature
---------------------------------	-----------------	-----------------------------------
Name of researcher	Date	Signature
---------------------------------	-----------------	-----------------------------------
Name of witness (if appropriate)	Date	Signature

MPhil/PhD Research Student
University of Central Lancashire
PR1 2HE
☎ 01772 89**5537**
E-mail: cdavidson4@uclan.ac.uk

Appendix 15: Baseline Questionnaire

Participant ID: ___________________________

The researcher will read the following questions to the participant and fill in the answers.

GP Information
1) Name of GP ______________________________ 2) GP surgery ________________________________ 3) GP address (Town/location will suffice): ____ ____ 4) GP contact number (if known) ______________________________

Participant ID: ____________________________

Demographic Information

5)

a. Date of birth ____/____/________

b. Gender:

☐ Male
☐ Female
☐ Other
☐ Prefer not to say

c. How would you describe your ethnic group? For example, White British, Indian, White and Black African.

____

d. Postcode _____________________

e. Marital status ____________________

f. Highest level of education _____________________

g. What is your current occupation or previous occupation?

____

h. Current weight ____________________

i. Height ____________________

Physical Disabilities Before Stroke

6) Pre-Stroke Modified Rankin

Which of the following best described you before the stroke:

☐ No symptoms at all

☐ No significant disability despite symptoms; able to carry out all usual duties and activities

☐ Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance

☐ Moderate disability; requiring some help, but able to walk without assistance

☐ Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance

☐ Severe disability; bedridden, incontinent and requiring constant nursing care and attention

Pre-Stroke Cognitive Information

7) Did you have any cognitive problems before your stroke, such as memory, speech or concentration difficulties? ☐Yes ☐No

   a. If 'Yes', please specify ___________________________________

   b. If 'Yes' were they: ☐Mild ☐Moderate ☐Severe

Initial Stroke Information

8) When was your most recent stroke? ____/____/________

9) Was this your first stroke?
   ☐ Yes
   ☐ No (please give the dates of all of your previous strokes below in the format MM/YYYY)

   ____/________ ____/________

   ____/________ ____/________

10) Thinking about your most recent stoke, what type of stroke was it?
   ☐ Clot
   ☐ Bleed
   ☐ Unknown

11) Which side of your body was affected?
   ☐ Right
   ☐ Left
   ☐ Neither
   ☐ Not Sure

12) Do you think your stroke was:
   ☐ Mild
   ☐ Moderate
   ☐ Severe

Symptoms of the Stroke

13) Please tell me about any other symptoms caused by your stroke.

____

☐Mild ☐Moderate ☐Severe

____

☐Mild ☐Moderate ☐Severe

____

☐Mild ☐Moderate ☐Severe

____

☐Mild ☐Moderate ☐Severe

____

☐Mild ☐Moderate ☐Severe

14) Current Modified Rankin

Do you have:

☐ No symptoms at all

☐ No significant disability despite symptoms; able to carry out all usual duties and activities

☐ Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance

☐ Moderate disability; requiring some help, but able to walk without assistance

☐ Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance

☐ Severe disability; bedridden, incontinent and requiring constant nursing care and attention

Current Stroke Function

15) Current Barthel
Please rate the following activities based on how independent or how much help you need with them.

1. ☐ Feeding (if food needs to be cut up = help)
   With help= 5, Independent = 10

2. ☐ Moving from wheelchair to bed and return (includes sitting up in bed)
   With help= 5-10, Independent = 15

3. ☐ Personal toilet (wash face, comb hair, shave, clean teeth)
   With help= 0, Independent = 5

4. ☐ Getting on and off toilet (handling clothes, wipe, flush)
   With help= 5, Independent = 10

5. ☐ Bathing self
With help= 0, Independent = 5

6. ☐ Walking on level surface (or if unable to walk, propel wheelchair)
*score only if unable to walk
Walking: With help = 10, Independent = 15
Propelling a wheelchair: With help= 0*, Independent = 5*

7. ☐ Ascend and descend stairs
With help= 5, Independent = 10

8. ☐ Dressing (includes tying shoes, fastening fasteners)
With help= 5, Independent = 10

9. ☐ Controlling bowels
With help= 5, Independent = 10

10. ☐ Controlling bladder
With help= 5, Independent = 10

Current Mood

16) PHQ-9

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?

☐ 1. Little interest or pleasure in doing things.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 2. Feeling down, depressed or hopeless.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 3. Trouble falling/staying asleep, sleeping too much.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 4. Feeling tired or having little energy.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 5. Poor appetite or overeating.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 7. Trouble concentrating on things, such as reading the newspaper or watching television.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 9. Thoughts that would be better off dead or of hurting yourself in some way.
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

Total score: ☐

If the participant has been bothered by <u>any</u> of the 9 problems listed above, please get them to answer the following:

☐ How *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?
(0 = not difficult at all 1 = somewhat difficult 2 = very difficult 3 = extremely difficult)

Psychological Information

17) GAD-7
Over the **<u>last 2 weeks</u>**, how often have you been bothered by the following problems?

☐ 1. Feeling nervous, anxious or on edge?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 2. Not being able to stop or control worrying?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 3. Worrying too much about different things?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 4. Trouble relaxing
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 5. Being so restless that it is hard to sit still?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 6. Becoming easily annoyed or irritable?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

☐ 7. Feeling afraid as if something awful might happen?
(0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day)

Total score: ☐

Please check the above scores against the scoring chart, and record results.

If the participant has checked off <u>any</u> problems, please get them to answer the following:

☐ How *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?
(0 = not difficult at all 1 = somewhat difficult 2 = very difficult 3 = extremely difficult)

Post-Stroke Cognitive Information

18) Has your stroke caused any cognitive problems? ☐Yes ☐No

c. If 'Yes', please specify ___________________________________

d. If 'Yes', are they: ☐Mild ☐Moderate ☐Severe

Other Illnesses

19) Do you have any other significant illnesses?
☐ No
☐ Yes (please list below)

____

____

____

____

Researcher Comments

Appendix 16: Interview Schedule

INTERVIEW QUESTIONS

Where [body image] is written, this should be replaced with aspects of how participant has described body image or the phrase 'your body'
'Tell me' can be inter-changed/replaced with 'show me', 'draw' etc.

As you know, our interview today is about body image.

Body Image

1. What is your interpretation of what 'body image' is?

- ➢ Summarise their interpretation e.g. it sounds like…

Stroke

I'm going to change tac a little bit now.

2. I'd like you to tell me about your stroke
    a. *Prompts: what happened when you had your stroke? How long were you in hospital for? How did you feel while you were in hospital? How did you feel when you first came home? How do you feel now?*

- ➢ *Summarise main aspects of stroke, leading into how they feel now in relation to their body*

Effects of Stroke on Body Image

When I asked you about body image, you said it was about X, Y and Z.

Only use if needed: You've described A, B and C about how your stroke has affected you.

If got photos to share: shall we start by looking at the photos that you have brought?

Do you think you could draw for me/show me photos/use Padlet… something that represents how you feel about [how you perceive your body/your body image] since you had your stroke?

3. With this in mind, how do you think your stroke has impacted on [how you perceive your body/your body image]?
4. Describe [or show me] how you feel about [how you perceive your body/your body image] now compared to before your stroke (or strokes).
    a. *Prompts: Please describe how your body feels (e.g. sensations, or how it feels physically)*

   b. Can you draw/show me me something to represent yourself before and after?

Do you have any images/colours/pictures that would represent that?

If your [friend/partner/child] was talking to me now, what would they see/think?

If mention being old: Can you describe what an old person looks like? Is that how you see yourself?

5. Describe any ways that [how you perceive your body/your body image] affects you
   a. *Prompts: does it affect things you might do everyday? Does it affect anything you'd like to do? Does it affect how you feel?*

- *Summarise feelings and affects*

Positive/Negative Experiences

6. Tell me about any occasions since your stroke where you have experienced a positive/good [how you perceive your body/your body image].
   a. *Prompt: explain what made it positive. How did it make you feel?*
   b. *If not had positive body image experiences: Why do you think that is?*

Can you show me something that represents how you felt or represents the situation?

7. Tell me about any occasions since your stroke where you have experienced a negative/bad [how you perceive your body/your body image].
   a. *Prompt: explain what made it negative. How did it make you feel?*

Can you show me something that represents how you felt or represents the situation?

Body image: affected by anything else?

8. Is there anything else that you think has affected [how you perceive your body/your body image] [e.g. X, Y and Z] since your stroke?
   a. *Prompts: Why? How did it make you feel?*

Body image:

9. If I ask you to think widely now, including [how you perceive your body/your body image], what would you say has affected you most since your stroke?

   a. *Prompts: What has impacted your life the most? What has impacted how you feel about yourself the most?*

10. How does that compare to how you feel about [how you perceive your body/your body image]?

Could you draw something that depicts how important [how you perceive your body/your body image] is compared to [what has affected you the most]?

- Text size, circles, colours?

Body image: What would help?

11. What would help you [or other people] with the way they feel about their [perceptions of their body/body image] after stroke?
    - *Prompts: why?*

Anything else?

12. Is there anything else you would like to talk about today in relation to [how you perceive your body/your body image] and your stroke?

Showing the Stott diagram (Stott et al., 2021)

13. I'd just like to show you a diagram that has been created to show how people might feel about their body after a stroke. I didn't make it and I've got no links to it so you can be as honest as you like about what you like and dislike about it

a. Tell me about whether it makes sense
b. Describe anything that you like about it
c. Describe anything that you don't like about it
d. Describe whether any of it resonates with you
e. Describe any ways that you think it could be modified or improved or anything that needs adding to it or taking away

Is there anything else that you'd like to say about the model before I close it?

Anything else?

14. Is there anything else you would like to talk about in relation to [how you perceive your body/your body image] and your stroke?

Closing the interview- summarising and ending on a positive note

- Thank you I really appreciate your time
- Talk about a positive → main points of journey → end with recovery progress/on positive note
    - e.g. sounds like a long journey but that you're well on your way to recovery
- The information that you've provided is really useful
- Is there anything else that you'd like to talk about today?
- What do you think about these ways of talking i.e. using different materials?
- *Confirmation of sexual orientation if not already clear from the interview.*

Checking feelings

- How are you feeling now? Sometimes talking can raise things for people i.e. you might not have thought about it before
    - Want to make sure you're okay before I leave you
- If upset, signpost people
- Thank you again for describing your experiences
- Don't forget, if you feel like you would like to talk to someone [or get some support] in more detail about any of the issues raised today, I will be providing you with some details of people or organisations to contact and there are also some details on the information sheet
- You can also of course contact your GP

My contact details and the chief investigator's details are on the information sheet should any questions arise later

Checking future contact

If done anything creative:

- Would you mind if I sent you a summary of my interpretations of the [drawings/pictures] you've done today and you can check if I've understood? This will be over the next few weeks.
    - How would you like to receive the summary?
    - If by post: I'll let you know when I have sent it, and then you can contact me in your own time to let me know if I have interpreted it correctly

- From the interviews, I'm going to create a model of what body image experiences might be like after stroke. Would it be okay with you if I sent you a copy when it's complete and asked you for some feedback? It's completely up to you.
    - What format?

- Would you like to be sent a summary of the results?
    - What format?

- I might be doing some repeat interviews with some people who I talk to. Would you be happy to potentially be contacted in the future about a repeat interview for this study?
    - Email, phone or post?

Are you happy for your contact details to be stored for these purposes?

In the future, I will be running focus groups and am inviting friends and relatives of people who have had a stroke.

I don't need to know for definite now as it's just to give me an idea of whether you might know of anyone, but do you know of anyone who might like to take part?

Are you happy for your contact details to be stored so that I can contact you if I'd like to find out more about speaking to [relatives/friends]?

Thank you, I'll now stop the recording.

STOP THE RECORDING

Thank you

I'll send those support details out [on additional sheet]: *Improving Access to Psychological Therapies (IAPT) services, Stroke Association, Headway and Mind*

If you think of any questions, please don't hesitate to let me know

I'll be in touch in the future

Prompts (where required)

General prompts:

- Tell me [show me] more about that
- Describe [show/depict/draw] that in more detail
- Explain [show/depict/draw] what you mean by that

Information prompts:

- Can we explore that a bit further?
- How has that impacted on you?
- Observe and reflect back e.g. it appears that that has upset you
- What does 'normal' mean?
- So from what you've said…
- It seems like…

Phrases to support participants if they get upset:

- Acknowledge emotion: use their words back to them
- You might not have thought about this before, but you could talk to [*signpost*]
- It could be useful to talk to someone.
- I notice that you look upset/thoughtful. It could be helpful to speak to someone about it.
- It's fine/normal to feel like that, it's not just you
- That's a normal reaction
- I've heard a lot of people saying that kind of thing
- It appears that's upset you
- What you've said seems to have upset you. That's understandable. Would you like a minute?

If someone else joins the interview:

- I don’t want to seem rude but I wondered if we could have our chat in private?
- Maybe at the end if it’s okay with [NAME], you could come in and have a chat?
- If additional person stays: you will be on the recording, but nothing that you say today will be used in the research because I haven’t consented you

Appendix 17: Example of the GP Notification of Participation Letter

University of Central Lancashire
UCLan

Developing a Model of Post-Stroke Body Image Perception, V1.0
Phase 2: GP Letter, Participation, 24/09/2020
IRAS ID: 280678

Hospital logo

Date:

Dear Dr

Re:

Patient Name ____

Address ____

____

This letter is to inform you that the above-named patient has agreed to participate in a research study, Developing a Model of Post-Stroke Body Image Perception. This is a one-to-one interview study aimed at exploring body image perceptions after stroke. Your patient may also be invited back for a second interview after 6-12 months.

At the beginning of the interviews, participants will be asked some questions about functional ability (Modified Rankin and Barthel Index) and also how they are feeling PHQ-9 and GAD-7.

Participants who complete two interviews will complete a set of measures for each interview.

You do not need to do anything in response to this letter. However, if your patient screens as depressed or anxious or indicates that they are in crisis based on questionnaire responses and the interview, we will notify you and also advise the participant to contact you.

Yours Sincerely,

Catherine Davidson

MPhil/PhD Student
University of Central Lancashire
Preston
PR1 2HE

Tel: 01772 895537
Email: cdavidson4@uclan.ac.uk

Appendix 18: Example of the GP Cause for Concern Letter

Developing a Model of Post-Stroke Body Image Perception, V1.0
Phase 2: GP Letter, Cause for Concern, 24/09/2020
IRAS ID: 280678

Hospital logo

Date:

Dear Dr

Re:

Patient Name ____

Address ____

____

The above-named patient is currently participating in a research study, 'Developing a Model of Post-Stroke Body Image Perception'. This involves a one-to-one interview, aimed at helping us to understand body image perceptions after stroke.

Within this study, patients are screened for depression using the PhQ-9 and anxiety using the GAD-7. Our data collection indicated that your patient named above has scored highly on the following measure/s:

PHQ-9 GAD-7 Both

To score highly on the PHQ-9, they have scored 15 or above. This indicates that they have expressed moderately severe, or severe symptoms of depression and/or low mood. To score highly on the GAD-7, they have scored 10 or above. This indicates that they have expressed moderate or severe anxiety.

We are, therefore, writing to you in order that you may contact your patient for follow-up. As part of the regulatory reporting requirements, we would appreciate your acknowledgement of this letter either via a phone call to 01772 895537 or via a secure email to cdavidson4@uclan.ac.uk.

If you require any further information, or if you wish to discuss something directly please contact me on the details below.

Yours Sincerely,

Catherine Davidson

MPhil/PhD Student
University of Central Lancashire
Preston
PR1 2HE
Tel: 01772 895537

Email: cdavidson4@uclan.ac.uk

Appendix 19: Examples of Methods to Derive Themes and Subthemes

Method	Examples of use	Theme/ subtheme corresponding with example/s
Abstraction (putting like with like),	"you get a bit conscious knowing that you've had a stroke, so that what you think people look at, look at you and think, might not be correct. Erm, but do you know what, this is how I am and, and if people don't like it then they can…know what they can do (laughing)" (P14) "So, the second one wasn't really bad because it was my hand. Because my face, because I knew the second one, right I've had a stroke again, so, ya'know, I could take it. But, the first time was really bad, it took me like three months, you know. So, s-second one was alright" (P23)	1c. Evidence of adjustment or acceptance to changed body image
Subsumption (similar to abstraction, but where an emergent theme becomes a main theme to bring together subthemes)	"I can't do the things that I want to do, and I should be able to do because my body won't let me…. Your mind still wants to do, but your body won't do it." (P13) (2a. Body is viewed as being untrustworthy; it is fallible and must now be accommodated for) "And after stroke, it definitely takes like more focus, more devotion, more determination to do everything to get back to normal and sometimes it's hard" (P22) (2b Bodily changes affect desired or perceived self-presentation) "…Or I'm now got drugs for the rest of me life, which I only associated with me grandmother and me grandfather ya'know, bein' on drugs" (P04) (2c. Perceiving body image as being like that of an older person and either accepting and reacting or marginalising)	2. BODY NOW PERCEIVED AS AN 'OBSTACLE' TO NORMALITY:

Polarization (looking for differences rather than similarities)	“If there are other people around then I want to look, erm, acceptable […] I prefer to be tidy so that I erm, would not put people off by my appearance. However, I’m me erm, I don’t have to be determined by what I think other people would view me like” (P29) “It’s, image. Int’it; she’s a nice lady (laughs) she’s got nice clothes on …I wonder where she goes to the shops. (laughs)” (P30)	1a. Continuation in opinions on how important body image is
Contextualization (considering the temporal moment of an experience)	“the more you sort of interact with different people, uh, the more conscious you are…...that erm, you, you, you want to be able to move in the same way that they move. it was probably three weeks before I went out err, just in the street and that was a walk with the physios (smiles) and I really did feel conscious about it then […] and you just get ev-you think every eye is watchin’ ya (laughs)” (P02) “I’m conscious that if I can’t [brings hands up and makes gestures as if counting out money], if it takes me a bit longer to pick something up or to pay [gestures paying] you know, if I’m trying to get change out of my purse [gestures taking coins out of a purse] or money, then I’m very conscious that it takes a but longer. And I do tend to say, “I won’t be a minute, I’ve just had a stroke.” (slight laugh) You know, and er, erm you feel like you’ve got to explain why that’s happening.” (P14)* “I did it every day, erm… but now I’m not doing. I don’t think I’ve wore any makeup or perfume except on, on Saturday night and at Christmas, was Christmas day when I went to my daughter’s. Erm I’ve never bothered. CD: Why do you think that might be? P27: Because I’m not going out. So, I don’t think it’s worth it.” (P27)	1b. Societal pressures to be ‘normal’: wanting to portray ‘normal’ self even if they feel different
Numeration (considering the	“I don’t want to be reminded that (pause) I’m now old [amused face]. Or I’m now got drugs for the rest of me life, which I only associated with me grandmother and me grandfather ya’know, bein’ on	2c. Perceiving body image as being like that of an older

frequency of experiences)	drugs (P04) “when she was quite old, she was late 80s, […] her mouth was lopsided and ironically it was the same side [smiling while talking]. And, and somehow, I think I thought I, I kind of looked like that. [slight laughter in voice] I mean mine was nowhere near as bad, but because it reminded me so strongly and funnily enough, I look very like my mother, so perhaps that emphasised it even more [quizzical look towards screen].” (P13) “if a man is old, he’s silver fox. If female is old, she is perceived differently than a, than a man and I don’t want to be received like I’m old bag or something, no.” (P22) “I think what’s happened is, the stroke has raised awareness of ya bodily function but it’s also raised awareness of my age as well that perhaps wasn’t there before.” (P04)* “it took about a month, but I managed it after that, I were walking not shufflin’ if you get what I mean? […]I were lifting me legs to get a stride, rather than like what I call the old man shuffles (laugh).” (P06)* “Maybe I’m just getting to that age where it’s my age group that has them and, and obviously that’s why I’m, I, I’ve heard about a lot more people having them because it’s affecting my peer group.” (P15)*	person and either accepting and reacting or marginalising

Key:

Quotations are presented in main thesis unless denoted by *, whereby quotation is an additional example not already presented in main thesis

Appendix 20: Additional Supporting Quotations

Theme	Additional quotations
1a	“I mean the kids would tell me, if I didn’t look right when they came round, they’d no doubt say, “Are you ill?” (Laughs) you know, if I’d forgot, if I’d forgot, forgot to do my hair, or. I mean I’m not one of these that have backcombed hair and everything, but I’ve gotta, I’ve gotta be presentable to people. (P16) “probably it’s infectious, probably I got it, that from her. Okay, I don’t put lipstick but I just have a quick look in mirror; is my hair alright.” (P22) “my parents always told me to be neat and tidy and to dress as well as I could. We were never erm, very well off as children, when I was child should I say. So, the latest fashions, the latest items to have whenever obtainable so I learnt to accept it. And erm, the body image idea, from, I presume, came from that sort of thing, as in you are what you are, enjoy what you can do. Erm, you’re loved, you’re cared for (voice breaks). (P29)
1b	“Because we’re all, we’re all kind of vain humans and we all want to look as ‘normal’ as possible. But, [shrugs right shoulder] y-y’know. I can’t at the moment.” (P02) “ I had to kinda try that in secret with my son standing by while [wife’s name] was either at work or something an’ (pause) because I didn’t want her to see me struggling, I didn’t want her, her to see me staggering or falling cus that was her biggest fear is that I’d fall, uhh, when she wasn’t around so y-you tend to try and do things yourself and then let other people see you doing it.” (P02) “But you become very conscious about [puts palms together] how things look. I’d never compared my hands before, but you do start to feel very conscious about it. […] But like I say, the hand, I don’t think people see, although I don’t think other people see it’s just how I see it.” (P02) “you just get really embarrassed I mean, you’re twitching (laughs). You’re standing twitching ya, in your leg and you can’t do anything, really can’t do anything about it.” (P02) “but I don’t know why my lip’s going up (laughs), which is bugging me. But erm, not everybody notices that my lip’s gone up, it’s only when I point it out, they say that it’s erm, but they might just be being nice (laughing).” (P14)

	“I’ve, not as much as to say, you’re letting yourself go but, er, I don’t feel as though, because I am not going out like I used to, I suppose I am, negl-ya’know, not neglecting, but it doesn’t concern me as much.” (P08) “I did it every day, erm… but now I’m not doing. I don’t think I’ve wore any makeup or perfume except on, on Saturday night and at Christmas […] I’ve never bothered. […] Because I’m not going out. So, I don’t think it’s worth it.” (P27) “I’m very conscious that it takes a but longer. And I do tend to say, “I won’t be a minute, I’ve just had a stroke.” (slight laugh) You know, and er, erm you feel like you’ve got to explain why that’s happening.” (P14)
1c	“I’ve looked at, through some photos in the past, in the past few weeks, no, and I, I think I’ve been one of the lucky ones I think, in that the impact (pause) has been minimal.” (P04)
1d	“I think, I feel normal now, I look the same yeah, yeah. […] Yeah, before I didn’t the first time, but now I look the same. I feel happy now, yeah.” (P23) “I suppose as I’ve been able to realise that, or build up to standing erm, where I couldn’t do, or standing with almost bilateral weight taking, […] yep little movements when my hand has relaxed to be able to straighten out […] that I’ve seen as an improvement and therefore has been I suppose a positive body image. […] The physios have said that I’ve done well in various things like my body posture, my ability to do things, exercises erm, that sort of thing so yeah I suppose that’s been it.” (P29) “I just feel as though I’m, I’m very, very fortunate and, and you wouldn’t know that I’ve, unless I told ya…[…]that I’d, that I’d had a stroke. […] You know, if you’re stood in front of me and looked at me, you would never know that I’d had a stroke.” (P08) “Having recovered from a first stroke and seen a little bit of improvement since my second stroke. I am pretty much determined that I will get back through effort and exercise and repeated exercise, get back to gaining much better control of my body. Erm, from that I presume that I consider my body to be under my control. Erm, and now that it isn’t, I want to regain control. Erm, so that I can once again do the things that I enjoy because I miss doing the things that I enjoyed before. […] Erm, I suppose, yeah. That’s, that’s what I how, that is how I consider it, I consider it temporary. (P29)

2a	“I’ve always been a really confident person. But this, the stroke probably took 90% of that away at the start.” (P02) *“In relation to Stott summary diagram of body experience (Stott et al., 2021):* “in hospital they say it’s your ‘affective’ arm, ‘affected’ arm, not your bad arm, not your dead arm, not your lump of lead…it’s your affected arm. […] Um. And I, I totally understand why they do that, because you do, s-you do feel [while leaning on elbows on desk, clenches left hand and moves it back and forward while talking] what, you know, what use is this to me?” (P02) ““Erm, I just have to be really careful that I treat myself like a toddler and always go the toilet before I go out for a walk.” (P13) “…for weeks, I couldn’t carry a hot drink in my left hand for obvious reasons, but I do now. But when I do it, I watch it all the time. I obviously don’t really completely trust my left hand” (P13) “you kinda hate those parts that won’t work.” (P02) “My thoughts were, oh no, not again and I am cross with myself for this happening, I am cross with my body for this happening again.” (P29) “And, and one of the neighbours who I get on really, really well with, they, he actually said to me, he said, he says, “I couldn’t believe the difference in ya”, he said, “It was almost like” umm, “you, you were, you were walking like a toddler”, and I said “I’m working, walking worse than a toddler”.” (P02) “But if I’m sitting down or anything, they [*legs*] feel fine till I try to use them (laughs).” (P25) “that there is a limit to life” (P04) “So, I’ve been on the scales this morning which I would never have normally done previously, so I’m 13’1 but a couple of weeks ago I was 13, 12, 13, just below 13 and I’m thinking hoh! I’ve put a couple of pounds on. […] So, I’m driven by the risk reduction as well as, but as a consequence of that, me pants fit nice and I’ve bought some 34 [smiling] waist pants recently and I was on like 35, 36 previously.” (P04) “I just want a new one. New body.” (P10).
2b	“I’m an adult, I should have been capable of looking in a mirror and accepting

	that if I did it, I would get better. But I’d rather risk, well I don’t think I thought about it in those terms. I just couldn’t face looking in a mirror full stop [smiling and shaking head]. I just didn’t think beyond that.” (P13) “well something’s wrong with her.”, or “look at the state of that,” (P31)
2c	[…] for me to be in that category, was a m-y’know, I’m thinking [makes outwards motion with hands and looks up] wow, y’know, it’s [indicates impact by placing fist into other palm] impactful [puts hands up around shoulder height and indicates impact] on your, I don’t know, not your wellbeing, but it’s ki-just like, blimey, I’m in that situation now.” (P04) “Maybe I’m just getting to that age where it’s my age group that has them [strokes] […] I remember that the first guy I ever met who had a stroke, he had three days after his 60th birthday. So, yeah, maybe I’ve, I’ve, I’ve linked strokes and being in your sixties together at some point.” (P15) “…it makes me feel old. Because you know how older people, their voices go quieter and qua-, slightly quavery when they get very old? […] Well, mine sounds like that sometimes, especially if I’ve done a lot of talking.” (P13)

Appendix 21: Standard Stroke-Specific Definition of Body Image

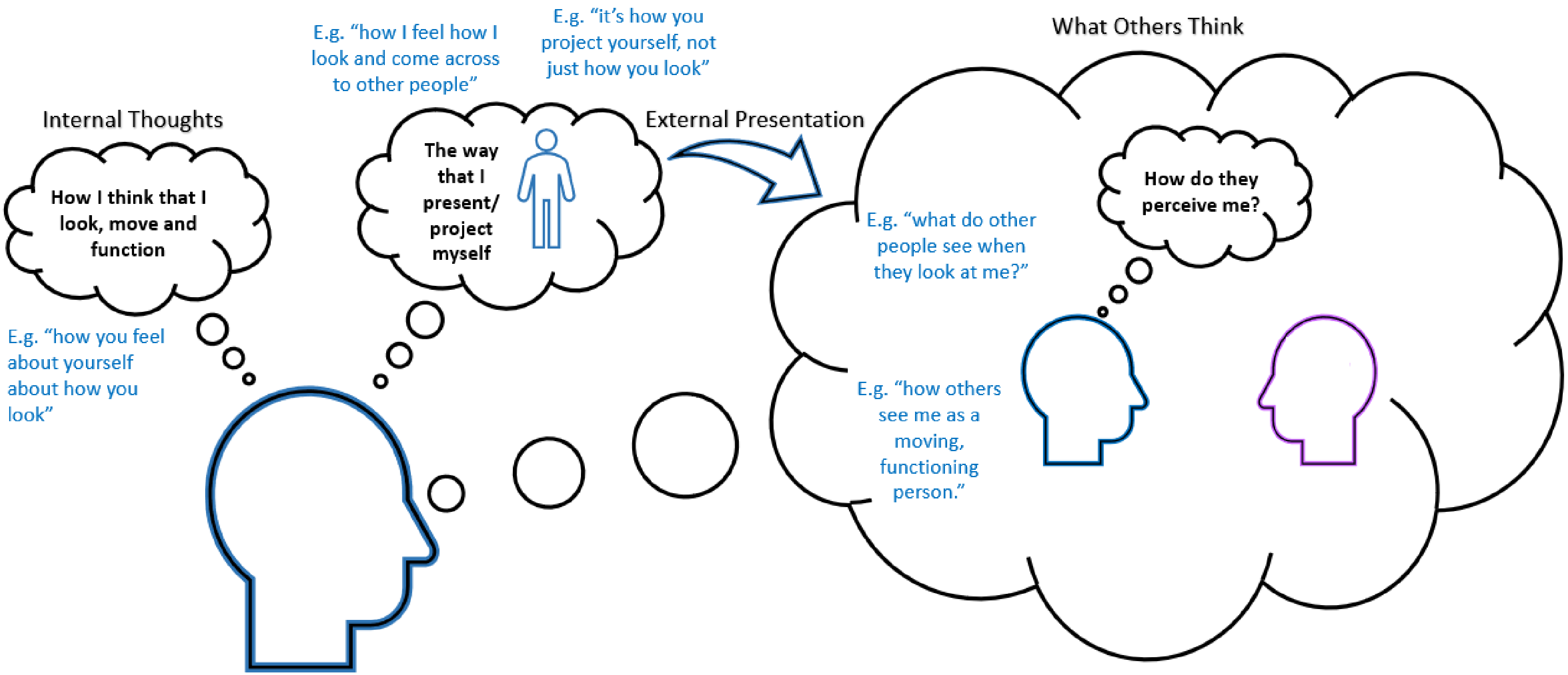
Definition of Body Image

Body image as perceived by the participants in this study appears to have three main components. People hold **internal thoughts** about how they think that they look, move and function. This translates into a view of their body which they self-present to the outside world (**external presentation)**. They then hold perceptions of how they think other people view them (**what others think)**.

Elaboration:
For some participants, body image was described as how they thought that they looked (**internal thoughts**) or presented themselves (**external presentation**). For others it was a physical concept, mostly relating to function. Although less often, some people also related body image to the common media-portrayed ideals of weight, diet or height. For people who have not had a stroke, body image is commonly perceived as how the body appears to yourself and others. For people who have had a stroke, this concept of appearance seems to relate to how the body appears as a moving, functioning entity. This likely reflects sustained stroke-related impacts to bodily movements or the fact that after stroke some people had to think consciously when and how they wanted to move their body – something that was previously intuitive.

For some participants, there was focus on how they felt they were seen by others (**what others think**). They sought to self-present to others in the same way that they had before their stroke. They were striving to achieve their perceived ‘normal’ pre-stroke body image.

In relation to social roles and relationships, participants described that different people they knew held different images of them, depending on shared history and relationship roles. For example, grandchildren might view them as an older person, whereas a partner still remembers them as they were when they were younger.
The figure below represents a broad definition, aiming to encompass the views of all participants who were involved.



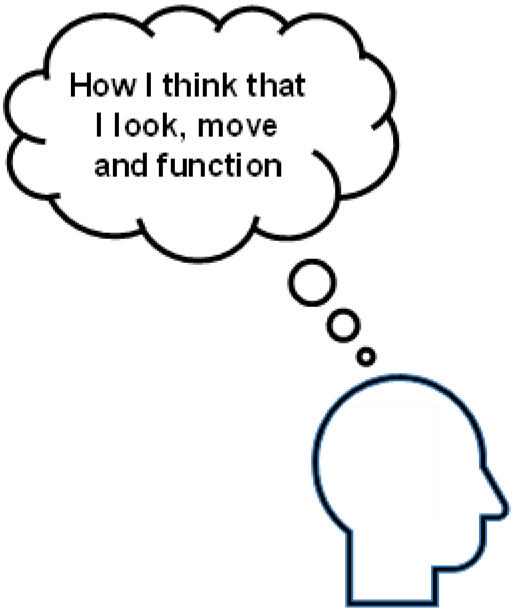
It is important to recognise the variability in the way that different people will recognise and identify with the term ‘body image’. People may identify with the whole definition or only associate parts of it with what body image means to them. In defining body image, participants suggested a variety of factors which had the potential to impact body image perception. These included external/social factors such as upbringing and parental influence and media stereotypes; and psychological, internal factors such as confidence.

Appendix 22: Aphasia-Friendly Stroke-Specific Definitions of Body Image

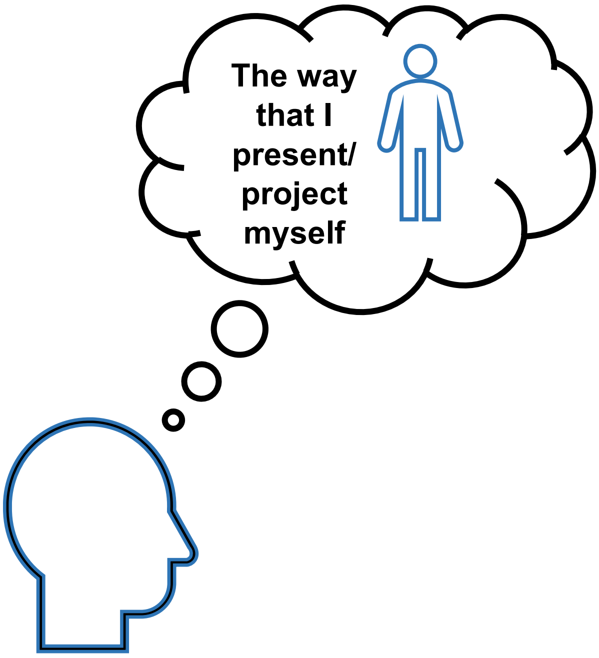
Definition of Body Image

Body image is made up of three parts:

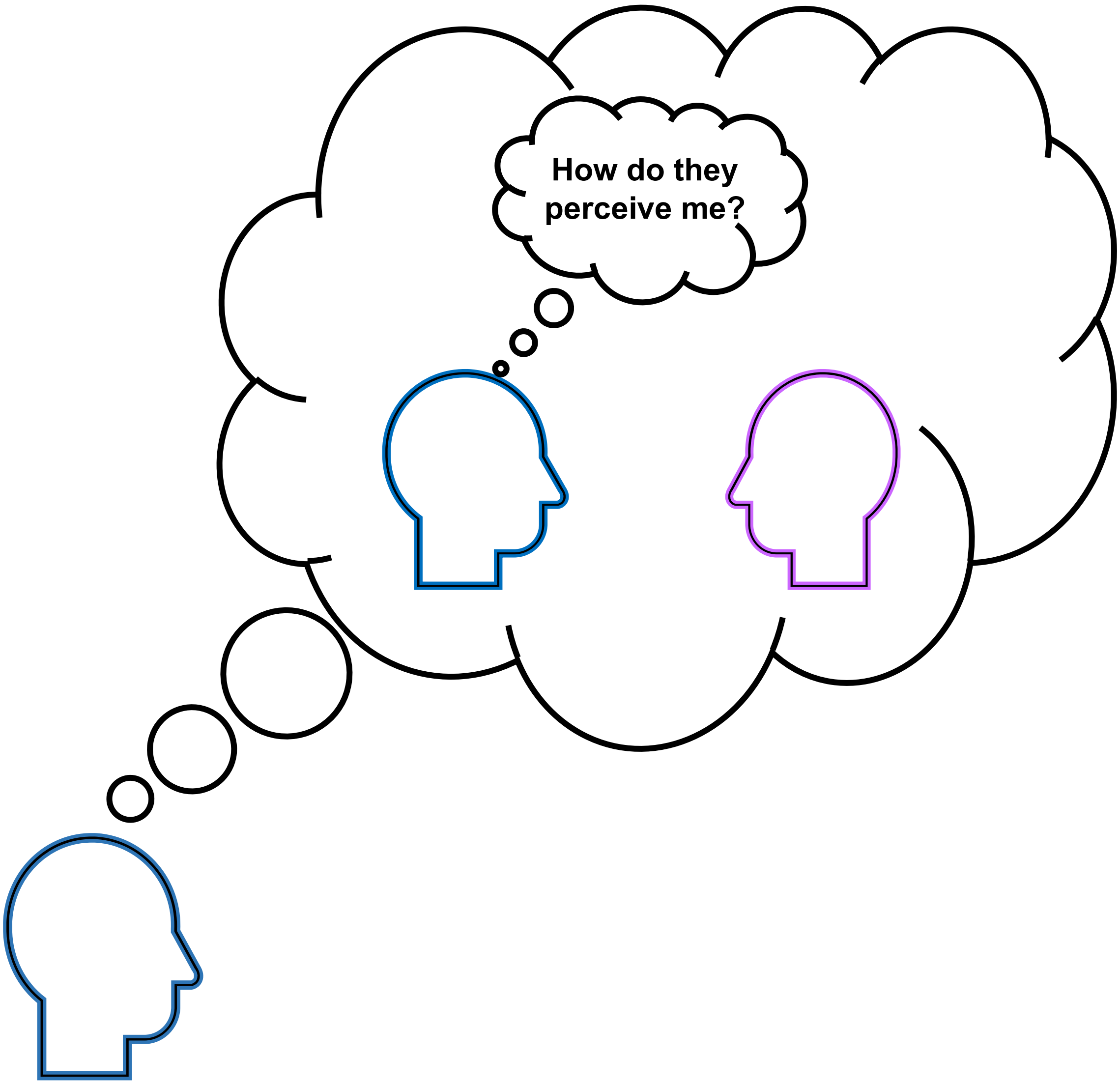
People hold **internal thoughts** about how they **think that they look, move and function**



This translates into a **view of their body** which they self-present to the **outside world (external presentation)**



They then hold perceptions of **how they think other people view them (what others think)**



Elaboration:

For some participants, body image was how they thought that they looked (**internal thoughts**) or presented themselves (**external presentation**).

For other participants, it was a **physical concept** related to **function**.

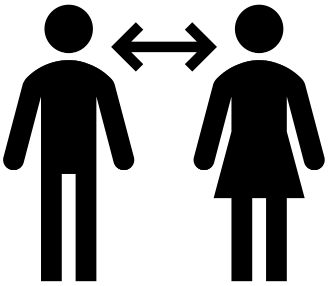
Some participants also thought body image was linked to **ideal bodies** shown in the **media**, such as **weight, diet or height**.

For people who have **not had a stroke**, body image is usually **how the body appears** to yourself and others.

For **people with stroke**, this idea of **appearance** also includes how the body appears when it **moves and functions**. This might be because of **stroke-related impacts** to bodily movements or now having to **think about moving**.

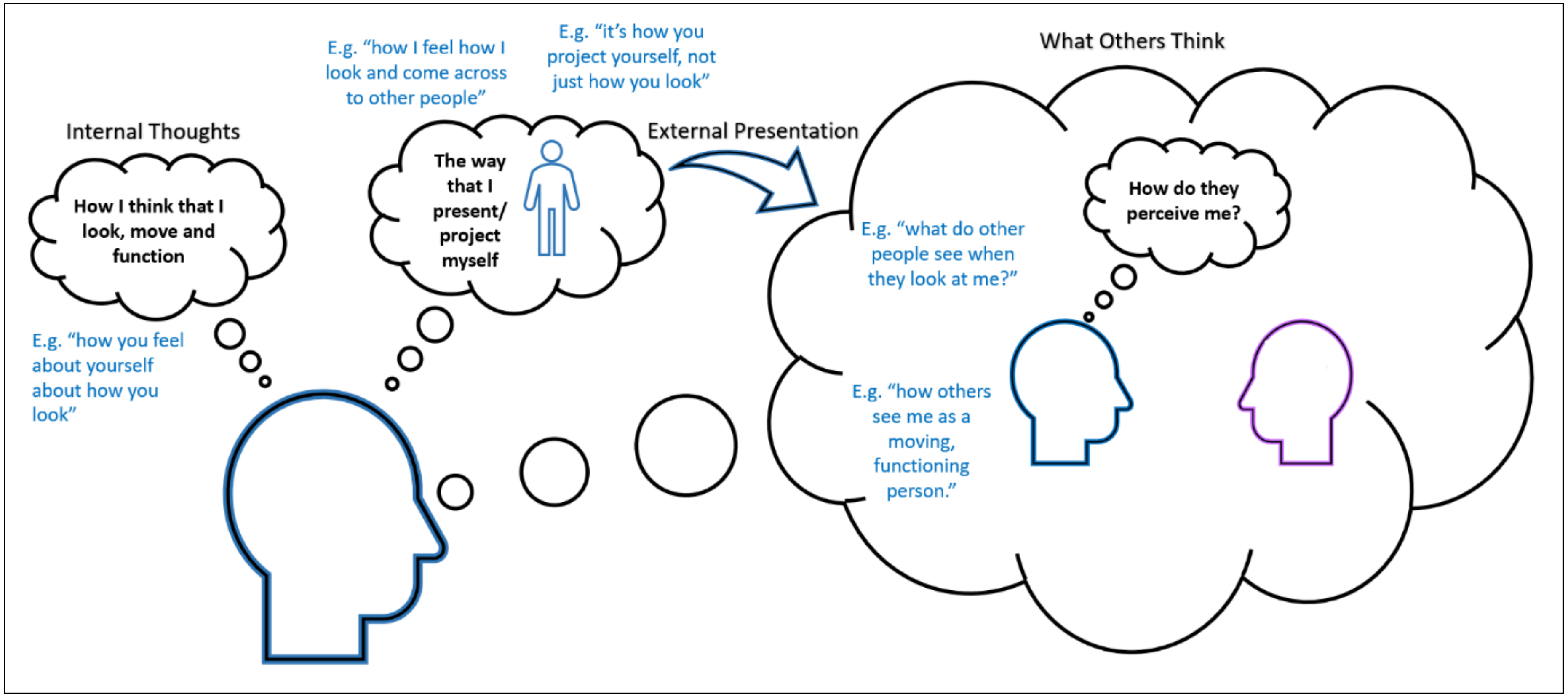
Some participants focussed on how they felt they were **seen** by others **(what others think).** They wanted to **present themselves** to others in the **same way** that they had **before their stroke** and to have their perceived **'normal' pre-stroke body image**.

In relation to **social roles and relationships**, participants described that **different people** they knew held **different images of them**, depending on shared history and relationship roles.



For example, **grandchildren** might view them as an **older person**, whereas a **partner** still remembers them as they were when they were **younger**.

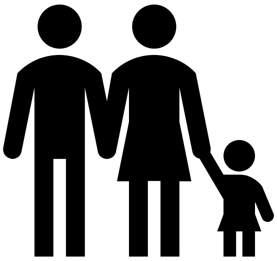
The **figure below** represents a **broad definition**, aiming to encompass the views of all participants who were involved.

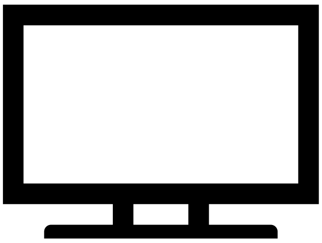

Internal Thoughts
How I think that I look, move and function
E.g. "how you feel about yourself about how you look"
E.g. "how I feel how I look and come across to other people"
E.g. "it's how you project yourself, not just how you look"
The way that I present/ project myself
External Presentation
What Others Think
E.g. "what do other people see when they look at me?"
How do they perceive me?
E.g. "how others see me as a moving, functioning person."

Different people will recognise and identify **differently** with the term **‘body image’**. People may identify with the **whole definition** or only associate **parts** of it with what body image means to them.

Participants suggested **various factors** which had the potential to **impact body image** experience.

These included external/social factors such as **upbringing** and **parental influence** and **media stereotypes**; and psychological, internal factors such as **confidence**.





Appendix 23: Example of the Participant Information Sheet for the Expert Panel Group

PARTICIPANT INFORMATION SHEET: EXPERT PANEL MEMBERS
EXPERT PANEL GROUP

1. Title of Study
Developing a Model of Post-Stroke Body Image Perception

2. Version Number and Date
V1.0, 11/01/2022

3. Invitation to Participate
We would like to invite you to take part in a research study which is part of a PhD project at the University of Central Lancashire (UCLan). Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask questions. Thank you for reading this information sheet.

4. What do we want from the study?
After someone has had a stroke, they might feel as if their body image has changed. We have explored how people experience any changes that might happen to their body after having a stroke and how those changes might affect them. We now want to explore how best to intervene with or treat these changes. As part of this, we want to gather the opinions of healthcare professionals who can suggest how post-stroke body image issues could be addressed.

5. Why have I been invited to take part?
You have been invited to take part because you are a healthcare professional with expertise relevant to exploring and identifying psychological intervention options.

6. Do I have to take part?
Taking part is voluntary. If you do not wish to take part, you will not be affected in any way. If you would like to take part, then your participation will constitute as consent.

7. What will happen to me if I take part?
If you agree to take part, you will be invited to an expert panel discussion group. This will ideally involve 6-12 people. Before the group begins, the researcher will check that you are still happy to participate.

The researcher will ask some questions and facilitate discussions between panel members. Another researcher may also be at the group to take notes.

The group will take place virtually. We anticipate that it will last about 2 hours. After the group, you will have chance to ask questions. You may stop participating at any time without giving a reason.

8. Are there any special arrangements being made because of COVID-19?

For your safety, we will use virtual conferencing software, such as Microsoft Teams, or telephone.

9. How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The University privacy notice for research participants can be found on the attached link https://www.uclan.ac.uk/data_protection/privacy-notice-research-participants.php

No personal data will be transferred outside the European Union.

We will only use information from you that we need for the research study. This information will include:

- **Your name and contact details-** so that we can contact you and send out study materials
- **Audio and/or screen capture recordings of the expert panel group** – we will transcribe these and use them to help us understand your opinions of what we discuss. Screen capture recordings will be deleted after transcription.
- **Creations that you might make during the group-** the researcher, with your permission, will scan or photograph these and use them to help in explaining the results of the study

10. How will my data be stored?

We will keep all information about you safe and secure in line with the University Data Protection Code of Practice. All data that we collect will be transferred onto and stored on a secure UCLan drive.

National laws may require us to show information to university or government officials (or sponsors), who are responsible for monitoring the safety of this project. In this situation, directly identifying information (e.g. names, addresses) would be safeguarded and maintained under controlled conditions.

11. Will my data be anonymised?

We will write our reports in a way that no one can work who took part in the study.

12. How long will my data be stored for?

Your data will be stored securely at UCLan for the duration of the PhD project and an additional 5 years. Then, it will be fully anonymised and added to the UCLan data repository for future use in accordance with the Research Data Management Policy. At this time, all data that could identify you will be deleted or shredded. Anonymised data will be made open access as appropriate. Your contact details will be destroyed once we no longer need to contact you.

13. What are my choices about how my information is used?

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. You can stop being part of the study at any time, without giving a reason, but with your permission, we will keep information about you that we already have.

14. Are there any possible disadvantages or risks in taking part?

There are no anticipated disadvantages or risks in taking part.

15. Are there any benefits from taking part?

There is no intended benefit to you from taking part. You may find participation in the research rewarding on a personal level. It is hoped the information we get from this study will help provide information to inform psychological and emotional care in the future.

16. What will happen if I want to stop taking part?

You are free to withdraw at any time during the study without giving any reasons or explanation, and without incurring a disadvantage.

17. Expenses and / or payments

There will be no reimbursement for your time

18. What will happen to the results of the study?

Findings will be shared widely using a range of methods, these may include:

a) Presentations at a range of conferences
b) Publication in a PhD thesis and journals

19. Who has reviewed the study?

The study has been reviewed and given a favourable opinion by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing, and dignity.

20. Where can you find out more about how your information is used?

You can find out more about how we use your information:

- By asking one of the research team
- By contacting the researcher through email (cdavidson4@uclan.ac.uk) or telephone (01772 895537)

You may keep this information sheet.

21. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the Chief Investigator for the project, Professor Liz Lightbody on 01772 893648 or celightbody@uclan.ac.uk and we will try to help. If you remain unhappy or would like to speak to someone external to the project, or have a complaint which you feel you cannot come to us with, then please contact the Research Governance Unit at OfficerForEthics@uclan.ac.uk.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

22. Who can I contact if I have further questions?

If you have any further questions, you can contact the researcher (PhD student) or the Chief Investigator for this project. Contact details are below.

23. Contact details of investigatory team

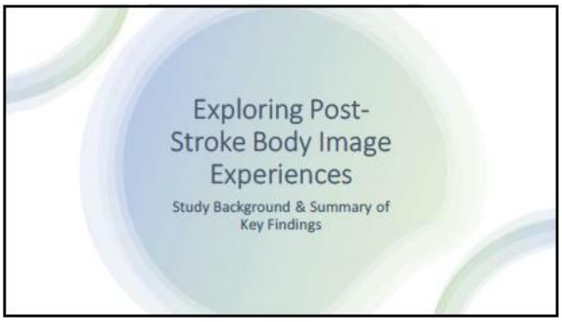
Researcher/PhD Student:
Name: Catherine Davidson
Contact number: 01772 895537
Email address: cdavidson4@uclan.ac.uk
Mailing address: BB444, Brook Building, University of Central Lancashire, Preston, PR1 2HE

Chief Investigator:
Name: Professor Liz Lightbody
Contact number: 01772 893648
Email address: celightbody@uclan.ac.uk.
Mailing address: BB415, Brook Building, University of Central Lancashire, Preston, PR1 2HE

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 24: Documents Sent to Expert Panel Members Ahead of Session

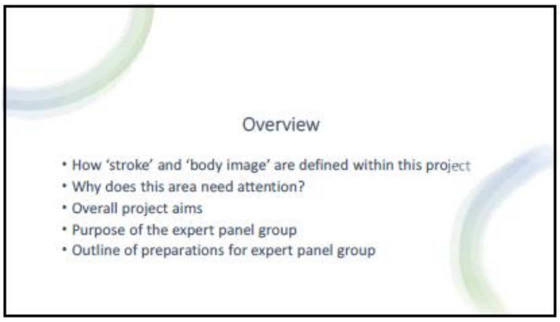
Summary and background to the thesis:



Exploring Post-Stroke Body Image Experiences

Study Background & Summary of Key Findings

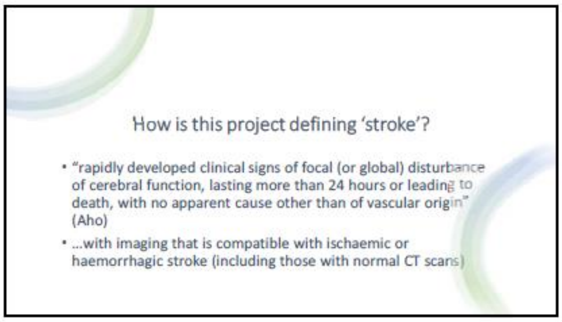
1



Overview

- How 'stroke' and 'body image' are defined within this project
- Why does this area need attention?
- Overall project aims
- Purpose of the expert panel group
- Outline of preparations for expert panel group

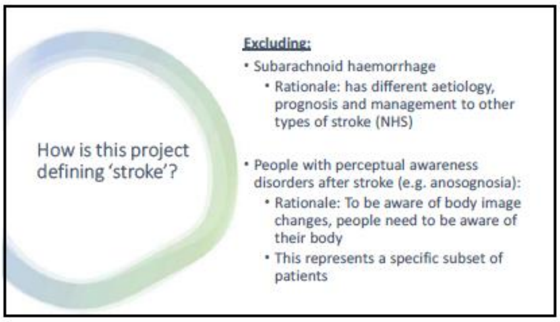
2



How is this project defining 'stroke'?

- "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" (Aho)
- ...with imaging that is compatible with ischaemic or haemorrhagic stroke (including those with normal CT scans)

3

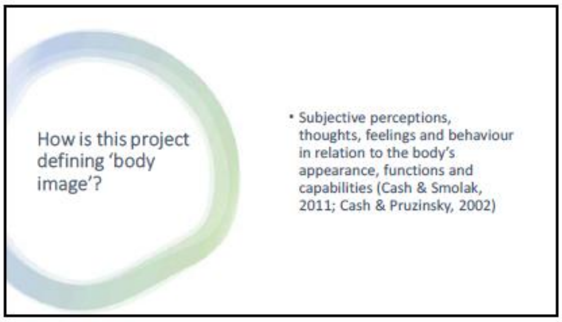


How is this project defining 'stroke'?

Excluding:

- Subarachnoid haemorrhage
  - Rationale: has different aetiology, prognosis and management to other types of stroke (NHS)
- People with perceptual awareness disorders after stroke (e.g. anosognosia):
  - Rationale: To be aware of body image changes, people need to be aware of their body
  - This represents a specific subset of patients

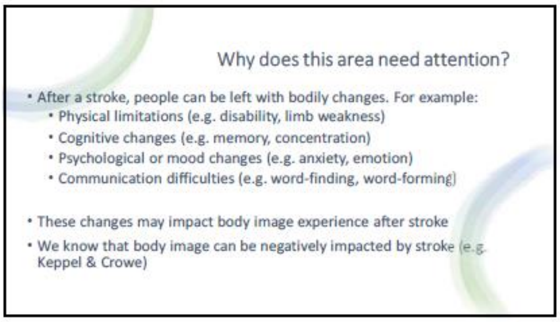
4



How is this project defining 'body image'?

- Subjective perceptions, thoughts, feelings and behaviour in relation to the body's appearance, functions and capabilities (Cash & Smolak, 2011; Cash & Pruzinsky, 2002)

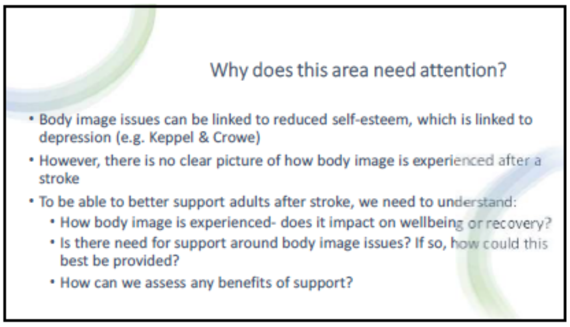
5



Why does this area need attention?

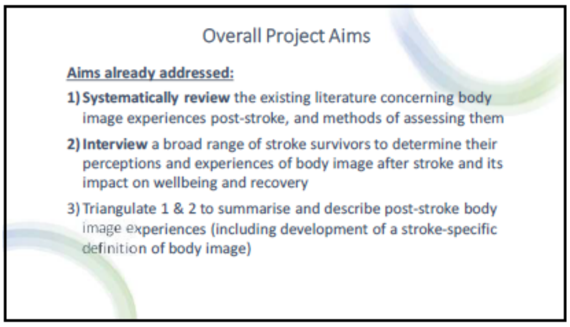
- After a stroke, people can be left with bodily changes. For example:
  - Physical limitations (e.g. disability, limb weakness)
  - Cognitive changes (e.g. memory, concentration)
  - Psychological or mood changes (e.g. anxiety, emotion)
  - Communication difficulties (e.g. word-finding, word-forming)
- These changes may impact body image experience after stroke
- We know that body image can be negatively impacted by stroke (e.g. Keppel & Crowe)

6



Why does this area need attention?

- Body image issues can be linked to reduced self-esteem, which is linked to depression (e.g. Keppel & Crowe)
- However, there is no clear picture of how body image is experienced after a stroke
- To be able to better support adults after stroke, we need to understand:
  - How body image is experienced- does it impact on wellbeing or recovery?
  - Is there need for support around body image issues? If so, how could this best be provided?
  - How can we assess any benefits of support?



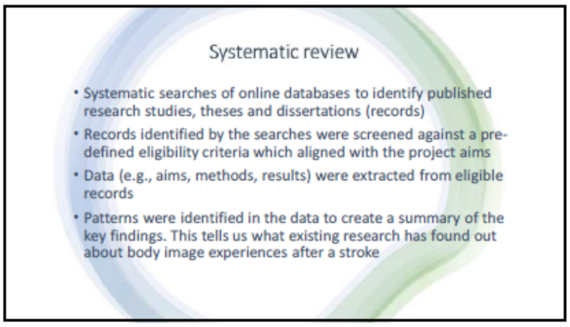
Overall Project Aims

Aims already addressed:

1) **Systematically review** the existing literature concerning body image experiences post-stroke, and methods of assessing them

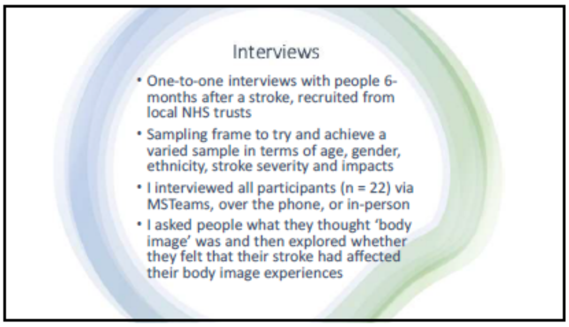
2) **Interview** a broad range of stroke survivors to determine their perceptions and experiences of body image after stroke and its impact on wellbeing and recovery

3) Triangulate 1 & 2 to summarise and describe post-stroke body image experiences (including development of a stroke-specific definition of body image)



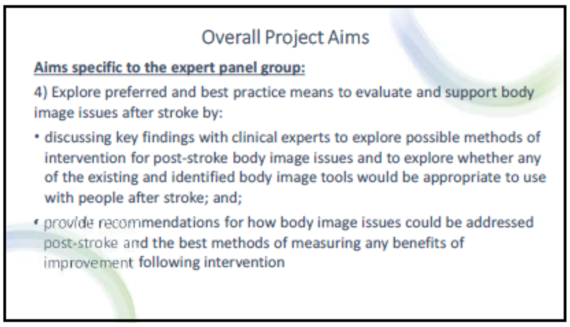
Systematic review

- Systematic searches of online databases to identify published research studies, theses and dissertations (records)
- Records identified by the searches were screened against a pre-defined eligibility criteria which aligned with the project aims
- Data (e.g., aims, methods, results) were extracted from eligible records
- Patterns were identified in the data to create a summary of the key findings. This tells us what existing research has found out about body image experiences after a stroke



Interviews

- One-to-one interviews with people 6-months after a stroke, recruited from local NHS trusts
- Sampling frame to try and achieve a varied sample in terms of age, gender, ethnicity, stroke severity and impacts
- I interviewed all participants (n = 22) via MSTeams, over the phone, or in-person
- I asked people what they thought 'body image' was and then explored whether they felt that their stroke had affected their body image experiences

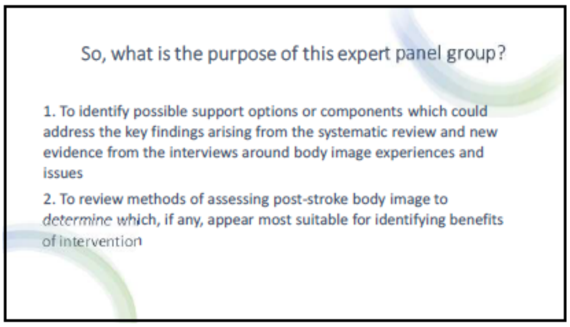


Overall Project Aims

Aims specific to the expert panel group:

4) Explore preferred and best practice means to evaluate and support body image issues after stroke by:

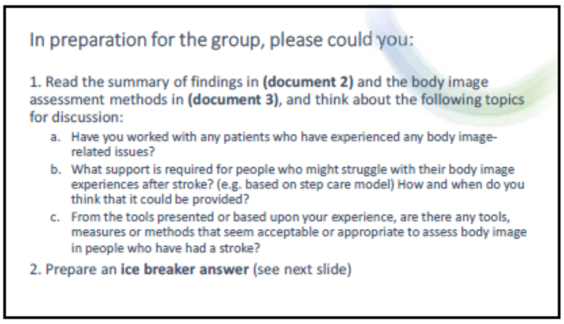
- discussing key findings with clinical experts to explore possible methods of intervention for post-stroke body image issues and to explore whether any of the existing and identified body image tools would be appropriate to use with people after stroke; and;
- provide recommendations for how body image issues could be addressed post-stroke and the best methods of measuring any benefits of improvement following intervention



So, what is the purpose of this expert panel group?

1. To identify possible support options or components which could address the key findings arising from the systematic review and new evidence from the interviews around body image experiences and issues

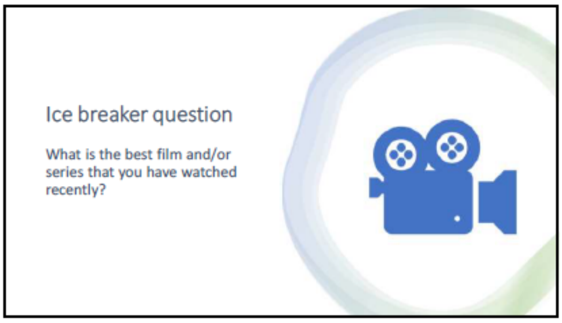
2. To review methods of assessing post-stroke body image to determine which, if any, appear most suitable for identifying benefits of intervention



In preparation for the group, please could you:

1. Read the summary of findings in **(document 2)** and the body image assessment methods in **(document 3)**, and think about the following topics for discussion:
    a. Have you worked with any patients who have experienced any body image-related issues?
    b. What support is required for people who might struggle with their body image experiences after stroke? (e.g. based on step care model) How and when do you think that it could be provided?
    c. From the tools presented or based upon your experience, are there any tools, measures or methods that seem acceptable or appropriate to assess body image in people who have had a stroke?
2. Prepare an **ice breaker answer** (see next slide)

13



Ice breaker question

What is the best film and/or series that you have watched recently?

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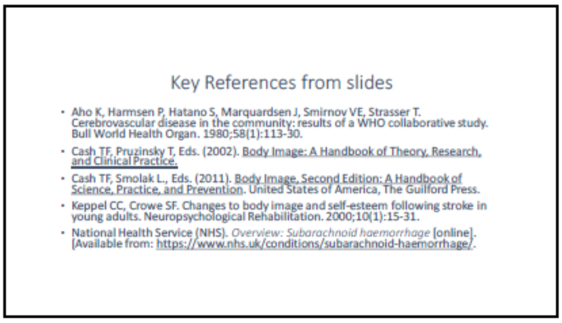
Thank you

Many thanks in advance.

I really appreciate your time and support and look forward to speaking with you all on the 11th May.

15

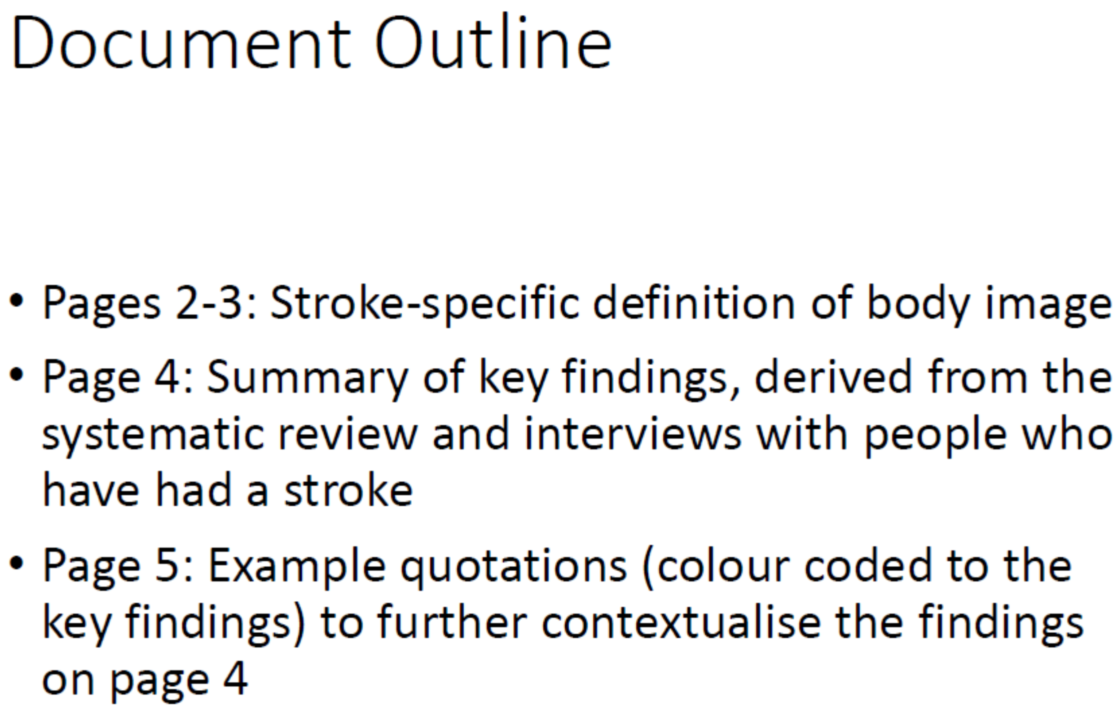


Key References from slides

- Aho K, Harmsen P, Hatano S, Marquardsen J, Smirnov VE, Strasser T. Cerebrovascular disease in the community: results of a WHO collaborative study. Bull World Health Organ. 1980;58(1):113-30.
- Cash TF, Pruzinsky T, Eds. (2002). Body Image: A Handbook of Theory, Research, and Clinical Practice.
- Cash TF, Smolak L., Eds. (2011). Body Image, Second Edition: A Handbook of Science, Practice, and Prevention. United States of America, The Guilford Press.
- Keppel CC, Crowe SF. Changes to body image and self-esteem following stroke in young adults. Neuropsychological Rehabilitation. 2000;10(1):15-31.
- National Health Service (NHS). *Overview: Subarachnoid haemorrhage* [online]. [Available from: https://www.nhs.uk/conditions/subarachnoid-haemorrhage/.

16

Summary of key findings:



Document Outline

- Pages 2-3: Stroke-specific definition of body image
- Page 4: Summary of key findings, derived from the systematic review and interviews with people who have had a stroke
- Page 5: Example quotations (colour coded to the key findings) to further contextualise the findings on page 4

Developing a stroke-specific definition of ‘body image’

I asked each participant what they thought ‘body image’ meant. The following definition is a synthesis of their responses to create a definition of body image specific to people who have experienced a stroke:

Definition of Body Image:

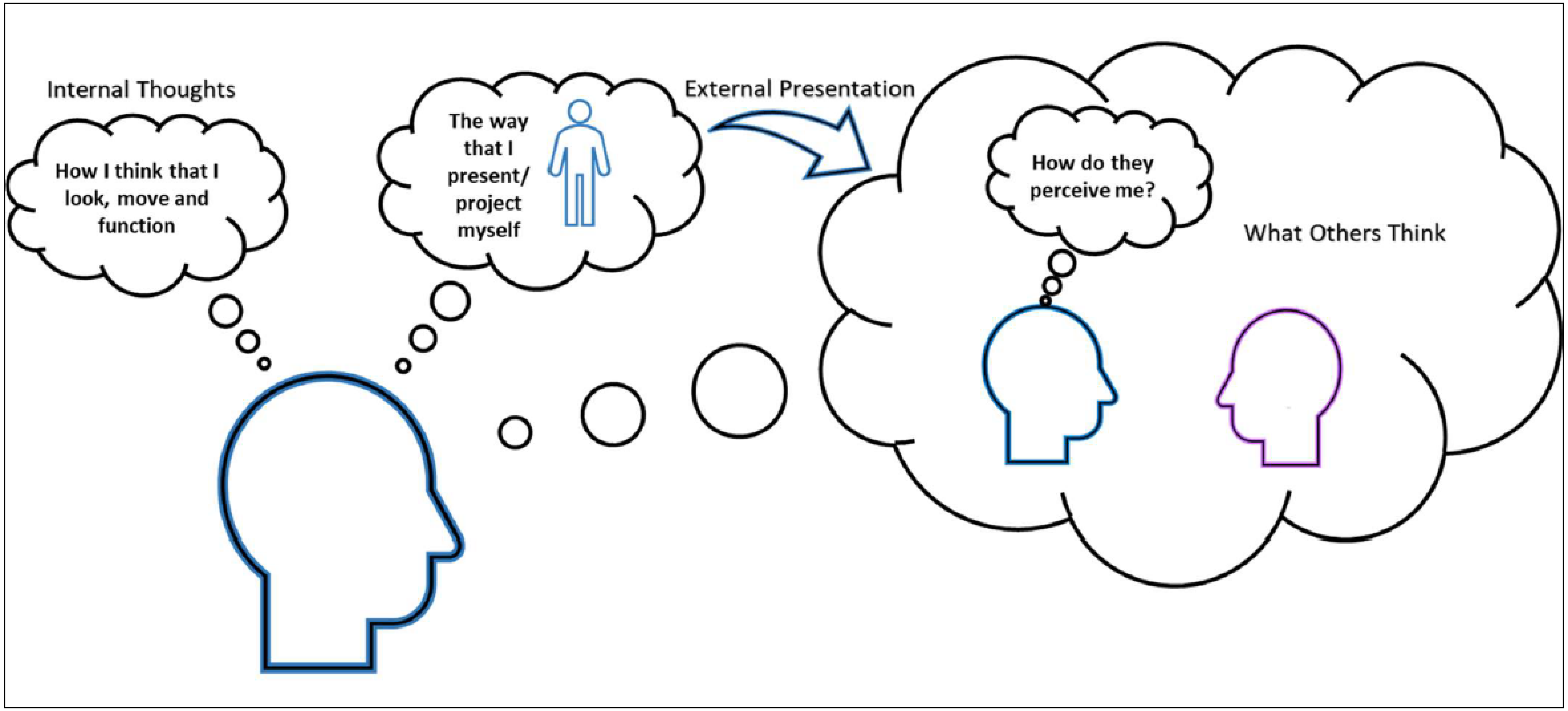
For some participants, body image was described as how they thought that they looked (**internal thoughts**) or presented themselves (**external presentation**). For others it was a physical concept, mostly relating to function or less often, the common media-portrayed ideals of weight, diet or height. In the general population, body image is commonly perceived as how the body appears to yourself and others, but for people after stroke, there was a nuanced focus on not only bodily appearance, but how it appears as a moving and functioning entity. This likely reflects sustained stroke-related impacts to bodily movements or the fact that after stroke some people had to think consciously when and how they wanted to move their body – something that was previously intuitive.

For some participants, there was focus on how they felt they were seen by others (**what others think**). People with stroke sought to self-present to others in the same way that they had before their stroke. They were striving to achieve their perceived ‘normal’ pre-stroke body image.

In relation to social roles and relationships, it was also described that different people they knew held different images of them, depending on shared history and relationship roles. For example, grandchildren might view them as an older person, whereas a partner still remembers them as they were when they were younger.

Overall, body image as perceived by people after stroke appears to have three main components. Generally, after stroke, people hold **internal thoughts** about how they think that they look, move and function. This translates into a view of their body which they self-present to the outside world (**external presentation)**. They then hold perceptions of how they think other people view them, (**what others think)**. The figure on the next page represents a broad definition, aiming to encompass the views of all participants who were involved.

Figure to represent project-derived definition of body image



It is important to recognise the variability in the way that different people will recognise and identify with the term ‘body image’. People may identify with the whole definition, or only associate parts of it with what body image means to them. In defining body image, participants suggested a variety of factors which had the potential to impact body image perception. These included external/social factors such as upbringing and parental influence and media stereotypes; and psychological, internal factors such as confidence.

Summary of Key Findings (*example of new evidence from interviews*)

Body image is experienced more negatively after a stroke, compared to pre-stroke experiences & the general population: although need to be aware of individual differences in experiences

Some people who said that they didn't perceive that their body image had been impacted by their stroke would then provide examples of how it had been impacted

Gender differences emerging:
♀ = appearance & social-presentation
♂ = function & functional appearance

Varying evidence around whether lesion location, age, time since stroke and other personal and stroke characteristics- difficult to draw conclusions

Body image experience is contextual and can change across different situations

Body image becomes more noticeable after being discharged from hospital environment

Body image becomes more pertinent when in public or social situations

Some impairments are only perceived as bothersome when moving or being used

Body image is less impacted when people feel a sense of continuity with their pre-stroke 'normal' self and body image

Normal = the image held of self and capabilities before stroke

Adapting and trying to accept vs struggling to accept vs striving to improve body to be able to perceive it as 'normal' again

Feeling lucky/ grateful to not have greater impairment

Not necessarily objective impairment that has the greatest impact, but the impacts of bodily changes on 'normal' self, capabilities and image

Changed relationship with or perception of the body due to bodily changes

Negative perceptions of bodily parts that have been impacted by stroke, emphasised by use negative, third-person or objectifying language

Disconnect between current and desired body image

Body viewed as time-consuming, requiring more energy and concentration, so leaving less time and capacity for previously valued activities; tiredness, fatigue, exhaustion

Body viewed as something which must be actively considered and can't be taken for grant as before stroke

Body perceived as unreliable & untrustworthy:

More aware of age or mortality

Positive changes: seeking to improve body

Bodily perceptions assimilated with aging e.g. slowing down

Accepted as part of normal life trajectory or pushed back against

Concern around what other people think of them and how they are seen, which affects relationships and socialising

Negative perceptions of body image e.g. "lopsided", "abnormal" are linked to concerns of being perceived negatively by others e.g., "irregular", "drunk". This could cause negative feelings e.g. ""ashamed", "embarrassed", "conspicuous"

Continuity before and after stroke between how concerned people are with their appearance, self-presentation and how they are seen by others

Wanting to portray 'normal' self even if they feel different

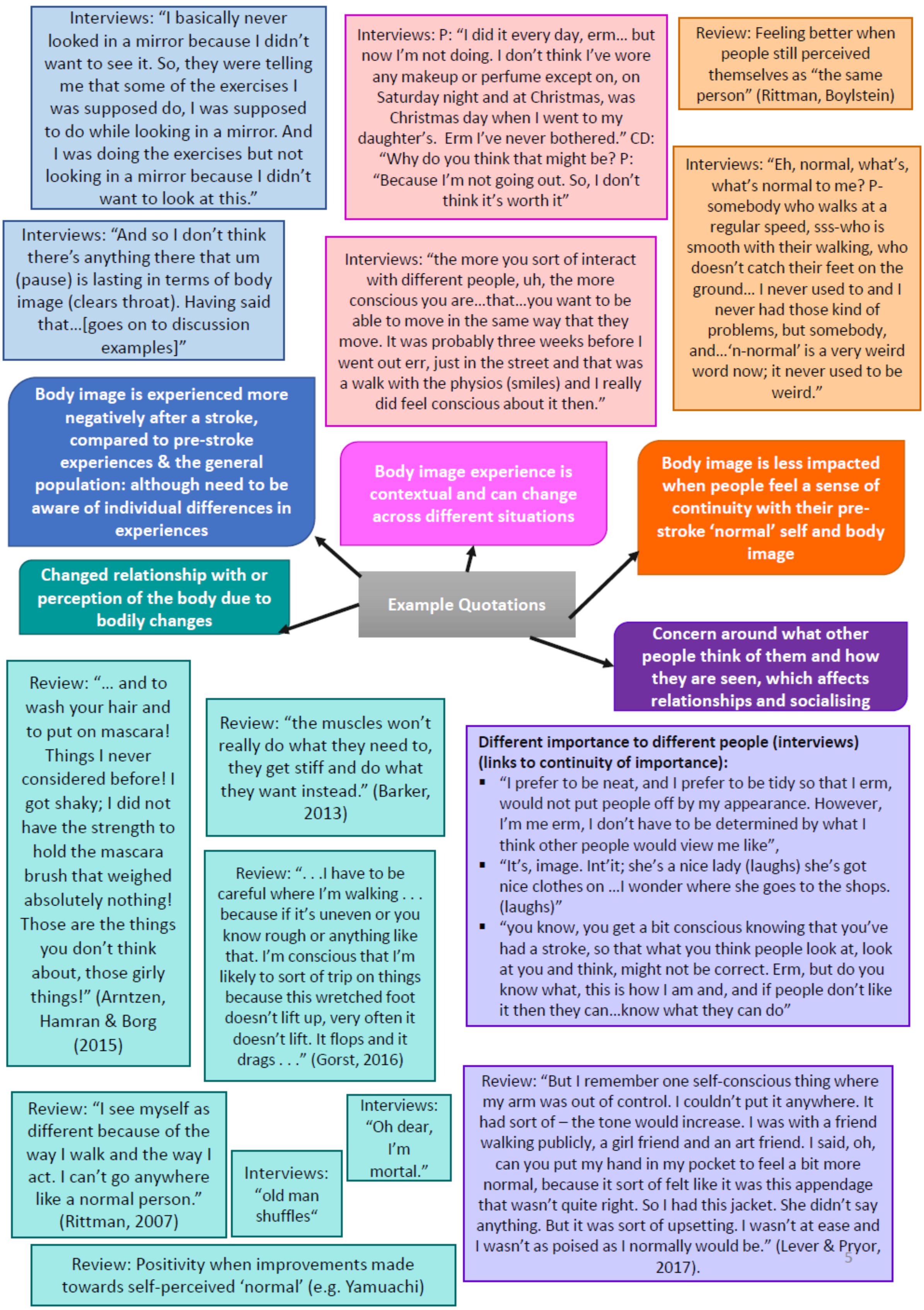
Attempts to hide bodily impairments or compensate with hair styles, makeup

Physical difficulties in maintaining desired self-presentation e.g. if can't use certain clothes fastenings, do hair, makeup

Social withdrawal or reduction in social activities

Conversely: difficulties around bodily changes that aren't obvious to others not being acknowledged or validated

Identify impacted by changes in[4] relationship roles



Interviews: "I basically never looked in a mirror because I didn't want to see it. So, they were telling me that some of the exercises I was supposed do, I was supposed to do while looking in a mirror. And I was doing the exercises but not looking in a mirror because I didn't want to look at this."

Interviews: "And so I don't think there's anything there that um (pause) is lasting in terms of body image (clears throat). Having said that…[goes on to discussion examples]"

Body image is experienced more negatively after a stroke, compared to pre-stroke experiences & the general population: although need to be aware of individual differences in experiences

Changed relationship with or perception of the body due to bodily changes

Interviews: P: "I did it every day, erm… but now I'm not doing. I don't think I've wore any makeup or perfume except on, on Saturday night and at Christmas, was Christmas day when I went to my daughter's. Erm I've never bothered." CD: "Why do you think that might be? P: "Because I'm not going out. So, I don't think it's worth it"

Interviews: "the more you sort of interact with different people, uh, the more conscious you are…that…you want to be able to move in the same way that they move. It was probably three weeks before I went out err, just in the street and that was a walk with the physios (smiles) and I really did feel conscious about it then."

Body image experience is contextual and can change across different situations

Example Quotations

Review: Feeling better when people still perceived themselves as "the same person" (Rittman, Boylstein)

Interviews: "Eh, normal, what's, what's normal to me? P- somebody who walks at a regular speed, sss-who is smooth with their walking, who doesn't catch their feet on the ground… I never used to and I never had those kind of problems, but somebody, and…'n-normal' is a very weird word now; it never used to be weird."

Body image is less impacted when people feel a sense of continuity with their pre-stroke 'normal' self and body image

Concern around what other people think of them and how they are seen, which affects relationships and socialising

Review: "… and to wash your hair and to put on mascara! Things I never considered before! I got shaky; I did not have the strength to hold the mascara brush that weighed absolutely nothing! Those are the things you don't think about, those girly things!" (Arntzen, Hamran & Borg (2015)

Review: "the muscles won't really do what they need to, they get stiff and do what they want instead." (Barker, 2013)

Review: ". . .I have to be careful where I'm walking . . . because if it's uneven or you know rough or anything like that. I'm conscious that I'm likely to sort of trip on things because this wretched foot doesn't lift up, very often it doesn't lift. It flops and it drags . . ." (Gorst, 2016)

Review: "I see myself as different because of the way I walk and the way I act. I can't go anywhere like a normal person." (Rittman, 2007)

Interviews: "old man shuffles"

Interviews: "Oh dear, I'm mortal."

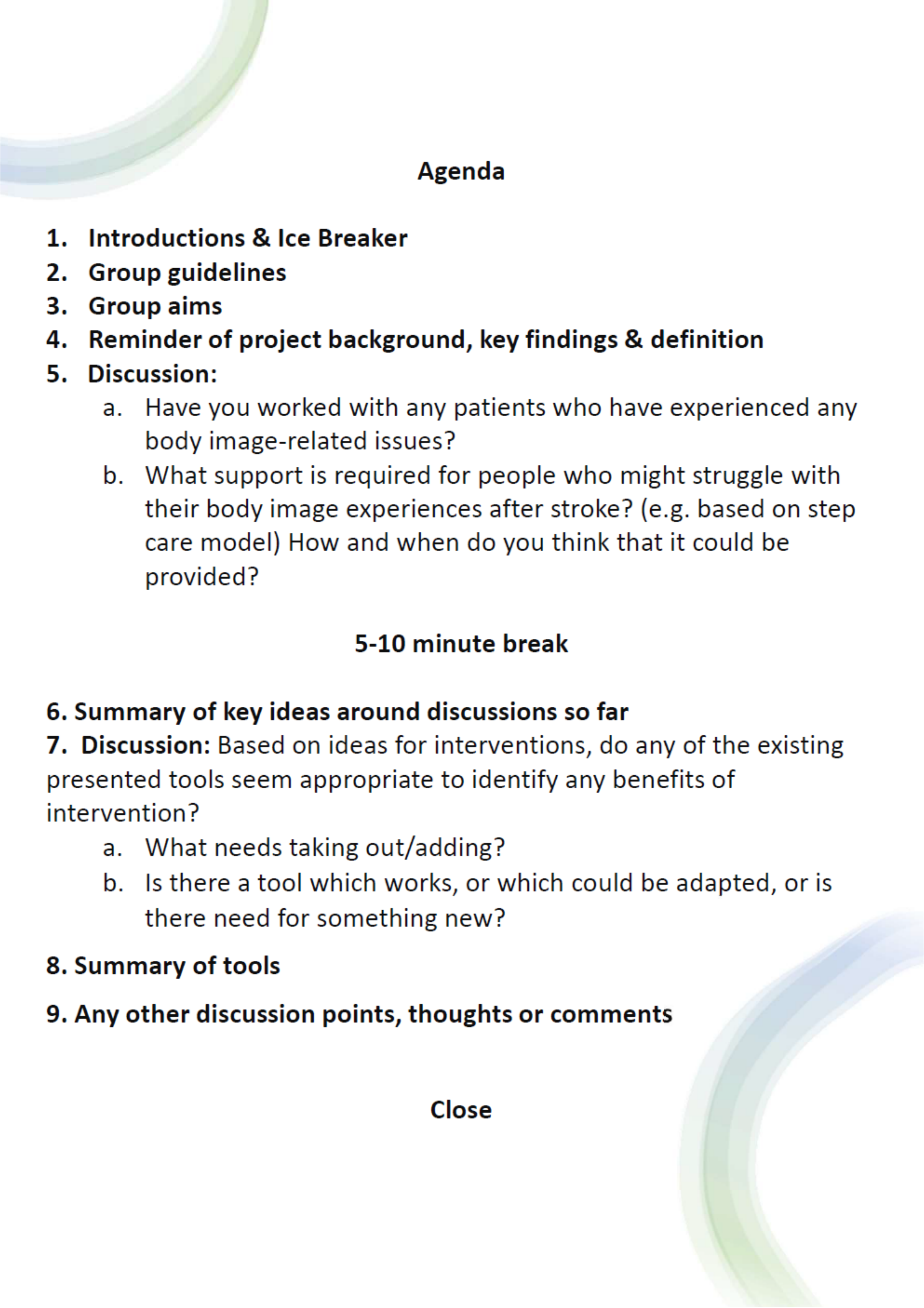
Review: Positivity when improvements made towards self-perceived 'normal' (e.g. Yamuachi)

Different importance to different people (interviews) (links to continuity of importance):

- "I prefer to be neat, and I prefer to be tidy so that I erm, would not put people off by my appearance. However, I'm me erm, I don't have to be determined by what I think other people would view me like",
- "It's, image. Int'it; she's a nice lady (laughs) she's got nice clothes on …I wonder where she goes to the shops. (laughs)"
- "you know, you get a bit conscious knowing that you've had a stroke, so that what you think people look at, look at you and think, might not be correct. Erm, but do you know what, this is how I am and, and if people don't like it then they can…know what they can do"

Review: "But I remember one self-conscious thing where my arm was out of control. I couldn't put it anywhere. It had sort of – the tone would increase. I was with a friend walking publicly, a girl friend and an art friend. I said, oh, can you put my hand in my pocket to feel a bit more normal, because it sort of felt like it was this appendage that wasn't quite right. So I had this jacket. She didn't say anything. But it was sort of upsetting. I wasn't at ease and I wasn't as poised as I normally would be." (Lever & Pryor, 2017).

Agenda:



Agenda

1. **Introductions & Ice Breaker**
2. **Group guidelines**
3. **Group aims**
4. **Reminder of project background, key findings & definition**
5. **Discussion:**
    a. Have you worked with any patients who have experienced any body image-related issues?
    b. What support is required for people who might struggle with their body image experiences after stroke? (e.g. based on step care model) How and when do you think that it could be provided?

5-10 minute break

6. Summary of key ideas around discussions so far

7. Discussion: Based on ideas for interventions, do any of the existing presented tools seem appropriate to identify any benefits of intervention?

a. What needs taking out/adding?
b. Is there a tool which works, or which could be adapted, or is there need for something new?

8. Summary of tools

9. Any other discussion points, thoughts or comments

Close

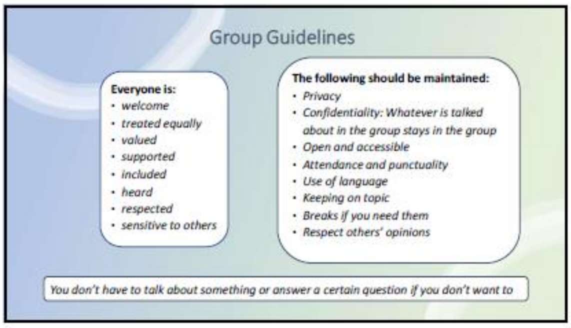
Appendix 25: Microsoft PowerPoint Slides Presented During the Expert Panel Group

Quick reminders:

- Participation acts as consent
- Participation is voluntary and you can stop taking part at any time
- Group will be recorded through MSTeams & Dictaphone- audio and video; transcribed
- Anonymous in write-up
- Any questions?

Introductions & Ice Breaker

- **Name**
- **Professional Background**
- **What is the best film and/or series that you have watched recently?**



Group Guidelines

Everyone is:

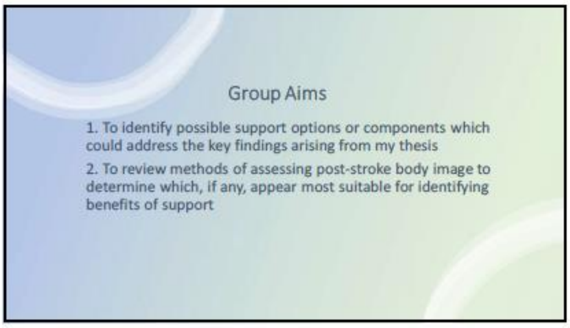
- *welcome*
- *treated equally*
- *valued*
- *supported*
- *included*
- *heard*
- *respected*
- *sensitive to others*

The following should be maintained:

- *Privacy*
- *Confidentiality: Whatever is talked about in the group stays in the group*
- *Open and accessible*
- *Attendance and punctuality*
- *Use of language*
- *Keeping on topic*
- *Breaks if you need them*
- *Respect others' opinions*

You don't have to talk about something or answer a certain question if you don't want to

Discussion



Group Aims

1. To identify possible support options or components which could address the key findings arising from my thesis
2. To review methods of assessing post-stroke body image to determine which, if any, appear most suitable for identifying benefits of support

Brief summary of my thesis

- Stroke → bodily changes → body image experience
- Body image linked to reduced self-esteem and depression after stroke
- No clear picture of how body image is experienced after stroke
- To better support adults after stroke we need to understand:
  - Experience
  - Impacts
  - Need for support
  - How to evaluate support

Overall Project Aims

1

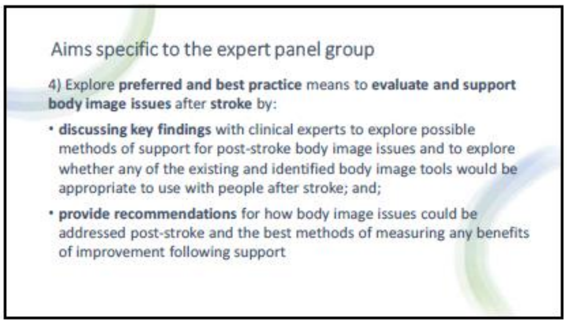
Systematically review the existing literature concerning body image experiences post-stroke, and methods of assessing them

2

Interview a broad range of stroke survivors to determine their perceptions and experiences of body image after stroke and its impact on wellbeing and recovery

3

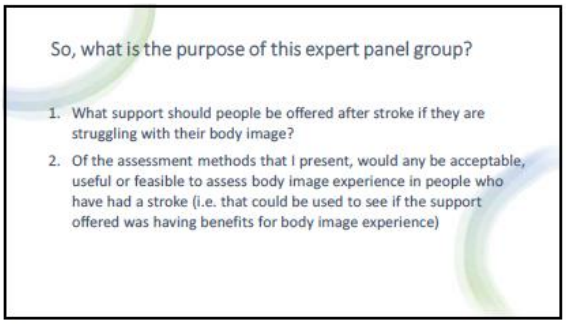
Triangulate 1 & 2 to summarise and describe post-stroke body image experiences (including development of a stroke-specific definition of body image)



Aims specific to the expert panel group

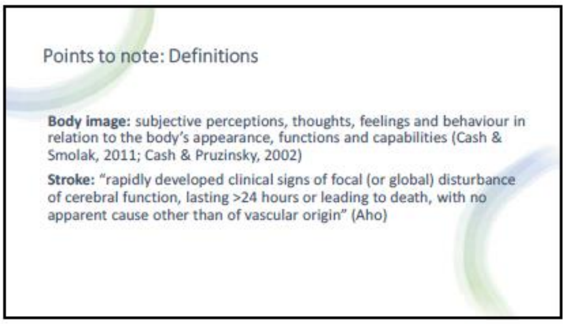
4) Explore **preferred and best practice** means to **evaluate and support body image issues** after **stroke** by:

- **discussing key findings** with clinical experts to explore possible methods of support for post-stroke body image issues and to explore whether any of the existing and identified body image tools would be appropriate to use with people after stroke; and;
- **provide recommendations** for how body image issues could be addressed post-stroke and the best methods of measuring any benefits of improvement following support



So, what is the purpose of this expert panel group?

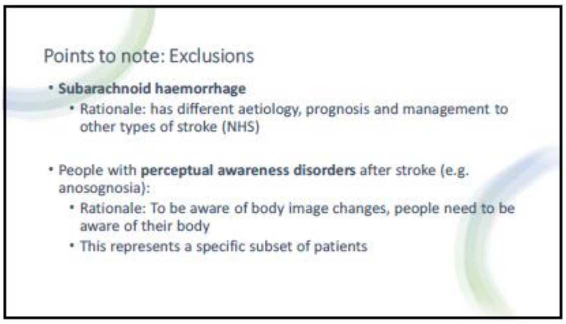
1. What support should people be offered after stroke if they are struggling with their body image?
2. Of the assessment methods that I present, would any be acceptable, useful or feasible to assess body image experience in people who have had a stroke (i.e. that could be used to see if the support offered was having benefits for body image experience)



Points to note: Definitions

Body image: subjective perceptions, thoughts, feelings and behaviour in relation to the body's appearance, functions and capabilities (Cash & Smolak, 2011; Cash & Pruzinsky, 2002)

Stroke: "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting >24 hours or leading to death, with no apparent cause other than of vascular origin" (Aho)

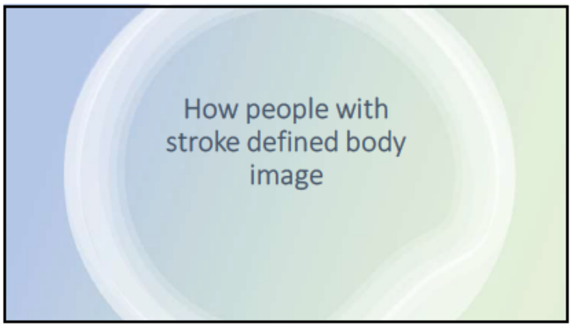


Points to note: Exclusions

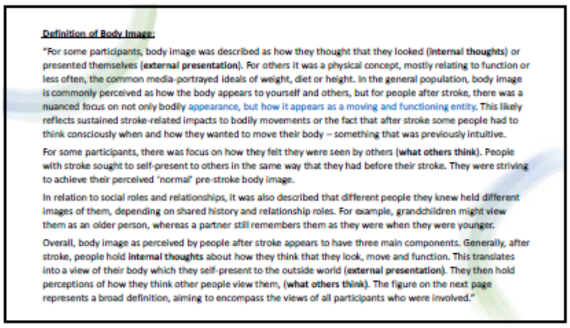
- **Subarachnoid haemorrhage**
  - Rationale: has different aetiology, prognosis and management to other types of stroke (NHS)
- People with **perceptual awareness disorders** after stroke (e.g. anosognosia):
  - Rationale: To be aware of body image changes, people need to be aware of their body
  - This represents a specific subset of patients

Any questions?

Summary of Key Findings



How people with stroke defined body image



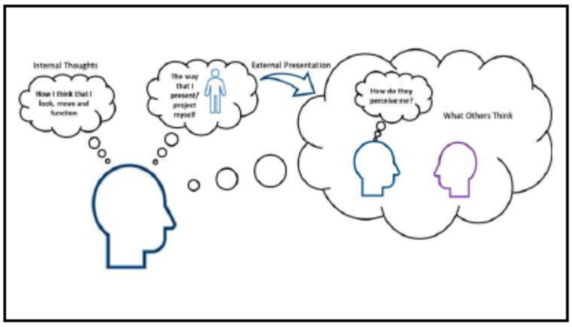
Definition of Body Image:

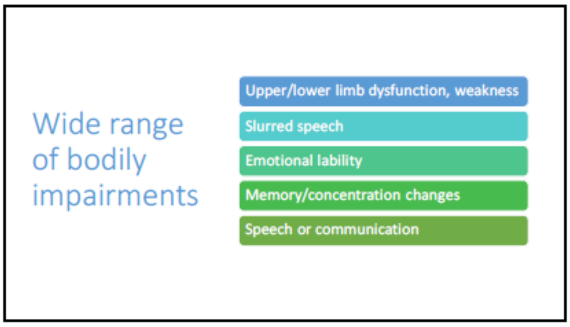
"For some participants, body image was described as how they thought that they looked (**internal thoughts**) or presented themselves (**external presentation**). For others it was a physical concept, mostly relating to function or less often, the common media-portrayed ideals of weight, diet or height. In the general population, body image is commonly perceived as how the body appears to yourself and others, but for people after stroke, there was a nuanced focus on not only bodily appearance, but how it appears as a moving and functioning entity. This likely reflects sustained stroke-related impacts to bodily movements or the fact that after stroke some people had to think consciously when and how they wanted to move their body – something that was previously intuitive.

For some participants, there was focus on how they felt they were seen by others (**what others think**). People with stroke sought to self-present to others in the same way that they had before their stroke. They were striving to achieve their perceived 'normal' pre-stroke body image.

In relation to social roles and relationships, it was also described that different people they knew held different images of them, depending on shared history and relationship roles. For example, grandchildren might view them as an older person, whereas a partner still remembers them as they were when they were younger.

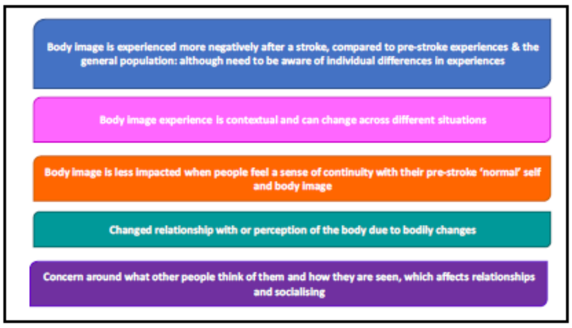
Overall, body image as perceived by people after stroke appears to have three main components. Generally, after stroke, people hold **internal thoughts** about how they think that they look, move and function. This translates into a view of their body which they self-present to the outside world (**external presentation**). They then hold perceptions of how they think other people view them, (**what others think**). The figure on the next page represents a broad definition, aiming to encompass the views of all participants who were involved."



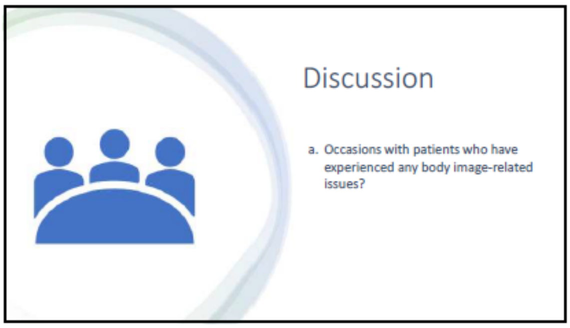


Wide range of bodily impairments

- Upper/lower limb dysfunction, weakness
- Slurred speech
- Emotional lability
- Memory/concentration changes
- Speech or communication



- **Body image is experienced more negatively after a stroke, compared to pre-stroke experiences & the general population: although need to be aware of individual differences in experiences**
- **Body image experience is contextual and can change across different situations**
- **Body image is less impacted when people feel a sense of continuity with their pre-stroke 'normal' self and body image**
- **Changed relationship with or perception of the body due to bodily changes**
- **Concern around what other people think of them and how they are seen, which affects relationships and socialising**



Discussion

a. Occasions with patients who have experienced any body image-related issues?

Discussion

b. What support is required for people who might struggle with their body image experiences after stroke?

How and when do you think that it could be provided? (e.g. based on step care model)

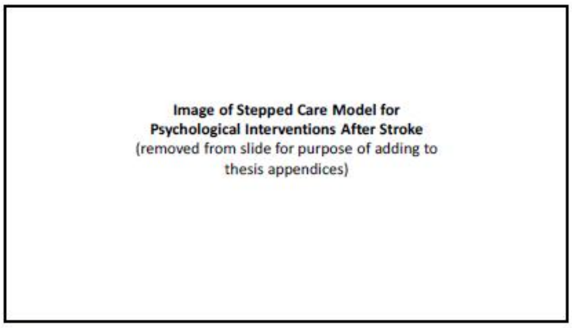
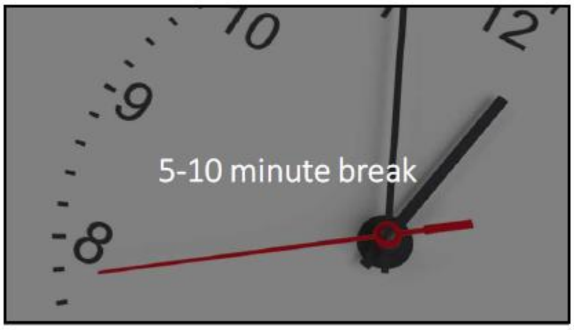


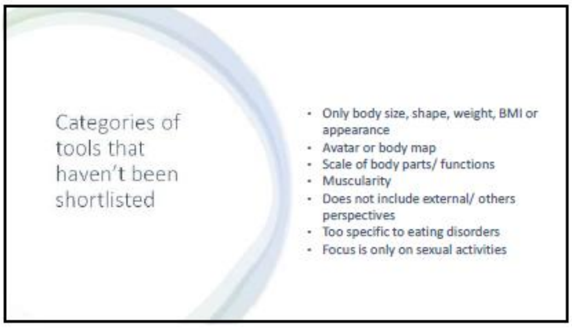
Image of Stepped Care Model for Psychological Interventions After Stroke
(removed from slide for purpose of adding to thesis appendices)



5-10 minute break

Summary of key ideas discussed so far

Body Image Assessment Methods



Categories of tools that haven't been shortlisted

- Only body size, shape, weight, BMI or appearance
- Avatar or body map
- Scale of body parts/ functions
- Muscularity
- Does not include external/ others perspectives
- Too specific to eating disorders
- Focus is only on sexual activities

Discussion

c. Based on ideas for support, do any of the existing presented tools seem appropriate to identify any benefits of support?

- ➢ What needs taking out/adding?

Discussion

For each method, please could you think about:

- ○ How easy it would be to complete for someone who has had a stroke
  - Thoughts on format, spacing, length, language
  - Anything ambiguous
- ○ Relevance to stroke patients
- ○ Any areas of body image not covered
- ○ Ease of use for clinicians
- ○ Ease of implementation into organisations i.e. would it be feasible?
- ○ What needs taking out/adding?
- ○ Overall opinions

Semantic Differential Self-Concept Scale (taken from Ellis-Hill, 1998)

For this tool, the adjective pairs used could be adapted for use in different studies. It is more of a method/approach than a set tool.

Image of scale
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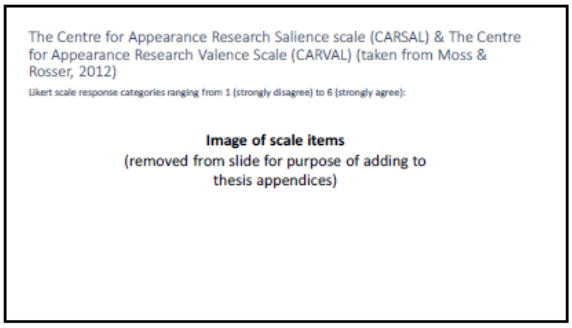
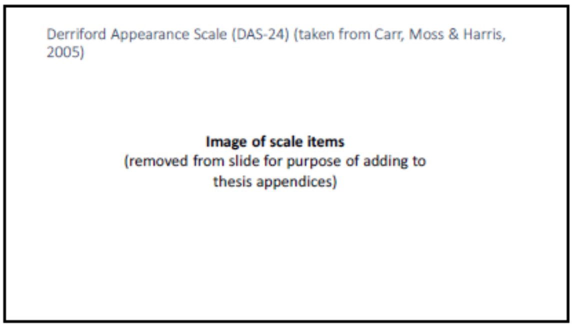
thesis appendices)



The Centre for Appearance Research Salience scale (CARSAL) & The Centre for Appearance Research Valence Scale (CARVAL) (taken from Moss & Rosser, 2012)

Likert scale response categories ranging from 1 (strongly disagree) to 6 (strongly agree):

Image of scale items
(removed from slide for purpose of adding to
thesis appendices)

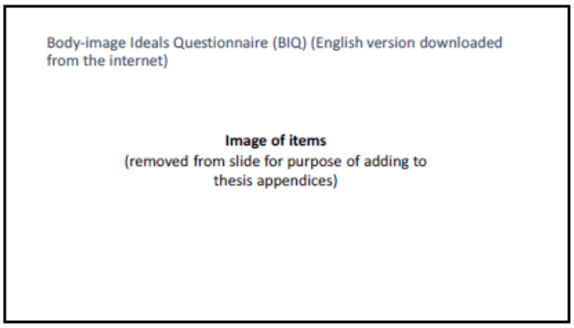


Derriford Appearance Scale (DAS-24) (taken from Carr, Moss & Harris, 2005)

Image of scale items
(removed from slide for purpose of adding to
thesis appendices)

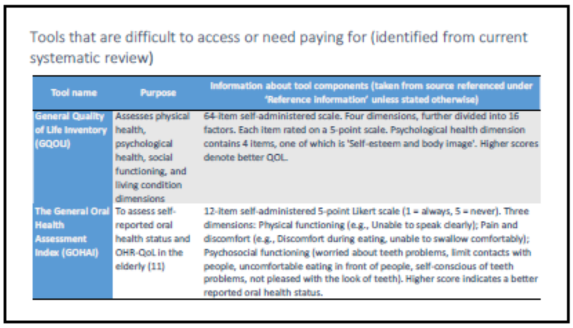
Appearance schemas inventory (taken from Cash & Labarge, 1996)

Image of inventory
(removed from slide for purpose of adding to
thesis appendices)



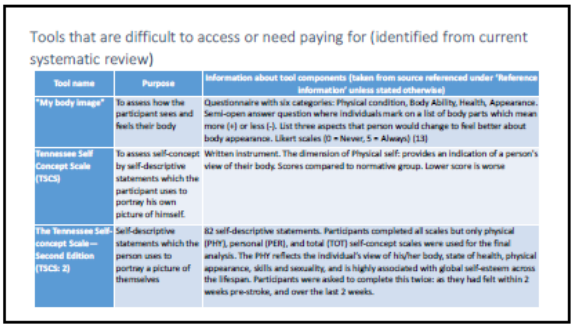
Body-image Ideals Questionnaire (BIQ) (English version downloaded from the internet)

Image of items
(removed from slide for purpose of adding to thesis appendices)



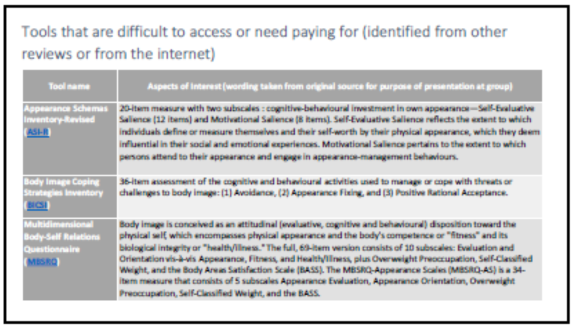
Tools that are difficult to access or need paying for (identified from current systematic review)

Tool name	Purpose	Information about tool components (taken from source referenced under 'Reference information' unless stated otherwise)
General Quality of Life Inventory (GQOLI)	Assesses physical health, psychological health, social functioning, and living condition dimensions	64-item self-administered scale. Four dimensions, further divided into 16 factors. Each item rated on a 5-point scale. Psychological health dimension contains 4 items, one of which is 'Self-esteem and body image'. Higher scores denote better QOL.
The General Oral Health Assessment Index (GOHAI)	To assess self-reported oral health status and OHR-QoL in the elderly (11)	12-item self-administered 5-point Likert scale (1 = always, 5 = never). Three dimensions: Physical functioning (e.g., Unable to speak clearly); Pain and discomfort (e.g., Discomfort during eating, unable to swallow comfortably); Psychosocial functioning (worried about teeth problems, limit contacts with people, uncomfortable eating in front of people, self-conscious of teeth problems, not pleased with the look of teeth). Higher score indicates a better reported oral health status.



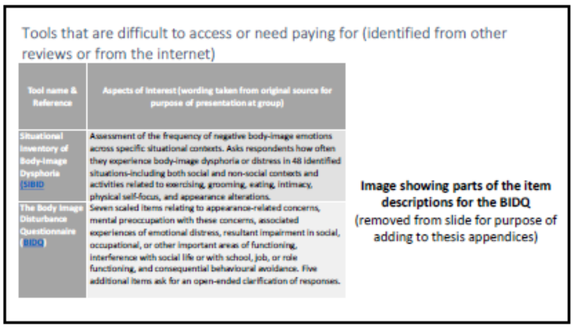
Tools that are difficult to access or need paying for (identified from current systematic review)

Tool name	Purpose	Information about tool components (taken from source referenced under 'Reference information' unless stated otherwise)
"My body image"	To assess how the participant sees and feels their body	Questionnaire with six categories: Physical condition, Body Ability, Health, Appearance. Semi-open answer question where individuals mark on a list of body parts which mean more (+) or less (-). List three aspects that person would change to feel better about body appearance. Likert scales (0 = Never, 5 = Always) (13)
Tennessee Self Concept Scale (TSCS)	To assess self-concept by self-descriptive statements which the participant uses to portray his own picture of himself.	Written instrument. The dimension of Physical self: provides an indication of a person's view of their body. Scores compared to normative group. Lower score is worse
The Tennessee Self-concept Scale—Second Edition (TSCS: 2)	Self-descriptive statements which the person uses to portray a picture of themselves	82 self-descriptive statements. Participants completed all scales but only physical (PHY), personal (PER), and total (TOT) self-concept scales were used for the final analysis. The PHY reflects the individual's view of his/her body, state of health, physical appearance, skills and sexuality, and is highly associated with global self-esteem across the lifespan. Participants were asked to complete this twice: as they had felt within 2 weeks pre-stroke, and over the last 2 weeks.



Tools that are difficult to access or need paying for (identified from other reviews or from the internet)

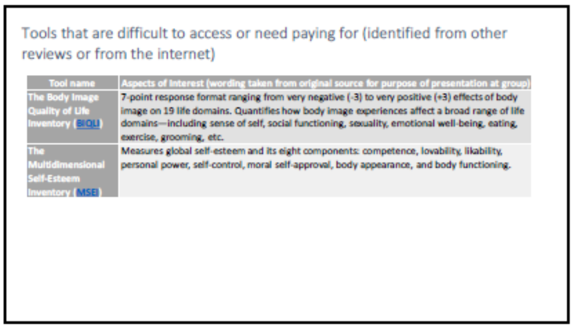
Tool name	Aspects of Interest (wording taken from original source for purpose of presentation at group)
Appearance Schemas Inventory-Revised (ASI-R)	20-item measure with two subscales : cognitive-behavioural investment in own appearance—Self-Evaluative Salience (12 items) and Motivational Salience (8 items). Self-Evaluative Salience reflects the extent to which individuals define or measure themselves and their self-worth by their physical appearance, which they deem influential in their social and emotional experiences. Motivational Salience pertains to the extent to which persons attend to their appearance and engage in appearance-management behaviours.
Body Image Coping Strategies Inventory (BICSI)	36-item assessment of the cognitive and behavioural activities used to manage or cope with threats or challenges to body image: (1) Avoidance, (2) Appearance Fixing, and (3) Positive Rational Acceptance.
Multidimensional Body-Self Relations Questionnaire (MBSRQ)	Body image is conceived as an attitudinal (evaluative, cognitive and behavioural) disposition toward the physical self, which encompasses physical appearance and the body's competence or "fitness" and its biological integrity or "health/illness." The full, 69-item version consists of 10 subscales: Evaluation and Orientation vis-à-vis Appearance, Fitness, and Health/Illness, plus Overweight Preoccupation, Self-Classified Weight, and the Body Areas Satisfaction Scale (BASS). The MBSRQ-Appearance Scales (MBSRQ-AS) is a 34-item measure that consists of 5 subscales Appearance Evaluation, Appearance Orientation, Overweight Preoccupation, Self-Classified Weight, and the BASS.



Tools that are difficult to access or need paying for (identified from other reviews or from the internet)

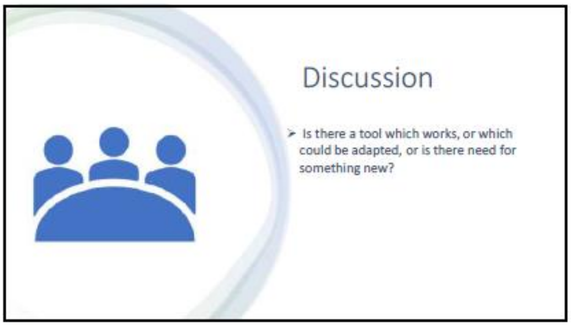
Tool name & Reference	Aspects of Interest (wording taken from original source for purpose of presentation at group)
Situational Inventory of Body-Image Dysphoria (SIBID	Assessment of the frequency of negative body-image emotions across specific situational contexts. Asks respondents how often they experience body-image dysphoria or distress in 48 identified situations-including both social and non-social contexts and activities related to exercising, grooming, eating, intimacy, physical self-focus, and appearance alterations.
The Body Image Disturbance Questionnaire (BIDQ)	Seven scaled items relating to appearance-related concerns, mental preoccupation with these concerns, associated experiences of emotional distress, resultant impairment in social, occupational, or other important areas of functioning, interference with social life or with school, job, or role functioning, and consequential behavioural avoidance. Five additional items ask for an open-ended clarification of responses.

Image showing parts of the item descriptions for the BIDQ
(removed from slide for purpose of adding to thesis appendices)



Tools that are difficult to access or need paying for (identified from other reviews or from the internet)

Tool name	Aspects of Interest (wording taken from original source for purpose of presentation at group)
The Body Image Quality of Life Inventory (BIQLI)	7-point response format ranging from very negative (-3) to very positive (+3) effects of body image on 19 life domains. Quantifies how body image experiences affect a broad range of life domains—including sense of self, social functioning, sexuality, emotional well-being, eating, exercise, grooming, etc.
The Multidimensional Self-Esteem Inventory (MSEI)	Measures global self-esteem and its eight components: competence, lovability, likability, personal power, self-control, moral self-approval, body appearance, and body functioning.



Discussion

- ➢ Is there a tool which works, or which could be adapted, or is there need for something new?

Summary of thoughts around assessment methods

Any other discussion points, thoughts, comments or questions

Thank you!

Appendix 26: All Identified Assessment Tools with Rationale for Inclusion or Exclusion for Assessment by the Expert Panel Group

Tool name & abbreviation	Include or exclude	Reason/s for inclusion or exclusion
Identified from Thesis Systematic Review		
Bath Body Perception Disturbance Scale© (BBPDS) (Lewis & McCabe, 2010)	Exclude	Avatar
The Body-Cathexis Scale (BCS) (Secord & Jourard, 1953)	Exclude	Scale of body parts/ functions
Body Esteem Scale (BES) (Franzoi & Shields, 1984)	Exclude	Scale of body parts/ functions
Body Perception Tool (BPT) (Turton et al., 2013) & Visual Discomfort Rating Scale	Exclude	Avatar
General Quality of Life Inventory (GQOLI) (Li et al., 1995; Li et al., 1997)	Include	Cannot justify excluding as cannot access tool
GOHAI (The General Oral Health Assessment Index) (Atchison & Dolan, 1990)	Include	Only about mouth and oral health, but a few of the individual questions map onto definition of body image
Image Itself Scale (Paula, 2010)	Exclude	Size, shape, weight or BMI or appearance
Male body image questionnaire- Swansea male body image questionnaire (SMBIQ) (Edwards et al., In preparation)	Exclude	Muscularity and physique

Tool name & abbreviation	Include or exclude	Reason/s for inclusion or exclusion
“My body image” (Lovo, 2001)	Include	Cannot justify excluding as cannot access tool
An oral health transition scale (Locker, 1998; McMillan et al., 2005)	Exclude	Only about mouth. Questions do not map onto findings. No indication of external perspectives
The PainQuILT™ (Lalloo et al., 2014; Lalloo et al., 2013)	Exclude	Avatar
Semantic Differential self-concept scale (Ellis-Hill, 1998)	Include	Has potential as an applied technique if right word pairs could be identified
Tennessee Self Concept Scale (TSCS) (Fitts, 1965)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
Tennessee Self-concept Scale—Second Edition (TSCS: 2) (Fitts et al., 1996)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
Identified from Kling Review (Kling et al., 2019)		
The Appearance Evaluation subscale and Body Areas Satisfaction Scale of the Multidimensional Body Relations Questionnaire (Brown et al., 1990)	Include	Difficulties accessing: paid (Cash, 2012) Cannot justify excluding as cannot access tool
The Body Appreciation Scale-2 (BAS-2) (Tylka & Wood-Barcalow, 2015)	Exclude	Assesses generalized attitudes towards the body, but does not include external/others perspectives

Tool name & abbreviation	Include or exclude	Reason/s for inclusion or exclusion
The Body Dissatisfaction subscale of the Eating Disorder Inventory-3 (EDI-3) (Clausen et al., 2011)	Exclude	Eating disorders Not complex enough to address stroke-related body image
Body-Esteem Scale for Adolescents and Adults (BESAA) (Mendelson et al., 2001)	Exclude	Size, shape, weight or BMI or appearance
BSQ (identified from my review and Kling review) (Cooper et al., 1987; Cordas & Neves, 1999; Stott, 2019)	Exclude	Size, shape, weight or BMI or appearance
The Centre for Appearance Research Valence Scale (CARVAL) (Moss & Rosser, 2012)	Include	Short, with broad questions that map onto thesis findings (feelings & thoughts about appearance)
The Drive for Muscularity Scale (McCreary & Sasse, 2000)	Exclude	Muscularity, including muscle mass and steroid use
The Weight and Shape Concerns Subscales of the Eating Disorders Examination Questionnaire (Fairburn & Beglin, 2008)	Exclude	Size, shape, weight or BMI or appearance
Identified through Online Searches		
Appearance Schemas Inventory (ASI) (Cash & Labarge, 1996)	Include	Questions seem to map onto findings
Appearance Schemas Inventory-Revised (ASI-R) (Cash et al., 2004b)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool

Tool name & abbreviation	Include or exclude	Reason/s for inclusion or exclusion
Multidimensional Body-Self Relations Questionnaire (MBSRQ) (Brown et al., 1990)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
The Multidimensional Self-Esteem Inventory (MSEI) (O'Brien & Epstein, 2022)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
Body Exposure during Sexual Activities Questionnaire (BESAQ) (Cash et al., 2004a)	Exclude	Sexual activities: relevant in some contexts, but too specific
Body Image Assessments: Assessment of Body-Image Cognitive Distortions (ABCD) (Jakatdar et al., 2006)	Exclude	Eating disorders
Body Image Coping Strategies Inventory (BICSI) (Cash et al., 2005)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
The Body Image Disturbance Questionnaire (BIDQ) (Cash et al., 2004c)	Include	Looks relevant from available snapshot (Collison & Mahlberg, 2018) Cannot justify excluding as cannot access tool
Body-image Ideals Questionnaire (BIQ) (Cash & Szymanski, 1995)	Include	Questions seem to map onto findings

Tool name & abbreviation	Include or exclude	Reason/s for inclusion or exclusion
The Body Image Quality of Life Inventory (BIQLI) (Cash & Fleming, 2002)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
The Body Image States Scale (BISS) (Cash et al., 2002)	Exclude	Only account for one time-point Size, shape, weight or BMI or appearance
Situational Inventory of Body-Image Dysphoria (SIBID) (Cash, 2002b)	Include	Difficulties accessing: paid Cannot justify excluding as cannot access tool
Identified from CARVAL (Moss & Rosser, 2012)		
Centre for Appearance Research Salience scale (CARSAL) (Moss & Rosser, 2012)	Include	Short, with broad questions that map onto thesis findings (feelings, thoughts & perceptions about appearance)
Derriford Appearance Scale (DAS-24) (Carr et al., 2005)	Include	Questions map onto all aspects of definition

Key:

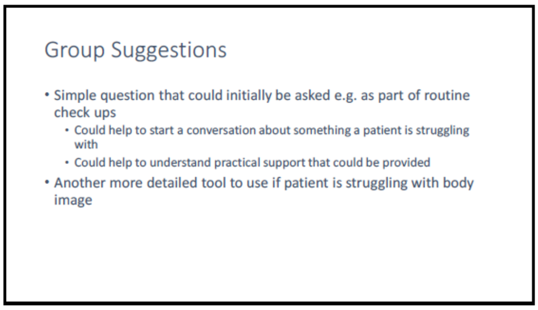
Eating disorders = too focussed on eating disorders

Size, shape, weight or BMI or appearance = Only focussed on body size, shape, weight, BMI or appearance

Expansion on justifications:

- Eating disorders or only focussed on body size, shape, weight, BMI or appearance: does not address the complex, multidimensional nature of body image experience
- Avatar: more about appearance, not internalisation in terms of self-perceptions. Would not capture people feeling differently in different contexts (e.g., it's not until people come out of hospital that they might feel differences)
- Scales: if issues with specific body parts are not in the forefront of people's minds, then it's not a significant issue for them
- Components of broader tools: could be useful if they reflect thesis findings. These have not been discounted on the basis of being part of a larger measure, even if they are small; they could contain a framing question which asks something more simply than a larger scale
- BAS-2- does not include any external thoughts; reflects more what developed for e.g., college students
- Anything which needs to be paid for is unlikely to get widespread adoption in the NHS

Appendix 27: Additional Microsoft PowerPoint Slides Presented During the Individual Expert Sessions



Group Suggestions

- Simple question that could initially be asked e.g. as part of routine check ups
  - Could help to start a conversation about something a patient is struggling with
  - Could help to understand practical support that could be provided
- Another more detailed tool to use if patient is struggling with body image

Tools suggested during discussion group

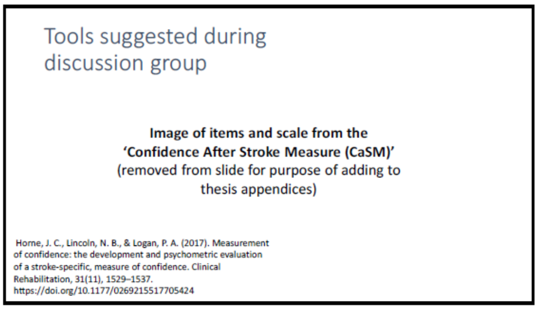
Image of 'Nottingham ADL Scale'
(removed from slide for purpose of adding to
thesis appendices)

Barer D. H. (1989). Use of the Nottingham ADL scale in stroke: relationship between functional recovery and length of stay in hospital. *Journal of the Royal College of Physicians of London*, *23*(4), 242–247.

Tools suggested during discussion group

Image of 'Nottingham Extended ADL Scale'
(removed from slide for purpose of adding to
thesis appendices)

Retrieved from: https://www.nottingham.ac.uk/medicine/documents/published-assessments/neadl.pdf



Tools suggested during discussion group

Image of items and scale from the
'Confidence After Stroke Measure (CaSM)'
(removed from slide for purpose of adding to
thesis appendices)

Horne, J. C., Lincoln, N. B., & Logan, P. A. (2017). Measurement of confidence: the development and psychometric evaluation of a stroke-specific, measure of confidence. Clinical Rehabilitation, 31(11), 1529–1537. https://doi.org/10.1177/0269215517705424

Appendix 28: Expert Panel Group Topic Guide

Expert Panel Group Topic Guide

QUICK REMINDERS

- Participation acts as consent
- Participation is voluntary and you can stop taking part at any time
- Group will be recorded through MSTeams & Dictaphone- audio and video; transcribed
- Anonymous in write-up
- Any questions?

INTRODUCTIONS & ICE BREAKER

GROUP GUIDELINES

- To ensure that everyone feels heard and happy to take part

Everyone is:

- *welcome*
- *treated equally*
- *valued*
- *supported*
- *included*
- *heard*
- *respected*
- *sensitive to others*

The following should be maintained:

- *Privacy*
- *Confidentiality: Whatever is talked about in the group stays in the group*
- *Open and accessible*
- *Attendance and punctuality*
- *Use of language*
- *Keeping on topic*
- *Breaks if you need them*

- *Respect others' opinions*

GROUP AIMS

1. To identify possible support options or components which could address the key findings arising from my thesis

2. To review methods of assessing post-stroke body image to determine which, if any, appear most suitable for identifying benefits of support

BRIEF SUMMARY OF THESIS

- Background & methods
- Definition of body image derived from thesis
- Summary of key findings

Discussion a)

Have you worked with any patients who have experienced any body image-related issues?

How do you think body image struggles present themselves?

At the moment, if you came across a patient who seemed to be struggling with their body image, what would you do?

Describe if you ever signpost anyone for support with their body image? How would you do this? How would you approach it?

Discussion b)

b. What support is required for people who might struggle with their body image experiences after stroke?

How and when do you think that it could be provided? (e.g. based on step care model)

Prompts: why do you think that would help?

How would you implement that?

Who would need to be involved?

5-10 MINUTE BREAK

During the break, CD will summarise discussion so far

PRESENTATION OF BODY IMAGE ASSESSMENT METHODS AND FINAL DISCUSSION SECTION

- Categories of tools not shortlisted and presented

Discussion c)

c. Based on ideas for interventions, do any of the existing presented tools seem appropriate to identify any benefits of intervention?

- **For each tool, please could you think about:**
  - **How easy it would be to complete for someone who has had a stroke**
    - **Thoughts on format, spacing, length, language**
    - **Anything ambiguous**
  - **Relevance to stroke patients**
  - **Any areas of body image not covered**
  - **Ease of use for clinicians**

  - **Ease of implementation into organisations i.e. would it be feasible?**
  - **What needs taking out/adding?**
  - **Overall opinions**

ANY OTHER DISCUSSION POINTS, THOUGHTS, COMMENTS OR QUESTIONS

THANK YOU AND CLOSE

Prompts:

- What are your thoughts?
- Which tool do you most like? Which do you least like? Why?
- Are there any parts of the other tools that we have looked at today that you think are also important?

Ensuring all members of the group have opportunity to provide responses to a question:

- *What are your experiences…?*
- *Can I open that to the group?*
- *[Name] what do you think?*
- *From your perspective [Name], what do you think?*

***If participants go off topic:** Acknowledge the deviation, but can I just bring you back to XX*

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