Legislation, Policy and Equality: Evaluating deaf people's access to the National Health Service

by

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Abstract

The Equality Act 2010 imposes a duty on healthcare providers to make an adjustment for people who are disabled to enable them to access the service in such a way that is equal to a person who is not disabled. Existing research shows that many deaf people have had poor experiences when accessing the National Health Service (NHS), which has resulted in negative outcomes when reasonable adjustments have not been made. Although medical settings have a duty to make adjustments for deaf people, it is unclear what the 'reasonable adjustment' should be. Therefore, this thesis aims to investigate what the 'reasonable adjustment' duty implies, as outlined in the Equality Act 2010, in the specific context of paramedic practice, as no official definition has been given within the legislation.

This qualitative study uses an Interpretative Phenomenological Analysis (IPA) framework which investigates the lived experiences of both deaf people and paramedics when communicating in medical emergency encounters. Analysis of the interviews with these two participant groups are drawn together into common themes to gain an understanding of the issues experienced by both groups, what they were concerned about, and how interaction was facilitated with each other. This research also draws upon NHS hospital policies across England to understand how hospitals intend to make the 'reasonable adjustment' duty that is placed on them through the Equality Act 2010. The policies are then reviewed alongside the identified themes from both participant groups to explore similarity or discrepancy between policy aims and outcomes, including whether the adjustments that need to be made for deaf BSL users are understood.

The findings in this thesis demonstrate that qualified British Sign Language interpreters are essential to facilitating deaf people's access to healthcare, and NHS policies struggle to meet the anticipatory duty outlined in the Equality Act. This study concludes that medical settings and personnel must be prepared for when emergency situations arise, and must have clear policies and expectations about how to obtain a qualified interpreter within a reasonable timeframe, and the communication methods that are acceptable until a qualified interpreter arrives.

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Acknowledgements

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Martin, I would also like to add, thank you for encouraging me to apply for this after my undergraduate degree. People still ask me about how and why I ended up doing research, and I still clearly remember coming to your office to talk about researching deaf access to the NHS; we were supposed to be talking about a Masters and we ended up talking about something higher, I also clearly remember the interview on what was, and still is (to me at least), the hottest day of the year. I honestly do not think I would be here without your initial encouragement, guidance and mentoring.

To Dr Laura Snell, and yes, I used your title deliberately! It seems fitting that during my undergraduate degree I saw you finish your PhD and you get to see me finish my research. You have my upmost gratitude for helping, supporting and guiding me throughout not only my undergraduate degree, but also my postgraduate degree. My English language has improved so much because of you, so this is a huge thank you for everything and not for only being my language support tutor, but also for being my friend.

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Chapter 1. Introduction

1.1 Introduction

Note on terminology: throughout this thesis I will use the term 'deaf' when referring to people who have a hearing loss and use British Sign Language to communicate as either their first or preferred language - this will be discussed in more depth in Chapter Two.

This study aims to investigate how deaf people who use British Sign Language (BSL) access the National Health Service (NHS). This has been explored through the lived experiences of deaf people who have used the NHS for hospital appointments or the emergency services. In order to gain an in-depth understanding of how deaf people access the NHS, interviews have been undertaken with deaf people and healthcare professionals; the purpose of this was to collect data about how deaf people have communicated with and without a BSL interpreter, and how access is facilitated for deaf people when using the health service.

This study also aims to explore how equality legislation and guidance influences the anticipatory duty placed on hospitals and in turn, how hospital policies then anticipate the individual needs of deaf patients. This will be discussed alongside the common themes identified through the interview data in order to understand how hospital policies take steps to facilitate deaf people's access, which enables them to access healthcare without being at a 'disadvantage', through the duty placed on hospitals and other medical settings through the Equality Act 2010 legislation.

1.2 Justification for research

Deaf health is a topic of great interest to me, and during my undergraduate degree I researched deaf health for my dissertation. I quickly discovered that there was not a lot of research relating to deaf health, and most of the existing research about deaf health related to mental health. The research that did investigate deaf health provided statements about the need for interpreters and most studies involved claims stating that hospitals and GPs must provide interpreters according to the Equality Act 2010. My interest in understanding the Equality Act 2010 grew, and I was intrigued to investigate how hospitals interpreted this legislation.

Research from Royal National Institute for the Deaf (2004), ASLI (Association of Sign Language Interpreters 2012) and SignHealth (2014) have all produced information showing that access is poor for deaf patients, and some have produced worrying statistics around general access, communication methods and understanding of medical information (e.g. understanding medication and understanding diagnosis). This is fully explored in Chapter Two, which provides a literature review of the research and media stories that have investigated the experiences of deaf patients. These reports and stories have only ever explored the deaf experience and never explored the view from Healthcare Professionals (HCPs) or the content of hospital policies. However, one study by Reeves et al. (2002) did request policies from GP practices, Primary Care Trusts and A&E departments, but these policies were never reviewed due to a number of issues with the health departments not sharing the information (see Chapter Two). Reeves et al. (2002) also interviewed GP, primary care and A&E managers (see Chapter Two), but the interviews did not discuss the personal experiences of treating deaf patients.

From personal experience, a communication breakdown is not a one-way street and this is why both sets of participants were interviewed to see if the communication issues are the same for both parties. I wanted to not only investigate how deaf people have accessed the NHS and the issues they have faced, but also to investigate how the paramedics feel when they are treating deaf patients and how they overcame the communication barrier that both parties faced.

1.3 The originality of this research

No research has looked at all three aspects - deaf people, paramedics, and hospital policies - in the same study. By exploring all three aspects, this research will:

- Provide an understanding of the issues faced when there is a communication barrier.
- Explore how two sets of participants felt and overcame these language barriers.
- Outline the adjustment of provisions that both sets of participants want, and need, based on their experiences.
- Explore the term 'reasonable adjustments' and how this is facilitated for deaf people.

This research will, for the first time, try to identify the common themes between the lived experiences of the deaf participants and paramedics, and explore whether these themes are relatable to each other. Other research has only focused on one participant group, so the aim of reviewing two participant groups in this research is to provide a much greater understanding of the complex issues faced in medical settings.

Another original element of this research is that the lived experiences are being combined with the hospital policies to gain a new understanding of how hospitals plan to anticipate the needs identified through the lived experiences of both deaf patients and paramedics.

1.4 Researching disability, deafness and deaf people in both the deaf and Hearing worlds

I am, in theory, a disabled researcher: I have a hearing impairment and like a number of deaf people in the world, I grew up orally, so my first language is English and I lip-read. I say 'in theory', because by law (Equality Act 2010) I fall under having a physical impairment that has a substantial effect on my life:

> "You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities." (GOV.UK website)

I do not class myself as disabled, and all of my friends would not define me as disabled. In fact, if they were to define me it would probably be along the lines of being ginger rather than having a hearing impairment. However, I experience the same issues as all deaf people, and I understand the same frustrations and issues that a lot of deaf people face every day.

I do find myself straddling two worlds; I have experienced the hearing world as I grew up in it, however, I also experience the deaf world with the frustrations that deaf people can face in the environment and I live the deaf experience. There are arguments in academia about non-disabled researchers conducting disabled research (Barnes & Mercer, 1997; Drake 1997; Stone & Priestley 1996) and there are some who push for more disabled researchers in academia as they can give a better insight into the research and feel that it stands for more (Oliver & Barnes, 1997; Kusters, et al., 2017).

Something that I always found interesting is the concept of being one or the other; in this case, a person is a non-disabled researcher or a disabled researcher. Why can a person not be both? In my world I have hearing friends, but I also have deaf friends and I have other disabled friends. There is no conflict between us all, and one does not have to justify being with the other. My personal standpoint on disabled people doing disability research is that disabled people probably do provide a better insight especially on disability topics (Kusters, et al., 2017; Young & Temple, 2014); however, I would not say that a non-disabled researcher stands for any less than a disabled person doing the research.

As a person and a researcher, I have a stance on both. I play competitive squash and all of my squash friends are hearing; therefore, I interact in the hearing world as I can communicate orally and I understand the hearing world. I used to play Sunday league football for a deaf football team, so I interacted in the deaf world too as I can sign. I might not have a profound hearing loss, but I still understand the same communication difficulties but in different situations. If the environment is noisy, I will struggle to hear even with hearing aids, as most hearing aids amplify all noise. If you have your back to me, I will struggle to hear as I cannot see your lips and the sound of noise is traveling away from me and not towards me. Sometimes I just do not understand people - it could be an accent that means I cannot keep up with the situation - and other times I have just missed some words and not caught the full context of a situation. I understand the same frustrations as a deaf person, I have experienced much of the same shared history as the deaf community of going through school without much support and struggling because of this.

However, I personally find myself at an advantage because of it; I find myself being able to look at a situation from more than one angle, being able to understand and respect others and use this to try and inform a person of another point of view. Their experience does not have to be right or wrong, but it is what they have found. This is why my interest in this topic made me want to interview both deaf participants and paramedics, as when I read articles such as those in the literature review (Chapter two), it never came across as the full picture to me because it never reflected a range of views, in different situations, where there might not be time for an interpreter to be present.

From my own perspective, deafness is not straightforward. Just because one individual may struggle in a particular situation does not mean another will, and this is why I wanted to show the full story from two sets of participants, not only to find out what does not work, but also to explore if anything does work. Alongside investigating the two groups of participants, I wanted to look at what part the hospital policies have to play in this.
Positioning myself within this research is an interesting topic and one that cannot be ignored. As Ladd (2003) states:

> "We need to recognise our own implication in the production of data and must thus begin to include ourselves (our own practices and their social and historic basis) in our analyses of the situations we study" (Ladd, 2003: 273)

Etherington (2004) also makes a very valid point about "being aware of the personal, social and cultural contexts within which we live and work, and realising that these aspects of our lives impact on our interpretation of the world" (Etherington 2004:19). Within Chapter Three, I discuss my epistemological and ontological alignment in detail, however, my own experiences throughout my life have impacted on the research design and how I personally interpret the research data.

My interest in this research is a love for equality, and more importantly watching equality unfold and be debated. I fully believe that we are, as a society, attempting to progress so that all human beings are equal – albeit a very slow process, but progress nonetheless. I believe we are currently moving into an 'Equality Age', which is not just about disability but all protected characteristics. Although, as stated above, this is very slow progress, all it takes is to look at the recent national media to see that inequality is becoming more unacceptable, which is quite rightly so. Most people who are in the protected characteristics category – myself included – would argue that not enough is being done for full and equal access. However, if you consider the current literature presented within this thesis, nearly all of the stories are negative and show poor access of some sort. I have noticed that most reports in the media are also negative, showing some sort of poor performance depending on the disability or protected characteristic. I personally believe that we rarely see the good parts of equality, the times where society has managed to adjust and allow everyone to access what they want and tried to minimise any form of discrimination.

This is where my personal position will affect this research as when I conducted the interviews, I was not just trying to identify the issues but I was also trying to identify the good aspects, in the hope that the good can strive forward and be implemented more often.

1.5 Research Questions

The study will address four research questions:

1. How is access to the National Health Service facilitated for deaf people, and in particular deaf BSL users?
2. How are disability and human rights legislation applied to deaf people within the context of the UK's National Health Service?
3. What practical and ethical issues arise for health service providers when the service users are deaf BSL users?
4. How is the term 'reasonable adjustment' represented in acute health care policies and practices in relation to deaf BSL users?

1.6 Thesis structure

Following this introduction, *Chapter* Two *'Understanding deaf people as users of healthcare'* will provide information about the current affairs of deaf people accessing the National Health Service. This chapter will outline the current published information on deaf people's experiences of accessing the NHS since 2002.

Chapter Three 'Theoretical approaches and methodology' will provide an outline of the theory and method used to conduct this research. This includes the theoretical approach to the research and intricate details of my own understanding about how to apply the theoretical approach to this study, along with justifications for the research design. This chapter will also outline my ontological and epistemological alignments, along with how I situate myself within this study. This chapter then outlines the participant recruitment, and how data was collected and analysed, which includes justifications about how the data has been presented.

Chapter Four 'Deaf people as healthcare users: Legislation and NHS guidance' provides a brief explanation of current and previous equality legislation. This chapter explores the Equality Act 2010 and investigates the terms used within the legislation which could be cause for debate. The final section of the chapter will present and discuss some of the guidance documents and new standards for the hospitals regarding ether policies or expected requirements in relation to equality and disability, including the recent Accessible Information Standard.

The next three chapters present the findings from the participant interviews and hospital policies. *Chapter Five 'Deaf people as healthcare users: Hospital policies'* explores a collection of hospital policies which have been requested from across the nine regions of England. This chapter begins with a reminder of the Equality Act 2010 and the duties imposed on hospital policies through this legislation. The chapter then guides the reader through the replies for each policy and the titles of the documents that were received through the freedom of information requests. Following this, a summary of each policy is provided and anything that mentions equality or adjustments is highlighted to explore how the hospitals are making adjustments for deaf patients.

Chapter Six 'Deaf people as healthcare users: Deaf experiences' will explore the initial themes discussed by the deaf participants. This chapter begins by introducing the participants (note: their names are pseudonyms) and then walks the reader through the interviews, starting with exploring the general reasons that the participants needed to use the NHS and how they wanted to communicate during the appointments. The chapter then moves on to explore their experiences through the initial common themes identified.

Chapter Seven 'Deaf people as healthcare users: Paramedics experiences' explores the initial themes presented from the interviews with healthcare professionals. This chapter begins with exploring the paramedics and their position within the NHS, and how long they had been doing their jobs. Following the introduction of the participants, this chapter explores the paramedics' overall feelings on communicating with a deaf person and then continues to explore the rest of the themes, such as how the paramedics communicated and the issues they faced when treating someone when there was a communication barrier.

Chapter Eight 'Deaf people as healthcare users: Making sense of a complicated situation' will critically analyse the common themes identified in the data collected from the Paramedics and deaf participants. These common themes have been carefully brought together to explore some of the key themes discussed by both groups of participants. Alongside this discussion, the hospital policies have been included to investigate how the common themes are addressed within the hospital policies. The final section of the discussion chapter will address the five research questions.

Chapter Nine 'Deaf people as healthcare users: The reality for users and providers' will draw together the themes outlined in chapter eight and discuss the challenges that deaf people face when accessing health services. This chapter also aims to explore the key terms from the Equality Act 2010 and what these terms mean in the context of deaf people's needs, and how this enables them to access healthcare, along with how these 'reasonable adjustments' are met by healthcare staff.

Chapter Ten 'Conclusion and the way forward' will summarise the thesis and answer the research questions, outline the originality of this research and explore the limitations of the study. This chapter will also highlight any future research that could be undertaken to follow on from this study.

Having outlined the scope of this study, the opening chapter begins by defining what is meant by 'deaf people' within the context of this research; this then leads into investigating and presenting previous research and media reports of deaf people accessing healthcare.

Chapter 2. Understanding deaf people as users of healthcare

This chapter aims to provide information about the number of deaf people currently in the UK. It is vital to understand the issues that the deaf population face, and why accessing healthcare can be so different for deaf people compared to those without a hearing loss or those who speak a different language. This chapter will introduce deaf people, the deaf population relating to sign language, and provide a context for the current literature exploring the issues that deaf people face when communicating. This chapter will review literature from a range of sources, such as reports produced by deaf organisations, National Health Service (NHS) publications and journal articles about deaf people's access to healthcare in the UK.

2.1 The deaf population

The term 'deaf' can be confusing as there are many different terms for someone who has a hearing loss, such as: hard of hearing, hearing impaired, profoundly deaf or deafened. The number of people in the UK who have any level of hearing loss is estimated to be between 11 - 12 million people (Gov.uk website 2017; Hearing Link 2020). According to Action on Hearing Loss (2020), by the year 2035 there will be an estimated 15.6 million people in the UK that have some form of hearing loss.

Many people who have a hearing loss will use a hearing aid or possibly a cochlear implant, which might help with communication. Alongside using hearing aids or cochlear implants, some people might also lip-read or find other methods which help them to hear and communicate. People who have a more severe - profound hearing loss may also use sign language to communicate. In Chapter One I outlined that within this study, I would refer to all people with a hearing loss that use BSL as a first or preferred language as 'deaf'. It is important to briefly outline that within sign language communities, many deaf BSL users may refer to themselves as 'Deaf' which comes from those who belong to the deaf community (Ladd, 2003); this term was created by the Deaf community to define its members who are sign language users and share the same cultural experiences (Woodward, 1972). De Meulder (2018) explains that a new sociolinguistic order has arisen within sign language communities, and has made reference to deaf 'new signers'. The term 'new signers' can be applied to "different profiles of people that exist in parallel" (De Meulder, 2018:7); to be clear, this can apply to anyone who uses sign language either from growing up in a residential deaf school or a person who has adopted sign language later in life. Throughout this thesis, I will refer to all deaf BSL users as 'deaf', in the same way that deaf new signers have been described.

According to Action on Hearing Loss (2020), there are an estimated 900,000 people who have severe – profound hearing loss in the UK by 2035, however, the reported number of people that use British Sign Language (BSL) to communicate in the UK is harder to understand. This thesis aims (but is not limited) to investigate how deaf people who use British Sign Language access healthcare, and how this communication is facilitated between healthcare professionals and deaf patients. Therefore, the rest of this chapter will provide information on deaf people who use BSL to communicate as there are a number of factors that should be considered when communicating with deaf BSL users in order to understand the impact of their communication needs, and how this affects the delivery of health information for deaf BSL users.

2.2 Deaf population and British Sign Language

It is important to establish the number of deaf BSL users in the UK and even though it is quite difficult to confirm the exact number, we have a rough estimate of how many people use sign language as a first or preferred language. For example, the 2011 Census suggested there were 22,000 people who used a signed language and 15,000 that used BSL. The national census in 2011 by the Office for National Statistics (2013) estimated the lowest number of BSL users in the UK compared to the estimates provided by some deaf organisations:

- National Census (2011) – 22,000
- Disability Resource Centre (2012) – 50,000
- British Deaf Association (2013) – 156,000

More recently, the Gov.uk website stated that: “11 million people in the UK are deaf or hard of hearing. There are 151,000 BSL users in the UK” (Gov.uk website 2017). However, extrapolated data taken from the 2020 GP patient survey question “are you a deaf person who uses Sign Language?” (GP patient Survey 2020), suggests that there are an estimated 253,290 sign language users in England. This is based on a sample of 740,000 respondents of whom 0.45% self-identified as sign language users.

Using the Gov.uk estimation, as it can be assumed that this is the official number that the government recognises because it is included on their website, we can compare this with the number of qualified British Sign Language interpreters in the UK. In 2017, the government recognised there were 151,000 BSL users in the UK and the National Register of Communication Professionals for Deaf and Deafblind people (NRCPD) confirmed that there were 1,026 qualified British Sign Language interpreters in the UK (NRCPD 2017). The evidence shows that there are not enough qualified interpreters to BSL users in the UK and although the number of qualified interpreters is growing, there is still a huge difference between the number of BSL users and the number of interpreters. Interpreters play a huge role throughout this research and although interpreters were not explicitly interviewed, there were many references to BSL interpreters throughout the interview process. It is important to highlight that the low number of interpreters to deaf BSL users becomes even lower when self-restrictions such as training and competence to interpret medical appointments are considered, and this is explored later on in the thesis.

2.3 The background to the current literature

It is important to briefly highlight and address some of the critical factors that are a direct consequence of not having adequate communication in a medical setting and why these are important, for example, reading and writing skills. A deaf BSL user may not have the same level of written literacy skills as that of a hearing person. Conrad (1979) conducted research with deaf children and his findings indicated that a deaf child's reading skills were considerably lower than those who were not deaf: "It will be seen that of the deafer section of the population almost 50 per cent have no reading comprehension at all - they are totally illiterate" (Conrad 1979: 121).

Although Conrad's report was published in 1979, later research by Powers, Gregory, and Thoutenhoofd (1999) showed similar results. In addition, the results were still very much the same in 2014 when City University London published a report which showed that deaf children were still 'falling behind' (Sawtell 2014) in their reading ability:

> "Over half of the deaf children assessed had reading difficulties that were at least as severe as the problems faced by hearing children with dyslexia and in some cases they were more severe" (Sawtell 2014).

This is extremely important as the following literature will demonstrate the situations that some deaf people have faced, and this is a vital factor as to why many deaf people do not want to communicate without an interpreter, especially as some may not feel comfortable with reading and writing. This is also something to keep in mind throughout the whole thesis, especially when the research investigates how deaf people have communicated when in medical settings.

The issue with reading and writing has been deliberately highlighted first, because the use of pen and paper is arguably the first thing most people would think of using when speaking is not an option. The second point that needs to be addressed is consent. The importance of giving consent is extremely vital in any medical situation, not only to allow HealthCare Professionals to give potential life-saving operations, but also to ensure that patients are aware of the after-effects of the operation, such as taking medicine, or simply to understand what is medically wrong and the decisions made or options about what can be done. Giving consent would normally be an easy task, however, explaining to a deaf BSL user about the need to operate is not straightforward. This is also why reading and writing was addressed first. Francis and Johnston (2001) published a book titled 'Medical Treatment: Decisions and the Law' in which they discussed consent and who can be involved in giving consent, along with the issues that can arise when a patient is disabled or has an impairment.

Francis and Johnston (2001) explained that consent cannot be obtained without communicating the nature and effect of the treatment; the communication may be given orally, or in writing, in order for the treatment to be lawfully provided to the adult patient. However, when there is a language, or literacy barrier and the patient is unable to understand the language that the information is being communicated in, then they cannot give a valid consent:

> "It may be a statement of the obvious, but clearly the patient who is unable to understand the language in which the treatment information is given or unable to hear it, or read because of illiteracy, disability or unconsciousness cannot give a valid consent" (Francis and Johnston 2001: 27).

According to the NHS Confidentiality Code of Practice (Department of Health 2003), there are different types of consent such as explicit/express or implied consent. However, if the patient cannot communicate to give consent to the HCPs, then other means of being able to give consent need to be arranged. Francis and Johnston argue that giving valid consent must be in a language that they understand, even if it is written down. As Conrad (1979), Powers et al. (1999) and Herman, et al. (2017) have shown, the reading ability for some deaf people can be low and therefore, they may not fully understand their treatment even if it is written down, thus not giving valid consent. This is where one of the biggest topics within this research starts to be addressed – BSL/English interpreters. The arguments relating to 'reasonable adjustment' and the use of BSL/English interpreters will be covered throughout this thesis, but for the purposes of this chapter for understanding the current literature, it is important to consider the rights that deaf people have, what deaf people want and need in medical settings, and the implications when this does not happen.

The use of BSL/English interpreters is vital for many deaf people, especially when sign language is their first language or preferred method of communication. The use of interpreters should also be considered from the medical viewpoint relating to the issue of consent. According to the NHS Confidentiality Code of Practice (Department of Health 2003), consent must be given in a language or an accessible format that the patient can understand, which links to the Equality Act 2010. The NHS Confidentiality Code of Practice states:

> "7. Seeking consent may be difficult, either because patients' disabilities or circumstances have prevented them from becoming informed about the likely uses of their information, or because they have a difficulty communicating their decision (be it to consent or object).
> a. In the former case, extra care must be taken to ensure that information is provided in a suitable format or language that is accessible (e.g. providing large print or Braille versions of leaflets for those with reading difficulties) and to check that it has been understood" (Department of Health 2003: 30).

The document continues:

> “8. Failure to support those with disabilities could be an offence under the Disability Discrimination Act 1995, and may prevent consent from being gained. Support for communicating with patients having specific disabilities can be obtained from a range of agencies” (Department of Health 2003: 30).

The NHS Confidentiality Code of Practice was published in 2003 and showed that medical settings must take care so that people who may struggle to understand or to communicate will be provided with information in a suitable language or an accessible format. As previously established, reading and writing may not be an accessible format for a deaf person, and if BSL is their first or preferred language, communicating consent in BSL is most appropriate. However, there are many occasions where family and friends have been asked to interpret medical appointments, but Francis and Johnston (2001) state that only the patient can make the decision about their treatment:

> “There is a frequently held misconception that the competent patient’s next of kin has some right to be consulted or even to decide on treatment. This is not so. No-one other than the patient can make a decision about his [sic] treatment so long as he is an adult and has the relevant capacity. Whether others are consulted at all will be governed by the duty of confidentiality owned to the patient and the consequent need to obtain the patient’s permission to do so” (Francis and Johnston 2001: 27).

Although this chapter has mostly referred to the communication needs of deaf people in medical setting and appointments, it is critical to highlight that the communication needs are not just important to the deaf patient but also the medical professional. Peterson et al. (1992) and Ohm et al. (2013) show that getting the patient’s history is vital in making a diagnosis. This shows that good communication is required in making a correct diagnosis and the use of reading and writing, or third-party information through a family or friend acting as an interpreter, might affect the diagnosis and treatment of the deaf patient due to broken information, thus affecting the diagnosis or treatment.

Although this study does not investigate the physical health of deaf people, it is important to highlight the Sign Health 2014 study which did investigate this. Sign Health (2014) highlighted that deaf people are more likely to be overweight and that high blood pressure is nearly twice as common and more worryingly, under-diagnosis and under-treatment of serious conditions is higher in deaf people. Sign Health (2014) showed that the overall health, diagnosis and treatment of deaf people was poor. The impact of this could be that many deaf people may need to access health services more often, however, there are many concerns over the accessibility of health services in the UK, as shown below.

2.4 The Equality Act 2010

The Equality Act 2010 is a huge part of this research and an analysis of the Equality Act 2010 is discussed in Chapter Four. In the most recent legislation, the Equality Act 2010 clearly stated that public services must make a 'reasonable adjustment' (Equality Act 2010). Further important terms such as 'accessible format' and 'substantial disadvantage' are also used in the Equality Act 2010, and are further explored in Chapter Four which focuses on the legislation. However, for the purposes of this chapter it is important to briefly outline the duty that healthcare services are required to fulfil:

Section 20.3 states:

> "The first requirement is a requirement, where a provision, criterion or practice of A's puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to avoid the disadvantage." (Equality Act 2010: Section 20.3).

Section 20.5 states:

> “The third requirement is a requirement, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to provide the auxiliary aid.” (Equality Act 2010: Section 20.5).

Section 20.6 states:

> “Where the first or third requirement relates to the provision of information, the steps which it is reasonable for A to have to take include steps for ensuring that in the circumstances concerned the information is provided in an accessible format.” (Equality Act 2010: Section 20.6).

In 2015 the Accessible Information Standard (AIS) came into force, and the overall reason for the standard being created was to inform health and social care organisations about “how they should make sure that patients and service users, and their carers and parents, can access and understand the information they are given” (NHS England 2015: 1). A full discussion of the Equality Act 2010 and Accessible Information Standard, and the requirements of both, is included in Chapter Four; however, it is important to highlight the Equality Act 2010 and the legal duty this imposes on healthcare settings before reading the remainder of this chapter.

2.5 The inequality of deaf people accessing healthcare

Access for deaf people who need to use healthcare services is not widely documented. Currently there is a lot of research for deaf people accessing mental health services, however, the experiences of deaf people accessing physical health services such as GP practices, hospitals and A&E departments has not been well researched. This section of the chapter will explore the issues that have been identified through research publications and reports, and highlight literature about deaf people needing to access any form of primary or secondary healthcare for physical treatment.

One of the most common difficulties that deaf people have faced when needing to access primary or secondary healthcare services can be related to the communication barrier and the lack of access for people whose first language is not spoken English. This communication barrier can be a cause of many issues that deaf people face, with some issues being straightforward in the sense that it is something that could be expected, such as staff not having deaf awareness training, and others being more complex, such as the dangers of using family or friends as interpreters. Middleton et al. (2010) highlighted that the communication preferences of deaf people varied: 11% preferred to use sign language in everyday life; 70% used speech; and 17% used a mixture of both sign language and speech. In a clinical setting, the preferred method of communication changed greatly. 50% of the sign language users preferred to have their consultation with a sign language interpreter and 43% indicated they would prefer to only have a consultation with a signing health professional. The remaining 7% of sign language users said they would be happy to have the consultation in speech, as long as the health professional had good deaf awareness, which meant that the patient could lip-read.

The Sign Health (2014) 'Sick of it' study showed that how the participants wanted to communicate was drastically different to what actually happened. Around 80% of deaf people wanted to communicate in BSL, but only around 30% got the chance to communicate in their preferred method. Most of the 80% that wanted an interpreter eventually used spoken English and lip-reading to communicate, of which 3% really chose to communicate in this way, and a minority of this percentage used written notes to communicate.

There are a number of inequalities that have been identified for deaf people who need to access general healthcare, such as GP practices or more acute hospital appointments. The more obvious reason that can be identified is the language barrier between deaf people using BSL and the consultants who use spoken English. However, this language barrier is more complex than just simply not being able to communicate.

Research shows significant concerns for deaf people who are trying to access health services. Reeves et al. (2002) published research which showed that deaf people had issues with simply making appointments at their GP surgery, which is the first line of primary care for the NHS. Reeves et al. (2002) highlighted that many deaf people also had issues in the waiting room and knowing when they were next for their appointment due to doctors and medical staff forgetting that they were deaf. As stated above by Middleton (2010) and Sign Health (2014), Reeves et al. (2002) also stated:

> "…problems were significantly worse for the 50% of Deaf people who were without communication support. More than half the sample expressed a preference to be supported by a British Sign Language (BSL) interpreter at consultations, yet interpreters were present at just 17% of GP and 7% of A&E consultations" (Reeves et al. 2002: 2).

The lack of provision of interpreters or alternative communication methods does not only affect the appointment itself, but also affects the person's general access and their confidence that they have been understood by the health professional. Reeves et al. (2002) also documented that not only did deaf people struggle to communicate with their GP, but they also struggled with the receptionists as well. Interestingly, the importance of communicating with GPs and receptionists was also documented in SignHealth's 2014 publication:

> "It is worth mentioning the importance of receptionists. Health policy normally ignores receptionists and yet they play a crucial role as far as patients are concerned. Your experience of a health service can sometimes be decided by how good the receptionist is. This is particularly the case if

> you are Deaf and may have ‘extra’ contact with the receptionist, e.g. asking for an interpreter, being called from the waiting room, etc.” (SignHealth 2014).

Ubido et al. (2002) also highlighted that many deaf women who attended an appointment on their own did not understand what the doctor was saying. For example, participants stated that when the doctor wrote the information down it was hard to read, and another woman said that she would read the prescription she was given to get a clue as to what the doctor had said. One woman said that she had attended the hospital for a routine check-up, but she actually had a bowel operation. Another woman thought she was having an antenatal check and did not realise that her baby was being induced (Ubido 2002).

Reeves et al. (2002) also demonstrated that many deaf people struggled to make themselves understood. An example of this was when a research participant explained that they went home in pain because the doctor did not communicate much, but the next day the deaf person went to a walk-in clinic and was told that the foot was broken, and received treatment in the clinic instead of A&E. Ubido (2002) also highlighted worrying figures about the understanding between deaf patients and medical professionals, highlighting that only one in ten deaf women could understand the doctor when they attended an appointment on their own, and over half of the respondents said they would use the health service if more help or services for deaf women were available. More worryingly, Reeves et al. (2002) documented that many deaf people had difficulty in understanding the purpose or correct application of medication.

Much like the issues highlighted by Reeves (2002) and Ubido (2002), the Royal National Institute for the Deaf (RNID) produced a report titled ‘A Simple Cure’ (RNID 2004). The report stated that 24% of patients had missed GP appointments because of poor communication, such as not hearing their name being called out. The main findings of the report (RNID 2004) showed that deaf and hard of hearing people experienced the following issues:

- 35% had experienced difficulties when communicating with GPs or nurses.
- 32% found it difficult to explain their health problems to their GP.
- 15% said they avoided going to see their GP because of communication problems.
- 28% found it difficult to make an appointment at their GP surgery.
- 35% were unclear about their condition because of communication problems.

The report also revealed that 33% of BSL users were unsure about the instructions for medication or had taken the wrong dose of medication because of communication issues. In addition, the report highlighted the following issues when accessing hospitals:

- 42% of deaf and hard of hearing people who had attended for a non-emergency had difficulties in communicating with hospital staff; this number rose to 66% for BSL users.
- 77% of BSL users had issues when communicating with hospital staff for both non-emergency and emergency appointments.

These statistics show that a number of deaf and hard of hearing people struggle when trying to access healthcare services or communicate with NHS staff. Although some of these statistics may seem to be relatively low, such as the number of missed appointments (24%), the RNID explained that this percentage alone would cost the NHS approximately £20 million per year (RNID 2004).

SignHealth published research in 2014 that also raised the same concerns about deaf people trying to access healthcare. This report stated that 70% of deaf people had wanted to see their GP but had not attended the surgery. The online survey from this report showed that 31% of deaf respondents had not been able to access other services, and

56% reported to have not used health services because they did not have an interpreter present. 33% of the respondents did not use their GP because they could not easily arrange an appointment which, in turn, shows that a number of deaf people did not use any of the available health services because of the barriers they experienced. For the deaf people who did get into the consultation room, SignHealth (2014) reported that 18.7% of deaf people agreed that the HCP was good at giving them enough time and 14.8% of deaf people said that they felt like they were listened to by the HCP.

Another report from Healthwatch Leicester (2014) showed a survey from the area asking deaf and hard of hearing people which services they were happy with. Concerning figures showed that the highest number of people were most unhappy with the primary services. The report showed that 75% of people were unhappy with the A&E department and NHS 111 services, 63% of people were unhappy with ambulance services, 64% were unhappy with a home visit by the GP, 62% were unhappy with the Walk-in Centre and 48% of people were unhappy with hospital appointments (Healthwatch Leicester 2014). The report also showed that 73% were unhappy due to poor communication, 57% said there was no interpreter, and 48% said they were worried and did not understand (Healthwatch Leicester 2014).

Healthwatch Cumbria (2015) reported the same issues for deaf people as Signhealth (2014) and suggested that when the deaf community try to access the GP, they have to make an extra journey: around 65% of respondents said they travelled to the reception to book an appointment and then had to make a second journey to attend the appointment. Furthermore, "81.25% said that communication problems put them off making an appointment with their GP and 80% said communication problems put them off making a hospital appointment" (Healthwatch Cumbria 2015: 6).

2.6 Failure in accessible provision.

As previously identified within this chapter, the use of reading and writing is not reliable, and studies by Middleton and Turner (2010) and SignHealth (2014) show that the majority of BSL users understandably preferred to communicate in sign language.

Despite such a clear preference for deaf people who wanted to communicate in sign language, several studies have highlighted issues when a British Sign Language interpreter had not been used. Reeves et al. (2002) showed that communication was poor between the deaf BSL users and the healthcare professionals, and it was difficult to access a sign language interpreter. For example, the participants stated that GP appointments were hard to book: "...fully booked or have to wait a week or two to get one. Get frustrated" (Reeves et al. 2002: 30). Also, the low number of interpreters proved to be a big problem for some deaf BSL users: "Difficult to get an interpreter at short notice. I don't bother anymore..." and "...waited two months before finally found an interpreter for a doctor visit" (Reeves et al. 2002: 30). At the time when this report was published, the number of interpreters was very low. Even though the number of interpreters has increased from 943 (NRCPD 2016) in 2016 to 1026 in 2017 (NRCPD 2017), this is still a common occurrence for deaf people.

The same issue was also reported for deaf people who needed to use A&E at hospitals. For example, Reeves et al (2002) highlighted that around 36% of people in the study said they had no support at all and only three people used a professional BSL interpreter. The issue of deaf people accessing A&E without an interpreter was also reported by the Royal National Institute for the Deaf (RNID 2004), which showed that 70% of BSL users admitted to A&E departments were not provided with an interpreter.

Middleton and Turner (2010) discussed the idea of healthcare professionals who can sign fluently enough to hold a consultation with a deaf signing patient. This discussion started with deaf participants who indicated in the questionnaire that they were: "concerned that the introduction of an intermediary compromised the privacy of their interaction with the professional and that private medical information would be shared by the interpreter with others” (Middleton & Turner 2010: 815). As discussed earlier in this chapter, the interpreting profession is very small and the ratio of interpreters to deaf sign language users is extremely low. This means that if an interpreter arrives at one assignment and then moves to another, it is highly likely that the interpreter will know both clients that they are interpreting for. This is a potential worry for deaf patients and although qualified interpreters are bound by a code of ethics and confidentiality, it could still be an issue if the interpreter is interpreting a sensitive medical diagnosis or other matters that are extremely personal to the deaf patient. The study also showed that there was an indication from some deaf participants that they would prefer to have an interpreter who is outside their deaf community.

The study discussed healthcare professionals that can sign, and Middleton and Turner (2010) stated that there were no current plans to train healthcare professionals in BSL. However, the researchers explained that it is unrealistic to train healthcare professionals in BSL as it is “in-effective, cost wise” to be able to “conduct a consultation, fluently at a high enough signing level” (Middleton & Turner 2010: 815). The research indicated that some of the specialist psychiatric centres in the UK use BSL, and in the United States of America there are generic clinicians who use sign language directly with patients (Middleton & Turner 2010; Steinberg 2005).

Despite the Equality Act 2010 outlining specific terms such as accessible format and information, the issues around the use of British Sign Language interpreters are highly concerning. Lacey-Davidson (2012) argued that the use of professional interpreters who are members of the NRCPD is the only way for deaf people to receive fair access.

In Reeves et al.’s (2002) study, none of the interpreters that were present in the A&E setting had been arranged by the A&E department themselves. Also, one of the nurses was interpreting and asked the deaf patient if they wanted a professional interpreter, however the deaf patient was happy with the nurse’s signing skills.

Lacey-Davidson (2012) highlighted instances when NHS staff with BSL qualifications had interpreted for deaf people. The report stated that on one occasion a nurse was moved to another ward to cover the rounds because of a deaf patient. This type of situation creates an interesting predicament - although it is important that deaf BSL users have a fully qualified interpreter present when health information or conditions are being communicated, it might not always be practical for an interpreter to be with a deaf patient for all of the time that they are in the hospital. A doctor’s rounds are never the same and doctors can consult with patients at any time, which means that information about a patient’s health could be delivered at any point during the day. Therefore, in terms of equality, it could be argued that an interpreter would need to be with the patient all the time, ready for a consultation, unless a particular time was arranged for all the health teams to be present. Alternatively, it could be argued that it is not necessary for an interpreter to be present at all times, as nurses or other HCPs could use written notes and gestures (such as pointing) to communicate with the deaf patient, for example during mealtimes.

One of the more worrying issues that has been identified across a number of studies is the use of unqualified interpreters in medical situations. For example: “…a receptionist took a break from their duties in a GP surgery to ‘practise their skills’ as they were studying BSL level one” (Lacey-Davidson 2012:7). Although it was not stated that the receptionist was used as an interpreter, it can be assumed that the receptionist was acting as an interpreter for deaf patients. According to the report, the level one BSL course, which was run by Signature (2012), contained vocabulary such as: “weather, numbers, activities and interests” (Association of Sign Language Interpreters 2012:7). This is quite basic vocabulary and would not involve any signs relating to medical treatment. Lacey-Davidson (2012) made a valid point that a GP surgery deals with a wide range of health problems, from having a cold to cancer, and that a level one BSL user would not be able to accurately interpret these signs or interpret what the patient is complaining about (see Chapter Eight). Reeves (2002) highlighted a separate occasion when a GP practice manager stated that a member of the reception staff had a level 2 BSL qualification and could act as an interpreter for patients. To put this into context, qualified BSL interpreters registered with the NRCPD are level 6 and have been on a registered NRCPD approved course (NRCPD [b], 2020), which shows that a level 2 qualification would not be appropriate for a medical setting.

Ringham (2012) highlighted a number of key findings about the importance of having fully qualified interpreter standards:

- 36% of Deaf people made a complaint about a sign language interpreter because they could not understand them.
- 48% were unhappy with the standard of sign language interpreters that were provided.
- 41% left appointments feeling confused about their medical condition because they could not understand their interpreter.
- 29% were left confused about how to take their medication because they could not understand their interpreter (Ringham 2012).

Healthwatch Cumbria (2015) also found similar results to Ringham (2012) with around 49% of deaf respondents not clear about their diagnosis or health problem, and 33% unclear about medication instructions. In a hospital setting 39% of respondents were not clear about their diagnosis or health problem, 41% were not clear about medication instructions and around 55% were unclear about further treatment (Healthwatch Cumbria 2015).

Processes for booking interpreters also appeared to be an issue as Lacey-Davidson (2012) indicated that health service staff did not know that it was their responsibility to book interpreters for their patients, nor how to initiate booking procedures, or the level of interpreter that was needed. Ringham (2012) stated:

- 68% asked for a sign language interpreter to be booked for a GP appointment and 66% asked for an interpreter for hospital appointments, and none were provided.
- 84% felt frustrated after a health appointment because an interpreter was not provided.
- 67% were not sure that their GP surgery would be able to book an interpreter and 61% were unsure if hospital staff would be able to book an interpreter.
- 74% had to remind GP staff about their communication needs and 80% had to remind hospital staff.

SignHealth (2014) also showed that an alarming number of unqualified interpreters were being used, along with some hospital staff members who had low level sign language skills. However, another part of the report showed that some professional interpreters were also being used, although a number of these were only at a junior level and not qualified interpreter standard.

The confusion over the use of an interpreter places deaf BSL users in an unfortunate situation where they are forced to use family or friends to act as interpreters. Reeves (2002) highlighted situations where deaf people did not receive any interpreter support. One deaf participant stated: "Didn't get full information. Daughter [13 years old] can only sign simple words, so couldn't explain more difficult words, which I missed" (Reeves et al. 2002: 53). Reeves et al. (2002) found that 48% had a (hearing) adult relative or friend present, and as previously mentioned above, one woman was accompanied by her 13 year old (hearing) daughter. Four people (10%) were supported by a deaf adult and just three (7%) had a professional BSL interpreter with them" (Reeves et al. 2002: 53).

Lacey-Davidson (2012) also highlighted that friends and family members were being used as interpreters. This report highlighted one instance when a deaf person stated that "they had to use their 7 year old child, whilst in another situation the deaf adult said they only use their children (aged 10 and 13 years) when it's something serious" (Lacey-Davidson 2012:8). The report highlighted several examples of this type of situation, and Lacey-Davidson stated that this is a worrying issue as deaf adults lose the ability to keep information confidential and there is also a high risk of information being interpreted incorrectly. Another serious situation discussed in the report involved a deaf man who used his mother as an interpreter: the mother had decided to withhold the diagnosis of cancer from her son, but this was only made apparent when the mother could not attend an appointment and an interpreter was used, and the patient was then made aware of his diagnosis. Other examples of inappropriate interpreters have been highlighted through some media articles, such as Palmer (2013) who reported that a hearing son told his deaf father that chemotherapy was not working, and Siddique (2014) who found that a pregnant couple had to use their 12 year old daughter to interpret.

Healthwatch Cumbria (2015) also showed that many deaf people were taking family members, including children under the age of 16 years old, to GP and hospital appointments. This report explicitly stated the most common reason these people were taken along was to help interpret (Healthwatch Cumbria 2015). Healthwatch Central Bedfordshire (2020) also reported that 90% of its respondents accessed healthcare using support from family or friends.

2.7 Are interpreters a reasonable adjustment?

Since the introduction of the Equality Act 2010, there has not been much change for deaf people who use British Sign Language as a communication method. In 2015, Emond et al. published an article highlighting the same experiences as previously outlined in this chapter – poor access, poor communication and poor health. Emond et al. (2015) also discussed the duty of the Equality Act 2010 and highlighted that these adjustments are clearly not being made, and that a lack of reasonable adjustments in relation to overcoming the communication barrier not only has an effect on deaf people's health, but also possibly their life (Emond et al. 2015). McAleer (2006) also highlighted the need of clear communication between medical professionals and deaf patients who are in hospitals.

It is hard to ignore the strong emphasis from previous research about the importance of using interpreters. As mentioned above, Lacey-Davidson (2012) argued that the only way for deaf people to receive fair access, and to fully access the NHS, is with a professional interpreter. Alexander, Ladd and Powell (2012) also argue:

> "A qualified interpreter should be present in a consultation between a clinician and a patient who uses BSL to enable full communication for both professional and patient. Without an interpreter, the clinician cannot make an adequate clinical assessment or explain the diagnosis and treatment, and the patient is denied the opportunity to discuss his or her concerns."
> (Alexander, Ladd & Powell 2012:797)

Furthermore, recent Healthwatch reports from Wakefield (2014) once again show that deaf people's access to healthcare is poor as a man with a terminal diagnosis in a hospital used a family member to discuss a long discussion about discharge with staff. Throughout the man's stay, he used lipreading and written communication to overcome the communication barrier, and Healthwatch Wakefield (2014) outlined that this was unacceptable.

Healthwatch Kirklees (2014) also publicised issues with deaf people feeling unclear about information when leaving a surgery or hospital. This report showed that simple deaf awareness plays a huge factor when an interpreter is not available, or when medical staff do not speak clearly or face the deaf patient. The report continued to show that many medical staff did not make sure that the deaf patients understood what was being said, with some deaf patients not wanting to ask medical staff to explain things further.

Many reports show poor access for deaf BSL users and many deaf people are clearly unhappy with the service that the NHS offers, as outlined from this chapter. An interesting quote towards the end of Alexander, Ladd and Powell's (2012) publication summarises the current situation for deaf accessing healthcare:

> "Patients from the Deaf community have the same need for good communication and safe care as everyone else. Clinicians have a responsibility to recognise that communication is a two-way process, and that they need assistance to communicate with this group of patients. So what should you do when you meet your next patient from the Deaf community? Putting yourself in their shoes and asking them how best to communicate would be a good start.' (Alexander, Ladd & Powell 2012:980)

Collinson (2018) published an article which demonstrates a slightly different accessibility issue - the use of a video relay interpreter (VRI). VRI will be discussed in-depth later in the thesis (see Chapter Eight), however, Collinson (2018) highlights many issues with using this communication method such as a drop in internet connection, and hospital staff using this method at inappropriate times (such as when telling a patient that they have had a miscarriage). The issues with the use of video relay interpreting were also highlighted in the Healthwatch Plymouth (2018) report, with participants commenting that they could not see the facial expressions of the interpreter and they found the whole experience stressful and embarrassing (Healthwatch Plymouth, 2018). Healthwatch Wokingham (2018) also reported poor communication provision:

> "We were disappointed to conclude that the extent to which local health and care organisations are complying with the Accessible Information

> Standard in relation to Deaf people is significantly limited." (Healthwatch Wokingham 2018:7)

2.8 Interpreting and Translanguaging theories

A number of studies outlined in this chapter make reference to the use of interpreters. These interpreters have different forms such as trainee or qualified interpreters and also, ad hoc interpreters such as family or friends. Language brokering is a key theme within interpreting literature which needs to be explored: "Language brokering refers to interpretation and translation between linguistically and culturally different parties" (Ataman, 2008: 247). Children of deaf parents can, at times, be described as language brokers (Napier, 2008), which is separate to interpreting. Ataman (2008) highlights that the parent-child role is reversed and essentially, the child acting as the language broker has a stake in the success of the verbal communication. If the child is successful in the brokering, then both parties that the child is broking for will have the illusion that they have spoken to each other. Napier (2008) highlights that not all hearing children of deaf parents have the ability to interpret and some will struggle with the interpreting process, such as message transfer, despite being able to sign well. It is important to highlight the influence that the language broker has over the conversation; for example, Napier (2008) recalls that when interpreting at a parent-teacher meeting, the teachers were not as critical because she was present. This suggests that when language brokers are being used, adults might alter what they are saying to suit the child who is interpreting, rather than saying what needs to be said like they would through a qualified interpreter.

How deaf people are presented by interpreters is another theory that needs to be considered. The role of the interpreter plays an important part in ensuring that the deaf person is correctly represented (Napier, et al. 2019; Young, et al. 2019). Napier et al. (2019) highlights that deaf people have the view that using an interpreter who is familiar to them has an added benefit that things will go more smoothly, compared to interpreters who may not know the deaf person in the same way and try to cover up if they do not understand something. Being familiar with the interpreter is also linked to the level of confidence that the deaf person may have about how they will be represented, with interpreters who are familiar making the deaf person feel more comfortable (Napier, et al. 2019). The deaf person's anxiety levels could be raised when the interpreter is not known to them, due to the anticipation of the unknown and the limited control over how they will be represented by the unfamiliar interpreter (Napier, et al. 2019).

Translanguaging is an interesting concept, particularly when applied to signed languages. When communicating, both deaf and hearing people use a wide range of resources to communicate:

> "These examples include combining and rapid switching between linguistic features and modalities such as signing, gesturing, speaking, mouthing, writing (in the air, on paper, on hands or arms), typing (on mobile phones, on calculators, on com- puters), fingerspelling in different (named) languages, pointing at text, placing a sign on a Power- Point slide, and so on…" (De Meulder, et al. 2019: 893)

The concept of translanguaging practice is something that deaf people will engage with as a communicative strategy (De Meulder, et al., 2019). When a deaf person adopts translanguaging as a strategy they must draw on their linguistic repertoires (Napier, et al., 2019), and it is viewed as a means of transforming linguistic inequalities and maximising semiotic repertories (De Meulder, et al., 2019). As shown throughout this chapter, many deaf people are left without equal linguistic access - such as an interpreter - and therefore deaf people may have to rely on translanguaging as a strategy to communicate. The use of translanguaging to communicate may not only occur when an interpreter is not present, but it may also happen when an interpreter is present. Napier (et al. 2019) reveals that some deaf people in the workplace have had to use a translanguaging strategy even when an interpreter has been present. For example:

> "Lack of trust in the interpreter, either because they have a lack of technical (linguistic) skills, and/or because they lack adequate interpersonal, social (affective) skills, or lack of familiarity with them, was seen by participants as contributing to poor quality interpreted situations. Participants gave examples of where they felt they had to monitor the interpreter, if they could, by lipreading the spoken English interpretation of what had been signed in BSL." (Napier, et al. 2019; 108)

Language brokering, interpreting representation, and translanguaging are all important theories that require consideration when deaf people are communicating with or without an interpreter, and these points will be highlighted again in Chapters Eight and Nine.

2.9 Summary

This chapter has provided a review of the current literature relating to deaf people accessing medical settings and the issues identified, along with some general statistics which provide an overview about how deaf people view the suitability of the NHS.

There are many poor experiences presented in this chapter, and the evidence ranging from 2002 to 2018 consistently raises concerns about the support provided to deaf people when they are unwell. Most of these concerns revolve around the lack of communication and not being able to communicate in their first or preferred language, thus having to rely on lip-reading along with reading and writing. As explored at the start of this chapter, there are many issues with this type of communication, and the evidence from this chapter suggests that the use of fully qualified British Sign Language interpreters is being overlooked, and deaf BSL users are left to battle in communication with HCPs. The evidence also indicates that many deaf people do not fully understand key information being presented to them, such as medication or treatments. Figure 1 (below) summaries the common issues identified across all reports within this chapter and outlines the years that they have been reported.

Issues identified across all reports for deaf people accessing healthcare	**Year identified**
• Identified that deaf people had difficulties with: ○ Making appointments ○ Waiting rooms and knowing when they are next ○ Communicating with receptionists ○ Communicating with health professionals ○ Making themselves understood ○ Understanding the purpose or correct application of medication	2002, 2004, 2010, 2012, 2014, 2015
• Identified issues with lack of provision of BSL/English interpreters during healthcare appointments and emergencies	2002, 2004, 2010, 2012, 2014, 2015, 2018
• Identified that healthcare staff should have deaf awareness training	2002, 2004, 2010, 2014
• Reported that many interpreters not at fully qualified standard	2002, 2012, 2014
• Identified issues with the procedures for booking interpreters	2002, 2004, 2012, 2014
• Identified the dangers of family or friends acting as interpreters	2002, 2012
• Reported that high numbers of deaf people wanted to see their GP but did not attend the surgery	2004, 2014

Figure 1: Summary of reports published between 2002 – 2018

The evidence is quite overwhelming that there is a long-standing issue with communication and access for deaf people in medical settings. However, all of the research has suggested that qualified BSL interpreters should be used for support, but none have looked at the issues relating to ‘accessible information’ and ‘reasonable adjustment’.

The existing literature has not questioned what ‘accessible’ or ‘reasonable’ means, along with understanding the communication needs of the HCPs when treating deaf patients. This research aims to explore if the issues faced by both deaf and healthcare professionals have common themes between them, and how hospitals plan to overcome the communication barriers; these issues will be researched using the methodology outlined in the next chapter.

Chapter 3. Theoretical approaches and methodology

This chapter will explain the methodology used throughout the research, beginning with the theoretical perspective that underpins the research and the chosen methodology. Following on from this, I will discuss the qualitative data collection including the use of semi-structured interviews, and the recruitment of participants, along with the use of sign language. Towards the end of this chapter I will outline the methods and challenges relating to the participant interviews and data collection from hospital polices and finally, discuss the analysis and presentation of data.

3.1 Theoretical perspective – Epistemology & Ontology

It is important to start this chapter by acknowledging the theoretical perspective which has influenced this research. Establishing the ontological and epistemological stance is an important foundation, as I recognise that my own experiences in life will have had an influence on the research study and design.

Ontology is the study of being or "what is" (Crotty 1998; 10) and explores beliefs about reality and its existence. As Mason (2002:14) states: "what you see as the very nature and essence of things in the social world". There are two main ontological positions, the first is objectivism and the second is subjectivism. My understanding of objectivism is explained as seeing reality as one and this can be objectively looked at and measured.

> "View that things exist as meaningful entities independently of consciousness and experience, that they have truth and meaning residing in them as objects and that careful research can attain that objective truth and meaning." (Crotty 1998;5)

My understanding of subjectivism is that there is no objective reality, however, each interaction will create its own social construct and we all have our own versions of reality.

My approach to this research, from an ontological perspective, is subjective; how I understand this in the context of this research is that my participants each have their own version of events in their particular experiences in society and the subjective perspective helps me to understand why participants experienced something in a certain way. A studies research question can be broken down and lend themselves to either perspective, for example a study that wanted to measure physical changes such as height and weight lends itself to a more objectivist approach and tend to have a more quantitative standpoint. Alternately, the complexities of the social world – including explorations of human experience and the sense they make of the world – lend themselves to a more subjectivist, interpretative approach. As this study is concerned with the interpretation of lived experiences this suggests a phenomenological research approach is likely to be appropriate choice. In some sense, phenomenology has its own particular epistemology – concerned with the expression of lived experience and derivation of meaning from this.

Epistemology explores how the researcher understands the world and "therefore concerns the principles and rules by which you decide whether and how social phenomena can be known, and how knowledge can be demonstrated" (Mason 2002: 16). My particular epistemological approach is constructivism:

> "Constructionists believe that the social world is actively constructed through interactions and that symbols, like language, are key to interacting. The goal of research is to understand how people construct and make sense of others and of the world" (Kaloof et al. 2008: 195)

My understanding of constructionism, particularly in relation to this research, is that our interactions through language and body language give us construal meaning. Each person will experience their own interaction and will have built their own understanding of the world, reality and meaning to make sense of their life. An example of how I interpret constructivism in this research is that each paramedic or deaf participant will have their own experience of interacting with each other. This interaction will construct meaning, sense and knowledge to each individual person in that particular situation. The knowledge that we build from our interactions then influences how we interact with others (this could be a positive or negative interaction) and builds upon a person's knowledge of the world, and can sometimes influence later interactions. In terms of my interpretation of constructionism, I believe that to understand the world that we live in, we need to investigate how people interpret, define and experience the situations they have been in.

3.2 Phenomenology – Exploring people's lived experiences

The theoretical perspective that underpins this research is important and due to collecting data from three groups, finding the right theoretical approach presented a challenge. It was clear from the start that phenomenology was going to be a key philosophical stance due to both the deaf participants and healthcare professionals reflecting on their lived experiences of being in a certain situation.

> "Phenomenology is a philosophical approach to the study of experience. There are many different emphases and interests amongst phenomenologists, but they have all tended to share a particular interest in thinking about what the experience of being human is like, in all of its various aspects, but especially in terms of the things which matter to us, and which constitute our lived world." (Smith et al., 2009: 1)

Trochim (2006) explains that phenomenology is considered as a philosophical perspective which has a long history in social research, such as psychology, sociology and social work. The philosophical perspective focuses on a subjective experience and interpretations of the world:

> “It has a long history in several social research disciplines including psychology, sociology and social work. Phenomenology is a school of thought that emphasizes a focus on people's subjective experiences and interpretations of the world. That is, the phenomenologist wants to understand how the world appears to others” (Trochim, 2006).

Generally, there are two main types of phenomenology - descriptivist and interpretivist. Husserl’s descriptivist philosophical theory about how science should be conducted mostly viewed descriptive comments and the researcher separating themselves from all bias before starting research, which has been referred to as a process of bracketing (Smith et al., 2009). Husserl’s view of phenomenology was mostly to describe the phenomena, as each experience was individual to each person so it would outline the individual lived experiences and the researcher would study the phenomenon as it appeared without any other influence.

> “As human beings generally go about the business of daily living without critical reflection on their experiences, Husserl believed that a scientific approach was needed to bring out the essential components of the lived experiences specific to a group of people.” (Lopez & Willis, 2004; 727)

Heidegger’s interpretivist view on phenomenology was developed from Husserl’s descriptive theory. Heidegger’s view was that a phenomenon could be interpreted and this method relied on human experiences regarding how we are ‘being’ in the world, which Heidegger called ‘Dasien’ (Polkinghorne, 1983). To break this down further, Heidegger believed that how people perceived their realities is influenced by the world that they live in and, to understand this, an element of interpretation inevitably happens when describing the phenomena (Lopez & Willis, 2004).

The main difference between Husserl's and Heidegger's theories of phenomenology leads to one question - is it possible to completely remove any bias, assumptions or preconceptions with the idea of bracketing?

> "…Husserl's descriptive or transcendental phenomenology was so called because the observer could transcend the phenomena and meanings being investigated to take a global view of the essences discovered; i.e. settling for generic descriptions of the essences and phenomena without moving to a 'fine-grained' view of the essences and phenomena under investigation. This meant that there was an objectivisation of the meanings of human experiences" (Sloane and Bowe, 2014: 6)

Compared to Heidegger:

> "Heidegger was of the view that the observer could not remove him or herself from the process of essence- identification, that he or she existed with the phenomena and the essences. (Sloane and Bowe, 2014: 6)"

As Husserl's theory was quite objective and the researcher was to distance themselves as much as possible, Heidegger believed that language and interpretation of how a person makes sense of their world is a contributing factor in exploring a phenomenon (Smith et al., 2009), and why interpretative phenomenology was established and is also known as hermeneutic phenomenology.

There are many different forms of phenomenology (Caelli, 2001) and choosing one is an important factor when conducting research. Interpretative phenomenology could be a sensible approach to this research, however, I felt there was another theoretical perspective that was more suitable and could also be adopted for this research -

Interpretative Phenomenological Analysis (IPA). IPA could be viewed as a more modern phenomenological approach and is similar to Heidegger's interpretative phenomenology. It is worth highlighting that IPA has become increasingly popular in the research of health settings and to some extent, the adoption of IPA can be justified pragmatically, as it offers a clear and comprehensible framework of methods for undertaking phenomenological analysis which is explained in the next section.

3.3 Methodology – Interpretive Phenomenological Analysis

This research will use Interpretive Phenomenological Analysis (IPA) as the philosophical approach. Although IPA is normally used in psychology research, it is growing and developing in different fields:

> "Interpretative phenomenological analysis (IPA) is a recently developed and rapidly growing approach to qualitative inquiry. It originated and is best known in psychology but is increasingly being picked up by those working in cognate disciplines in the human, social and health sciences."
> (Smith et al., 2009: 1)

Smith et al. (2009) state that IPA's first real introduction into research came in 1996 and "captured the experiential and qualitative, and which could still dialogue with mainstream psychology" (Smith et al., 2009:4). Smith et al. (2009) explain that IPA draws on three theoretical underpinnings which bind together to create Interpretative Phenomenological Analysis: phenomenology, hermeneutics and ideography. Phenomenology is the examination of a human experience; hermeneutics is the theory of interpretation; and ideography is the theory of the particular. Ideography relates to IPA in two ways: the first is the detail that the theory of the particular produces which then allows a depth of analysis, and the second is that IPA commits to understanding how a particular experiential phenomenon has been understood (Smith et al. 2009).

> "In summary, IPA is a meticulously idiographic and hermeneutic phenomenological approach that seeks to illuminate the way individuals make sense of their lived experiences" (Peat et al 2019:9)

IPA fits well with this study, and can be broken down into segments which relate to the theoretical underpinnings explained above:

- Phenomenology – this relates to the lived experiences of both the paramedics and deaf participants which were obtained from the interviews. This also includes trying to understand what it is like from the participant's point of view.

- Hermeneutics – this relates to how it has been interpreted. In this study double hermeneutics is happening: 1) the participants are trying to make sense of their own experience when explaining it, and 2) the researcher is also trying to make sense of the participant's world/experience.

- Ideography – this relates to the understanding of the particular, and this study focusses on communication and access. The 'particular' that ideography refers to allows the researcher to conduct a deep analysis of the phenomenon. The second part of ideography commits the framework to understanding how a particular phenomenon has been understood.

An approach based on IPA also commits to several things which are vital when exploring a phenomenon and analysing it. IPA concerns itself with trying to understand what it is like from the point of view of the participants; this relates to this study as the deaf experience has been explored before, but the combination of a deaf person's experience and a paramedic's experience of treating deaf patients has never been investigated previously. To do this the researcher, to an extent, has to take the side of the participant, which to me was extremely important. I wanted to tell the story of what it is like to treat someone when a communication barrier occurred. This is where the double hermeneutics comes in: we have explored that the double hermeneutics relates to the participants making sense of the experience, along with the researcher also making sense of the participant's experience. In this case, my role was not just to find out what the participants knew or did, but it was also to find out what the participants did not know, for example, training or awareness from the paramedics.

> "Either way, meaning is central, and the aim is to try to understand the content and complexity of those meanings rather than measure their frequency" (Smith & Osborn, 2015:66)

IPA is the chosen methodology for the interviews with both deaf and paramedic participant groups. The hospital policies play an interesting role within this research, but an IPA approach could not be used for analysis as policies do not have a lived experience and instead a thematic analysis of policies was undertaken. There is an intended link between policies and the behaviour of practitioners (and by inference, consequences for the experiences of people in encounters with professionals and the professionals themselves) then the thematic analysis of the policies can be effectively combined with the IPA of individuals experiences. This enables a deepening of the IPA and credible conclusions to be drawn about the functionality, or lack of it, of these policies which are meant to inform practice and improve patient and staff experience. Smith & Eatough (2019) produced an article which "illustrates how IPA continues to evolve and develop, seeking to remain fresh and open to new ways of thinking" (Smith & Eatough, 2019: 163), and I believe that using hospital policies in this way will help to explore the participant phenomena further.

The figure below is a visual representation of how healthcare professionals and deaf participants should be feeding into the hospital policies:

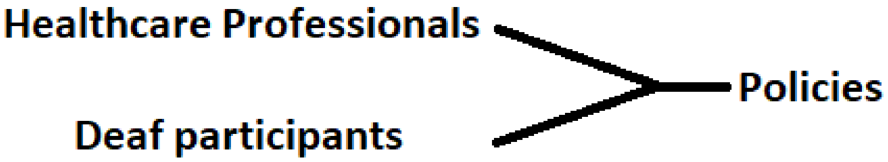

Figure 2: Visual representation of how participants and policies link

In theory, the hospital policies should also feed back to the healthcare professionals and deaf participants, by supplying information to the healthcare professionals on how to make reasonable adjustments; it should also provide information to deaf people on what is available for them to help with accessing the NHS.

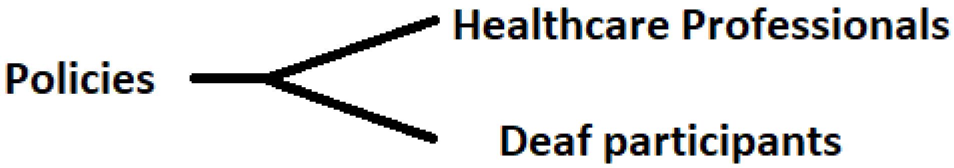

Figure 3: Visual representation of how policies should inform participants

IPA was not the only method that was considered for this research, I also considered Actor Network Theory (ANT) combined with IPA. Initial research into ANT showed that it explored how actors – which in this study would be the deaf participants, healthcare professionals, and hospital policies – have a relationship within a network. I planned to use ANT as a tool to explain the foundations of this research as ANT is designed to explore how the actor and networks interact. ANT is a flexible approach and therefore, one person's reading on actor network theory will differ to another person's (Cressman, 2009).

A very brief overview of how ANT was going to be applied to this research will be explained below:

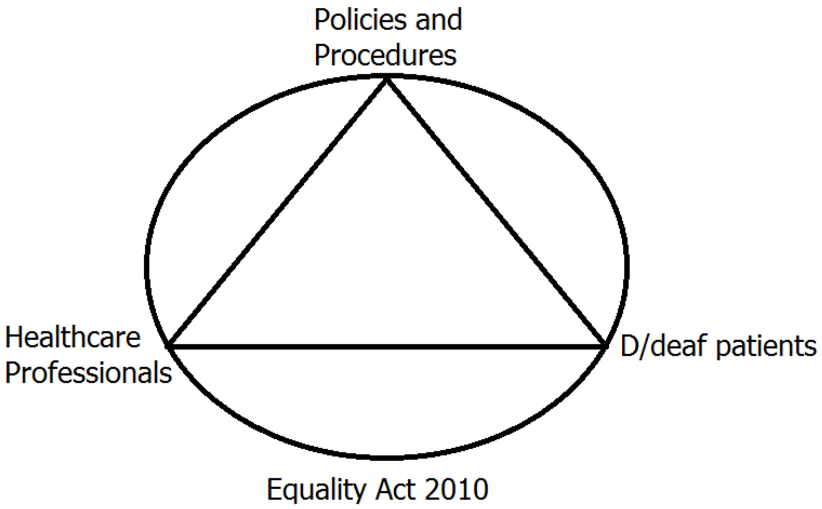

Figure 4: Actor-Network Theory

The image above uses ANT to demonstrate the four key elements of this study. The Equality Act 2010 is the network that surrounds the actors, and the three actors (policies and procedures, healthcare professionals and deaf patients) all link together when investigating access as they are all influenced by the Equality Act. In this study, the key terminology that has been taken from the Equality Act is the "reasonable adjustment" and that information needs to be in an "accessible format", as these two statements both link to access for deaf patients.

ANT "can also be used to better analyse and evaluate networks" (Cressmen, 2009: 10) and can go into a lot of depth. ANT could also be used to explain the network of the NHS as Cressmen states:

> "A network, in this sense, can be considered both form and process. On one hand, a network refers to a particular architectural form, or organizational structure, wherein people and institutions (amongst other entities) interact. On the other hand, the term network can also be considered a verb, a process that occurs within the networks." (Cressmen, 2009: 11)

After spending a significant amount of time looking into both IPA and ANT, I found myself lost with what this research was investigating; with so many ideas and thoughts swirling around, I needed to go back and ground myself about what this research was intended to investigate. Initially, I explained that this thesis was exploring how deaf people accessed the NHS and along with this, I always planned on investigating the views from paramedics and how they communicated with deaf people when treating them; this would ultimately give me a snapshot of two groups of people communicating with each other when there is a language barrier present, and how they both found the experience. The hospital policies would then be explored to see what reasonable adjustments the hospital was making for deaf people.

I watched a debate from the House of Lords which was about the 'Sick of it' report that Sign Health published in 2014 - the debate "How will the government improve the health of deaf people?" was held on the 31st March 2014. Towards the end of this debate, there was a crucial statement made from the Minister, Baroness Jolly:

> "However, it is up to the service providers to anticipate the requirements of disabled people and the reasonable adjustments that may have to be made for them in advance, before any disabled person attempts to access their service. The reasonable-adjustment duty is an anticipatory duty, so it is just not acceptable for health services not to be equipped to provide communication support for those who need it. This may involve the use of British Sign Language, but it may also involve the use of basic technology such as display screens in GP waiting rooms." (Baroness Jolly, 2014: Hansard text, Column 832)

There was one sentence that changed everything for me: "The reasonable-adjustment duty is an anticipatory duty". At this point, everything became clear. I put the pieces together: 1) reasonable adjustment, 2) accessible format and 3) anticipatory duty. This did not change any of the data collected, or data analysis, as it still looked into the communication between the two groups of participants; however, these insights into policy translation might be best achieved phenomenologically with a more simple documentary analysis of policies, without recourse to the deeper networked analysis of ANT. This might also be justified in that the interviews and following the phenomenological approach to small sample sizes but achieving greater depth of analysis take place in a single locality, whereas the policies represent a link of national legislation, NHS system-wide, perhaps regional, and local hospital trust policies – so any attempt at ANT would be flawed within the resources available to me, as a national network analysis would have been beyond my scope.

3.4 Qualitative data collection

As IPA was the theoretical approach for this research, my data collection was qualitative as I wished to explore my participants experiences in depth. The qualitative data collection involved conducting interviews with three groups of participants:

1. Deaf people - five participants were interviewed; they had all attended an appointment at a hospital and were all over the age of 18.
2. Ambulance crews – five participants who had experiences of working on ambulances, and were either paramedics or emergency medical technicians; they all had experience of treating deaf people.
3. The third data collection group was the hospital policies, which were collected through freedom of information requests.

The interviews with both deaf participants and paramedics were in-depth and adopted a semi-structured format. All of the interviews were conducted in a language that the participants felt comfortable using and because of this, all of the deaf participants communicated using British Sign Language.

The data collected from both the paramedics and deaf participants should be reflected in the hospital policies; theoretically, the literature explored in the previous chapter should also be reflected in the hospital policies. In relation to the three sets of data, they were all explored independently:

- Deaf participants – I explored how they accessed the NHS through their own lived experiences, the issues that arose, how they wanted to communicate with healthcare professionals, and anything that was good about their experience.
- Paramedics – the data collected from this group explored how they communicated with deaf people when treating them, what they did to communicate, how they felt, any issues that arose and anything that they found which worked.
- Hospital policies – the policies were explored for information to relevant equalities duties, with specific attention to adjustments or anything that related to allowing deaf people to access the hospital.

The interviews that were conducted with the paramedics and deaf participants were all separate interviews, and no participant group had connections with any other participant group. Likewise, the hospital policies were not intended to relate to any of the participants which is why the hospital policies were anonymised so that no links could be made to the hospitals, apart from what region the policies were taken from.

Researching three sets of data showed if the hospital policies actually related to, and anticipated, the needs of deaf participants (which links with research questions 1, 2 and 4). These anticipatory needs would be reflected in the interviews of the deaf participants and, if the issues arising from paramedics were reflected in the policies (research questions 3 and 4). An example of this could be taken from the literature review: as most reports in Chapter Two mentioned the need for qualified BSL interpreters, the policies should be anticipating the need for interpreters and should therefore explain how they facilitate this need. Technically, the paramedics' experience should also be reflected in the policies.

Although the interviews with healthcare professionals were conducted with ambulance crews (paramedics and technicians), and not within the hospital, it still explored the connections with hospitals and what was experienced when communication was an issue. This allowed for examination of the particular circumstances of emergency care, and whether policies arguably designed with hospital settings in mind could extend influence and impact to these encounters between ambulance personnel and deaf patients.

It is important to note that not everything said by the healthcare professionals related to the policies, as the interviews with the healthcare professionals were intended to explore the phenomenon of treating deaf people and how they adjusted so they could communicate.

3.5 The use of sign language in the interviews

In this section I am concerned with signing as part of the research process. This research involved interviewing both deaf BSL users and hearing participants. I wanted all of the participants to feel comfortable and I wanted them to be able to communicate by whatever means they preferred. The hearing participants were fairly straightforward as all of the paramedics spoke English, but the deaf participants were slightly different. Deaf participants were offered a BSL interpreter for their interviews and these were digitally video-recorded with consent. I began to learn BSL at the age of 16 and continued to learn through my university undergraduate degree. My BSL skills are equivalent to post-level 3 Signature qualification which means I can hold a conversation in BSL, however, I would not class myself as fluent in BSL. Although Snell (2013), Atherton et al. (2001) and Harris (1994) all conducted interviews themselves in sign language, arguments can be made for the use of interpreters to help with communication in research (Foster 1996).

Using interpreters raises some important issues for data integrity and analysis. I acknowledge that the use of interpreters can cause interpretive issues and the data collected could be altered through the interpreter’s own knowledge and understanding of

British Sign Language (Young & Temple, 2014). As explored at the start of this chapter I outlined that my epistemological position is constructionism, and I recognise that each person will interpret the world presented to them differently. With this in mind, and as the interviews were recorded by video, even though an interpreter was used I was able to review the footage myself. It is important to highlight that I was not interested in how a participant signed in a linguistic way, but the story they had to tell.

The interviews were fairly straightforward, as I informed the participants that if they requested an interpreter, then one would be arranged. During this research, three interviews took place with an interpreter and researcher present, and two interviews were conducted by the researcher without the use of an interpreter. The interpreter who was used is registered with the National Registers of Communication Professionals working with Deaf and DeafBlind People (NRCPD), and is bound to their confidentiality procedures. For example, the NRCPD website states:

> "If you gain access to information as the result of an assignment you must only share it with someone else if you have the service user's consent or the law requires or allows you to, such as when it is necessary to prevent harm." (NRCPD [c] 2020)

Prior to conducting the interviews, the interpreter was briefed about the research and the questions that were going to be asked. The interpreter was also reminded and informed about ethics, specifically that the identity of all participants is to be kept anonymous and that pseudonyms will be used during the research to protect their identity. Before the interviews were conducted the participant, researcher and interpreter had an informal conversation to get to know each other and the participants were made aware that the interpreter was bound to confidentiality, that protecting their identity was a high priority, and the interpreter was expected to maintain the highest level of professionalism and confidentiality. All of the participants were happy with this, and the interviews went ahead as planned.

3.6 Semi-structured interviews as a research method

The use of semi-structured interviews was a key component in this research. As the research was qualitative and I wanted to investigate and explore the experiences of both the paramedics and deaf participants, a semi-structured interview was appropriate. Semi-structured interviews are designed to be flexible and allow the participant to guide the interview to what they want to cover (Smith, 2009). Semi-structured interviews also attempt to "give enough space and flexibility for original and unexpected issues to arise, which the researcher may investigate in more detail with further questions" (Pietkiewicz & Smith, 2014: 10).

Many studies that have involved research with deaf people have successfully used semi-structured interviews to investigate the thoughts or experiences of the participants, such as Reeves et al. (2002), Ladd (2003), Snell (2013) and SignHealth (2014). Punch (2005) also explains that the semi-structured approach is a good way to help researchers understand others:

> "It is a very good way of accessing people's perceptions, meanings, definitions of situations and constructions of reality. It is also one of the most powerful ways we have of understanding others" (Punch 2005: 168).

As this research aimed to explore the experiences of the participants and particular details, such as how they communicated, it was vital that face-to-face or one-to-one interviews were used. Alternative methods for acquiring data, such as questionnaires and focus groups, were not appropriate for this study. English is mostly a second language for deaf people and questionnaires involve a lot of reading and writing which could ultimately affect the data (Anderson, 1993). Focus groups were a possibility, however, ethical issues arose such as confidentiality and anonymity. As there was a high potential for the interviews to contain very sensitive material, individual interviews were the most appropriate.

A template of interview questions was drawn up for the semi-structured interviews. The interview questions covered the basic topics that the research needed to investigate, but the semi-structured approach allowed the participants to explore the questions however they wished. This allowed for a more in-depth interview as I could then ask the participant to expand on an answer to a question (Mason, 2002). When constructing the interview schedule, I was influenced by Smith and Osborn (2003) as I used a very general question and hoped this would trigger my respondents to talk about their experience, and then I used the funnelling technique to explore my participants' stories:

> "It is a good idea to aim for the interview to start with a question which allows the participant to recount a fairly descriptive episode of experience"
> (Smith, et al., 2009: 59)

The use of the funnelling approach became very helpful during the interviews when one question was asked which was broad and open ended (Smith & Osborn, 2003) – such as "When you have treated deaf patients, how did it make you feel?". I was then able to follow up depending on the response, which enabled me to explore in further detail and eventually narrow the experience into me asking a closed question. I placed the rest of the topics that I wanted to cover into a sequence, whilst also making sure they linked to my research questions as much as possible. However, as outlined later in this chapter (section 3.9), my topics ended up acting more as prompts due to the flow of the interviews.

3.7 Recruiting participants & sample size

I decided that I wanted to interview both paramedics and deaf patients. It is important to note that the interviews did not take place in any hospitals or on NHS grounds, and the deaf patients were not linked to the paramedics, as mentioned previously. Posters were put on social media sites, such as Facebook and Twitter, and a snowballing method was used to recruit participants. I already knew a number of paramedics and deaf participants which helped with gaining participants as some of them passed on the information to others (as stated – snowballing). Other people who were neither deaf nor a healthcare professional shared links to the posters, especially on social media, to pass the information on to friends who were either deaf or healthcare professionals.

As this research followed a phenomenological approach, according to Creswell (1998) the sample size should be around 5-25, and Morse (1994: 225) stated at least six participants. For this research, I conducted interviews with five participants from each group, which equalled 10 interviews in total. Although having a minimum of five participants from each group is not a full representation of all views, it provided valuable data on how two groups of participants communicate with each other when there is a language barrier present in an important situation, and how this was overcome by both groups. Interviews for both sets of participants lasted between 40 – 60 minutes.

Sample sizes in phenomenology are thus typically, and justifiably, relatively small and as IPA focuses closely on each participant's experience, there is not a generic number for an intended sample size. Another point that needed to be taken into consideration was how the data was going to be presented, either as a general account or as an in-depth analysis. As this study explored the reasons as to how and why individuals communicate and if they were comfortable about this, I believed it is important to show what the participants said as this research is designed to show in-depth complications in communication and situations.

> "The main concern in IPA is give full appreciation to each participant's account (Case). For this reason, samples in IPA studies are usually small, which enables a detailed and very time consuming case-by-case analysis. At an early stage, the researcher must decide whether he or she wants to

> give a comprehensive and in-depth analysis about a particular participant's experience or present a more general account on a group or specific population. Doing both is rarely possible, so the final goal will determine the subsequent methodology and research design. It is inappropriate to use a large sample size just because that is more common in psychological studies." (Pietkiewicz & Smith, 2014: 9)

As previous research has shown the need for better communication, this research was also tasked with investigating if communication is the only factor in deaf people accessing the NHS. This is why the sample size was small, but the presentation and analysis of data collected from participants was intended to be rich, and the hospital policies were evaluated alongside the participant's analysis.

The selection of participants was straightforward as anyone that fulfilled the relevant criteria of being deaf or was a healthcare professional who had treated a deaf person, was interviewed. It was accidental that both groups had five participants. There was potential interest from another three HCPs [one paramedic and two nurses], however, there was no response to my follow up emails and messages, so it was assumed that the potential participants had lost interest and they were not contacted again. I should highlight that I initially wanted to interview any healthcare professional that would come forward, however the only participants that came forward for interview were paramedics; although this was not what I had planned, it still provided valuable information, particularly in emergency situations which was an environment that was very different in comparison to situations explored within previous literature in Chapter Two.

3.8 Gaining informed consent from participants

All participants were given a participant information sheet and a consent form (Appendix 3 & 4), and both documents were created whilst gaining ethical approval. The participant information sheet provided the reader with:

- Information about the researcher
- Aims of the research
- Participant's role
- How the information will be used
- Confidentiality
- Complaints procedure
- Researcher's contact details

The consent form provided a written record for both myself and the participant, and also allowed the participant to select their own pseudonym to protect their identity. By allowing the participants to choose their own pseudonym, they will have the opportunity to find their contribution in the final thesis, if they wish.

All documents were in written English, however, before each interview I checked that each participant had read both forms and if they had any questions, they were able to ask them before the interview started. However, as some of the interviews were conducted in BSL, I explained the information and consent forms in BSL, if that was what the participant wanted. As the BSL interviews were recorded, I also had a visual record of the deaf participants being informed of their rights and agreeing to give their consent and approval to take part in this study. Two copies of the consent form were required to be signed before the interviews, one copy was for the participant to take away with them and the other for the researcher's records. All participants were aware that participation was voluntary and if they wanted to withdraw from the study, they had two weeks from the interview to do so; none of the participants withdrew from the study.

3.9 Conducting interviews

As a qualitative method was selected for this research, the interviews that took place were in a one-to-one and semi-structured format. The interviews were preferably done face-to-face, but I was open to conducting the interviews over Skype, instant messaging or phone call. All of the deaf participants were interviewed face-to-face and I travelled to all of the deaf participants, expect one interviewee who I met on university grounds. Two of the healthcare professionals were interviewed face-to-face and three were conducted over the phone. To facilitate the interviews, I used the semi-structured template of questions that I had drawn up before the interviews – both groups of participants had their own set of questions (see appendix 1 & 2).

The BSL interviews were recorded via a video camera, which was positioned to capture the interviewee and interviewer. The BSL interviews were mainly recorded through the use of video recording as there is no other suitable alternative for recording interview data. If some of the deaf BSL participants had not been able to meet face-to-face, I was happy to use Skype with some recording equipment, or alternatively email, however this situation did not arise as all deaf participants were happy to meet with me. There was some travelling involved which I was happy to do, and I funded this myself. The face-to-face interviews conducted in spoken English were recorded via my mobile phone.

I found that the telephone interviews were much like the face-to-face, however it was vital to make sure that when the participants were answering, they had finished before I asked another question so that we did not talk over each other.

It was also important to make sure that the interviews were conducted in a quiet room so that the recordings would not pick up any unnecessary background noise. A pilot interview was conducted with a family member to make sure that the phone application that I had downloaded recorded both my voice and the participant's voice correctly. As an extra safety measure, I had an external recorder as well as the app recording, and I played the phone call through a speaker so there was a double recording if one failed or had technical difficulties. Interview data was stored in compliance with UCLan's research data management policy with a commitment to keep securely for 5 years, and once the data was transcribed, the recorded data was destroyed to keep participants anonymised.

Irvine (2010), and Burke and Miler (2001), both provide information on conducting telephone interviews. I found that the consent was much the same as a face-to-face interview, as the participants had already made contact and all the relevant documents such as the participant information sheet and consent forms had already been sent. The only difference regarding ethics was that I had to inform the participants that they were being recorded and like Burke and Miler (2001), I made sure that they were happy with the consent forms and participant information sheet so that it was also recorded. I found the telephone interviews, in comparison with face-to-face interviews, to be slightly more difficult, as it felt easier to extract information from the participants when face-to-face than over the phone. This may have been due to the lack of facial expressions and body language, and this is also what Irvine (2011) explains as 'acknowledgement tokens' which keeps participants talking and giving more information.

There was an interesting interview at the beginning of the data collection process which heavily affected how the other interviews were conducted. This interview could not be used for the research because the participant was a healthcare support worker and not a defined healthcare professional; the main difference between a healthcare support worker and professional is that the healthcare worker would support the professional and would not hold relevant professional education credentials. At the time of the interview, I did not know my participant was a healthcare worker, but as this research intended to investigate more important elements of a clinician's experiences, such as obtaining history of events, rather than moving a patient around a hospital, it was not appropriate to include the interview in the research.

As the interview took place, I noticed that the discussion with the healthcare assistant did not flow, the questions felt very clunky and although the participant could not answer many of the questions, the interview was a worry. The next participant was being interviewed the following day, so after the healthcare assistant's interview I reflected on what could be done to improve the interview style so that it did not stop-start. Instead of asking the questions in a set order, I tried to make the interview flow by aiming for a more conversational interview style. This involved asking the first few questions (such as job role and how long the participant had been doing it), but after this I asked a very open question such as: "When you have treated deaf patients, how did it make you feel?". If the answer was "frustrated", then my response would be "why?" After this, we would have a discussion and as I knew most of the questions from memory, I asked most of the questions instinctively which made the interview feel more natural and it did not break the interview up. This was a major change and interestingly, this led the participants – especially the healthcare professionals – to tell the story of their experience, and there was a much more natural feel to the interviews. The template that had been drawn up was still being used, but was much more in the background within the initial stages of the interviews. When the stories came to a natural halt, I looked at any notes that I had made during the interview and made sure they were covered. During the later stages of the interviews, the template came back into use and I checked to make sure that the topics/questions had been covered. This sometimes led to a little repetition towards the end of the interviews, but not much.

3.10 Transcribing and translating the interviews – the challenge of being hearing impaired

After the interviews have been conducted, a transcription was completed to allow the interview data to be analysed. As there were two groups of participants, there were two different types of transcription needed.

The interviews with the healthcare professionals were in spoken English, so they were quite straightforward to transcribe. Issues can arise when there is background noise and if the participant talks too fast or quietly. As someone who is hearing impaired, I was worried about transcribing and not being able to hear the participants talk clearly enough. There were times when I had an issue with hearing words, however I played the audio clip to an interpreter who managed to confirm what the word was. Another issue that arose from the transcription process was the use of medical terminology by the participant. On one occasion, a participant used an abbreviation which I struggled to hear, however, I have a family member who is in the medical profession and was able to confirm the abbreviation and what it meant. Apart from this, all the interviews were fine and the audio was clear enough to do the transcriptions myself. The transcriptions were solely focussed on the participant's comments. Similar to Hammersley (2010) who discussed the act of 'constructing or reproducing' transcriptions (Hammersley, 2010), I needed to make decisions at the start of my transcripts and I made the decision to leave out additional sounds such as: background noise/laughing/pauses.

As for the deaf participants, the transcription was a little more complicated because all, of the interviews were in BSL. This was not as straightforward as the interview had to be translated and then transcribed.

> "In social research the term "translation" is generally used to reference the act of turning a written source text into a written target language Text. Research involving signed languages challenges and extends this meaning. As there are no agreed-upon written versions of signed languages…" (Young & Temple, 2014:146)

As the data that I was collecting was about experiences or thoughts and not linguistic style, much like Higgins (1980) suggested, the most important thing was to understand what was being said and not how they signed it:

> "Because I was not concerned with a linguistic analysis of the conversations with the deaf people, translations were not as difficult as they could have been. What was important was to understand what deaf people meant, not how they signed it" (Higgins 1980: 191)

Other researchers (such as Higgins 1980; Atherton et al. 2001; Snell 2013) have conducted interviews with deaf people and have shown that when research involves collecting data that is about experiences, it is more important to understand what the participant means and not how it was signed. Interestingly, I experienced the same issues as Atherton et al. (2001): 'Occasionally a sign which was understood within the context of an interview is found to be unclear during transcription'. Snell (2013) and Barnes (2017) also had this issue at times. However, I found myself in a fortunate position that I have access to a qualified interpreter, so if I was confused or lost then I could get help to get myself back on track.

For someone that has a slight problem hearing, the use of an interpreter was valuable not just for the odd sign that was unclear, but during the spoken transcriptions too. For the spoken transcriptions I used headphones which helped to focus the noise directly and fortunately, I have good quality noise cancelling headphones which helped a great deal. I also played all files through VLC media player which allowed me to increase the volume noise if I needed it. However, if a word or sentence was still a problem, I had someone I could ask. The interpreter used was registered with the National Register of Communication Professionals working with Deaf and Deafblind people (NRCPD) who are bound to a code of conduct which includes confidentiality and ethics. This interpreter was also the same interpreter that was used for the interviews, so they understood the research, and was only used to clarify any uncertainty when transcribing.

The process I used to transcribe the interviews was a particular challenge and this needs to be highlighted. One of the challenges noted with research, particularly from sign language users who take part in research, is how the researcher translates and transcribes the data. Young & Temple's (2014) in-depth discussion about the challenges of transcription in research came to the conclusion that there is not a simple standard guide on how to translate and transcribe participant data. As stated above, this was not a linguistic analysis and therefore, my priority was to capture the meaning of an utterance or signed utterance, rather than the exact signs used. Hammersly (2010) discussed different styles of transcription such as 'strict transcription', which primarily results in the words heard on the recording being written down. On reflection, this was quite relatable and fitted with how I transcribed the interviews with the paramedic participants, as I found this to be fairly straightforward. Hammersly (2010) also mentioned the 'description' style of transcription, and I believe this related to how I transcribed the deaf participants' interviews:

> "Even more obviously than with strict transcription, they involve processes of interpretation and judgement. This derives from the fact that there are many different true ways of describing the same phenomenon…" (Hammersley, 2010: 16)

Translating and transcribing BSL into written English was a challenge, as BSL has its own gramatical structure, and although it was possible for me to have transcribed verbatim and use the exact signs, I was also juggling the use of an interpreter for some of the interivews. I feel that it should be highlighed that the idea of strict transcription and descriptive transcription was used in both sets of participant groups but in different ways. Regarding the paramedic group, I mostly used 'strict transcription', with less of the 'descriptive transcription'. However, the deaf participant group was the opposite, with the majority involving 'descriptive transcription' and the minority involving 'strict transcription'. This was due to the amount of interpreting that occurred from BSL into written English. I decided that although I was going interpret, translate and transcribe all the deaf participant interviews, I was going to capture the meanings of utterance, rather than exact signs, and there were a few reasons for this decision. Firstly, some of my interviews with deaf participants had an interpreter and secondly, the paramedics interviews were also transcribed into written English format and I wanted to keep a consistency throughout the thesis. As Hammersly (2010) highlights:

> "… we must not treat transcripts as sacred and infallible texts. Even strict transcription of the words spoken does not guarantee to tell us what someone was meaning to say or what they were doing. We have to interpret the words, and in doing so we will and should draw on our experiences of observing the events concerned…" (Hammersly, 2010: 20)

3.11 Collecting the policies

The policies were collected for this research between 17/07/2014 - 11/08/2014 through Freedom of Information (FOI) requests:

> "The Freedom of Information Act 2000 provides public access to information held by public authorities.
>
> It does this in two ways:
>
> - public authorities are obliged to publish certain information about their activities; and
> - Members of the public are entitled to request information from public authorities." (Information Commissioner's Office 2017)

The Information Commissioners Office (2017) explains that if a person makes a request, there are two duties for the public body to respond with: 1) disclose whether the body has the information, and 2) provide the information.

For this to happen within this study, firstly, hospitals which had A&E departments were selected during this process and at least two hospitals were contacted from each of the nine regions of England: North West, North East, Yorkshire and the Humber, East Midlands, West Midlands, East of England, South West, South East and London. Secondly, as all hospitals have their own webpages for freedom of information requests, I requested the information through the hospitals' websites. It is important to note that only hospitals from

England were selected as Scotland, Wales and Northern Ireland have their own devolved NHS governance systems.

For this study I wanted to review at least one hospital policy relating to how deaf people accessed hospitals from each region. To make sure I received at least one policy, I contacted two hospitals from each region. The reason for collecting at least one policy from each region was to gather a sample of policies to show the adjustments and anticipations that are being made by the hospitals across England. However, if both hospitals from the same region responded, then I continued to review all of the policies received, as there was no reason to only select one policy to review if I received two. Most of the hospitals responded to the FOI requests apart from two, which were from the South East and East Midlands regions. Another three hospitals did respond, but they did not attach any policies; these hospitals were from the East of England, West Midlands and London regions. Once I had received the polices I made the decision to anonymise the names of the hospitals and instead, use the region that they came from. I did this for a few reasons: firstly, my participants all used pseudonyms and for consistency I wanted the same for the hospitals; secondly, I wanted to show that this research is not trying to belittle or shame any hospitals.

One important point to note was that the policies were collected before the new Accessible Information Standard was published. This Standard provided information for hospitals to help them identify the needs of service users (see Chapter Four). Some of the policies reviewed will have possibly changed due to the Accessible Information Standard coming into effect in 2016, however, the review of policies had already been started and it would be near impossible to keep up-to-date with the policies from all hospitals during the PhD process. Another point to add is that although the Standard came into effect in 2016, it does not mean that all of the policies would have been changed by this point so even if a later policy collection had been conducted, the policies might not have been current. The Accessible Information Standard will be reviewed later in Chapter Four.

3.12 Analysing and presenting the data

After the transcripts of the participants' interviews were completed, the analysis could then be started. As previously mentioned, this research aimed to investigate the common themes between participants. Thematic analysis can be drawn from other work such as Miles and Huberman (1994), Boyatzis (1998) and Braun and Clarke (2006), although each one has slightly different examples. Braun and Clarke provide a common approach to data analysis with six stages to the thematic analysis: familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke 2006: 87).

This research needed a flexible approach to the analysis and it was imperative to explore not only the phenomenon of the participant, but also the situation that the participant was in; because of this I found myself influenced by Smith's IPA.

> "It is also important to remember that qualitative analysis is inevitably a personal process, and the analysis itself is the interpretative work which the investigator does at each of the stages." (Smith and Osbourne 2015)

The process of analysis involved a number of different stages. To begin this, I carefully familiarized myself with the data, one interview group and one individual at a time. Once I had read the data that had been transcribed, I began to break down the transcripts in NVivo. This did not work very well as NVivo took away the situations that the participants were in and therefore, created a very messy thematic analysis which ultimately felt like it did not make any sense. I decided to go back to basics and not to use NVivo for the transcripts. Instead, I printed out all transcripts and highlighted anything that related to my research questions. Once I had highlighted everything valuable to my research questions, I then went back through the data paying particular attention to what was already highlighted and also using a different colour highlighter to indicate anything else of interest and began to create codes from the information. Whilst highlighting, I made notes on my thoughts on the edge of the pages, which could change daily, especially once I had completed a whole group and gone back through the information again. After highlighting the transcripts, I then sat with one interview group and pulled together the themes that occurred within their groups.

To fully understand the themes, it was important to grasp the situations they were in and therefore, when writing I felt that it was important to break down what each participant said during each theme and allow the data from the participants to provide the information. This is when the influence of Smith's IPA started to introduce itself in the form of how the data was going to be presented and written up.

> "Transcripts of interviews are analysed case by case through a systematic, qualitative analysis. This is then turned into a narrative account where the researcher's analytic interpretation is presented in detail and is supported with verbatim extracts from participants" (Smith et al., 2009:4).

This was done separately for both the paramedics and deaf participants as I wanted to provide rich data that attempted to explore the full aims of this research. Smith explained that within IPA: "analysis is an iterative process of fluid description and engagement with the transcript. It involves flexible thinking, process of reduction, expansion, revision, creativity and innovation" (Smith et al., 2009: 81). Once the themes were completed, I then read back through the transcripts and marked off the themes to make sure that they were thorough and exhaustive, and after this was completed then came the discussion/write up. Each interview group had their own common themes which have been presented individually in chapters Six and Seven. The presentation of data, particularly both participant groups, was particularly important to me. I believe that although IPA commits itself to a double hermeneutics as explored above, I also believe it is my role - as a researcher and to my participants - to tell their story in a transparent way. What I mean by this is that after analysis, common themes were created. Within this process, following the spirit of IPA, I also wanted to respect what the individual participants said, using their own words as much as possible to illustrate the meaning of the experiences captured within the identified themes. I have done this for different reasons; firstly, to clearly reflect what my participants have said; and secondly, for the readers of this thesis to also understand how I have interpreted the experiences of my participants:

> "…more often, the analysis can move on to incorporate interviews with a number of different individuals. If one is analysing more than one interview, then from an IPA perspective it is important to begin each transcript afresh, allowing the material to speak in its own terms rather than being overly influenced by what other participants have said" (Smith & Osborne, 2015:45)

As this research aimed to investigate the experience of clinical encounters from the perspectives of both staff and deaf patients, with a particular focus on communication and translation of the policy notion 'reasonable adjustment' into actual practice, the different elements of data analysis presented then fed into a bigger picture. Although each interview group explored its own agenda, the goal of this study revolved around whether the themes expressed within the two groups matched each other, and whether or not the hospital policies anticipated the issues expressed by both groups and attempted to address the term 'reasonable adjustment'. Smith and Osborne explain: "Once each transcript has been analysed by the interpretative process, a final master table of group themes is constructed." (Smith & Osborne 2015:46). This is very similar to what this research was trying to achieve, but in a slightly different way. Smith and Osborne (2015) mentioned a 'master table of group themes' which is quite similar to what I wanted to do; however, I also had a third discussion point using hospital policies which needed to be brought into an overarching synthesis alongside the interview data. The diagram below provides a visual representation of how the data was pulled together:

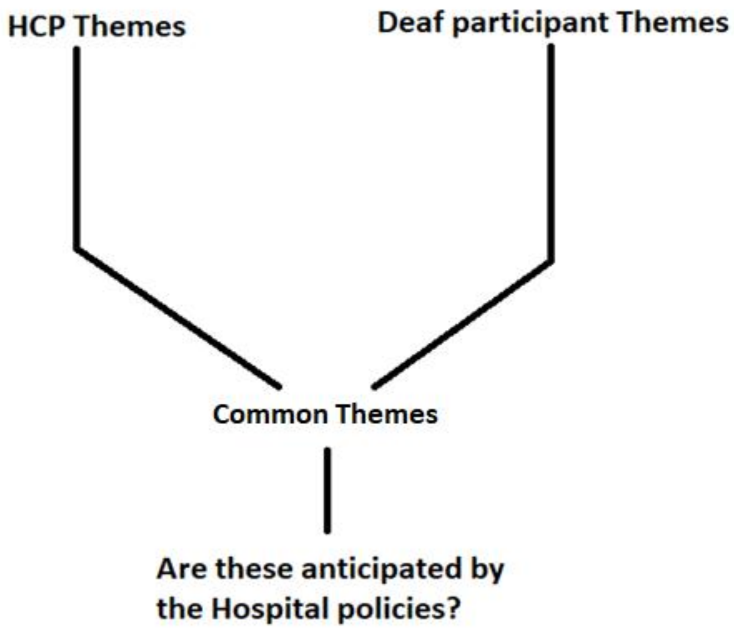

Figure 5: Visual representation of pulling the data groups together

The common themes were discovered in a similar way to how the initial individual participant themes were found and this is where the concept of a 'master table' comes in. To generate the common themes in the idea of a 'master table' was one of the hardest challenges. Upon reflection, an unintentional double thematic analysis had occurred, with the first being presented in Chapters Six and Seven with the common themes in the deaf and paramedic participant groups as a result of IPA, using the transcripts from the interviews. The second thematic analysis then took place for Chapter Eight, where I took the already identified themes generated from Chapters Six and Seven to create a combined set of common themes between the two participant groups, similar to how Smith and Osborne (2015) describe the idea of a master table. However, this second thematic analysis was created from my first thematic analysis and did not involve looking at the participant transcriptions, but instead used the data which had already been pulled out. The data from Chapters Six and Seven was reviewed and new common themes were generated to reflect the topics that both participant groups had spoken about, which looked to explore any common views and issues between the groups. However, the challenge here was generating and defining new themes which embodied both sets of participant data but also looked at answering the research questions in a clear way which demonstrated the experiences of all participants.

3.13 Using NVivo to analyse the hospital policies

NVivo is purpose-built for qualitative and mixed-methods research, and is a data analysis software tool used to manage, store and organise data. I initially planned to use NVivo to help find themes and code the data for hospital policies and all participants. As explained above, I decided not to use NVivio for the interviews, but I continued to use it for hospital policies and found this extremely useful. Most of the policies were huge documents and sometimes more than one document was received. The use of NVivo greatly helped as I uploaded all of the documents and started flagging anything that related to facilitating the needs of deaf people (research question 3). This provided an initial review of the policies and then I went back through the policies to make sure that anything related to deaf people was flagged and highlighted. Overall, 23 files were flagged and highlighted, and within the 23 files there were 210 different codes/flags relating to facilitating the needs of deaf people, including any issues that brought awareness to the reader regarding deafness, job roles and responsibilities.

The next big decision was the presentation of data and I decided to walk through the policies individually, much like how I presented the participant data. Beyond any interest in thematic commonalities across policies, I wanted to walk through each policy to explore what was actually in a hospital policy and to reflect on how different they all were. However, this created a problem as once I had completed the analysis, the information posed challenges in organising into a simple digestible format. As previously explored, the policies should anticipate the needs of deaf people, including those who use BSL, and I wanted to reflect on how these policies had outlined how they were going to anticipate the needs of deaf people. Due to the issue that walking through each individual policy had created, I needed to find a different way to present the data. The data was broken down into common themes which were then individually addressed for each policy to make the information easier to read, whilst also reflecting the uniqueness of each document whilst maintaining a specific analytic focus on the matter of reasonable adjustment.

The initial reading of all policies showed that they are all very different in their interpretation and anticipation of duties, and this came as a surprise as I thought there would be more input from higher authorities such as NHS England or the Department of Health, which would influence hospital policies in regards to disabled people to ensure they were more standard and generalised across the country.

3.14 Conclusion

This chapter has explained the methodology that was used throughout this research, including the theoretical perspective and my interpretation of IPA, and how it was used to link all the participants together and branch out to the hospital policies. This chapter explained how the interviews were conducted, including the limitations of recording equipment with deaf participants who use sign language, the semi-structured interviews and how participants were recruited. The collection of policies was also explained, along with how the data collected from the policies and participants were analysed and presented.

This chapter has also explored my personal positioning in this research of being in both the 'deaf' and 'hearing' worlds, and because of this it was important to highlight my own personal challenges with some of the data collection and how these were overcome. This also included my own understanding of theory and the epiphany of grasping IPA, and how this theory was adopted for the research. The purpose of research is to gain a new piece of knowledge and for me, this epiphany was a piece of the 'jigsaw' that helped me to gain that piece of knowledge.

Chapter 4. Deaf people as healthcare users: legislation and NHS guidance

This chapter will explore the equality legislation which attempts to prevent unlawful discrimination against people who have protected characteristics, and investigate some of the key duties that are placed on public sector organisations such as the NHS. This chapter will explore the Accessible Information Standard, which should inform hospital policies about making 'reasonable adjustments' for people who have protected characteristics, and review the post implementation report from the new Standard to investigate if it has had much impact.

4.1 Equality Legislation and The Equality Act 2010

This research heavily relates to the Equality Act 2010, due to it being the most recent equality legislation that has been passed. Therefore, it is vital to discuss exactly what is stated within the Equality Act 2010 as this enforces public sectors to make adjustments for people with protected characteristics. Before discussing what is stated in the Equality Act 2010, it is important to briefly consider previous equality legislation and how it has originated and developed.

It is worthy to note that this is not the only legislation and previous equality legislation has had a major influence on the Equality Act 2010. Previous legislation includes: National Assistance Act 1948, Chronically Sick and Disabled Persons Act 1970, Disabled Person Act 1986, Disability Discrimination Act 1995 (DDA 1995). A brief summary of these previous Acts shows that although people with disabilities did not have any real anti-discriminatory rights until 1995, The National Assistance Act 1948 attempted to provide welfare for people who are sick as disabled. The Chronically Sick and Disabled Persons Act 1970 provided specific provisions for people who are disabled, which included: education and support at home, access to public buildings, disabled badges, representation on public bodies, segregation in hospitals and war pensions (BBC Lancashire 2010). Following this, The

Disabled Person Act 1986 made social services produce a written assessment which would then provide the co-ordination of resources to reflect the disabled person's abilities when deciding on the level of care that the individual person would need (Disabled Persons Act 1986).

However, it was not until the introduction of the Disability Discrimination Act 1995 that we saw a major change. The DDA 1995 gave rights to disabled people which would prevent anyone from being able to discriminate against them on the grounds of disability. Therefore, it became unlawful for anybody who was providing a service to a disabled person to treat them less favourably because of their disability. The DDA 1995 was also the first act to define what disabled means; it was also the first act to state that service providers need to make adjustments for disabled people (Disability Discrimination Act 1995). The DDA was amended in 2005 and some changes were introduced to help improve disability discrimination (Office for Disability Issues (2009).

The Equality Act 2010 is the newest disability legislation in the UK and it has introduced many requirements that public sectors have to meet. Most of the requirements are clear when reading the legislation, however some of the terminology such as "reasonable adjustments" and "where it is reasonable" pose interesting questions, such as: what is a "reasonable adjustment"?

The Equality Act explains the duty to make adjustments for people who have disabilities, and this duty has three requirements. However, as the second requirement is related to a physical impairment and not deafness, it will not be discussed. In the quotations included below, the person that a duty is imposed on is referred to as 'A' (Equality Act 2010: Section 20.1).

Section 20.3 states:

> "The first requirement is a requirement, where a provision, criterion or practice of A's puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to avoid the disadvantage." (Equality Act 2010: Section 20.3).

Section 20.5 states:

> "The third requirement is a requirement, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to provide the auxiliary aid." (Equality Act 2010: Section 20.5).

Section 20.6 states:

> "Where the first or third requirement relates to the provision of information, the steps which it is reasonable for A to have to take include steps for ensuring that in the circumstances concerned the information is provided in an accessible format." (Equality Act 2010: Section 20.6).

This is written very broadly, however, if we put this is into the context of this research and a deaf patient using the NHS, we can explore the Equality Act in more detail. For example: Section 20.3 explains that if the healthcare practitioner's provision of care puts the deaf person at a substantial disadvantage, when compared to a person who is not deaf, then they must remove the disadvantage. Section 20.5 requires the NHS to provide an auxiliary aid (in this case an auxiliary aid could be an interpreter, lip-speaker or human support) for the deaf person if they are put at a major disadvantage in comparison to a hearing person. However, section 20.6 states that in the first and third requirements (20.3 & 20.5), the provision of information must be delivered in an accessible way to the deaf patient. An example of this could be when a deaf sign language user communicates with someone who does not know sign language, or when they need to read some important documents.

This is where the interpretation of the term ‘reasonable adjustment’ can cause a problem. As demonstrated in Chapter Two, a deaf BSL user’s reading and writing skills are lower than a hearing person. Therefore, does this mean that an interpreter is the reasonable adjustment? Another thing to consider is how information can be in an accessible format for a deaf patient: would this mean that a qualified sign language interpreter needs to deliver the information to the deaf patient? However, this might not be the same for every deaf patient and in theory, the accessible format could be whatever the deaf patient is comfortable with.

The Equality Act states “where it is reasonable to avoid the disadvantage”, but does not state what ‘reasonable’ means. This is extremely important as one person’s adjustment could be different to another. The word “where” is also a topic of debate, although in medical situations it would seem reasonable to always have information in an accessible format so that patients are comfortable and understand what is going on. This is where the importance of the interpretation of the Equality Act comes in, as this is key to hospital policies because they have a duty to make adjustments for people who have disabilities and allow them to fully access healthcare in the same way as a person without a disability.

A further question relating to the Equality Act 2010 is the discussion around what a ‘substantial disadvantage’ is. The term ‘substantial disadvantage’ is broken down further to be defined as “…more than minor or trivial…” (GOV.UK, 2022), however it is left unclear what is classed as minor or trivial. It might be reasonable to suggest that anything such as selecting a meal when in hospital overnight could be seen as minor or trivial, however, it could be argued that anything which involves needing to communicate one’s needs would leave someone at a major disadvantage, thus any food allergies or religious beliefs which need to be communicated to staff members could be classed as a substantial disadvantage.

The term ‘reasonable adjustment’, and the lack of any formal definition about what it means in relation to a deaf person as a healthcare user, or who makes the decision as to what is reasonable, is a fundamental question to this research and needs to remain as a subliminal thought throughout this study. This will be further explored later in this chapter in an attempt gain an understanding of how guidance such as the Accessible Information Standard breaks down the interpretation of ‘reasonable adjustment’ for a deaf BSL user and how are the needs of deaf people met.

The term ‘protected characteristics’ is a broad term and does not just cover those who have disabilities. The idea behind the term ‘protected characteristics’ is to stop people being discriminated against for the following reasons:

- Age
- Disability
- Gender Reassignment
- Marriage and civil partnership
- Pregnancy and Maternity
- Race
- Religion or Belief
- Sex
- Sexual Orientation

(Equality and Human Rights Commission [a] 2019)

All of the points above are classed as protected characteristics, and these people are protected under the Equality Act 2010. However, as this research is only looking at disability and, those who are deaf or deaf BSL users in a healthcare setting, I will only be focusing on legislation and NHS guidance which contains information regarding disabilities.

4.2 Accessible Information Standard

In June 2015, a new Accessible Information Standard was approved. This new standard applies to all organisations that provide adult social care and the NHS – this includes NHS trusts, foundation trusts and GP practices.

> "All organisations that provide NHS or adult social care must follow the standard. This includes NHS Trusts and Foundation Trusts, and GP practices. Organisations that commission (pay for and make decisions about) NHS and adult social care services must also make sure that the support the standard." (NHS England 2015: 2)

From 1st August 2016, an Accessible Information Standard was implemented and applied to service providers across the NHS. This standard: "directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss" (NHS England, 2016: 10). The aim of this standard is to inform organisations about "how they should make sure that patients and service users, and their carers and parents, can access and understand the information they are given" (NHS England 2015: 1).

The standard was updated in July 2015 and it specifically stated:

> "The accessible information standard also tells organisations how they should make sure that people get any support with communications that they need, for example support from a British Sign Language (BSL)

> interpreter, deafblind manual interpreter or an advocate" (NHS England 2015: 1).

The Accessible Information Standard sets out five aims for organisations to meet:

- Ask people if they have any information or communication needs, and how to meet their needs;
- Record the needs clearly;
- Highlight or flag the person's file or notes so it is clear that they contain information on communication needs;
- Share information about people's information and communication needs with other providers, if they have permission;
- Take steps to ensure that people receive information which they can access and understand, and if they need it, receive communication support (NHS England 2016).

The idea behind the Accessible Information Standard is to break down the 'reasonable adjustment' that was imposed on public sectors by the Equality Act 2010 and to specifically state the adjustments. The Accessible Information Standard actually recognises that many people are not receiving information in an accessible format:

> "Despite the existence of legislation and guidance – as outlined above – in reality many service users continue to receive information from health and social care organisations in formats which they are unable to understand and do not receive the support they need to communicate. This includes, but is not limited to, people who are blind or have some visual loss, people who are d/Deaf or have some hearing loss, people who are deafblind, and people with a learning disability." (NHS England 2016: 11)

Importantly, the standard recognises that in regard to deaf BSL service users, if the use of a sign language interpreter or another communication aid is required, then one should be provided:

> *"A* person who is d/Deaf or has some hearing loss may require support from a communication professional, including a British Sign Language (BSL) interpreter, BSL interpreter who uses Sign-Supported English, Lipspeaker, Notetaker, or speech-to-text reporter (STTR)" (NHS England [a] 2017: 76).

The Accessible Information Standard was a nationwide change for all NHS bodies to support and implement, and each of the five aims mentioned above is set out for what professionals and organisations must, should or may do when they treat or meet a person who is disabled. Although the Accessible Information Standard does not specifically state how to get interpreters, the standard does state the need to flag a disabled person's needs. Therefore, when a disabled person books an appointment, the support that has been requested can be booked by the NHS service ready for when the disabled person attends their appointment and thus, the information that is being given by the health care professional can be presented in an accessible format that the disabled person can access.

4.3 Accessible Information Standard: Post-Implementation Review – Report

In July 2017, NHS England's Patient and Public Participation and Insight Group created a report to see how the Accessible Information Standard was impacting on NHS trusts: "During January-March 2017 NHS England led a post-implementation review of the standard, with the aim of assessing its impact and ensuring that it is, and continues to be 'fit for purpose'" (NHS England [b] 2017: 5).

The review was:

> "…sought from individuals and organisations affected, or expected to be affected, by the standard. This included organisations that provide and/or commission NHS care and/or publicly-funded adult social care, voluntary and community sector groups, and patients, service users, carers and parents with information and/or communication needs relating to disability, impairment or sensory loss." (NHS England [b] 2017: 5)

During the review period, NHS England managed to complete 231 surveys with health and social care professionals and organisations, along with 1,312 surveys with patients, service users, carers and patients, and 66 surveys for support, supplier and representative organisations (NHS England [b] 2017). Each survey was sent out in different ways, such as small meetings, events and focus groups. Although the standard was brought about to enable a number of different disabled persons to be able to use the NHS, the review explored in this chapter will only focus on the sections that relate to deaf people's access and not responses around other protected groups as outlined in the Equality Act 2010. NHS England provided the survey through BSL videos which were available on their website, or a BSL DVD was made available for those who could not access the web page.

NHS England held meetings and events for patients, service users, carers and parents, and held face-to-face workshops for people to attend and give their views on the new Accessible Information Standard. Members of the "Accessible Information Advisory Group attended each workshop to ensure that the views of some of the key groups intended to benefit from the standard were heard" (NHS England [b] 2017: 8).

Although the standard was a national change, the review was to get an idea about how the standard has changed disabled people's access. The first workshop was hosted by Action on Hearing Loss (now known as RNID), in London, to enable deaf people to have their say, and this event was attended by five people. CHANGE hosted two workshops in Leeds and Coventry for those that had learning disabilities, and this was attended by eight and 13 participants. Sense hosted a workshop in London for those who are deafblind, and this was attended by four people. The Royal National Institute of Blind people (RNIB) also helped to give the views of those who are blind or have a visual loss, and other organisations and groups also held meetings or events to support people to participate in the review (NHS England [b] 2017).

Regarding the health and social care professionals and organisations, the total number of completed surveys was 231, which breaks down as follows:

- 36 respondents from GP practices
- 34 respondents from acute hospitals/acute foundation trusts
- 29 respondents from community service organisations/foundation trusts
- 24 respondents from learning disability service providers
- 18 respondents from voluntary or community sector providers
- 16 respondents from local authorities.

From the 231 surveys of health and social care professionals, the first set of statistics showed that 41.5% said that the standard was 'good' or 'very good'; 52.8% said that the impact was 'neither good or bad' and 5.7% said it was 'bad' or 'very bad'. The second set of statistics was about how they had implemented the standard into their organisation: 65.5% stated they had implemented it 'to some extent' or 'mostly' into their organisation; 25.6% had implemented it 'completely' or 'completely and demonstrating good practice' in their organisation; and 7.2% stated they had not implemented the Accessible Information Standard at all. The third set of statistics showed people's view about whether or not the standard was giving any benefits: 27% said they had noticed 'significant' or 'some benefits', and 39.8% stated that it was too early to say if the standard had any benefits. (NHS England [b], 2017:9)

A comments section was available in the survey and most of the participants were "supportive of the standard/thought it was a good thing" (NHS England [b] 2017:11).

However, points were raised about their awareness of how to implement the standard with what actions needed to be taken, and also the cost of implementing the standard. Interestingly, the costs which were a concern did not include the use of auxiliary aids, as most participants stated that staff time was the problem in regard to cost. To be specific, it was staff who needed to coordinate and oversee the implementation alongside the changes to systems and documentation.

The review also gave feedback from health and social care professionals who attended workshops and events. There was a consensus that the impact of the new standard was variable across the nation with some organisations finding that the impact was making progress for them and service users, and others claiming that there had not been much of an impact at all. Participants who attended the workshops and events also claimed that there were challenges relating to the "lack of awareness, difficulty in sharing information about individuals' information and communication needs (both within and across organisations), and access to alternative formats/communication support" (NHS England [b] 2017: 11).

The report then focused on the feedback from patients, service users, carers and parents, with the total number of completed surveys being 1,312. Some of the feedback was not surprising and a lot of it was similar to the findings in Chapter Two of this thesis. For example:

- 79% said that it was difficult to see, hear, speak, read or understand 'most of the time' or 'sometimes'
- 43.8% of respondents said that they had not heard of the standard before
- 31.8% felt that the impact had been neutral
- 15.2% said that the impact of the standard had been 'good' or 'very good'
- 7.7% said that the impact was 'bad' or 'very bad'. (NHS England [b], 2017:12)

Worryingly, the feedback from many patients, service users, carers and parents showed that they still had not received accessible information or communication support from NHS and social care providers. Respondents said that this caused difficulties, with some respondents stating it caused them distress and poor experiences by being unable to communicate effectively with staff which then meant they had a poor understanding about what was going on, which resulted in the service user not being involved in the decision-making. However, other participants in the survey outlined positive steps that NHS services and staff had taken to meet their needs.

Again, the outcomes of what patients felt needed to be improved can be linked with the common themes that have already been demonstrated throughout this thesis so far. This included: greater staff awareness and understanding, training for staff about communicating with people with a disability/impairment/sensory loss, and for British Sign Language interpreters to be consistently and reliably arranged for appointments. Many participants who took part in the survey suggested that greater monitoring/enforcement of the standard should be set, as respondents felt this would increase the positive impact of the standard and ensure potential benefits.

The report moved on to provide a summary on the overall impact of the standard. Some of the percentages do not total 100% as some questions did not apply to everyone, however the information still gives an understanding of what people thought regarding the impact. If we consider the impacts of the standard between the healthcare and social care professionals, we can see there was much difference with how the two groups perceived the new standard:

Healthcare and social care professionals

- 52.8% - neutral
- 41.5% - good or very good
- 5.7% - bad or very bad

Patients, service users, carers and parents

- 31.8% - neutral
- 15.2% - good or very good
- 7.7% - bad or very bad (NHS England [b], 2017:16)

Alongside completing the review, patients, service users, carers and parents were also asked to complete some additional questions. These questions were to measure any improvements that could be made from people's experiences/access: 20.8% said they had noticed 'some' or 'big improvements', and 52.7% said that they had not noticed any improvements over the last six months. In regards to accessible information, 9.4% said they had noticed a significant improvement and 20.4% said they had not noticed any improvements at all.

The report from the Accessible Information Standard shows some worrying statistics with the majority of organisations only making some or most of the adjustments, and only a small number making complete adjustments to the standard. It is still very concerning that the majority of HCPs think that the standard has not made much impact since it was introduced. Disabled people's views on the standard were similar, with the majority stating that they had not heard of the new standard, and those that had heard of it found that it had not made any real impact. It is still a concern that a high percentage of disabled people are still having trouble understanding health care professionals. It is quite conclusive that the impact of the standard has helped some people, however, the results are the same as those shown in Chapter Two, which highlighted deaf people's stories and reports.

One part of the Accessible Information Standard that is quite important is the concept of 'needs' and 'preference' (NHS England 2015) regarding communication support, and this topic can cause a huge debate. The 'needs' and 'preference' can be found in the Accessible

Information Standard, however the quotation below has been taken from a section on the NHS England website (2021) about meeting the costs of individual needs:

> "The Standard does not necessarily require the provision of information in a patient's *'preferred'* format; rather it requires the provision of information in *a* format that the patient can read or otherwise access and understand. It is the patient's information and communication *'needs'* which must be met, which may differ from their preferences. The 'judgement' or 'assessment' about whether this requirement has been fulfilled lies with the individual patient themselves, i.e can they read, access and understand the information? Can they 'use' the information as it was intended? If they can, then the organisation has met this aspect of its obligations under the Standard." (NHS England 2021)

What is interesting about this 'needs' versus 'preference' is that in the context of deaf people, some might not want an interpreter for an appointment with the doctor and choose to communicate through reading and writing alongside lip-reading. However, information that is important, such as consent forms or medication, would need to go through an interpreter to make sure that complicated jargon was understood, and to aid the service user to make sense and fully understand the context and information. Does this mean that a service provider can refuse to book an interpreter because in a simple routine appointment the deaf person may choose to read and write, and therefore they do not need an interpreter? This will be explored later in the discussion part of the thesis as this was brought up during the interviews.

4.4 Chapter conclusion

This chapter has explored the equality legislation that enforces healthcare settings to make reasonable adjustments for people who are deaf BSL users. Inequalities in the healthcare sector, particularly in relation to deaf BSL users, is something that seems to be constantly reviewed.

Evidence though the Post Accessible Information Standard suggests that people who need healthcare but need to access the service differently because of their individual needs can be quite difficult. Even with the new Accessible Information Standard and its new requirements, many people still have the view that not much has changed in the way of access and struggle because of this. Equality legislation makes it clear that steps should be taken to make adjustments for people who need it, but there are a number of barriers that still stop this. The NHS has adopted a number of methods to try and battle inequality, and it is near impossible to keep up with how the NHS is adapting.

Although the Equality Act 2010 does make it clear that hospitals need to adjust so that everyone can access healthcare, there are limitations to this. The Equality Act 2010 needs to be interpreted correctly for the adjustments to be made and to minimise the substantial disadvantage that many deaf people face. Although the NHS may provide guidance for medical settings, it is still necessary for the medical settings to put the guidance into practice through the use of policies. This is also why an investigation into hospital policies can provide a valuable insight into how they have anticipated the needs of people who need to access hospitals in a different way.

Chapter 5. Deaf people as healthcare users: Hospital policies

5.1 Introduction

This chapter will investigate how hospital trusts set out policies to meet their obligations under the Equality Act 2010 in relation to allowing deaf people to access the hospital in a way that does not leave them at a disadvantage. Freedom of information requests were sent out to two random hospitals in each region of England. In total, 18 trusts were approached and 16 responded. However, only 11 responses contained policies, and these will be reviewed in the chapter.

The aim of this chapter is to provide a snapshot of the 11 hospital policies and review them for the following reasons:

- To investigate the interpretations of the Equality Act 2010
- To gain an understanding of how reasonable adjustments are met
- To understand the booking procedure for interpreters
- To understand how the NHS attempts to overcome barriers for disabled/deaf people.

5.2 Background to hospital policies

The Equality Act 2010 states that hospitals have to make a reasonable adjustment for a disabled person; this reasonable adjustment, has to be enough to stop the disabled person from being at a substantial disadvantage and in relation to the provision of information, the hospital must take steps to ensure that the information is provided in an accessible format. As a reminder, the Equality Act 2010 states:

> "Where this Act imposes a duty to make reasonable adjustments on a person, this section, sections 21 and 22 and the applicable Schedule apply; and for those purposes, a person on whom the duty is imposed is referred to as A…

> The first requirement is a requirement, where a provision, criterion or practice of A’s puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to avoid the disadvantage...
>
> The third requirement is a requirement, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to provide the auxiliary aid.
>
> Where the first or third requirement relates to the provision of information, the steps which it is reasonable for A to have to take include steps for ensuring that in the circumstances concerned the information is provided in an accessible format.” (Equality Act 2010: 20)

As discussed in Chapter Two, deaf people use sign language as a way of communicating and as Kyle and Woll (1985) state, it is a natural form of communication for people with a hearing loss. Sign language is also a way for deaf people to communicate fully and effectively, depending on the standard of the interpreter, unlike if they were to use other methods such as reading and writing, which (as discussed in Chapter Two) is not necessarily a reasonable communication method for deaf people to use. As deaf people are classed as having a disability due to an impairment, there is a duty on hospitals to adjust and therefore enable deaf people to fully access the service.

5.3 Why review hospital policies?

As shown throughout Chapter Two, there is a high incidence of communication issues for deaf people in hospitals. The statistics from deaf organisations show that many deaf people want to communicate in BSL as it is their first or preferred language. As stated in Chapter Two, deaf people should be provided with a qualified sign language interpreter. However, the statistics from deaf organisations and current reports have shown that deaf people often do not receive qualified sign language interpreters, and therefore this chapter aims to investigate how BSL interpreters are obtained as mandated by policy documents within healthcare settings.

Although the lack of qualified interpreters is a clear issue, this chapter also aims to outline how policies understand the accessibility issues faced by deaf BSL users. For example, Chapter Two highlighted the lack of British Sign Language interpreters, so the policies will be reviewed to see if they outline what should happen when service cannot get an interpreter. Also, it was useful to review these policies to understand their plan for avoiding the use of family and friends when professional interpreters are not available. The policies were then also reviewed alongside the common themes identified in the interview data collected from the deaf and paramedic participants to understand if the policies address or connect with the same themes.

Whilst reviewing the policies, it was important to stick to the aims of this research. As a reminder, the two aims that are most relevant to this chapter are:

- How is access to the National Health Service facilitated for deaf people, and in particular sign language users?
- What practical and ethical issues arise for health services providers when service users are deaf sign language users?

My method for reviewing the policies was to use a coding/flagging technique to see what adjustments the different hospitals have put in place. This was accomplished by systematically reading and re-reading the policy documents in a process similar to the thematic analysis described by Braun and Clarke (2006), with particular data extracted which was found to be identifiably relevant to the above aims. This information was highlighted and organised using NVIVO (as discussed in the Chapter Three) for ease of reading and understanding. This chapter generated themes to understand the differences and similarities of anticipation from each policy.

As outlined in Chapter Three the names of the hospitals that have been reviewed are not identified in this study. I believe that as my participants are protected by anonymity throughout the study that this be extended to the services. The goal of this study is not to single out hospitals or NHS trusts, but rather to gain knowledge of use in improving services generally.

Freedom of information requests were sent to 18 trusts and 16 of the trusts responded; however, only 11 of the responses contained policies that the hospital trusts deemed to be relevant to making adjustments for deaf people when accessing their services.

5.4 Accessible Information Standard

It is important to highlight the issue of the Accessible Information Standard in this section of the chapter. When the hospital policies were requested, the Accessible Information Standard (AIS) had not yet been published and therefore, none of the policies will have made reference to the AIS. However, it is also very important to note that the AIS was articulated due to health and social care settings failing to meet the needs of people who may need adjustments (NHS England 2016).

As outlined in Chapters Two and Four, the impact of the AIS was poor and many deaf people are still struggling to access the NHS, and very little has changed since the publication of the AIS. It is important to highlight that research articles in Chapter Two have shown that the access for deaf BSL users has been poor and the first publication shown within this body of research was published some 20 years ago, which outlines a clear accessibility issue for deaf patients. The Accessible Information Standard did not bring forth any new legislation, but it clarified obligations outlined in the Equality Act 2010 which many health and social care settings had failed to meet. This research, as a whole, aims to understand if accessibility issues for deaf people are wider than BSL interpreters, such as: what if it is an emergency and I cannot get an interpreter; how is this then overcome, do policies recognise such situational differences or have contingency plans in place? The Accessible Information Standard does not outline issues such as these, but it is worth exploring whether or not these issues are explicitly considered in the hospital policies. Therefore, this chapter represents findings from the documentary analysis of the policies and will be drawn into the analysis of participant common themes (Chapter Eight) to understand how polices overcome any issues.

5.5 Hospital policies received

Before reviewing each policy, it is significant to point out the variation in the titles of the equality policies received from the trusts. The table below shows the variation in titles of the documents received:

Hospital region	Name of policy documents
EoE1	Interpreting and Translation Policy
NW1	Equality Strategy, Interpreting agency documents x3
NW2	Interpretation and Translation policy & Interpreter Guidance
SE1	Equality and Diversity Policy, Single Equality Scheme, Deaf and Hard of Hearing General Information
NE1	Equality Diversity and Human Rights Policy, Interpreting and Translation Policy, Guidance Document for Using Interpreting & Translation Services, Hospital Passport, Hospital Passport Guideline, Learning Disability Guidelines
NE2	Interpretation and Translation policy, EDS2 Information Document

EM2	Interpreting and Translation Services
WM1	Interpreting Services Policy Access and Delivery
SW1	Translating and Interpreting policy
SW2	Equality and Diversity Policy, Interpretation and Translation Policy and Procedure
L1	Human Rights, Equality and Diversity Policy, Equality and Diversity CQC Outcome

Table 1: Hospital policies

Seven individual hospitals sent one policy document, and the other seven trusts sent more than one document. A number of these documents have 'equality' somewhere in the title, but a lot of the documents also use 'interpreting' or 'diversity' in their title. The document titles present both similarities and differences. With regard to the similarities, several policies from different regions have used 'Equality' as the term and title for their guidance and information for people across the whole of England; however, NW, NW2, SW1 and SW2 - which are from the same region - have different document titles and many of the documents received from each of those regions also varied. This shows substantial local independence to articulate policy, which may work against a uniformity of adherence to statutory obligations. In effect, each hospital trust has set up their policies in different ways. This creates confusion about where to look for information and shows there is little standardisation between NHS Trusts. Other issues with this are that some trusts have only sent one document, whereas others have three or four documents, which also means that readers have to work through all the documents to possibly obtain the information that they need; with potential implications for staff comprehension and adherence.

5.6 The duties placed on hospitals and the explanations of the policies

This section will investigate how each policy described the role of the document they sent as this gives a snapshot of why the hospitals have provided a policy document about the need for interpreting and equality. This section will also explore the aims and objectives of each policy.

EoE1

The EoE1 freedom of information request produced one document which was an interpreting and translation policy, with the purpose being to "describe the essential practices and processes for the provision of interpretation and translation services" (EoE1:3). The policy explains that the document will "raise the awareness of interpretation and translation needs including encouraging staff to proactively plan for service users' needs… and staff have knowledge of how to access interpretation and translation services." The policy also states that hospital staff have "legal as well as moral obligations to provide interpreting services to people who do not speak or understand English." (EoE1:3)

The aims and objectives of this policy are to provide details of how an interpreter can be accessed 24 hours per day, and it provides guidance for staff working with an interpreter. The subsection of the aims and objectives states that the policy is to ensure that the trust fulfils its legal and moral obligation to provide access to trained interpreters. The trust's policy recognises that whilst the interpretation and translation policy deals with the use of a professional interpreter for clinical and legal needs, they also need to acknowledge the day to day communication needs that are necessary to enhance the quality of life for some service users who may be vulnerable due to their potential cultural and linguistic isolation, and the document is intended to support them.

EM2

This policy states that the purpose and outcomes of the document are to provide a framework to support communication with service users and carers for people where English is a second language, and people with hearing or visual impairments. The policy then states: "The policy sets out clear standards across the organisation to promote good practice and minimise risk which stem from communication barriers and it covers the use of face-to-face (including via British Sign Language and video relay), telephone interpreting and written translation services in accordance with identified need.” (EM2:4)

NW1

The Equality Strategy begins by explaining a vision that the trust “recognises the need to embed the principles and practices of equality and diversity within the organisation thus enabling patients, service users, the local population and staff to be confident about the trust’s commitment to eliminating discrimination and promoting diversity.” (NW1:3) The strategy then moves on to explain that it will follow the Equality Act 2010 and outlines the legal duties in relation to equality and diversity for public bodies including the health service.

The Equality Strategy explains the General Equality Duty that the trust will follow. The General Equality Duty means that trusts must give due regard to: “Removing or minimising disadvantages suffered by people due to their protected characteristic” (NW1:3). Trusts must take steps to meet the needs of people with protected characteristics and encourage people who have protected characteristics to participate in public life, where participation is disproportionately low. The strategy clearly states “that this may involve treating some people more favourably than others when trying to remove or minimise any disadvantages.” (NW1:4).

The policy then moves on to the specific duty that the Equality Act 2010 sets out. The specific duties that NHS organisations must follow involve: publishing information to show it is complying with the public sector Equality Duty annually, and preparing and publishing equality objectives (which must be specific and measurable) every four years.

The strategy then moves on to the commitment of the trust and how it defines equality and diversity. The strategy states that the Equality Act governs the way they work through policies and procedures, and the way they deliver services to people with protected characteristics. The strategy then moves on to explain the Equality Delivery System which is being used to influence the equality objectives of the hospital.

NW2

The introduction to the document shows that, generally, the policy refers to non-English speaking patients, including those who use British Sign Language. The policy gives information about when to use the Interpreting and Translation Service, and makes it clear that the trust must employ the services of professional interpreters. The policy also shows that in all clinical situations, the Interpreting and Translation Service must be used when staff cannot communicate effectively.

NE1

This policy starts by explaining how the trust is committed to providing the best service for service users, and carries on to explain that they will follow the three public sector duties under the Equality Act 2010. This policy also explains how they must have due regard for the need to:

- "Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act;
- Advance equality of opportunity between people who share a protected characteristic and those who do not;
- Foster good relations between people who share protected characteristics and those who do not." (NE1:4)

The policy explains that equality means that the trust must have fair policies, practices and services. Furthermore, the policy explains that it is a basic human right to have dignified treatment for everyone and that human rights represent all the things that are important to us, such as the right to be able to choose how to live our life and being treated with dignity and respect. The Human Rights Act 1998 is central to this and forms the foundations of the NHS Constitutions.

This policy moves on to explain how it is vital that staff can communicate effectively and understand what the service user is saying; if this is not the case, the policy states that staff would not be able to provide care in the same way and that the service user would receive a lesser service. Within the equality legislation, this would be referred to as a negative impact and ultimately, it would be unlawful.

NE2

The Interpretation and Translation Policy started with an introduction which stated how the trust is committed to ensuring that everyone whose first language is not English will get the same access and support that they need to communicate with healthcare staff and to access health services. The introduction makes reference to some literature and states that the use of professional spoken language interpreters has been shown to improve clinical care and outcomes, and reduce communication errors. The introduction then makes reference to the Equality Act 2010 which states that public organisations have a duty to eliminate unlawful discrimination, harassment and victimisation. The aims of the policy are to provide advice for staff about how to book and work with interpreters, and to explain the process for the translation of written materials.

WM1

The introduction to this policy explains that the trust aims to "design and implement services, policies and measures that meet the diverse needs of our service, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account the Equality Act (2010) including the Human Rights Act 1998 and promotes equal opportunities for all". (WM1:5)

The objectives of this policy are to: outline the procedure through the Central Booking Service; state the code of practice for interpreters; provide guidelines for staff when using interpreters; facilitate communication for those whose first language is not English or do not speak English, or those who have difficulty understanding more complex English language, or deaf/blind/partially sighted people; and to reduce the scope for errors.

SE1

The introduction to the Equality and Diversity Policy explained that the trust recognises its legal responsibilities as contained in the Equality Act 2010 and the aims of the Public Sector Equality Duty:

- "Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act;
- Advance equality of opportunity between people who share a protected characteristic and those who do not;
- Foster good relations between people who share protected characteristics and those who do not." (SE1:2)

The policy clearly states: "the trust is opposed to all forms of unlawful and unfair discrimination and victimisation. The trust expects its staff to treat all patients, visitors and service users with dignity and respect, in a non-discriminatory manner and in accordance with their individual needs". (SE1:2)

L1

The document that will be discussed in this section is the Human Rights, Equality and Diversity policy. The aim of this policy is to help tackle discrimination, promote human rights, equality and diversity for both staff and service users. The introduction to this policy outlines the rights and responsibilities of the trust, staff and patients. The policy explains how it wants to ensure that there is no unlawful or undesirable discrimination, and the purpose of the policy is to set out the steps that the trust will take to ensure that it does not discriminate.

The policy then moves on to explain how the trust is committed to the principles of human rights and equality of opportunity for all in employment and service delivery. This statement explains how the trust is committed to ensuring the delivery of positive outcomes for those with protected characteristics. The policy shows its commitment to equality with how it is also following a legal duty to provide all services fairly. To ensure this, they work with partners to provide services that promote equal opportunities to all by:

- "Building on good practice
- Consulting with and involving our service users and staff
- Providing avenues for people to provide feedback on our services
- Carrying out the equality analysis of new and existing policies and practices, any proposed changes and service area reorganisation, in order to make sure that no protected characteristic group has a negative impact…" (L1:5)

SW1

The Translating and Interpreting policy begins by explaining the aims of the policy and that all service users have a right to equal access to information about their treatment and care. The policy states that if any patients have specific communication needs, then staff must make every effort to support them and make sure their needs are met.

SW2

The Equality and Diversity Policy begins with the purpose of the policy which is to explain how the trust complies with the Equality Act 2010 and the Public Sector Duty 2011. The policy then moves on to describe the key principle that equality is for everyone and that the policy is about making sure all staff have access to the services and opportunities they deserve. The key principles also state that everyone has human rights to fairness, respect, equality, dignity and autonomy equally. The purpose of the policy is to show how the trust is committed to achieving equality and diversity in everything that is done for both staff and patients. This policy also follows and complies with the NHS Constitution which "has equality and human rights at the heart of its first principle…" (SW2:5).

5.7 Summary

This section aimed to show how each trust set out its policy and in turn, this showed the intention of each trust as it outlined its duty in line with the Equality Act 2010. Although some policies may not explicitly state the Equality Act 2010, they do make reference to equality in some way, so it could be assumed that they are referencing the Equality Act 2010. A broad conclusion based on just the explanations of the policies is that all trusts understand the importance of the Equality Act 2010, and show their commitment to the Act. Some of the policies described their role a little further than others, such as EOE1 which stated that they have "legal as well as moral obligations to provide interpreting services to people who do not speak or understand English", and NE2 which made reference to some literature when exploring the need for, and use of, professional interpreters. Policies such as EOE1 and NE2 have also provided a little more information than others as to why these policies exist, but as EoE1 has expressed a legal and moral obligation, and NE2 recognises the importance of professional interpreters, maybe this should apply to all policies as they are all surrounded by the duties laid out in the Equality Act 2010.

5.8 British Sign Language Interpreters

This section aims to investigate how hospital policies have dealt with the issue of BSL interpreters, and will include information about qualified BSL interpreters and how to book a BSL interpreter.

EoE1

The trust acknowledges that it is responsible for ensuring access to a registered and qualified interpreter service. The policy provides a list of interpreting organisations and clearly states that providers other than these must not be used. The approved providers are: The Big Word, Deaf Blind UK, Royal Association for Deaf People and Action on Hearing Loss (now known as RNID).

The policy explains how each department deals with the booking of interpreters. The policy begins with general practitioners and clearly states that: "The General Practitioners are responsible for notifying the trust of an interpreting need prior to a planned admission" (EoE1:4). Furthermore, it states that outpatient departments are responsible for providing an interpreter, which has been identified by a GP or via other means, and it requests that hospital staff make a note of this within the patient's notes. However, the inpatient department are expected to make their own booking arrangements and the policy states that the Accident and Emergency Department have a responsibility to be aware of the procedure for booking an emergency interpreting service. Interestingly, this information suggests that there is not a central booking place and therefore, the process for requesting an interpreter depends on which department the service user is in.

The policy explains when an interpreter should be used; it explains that communication with healthcare staff is vital to clinical care and that the need for an interpreter should be highlighted and flagged throughout the patient's pathway. Furthermore, if an interpreter is to be used, then the staff must check with service users to make sure that they have no objection to a particular interpreter. This policy states that only authorised and appropriately trained interpreters are to be used, due to all interpreters following a code of practice. Staff members who are not registered with an interpreting provider can be used but only for basic communication, such as ward routines, and this can only be done with the consent of the patient. The policy clearly states that any clinical information, medical terminology or decision-making should always be done through the authorised interpreting services, with the only exception being an emergency.

The EOE1 policy explains how to book an interpreter, and the policy has its own sub-section for sign language interpreters and a specific contact number for The Royal Association for the Deaf who can provide the trust with interpreters. The policy also has an out-of-hours/24hr emergency contact number. The policy also gives information on how to work with an interpreter while a consultation is happening. There is an appendix showing a flow chart for staff to follow in order to help them determine if an interpreter is needed, along with the contact information for both Action on Hearing and the Royal Association for Deaf People, who can both provide interpreters.

EM2

According to this policy, GPs and other organisations who make the referrals are asked to contact the hospital and let them know if a patient has any needs, such as needing to use an interpreter. This hospital also uses a system alert which identifies when a patient has previously been in the hospital, and this flags up what needs the patient had. Both inpatient and outpatient departments have to book their own interpreters, although it is dependent on whether the patient is referred for an imaging examination, in which case both the inpatient and outpatient departments need to contact the imaging department who will provide an interpreter. Under the subheading "How to decide if an interpreter is needed" (EM2:7), it explains that an interpreter should be used if the patient is deaf, has a hearing impairment or uses sign language. The policy recognises that: "Nationally there is a shortage of fully qualified British Sign Language Interpreters" (EM2:10). However, the policy does address the time that it can take to book an interpreter and therefore, it requests that interpreters are booked as far in advance as possible. The policy recognises that the use of pen and paper/notes is not appropriate for many deaf patients and also, that there are other forms of communication support, such as: Sign Supported English, lip speakers, notetakers, speech-to-text reporters, electronic note-takers, deafblind communicator guides and interpreters, and hearing loop systems.

It is also the responsibility of the interpreting agency to provide appropriate interpreters who are qualified and competent, which includes face to face, video relay and telephone interpreters. The trust expects a suitably qualified and experienced person to be responsible for assisting the interview/consultation and interpreting accurately, and also for interpreters to make it known if they are known to the service user. This part of the policy also makes reference to using qualified interpreters as they have to follow a professional code of practice.

The appendices in this policy provide information for the reader about how to book a British Sign Language interpreter, including an extension number, email address and page numbers that staff can contact. The appendix also gives information about accessing emergency interpreters out of office hours and provides a phone number for staff to ring for a British Sign Language interpreter.

NW1

NW1 replied to the FOI with four documents. Three of the documents related to the interpreting agency they use, which provided information on how to make a booking and general information about the interpreting company; one of the three documents was saved under the name of 'Customer Instruction A4 poster'.

The other documents that were attached with the FOI request related to the booking procedure for interpreters. However, this booking procedure was not produced by the hospital, but from the agency they use to supply the interpreters. The document that provides information on how to book an interpreter claims that there is a customer support service 24/7, 365 days per year and at any location; this suggests that the document is generic and not specific to the hospital. The booking of an interpreter can be done though a portal, as long as the user has a pin and password. However, there is no information for staff on where to access this pin and password in any document. The document does mention that the booking of British Sign Language interpreters, deafblind and lip-speaking interpreters involves the same booking process as all other interpreters. The booking process involves following a website to a portal, logging in to the portal with the correct pin and password, entering information about the booking (e.g. the language required, date, time and expected duration, address and any other specific details). After this information, a telephone number is provided in case a booking cannot be made through the portal.

After the booking information, the agency explains that there will be an email confirmation and when the interpreter arrives, they should present their identity card; this identity card suggests that it is an agency identity card and not a qualified governing body identity card. The other two documents provided no additional valuable information in relation to providing reasonable adjustments apart from a telephone number and A5 leaflet with information about how this agency is providing services to the NHS. However, the leaflet and the other documents provided by NW1 did not make reference to the use of qualified interpreters.

NW2

NW2 replied with an extremely detailed FOI response, which is quite important to explain. NW2 stated that they had no specific NHS handbook for booking interpreters for deaf and deafblind patients, but the trust did have an interpretation policy which describes how they facilitate communication between the employees and service users, including British Sign Language; a copy of this policy was attached to the response. NW2 stated that alongside the interpretation policy, they have a document that provides guidance about best practice when working with interpreters. NW2's response specifically states "this includes a section on special considerations to consider for BSL patients" (NW2), and a copy of this document was also attached to the response.

The trust mentioned that they had commissioned other types of support, in particular deafblind patients have been supported by a "bespoke company" (NW2) who also provide

BSL interpreters. The following quote, taken from the FOI response, clarifies the type of interpreters they use:

> "Because BSL is specialized, all BSL interpreters must be qualified and registered. As such we use a bespoke company selected as part of a national framework agreement for the delivery of interpreting services where all BSL Interpreters used by the Trust must be registered with the National Registers of Communication Professionals working with the Deaf and Deaf blind People (NRCPD)." (NW2)

The response also mentions that NW2 embarks on a deaf awareness training programme where BSL interpreters and deaf trainers provide half a day of training for all staff. The trust states that where staff know that a patient is deaf or deafblind, they book appointments directly through the Interpretation and Translation Appointment Management Service, which is an electronic booking site available for staff. The response also gave an interesting statistic claiming that they undertake 66-76 jobs per month, and the three latest invoices totalled £6,500 - £8,000 per month. From this statistic a raw average cost per booking is around £100 - £105. (NW2)

This policy provided a table showing when to use an interpreter: professional interpreters should be used in any other interpreting session, including when consent is needed, when safeguarding is a concern, when bad news is being delivered, for admissions and discharge, and for complicated medication discussions. This document explained that qualified professional interpreters should be used as they provide impartial, confidential and accountable interpretations.

The policy makes it clear that any occurrences and incidents need to reported, and this includes:

> • "Interpreter arriving late or leaving before a session is finished.
>
> • Interpreter that isn't wearing a valid ID badge, doesn't have any official paperwork or refuses to allow you to sign their paperwork.
>
> • Any occasion when you feel the interpreter isn't interpreting effectively.
>
> • Any occasion where you feel there may be a conflict of interest (for instance if the interpreter knows the service user, is related to them, or any other reason why the interpreter may not be neutral).
>
> • Any breaches, or suspected breaches, of confidentiality.
>
> • Any occasion when the quality of interpretation is in doubt for any reason." (NW2:8-9)

The second document that was attached to the FOI response was entitled 'Working with Interpreters Guidance'. This guidance is fairly straightforward and provides a good amount of information about how to work with an interpreter and the role of an interpreter, ranging from an interpreter's code of conduct to making sure that staff challenge unwanted interpreter behaviour. For example, if an interpreter is getting too involved in decision making, the guidance gives general advice for working with the interpreter and also, makes reference to special considerations for working with British Sign Language interpreters. The guidance gives instructions to the reader when working with BSL interpreters, ranging from good lighting (which would not affect a spoken language interpreter) to making sure that there is ample time to book an interpreter.

<u>NE1</u>

The document titled Interpreting and Translation Policy provided information on how to book an interpreter for those with communication needs, including British Sign Language interpreters. The policy then gives guidance on using an interpreter/translator, for example:

> • “An interpreter must be booked when a language need other than English is identified by Trust Staff or through a referral document.
> • Face to face interpreting must be used for all clinically significant events (see below), whether or not these take place on or off Trust premises.
> • Face to face interpreting must take priority and MUST be used in the majority of cases. However, on occasion such as in an emergency or in the event of a rare language the only option initially may be to use a telephone interpreter.
> • All staff will ensure that this service is provided fairly and that the health needs of the individual service user and their carer are met.” (NE1:6)

This particular trust has signed a contract with a single interpreting and translation service provider, and the contact information for this service can be found on the trust’s intranet page about equality and diversity. If the contract provider cannot provide an interpreter, then staff need to contact the equality and diversity lead for a different supplier.

The document that goes with the Interpretation and Translation policy is the Guidance Document for Using Interpreting and Translation Services. The purpose of the guidance is to help staff when booking and working with interpreters. The guidance explains that in every department there are language identification posters and cards which should help to identify the language a person reads and speaks. The guidance states:

> “The cost of using professional interpreters is often cited as a barrier to using these services: what often is not examined is the cost of using untrained or ad hoc interpreters (family, friends, and other patients). Family members, acquaintances and untrained staff MUST NOT be asked to act as interpreters at clinically significant events or called upon as ad hoc interpreters.” (NE1:2)

The guidance also gives information about patient consent and explains that the use of an interpreter is vital when seeking consent from a service user, especially from someone who uses British Sign Language. "One reason for working with an interpreter is to seek consent from a service user who speaks a language without a written version for example British Sign Language. Non-written service user consent has validity issues, and the following points must be considered:

- It is vital that the service user fully understands what they are being asked to do, and all the issues pertaining to the consent
- The service user understands what they have agreed to; this must be checked by reiteration
- Their decision must be recorded fully in writing
- The act of giving non-written consent should be formally witnessed." (NE1:8)

NE2

The NE2 policy explains the definition of interpreting:

> "Interpreting is defined as the transmission of meaning from one language to another, which is easily understood by the listener. This includes the conversion of spoken language into other languages, British Sign Language (BSL), which is a recognised language in its own right, and other sign language.
> It should be noted that interpreting is quite different to advocacy and should not be used as a form of advocacy which involves the advocate in speaking up for, or acting on behalf of, the service user." (NE2:2)

The policy explains how to identify the type of interpreting service needed and states that referring practitioners should highlight the need for language or communication support, and if these needs have not been identified by the referrer, or it is an emergency situation, then the person assessing the patient is responsible for identifying the need for an interpreter. If the patient is deaf, the policy explains that there are different communication methods such as: British Sign Language, lip speakers, Sign Supported English, note-takers, speech-to-text reporters, electronic note-takers, and people who are Deafblind may need Deafblind communicator guides and interpreters.

The policy stated that if an interpreter or communication aid is needed, then an alert sticker should "be stuck on the front of the patient's case folder, and the requirement for interpretation services noted on the front sheet inside the notes. Where e-records are used, this should also be recorded on e-record" (NE2:3). If the patient is referred to the hospital, then it is the duty of the clinician who received the referral to ensure an interpreter is booked.

The policy provides information on how to book British Sign Language interpreters. Interestingly, the policy immediately states that when booking BSL interpreters, staff should ask for advice about whether one or two interpreters are needed, as this will depend on the length of the meeting. Alongside this, the staff are advised to send preparation material in advance so the interpreters can prepare as much as possible. The policy then moves on to explain how best to work with British Sign Language interpreters which includes - but is not limited to - checking the interpreters' identity and job reference number, the positioning of the interpreter and patient, and allowing plenty of time when using visual aids etc.

In the appendix of the NE2 policy, the guidance about how to book an interpreter, and in particular BSL interpreters, includes a phone number for office hours and an out of hours/emergency phone number for contacting the interpreting agency.

WM1

This policy explains how to book interpreters through the trust's central booking system. The trust has provided a flow chart to help staff determine what type of interpreting service they need. The trust has in-house interpreters, but it does not state if this includes BSL interpreters or just spoken language interpreters. This part of the policy also states that only a limited number of British Sign Language interpreters who are trained to the appropriate level are available, and because of this it is vital that staff give as much notice as possible to help secure bookings.

The appendix shows the flow chart for staff to follow and lists the occasions when a face-to-face interpreter/BSL interpreter should be used. This includes:

- Consent for surgical intervention or invasive procedure
- Out Patients – first booking
- Maternity consent
- Completing documentation
- Activities of daily living
- Discharge planning
- Diagnosis
- Treatment

The policy then explains that British Sign language has its own grammatical structure and there is not a word-for-word correspondence between BSL and English. The policy also gives information about how to position a BSL interpreter and general information to consider when working with a BSL interpreter such as: making sure that interpreters have good lighting on them and not behind them, maintaining eye contact with the deaf patient even when they are looking at the BSL interpreter, and asking questions to the deaf patient and not the BSL interpreter.

SE1

The 'Deaf and Hard of Hearing General Information' document provides information on where staff can find communication support. Based on this document, it can be detected that this trust can supply a communication book or an induction loop system. The document becomes a little confusing as it makes reference to a BSL speaker and a non-BSL speaker, but these are not defined very well; the BSL speaker is defined as a "BSL Sign Language (BSL) interpreter" (SE1:2) and a non-BSL speaker is defined as "An alternative Sign Language interpreter" (SE1:2), which is also a very confusing term. It could be assumed that a non-BSL speaker means other professionals such as a lip-speaker, a Sign Supported English interpreter or possibly other sign languages such as American, however this is very confusing and unclear. The guidance gives information on booking an interpreter when it is an outpatient appointment:

> "Where the Trust is made aware of the need for a sign language interpreter when arranging an outpatient appointment or prior to admission to the ward an interpreter will be arranged for the day of the appointment/admission. A charge is applied for this service– please seek permission from your clinical or department lead." (SE1:2)

The guidance also offers information about a number of organisations where staff can obtain assistance in the "long term", along with brief guidelines for how to work with a BSL interpreter and lip-reader/speaker.

L1

The only information that related to BSL in the document received from L1 was in the Equality and Diversity CQC [Care Quality Commission] Outcome. This document provides the reader with information on how to care for deaf people, including general information about deaf awareness. For example, the document explains that some deaf people can sign, and if a deaf BSL user does try and communicate, then it is important to have a notepad and pen handy as "Deaf people do not expect everyone to be able to sign fluently so be prepared to write down” (L1;12). This document then gives the reader a few guidelines on communicating with deaf people. However, this document does not give any information about BSL interpreters or scenarios where staff might need help.

SW1

The policy provides information about the resources that can meet people’s communication needs, such as the use of sign language interpreters. The last part of the document provides detailed information on British Sign Language interpreting. It states that the trust is committed to working in collaboration with the local deaf community and ASLI (Association of Sign language Interpreters).

The trust recognises that trained British Sign Language interpreters significantly exceed current NHS rates of pay for interpreters and therefore, the trust cannot attract BSL interpreters to join its bank of temporary staff. Instead, this trust is maintaining a list of registered and approved freelance BSL interpreters. Interestingly, this policy states that the bookings for BSL interpreters are made by the trust and if patients want their own BSL interpreter, then the patient must cover the cost. This trust also has the criteria that BSL interpreters must be at least one of the following:

- “An associate or full member of ASLI
- Registered with NRCPD
- MRSLI (Member of the Register of BSL/English Interpreters)
- A trainee interpreter
- A junior trainee interpreter.” (SW1:7)

SW2

This trust defines interpreting as “the oral transmission of meaning from one language to another, which is easily understood by the listener.” (SW2:6). This part of the policy explains that it includes spoken language into British Sign Language, and acknowledges that British Sign Language is a recognised language in its own right, and that there are other sign languages. The policy then continues to explain that there is a difference between interpreting and advocacy, and that it is important to establish if the appropriate communication support is an interpreter or an advocate prior to a consultation. The policy then explains how is it important that staff have the ability to communicate with their patients; it is fundamental to clinical care that they can communicate. This trust wants the referring practitioner to have highlighted the need for language support and then this need should be flagged throughout the course of care.

After this, the policy provides a table which tells the practitioner about the types of provision available. The table does not specifically state BSL interpreter, apart from a note at the bottom which states: "Due to accessibility of BSL interpreters in the South West, face-to-face signing may not be available out of hours…" (SW2:7). The table does mention face-to-face interpreting, which would mean that BSL interpreters need to be used for the following situations:

- Advanced care (medical terminology, consent)
- Discussions about protection
- Obtaining consent
- Outpatient consultations
- Pre-assessment appointments
- Complaints
- PPI activities
- Emergency Department
- Emergency maternity admissions

This trust recommends the use of ASLI registered interpreters and provides a telephone number for the supplier they use. Interestingly, the policy states: "Most patients arrange the interpretation directly with the agency" (SW2:9). This is interesting as it is clearly the duty of the hospital to provide interpreters, and this appears to be completely different to other hospital policies. In addition, the trust states that it currently has no provision for BSL interpretation out of office hours.

This trust also provides information on training for staff which includes guidelines about how to work effectively with interpreters, sign language awareness training and how to work with signing interpreters. Finally, the policy provides information about how to book interpreters and good practice guidance for working with a face-to-face interpreter.

5.9 Summary

The hospital policies relating to the use of BSL interpreters, and how they are booked, provide a very mixed response. Some policies provided a wealth of information on deaf BSL users and the use of interpreters. However, many have failed to recognise the qualified interpreter status and some broad assumptions can be made showing that hospitals rely on agencies to find an interpreter for them. Interestingly, only SW1 and NW2 mentioned the governing bodies that they will accept as interpreters (ASLI, NRCPD and MRSLI); SW1 did also include the use of trainee and junior trainee interpreters, and this issue will be discussed later on in the thesis in the discussion chapter.

This section also provided, for the first time, information on when trusts expect a BSL interpreter to be used, for example: consent for surgical intervention or invasive procedure, out patients – first booking, maternity consent, completing documentation, activities of daily living, discharge planning, diagnosis, treatment, advanced care (medical terminology, consent), discussions about protection, obtaining consent, pre-assessment appointments, complaints, emergency department and emergency maternity admissions.

One final point relates to the provision for 24/7 or out-of-hours interpreters. Only three trusts (NE2, EOE1 and NW1) provided information to show that they have provision to obtain a BSL interpreter 24 hours a day. It is also important to note that all of the trusts that were reviewed have emergency departments.

5.10 Family, Friends and Staff as interpreters

The use of family and friends as interpreters was one of the major issues identified in Chapter Two Some of the hospital policies mentioned the use of family and friends as interpreters; it is also important to highlight that any staff who may know BSL were included in this section. NW1 and L1 are not reviewed in this section as they did not provide any information on the topic of family and friends acting as interpreters.

EoE1

Regarding the use of relatives, carers, friends or children, the EoE1 policy states that they are allowed to interpret for service users but staff should be aware that information may become distorted. Alongside information being distorted, the policy also makes the reader aware that sensitive and confidential issues may arise, and that the service user may not want their family to know. Therefore, if the service user wants a relative, carer or friend to interpret for them, the hospital staff must "make it clear to the interpreter that information is repeated verbatim" (EoE1:6). Children should not be used as interpreters and any service users who bring children along to act as an interpreter should be discouraged. The only time a child should be asked to interpret is for basic information and in the case of an emergency.

EM2

The EM2 policy addresses the issue of relatives, carers and friends being used as interpreters, and clearly states that they must not routinely be asked or expected to interpret as there is an increased risk of inaccuracy. The policy also makes reference to non-interpreters censoring information from the service user. Alongside non-interpreters censoring information, the policy acknowledges that if a relative, carer or friend interprets, then there might be a lack of confidentiality, a lack of impartiality or a conflict of interest, and some people might end up giving advice or advocacy to the service users. The policy also states that children under 16 must not be used as an interpreter; if an emergency situation arises where a child is the only person available, then only basic information should be asked to be interpreted, and this should then be documented in the service user's notes with information as to why the child had been used as an interpreter.

NW2

The NW2 policy makes it clear that staff and patients' family members must only be considered as interpreters if there is no other option in emergency situations; if this situation does arise and it is during office hours, then staff must always phone the Interpreting and Translation Service to see if a professional interpreter is available and only consider using an ad-hoc interpreter if there is no risk to the patient's dignity or safety. In relation to BSL users, children must never be used. Staff using hand signals or other visual aids should only be used for basic communication and where patient experience/safety/clinical effectiveness are not an issue. This policy encourages staff to consult the guidance for working with interpreters and advises against staff members or the patient's family or friends being used as interpreters. The policy also explains what happens if staff, family or friends are used as interpreters inappropriately. If this is the case, the trust wants all occurrences to be incident reported.

NE1

The policies from NE1 provide information about why families, friends or carers should not be used as interpreters, and explains they should only be used if it is the choice of the service user and in that case, then only for day-to-day issues and not for clinical purposes. The guidance explains that if the service user only wants a member of their family to interpret for them, then a professional interpreter should still be booked for the session and they are to sit and listen to the session and make sure that no information is added or changed in any way. The guidance continues to explain that children under the age of 16 years must not be asked to interpret at all.

The use of staff members as interpreters is also not allowed. However, this trust recognises that if the staff member is fluent in a language and they are waiting for an interpreter, then the trust will allow the staff member to interpret basic care and emergency situations only. The policy states that the staff member must only interpret and they must not translate any complex terminology.

NE2

The use of family, friends and carers to interpret is considered to be bad practice and NE2's policy gives reasons as to why they state this, such as: inaccurate interpreting, biased interpreting, emotional involvement and conflicting interests, and breaking patient confidentiality. This policy makes it clear that children and young people should never be asked to interpret for anyone.

WM1

In regards to the use of family, friends and staff, this trust states that they should not be used as interpreters unless in an extreme situation where a service user/patient presents and requires immediate treatment or intervention and a professional interpreter cannot be accessed within a reasonable timeframe; only then might a decision be made to use a family member and if this happens, it should be recorded in the patient's notes.

SE1

In the case of patients wanting to use family members for interpreting, this guidance states that this type of request should be respected, except in the case of vulnerable patients. For emergency situations, non-clinical BSL interpreters are listed on the trust's intranet under an interpreter list, however this information was not available for review. The guidance also does not define what a non-clinical BSL interpreter is.

SW1

The SW1 policy considers the use of relatives, carers and interpreters/communicators. This trust wants to avoid relatives and carers being used as interpreters and provides reasons for this, such as personal and emotional involvement, and the complexity of medical terminology. The trust states that there are some exceptions to this:

- "In an emergency medical treatment situation, when there is no time to get an interpreter.
- Where the patient's needs are such that only the main carer may be able to convey information to them in a form understandable to them e.g. patients with learning difficulties or mental illness / incapacity.
- For parents / legal guardians of children. This will need to be assessed on a case-by-case basis, depending on the age and circumstances of the child, and the nature of the information being imparted." (SW1:7)

SW2

Within the SW2 policy, it states that the trust allows staff to interpret basic information about care or personal history, but staff must not routinely be asked to interpret clinical information. The same information is stated in relation to using carers, relatives and friends as interpreters. However, children should not be asked to interpret; even in the case of acute emergencies, staff should only use the accompanying child to elicit and communicate basic information, such as to ask 'what happened?' and 'how did you get here?'.

5.11 Summary

Throughout the policies, the use of family or friends, and especially children, as interpreters has generally been frowned upon as most hospitals do not want family and friends to interpret. A few of the policies mentioned the emotional involvement as an issue when family act as interpreters, and many mentioned that the information may not be clear and can become distorted. One policy (NW2) also made reference to the patient's dignity or safety and the need to be cautious when using ad-hoc interpreters. Interestingly, there was one re-occurring theme about emergency situations: if there was an emergency and a qualified interpreter was not present, then it was more acceptable for family, friends or children to be used to interpret.

5.12 Chapter summary

The respective policies are in place to guide staff in certain situations. This research has established that the Equality Act 2010 is the fundamental foundation for starting the policies as they have a duty to make a “reasonable adjustment”. Hospital trusts have the task of establishing a way to make an adjustment, however, the policies show that each trust has diverse reactions to doing this, with some providing good and clear information to staff members, and also to the public who should have access to these documents.

In relation to the legislation and reasonable adjustments, most policies made reference to the use of BSL interpreters and some even provided information on how to work with a BSL interpreter. Most of the policies stated that family, friends and children should not be used unless in an emergency, although it is not clear what is classed as an emergency; common sense could assume that an emergency situation would be classed as life threatening.

In relation to the booking of interpreters, the policies have shown the variation in each trust and more importantly, when deaf patients are being referred from a GP practice, some hospitals have made reference to the GP surgery being responsible for informing the hospital that an interpreter will be needed. This information is vital and raises the question about whether or not GP surgeries know this information and more importantly, are they doing it? This then ultimately asks the question: is this a major reason as to why deaf people who use BSL are not being given interpreters for appointments because the information is not being passed on?

The policies have revealed some interesting findings such as the variations in booking systems and how to go about getting an interpreter, some policies contained phone numbers and email addresses for staff to use to contact an agency. This is interesting because of the variation between each trust and their different ways of contacting interpreters, despite some hospitals being in the same region. The responsibility for booking an interpreter is also an interesting factor as some hospitals have a designated department for the HCP to ring in order to book the required interpreter, whereas other trusts require each department (Outpatient/Inpatient/A&E) to book their own interpreter; this again shows the variation from each trust and suggests there is no single system that all hospitals follow regarding how interpreters are booked. One vital point that has been highlighted in this chapter is the lack of emergency interpreters. This chapter has revealed a worrying statistic that out of the 11 policies, only three trusts showed provision for being able to get a qualified interpreter 24/7. Alongside this, nearly all of the policies expressed their dismay at using family, friends or children as interpreters, and most explored why they should not be used.

It is important to note that this chapter has reviewed 11 policies out of a possible 18. Two of the trusts did not reply to the FOI request and the other five trusts provided policies that did not contain any information relating to the provision of BSL interpreters or deaf patients. In Chapter Nine this policy analysis will be synthesised with the common themes derived from the IPA study of deaf participants and paramedics, to better understand how written policy relates to individuals’ experiences and key issues identified through the interviews.

Chapter 6. Deaf people as healthcare users: Deaf experiences

This data chapter will explore the lived experiences of the deaf participants. Their experiences relate to accessing healthcare appointments, how they communicated with medical staff and their own personal feelings about the experience. The interviews also explored how deaf people want to communicate and how this is enabled by hospital policies. Overall, there were five deaf participants who took part in the interviews; each one was a deaf BSL user and communicated using BSL, and all interviews took place using their preferred language. Video recordings of interviews were translated from BSL into written text as a first stage of the analysis.

All of the participants' names have been protected by self-selected pseudonyms, and all were over the age of 18 years old. The five participants were:

Interviewee 1 – Muriel
Interviewee 2 - Marco Gilberto
Interviewee 3 – Foxy
Interviewee 4 – Emma Bourne
Interviewee 5 – Hedgehog

Table 2: Deaf participants

Each of the participants needed to attend hospital for a variety of reasons, ranging from audiology appointments to cancer treatment. The purpose of the appointment should have no impact on the need to make reasonable adjustments, although some instances may require a greater level of adjustment.

The term 'reasonable adjustment' is explored within these interviews. As previously mentioned in the House of Lords debate (Chapter Three), the duty of reasonable adjustments is an anticipatory duty. Therefore, in theory the duty is on the hospital to make the right adjustments for each patient so they can access the health service fully and have no disadvantage to that of a hearing person. As outlined in Chapter Two, there is a strong case for needing BSL interpreters in medical settings and many publications throughout Chapter Two highlight the need for BSL interpreters, with heavy criticism of hospitals and GPs when interpreters have not been supplied and deaf people have been put in some terrible situations.

This chapter does not reiterate what has already been published, but explores in depth how deaf people are communicating at the time of this research, and how they want to communicate when in medical settings. From this, the chapter explores what has worked well and what has gone wrong in terms of communication. This chapter also explores the participants' views on interpreters in the medical setting, focussing on the use of trainee and qualified interpreters, alongside their thoughts and feelings of family and friends being responsible for interpreting. In addition, this chapter will explore awareness within medical settings. The exploration of all these aspects should then inform and relate to the hospital policies, due to the duty of anticipation placed on hospitals by the Equality Act 2010.

The themes identified within this chapter were drawn from my interpretation of the data from the participants. I used a deductive approach to develop the themes as I was unsure of the specific themes that would be generated; however, I did have some preconceived ideas about the themes that I expected to find, such as the use of interpreters. (Gerring, 2011).

The table below outlines the common themes and how they linked together. For example, all the participants had a reason for going to the hospital and although the reasons between participants varied, they still linked in with the theme.

Reason for going to the Hospital: • Audiology • Giving birth • Physical injury
Communication during appointments: • Reading and writing • Family interpreters • Specific interpreters
Booking the interpreters: • Relationship between GP and hospitals • Levels of trust through booking interpreters
Fully qualified interpreters, trainee interpreters and specific interpreters: • Gender specific interpreter • Importance of qualified interpreters
Family and friends as interpreters: • Appropriateness of family as interpreters • Last resort to communicate • Failure to provide interpreters
Not wanting an interpreter and interpreter confidentiality: • Individual preference • Confidentiality concerns
Doctors and Interpreters – the need for full professionalism and full access: • Interpreters not turning up • Interpreters leaving early • Doctors and interpreters causing negativity
Deaf awareness – the good and the bad: • Lack of deaf awareness • Good deaf awareness practice

Table 3: Common themes for deaf participants

6.1 Reasons for going to the hospital

Most of the interviewees attended the hospital regularly for audiology appointments, ranging from needing to get new hearing aids or hearing aid ear moulds, to needing to go because they have a cochlear implant; these types of appointments can be quite regular. Muriel, for example, spoke about attending general appointments but she also explained that she went to the hospital for a physical injury when she needed to have a skin-graft and surgery. Other reasons for going to the hospital included:

> "I go to the hospital for two reasons: [firstly] audiology to get new hearing aids or ear moulds or batteries; and [secondly] I have children, so to give birth two times." (Emma, transliterated from BSL)

> "I was going regularly for my cochlear implant and I went a few weeks ago, but for physical health it was a few months ago." (Marco, transliterated from BSL)

Hedgehog used the hospital quite regularly due to being unwell and actually needed to use the health facilities quite frequently: "In the past I used to attend the hospital regularly, sometimes it was every week and sometimes it was every month due to my health…"

Foxy also needed to go to the hospital for a number of reasons:

> "At the moment, I go for audiology, I've been quite ill with migraines this year so have had about 2 or 3 appointments for those. I've had an MRI and I've had electrodes put on my head. But I used to go there loads when the kids were younger. I obviously went when I was pregnant and after that to A&E – always something happening with the kids. So, it varies how often and why I go there." (Foxy, transliterated from BSL)

6.2 Communication during appointments

It was important to clarify how each individual wanted to communicate and this varied depending on the appointment. As all the participants used BSL as their first or preferred language, it is easy to assume that most would use a BSL interpreter to communicate. However, Emma explained that it depends on the situation:

> “When I go to Audiology, I’m by myself, because being one-to-one is fine to chat. If it’s tricky then I’ll ask them to repeat or find another way such as writing things down. When I gave birth, my boyfriend - who is hearing - can sign alright and he was with me, but it was hard because it took hours and hours and he became tired. Looking back, maybe it would have been useful to have an interpreter there.” (Emma transliterated from BSL)

Emma explained the situation when she attends audiology appointments:

> “…with audiology my boyfriend isn’t there, I go by myself. If it was a group situation where there was a lot of people talking then I would definitely have an interpreter, but when it’s one-to-one it’s fine. I can lip-read okay… well just enough.” (Emma, transliterated from BSL)

Foxy explained that it varies as she wants to communicate using a BSL interpreter, however, it can depend on whether or not the hospital has booked an interpreter for her:

> “It really varies, if it’s audiology then they usually book an interpreter, because I regularly attend there so they know… but if I’ve been referred to a specialist department then I have to let them know I need an interpreter.” (Foxy, transliterated from BSL)

Hedgehog explained that the hospital will usually book an interpreter for him and normally, there is an interpreter present for his hospital appointments:

> "They have already booked an interpreter for me, so when I arrive, there will already be an interpreter there as they know I am a deaf person and

> need an interpreter… well most of the time they have booked an interpreter." (Hedgehog, transliterated from BSL)

Marco explained that he communicates using BSL and actually has a preference for using a specific interpreter:

> "I use BSL. The cochlear implant centre are very good, they provide interpreters and email me dates for appointments. I ask if they can book a specific interpreter and they do. For physical health it's difficult, because they're clueless. So, I have to book an interpreter through the doctor. It's very complicated." (Marco, transliterated from BSL)

Muriel, on the other hand, had a different view about having an interpreter for medical appointments as she felt it depended on the type of appointment:

> "…It depends on what it is. If it's really personal, then I won't have an interpreter with me. For example, this year at the doctor's they told me I must have an interpreter, but I said I didn't want one…" (Muriel, transliterated from BSL)

It is important to note that Muriel explained that she is confident in her English reading and writing skills. As explored in Chapter Two, the average deaf person's reading and writing skills are lower than a hearing person, but Muriel was more comfortable to communicate with pen and paper, as she explained:

> "… I never use an interpreter at the GP… it's rare. We communicate via written notes to each other." However, when Muriel needed surgery, she wanted an interpreter to be present so that she did not need to rely on written communication: "…I thought that this was important and needed

> to be interpreted as I needed to know what they were doing, what the procedure was…" (Muriel, transliterated from BSL)

6.3 Booking the interpreters – the unspoken role of the deaf person?

As mentioned in the legislation and NHS guidance chapter, it is a duty of medical settings to book interpreters for deaf patients as well as to pay for the interpreters. Many deaf participants commented that they were the ones who had to either contact the hospital to remind them or confirm that an interpreter was booked for them.

Marco explained that it can depend on the hospital department, for example:

> "It depends, hospitals have lots of departments, so when I go to an appointment, they've booked an interpreter in advance, but if I've been referred to another department then they might not be an interpreter and they say it's because they haven't been told that I need one. So before leaving hospital, I have to remind them that I need an interpreter" (Marco, transliterated from BSL)

Marco highlighted some of the frustrations relating to the booking system between GPs and hospitals:

> "The appointment system needs to be sorted out. It's obvious that most departments don't know how to sort out their booking system. They're also very limited in passing on information to each other within the hospital, to the different departments. For example, heart, kidney, lungs, blood transfusions. Going back to the doctor, my local GP is very good and they know I need an interpreter for a GP appointment. If the GP refers me to a department in the hospital, they are very good at letting them know that I need an interpreter. But it's their responsibility then to sort out the

> interpreter, not the GP's. When I go there, I know the interpreter is there because I have had to make sure, I've called them through Type Talk to check that the specific department have booked an interpreter… I don't want to waste my time. I have work and a family; I don't want to get there and find there's no interpreter. I'd rather not attend the appointment as I need to know and be able to access the important information, so that's why I'm more pro-active. When there is a referral, I directly remind them, but it should be that once the referral is made, they are able to deal with it without me being worried and needing to make sure that they have."
> (Marco, transliterated from BSL)

Marco also shared his thoughts on the agencies that book the interpreters and how he thinks that they could do more to provide qualified interpreters:

> "In the area that I live – they are very good at making sure there is translation available for foreign, disabled, deaf or whoever because they have good connections to agencies, which is great. So, they assume the problem is solved as they've given the agency the name of the person, date, time and place to meet and they think that is all they need to do. But the interpreting agencies have more knowledge than the hospitals, so the hospitals will think 'they have the support available, job done'. But they don't know the other side of the situation, for example, trainee interpreter or qualified interpreter. I've complained once or twice through PALS, within the hospital, and when I tell them they look shocked and contact the interpreting agency who say 'next time we'll provide a qualified interpreter', which means the interpreting agency knew they were providing a trainee interpreter, but only because I complained did they say sorry. Generally, for me the hospital have been good, but they don't know

> the insides and outs of the people who deal with the translations and bookings.” (Marco, transliterated from BSL)

Marco also provided an account from when he was younger and went to the doctors with his mum when needing to communicate with the doctors:

> “… When I was growing up, I was about 11 or 12 and would always have different doctors. The doctor would try talking to me and my mother flipped and said ‘He signs, why are you talking to him?’ The doctor replied ‘But he can lip-read’. And my mum said ‘No, it’s tiring!’ After that, they provided interpreters. That’s the only memory from my childhood. But now I can look back and since then, I have to be the one to remind them that I need an interpreter. I want to understand the world. I want to be given a form to register for the GP – if I move area – where at the bottom it asks if I need communication support, and I can tick a box that says BSL, then they put it on the system and it’s finished. I would then come in and an interpreter would be there, rather than me reminding reception to please book an interpreter.” (Marco, transliterated from BSL)

Hedgehog also provided an account of when he had to remind medical settings to book interpreters:

> “In the past if there’s been no interpreter, I have repeatedly reminded them to book an interpreter and it did improve. Now they regularly book interpreters for hospital appointments but not for GPs. For example, I can phone the doctors in the morning and they say it’s impossible to get an interpreter, which I know, but if I book an appointment for the next week then they can book an interpreter, if I request it. They won’t automatically book an interpreter unless I request it… but the hospital knows, it says in

> their system that I need an interpreter… for me here… hospitals are better at booking interpreters than my GP.” (Hedgehog, transliterated from BSL)

Hedgehog felt that the hospital he attends has recently become more reliable when booking interpreters:

> “Yes, so in the past I would always remind them, but now there is always one there. When I phone up, they say there’s already one booked, its already sorted out. I feel like I don’t need to phone, but in my mind I would rather make sure. It’s natural. By doing this, maybe the next person won’t need to call up to check an interpreter has been booked as they will have automatically booked one. But I like to check and make sure. Maybe in the future no one will have to call and check if an interpreter has been booked. It would be good to know.” (Hedgehog, transliterated from BSL)

As mentioned in the previous section, Foxy explained that if she is referred to a different department, then she reminds them that she needs an interpreter, but this can sometimes be difficult:

> “… I have to let them know that I need an interpreter. That can be difficult as it’s done by phone call, so it becomes time consuming. Usually if there’s no interpreter at the first appointment then I will make sure to let them know at reception to book an interpreter. Sometimes they will turn up, sometimes they don’t turn up. It really varies, the hospital might not have booked one.” (Foxy, transliterated from BSL)

Foxy also stated that she tries to raise awareness about needing a BSL interpreter by making the hospital staff write on her notes to remind them, however, this does not always work out as planned:

> "… I always make sure they write on my notes that a BSL interpreter is required. Once, the receptionist booked an interpreter and a foreign language spoken interpreter turned up. I reminded them that I needed a sign language interpreter, so make sure they state that a BSL interpreter is needed." (Foxy, transliterated from BSL)

6.4 Fully qualified interpreters, trainee interpreters and specific interpreters

One major theme that was identified in the findings was the importance of using fully qualified interpreters and specific interpreters. The specific interpreters might include wanting a certain person for the appointment, or wanting a male or female interpreter.

Muriel explained that although she does not always have an interpreter, when she does use one, she wants them to be female:

> Mark: When you go to the hospital do you always have an interpreter?
>
> Muriel: Not always… Sometimes I arrive and it's a man… not impressed. I send them away, tell them to leave, I then write down that I won't use a male, I want a female and that's it. I wrote down that next time I want a woman interpreter. Why would they give me a male? I've got nothing against them, but I wouldn't want a male voicing me over… I'm a woman, the doctor would hear a man's voice, but see a woman signing. Also, if you're talking about personal things… just no! (Muriel, transliterated from BSL)

Muriel also explained that if she has trainee interpreters, she will send them home as she wants a qualified interpreter who is competent:

> "… if an interpreter turns up and is a trainee, I send them home. I won't have them interpreting for me. I would rather use written notes as I know that's the right information. If a qualified interpreter turns up then I will use them. Some qualified interpreters are awful, but I'll stop using them and communicate using written notes. I'm lucky because I know my rights and can be assertive and say 'No'. I know when an interpreter is good or poor. So, if a trainee turns up, I tell them to go home because it's dangerous to have a trainee in a hospital situation." (Muriel, transliterated from BSL)

Marco had a similar perspective to Muriel regarding the use of qualified interpreters, however, Marco explained that he sometimes asks for specific interpreters who he likes working with:

> "… I do ask for some specific interpreters that I know, but it's bad, the agency use in-house interpreters. Sometimes in-house interpreters, some of them are good, some of them are not qualified, fully qualified. So, it puts me out… I know the agency are using in-house interpreters because it's cheaper, but I did ask for specific interpreters… it's difficult." (Marco, transliterated from BSL)

Marco also explained why he thought it was important to have qualified interpreters in the medical settings:

> "… Because qualified interpreters have been through university, they know the linguistics and jargon and are able to translate from English to BSL. I'm not criticising trainee interpreters, it's good they are learning, but at the same time, the information needs to be properly translated. For example, 2 weeks ago my partner had an ultrasound scan and the trainee

> interpreter translated very little - their interpreting was staggered. I'm able to see the difference, as about 6 years ago I had a fully qualified interpreter at an ultrasound scan and the information that the midwife said was interpreted clearly. But 2 weeks ago, I was watching the trainee interpreter and it was like silence, but I could see that the nurse was talking. The trainee interpreter seemed to start… then stop… saying it was 'difficult'. So, I can tell the difference between a qualified interpreter. So for me, I feel strongly that it's important to have a fully qualified interpreter. Because what if it's a life-threatening situation regarding serious health issues such as cancer?" (Marco, transliterated from BSL)

Marco then explored his feelings when he did not have a qualified interpreter with him during appointments:

> "Naturally I would worry, because I know the information wouldn't be translated fully, so it's difficult for me when a trainee is right there. I can't just say, 'You are a trainee, I don't want you', because at the same time I want to encourage more interpreters, because you have to remember that there are only a small number of interpreters in the UK. So, it is difficult. But at the same time, trainee interpreters should know when it comes to hospital appointments to say, 'No I'm not ready, I need training first.' But some trainees think it is appropriate to go. That's where the interpreters should know better, and communication/interpreting agencies should know better. A quality service is important, it should be priority number one." (Marco, transliterated from BSL)

Marco expanded on his views about the importance of having an interpreter, and the difference between a qualified interpreter and a trainee:

Mark: If an interpreter wasn’t there in the hospital with you, do you think you’d understand everything… all the information?

Marco: No! Definitely not, because once we were writing on paper to each other and it was okay, but if I was hearing, he would have spoken to me instead of writing things down, so he would have said more than he was writing down which was cut off and brief. Did it mean I fully understood? Not really, so it’s difficult.

Mark: When you’re with an interpreter and they’re relaying the information, do you sometimes feel it isn’t clear?

Marco: With fully qualified interpreters I am always happy with the translated information. But sometimes different interpreters come from different areas, for example… I live in… and I know the interpreter system has changed. Before, it used to be local interpreters from the council, but now their contract has finished which means different interpreting agencies are taking contracts which means that some interpreters are from outside my area and sign a bit differently. So before, when it was local qualified interpreters, I was happy with the interactions. With trainee interpreters there are problems.

Mark: Okay, with a trainee interpreter at the hospital, if they relay information that isn’t clear, do you ask them to repeat it? Or…?

Marco: I can tell from a trainee interpreter’s facial expressions when they are listening and processing… having time to think… and if they are struggling. So, I watch them, they explain, then I ask them to say it again. I’m able to tell when the trainee interpreter hasn’t given a full explanation,

> so then they ask the doctor to repeat and I'm just sat there waiting and waiting." (Marco, transliterated from BSL)

Marco was also asked about his views and experiences of using male or female interpreters:

> "It varies. Funnily enough, up until about 6 or 7 years ago there were lots of female interpreters, then finally there was a male interpreter about 1 or 2 months ago. I'm not bothered… what I'm bothered about is information translation, that's all." (Marco, transliterated from BSL)

Foxy provided a detailed explanation of the importance of having interpreters present for her appointments and explained how things felt when an interpreter was not present, which included when the interpreter had to briefly leave the room. For example:

> "Mark: For your MRI scan, did you have an interpreter present there?
>
> Foxy: The interpreter was there prior to the scan to explain what they were going to do, but during the actual test the interpreter had to leave the room which meant there was communication difficulties then.
>
> Mark: How did that make you feel?
>
> Foxy: Sometimes I prefer the interpreter to be there, especially if I'm being spoken through a speaker in the machine or there's speech going on outside. If I know I'm on my own then I feel anxious and there is no one there to calm me and tell me to relax. It made me feel as if I wasn't in control which can be emotional and I start thinking that there's definitely

> something wrong with me as there's no one there to talk to… to reassure me.
>
> Mark: So, if there has been no interpreter how have you felt?
>
> Foxy: I definitely feel stressed. Especially if it is something that I have no knowledge about that I want to question but I feel like I can't go into depth. Sometimes because of that, I will leave feeling more worried than I was when I arrived." (Foxy, transliterated from BSL)

Foxy also explained that using qualified interpreters helps her understanding, especially when technical terms or medical jargon are used:

> "Usually I understand, but sometimes when they use jargon – words I've never heard before – about medication or treatment… I will always use clarification. I know through experience as a mother, and that I have been deaf my whole life, that if I am not sure then I need to ask for clarification. If there is a qualified interpreter present, then I know it will be easy and smooth. Sometimes the interpreter will struggle with it themselves, so there will be a delay. If they don't know when there's a delay and I wonder what's going on because of the wait. But usually the interpreter will ask the doctor to explain what he means for this or that. They are being accountable for making sure they give me the right information. Sometimes the interpreter doesn't understand… so it's important to have a qualified interpreter as they can adjust and know that if I'm unsure then they can ask for clarification – it's their role." (Foxy, transliterated from BSL)

As a mother, Foxy had experienced needing an interpreter when her children were ill, and she explained that it can be quite strenuous when no interpreter was present:

> "…It's easier if there's an interpreter there because then we both understand together, rather than them waiting for me to get the information from the doctor, understanding it by questioning and clarifying, then relaying it. We are there because we want to know what's going on. It's easier when there's an interpreter there, we can relax more and I can be there to support my child." (Foxy, transliterated from BSL)

Foxy also prefers specific interpreters depending on the appointment, which in this case were maternity or gynaecology appointments:

> "Well, if it's a maternity or gynaecology appointment, I would of course want a woman as they have empathy, and it's personal… I think there was one appointment when a man came and I said that I couldn't continue with the appointment as it was difficult with it being a man. I got told 'Well, he's an interpreter'. And I said 'I know he's an interpreter, but a male and female are different and it's important." (Foxy, transliterated from BSL)

Hedgehog also talked about qualified interpreters and using specific people, as he explained that he had always had a qualified interpreter and is not bothered if they are male or female. However, Hedgehog did have a poor experience with a qualified interpreter - which will be discussed later in the chapter - and he explained that the hospital knows that they should not book this particular person:

> "Mark: When you have had an interpreter at the hospital, have they always been qualified?

> Hedgehog: Always, I know who they are and if there is a new face, I will ask them and make sure they are fully qualified. Also, the hospital knows I have a specific person I don't like interpreting for me. They know that person and they know not to book that person… which is good!
>
> Mark: Okay, do you have a preference as to whether your interpreter is male or female?
>
> Hedgehog: I'm not bothered, I'll have both." (Hedgehog, transliterated from BSL)

Emma did not have an interpreter during the birth of her children, which will be discussed in the next section, however, when asked if she had a preference for a male or female interpreter, Emma explained:

> "I would maybe prefer a woman, but at the end of the day they would have given me communication support so I wouldn't have minded." (Emma, transliterated from BSL)

6.5 Family and friends as interpreters

The use of family and friends as interpreters is an issue that cannot be ignored as this was mentioned by some of the participants. As discussed in the Chapter Two, using family and friends as interpreters has been shown to have some devastatingly poor outcomes.

Emma gave an interesting account of family members acting as interpreters, in particular her boyfriend would always interpret for her, although it is depended on the situation. For example, Emma had experienced family interpreters during childbirth:

> Mark: When your boyfriend has interpreted for you, in what situation was it?
>
> Emma: For both births. He came with me for support and also communication support.
>
> Mark: Did you want an interpreter for the birth of your children?
>
> Emma: No… I always knew what my boyfriend was saying; his signing is good enough for me and I could receive it fine. The first time was fine, but the second time took longer, and he became tired but they never offered an interpreter.
>
> Mark: If they had offered you one, would you have taken it?
>
> Emma: Yes, I would have. But it was a difficult situation. My boyfriend was there supporting me because we're together and were sharing the journey of childbirth but he had the added communication responsibilities and became tired. (Emma, transliterated from BSL)

It is important to note that Emma was happy to have her boyfriend to interpret for her in these situations; she found that the communication was mostly clear so she was happy, and she felt like the hospital were happy for this to happen as well. However, Emma did find that there were times when she was confused; for example, with forms such as consent for an epidural, she thought it would have been more appropriate for her to have an interpreter. However, this shows the trust that she had in the hospital, which might have contributed to the fact that she was happy with her boyfriend acting as her interpreter. For example:

"Emma: There were occasions when the doctor or nurse would talk to me and it wasn't clear. If they spoke to me one-to-one then it was fine, but if their eyes were looking around then I just wouldn't get it. My boyfriend became limited with his signing, he wouldn't sign everything, just summarise what was important and tell me.

Mark: Were you happy with that? How did it make you feel when it was quite limited?

Emma: I'm trying to think of an example. Maybe as the end of the second birth – there were problems, I had foot cramp – my boyfriend got involved with the conversations. I had to stay in a long time as there were problems with cramp in my foot but I wanted to go home as it was only cramp, but they were worried it was linked to me having an epidural. So, people were chatting away in front of me and my boyfriend got involved and finally got that answer. So, in the end I got a form and decided myself to leave…

Mark: The hospital was fine that there was no interpreter there and it was your boyfriend who ended up coming in and interpreting for you?

Emma: Yeah, the hospital didn't say anything about there being no interpreter and just carried on. In regard to the form for the epidural, it was night time, it was late and I'd been there for hours… it was explained to me and repeated and clarified but my head was all over the place and my boyfriend told me it was important that I receive the information… I was supposed to keep still but was having the information repeated to me. It was quite a confusing time.

> Mark: You said before that you wasn’t too bothered about having an interpreter but would you have wanted one in that situation?
>
> Emma: You give your trust to them. They know what they are doing as they do it every day… Maybe not for the full, but for the forms… it would have been good [to have an interpreter]. It was an important situation. If they had asked me, if they had offered, I would have accepted.” (Emma, transliterated from BSL)

Marco also gave an account of when he had a family member as an interpreter, although in Marco’s case it was slightly different as his partner is a qualified interpreter, but he will only use her if it is a last minute appointment. Marco stated:

> “…my partner is a qualified interpreter. She interpreted for me once or twice when it’s been a last minute appointment to see the GP, when it’s been ‘are you available this afternoon?’ or they can’t find an interpreter… if my partner wasn’t a qualified interpreter I would be worried, because I don’t want to put pressure on her in that situation, because she’s my partner and not my interpreter. But she naturally translates. If she wasn’t a qualified interpreter, I wouldn’t have her do that.” (Marco, transliterated from BSL)

Muriel had also used a family member as an interpreter. As stated above, Muriel normally communicates with medical personnel using a pen and paper, however, Muriel needed to have an operation and felt like she should have an interpreter to help clarify the situation:

> “…They were there when I had the anaesthetic administered, but that was it. But then they [my interpreter] wasn’t booked by the hospital. I had to ask my partner at the time who’s a fully qualified interpreter if she could

> come with me… That was the first time I had an interpreter. Growing up I never had an interpreter. So, because I didn't want one, they didn't provide one. Especially if they are coming to talk about my leg… its important, I don't want to write notes. But if there is no interpreter then what am I supposed to do?" (Muriel, transliterated from BSL)

As shown below, Foxy provided a detailed account which was quite recent - in 2018 - and involved the hospital asking her to bring along a family or friend to interpret for her:

> "Foxy: After my MRI scan, I had a follow up appointment to talk about the results and there was no interpreter as they had forgotten to book one, so they asked me to bring a friend or family member. I didn't feel comfortable but my partner came with me, so I used her because I wanted to know if I was alright… that was the main priority… so I put up with that. Luckily, I trust her and was able to remind her of the questions she knew I wanted to ask…
>
> Mark: Did they say why the interpreter wasn't booked?
>
> Foxy: It was obviously the department. If a department regularly sees deaf people then they know automatically, it's routine that a deaf BSL user needs an interpreter…
>
> Mark: How did you feel when your partner was interpreting for you?
>
> Foxy: My partner and I have a great relationship, but sometimes you want some privacy, or she becomes worried for me. So, it's not fair to burden her. I like to be independent, to receive the explanation/feedback then ask questions myself. So, if the doctor is telling the information to my partner

> and then she tells me, there’s the chance of receiving the wrong information or wrong context. It’s difficult. I can leave, then question her [my partner] and ask her if they said this or that and she’s not sure… it’s a missed opportunity for questions.
>
> Mark: Is your partner a confident signer?
>
> Foxy: No, not at all. She has very basic signs, pre-level 1. She is picking it up the more we are together, but that was a big appointment for her, a lot of responsibility. Some information is better than nothing… especially as the appointment was important. I had been waiting a long time for that appointment, it had been postponed a lot. I knew that if I missed that appointment then I would be waiting a long time again for another one and with booking an interpreter etc… it just drags on. We knew it was better than nothing, but I won’t be doing it again!” (Foxy, transliterated from BSL)

Foxy then explored her own and her partner’s feelings about the situation:

> “Foxy: She felt bad if she signed wrong or missed information, so I think she felt bad. But she knew, she told the doctor to book an interpreter for next time which showed it was an important appointment that needed an interpreter.
>
> Mark: And how did you feel… that your partner was potentially signing a very important appointment?

> Foxy: I felt frustrated that they didn't understand my needs as a deaf person. I'm not the same as other patients who have easy conversations with them. I felt pressurised…. I wanted to ask more questions. My partner understands my signing, but to explain to the doctor how it was different to being in an appointment, its hard…. And to become frustrated and remind my partner that I asked something and I want an answer wouldn't be fair… we are there as partners, but the relationship became tense. I was worried, and she was worried that she had given me the wrong information whist making sure I was okay." (Foxy, transliterated from BSL)

6.6 Not wanting an interpreter and interpreter confidentiality

During the interviews some of the participants expressed that they did not actually want an interpreter. Previously in this chapter, we briefly explored that Emma and Muriel were happy to use pen and paper for most of their appointments and were also happy to have family members to interpret for them, however some participants expressed their concerns over the interpreter's confidentiality and feeling embarrassed because of personal/intimate issues, or being worried that interpreters will talk to each other in a social environment.

Muriel expressed huge concern about this and explained that this is why she is happy to use pen and paper for personal appointments:

> "Pen and paper… that's a reasonable adjustment that suits me – I'm fine with that… because I know a lot of interpreters, and personally, I don't want the interpreters to know. I know they keep confidentiality and that's good, but they know about me, and I don't want them to. Simple things like blood pressure and general treatment is fine, but not for personal. I'm happy to write notes. I know some deaf people are not able to read English and must have an interpreter, but I can. They tried for force me to have

> an interpreter, but I stood my ground and said ‘No’.” (Muriel, transliterated from BSL)

Muriel explained in more depth about the confidentiality issues she mentioned above:

> “… I know some interpreters try to keep confidentiality, but if they speak to other interpreters socially, it might mean there are two interpreters that know about my personal issues. I don’t want that… I don’t want the interpreters to look at me with that knowledge, it makes my skin crawl to think about it. Also, deaf people become familiar with who interpreters are. When my partner – who’s a qualified interpreter – came with me it’s fine, it’s different, it’s not forced. But when someone I know, but am not close to, comes with me, I don’t want it… I said ‘No’!” (Muriel, transliterated from BSL)

Muriel also provided an example of when a student that she taught turned up to an appointment and she sent them home because they knew each other:

> “When I see an interpreter I either feel relief or frustration. My student turned up – someone I had taught once – and I asked what they were doing there. They said they didn’t realise it was my name… but I said ‘You should know that’s my name.’ They were a post-graduate student. I told them to never come and interpret for me again… they shouldn’t have been there… I was their teacher, I said to the student: “You should have apologised and said I can’t take it, that’s my teacher”. It’s their ethics, so I said to ‘Go home!’” (Muriel, transliterated from BSL)

Emma – like Muriel – normally uses pen and paper to write things down during appointments and is happy to do so. As mentioned above, if Emma was offered an interpreter, she probably would have accepted one, although not for the full consultation but for interpreting/translating the medical forms. However, this still did not affect Emma as she was happy for her boyfriend to interpret for her:

> "… Most of the time it was clear, but my boyfriend is not a qualified interpreter… but it was good for me… Giving birth is personal – it's my body. My boyfriend is not bothered, but if there was an interpreter there, then it would be a lot of people. But actually, at that time my head was just focused on needing to get the baby out, not thinking about feeling embarrassed." (Emma, transliterated from BSL)

Foxy explored the need to have an interpreter that she could trust to keep her information confidential. Similar to Muriel's comments above, Foxy explained that interpreters know a lot about them, but they do not really know anything about the interpreters:

> "When I had bad anxiety and asked for a referral for counselling, I asked for an interpreter that I had a good relationship with, because I was going to be talking about my feelings and needed to feel safe, knowing that I could trust them. The deaf community is small and you meet a lot of interpreters, so you want to make sure the information is kept confidential. So usually when I see my counsellor, I have a specific interpreter who I like, but it depends if they are available… sometimes the appointments are booked with little time to look for someone." (Foxy, transliterated from BSL)

Foxy explained that her preference for certain interpreters relates to the interpreter's ethics and confidentiality:

> “I know interpreters have a code of ethics that includes confidentiality and other elements, but they’re still the third person. Things that are talked about are personal to you. The interpreter now knows a lot about me but I don’t know them. That’s why I have preferred interpreters who I have known for years and built up a relationship with them…” (Foxy, transliterated from BSL)

6.7 Doctors and Interpreters – the need for full professionalism and full access

Some of the participants had experienced a lack of professionalism, which ranged from the interpreters needing to leave early to doctors forcing interpreters on the deaf participants, or doctors showing that they were not happy about using pen and paper when an interpreter did not turn up.

Foxy provided a number of examples where she had experienced a lack of professionalism from both interpreters and doctors. We have already identified that Foxy was asked to bring a family member or friend to interpret, and it could be argued that the hospital was unprofessional for doing this. Foxy also explained what happened when she attended an appointment and an interpreter did not turn up:

> “Some appointments, when the interpreter doesn’t turn up, I go ahead with as I don’t want to wait for ages for another appointment. So, usually when I go in, I’ll ask if we can use pen and paper… and they clearly aren’t happy about this, they write brief notes and wonder why the appointment takes a long time. I’m sure there should be more information, but they are busy. Sometimes what has been written down is enough, other times I’ll ask to book another appointment with an interpreter, it depends what the appointment is for.” (Foxy, transliterated from BSL)

Foxy also recalled a situation where an interpreter had left during the appointment:

“Foxy: Sometimes the interpreter has other appointments and has left, that’s the problem when the waiting time has taken too long… it affects their schedule. Maybe the waiting time is an hour and the interpreter can’t stay because they have another appointment. So, it has happened occasionally… Also, overnight appointments, it’s hard to get an interpreter in an emergency in the evening. They used to have a contract with an agency but that finished. It means that usually in the evening there is no interpreter for A&E. Usually I have to ask a nurse or doctor to write notes for me… it’s usually fine and their attitude is good. But an interpreter is not always available in the evenings or bank holidays.

Mark: Have you ever had an interpreter leave you whilst you’re waiting for an appointment?

Foxy: Yes, that’s happened. So, I had an appointment at 2 o’clock which was delayed until about 2.30-3.00 and the interpreter said ‘Sorry, I have to go to another appointment that starts at 3.30-4.00 in another place, so I’m sorry but I have to go’. I just thought ‘You are booked with me though’…

Mark: So, what happened with that appointment?

Foxy: Usually, the interpreter asks to book another appointment, without my permission actually. They’ll ask if I’m available on another date, and I think ‘Oh, I have to come back on another date!’ I ask why can’t we carry on with pen and paper, but the interpreter has already made another appointment for me. That’s why I said I like to have the same interpreters

> who I know… if it's a new person then I'm a bit more wary of them." (Foxy, transliterated from BSL)

Foxy expanded on her views about needing full access 24/7 and how her experience of using A&E and GP services has varied, and this has affected her use of some services:

> "Foxy: … there is never an interpreter at the GP. They refuse to book one actually. They say, 'Who do I pay?' It makes it complicated… we never have one at the GP. We have a great relationship though and we have been going there for years. If they book me with a new GP, I ask to change to my regular GP who I know.
>
> Mark: What's your experience with A&E?
>
> Foxy: … very up and down. Sometimes it's great and they provide an interpreter, but now interpreters don't work evenings, bank holidays or weekends, so it becomes difficult. Life continues 24/7, but interpreters have their own lives and family etc. If it's during the week then it's easier as agencies are open Monday to Friday and if someone's available, they will come. But on evenings or weekends, it's rare.
>
> Mark: How does it make you feel, knowing that if you go on an evening or weekend, there's not going to be an interpreter there?
>
> Foxy: I'll always try and avoid going, but if the children are seriously ill then I will go, but make sure to remind them to write things down and question them as to what's happening next or how long it will take or what the treatment will be… My children are deaf as well. I have to make sure that I fully understand the information then I can explain it to them. It's a

> scary environment for kids, especially when they are ill and feeling rubbish. It's a big responsibility on me to have to explain to them what's going on. Or the doctor is questioning them. Means I have to question them and relay their answer to the doctor." (Foxy, transliterated from BSL)

Muriel faced an interesting situation where she did not want an interpreter and the doctors told her that she needed one because writing notes would take too long:

> "… this year, at the doctor's they told me I must have an interpreter, but I said I didn't want one. They tried to force me but I know my rights – I didn't want an interpreter. They said it will take too long writing notes back and forth. I said I didn't want it, I asked to make a double appointment and there would be plenty of time. I was adamant I didn't want an interpreter. I then received a letter saying that I've missed my appointment, but what appointment? They didn't give me an appointment – it's false, like I'm in trouble. I haven't received a letter confirming the appointment…" (Muriel, transliterated from BSL)

A few participants mentioned that their interpreters had left during operations and not been present when they woke up; this had a knock-on effect for understanding the medication as some participants found that the medication was explained to them after the operation. Marco provided a good example of this and explained that he would prefer to have the interpreter present for the full operation. This information was shared as part of the conversation about understanding medication when he left the hospital:

> "Not for the operation, from appointments when I've been ill, they've given me tablets and an interpreter was there, but when I had my operation there was an interpreter there prior to it… my question is where is the interpreter after the operation? It would be nice for the interpreter to stay

> until after the operation because that's when the nurses and doctors explain about medication… maybe they think we need the interpreter prior to the operation, when the doctor explains what's going to happen… But what if the operation went wrong? What if I had a bad reaction or had some side effects and needed an interpreter there? It's bad because my family were in the waiting room, but I can't ask them to translate because they are worried about my health and operation, they are not there to translate for me." (Marco, transliterated from BSL)

Foxy could also relate to Marco's experience regarding understanding the treatment or medication and not being given the full information. For example:

> Foxy: When they give me medication I think 'what's this for?' But they have given it to me so I take it anyway. I think it's natural to worry about it, but how should I respond? I don't always know what to do.
>
> Mark: Is that with an interpreter present?
>
> Foxy: Some appointments, yes. Not all of them. Especially when I got given medication for my anxiety, for example. I decided to just stop taking it because I felt better, but you aren't supposed to just stop straight away, you are meant to gradually reduce it, so I relapsed. My anxiety became worse and I went back to the doctor who told me I shouldn't have done it that way, but I didn't know as I hadn't been given the full information. (Foxy, transliterated from BSL)

Hedgehog spoke about a poor experience with an interpreter during an operation – the interpreter was unprofessional and then left during the operation:

> "…I had a tube put down my throat to my lungs. The interpreter was awful. They had no empathy; they were laughing and he left during my routine. I woke up and was dazed and confused and the interpreter wasn't there. I tried to pull the tube out of my nose and the doctor panicked, grabbed my hands and injected me with more anaesthetic to put me back to sleep. Then when I woke up, I wondered what had happened. Then I remembered the interpreter, he was a new interpreter, but awful behaviour… I reported him… they replied that he shouldn't have left and he shouldn't have laughed… the doctor thought the interpreter was staying throughout, they didn't know why the interpreter had left. They were booked for the full process, so the doctor wasn't happy." (Hedgehog, transliterated from BSL)

6.8 Deaf awareness – the good and the bad

One major theme within the findings was the deaf awareness of the medical profession; this is a complex theme and the findings show a mixture of good and bad awareness. This varied from doctors not knowing how to work with interpreters or the deaf participants having to explain things to medical personnel, to doctors being able to adjust to the needs of the participants without having interpreters present and managing to get through the situations.

Foxy provided a couple of interesting experiences; the first was when she was put in the situation explored previously in this chapter, where she had to bring her partner - who was not very proficient in sign language at the time - to come and interpret a medical appointment for her. When asked if the doctor said anything about the use of family interpreting, Foxy responded:

> "The doctor was clueless. I explained that she wasn't an interpreter and it's important that a qualified interpreter be provided, the same as she was

> a qualified doctor and had studied for her degree. It's the same with an interpreter, there is training and they are a professional… There was some jargon that my partner had no idea how to sign, so I had to ask the doctor to write it down so that I could see it and understand, to make sure I was getting the right information. It's lucky that I was aware of when my partner wasn't confident so that I could interrupt the doctor and ask for the information directly so that it was clearer. It's a shame the doctor was clueless as he was a lovely man, so when I explained about needing a qualified interpreter he understood why." (Foxy, transliterated from BSL)

Foxy also mentioned the positioning of the doctor and interpreter, and how doctors do not know how to work with an interpreter:

> "… When I go into an appointment, we have to move the chairs around, and the doctor asks why. I like to see both the doctor and interpreter when telling me information, not to have the interpreter to one side. So, I have to use some of the time explaining that, and how to work with an interpreter – seeing them speak and the interpreter signs – and also the doctor speaks directly to me and isn't saying 'Tell her… tell her'. So, that can mean time is extended. I would like to arrive, get the information then leave, but it doesn't work that way for various reasons… they have a positive attitude which is lovely… but awareness is different!" (Foxy, transliterated from BSL)

Foxy also gave an example of where she was going through childbirth and she did not have an interpreter with her; she had a traumatic labour and needed to have an emergency caesarean, so she was in quite a lot of pain and was quite destressed. Foxy needed to sign a consent form but could not understand what was happening and the doctor actually showed some good awareness in this situation. Foxy explained:

> “It was horrendous. I needed an emergency caesarean and they were asking me the questions but I couldn’t hear them through the pain, I closed my eyes but the doctor carried on talking to me… in the end I just signed it because I couldn’t be bothered with the discussion any more. It was a difficult situation, I was stressed, so just signed it… I couldn’t be bothered trying to understand what they were telling me, so I told them to just give me the form and signed it. It would have been different if there was an interpreter there as it would have been calm and easy going, but I was stressed and in pain. There were numerous people going in and out of the room… there were too many people in the room, meaning the communication was not easy… at one point the doctor told everyone else to leave the room so I could calm down and we could sit face-to-face as he knew it was hard for me to understand. So, I just took it and signed it.”
> (Foxy, transliterated from BSL)

Muriel gave examples of times when she had experienced poor awareness when she was in hospital and did not have her partner with her (as explained previously in this chapter) and therefore, Muriel relied on writing notes:

> “… I didn’t know when the doctors were going to come and see me, and I didn’t know when they were going to want to talk to me, so I couldn’t ask for an interpreter 24/7. So, I relied on written notes. I have got a hearing aid which I take off when I need a rest. A nurse came over to me and started talking at me. I asked her to hold on and put my hearing aid in and she asked why I don’t wear it all the time. I said ‘this is for my ease, not yours’. She was shocked and I took it back out again. She walked away and I went back to resting. She had seen me writing notes with other

> people, I don't know why she talked at me." (Muriel, transliterated from BSL)

Another example of the variation in awareness was shown when Muriel had an interpreter with her, but a nurse claimed that the interpreter was not allowed in with her. However, the nurse that was in charge saw what was happening and stepped in:

> "I had a qualified interpreter, the nurse told me the interpreter wasn't allowed to come with me for a blood test. I said 'She can come with me, I know the process'… the boss then said 'She's allowed, come on' and ignored the nurse who became busy looking through my notes." (Muriel, transliterated from BSL)

Emma claimed that she normally had a good experience in hospital, although she found that sometimes there can be a slight issue with certain things, such as doctors calling her name. For example:

> "… I had to tell them straight away that I was deaf and needed to lip-read them… when I had to stay in hospital for 2-3 nights after giving birth, lots of different people coming up to me and I straight away informed them, 'I'm deaf and I need to lip-read' and they would look at me and I would lip-read… which is perfect! However, some people after I told them would look all around and not at me and I would have to remind them that I was deaf." (Emma, transliterated from BSL)

Hedgehog gave an exceptional example of good deaf awareness and what can happen when a doctor takes the time to explain things:

> "Once, when there was no interpreter… the appointment that I went for was for an operation and the doctor wasn't sure what to do because there was no interpreter, he wasn't sure if we should go ahead with the operation or not. So we sat down and tried communicating without an interpreter, and it was lucky that I could lip-read him and he was young, which was good because most doctors are old… we had a chat and he was happy that I understood, but I didn't realise that he had told me that I possibly had cancer as I had cells there. I was shocked and then was told that they were found after the second CT scan. That's why I was shocked because I wasn't expecting that and there was no interpreter there…" (Hedgehog, transliterated from BSL)

Hedgehog explained his personal view about this situation:

> "I'm pleased with that doctor; he did make sure I fully understood what he was talking about which was a good thing. He told me that if I didn't understand then we would re-arrange the appointment with an interpreter. But we were lucky, and he seemed confident that I understood so we decided to carry on. It was then that he told me I had a 50% chance of cancer, so I understood why. He made sure I understood… we were a similar age… if he was older, who knows. Normally, older doctors waffle on and go into depth and use words that I wouldn't get, but he used simple and clear English so I could understand. I liked that. I'm grateful he decided to tell me rather than delay the operation, that's why he told me so we could agree that I needed the operation. And he said next week and I was shocked but I thought I was lucky really!" (Hedgehog, transliterated from BSL)

Hedgehog explained how the doctor communicated visually with him during this appointment:

> "There was writing and pointing at the body to make sure I understood visually. There was writing like drawing and words such as benign or malignant, cancer and tumour, borderline then the other illnesses… and it was clear through the picture what they were explaining to me. I knew why they wanted the operation. It was good and visual to make sure I understood. It wasn't a lot of drivel. It was useful to show the body and where they were going to operate and go past my heart… the visual explanation was good!" (Hedgehog, transliterated from BSL)

6.9 Chapter Summary

This chapter has presented the interviews through the lived experiences of the deaf participants who have needed to access the National Health Service for health reasons by going to the hospital or to see their local GP. This chapter explored the issues and barriers that deaf people faced when needing to communicate with healthcare professionals. This chapter also highlighted the common themes from the participants and even though each participant was in a different situation, the access and communication issues still presented as common themes for deaf people. The common themes mostly revolved around the use of qualified interpreters. In previous research (Chapter Two), the issue around interpreters and communication was also highlighted.

Some new common themes were identified, such as the need for professionalism from doctors and the clear issues around access, especially at unsociable hours. There was also a clear establishment for the need for qualified interpreters, and an insight into the dangers of using trainee interpreters or family and friends; these common themes will be further discussed in the critical analysis chapter (Chapter Eight).

Chapter 7. Deaf people as healthcare users: Paramedic experiences

This chapter will explore the lived experiences of paramedics who have treated patients who are deaf or deaf BSL users. The findings presented in this chapter are based on semi-structured interviews with questions that set out to gain an understanding of how paramedics communicated with deaf people.

The previous chapter explored the deaf participants' experiences and concerns about the adjustments being made, and the communication issues between deaf people and medical personnel. This chapter will explore the paramedics views on how they adjusted and what they used, or did, when they treated deaf people. The reason for this is to explore the adjustments between the two groups of participants to gain an understanding of the full picture. For example, many of the deaf organisations that have put forward papers have exclaimed that BSL interpreters are needed in hospitals and GP surgeries.

This chapter will explore a different perspective by investigating the paramedics experiences of communicating with deaf patients. This chapter is not intended to argue the differences between how paramedics and deaf participants communicated but instead, this chapter will explore what they thought they needed to communicate and the common themes between the paramedics' experiences.

When interviewing the paramedics, they told their story from the moment they got the job through on the ambulance to the moment they dropped the patient off at the hospital. Most of the interviewees talked about deaf BSL users and how the paramedics found the experience of communicating with someone who did not communicate orally. As the interviews were semi-structured, the conversation did not just stick to what the paramedics did, but how they felt when communicating and what they thought they needed (if anything) to help them in the future. Some of the interviewees also talked about people who are hard of hearing and how they communicated, and two interviewees talked about communication between the paramedics and a deafblind person.

This study interviewed five participants who were all ambulance staff, either paramedics or emergency medical technicians. The qualifications of the ambulance staff did not make much difference in this study as the clinical side of the phenomenon was not explored; it did not matter what was wrong with the deaf patient, but what was important was how they communicated. I recognise that there is a medical skill difference between a paramedic and an emergency medical technician, however, for the purpose of this study I will refer to all staff participants as paramedics to minimise any confusion.

The five participants were:

Participant 1: Paolo – Paramedic (9 years, and 3 years as an Emergency Medical Technician)
Participant 2: Fred - Senior Paramedic (4 years)
Participant 3: Christy – Emergency Medical Technician (8 years)
Participant 4: Bart – Emergency Medical Technician (15 years)
Participant 5: Margaret - Emergency Medical Technician/Student Paramedic (3 ½ years)

Table 4: Healthcare Professional participants

7.1 The overall feeling of communication

At the start of each interview, after the formalities of job titles and how long they had been doing the job, the first real question in relation to the phenomenon was: "How did you find the communication?" This allowed the participants to explore how they felt about the whole experience and their responses varied depending on a number of different factors, which included the resources that were available to them (this will be explored later on in the chapter) and also, the previous experience of the participants.

Paolo, who had vast experience of being with deaf people and other people who cannot speak the same language as him, found that he did not really have any problems as the resources that he had were enough for him to be able to communicate effectively:

> "No it was fine… but I'm used to it because being deaf is very similar to not being able to speak English if that makes sense, I mean we probably see… out of 10 patients that we see in a shift around 2-3 probably don't speak any English… so having communication problems for us in London isn't really… well, [firstly] it's not massively common, [secondly] it's not that much of an issue because we have learnt other ways to work around it." (Paolo, transcribed from English)

However, both Christy and Bart had more of a negative response with both finding their experiences 'frustrating' and 'awkward'. This was particularly interesting as both Christy and Bart had a small understanding of very basic sign language. Christy said that he "…can do basic Makaton and sort of finger sign A/E/I/O/U" (Christy, transcribed from English) and Bart stated that he had "…very basic sign language from a long time ago" (Bart). Both paramedics did not make reference to using these during the rest of the interview and even though they did have a little experience in sign language, it was not enough for them to be able to communicate effectively so they did not use it.

Fred and Margaret had a slightly different experience to the others as they had both treated a deafblind person and when asked how they found the communication, both said that they were "scared" and "worried" (Fred & Margaret, transcribed from English). However, this situation was totally different as the deafblind patient did not communicate using manual sign language but instead communicated using Tadoma, which is where "the hand of the deaf-blind receiver is placed over the face and neck of the talker such that the thumb rests lightly on the lips and the fingers fan out over the cheek and neck" (Reed, 1996:1)

7.2 The importance of being able to communicate

Many of the participants referred to the importance of being able to communicate either directly or indirectly. Although all the participants said they got through the communication barrier, many of them mentioned the importance of it. Christy made reference to the importance of being able to get the history of the patient:

> "Trying to get the history was the most important, erm, history of events because you know... exactly where the pain is, what type of pain or what has happened and things like that can be difficult". (Christy, transcribed from English)

Bart talked about a lack of language proficiency and not being able to communicate, and that "delayed patient care is the biggest one, misunderstanding and potentially mistakes… If I miss interpret something or you miss interpret something as you might then that can lead to mistakes being made". Following this, Bart provided an example of a situation that had been misinterpreted:

> "…we thought we had a patient's consent once and we went to cannulate and the patient withdrew his arm because he didn't know what we were doing, so we thought we communicated it well and we hadn't, but in the end it all worked out fine, once he knew what we were doing." (Bart, transcribed from English)

Bart also provided an example of another situation when he could not communicate fully and found it difficult to get the full information:

> "… they are able to communicate with us pretty well and explain what is wrong, the actual problem comes when we are trying to get more in-depth

> information, because obviously we can't do that, they can tell us what is initially wrong but if I wanted to ask 'how long has this pain been going on for?' What we tend to do is point at our watch and some people get that and some people don't, some people think I'm in a hurry. So, we have got to be very careful. Two of the people I went to were in homes where they were being looked after, actually had a sign language person with them which did make it quite handy. But during the initial phase while we were waiting for them it was a bit tricky to get the information." (Bart, transcribed from English)

Fred and Margaret had a different experience with the deafblind patient. As the deafblind patient could adjust, and her way of communicating was very unique, they did not actually find a problem with communicating with her - this will be explored later in this chapter. However, when asked how they might have felt if the deafblind patient could not have communicated using Tadoma, Margaret replied:

> "…worried because I wouldn't know how she felt or anything… I wouldn't have been able to reassure her in anyway or make her feel safe or easier… I wouldn't have been able to ask what was wrong with her… it would have been up to her to point if there was any pain." (Margaret, transcribed from English)

7.3 Adjustments made and how communication was made possible

Each participant provided an interesting response about how they communicated with their patients. All of the participants made reference to how it would be practically impossible to have an interpreter present on the ambulance. This section will explore the thoughts and issues that the paramedics faced, and what they did to remove the barriers to communication.

Bart made an interesting statement regarding communication and how he got around it:

> "Well he was trying to communicate via sign language… the communication side of it was quite difficult because I think they were getting a little frustrated in the fact that neither me or my colleague really understood what they were saying, and when you're in the back of the ambulance you don't really want to hand them a pen and paper… so we were trying to communicate… he had pain somewhere and what we were trying to find out from him was whether the pain was in his chest or in his lower back, or how was the pain and stuff like that, and we were pointing to his chest saying where's the pain but he wasn't understanding what we were saying." (Bart, transcribed from English)

Finding ways of communicating is very important and Bart explained how he communicated with his patient without an interpreter:

> "It was a case of trial and error, so we would… for example if I was trying to suggest to you where is the pain? I would say something like… or point to the chest and then he would get a bit confused because he would think I was going on about breathing, and from there we would say a band [with a gesture around the chest indicating a tight band constricting the chest which affects breathing] and from there he knew exactly what we meant and he said no. So, it was trial and error with regard to communication, so… erm he was able to do some lip-reading as well so if we slowed our speech down, he was able to communicate quite well because he could lip-read." (Bart, transcribed from English)

Bart also made reference to a phrase book that he had available to use:

> “We had a phrase book… we got the common things put down, it’s all in multiple languages, so: ‘Have you got pain anywhere?’, ‘Are you short of breath?’, ‘How long has this been going on for?’ So, we do have these books but they are really old and ancient unfortunately, and the last one I used had two pages missing where it’s all been ripped to bits”. (Bart, transcribed from English)

The books did not have any sign language in them, but Bart stated that they still had the written phrases that people could look at. However, Bart did not really like to use them as, to him, it did not feel like good practice: “I mean, I suppose from there you have got the phrase but again, getting a book out and pointing at a phrase isn’t best practice.” (Bart)

Christy had a slightly different experience depending on whether the patient was a deaf BSL user or if they were hard of hearing.

> “It’s the same frustrations all the time, not so much with the hard of hearing but with the totally deaf person, I found it quite frustrating because obviously, a lot of them are deaf they are unable to talk at the same time so trying to get the information from them is really hard”. (Christy, transcribed from English)

When asked how Christy got around this communication issue, Christy came up with a number of different answers. The first was to use sign language cards that are in the ambulances, when asked if they were helpful Christy replied:

> “Quite helpful yes, they were helpful, they gave you basic sign language that you could use towards the patient like where’s the pain, shoulder

> shrugging and things like that, it was quite helpful." (Christy, transcribed from English)

Unfortunately, the cards that Christy was referring to "had gone missing a long time ago and they have never been replaced". (Christy, transcribed from English)

The second communication method that Christy mentioned was using pen and paper. Chapter Two highlighted the issue with using reading and writing as a communication method, however, Christy explained that this was not a problem:

> Mark: Do you feel like when you wrote it down on a piece of paper they understood?
>
> Christy: They did because they could see it. You write the question 'where is the pain' and they just write back what it is.
>
> Mark: So do you put it down quite simply?
>
> Christy: Oh I use plain English. I'm a great believer in plain English, I don't use technical terms, or anything else like that. (Christy, transcribed from English)

Although Christy did not have a problem with using pen and paper, he explained that the piece of paper was not big enough and that "passing it backwards and forwards all the time… takes far too long". (Christy, transcribed from English)

Paolo had a similar experience to Christy as he either used a communication/picture booklet, pen and paper, or there was a family member who could interpret for him. Paolo also said that he used gestures, such as pointing, alongside the booklet and paper. When asked to explain the booklet, Paolo stated: "So, it's a booklet that we produced along with a deaf charity or a deaf association… well we worked with them and it's basically a book of pictures that we can point to." (Paolo, transcribed from English) Paolo then explained that in the district where he works, "every operational member of staff is given one." (Paolo, transcribed from English) Paolo was also asked about the use of pen and paper and he explained: "It was fine, they didn't seem to mind, they were quite happy to write stuff on it." (Paolo, transcribed from English)

Fred and Margaret also made reference to having access to a picture booklet; Fred explained that the communication books have the "BSL alphabet" and "pictures" (Fred) that they can use to show patients, and Margaret explained that the books had "pictures" (Margaret) that both parties can point at. However, when they were treating the deafblind person, the picture booklet was pointless, although it is available to use with a deaf BSL user or someone that was deaf.

7.4 Using family members as interpreters

The use of family members as interpreters cannot be ignored, as we know from previous literature that this is not ideal due to family members changing what has actually been said (for example, Chapters Two and Six). Paolo made reference to the use of family members acting as interpreters and when asked if he had any concerns about this, Paolo said that he did not. When the interviewer explained that there had been occasions when a family member had been left in an awkward situation or that a family member had changed the story, and the participant was then asked whether or not this concerned him, Paolo explained: "…erm… a little bit but there isn't much more we can do… really… to be fair, when we are out on an ambulance, so you know I don't think anyone's changed it. To me, it's exactly the same when we go to someone who doesn't speak English and we have to get someone who translates." (Paolo, transcribed from English)

However, if the situation is an emergency, Paolo stated that having a family or friend to interpret is okay until the qualified interpreter arrives, as hospitals cannot have interpreters onsite at the hospital all the time:

> Paolo: Hmm, I think it's fine to start with while the hospital are trying to arrange an interpreter.
>
> Mark: So, emergency settings?
>
> Paolo: Yeah absolutely, a hospital can't have an interpreter 24/7 so I think family and friends to interpret if it is appropriate whilst they are waiting for the interpreter to arrive, otherwise you're just delaying the patient's treatment.
>
> Mark: Do you think that a hospital should have an interpreter on call?
>
> Paolo: No… it would be very expensive and I would imagine that the amount of patients that use sign language that come through the door in the emergency department, where it is unplanned, is a very small number of patients… don't get me wrong, they should have a contact or someone they can contact to arrange an interpreter but I don't think they need to have one on call or onsite 24/7. (Paolo, transcribed from English)

Clearly, here, Paolo is unaware that expense should not necessarily be the arbiter of providing a reasonable adjustment. It is not unusual, however, for financial considerations to loom large in NHS decisions for allocating resources, regardless of equalities impact, and this may have influenced the response. There is the further complication here of perceived practicalities of providing an on-tap adjustment in the context of emergency or unplanned care. These issues are returned to in chapter nine

Bart was also asked if he had been in a situation where a family or friend had to interpret:

> "Erm, well, we trusted them because we just had to take their word for it, so it's not a lot… really, else that we could do. What they were saying seems to add up and they were signing back and forth to each other so I assume they understood what was going on." (Bart, transcribed from English)

Fred has never been in a situation where a family or friend had interpreted for the patient, however, he gave his views about using family or friends as interpreters:

> "If we have got no choice then we have got to do it, because it's the best of the situation that we have got especially in this job. When it is emergency care we potentially don't have much time to mess around, erm… yeah, we would just have to trust what they say and do it and just go off what we can and we would have to read the expression of the patient as well. If we started doing something that they don't want done, but we have been told they do want it done, then we would have to look at how they are reacting to us." (Fred, transcribed from English)

Margaret provided an interesting view on the use of family and friends as interpreters, although she had no experience of being in that situation:

> "…erm, no because you can only do the best you can really and we can only go on by the people that know her… if you couldn't communicate with her any better you would have to take what everyone else says as gospel.

> I probably wouldn’t have left her at home or anything like that because I wouldn’t have gotten a clear story… she would have always gone into hospital because I wouldn’t have understood completely what was wrong with her.” (Margaret, transcribed from English)

Although Margaret did say that she would have to take what everyone says as “gospel”, she later stated that she would still be wary of other people communicating:

> “You always have to be a bit wary of that because they might be communicating something that the patient doesn’t wish. I’ve been in situations like that with verbal language barriers but never with communication like that, and dementia patients I suppose… but you can’t fully believe the relatives just in case they are… well, lying really.” (Margaret, transcribed from English)

Christy gave an interesting response when asked how he felt about family and friends being used as interpreters:

> “I think it’s really good on scene… for ourselves and that they are telling us everything or that we believe that they are telling us everything, the only bit is communication back, are they actually telling… are they actually giving the right information back to that patient? We don’t know and we have got no way of knowing because it’s done so fast.” (Christy, transcribed from English)

Christy was then asked if it worried him, and he replied:

> “Not really no, or it never has done, but then again I’ve never been in a sensitive situation where I’ve had to be worried.” (Christy, transcribed from English)

7.5 Contacting the hospital/requesting for interpreters at the hospital

As shown above, Bart explained that a lack of language proficiency can delay patient care and potentially cause mistakes. We know that it is practically impossible to have an interpreter on the scene with the ambulance crews, but once the initial assessments or treatments have been conducted, I was interested to find out whether or not the paramedics called ahead to inform the hospital that their patient was deaf.

Bart explained that they would only phone ahead if it was urgent:

> "Only if it is urgent, if it's not life threatening then we won't do that, we have a policy in place that… what we call a red call and that would be when we pre-alert the hospital to a situation and we would say 'by the way this person is deaf' but other than that we wouldn't pre-alert them at all no." (Bart, transcribed from English)

Similarly, Fred and Margaret both said that they did not contact the hospital as they were not rushing their deafblind patient into hospital. Margaret reiterated what Bart said by only phoning ahead when it is an emergency:

> "No, I don't believe I did no… I don't believe we were rushing her in… it was quite a while ago, but I don't think we were rushing her into hospital so I didn't let anyone know." (Margaret, transcribed from English)

Paolo also agreed with Fred, Margaret and Bart, and stated that they only phone the hospital if the patient is really ill; on this occasion, Paolo did phone ahead because "…they were very poorly" and "…when we did the pre-alert to say that they were coming in we told them that the patient was deaf." When asked where that call would have gone to, Paolo stated "…that would have gone to our control, who would have passed it to the hospital via telephone." (Paolo, transcribed from English)

During the interview, an interesting part of a conversation related to the point at which an interpreter would be available, which is related to why paramedics cannot always phone ahead to the hospital. For example:

> Paolo: "…we don't always tell the hospital that we are always coming, they only know we are coming if we have a really ill patient, but apart from that we just turn up so they wouldn't know."
>
> Mark: "Could you phone ahead?"
>
> Paolo: "We can't… we deal with 5000 calls a day, so we only phoned with this patient because they were really ill." (Paolo, transcribed from English)

Christy, on the other hand, had a completely different experience as he stated:

> "Oh yeah, I try and let the hospital know… 9 times out of 10 though when we have rung the hospital, they have done nothing anyway, so now I will admit we just don't let them know. Now we just wait until we get there." (Christy, transcribed from English)

Christy explained his frustrations after contacting the hospital and telling them that they need somebody there, but nothing was done about it:

> Christy: "… we told the hospital that this person, needs… you know, this person is deaf and we will need somebody there and nothing has been done about it."

> Mark: “How does it make you feel?”
>
> Christy: “Annoyed.”
>
> Mark: “Why?”
>
> Christy: “Well, because it’s that person’s only way of communication, there is so much missing from it and every person deserves that right. I mean that all the foreign language students have got a telephone and you know a deaf person has nothing. Yeah, it’s annoying but… I suppose it’s the way we have got used to living in the past and until somebody does something about it nothing gets done.” (Christy, transcribed from English)

Although, as mentioned above, Fred said that on this occasion he did not contact the hospital to let them know he was coming in with a deafblind lady, he explained later on that if the deafblind lady had not been able to communicate via Tadoma, it might have changed his approach to informing the hospital as he would have no means of being able to communicate with her. The following extract highlights this point:

> Fred: “Yeah…erm… well, if we didn’t have an interpreter and she couldn’t communicate like she did, we would have been very stuck. We would have just had to do our best for her and hope that we just aren’t going against her wishes or anything like that.”
>
> Mark: “Would you have contacted anyone on the way if you couldn’t communicate with her?”

> Fred: “I would have done in that situation yes, if we knew we were going to need someone quickly because there is no other way of communicating with this person then I would have done.” (Fred, transcribed from English)

7.6 Timescales for having an interpreter present

After exploring whether or not Ambulance crews phoned ahead to the hospital, the next interview question explored when the medical professionals felt like it was possible to get an interpreter and more importantly, if they thought it was important for a qualified interpreter to be present. Christy talked about the frustration of not having an interpreter at the hospital and although he acknowledged that it was practically impossible for them to have one, he still talked about why this was frustrating. For example:

> “It’s frustrating because the patient likes to hear what you’re handing over because it’s about them, and it’s handy if there was one there but there has never ever been one there and I don’t think they would have, and I don’t think they would have got them there anyway, I don’t know.” (Christy, transcribed from English)

Following this, Christy explained the importance of the handover:

> “I think it’s very important that they know what’s going on, because I believe in open honesty, so if I’m telling a nurse something, I want them to know what I’m telling the nurse, because if I’ve got it wrong they want to be able to interject with that conversation and say ‘no that’s not what has happened, the pain is in me left leg and not my right leg’. So, it is important.” (Christy, transcribed from English)

Christy was then asked if he wanted to have an interpreter present at the handover and he responded:

> "Oh yes, especially at the handover… because that is how mistakes happen as well, we take them in for shortness of breathing and tell them it's shortness of breathing but they are getting chest pain… do you know what I mean? So, because they are left with such a long time without an interpreter, they can't get it over all the time because they can't always shout chest pain, so they just sit there quietly." (Christy, transcribed from English)

Bart agreed with Christy that an interpreter at the handover stage would be preferable:

> "I would say handover simply because if we are communicating to them it's important, well, in case we have missed something, it would be a chance for me to say to the interpreter… well, the interpreter can actually listen to me and sign to the person, what I'm handing over so if I've missed something, say their allergies, they can do that." (Bart, transcribed from English)

Paolo had a different view on when he thought it was most appropriate for a sign language interpreter to be present: "…within a reasonable timeframe at the hospital, I don't think we could do it pre-hospital." (Paolo, transcribed from English)

When asked for specifics on a reasonable timeframe for an interpreter to be present, the idea of an interpreter at the handover was suggested; Paolo replied to this suggestion "no, beyond handover… because we don't always tell the hospital that we are always coming, they only know we are coming if we have a really ill patient, but apart from that we just turn up so they wouldn't know." (Paolo, transcribed from English) Paolo carried on to explain that the reasonable timescale for an interpreter to be present would depend on the region:

> "… within 2 hours… I mean you are in London but I suppose it's different to where you are in the country… I mean you could say you could go down to within the hour but you have to factor them actually getting in… but in other places in the country you could be 2 hours away from the hospital".
> (Paolo, transcribed from English)

Fred and Margaret struggled to answer this question as they both have no experience of using an interpreter as their deafblind patient could communicate with them using Tadoma. However, Fred commented: "erm, the earliest you would be looking at is in hospital, whether there would be one when we arrived I'd doubtful, they would have to get one in but I can't… I wouldn't be able to say for certain as I've never had to go down that route." (Fred, transcribed from English)

7.7 Video remote interpreters

Some of the participants talked about the use of Video Relay Interpreters (VRI) which is where a sign language interpreter is used over the internet through a video call such as Skype or FaceTime, instead of an interpreter being present. The use of VRI has been researched and although VRI has been shown not to be the best practice because of a variety of different issues, such as poor internet connection or poor video quality (Collinson, 2018; Napier et al. 2017; Lee 2020), it might be appropriate as a last resort for ambulance crews who cannot access a BSL interpreter when they need to. Paolo already knew a little about the use of VRIs, as shown in the following comments:

> Paolo: "Well, we are looking at getting that because we have iPads now so we can do it via Skype… I know that 111 so quite a lot of… well, are using next generation technology relay and then they are going to be looking at the BSL phone service, which they use at 111."

> Mark: "Do you have WIFI on the ambulances then?"
>
> Paolo: "No, but we do have our iPads which have 3G and 4G." (Paolo, transcribed from English)

Christy also commented on the use of VRI and said that if it was available, he would use it:

> "Oh definitely yes! Well, we have got computers on the vehicles that have got internet access, and we could open up Internet Explorer and we could use something like that… that would be really good." (Christy, transcribed from English)

7.8 Qualified Interpreters

Previous literature (see Chapter Two) shows that a number of unqualified interpreters have interpreted for deaf patients at hospitals. I have explored the use of family and friends as interpreters from the HCP's point of view and although most HCPs used the family and friends, they were sceptical about doing this and only did it because they did not have a choice, as it would have been impossible to get an interpreter before they left the scene. The findings of this research suggest that the use of qualified interpreters actually depends on the situation. For example, Bart suggests:

> "I would say, that they wouldn't necessarily need to be qualified, I think that it's anybody that is able to help us out in a little bit of a difficult situation, I wouldn't say that they need to be qualified, I mean qualified is great but say, for example, if I was to have a bit of a course or one of my colleague had a course that would be enough to just have the basic and once we get into hospital we can get the real nitty gritty sorted out." (Bart, transcribed from English)

However, Bart said once they get to hospital, they "should definitely have a professional interpreter" (Bart, transcribed from English). Bart explained his thoughts about when he dropped a patient off at the hospital who had a friend with him to interpret:

> "I think it's a little unprofessional, isn't it. I mean, it's a case of we should have support there and if their friend wasn't there to interpret for them… because their friend is now stuck there really, I mean over a three hour wait for an interpreter? I mean I don't know how long it took but I would have thought, you know two hours max to get to where they needed to be, but three hours is ridiculous… and also what right does that friend have to know about that person's medical condition?" (Bart, transcribed from English)

Paolo agreed with this as he did not think it would be viable to have an interpreter pre-hospital as they are on "average anything between 20 mins – 1 hour on scene" (Paolo, transcribed from English). When asked if he thought a qualified or trainee interpreter should be used at the hospital, Paolo stated: "Oh, definitely a qualified interpreter" (Paolo, transcribed from English). In addition, Paolo was then asked if he thought there should be an interpreter at the hospital or if he thought the hospital can deal without an interpreter and he replied: "No, I think they should have an interpreter at the hospital, well, if the patient wants one." (Paolo, transcribed from English)

Christy also gave his thoughts on the use of qualified interpreters and stated:

> "Well you have got to be proficient in what you're doing, haven't you. You have got to be able to explain the technical stuff, it's no good somebody just talking about… that has the knowledge of toys and hobby craft telling you that you're… you have cancer and things like that." (Christy, transcribed from English)

Christy also agreed with Bart and brought up the fact about professionalism and confidentiality:

> "Oh yes, an actual qualified interpreter, because I think that professionalism as well, and that, you know, an ordinary lay person might not have the sense of data protection, working under the Caldicott principle and everything else, and isn't as trustworthy, if that makes sense. Whereas if they know this person is qualified, then they know that they can be open with that person". (Christy, transcribed from English)

Fred had a slightly different view about the use of qualified interpreters:

> "Erm, I think dealing with jobs that we deal with, it would be gold standard to have a fully trained, fully qualified, fully competent interpreter. However, given the number of calls that we go to and some would be deafblind, I would think that a trainee interpreter would probably be suffice, with the risk of being a bit broken but I think we would get by."
> (Fred, transcribed from English)

Margaret also agreed with Fred; when asked if Margaret would be happy with a trainee or fully qualified interpreter, she replied: "Erm, I wouldn't mind… I mean the trainee is going to do a better job than what I would do… if they know enough then it's fine." (Margaret, transcribed from English)

7.9 Preparation before going to the job and do they know they are going to a deaf patient?

The paramedics were asked if they knew they were going to a deaf BSL user when they received the job. Both Fred and Margaret did not know that they were going to the deafblind lady. Interestingly, Fred stated that he did not know and he was also not the first person on scene, so the first paramedic told him how the deafblind lady communicated:

> “So, it was actually the first paramedic that was on scene, as there was a car already there, who then told us when we arrived, who was told by the care staff that this is how she communicates and this is the way to do it.” (Fred, transcribed from English)

Bart also explained that he does not get told that they will be going to a deaf patient. However, Bart explained what happened when a deaf person makes a call:

> “No, because what usually happens, if a deaf person makes a call it comes through on our system as a silent caller and that’s not to mean that they… well, it means they won’t respond to questions because they are not going to know that somebody is speaking to them, so we get that but the ambulance service has got what’s called… erm… type-talk or something? But we won’t get specific information saying that someone is deaf and we won’t know that until we turn up.” (Bart, transcribed from English)

Christy also stated that he did not know when he gets given a job with a deaf patient;

> “No, we never know… I know they do have these text phones that they use but that information is never passed onto us.” (Christy, transcribed from English)

I wanted to explore whether or not the paramedics knew that they were going to a deaf patient for two reasons: the first reason was to see how early the paramedics knew that they were going to treat a deaf patient; and the second reason was to see if they were able to prepare whilst on the way to the deaf patient. As previously explored in this section, most of the participants did not know that they were going to treat deaf patients, however, they still gave an account on what they would do if they knew.

Paolo had a different experience as he was told that he was going to treat a deaf BSL user and this is how he found out:

> "…EMD (Emergency medical dispatcher) puts it on the call log, so it comes down to the MDT (Mobile data terminal)" (Paolo, transcribed from English).

As a result of this process, Paolo could prepare by having his booklet with him, which he just grabbed from his bag.

Christy stated that he never knows that he is going to a deaf patient, however, when asked if he would be able to prepare beforehand, Christy stated:

> "We could prep, erm… we used to have sign language cards but they had gone missing a long time ago and they have never been replaced, and you could prepare yourself by getting one of the out your bag ready and look up things really." (Christy, transcribed from English)

Earlier, Bart talked about getting the information through and said that it would be useful to know that they were going to a deaf patient:

> "Yeah, it would be handy because we could go prepared with your phrase book and you're not caught out, and you have time to think about how you are going to ask questions and stuff like that. So, it would definitely be handy." (Bart, transcribed from English)

7.10 The training needs of paramedics

Fred and Margaret did not really talk about preparation, although they both gave accounts of the picture books that we explored earlier in this chapter. However, Fred mentioned that although they have communication books, and it went fine when he treated the deafblind person who communicated via Tadoma, if the situation had been different and the deafblind lady could not communicate in this way, then "this is just one of the situations we are just not geared up to deal with at all." (Fred, transcribed from English) Fred also talked about the fact that they do not receive any formal training, however, Fred thinks that having an awareness would be beneficial: "Yeah absolutely, it would be good to at least have an awareness of it and know what is out there. I mean I didn't know that manual sign language was actually a thing." (Fred, transcribed from English)

An interesting finding during Fred's interview was the need for more guidance to support him and other crews that are out on the ambulances:

> Mark: "So, do you feel like it would be nice to know what the procedure is when you come across something a bit more complicated? Like the deafblind lady?"
>
> Fred: "Yeah and the support available to us, as crews."
>
> Mark: "It seems like it's being made up/adapted as you go along?"
>
> Fred: "Yeah that's pretty much what we have to do." (Fred, transcribed from English)

Fred also stated that if they had training or more awareness, they might be more prepared for when they actually arrive at the job. For example, with his experience of treating the deafblind person, Fred stated:

> “We do minimal training on talking to people that are deaf/deafblind and usually we get given little communication books; so it has your BSL alphabet and it has pictures for pointing things out, but we were never prepared to have someone hold onto our throats, and it almost felt a bit risky even though she was mid 80s, it did feel a little bit risky letting someone actually grab hold of your voice box. She was in a care home and they know very well what she is like and were very supportive of us doing it.” (Fred, transcribed from English)

Fred provided a very interesting explanation about what he considers to be a ‘reasonable adjustment’, which was based on his experience of treating the deafblind lady and his concerns about not having any way to communicate without relying on someone else:

> “Hmmm… a reasonable adjustment would probably be… awareness for crews and probably an extra section in our communication book for deaf and blind… at the moment I would be able to muddle through someone that is deaf if we didn’t have an interpreter… I would be able to muddle through someone that is blind, chances are they would be able to talk anyway, and we can just about muddle through if they don’t speak the same language, but if they are deaf and blind and we haven’t got an interpreter then we wouldn’t have anything at all…” (Fred, transcribed from English)

Margaret gave an interesting account of what she feels she needs to help her with treating deaf or deafblind people. Similar to Fred, Margaret did not get any training on situations like this and when asked if she thought she would benefit from having some training, Margaret replied:

> "It would depend on what sort of stuff they taught you, even if we had a basic knowledge of some hand communication that would be better than nothing… even if it was the basic, like pain or something… you know totally basic words would probably be very helpful." (Margaret, transcribed from English)

When asked if she thought having any deaf awareness would have helped the situation, Margaret stated: "Yeah, probably, because it does make you realise a bit more with what's involved." (Margaret, transcribed from English). Margaret gave accounts of where the awareness would have been particularly helpful when treating patients who can lip-read:

> Mark: **"**So, the communication with people who lip-read, how did you find the communication with them?"
>
> Margaret: "Erm, okay… it's remembering not to turn your back on them and they can't hear you if you're looking down to the floor. So, it's remembering to have eye contact with them the whole time."
>
> Mark: "So, it's the awareness?"
>
> Margaret: "Yeah, it's being aware of it all the time because you do forget, because it's not all the time that we come across someone that's not easily able to communicate with you properly." (Margaret, transcribed from English)

When asked how equipped she felt to deal with BSL users, or any sort of situation where there is a need for translation or interpreting, Margaret replied:

> "Hmmm not really, a book doesn't really cover it for me… but then we don't come across it that much… because then it would cause much more of a problem than what it does… and a lot of people learn to cope with it if they are deaf or blind, they tend to learn to live with it and they find ways round it so they can communicate with you… I suppose it's more of the older generation that you might not because they don't have the techniques." (Margaret, transcribed from English)

Although Margaret found that others can adjust to help communication between the two, she also shared concerns when she cannot fully communicate with someone:

> "…I could be missing something clinical… could also be something as simple as where the pain is, you know… it could mean a lot more things from just where the pain is on someone if they can't properly communicate or I can't communicate with them… you know I could miss something quite badly I suppose." (Margaret, transcribed from English)

Margaret felt that this kind of communication issue could be helped by:

> "Probably having a better booklet that we can carry, even if it had other things in such as braille and things like that, so there is a bit more communication because you can't always get an interpreter you know… there isn't always a carer or relative so something that is a bit more hands on… that would make more sense." (Margaret, transcribed from English)

Although most of the participants mentioned the need for training, Paolo's experience was slightly different as he had already been given training, and he receives disability training every few years. However, Paolo agrees that training is important for all HCPs:

> Mark: "Have you always have deaf awareness training or is it something that is new?"
>
> Paolo: "Erm… well we have had it for a little while now, because those booklets came out years ago, I wouldn't be able to tell you when they came out though…"
>
> Mark: "Okay, when was the last deaf awareness training that you had?"
>
> Paolo: "Roughly, around 2016/2017."
>
> Mark: "Do you think everyone should be trained on disability and deafness, and what to do when they come across them?"
>
> Paolo: "Yeah, every paramedic should do, yeah." (Paolo, transcribed from English)

When asked what Paolo thought was a 'reasonable adjustment', he referred back to the use of VRI, along with the booklets that they already have:

> "I mean if we can get this Skype contract with an interpreting company that we can use with the iPads, then that's fair and reasonable. The books that we have got have been made in conjunction with the deaf societies. From an ambulance point of view, I don't think there is much we can do." (Paolo, transcribed from English)

Christy also had no training at all, and earlier in the chapter we explored that Christy had a little experience of communicating with people who are deaf or who have disabilities.

However, when asked if he received any training to do with deaf awareness or disabilities, Christy replied “nothing at all” (Christy, transcribed from English). When asked if Christy would have benefited from disability and deafness training, he commented:

> “Oh yes, absolutely yes, just a refresher on Makaton would have been good, because Makaton is so easy, and you can get your point across to any deaf person with Makaton, so I think we could benefit with some sort of training on that… we don’t even touch on deaf awareness in our training, we touch on how to communicate with people, by getting down to their level and things like that but there is no specific communication with deaf people…” (Christy, transcribed from English)

Clearly, though Christy is well-meaning here, knowledgeable observers would be disappointed by the conflation of Makaton with BSL and the idea that the former could adequately substitute for the latter. This is potentially indicative of deeper knowledge deficits across staff understandings of patients’ experiences, equalities duties, and ultimately what might constitute meaningful adjustments. These and other critical issues arising from the analysis are taken up in chapter nine.

Christy also shared his thoughts about the NHS and reasonable adjustments:

> “Well yeah, we have got to adjust to people’s needs… and I think every company, should adjust to people’s needs. If we just change the subject slightly then wheelchair users… every shop has to have a ramp now so, yes, I think the NHS in the whole needs to think a little bit more about it maybe…” (Christy, transcribed from English)

Following this comment, Christy was asked to explain his understanding of a ‘reasonable adjustment’ and he stated:

> "Hmm… Just having the means to communicate really… yeah, just some means, I don't know what means could be available but yeah, having the means to communicate." (Christy, transcribed from English)

Bart also talked about training and that it would have been useful to have some basic sign language skills:

> "It would have been handy if we had some sort of basic sign language training. The sign language training that I had was off my own back, it was actually learnt at college, but it would have been handy if at the initial training sessions that we had it… because when you're training to be a technician it's a two month course and there is not one single module on that two month course that's disability awareness… It would be beneficial, learning how to communicate correctly, properly, and not cause offence." (Bart, transcribed from English)

Bart felt that a basic understanding of sign language was important for ambulance crews because:

> "I would say I think it's important for all ambulance crews to have basic understanding of sign language so they can get the basics out of the way… at the end of the day if you go to somebody who has collapsed on a street and they are deaf and you want to get some information out of them, it's going to be hard to isn't it, but it would be nice if the hospital had an interpreter there or a sign language person there. So the initial stage when we turned up straight away they can get the information… as an example… we took this person in and they didn't have a sign language person there at all so they actually had to ring an agency to get someone to come down.

> Now if that person is having chest pains, an MI [myocardial infarction] you haven’t got the time for that, have you.” (Bart, transcribed from English)

Similar to the other responses, Bart viewed a ‘reasonable adjustment’ to be “much more detailed phrase books, and… I would say a voluntary introduction to disability awareness, as there is no training on that whatsoever.” (Bart, transcribed from English) Bart also agreed that disability awareness should be implemented into their training: “Oh yeah, I do yeah! It should in part of a module yes, it doesn’t need to have an assessment at the end of it but there does certainly need to be an awareness around it, and basic sign language phrases.” (Bart, transcribed from English)

Bart indirectly spoke about awareness previously in the interview and because he did not have any awareness, he found that when he worked with an interpreter, he spoke to the interpreter instead of the deaf patient:

> “What I found though, when I was initially doing it [working with an interpreter], I was actually talking to the interpreter and not to the person and then as soon as you realise you are doing it, you stop doing it, I know it sounds silly, but it’s a case of… well it’s rude isn’t it… but once I realised I was doing it I stopped and started talking to the person not the interpreter.” (Bart, transcribed from English)

Interestingly Bart, like Paolo, actually stated that once the deaf person gets to the hospital, they should have an interpreter at the hospital. However, Bart thinks that the hospital should:

> “…at a minimum… have one interpreter onsite at all time… because you can’t do a 9-5 on the NHS, can you, because you can have a car crash at any time. Or what they should do is implement a one hour policy so if

> someone did come in, they could get an interpreter within one hour. And again, disability awareness, but then again I think they do that in hospitals anyway.” (Bart, transcribed from English)

Similar to this, Christy agreed earlier that using family members is “really good on scene” (Christy, transcribed from English), however, once at the hospital Christy agreed that deaf patients should really have an interpreter. Bart, Paolo and Christy made interesting points - it is practically impossible for interpreters to be on the ambulance with the ambulance crews and therefore, it is probably not a reasonable adjustment to have an interpreter present. However, this suggests that the term ‘reasonable adjustment’ might fluctuate; for example, it is not reasonable for an interpreter to be available on the ambulance, but it is reasonable for an interpreter to be present at the hospital.

Although many of the participants found ways around the communication issues they experienced, it was interesting to hear how each of the healthcare professionals cared for their patients. Most of the frustrations they faced were not always because there was a communication barrier, but there was a sense of frustration during the interviews because they felt like they could not give the full care possible. Bart actually made reference to this: “It felt a bit awkward, because I mean we wanted to give the best possible care we can and obviously, we haven’t been able to do that this time around.”

7.11 Chapter summary

This chapter presented the data collected from the interviews with the paramedics. This original part of the study presented some very interesting findings. Interestingly, most of the participants mentioned frustration or awkwardness when trying to communicate with deaf patients. The common themes generated from the participants were mainly about communication and how the paramedics adjusted for their deaf patients.

There was some interesting data about family and friends being used as interpreters; many of the participants preferred not to use family or friends to help with communication, but many did use them as there was no other clear communication option, however they did so cautiously. All participants commented on the importance of using qualified interpreters and although this would be impossible to obtain in their situation, all of the paramedics agreed that deaf patients should have the use of a qualified interpreter when at the hospital.

Unfortunately, there would appear to be some questionable views on appropriate application of equalities obligations and patients' entitlements. In this vein, there appeared to be multiple different interpretations of what 'reasonable adjustment' means for these practitioners. Some of the participants interpret it in terms of their own personal point of view, some from the patient's point of view, some from the institutional point of view of the NHS as a whole. It may be the case that most practitioners are unaware or misinformed about the detail contained within equalities legislation, especially the duties of public service organisations. Such ignorance may be wilful, practitioners not seeing attending to equalities matters as part of their professional role, or this may reflect a lack of organisational attention to relevant staff education and continuing professional development. More prosaically, individual staff may rhetorically value equalities goals but struggle to move beyond abstract understandings to deliver real practical solutions, especially in the complex and somewhat unpredictable circumstances of emergency care.

The common themes presented in this chapter will be discussed in the critical analysis chapter (Chapter Eight). The next chapter of this thesis will present the hospital policies and investigate how hospitals meet their obligations under the Equality Act 2010.

Chapter 8. Deaf people as healthcare users: Making sense of a complicated situation

This chapter aims to draw together both the interviews with deaf people and paramedics, and place these in one central place to explore alongside each other. As discussed in the methodology chapter (Chapter Three), this research aims to bring together the experiences from both groups of participants to identify and investigate the issues that deaf people face when accessing healthcare, and to identify the issues that paramedics experience when treating deaf patients.

This chapter will also bring the hospital policies into the discussion to see if the policies address the issues that either of the participant groups have raised and to gain an understanding of whether hospitals are anticipating the adjustments that need to be met from both the paramedic and deaf participants' experiences. By exploring and discussing the common themes between the two participant groups and correspondence (or otherwise) with policy, this chapter aims to gain an understanding of how each group affects the other and identify examples of good and poor practice that have occurred within healthcare environments. Figure 6 (below) shows a visual representation as to how this chapter aims to pull the themes from both groups into common themes; these themes will then be discussed, and the chapter will consider how the hospital policies relate to these themes.

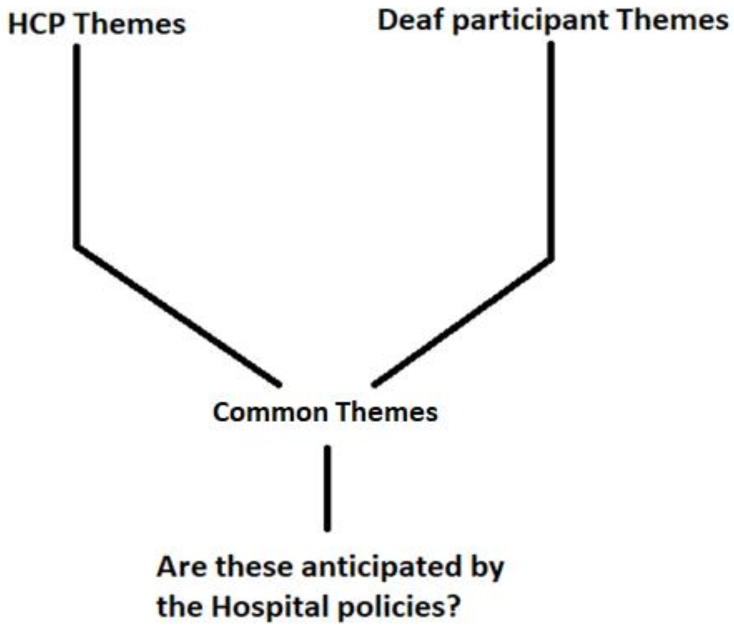

Figure 6: Participant themes to common themes and hospital policies

This chapter also relates to what deaf people require to be deemed as ‘reasonable adjustments’ and ‘accessible format’. These terms have not been explored before but are very important as they are the key words that hospitals and other medical settings must adhere to under equality legislation; this will then be discussed in the next chapter.

Table 4 (below) presents the common themes that the deaf participants and healthcare professionals discussed during their interviews; any themes that related to the hospital policies will also be discussed.

Interpreters ○ Qualified, trainee and specific interpreters ○ Family interpreters
Access ○ Booking interpreters and moving from GP to hospital ○ Requesting interpreters at the hospital ○ Timescales for interpreters & 24/7 access
Flexible communication ○ Importance of being able to communicate ○ Making adjustments/flexible adjustments ○ Trial and error ○ VRI as an option
Deaf awareness ○ Preparation ○ Training
Professionalism ○ Not feeling professional ○ Interpreter issues – confidentiality, poor interpreters and interpreters leaving

Table 5: The common themes

8.1 Interpreters

8.1.1 Qualified, trainee and specific interpreters

The use of interpreters was always going to be a key theme during this research as it has shown to be a huge topic in previous research, as shown in Chapter Two of this thesis. This research has shown that simply having an interpreter present is not always what is needed. Obviously, having an interpreter in most situations is preferable to not having an interpreter, however, this research has shown that it can go a lot deeper than ‘just having an interpreter’.

For clarification purposes, the difference between a trainee and qualified interpreter is explained by the NRCPD:

> "To become a Registered Sign Language Interpreter you need to show us that you are highly skilled in a signed language like BSL, ISL or ASL and second language that can be another signed language or a spoken language. One of those languages must be native to the UK and Ireland" (NRCPD [b], 2020).

A trainee interpreter is anyone else that is on the pathway to becoming a qualified interpreter. A trainee interpreter will need to "demonstrate competence as detailed in the national interpreting standards established for both spoken and signed languages. The national standards define three areas required for an interpreter: theoretical knowledge, language fluency and practical interpreting" (Association of Sign Language Interpreters Website: 2020). To be classed as a trainee interpreter, they must be on an accredited training path and only then will that person be described as a trainee interpreter.

Registered and highly experienced interpreters who have the correct training to interpret important and sensitive situations are preferable (Reeves et al. 2002, RNID 2004, Middleton et al. 2010, Ringham 2012). Most of the deaf and paramedic participants want to use qualified interpreters, and it is important that the qualified interpreters understand medical scenarios and are competent when interpreting these situations.

The use of trainee interpreters or unqualified interpreters was a worry for some of the deaf participants much like Lacey-Davidson's report (2012), and Marco and Muriel touched on the danger of using Trainee Interpreters. This, once again, relates to signing and interpreting experience, and particularly the interpreter's understanding and fluency, which can cause confusion. This is why most of the deaf participants described feeling hesitant when they are around trainee interpreters in medical situations.

A qualified interpreter is someone who has met the National Occupational Standard for interpreting: "A National Occupational Standard (NOS) is a document that describes the knowledge, skills and understanding an individual needs to be competent at a job" (Katz 2018:1). This generic standard for all interpreters is the initial groundwork for as one of the nine standards from 2018 is to: "Assess your ability to undertake interpreting assignments" (Katz 2018: 2). The NOS framework is something that is important, not just for BSL interpreters but for all language interpreters, as it states the basic fundamentals for a person to be classed as a qualified interpreter. During the interviews, most of the deaf participants stated that during complicated procedures, it is important to have clear and precise information interpreted to them. Although nearly all of the participants from both groups in this study mentioned that all interpreters should be qualified, the NRCPD only states that trainee sign language interpreters (TSLI) should not be used in criminal justice system or mental health settings (NRCPD [a] 2020; Association of Sign Language Interpreters 2012). Alongside this, TSLIs should be cautious when accepting work in social care environments (NRCPD [a] 2020). The NRCPD and ASLI do not warn against general medical appointments for trainee interpreters, however it is clearly important that deaf people have access to qualified interpreters and there is a strong argument which suggests that only qualified interpreters should be used.

The use of specific interpreters was a new sub-theme within the research; some of the deaf participants commented on having gender specific interpreters and wanting interpreters that they like or have worked with before. For the purpose of clarity, within the context of this thesis the term 'specific interpreter' is an interpreter that has been requested by the deaf person. This could be as wide as a gender specific interpreter, or as narrow as one particular person who is an interpreter.

The times when gender specific interpreters were wanted included childbirth, gynaecology appointments or areas that had something to do with intimate/personal parts of the body, which can be understandable. Other reasons for wanting specific interpreters might be as simple as not wanting the other gender to voice over for them in important situations. Some of the deaf participants indicated that they had asked for specific interpreters, but it was interesting to find out that sometimes the interpreter who had been requested was not available for the next appointment. This applies to not only the interpreters that the Deaf participants liked working with, but also the interpreters that the deaf participants did not like working with; it could be suggested that there needs to be a closer relationship between the hospitals and interpreters so that the preferred interpreters can be used again.

The use of specific interpreters can be related to the interpreting theory of how deaf people are represented by interpreters, as shown in Chapter Two. Napier et al. (2019) highlights that familiar interpreters can reduce a deaf person's anxiety as they already know the interpreter, how they sign, and their level of proficiency. Napier et al. (2019) and Young et al. (2019) both discuss the importance of correct representation of the deaf person through an interpreter, which is a key role for a qualified interpreter. Interpreters who do not know the deaf person in the same way may end up covering up something if they do not understand correctly (Napier et al. 2019), which could also be related to the experiences of Marco and Muriel within this study.

8.1.2 Family interpreters

Previous research (see Chapter Two) has highlighted the implications of using family members as interpreters, and the use of family interpreters has been shown not to be best practice (Siddique 2014; Palmer 2013; Ringham 2012; Lacey-Davidson 2012). This study found the same results as previous research and worryingly, four out of the five deaf participants gave examples of family members being used as interpreters. The findings also showed that on some occasions the deaf participants were asked to bring family or friends to interpret, and some of these situations where family or friends were used are considered to be important medical appointments.

The research provided an in-depth understanding of what goes through the minds of the deaf patient when using a family or friend to interpret, and the emotional stress they experience. Even those who have partners who are qualified BSL interpreters have felt like they have been left in a position of having no choice but to use their family to communicate, and because of this there is an added pressure on both the family member undertaking the interpreting duty and the deaf patient because they are put in a situation that they do not want to be in. deaf participants such as Foxy, and on occasions Emma, explored what it is like to use family members as interpreters and their experiences included: mental and physical exhaustion; pressure on both parties; emotional stress; missed communication; lack of information; wanting to ask more questions but holding back due to worrying about their partner and their relationship or simply, the privacy side; and not wanting to burden their partner, which was then followed by the deaf participants worrying about their partners feeling concerned for them.

Interestingly, all of the paramedics acknowledged that the use of family and friends is not the best method, and they were aware that communication may be broken. However, as all the paramedics worked on ambulances, most of the time they were left with no choice and it was the only way of communicating until they could get the deaf patient to a hospital where a qualified interpreter could be reached - this will be discussed further in the section 'making adjustments/flexible adjustments' later in this chapter. However, all of the paramedics agreed that fully qualified and competent interpreters should be used in medical situations.

Regarding the hospital policies, eight out of the 11 policies made reference to the use of qualified or professional interpreters. Interestingly, SW1 gave an example criteria stating that BSL interpreters must be one of the following: "An associate or full member of ASLI, Registered with NRCPD, MRSLI (Member of the Register of BSL/English Interpreters), A trainee interpreter, A junior trainee interpreter" (SW1). It is important to note that the junior trainee interpreter category was stopped by the NRCPD in 2012 (NRCPD 2012). Although the junior trainee interpreter has ceased, it should be highlighted that SW1 would accept trainee interpreters despite recognising fully qualified interpreter standards.

Another interesting point is that SW1 was the only hospital to mention the use of specific interpreters, however, SW1 claimed that if patients wanted to use their own BSL interpreter then the patient must cover the cost of that interpreter. This becomes a debate about needs vs preference. The NHS England (2021) website contains notes about meeting the cost of an individual's needs and this has been made available since the passing of the new Accessible Information Standard, along with guidance for organisations on meeting communication needs and providing accessible information. According to the NHS England (2021) website, a 'preferred format' for communication methods is not required within the Accessible Information Standard. The Accessible Information Standard requires the provision of information to be in a format that the patient can access and understand, and therefore it is the patient's communication and information needs that should be met and not their preferences (NHS England 2021). Technically, if a deaf person can communicate in written English and is competent enough to communicate in this method, then a BSL interpreter would not be needed. However, the judgement on whether or not the requirement to provide accessible information and communication support has been met lies with the patient:

> "The 'judgement' or 'assessment' about whether this requirement has been fulfilled lies with the individual patient themselves, i.e. can they read, access and understand the information? Can they 'use' the information as it was intended? If they can, then the organisation has met this aspect of its obligations under the Standard." (NHS England 2021)

The NHS England website explains that the best practice is to accommodate the patients' preference (NHS England 2021), however, this is not a requirement of the Accessible Information Standard. Through the interviews with the deaf participants, we gained an understanding of why some people want specific interpreters, and this is mainly because they are happy and comfortable with the communication.

The experience of some of the deaf participants in this research (Marco and Muriel) explored the dangers of using trainee interpreters; although the use of trainee interpreters is not always a negative as the information is provided in an accessible format, it does not necessarily mean that all the information can be understood and therefore, trainee interpreters might not meet the needs of the deaf patient. This evidence shows that in this case 'needs' and 'preference' are the same thing, and accommodating the preference of the deaf patient is actually the most suitable way of meeting their needs and making the correct adjustments for the service user.

Another example of needs versus preference was when Muriel faced a situation when the hospital told her that she had to have a BSL interpreter even though she did not want one, as she was happy to communicate using written notes. Muriel was confident that she could communicate using written notes and therefore it should have been her choice, as interpreters or a certain communication method should not be forced upon a patient.

However, it is important for medical settings to understand that although Muriel wanted to communicate using paper and pen during this particular appointment, when she was then admitted into hospital she wanted to communicate with a BSL interpreter. This shows that the 'needs' and 'preference' of the deaf patient can change depending on the situation. On one occasion, Muriel wanted to have a private consultation with just her and the doctor, without another person (interpreter) in the room; on a different occasion, Muriel was in an acute scenario where having an interpreter was most appropriate as the situation was more severe, and using an interpreter was the most effective way for her to communicate.

It is key to highlight that understanding what is being communicated, especially in a medical setting, is a right which is afforded to deaf people through the Equality Act 2010. Not providing a suitable communication method means that the deaf patient cannot make a fully informed decision, which is a human right for everyone.

One final point can be made regarding this policy: if a trainee interpreter turns up for a booking but the deaf patient does not understand the interpreter (as shown by Marco, Muriel and Hedgehog's experiences) and a different interpreter is required, it is unclear whether the deaf patient would then be charged for needing another interpreter. Once again, this raises the argument about what is considered to be a 'reasonable adjustment', along with the discussion about needs vs preference. It is not reasonable to use a communication/auxiliary aid that a service user cannot understand as it is not fulfilling the 'reasonable adjustment' requirement and it also defeats the purpose of having a communication professional present. If the patient has an appropriately qualified interpreter that they have used before and can understand, then it would be most appropriate to use that interpreter instead.

The SW1 policy raises the issue of cost and suggests that BSL interpreters are too expensive to have as 'temporary bank staff' (SW1 policy), however, Marco suggested that agencies are to blame for sending trainee interpreters because they are cheaper than a qualified interpreter. The issue of cost raises an ethical issue, as previously explored in this chapter, appropriate interpreter provision is vital for most deaf patients. In addition, the evidence in this research has suggested that fully qualified interpreters are desired by both the deaf and Paramedic participants. If cost is an issue, maybe this is why there is an abundance of evidence with interpreters not being booked or trainee interpreters being used by agencies and hospitals because they are either free or cheaper.

When a patient has an interpreter they particularly like, or a communication method that they want to use, it is unknown why this request would be rejected. The deaf patient most likely wants a specific interpreter due to being able to fully understand the information, thus their preference fully meets the needs of the deaf patient. Although the issue of cost has been raised, the NE1 policy states that: "The cost of using professional interpreters is often cited as a barrier to using these services: what often is not examined is the cost of using untrained or ad hoc interpreters (family, friends, and other patients)" (NE1 policy). The NE1 policy provides an interesting contrast to the argument around cost, showing that the financial cost of not using a professional interpreter could be detrimental to the patient. NE1 continues to explain that by not using the right support from the beginning, there could be a cost to the patient's care and health with possible further costs later on if things go wrong. As this chapter has shown, using ad hoc interpreters has had some poor outcomes for all deaf participants. This also shows the inconsistencies of hospital policies, as SW1 mentions the cost of an interpreter being an issue, compared to NE1 which outlines that not using professional interpreters at the start could lead to negative outcomes later on, leading to possible additional costs.

As discussed in Chapter Two, some of the interpreting concepts can be related to many of the experiences that the deaf participants have explored. For example, the theory of language brokering can be applied to the use of family and friends acting as interpreters. Both Ataman (2008) and Napier (2008) discussed the topic of children acting as interpreters and this taking the form of language brokering; however, this could also be applied to family and friends also being language brokers, particularly those who are not qualified interpreters. This raises questions about how much correct information is being interpreted and also, how much the medical professional might have altered what they have said to suit the ad hoc interpreter.

8.2 Access

Accessing medical facilities was another theme raised by the research participants, and this was also consistent with the reports presented in Chapter Two (Reeves et al. 2002, RNID 2004, Middleton et al. 2010, Ringham 2012). There was a fair amount of new information explored by the participants and most of this revolved around the use of BSL interpreters. The process for booking interpreters was an interesting topic and even though it is a duty of the hospital to organise BSL interpreters for appointments (NHS England 2015; NHS England [a] 2017; Equality Act 2010), some of the deaf participants explained that they had to check that hospitals had remembered to book the interpreters. As many participants stated that they regularly checked with the hospitals to make sure that interpreters were booked for their appointments, even though it is up to the hospital to provide an interpreter, this suggests an unspoken role of the deaf patient is to make sure that an interpreter has been booked for their appointment.

Interestingly, there does not seem to be a pattern for each experience: some of the deaf participants explained that they can go to the hospital and have a BSL interpreter provided, and at other times they can go to a different department in the same hospital and might not be provided with an interpreter. A similar finding was reported with GP appointments: some participants commented that their GP was good at providing an interpreter, whereas others said they struggled to get an interpreter at their local GP and the hospital was much better. This shows the reason for most deaf people wanting to check and remind the hospitals that they need a BSL interpreter, because they never know if one is going to be booked for them or not, and the section above has explored what happens when an interpreter is not present. As many deaf participants indicated that they were unsure if an interpreter had been booked for them, this could explain why some deaf people do not feel confident about using the health service. Furthermore, it suggests that there might be a lack of organisational skills and confusion within medical settings regarding interpreters, resulting in deaf people having poor confidence in the NHS when needing to use the service.

8.2.1 Booking interpreters and moving from GP to hospital

The hospital policies show inconsistency on the subject of booking interpreters, including how interpreters are booked and who is responsible for booking interpreters, both of which vary from hospital to hospital. From the analysis of the hospital policies (Chapter Five), it would appear that there is no standard process for booking an interpreter and furthermore, how the patient is admitted into hospital might affect how their interpreter is booked, depending on the hospital. For example, EoE1 states that when there is a planned admission, the GP is responsible for notifying the trust. However, if the patient is an outpatient, then the outpatients department are responsible for booking an interpreter. EoE1 also states that Accident and Emergency Departments are responsible for booking their own interpreters and inpatients are expected to make their own arrangement, although what the arrangement for inpatients is supposed to entail remains unknown. However, the policy from EM2 is slightly different: similar to EoE1, GPs and other organisations are expected to pass on any communication needs, but both inpatient and outpatient departments will book their own interpreters unless there is an imaging examination, in which case the imaging department will book the interpreter.

The list below provides a summary of the various ways in which the other hospitals book interpreters:

NW1 – books interpreters through an agency portal.
NW2 – phones their own interpreting and translation service.
NE1 – uses the interpreting and translation service, contact information on the trusts' intranet.
NE2 – phones a designated interpreting agency.
WM1 – uses the trusts' own central booking system.
SW1 – books via the Trusts' intranet.
SW2 – phone number

A very interesting policy provided by SW2 had an agency phone number for booking interpreters, however the policy stated that most patients will contact the agency themselves when they want a BSL interpreter. What is particularly interesting about this statement is that SW2 has stated that they follow the Equality Act 2010. As explored previously, the Equality Act 2010 quite clearly states that it is up to the service providers to take steps to provide an accessible format (see Chapter Four), not the service user, and therefore it can be suggested that SW2's policy is not fulfilling the requirements of the Equality Act 2010.

As the process for booking an interpreter is very varied, it is probably unsurprising that many deaf people check to make sure that interpreters are booked for them. It seems that ensuring they are provided with an interpreter is now the unspoken responsibility of the deaf person, especially as two hospitals in the same region might have totally different ways of booking an interpreter. It is also possible that the booking of interpreters is confusing for the hospital staff, especially when the process for booking interpreters can depend on the department. It is possible that communication and information might get lost between hospital staff and one might assume that the other has booked an interpreter for an appointment, and if neither have made the booking then no interpreter will turn up.

Previously in this chapter it was briefly suggested that hospitals could have a closer relationship with interpreters, and a better relationship between all parties could potentially help with the process of booking interpreters for appointments. For example, hospitals could write the name of the interpreter that has been booked on the appointment letter. This would then allow time for the deaf person to contact the hospital if they were not happy with the interpreter that had been booked and this could then be changed to another interpreter. If the deaf person had a preference for a particular interpreter, they could then provide the contact information for the interpreter; as the deaf person would be asking for an interpreter that they are happy with, as previously explored, this would meet the needs and preference of the deaf patient while also providing fully accessible information.

8.2.2 Requesting interpreters at the hospital

So far, we have explored the process for booking interpreters for booked hospital appointments. This research also explored what happens from the paramedics perspective of going to patients in an ambulance and then needing to take them to hospital. The paramedic participants had a slightly mixed response to phoning ahead when taking a deaf person to the hospital, with all but one participant stating that they only phone ahead when it is an emergency and the patient that they are taking to the hospital is very unwell. It was explained by Paolo that it would be near impossible to phone ahead all the time due to the volume of patients that they see in a day.

The findings showed a contrast in the Paramedics' experiences though, with Christy explaining that he used to let the hospital know in advance that a patient was deaf but because nothing was done when he contacted the hospital, he then stopped. Fred also explained that normally he would not contact the hospital unless he was rushing a patient in, however, if they could not communicate with a patient at all, then he might have changed his approach and contacted the hospital to make them aware that they cannot communicate with the patient. A major point that should be considered from this example is that Christy stopped doing what he thought was the right thing because the hospital/trust/staff member who was contacted did not act on the information that Christy gave them in advance; Christy stopped doing it even though it should be considered as good practice. Both this research, and previous research (Chapter Two), have shown the potential risks and damage that can occur when an interpreter is not present, and Fred indicated that if he could not communicate with his patient, he would then inform the hospital that they needed to be prepared. However, none of the hospital policies mentioned ambulances/emergency medical crews or emergency procedures for when a communication aid might be required for a patient and how to deal with this request.

If the paramedics were to phone ahead to the hospitals, the extra time could be used to find an interpreter, especially for a deaf patient who might be seriously ill. This chapter has already explored the importance of interpreters, and even those who did not always want an interpreter leaned towards having an interpreter for very important information. To use Christy's example, foreign languages can be overcome by a phone call which provides another means of being able to communicate. This cannot be done with a deaf person who uses British Sign Language, and although the use of Video Relay Interpreting (VRI) could be an option, it is not a long-term option due to a number of key issues such as internet connection and video quality (this is discussed later in this chapter in the section titled Flexible Communication). This means that a face-to-face interpreter is going to be needed. However, in an emergency situation when speed can be very important, having an interpreter present can also be vital so VRI could be a possible option.

8.2.3 Timescales for interpreters & all hours interpreter access

The timescale for getting an interpreter is also important, but none of the 13 hospital policies mentioned the timescales for booking interpreters. All of the paramedics commented that they want interpreters, however they were slightly split on when they thought it would be most appropriate for the interpreter to be present. Two of the paramedics stated that they wanted interpreters present when they were completing the handover to the hospital so that the patient understood and could also provide input in case anything had been missed or miscommunicated. Others could not really give a timeframe for interpreters to be present as they were unsure, but a general idea for an interpreter to be present, from the perspectives of the paramedics, was within the first two hours.

Constant interpreter access was mentioned a few times during the interviews: a couple of the deaf participants explored the need for continual interpreter access and interestingly, the paramedics commented on continual interpreter access as well. To use Bart's words, "you can't do a 9-5 on the NHS, can you, because you can have a car crash at any time" (Bart HCP). Foxy explained that although the NHS provides all hours access, it extremely hard for deaf people to access the services because interpreters do not always provide round the clock support.

The issue is the lack of interpreters available during unsociable hours, for example, during the evening, on weekends and bank holidays. The paramedics agreed that an interpreter should be available and contactable even out of hours, with some stating that an interpreter should be on call and others stating that an interpreter should not necessarily be onsite but should be contactable. In addition, in relation to the earlier points about the timescales for getting an interpreter, it is preferable to have an interpreter within two hours of being admitted to the hospital (Paolo, Bart). However, as Foxy explained, interpreters are humans and like everyone else they have lives and families; this might explain why it can be difficult to get an interpreter during unsociable hours. Reeves et al. (2002) also briefly covered the issue about accessing interpreters in A&E and the results were extremely similar to this study as they showed that getting an interpreter is near impossible for deaf people.

In relation to the hospital policies, three mentioned being able to access interpreters 24 hours per day, however, this does not mean that an interpreter will be available in an emergency as most of these policies involve contacting an agency who would then need to contact the interpreters. This situation is an extreme scenario but it can happen. Previously in this chapter, the need for hospitals to have a closer relationship with interpreters was mentioned and from the hospital's perspective, it could be very useful to have direct numbers for interpreters who would be expecting unsociable calls from a hospital who needs them in an emergency. One important comment from Foxy explains how she tries to avoid using emergency medical settings during evenings and weekends because, in her experience, she cannot get an interpreter at these times. Foxy's experience of not getting an interpreter is also similar to the RNID (2004) report which showed that 70% of BSL users were not provided with an interpreter when attending A&E. Similar results were shown in the Sign Health report (2014) in relation to GP appointments, as

70% of deaf people wanted to see their GP but did not go to the surgery because there was no interpreter or they could not access the facilities. All these reports show that in a variety of medical settings, if there is a failure to obtain interpreters then deaf people try to avoid going. This leaves deaf people in a dangerous situation risking their health and possibly their lives, or the lives of others. This is a long-standing issue that needs to be addressed and if deaf people do not want to use health services, then it strongly suggests that medical settings are failing their obligations under the Equality Act 2010.

8.3 Flexible Communication

Flexible communication was an extremely interesting and complex theme. Communication is a two-way process: if one person does not understand, then most of the time both participants who are trying to communicate will not get the full information due to broken communication.

8.3.1 Importance of being able to communicate

This section will start by considering how important it is to be able to communicate fully and effectively, then it will move on to investigate how people manged to communicate and the flexibility or adjustments that were required. Previously in this chapter, the importance of communication was explored under the 'interpreters' section, specifically how broken communication can cause problems and stress for a deaf patient. This can even occur with sign language interpreters, for example, with trainee interpreters who are not as experienced or fluent so interpretation can be broken, as explored by Marco and Muriel. We have also explored the dangers of not being able to communicate or underestimating the importance of communication through the experiences of the deaf participants, with some not fully understanding what medication is for - this has also been well documented in other research (Reeves et al. 2002; RNID 2004; Ringham 2012).

Other reasons identified by the deaf participants that highlight the importance of being able to communicate relate to things that are typically overlooked, such as: medical jargon, medical forms, fully understanding procedures and consent forms. The views from both sets of participants ran somewhat parallel, and this research explored how important it is for both paramedics and deaf patients to be able to communicate, with both groups suggesting that it is 'hard' and 'frustrating' when communication breaks down. The experiences of the paramedics showed that although they all understood how important communication was, the initial investigation of what had happened was not the problem; the problem that most of the paramedics identified was when they needed to get more in-depth information such as the medical history of the patient, or where the pain is and what type of pain is occurring.

Although this research does not discuss how to medically diagnose a patient, it is impossible not to highlight the importance of getting the history of events (Bart and Christy). Obtaining the patient's history has been shown to be key to making a diagnosis (Peterson et al. 1992; Ohm et al. 2013). When diagnosing a deaf patient, it is important that there is a clear means of being able to communicate, possibly through the use of a qualified interpreter. As explored from some of the interviews with the Paramedics in this study, the in-depth information is where the communication tends to collapse; therefore, having a good means to communicate where all parties understand each one is extremely important. Communication is valuable for finding out information and clear communication can also enable deaf patients to feel reassured and safe, as explored by Margaret.

8.3.2 Making adjustments/flexible adjustments

Making adjustments and flexible adjustments was valued by both sets of participants, and although a lot of what has been discussed revolved around interpreters, there was evidence of how both paramedics and deaf participants overcame the communication barrier when put in a situation where they needed to communicate. The findings provide some really positive examples of good adjustments from the experiences of both the paramedics and deaf participants. Most of the paramedics found that even without an interpreter, they could get some information from their patients. Interestingly, most of these methods of communication were through a visual form, for example, pointing. However, the method of adjustment depended on the patient as there are many different forms of deafness, and the adjustments made by Paolo, Christy and Bart were totally different to that of Fred and Margaret, whose main experience was treating a deafblind patient. The situation that the paramedics experienced meant that they were not near a hospital, and most likely not near an interpreter that could help them communicate. Interestingly, the paramedics used family members or friends to help them communicate. As discussed previously in this chapter, the use of family members or friends is not best practice but due to the situation that the paramedics were in, they had to adapt and adjust, and from their experiences they did not have a problem using family or friends as interpreters.

All of the paramedics commented on the use of family and friends, showing that they understand that problems might occur, and they all showed a little caution when using interpreters who were related to the patient. However, all paramedics recognised that although it might not be best practice, it is still a means of being able to communicate at an important time. The paramedics acknowledged that using unqualified interpreters is not ideal, however, in an emergency situation it would be impractical to have an interpreter present, and therefore the first time that an interpreter should, and could, be present is when they get to the hospital. This shows that although the use of family and friend interpreters is not particularly suitable, using these types of interpreters might be an option when there is no alternative. However, all paramedics agreed that at any follow-up appointments, or after a few hours at the hospital in emergency cases, there is no excuse to still be using family or friends as interpreters.

Both deaf and paramedic participants described how they made adjustments and there were similarities in some of their approaches. For example, some of the deaf participants indicated that they will utilise written communication in certain situations, and some of the paramedics also suggested that reading and writing can be a method of communication. Although legislation states that service providers must make an adjustment, what this study has shown is that on some occasions, both parties make adjustments to suit the other. Although both sets of participants agreed that reading and writing has been used (Muriel, Hedgehog, Christy, Bart and Paolo), it is not a flawless approach as it has some drawbacks, such as being time consuming. Other communication methods used by the paramedics included communication booklets, picture booklets or picture cards. Many of the paramedics commented on the use of additional resources and showed that these were useful for certain situations when communication became a problem. These types of resources are useful but the findings suggest that they can be broken or lost. However, when the Paramedics have used them, it has been shown to be a valuable communication method. Although many of the paramedics found this to be a good approach, Bart did not feel very comfortable communicating through this method as he did not find it very professional, even though it was successful.

8.3.3 Trial and error

The final communication method that was highlighted was the most interesting as quite a simple approach of 'trial and error'. The trial and error approach also worked for some of the paramedics. This included using a variety of different communication methods such as gesturing or pointing and gaining an understanding of what was wrong, or using the gesturing and signalling or pointing as an initial starting point then incorporating other communication methods such as reading and writing or the communication books, if they had one.

The deaf participants have shown that when an interpreter is not present, they will communicate with paramedics through reading and writing or lip-reading. It is important to remember that when the deaf participants talked about adjustments with communication, they were mainly referring to hospital or GP appointments and not during an emergency setting like the paramedic interviews. However, apart from the interpreters who were present for the deaf participants, none of the hospitals or GP surgeries provided alternative adjustments such as communication booklets, and this meant that the deaf participants relied on either lip-reading or using written notes. Some of the deaf participants were satisfied with this method or adjustment; however, when communicating in this way, especially during hospital appointments or GP appointments, one can question who is making the adjustment. This question becomes even more curious when we consider a situation with the added pressure of important information that needs to be communicated thoroughly, such as surgery or needing to change a lifestyle. From the interviews with the deaf participants, we gained an understanding that in emergency situations, reading and writing mixed with lip-reading might not be the best method. Although it is a way of being able to communicate, in reality it was frowned upon by nearly all of the deaf participants, especially in important situations.

This research found that even when communication might be a problem, showing good deaf awareness (which will be discussed later in this chapter) can work. Furthermore, as shown in Chapter Six, Hedgehog had an amazing experience where the HCP had good deaf awareness when there was no interpreter present. This example from Hedgehog included the full range of adjustments previously mentioned by the paramedic participants, for example: lip-reading, reading and writing with the use of plain English, pointing and gesturing, short and clear information, use of visual pictures, and providing the information slowly by not rushing through the appointment and explanations. Due to this, Hedgehog’s operation was not delayed whilst waiting for another appointment to be booked with an interpreter present, which potentially saved his life.

This suggests that there might be a variation in adjustments depending on the situation. An overall view from previous research makes the information on adjustments seem like a ‘one size fits all approach’ is appropriate, especially with such an emphasis on the use of qualified interpreters, and on occasions there is an understanding that interpreters cannot be present for everything, in particular emergency situations. However, this does not stop the expectation from both paramedics and deaf participants that within a reasonable timescale a qualified interpreter should be made available. Without an interpreter present, the adjustment then changes to reading and writing alongside lip-reading, which is more or less the deaf person making the adjustment; again, this seems to be acceptable in emergency settings but less acceptable for hospital or GP appointments. It is important to note that although some deaf patients might be happy to communicate with reading and writing, lip-reading and other communication methods, it is still the duty and responsibility of the hospital or service provider to make the adjustment to suit the service user. The ability to communicate through reading and writing, lip-reading and gesturing was something that was presented as being tolerated by the deaf participants but is not something that should be expected from deaf patients.

The trial and error approach that has been described in this section could be linked with the concept of translanguaging. As discussed in Chapter Two, translanguaging is the adoption of a communicative strategy (De Meulder, et al. 2019) where the deaf person will draw on their full linguistic repertoire (Napier, et al. 2019). The concept of translanguaging occurs when linguistic inequalities are present (De Meulder, et al., 2019), which also supports the findings of this research. Although some deaf participants within this study were fine with this method of communication, it was far from ideal. Much like the section previous to this (which discussed making adjustments/flexible adjustments), it is important to consider who is making the reasonable adjustment when the trial and error approach or translanguaging concept is being utilised.

8.3.4 VRI as an option

There was one more very important point that was raised by the paramedics, and this was the use of Video Remote Interpreting (VRI). The use of video remote interpreters is something that was only explored by a couple of the paramedics and is quite a challenging topic to cover. VRI and Video Relay Service (VRS) is a communication method between a BSL interpreter, deaf person and hearing person. The idea behind VRI and VRS is that an interpreter can be accessed at any point through a live video feed, such as Skype or Facetime (see Figure 7).

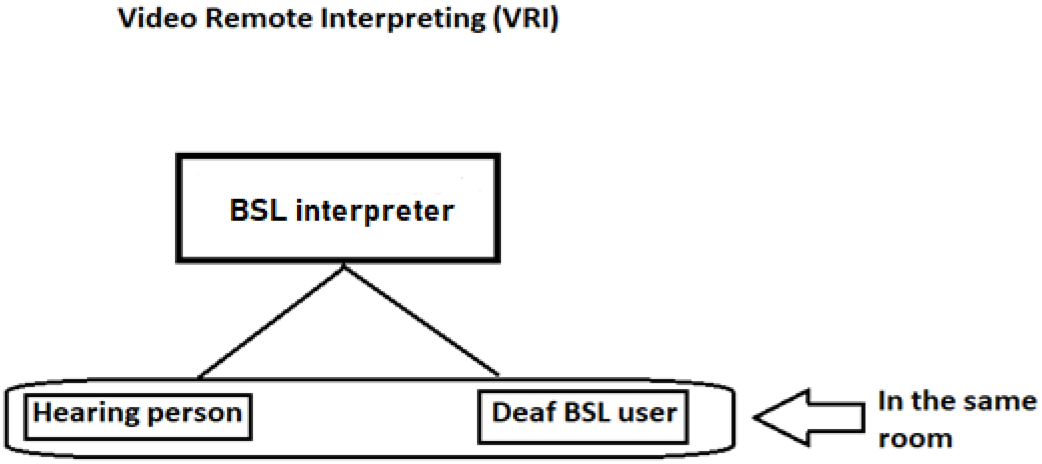

Figure 7: Video Remote Interpreting

VRI and VRS are very similar as both involve a person being in a remote location. However, as shown in Figure 7 (above), VRI involves the hearing person and deaf BSL user being in the same room. VRS does not require anyone to be in the same room, and this was mentioned by Paolo when he referred to the 111 service that is available to the public for when they need medical assistance but do not know what to do. Figure 8 (below) shows a diagram of the interaction where the deaf BSL user would communicate with the interpreter through a video call, and the interpreter would then interpret and relay the information with the hearing person through a voice call, while still on the video call with the deaf BSL user.

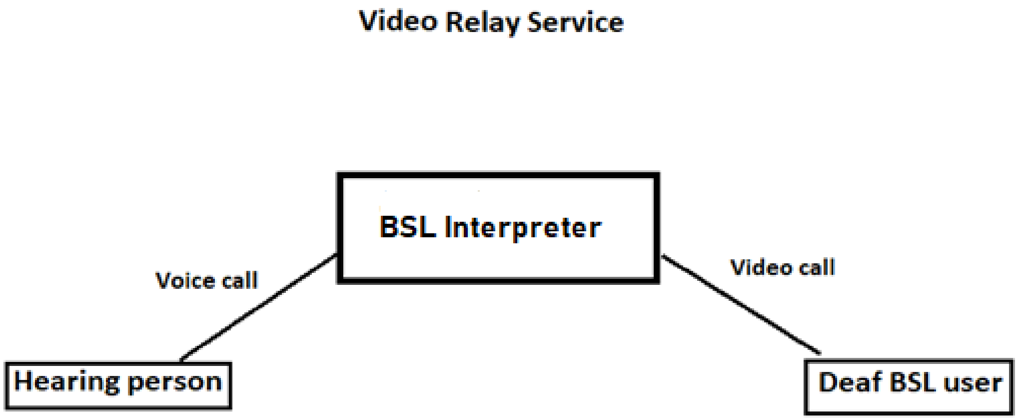

Figure 8: Video Relay Service

At the time of writing, the 111 BSL service is currently being provided by InterpreterNow. This service is accessed by a deaf person downloading the InterpreterNow application on their smart device (mobile phone, tablet, computer etc.) and registering their name, and then connecting with an interpreter who will help them. This service can be used at limited times between 0800 – midnight, which would not be much use to any deaf BSL users who become unwell in the early hours of the morning. As previously explored in this chapter, access for all hours interpreting is an issue for deaf people and although this service enables deaf people to have easier contact with healthcare providers. It is also useful to note that this service requires the user to download the InterpreterNow App and register, so it might be worthwhile for all deaf users to register in preparation, just in case there is an emergency.

According to the InterpreterNow website, they are already supplying 111 services, and a number of NHS Trusts, hospitals and GPs surgeries have signed up for VRI. The VRI and VRS services supplied by InterpreterNow have also expanded outside of health settings as they provide services for 101 non-emergency police.

The use of VRI or VRS was only mentioned in one policy, and it is not known if this was through InterpreterNow or another local service. The use of VRI or VRS was not explored by any of the deaf participants, however, VRI and VRS services was something that the paramedics thought they could utilise for important situations. There is some controversy regarding the use of VRI and VRS - although the services might seem to be easily accessible and therefore a good idea, there are a number of big factors that contribute to the issues of using a video relay service, particularly the need for strong internet reliability and high quality video. VRI and VRS is not widely researched in the UK, but the United States of America uses Video Relay and it is suggested that these reports show that large numbers of deaf participants who have used the service were not happy with the use of VRI (Kushalnagar et al. 2019). A number of reports mention that the interpreter must be a qualified interpreter when using VRI or VRS, and even with experienced and qualified interpreters there can still be common issues that affect the communication. For example:

> "The three most typical issues that negatively impact on the interpreter's ability to function in a video remote call centre are: (1) reliance on a two-dimensional (2D) format which can impair sign language comprehension (17.5%), (2) technological capabilities and reliability (12.3%) and (3) having to interpret for a wide variety of deaf caller signing styles (10.5%)." (Napier et al. 2017:14).

It is important to note that the use of VRI and VRS is not designed to be a replacement for face-to-face interpreting, but instead for situations which are an emergency and where communication is needed quickly:

> "...it is not intended to replace the need for face-to-face interpreting, in fact, we see this as complementary to face-to-face provision. This is especially true when an interpreter is on route or when a deaf patient presents themselves at non-scheduled appointments or as 'parents' of a

> hearing child seeking information etc. We tend to say that VRI should only be used when nothing else would happen!" (InterpreterNow website 2022)

These examples are the key issues that relate to the use of VRI and VRS, however the use of video relay is slowly growing, and video relay is significant as sometimes it can work well. However, VRI and VRS should be used with caution and it should not be assumed that this is a 'quick fix' for the provision of adjustments. Lee (2020) talks about the challenges of video interpreting.

> "Signed language users and the interpreters need to see each other clearly and any interruption to the video signal can make communication impossible. While spoken language users can rely on either the audio or video channel, interpreters and users of signed languages are limited to the video channel; this has implications for attention to the video signal, as well as the need to have very reliable video connections" (Lee 2020:107)

When no other option presents itself, then video relay could be used to enable communication, but it should not be relied upon. Only one policy mentioned the use of VRI, but many policies explored when they expected an interpreter to be present, such as when discussing diagnosis or treatment. However, none of the policies explored any flexibility in communication; as we can see from the experiences of the paramedics and deaf participants, there were times when it was impossible to get an interpreter and the paramedics and deaf participants worked together to try and communicate. The hospital policies do not show much flexibility in supporting situations where communication can be made possible without an interpreter. In other words, the policies are quite rigid and read as a 'one size fits all' approach. However, the research has shown that all situations are different and the hospitals and paramedics need to be ready to adjust quickly, and not always just turn to interpreters as there could be a long wait between making the request and an interpreter being present.

8.4 Deaf Awareness

Deaf awareness was quite an important theme that came out of the interviews with both the deaf and healthcare participants. The interviews presented the issue of deaf awareness in different formats depending on the situation, however both sets of participants demonstrated a need for there to be some form of training or awareness to help with communication.

8.4.1 Preparation

Some of the paramedics commented on the preparation undertaken on the way to meeting a deaf patient. At the time of the interviews, most of the paramedics did not know that they were going to treat a deaf patient, however, most of them felt like it would make a difference if they did know. This was expressed in different ways, such as being able to get the communication books out and ready, if they had them, or using the time to think of ways to communicate once they get to the job. Paolo explained that where he works, most of the time he will be told that he is going to a deaf patient and will prepare by having his communication book ready or in a place where it is easily accessible. Bart mentioned that being prepared is useful as it stops him from feeling caught out, and being able to think about how he is going to ask questions while on the way to the patient might enable him to communicate effectively.

Following on from the paramedics’ views about being prepared, the deaf participants also indirectly commented on the need for things to be prepared beforehand. Foxy provided a perfect example of this when she had a traumatic labour and needed an emergency caesarean. This occurred when she was in quite a lot of pain and there was no interpreter, and the information that the doctor was trying to communicate to her was failing. In this situation, Foxy needed to sign a consent form but she explained that she was stressed, in pain and did not understand what was being communicated to her; she eventually lost patience with the situation and signed the form without reading it or knowing what was on it.

Consent was an issue that was addressed in Chapter Two of this thesis, and it could be suggested that if a BSL interpreter was not present, then questions should be raised about whether the deaf patient had given informed consent for the operation. One of the paramedics (Bart), explored an experience when he thought he had communicated and gained consent, but actually the deaf patient that he was treating did not fully understand and withdrew his arm to stop them from going further. In this situation, Bart understood what the problem was and explained again in more detail. It is vital that HCPs understand and are given resources to be able to communicate effectively with patients, but this again falls back to being prepared. The Department of Health (2003) gives guidance for hospitals and Trusts, explaining that the process of gaining consent may need to be in a format that patients understand; to do this, additional resources are required but evidence shows that this is still not happening in hospitals. It is also important to note that Francis and Johnston (2001), stated that if a patient cannot understand the language, then they cannot give valid consent.

The deaf experience shows an important variation to the idea of preparation. When the paramedics described preparation, it revolved around how they would plan to communicate and getting communication aids ready so they can deliver the best care quickly and avoid a situation where both the paramedics and deaf patient are left feeling vulnerable. However, the deaf view about preparation revolved around being given information or things being done before the situation arises, and having things explained when there is time for questions and additional explanations if something is not clear. It is important to consider the effect that good preparation can have in relation to adjustments and also, how much is understood regarding giving consent. The example from Foxy, briefly reiterated above, raises the question about whether or not Foxy understood and therefore, whether she could give consent; however, this cannot be answered in this research.

8.4.2 Training

The next sub-theme relating to deaf awareness was the training needs of the HCPs, which is something that all paramedics agreed upon. It would be practically impossible for HCPs to maintain their skills as medical practitioners and to maintain sign language skills to a level where they can fluently communicate with a deaf BSL user who might be in desperate need of help and extremely stressed, which would be very difficult for medical practitioners to keep up with. All of the paramedics agreed that basic deaf awareness should be included in their training, and some also felt it is necessary for the training to include information on the support available for the crews that are working on the ambulances. Out of all of the paramedic interviews, only one participant said that they had received training on communicating or deaf awareness information; some of the others said that they had done minimal training and others had no training at all.

This thesis has mainly looked at deaf BSL users, however, this only one part of being deaf. Fred and Margaret referred to treating a deafBlind person and admitted that their biggest worry was that the deafBlind person might not use Tadoma - a communication method in which the hand of the deaf-blind receiver rests on the lips of the speaker (Reed 1996) which would have resulted in them both being stuck about how to communicate. This really shows that HCPs do not have enough training or information when put in situations where they cannot communicate, which results in them falling back to a trial and error approach when communicating with deaf patients.

Training in deaf awareness was also a topic that came up during the deaf participant interviews, with a number of participants claiming that more awareness would be beneficial in appointments. This ranged from not wanting to waste time by explaining to the doctor why the chairs are being moved around, to understanding that when communicating without an interpreter the HCPs need to remember to look at the deaf patients and to take more time to communicate. There is also a need for interpreters to be aware of the type of information that is going to be delivered as interpreters also need to be able to prepare themselves to correctly interpret information across to the deaf patients.

From the interviews, we can see that preparation and training for healthcare professionals are two of the key points that both sets of participants agreed upon. When reviewing the hospital policies to see if any of the hospitals had mentioned preparation, it was identified that none of the 11 Trusts made reference to being prepared pre-appointment. This deaf awareness section provides a valuable insight into how preparation could affect the outcome of the situation. We can see from the deaf experiences that when situations became stressful, communication completely breaks down, causing more confusion and stress. If the patient knew about some of the possible complications beforehand, in pre-appointments or pre-operations, and understood what would happen if this situation arose, then the deaf person would already know what was happening.

Interestingly, some of the policies provided deaf awareness guidance as appendices, alongside some mentioning about interpreter awareness and how to work with an interpreter, which is probably quite useful for the HCPs. However, there was no further guidance for HCPs on preparation. From the interviews with the paramedics, we can see that preparation is also important to them, as it can help them think about how they are going to ask questions, and ensure they are in the right mindset when there is a communication barrier, instead of feeling flustered because they were not expecting a communication problem. This preparation means they can be ready with a communication book or a pen and paper, thus breaking the communication barrier as best as they can.

In relation to training, three of the policies mentioned about staff going on some type of awareness training; this could be sign language training, interpreter training or deaf awareness training. This is very intriguing as all of the paramedics, apart from one, mentioned that they have little or no awareness training, and they all felt they would benefit from this training to show them how best to deal with communication issues. This relates not only to deaf people but other patients such as those who are deafBlind; as Fred and Margaret pointed out, if their deafBlind patient could not have communicated with them, they had no resources or training that could have helped. Some of the deaf participants explored the need for training within HCPs, such as making HCPs aware that interpreters will need to follow deaf people into appointments (Muriel). It was also suggested that HCPs need to understand that chairs will need to be moved around to accommodate a BSL interpreter as well as knowing how to communicate with an interpreter present (Foxy).

8.5 Professionalism

One of the common themes presented from both sets of participant groups was the need for professionalism. The expectation of being professional depends on the profession. For example, professional practice for each HCP is set out by their regulatory body: "…a duty to accept professional accountability and maintain the standards of professional practice as set by the appropriate regulatory body applicable to your profession or role" (Department of Health & Social Care: 2015). Within the NHS lies a constitution that establishes the principles and values of the NHS in England. This constitution has seven principles that guide the NHS:

> "It provides high quality care that is safe, effective and focused on patient experience; in the people it employs, and in the support, education, training and development they receive; in the leadership and management of its organisations; and through its commitment to innovation and to the promotion, conduct and use of research to improve the current and future health and care of the population. Respect, dignity, compassion and care should be at the core of how patients and staff are treated not only because that is the right thing to do but because patient safety, experience and

> outcomes are all improved when staff are valued, empowered and supported." (Department of Health & Social Care: 2015)

This principle explores the wider role of the NHS in enabling its staff to be professional and explains that the NHS has a duty to not only provide safe and high-quality care, but also to support and enable the HCPs to deliver this to their patients.

8.5.1 Professional Standards

Some of the paramedics showed that they did not always feel professional when treating deaf patients (Christy and Bart). This was not because they could not communicate effectively with the deaf patients, but because they did not feel like they had the appropriate professional resources or information about who to contact when they arrived at the hospital for an interpreter to be present. It is important to note that when in the hospital, all of the paramedics and deaf participants agreed that when an interpreter is used, they should be fully qualified interpreters; this again raises the issue of not being professional when unqualified interpreters are not used.

In addition, the paramedics agreed that when in a hospital setting it is best practice to have an interpreter; this attitude was shared by all of the paramedics and explains why they did not feel professional when treating deaf patients. Most of the paramedics agreed that from their point of view, the best adjustment in an emergency situation is to give deaf people some means to comfortably communicate with paramedics. However, as previously discussed, many of the paramedics felt that an interpreter should be provided when the deaf patient gets to the hospital, and some of the paramedics felt embarrassed or frustrated when family or friends were still interpreting at the hospital; this is very similar to Ringham (2012) report, which highlighted that 65% of the study participants were embarrassed because a family or friend was interpreting. Interestingly, what embarrasses the deaf participants is also embarrassing for the healthcare professionals.

This highlights that both groups of participants feel that it is appropriate and correct that interpreter provision, when at the hospital, is the correct adjustment that needs to be made.

These points relate to the statement at the start of this section about the NHS constitution and the high standard of care and patient safety. The paramedics cannot provide high professional standards when they lack the resources and training which enables this to happen; when the paramedics are not supported with appropriate resources or education, it does not empower them to maintain high professional standards. An example of this was where it was obvious to the deaf participant that they did not want to communicate via reading and writing, but reluctantly had to. This may have resulted in minimal information being passed to the deaf patient because the doctor kept it brief (Foxy). If the paramedics are not empowered to deliver high standards, this can then jeopardise the care, compassion, dignity and respect of the deaf patient, and therefore does not fulfil the key principles that the NHS is based on.

8.5.2 Interpreter issues – confidentiality, poor interpreters and interpreters leaving.

From the perspective of the deaf participants, the need for high professional standards not only related to paramedics when treating or communicating with deaf patients, but also related to the BSL interpreters who needed to present an equally high standard of professionalism.

There was a consensus about high professional standards from the deaf participants in relation to the use of BSL interpreters. Within this research, and previous research (Middleton et al. 2010), confidentiality can be a concern for deaf BSL users. Interpreters registered with the NRCPD adhere to a Code of Conduct which includes them not disclosing information about any appointment:

> "2.1. If you gain access to information as the result of an assignment you must only share it with someone else if you have the service user's consent or the law requires or allows you to, such as when it is necessary to prevent harm." (NRCPD [c] 2020)

Even though interpreters are bound by this code of confidentiality, there is still a small concern about interpreter confidentiality for deaf patients (British Deaf Association 2012, Middleton et al. 2010). Although there was no evidence during this research to show that interpreters had broken confidentiality, it was suggested that interpreters knew lots about the deaf patient but the deaf participants did not know anything about the interpreters (Muriel). This concern is something to be mindful of, as interpreters are bound to confidentiality much the same as doctors or other professionals. It is also interesting to note that doctors know a lot about the patient as well, but as the deaf community is quite small, some deaf people might worry that they will have an intimate medical appointment with an interpreter present, and there be a high probability that they will see that interpreter again in a different situation that might have nothing to do with health, thus the confidentiality issue.

Another issue identified by the deaf participant's related to interpreters not maintaining high professional standards as they should have been. For example, there were a number of examples when interpreters had left during operations (Marco, Foxy, Hedgehog). As previously mentioned in the deaf participant interview chapter, interpreters leaving after an operation is not good practice as most of the deaf participants explained that they wake up feeling dazed and confused, which makes communication harder for them, especially if no interpreter is present. This also hinders extra information normally given after an operation about medication, specifically about what to take and when, which can cause confusion for the deaf participants; this situation would be made much easier if the interpreter stayed until after the operation, or even if they came back at a later stage.

The final point relates to the behaviour of some interpreters, which was explored through the experiences of the deaf participants. Hedgehog provided what was hopefully an extreme example of unprofessional behaviour when the interpreter laughed at the deaf patient before the start of an operation, thus making Hedgehog feel like he had no empathy, which in turn meant that Hedgehog lost trust in the interpreter. This interpreter also left during the operation, despite the doctor saying that they were booked for the whole process.

Foxy also had an issue with interpreters leaving: the waiting time for Foxy's appointment was around an hour and the interpreter left due to having another deaf client, so Foxy missed out on her appointment and had to come back another time. Again, this is an example of poor behaviour from the interpreter and this could have caused Foxy some serious harm, especially if the appointment was vitally important to her health. In addition, the interpreter booked another appointment on behalf of Foxy which took away her choice to not use the same interpreter again.

This is arguably one of the many issues with professional interpreters and although this could be a rare occurrence, the interpreting profession needs to be made aware of examples like this, especially as poor professionalism can have a huge impact of a deaf person's life. This research has shown that the interpreting profession plays a vital part for deaf service users, and HCPs rely upon them for communication support. However, the experiences explored in this research have also shown what happens when interpreters do not have high standards of professional practice, which the interpreting profession as a whole need to be made aware of.

It is important to highlight that for many deaf patients, their lives are effectively in the hands of the interpreter during their health appointments, especially as information communicated at that appointment or operation is going to affect what happens next in the life of that deaf person. However, medical settings also need to recognise the need for registered interpreters. Interpreters who are registered with a governing body will be expected to maintain high professional standards and interpreters must adhere to these standards; if they do not, the interpreters can be held accountable for their actions.

8.6 Chapter summary

This chapter has drawn together the themes from all of the data collection groups; the findings have been presented in a way that clearly shows the thematic links between both sets of participants, with a snapshot of where the hospital policies are positioned in relation to the experiences of the paramedics and deaf participants. It is vitally important to remember that the themes were presented individually for clarity, and to show how the same experiences occurred but from different perspectives.

The next chapter aims to highlight and discuss the key findings of this research. This includes discussing the synthesised analysis data presented in this chapter and understanding how this relates to the Equality Act 2010 and the term ‘reasonable adjustment’, and asking the question as to what is ‘reasonable’. The next chapter also aims to present and understand how organisational bodies, such as the Department of Health and NHS England, interpret the duties set out in the Equality Act 2010, and what guidance they have designed for medical settings to follow. Alongside this, the next chapter attempts to make sense of the issues that deaf people face as healthcare users.

Chapter 9. Deaf people as healthcare users: The reality for users and providers

9.1 Introduction

The scope of this chapter is to discuss the data presented in the previous chapters of this thesis to gain an overall understanding about how deaf people access healthcare. The aim of this chapter is to gain an overall understanding of what is expected through the Equality Act 2010 and its terms of 'reasonable adjustment' and 'accessible information'. This then follows on to the guidance produced by the Department of Health/NHS to understand how they have interpreted the duty placed on the NHS by the Equality Act 2010. The purpose of this is to draw conclusions about the hospital policies and consider whether the policies fall in line with the themes presented by the two participant groups.

9.2 What is deemed to be the 'reasonable adjustment' and 'accessible format'?

The Equality Act 2010 creates legal rights for deaf people and people with protected characteristics. We can see through everyday living on the news and through the lived experiences of the deaf participants in this study, that despite having the right to be equal, this does not always happen. One topic that was not discussed in previous chapters was the recognition of BSL in 2003 by the UK government. The Secretary of State for Work and Pensions (Mr. Andrew Smith) stated:

> "...The Government recognise that British Sign Language (BSL) is a language in its own right regularly used by a significant number of people. For an estimated 70,000 deaf people it is their preferred language for participation in everyday life. BSL is a visual-gestural language with its own vocabulary, grammar and syntax." (Smith, 2003)

The recognition of BSL as a language should have been a huge success for the deaf community and the use of BSL. However, not much change has happened since this recognition in 2003, unlike Scotland's BSL Act 2015 which provided legal rights and required some authorities to provide plans about how they were going to implement the Act:

> "The British Sign Language (Scotland) Act 2015 came into force in October 2015. It promotes the use of BSL in Scotland, primarily by requiring certain authorities to develop BSL plans that outline how they will promote and raise awareness of the language." (Scottish Government website: 2020)

However, even though British Sign Language was only recognised by the British Government and did not provide any legal status, the language and interpretation of the Equality Act 2010 informs us that deaf people have a right to communicate in their own preferred language, and duties are placed on public services to seek adjustments to suit the service user.

Chapter Two presented many published stories which have shown issues with deaf people's access to the NHS, despite equality and diversity in society being expected. The UK has an Equality and Human Rights Commission to support and protect those mentioned in the Equality Act 2010, but even the Commission has stated:

> "Britain is fortunate to have a strong equality and human rights legal framework to protect people from discrimination and violations of their basic rights and freedoms. However, the experiences of many people across England, Scotland and Wales often do not reflect what is set out in law" (Equality and Human Rights Commission 2019).

Legislation has been put in place to protect deaf and disabled people from any form of discrimination within society. This legislation aims to eliminate any unjust actions from society and aims to allow everyone the same access. Interestingly, when society talks about equality, we immediately look towards the equality legislation such as the Equality Act 2010. However, if we broaden the perspective of the Equality Act 2010 and the protected characteristics named within this legislation, then we see that these characteristics also relate back to the Human Rights 1998 legislation.

Human Rights 1998 – Articles	**Equality Act 2010 – Protected characteristics**
Article 8: Right to be respected for your private and family life	Sexual Orientation, Marriage and Civil Partnership
Article 9: Freedom of thought belief and religion	Religion or Belief
Article 14: Protection from discrimination	Age, Disability, Race, Sex, Sexual Orientation, Pregnancy and Maternity, Gender Reassignment,

Table 6: Human Rights 1995 and The Equality Act 2010

The Equality and Human Rights Commission states:

> "One effect of these laws is to oblige our public authorities, such as hospitals, the police and local councils, to treat everyone with dignity, respect and fairness. Another is to protect people's right to voice their ideas openly and to peacefully protest if they disagree with government actions or policies...
>
> The Human Rights Act 1998 is one of the most important pieces of legislation for public authorities. Everyone who works in public authorities must act in a way that is compatible with this Act. By providing services in a way that is compatible with the Act, a public body not only meets its

> duties but makes a positive difference to people's lives." (Equality and Human Rights Commission [b], 2014: 3)

The protection from discrimination within the Human Rights 1998 legislation is not 'free-standing', which means that the discrimination right can only be broken when at least one other right within the act is also broken (Equality and Human Rights Commission, 2014). There is a strong argument that Article 8, which protects people's right for a private life, could be breached if deaf/disabled people cannot access public authorities such as hospitals, especially as Article 8 states that it is relevant in a wide range of areas such as: "the right of people using healthcare or social care to be treated with respect for the dignity and person autonomy" and also "an individual's right to refuse medical treatment" (Equality and Human Rights Commission, 2014: 34). However, this right to be 'treated respectfully and with dignity' and to 'refuse treatment' also comes at the cost of being able to understand what is going on and what the treatment is, and therefore being able to access information is an obligation for public authorities, and also to promote and protect people.

The terms 'reasonable adjustment' and 'accessible format' have proven to be controversial. As mentioned in Chapter Four, the Equality Act 2010 is written broadly, which results in statements within the legislation being left open for interpretation. The lack of any formal definition is a contributory factor to everything raised throughout this thesis.

Therefore, it is vital to determine what 'reasonable adjustment' and 'accessible format' means for deaf people who need to access healthcare services. Although these terms are important, no study has discussed how the 'reasonable adjustment' or 'accessible format' is met, and more importantly – who decides what is reasonable and what is the most appropriate accessible format. Hospitals or healthcare settings have the duty to make the adjustment and therefore, they should consider what is reasonable and the obligation is upon them to decide what is the reasonable adjustments; however, the adjustment is for the deaf person to access the service and they will know the best way they need to communicate, and therefore what is 'reasonable' should be tailored to suit them. An important factor with the terms 'accessible format' and 'reasonable adjustment' is that in the context of someone who is deaf, the 'accessible format' is the 'reasonable adjustment' - essentially, they are one and the same thing. When reviewing previous research (Reeves et al. 2002; Ubido et al. 2002; RNID 2004; Middleton et al. 2010; Lacey-Davidson 2012; Ringham 2012; SignHealth 2014) and anecdotal evidence (Bates 2009; Palmer 2013; Siddique 2014), it is suggested that the most appropriate method for deaf people needing to communicate in a healthcare setting is British Sign Language, as the root of nearly all the issues identified in these studies and stories relate to the lack of qualified BSL interpreters and communication issues.

When reviewing the most recent guidance from NHS England's Accessible Information Standard (2015), this document clarified what was expected from hospitals and service providers:

> "Despite the existence of legislation and guidance – as outlined above – in reality many service users continue to receive information from health and social care organisations in formats which they are unable to understand and do not receive the support they need to communicate."
> (NHS England 2016: 11)

As highlighted in Chapter Five, the Accessible Information Standard also explicitly stated that those who need support with communication should get the support they need and in relation to a deaf person, this can be in the form of a British Sign Language interpreter:

> "The accessible information standard also tells organisations how they should make sure that people get any support with communications that they need, for example support from a British Sign Language (BSL)

> interpreter, deafblind manual interpreter or an advocate” (NHS England 2015: 1).

This statement by NHS England summed up the inequality that deaf people face when needing to access healthcare. This statement indicates that NHS England has recognised the lack of support that deaf people find themselves experiencing when trying to access hospitals. This sets out how NHS England envisages the terms ‘reasonable adjustment’ and ‘accessible format’ and therefore, the process of booking a BSL interpreter, and the importance of a BSL interpreter, should be implemented into hospital policies. It is interesting to note that the legislation has not changed since 2010, as the terms and duties set out in the Equality Act are still the same; the accessible information standard merely gave clarity, because the access for deaf people and other disabled people was poor.

My analysis of policies, on the surface at least, have shown that many of them also accept that BSL interpreters will be needed, with 10 out of the 11 policies that could be reviewed having referred in some way to the booking of BSL interpreters. Given the statements laid out by NHS England within the Accessible Information Standard and most of the hospital policies having made reference to British Sign Language interpreters, this shows that they expect to provide a sign language interpreter and that healthcare settings should have provisions in place for deaf people to access healthcare with the support of a qualified BSL interpreter. Alongside what has been laid out, the experiences from the deaf participants in this study have shown the impact of not having a qualified sign language interpreter. Therefore, it is rational to establish that ‘reasonable adjustments’ and ‘accessible information’ in the context of deaf people who use British Sign language includes the provision of a qualified BSL interpreter who not only provides information in an accessible format, but it is also the reasonable adjustment that healthcare settings need to, ultimately, make to facilitate access for deaf people. The term ‘ultimately’ has been deliberately included in that last sentence as some healthcare services might need to gradually work towards providing a BSL interpreter depending on the situation or the setting, which will be discussed next.

9.3 Trying to make sense of what is going on

This chapter has now established the adjustments and access that should be made for deaf people when needing to use the health service, in the correct provision for qualified BSL interpreters. The previous chapter explored the issues in depth, and shared the issues for both deaf participants and paramedics.

The deaf participants and paramedics gave their experiences from different settings: the deaf participants mainly gave their experiences from a static setting, for example in the hospitals or GP practices, whereas the paramedics gave their experiences from acute and mobile settings. This provided a lot more information than was originally intended and provided a much wider snapshot of the issues faced, and how they dealt with the situation. As the communication issues explored by both sets of participants were mainly the same, the concluding findings suggest that each type of setting - static, acute or mobile - can still raise the same communication issues, but how these issues are overcome and what is expected in the various settings can differ greatly.

Interestingly, those that were in a static setting, such as a hospital or GP practice, mainly relied on the provision of a BSL interpreter. If an interpreter is not available, some deaf people might rely on somebody else to communicate for them, such as Foxy's experience, which is arguably one of the most inappropriate alternatives to not having a BSL interpreter. As discussed in Chapter Two, when an ad hoc interpreter is used, it is unlikely that any interpreting is happening and rather, the theory of language brokering is occurring, which could be altering what would normally be said if a qualified interpreter was present (see Chapter Two). Alternatively, some deaf people might attempt to go through the appointment without any other type of provision and rely on the doctor's knowledge of deaf awareness, as shown with Hedgehog's experience, although there is a serious amount of risk with this type of practice, as explored in previous research (see Chapter Two).

When reviewing the acute or agile settings, such as ambulance crews, what is expected in terms of reasonable adjustments and accessible information drastically changes. The provision that is expected in a static setting is not the same as what is expected and can be achieved in an emergency setting. All of the paramedics in this study commented on it being near impossible for a BSL interpreter to be present at the beginning of an emergency situation, and because of this they had to find other ways to communicate. The other means of communication included the use of pen and paper, communication books if the paramedics had them, or the use of family or friends to help gain relevant information. Apart from the communication booklet, as highlighted in Chapter Two, the use of pen and paper is not a reliable method (Conrad 1979; Sawtell 2014), and the effect of using family and friends has been proven to be inappropriate in this study, and previous studies reviewed in Chapter Two. Also, as highlighted in Chapter Two, the concept of the translanguaging strategy can also be seen as a communicative method for deaf people, particularly when they experience linguistic inequalities such as when an interpreter is not present (De Meulder, et al., 2019), although this can also occur when an interpreter is present Napier et al. (2019). Communication methods such as reading and writing are not reliable, but arguably make strategies such as translanguaging also not reliable. As translanguaging strategies can also be adopted when qualified interpreters might lack certain interpreting skills (Napier et al., 2019), it is possible that when language brokering is happening with ad hoc interpreters, deaf people might also need to fall back on a translanguaging approach.

There is an understanding from both paramedics and deaf people that in emergency situations only it is more acceptable to rely on pen and paper as a communication method, or family and friends to help aid communication and provide information even though it is a method that should be avoided. For example, some of the deaf participants understood that there cannot be an interpreter constantly (Muriel), and that interpreters are harder to acquire during evenings and weekends (Foxy). This showed a shared acceptance from both groups of participants in this emergency situation, but when the patient then moved to the hospital, it became apparent that there was a huge shift in what was expected in place of communication and reasonable adjustments. This change in expectation was shown through all the paramedic participants expressing their views that they thought deaf people should be given a BSL interpreter in a hospital setting, however, they all acknowledged that when on an ambulance it would be near impossible to expect to have an interpreter present.

As explained earlier when establishing the 'reasonable adjustment', healthcare services should 'ultimately' aim to provide qualified BSL interpreters. However, instead of viewing a 'reasonable adjustment' as a single provision that allows deaf people to communicate and make informed decisions, healthcare services should be providing other resources when an interpreter is not available. For example, this study has established that acquiring a BSL interpreter in an emergency situation, such as an ambulance, is in practical terms, impossible. In this type of emergency and agile setting, communication books should be used and if the healthcare professionals need more information, then the use of ad hoc resources, if practical, would be more acceptable as the time that ambulance crews spend with patients can be quite limited. However, when the deaf patient then moves from the ambulance to hospital, it becomes reasonable for registered and highly experienced interpreters to be used, rather than ad hoc resources.

This shows that the healthcare setting impacts on what is expected and the idea that qualified BSL interpreters should always be seen as the 'reasonable adjustment', but it should also be viewed as something that healthcare providers can gradually work towards, depending on the setting. This also applies to when the deaf patient first gets to the hospital: obviously, the interpreter would need time to get themselves to the hospital and additional provision would need to be made while waiting for the interpreter, but again, this depends on the severity of the incident and the reason as to why they are in hospital, and if there is time for an interpreter to get to the hospital before a lifesaving procedure might occur, which can only be decided by the healthcare professionals who are in the situation.

9.4 The contradictions

This thesis has now established that in the context of a deaf person accessing healthcare, a BSL interpreter is needed. It has also been established through recent guidance, such as the Accessible Information Standard, that it is expected that trusts will find and apply the correct provision which allows deaf people to access healthcare in a format that they understand. Establishing the 'reasonable adjustment' and the dependency of the situation, which affects what the reasonable adjustment is, as explored above, is something that healthcare providers need to consider. It is also important to remember that as Minister Baroness Jolly pointed out, the reasonable adjustment that is required through the Equality Act 2010 is also an anticipatory duty (Baroness Jolly, 2014), so hospital trusts must make sure they have appropriate provision with a clear action plan on how to obtain the provision at all times.

All of the trusts that provided policies had emergency departments, but only three provided some type of provision for emergency interpreters. This is no different to the findings reported by Reeves (2002) and RNID (2004) which showed extremely low numbers of interpreters being available for emergency appointments. When reflecting on the trusts not having emergency provision for interpreters, it is not surprising that deaf people's experiences of going to emergency departments is poor and therefore, they try to avoid going to emergency departments unless severely unwell; if there is no out of hours contact for interpreters within the policies, then the healthcare staff cannot acquire an interpreter for the patient. It is also important to highlight that none of the policies mentioned ambulances and what is expected from emergency crews bringing in a deaf patient, leaving the paramedics and possibly hospital staff struggling with what to do when they need to communicate with a deaf BSL user. This presents a huge gap within hospital policies and the Accessible Information Standard as the paramedic participants within this research outlined that once they arrived at the hospital with a deaf patient, they would then expect an interpreter to arrive within a reasonable timeframe, however no benchmark has been set outlining what is expected from emergency departments in this type of situation.

This lack of provision for emergency interpreters also causes a contradiction. Eight out of eleven hospital policies reviewed in this study commented on not using family and friends as interpreters. However, these policies have failed to find an alternative which stops family and friends from being used as interpreters. Interestingly, the need for emergency interpreters is something that is overlooked, as even the most recent guidance in the Accessible Information Standard (2016) overlooked the need for emergency interpreters. This also shows the lack of consideration from the hospital policies as they expect family and friends not to be used as interpreters, but they fail to provide an alternative for the deaf patient.

This can be related to the experiences explored in this study (Foxy and Marco) and previous reports (Palmer 2013; Reeves et al. 2002; Association of Sign Language Interpreters 2012) that showed that when an interpreter was not booked, family and friends stepped in to be interpreters. Unfortunately, this study did not investigate why the deaf participants allowed their family and friends to interpret; however, Foxy provided a small insight as to why she used her partner as an interpreter – this was quite simply "I wanted to know if I was alright… that was the main priority… so I put up with that" (Foxy). It is important to also point out that this comment from Foxy, which was about an MRI result, and other examples such as Palmer (2013) who shared an experience of a cancer consultation, took place in static and calm situations where the appointments had been planned.

However, in emergency admissions, stress levels could be higher and there might be more panic, and as explored by Emma, tiredness can affect the level of information being interpreted; combining all these factors with the adrenaline of an emergency situation, and the fact that family or friends might not be qualified interpreters, and are therefore untrained in dealing with this type of situation, it is reasonable to question how much information will be interpreted correctly.

The situation that has just been described through emergency admissions and the quality of interpreting from family or friends, can also be related to the experiences of the deaf participants in this study. Marco and Muriel both commented on the lack of information about trainee interpreters. Interestingly, Foxy even commented that qualified interpreters do not always understand terminology or other medical jargon. These experiences can be used to reflect a very dynamic picture: not only does this address the importance of being able to acquire a qualified interpreter to help maintain relationships and supporting roles for family and friends who may attend an appointment with the deaf patient, but it also shows the importance of healthcare and how it must be communicated clearly so that the deaf person understands the outcomes of any diagnosis and treatments about them; if any information is not clear then the deaf person has the opportunity with the interpreter for this to be explained further. This should also be considered for children of deaf parents, which was not explored in Chapter Eight as it was only discussed by one participant, but was highlighted by Foxy in Chapter Six and should therefore still be mentioned. Deaf adults who have children, such as Foxy, also need to be able to access healthcare in a format which is accessible to the adults for the same reasons, especially when treatments and medications are involved, as these need to be explained and understood clearly by the adults. As discussed in Chapter Two, Ringham (2012) reported that 41% of deaf people were confused about their medical condition and Healthwatch Cumbria (2015) reported that 41% were not clear about medication instructions. Although the figures from Ringham (2012) and Healthwatch Cumbria (2015) were about the adults who took part in the research, these figures can still be related to deaf adults who have children. This has not been considered in the Accessible Information Standard and was not mentioned in any hospital policies, but if deaf people are unsure about treatment and medication for themselves, then this is the same for adults who are responsible for children.

The final point that needs to be raised in this section is the timescale for getting an interpreter. Several hospitals acknowledged that family and friends should not be used as interpreters unless in an emergency, but when does this timeframe pass and where is the provision to stop family and friends from having to interpret? In other words, when does an accident or illness stop being urgent? This question is something that can only be answered through the judgement of the healthcare professionals that are in that individual situation. However, it is important to highlight that the Equality Act is an anticipatory duty and the Accessible Information Standard identifies that interpreters are a requirement which need to be provided. Therefore, suggestions can be made that once a deaf person attends the hospital then the process for ascertaining an emergency interpreter should be started with an expectation that an interpreter will arrive within an agreed and anticipated timeframe.

This research outlines a small understanding about what is expected of the provision in hospitals, from the paramedics, who suggested that everyone who wants an interpreter even in an emergency situation should be able to have one. Bart and Christy explored why they felt it was important, which was mainly so that all patients can be involved and understand what is being said, but more importantly, for the patient themselves to correct any wrong information that is being passed between the paramedics and hospitals. Involving the patient in this way and allowing them to correct this information can also be related to getting the patient’s history, which has been shown to be key to making a diagnosis (Peterson et al. 1992; Ohm et al. 2013). In the experiences of the paramedics, they suggest that even in emergency situations, interpreters are vital and should not be overlooked. Family and friends should only be used be used as interpreters as a last resort when in emergency situations. However, hospital policies leave no alternative for family, friends and medical staff to take action in stopping this from happening.

As discussed in Chapter Two, the number of interpreters registered with governing bodies, such as the NRCPD, is low compared to the number of deaf people and therefore, there is a shortage of interpreters. However, this should be seen as a reason to 'make sure that there is provision in place for emergency interpreters', instead of viewing it as 'there is a lack of interpreters, we cannot acquire one'. There also needs to be a consideration for a benchmark within the timescales for getting an interpreter. In the case of a life-saving emergency operation, it would obviously be impossible to acquire an interpreter if the operation needed to happen right away, but other types of treatments or diagnoses may result in a stay in the hospital until they recover. This still requires a qualified interpreter for the deaf patient, and raises the issue about how long it reasonably takes for an interpreter to get to the hospital, and how long their support might be required. The paramedics in this research recommended that they would prefer an interpreter at the handover, however, others commented that it would be reasonable within a couple of hours and this would be variable depending on where the interpreter is coming from. This should fall into the anticipatory duty of the Equality Act and be outlined in the Accessible Information Standard so that hospitals are ready for emergency situations to occur which would have created a benchmark of what is reasonable when obtaining an interpreter. However, because the benchmark did not happen, this also identifies a gap in the Department of Health and NHS guidance, and subsequently hospital policies, about their understanding of how deaf people need to access the NHS in emergency situations in a way that is equal to those who are not deaf. There was one particular point that was made by Paolo that I will address here. When asked about what Paolo felt was a reasonable adjustment, he stated that having an interpreter on-site at the hospital would be very expensive. Whilst financial considerations obviously are important to the functioning of NHS, the Equality Act 2010 still places a duty on hospitals to be ready and anticipate deaf people needing to use the emergency department. I argue that this means that hospitals should have already factored in financial costs before the deaf person has already arrived.

9.5 Knowledge and communication should not be undervalued

This chapter has now established what should be expected in terms of a reasonable adjustment for deaf patients in healthcare settings with the provision of a qualified interpreter, and how this could gradually be achieved in emergency or acute settings when it would be impossible to immediately have an interpreter present.

Knowledge of deaf awareness can go a long way, especially when communicating without an interpreter, as expressed by some of the paramedic participants (Paolo, Christy and Bart). Preparation in terms of the paramedic situation would mainly be in the form of resource provisions, such as communication books and knowledge of deaf awareness, which would most probably come in the form of training. All paramedics commented that as a result of their experiences they should have disability awareness training. This could suggest that treating and communicating with deaf patients is not the only situation where the paramedics may find the situation frustrating or more difficult to adjust to. This study analysed the different ways that the paramedics communicated when there are limited or no provisions. From this, there was an accumulation of trial and error methods that were used to communicate. This should not be considered as a negative in the acute situations that the Paramedic experiences were based on, but something that should be taken forward as another means of trying to communicate. There was an interesting comment by Christy about the use of Makaton. Whilst I believe Christy to have meant this in well-meaning and I do not believe he suggested Makaton as a full replacement to BSL or a BSL interpreter. It is important to highlight that visual communication methods mixed with a trial and error approach should only be used in an emergency when there is nothing else until a BSL interpreter arrives.

The method of trial and error that formed part of the paramedic experiences was heavily related to the knowledge that they had from their own personal experiences. For those who have not been in the situation of needing to communicate with a deaf patient, training would be appropriate, as even the paramedics in this study valued communication/awareness training. The idea of prior knowledge should also be regarded as something that can prove valuable to both paramedics and hospitals. If the patient is deaf and uses sign language, then it is important to share this information as far in advance as possible so that provisions can be made ready, and also to give paramedics the time to adjust how they are going to communicate, especially if a BSL interpreter is not going to be present.

The importance of knowledge and communication needs to be highlighted in relation to the hospital policies. The policies should aim to show how the hospital expects its staff to clearly meet the legal requirements of the Equality Act 2010 and the duty that this legislation places on them. Previous research (see Chapter Two) highlighted many issues with the procedures for booking interpreters and although the statistics reported were mainly from GP practices, it can still be very relatable to hospitals with the same issues arising. This research has explored the use of qualified interpreters and specific interpreters which provided a deeper understanding about why they are so important. The sole purpose of an interpreter in this type of situation is to make sure that the information is being relayed to the deaf patient in a format that is accessible so that decisions, treatment or diagnosis can all be understood fully by the deaf patient. This interpretation is conducted not only for the deaf patient, but also for the HCP, as the interpreter supports the deaf patient in relaying the correct information, such as what happened or their medical history. Middleton et al. (2010) showed that in a clinical setting, deaf people wanted to communicate in BSL and although the majority used speech to communicate, in Middleton’s study the use of BSL greatly rose when in medical situations. Ringham (2012), Lacey-Davidson (2012) and Sign Health (2014) all reported the importance of using qualified interpreters, and these are the more recent publications which were published after the Equality Act 2010 became a requirement. As shown in Chapter Eight and Chapter Two, the theoretical concept of translanguaging is something that needs to be considered not only as a communication method when linguistic inequalities occur (De Meulder, et al. 2019), but also when interpreters lack linguistic skills and the deaf person has to monitor the interpreter present and then fall back on a translanguaging strategy. This could suggest that qualified and specific interpreters that have been requested by the deaf person are the closet way to avoiding translanguaging or trial and error strategies, which might lead to more positive linguistic access.

This research did not set out to critically review the hospital policies, but used the policies to investigate how the issues uncovered by the experiences of both the deaf participants and paramedics were overcome in medical settings and how access to healthcare was facilitated for deaf people. The inclusion of the hospital policies has exposed a lack in provision not only for deaf patients, but also for the healthcare professionals. The Accessible Information Standard that was published in 2015, and the post-implementation review in 2017, showed that the standard did not make much of an initial impact. Existing knowledge from previous research (Chapter Two) set out the importance of interpreters and highlighted the need for qualified interpreters, but yet the hospital policies and other guidance, such as the Accessible Information Standard, fail to set the standard of only acquiring qualified interpreters. This research also showed the importance of using qualified interpreters and not trainee interpreters, especially in high-risk situations such as a healthcare setting where information needs to be clear. To use a trainee interpreter in a situation such as healthcare, where the deaf patient and HCPs both need to make informed decisions to progress with the next steps, such as treatment or diagnosis, could be viewed as quite careless and an extra risk that should not be taken. Interpreters gain their fully qualified interpreter status for a reason (as discussed in the previous chapter) by meeting the National Occupational Standard for interpreting and being competent to interpret at a national standard (Katz 2018); to disregard the need for qualified interpreters in such important situations as health appointments makes it seem pointless that the professionals are required to meet the national standards. It is not surprising that the Accessible Information Standard did not have much impact when it failed to standardise qualified interpreters as the reasonable adjustment. The Accessible Information Standard also failed to highlight the need to anticipate emergency situations and set a precedence on what is expected when waiting for an interpreter, which would make hospitals have appropriate resources ready for when the emergency situations occur.

Within the hospital policies that provided a means of contacting a BSL interpreter, there were several different methods presented. Some of these methods included a type of portal that booked interpreters, or a phone number, or booking with an external interpreting agency. The use of agencies was not something investigated in this research, but it is something that should not be ignored. Many of the hospital policies relied on agencies to provide appropriate interpreters, such as EM2. It is important to highlight that the 'reasonable adjustment' duty from the Equality Act 2010 is placed on the hospitals or medical settings, not the agencies supplying the interpreters. Some of the policies suggest that as they have the use of an interpreting agency, then the agency assumes the responsibility of the trusts 'reasonable adjustment' for deaf people. Interestingly, another guidance document that came out in 2018 from NHS England, which provides information on interpreting and translation services for primary care, states:

> "The Equality Act 2010 places an additional duty on public sector bodies who are subject to the 'public sector equality duty' including independent contractors working in a primary care setting. This requires such bodies to have due regard to alleviate disadvantage experienced by people who share a protected characteristic, or to meet their particular needs, by making reasonable adjustments." (NHS England 2018:14)

Ultimately, it is up to the hospital or medical setting to make sure that an interpreter is fully qualified and holds the relevant qualifications and registration. It should be made very clear in hospital policies what the minimum criteria is, and this should then be set out to agencies - should hospitals wish to use them - to stop any inappropriate interpreters from interpreting in healthcare settings. The NHS England guidance from 2018 also clarifies this point:

> "Organisations must ensure that the communication and language professional holds relevant interpreting qualifications and, in the case of British Sign Language (BSL), has achieved BSL level 6 or an honours degree in their second language, in line with NRCPD (The National Registers of Communication Professionals working with Deaf and Deafblind People) registration requirements. Those working in health and social care settings should have sufficient knowledge of medical terminology in order to communicate information effectively." (NHS England 2018:17)

NHS England have now explicitly stated that hospitals and other medical settings must ensure that BSL interpreters have achieved BSL level 6 or have an honours degree in their second language. The NRCPD ([b] 2020) website has a list of approved courses that meet the required professional standard, which upon completion allow a person to then apply to be on the approved register as a qualified BSL interpreter. However, although an interpreter can hold registered interpreter status, there are no specific approved courses which educate interpreters to work in medical settings and therefore, having sufficient knowledge still proves to be an issue.

Although there has been relatively recent guidance about what is expected from NHS England in the provision for deaf patients, Collinson (2018) published an article in 2018 on the BBC showing that many deaf people are still struggling to access healthcare due to not having a face-to-face qualified interpreter. This study explored video interpreting as a couple of the paramedics had commented on this, and the previous chapter highlighted some of the issues that can arise with video interpreting. The BBC article highlights some of the recent anecdotal stories which show some of the issues with video interpreting and although these interpreters might be qualified, there are still many other factors that must be considered; for example, one report showed that a deaf person was told they had a miscarriage via a video interpreter (Collinson 2018). This can be related to the professionalism explored by both the deaf participants and HCPs within this study; informing a deaf patient that they have had a miscarriage over video is not only unprofessional but also goes against the 'safe, effective, respect, dignity and compassion' set out in the NHS Constitution for England (Department of Health & Social Care 2015). This shows that there needs to be more provision implemented within policies for hospitals and other medical settings, and also shows that it might not be possible to have a qualified interpreter straightaway, which means that other methods of communicating need to be explored while waiting for the interpreter to arrive; this is also dependent on the correct provision and resources for getting an interpreter, and preferably a face-to-face interpreter for reliability and to maintain professional standards and outcomes for all. As shown from Collinson (2018), Napier et al. (2017), Kushalnagar et al. (2019) and Lee (2020), the use of video relay interpreting is not ideal. However, some of the paramedics made reference to the use of VRI and VRS, and felt that it was something that they could use when communication is very broken and they are really struggling to get important information across; they felt that VRI or VRS was something that they would use if they had access to it. Arguably, if the use of VRI meant that the paramedics would have the immediate ability, in some way, to save a life, then it is safe to assume this is an acceptable approach as the preservation of life would arguably trump all other considerations.

9.6 Conclusion

This chapter has reasonably established what is regarded as a 'reasonable adjustment' and an 'accessible format' that is in the form of a fully qualified interpreter for deaf patients. This chapter has also established that hospitals and other medical settings are expected to acquire a BSL interpreter, and this has been clearly recognised through various NHS guidance and through the 2016 Accessible Information Standard. This chapter has also established that having an interpreter is not only important to a deaf patient in a medical setting, but it is important and expected by the healthcare professionals.

There is a slight misinterpretation relating to the 'reasonable adjustment' and 'accessible information' duty set out from the Equality Act 2010. NHS guidance and previous research points to the need for qualified BSL interpreters and the goal for many medical settings and NHS guidance see the 'adjustment duty' in the form of a BSL interpreter. This could be because a qualified BSL interpreter is seen as a straightforward adjustment. The main initial and obvious issue between a deaf patient and healthcare professional is a language barrier. The language barrier can be overcome by providing a mediator who can bridge the gap, which in this case would be a BSL interpreter. However, this is not the only adjustment and accessible format that medical settings should solely rely upon, as it is not always fit for purpose.

This chapter, and this research as a whole, has shown the importance of an interpreter for various reasons in medical situations. One of the main issues that has been identified in this research is that medical settings, such as hospitals and GP practices, now rely solely on getting an interpreter and there is nothing in-between obtaining an interpreter and not having one. This chapter has shown that in many situations is it physically impossible to obtain an interpreter, especially at short notice, and there is no accommodation and facilitation within policies or guidance for the in-between situations, such as when a person experiences an emergency situation and then transition of when that emergency situation passes and what is expected in the provision of access for that deaf patient along their journey of care within the hospital.

This research also explored the issues around getting interpreters at short notice, which again, is something that has not been considered by many policies or has been disregarded by policies because it is harder to get an interpreter at short notice; getting a qualified interpreter in an emergency, is just as important as any other situation and should still be expected as part of a 'reasonable adjustment'. There should not be a resignation from either deaf people or medical settings that if it is an emergency, or unsociable hours, there will not be a qualified interpreter present. Instead, the medical settings must anticipate the need for emergency interpreters, particularly when they have A&E departments. This includes finding provisions for unsociable hours and emergency situations and allowing deaf people to receive the treatment and information the same way as someone who does not have a communication barrier. To not anticipate this need all the time, is arguably a failure to meet the duties set out by the Equality Act 2010.

At the beginning of this chapter an idea was presented around 'reasonable adjustments' and the use of qualified interpreters as the 'ultimate reasonable adjustment' or 'final adjustment' that medical settings need to deliver for deaf patients. Providing that all healthcare professionals and qualified interpreters maintain their professional standards, in theory and practically, this is the best outcome for both medical personnel and deaf patients. Strangely, although this is the best outcome for everyone and is the best adjustment that can be made, it should be viewed as the minimum expectation regarding a 'reasonable adjustment' that hospitals can offer deaf people to facilitate healthcare. If a medical setting relies solely on interpreters as the reasonable adjustment, that leaves the deaf patient with two options: 1) you have an interpreter, or 2) you have nothing. This research, and previous research, has shown that having nothing leads to very negative outcomes for everyone. Medical settings need to have provisions for additional resources whilst waiting for an interpreter to arrive at the hospital. These additional resources could be in the form of communication books and deaf awareness training, so that the healthcare professionals know how best to facilitate communication when there is a language barrier through a visual representation rather than relying on a spoken language. Resources could be shared from different trusts and included within policies which are clear and easily accessible.

This thesis argues that to fulfil the requirement of what the ‘reasonable adjustment’ is extra anticipatory provisions and resources in place such as: appropriate access to interpreters at any time, clear standards of timeframes for acquiring an interpreter, clear standards for who is classed as qualified interpreters, appropriate methods of communicating when an interpreter is not present such as communication books, HCP’s to have the right training to help communication when there is a language barrier when an interpreter is not present but on their way to the medical setting and finally, when qualified interpreters stop being seen as ‘good practice’ and start being seen as ‘legal practice’, only then can it be classed as starting to make a more wholesome ‘reasonable adjustment’.

Chapter 10. Conclusion and the way forward

The final chapter of this thesis will summarise the key findings of this research and attempt to answer the research questions set out at the beginning of this thesis. Following this, the original features of this study will be outlined, and the limitations of this research will be highlighted. The rest of this chapter will then explore any recommendations from this study and any further research that could be undertaken. Lastly, this chapter will conclude with my own personal reflection and final thoughts on this study.

10.1 What does it all mean?

This research set out to answer four research questions:

1. How is access to the National Health Service facilitated for deaf people, and in particular deaf BSL users?
2. How are disability and human rights legislation applied to deaf people within the context of the UK's National Health Service?
3. What practical and ethical issues arise for health service providers when the service users are deaf BSL users?
4. How is the term 'reasonable adjustment' represented in acute health care policies and practices in relation to deaf BSL users?

The order in which the research questions are presented in this chapter will be chronological.

Research question one [How is access to the National Health Service facilitated for deaf people, and in particular deaf BSL users?] can be answered through the experiences of the deaf participants and the analysis of hospital policies, in order to find out how access is facilitated when at the hospital. This study explored how deaf people communicated with healthcare staff and provided an insight into how a range of deaf BSL users wanted to communicate in medical settings. Most of the participants understood that in emergency settings they would have to wait for an interpreter to be present; however, during normal hospital appointments the deaf participants presented huge range of responses, and how the NHS facilitated access, was dependent on how the participant wanted to communicate. Three out of five wanted to use a British Sign Language interpreter to communicate, but when investigating the policies to understand how this happens, it is relatively unknown. Ten policies had some sort of method to contact an interpreter - this would suggest that they contact a language agency who then contacts an interpreter - and only four policies showed consideration to emergency interpreting situations.

This suggests that the hospitals do have knowledge and understanding that BSL interpreters are very important in medical appointments, but nevertheless there are still too many examples from the deaf experience that suggest that the policies are not enough to fully facilitate access for deaf BSL users. This research has not been able to identify where this breakdown occurs in the process of providing interpreters; we know that many deaf participants contact hospitals to check that an interpreter is booked, or if they have gone to an appointment and no interpreter was present, they will ask for it to be written on their notes that an interpreter must be booked for the next appointment.

In Chapter Four, the Accessible Information Standard was explored and it was noted that there is supposed to be a system for flagging patients’ needs for appointments so that the communication needs of each patient can be met. This could lead to the assumption that maybe the booking system and the expectations set out in the Accessible Information Standard are still not fully integrated, or that booking an interpreter is something that is overlooked and that staff are unsure how to do this. One very important point for facilitating access is the use of emergency interpreters. No policy or guidance explores a reasonable timeframe for getting an emergency interpreter and, as stated previously, only four policies showed contact details for emergency interpreters.

Only one policy did mention a reasonable timeframe, however, it failed to give further information on what it expects the reasonable timeframe to be. Nearly all of the policies have stated that using friends and family as interpreters is highly frowned upon, and this should not happen unless it is a life-threatening situation, and even in such a situation the policies suggest as little interpretation from family and friends as possible. However, the hospital policies have not considered that in order to avoid family and friends being used as interpreters, the hospital staff need to have a process for contacting an emergency interpreter at all times. Without being able to contact an emergency interpreter, the deaf patients and their family or friends are being left with no choice but to interpret. Even with childbirth - which sits between an appointment and an emergency, or a planned emergency - there is nothing. From this study, we see that there can be complications when an interpreter is not present for childbirth. If a deaf patient did want an interpreter in an emergency such as childbirth, which is something that most people know is coming, why not be ready with an interpreter who is expecting a phone call from the hospital?

Deaf people who did not want, or did not receive, an interpreter mainly communicated through reading and writing combined with lip-reading. This method was suitable for some and meant that the deaf patients had a means of being able to communicate. If the deaf patient wanted a more private appointment between them and the doctor, then this was the main method of communicating, but this meant that the deaf patient was relying on the doctor to know some deaf awareness to help with communication and clarity in these situations.

When research question two [How are disability and human rights legislation applied to deaf people within the context of the UK’s National Health Service?] is considered, it is evident that the Equality Act 2010 and The Human Rights Act 1998 both require public bodies to make adjustments and not to discriminate against people with protected characteristics. Earlier in this study, the requirements of the Equality Act 2010 were examined to show how public bodies have equality duties placed on them to make adjustments, so that if a person is at a disadvantage, reasonable steps must be taken to avoid the disadvantage. This might be through auxiliary aids such as interpreters, note-takers, lip-speakers, or another type of accessible format that the person is comfortable with. Legislation is written broadly and can be interpreted in different ways, but the Accessible Information Standard can arguably show the intention of how the Equality Act 2010 is to be interpreted.

Chapter Four showed that the Accessible Information Standard, published by NHS England, outlined the intention and interpretation of the Equality Act 2010, which requires medical settings to provide interpreters or other communication aids. As highlighted in Chapters Five and Nine, the Accessible Information Standard stated that many health and social care services are failing to provide information in accessible formats. This outlines that deaf BSL users have clearly got equality rights, however, despite multiple research publications shown in Chapter Two, alongside the findings in this research, it appears that many deaf people find themselves powerless to exercise these rights and are left to seek medical treatment in a way that is unequal to those who are not deaf.

Research question 3 aimed to investigate the practical and ethical issues that paramedics face when treating deaf BSL users. Some of the paramedics explored a number of issues they faced when an interpreter is not around. All of the paramedics were aware of family and friends interpreting for deaf patients and the potential issues that could arise, and showed awareness that family and friends may not fully interpret what was being said. However, from their point of view, it is a good way to get a lot of information quickly, especially if they do not have any other means of communicating and they need to act quickly.

Some of the paramedics showed their concerns about gaining consent when treating deaf patients, and some of the paramedics felt that everyone should fully understand and have a good means of being able to communicate. From the interviews in this study, we saw examples of good communication methods from the paramedic participants who showed good awareness and thought processes to find out the information they needed, to help and support their deaf patients.

Other practical issues that the paramedics explored included knowing in advance that they might be going to a deaf patient; being given the opportunity to be prepared and not feel caught out was something that a number of the paramedics wanted. The paramedics who did know that they were going to treat a deaf patient could then act and start to think about how they intended to communicate when they arrived. The last practical issue that was highlighted was the need for deaf awareness or disability awareness. Most of the paramedics claimed that they did not have any deaf awareness training, and actions such as facing the deaf person when trying to communicate were sometimes taken for granted.

As many of the paramedics did not have awareness training, they all felt that it would be of some benefit to have an awareness. Some also felt that it would be good to get an idea of the full range of resources available to them - such as communication books - so that when they are trying to communicate, they have more options of communication aids other than pen and paper. Some HCPs felt that it would be good to have some basic sign language, but others felt that it would be impractical for them as they would not retain the language. Interestingly, some of the HCPs mentioned technology as something that is slowly being integrated on the ambulances, such as smart tablets/computers. Some of the HCPs commented that it could be beneficial to have some kind of resource that they could access via these devices, which could provide support for both ethical and practical issues.

Although all of the health participants were ambulance crews and their experiences were not in a hospital environment, this study has still gained an insight of the ethical and practical issues that arose during hospital appointments through the experiences of the deaf participants. Practical issues explored by the deaf participants included topics such as deaf awareness, for example: going into an appointment room and moving chairs around to accommodate the BSL interpreter. In addition, some deaf participants felt that HCPs are unsure about how to work with interpreters. It is also evident that some of the deaf experiences in this study have shown that there can be friction between HCPs and interpreters, for example when a nurse said that an interpreter was not allowed in the room during a blood test.

There was one ethical issue that both parties fully agreed upon and that was the use of fully qualified and competent interpreters. This shows that the paramedics want the deaf patients to be able to communicate with them, and they also feel that it is important for this to happen. Within this study alone, four out of the five deaf participants made remarks about family members stepping in and doing interpreting duties, and some of these situations happened within the last few years. As mentioned in the previous chapters (see Chapters Eight and Nine) the discussion about flexible adjustments/communication. The paramedics all agreed that having an interpreter is the best adjustment, but only once they took the deaf patient to the hospital. The paramedics all agreed on getting an interpreter at the hospital because, from their experiences, it would be impossible for them to be able to get an interpreter before this point. It is important to remember the paramedics experiences were from an emergency experience. Before reaching the hospital, the deaf patient’s access to healthcare was facilitated through the ambulance crews with the use of communication books, reading and writing, lip-reading, and trial and error of a mixture of communication approaches. According to the experiences of the paramedics, this approach was enough for them to be able to transport the patient to the hospital to enable the deaf patient to get further treatment. At the hospital, the deaf patient would ideally have full access with the use of a qualified BSL interpreter, as the patient would then be in a position where it is possible for an interpreter to be present.

This finally brings us to research question four [How is the term 'reasonable adjustment' represented in acute health care policies and practices in relation to deaf BSL users?]. The term ‘reasonable adjustment’ has been repeatedly referred to throughout this thesis and the answer to this question needs to be considered in different situations. The first scenario is booked appointments where the hospital has sent a consultation appointment to the deaf patient. When this type of situation occurs, the 'reasonable adjustment' is clearly a fully qualified interpreter and with the Equality Act 2010 being an anticipatory duty, acute health care settings have no excuse to not provide qualified interpreters. Some of the hospital policies mentioned cost, and it was also highlighted in the Accessible Information Standard. This research took the stance that if an interpreter is required, then one should be provided, and the cost should not be a factor or an excuse for why one has not been provided as it is requirement by law which must be funded by the healthcare setting.

The second scenario that needs to be addressed is the term 'reasonable adjustment' in emergency situations. The 'reasonable adjustment' for emergency situations is still a qualified interpreter, however, this research has shown it is nearly impossible and unreasonable to expect an interpreter to be present from the moment the deaf person arrives at the hospital. How the reasonable adjustment appears to be fully met in this situation relies heavily on the anticipatory duty and hospitals being ready for this type of situation to happen, and clearly outlining the time in which they expect an interpreter to turn up, whilst also considering other appropriate communication methods. It is important to note that the information presented in Chapter Eight from both the deaf and paramedic participants demonstrated the common themes between the groups and how these themes are overcome or addressed in hospital policies, and highlighted how hospitals completely fail to anticipate the needs of deaf people accessing medical care, especially in emergency situations. It is clear that this is at least part of the reason why deaf BSL users struggle to access acute healthcare settings and, from the publications in Chapter Two, this broad conclusion could be applied to other health settings because policies are not ready, nor appropriate, to fulfil the Equality Act 2010.

10.2 Original features of this study

This research has explored the experiences of deaf people who use British Sign Language, when accessing and communicating in emergency medical settings. At the same time, this research explored the experiences of ambulance/paramedic professionals when they treated deaf people and how this was facilitated when trying to get important information when there was a communication barrier.

Chapter Six, which explored the experiences of the deaf participants, presented an in-depth insight into the individual experiences of the participants and from that, common themes were populated. Although all of their experiences involved different situations, the issues of access and communication were still the same. However, this chapter also showed evidence of adjustments which enabled consultations or appointments and allowed some of the participants to have partial access to a service which should be built upon. Chapter Seven explored similar experiences but from the opposite side, by providing an in-depth insight into how the healthcare professionals communicated with their deaf patients, the issues they faced and how they overcame them, which has never been researched before.

As a result of interviewing both sets of participants to explore and analyse their experiences, this study has investigated critical terms such as 'reasonable adjustments' and 'accessible format', which are both duties that hospitals and other medical settings are obligated to adhere to in the Equality Act 2010 - this has never been investigated before. This study showed the complexities of healthcare for deaf people and also, how complex the terms 'accessible format' and 'reasonable adjustments' can be, depending on the situation. This study also showed how these could be overcome, ranging from emergencies to being admitted into the hospital, and explored how the adjustments change and develop, depending on the situation.

The final original element of this research is that the lived experiences were combined with the hospital policies to gain a new understanding of how hospitals plan to anticipate the needs of deaf people. Through this, it was also identified that policies expect BSL interpreters to be provided, although many hospitals struggle to provide interpreters continually, and particularly out of hour interpreters has proven to be an area that does not have sufficient provision for deaf people.

10.3 Limitations of this research

Although there were many original aspects to this study, there were also certain limitations that need to be highlighted. These limitations were mainly topics that were not explored due to space and because they required further analysis but pulled away from the main discussion.

Another limitation of the study is understanding the practitioners' view of what happens when treating a deaf person from inside the medical setting. Unfortunately, no nurses or doctors who work within medical settings came forward to participate in this study so it was not possible to gain an understanding of the experiences and views of HCPs working in static settings.

The final limitation of this study was not exploring the professional identity of the HCPs when communicating and feeling frustrated, or asking for an interpreter and not being provided with one. This research was designed to investigate the communication and access experiences of deaf people, not the consequences of this from the professional's experiences.

10.4 Recommendations for further research

Following on from this research, there are several topics and areas that could be explored in the future. The interpreting agencies and hospital policies could potentially be explored to see what happens if they fail to provide an interpreter. This includes investigating the relationship between the hospitals and agencies, and what happens if the agency fail to obtain an interpreter. The views of deaf people and agencies is another topic for exploration, as in this study some of the deaf participants commented on agencies and their provision of interpreters, but this could not be taken further. The expectation that agencies will provide the correctly trained interpreter is another avenue that should be investigated, particularly to explore how agencies have perceived their duty to supply appropriate qualified interpreters.

10.5 Recommendations from the study

This study has investigated some of the intricate issues around deaf people accessing healthcare and this has highlighted some new information that, in my view, should be considered.

The first recommendation is for NHS trusts to have a closer relationship with BSL interpreters themselves and not just through an agency. Unsociable hours such as evenings, weekends and bank holidays, have proven to be a problem for medical settings when trying to obtain an interpreter, so it could be useful to open the avenues of communication with registered interpreting bodies as a starting point, and build a relationship to see if an agreement could be struck so this is no longer an issue. This also includes appropriate communication provisions for when an interpreter is not immediately available, and policies must clearly outline standards for obtaining a qualified interpreter in an emergency situation.

The second recommendation is for interpreters to make their specialist knowledge and experience known and easily accessible. At this current time of writing, interpreters can only be defined by their qualification status and the area that they work in, and their experience and speciality is unknown. An interpreter's experience can be key to some appointments and this is not just related to health settings, but other public bodies too. It would be valuable for interpreters to make it known when they have a speciality.

The third, and final, recommendation is to move away from the idea that having a BSL interpreter is good practice. It needs to be formalised that the use of a BSL interpreter, especially in terms of health settings, is essential practice. This research and previous studies have provided evidence of the poor and worrying outcomes when a qualified interpreter is not used, and statements from the Equality Act 2010 and the Accessible Information Standard mention the use of BSL interpreters but they need to formally state that the use of qualified interpreters is essential practice. Hospital polices must reflect the anticipatory duty and be ready with qualified interpreters, with clear expectancy and accountability on when an interpreter will arrive, particularly in emergency situations, so that deaf BSL users can access healthcare, no matter the situation, in the same way as those who are not deaf.

10.6 Personal reflection and final thoughts

So, this is the end. I remember when I started my research journey, I was so excited! I remember the nerves in the interview when I was applying for my degree on what felt like the hottest day in my lifetime. I remember starting my journey and just reading and reading as much as I possibly could about deaf people accessing the NHS. When the research process actually began and I started to read about IPA, Actor Network Theory and Phenomenology, I was so confused. I remember being told about the roller coaster of the journey and I thought 'that won't happen to me' – but it did. The doubts about 'can I actually do this, or am I clever enough to complete this?' English has always been troublesome for me; I've always known what I want to say but sometimes the words can get jumbled and what I'm trying to say can get lost. This journey has taught me so much and even I know that my English language has improved. The challenge of understanding all the complexities, and the emotions that came with trying to understand these was, for me at least, hard. But I did it. It was a long journey for me, but nevertheless I would not have done it any other way.

I always knew what I wanted to research, which was to investigate the two groups of people and explore how these groups felt and eventually communicated. I wanted to explore how this related to the Equality Act 2010, which on its own is a crucial piece of legislation that, in my eyes at least, is nowhere near perfect but is a good starting block which will hopefully one day be built upon. Pulling all of these aspects together was by far my biggest challenge. What I was not expecting was the use of interpreters to be such a big part of this research. Defining the terms 'reasonable adjustment' and 'accessible information' was also something I was very interested in. I attended a conference that stated that it is a legal right for deaf people to have an interpreter in medical settings, but the Equality Act 2010 does not specifically state that, and there was a lack of evidence. The hospital policies were also an interest of mine, specifically how the policies plan to make adjustments for deaf people. If I am honest, the hospital policies were actually underwhelming; I found that the policies seemed more interested in writing about what guidance they were following and how they were committed to equality and diversity, rather that clearly stating the resources and procedures for staff to follow.

The interviews with both groups of participants were by far the most eye-opening and mind-expanding experience of this entire research. Both participant groups shared their own stories in their own way. Some of the deaf participants' stories were difficult, but it reflected the emotions and stress that not being able to communicate can cause. The interviews with the paramedics were amazing, especially when the paramedics described their initial feelings about communicating and I could sense their frustrations. One thing that this thesis did not reflect was how much each paramedic cared for their patients and although there were barriers, it was obvious that each paramedics did their best in the situation they were in.

Emergency and life-threatening situations demand that any communication rights are superseded by the need to keep someone alive. However, the need to communicate beyond life-threatening situations raises serious questions for public bodies and healthcare departments who have not enforced any systematic approaches to aid both deaf people's needs when accessing healthcare and also to give paramedics the opportunity to communicate clearly with their patients and provide the best possible care and outcomes for all. When systematic approaches are not addressed, this leaves both participants to muddle through and make the best of the situations they have been left in, as exposed in this study.

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Appendix 1: Questions for all Healthcare Professionals

1. What is your job title and role?
2. How long have you been doing that job?
3. What level of language fluency and understanding do you feel is necessary for patients to understand your role and advice?
4. What issues does a lack of adequate language fluency and skills create for you?
5. What level of language fluency and understanding do you feel is necessary for interpreters to mediate effectively between yourself and the patient (in all language settings)?
6. What are the procedures for booking an interpreter in your healthcare setting?
7. How many deaf people have you treated?
8. Have any of them been sign language users?
9. Can you tell me about your experience of communicating with deaf patients?
10. If you know that the deaf patient uses sign language, how do you prepare to communicate with them?
11. Are you aware that some deaf people require the support of an interpreter when interacting with hearing people?
12. Do you feel that someone interpreting for a deaf person needs similar, higher or different communication skills to those of a spoken language interpreter?
13. How are you able to assess whether someone interpreting for a deaf person has appropriate training or qualifications for your particular medical setting?
14. Have you experienced a situation where a deaf person’s family or friend acted as an interpreter? If yes, what do you think about this?

15. Have you ever read your Trust’s policies about treating deaf people? If not, do you know how to access the policies?

16. The Equality Act states that public services must make a ‘reasonable adjustment’ for disabled people - what do you class as a ‘reasonable adjustment’ for a deaf patient in your particular health care setting?

Additional questions for Paramedics:

17. Whilst on your way to the scene have you ever been alerted that the patient was deaf? If you did, what did you do or think?

18. Where you told about their preferred method of communication?

19. How did you adjust if the patient’s preferred method of communication was not your own?

20. Did you find out all the details about your patient that you needed to know? If not, what did you do?

21. When you arrived at the hospital, who did you inform that your patient was deaf?

22. At any point did your deaf patient request an interpreter? If so, what did you do?

Appendix 2: Questions for deaf participants

1. How often do you go to the hospital?
2. How do you communicate with people there?
3. Were you aware that you could have an interpreter present if you wanted one?
4. Have you ever had an interpreter present for a hospital visit?
5. Who was the interpreter? (Family friend or a qualified interpreter?)
6. Was the interpreter male or female?
7. Were you happy to have this person there with you?
8. How do you feel they helped you understand what was going on?
9. Was there anything you didn't understand, even after the interpreter had explained it to you?
10. How long was the interpreter with you?
11. How did you communicate with people before or after the interpreter had left?
12. If you had to sign any papers (such as a consent form for an operation) was the interpreter present?
13. Did you understand everything that was explained to you by the Healthcare Professional?
14. Did you understand what treatment you were going to receive and what was involved (operation, staying in overnight/a few days, in pain, needing to take drugs, etc)?
15. If you did not understand something, did you feel comfortable about asking for clarification?

16. When you left the hospital, did you understand all aspects of your treatment?

17. Did you feel that the hospital met all your needs as a deaf person?

Appendix 3: Participant Consent Form

Project title: Legislation, policies and equality: Evaluating deaf people's access to the National Health Service

Name of researcher: Mark Lafferty

Name of Participant: ………………………………………………………………….

Pseudonym to be used: …………………………………………………………….

1. I have read the Participant Information Sheet. ☐
2. I have been given the opportunity to ask any questions about the research. ☐
3. I understand that I can withdraw from the study at any time until 2 weeks after the interview date. ☐
4. I understand that any information used in publications or the thesis will be used confidentially. ☐
5. I agree to take part in this voluntary study. ☐

Participant signature: …………………………………………………………………..

Date:

Researcher signature: ……………………………………………………………….

Date:

Appendix 4: Participation Information Sheet

Project title: Legislation, Policies and Equality: Evaluating deaf people's access to the National Health Service

Researcher: Mark Lafferty

Information about the researcher

My name is Mark Lafferty and I am a postgraduate research student at the University of Central Lancashire. I have sign language qualification in excess of Signature level 3.

Aims of the research

This research will investigate deaf people's access to NHS services, particularly hospitals and GP surgeries. The aim of the research is to explore equality policy, disability and human rights legislation, and to consider how the NHS interprets 'reasonable adjustments' in the Equality Act 2010. This research will involve collecting policies from hospitals around the UK, and information from healthcare professionals, in order to identify any issues which relate to deaf people, such as the booking of interpreters and communication issues when dealing with deaf patients. Another objective of this research is to interview deaf people about their current views and experiences about accessing NHS healthcare services.

Participant's role

You will be asked to take part in an interview which will take around an hour. The interview will ideally be face-to-face; however I am very flexible about this and the interviews can be conducted via Skype, MSN or email if you prefer. Interviews can take place wherever is good for you on a date convenient to you. I can book a room at the University of Central Lancashire or I can travel to you. I plan on conducting one in-depth interview, unless I have more questions, or the interview is cut short.

Your participation is completely voluntary, and you have the right to withdraw from the interview at any time without giving any reason. Whilst the interview is being conducted, if you decide to withdraw your participation, please tell me immediately and I will stop the interview. I will confirm your withdrawal and leave my contact details in case you would like to rearrange. However, after the interview has been completed, if you wish to withdraw you have two weeks to let me know. If this happens, your interview will be erased and not included in the final thesis and all information that you have given including your contact details will be destroyed.

The interviews can take place in spoken English or sign language. The interviews will need to be video recorded. The interview will then be transcribed into a written format. If you wish to review the transcription, then please let me know during the interview. You may also make amendments to the transcription if you wish.

Before we begin the interview, you will be asked to sign a consent form which will state that you are happy to take part in the interview and that you have received this participant information sheet.

How will your information be used?

The information that you provide will be used in my thesis. Some of the information that is collected may also be used in presentations, journal articles and written feedback about the research which will be given to all participants. Your information will always be shared anonymously, and you will be able to select your own pseudonym in place of your actual name.

Confidentiality

All information will be treated as confidential and will be kept securely which only I can access. After the thesis has been completed the confidential information will be destroyed. The final thesis will not contain any identifiable information. However, you will have the opportunity to choose your own pseudonym which means that you will be able to identify yourself in the final thesis.