

**Hubble, Bubble, Toil and Trouble:
Meddling in Mental Health Services Using Participatory
Action Research**

by

Katherine Allen SRAsT (M) MA MSc

A thesis submitted in partial fulfilment for the requirements for the degree of
Doctor of Philosophy, at the University of Central Lancashire

November 2018

STUDENT DECLARATION FORM

Type of Award PhD
School Nursing

Sections marked * delete as appropriate

1. **Concurrent registration for two or more academic awards**

*I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution

2. **Material submitted for another award**

*I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work

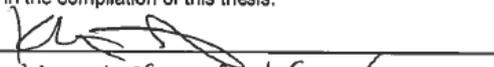
3. **Collaboration**

Where a candidate's research programme is part of a collaborative project, the thesis must indicate in addition clearly the candidate's individual contribution and the extent of the collaboration. Please state below:

Not applicable.

4. **Use of a Proof-reader**

*No proof-reading service was used in the compilation of this thesis.

Signature of Candidate 

Print name: KATHARINE ALLEN

**Hubble, Bubble, Toil and Trouble:
Meddling in Mental Health Services Using
Participatory Action Research**



Dedicated to Ellen Nash, original PAR Excellence member

Abstract

This thesis explores whether participatory action research (PAR) can be a vehicle for knowledge democracy in mental health by telling the compelling tale of a team of mental health service users formed to conduct a PAR project in adult NHS mental health services. PAR is a methodology that seeks change through action and the collaborative efforts of participants, often people from marginalised groups. The team, self-named PAR Excellence, actively participated in every step of the research process, from the initial identification of the research topic (shared decision making in mental health), literature review, research design, data collection and analysis, to dissemination. The original contribution to knowledge is in two parts: findings on shared decision making and the use of recorded service user experiences in mental health, and findings on the PAR process itself. Through these intertwining efforts, an original analysis of knowledge democracy in the context of adult NHS mental health services in the UK has been reached.

Having chosen shared decision making in mental health, PAR Excellence developed a multi-media library of service user experiences to be used as a shared decision making resource. They explored with NHS mental health staff whether this approach supported shared decision making through qualitative focus groups and interviews. It was concluded that whilst the use of recorded service user experiences as a shared decision making resource was generally welcomed in principle by staff, in practice there was limited utilisation of the resource. However, it was highly valued as an opportunity for staff reflective practice, and when used judiciously, showed the potential for having a profound effect for service users. It was also found that shared decision making is a complex concept that has many different meanings amongst staff, and they

work in a system where true shared decision making cannot consistently occur. However, it was discovered that staff found the involvement of service users in the research process gave the project authenticity and credibility over research generated purely by traditional researchers, and were therefore more likely to engage with it. The shared decision making resource also provoked a particularly positive response in staff members who have used mental health services themselves.

Throughout the project, qualitative focus groups were also held with PAR Excellence to explore the participatory process and its outcomes overall. These findings established that the motivations of the team (who were highly critical of mental health services) were rooted in a profound understanding of the power mental health services had over them, dissatisfaction with services, and a deep sense of injustice. This led the team to express a concept of subversive “meddling” in mental health services to address these issues. They found that whilst personal transformation through PAR was achievable, the potential for more general, external transformation was limited due to the enmeshment of the political and economic climate in which mental health services operate.

Contents

List of Diagrams, Tables, Figures, and Pictures	9
Acknowledgements	11
Abbreviations.....	13
CHAPTER ONE: THESIS INTRODUCTION.....	14
CHAPTER TWO: BACKGROUND TO THE PROJECT	29
2.1 Introduction to Chapter Two	29
2.2 People who Use Mental Health Services: Inequalities, Stigma and Powerlessness	29
2.3 Power, Psychiatry, and the Medical Model.....	31
2.4 Mental Health Stigma, Discrimination, and the Political Climate	33
2.5 Knowledge Production, Epistemic Injustice and Knowledge Democracy	36
2.6 Challenging the Orthodoxy: Service User Involvement and Participation	40
2.7 PAR: A Knowledge Democracy Solution?	47
2.8 Conclusion to Chapter Two	51
CHAPTER THREE: METHODOLOGY	54
3.1 Introduction to Chapter Three.....	54
3.2 Section One: PAR Methodology.....	55
3.3 Section Two: PAR in Practice – The Establishment and Activities of PAR Excellence.....	79
3.4 Conclusion to Chapter Three.....	105

CHAPTER FOUR - ACTION: BY PEOPLE, FOR PEOPLE: SHARED EXPERIENCES TO SUPPORT SHARED DECISION MAKING IN MENTAL HEALTH.....	107
4.1 Introduction to Chapter Four.....	107
4.2 Background to Shared Decision Making in Mental Health Care	108
4.3 Shared Decision Making in Mental Health: Integrative Literature Review	112
4.4 Development of the Shared Decision Making Resource	126
4.5 Research Methods (Shared Decision Making)	134
4.6 Findings	150
4.6.1 Shared Decision Making Findings	151
4.7 Shared Decision Making Discussion	190
4.8 Conclusion to Chapter Four.....	196
CHAPTER FIVE – PARTICIPATION: HUBBLE, BUBBLE, TOIL AND TROUBLE WHILST MESSING ABOUT ON THE WAY TO HOPE STREET	200
5.1 Introduction to Chapter Five	200
5.2 Research Methods (Participation)	202
5.3 Participation Findings	207
5.4 Conclusion to Chapter Five	305
CHAPTER SIX: OVERALL DISCUSSION AND CONCLUSION. PAR: A VEHICLE FOR KNOWLEDGE DEMOCRACY IN MENTAL HEALTH?	308
6.1 Introduction to Chapter Six.....	308
6.2 PAR: An Appropriate Choice?	309

6.3 Knowledge Democracy within PAR Excellence.....	311
6.4 Knowledge Democracy Outside of PAR Excellence.....	318
6.5 Final Conclusion: A Case for Cautious Optimism	339
REFERENCES	345
Appendix A: PAR Recruitment Flyer	365
Appendix B: PAR Participant Information Sheet.....	366
Appendix C: PAR Consent Form.....	370
Appendix D: PAR Excellence Group Agreement.....	372
Appendix E: PAR Excellence Criteria for Choosing a Research Topic.....	375
Appendix F: Integrative Literature Review Search Strategy	376
Appendix G: Literature Review Flow Chart	377
Appendix H: Integrative Review Record of Included Papers	378
Appendix I: Recruitment Flyer for Service Users Recording Their Experiences	387
Appendix J: Guidance for Service Users Recording Their Experiences	389
Appendix K: Service Users Recording Their Experiences Information Sheet	392
Appendix L: Consent Form: Service Users Recording their Experiences....	397
Appendix M: Staff Recruitment Flyer.....	399
Appendix N: Staff Participant Information Sheet	401
Appendix O: Staff Consent Form	406
Appendix P: Service User Participant Flyer.....	408

Appendix Q: Participant Information Sheet: Service User Research Participants.....	410
Appendix R: Consent Form: Service User Research Participants.....	415
Appendix S: Staff Focus Group Guide	417
Appendix T: Staff Post-Resource Interview Guide	418
Appendix U: PARE Focus Group No 1	419
Appendix V: PARE Focus Group No 2	420
Appendix W: PARE Focus Group No 3	421
Appendix X: By People, For People: Shared Experiences to Support Shared Decision Making in Mental Health	422

List of Diagrams, Tables, Figures, and Pictures

Diagram 1: Visual Mapping Exercise: the Service User Journey Significant Touch Points	98
Diagram 2: Participation Themes	208
Diagram 3: C'est LA Vie	303
Diagram 4: Japanese Knot Weed	304
Table 1: Summary of Potential Research Topics	101
Table 2: Final Top Three Priority Research Topic Areas	102
Table 3: PAR Excellence Non-Linear Approach to Thematic Data Analysis	146
Figure 1: The Project Tree	18
Figure 2: Project lines of inquiry into knowledge democracy	20
Figure 3: Overview of Project Activities	83
Picture 1: Participatory Learning: Qualitative and Quantitative Research Terms	93
Picture 2: Participatory Learning: Practising Research Design for the Topic of Gender Inequality in Mental Health	94
Picture 3: Participatory Learning: Practising Research Design for the Topic of Mental Health Stigma	95
Picture 4a: Sorting Statements into Topics	99
Picture 5: First Storyboard	129
Picture 6: Second Storyboard	130
Picture 7: Third Storyboard	130

Picture 8: Coding Data	143
Picture 9: Coding Data	143
Picture 10: Identifying Themes from Interviews.....	144
Picture 11: Untangling Data from Response to Data	147
Picture 12: PAR Excellence Responses to Data	148
Picture 13 PAR Excellence Responses to Data.....	149
Picture 14: PAR Excellence Responses to Data	150
Picture 15: Identifying Themes and Sub-Themes	205
Picture 16: Establishing Relationships Between Themes.....	206
Picture 17: The Witch	250
Picture 18: Slaying the Psychiatrist	252
Picture 19: Fish Tank.....	253
Picture 20: PARE Village First Visit.....	255
Picture 21: PARE Village Second Visit.....	256
Picture 22: PARE Village Final Visit	258
Picture 23: Open Water Swimming.....	273

Acknowledgements

My most sincere and heartfelt thanks and gratitude go to every single member of the astounding PAR Excellence team: Chris Balchin, Gillian Blackburn, Neil Caton, Chris Lodge, Chris McAteer, Richard Wallwork, and Ellen Nash, who tragically passed away early on in the project but who left an indelible mark and to whom this thesis is dedicated. Each one of these people gave so much, in their own, unique ways. The project just would not have been possible without their generosity: they gave not only their time, but their spirit and emotion. Their consent to be named here is testament to their commitment, belief and pride in the project.

Also, we all as a team are indebted to the other people who contributed to the shared decision making resource by recording their experiences – this project would have been very much poorer without their generous, insightful and moving contributions: Alyssa, Brian, Chris, Lyn-Rosamund, J, Janet, and Joy. We thank them profusely and applaud them all.

My wholehearted thanks too go to my supervisors, Professor Joy Duxbury and Professor Mick McKeown. Their endless patience, support, kindness and good humour throughout has not only been a lifeline to me: their belief in the project has also meant a colossal amount to the PAR Excellence team, and has significantly contributed to keeping the team motivated over the years. It has been a privilege to have had them as my supervisors. This was during a particularly tough period in my life personally, facing an increasingly unsupported, difficult and unstable time at work in the latter years of the project, which ended in a distressing redundancy process in the final year of my studies. This meant that, not ideally, I had to find a new job, relocate cities and begin a demanding new role in the last six months of my studies. Consequently, they

didn't get things when they should have, and have had to supervise me long-distance, but they did everything they could to support me to submit on time. I would also like to thank Professor Tim Thornton, my research degree tutor. Our yearly annual review debates were an inspiration and a delight. And he is right: it was at times difficult to sleep at night!

Finally, I profusely thank John Keaveny, who was an NHS adult mental health network director and my manager at the outset of the project. Without his approval, the project would never have happened. Also, his support meant a great deal to the PAR Excellence members. So much so, that years after he left, the team insisted on his presence at their project closing event. His values and behaviours are completely contrary to the criticisms of NHS mental health services presented throughout this thesis. The world of NHS mental health services would be a better place if there were more people like him around.

Abbreviations

CASP: Critical Appraisal Skills Programme

CCG: Clinical Commissioning Group

CMHT: Community Mental Health Team

CPA: Care Programme Approach

CPN: Community Psychiatric Nurse

CAT: Cognitive Analytical Therapy

DH: Department of Health

EBE: Experts by Experience

IRAS: Integrated Research Application System

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

OT: Occupational Therapist

PAR: Participatory Action Research

PARE: PAR Excellence (team name variant)

PAR Excellence: Participatory Action Research Excellence (team name)

SDM: Shared Decision Making (appendices only)

SIS: Social Inclusion Team

STaR: Support, Time and Recovery Worker

TCS: Transforming Community Services

CHAPTER ONE: THESIS INTRODUCTION

1.1 Introduction to Chapter One

This thesis is an account of a complex participatory action research (PAR) project, facilitated¹ by myself and involving a group of mental health service users who called themselves and the project PAR Excellence. This introductory chapter gives an overview of the thesis, sets out its original contribution to knowledge, gives details of the forthcoming chapters, describes my personal position, and includes a note on terms.

The thesis explores whether PAR can be a vehicle for knowledge democracy in mental health by telling the compelling tale of the PAR Excellence team. The team chose a research topic of shared decision making, agreed to develop a multi-media library of service user experiences, and explored whether this approach supported shared decision making in mental health. The library booklet can be found at Appendix X.

The thesis details the conduct and findings of the PAR Excellence team's research as well as findings on the participatory process itself and its impact on team members. By revealing these activities and processes, the notion of whether the epistemic injustices often faced by people who use mental health services can be transformed through the knowledge democracy that PAR seeks to instil is considered.

The project sought to explore this by investigating three questions:

¹ Whilst a strictly Freirean standpoint regards facilitation of participation as a problematic notion, risking consolidation of power imbalances, the ordinary use of the facilitation terminology perhaps best describes my role in the project. It is also the term that PAR Excellence members preferred, when questioned.

- Firstly, is PAR an appropriate choice to bring about knowledge democracy?
- Secondly, could knowledge democracy be achieved internally within the a project?
- Thirdly, could the project establish knowledge democracy in its local setting?

However, surpassing the aim of fulfilling the usual academic rigours of the execution and reporting of a research project to doctoral level, by some margin, is the hope that this work fully recognises, credits and celebrates what the members of PAR Excellence achieved. This group of people not only generously gave up inordinate amounts of their time, but they also lay their hearts and minds on the line. In doing so, they made themselves vulnerable to challenge and scrutiny from each other, mental health services staff, and, myself. They also shared distressing and traumatic experiences at the hands of mental health services and society with no guarantee that this would lead to change for them personally, or for others. They were asked not only to be critical of the mental health system, but self-critical and also critical of me as a researcher and NHS worker, and the power I hold. They also embarked on a process that none had any traditional background or experience in – that of social research, yet remained fully committed throughout to conducting the project in the most rigorous and ethical manner possible.

The team embraced all the usual difficulties associated with any research project, and enhanced it considerably by their thoughtful questioning. Although a great deal of fun was had along the way, in part and at times, some of this was not at all easy for any of us. Yet, they trusted and persevered in a process that was not finite or straightforward, and they placed their faith in my overall proposition to them that, by giving up their time and emotional and mental

energy for a few quid in travel expenses, some cheap coffee, biscuits and the odd sandwich, they could change the world in some way in an area that was exceptionally meaningful to them.

And, they trusted in me. My genuine and heartfelt hope for this thesis is that my astounding PAR Excellence team has not been done a disservice, and it does full justice to what the team accomplished.

1.2 Thesis Structure

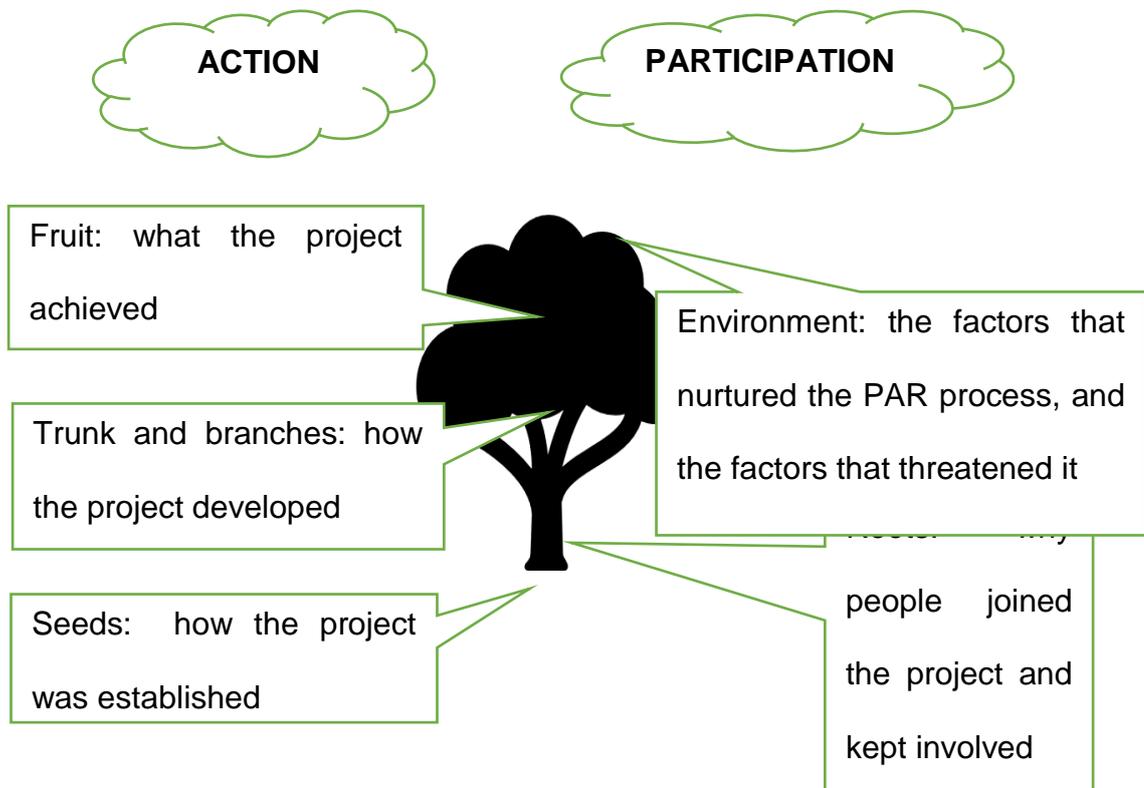
This is not a traditionally structured thesis, with a straightforward set of chapters. Writing about a PAR project demands a different approach to the traditional linear approach. This is due to the cyclical nature of PAR, and the differing aims of this means of research that demands a more narrative approach and alternate focus: that is, a strong emphasis on personal growth and empowerment that transcends mere knowledge generation (Herr and Anderson 2005).

Rather than the usual thesis structure, the project is presented as two sub-studies. Following the background chapter (chapter two) and methodology chapter (chapter three), chapter four describes the action element of the project (first sub-study), and chapter five explores the participation element of the project (second sub-study). In practice, participation and action in PAR are not such distinct elements: both aspects of PAR occur simultaneously, with one consistently informing the other (Rahman 2008). However, for the ease of navigation for readers and as an approach to structuring this thesis, these elements have been described in distinct chapters. Chapter six is the overall discussion and conclusion chapter.

The non-linear and unorthodox nature of this thesis is a reflection of the less than straightforward nature of PAR and, subsequently, the project itself. An attempt to use a more familiar thesis structure would not have fully captured the true scope of the project. Highly unusually, the literature review sits within chapter four (the action chapter), as it was very much part of the PAR process and undertaken in a participatory manner with the PAR Excellence team. Another less usual feature of this thesis is some aspects are deeply personal: PAR by its nature requires a wholly reflective, reflexive and relational standpoint (Bryman 2008). Therefore, my writing is judiciously within this vein. There is also an endeavour to keep the thesis as free from jargon as possible, hence the minimal use of acronyms (for example, SDM for shared decision making). This is because PAR Excellence team members had a strong dislike of acronyms and jargon – an objection, it will be shown, that is shared by proponents of PAR, who recognise the exclusive power such use of language generates. This objection formulated part of the team's critique of both the NHS and academia.

Because of the unorthodox nature of this thesis, a metaphor of a seed growing into a tree is used throughout to support readers to link chapters and illuminate the unpredictability and fragility of the PAR process (Figure 1: Project Tree). The project tree shows what element of the project is discussed where – either under action (chapter four), or participation (chapter five).

Figure 1: The Project Tree



This and other creative work such as drawings and metaphors feature throughout the thesis, reflecting the creativity and innate capabilities of the participants. PAR Excellence members introduced the use of metaphor early on in their discussions, and it became a consistent approach throughout the project. Metaphors allow the communication of complex information that captures the richness and vividness of experiences (Gibbs 1999). It was a communication method that naturally emerged in the interactions between the team and myself, and was fully embraced as a way of us all expressing our intricate thoughts.

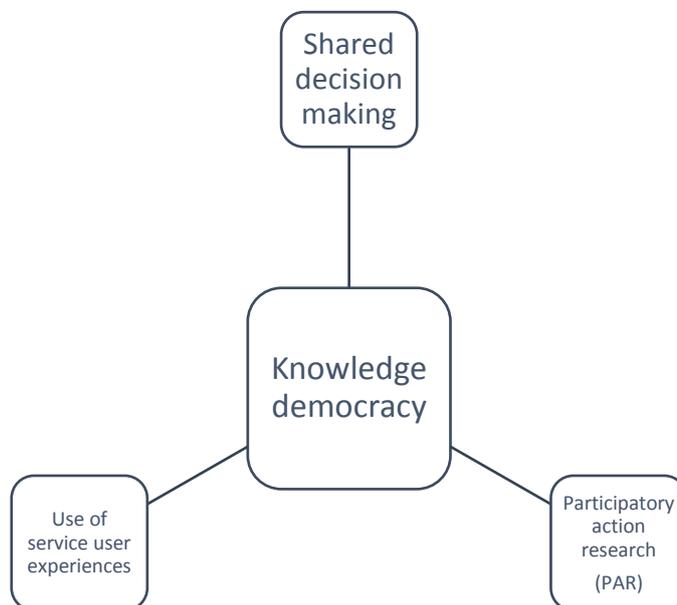
As the project unfolded, it emerged that there was an underlying drive across all the elements to bring about knowledge democracy in mental health. At the outset, the overall attention on knowledge democracy was not explicitly

identified as the main focus of inquiry but reached iteratively in the course of the participatory process; although it was implicitly foregrounded by the decision to use PAR. That the PAR Excellence team chose shared decision making (essentially knowledge democracy in practice) was either happy coincidence, a reflection of the people attracted to PAR and their underlying values, a reaction to the acknowledged deficits in routine mental health care, or all of these in combination. It may also be related to how PAR is conducted, and how the process focussed the team on what will be seen as a fundamental issue in mental health. Indeed, the nature in which the way knowledge democracy evolved as an overarching topic is a cause for celebration and pleasing to myself, for it demonstrated a true commitment to the democratic principles of PAR. It does, however, mean that during most of the stages of this project, knowledge democracy was being implicitly, not explicitly explored with PAR Excellence and the mental health staff who participated in the action elements of the project.

The very notion of knowledge democracy is both an end objective of PAR and an implicit part of its process. For theorists and practitioners of participatory methods, the possession of, and active participation in the development of knowledge is fundamentally about accessing and holding power: this is what is meant by calling attention to the empowering or emancipatory ideals and goals of the process. In our PAR Excellence project, we were simultaneously working together to achieve an impact upon knowledge democracy within local mental health services as well as within the team. There are three interlocking lines of inquiry under the knowledge democracy umbrella in this project: shared decision making, the use of service user experiences, and PAR itself as a possible vehicle for knowledge democracy. These links are demonstrated in

Figure 2.

Figure 2: Project lines of inquiry into knowledge democracy



1.3 Original Contribution to Knowledge

The original contribution to knowledge is twofold. Firstly, the use of a multi-media library of recorded service user experiences to support shared decision making in mental health lead to original contributions to knowledge on this topic, for the integrative literature review that the team participated in did not locate any studies where such an approach had been taken, let alone within the context of a PAR project. Secondly, the experience and process of being a participant in a PAR project is seldom reported (Herr and Anderson 2005), particularly in an adult mental health National Health Service (NHS) setting. This is despite a plethora of commentary urging more participatory ideals and use of PAR. This PAR Excellence project is unique in the UK. The team successfully created a tangible shared decision making resource through the use of PAR in an adult NHS mental health setting and located the potential of

such a resource. They also confirmed the promise of PAR in relation to personal creativity, growth and empowerment of participants when used in this setting. These intertwining features have produced an original analysis of knowledge democracy in the context of adult NHS mental health services in the UK.

1.4 Chapter Outlines

The background chapter (chapter two) gives an extensive justification as to why PAR represents a possible means for seeking actions geared towards providing solutions to the myriad, historic and complex issues faced by people who use mental health services. PAR is presented as constituting a set of practices and processes in tune with rhetorical policy prescriptions for service user involvement and empowered voices that can potentiate discussion and action relevant to matters of mental health and marginalisation, distribution of power in mental health services, knowledge democracy and epistemic justice, and the role of research in investigating or solving associated problems.

The following methodology chapter (chapter three) discusses PAR as a research approach through an overview of its epistemological perspective, historical roots and key players, and its relation to critical theory. It sets out criticisms of PAR, and presents some responses to these criticisms through a discussion of quality and ethical matters. The chapter then describes in detail how PAR Excellence was established, how the team operated, and in particular how they chose the research topic of shared decision making in mental health. It also gives a brief overview of general perspectives on data collection and data analysis in PAR. These activities are expanded upon in the fourth and fifth chapters.

Chapter four (action chapter) describes the project that PAR Excellence chose to conduct: “By People, for People: Shared Experiences to Support Shared Decision Making in Mental Health”. The chapter includes an introduction and literature review of shared decision making in mental health, describes how a shared decision making resource of recorded service user experiences was developed, presents the research that PAR Excellence undertook with NHS mental health services staff regarding shared decision making and the use of the resource, and discusses the findings. This is a lengthy chapter and at first glance somewhat unwieldy: it has been put together as such because the activities described cohere under the umbrella of what the team actually did to bring about change in an NHS mental health setting, including all the preparatory work.

The following, fifth chapter (participation chapter) is concerned with the PAR process as experienced by PAR Excellence members and, to a lesser degree, myself. It follows the action chapter so that these findings can be understood in the context of what the team did, although in reality the activities associated with both these chapters were concurrent and informed each other simultaneously. The methods for collecting this data are described, and the PAR Excellence team’s experiential findings of the philosophical and practical aspects of the PAR process are explored. Again, this is a lengthy chapter, for it is where the voices of the PAR Excellence members are given the space to shine. It is the heart of the thesis.

The final, sixth chapter is the discussion and conclusion chapter. The first three questions regarding PAR as a vehicle for knowledge democracy are revisited and answered. The ethical dilemmas thrown up by the project are also

discussed. The conclusion sets out the original contribution to knowledge made by this thesis. It is argued that there were varying degrees of success in terms of instilling knowledge democracy within and outside of the PAR Excellence team, but the provision of a communicative space provided by the project gave the opportunity for some significant personal transformation in team members that has the potential for future attempts at change. The project has also provided a platform for the voices of people who use mental health services to be heard, and for that alone, it had been a worthwhile endeavour.

1.5 Personal Position

We just couldn't be blind and silent when we were witnessing – and suffering – the collapse of positive values and attitudes towards humankind (Fals Borda 2001 p27).

Here, I indicate my personal positioning in relation the project. This is an early example of the reflexivity essential to anyone wishing to conduct PAR on the grounds of quality and in an ethically sound manner (Bryman 2008, Kindon et al 2007). The project emerged as part of my work within a NHS Trust, where I was senior manager for service user and carer engagement and leadership for adult mental health services. However, my interest in participation in research stemmed from much earlier in my career. I had previously worked in international development in Sri Lanka, where I first came across the term PAR. I saw PAR as an essential response to some of the mistakes made and conduct by international development agencies, particularly following the 2004 tsunami: mistakes that in my view would not have happened had local communities been put at the heart of development work. It occurred to me that PAR might be an answer to some of the mistakes made in the mental health field.

In my NHS role, I established an experts by experience programme (EBE) for mental health service users and family members, which sought to involve service users and families in strategic decision making, as well as providing an influential platform through activities such as staff training and service development. I also wished to promote service user involvement in research, and considered PAR as an appropriate framework. In light of this, the dissertation that I submitted for a Master of Science in health and social care research was a literature review on PAR in mental health and a PAR research protocol.

I came into my NHS post being highly critical of NHS mental health services: I had been working in the mental health voluntary sector, and had seen directly how badly people could be treated by statutory services. My position has not softened since working in the NHS. My approach to service user participation has remained a rights based one throughout, believing that people have a right to be involved in the services that have such a huge impact on their lives, from on an individual basis in their interactions with staff, to a strategic level where significant decisions about services are made.

My role supporting service user involvement within the NHS located me both 'in and against' the mental health system². This is a positioning replete with tensions, not least in terms of allegiances to employer or service users, empowerment or co-optation, amidst legitimate anxieties regarding my own capabilities or power to realise tangible change in the face of participants'

² This phrasing is borrowed from the classic socialist pamphlet 'In and Against the State' (Mitchell et al. 1979) which exposed the contradictions of working within the public sector, in increasingly disciplined occupations, whilst striving for a fairer society and better quality services; services that, amongst other things, collectivise rather than individualise dissent, and operate not to alienate staff from service users.

demands. Working within a public service system naturally instils appreciation of the pressures upon the professional workforce to deliver care within straightened resource allocations. The potential to be reasonably forgiving of some of the inadequacies of services because of these economic conditions has been tempered by first hand exposure to staff who are seemingly personally indifferent to the very need for empowerment and involvement, or senior personnel charged with responsibilities for engagement who appear more concerned with superficial public relations gloss, rather than substantially, meaningfully addressing power imbalances. My experience of struggling with such circumstances and tension has been personally difficult, and my consciousness raising, though illuminative of the socio-political context in these times of austerity, has not profoundly altered my partisanship for the value of genuine empowerment and autonomy for service users.

1.6 Note on Terms

Before embarking on this endeavour, it is important include a note on terms to establish consistency of understanding throughout the thesis. These terms need setting out here because many terms associated with both PAR and mental health are contested as well as complex, overlapping, and multi-layered.

1.6.1 PAR

PAR is one form amongst a panoply of action research approaches that exist on a spectrum with action community based research, community based action research, participatory rural appraisal and participatory research. These approaches, whilst having some differences, all come under the same umbrella in terms of values, aims, principles and practice, that is: sharing a commitment to democratic praxis with people and communities most affected by the issue of

inquiry (Janes 2016). One way to distinguish them is the degree of commitment to authentic participation and power sharing: some forms of participatory research, like other participation and involvement initiatives, are vulnerable to co-option, for example, consumerist approaches. Whilst this project placed a high emphasis on the participatory element of PAR, I draw on literature and theory relating to all of these similar approaches where relevant. When referring to literature relating to any of these approaches, I use the term “participatory approaches”, or where appropriate, simply ‘action research’.

1.6.2 Action Research

Action research is a precursor to PAR, and any discussion of PAR requires consideration of the action research literature. Where the term action research is used, this indicates that the author has specifically been writing about action research, but that its points are relevant to PAR as applied in this project.

1.6.3 Service User

The term service user is used solely throughout for clarity to refer to people who have used mental health services. Elsewhere in the literature, people can be referred to as patients, clients, consumers, lay people. and survivors, depending on professional group, location, situation, context, and the preferences of people themselves. It is important to understand the nuances of using the most appropriate term, as the terms used for people are loaded with assumptions and inferences, and the language we use is imbued with meaning and power (McLaughlin 2009). It is important to recognise that the term service user is not perfect. It is a contested term, hotly debated amongst people who use services and professionals alike (Neuberger and Tallis 1999) and highly criticised (McLaughlin 2009). However, it has been argued that service user is a term

more associated with a participative, active positioning, implying that someone is confident, informed and on a more equal status with healthcare professionals. Whereas, the term patient indicates a more passive role, and associated etymologically with suffering. It positions professionals as the all-knowing, powerful ones and objectivises the person (Neuberger and Tallis 1999): a standpoint that this project is by its very nature is seeking to challenge. Furthermore, service user is the term most used by PAR Excellence members, and the one they chose to use when they put their shared decision making resource together.

1.6.4 People Working in Mental Health Services

There is not a consistent term applied to people working in mental health services here, as there is such a broad spectrum of roles across clinicians, non-clinicians and managers. Where appropriate, specific job titles have been used (for example, nurse, psychiatrist, social worker). When a more general term is required, staff, professional or mental health worker is used interchangeably.

1.6.5 PAR Excellence

PAR Excellence is used to refer to the project, and the team of mental health service users. The team is also referred to as the team, and the team members. Although I was very much part of the team in practice, for clarity and distinction, I am for the most part referring to the people who have used mental health services recruited to the project when I discuss PAR Excellence team members. When I am referring to us all, I refer to myself in addition to the team members.

1.6.6 PARE

In some of the earlier documents associated with the project and found in the appendices, PAR Excellence is referred to as PARE. The team is also referred to as PARE by team members in some of the focus group quotations. This is because some team members preferred this acronym to PAR Excellence.

1.6.7 Facilitator

Following a conversation with the PAR Excellence team, I have referred to myself as facilitator throughout. Whilst at the outset I would have hoped to be writing as co-researcher, it would be disingenuous not to acknowledge that I remained the driving force throughout the process, and PAR Excellence members would agree that the project almost certainly would not have continued had I left.

The next chapter sets out a detailed background and justification for the project.

CHAPTER TWO: BACKGROUND TO THE PROJECT

2.1 Introduction to Chapter Two

This background chapter sets out some fundamental issues and debates in mental health, knowledge production, service user involvement and participation, and PAR. As highlighted in the introduction to the thesis, the literature review that usually sits here in a thesis is uniquely positioned in the later, action chapter following the methodology chapter. This is because the PAR Excellence team participated in the conduct of the review once they had settled on their research topic of shared decision making in mental health.

This chapter provides the overall context to the project by setting out the historical and contemporary issues facing people who use mental health services in relation to society, health care and research, presents the current policy landscape of service user involvement and critiques of current involvement practice, establishes why knowledge democracy might provide some solutions to the issues presented, and why PAR has the potential to be a vehicle for knowledge democracy.

2.2 People who Use Mental Health Services: Inequalities, Stigma and Powerlessness

To understand why PAR is put forward as a solution to the predicament facing mental health service users, it is necessary to fully understand the problems that it seeks to address. In order to do this, the inequalities, stigma and powerlessness experienced by people who use mental health services are discussed. The starting point of the project was based on the premise that people who use mental health services are disempowered, and that their knowledge is systematically neither valued or utilised on an individual,

institutional or societal level. There is a wealth of literature emanating from practitioners and service users that describes the generalised stigma, discrimination, exclusion and powerlessness experienced by people with mental health problems (Social Exclusion Unit 2004, Thornicroft 2006, Henderson et al 2014b). Despite explicit latter-day policy extolling the virtues of co-production and service user involvement, these remain critical issues that demand resolving.

The negative impacts of this panoply of disadvantage are not just poorer mental health outcomes and quality of life (Cohen 1992): people die as a direct result of mental health conditions and related social circumstances. Suicide is the leading cause of death in people aged 20 to 34 and men aged 35-49 (Office for National Statistics 2015). Also, people with mental health conditions face physical health inequalities that result in a life expectancy that is ten to twenty years lower than average (Independent Mental Health Task Force 2016, Hayes et al 2017), have more long-term health conditions, and earlier onset of long-term conditions (Chesney et al 2014, Disability Rights Commission 2006): people are dying earlier and suffering damaged health and functioning for treatable conditions. According to Siddiqui et al (2016), there are complex factors contributing to this picture, and the reasons for the greater health burden are several, complex, and intertwining: direct harms from psychotropic medication, socioeconomic disadvantage, stigma, a lack of focus on physical health, and, for some, reduced self-advocacy and engagement with professional services. However, the blame is frequently laid on the individual (Crichton et al 2017). It is also argued that the stigma surrounding mental health prevents people seeking and receiving help (Mental Health Foundation 2017, Clement et al 2015). The neglect of physical health needs by mental health

services is deemed to be one of the reasons psychiatric services face a crisis of legitimacy (McKeown and White 2015).

When people do have contact with mental health services, they can experience powerlessness (Berkowitz et al 1990, Rose et al 2015), and this means that services can hinder, not help (Thorncroft 2006, McKeown et al 2018). The Social Exclusion Unit (2004) found that lowered expectations from mental health service staff create barriers to the recovery of service users. Many service users do not speak highly of mental health services: they often rate mental health staff as one of the groups which most stigmatises them (Pinfold et al 2005, Henderson et al 2014b), and it is claimed that dissatisfaction with services is the biggest factor that leads to people withdrawing from services (Tehrani et al 1996). Service users can be devalued, often deprived of any real chance to contribute to decisions about the treatment and services that centrally affect their lives (Perkins 1996, Morrow and Weisser 2012, Ocloo and Matthews 2016, Grundy et al 2016). Furthermore, numerous studies have shown a divergence between the goals and practices of clinicians and the wishes and needs of those with whom they work (Perkins 2001, Cutcliffe et al 2015, Katsikitis et al 2017).

2.3 Power, Psychiatry, and the Medical Model

People who use mental health services can be considered disadvantaged not by their “conditions”, or “symptoms”, but by the power that is wielded over them and the way they are viewed and treated by society, healthcare and the research community. Lukes (1974) identified three types of power: overt tyrannical power that is exercised without consent of the oppressed, democratic power where people are consulted but do not rule, and power executed through social institutions, customs, and discourses that are so pervasive that people

are not aware of their own subordination. People with mental health conditions are subject to powerlessness in all these three categories. Within mental health care, power can be macro - explicit and large-scale displays of force, or micro, which surreptitiously circulates throughout interpersonal relations (Roberts 2010).

The powerlessness of people diagnosed with mental health conditions is both longstanding and entrenched. Foucault (1967) argued that, without the emergence of scientific knowledge and rational explanations of the world, there would be no mental illness as it is currently understood because defining forms of behaviour as normal or abnormal would not be appropriate. In this context, Foucault conceptualised an intimate relationship between knowledge and power, and observed that wherever power is exercised there must always be resistance (Foucault 1980, Hall 2001). The result of these epistemic forces is the assumed legitimacy of a range of harmful therapies and the intrusion of oppressive institutions into personal lives (Smith 1998). Spandler and Mckeown (2017) identify that the “litany of harms” experienced by mental health service users are cause for a truth and reconciliation process such as those used in reparation of human rights abuses and civil wars.

These harmful practices, which include invasive physical interventions such as lobotomies, electroconvulsive therapy, harmful medications and withdrawal of human rights through involuntary admissions to hospital, seclusion and restraint are not just things of the past (Wallcraft and Shulkes 2012). The United Kingdom’s Mental Health Act 1983 (Jones 2017) is a clear demonstration of the ongoing systematic ability of medical professionals to deny people their rights, in its provision of mechanisms for detention, administering treatments without consent, and forcing life decisions on living and occupational arrangements

under community treatment orders. Yet, it is argued that depriving people of their liberties on the grounds of a psychiatric diagnosis is counter to international human rights law (Wallcraft and Shulkes 2012). Furthermore, it is acknowledged that inpatient stays are not always safe, effective, or conducive to recovery (Independent Mental Health Task Force 2016). Added to this picture is the argument that, despite psychiatry presenting itself as scientific, value judgements are an integral and unavoidable part of psychiatric classification: there is a much greater level of subjectivity involved in each juncture of classification in psychiatry compared with other medical fields. The way people are categorised based on these value judgments have wide reaching negative implications and impacts on both people diagnosed with mental health conditions and the broader society through policy, health economics and social disadvantage (Browne 2017).

There is an absence of research supporting the notion held by bio-psychiatry and the pharmaceutical industry that “mental illness” is an illness like any other. But, the biological model of mental health causes huge damage to those diagnosed with a mental health condition, is pessimistic about people’s recovery, and discourages discussion of the meaningful aspects in people’s lives such as their families and the societies they live in (Read 2005). The results are that people can remain isolated and their proposed difference to other people reinforced (Mayall et al 1999). The next section considers how the political climate cements this notion of difference rather than address it.

2.4 Mental Health Stigma, Discrimination, and the Political Climate

Unfortunately, whilst some gains in tackling stigma have been made (Henderson et al 2014a), the current political climate undermines these efforts, and actively worsens the situation in some respects. This is significantly

problematic, as for many, the stigma they experience is worse than the distress associated with their mental health condition (Sartorius 2007). Henderson et al (2014a) found that while the overall level of discrimination against people with mental health problems across some life areas fell in recent years, there is no evidence that more people using mental health services experience no discrimination. They argue that the pattern suggesting a recent rise in discrimination following an earlier reduction may be linked to economic austerity. The welfare benefits system has become an increasing source of discriminatory experience, and experiences of discrimination change in relation to the prevailing economic climate. Added to this picture is inadequate mental health service provision with increased demand, and high levels of unmet need due to shortages of staff, deprivation of funds, lack of access to a full range of recommended interventions, and bed reductions. Whilst mental health accounts for 23 percent of NHS activity, spending on secondary mental health is equivalent to half of this, with clinical commissioning groups (CCGs) underinvesting in relation to physical health services. This has possibly contributed to worsening outcomes in recent years, such as increased numbers of people taking their own lives (Independent Mental Health Task Force 2016).

It is possible that the 2008 economic recession and subsequent changes in governmental social and healthcare policy may have had a disproportionately greater impact on people diagnosed with schizophrenia and bipolar disorder (Hayes et al 2017). The United Nations Convention on the Rights of Persons with Disabilities Inquiry (2016) found that the overhauling of a wide range of entitlements in several areas of the welfare system in the UK (including the social and private housing sector, contributory and non-contributory benefits, tax credits and out-of-work and in-work benefit, and major disability benefits

related to the specific and extra costs associated with disability) had regularly portrayed people with disabilities³ negatively. Such portrayals included people being dependent or making a living out of benefits, committing fraud as benefit claimants, being lazy and putting a burden on taxpayers (who are paying “money for nothing”). This is something of a reinvention of the Victorian distinction between ‘deserving and undeserving poor’ (Briant et al 2013). Although the government produced evidence of formal efforts and public awareness campaigns to improve the image of persons with disabilities, the inquiry collected evidence that people with disabilities continue to experience increasing hostility, aggressive behaviour and sometimes attacks to their personal integrity. The inquiry observed that various pieces of legislation related to recent welfare policies do not fully enforce the international human rights framework related to social protection and independent living, and in the field of social protection, people with disabilities have not been properly considered as right-holders and entitled to benefits with regard to their right to social protection. It is therefore not surprising that people with mental health problems, with the lowest rates of employment of any disabled group and therefore more likely to be reliant on welfare benefits (Social Exclusion Unit 2004, Barr et al 2015) continue to face stigma and discrimination, when this is effectively reinforced by governmental welfare reform. Next, how power is played out in the epistemic injustice these issues contribute to is discussed, in relation to matters of knowledge production.

³ Here, the term disability includes people diagnosed with a mental health condition.

2.5 Knowledge Production, Epistemic Injustice and Knowledge Democracy

In this section, I set out how knowledge production and research can at worst contribute to the disadvantage and powerlessness that people with diagnosed with mental health conditions face by actually causing harm, and at best, generally fail to engage people with mental health conditions apart from as passive objects of study. By knowledge production, I am referring to what counts as knowledge generally, and to research as a form of knowledge production. The section ends with a discussion of knowledge democracy, which aims to address the epistemic injustice that contributes to the difficulties presented. The service user movement has an explicitly political interest in research: while mainstream interest in user involvement in research and evaluation highlights feeding user knowledge and experience into existing research arrangements and paradigms, service users and their organisations emphasise the transformation of research philosophy, production, social relations, and objectives (Beresford 2002).

Foucault (1972) placed a special emphasis on the role of knowledge in power relations, arguing that all forms of knowledge are intimately related to power relations at all levels of social life. Those methodologically influenced by Marx such as critical theorists, argue that the views of those who are powerful in society come to be regarded as the truth. This is epistemic privilege. The implications of this position are that the powerful (those who own and control the means of production) are in a position to dictate what counts as valid knowledge. Critical theorists have retained a Marxist commitment to emancipation from relations of domination and exploitation (Williams and May 1996).

Harmful practices and oppression become acceptable through scientific knowledge, which treats the individual as an object of analysis to be studied in a detached way, in addition to removing the individual's rights to participate in the discussion (Smith 1998). Thus, scientific knowledge controls, dominates and keeps people under surveillance (Foucault 1967, Smith 1998). There is some evidence for this: a review of literature on mental health service users' views concluded that their views were disregarded by researchers if they did not coincide with those of mental health professionals (Kommana et al 1997). In their encounters with powerful individuals and institutions, people from disadvantaged groups face negotiations regarding the status of their knowledge (Mayall et al 1999). Spandler and Mckeown (2017) argue that the systematic refusal to attend to service users' experiential knowledge constitutes psychiatric abuse further to the harmful medical interventions highlighted earlier. This amounts to the epistemic injustice discussed by Crichton et al (2017), where the knowledge and sense making of people from certain groups are undermined: they just aren't taken seriously or afforded the same level of credibility as others, and are deemed as unreliable. It is clear that mental health service users are particularly susceptible to epistemic injustice due to the persistent negative stereotypes surrounding them. The damage done is threefold: in individual interactions between service users and practitioners where the practitioner considers the service user less credible (credibility deficit), through public perceptions of people with mental health conditions, and through the underfunding of psychiatric services (Crichton et al 2017).

Fundamentally, establishments monopolise the production and use of knowledge (Koch and Kralik 2006), and certain forms of knowledge and knowledge production such as quantitative data are privileged and fetishised

(Anderson 2017). 'Objects of research interest' are predominantly people from socially disadvantaged groups, who are designated as problematic and a threat to societal order, so warrant intervention to restore the problem they present. Or, need help or redress because of their disadvantage. Disadvantaged groups are then further disadvantaged once they become "the researched", as the balance of power lies with the researcher, and their own agendas are not commonly heard. The researcher's goals and values have greater status than "the researched", including in the traditional theory development of social research (Mayall et al 1999).

Research is a political activity (Mayall et al 1999), with an impact on communities that needs to be considered within its broader societal context. Generally, the form of knowledge production that is health research is an activity engaged in by professional researchers for their own specific purposes, and that these purposes may have had little or no relevance to the health service users (Wilson 2005). Health services research includes determining what services are needed, how they should be delivered, how they can be received, and what impact they may have on individuals and populations. Conventionally, what to develop and how to evaluate is the choice of professionals (Oliver 1999). Whilst there are some areas of influence outside of researchers' hands, such as time scales and funder/organisational priorities, they still have greater control than the researched. Furthermore, whilst researchers should pay due attention to people's accounts, they impure meanings to them based on their own values (Mayall et al 1999). Medical research had historically been driven by clinicians and scientists under the disease model, and have focussed on the vision and interests of the medical profession and industry. Yet, biasing knowledge on narrow technological

questions and ignoring social context and outcomes is unjustifiable, particularly as the social and emotional aspects of well-being are considered priorities by service users. There is a risk that social aspects are overlooked in health research, where effectiveness interventions are tied up with cost-effectiveness, even though these aspects are highly valued by service users (Oliver 1999).

Some areas of research have goals and methods that become lodged in tradition (Mayall et al 1999). Historically, mental health service users have not been given meaningful roles in research, or in efforts to change the services they use (Case et al 2014). Yet, this is to miss out on a great opportunity as it has been argued that collaborating with service users means that a research question can be explored and understood with greater depth, breadth and richness (Sweeney et al 2012). There are also moral and strategic imperatives for actively involving service users in research concerning their needs, aspirations and services. The fact that professionals' priorities and service users' priorities differ is why service users must be involved, but also why they are not (Oliver 1999).

The effects of epistemic injustice can have devastating effects on mental health service users (Crichton et al 2017). One solution put forward is that of knowledge democracy. Knowledge democracy acknowledges that there are multiple ways of knowing (epistemologies), in frameworks from social movements that encompass marginalised groups. Knowledge can be created and communicated in multiple forms, and is a powerful tool for action to struggle for a fairer world. Hall (2013) identifies a central issue of "knowledge asymmetry", where the people who provide knowledge gain from the gathering and organising of that knowledge. Debates regarding knowledge democracy have occurred in an attempt to better understand the relationship between

knowledge and equality, and by so doing, acknowledging that as it stands, knowledge economy and knowledge society do not provide social justice (Hall 2013). Service user movements have also offered a critique of the rational scientific basis of knowledge production, exposing the particularity of the standpoint from which knowledge is produced (Owen 2005). The next section considers what efforts have been made to instil knowledge democracy, though service user involvement and participation.

2.6 Challenging the Orthodoxy: Service User Involvement and Participation

In this section, the moves made by statutory authorities to embed service user involvement and participation through law, policy and guidance are presented. It will also be debated that these attempts have been less than successful in meeting the demands from service users for more power and control over decisions that profoundly affect their lives, and looks at the possible reasons why.

The Schizophrenia Commission (2012) found that the main message coming from service users and their families is that the system must give service users greater control, arguing that in an era of “patient choice”, the voice of people described as mentally ill people is still ignored. Despite on-going developments in service user involvement in mental health services, service users remain a relatively devalued group, often deprived of any real chance to contribute to decisions about the treatment and services that centrally affect their lives (Perkins 1996). Clinicians typically occupy a position of dominance and power in relation to service users (Sweeney 2012). Koch and Kralic (2006) argue that “expert” service users who question the authority of medical practitioners are

treated with suspicion, and that people who question medical frameworks can be considered “insane”.

The harms engendered by psychiatric services have provoked a well-recognised tradition of challenging this prevailing orthodoxy from service users themselves via activism in service user and survivor movements (Beresford 2002), and, indeed, professionally led critical groupings such as the Critical Psychiatry Network (<http://criticalpsychiatry.blogspot.co.uk/>), Critical Mental Health Nurses Network (<https://criticalmhnursing.org/>) and numerous critical psychologists (Cromby et al 2013, Bentall 2009). Even allowing for the trenchant critique of the professionals of the original anti-psychiatry movement such as Laing and Szasz (Crossley 1998, Kelly et al 2010), critical interlocutors such as Peter Sedgwick (1982), and latterly within or associated with the emergent Mad Studies movement (LeFrancois 2013), these radical challenges have not appreciably dented the prevailing bio-medical orthodoxy or instigated systems conducive to ideals of democratisation where service users’ voices are heard in relational interplays with health professionals (Femdal and Knutsen 2017).

This is despite the efforts that have also been made by the state to increase service user participation through legislation and policy: service user involvement in the UK healthcare agenda is a widely stated expectation (Stickley 2006). The active involvement of people who have at one time used, or who continue to use, mental health services has come to be seen as a central feature of both the policy and the practice of modern mental health care (Roberts 2010).

2.6.1 Participation and Involvement Obligations

There are now many stated statutory obligations, guidance and expectations for NHS organisations to demonstrate service user involvement. NHS commissioning organisations have a legal duty under the National Health Service Act (2006) to involve the public in the commissioning of services. Clinical Commissioning Groups (CCGs) must provide for what is termed the public to be involved in the planning of services, and the development and consideration of decisions and proposals for changes which would have an impact on services if implemented. As part of their governance arrangements, CCGs and NHS England are required to prepare annual reports which must explain how their public involvement duty in the previous financial year has been fulfilled (NHS 2017).

The most recent NHS statement regarding participation is the NHS England's Public Participation Policy (NHS 2017), which particularly concerns public involvement in the commissioning process. It acknowledges that participation is conducted on myriad levels by drawing on Arnstein (1969)'s ladder of participation. This ladder is used often to create typologies of participation in terms of intent and outcome. It differentiates between "citizen power", and tokenism, and is a reminder that participation is about power and control. The former includes citizen control, delegated power and partnership. The latter encompasses consultation, giving information, and placation (Cornwall 2008).

Involvement of service users is also included in Care Quality Commission standards (Care Quality Commission 2012) and included in the National Institute for Health and Care Excellence (NICE) Service User Experience guidelines (NICE 2011). A key principle of the government's mental health

strategy “No Health without Mental Health” (Department of Health (DH) 2011) was putting people who use services at the heart of what NHS providers do. This was also a principle of Equity and Excellence: Liberating the NHS (DH 2010), which as part of its purported democratic principles demanded that NHS Trusts must develop relationships with service users to ensure their meaningful involvement. According to the latter, involving service users in their care and treatment increases their knowledge and understanding of their health status. The DH states that service users need to be enabled to share in decisions made about their care and find out much more easily about services that are available. It puts forward the understanding that healthcare systems are in their infancy in putting the experience of service users first, and have barely started to realise the potential of “patients” as joint providers of their own care and recovery. To do this, it is advised, organisations may need to find effective ways of having conversations with their communities that can be developed in a systematic way. Through this process, it states, service users should have ownership of their local NHS, influence over how services are provided, health services that meet their needs and preferences, and ownership of solutions (DH 2010).

2.6.2 Limitations in Statutory Involvement and Participation

At first glance, it may seem that public institutions appear to be responding to the calls voiced by activists, development practitioners and progressive thinkers for greater public involvement in making the decisions that matter and holding governments to account (Cromwell 2008). However, there are concerns regarding how well participation works in practice. For all these laudable aims enshrined in health care law, policy and guidance, activities under the participation banner such as consultation can in practice be used as a means of

legitimising decisions already made, providing a thin veneer to lend the processes moral authority. Outcomes are open to being selectively read and used by those with the power to decide, and it is rarely guaranteed that what is said will be responded to or taken into account (Cornwall 2008). Commentators have argued that involvement initiatives tend to become little more than mechanisms by which state agencies also give their actual decision making processes legitimacy, thus failing to address inherently problematic structural issues. Furthermore, they exclude voices that are not deemed acceptable (Forbes and Sashidharan 1997). Pretty (1995) identifies problematic forms of participation such as tokenistic “representation” with no power, and ‘functional participation’, where people participate to meet project objectives more effectively and to reduce costs after the main decisions have already been made.

Whilst statutory involvement and participation strategies ostensibly look like an attempt to share or even give power to service users and some significant efforts to challenge traditional power/knowledge dynamics are evident (Owen 2005), the medical model still remains dominant (Crichton et al 2016). Indeed, it is argued that people who use mental health services can become co-opted by having to adopt psychiatry’s conceptual categories, diagnostic criteria and attendant valuations to be allowed to participate. This means that their involvement serves to perpetuate psychiatry’s ‘body of knowledge’ or ‘discourse’, along with the restrictive power that its discourse exerts over those who use, and who would seek to actively participate in, mental health services (Stickley 2006).

Hodge (2005b) found that, through patterns of linguistic interaction it is possible to demonstrate how power is used to exclude certain voices, give legitimacy to

the status quo and, in the process, reinforce existing structural power inequalities between service users and officials. Forbes and Sashidharan (1997) argue that, in service-led user involvement, the relationship between service users and services tends to be treated in purely functional terms, and Fairclough (1992) noted that the evaluation of the utterances of the non-powerful by the powerful can be used as a form of policing, reinforcing asymmetrical power relations in the process. This can lead to great frustration on behalf of the service users who are unable to engage in meaningful debate about the fundamental issues that really concern them (Hodge 2005b).

These profound concerns regarding the motivations, meaningfulness, and ethics of some involvement practices could be a consequence of a paradox of conflicting ideologies surrounding participation. (Beresford (2002) argues that the co-option of service user involvement into mainstream agendas is under a capitalist approach that is distinct in principle from the roots based calls for involvement from the survivor movement. Beresford identified two approaches to participation: 'consumerist' and 'democratic', which are based on distinct and different philosophical and ideological approaches. The consumerist approach generally starts with policy and the service system. The second is rooted in people's lives and in their aspirations to improve the nature and conditions of their lives. The former approach is associated with maximising profitability and effectiveness, framed mainly in market research terms of 'improving the product' through market testing and feedback, and has largely been based on consultative and data collection methods of involvement. The latter approach is primarily concerned with people having more say in the agencies, organisations, and institutions which impact upon them and for people to be able to exert more control over their own lives. Both approaches may be

concerned with bringing about change and influencing what happens. However, the democratic approach is concerned with ensuring that participants have the direct capacity and opportunity to make change. This is not an explicit concern of the consumerist approach, where the search is for external input which the initiating agencies themselves decide what to do with (Beresford 2002). On the same latter political spectrum, self-initiated mobilisation, whilst ostensibly a form of participation, may or may not challenge powerholders or influence the distribution of wealth. Self-mobilisation may actually be actively promoted by governments as part of efficiency goals that are entirely consistent with a neoliberal approach. This can be amply illustrated by former British Prime Minister David Cameron's notion of "The Big Society", which was actually planned as a tool for a reduction in public services and further "rolling back" of the state (Scott 2010). Or, as Cornwall (2008) puts it: empowerment as "do it yourself".

Whilst recognising that some convergence between these two polarised deals can produce good results by happy coincidence, service users' interest in participation has been part of broader political and social philosophies which prioritise people's inclusion, autonomy and independence, and the achievement of their human and civil rights rather than from a consumerist model (Beresford 2002). There can be no doubt that, to bring about a knowledge democracy that is based on the principles of empowerment and rights rather than on a consumerist perspective, a participation framework that is rooted in these philosophical principles is required. PAR has been put forward as precisely this kind of framework, and is discussed in the next section as a possible answer.

2.7 PAR: A Knowledge Democracy Solution?

It has been argued that service user involvement and participation practices in statutory agencies especially may not redress the power imbalances and disadvantage experienced by people who use mental health services, or bring about knowledge democracy and epistemic justice. These are big questions regarding democracy, power and legitimacy for service users and service providers alike (Bracken and Thomas 2001). Some PAR approaches prioritise working with oppressed groups of people who face issues including marginalisation and exclusion (Hagey 1997). So, could PAR, with its roots firmly in the democratic principles called for by service users (Beresford 2002) provide a more effective framework for addressing these issues? Here, through an overview of PAR's philosophies, a rationale for the use of PAR in response to the issues set out is given.

PAR is a research approach that seeks to empower people within communities of interest through collaboration, and achieve change through action as a result of this collaboration. It has been shown that PAR can be equitable, transformative and liberating for participants (Koch and Kralic 2006). PAR's central feature is the dissolution of "researcher" and "researched" roles, and focuses on collaboration between researcher and participants in the diagnosis of problems and identification of solutions (Bryman 2008). Participants are expected to participate actively with the researcher throughout the study, beginning with the initial identification of the research topic and design, up to the publication of findings (Sarantakos 1993).

The rationales for using PAR in mental health services are twofold. In principle, it has the potential to provide a framework for NHS mental health services to share power, and bring about service improvements that are meaningful to

service users. It also has the potential to both change power relations and improve quality in the research process: a service user's experience of distress and mental health service usage brings a depth to research that could not otherwise be achieved (Townend and Braithwaite 2002). However, in addition to attempting to generate knowledge and action that is useful to a particular group of people, it has also been argued that PAR has the potential to empower individuals at a deeper level to see if they are capable of constructing and using their own knowledge (Freire 1970, Reason 2005).

PAR seeks to practice the radical, suggesting that it is not enough to understand the world: it has to be changed for the better (Kindon et al 2007). It insists upon the importance of democratising social inquiry and strengthening participatory democratic ideals, particularly in relation to traditionally disempowered groups (Krimmerman 2001). PAR has its own inbuilt value system (Walter 2009), which is a political one rooted in democracy (Koch and Kralic 2006). Literature suggests that these participatory approaches hold the potential to democratise and decolonise knowledge production (Cornwall 2008, Flicker 2008, James 2016), and it is argued that service users can gain empowerment through active involvement in research (Thorncroft 2006).

There have been some attempts to use PAR in response to the mental health survivor movement's demands for a voice in planning and running services and to stimulate choices and alternative forms of treatment, but it remains in development in the field (Baum et al 2006). PAR is described as being particularly suited to systematically understanding the conditions under which people experience health disparities, and how to ameliorate the problem and create a more equitable and effective health care system (Olshanky et al 2005). When researchers and communities work together in a collaborative,

participatory way, expertise and insights develop that would not otherwise be possible (Walter 2009). It is argued that this process increases the relevance of research whilst maintaining scientific rigour through collaboration between researchers and service users (White et al 2004). Yet, despite a growing interest in PAR and acknowledgement of the value of generally involving service users in research (Sweeney et al 2012, Simpson et al 2014, Rose 2014), more traditional, "scientific" notions of research remain the norm. Conventional research – particularly around pharmaceutical research, has spearheaded evidence-based healthcare that operates within narrow frameworks (Oliver 1999). This can easily be seen in the hierarchy of evidence that forms the basis of evidence based practice and medicine that doesn't even explicitly feature PAR, rather, placing more traditional science such as meta-analyses and randomised control trials at the top of the hierarchy, and qualitative research at the lower end (Sackett et al 1997). Furthermore, whilst grant applications for health research and ethical clearance generally now stipulate demonstration of "public involvement", this does not constitute PAR being seen as a mainstream approach. We have seen how some of these involvement practices, even if well-meaning, can potentially be at best dubious, and at worst, harmful.

If we take our problem as being a lack of knowledge democracy as part of the picture that disempowers certain groups in society, then PAR, in its attempts at redistribution of power, is a political activity, as well as an epistemological principle and a research methodology. The political arm of PAR is the assertion of people's right and ability to have a say in decisions that affect them and claim to generate knowledge about them (Reason and Bradbury 2008). PAR is therefore an appropriate choice to attempt to address the epistemic injustice

faced by people who use mental health services that contributes to a myriad of other forms of disadvantage, through its pursuit of knowledge democracy.

2.8 Conclusion to Chapter Two

Do not monopolise your knowledge nor impose arrogantly your techniques, but respect and combine your skills with the knowledge of the researched or grassroots communities, taking them as full partners and co-researchers. Do not trust elitist versions of history and science which respond to dominant interests, but be receptive to counter-narratives and try to recapture them. Do not depend solely on your culture to interpret facts, but recover local values, traits, beliefs, and arts for action by and with the research organisations. Do not impose your own ponderous scientific style for communicating results, but diffuse and share what you have learned together with the people, in a manner that is wholly understandable and even literary and pleasant, for science should not be necessarily a mystery nor a monopoly of experts and intellectuals (Fals Borda 1998 p235).

This chapter has set out the marginalisation, stigma, disempowerment and epistemic injustice experienced by people who use mental health services in many areas of life. Despite a growing focus on service user involvement and participation at a health care policy level, attempts to practice it by powerful organisations are often at best ineffectual and meaningless, and at worst, reinforce powerlessness. This possibly is in part a consequence of a politically conflicting set of underlying assumptions and principles. It has been argued that the pursuit of knowledge democracy through PAR could resolve this conflict, and in doing so, provide a solution to the some of the issues facing people who use mental health services presented in this chapter.

We have seen that people from disadvantaged groups have complex relationships with powerful sectors of society, and may be working within or

against the political and social structures that condition their daily lives (Mayall et al 1999). Foucault asserted that power results from the interactions between people, from the practices of institutions, and from the exercise of different forms of knowledge. Yet, Foucault's account of power allows for subversion and change, arguing that power always generates resistance. Whilst the knowledge/power relations are very effective, they only dominate through rules of conduct, texts and institutional practices where meanings are produced. But change can occur through transformation of the institutions concerned and the way in which subjects are constructed through knowledge (Smith 1998).

The whole power challenge principle in PAR means that it may be particularly useful for improving health services because through PAR, people are enabled to see the ways in which the establishment monopolises the production and use of knowledge (Koch and Kralic 2006). We must stop holding people as objects, and build relationships as co-researchers. This means engaging people as full persons, basing explorations directly on their understanding of their own actions and experiences (Reason and Bradbury 2008). It is argued that PAR has huge transformative potential, and participation has been seen as a means to overcome professional dominance, yet too often this potential goes unrealised (Pain et al 2007, Baum 2006). The impact of service user involvement in research could be revolutionary. There needs to be a focus on methodologies for service user involvement in guiding research, identifying research priorities and shaping research questions. It is also essential that these methodologies are evaluated (Oliver 1999). Yet, few authors have interrogated the warrant of the emancipatory claim of PAR (James 2016).

The following chapter contains an in-depth exploration of PAR methodology, and a description of the establishment and activities of a PAR team of mental health service users, called PAR Excellence.

CHAPTER THREE: METHODOLOGY

3.1 Introduction to Chapter Three

This methodology chapter is divided into two sections. Section one is an in-depth discussion of PAR as a research methodology. Section two presents how PAR was applied in this project by describing the establishment of a PAR team (PAR Excellence). In terms of the tree analogy running through the project, this chapter is the manual for the project, bringing together PAR theory with practice. However, because of the non-linear nature of this thesis (which is reflective of the non-linear nature of PAR itself), some methods sub-sections are found in other chapters. The following action chapter contains details of the methods that PAR Excellence decided to utilise to explore their chosen topic of shared decision making and the use of shared service user experiences. The participation chapter after that contains details of the methods used to explore PAR Excellence's experience of the PAR process.

The contextual depth that this chapter provides on PAR methodology is particularly important because it spells out the justification for the decision to use PAR in relation to the issues for people who use mental health services set out in chapter two. It also provides the necessary context for the ensuing description of the activities carried out by PAR Excellence. Overarching the whole chapter is the understanding that PAR is a challenge to societal understandings of marginalised groups, and to traditional research. The chapter draws on the overlapping and intertwined PAR and action research literature: both approaches are on a spectrum of the emancipatory participatory research tradition (Rahman, 1985) as well as the organisational development tradition (Whyte, 1991).

There are particular arguments for using PAR in mental health. First and foremost, when there is a paramount health goal of challenging disparities (as there is in this project), research practice that is within the emancipatory perspective and fosters the democratic participation of community members to transform their lives is demanded (Wallerstein and Duran 2017). The further justifications for using PAR in this study are twofold. Firstly, the study is based within NHS mental health services that, as discussed in the previous chapter, hold power over service users. Secondly, rather than resolving some of the issues facing people with mental health problems, mental health services can in fact exacerbate them (Thornicroft 2006). Therefore, as PAR seeks to empower people who are traditionally marginalised (Koch and Kralik 2006) and bring about change (Kindon et al 2007), it is therefore a wholly suitable methodology for the purposes of this project.

3.2 Section One: PAR Methodology

3.2.1 Section One Introduction

This section presents the significant aspects of PAR, beginning with a short discussion of three of its key pioneers: Lewin, Freire, and Fals Borda. These individuals in particular are discussed because their thinking and practice had a strong influence on this project, so by understanding their motivations and ambitions, a context to the project, its goals and its conduct is provided. Also, by understanding these PAR roots, why the approach to PAR that was taken in the project was chosen over other PAR approaches is illuminated.

Then, the crucial elements of PAR in relation to the aims of this project are discussed: its relation to critical theory, democracy, knowledge democracy and values. That is followed by a discussion of some of the critique of PAR,

concluding with how some of these critiques can be answered through a discussion of quality in PAR and the role of reflexivity. Firstly though, how PAR is a break from tradition is explored.

3.2.2 PAR: Breaking from Tradition

It will become evident in the discussion of PAR's key pioneers that it is a fairly recent challenge to the traditional research approaches bound up in mainstream notions of science. However, PAR's political and philosophical underpinnings can be traced back to Marx and Engels in their call for the working classes to create their own history through the means of mental production as well as material production (Rahman 2008). PAR connects with this position by providing people with opportunities to become subjects of their own history through research (McIntyre 2008). PAR isn't always seen as exclusively research orientated (Fals Borda 1991), but it is argued that participation in knowledge production is concomitant with the movement to achieve social justice (McTaggart 1997). PAR's perspective is that underprivileged people can collectively investigate their own reality, by themselves or with friendly outsiders, and take action to advance their own lives and reflect on their own experiences (Rahman 2008).

Alongside its emancipatory aims, PAR is also a clear challenge to scientific positivism (Kindon et al 2007). PAR's epistemological perspective is that knowledge is co-constructed and produced through the relationships between researchers and participants, and that these relationships are mediated through values. PAR highlights the relationship between the researcher and the researched through reflexive examination of the researcher, and brings into question how knowledge is constructed. In PAR, the importance of specifically

working towards social justice informs the assumptions and values that shape research and action (Langhout and Thomas 2010). To grasp PAR as a research methodology, it is essential to understand how it differs significantly to traditional research in its aims and activities. PAR is research that is not “on” people, but “with them” (Olshansky et al 2005), where researchers and participants work together to examine a problematic situation or action to change it for the better (Wadsworth 1998). It is a research approach that seeks to empower people within communities of interest, and achieve change through action (Koch and Kralik 2006). It seeks to practice the radical, suggesting that it is not enough to understand the world: it has to be changed for the better (Kindon et al 2007). PAR its own inbuilt value system (Walter 2009), and aims to be value-led, rather than value free (Mullett 2015). The role of the researcher and the function of the research are dependent upon the values, desires and needs of the community (Stoecker 1999).

Through its concern with changing situations rather than just interpreting them (McTaggart 1997), PAR aims to make a difference by working collaboratively with people from communities of interest through participatory processes that promote equality as participants construct meaning during facilitated, group discussions (Koch and Kralik 2006). People are expected to become partners in the whole research process by participating actively throughout the study (Koch and Kralik 2006), beginning with the initial identification of the research topic and design, up to the publication of findings (Sarantakos 1993). PAR’s dissolution of “researcher” and “researched” roles necessitates collaboration between researcher and participants in the diagnosis of problems and identification of solutions, which can happen iteratively throughout the entire research process (Bryman 2008). The problem that needs solving or objective

that needs reaching must arise from the community of interest, and that community must want to see change. It cannot be imposed from outside, including by a researcher (Walter 2009).

Quite how much PAR challenges traditional research approaches will become more apparent as the story of the project unfolds in section two of this chapter and the further chapters on action and participation. Next, there is a short discussion of some of the key players in developing PAR as it is currently understood.

3.2.3 PAR Key Players: Lewin, Fals Borda, and Freire

Lewin, Fals Borda and Freire were by no means the only significant players in the development of action research and PAR, but they remain some of the most influential and written about in their thinking and response to the situations they were witnessing. PAR began developing globally in the late 1960s, with early references and theoretical reflections found in Germany and trends traceable to Latin America, Africa and South Asia (Rahman 2008). These simultaneous movements across continents occurred completely independently of each other as, it is argued, a response to the urgent need for understating a tragic, unbalanced world (Fals Borda 2001). There are two particular pioneers of the principles and practices of PAR: Paulo Freire and Fals Borda. However, before them, Kurt Lewin described something called action research. So we will start with Lewin, for to understand PAR, it is essential to understand its building block, action research.

3.2.3(i) Kurt Lewin (1890-1947)

Kurt Lewin was a German-American social psychologist to whom the creation of the term action research is generally accredited (Olshansky et al 2005,

Adelman 1993). In the 1940s, Lewin challenged the gap he saw between theory and practice, and sought to solve practical problems through a research cycle involving planning, action, and investigating the results of the action (Lewin 1948/1997). He rejected the positivist belief that researchers study an objective world separate from the meanings understood by participants as they act in their world. Lewin used the term action research to describe research that seeks to understand human experiences and then take constructive action to ameliorate difficult and/or oppressive situations (Olshansky et al 2005). There is a clear distinction between his work and participatory research – participants were not seen by Lewin as active participants in setting the research agenda, making decisions or being active in study design (Koch and Kralik 2006). However, it is a definite precursor to PAR, and strong affinities to general PAR principles can be seen in some of its key features. Action research is done by or with insiders of a community. It is orientated to action to address a particular problematic situation, and is best done with people who have a stake in the problem and where there is a perceived need for change (Herr and Anderson 2005). Action research aims to enable communities and organisations to mobilise their diverse and complex internal resources as fully as possible (Greenwood and Levin 1998).

Furthermore, Lewin felt that the best way to move people forward was to engage them in enquiries about their own lives, and stressed the fundamental role of democratic collaboration and participation (Walter 2009). Boog (2003) argues that action research was intended to be emancipatory research. Although a variety of action research approaches have developed along divergent theoretical pathways, these approaches are all supported by a participatory worldview and are meant to be a multi-sided process of research,

self research and education directed at individual empowerment and collective empowerment and/or emancipation. Action research for Lewin was exemplified by the discussion of problems followed by group decisions on how to proceed. Action research must include the active participation by those who have to carry out the work in the exploration of problems that they identify and anticipate. After investigation of these problems the group makes decisions and monitors the consequences (Adelman 1993).

Lewin's ideas on democratic participation in the workplace did not ostensibly include any critique of the wider society. He also framed his interpretations in the form of scientific axioms and he valued experimental research over other forms (Adelman 1993). However, Lewin was particularly concerned with raising the self-esteem of minority groups, to help them seek independence, equality, and co-operation through action research and other means (Lewin, 1946). He wanted minority groups to overcome the forces of exploitation and colonialism that had been prominent in their history (Adelman 1993). It is through this that we can see how action research is linked to the political standpoints of Marx and Engels in the past, and to the future in Fals Borda and Freire, who took some of the principles of action research for broader political emancipatory aims through further challenge to traditional systems of knowledge production.

3.2.3(ii) Orlando Fals Borda (1925-2008)

The Columbian Fals Borda gave conceptual and experimental leadership to PAR, calling for action research to give people a true sense of ownership of their inquiries so that they can autonomously develop their own independent analysis of their lived reality (Rahman 2008). 1970 was deemed by Fals Borda as a turning point year: he and a number of his colleagues were dismayed with

the lack of radical critique and re-orientation in social theory and practice that they perceived as necessary in universities and other institutions. They left their traditional academic posts to develop institutions and procedures for research and action based on local and regional problems. These focussed on emancipatory, educational and cultural processes in response to the poor conditions that people were experiencing. Fals Borda and colleagues believed these conditions were caused by capitalism and modernisation.

The aims of these different practices were to hear ordinary people's knowledge by conducting research with collectives and local groups to lay the foundations for their empowerment (Fals Borda 2001). This move of social science academics from universities to work with land movements and community-based organisations transformed the concept that knowledge emanated from the academy and created an openness to knowledge learned from people's experience (Wallerstein and Duran 2017). At this time, Freire was also, independent of Fal Borda and his colleagues, working on challenging people's poor conditions through participatory practices.

3.2.3(iii) Paulo Freire (1921 – 1997)

The Brazilian Freire had a significant impact on the development of PAR through his liberationist perspective (Reason and Bradbury 2008). Through the publication of *Pedagogy of the Oppressed* (1970) and other writings primarily focused upon participatory learning, he influenced the transformation of the research relationship from one in which communities were objects of study to one in which community members were participating in inquiries. Freire encouraged poor and deprived communities to examine and analyse the structural reasons for their oppression (Baum et al 2006, Koch and Kralik 2006).

Freire argued that reality is not objective truths or facts to be discovered, but rather includes the ways in which the people perceive facts. For him, objectivity can never be isolated from subjectivity (Wallerstein and Duran 2017). Freire, as well as Fals Borda, also advocated that education should be focussed on allowing people to analyse and transform their own reality in their search for liberty and equality (Castillo Burguete et al 2017).

These three pioneers formulated a particular approach to PAR that was adopted in this project from the very outset. Fals Borda and Freire advocated efforts to harness the potential of Lewin's earlier action research to empower communities disadvantaged through poverty and social and educational marginalisation. Their motivations included social change that began from within communities. This was something that had initially captured my attention whilst working in international development in Sri Lanka: international development had been under some blistering critiques as really being a new form of imperialism (Hayter 1971, Biccum 2005). As a response, there was a growing movement to use participatory approaches to support disadvantaged communities to gap analyse, plan and act together with external service providers to enrich people's lives (Bar-On and Prinsen 1999).

Whilst it is described later in this chapter that the growing demand for participatory approaches in international development has also been subject to accusations of a different type of unhelpful dogma, it is with these early PAR principles that I had in mind at the outset and throughout the project. Having developed the view over many years of working and studying in the field that people who use mental health services are a disadvantaged group (as set out in detail earlier in chapter two), I concluded that it might be possible to empower this group and bring about some social change through the use of PAR, which

was in its infancy in mental health services (Baum et al 2006). I wanted to apply the same PAR approaches being practised in international development to my own field, in my home country of the UK, where I considered that people who use mental health services were presented with some very similar challenges to those people who were supposedly beneficiaries of PAR in developing countries – particularly around epistemic injustice, but also in terms of stigma, social exclusion and economic disadvantage (albeit relative). I was also intrigued to explore how this non-traditional approach to research that represents a significant challenge to the usual hegemony of knowledge types in more familiar knowledge production associated with established epistemologies and scientific methods might alter and possibly greatly enhance the research process.

The approach to PAR advocated by Fals Borda and Freire that directly expected communities to develop their own research priorities and conduct their own research was chosen over other potential PAR approaches. Not all PAR is undertaken with who are considered to be disadvantaged groups by the researchers, and broad social reform is not always considered necessary in PAR: it can have more modest aims (Koch and Kralik 2006). Outside of healthcare, PAR has been used in industries and the commercial sector such as those described by Whyte (1991) to engage workforces to problem solve and take action to improve workplaces and productivity. In healthcare, various efforts under the guise of PAR have been made in an attempt to understand service user experiences and/or bring about change in services, such as undertaking PAR with staff as the participants in academic/service provider collaborations (for example, Mahone et al 2011). PAR has also been cited as the methodology in projects that have had elements of participation by people

who use healthcare services, but where the topic was already chosen externally (see Cook et al 2010). Or, PAR has been supposedly conducted where a research topic has emerged from the community of interest (for example, Clements 2010), but where the research has not led to any action.

These approaches were discarded in favour of the PAR approaches advocated by Fals Borda and Freire because I considered that any of these approaches would be continuing power imbalances between staff and mental health service users and therefore not challenging epistemic injustice through promoting knowledge democracy. I instead wanted to utilise their approach that went into the heart of communities and use the knowledge within as the building blocks for bringing about change, with as little influence from staff or the academic community as possible. The only initial exception was my overture to a group of mental health service users that PAR was a worthwhile investment of their time, and may lead to some transformation in some way by putting their knowledge at the forefront of all decision making in a research project. How the influence of these pioneers translated into decision making about how the project was conducted is discussed in section two of this chapter.

There are a range of political, psychological and philosophical standpoints taken by PAR researchers, including poststructuralism and feminism (Kindon et al 2007). However, something all these approaches share is the principle of not just observing the world: research should change it for the better. This is also the foundation of critical theory. Critical theory was chosen as the underpinning theoretical framework for this project for this reason, and is described in the next section.

3.2.4 PAR and Critical Theory

An array of theoretical perspectives can be used to inform a PAR project, for the philosophical origins of PAR can be variously attributed to liberal humanism, pragmatism, phenomenology, social constructionism and systemic thinking as well as critical theory (Reason and Bradbury 2008). However, critical theory is especially emphasised as being related to and informing PAR, as it particularly raises questions about the conditions that sustain unjust and unequal forms of social life. has an affinity for progressive forms of democracy, and is concerned with achieving social justice (Koch and Kralik 2006, Langhout and Thomas 2010). Critical theory also has a commitment to emancipation from domination and exploitation that is rooted in Marxism (Williams and May 1996). It is therefore a useful framework for this project because it relates to the issues that Lewin, Fals Borda and Freire raised and sought to address, and because this project also seeks to explore these issues in the context of people who use mental health services – a marginalised group.

PAR's roots in critical theory lie in its seeking to challenge, not just understand (Crotty 1998). Critical theorists argue that the views of those who are powerful in society come to be regarded as the truth. The implications of this position are that there is a link between power and knowledge, and that the powerful (those who own and control the means of production) are in a position to dictate what counts as valid knowledge (Williams and May 1996). While interpretivists place confidence in the authentic accounts of lived experience that they locate in their research, this is not enough for critical theorists, who see in these accounts voices of an inherited tradition and prevailing culture. Critical theorists use critical reflection on social reality to take action for change by radically calling into question the cultures that they study (Crotty 1998).

Key thinkers of critical theory such as Habermas and Horkheimer over time debated and refined critical theory and used notions of democracy to locate critical theory's significance in society. Habermas concluded that democracy reaches its limits when confronted with the internal logic of the economic system, whose very efficiency rests on the fact that it is not organised democratically but according to a principle of strategic rationality (Wellmer 2014). The role of democratised social relations is also a key consideration in PAR, which is another element that ties critical theory and PAR together.

3.2.5 PAR, Democracy and Knowledge Democracy

PAR is related to critical theory in part because they both share a concern with new forms of democracy. PAR is rooted in democratic principles – not only in terms of knowledge democracy, but democracy in its political form. It is this that makes PAR an explicitly, consciously political activity (rather than implicitly and unconsciously such as traditional research approaches). As Greenwood and Lewin (1998) state, democracy is a complex notion, with divergent definitions and understandings. Meanings range from participation, to egalitarianism, to decision making by consensus, to decision making by majority rule. They place action research as a democratic activity that creates arenas for lively debate and for decision making that respects and enhances the diversity of groups. This is a rejection of the dominant view of democracy as majority rule.

By returning to the roots of action research, it can be seen how it challenged normative notions of democracy early on: it is argued that action research has the potential to destabilise the current culture weighted towards a positivist paradigm because of its focus on democracy (McIntosh 2010). Kurt Lewin and his students conducted quasi-experimental tests in factory and neighbourhood

settings to demonstrate, respectively, the greater gains in productivity and in law and order through democratic participation rather than autocratic coercion (Adelman 1993).

PAR has a commitment to democratic praxis with the people and communities most affected by the issue of inquiry (Janes 2016). One of its key concerns is knowledge democracy. According to Rahman (1985), PAR approaches have the potential to combat domination by elites of the means of knowledge production, and the increased influence of an informed public is central to its value to people whose knowledge has been marginalised. The issue in relation to this project is that there are only a limited number of research approaches which are considered to be scientifically sound (McIntosh 2010). This is of particular interest in healthcare and notions around evidence. The traditional scientific understanding of the world has determined medicine as a profession with unique knowledge and power (Ilich 1977). In the hierarchy of evidence used to determine what leads to valid and reliable knowledge, it is that done to others which is considered powerful, not done with them (McIntosh 2010). This approach to evidence based practice has been adopted in in most health fields, including mental health, and even social work, despite having a tradition of resistance to what has been considered as paternalistic approaches (Trinder 2001).

Literature suggests that participatory approaches hold the potential to democratise and decolonise knowledge production (Janes 2016), through challenging whose knowledge counts (Hall 2012), and whose ways of saying, writing and testifying count (Openjuru 2015). PAR should provide a mechanism to change the social power that determines what is credited as valid and useful knowledge, particularly in addressing multiple dilemmas of power in the

research process and the inequality of power between the researcher and the researched (Macintosh 2010). Morton-Cooper (2000) describes action research as not simply a set of research methods, but a way of approaching the study of humans in which sharing takes place within mutually supportive environments. In this environment, traditional claims of knowledge validity can be examined and contested and new ways of thinking, seeing and acting generated. Findings in PAR are not knowledge about, or knowledge of, but constitute knowledge that is lived and experienced by members of the community (Mullett 2015). Knowledge can be transferable to someone in a similar context, and may generate theory that can be used to explain similar problems in other contexts. Action research can also result in products and instruments that can be used in other settings (Herr and Anderson 2005).

So far, we had seen that PAR methodology and its ancestor action research has a rich theoretical foundation, with some highly laudable aims and values that ostensibly are difficult to question. However, this does not prevent PAR being open to some significant critique. Indeed, its claims to emancipation render it particularly open to questions about both its authenticity, effectiveness, and even potential for doing more harm than good. These issues are explored in the next section.

3.2.6 Critiques of PAR

Critiques of PAR broadly fall into two categories: concerns regarding its legitimacy, and questions about its feasibility. Broadly, it has been described as Western cultural imperialism through its focus on ideals of democracy used to advocate participation (Cornwall and Jewkes 1995). There are concerns about how few studies there are providing empirical documentation of the advantages

of PAR (White et al 2004). There are also concerns regarding the difficulties of implementing PAR in practice (Walter 2009). Aside from those criticising PAR from an informed and participatory standpoint ('from within'), clearly those who favour the dominant medical paradigm in health research challenge the legitimacy of participatory action altogether, using general questions around reliability and validity (Koch and Kralic 2006, White et al 2004).

3.2.6(i) Legitimacy Concerns of PAR

A number of critics argue that participation itself is a form of power, thus throwing doubt on PAR's utility and legitimacy. Cooke & Kothari (2001) challenge the whole orthodoxy of participation, arguing that communities are too often viewed naively, concealing power relations and masking biases. Other criticisms include the re-authorisation of researchers as experts in participation, de-legitimisation of research methods that are not participatory, retention of researcher control, expectations of participants to perform "appropriately" within the process, and production of participants as subjects requiring research and development (Kesby et al 2007). Cooke and Kathari (2001) proposed that there are three tyrannies in participatory practice: the tyranny of decision making, in which community decision making processes are overridden by development experts; the tyranny of the group, where group dynamics may reinforce the individuals in the community already in power; and the tyranny of methods (Wallerstein and Duran 2017). But, although PAR presents many challenges in practice (Walter 2009), more crucially, like the issues around service user involvement in health services outlined in chapter two, the central issues may actually lie with the comprising of the values of PAR through the misuse of participatory methods. Cooke and Kothari (2001) use participation in

development work to explore and illuminate some real structural power issues in participation.

Mosse (2001) argues that participatory ideals can be operationally constrained by institutions with bureaucratic goals, and Cooke (2001) warns that the inclusion of participants runs the risk of symbolising an exercise in power and control over individuals. Furthermore, James (2016) identifies the conundrum that as PAR is increasingly utilised as a means of accessing 'over researched' communities, there is the risk of and appropriating community knowledge and labour, and although participatory approaches are a promising praxis, they risk be appropriated to rationalise less democratic knowledge work, and reinforce epistemic privilege.

Furthermore, some find PAR's tone to be moralising and overbearing (Walter 2009), but whilst PAR claims superior ethical codes (Robson 1993), these assumptions may lead to an underestimation of the risks to participants and researchers of PAR. The intense relationships that may develop during the PAR process may be damaging to both participants and researchers, and this is an issue that is difficult to resolve (Koch and Kralic 2006). Although participatory researchers expect that building collaborative relationships with community members will be sufficient to surmount any differences, power differentials can and often do remain substantial. Academic researchers almost always have greater access to resources, scientific knowledge, research assistants, and time (Wallerstein and Duran 2017).

These concerns are not generally covered by traditional ethical standards (Khanlou and Peter 2005), and therefore, PAR is left vulnerable to unethical

practice because the right questions of it are not asked in the usual ethics procedures.

3.2.6(ii) Difficulties of PAR Implementation

It is argued that PAR is just an ideology, rather than a research method, which leaves it questionable in terms of its usefulness in practice. This methodological nature limits PAR's full applicability in broad social research. One of the reasons for this is that the cyclical process of PAR doesn't end until the problem is solved. This renders PAR implementation as problematic and possibly unfeasible: potentially the PAR process could repeat for ever, because it is questionable as to when a social problem is really resolved (Walter 2009).

From a positivist perspective, action research is considered to be lacking in rigor (Bryman 2008) and subject to research bias (Waterman et al 2001). The elimination of detachment between researcher and researched in PAR is also perceived as leading to biased and unscientific research (White et al 2004). Criticisms focus on how participation, democracy and external ownership can greatly reduce validity and reliability, questioning whether PAR leads to good, scientific, valid, reliable, usable research outcomes. There are also concerns that PAR is not able to have an effect beyond individual projects (Kesby et al 2007).

Walter (2009) also identifies some practical issues with carrying PAR out. The democratic group process may lead to competing research agendas, and categorising a group with a shared problem as a community does not automatically result in consensus. There is also limited application of PAR because of a lack of knowledge about PAR and strategies for its implementation. The methods of actual PAR application are rather vague,

reports of PAR implementation are presented neither in terms of specific or observable behaviours, and a lack of defined procedures makes PAR difficult to apply systematically and replicate. There are also many historic, practical, and methodological obstacles to the development of the participatory relationships necessary for PAR. Approaching potential collaborators can be time-consuming and demanding, but budget allocations may not account for the time needed to develop partnerships (White et al 2004).

It can be seen that some of the critique around PAR methods in particular are within the more scientific tradition that PAR openly challenges. Indeed, Fals Borda (2001) placed traditional notions of value neutrality and aloofness in investigation as being part of the problem alongside the problems in real life and structural crises that require transformation. Wadsworth (1998) argued that epistemological pathologies that include the notion of an objective, value-free, expert science were responsible for perpetuating and reinforcing social injustices and inequalities. Through its attempts to close the gap between research and researched, action research can negate power in the research process (McIntosh 2010). Barnes (2002) makes a link between service user organisations (who in theory can gain from PAR) and long-established feminist work on standpoint theory and situated knowledge. These are cornerstones of feminist theory that challenge the positivistic notions of objectivity and truth, asserting that the situatedness of the knowing subject endows them with a privileged access to truth, and/or views the process of approximating the truth as part of a dialogical relationship among subjects who are differentially situated (Stoetzler and Yuval-Davis 2002).

But, the issues regarding the ethical and authentic conduct of projects described should be a real cause for concern to anyone undertaking PAR.

Clearly, care must be taken to ensure that PAR knowledge production processes are not instruments of further marginalisation when working with vulnerable groups (Mullett 2015). In answer to these criticisms, Kesby (2008), whilst recognising that participation is power its own right, advocates that participation can be legitimate and less dominating if understood as a situated, partial form of knowledge and power. He acknowledges that power cannot be escaped, so argues that judgments about degrees of tyranny must be made and that power will need to be deployed and succumbed to if transformation is to be effected. Furthermore, people need alternative forms of self-governance such as participation if they are to achieve the strategic agency necessary to deconstruct, resist, and outflank the most dominant powers constituting their lives. In the next section, it will be seen how some other PAR writers have responded to questions regarding the issues outlined above by firstly considering quality in PAR, and then ethics in PAR. There then follows a discussion of reflexivity, which is a key tenet of continuously checking the particular quality and ethical concerns associated with PAR.

3.2.7 Quality in PAR

The argument that PAR is not answerable to the questions regarding validity, reliability and objectivity associated with positivist research has been articulated many times (Moser 1980, Koch and Kralic 2006). Unlike traditional research, action research doesn't necessarily seek to produce knowledge that can be generalised or applied: rather, it can be shared, and improve the knowledge about existing situations that are unique to the people in the situation. Also, key to action research is to share the learning that led to the creation of knowledge (McNiff and Whitehead 2009), which is the focus of the fifth chapter discussing PAR Excellence's own findings on the PAR process.

(Koch and Kralic (2007) argue that in PAR, questions of reliability and validity can be framed in terms of rigour and quality. It must be reiterated here that objectivity and distance between researcher and researched is not an objective in PAR: rather, relationship building is an essential requirement to the PAR process (Pain et al 2007). In an endeavour to establish a suitable means of assessing quality in PAR, Koch and Kralic (2007) adapted Guba and Lincoln (1989)'s standards for qualitative research into questions to be asked of PAR projects. They are: what is the world view, is the inquiry credible, Is the inquiry transferable, is the study dependable, is the study believable, what values and interests do researchers bring to the inquiry, and is the work accessible.

3.2.7(i) Ethics in PAR

As highlighted in the preceding section regarding critique of PAR, a significant concern is the ethics of the process. However, due to PAR's unique nature, ethics regulations that have been developed for biomedical science and misunderstandings of PAR methodology can present challenges for the ethical review of PAR. It must be recognised that the ethical framework for medical research is incompatible with some of the fundamental aspects of participatory approaches. (Khanlou and Peter 2005). The principle of confidentiality, for example, conflicts with some PAR methods (Burr and Reynolds 2010). Furthermore, PAR presents complex ethical challenges and difficulties in adhering to ethical guidelines because there is no one way of carrying out PAR (Khanlou and Peter 2005). However, PAR can also extend and enhance the core ethical principles that govern research, particularly around maximising benefits for participants by both building their capacity and ensuring that research is pertinent to them through the participatory process. PAR also promotes especially strong respect for participants as their knowledge and

experience is so highly valued and utilised through its egalitarian and democratic principles.

Khanlou and Peter (2005) recommend the use of Emanuel et al (2000)'s ethical guidelines in conjunction with the context presented by Green et al (1995)'s guidelines for participatory research in health promotion. They are: social or scientific value - all research projects must improve the wellbeing of people or increase knowledge (Khanlou and Peter 2005). However, in addition to these standard research requirements, PAR has an additional requirement that it has emancipatory potential (Kemmis and McTaggart 2000). A further requirement for PAR is that it has social validity (Green et al 1995, Khanlou and Peter 2005). There must be fair subject selection, and a favourable risk-benefit ratio: like any research project, the potential benefits of a PAR study need to be weighed up against the potential risks (Emmanuel et al 2000, Khanlou and Peter 2005), and the people who bear the risk and burden of the research should be able to benefit from the research (Emanuel et al 2000). Participants must give informed consent. Because the roles of researcher and participant become indistinct during the PAR process, there can be confusion over who is gaining informed consent from whom and how (Khanlou and Peter 2005). Participants must be provided with information about the purpose of the research, its procedures, its potential risks and possible benefits (Emanuel et al 2000, Khanlou and Peter 2005). Informed consent should continue to be negotiated between participants: an added dimension of PAR is the on-going information exchange and mutual negotiation that takes place that broadly constitutes informed consent (Khanlou and Peter 2005). Respect for potential and enrolled participants must be demonstrated. PAR fundamentally draws on the principle of respect for and understanding of the community of interest, recognising their rights, knowledge,

and providing the opportunity for them to set their own agenda and take ownership of processes (Cornwall and Jewkes 1995). Finally, projects should be independently reviewed. The initial set-up of PAR Excellence was granted University ethical approval. The shared decision making research element was granted NHS ethics committee approval via the Integrated Research Application System (IRAS), university ethical approval, and local NHS research and innovation permission, thus demonstrating due diligence and attention to quality and ethical considerations.

The mechanism to keep checks on quality in PAR is that of reflexivity, which was used throughout the project in focus groups, team meetings, workshops and reflexive accounts to give space for the whole PAR Excellence team to regularly reflect on quality and ethical concerns. As recommended by Khanlou and Peter (2005), PAR Excellence members were involved in identifying risks as a group and on an individual level throughout by the use of reflexivity. The next section describes why reflexivity is so critical to PAR.

3.2.8 Reflexivity

A key aspect of PAR is that of reflexivity, which highlights the significance of the researcher in the research process and writings, and asserts that PAR researchers should be reflective about the implications of their methods, values, biases and decisions for the knowledge they generate. This reflexivity requires the researcher to develop a sensitivity to their own cultural, political and social context (Bryman 2008). Reflexivity takes the form of reflection on our (mis)understandings, negotiating the meanings of the information gathered collaboratively, and paying attention to our changing positionalities and subjectivities through the research process (Kindon et al 2007).

Furthermore, as PAR makes no pretence of being detached or objective, attentiveness to emotions is paramount – both to minimise the potential for harm, and to account for the influence of emotions on research findings and action-oriented outcomes (Klocker 2015). This sensitivity and reflexivity is appropriate for research with revolutionary aims (Mayall et al 1999). Reflexive engagements with emotion can lead to insights that are particularly revealing about the research process and the motivations of the researcher, as well as being highly informative about the subject area (Humble 2012).

The narrative style of action research allows for reflections on both the process and findings of the research (Herr and Anderson 2005), and the reflexive nature of conversation leads to an understanding of people's meanings, and to make behaviours intelligible to others (Williams and May 1996). To understand our competing interpretations, it is important that we understood one another's standpoint (Richards 1999). This is particularly pertinent to action research, where each person's understanding and practice of action research doesn't stand on isolation from other aspects of their being in the world (Wicks et al 2008).

As a practical way to improve rigour in qualitative research, researchers are encouraged to maintain a personal research diary (Vaismoradi et al 2013). One of the fundamental tensions in action research is to manage the deep involvement required and reflective distance: active engagement in the process is necessary to bring about social change, but there needs to be a critical distance to the process. It is therefore necessary to remain critically reflective throughout the action research process (Levin 2008).

In general, reflection can also be seen as a challenge to the prevailing orthodoxy of evidence-based practice based on traditional research approaches. Reflection as a process of learning or method for engaging in research can counter the effects of the culture of audit and focus on a narrow notion of evidence, but it requires a reconstruction of reflection as intellectual, spiritual and fulfilling (McIntosh 2010). A key element of reflexivity is positionality. As it has now been made abundantly clear, PAR is not concerned with the researcher being an objective outsider to the research field. There has been a tendency for action researchers to be insiders in the organisations they are researching. It is, however, necessary for researchers undertaking PAR to be explicit regarding their role, as clarity is required for thinking through issues around ethics and utility (Herr and Anderson 2005). In the next section documenting the establishment and activities of PAR Excellence, it is shown how quality and ethical considerations relevant and appropriate to PAR were applied in this project.

3.3 Section Two: PAR in Practice – The Establishment and Activities of PAR Excellence

3.3.1 Introduction to Section Two

Section two of this methodology chapter is an in-depth description of how PAR was conducted in this project, drawing on some of the elements discussed in section one. It details how a PAR team (self-named PAR Excellence) was established, how it operated, its activities, and quality and ethics concerns. The name PAR Excellence will be used throughout to refer to the team.

The influence of the three PAR key players discussed in section one of this chapter (Lewin, Fals Borda and Freire) can be seen in much of the decision making about the setting up and conduct of the project described in this section. Fundamental to all of these decisions was the collaboration with people usually 'researched on' as co-researchers advocated by all three players. As highlighted by Fals Borda, to do this, people's knowledge needs to be valued and heard (Fals Borda 2001), and an openness to knowledge learned from people's experience is essential (Wallerstein and Duran 2017). Also, to enable people to create knowledge, they must have a sense of ownership so that they can form their own analysis of their lived reality (Rahman 2008). This valuing of the knowledge of people who use mental health services was dominant in all activities, through the use of the participatory techniques described in this section (for example, a mapping exercise of the journey into and through mental health services from the perspective of the PAR Excellence team). These activities were designed to create safe spaces for open and transparent sharing of the knowledge within the PAR Excellence team, and place a high value on this knowledge in order to develop further knowledge creation.

Key to this process was Freire's influence to enable personal growth through an exploration of the PAR Excellence team's own situation (through the aforementioned mapping exercise and subsequent in-depth discussions) and through the research education programme that was a linchpin of the project. Freire (1970)'s focus on participatory learning was applied through the use of approaches described in this section that engaged the team in interactive, experiential educational activities designed to harness the current knowledge within the team and develop it in relation to their further inquiry design and conduct. Furthermore, Lewin's influence can be seen in the PAR Excellence team's decision to take the action of developing a shared decision making resource of service user experiences to be used in mental health services, and investigate the results of the action (Lewin 1948/1997). This is an example of how action research can be used to attempt to address a particular problematic situation by the people with a stake in the problem (Herr and Anderson 2005), and mobilise the diverse and complex internal resources within the community affected (Greenwood and Levin 1998) – in this case, people who use mental health services.

In the interests of full transparency, it should be made clear here that the circumstances within which the project was set up meant that certain deviations from a purist application of PAR were required in the outset. The project was initiated by myself rather than by people from the community of interest. As an NHS worker and PHD student (but not completely removed or disinterested from the targeted community), this meant that some initial decisions were required in order to progress. However, I approached the university at the same time as a service user interested in conducting PAR in his mental health workplace who subsequently became a member of the PAR Excellence and the

project eventually was conducted in their team. So in a small but significant way, a general interest in PAR had been shown from a member of the community.

Also, the broad research area of information exchange and some loose aims and objectives were set at the outset. Whilst this gave an initial starting point to support recruitment into the project and a framework on which to build initial discussions, it was predominantly to serve university ethics and NHS research approval purposes. This early compromise of one of PAR's key values demonstrates just how complex it can be to establish a true PAR project within institutional constraints.

A set action learning loop of plan, do and review in line with some literature on the conduct of action research and some PAR literature (Lewin 1997, Walter 2009) was in the initial project plan. However, this loop didn't come to fruition: rather, the project was one complete learning arc instead of a loop. This was because of the scope of the action element of the project (to develop a complex resource and research it), and the timescale: the planning, doing and researching of this one piece of action taken took up the whole lifespan of the project. Therefore, there was not the opportunity to apply learning from the action and research conduct for a further iteration of the project.

Aside from this initial framing, the study mostly proceeded in-line with more unadulterated PAR approaches: that is, the team collaboratively chose a research topic, designed a study, and co-conducted most elements of the research and disseminated findings alongside me. However, It will also be demonstrated throughout that levels of participation fluctuated in the conduct of the research. What emerged was the need to take a pragmatic approach to

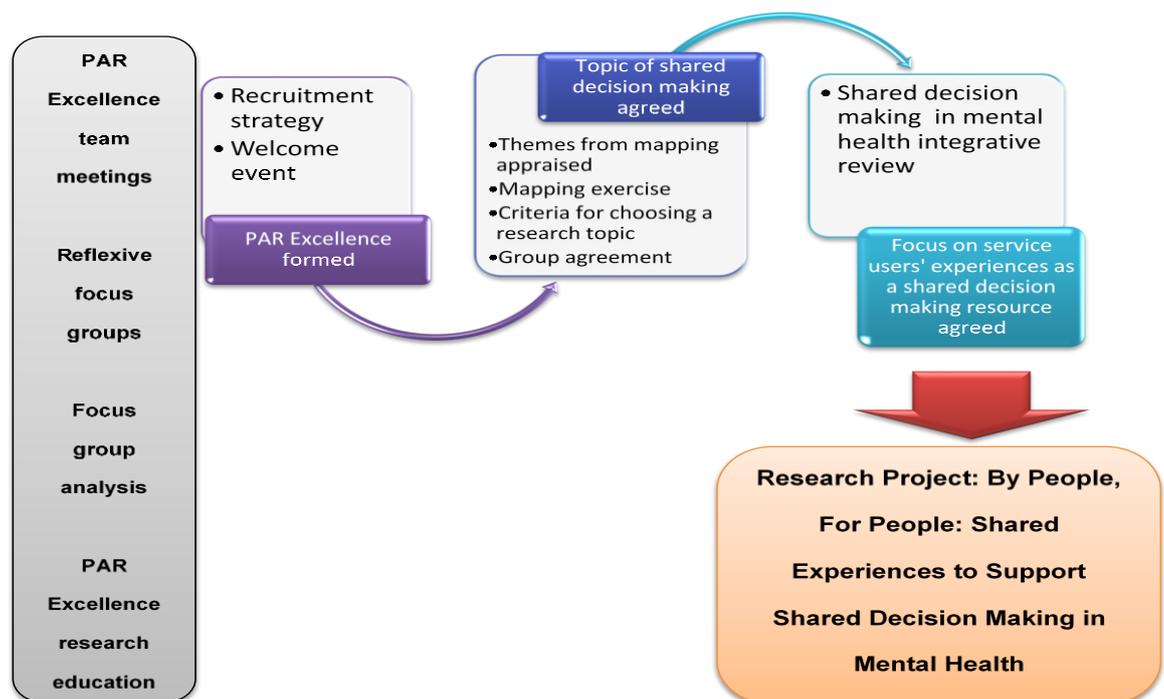
PAR: although at times there was some deviation from the fully participatory path in every aspect of the project that I had hoped for, to keep the project on track it was sometimes necessary to make decisions and take action to establish and maintain the project. Some of these reasons were about the institutions that were involved in the project (the university and the NHS), and some were because of the nature of the team.

It is important that participatory researchers are flexible rather than purist in their understandings of what constitutes the most appropriate level of participation in a project (Kesby et al 2007). It is for this reason that I provided some guidance at times – especially as the emotional wellbeing of a PAR team is the responsibility of the ‘lead researcher’ (Klocker 2015). The success of groups is due in some part to the facilitation and support provided by people who can draw on research and related skills to provide a safe, supportive environment (Simpson et al 2014). This was especially important because managing the expectations of PAR Excellence members was paramount to their wellbeing. There were lofty aims of the project at the outset, and PAR Excellence members expressed high levels of ambition to bring about significant change and in some respect correct the ills they saw of their treatment by mental health services. So, failing to make the types of differences that seem sufficiently ‘big’ and ‘important’ can be deeply distressing and dispiriting. In some cases, change efforts may compound trauma and disadvantage rather than redressing it (Klocker 2015). I endeavoured to manage the teams’ expectations predominantly via the research education programme by instilling a good grasp within the team of what can be achieved in a small scale action research project within the time scale and with the limited resources available to us. This supported the team to decide to develop a

criteria for choosing a research topic that included the question of achievability and relevance (detailed later in this section). I also provided guidance based on my experience of working in NHS mental health services and particular knowledge of the Trust we were working with to encourage realistic aims without curtailing the commitment and passion for change within the team. This was done in the most democratic way possible by encouraging the team to reach a consensus on the most appropriate choices for the scope of the project through group discussions.

Figure 3 shows an overview of the project activities.

Figure 3: Overview of Project Activities



3.3.2 Development of PAR Excellence

In this sub-section, the setting, recruitment activities, initial welcome event, PAR Excellence meetings, group agreement and research education programme are described. White et al (2004) identify that the key elements to the implementation of PAR are participant recruitment and selection; role and relationship clarification for lead researchers and participants, and research education. During the establishment of team, the name PAR Excellence was chosen by the team members. It was chosen as team members felt it reflected two aspects of the project: to pare as in to peel away top layers of a topic to expose layers underneath, and to state a commitment to the pursuit of excellence in PAR.

3.3.3 Setting

The setting for the project was adult mental health services within a UK NHS Foundation Trust. The Trust is the main provider of a range of multi-disciplinary mental health services across a large county-wide geographical area. These include inpatient wards, crisis and home treatment, community mental health, supported accommodation, short-term psychological therapies and social inclusion services.

The setting of an NHS mental health service provider is highly relevant to PAR because, as set out in chapter two, NHS mental health services can be problematic for service users for various reasons. For example, mental health services can in fact exacerbate the issues that service users face, despite being provided by professionals who are supposedly especially qualified to understand and offer expert assistance to people with mental health problems (Thorncroft 2006). Furthermore, NHS services tend to be power holders, not

just in interactions between service provider and service user, but by ultimately being able to deprive people of their liberties and enforce treatment to people against their will under the Mental Health Act 1983 (Jones 2017)

3.3.4 Recruitment to PAR Excellence

Anyone who is an ultimate or immediate beneficiary of a PAR study should be regarded as a potential participant (Fenton et al 1993). Therefore, PAR Excellence team members were recruited from the adult mental health services of the Trust.

PAR does not initially employ the sampling techniques associated with more traditional types of research, such as random sampling. Danley and Ellison (1999) identify that sustained participation is the main selection criteria, arguing that personal investment and motivation are the best predictors for sustained participation. This was accomplished by the inclusion of people who use NHS mental health services.

White et al's (2004) three issues of retention were also considered. PAR raises particular issues around the retaining of participants, because of the commitment and time scales involved. Firstly, the project aimed to be maximise participatory processes: McTaggart (1991) identified that if participants notice that their involvement is tokenism, are only included in selected activities, and receive little recognition for their work then they will leave. Therefore, full participation in every decision from the outset was expected. This included practical concerns such as meeting times, locations, etc, as well as group agreements, and all research decisions. Secondly, the burn-out that can occur in participants was avoided by constant checking in and agreements in the team on time commitments, and de-briefing sessions were available after meetings

and research activities. Thirdly, accessibility for participants was an on-going consideration. Care was taken to ensure information was available in appropriate formats for individual participants, and meetings took place in accessible buildings at times chosen by team members. Individuals were also contacted regarding practical arrangements in a variety of methods to suit individuals' needs. For example, one team member was contacted via post and telephone rather than email. Other steps included meeting team members outside of meeting venues to accompany them into meetings.

In a slight deviation from purist PAR in order to get the project started and to fulfil traditional university and NHS ethical requirements, a simple recruitment criteria was established. This was kept as broad as possible, to encourage accessibility.

Inclusion Criteria

- People over the age of 18 who either currently use adult NHS mental health services, or have done so within the past two years. The services under inquiry were for adults. Therefore, people not old enough to use these services would not be able to contribute to the project as they would not have had the relevant experience. The two year time frame was to ensure that participants had an up-to-date knowledge of using mental health services.
- People who are able to contribute in a group setting. This was because an essential component of PAR is the sharing knowledge and listening to other people's views to reach decisions collaboratively and democratically.

Exclusion Criteria

- People under the age of 18.
- Carers of people who use mental health services. This project was explicitly concerned with people's direct experience of NHS mental health services and that of being a disempowered group by the nature of being diagnosed with a mental health condition.
- People who lack the capacity to give informed consent to participate in the project. Participants in the project needed to be able to freely share their knowledge and experiences, as well as have the capacity to agree to group agreements.
- People who are currently in secure services. This exclusion criteria was necessary on the grounds of practicalities. Participants needed to be able to attend group meetings in a venue accessible to a broad range of people.
- People who are not able to speak and read English. This exclusion was necessary on the grounds that participants needed to understand complex information written in English during research education workshops and data analysis and be able to contribute fully and comfortably to group discussions.

These criteria were ethically troublesome to me: I did not want to exclude anyone who wished to be part of the project. However, I had to balance this with the practicalities of getting people together, and as a student with no research grant I lacked the resources to make the project accessible to people who were not fluent in English. This is another example of uneasily having to make some pragmatic decisions in order to ensure that the project progressed, and that were made without being able to involve members of the community of interest.

The study was advertised by a recruitment flyer (Appendix A) circulated via the Trust's involvement communications (website and newsletter) and via personal visits by myself to service user groups. distributed to service users via Trust staff, circulated to external groups such as the local voluntary mental health sector database and independent service user groups, the university's service user involvement project, and the Trust's existing service user involvement programme members.

In line with general research governance and ethical principles, potential participants met with me on an individual basis so I could explain a participant information sheet (Appendix B) and they could sign an informed consent form (Appendix C) after I had explained it to them. Participants were not expected to sign the consent form immediately and were encouraged to take the information sheet and consent form away so that they could consider their participation. However, all participants did sign immediately. Seven people initially agreed to join PAR Excellence. One died unexpectedly a few months after the project began and to whom the project and thesis is dedicated. Another person joined in the third month of the project but withdrew after eight months due to poor health. This person did have an impact on the project in terms of their involvement in early decision making, and attended a focus group. Therefore, data relating to this member is included in this section and in chapter five. Six of the members were already known to me via an experts by experience programme I had established and managed within the Trust. As is explored in chapter five, this turned out to be a significant element of people's motivation to join the project.

3.3.5 Welcome Event

A half-day welcome event and lunch was held and attended by seven PAR Excellence members. The event began with some participatory activities to enable people to find out more about each other, and discover people's knowledge, experience and beliefs about mental health, participation and research. There then followed an introduction to the project and PAR, followed by an activity to introduce the team to some basic general concepts about research. The event concluded with the team agreeing on the details for their first meeting and research education workshop.

3.3.6 PAR Excellence Meetings

The first meeting was spent putting a group agreement together and deciding on some practicalities, such as that meetings would be monthly for two hours in a non-NHS building. During the four year course of the project, the team generally continued to meet at least monthly, but the format of meetings altered as the project progressed. The meetings were where all decisions were made: choosing the research topic, designing the research, compiling focus group guides, consent forms, recruitment flyers, and design of the shared decision making resource that PAR Excellence chose to create. Sometimes there were additional research education workshops, and sometimes these replaced the monthly meeting. Once research activities such as data collection and analysis started to commence, formal business meetings ceased in their original format. Meetings became much more task focussed as the project continued, such as reviewing papers for the shared decision making literature review, spending time preparing for conferences, or editing the shared decision making resource that the team decided to develop. There were also flurries of activity around

data analysis when some members of the team met weekly with me or even more. For PAR to succeed, participatory relationships must be developed that are distinct from the usual researcher-participant relationship. The quality of relationships impacts on the quality of participants' experiences, and the quality of the project. The commitment of participants, intensity of collaboration and the meaningfulness of the results all depend on non-hierarchical partnerships that are built on trust and respect, where all parties can communicate openly, and differing strengths and perspectives are acknowledged (White et al 2004). Quality participatory relationships were established in team meetings through participatory tools used to facilitate discussion. Meetings were conducted in an informal style, clear communication was used in a variety of styles and formats, and in a style that was approachable, non-threatening and that did not create barriers (for example, the use of inaccessible technical language). The participatory tools that were used included diagramming and mapping.

3.3.7 Group Agreement

The importance of the group agreement in PAR should not be underestimated. Role clarification is a key aspect in PAR of developing the collaborative partnership, implementation of activities, and ensuring accountability of lead researchers to participants and vice-versa. This clarification is an attempt to eliminate any pre-conceived ideas about the researcher/participant role, minimise confusion, and provide information on how decisions will be made (White et al 2004).

The full group agreement can be found at Appendix D. The key components of the group agreement were values and commitments, how decisions would be made, team members' responsibilities, and conduct. Of particular interest was

the decision making element, in that the group agreed that they would use a majority voting system. However, notions of democracy are a contentious and pertinent issue in PAR as this style of democracy is not seen as truly participatory. Indeed, PAR seeks to challenge such a traditional notion of democracy (Greenwood and Levin 1998). In reality, a majority vote never needed to take place, as the use of participatory activities enabled the team to reach decisions by negotiation and consensus.

3.3.7(i) Group Values and Commitments

- Further the cause - of improving the treatment of people who use mental health services
- Commitment to the mission of the group
- Pursue excellence in participatory action research
- Honesty
- Dignity and respect for others

3.3.7(ii) Decision Making

Decisions will be made by those present at meetings via majority vote.

3.3.7(iii) Responsibilities of PAR Excellence Group Members

- Read meeting notes and keep up-to-date with developments
- Speak up, take part and contribute
- Speak one at a time
- Be respectful of different opinions
- Be respectful of different abilities
- Treat people with dignity

- Represent the group professionally
- Contribute to recruiting and supporting new members
- Be punctual

3.3.7(iv) Conduct

- In the event of a group member feeling offended/upset, they should check this out within the group
- Behaviour that is deemed unacceptable because it is not in line with PAR Excellence's Values and Commitments will be managed within the group
- Any decision to ask a member to leave will be made democratically by the group

3.3.8 Research Education

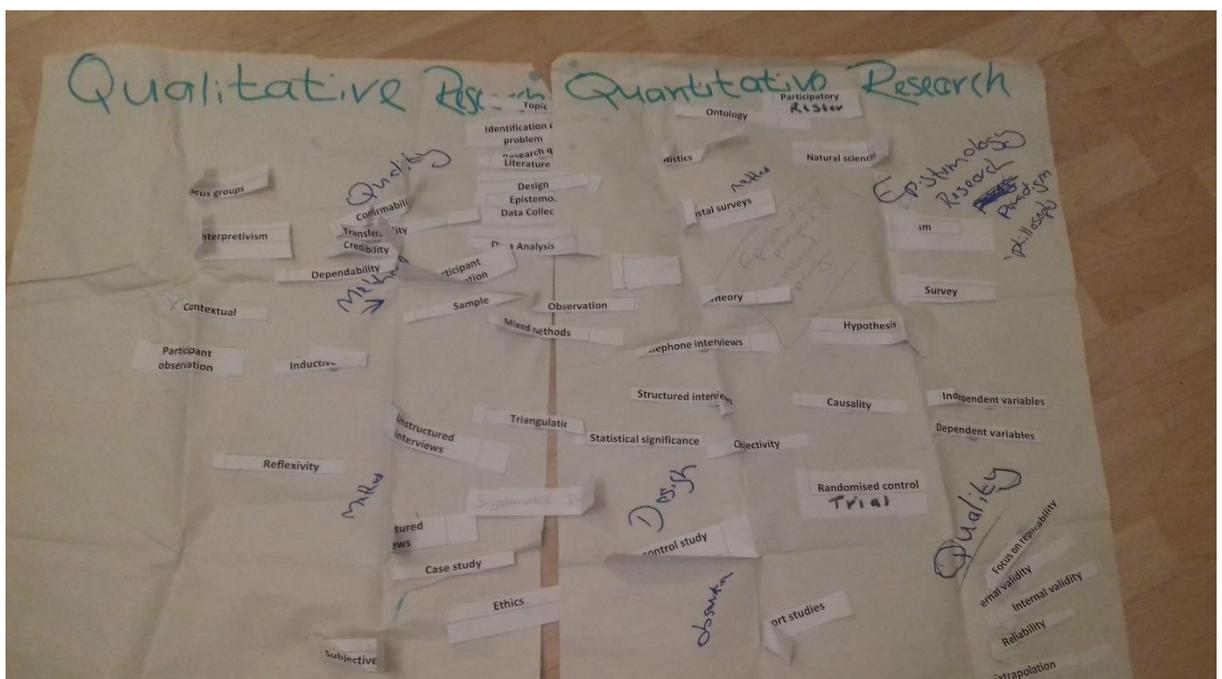
A key element to the implementation of PAR is research team education (White et al 2004), and capacity building is an active ingredient of participatory action (Koch and Kralik 2006). This includes valuing participant's knowledge which sharpens their capacity to conduct research about their own interests, but also supports participants to appropriate knowledge produced by the dominant knowledge industry for their own interests (White et al 2004).

PAR Excellence members had a discussion of their learning needs in their initial meeting with myself, and at the introductory event. Learning and development needs were also discussed on an ongoing basis during meetings, and the research education programme element of the project was developed accordingly. The programme was to ensure that all participants understood basic research methods and the mechanism of conducting well-designed

studies (White et al 2004). The principles and practice of PAR featured throughout research education workshops: capacity building efforts are more than imparting knowledge, or building self-esteem: they must include creating safe environments where equity is tangible to all partners in the research (Mullett 2015).

During the education workshop on research design, PAR Excellence were introduced to CASP tools (CASP 2017), and were asked to apply them to a number of relevant mental health papers. Other activities included interactive games such as a quiz. One activity involved the team putting research terms into qualitative research, quantitative research columns, or both. All of these activities were specifically built to stimulate open and honest conversations and encourage the team to express their own understandings of mental health, and the role of research. There was also a focus on fun, and a formal, direct lecture style was avoided. Photograph 1 is an example of the interactive learning activity of discussing research terms.

Picture 1: Participatory Learning: Qualitative and Quantitative Research Terms



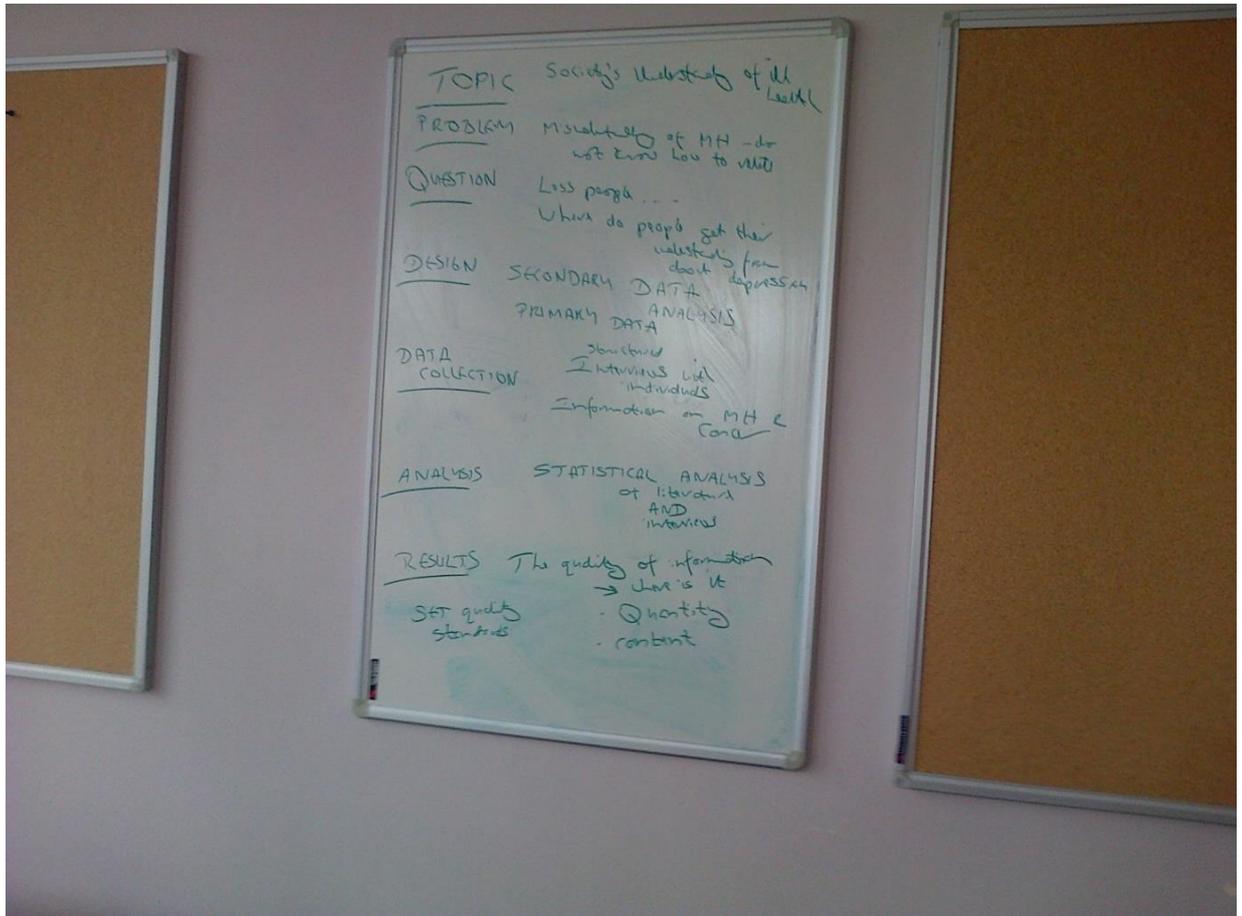
Another activity was to look at media stories about mental health that were of interest to the group such as stigma, and gender issues in mental health. The group were asked to articulate the problem as they saw it, and design a research project around the issue reported. Picture 2 shows how the team practised designing a research study, including forming a research question about gender inequality in mental health.

Picture 2: Participatory Learning: Practising Research Design for the Topic of Gender Inequality in Mental Health



Picture 3 shows how the team trying to design a research project on the topic of stigma in mental health.

Picture 3: Participatory Learning: Practising Research Design for the Topic of Mental Health Stigma



The team also attended a workshop on reflexivity, and worked through Reed and Frisby's (2008) reflexive questions. These questions were used to inform the team's development of a semi-structured guide for their own focus groups:

- What are the intended and possible unintended consequences of the research?
- What are the power relations within and surrounding the project and what

steps are being taken to level imbalances and mobilise power?

- What ethical issues are framing the research and its representation?
- Who owns the research, how will it be produced, communicated and acted upon?
- How are the researchers accounting for their own social location and insider/outsider status?
- What emotions and struggles are being encountered in building relationships?

At a later stage, PAR Excellence as a team worked through an interactive online learning package on research ethics provided by the university, and we then had a follow-up workshop to apply the principles learnt to our project and to prepare for attending the NHS ethics committee. The team also began the NHS National Institute for Health Research Good Clinical Practice online training course as directed by the university's Head of Ethics, but abandoned it before completing all the modules as the team felt that they had already covered the contents, were confident of their knowledge around the issues presented, and that some of it was not relevant.

Other learning activities included role plays in gaining informed consent from participants, individual interviewing, and conducting focus groups. Much other learning took place when the team were carrying out in activities, for example, the literature review. The team developed their knowledge by looking at a variety of papers and by using Critical Appraisal Skills Programme (CASP (2017)) tools to assess quality.

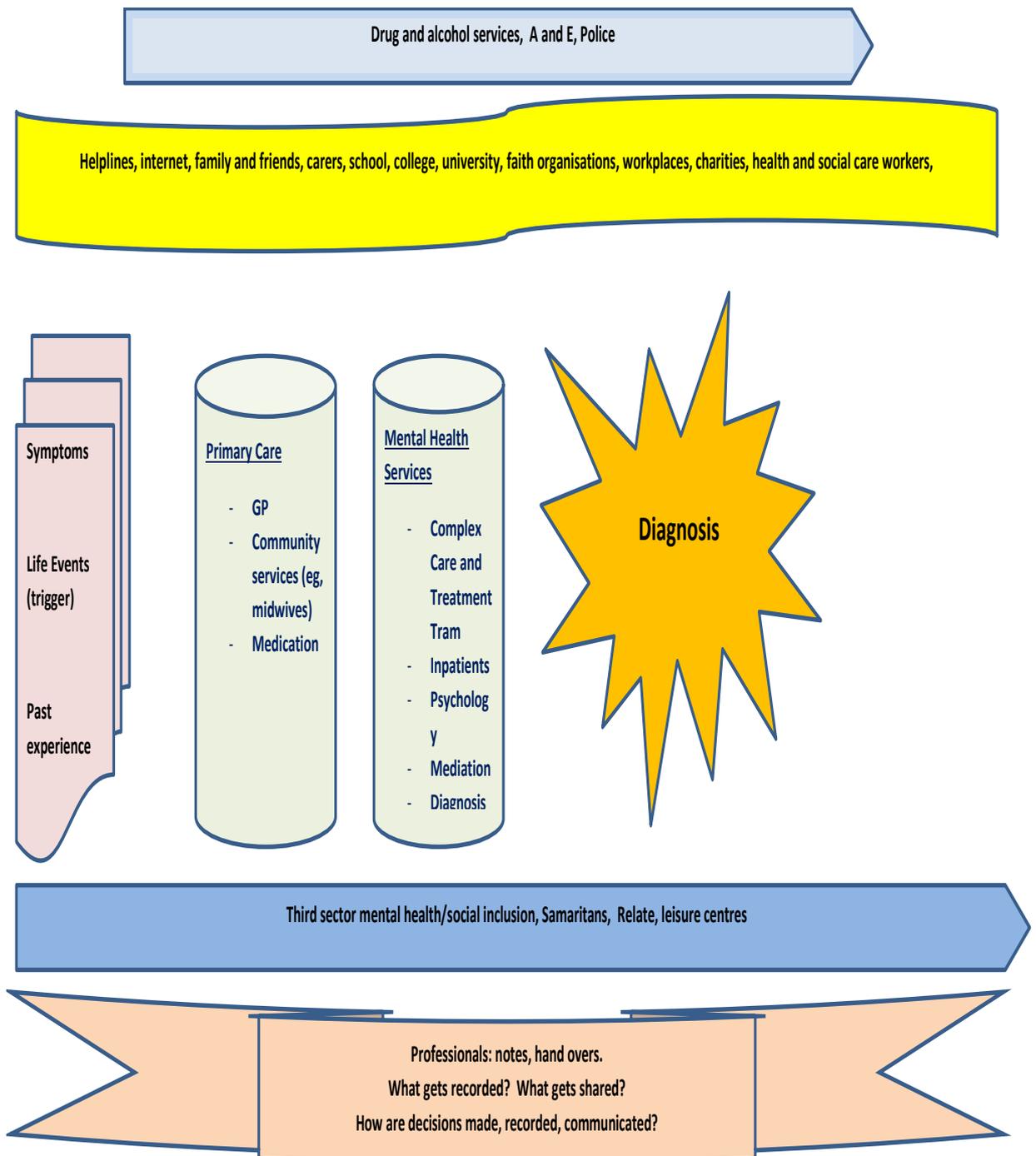
3.3.9 Choosing a Research Topic

Following three initial meetings that were used to establish the group agreement, the next four meetings were used to work towards choosing a research topic. This was an extremely critical part of the whole project, for as discussed earlier, in PAR, the problem that needs solving or objective that needs reaching must arise from the community of interest, and that community must want to see change. It cannot be imposed from outside, including by the researcher (Walter 2009).

At my suggestion, the team undertook a shared mapping exercise of the journey through mental health services from before entering health services (including GP, family and community contact) to discharge from mental health services, hoping that this would indicate the most significant touching points with services. The use of visual mapping as a technique is a well-known tool in participatory approaches. It is most commonly associated with small group activities, and what is expressed can be seen, touched and moved. Visual mapping provides lasting tangible data, in contrast to the invisible, and unalterable nature of verbal communication. The use of visuals such as mapping provide a means of expressing realities that are difficult to express verbally. They are instruments of empowerment, showing up patterns of marginalisation and where action is required. They can also provide credible and potent aids for asserting and securing rights (Chambers 2008).

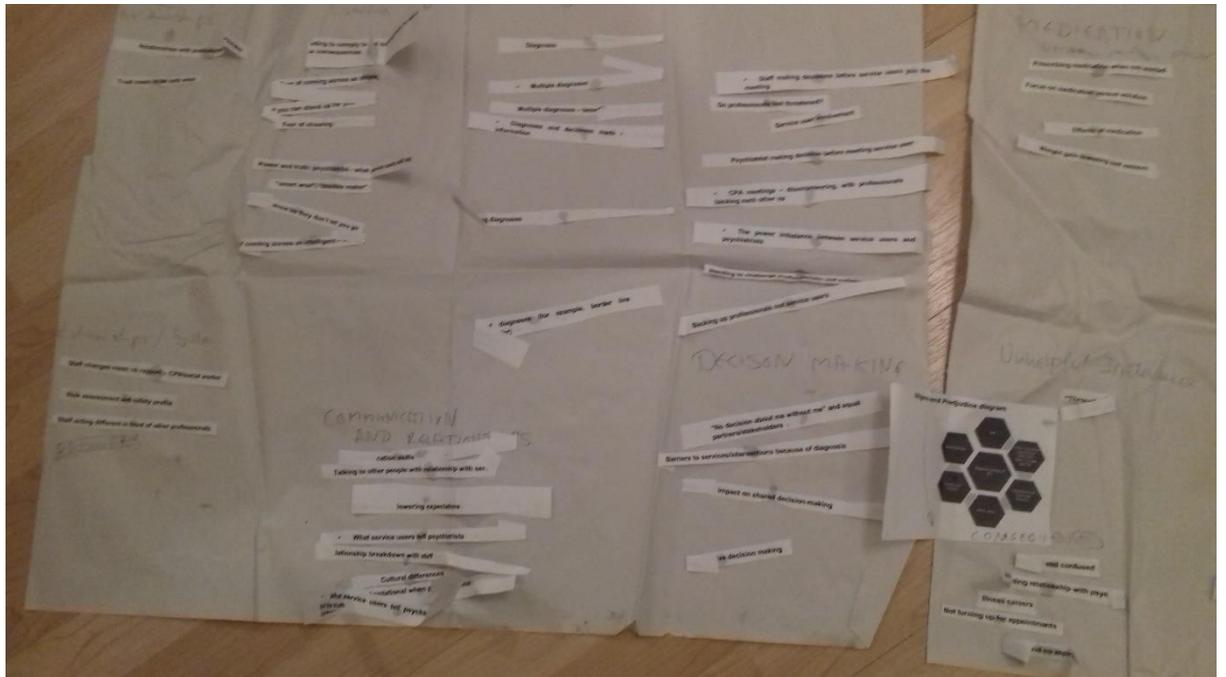
The map was reproduced electronically, and can be seen in Diagram 1.

Diagram 1: Visual Mapping Exercise: the Service User Journey Significant Touch Points

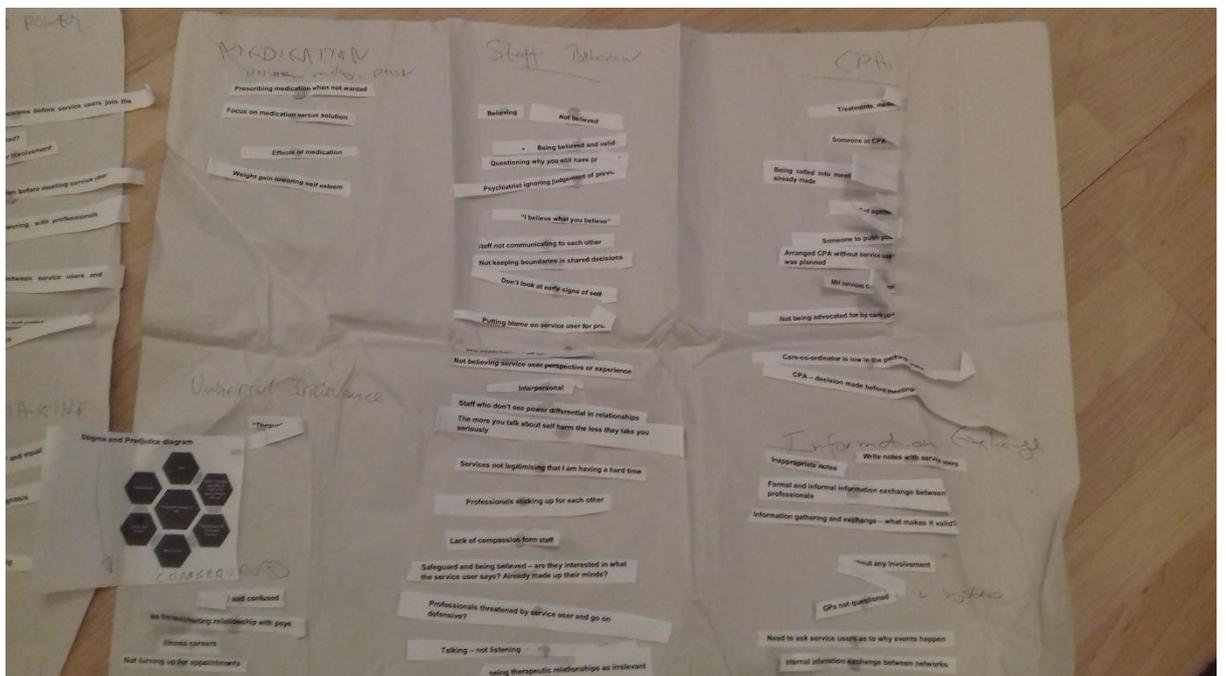


Key words and statements from these conversations were sorted into eighteen potential topics by the team, as shown in pictures 4a and 4b:

Picture 4a: Sorting Statements into Topics



Picture 4b: Sorting Statements into Topics



To reach a consensus on which theme to choose as a research topic, the team devised criteria that they applied to each theme. The full criteria form can be found at Appendix E. The criteria questions were:

- I. Is change achievable?
- II. Will it be high impact?
- III. Is it timely?
- IV. Will it change things?
- V. Is it able to influence?
- VI. Is it current?
- VII. Will it be out of date/obsolete?

By using these criteria, the team finalised a shortlist of four topics: Care Programme Approach (CPA), decision making, social networks, and power.

The potential topics can be found in Table 1. The blacked out topics are those discarded by the team following application of their criteria for choosing a research topic.

Table 1: Summary of Potential Research Topics

Medication	Staff Behaviour	Care Programme Approach (CPA)	Information Exchange
Consequences	Relationships	Unhelpful Irreverence	Communication and Relationships
Relationships/System	How to behave as a service user? (Collaboration?)	Diagnosis	Power
Decision Making	Recovery	Treatment	Support Networks
Systems Failure	Good Practice		

Following discussion, the team discarded CPA. They then re-applied their criteria for choosing a research topic to their shortlist of three potential topics. Through this self-devised process, the team settled on the topic of decision making. Following further discussion, and a review of the statements associated with the topic made by the team, a consensus was reached to focus on shared decision making. It was also thought by the team that the topic of power would be encompassed within shared decision making. The statements from the team associated with each topic can be seen in Table 2.

Table 2: Final Top Three Priority Research Topic Areas

Decision Making	Support Networks	Power
<p>“No decision about me without me” and equal partners/stakeholders</p> <p>Barriers to services/interventions because of diagnosis</p> <p>Stigma and impact on shared decision making</p> <p>Passive aggressive decision making</p>	<p>Lack of family support</p> <p>What is NHS role in support networks?</p> <p>Support networks so important</p> <p>Reconnect with networks</p>	<p>Staff making decisions before service users join the meeting</p> <p>Do professionals feel threatened?</p> <p>Service user involvement</p> <p>Psychiatrist making decision before meeting service user</p> <p>CPA meetings – disempowering, with professionals backing each other up</p> <p>The power imbalance between service users and psychiatrists</p> <p>Needing to challenge professionals – not collaborating</p> <p>Backing up professionals not service users</p>

3.3.10 Data Collection and Analysis in PAR

This final section to the chapter considers the broad implications surrounding data analysis and data collection in PAR. These are relatively brief discussions: chapters four and five (action and participation chapters) contain more in-depth descriptions of the data collection and analysis activities that PAR Excellence undertook. This unusual jumping around that is not consistent with a traditional thesis structure is reflective of the sometimes messy, confusing and unpredictable nature of PAR itself. The decision to return to data collection and

analysis in later sections was made in an attempt to tie in these activities at the most relevant point in the telling of the project. Therefore, here is an overview of general data collection and analysis concerns in PAR.

3.3.11 Data Collection in PAR

PAR Excellence participated in data collection, and their involvement is described in the further chapters on action and participation. This sub-section is concerned with focus groups because this is the data collection method mostly used throughout the project (with the exception of some individual staff interviews for pragmatic reasons explained in the action chapter) and PAR generally. It discusses why focus groups are a data collection mainstay of PAR.

Focus groups are particularly suited for use in PAR, because group processes are central to facilitating change, and the transformational potential of focus groups lie in the equal value of different ways of knowing (Chiu 2003) – an epistemological perspective that is crucial to PAR and this project. Focus groups chime with PAR in that they are interested in how people discuss things in a group – how they respond to each other's views, and how they build up a view through group interactions. Focus groups offer an opportunity to study how a phenomenon is collectively made sense of, and how meanings are constructed around it. Furthermore, focus groups can allow participants' perspectives to reveal themselves in a different way to that of individual interviews, and their unstructured nature means that participants have more ownership of the research process (Bryman 2008).

Furthermore, focus groups are appropriate for radical social transformation through consciousness raising and empowering participants (Johnson 1996, Padilla 1993). Through focus groups, critical thinking amongst participants can

be induced as they recall their experiences, and they can be adapted to facilitate critical awareness raising: a systematic and focused way of managing the change process through problem solving, decision making, and reflection (Chiu 2003).

3.3.12 Data Analysis in PAR

PAR Excellence's involvement in data analysis is described in great depth in the further chapters on action and participation. PAR's commitment to collective knowledge production continues with data analysis, which should be completed with the participants rather than separately from the participants. Whilst it is becoming increasingly less rare to include service users in data collection, it is still not common to involve service users in data analysis and interpretation. This means that a unique and significant perspective on the data is lost. Furthermore, to omit the participation of service users in data analysis and interpretation means that they can have no influence on how data are interpreted once it has been collected, and so an alternate and important way of viewing the data will be wholly absent (Sweeney et al 2012). Whilst different perspectives and standpoints inevitably produce different ways of understanding and interpreting phenomena (Rose 2004), exploring and understanding alternate perspectives and standpoints increases the credibility of interpretations (Sweeney et al 2012).

The forms that analysis take vary due to the methods and the situational and collectively negotiated process. The research objectives or questions will determine the most appropriate data analysis methods, in conjunction with the data collection methods agreed upon. In PAR, analysis may span the spectrum from quantitative and qualitative approaches to a process of collective

negotiation and interpretation, and self-analysis can also feature (Cahill 2007). Data analysis is a key site of knowledge production in qualitative research (Gillard et al 2012). Participants can be involved in data analysis to generate solutions for change actions, and collectively reflect on the issues identified. Transcripts are a collective product owned by the group, rather than primarily belonging to a researcher.

Participation in data analysis can be a useful tool in supporting critical reflection and facilitating critical awareness, adding to the transformational potential of the focus group in contrast to the more conventional object and subject research relationship (Chiu 2003). Harris et al (2001) recommend that the PAR data analysis process must take on a commitment to “counter stories” that challenge the hegemonic logic of what is understood as “natural”. Taking this approach ensures that data analysis in PAR is a critical process of producing new subjectivities, knowledge and action (Cahill 2007).

3.4 Conclusion to Chapter Three

This chapter has presented PAR as a methodology, and given an in-depth description of some of the PAR Excellence team’s activities to demonstrate PAR methodology in practice. It can be seen that a great deal of care and attention was applied in conducting the project in terms of quality and ethics as understood in participatory terms. However, it can also be seen that a purist approach to PAR was not always possible. This was either due to pragmatic reasons to ensure the project was initiated and progressed, expectations from the institutions invested in the project (that is: the university and the Trust where the project was conducted), or how the project unfolded in relation to team members. In the next chapter, the action that the team took in relation to their

chosen research topic of shared decision making is presented, and the findings from their research.

CHAPTER FOUR - ACTION: BY PEOPLE, FOR PEOPLE: SHARED EXPERIENCES TO SUPPORT SHARED DECISION MAKING IN MENTAL HEALTH

4.1 Introduction to Chapter Four

The last chapter was concerned with the methodology of PAR. It also described the establishment of a PAR team of mental health service users called PAR Excellence, and how they reached a research topic, made research design decisions, and were involved in research conduct and dissemination. This chapter is now concerned with the action that PAR Excellence chose to take, having decided that shared decision making in mental health was their research topic. This chapter contains the following sections: introduction to shared decision making in mental health, a literature review of shared decision making in mental health, methods, findings, and conclusion. The question of whether the epistemic injustices often faced by people who use mental health services can be transformed through knowledge democracy is considered by exploring whether PAR was appropriate choice to bring about knowledge democracy, and whether the project could establish knowledge democracy in its local setting.

After participating in the literature review of shared decision making in mental health, the team decided to develop a library of recorded service user experiences to support shared decision making. Their aim was to explore the use of mental health service users' experiences as a shared decision making resource for service users and staff. They explored shared decision making and the use of the resource with mental health staff through qualitative focus groups and interviews, and thematically analysed the data. It was concluded there is no consensus on shared decision making concepts and practice amongst staff,

and whilst shared decision making and the use of service user experiences were welcomed in principle, in practice, both are difficult to achieve. However, access to service users' experiences had a profound and positive effect on some staff members' reflective practice. It was also found that PAR as a research approach was valued by staff, and was a methodology that helped to gain access to the settings where the action took place.

In terms of the seed metaphor running through the thesis, this part of the project was the growth following the green shoots, when the team emerged from the soil to branch out – an exciting but highly unpredictable and vulnerable time. This action that PAR Excellence chose to take was an attempt to bring about knowledge democracy by placing service user knowledge on an equal platform alongside professional knowledge through the use of service user experiences. It was an endeavour to address some of the power imbalances between service users and staff by using these experiences to support shared decision making. As will be presented in the literature review findings, it is argued that to enable shared decision making, power and knowledge must be shared, and different types of knowledge given equal credence. Therefore, this chapter draws on all the issues presented in previous chapters so far around the powerlessness and epistemic injustice faced by mental health service users. It also chimes with forthcoming chapters that delve into issues around participation within mental health services.

4.2 Background to Shared Decision Making in Mental Health Care

Shared decision making is embedded in the NHS Constitution, which states: 'you have the right to be involved in discussions and decisions about your health and care...and to be given information to enable you to do this. Where appropriate this right includes your family and carers'. The NHS commits to

offer 'easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices' (Department of Health (DH) 2013 p9).

The NHS Mandate includes the objective 'to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment' (DH 2014 p11). According to the DH, outcomes experienced reflect the quality of interaction with professionals, and involving service users in their care and treatment increases their knowledge and understanding of their health status. Information, the Government argues, is the key to better care, better outcomes and reduced costs, and it intends to bring about an NHS information revolution, aiming to 'give people access to comprehensive, trustworthy and easy to understand information from a range of sources on conditions, treatments, lifestyle choices and how to look after their own and their family's health' (DH 2010 p13). The DH states that service users need and should have far more information and data on all aspects of healthcare, to enable them to share in decisions made about their care and find out much more easily about services that are available. This is a position that is supported by service users: Thornicroft et al (2002) found that one of the top ten service delivery priority areas for mental health service users is access to information.

The DH's mantra is: 'no decision about me without me' (DH 2010 p13). This drive for shared decision making is broadly accepted as being the way forward: informed choice and involvement in treatment decisions are integral to the overhaul needed to laws and practices to ensure that service users gain full equal human rights to others (Wallcraft and Shulkes 2012). The Independent

Mental Health Task Force (2016) states that critical to the success of future mental health services is the placing of service users at the heart of each and every decision made, in services which are led by the needs of individuals.

Ostensibly, the DH's rhetoric chimes harmoniously with the power issues discussed in chapter two. Collaborative decision making is a way of addressing the epistemic injustice experienced by service users (Crichton et al 2016). However, the concept of shared decision making is challenged by the traditional patient-clinician relationship, as shared decision making is reliant on a two way exchange of information that is not generally practised (Kaspar et al (2011). Furthermore, shared decision making requires a sharing of power as power and knowledge are inextricably intertwined, but establishments monopolise the production and use of knowledge (Koch and Kralik 2006).

Whilst it is hoped that the widespread use of shared decision making methods may reorientate the culture of mental health care (Thornicroft and Tansella 2014), it is immediately apparent that shared decision making in mental health is problematic, and the systematic powerlessness mental health service users can be subjected to in practice is fully demonstrated by the NHS itself through the use of the Mental Health Act: 'if you are detained in hospital or on supervised community treatment under the Mental Health Act 1983 different rules may apply to treatment for your mental disorder. These rules will be explained to you at the time. They may mean that you can be given treatment for your mental disorder even though you do not consent' (DoH 2014 p8). This statement pithily demonstrates why implementing shared decision making in mental health presents unique challenges for both service users and service providers: in essence, some people with mental health problems cannot enjoy the same rights to self-determinism as others. Furthermore, studies have shown

a divergence between the goals of clinicians and of the service users they work with (Perkins 2001), meaning that shared decision making will be difficult to achieve. There are also critics of shared decision making in healthcare and it is by no means universally accepted as an appropriate approach. It has been argued that most people do not want to participate in decisions, and that revealing the uncertainties inherent in medical care could be harmful. It is also perceived that it is not feasible to provide information about the potential risks and benefits of all treatment options, and that increasing service user involvement in decision making will lead to greater demand for unnecessary, costly or harmful procedures which could undermine the equitable allocation of health care resources (Coulter 1997). The following literature review reveals that there are no easy answers or solutions to resolve any of these issues.

4.3 Shared Decision Making in Mental Health: Integrative Literature Review

Aim

To identify and systematically review literature on shared decision making in mental health.

Objectives

- To conduct an integrative review of the literature using a systematic approach
- To identify themes in the literature on shared decision making in mental health to produce a foundation for PAR Excellence to develop their project by building on existing knowledge
- To identify gaps in knowledge on shared decision making in mental health that can inform PAR Excellence's project and support the development of their research aims and objectives

4.3.1 Literature Review Method

This was an integrative, mixed methods literature review. (Full details of the search strategy can be found at Appendix F.) The integrative review method is the only approach that allows for the combination of diverse methodologies and the simultaneous inclusion of experimental and non-experimental research as well as theoretical literature in order to more fully understand a phenomenon of concern (Whittemore and Knafelz 2005). Therefore, an integrative review was the most appropriate approach here, as PAR Excellence were at the very broad topic stage and required the literature to support them in narrowing down their area of investigation.

In the initial stages, an iterative process was used to hone the search strategy and inclusion/exclusion criteria. PAR Excellence were active in the review: they agreed on the initial inclusion and exclusion criteria, which they refined when they began looking at the literature found. A particular decision to only focus on shared decision making in mental health rather than health overall was taken: this was justified by the particular and unique nature of the field, and the team's personal interest in it. They critically appraised a sample of research papers only using the appropriate Critical Appraisal Skills Programme (CASP 2017) tools, and agreed on the level of flaws in deciding whether to reject papers. Papers with no or few flaws, or some flaws that were unlikely to affect validity and reliability were accepted. As well as considering quality issues, they were also concerned with the meaningfulness of the research to service users' experience, and they also rejected papers if they identified disempowerment issues in the research conduct. This was a very labour intensive exercise, requiring a high level of facilitation, and informed the subsequent shortlisting and appraising of further papers undertaken by myself.

An analysis of the themes undertaken by myself only found within and across the papers was then undertaken by using a constant comparison method, which is a recommended overarching approach in integrative reviews (Whittemore and Knafelz 2005). The themes were systematically categorised and merged.

4.3.2 Review Findings

Five themes were found: philosophies of shared decision making in mental health, mental health service users' perspectives on shared decision making, unique barriers and facilitators to shared decision making in mental health, shared decision making tools and resources and gaps identified. Some themes

are made up of sub-themes. A flow chart and list of included papers can be found at Appendices G and H. It should be noted here that language disputed in chapter two around diagnostic labels and illness terminology is used, where employed by the authors. The level of this usage demonstrates the dominance of the medical model of mental health, even in discussions of a supposedly empowering topic.

4.3.2(i) Philosophies of Shared Decision Making in Mental Health

This theme contains the two sub themes of definitions and characteristics, and rationales.

4.3.2(ii) Shared Decision Making Definitions and Characteristics

Common definitions of shared decision making cover a broad range of features, and it is frequently described conceptually as a challenge to mental health's traditional paternalistic model (Beitinger et al 2014, Perestelo-Perez et al 2011, Chan et al 2012, Tibaldi et al 2011, Duncan et al 2010, De las Cuevas et al 2012, De las Cuevas 2013, Drake 2009b, Simmons et al 2010). There is much focus on collaboration between service users and professionals (Chong et al 2013b, Chan et al 2012, Drake et al 2010a), Duncan et al 2010, Salyers et al 2012), and of working in partnership (Simmons et al 2010). There are regular references to service users being seen as equal partners in the decision making process - experts who bring knowledge about their values, preferences, goals and support (Perestelo-Perez et al 2011, Shepherd et al 2014, Curtis et al 2010, Drake et al 2009a, Goscha and Rapp 2014, Sullivan and Rae 2014). Professionals bring knowledge about conditions, evidence, possible interventions, risks, benefits and alternatives to options (Drake et al 2009b, Simmons et al 2010), and key to the concept of shared decision making is

ensuring that both the service user and the professional are equally and actively involved and share/exchange expertise and information to reach an agreement for which they hold joint responsibility (Drake et al 2010, De las Cuevas et al 2013, De las Cuevas et al 2014, Fukui et al 2015, Goscha and Rapp 2014).

4.3.2(iii) Rationales

There are various stated rationales for shared decision making, ranging across a spectrum from an empowerment model to a compliance model. At one end, shared decision making is seen as central to recovery orientated health care (Chong et al 2013b, Perestelo-Perez et al 2011, Shepherd et al 2014, Drake et al 2010a, Duncan et al 2010, Fukui et al 2015, Matthias et al 2012) with a values base of self-determinism, choice and empowerment and central to person centred care (Perestelo-Perez et al 2011, Corrigan et al 2012, Anthony 2010, Drake et al 2010a, Drake 2009b, Decision Support Centers (sic) 2013, De las Cuevas et al 2013, Fukui et al 2015, Goscha and Rapp 2014, Hamann et al 2011, Gordon and Green 2013), and a way to improve unsatisfactory alignment between service users and doctors around medication (Gordon and Green 2013). It is argued that shared decision making in mental health is especially pertinent, due to the coercion that some service users have experienced (Hamann et al 2011). Between these models is a focus on evidence-based practices, outcomes and high quality services (Perestelo-Perez et al 2011, Hamann et al 2011, Salyers et al 2012), and Lindhiem et al (2014) found that assessing service user preferences and involving service users in treatment decisions has a modest effect on satisfaction, completion and outcome.

Whilst recovery is frequently alluded to in the literature, there is no consensus regarding what recovery means or how it is achieved, and reaching a shared

conceptual model is challenging (Stratford et al 2013). Matthias et al (2012) argue that medication management is a key component in recovery. Others locate recovery within the service user movement's desire for individual control, autonomy and self-determinism (Drake et al 2010a, Duncan et al 2010).

At the other end of the spectrum, shared decision making is seen as a potential means to increase treatment adherence (Tibaldi et al 2011, Lindhiem et al 2014, De las Cuevas and Peñate 2014, Goscha and Rapp 2014, Hamann et al 2011a, Hamann et al 2011b, Hamann et al 2009, Stein et al 2013). However, this is a perspective that is worrisome, running the risk that shared decision making becomes a euphemism for persuasion or pressure to consent (Anthony 2010). It is argued that notions of adherence are significantly limited, promoting a value based perspective that suggests that people who do not opt for prescribed treatments are somehow flawed or otherwise symptomatic (Corrigan et al 2012).

4.3.2(iv) Mental Health Service Users' Perspectives on Shared Decision Making

Most considerations of mental health service users' desire for and perspective on shared decision making has not focussed on the service user collective movement calling for greater rights to self-determinism, with the exception of Curtis et al (2010)'s mention of the challenge to the provider-centric framework by the survivor movement, and Drake et al (2010a)'s discussion of shared decision making's historical links and congruence with the foundational tenets of the survivor movement. Rather, there is discussion of how much mental health service users wish to be involved in shared decision making on an individual basis (Hamann et al 2011). It is acknowledged that some service

users do not know that they can be involved in shared decision making (Simmons et al 2010), whereas some are clear that most mental health service users express a desire to participate in decisions and for collaborative relationships with their professionals (De las Cuevas 2012, Beitinger et al 2014, Perestelo-Perez et al 2011, Drake et al 2010a, Woltmann and Whitely 2010). Yet, they perceive their role as mostly passive (Drake 2009b). Many service users, it is argued, do not see themselves as equal partners or feel empowered to make decisions about their treatment and services (Drake et al 2010, Curtis et al 2010), and it has also been found that service users tend to consciously decide to at least verbally defer to their case managers, remain silent about their preferences or wishes (Woltmann and Whitely 2010), or defer final decisions back to the professional (De las Cuevas 2012).

There is less research focussing primarily on service users' perspectives on shared decision making than there are on outcomes and implementation studies. Woltmann and Whitely (2010) found that service users viewed shared decision making in a different light to the literature, seeing it as something that occurs over time rather than as a one-off event, although this is what most current research is based on. De las Cuevas et al (2014) explored the impact between service users' desired level of participation in shared decision making and actual levels on treatment adherence, suggesting that when service users participate as they wish, there is greater treatment adherence, whereas Hamann et al (2011) found that people with a diagnosis of schizophrenia who want to participate in shared decision making are more likely to be dissatisfied with their care or sceptical about medication.

There may also be different perceptions between service users and professionals about how much input service users have into decisions, with

service users feeling that they have little meaningful input (Drake et al 2010a). This may not be an unfounded fear: Hamann et al (2011) found that service users who received training in shared decision making were perceived as being “difficult” by psychiatrists – maybe because they expressed greater scepticism towards their treatment.

4.3.3 Barriers and Factors to Shared Decision Making in Mental Health

This theme contains the two sub-themes of unique barriers to shared decision making in mental health, and factors that impact on shared decision making in mental health.

4.3.3(i) Unique Barriers to Shared Decision Making in Mental Health

There is broad acknowledgement that implementing shared decision making in mental health brings about its own unique challenges (Duncan et al 2010, Perestelo-Perez et al 2011), and that is not practiced as much in mental health as elsewhere (Beitinger et al 2014). The inherent power imbalance alongside providers’ ability to legally override service users’ preferences means that there is a different dynamic in mental health compared to other healthcare areas (Curtis et al 2010), and although a positive attitude amongst professionals is recorded, how much it is reflected in daily practice remains questionable (Shepherd et al 2014, De las Cuevas 2012). Yet, the very nature of the possibility of involuntary treatment means that shared decision making is especially important in the field (Beitinger et al 2014).

Some of these are general challenges because of the complex, fluctuating, and multi factorial nature of mental health conditions (Simmons et al 2010). Other barriers include time and budget constraints (De las Cuevas et al 2014). Drake et al (2009b) argue that mental health systems lack the requisite computer

infrastructure, and that service users face confusing and myriad choices without any statistical understanding and are influenced by information biased by industry. De las Cuevas et al (2013) compared shared decision making in psychiatry with shared decision making in primary care, finding that there are quite different perspectives on shared decision making between the settings, with its application in mental health being more limited. Hamann et al (2011) found that people with a diagnosis of schizophrenia are less likely to wish to engage in shared decision making when compared with people with multiple sclerosis. Furthermore, service users who perceive their decisional capacity to be a barrier or have had a poor education have been found to be less likely to prefer to participate in shared decision making (Perestelo-Perez et al 2011, Hamann et al 2011). Other impinging factors include age and culture (Perestelo-Perez et al 2011), and other more general factors associated with service delivery (Chong et al 2013b).

The views of professionals present particular challenges in mental health settings that continue the tradition of being provider-centric, where expertise is seen as located in the professional and involvement is limited to the service user acceptance or rejection of the expert opinion. The use of legal constraints, coercion, involuntary treatment, and assumptions about service users' ability or interest to participate reinforces this paternalism (Gordon and Green 2013, Curtis et al 2010). It is also argued that "impaired metacognitive capacities" are indeed a barrier (Chan et al 2012). There are views that service users cannot participate in decisions regarding medication and hospitalisation due to delusions and lack of insight, despite the argument that service users with diagnoses such as schizophrenia are capable of making rational decisions (Shepherd et al 2014, Hamann et al 2009, Beitinger et al 2014, Chong et al

2013b, Drake et al 2010a, Drake 2009b). Another factor is a “belief gap” around medication between service users and professionals (Tibaldi et al 2011), and psychosocial matters are considered more suitable for shared decision making by psychiatrists than medical and legal decisions (Hamman et al 2009). Psychiatrists in particular produce barriers around the use of shared decision making in medication use, including their high degree of faith in antipsychotics, pessimism about condition course, beliefs about causation and the impact of delayed treatment (Gordon and Green 2013). Professionals can also have reservations about the risks involved (Gordon and Green 2013), although service users should be able to take risks and “fail”, and make the “wrong” choices (Corrigan et al 2012).

4.3.3(ii) Factors that Impact on Shared Decision Making in Mental Health

The literature on the factors that impact (positively or negatively) on shared decision making in mental health is inconsistent and therefore inconclusive. There is a diverse range of investigation into what impacts on shared decision making, including visit length, on which there is there is differing opinion and evidence (Matthias et al 2012, Salyers et al 2012, De las Cuevas et al 2013). It is suggested that service user characteristics such as age, education, type of appointment and treatment condition play a role in predicting shared decision making (De las Cuevas et al 2013), and that professionals with broader experience are more likely to engage with the concept (De las Cuevas 2012). Goscha and Rapp (2014) found that it is important for staff to support service users to identify an important and meaningful goal, albeit as a means for medication adherence, and professional attitudes and behaviour are an important facilitator (Chong et al 2013b). Hamann et al (2009) found that whilst most psychiatrists reported a desire to engage in shared decision making, they

considered several factors to decide whether or not to share decisions. Chong et al (2013a) also found that professionals thought that shared decision making should be condition dependent and that there are differences between different professions, arguing that more consideration needs to be given to interprofessional collaboration. Elsewhere, Fukui et al (2014) found that the demographic characteristics of service users, or type and gender of professional did not affect shared decision making scores.

4.3.4 Shared Decision Making Tools and Resources

This theme contains three sub-themes: shared decision making aids and tools, shared decision making measurement tools, and resources required for shared decision making.

4.3.4(i) Shared Decision Making Aids and Tools

Aids and tools are often seen as key to achieving shared decision making (Anthony 2010, Drake et al 2010a, 2010b). They may be of use for decisions about whether to stop taking medication (Sullivan and Rae 2014). Andrews et al (2010) and Drake et al (2010b) describe the development of an electronic online decision support system. Purported advantages to computerised aids include linkage to other electronic records, aggregation of data of services and outcomes, and incorporation of algorithms for evidence-based care. Their Dartmouth Decision Support Tool is specific to mental health settings.

CommonGround is another computerised decision support system, used in three studies (Deegan 2010, Stein et al 2013, Goscha and Rapp 2014). Stein et al (2013) investigated its impact on medication adherence when used within a decision support centre, finding that neither intervention increased medication adherence, although its use alongside a peer support system can support

shared decision making in a medication meeting (Deegan 2010), and peer support to use decision aids has been utilised and welcomed by service users (Goscha and Rapp 2014). However, some psychiatrists have reservations about CommonGround, perceiving it to add to workload and inefficiency.

4.3.4(ii) Shared Decision Making Measurement Tools

There is some focus on the actual assessment of shared decision making: one paper focussed on the usefulness of a shared decision making rating scale, which was found to be useful (Salyers et al 2012). Measurement tools and coding systems were used elsewhere to assess shared decision making approaches and features such as a 9-item Shared Decision Making Questionnaire – a service user self-report tool (De las Cuevas et al 2013), a Autonomy Preference Index and a Problem Solving Decision Making Scale (Hamann et al 2011), an Informed Decision Making Scale (Fukui et al 2015) and a Shared Decision Making Scale (Fukui et al 2014).

4.3.4(iii) Resources Required for Shared Decision Making

Service users need information in multimodal sources, repetition (Drake 2009b), that is user friendly, and that can involve other service users (Corrigan et al 2012). Contrary to some research (Salyers 2012), it is argued that resources required for shared decision making include time (Chong et al 2013b), as well as facilitated communication and easy access to scientific knowledge (Torrey and Drake 2010, De las Cuevas et al 2014, Drake 2009b). Staff training is also considered a requirement, leading to a positive effect on service users' quality of life, unmet needs, increased satisfaction with care, and greater reported involvement and agreement about treatment. Also, training has increased staff confidence, understanding of service users' requirements and concordance to

treatment guidelines (Sullivan and Rae 2014). Engagement strategies are also required by professionals to overcome barriers created by impaired insight and language use in service users (Chan et al 2012) and training in dealing with difficult decisional situations (Beitinger et al 2014). Training for service users, too, has been shown to increase desire for shared decision making and increased preferences for participation (Hamann et al 2011b). On a broader level, a supportive social network, twenty-four hour crisis team access and an ability to move easily to higher levels of care are required to enable shared decision making to take place (Gordon and Green 2013), as are transformed office practices that are time efficient, welcoming and that promote shared decision making (Torrey and Drake 2010). Challenging the mental health stigma from professionals about service users' capacity and perceptions about professionals' ultimate responsibility is also necessary (Perestelo-Perez et al 2011).

4.3.5 Gaps Identified

Current levels of evidence into shared decision making in mental health are significantly limited (Perestelo-Perez et al 2011). There are very strong messages from the literature about the urgent need for further research into decision making science, clinician training, implementation, service user empowerment and computer infrastructure (Beitinger et al 2014, Duncan et al 2010, Curtis et al 2010, Drake 2009b, Drake 2010b), interventions to empower service users to take greater initiative, peer instruction, the impact of shared decision making on recovery (Matthias et al 2012), and interventions to improve service users' decision making capacity (Hamann et al 2009). More research is also required on how decisions are actually executed and whether or not decisions are actually acted upon, as well as how to mitigate the difficulties that

service users experience in bringing ideas forward that are different to professionals' ideas (Duncan et al 2010, Woltmann and Whitely 2010), such as implementation strategies that empower, enable and motivate service users who currently do not wish to participate in shared decision making (Hamann et al 2011). Also, possible factors that could hinder shared decision making implementation require consideration (Perestelo-Perez et al 2011). It is also argued that research into the impact on health outcomes and treatment compliance is required (Perestelo-Perez et al 2011).

4.3.6 Literature Review Conclusion

Due to the vastly broad range of understandings and findings about shared decision making in mental health, it is not possible to reach any definitive conclusions on what it is, why it should happen, how it should happen, and what its outcomes should be. The review has illuminated some significant problems with this lack of consensus: a particularly worrying feature is the framing of shared decision making as an approach to increasing service user compliance with medication. This is conceptually extremely problematic as it is not congruent with the ethical reasoning found elsewhere for shared decision making that is concerned with service user choice, empowerment and autonomy, and equal partnerships. A compliance model of shared decision making still indicates that the professional knows best, and that strategies need to be employed to convince service users to follow the professional's preferred course of action. It also means that the appropriate systems, policies, practices and resources to enable shared decision making to happen cannot be put in place, because there is no agreement on what shared decision making should achieve.

This is linked to the fact that whilst there is general acknowledgement that shared decision making in mental health presents particular challenges and requires specific interventions and resources (including the use of decision making aids and staff training), there is little consensus in the research findings about what does and doesn't work, or what factors impact on shared decision making in mental health. What does seem clear is that shared decision making is considered to have the potential to be a positive approach to care. It is notable too that a strategic approach to implementation is recognised as being a necessary investment to achieve change (Drake et al 2009): it is not likely just to happen without some structured efforts to promote it. One essential element of a structured approach is the provision of a range of accessible information about the options available to people.

PAR Excellence used these review findings alongside key statements about shared decision making from policy documents to support reaching a consensus on their focus. Their conclusion was to explore the use of mental health service users' experiences as a shared decision making resource by creating a library of service user experiences that staff could use alongside service users, and that service users could also directly access to support their engagement in shared decision making. Their decision was based on many of the features of the literature review findings: the need to make use of peer knowledge, the need for staff training, and the need for accessible and understandable information. The next section describes how this resource was developed.

4.4 Development of the Shared Decision Making Resource

4.4.1 Rationale for Using Service User Experiences as a Shared Decision Making Resource

As clearly indicated by the findings of the literature review, a key component of shared decision making in mental health is the provision of accessible information for service users. It was based on this alongside their own personal experience that PAR Excellence decided to develop a multi-model library of service user experiences in online and booklet form so that information about what helped people could be shared with others. The intention was for the library to be used by staff in their interactions with service users, and also for service users to access the resource independently. This was also an approach that would lead to original contributions to knowledge, for the literature review did not locate any studies where such an approach had been studied, or within the context of a PAR project.

It was thought by the team that their approach might support service users and staff to engage in shared decision making through the provision of knowledge and experience from other service users. The team also hoped that these experiences would enable other service users to take control of their own recovery. They also wanted to show service users that they matter. They wanted to empower people to be partners in deciding about their care. They hoped that the library would give other service users ideas, inspiration and hope for the future, and might help service users and staff to talk about what would be the right approach for individuals. As put by one team member in discussions with staff during a focus group on shared decision making:

“The point of the project it to use the experiences of the people who have been through or are going through mental health services to identify some of the positive things that they were able to do. And some of those things are self-propelled. The idea is then that people will look at that and then they'll see a reason to inquire. They'll say well...somebody was able to go and do that. Now, I haven't thought about that, so can you tell me the information about that...can you show me why. The idea of the project is to test whether or not seeing that sort of thing will make it any easier for that person to understand why it's a good idea. It's quite key because we're saying basically, that there's a series of various points at which information about what was possible or what's been done or how to decide is important”.

(PAR Excellence member)

4.4.2 Developing and Creating the Service User Experience Library

Service users in other forums and known to PAR Excellence members were invited to record their experiences for the resource in a manner of their choosing. A recruitment flyer (Appendix I) was developed by PAR Excellence and circulated to service user groups associated with the NHS Trust hosting the project, including the service user steering group at the community mental health team (CMHT) where the project was conducted. PAR Excellence members themselves had flyers to circulate. Staff in the two teams involved in the project (CMHT and Social Inclusion Service (SIS)) were also asked at staff meetings to promote recruitment to their service users.

Some time was given by PAR Excellence to consider how to best describe the resource. The team were not comfortable with the term “stories”, as it seemed to imply that their accounts were fictional. Narratives was also rejected, for similar reasons. The use of the term “experiences” was agreed as it was thought that this gave due credence to the contributions that people were going to make.

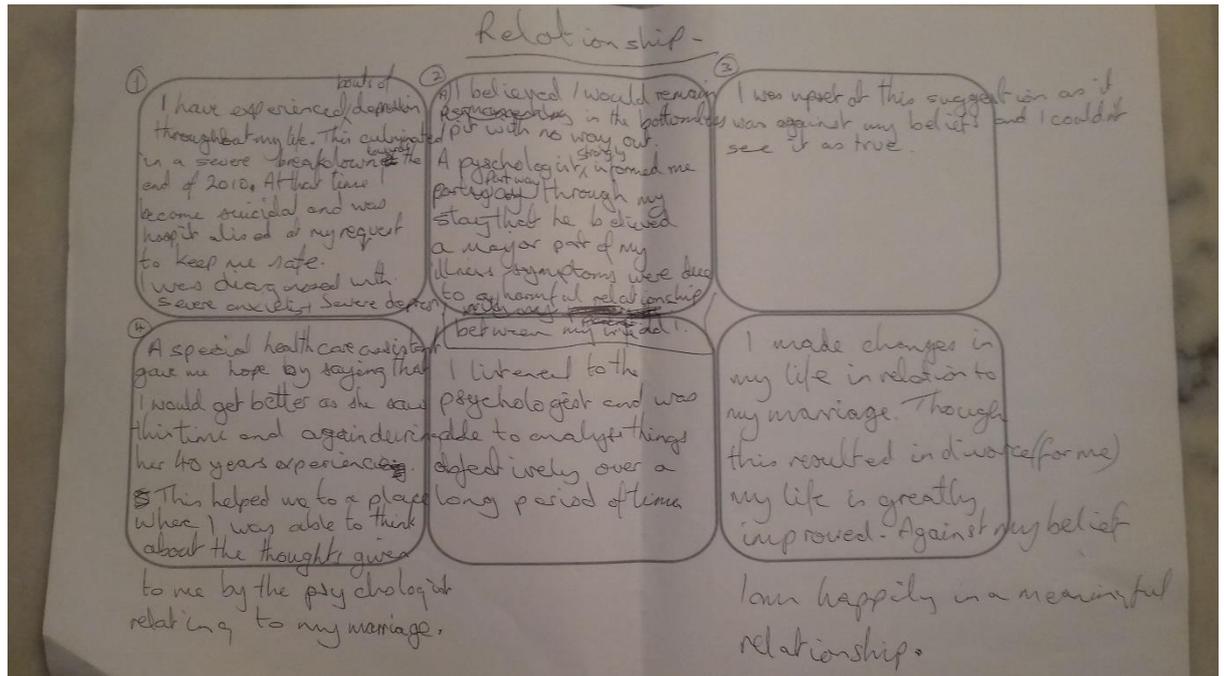
PAR Excellence complied guidance notes and a presentation to support themselves and other service users contributing to the resource to decide what they would like to discuss and refine their telling of their experiences. The guidance notes can be found at Appendix J.

Everyone interested in recording their experience was given a participant information sheet and consent form to sign (Appendices K and L). These were revisited and a second copy signed on completion of the recording before it was used. People interested in sharing their experiences were invited to attend a half day workshop where they were encouraged to create a story board to support the shaping of their experience recording and decide their key messages by using words or drawings. They were asked to consider some important elements in their achievement of a goal, big, or small. They were encouraged to identify a significant end point, describe the starting point, and detail who, why and/or what got them from one point to another.

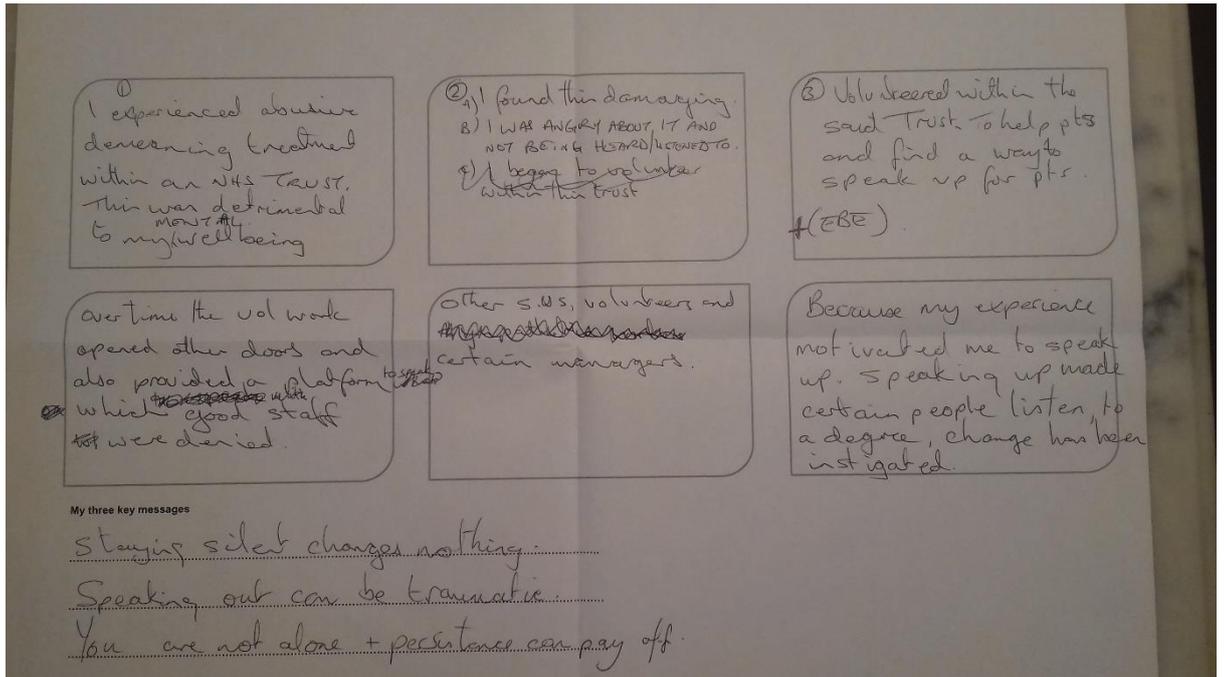
Below are some examples of the story boards. The first story board (Picture 5) is an example by a member of the PAR Excellence team. Following some team members trying out the storyboard technique, the story board was refined to include space for three key messages to support service users sharing their experiences to summarise their thoughts (shown by the second story board in

Picture 6). This was then practised by other team members. The final refinement was to include suggestions for information that service users might like to consider including in their recording, and this became the final version that was used by service users to develop the telling of their experience (shown in the third story board in Picture 7).

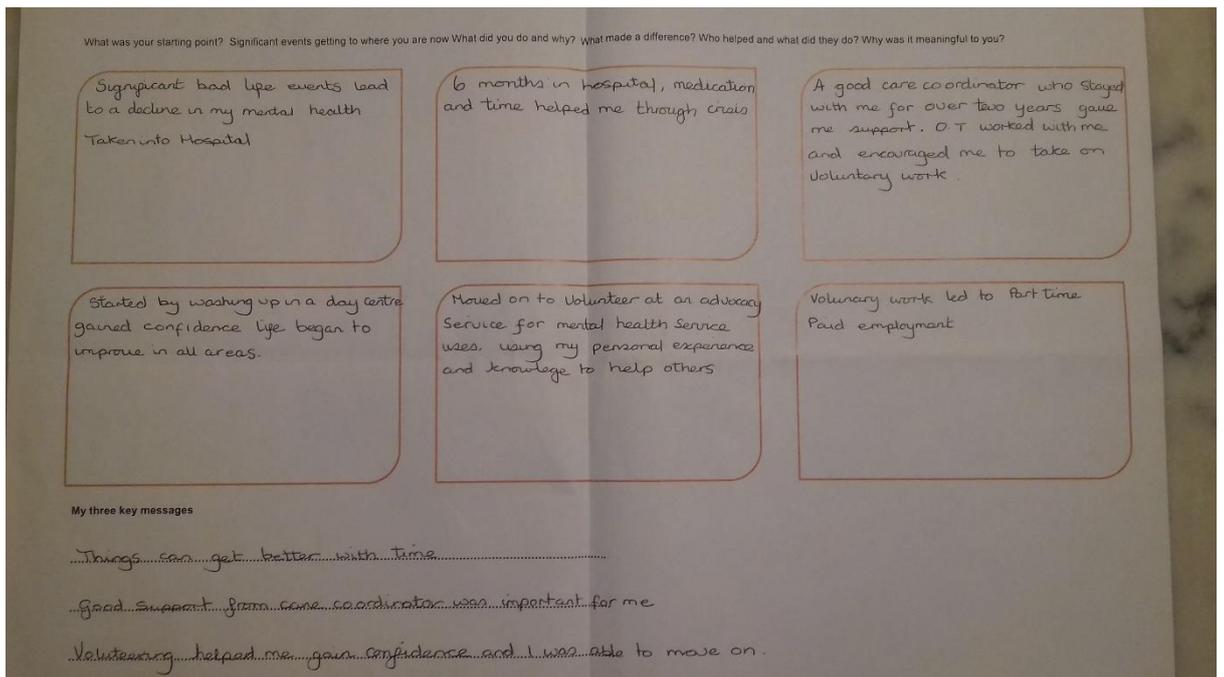
Picture 5: First Storyboard



Picture 6: Second Storyboard



Picture 7: Third Storyboard



Somewhat unexpectedly and surprisingly, members of PAR Excellence did not put themselves forward to be actively involved in the collection of service user experiences. All of the tasks surrounding this activity this was conducted by myself alone. It would not be an exaggeration to state that the project would

have completely halted at this stage had I not carried out the actions decided and directed by the team. At this point, I became uncomfortable and frustrated at the amount of work I was doing alone, because it seemed that the participatory element of the project had disappeared, leaving me with sole ownership and accountability of delivering the outcomes the team had wanted. This issue was discussed with PAR Excellence during the last focus group. It emerged that it was mostly a question of timing, with the period when I was collecting the experiences coinciding with periods of ill-health, or significant life events for team members. However, for me a sense of momentum got lost during this phase.

Service users who decided to share their experiences met with me to record their experience (either by dictating it or by video or audio recording), or by submitting a written piece. These were all then reviewed by PAR Excellence. Once the booklet and website were completed, I met with everyone again individually to show people the finished edit and context in which their experience was going to be presented. People had the option of withdrawing their experience at any time up until the point of publication of the booklet and were able to withdraw their recording from the website at any time, as described in the information sheet and consent form.

The booklet text can be found at Appendix X and online at www.sharedexperiences.online/⁴. The resource included twelve different recorded experiences. Five of these experiences were from PAR Excellence members themselves. With the exception of one contributor, all the people who

⁴ Due to the consent requirements for ethical approval from the NHS Ethics Committee, a password was required by staff and service users to access the online experiences.

contributed were already known to me from past or present work that they had been involved in with me: namely, the experts by experience programme that I had been running for some years.

The booklet contained some information about shared decision making and PAR, as well as seven written experiences. The online version contained the same information, plus four people talking on video, and one audio recording. There was a snapshot of each experience, highlighting the key points. Each shared experience described things that have helped people to achieve something in their lives. They showed what is possible, and that people are not alone. PAR Excellence also developed a staff development session on shared decision making and the resource, and this was presented at two staff meetings.

4.4.3 Compiling the Service User Experience Library

PAR Excellence considered how the experiences should be grouped together – by diagnosis, content of experience, or outcome. Ultimately, this became a moot point, because there weren't so many experiences that they required cataloguing in any particular way. However, the discussion around cataloguing or headlining the experiences by diagnosis was interesting in itself: the approach was dismissed in the end because people can have multiple diagnoses, and/or receive different diagnoses at different stages in their life and from seeing different professionals. Diagnosis was only featured in the snapshots of the experiences as significant to the experience if the person telling their experience placed store in it. Surprisingly, the use of diagnosis was not discarded due to political sensitivities regarding the medicalisation of mental

health that diagnoses indicate, despite the fact that critique and distrust of the medical model was strongly evident in the teams' focus groups.

All of the background resource content was developed by PAR Excellence during team workshops, and the website and booklet title and logo was created by one team member, who created the title "By People, for People: Shared Experiences to Support Shared Decision Making in Mental Health". This member also advised me on how to set up a website, and led the team in the development of the structure of the website (choosing the format and determining the headings and sub-headings). I then populated the website alone using the text already developed by the team. The team gave much thought to the presentation of the booklet and website.

The team found a tension in overall presentation between authenticity and trustworthiness: on one hand, they wanted the resource to be removed from NHS corporate branding to ensure that service users quickly saw it as different to the usual NHS leaflets, and the authenticity of it being a resource developed by service users be immediately apparent. On the other hand, they also recognised that whilst NHS branding may arouse mistrust in some, it might give the resource credibility for others. The compromise was to include an NHS logo, but not to adhere to any other NHS branding regulations. This meant that we effectively went "undercover", as I had to by-pass the usual NHS communications policies and procedures to get the booklet printed and web pages up and running. I had to set up a website externally to the NHS Trust's own website (strictly against Trust policy), for had I taken the booklet and web pages through the Trust's official routes, it would have been adulterated to adhere to NHS branding protocols to a point that was not acceptable to the team. I worked on two principles: proceed until apprehended, and it is easier to

seek forgiveness than it is to seek permission. The disadvantage was that I was unable to call upon any organisational expertise in creating booklets and web pages, and therefore the finished products were not as polished or professional as they could have been. However, the team thought that the perceived authenticity of their endeavour superseded the need for more gloss. This is an example of the subversive approach that we as a team took that is explored later in the participation chapter. The next section of this chapter concerns the research that PAR Excellence conducted into shared decision making and the use of the library with mental health staff.

4.5 Research Methods (Shared Decision Making)

This section describes the research element of the project, where PAR Excellence explored shared decision making and the usefulness of the shared experiences library as a shared decision making resource with staff through qualitative focus groups and interviews. PAR Excellence members participated in various ways to varying degrees throughout the conduct of the research, although all activities were organised and led by me. Initially, a justification for the team's choice of using a qualitative framework is given. The recruitment of research participants, ethics, data collection and data analysis methods used and findings are detailed, and the chapter ends with a discussion and conclusion.

4.5.1 Qualitative Research and PAR

PAR does not confine itself to qualitative research: an authentic exercise in participation where a topic is chosen by the participatory team could lead to quantitative research if that was the right research strategy for the questions (Baum et al 2006, Bryman 2008), and work with disadvantaged groups can use many methods (Mayall et al 1999). However, qualitative research does

generally lend itself to the overall philosophical position of PAR. It has long been argued by feminists that quantitative research keeps power to itself, with researchers deciding what should be investigated, and is unresponsive to the complexities of the social world (Oakley 1999, Mayall et al 1999).

It is therefore not surprising that PAR Excellence were attracted to qualitative methods, as PAR's value base and qualities are shared with the qualitative paradigm (Walter 2009). Some of the characteristics of qualitative research discussed by Streubert Speziale and Carpenter (2007) match PAR's philosophy and features: it is underpinned by the belief that there are multiple realities, which complements PAR's insistence on recognising different types of knowledge. It is committed to in-depth understanding of phenomena, and to participants' viewpoints. Findings are recorded in a literary style rich in participant commentaries. However, interestingly, whilst qualitative methodologies seek to cause minimum disruption to the environment that is being researched, it can be argued that the purpose of PAR is to indeed cause disruption by challenging orthodoxies and taking action to bring about meaningful change. Furthermore, whilst it is argued that the flexibility required for qualitative research risks inconsistency and a lack of coherence (Holloway and Todres 2003), it is recognised that PAR is a not always a straightforward process, and certainly a great deal of flexibility is required (Cornwall and Jewkes 1995).

4.5.2 Recruitment of Research Participants

The initial aim of the project was to recruit both staff participants and service user participants. PAR Excellence chose two teams within an NHS Trust's mental health division: a social inclusion service (SIS), and a community mental

health team (CMHT). They were chosen because a PAR Excellence team member also worked at SIS, and had initially been motivated to conduct a research project within his own team. As discussed in the methodology chapter, this “insider-insider” approach is a common feature of action research and brings strengths to the process rather than being an issue as it might be considered in a traditional research project (McNiff and Whitehead 2009, Herr and Anderson 2005). The CMHT was chosen because it was in the same area as the SIS. The criteria was simple: any member of staff in either of the two teams was eligible to take part in the project. Staff research participants were recruited by me alone via staff meetings and email flyer (Appendix M), and a participant information sheet (Appendix N) was explained at staff meetings. Staff completed a consent form (Appendix O) before data collection occurred.

Service users were invited to become research participants via the shared experiences booklet and website, via the local service user steering group, and by being approached directly by me when they were in a waiting room. The shared experiences booklets that included an invite to become a research participant were freely available in the waiting room, and a service user recruitment flyer (Appendix P) was placed in the waiting room and given to staff to circulate. A participant information sheet and consent form (Appendices Q and R) for service users were also created. However, no service users came forward to participate directly. Some service users did, however, ask members of staff to convey their thoughts about the shared decision making resource. This was a significant disappointment and limitation, leaving a significant gap in findings.

4.5.3 Ethics

The research project was granted ethical approval by the NHS North West Research Ethics Committee, and subsequently the University of Central Lancashire Ethics Committee. Four PAR Excellence members attended the NHS ethics committee meeting alongside myself.

Whilst not technically research participants, people recording their experiences were also considered in the application for ethical approval. As discussed earlier, they too were given a participant information sheet and consent form to take away (Appendices K and L), and had the information on the participant information sheet and consent form described to them verbally. They were asked to sign the consent form before they made their recording or submitted their written narrative, and another copy of the consent form when they were invited to view the final version of their experience and the booklet and website.

4.5.4 Data Collection

Two focus groups with staff were conducted at the outset of the project, in each participating team (CMHT and SIS). There were six members of staff at one, and three at the other respectively. A semi-structured focus group guide developed by PAR Excellence was used (Appendix S). A range of job roles were present, representing the multidisciplinary teams (excluding medical professionals). Both groups were facilitated by myself and a PAR Excellence member.

A staff development session on shared decision making and the shared decision making resource followed the focus groups and staff were invited to use the resource alongside service users as well as distribute it to service users. One session was delivered to the CMHT alongside a PAR Excellence

member, and one was delivered to the SIS with the PAR Excellence member who was also a staff member in the SIS team.

After three to five months, eight individual staff interviews across the two participating teams took place. Six of the eight interviews were conducted by a PAR Excellence member and myself, and two interviews were conducted by me alone. A PAR Excellence member had agreed to conduct these interviews with me, but was suddenly unavailable on the day. A semi-structured interview guide was developed by PAR Excellence (Appendix T). However, the guide was deviated from by the PAR Excellence members, who introduced new questions during interviews (in contrast to probing questions to follow up the questions in the guide). One of these staff participants who attended both a focus group and interview was the PAR Excellence member working in the SIS, in keeping with the “insider-insider” approach to action research.

The original research plan had been to conduct a second set of focus groups rather than individual staff interviews. However, the practicalities of getting staff together for second focus groups deemed it impossible. With the local team managers, a pragmatic decision was made to deviate from the original plan and conduct individual interviews instead, to increase the number of staff that data could be collected from. All staff who had attended the first focus group and/or the shared decision making staff development session were invited to attend an interview.

There was much debate amongst PAR Excellence about the merits of focus groups and individual interviews. One member thought that some staff members might not feel able to speak openly in a group session. However, the team decided on focus groups as they hoped that there was a better chance of

culture change within the team through group activities, where staff could share positive approaches and experiences to improve shared decision making and possibly agree on future action to develop shared decision making practice. It was therefore unfortunate that second focus groups were unable to take place. However, the individual interviews still produced useful insights into shared decision making and the shared experiences resource. All focus groups and interviews were audio recorded and transcribed.

4.5.5 Data Analysis

This section is a very detailed account of the data analysis of the focus groups and interviews. This is important to thoroughly document, for data analysis is a key site of knowledge production in qualitative research (Gillard et al 2012), and therefore vitally important to the project's overarching concern with knowledge democracy. Much of this section draws strongly on the work of Braun and Clarke (2006). This is because the reporting of the details of qualitative analysis are often lacking, in part because the complex, messy, and often intuitive tasks involved do not always sit easily with the academic conventions required of clean retrospective reporting (Simons et al 2008). Furthermore, there is very little written about the chosen strategy here of thematic analysis, and it is rarely clearly defined (Braun and Clarke 2006, Vaismoradi et al 2013). Thematic analysis is a process for encoding qualitative information, and a method for identifying, analysing and reporting patterns (themes) within data (Braun and Clarke 2006). A theme is a pattern found in the information that can describe and organise possible observations, to interpreting the phenomenon. Thematic analysis can allow social constructions of meaning to be articulated and described as "social facts" (Boyatzis 1998).

Qualitative thematic data analysis was chosen for a number of reasons. One of these was pragmatic. Thematic analysis is not considered to require the higher complexity levels of other approaches to data analysis such as phenomenology and grounded theory (Vaismoradi et al 2013). It therefore seemed an appropriate choice initially proposed by myself to the team as PAR Excellence members were inexperienced in research. So, one element of the decision to use thematic analysis was that the choice should be suitable for PAR Excellence to be able to use and make sense of – particularly given the time constraints in terms of both project length and people’s availability to develop skills and knowledge in different approaches.

Clearly, as PAR Excellence were not familiar with different approaches to qualitative data analysis, there were not wholly able to make an informed decision and relied on me to guide them. They did not, however did not express an interest in exploring other options, trusting my judgment regarding a suitable choice. I put it to the team that thematic analysis was wholly appropriate in terms of where the team were in terms of a skills set, and an essential step in their development as researchers. Thematic analysis is seen as an accessible and foundational qualitative method, and provides core skills that can then be applied to other qualitative approaches to analysis. Indeed, one of the advantages of thematic analysis is that is particularly useful for participatory approaches (Braun and Clarke 2006).

However, that is not to say that the decision to use thematic analysis was a compromised or unsuitable one, or easy option. Although thematic analysis is considered a foundational method, this does not mean that it necessarily produces simple and low quality findings. It still requires a level of interpretation of the data, and is not merely descriptive (Boyatzis 1998, Vaismoradi et al

2013). It is important to match theoretical frameworks with methods, and as thematic analysis is a flexible approach for providing a rich, complex and detailed account of the data (Braun and Clarke, 2006), it matches well with PAR with its need for flexibility and standpoint of the social world being a complex one. It can be used within an emancipatory epistemological perspective, as it examines the ways in which events, realities, meanings and experiences are the effects of a range of discourses operating within society (Braun and Clarke, 2006). Furthermore: other types of qualitative data analysis are bound to specific research epistemologies, such as discourse analysis or grounded theory (Vaismoradi et al 2013), whereas thematic analysis is not welded to a theoretical framework and can be used across different frameworks (Braun and Clarke 2006). As PAR does not have its own typically associated method of data analysis, thematic analysis was a perfectly appropriate method choice.

The first stage was to develop codes, followed by themes. The approach to developing a thematic code was inductive – that is, driven by the data (Boyatzis 1998). Rather than asking pre-conceived questions of the data (Coffey and Atkinson 1997) or using a coding framework (Braun and Clarke 2006), an inductive approach was used, where themes that arose as issues in the data were identified (Neale 2016). Themes were identified where something important was being said in relation to the topic of shared decision making (Braun and Clarke 2006). The process followed was that suggested by Braun and Clarke (2006), with some adaptations to accommodate PAR Excellence's input. The team in particular found the recommended reading of transcripts to become familiar with the data a difficult task. Therefore, the team started participating during the coding stage. Coding was done by reading the transcript and listening to the recordings.

PAR Excellence partly participated in open coding of the focus groups and interviews. The team agreed to a series of six weekly workshops of three hours, and people were invited to attend when they could or wanted to. Two workshops were unattended. It became clear during the early workshops that PAR Excellence and myself needed to re-review our perspectives, in keeping with the reflection required for PAR. It was vital to do this to recognise the active role we were playing in the identification of patterns and themes (Taylor and Ussher 2001). Indeed, an ongoing reflexive dialogue on the part of the researcher or researchers with regards to analytic choices made throughout the process is essential (Braun and Clarke 2006).

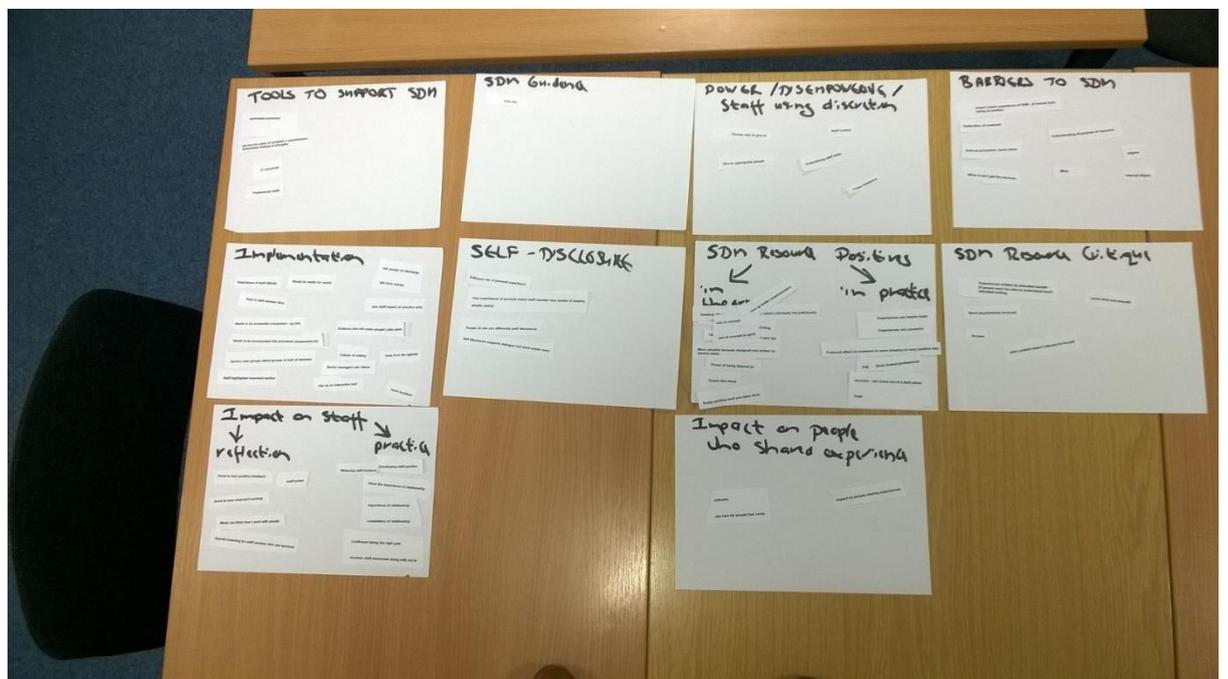
The coding undertaken with PAR Excellence ended up being also the analysis and interpretation in a fluid way, rather than a linear one, with an identification of themes occurring iteratively during coding. Whilst not deliberative, this is a well-recognised approach to thematic analysis (Vaismoradi et al 2013). Once PAR Excellence had undertaken some of the coding (approximately half of the SIS focus group and two thirds of the CMHT focus group), I completed the coding, and codes were entered into a qualitative data analysis software package (NVIVO) to enable efficient and systematic storage, organisation and retrieval of data (Sweeney 2012). About three quarters of the final set of codes had been identified by PAR Excellence. I identified further codes both within data PAR Excellence had coded, and the data that PAR Excellence didn't code. I then identified overall themes and sub-themes.

Pictures 8 and 9 show how the data was put into labels to assist the coding and thematic mapping activities.

stage, although they didn't offer any critique and were wholly supportive of the decisions I presented.

However, it became clear to me during this process that whilst PAR Excellence's participation in coding the data was important, they had missed out on a significant aspect of the process by not being involved in identifying themes and sub-themes. I reviewed this approach with the team, and whilst some members did not wish to be involved in any further coding activities, they were interested in the thematic analysis. There were two other members who were interested in participating in both coding and identifying themes and sub-themes. Therefore, for the interview data, five out of the eight staff interviews were coded by myself with one member of PAR Excellence. The thematic analysis of the interviews was then conducted by PAR Excellence as a team, as shown in Picture 10.

Picture 10: Identifying Themes from Interviews



The reason for PAR Excellence not participating in all of the coding for either the focus groups or interviews was simply one of time: coding is a time intensive activity, and an added pressure was the availability of PAR Excellence members, who were volunteering their time, and had strong commitments outside of the project, including employment. Although many hours were set aside to undertake coding with PAR Excellence, it was not long enough to fully complete the task due to the timescales of project completion and submission of this thesis.

Another issue that became apparent was that coding data as a group increased the time needed because the data raised so many issues that the team wanted to discuss in relation to their thoughts and experiences of mental health services – most of them highly critical. This showed that the mere act of listening to data can in turn support the creation of more in-depth data about people's experiences with mental health services and therefore could be used as a highly effective data collection method in its own right. It became apparent early on that the interpretation and critique of the data took precedence over the coding activity to team members. This actually made the completion of the coding task problematic in the initial stages, as it was difficult to identify what the data was "saying", and what team members were "hearing". The team started to identify or and examine the underlying ideas, assumptions, and conceptualisations and ideologies of the data (Braun and Clarke 2006). It was especially interesting to note differences in our reactions to the data, and discuss those to deepen the quality of our reflexive thinking.

This created a conundrum. The discussions ensuing from listening to the data to code it was highly relevant and deeply meaningful to PAR Excellence members. However, the discussions weren't being captured and there were no

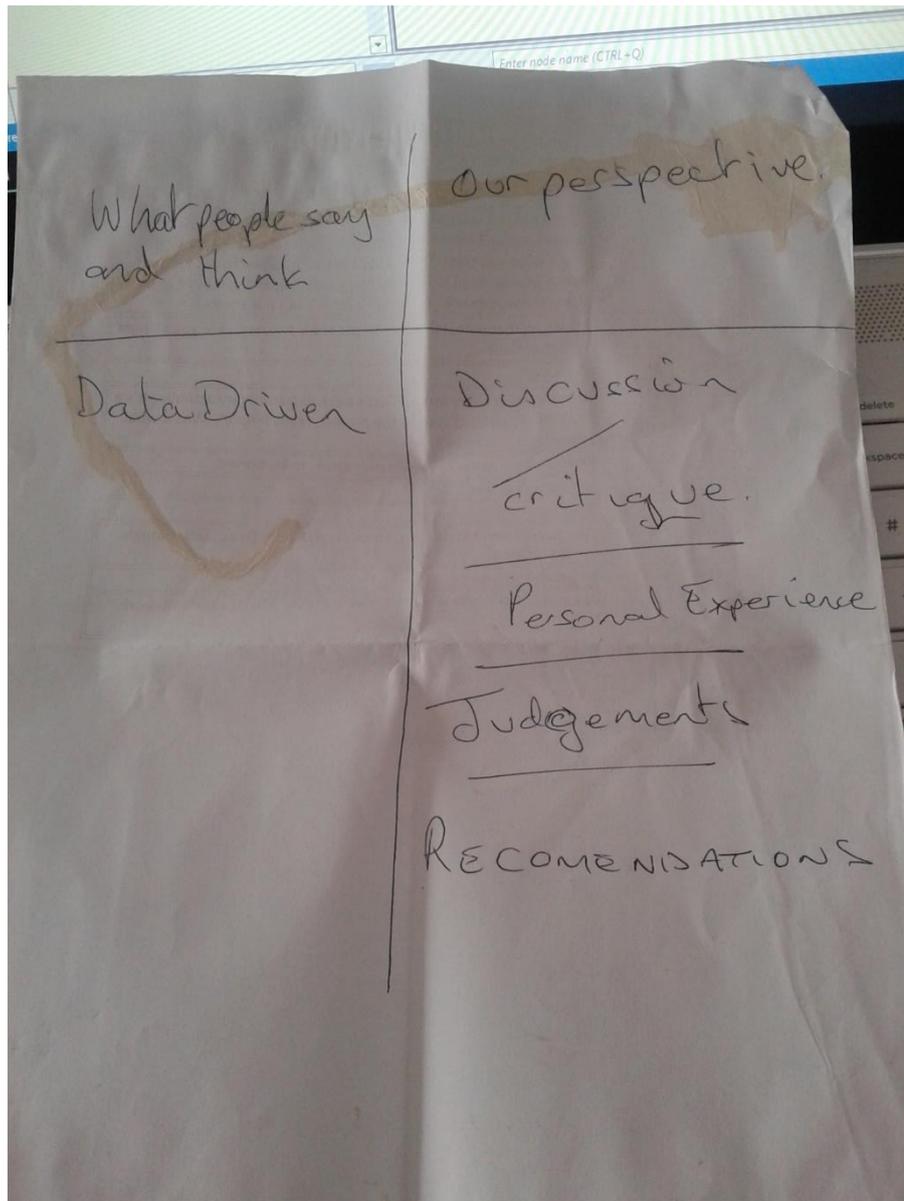
plans for creating any purposeful avenue for the issues and thoughts being raised in response to the data. And, whilst the discussions were of great importance to the team, it meant that the task of coding was even more time consuming.

Eventually, I proposed a solution to separate out what the data is saying from the team's responses to it as shown in Table 3, and was captured by a team member (Picture 11).

Table 3: PAR Excellence Non-Linear Approach to Thematic Data Analysis

What people say and think	PAR Excellence perspective (latent analysis (Braun and Clarke 2006))
Data driven Codes Key words Key concepts Key themes	Discussion Critique Personal experience Judgement Recommendations

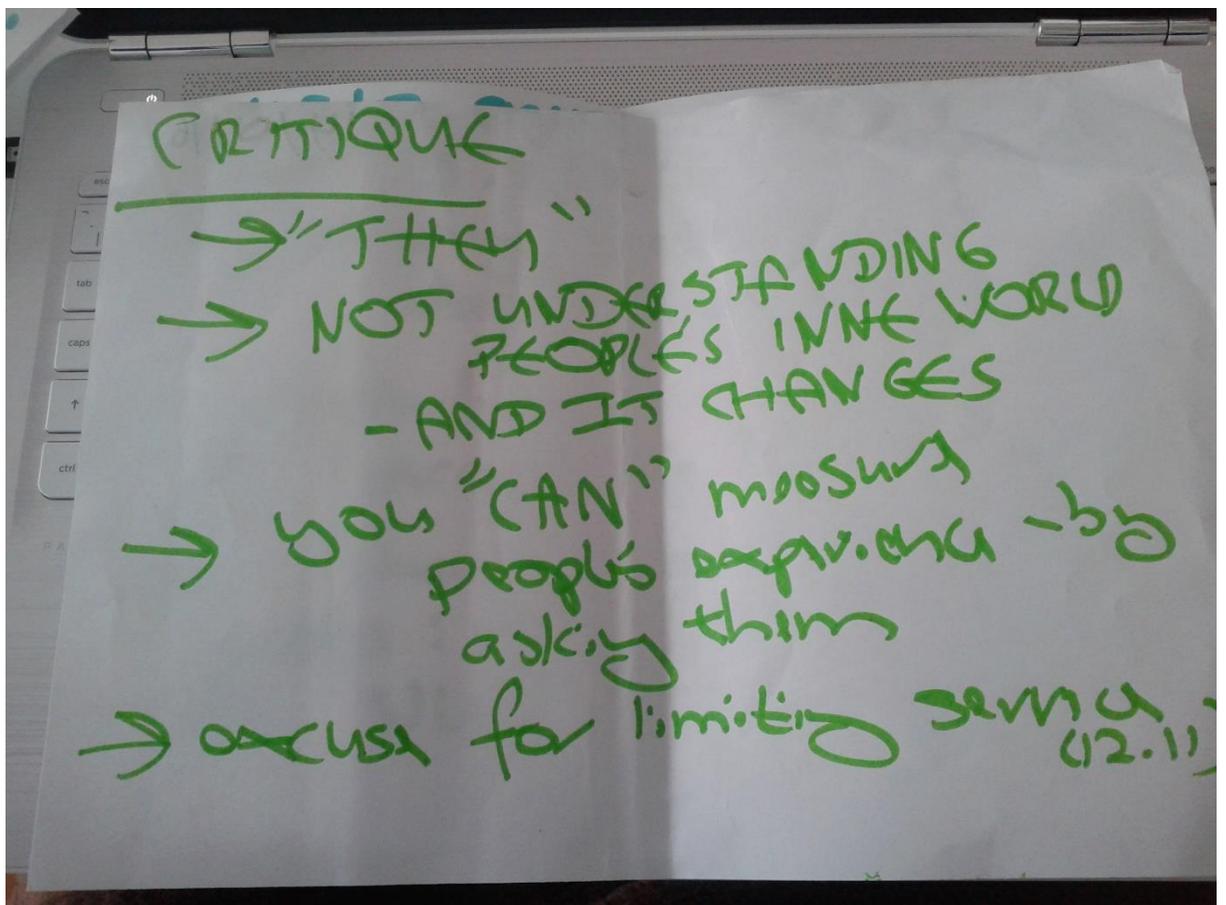
Picture 11: Untangling Data from Response to Data



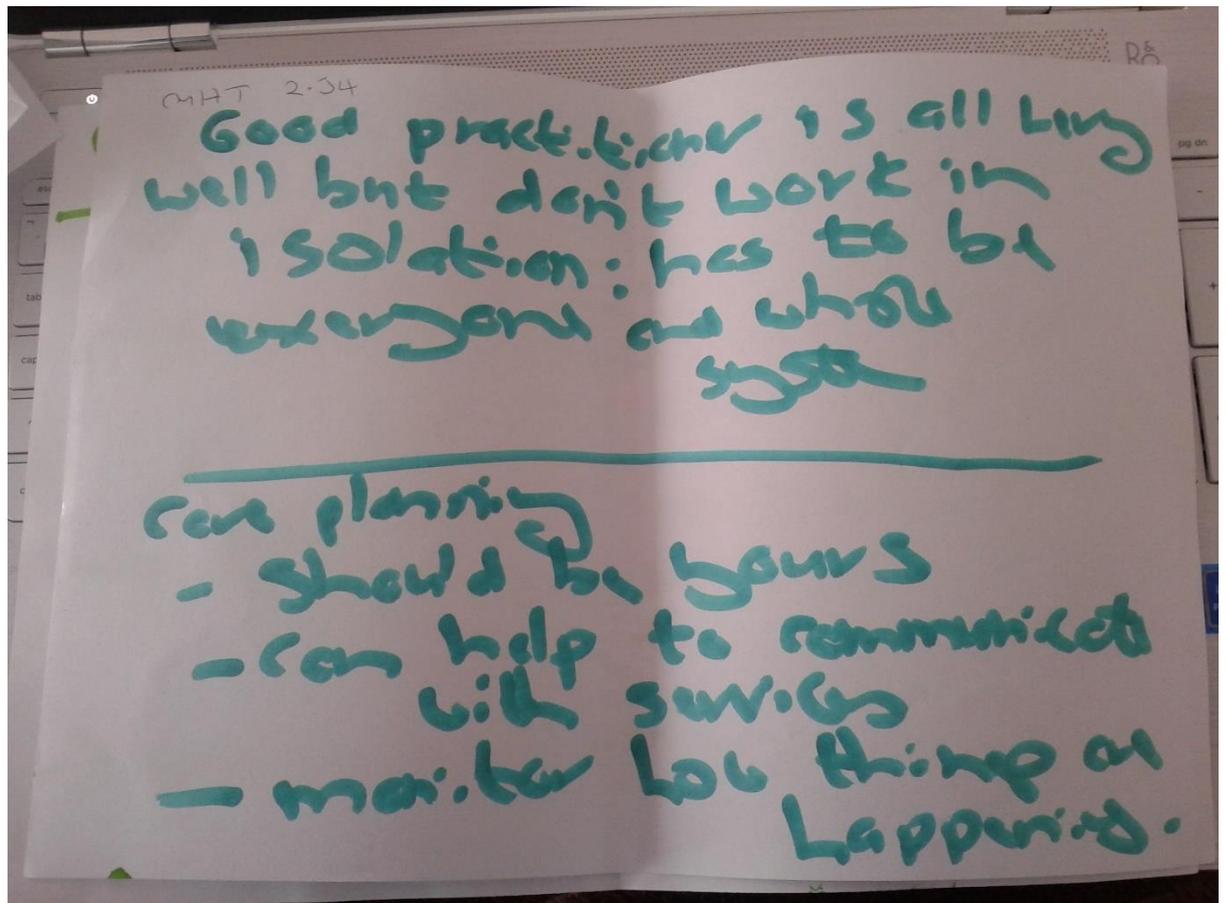
This proposal exposed that some members of the team had believed that their task was to critique what they were reading and hearing. This discovery showed a gap in the research education programme, and that more thought should have been put into preparing the team for data analysis rather than hoping that they would pick it up as they went along. It also did demonstrate quite how much we were all learning about PAR together. Our development of a system that got at least some of the task done (data analysis) but also gave ensuing discussions and critique due respect and consideration showed significant collaboration and

comprise from us all. I had to give up some task completion focus, and the team had to give up some space to reflect on their personal responses to the data. However, this left some unresolved concerns: it meant that the team did not participate throughout in data analysis because of deadlines, but also, there was nowhere put their responses to the data to good use beyond the cathartic element of sharing reactions with peers. Pictures 12-14 show some of the teams' responses to the data.

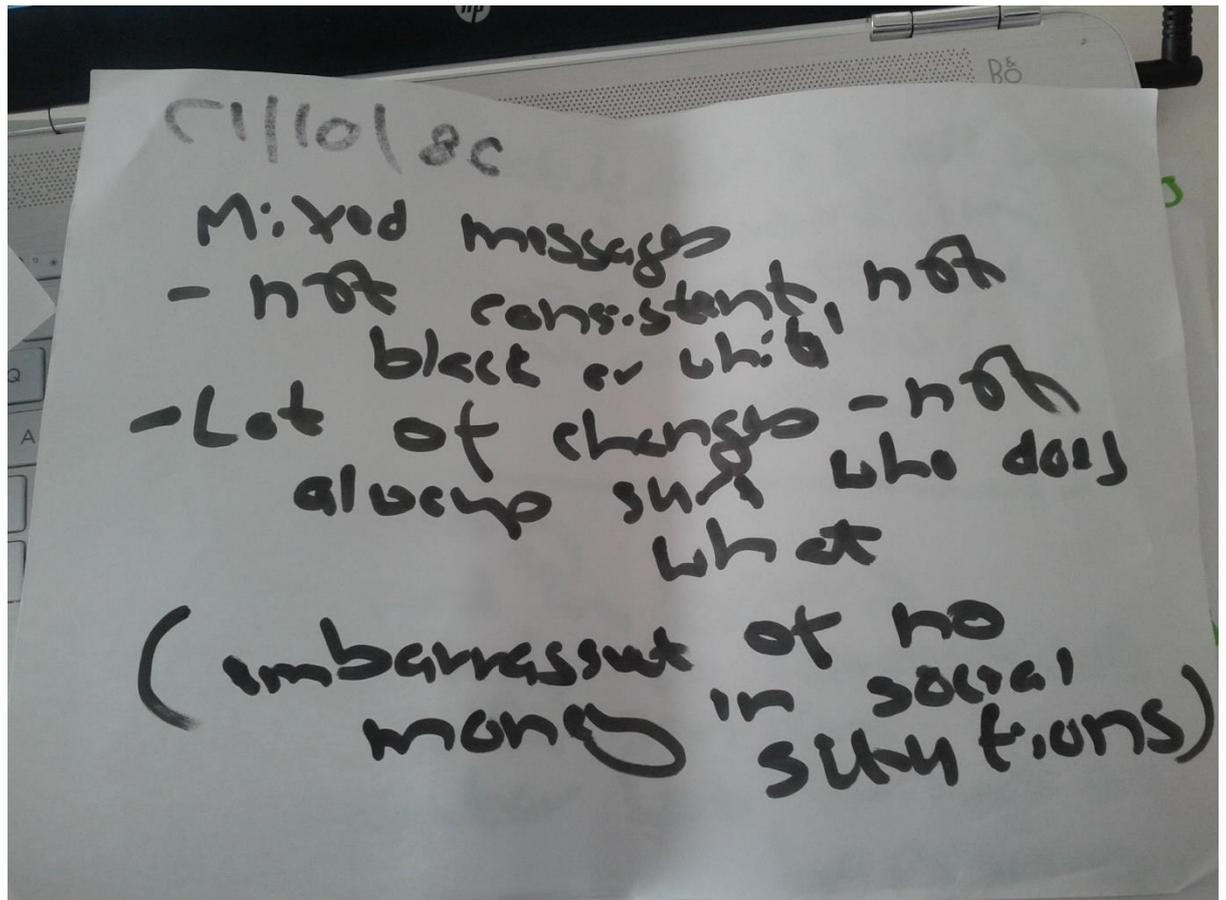
Picture 12: PAR Excellence Responses to Data



Picture 13 PAR Excellence Responses to Data



Picture14: PAR Excellence Responses to Data



In the next section, the findings from the focus groups on shared decision making and the individual interviews on the shared decision making resource are presented.

4.6 Findings

The findings are divided into two distinct sub-sets. Firstly, the findings from two staff focus groups about their views on shared decision making are presented. Secondly, the findings from the eight staff interviews about their views and experiences of the shared decision making resource are presented. Originally, PAR Excellence had wanted to use the initial staff focus groups on shared decision making as a baseline, and then explore if there had been any changes in staff understanding and practice after using the shared decision making

resource through further data collection. All the themes are illuminated with pertinent quotes from participants. Participants are numbers P1, and so forth.

4.6.1 Shared Decision Making Findings

There are a set of three main themes (one with sub-themes) that have many interweaving features. The first theme is barriers and complexities of shared decision making and has the sub-themes of ethical issues and reality. The second theme is the impact of roles and identities on shared decision making. The final theme is requirements to achieve shared decision making

4.6.2 Barriers and Complexities of Shared Decision Making

The theme of barriers and complexities of shared decision making has two sub-themes: ethical issues and reality. It was clear from the focus groups that shared decision making in mental health is far from straightforward for staff. The two sub-themes of ethical issues and reality are closely interlinked, for the ethical issues were in some part due to the constraints regarding the reality of the situation that staff were working within.

4.6.3 Ethical Issues

Staff felt that they were faced with ethical dilemmas when considering shared decision making with service users. A particular issue was hesitance to ask and record service users' views and preferences, knowing that it might not be possible to meet them. This could be down to resource issues, or the way that services are provided. Staff also have to consider how much service users can really participate meaningfully in shared decision making – not just because of service constrictions, but because of their ability to engage that might be affected by their condition, circumstances, and/or confidence and understanding of their rights.

“What most of my service users say: “What's the point?”. Because if I go into hospital or I go to a certain place what will happen to me will be a) what that place does and b) depends on what staff are on and what else is happening. What I write down on here counts for nothing. It's lovely and cosy and joint decision making for the hour you're filling it in. It doesn't count”.

(P1)

However, for some staff, there was a view that there was still value in asking service users for their views:

“But if they know that's the...the realities are, you know, this is what...we can make sure they know your wishes...but the realities are you may not get that, but at least they will know. Just like the same...the same position as anyone who has got capacity. You can ask for it, you may not get it. But at least you've been heard, and you had some power to try and influence it”.

(P2)

Another area presenting staff with a conundrum was the care plan. Care planning was seen as the crux of and key tool in shared decision making. However, for some staff there were questions regarding even the basic premise of the care plan: does making someone have a care plan mean that by default they haven't shared in a decision, because they have to have a care plan? This then led on to broader questions about how people execute their decisions: is by turning up, or not turning up to appointments still exercising decision making,

at the most fundamental level? The argument here was that, by choosing whether or not to engage in services, people are exercising agency. However, this was hotly debated, and seen by some as a blunt way of service users expressing their preferences that was unsatisfactory as it showed a lack of ability to engage on behalf of services. This also indicated a basic confusion from some staff regarding the difference between service users making their own decisions, and shared decision making.

Issues in the practice of writing care plans were identified, where they can actually be used to disempower people via clumsy attempts to write them in the first person. This was described as:

“Stealing their voice”.

(P3)

A further complicating factor surrounding care planning was the purpose of the plan. The multipurpose nature of care plans means that they need provide a means of professionals showing what they are doing rather than as a tool for engagement:

“As a care coordinator and a professional in mental health you need a plan of what you are doing with that service user, what you're...what everybody's...you've got to move them forward, haven't you?”

(P1)

Another significant issue in shared decision making practice raised was that of preference versus choice. Dilemmas concerning asking people for their views

when they might not be able to be taken into account crystallised around the use of advance statements. Like care plans, advance statements are seen as a tool for achieving shared decision making. Yet, like care plans, they can also highlight a contested space between service users, staff and services. Although some staff regarded processes such as advance statements as a useful tool for shared decision making, some saw it as producing a quandary that preferences entered into an advance statement can't always be delivered – for example, requests for gender specific staff members. This threw up real ethical questions for staff: is it better to ask people so that they are at least listened to, even if the things they request can't be delivered, or is it disingenuous to ask people what they would like in potential situations, knowing full well that they may not be deliverable?

4.6.4 Reality

Shared decision making is clearly a principle, but in the reality of mental health service delivery, principle not always easy to implement because of the nature of the system. Staff felt discomfort at operating in a system that they know is disempowering and does not always meaningfully engage service users in shared decision making:

“I think a lot of our systems take control and power”.

(P1)

Another barrier identified was that shared decision making takes time:

“The biggest threat to that is often around the amount of time we have to do it”.

(P3)

A strong example of systems not being conducive to shared decision making was the experience staff had of decisions being made about service users before they were even present in the room:

“A fait accompli, then...then the person comes in when everyone's...it feels like these people got the story straight and it...and it's one of the big things that does need to change”.

(P2)

The issue of decisions being made with disregard for service users was particularly seen as an issue on wards:

“The CPAs (*care programme approach meetings*), particularly in the wards, tend to involve a bit of a pre-meeting and then the service user comes in as an afterthought. And I think for somebody who's, like, a paranoid schizophrenic especially in CPA doing that and you tell him, right, you can sit out here. We'll sit in this room here and we'll talk all about you. And then we'll invite you in. And I don't know about them, but I think if that were me in that position I'm thinking, oh my god, what are they all saying about me sort of thing? And then for somebody to come in and have about 20 people around you, you know, it could be...it's absolutely frightening for them, isn't it?”.

(P1)

So, staff can feel as powerless as service users at times in the face of the mental health system, and at times have to advocate for their service user:

"I'm working with a very articulate, intelligent young man at the moment who's in hospital and his CPAs are dreadful because a meeting takes place for a full hour, while he sat outside. And I'm so saying, excuse me, but can we bring the family in, can we bring the family in?"

(P1)

Another issue seen by staff as preventing shared decision making was a lack of resources, which they found frustrating:

"I think then there's a disappointment of not being able deliver".

(P7)

This limitation placed a difficulty for staff if they felt that service users did not understand the nature of the service, or had not been given enough information prior to service contact about its limitations:

"Preconceptions. People come into the service with preconceptions about what it is and I think sometimes they have those from either the similar named services in the community or word of mouth or whatever. You know, whatever makes them come in with, well, you know, I don't think that you're going to be able to do it for me or perhaps other things. That makes it a bit more difficult sometimes. It's not insurmountable but it can make it more difficult. And when...when another part of the...of the service they're referring to us haven't really explained to them what it is".

(P7)

The earlier preference versus choice debate tied in with the reality of both the system and the society within which staff practice. It was observed that everyone operates within systems and structures regardless, and using mental health services would not be any different. However, again, there seemed to be a case of staff missing the point of shared decision making, conflating it with service users making choices independently of staff, and “doing what they want”, rather than a process of collaboration:

“You have to operate within constraints. You can't just make choices and do whatever you want. You have to operate within rules and constraints that society has, that the law has. You might say well, it's not a joint decision because there are rules, but there are rules everywhere. But the point is you're working with them so that they make the right choices or their preferred choices within the rules that they have. That doesn't mean you're not giving them choice. It just means you're operating within the structures that you have. You can say that they can get a package of money and they're not allowed to spend it in a certain area. But in a way, why is that unrealistic? If that package of money is meant to help with a certain problem, then it's not unrealistic to say but you can't spend it to go somewhere else”.

(P3)

Some elements of reality was regarding service users themselves, with acknowledgement that they have tricky courses to take and that to engage in sharing decisions wasn't always going to be easy:

“Its overwhelming for people because it's such a new thing. And...and it is asking people to do something which is difficult”.

(P4)

Other aspects to the mental health system that left staff feeling limited in being able to share decisions was the individual budgets system known as self-directed support. Whilst ostensibly a means of putting people in charge of the care and support they receive by putting them in the driving seat of how money associated with their support needs is spent, the strict criteria for eligibility and narrow range of options available mean that it is seen still as a restrictive measure, rather than an empowering one. This loops back to the ethical issues again, in that is it better to ascertain choices, even though they can't be met?

“So, that is a system that does not involve the service user other than what they tell you because the machines...the system is doing the number crunching and is coming up with a figure. Take for example how budgets are generated for self-directed support. Information is inputted onto a system and a system works out that person's eligibility. So...for money, how much money they can have. So, that is a system that does not involve the service user other than what they tell you because the machines...the system is doing the number crunching and is coming up with a figure. So, I think a lot of the systems and processes that we use can have a lot of impact on power sharing”.

(P3)

These constraints led to a frustration for staff:

“There are specific things that they cannot spend that money on. So even if they chose to or they say I want to spend this money on X and that doesn't come in to an accept...what is the...an agreed, sort of, cohort of ideas, they can't do it. So, I would argue that there's very little choice and control from that perspective. And when the direct payment system was set up, people were given the sum of money and they were free to choose what they were going to do, going out socially, so on and so forth...And then there was a carte blanche, that area no longer comes into this. But there is no other provision for it anywhere else. So you are in effect offering a choice and then pulling the carpet, in my view, from under people's feet”.

(P3)

This theme has shown that there are some real tensions that staff have to manage in trying to implement shared decision making. There is not consensus between staff about what it should look like and some confusion around the difference between sharing decisions and service users making choices alone. Also, staff feel frustrated with the systematic and cultural barriers to shared decision making within services. This connects with the next theme, in which roles and identities are discussed.

4.6.5 Impact of Roles and Identities on Shared Decision Making

The roles and identities that people bring to the decision making process is at the heart of shared decision making practice, and there is an impact on the process of the different knowledge and experience each person brings that is tied up in their roles and identities. Some of the issues around the impact of this are the roles that service users see themselves in in relation to staff – that the

staff are the experts. Families too have a role in shared decision making, and can impact on the choices that service users make.

The roles and identities of staff impact on shared decision making practice. Different professions have different ways of understanding shared decision making, and this can have a significant impact:

“I think the way that you work, using those systems is the pivotal thing in sharing power. And a lot of social work value base comes from working anti-oppressively with people and recognizing systems and how society disadvantages people, say, with mental health problems. So, I think for social workers it's about really recognising that and creating situations amongst all of this that's going on where people are as equal as we can possibly make it”.

(P2)

For some other professionals, such as this psychologist, shared decision making was essential for the successful of their professional intervention:

“When deciding on how...the kind of interventions to...to use and what that person wants to work on, the individual has to be very active in that...in that process. They have to want to...to kind of participate in therapy. They have to want to...to address difficulties, they have to want to work at it actively. So, it can only work if that is shared”.

(P9)

However, there could be discomfort for staff if they felt that they were engaging in practice that did not fit with the roles within which they saw themselves:

“It is kind of a... it’s kind of a threat. It’s this subliminal thing that we do in mental health and it’s the threat and I really do...as much as I know it’s keeping the patients well, but it’s very difficult to do that. I mean, the phone call before is about a lady that’s refused since last February and now becoming unwell and we’re going to go down this whole path again. Cause it doesn’t...for me that decision...I know it’s a legal thing but as a nurse it just...it doesn’t feel right”.

(P1)

Another determining factor that affected staff discomfort was the type of service they were working in, and when services intervened because of risk to service users’ health:

“In previous service I worked in, which is an eating disorder service, there were times that I actually got the shared decision, dimension would break down in that if people were becoming very, sort of, dangerously underweight then our role, even as therapists would still be to facilitate their...their, sort of, detention I guess, in in-patient setting. So...there was a real, sort of, tension that would be created there by the two of, sort of, the blur between therapist’s role and also, kind of, take on more of a, sort of, care coordinator role”.

(P7)

Some staff thought that service users, in their identities as such, firmly considered themselves as being powerless, and therefore choiceless. Another

staff perceived factor in this was the person's "unwellness" and impact upon decision making:

"They have this fear, and so they feel that they don't have a choice. They have to go. Otherwise they're going to put me in hospital. And however much you explain that to somebody, if they've got a fixed idea and they're unwell, it's not going to change because it's a fear. So sometimes, it's...it's really difficult and I think that needs to be taken into account, that some people are really, really unwell and...and aren't able to...to make a decision".

(P1)

Yet, for other staff, being "unwell" should not prevent someone in engaging in shared decision making, which creates a tension in view of the above quotes where services have deemed it necessary to step in and taken over service users' decision making:

"Even if they're unwell or if they're using substances...they can still make decisions. They might not always be the best decisions to make, but I don't think it stops them from making decisions".

(P2)

An interesting dynamic emerged when staff members have used services themselves, which they thought gave them greater understanding into power and professional practice:

"And when you're vulnerable you are likely to experience higher levels of anxiety and...to notice more about those sort of power differentials.

Because I've been a service user and I can remember how it felt, going to the community mental health team and to sit in the waiting room, with your service users. And to go along in to see the consultant psychiatrist. And I found it quite unusual experience, because I've always sat on the other side of the fence. And it...and it really occurred to me, the differentials, when I was sat in the waiting room once. Because I was thinking, well gosh, normally I would be over there, but now I'm sat here. And there was a big difference. And I certainly felt quite vulnerable, because I didn't feel totally in control of what was going to happen to me”.

(P4)

Not only does having lived experience of using mental health services give those staff members more awareness of their position: some also used the sharing of their own personal experiences in an endeavour to empower and inspire their service users:

“I think something that I do do and I have done is I have shared personal experiences if I feel that that would help the person. Not only to...if this...this could happen to anybody. This...this situation that we're in...can happen to anybody. So sometimes I do tend to give a little bit of me”.

(P6)

The role of families in shared decision making was also seen as having an impact on the process:

“There's family pressures, isn't there? There's all sorts of issues around decisions that people make”.

(P7)

Families were not always seen as being helpful in achieving shared decision making – particularly parents:

“Certainly with some sort of younger people that are staying with their parents. Quite often you find that you end up dealing...you end up being expected to deal with the parents, through the parents about the young person and then it doesn't work. That's what I found. It just doesn't work because...because they're telling them what to do, you're trying to tell them these are the things you could do. And I'd rather speak to so-and-so straight away, you know, directly, it doesn't work as well if we don't. And they're going yeah, but he...you know, he won't understand unless we tell him. And in the end they come and start giving you lists of requests, you know. And you just think that's not...that's not what we do. We don't do that. So it can have a big impact”.

(P6)

However, there were also plenty of occasions when staff felt that families were imperative to shared decision making, because of the knowledge they had about the service user:

“There's the power of attorney for health and well-being now. So, whilst you are well you can determine who you would like to make decisions on your behalf if you become unwell. I've had quite a few cases where that's been in place, and somebody's lost capacity. And it's been really great

because there's a person that has known that person well, understands their wishes and views...past wishes and views, understands what their life choices have been like and so on and so forth. And they can then step in and make those decisions for that person. So I think that's a good example of sharing”.

(P1)

This theme has highlighted that the identities of staff impact on their views and practice regarding shared decision making, and that they are not always comfortable in their role. Also, how service users might view staff and themselves may have an impact, as well as that of their families. In the next, final theme, staff discuss what is required to bring about better shared decision making.

4.6.6 Requirements to Achieve Shared Decision Making

In this theme it emerged that achieving shared decision making really came down to the practice of individual staff members. There was a view that there are some tools within the mental health system that, whilst can be a hindrance to shared decision making, can also be provide a framework for shared decision making if used appropriately. Community treatment orders, advance statements and care plans, should, in principle support shared decision making, although if not applied correctly, can be used to wield power.

Staff saw in their roles an element of advocating for their service users against aspects of the mental health system that hindered shared decision making. Some staff saw that addressing power imbalances were integral to shared decision making:

“Equal rights in a shared decision. So, the health professional should not hold more power than the person who is using the service”.

(P5)

It was also deemed to be important to be transparent and realistic about what can be delivered for people, and an understanding that an investment in time to build a rapport with a service user was necessary. Although, it can be seen in the following quote that the process was used to reach a point where the service user ‘came round’ to a proposed course of action, raising questions about whether the described scenario demonstrated effective shared decision making, or coercion:

“If you've got an understanding of the power and you're open about what our limits are and you're not overselling it, because I think that's where things get difficult. But I...I mean, I've...I've worked with people...one guy in particular who desperately didn't want to go into hospital. So, we worked for a long time, I explained all about the limits of our power because that's one thing that came up. He had a view that you could just go along with a police officer and drag to hospital. So, that wasn't allowing him to take part. But we spent many weeks talking about what his rights actually are, the limits of what we can do, make sure he had the choices. In the end, he decided he needed to go into hospital and he wasn't made to go into hospital”.

(P2)

There was also a sense that it was the duty of staff to try and find the time to work against the system in some way, when it was getting in the way of shared decision making:

“So, if you don’t have the thinking time to properly plan and to spot when the system's pushing you along and you need to put the brakes on that and make sure that you are not the decision maker, you're doing something jointly”.

(P2)

Despite some staff's concerns about enforcing service users to have a care plan, it was also seen as a positive tool for shared decision making:

“The creation of that plan gives...give the service users an opportunity to...to pick and chose basically and discard things, isn't it? And in that sense, the face that that...that's like a focal point for the discussion around the options”.

(P4)

Also, although whilst seen by some staff as detrimental to shared decision making, the Mental Health Act was also considered a way of protecting people's rights:

“The Mental Health Act here, you've got section 2, and 3 you could argue is that one, but actually the...the law, the code of practice says you've got to really try and come up with a shared decision. You've got to look at the options. You've got to try and find the least restrictive way, and if you can avoid it, you must do. And you don't just subject them to it”.

(P2)

To conclude: it was evident that there was no consensus within either staff team about shared decision making, and there were some misconceptions and misunderstandings around its principles and practice. There was much awareness expressed about how mental health systems and roles hinder shared decision making, although thoughts were not consistently shared between different staff members. Whilst some elements of the mental health system hinder shared decision making, some elements of it could be used as a tool to engage service users in shared decision making, depending on how they were used. This encapsulates the overall conclusion of this section that in practice, shared decision making is dependent on individual staff attitude, determination and willingness to make the system work for them to practice shared decision making.

A further emergent finding is the role that staff's own use of lived experience of using mental health services plays in their understanding and practice. This comes to the fore in the next section and chimes with the overall proposal put forward by PAR Excellence of the importance of lived experience to other service users. The next section of the findings concerns whether the shared decision making resource of service user experiences that PAR Excellence created supported shared decision making.

4.6.7 The Shared Decision Making Resource Findings

Three themes were found in relation to the shared decision making resource: implementation of the resource, impact of the resource, and resource critique. (Please note: the participant numbering is not related to the participant numbering in the previous section.)

4.6.8 Implementation of the Resource

Staff support for the shared decision making resource in principle was mostly extremely positive, and the approach was generally very well received. However, utilisation of the shared decision making resource with service users directly was apparently very limited. Only three members of staff made use of the resource as it was intended, and not widely:

“I looked at it when you first gave it to me, and I haven’t looked at it since. I didn’t share it with any service users either just because – well I didn’t. It wasn’t a choice as such. A lacking of me, I am afraid”.

(P6)

It was difficult to locate the exact problem of the low uptake of the resource in practice. The efforts made to engage staff were seen as appropriate:

“You did everything you could to get it accessible to staff. You fitted in with everything we wanted really. You came to a team meeting, and you fitted in very well with us”.

(P6)

For one staff member, the resource’s content restricted their use of it:

“I did make use of the resource, but not as much as I thought I would, once I had seen the videos”.

(P5)

It was identified that pressures due to cuts, service restructures and reduced staffing may have an impact, although this was not a view that was shared by all:

“Unfortunately, things like this are pushed back down the list of things you need to do, and that is the climate we are in. All that, unfortunately, impacts on taking anything like this on, and to any ability. It is very difficult to take anything on in addition to your core duties. But that doesn’t mean it wasn’t useful”.

(P6)

Those who did make use of the resource reported mainly very positive outcomes. This occurred especially when staff members were very familiar with the resource, and could highlight pertinent points to service users. Some ways of increasing the use of the resource were put forward. It was felt that the resource would benefit from more experiences, and more localised ones. It was suggested that the resource be continuously contributed to and developed, and that this is something that service users could contribute to on discharge.

“Maybe getting more peoples’ stories, and adding to that. People are recovering all the time. Maybe when people are discharged we could ask people if they are willing to share any positive experiences they have had”.

(P1)

However, this was not a shared view, and other staff thought that there was just the right amount of content:

“I don’t think more stories, no. Because you can be overloaded. I think because there was a broad spectrum of experiences. Anymore and you can turn people off”.

(P6)

It was felt that staff would be more inclined to use the resource with service users if they had a clear understanding of how it would help them to do their job. It was acknowledged overall though, that efforts to maintain momentum were required. It clearly needs to be on the agenda on a continuous basis, and integrated into current systems – for example, assessment processes:

“It is keeping it on the agenda: that is the most important. People are enthusiastic initially aren’t they, and then it tails off. Regular updates with staff would be good, and keeping it current”.

(P1)

Some staff felt that there was a strength to the resource because it had been developed by service users:

“If you had come with it, I would have said, it is just your idea, and it would be just be part of policy and procedure. Because it came from a service user group it is about passion, and improving the quality of the service”.

(P4)

This was echoed in a general appreciation of service user involvement overall, with staff being both welcoming to the prospect of involvement, but also understanding of the need for a facilitator:

“I was conscious that there was a lot of involvement other than you but that you were leading on it. I just think it is brilliant. It carries a bit more weight. It carries a lot more weight than I do in relation to what it feels like to be involved in mental health services at any level. I can only applaud you. But I think it is important to have someone like yourself so you can liaise within. Or else it is difficult. Because people have different skills. Somebody who is not able to run this project can still have a very valuable input into it. But the project may flounder if they are unable to run it”.

(P7)

However, it was also noticed that some of the presentations to staff about the resource at meetings were done by me alone, and it was seen that having other members of PAR Excellence with me would have strengthened implementation:

“It would have been nice to see other people other than yourself at the staff meetings with staff. I think that staff would have had a better understanding if a couple of other people had come along. I appreciate that it would be hard for people to come to a big meeting – they can be intimidating.”

(P1)

Some members of staff were keen to see the resource becoming accessible to people who aren't using mental health services, seeing potential for the resource to have broader impact:

"I think you need to get it out there. It needs to be in GP surgeries and in libraries. It needs to be where people can get hold of it. Because we only see a small proportion of people who are struggling with their mental health. Lots of people are out there who are struggling who are receiving no help or support at all, or who self-manage. And that information needs to be disseminated out to communities".

(P2)

Staff who had really engaged with the resource ensured that it was always to hand:

"My copy is in my diary. It goes everywhere with me".

(P2)

However, there was a strong feeling that the way the mental health system works completely stymies the possibility of shared decision making, and one member of staff who had also been a service user was very frustrated by this:

"I don't believe that we do have shared decision making, still. All the decisions are made: it feels very much like you are not part of it. I still go into meetings where there are eight professionals, and I am one of them, and they have decided what they are going to say. I go in before a CPA, and say this this this and this, and they should be discharged. So I think we are a long way for shared decision making. But being a service user myself, I have always thought that. That you are being controlled. I am

very glad you chose shared decision making. It is one of the things that really frustrates me, and my patients”.

(P3)

One staff member who had felt that the resource had a profound impact on the team thought that every team should have the resource to improve staff understanding and practice:

“Each team should have videos of service users who have recovered. To say, “this person has been in my life, and made such a difference””.

(P3)

For members of staff who are also service users, whilst they may not have always made use of the resource, they did make explicit use of their own experiences:

“I had this patient kept asking me how I knew what his in his head. And I said, I have been there. I have to come clean”.

(P3)

This person also used their experience as a service user in their interactions with their nursing students in an attempt to increase their insight into what is possible, and challenge stigma:

“I say I have bi-polar, I have been on lithium for fifteen years, I have been sectioned twice”.

(P3)

However, the approach of sharing personal experiences was perceived as being controversial to some staff members:

“A lot of people, like (*Dr...*) don't agree that you should say anything. My attitude is why – it is not a crime. What have I to be ashamed of”.

(P3)

There were quite differing understandings regarding how the resources could be used, with staff seeing their role in relation to it differently:

“You have to choose who to give it to. You have to make sure you give it to the right person. Who can read, who can understand, who it is appropriate for”.

(P3)

This approach was seen as making a professional judgement on the use of the resource. However, some staff recognised that this staff control was problematic, and added to the power of staff over service users that the resource sought to balance:

“It is true then that I am the one holding all the cards... I am the one who is selecting which ones (*service user experiences*) I use during the conversation. You could argue that is not really fair, because someone should have access to all of them. It is difficult. Who is then is holding the power. Am I selecting it. Is it right for me to say: “for you, you sir, these are the things you need to know about from these patients”, and he's thinking: you don't know that. I might want to hear about that”.

(P8)

Some staff suggested that the resource would be better utilised in a group workshop style approach with service users:

“To have more of an interaction with a group – like an open informal discussion”.

(P3)

One staff member who hadn't used the resource instead gave an account of how he had grown from making a judicious use of his own lived experience of mental health services, to sharing with service users other people's experiences verbally:

“What I used to do, is use my own experience. Then, when the resource came out, I looked at it and I thought to myself: the problem I have with it is that most of the experiences are describing things that are conversations that are more clinical, rather than the social inclusion level. However, what it has done is almost develop the resource itself, though my knowledge of other peoples' social inclusion experience. Therefore, I use patients experience much more than I did before. It has almost become more of a prompt, rather than use the actual stories there”.

(P8)

However, this person did not wish to share this approach with colleagues, as he felt that it was a strategy that put him ahead of them:

“The nature of working is some sense of competition amongst your colleagues. I don't tell people that I do this a lot and how I do it. I keep

that myself because I think it is working better, and it is an advantage. I am quite protective”.

(P8)

To summarise: there was not widespread implementation of the resource. Some good ideas were put forward about greater implementation, and staff thought that a real strength came from the resource being developed by service users. It also supported staff to reflect on their own experiences as service users and how they use them with service users, and make greater exploit use of the verbal sharing of other service user’s experiences. It was highlighted that attention is required to build the resource into existing systems, and keep it high on the agenda. However, as explored in the next theme, despite limited implementation, the resource was not without impact.

4.6.9 Impact of the Resource

Most staff who had made use of the resource reported positive responses from service users, although not all responses were positive. The biggest reported outcome was on the staff who looked at the resource, rather than on service users directly.

Despite limited reported use of the resource with service users, staff did generally see the resource as having potential:

“It was the fact that people can recover, that people can make changes, even when they are in dark places”.

(P1)

The experiences in the resource were seen as a way of instilling hope to someone when they are not well by providing a connection to someone else who has also not been well:

“Often, its helpful to have a story to share. Or if someone is really feeling in a state of despair, it is good to have something to pick up say: “well, I have got something here written by somebody who has the same sort of issues that you are currently experiencing. Would you like to hear what they have got to say?” And quite often they say: yes I would. And that helps people to think gosh, there is where I am now, but look - there is a hope, there is a way forward. It is really useful for people who are in throes of illness, if you can find some way of finding a connection with someone who has got better. It inspires hope”.

(P2)

One member of staff who had familiarised themselves with the booklet had reached a significant and tangible outcome by making an explicit and informed use of the booklet with one of their service users:

“The young lady I shared the booklet with....there was one bit of writing around anxiety, and she suffers a lot with anxiety. She has kept herself in her house for six months. And someone in there had written that she had thought that her house was her shelter, but it was actually a prison. And that had great meaning for this young girl. So it was very powerful. What she had said had a profound effect on somebody else in the same situation. The effect was the realisation, over a period of weeks, that her home was not her comfort, it was a prison, and she did actually start to go out again, for the very first time. Because I had read it all, and I took it

along and put a little marker and said: “would you read this”, and about two hours later, she emailed me and said: wow. OMG, she put. And she has since then she has gone out”.

(P2)

Another member of staff found the resource useful because it consolidated a decision that one of their service users had taken to start voluntary work:

“I used it myself with people on two occasions. On one of those occasions, it was really helpful to the person. I think it confirmed what she was feeling about the volunteering that she was just starting. I think it confirmed that this is something that is actually going to improve how I use my time and therefore the amount of time I have to sit at home feeling fed up and distressed I am putting into supporting my recovery...hearing from someone saying this is the impact for me”.

(P5)

The fact that the booklet had been written by service users, rather than staff members was seen as a significant asset:

“This would have very little value if it had been written by therapists or psychiatrists. This is written by real people about real people. And that is why it is so critical that it is service user led. I think if you were coming along and asking psychiatrists about their experience of working with people it would have very little value to most of my patients”.

(P2)

That the project had emerged as a result of PAR was seen as a positive attribute in terms of impact, because it provided authenticity:

“I think that it is excellent that it was service user led, and quite right that it was service user led. I don’t think it would have had the impact had it not been service user led”.

(P2)

It was also thought that the resource could help carers by increasing their understanding and instil hope, so should be made available to them:

“I think that it is important to get it to carers. For people to read about other people who are experiencing what their loved ones are experiencing. And that can provide hope”.

(P2)

Having the experiences presented in a variety of media was also seen as a positive:

“The stories in the books – they were good, for people who weren’t savvy with the computer”.

(P1)

There were some members of staff who had not shared the resource, but saw its potential positives:

“The more feeling the people I work with that they are not alone, and the more they realise that people have been through similar experiences, or similar routes though our services maybe it would empower them to think: perhaps I can ask, perhaps I can talk, perhaps I can suggest. If they notice that other people are putting information out there, they can only be empowered. I can only think it can be good”.

(P7)

Whilst not a feature generally that the team decided to explore, the positive impact on a service user who contributed to the shared decision making resource by recording their experience was noticed by staff:

“For the person I know who did it, I think it was really helpful for her do to it, as it helped her to realise how far she had come. Which I think was cathartic. It was a difficult time for her...She enjoyed doing it. Also, she has had some good feedback from the people who have seen it”.

(P1)

Other staff saw the resource as being useful when it backed up what they themselves were saying to their service users:

“A lot of what was said was around the connectivity with other people....so other people saying what I am saying on a daily basis – I am quite happy hearing people saying it as well. It gives me a break from having to keep saying it! This is real life experience, and that is good”.

(P5)

The biggest reported area of impact of the resource was regarding staff reflection, rather than the hoped for impact on service users:

“I think anything that gets staff talking and changes practice is beneficial. The video really opened the team’s eyes. It will give awareness of how do we work, and how do we think about shared decision making. What you do is you get bogged down with the system. You don’t see the

person. You see the diagnosis, you see the medication. You don't really see the journey.

It made me think: wow, how powerful that journey is, and how you would treat somebody differently because you know what happened to them. And that was the power behind it. And it did bring a tear to a lot of people's eyes. And that we are doing a good job. That just bought it back that we could be that person with that awful childhood. And it made you want to do the job better. And that is amazing, hearing people's story".

(P3)

Another impact of the resource was on staff practice:

"And it was really good to see what perceptions people had, and it made me think how I work with people and how I am with people, and hopefully I picked up lots of things from it that I will carry forward".

(P2)

The resource consolidated good practice for staff, for example, the importance of relationships on outcomes:

"I think it helped staff to realise how important therapeutic relationships are, which I think it was really useful – really good. You don't always realise when you are working how important consistency can be. We underestimate that".

(P1)

Another perceived positive of the resource was to remind staff of the importance of hope:

“Hope is something, as professionals...it is too easy to lose sight of hope, and the importance for people to have hope”.

(P2)

The resource was also seen as powerful to staff because of its message regarding recovery:

“It was optimistic about recovery. And that is what we don’t see, People can get better and move on. That was what was uplifting to the team”.

(P3)

Another member of staff reported that, while they hadn’t actually shared the resource with service users, it had had an impact on their thinking:

“It has definitely made me think differently, which is in itself a positive, and have it in your mind when you have conversations. What else do we need to talk about, be more of an advocate for that person and make sure we don’t skip over what might have we skipped over. It has definitely influenced, and is definitely on my mind”.

(P5)

The resource had a further, positive effect on a member of staff because they were also a service user:

“I also use services myself, so it has a special meaning for me, as a service user as well as a staff member. The psychiatrist I went to see didn’t look at me once. And that really made me feel on periphery of what was going on. I am really grateful for your booklet, I really am”.

(P2)

The fact that this staff member had also been a service user gave them profound insights into the predicament that service users are in, and they understood what the resource was in some way trying to address:

“For me, the experience of going in to see a psychiatrist was of being done to. I felt that things were being done to me thorough this process, and I wasn’t really asked my viewpoint of what well would mean for me, or what being better felt. If you don’t understand that very early on in the process, you are never really going to have a goal that is meaningful to work towards”.

(P1)

There was also a sense that the resource had some potential to enable staff to consider power imbalances, although there was clear recognition that there are some inherent power imbalances within mental health, such as the Mental Health Act:

“I think it will go some way *(to address to power imbalances)* by increase staff’s understanding of situations. There will always be a power imbalance in terms of some aspects of mental health work – its the nature of the beast really. Mental Health Act assessments – there is a power imbalance there: you can take people’s liberties away at the end of the day. But actually, hearing people’s stories, might open up a better communication with staff. Some staff are better than others at doing with, rather than doing for”.

(P1)

There was also a perception that the resource would in some way be persuasive to senior managers in providing evidence of the positive outcomes for longer-term working rather than the current focus on quick throughput:

“The videos are quite powerful, aren’t they. I think senior managers need see them really to understand what is going on the ground. There is a great push for moving people through quickly, and those stories show that there is a benefit to longer pieces of work really. You need to show them to people who have got power really”.

(P1)

This theme has shown that the resource had an impact in unforeseen, unplanned ways. Whilst disappointing that there was not widespread use of the resource with service users, and that no service users chose to talk to PAR Excellence about it, staff did report some powerful uses of the resource. Interestingly, it also seemed to have a positive impact on someone who contributed to the resource. The greatest impact was actually on the staff themselves, in providing some reflective learning that some took into practice. The final following theme looks at the some of the problems that staff had with the resource.

4.6.10 Resource Critique

The previous themes have shown that the resource was generally well received by staff in principle, if not fully embraced in terms of practice. This theme explores some of the reported reasons behind this low level of implementation. Firstly, the practical matters are discussed. Following this is a discussion of where the resource was used with service users but not effective, and the

theme ends on an example of staff discomfort regarding application of the resource.

For some staff members, the content of the resource was not seen as being relevant to their work:

“In terms of the actual physical resource, I didn’t make use of it much at all...when the resource came out, the problem I had with it, was most of the experiences described in it were very clinical. But that is because I do social inclusion”.

(P8)

Some criticism came from a service user via a member of staff. They felt that shared decision making did not occur within mental health services, so did not engage with the resource. This service user’s frustrations echoed some of the staff’s concerns regarding shared decision making in general:

“It was in disagreement of the joint working, and what if people are unwell and can’t join in, or can’t get the services. There is all this frustration with what people can’t access, what they don’t agree with”.

(P4)

There was some suspicion reported from a service user to a member of staff, which was rooted in mistrust of the level of eloquence in the written experiences in the resource. The perceived level of professionalism was seen as a disadvantage in engagement in the resource, possibly rendering it inaccessible:

“How do people read that, if the person is ill, on the street. And, it came across as too professional, too academic, and not to be trusted. The person had written too well to be genuine”.

(P4)

This mistrust was shared by the member of staff generally about the reporting of experiences – particularly when they are positive:

“I worry sometimes, when someone is giving their story, is it really their story, And what has got them there, to get that confidence. You are so used to seeing people telling their stories because they have been told to”.

(P4)

On a practical level, some staff saw implementing the resource as being untenable because of workload:

“I don’t know how people could do it with heavy caseloads. It needs to be incorporated into normal processes – discharge planning, assessment, rather than something extra for people to think about”.

(P4)

There were some accessibility issues with the website: some of this related to the videos needing to be password protected due to data protection issues. However, there was a view that generally a slicker resource in different formats would have made it more accessible:

“I can’t help but think that it is not the right format for people. It is not smooth enough. I am someone wants to whip something out and say this is what this looks like... this is what this place looks like, this is how the room is set out. Because that is how I work with people. I am trying to support people to believe in something that I believe in, but that they are quite anxious about. That is what I would find helpful for people”.

(P5)

This staff member also had concerns about the videos in particular, believing that for some service users, they would not be able to engage in the material:

“Their concentration...it was not speaking to them. I found it quite slow. Painfully slow, which is problematic when people are anxious. I think the slowness of it felt a bit tedious”.

(P5)

There was also a view that the resource would not be implemented because it would be difficult to quantify its outcomes:

“I think the problem is...it will be very difficult to show it that it actually makes a better pound per person for the NHS type stuff. Because, it doesn’t work with everybody, and any one team still getting as many people referred to them, and in the last year our throughput has gone up slightly...its not revolutionary, although it is for individuals. I had a notion that we could put a value on it”.

(P8)

One staff member had difficulty coming to terms with what the resource in essence was trying to achieve – to empower service users through knowledge. It seemed that in doing so, this person thought it was diminishing the knowledge and skill of the professional. The staff member was not comfortable with handing over control of the information in the resource:

“I don’t like the online...I don’t want...I don’t like the thought that I am going to see somebody and what I am trying to get them to do to sit online and look at other people’s...It doesn’t sit comfortably with me. I think it is because I would want them to do it in their own time, and therefore...it’s back to control of the situation. I am not then able to suggest why that is a good one, or that one’s not appropriate. I am not involved. And therefore I don’t know what the person is thinking. I guess it’s the skill we have as professionals. The skill to find the right way of the stories of other people being brought into the discussion. I just don’t feel comfortable with the idea of getting them to sit down and do that”.

(P8)

Some of this anxiety stemmed from ensuring that the resource was used to its fullest, and the staff member thought that the resource might have limited impact unless its use was led by a professional:

“It sounds awful, but you are letting the person do it for themselves. And, there is nothing wrong with doing that and there is the empowerment argument. However, if you are not able to use it as a professional, to the advantage of the situation, you are not there, using that in your treatment. You are not doing with these things the positive things you can do with it”.

(P8)

This final theme has shown some practical issues and suggestions that would need considering before wider implementation of the resource. It has also exposed some unease about the loss of control the resource could create, and a fear of the loss of the voice of the professional. This concern acknowledges that professionals do bring useful knowledge to the relationship with service users, which is a cornerstone of shared decision making. But, as we saw in earlier discussions with staff, we again see a confusion between the equal partnerships that shared decision making promotes, and the loss of some professional power this means. In the next section, why some of these problems exist are explored.

4.7 Shared Decision Making Discussion

In the previous findings section, it was shown that whilst the use of recorded service user experiences as a shared decision making resource was generally welcomed in principle by staff, in practice there was limited utilisation of the resource. However, encouragingly, there were some profound uses made of the resource, including as a powerful staff reflective practice tool. It was also shown that staff found the involvement of service users in the research process gave the project authenticity over research generated purely by researchers, and were therefore more likely to engage with it. Overall, it was found that shared decision making is a complex concept that has many different meanings amongst staff, and they work in a system where true shared decision making cannot consistently occur. There can be no doubt that this confusion and lack of consensus played a part in the low use of the resource by staff in the manner it had been designed for, that is, directly in their interactions with service users. In this discussion, the reasons for this are explored through a consideration of the philosophical and practice tensions that the findings have illuminated. The

chapter ends with a conclusion that summarises the whole chapter, and reflects on whether the epistemic injustices often faced by people who use mental health services can be transformed through knowledge democracy in two ways: by exploring whether PAR was an appropriate choice to bring about knowledge democracy in this setting, and whether the project could establish knowledge democracy this setting.

4.7.1 Philosophical and Practice Tensions

PAR Excellence's findings reiterated the key findings of the literature review. It was confirmed that shared decision making needs continued and ongoing efforts to keep it on the agenda, requiring strategy, thought, time and investment to embed it into usual practices. Mental health workers are confronted by the challenge to facilitate greater, more active user participation by practising in a manner that elicits the resources, capabilities and potential that service users possess (Roberts 2010). Particularly highlighted was the problematic lack of understanding and consensus in mental health staff regarding shared decision making, which was also a finding of the literature review. Quite how problematic this is was played out in some of the concerns raised about the shared decision making resource, with some assumptions that the resource risked devaluing professional knowledge. This misconception showed a lack of clarity that shared decision making should be about power sharing and partnership. A lot was learnt by what was *not* said rather than what was. Many staff were unable to fully articulate what shared decision making is in line with either policy or literature, that is; the bringing together, valuing and respecting of different types of knowledge, equal partnership working built on relationships, and the role of shared decision making in recovery. This chimes with the few common understandings of recovery which may limit shared goals

(Simpson et al 2016). Indeed, the focus groups in particular were extremely difficult to analyse and glean any meaning from because the participants talked so much about anything other than shared decision making. As Braun and Clarke (2006) observed, data analysis can only be as good as the data collected. This meant trying to make sense of what staff were saying and locating any meaningful insights relevant to the research topic was highly challenging.

However, a new, positive dimension was illuminated that was not found in the literature review, although briefly touched upon in reference to the related, explicit use of peer support to support shared decision making. Both sub-sets of findings exposed the role that the lived experience of using mental health services in staff themselves can play in their practice and understanding of the power dynamics between professionals and service users. The findings showed that staff who are not employed specifically as peer support workers or to use their lived experience but do have their own personal experience of using mental health services sometimes use this knowledge explicitly and judiciously as a tool to relate to and empower their service users (although not without controversy from some colleagues). The shared decision making resource seemed to be most welcomed by these individuals. It is just possible that the resource might have liberated them further to use their own experiences in their practice, for PAR Excellence were endorsing this approach by creating the resource. The team were effectively saying: this is what people really want to hear; this is what is important to people; this is what would help people in their recovery.

There was recognition that there could be an inherent power issue if staff choose who with, when and how to use the shared decision making resource.

This echoes some of Costa et al (2012)'s concerns regarding ownership and psychiatry's appropriation of service user stories. However, balanced with that is the role that professional knowledge plays in the promotion and use of the resource. Certainly, the most effective reported use of the resource was when a member of staff was highly familiar with the resource content, and was able to use their professional judgement to signpost someone to the relevant section of the resource and for whom it was highly significant. This highlighted that the usefulness of the resource will depend on staff practice. Attitudes to service users accessing the resource outside of a judicious use of it by staff were mixed: some were keen that the resource be as accessible as possible by circulating it in lots of community settings outside of mental health services. Others saw it as being best used as directed by staff. Whilst the resource was reportedly most powerful when used thoughtfully by staff, there was also staff discomfort expressed at leaving people to look at resource alone that was at odds with the empowering aims of the resource. It can be argued that there is space for both: that service users should have free access to the resource so that they can consider how they might benefit from it, but that staff should also be familiar with the resource so that they can encourage service users to get the best from it. If this was achieved the resource would provide an exemplary method of the collaborative working that true shared decision making requires.

It is not surprising that there was much grappling and debate amongst staff. Whilst shared decision making can be seen as the promotion of the active self through choice making, today the perception of the active self appears with a new, different kind of freedom to make choices (Rose 2004). Concepts such as personal choice and the freedom to choose are key tenets of neoliberal rationality (Ayo 2012), and exemplify an individualistic stance within neoliberal

healthcare policy. Personal engagement in one's own health might be understood as an expected duty in contemporary discourses (Femdal and Knutsen 2017). However, as seen in the literature review and though PAR Excellence's understanding of it, shared decision making has its roots in an empowerment model. These conflicting foundational understandings echo the conundrum identified by Beresford (2002) and presented in the background chapter regarding service user involvement overall: that participation can be based on either consumerist or democratic ideals, but that these have distinct and different philosophical and ideological underpinnings. It is no wonder then that staff are confused.

The complexity of this challenge should not be underestimated. However, the findings showed that whilst staff can feel constrained, they can also be pragmatic, creative and resourceful when working within systems and constraints. Good practitioners can find ways of making the system work for service users through negotiation with service users and other parts of the system. To do so is difficult and complex, in a system that is not conducive to such challenging practice. It means that staff must become aware of and seek to eliminate aspects of their own practice that are an expression of reactive force. They need to become sensitive to and challenge the assumptions, attitudes and interventions that negate service users' possibilities for growth, development and participation in their own care. This is not straightforward: staff need to engage in significant periods of self-reflection, examining how their assumptions, attitudes and interventions emphasise illness, disorder, disease and dependency. But, in the current climate of underfunded, pressurised services, it could be difficult for staff to find this space (Roberts 2010). Furthermore, staff need to be concerned with assisting service users to

challenge their restrictive self-conceptualisations and to transform their self-limiting language and problem orientations. This means assisting service users to question the manner in which they understand themselves as being afflicted with diseases or disorders and the passive recipients of mental health care. They need to create a climate of hope, optimism and experimentation that service users can engage in (Roberts 2008).

Shared decision making will remain problematic whilst the best “clinical evidence” shapes how services are configured. There are clear tensions between current ideas regarding evidence based practice and personal experience (McIntosh 2010). The current hierarchy of evidence that dominates healthcare places traditional types of research (meta-analyses, randomised control trials) at the top, and personal experience at the bottom (Sackett et al 1997). But this tradition can scupper true service user involvement, and these structures that health services are expected to work within can render making service user voices tokenistic. With the current focus on audit, productivity, value for money and procedure, placing service user knowledge at the heart of provision is very difficult (McIntosh 2010).

It is argued that such narrow constraints fail to recognise that engagement in mental health services is emotional. The emphasis of evidence, effectiveness, audit, and procedures exclude alternative approaches in order to preserve procedures from contamination by messy, complex real-life phenomena. Within this climate, there is a tension because subjective understandings are seen as not having a concrete base, aren't generalisable, countable, are not rooted in what is deemed a sound methodological base: they are not scientific (McIntosh 2010). It can therefore not be a surprise that the implementation of the use of services user experiences to support shared decision making was limited.

4.8 Conclusion to Chapter Four

This large chapter has described the action that PAR Excellence decided to take in an NHS setting following choosing shared decision making as a topic. They refined their action choices by participating in an integrative literature review that showed that there is no consensus regarding shared decision making in mental health, and that a deliberative approach and the provision of accessible information was required. This led to the decision to develop a library of service user experiences that staff could use as a shared decision making resource. We explored shared decision making and the use of the resource with mental health staff, finding confusion regarding shared decision making and the resource, and limited use of it. However, we also made some valuable findings regarding the use of the resource. It was generally well received and supported by staff in principle, and did show some encouraging potential for having a profound effect for service users. It emerged that it could be particularly powerful in supporting staff to reflect on their own practice, being especially welcome for showing staff what they do well, and consolidating aspects of their practice that are important to service users, such as the need for sustained relationships to achieve good outcomes. The discussion considered how both shared decision making and the use of service user experiences in practice was always going to be difficult due to neo-liberal healthcare systems, conflicting underlying philosophies and a narrow view of what counts as evidence that is based on traditional, scientific understandings of research. This chimes with Bauman (2000), who highlighted the stresses and tensions for a public service workforce under neoliberalism, experiencing the ill-effects of what he calls 'liquid modernity'; an invidious state of affairs wherein professional care staff are

beset with a range of uncertainties, demoralised, and their capacity to provide high quality services is removed.

There were some limitations to the research. The lack of service users willing to become research participants as we had hoped means that we have a hole in our findings. Whilst we did not plan to include carers in this project, this clearly constitutes an important area to be explored further. The low level of use of the resource across the two teams means that our findings are somewhat limited. That there was no medical involvement in the research also reflects an area for further exploration – especially as doctors are often seen as holding the most professional power. Also, the resource was only introduced in community settings: whether it would be useful in inpatient settings would be an area for further exploration.

To implement the resource more thoroughly, a two pronged approach would be required. Firstly, it would need to be embedded into current systems as usual practice. The resource had the biggest reported impact when staff made judicious use of the resource by signposting service users to the significant aspects for that individual. It also has the potential for use as a staff directed group work tool. Secondly, it also needs to be accessible independently of staff to service users through more widespread circulation.

To conclude, we must return to the two overall questions posed at the start of the chapter that contribute to the original contribution to knowledge of the thesis: was PAR an appropriate choice to bring about knowledge democracy in this setting, and could the project establish knowledge democracy in this setting.

The answer to the first question is yes. The staff clearly identified tensions and concerns with power in their relationships with service users and the systems within which they operate. These cohere with the issues set out in the earlier background chapter. They also feature greatly in the next chapter, where the experiences of mental health services and motivations of the PAR Excellence team are explored in detail. This would indicate that an approach that is overtly about challenging power imbalances and seeks positive change is appropriate in NHS mental health services.

The second question is less straightforward, and required a more nuanced consideration. The answer overall would seem to be mostly no, in the manner in which the PAR Excellence team intended. The limited reported use of and effect by service users of the resource means that it is still not known if such an approach could bring about knowledge democracy in encounters between service users and mental health services from the essential viewpoint of service users themselves. A potential for the resource being a positive intervention was clearly articulated, but not especially in terms of establishing knowledge democracy.

However, the resource did go some way towards bringing about knowledge democracy on a small scale in two other, unforeseen ways. The experiences shared by service users in the resource gave staff a powerful and resonant reflective practice opportunity. In this sense, service user knowledge was put on an equal footing with other types of knowledge such as professional or academic knowledge, by placing service user voices centrally in an incident of staff reflective learning. That the resource delivered service user knowledge to staff in a formalised way and gave staff a useful insight into their practice from service users' perspectives is an example of knowledge democracy in practice.

There was also an element of knowledge democracy in how welcomed the project was in principle because it was PAR: staff saw the project as being highly authentic, credible and important because it was driven by service users. Indeed, it was accepted into the community mental health team precisely because it was PAR, rather than a clinical researcher's project. Both these examples demonstrate the potential for staff to embrace knowledge democracy in some forms, even if it didn't quite follow through as hoped with service users at this point.

The next chapter now examines in great depth the experiences that PAR Excellence had whilst we undertook the work described in this chapter.

CHAPTER FIVE – PARTICIPATION: HUBBLE, BUBBLE, TOIL AND TROUBLE WHILST MESSING ABOUT ON THE WAY TO HOPE STREET

5.1 Introduction to Chapter Five

In the previous chapter, the main actions taken by PAR Excellence to bring about change were presented: their literature review into shared decision making in mental health, their development of a multi-model library of service users experiences to support shared decision making, and their research with mental health staff on shared decision making and the use of the library. They found that shared decision making in mental health is complex, misunderstood, and challenging to achieve within the mental health system. They also found that although there was limited use of their shared decision making resource, it could have a profound impact on service users, and was particularly powerful as a staff reflective tool. Furthermore, PAR as an approach was strongly welcomed by staff.

This chapter is concerned with the experiences of PAR Excellence and myself as we collaboratively endeavoured to bring about change through PAR, and bring about knowledge democracy in both the research process and mental health services. It contributes to the original contribution to knowledge of the thesis by considering the question of whether knowledge democracy can be achieved internally within a PAR project. It is also the crux of the thesis, for it presents important findings into the act and art of conducting PAR itself from the perspective of people who have actually gone through the process - something that is seldomly written about (Herr and Anderson 2005). As set out in the methodology chapter, key to action research is to share the learning that led to

the creation of knowledge (McNiff and Whitehead 2009), and action research goes beyond knowledge generation to an exploration of the process itself as well as findings of the research (Herr and Anderson 2005). If practitioners are to move toward more democratic, critically reflexive and responsible participatory praxis, then the social relations of PAR must be interrogated to reveal how power is negotiated in these epistemological encounters (Janes 2016).

In terms of the tree analogy running through the thesis, it is also concerned with the roots of the tree, what nurtured the tree, and what threatened the tree. There is a short methods section that describes the data collection and analysis undertaken that connects with the earlier methodology chapter. There is then a findings section, which sets out how PAR Excellence examined their own position as individuals and a group. reaching a core concept of meddling in mental health services as a reaction to their own awareness of their position, and what happened throughout the project. This is a necessarily large section, as it provides a rare space for PAR Excellence's voices to shine and be given justice. This section is illuminated with many quotes from team members. The themes are illuminated with the use of metaphor: PAR Excellence introduced the use of metaphor early on in their discussions, and it became a feature throughout the project. Metaphors can be a powerful tool in presenting qualitative research by making things cohere, and linking parts into a whole (Sandelowski 1998). They provide ways of expressing ideas that are challenging to reproduce using literal language, allowing communication of complex information that captures the richness of experiences. They may also help to capture the vividness of experiences (Gibbs 1999).

The conclusion of the chapter lays out the case that PAR can be a vehicle for personal transformation, but that its impact is impeded by the broader

institutional, societal and political contact within which PAR projects are conducted. These conclusions are more fully considered in the final discussion chapter that follows this chapter.

5.2 Research Methods (Participation)

The details of how PAR Excellence members were recruited is in the methodology chapter. This section goes into more detail about the data collection and data analysis methods associated with the focus groups that were conducted with PAR Excellence to explore the PAR process.

5.2.1 Data Collection

Four specific focus groups were held at critical points across the lifespan of the project, and they informed how the next stage should be conducted. The justification for using focus groups in PAR specifically was set out in the earlier methodology chapter. Each PAR Excellence member was also given a reflexive diary to capture their thoughts on the process, and I kept a detailed reflexive account. During the focus groups I shared some personal reflections with PAR Excellence when I deemed appropriate and to support the discussions. This was predominantly when I believed that my personal revelations would generate deeper understanding in the team of PAR.

The first two focus groups were co-facilitated by myself and another member of PAR Excellence. The second two were facilitated by myself only. The member who had co-facilitated was not available for the second two focus groups, firstly due to illness, and then because of work commitments.

Three of the four focus groups included team members and myself drawing pictures to express our thoughts about and experiences of the project. These were drawn at the first focus group, third focus group and final focus group. The

use of participants' drawings as a research method also chimes with PAR in terms of its overall emancipatory aims. As Banks (1998) described in his discussions of developments in anthropology, the use of visual imagery can be part of an approach that is politically aware, particularly in relation to the underpinnings of the relationships between researchers and researched, and recognises the agency, rights and abilities of people who are traditionally researched on to enter a discourse about the construction of their own lives. There is a tradition of using drawings as a method in participatory approaches such as participatory rural appraisal, as the use of visual techniques can lead to the representation of realities that are cumbersome or impossible to express verbally, and are empowering methods for enabling people to express their knowledge and realities (Chambers 2008). Drawings can also serve as powerful confirmation of participants' verbal reports and observations. They are an important additional source of data, as drawings are able to create a path to participant feelings and emotions, and to lead to succinct presentations of their experiences (Kearney and Hyle 2004). They are artefacts of individuals' experiences, and can be used to communicate our deepest feelings, enhancing our understanding of the human condition (Prosser 1998).

The focus groups were semi-structured, using an interview guide devised and revised by PAR Excellence (Appendices U, V and W), with the exception of the final focus group. I decided to employ a participatory exercise approach for the final focus group purely on practical grounds: PAR Excellence were no longer regularly meeting at that stage, and there was no opportunity for the final interview guide to be devised collaboratively by the team. For the final focus group, I asked PAR Excellence to complete drawings to reflect their experience of the project. I then asked PAR Excellence to use post-it notes to decorate a

tree to identify the roots of the project, what had nurtured the project, and what had threatened or hindered the project. The focus groups were recorded and transcribed by a transcribing company.

It must be highlighted here that data collection occurred over the long period of three years. Clearly, many other significant things occurred to PAR Excellence members in that time. Some got jobs, including in mental health services. People's mental health conditions fluctuated, and most team members came in and out of mental health services as service users in the merry-go-round of discharge and re-admission. They were recipients of a range of different types of mental health service from psychological services to stays on wards. Another factor that influenced the team's thinking was that most members were also engaged in broader involvement activities and volunteering roles within the mental health trust where the project was being conducted, so their experiences in these roles affected their understandings of the issues explored.

Every PAR Excellence member had profound life changes for better or worse during the lifespan of the project, including job loss, parental illness and divorce, but also marriage, travel and exciting personal development opportunities such as education and paid and voluntary work. Some team members experienced serious financial difficulties, including at the hands of the welfare system. These significant life events obviously had an impact on PAR Excellence's beliefs and experience of mental health services outside of the project and society overall, which naturally influenced individual's insights and beliefs about the system. It is at times impossible to untangle the source of some of the teams' thoughts gained from other avenues from the discussion specifically about the project.

5.2.2 Data Analysis

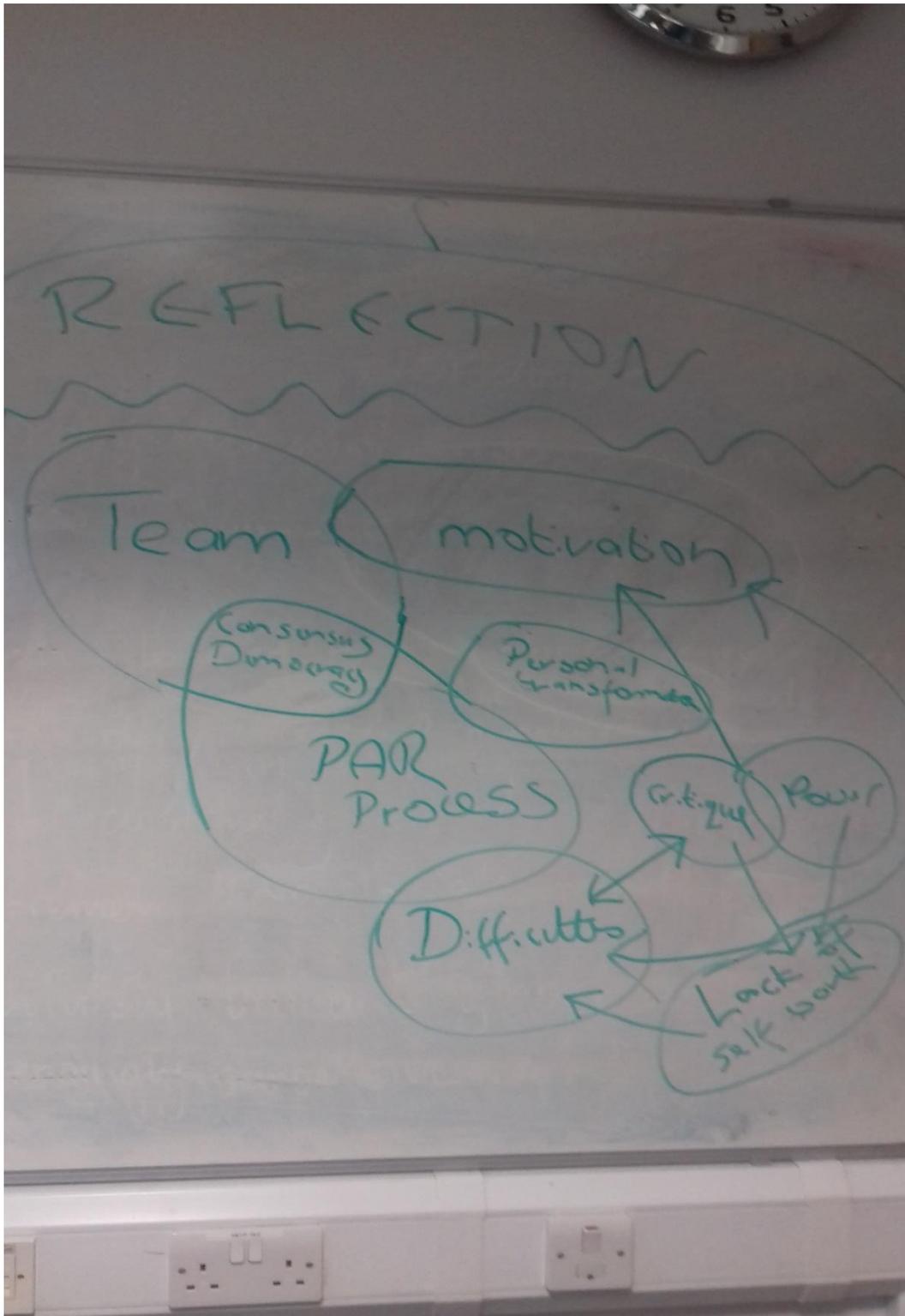
At the stage when PAR Excellence approached the data analysis of their own focus groups, we had all learnt much from trying to analyse the data from staff in relation to shared decision making, and the team's shared decision making resource.

The team agreed that the two members with the most interest in coding and theme identification should complete the task with me on behalf of the team. This was completed over a series of six half day workshops. The further identification of sub-themes within themes was done myself without input from PAR Excellence members. This was purely a logistical issue due to the time constraints of the project, and the availability of PAR Excellence members. The themes and sub-themes were then presented back to the team, who agreed with the findings. Some of the workings of the data analysis sub-team can be seen in Pictures 15 and 16.

Picture 15: Identifying Themes and Sub-Themes



Picture 16: Establishing Relationships Between Themes



5.3 Participation Findings

Eight themes were found: power, critique, motivation (the burning flame of anger, and the burning flame of hope), 'Hubble, Bubble, Toil and Trouble', PAR process (the magical mystery tour of PAR Village), enablers and disablers, team, (messing about on the way to Hope Street), and transformation. Each theme has a number of sub-themes, which are summarised in turn and illustrated with quotes from PAR Excellence members and from our reflexive accounts. The pictures drawn by us all during the focus groups are also presented. However, in practice the themes developed simultaneously and informed, interacted and overlapped with each other to form a complex picture. Some of the quotes are mine, from my input into the focus groups. and are attributed as 'me'. Insights from mine and team member's reflexive accounts are marked as such. Elements for my reflexive account are in italics. Quotes from team members are attributed as "P1", and so forth. Throughout the findings, I refer synonymously to PAR Excellence as such, as team members, and as the team. I do not include myself here as a team member: I am specifically referring to the group of people who I recruited to take part in the project. Whilst PAR is concerned with blurring the lines between researcher and researched, it emerged early on that I was set apart somewhat from the others as lead researcher, with overall accountability and responsibilities that went far beyond those of the others.

The first group of three themes relate to the context which PAR Excellence located themselves within and the grounding of the project.

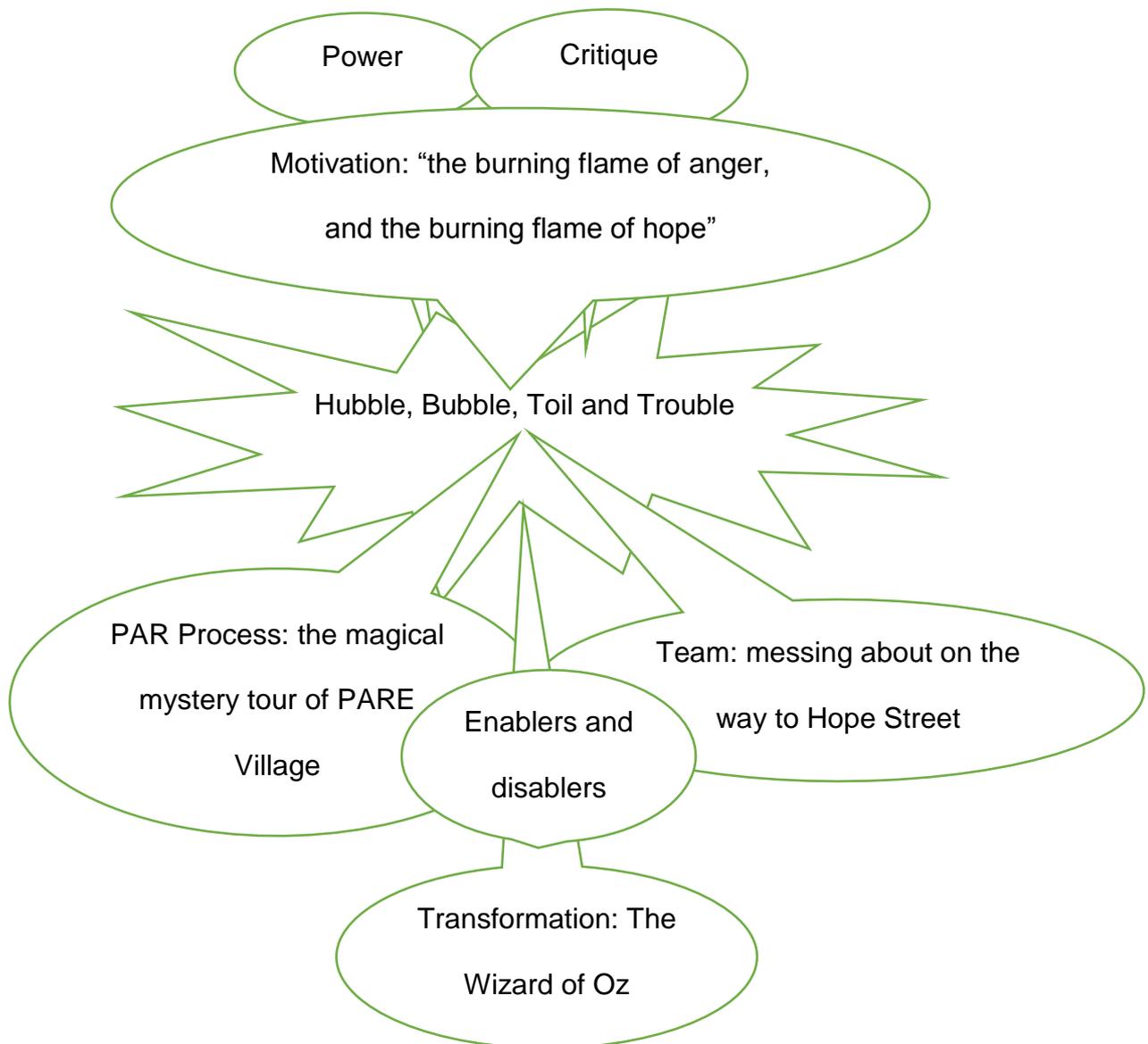
The central theme of 'Hubble Bubble Toil and Trouble' delves into the spirit of PAR Excellence's response to the issues they identified in the first three themes, and became the heart of the project by providing a concept to the

team's endeavours. It is the lynchpin between the group of themes before it, and the following themes.

The final group of four themes relate to how the PAR process unfolded, and what happened as a result of the project.

The relationships and overlaps between themes are shown in Diagram 2.

Diagram 2: Participation Themes



Each theme has a number of sub themes. In the theme of power, there are four sub-themes of: power within PAR Excellence, power of mental health services, power of research, and power of PAR Excellence.

In the theme of critique, there are two sub-themes of critique of mental health services, and critique of research.

The theme of motivation has four sub-themes: hope, personal development, facilitator support, and threats to motivation.

Hubble Bubble, Toil and Trouble has two sub-themes of dark arts and disruption.

The theme of PAR process contains two sub-themes of uncertainty, and choosing a research topic.

Enablers and disablers has five sub-themes of research education, role of the facilitator, role of the university, practicalities, and difficulties.

The theme of team contains the two themes of relationships and trust, and peer support.

The final theme of transformation contains the two sub-themes of impact on mental health services and personal transformation.

5.3.1 Power

There are four sub-themes within this main theme: power within PAR Excellence, power and NHS services, power and research, and the power of PAR Excellence. It should be emphasised that the issues discussed here are strongly related to the critique discussed further, and resonate with the motivations of PAR Excellence. A commonality across these the themes of power, critique, motivation and Hubble, Bubble, Toil and Trouble is that of “us

and them”, and of being on different sides. The first sub-theme is concerned with power relations within the PAR Excellence team itself.

5.3.2 Power within the PAR Excellence Team

It was essential throughout the project to keep a consistent check on where the power in the team lay, because of the reflexive nature of PAR. Comparing PAR Excellence’s understanding with my own showed some discrepancies. For the main part, PAR Excellence did not perceive that I held the most power in the group. However, it was acknowledged that I had some, because I had more research knowledge than team members. This was not something that was uncomfortable for PAR Excellence: it was believed that sometimes, someone will have to have more power, but that this isn’t necessarily a bad thing. There was also a sense that how power is used is more significant. For example, one team member said:

“I guess I'm aware of being taught, which I think has to happen, but I think Katherine does have power in that. I don't feel uncomfortable in that, no. We can afford people power at times”.

(P1)

There was also a belief that, although I had power through knowledge, I didn’t misuse it:

“Katherine when we started (*had the knowledge in the group*), because she knew what her vision was for the group, where it was going, and how it was going to go in her eyes. So when we first came along, we were blind, and having to be taught, but if she was somebody different, she could have had controlling power through that knowledge”.

(P2)

Furthermore, although there were power differentials between the team and me because of our different knowledge levels, the trust between the team and me prevented it being an issue:

“I think it is about trust. I think there is the inequality there, though, because I think it's more knowledge than power actually. But knowledge and power are interlinked”.

(P2)

The team were more concerned with the power held over the group from beyond the project, as if the project was in a microbubble, but at risk of being bumped and bounced by external forces. What would happen to power once PAR Excellence started working with NHS staff was a particular worry:

“I don't think there's any power relations in this group. I suppose I'll worry about it when we actually take whatever we focus on out into the professionals, you know, how they're going sort of view it”.

(P2)

Further concerns were also expressed regarding broader power holders – the university, government, and how PAR Excellence's research might have an impact, as reflected in a conversation between three team members:

“We have different bodies, don't we? We have the university themselves, and we've had people come in talking to us and given assurances”.

(P2)

“The government have power over this group as well, but they're not here”.

(P1)

“Because beyond us doing our best, and putting the case forward and doing whatever we're doing with the outcome, the end result piece of work beyond that is not in our control anyway”.

(P4)

The following conversation between four team members showed some consensus within the team that they didn't think I held power at all over the team at all, and in fact, went above and beyond in my efforts to not be the power holder:

“Oh, I don't feel there's any power imbalance”.

(P3)

“You don't seem to hold a sort of power over us or anything”.

(P4)

“Yeah, I think you go out your way to reassure us that you're not...I'm happy that you don't”.

(P1)

“I think you give up a lot of power that you didn't need to give up necessarily”.

(P2)

According to my reflexive account, PAR Excellence's experiences were heavily at odds with my own in terms of my own power. I was very conscious of the power I held; through my position, knowledge and the fact that I was, and remained, the driving force for the project. This was evident in the way that I could effectively veto ideas put forward by PAR Excellence members. Without exception, I was the one with the pen, and despite my best efforts to ensure that

all decisions were made by the team to remain true to PAR's fundamental values, sometimes I had to sway the team into a particular course of action. I also had to arbitrate when there were differences of opinion between team members, which gave me power ultimately. Although PAR Excellence were adamant throughout the project that I didn't control the team through the power I held, my power through my position and knowledge was alluded to as bringing a little discomfort, and having the potential to be a problem.

PAR Excellence are correct in that I held some degree of power because of my research knowledge, even if they appreciated that guidance was required for the effectiveness of the project. I needed to ensure that sound methodological, design and method decisions were made so that the research project was robust and ethical. It would not have been beneficial to the team to agree to poor research decisions, as this would have weakened their research. Because I had a responsibility to ensure that the project was robust, I also had to hold some power.

Whilst there were generally few contentious issues regarding research design decisions, there was a lot of debate whilst doing the literature review: some members felt particularly strongly regarding the exclusion of some papers, whereas I would have included them. These conundrums highlighted a real tension for me, as I did not want to exert my power through knowledge by arguing with the team – even if I managed I change their minds. This meant that some papers were left out that I would have included, which was a real compromise for me as I believe it weakened the literature review somewhat.

5.3.4 Power and Mental Health Services

Understandably, much consideration of power by PAR Excellence concerned mental health services. The team did not speak highly of services in general, and this connects strongly to the next theme of critique.

It was perceived that the negative attitudes displayed by staff that some people had experienced was a way of exercising power over them. PAR Excellence felt that staff could be dismissive and contemptuous of service users, and stigmatise them. People had felt devalued by staff at times:

“Those people will never be convinced that the service user has anything genuine to offer except to do what they’re told... Don’t cause them any hassle, basically. And therefore, the notion of organised service user representation and involvement in things, is abhorrent to some people”.

(P2)

These feelings of not being valued led to a mistrust of staff’s motivations:

“When we started, I was very cynical of staff. I knew they were good staff but in my head, most staff were not good. I don’t mean they’re awful but they were either there purely for the job, for the income, or they were actually there because...they’ve got power over these, nutters...”.

(P2)

The result of the power imbalance that PAR Excellence perceived led to general feelings of fear, self-stigma, lack of confidence, poor self-esteem, marginalisation and mistrust. Members felt they couldn’t be honest with staff, for fear of an outcome they didn’t want, such as hospitalisation. However well

founded or not these fears are, there can be no doubt that they affect the quality of service that some people receive because the interactions they have with staff are not based on trust and honesty:

“My experience early on, is that there was a fear factor that they knew I had. And although they never actually threatened to do it, they knew that I was sitting there, thinking, I have to get through this 20 minutes because if I don’t do it properly, I could get banged up. That was my fear. So I’d just sit there and then I’d get there and I’d think ‘thank god for that’ and I’d instantly forget everything that they’d said”.

(P5)

PAR Excellence members perceived a number of ways in which mental health services, and psychiatry in particular, gained and maintained power. They saw services as being interested in maintaining the status quo, and hadn’t experienced any endeavours by services to share power with service users that felt to be meaningful or trustworthy. They felt that some of the power held was embedded in the lengthy training that professionals had received, such as medical school, that meant that professionals would be loathe to give up any power. In fact, there was a feeling that, the more that power was challenged – even just in usual interactions with professionals - the more they would try to hold on to power:

“You can just imagine them saying: it’s all well and good but, you know, we don’t sort of want to get carried away...And it’s almost like you see psychiatrists clinging further and further on to: “I know the meds, I know what they do, so I’ll be the one to tell you”.

(P5)

This perceived antipathy to informed and empowered individuals is important, as it flies in the face of co-production rhetoric as well as impairing the relationship between service users and workers:

“I do actually remember (*former member*) saying that when she went to see a psychiatrist, that they didn't like it when she knew things”.

(P2)

Alongside these notions of mental health professionals clinging to power was a sense of psychiatry being a mystery invested in during training:

“This dark art which I get the impression is quite heavily protected by people who spend seven years at medical school...Well, I mean, years ago, you didn't have psychiatrists, I mean, all right you'd have a guy... like witch doctors and stuff...you had the exorcist. You know, you're not mentally stable; you're possessed by the devil. That's where it all starts isn't it? And its potions and ointments”.

(P5)

The following exchange shows quite how much power the team believed psychiatry to wield:

“Psychiatry is one thing, but it's the whole system in which the psychiatrist is embodied and the way it works”.

(P1)

“Well, they've created it. So psychiatrists down the years have created the system”.

(P2)

It's the politicians that run it though, effectively. I think they are heavily influenced by the psychiatrists”.

(P1)

The power associated with language was also seen as contributing to the status quo. PAR Excellence found the language used by professionals and services to be similar to a foreign language, with questionable uses:

“Psychiatry is very similar to how the Roman church used to be, in that everything was said and performed in Latin, so nobody knew what was being said”.

(P2)

As well as upholding the power of professionals in individual relationships with service users, the way language is used in mental health services caused anger and frustration. In particular it was seen as a way of preventing service users from becoming meaningfully involved in services. This too connected with notions of the dark art of mental health services:

“It's just ridiculous that's we've got so many things abbreviated down to three letters. It's no wonder nobody can understand the documents. Nothing is written in plain English. I was reading something and thinking what kind of idiot wrote this. It doesn't even read properly. I know that's me, but I come from a clear communication background and copywriting means that 99% of people who can read, can read it. There is no point in writing public documents that only 10% of the population can possibly understand. It's like a black art, isn't it?”.

(P6)

Some PAR Excellence members had experienced stigma and prejudice from mental health staff in relation to their participation in the project, or thought that staff would hold prejudiced, negative beliefs about them:

“I find people are quite shocked when they realised we're doing research. You know, even my OT and my support worker. They seem to assume that I am being researched, that I'm the subject and I think that people can't get their head round around that we are actually helping carry out the research”.

(P4)

This perception stemmed from the view that staff thought of service users as being intellectually inferior:

“There's a nurse who dealt with dementia before she retired with ill health. A very senior nurse who ended up in hospital met a member of staff who came up to her and said you don't want to be in here with them lot. You're too bright, too intelligent. And, you know, this is a nurse classifying mental health as behaviour and stupidity. And she really had a go at her about being in here. And another person I know is very intelligent, very high up in her particular job and she's had almost the same thing said to her”.

(P2)

There was also a notion that different professions might respond differently to the work that PAR Excellence were doing, with some more likely to be more positive:

“Something that strikes me is that I don’t think there’ll be much in the way of resistance to what we’re going to be doing from CPNs and STaR workers and people like that”.

(P5)

5.3.5 Power and Research

Just as there was an ‘us and them’ feeling towards mental health services, there was the same feeling somewhat towards the academic community from the team. A PAR Excellence member felt excluded from academia by a lack of status and opportunity, as well as some mystery:

“it’s hard for me to imagine after doing that course today and all the rest of it, what else they know, what these super humans know. I thought a researcher is a researcher. But that isn’t the case and I don’t know whether some of it is reputation, so you have the big grand professor types. And so then I think, well what do they know that I haven’t learned here? And it must be something”.

“When I look at say for instance these two research jobs going where I work at the moment, it sounds like and in writing it seems like the calibre of person that they’re looking for is a billion miles away”.

(P7)

There was also a perception that academics have their own language that is used to exclude people, when actually the activities that PAR Excellence were carrying out could be described using academic language, but that they had a different vocabulary around it:

“I think sometimes they create words that mean something to them and not to us”.

(P1)

“Because sometimes we do things and we forget that it's got a name on it. A sentence”.

(P7)

However, academia was also an arena where PAR Excellence could feel empowered by attending conferences. But, alongside feelings of acceptance, there remained some suspicions and further experiences of feeling dismissed by some members of the academic community:

“I had that experience of being in a lecture with people who weren't – it seems – aware of us, of any group like us, who had this idea that they were the knowledge and their knowledge surpassed service users into the point of one saying, for example, that the research that she had done counteracts what I was saying: that research shows service user participation with other service users is a good thing. She was saying it's a bad thing because she had performed research on people in her profession. But it was from her and from at least one other person in the room, there were some very negative vibes coming about service users”.

(P2)

Even though PAR Excellence had felt welcomed as equals by some academics they had encountered, they thought that they might be welcomed by other academics in a patronising way, or be seen as lesser somehow. On one hand, PAR Excellence's encounters with the academic supervisors of the project were extremely validating and motivating, and therefore highly valued. Likewise, the

interest shown by some individuals that team members met at conferences validated their knowledge and work. In contrast, some encounters left PAR Excellence members with some doubt. Some members thought that any admiration that they might receive for their work would be reserved for me as the facilitator, who had “managed to “get them” to do something. When considering being invited to do a big keynote lecture as an example, whilst there was not a consensus, there were some strong feelings about how they might be received:

“I think we would be seen as inferior...unless we presented it in the way that they wanted us to.... I think the perception is based on status. I fear that we -- and no matter how we carry ourselves and everything else we'd be a Shirley Temple sort of thing. Like, aww. Because basically the whole world it seems to me is based on status and cache and credentials. We could do something amazing and it is recognised by somebody and it ends up, you know, up there in whatever, and we have to go up there and present it - I think it would be seen as a fluke”.

(P7)

Furthermore, attempts from within the Trust the team was working with to involve the team in the Trusts’ research strategy was not successful:

“I got the impression from most people down there (*research event*) that we just didn't exist - we were irrelevant”.

(P7)

5.3.6 Power of PAR Excellence

Whilst a somewhat bleak picture emerged of how PAR Excellence viewed their position as powerless in relation to mental health services and the research community, there was hope that the project would be a mechanism for addressing these power imbalances. These hopes were rooted in a belief that service users do hold power through the knowledge they gain through their experience. There was a clear understanding of the impact the team's knowledge would have on the project itself:

“But when it comes to knowledge, we do have the knowledge through our own experience within mental health, with which we can bring...which will influence the direction we go with the actual research”.
(P1)

Furthermore, despite the powerlessness felt by the team in the face of health and academic institutions, they also considered their insights to give them an advantage in the execution of the project:

“It's a strength, because if we didn't have that knowledge and experience, and we worked in some sort of corporate body, then we're going from a perspective that is skewed”.
(P6)

The team also recognised that this gave them an element of power over me through their knowledge:

“Because we have that experience, don't we, that Katherine doesn't have”.
(P1)

The team also had a real sense of the value and “rightfulness” of their knowledge:

“I don't think there is a right or wrong because whatever your experience is, is right, no one can dispute that with you”.

(P3)

The team also believed that the profundity of their insight brought weight to their argument:

“We can actually bring a different viewpoint or dimension to it, because we have looked into it more deeply, as service users that we can give -- if somebody's got a half decent argument, we have”.

(P1)

In summary: PAR Excellence felt comprehensively powerless in the face of mental health services and sometimes in the academic community. However, the project clearly supported the team to identify their sources of power in their own knowledge. It also emerged that sometimes the team felt ok with power such as that held by myself, as they trusted me to use it judiciously, and were cognisant of my efforts not to hold all the power. Furthermore, although some team members had experienced some bruising encounters within the academic community, the community had also provided the team with opportunities to share their knowledge in the interest they garnered speaking at the Network for Psychiatric Nursing Research conference. This conference also enabled the team to meet another service user research group (SUGAR). PAR Excellence found these encounters highly motivating, empowering and validating.

This theme has also shown how critical the team felt towards health services and research. This is explored more explicitly in the next theme.

5.3.6 Critique

Having explored their own position in relation to mental health services and the academic community, it was natural that this would lead to PAR Excellence to offering a critique of both. There was an understanding that an element of critique was an integral part of PAR:

“I think you have to be critical when you do this stuff because if you go in saying it's all fine, what's the point in that”.

(P1)

There are two sub-themes within this theme of critique: critique of mental health services, and critique of research. All the conversations related to this theme indicated a deep sense of “us and them”, with psychiatrists in particular being seen as “aliens”. Even when there were discussion on good aspects of care, it was evident that staff were still “the other”.

In general, PAR Excellence felt demeaned in their roles as service users. But also, some of the views expressed came from the perspective of service users who had taken up paid roles in mental health services. Whilst changes in identity are discussed later in the transformation theme, this perspective proved to be crucial in some of the findings. Interestingly, whilst the experience of being a staff member and as also an ‘insider’ was mixed, provoking different coping strategies, in some instances it led to a deeper sense of critique, rooted in disillusionment and despair at seeing how services operate and how staff behave behind the scenes.

5.3.7 Critique of Mental Health Services

PAR Excellence's critique of mental health services centred on psychiatry. It was profound, deep-seated, and based on both personal experiences as service users, though their involvement in other participation activities, as staff members, and a broader understanding of psychiatry as the dominant model in mental health. It may seem unfair that psychiatry is singled out from the other professional groups, and possibly surprising, since they are the professionals who spend the least amount of time with service users. However, this reflects the level of dominance and importance PAR Excellence placed upon psychiatry in terms of the whole system, as well as the significant impact psychiatrists had on service users, despite minimal contact. There were concerns and suspicions that psychiatry, rather than helping people, could actually make things worse, or at best, was irrelevant. The following conversation shows quite how much psychiatry is mistrusted:

"I think for a lot of people psychiatry does more harm than good".

(P1)

"I think that bad psychiatry, mental health services, can harm people, probably even kill people".

(P4)

"I think it wouldn't make a great deal of difference if there was no psychiatrists. I don't think we need them".

(P3)

"I think psychiatrists aren't to be trusted at the best of times really....just dole out some pills, they will always be taking pills. That is the attitude really".

(P6)

This suspicion and mistrust was rooted for some in a clear sense of psychiatrists as being unworldly and “other”, both inhuman and unhuman:

“I think these psychiatrists would actually eat each other”.

“I thought they are a bit like aliens really”.

(P4)

There was also acknowledgement that psychiatrists were a product of their training, but there was a belief that the more training someone had and senior they were, the more remote they were, which chimed again with the sense of “other”:

“I think the blinkers are on the more clinically trained and literally the more senior the person, I think the heavier the blinkers because they’re further away from...”

(P2)

“Humanity?”

(P4)

Furthermore, there was a belief that psychiatrists operated in a prejudiced way, which impacted on their clinical decision making:

“I’ve experienced psychiatrists who quite clearly, were approaching things from prejudice. Simple prejudice. Making diagnoses on me based on their attitude of how somebody with that particular diagnosis would present. But when you present a certain way for one reason, and they don’t see that reason, they allocate that reason to something else”.

(P2)

There was a sense that psychiatrists were very limited in their understanding of non-medical models of mental health and incompetent regarding psychosocial research, despite being well remunerated. This was a revelation to one team member:

“I went to a research thing recently and again there were psychiatrists presenting about things that were psychosocial. They just don’t have a clue and they get paid tons for this. They just can't do that area of research, they don't get it. It really struck me that day. They don't understand it and that they were saying really basic things and they were presenting them as if there were new”.

(P1)

However, there was recognition that psychiatrists themselves operate within a system with certain expectations, and play a particular role that places limitations on how they operate and their effectiveness when it comes to building relationships:

“They are trapped. They’re trapped within their own little system...in their own workplace”.

(P6)

Despite the deep critique of psychiatry by PAR Excellence, there was some recognition that it can go well. There had not been consensus that some psychiatrists could be good, so deep seated was the mistrust and dislike of psychiatrists in some team members. However, some PAR Excellence members reported good experiences with some individual psychiatrists, and I

argued during data analysis workshops that it would be disingenuous not to make reference to those.

Good experiences were cited when a psychiatrist demonstrated a more holistic, psychological approach. However, even when psychiatric practice was being commended, it was offset by the flipside of the good experience:

“He actually did his questioning like a psychologist. Look at all the things in your life and then when it came to prescribing something new or whatever said well the side effects of this is that you can't really drink on it, you can use this on it...this might make you drowsy or it does have this side effect but it is probably better. And it was very much an inclusive thing - just the emphasis on understanding of the other things going on in your life. And he would talk about exercise, he would talk about things like that that would more like a psychologist would do. To say, modify your life to make it better rather than just carry on taking these pills and you'll be right. Rather than: are you still feeling a bit shit? Well, let's just up it a bit more so you're like a zombie. And then hopefully you won't come back to me again. Because you do get that”.

(P1)

There were recollections of when psychiatrists had in fact been the most compassionate professional encountered, and agreement that they are not all bad, as evidenced by the following exchange between team members:

“I always remember one psychiatrist I got in hospital...he's the only person I spoke to the whole time there of the staff that I felt that was

compassionate because he just listened. And I was like someone is actually listening to me...that set him aside from the nurses”.

(P1)

“It is true. A psychiatrist that I worked for did that as well. You never know until you've been under them, I think. Stuff like that can be particularly good at times. I know one psychiatrist that I think she's very good for a psychiatrist”.

(P2)

Recognition that some psychiatrists understand service user involvement, and really do get behind the cause was clear:

“I've been involved in restructuring within the Trust and there is a psychiatrist there who is passionate about getting service user involvement and also about the need for people to be more focused on the actual need of the patient as opposed to the need of the system”.

(P2)

PAR Excellence's critique of mental health services also went beyond psychiatry, into culture, systems, and the broader staff population. There was a sense again of “us and them”, with service users and staff being on opposite sides. Here is an example of PAR Excellence feeling criticised, when they felt that staff should be open to criticism:

“The very people who accuse you of being institutionalised...I find that bizarre because they are the ones in the institution. How can they accuse you of being institutionalised when -- that's just weird”.

(P4)

A key feature of PAR Excellence's critique of mental health services was how they were treated and thought of by staff. They believed that some staff did not have a good perception of service users:

“All the stuff that they say about service users, all the misconceptions and they're way off mark with loads of it”.

(P7)

Team members believed that these negative attitudes were also apparent in staff's understanding of service user involvement:

“The notion of organised service user representation and involvement in things...can be abhorrent to some people. Now, what the bloody hell was that all about? Professional service users, that's what they're called in their vocab. What they say is that they are people who don't like the fact they've been ill, began by not really listening to people who are telling them how to get better”.

(P6)

There was a perception that support for shared decision making was not consistent, and that service users are actually disliked:

“There are two camps basically. Both camps know that there is “no decision about me without me”. One camp doesn't like that because they

don't like service users, to be honest. They don't go into the beginning of a relationship thinking, "I actually quite like this person potentially". They don't do that. Now, they say it's because they have to keep a boundary and a clinical difference and all that sort of stuff, but they don't like them and I've heard them sitting about in the office saying they're just a waste of space".

(P7)

There was also a view that there are differences in approach to service user involvement in teams:

"I think there is a culture within community mental health teams where it's a bit more backward to be honest".

(P1)

Additionally, there was a sense of perspective around the economic climate, and what this might mean for service user involvement, although there was also some suspicion that this was used as a smokescreen by people who weren't interested in involvement:

"I'd heard from someone that (*senior medical professional*) absolutely does not support service user involvement and then it has to go out the window and all the budget cuts. And obviously, he did turn down any notions of peer support development or stuff like that, didn't he? So the organisational change affected what I thought could be changed from this process".

(P7)

It was reported that some mental health staff had erroneous beliefs about mental health, and this created a type of battle:

“I can take you to one particular deputy manager of a crisis team who genuinely believes that there’s no such thing as mental illness. So he’s very removed as far as I’m concerned. So these are the people we have to work against”.

(P2)

There was a sense of being in a system where people didn’t matter, and that throughput was the biggest concern. This stemmed from experience both as a service user and as a mental health staff member:

“And just the fact that everything is targets and you’re just a number...as a service user I feel, and it’s all about prevalence targets and sheep dipping”.

“So I really struggled processing people. I couldn’t...there was just no way that I could challenge, on a daily basis, staff’s opinion on service users because I would have been...I would have isolated myself”.

(P7)

Another perception by the team was that good staff would not stay, because of the system they work in. Therefore, staff left behind were of poorer calibre:

“Good staff will go around so many times, lose interest, and they will just go, and then who’re you going to be left with. You know, you’ve got no improvement and people who were totally demoralised, and that includes service users, and how can they work together in that situation”.

(P2)

There was a palpable sense of hopelessness about some staff, coupled with a belief that staff weren't even genuine when they are showing empathy anyway:

"I mean there's the ones that have given up, you know. The ones that say I'm just counting down to my pension, you can tell with them that they find it harder to put across that false empathy".

(P7)

However, mental health services were considered good when a psychological or holistic approach was used:

"The CAT (*cognitive analytical therapy*) therapist...they understand it differently. They don't think: who's this guy? He's knackered, he's lost the plot. They don't because they want you to leave your label at the door. Right, let's look at how certain things can affect your life. Let's look at ways that we can give you some ammunition or an exit from that way of thinking, so you don't go into any further problems. They just see you as a person that can be fixed that's had some difficulties and can be fixed much like a broken leg can be fixed. You know, so it's very much a different viewpoint".

(P6)

A perception that there would be support for service users involved in research from some mental health teams and professional groups was evident. Psychologists in particular were seen positively as being open and progressive. It was perceived that service user involvement in research would be welcomed by some professionals, as shown in the following exchange:

“But the professionals I work with (*early intervention team*), I don't think it would be a big surprise to be honest”.

(P1)

“I think some of the psychologists would applaud it”.

(P7)

5.3.8 Critique of Research

The critique that PAR Excellence maintained towards research stemmed from their general perceptions, and their experiences at the conferences they attended. A further significant event was the team's attendance at a local NHS research development workshop, where they interacted with professional researchers and mental health workers involved or interested in research

There was a perception that people were mostly interested in large-scale, well-funded “traditional” research approaches such as randomised control trials and medical research. As evidenced in the following conversation, there was a belief that people were driven by personal ambition, career and status, rather than a true interest in the experience of service users which was not really valued or of interest:

“The problem is that there they are seeing things from the perspective of: ‘I get a partnership with GlaxoSmithKline... and then I get access through the ethics board at (*NHS Trust*) and really all service users are subjects in a double blind or whatever’. They never need to talk to us about our experience or anything”.

(P7)

“They don't even know not to think that way”.

(P2)

“They are not interested because they are all about chemicals and hormones and are you going to get diabetes from the tablets because you have put weight on”.

(P7)

There was a general feeling that they would not be wholly accepted into the research community as equals when presenting their own research, and that it is an elitist field:

“I think we would be seen as inferior. Unless we presented or were particularly flash or presented it in the way that they wanted us to...I think their perception is based on status”.

(P7)

This feeling led on to a view that it would not be possible to start a research career because PAR was such a different approach to research. Therefore, the experience that team members were gaining would not be seen equally with that of more traditional researchers:

“I've applied for a couple of research jobs because of this but have realised that we're right at the beginning of what it sounds like compared to what your co-researchers, people are doing research, people in universities and the type of people that are going for research jobs. They're miles away from this which I don't know if it's just wording or whether it's perception or whether it's reality. What we are doing is separate from the mainstream. There is a professional distance from

what they are researching, rather than seeing what you experience as an asset”.

(P7)

Aside from PAR Excellence’s position in relation to traditional research, there was a general sense of frustration with research considered poor by the team. However, the team gained some confidence by being able to critique other research projects being conducted by traditional researchers. The following quote is in relation to some research presented that contained basic numerical errors:

“What frustrated me...I assumed initially that their research must have been peer reviewed for them to be able to stand there and talk about it. And by peer reviewed I mean reviewed by peers and considered good work. And that blew my mind. But it was obviously poor. And some of it was blatantly wrong, My guess is they'll have gone away and just manipulated the figures. But I pointed out to them, I said ‘because I know you're going to be presenting this again’”.

(P2)

There was also a firm grasp by PAR Excellence of how research can be inherently biased in the way that it is conducted, and through the issues it seeks to explore. A particularly pertinent example of this was around some research presented at a conference regarding violence on mental health wards that was based purely on nursing notes:

“So, for example, they might look at violence in a psychiatric ward and they had figures for different places where there was violence reported.

And always, always that violence was the fault of the service user. But we know that there are incidents that get reported where staff will say that wasn't acceptable, that was your fault, you caused that to happen or even a member of staff may lay into a patient. I mean that would be rare but it will happen and yet somehow, there were no figures for this, it was all patients are violent to staff and staff are always victims”.

(P2)

There was also a perception that challenge from a service user was not welcome, and that as a service user, you were treated differently – echoing the “us and them” feel of mental health services:

“I don't like saying that but I mean part of that was frankly going down to Warwick and listening to a load of the rubbish that gets through and there's some good stuff, don't get me wrong, really good stuff there. I also knew that there were some people who -- I would talk to one or two people outside of lectures and what have you and when they knew I was a service user, you could see the body language change and these are researchers and I even had a bit of a head-to-head with somebody in one of these lectures where I disagreed with what they were saying. I got no support from anybody within the room. It was all those that did speak were negative, in support of staff against service users”.

(P2)

However, it was later revealed that during this dialogue that the researcher had not known that the PAR Excellence member challenging her was a service

user. Consequently, there may be some self-stigma and prejudice occurring within the team. That is not to detract from the issues raised so far:

“This woman had basically said that service users will respond better to questions asked by staff than they will to questions asked of them by other service users. and when I challenged it, well, three people spoke, one of which was just talking about his experience of service users and that was before he knew I was one. And he was guardedly negative towards service users with his experience as a nurse. I then spoke and said what I said about that is not my experience. My experience is -- and I believe research says, I believe research backs me up, and somebody then turned around and said, "Oh no, you're wrong." And she said, "and, I know you're wrong," but then she backed it up with this, "Because I've done a piece of research that shows it." And she was the woman who said service users prefer to talk to staff". Somebody else spoke as well who had given an earlier lecture and they were sort of putting me down a bit and I thought all I'm going to do is end up in an argument and there will be a negative view towards service users”.

(P2)

Thus far, a collection of frustrations borne from an examination of PAR Excellence’s position as service users has been presented. There were some glimmers of hope, and involvement in the project had led to some enriching moments, particularly in attending conferences. However, the team’s views of both mental health services and the academic community were generally very dim, and members had experienced upsetting and disempowering encounters

in both arenas. The next theme explores how the overall picture of dissatisfaction and disillusionment fuelled participation in the project.

5.3.9 Motivation: The burning Flame of Anger, and the Burning Flame of Hope

This theme builds on the previous explorations of power and critique to provide an in-depth understanding of the motivations of PAR Excellence. There are four sub-themes within this theme: hope, personal development, facilitator support, and threats to motivation.

Whilst a fairly despondent picture of people's experiences and perceptions of mental health services has emerged so far, they provided the fuel for the fire in the belly of PAR Excellence. It was clear throughout that concerns with power imbalances and the critique of services in particular were a driving factor when team members decided to join the project, and remain involved:

"I think that was an influence on me to come here...the negative aspect of my experience, to get involved with this group to try and create some form of positive change".

(P3)

As the project progressed, the activities undertaken ensured that motivation levels continued:

"And then that whole journey through services (*mapping activity*) bit just re-galvanised for me why I wanted to get involved with it in the beginning".

(P6)

The motivation for people to become involved in the project and stay with it (for the most part: one member did leave the project in the initial months) was a mix of retribution for the perceived wrongs of the previous themes, altruism to make things better for others, and gaining something through personal development. There was also an element of wanting to support me personally as the facilitator.

5.3.10 Hope

The criticism and anger directed at mental health services explored in the previous theme co-existed with a strong sense of hope to make a difference to mental health services in two ways: though bringing about positive change, and through ambitions to produce a piece of high quality research. The quest for positive change within PAR Excellence was a continuous driving factor, and shared across the entire team:

“I think for me a benefit is actually feeling that what I'm doing is hopefully going to be worthwhile and I am actually doing something with my time that I hope is going to be a benefit to others”.

(P6)

There was also motivation around intrinsic notions of the right to be heard and involved as service users, and it was hoped that the project would change people’s attitudes broadly about service user involvement:

“People need to know and understand that our voice is a vital voice and our involvement therefore is vital. If we don't get involved, then that's not going to be heard; that's not going to be understood”.

(P2)

Coupled with the sense of hope, was a very strong sense of ambition. PAR Excellence were wholly committed to producing something of merit in its own terms, with the understanding that to be impactful and bring about the positive change the team sought, their research needed to be high quality, as demonstrated in the following exchange:

“I thought we were going to come up with some form of research that, not in an unpleasant way, would hit people on the head and say, “Look, come on, wake up”.

(P2)

“The motivation for me is feeling that at the end of this there may be a piece of work that is very high up and causes an effect that has to come down”.

(P2)

“And the quest for me is to come up with a body of work that is going to challenge something. Why can't we do this? Why can't we do that? I think there is a lot there that needs to be challenged”.

(P1)

This ambition went beyond bringing about change in the local setting:

“A world class piece of work...of course it's going to be internationally recognised. Publish work to be recognised at every level of the, whatever National Health Service”.

(P6)

Interestingly, whilst there was always ambition within the team to produce something further reaching than the NHS Trust where the project was conducted, this seemed to strengthen as disillusionment with the Trust grew:

“We’re going to put a piece of work together that could have an effect whether that was within (*the Trust*). And I suppose I was always a bit sceptical anyway about that, but the fact that we are producing an academic piece of work that could be beyond that, and I think when with then getting accepted to speak at conferences then you think, well, actually there’s something in all of this and it’s being seen by people with a bit broader thought.”

(P6)

The project took place during a particularly turbulent time at the Trust, with budget cuts, major restructures, and service redesign. During this time, the profile of service user involvement was diluted and lost much of its profile due to a merger of several different NHS Trusts as a result of governmental reorganisation of the NHS. This transformation of community services (TCS) saw the Trust change from being a specialist mental health service provider to a provider of a large range of physical and wellbeing services. This change affected the focus of the team by expanding their vision rather than curtailing it:

“The organisational change affected what I thought could be changed from this process, but then if you look at it from a wider point of view, your write up and your work might affect change in other places, you know, in other areas.”

(P7)

There was also an element of motivation stemming from the choice the team made in terms of a research topic, and believing that it could have a positive impact:

“I think that it's because this shared decision making is a really good one for me because it's kind of the topic at the moment as well and I do really feel as though we can actually make some difference or contribute some difference or add some weight to somebody else's argument by what we do. Who that might be I don't know yet. But there's somebody that would be able to piggyback with this”.

(P7)

One team member found that being involved in the project had made her more aware of research and its pitfalls, and this in turn gave her the motivation to ensure that the project was high quality:

“It pops into my mind when I'm -- like I say when I'm asked questions like by my workers when they are filling things in, like using such a tool, to assess me. That's when it comes back right at the forefront for me. The housing association phoned me up about how work had been carried out and I wasn't giving honest answers because I wanted to get rid of them, as I was hungry. And then it pops in my mind that we're going to be doing this so we have got to give it our best”.

(P4)

A concern with how other service users might perceive the group and the project was raised, and there were worries that the group might be seen as

traitors. This led to the aspiration that the project might inspire other service users to get involved. This notion of “traitors” and “sides” is a further demonstration of the depth of the “us and them” picture described in earlier themes:

“I was thinking more how other service users will perceive us – whether they’ll sort of think, you know, we sort of sold out or something. Or will it inspire them and think, “Well, I can get involved in something like that.” It might be that they’ll trust us more; it might be that they’ll feel that we’re not professional, I don’t know. I mean, when I talk about what I do to friends and groups I’m in, they seem quite interested in this sort of thing, you know? I think they would like to be involved in that sort of progression, really”.

(P4)

5.3.11 Support for the Facilitator

There was strong support for myself from PAR Excellence to gain my qualification. It was illuminated that the personal relationships I had with team members before the project started and/or that developed during its course were a motivating factor. That PAR Excellence demonstrated a personal commitment to me illustrates the importance of relationships between the facilitator and the team. The experts by experience (EBE) group referred to is one that I established and ran alongside this project, and all members belonged to both at some stage during the project’s lifespan:

“There’s one thing though that I felt was a real positive motivator and that was personal experience of how you motivate people...it basically comes back down to your drive from EBE, from experience with EBE, seeing

your motivations and the genuineness of it. If it had been somebody else, I mean, we went and did that training with a professor...and as much as I liked it, I don't think she would have motivated me the same. It would have felt more of just an academic thing relative to how it is, because we knew you, because I knew you".

(P2)

The team's ambition for a successful project extended to an aspiration for my own, personal success:

"You haven't forgotten Katherine's getting best possible marks!".

(P7)

5.3.12 Personal Development

Understandably, members of PAR Excellence were also attracted to the project for personal development reasons. Some members saw the project as an opportunity to develop research skills because of their academic ambitions:

"I wanted to be involved in it to find out what it's all about and selfishly, I want to be named on the paper published and all that sort of stuff".

(P1)

There was also a view that it might be beneficial generally in terms of career development:

"The experience of doing it as well is quite interesting. It benefits you in a career perspective, I think because I work in mental health so I think it

benefits me for that. Maybe others felt that you don't have to work in mental health for it to benefit your career”.

(P1)

As disillusionment with the NHS Trust hosting the project grew and hope of a positive local change lessened, the personal development aspect and support for me to complete my qualification increased:

“Yeah, that was my motivation to affect change, but also selfishly but not selfishly to personally develop. And then the personal development has become the top of the tree because I’ve become cynical simply because funding, planning, change within the service and everything has made me veer off now to just maybe getting out of it what I can and helping you with your PhD rather than...and the affecting changes going down the pan or the drain”.

(P7)

As the project progressed and the team developed, there was recognition that the group provided personal development that was almost therapeutic in nature:

“I felt that yes you’re putting work and you’ve given up some evenings and all that kind of stuff, but I always felt when I drove away that there was something nourishing about doing it, you’d got something back from that. Whether it was the camaraderie or something that you’d learned, developing your own insight, whatever it maybe, you know, pushing the project forward, there was always some reason that you thought actually, yeah, you know, rocking up here on a foggy, rainy Tuesday evening or

whatever, but you go away thinking actually, you know, it's time well spent".

(P6)

5.3.13 Threats to Motivation

Whilst levels of motivation generally were high, there were some significant threats to motivation. The level of cynicism and scepticism that flowed from some of the issues raised seeped into the team workings, causing worries regarding the project's potential impact:

"It does concern me that we will make any real difference. I do worry that we can be seen like the elephant man or something, sort of a token sort of thing, that does worry me".

(P7)

The powerlessness felt in the face of external forces was also demotivating at times:

"A power, an external power, can actually cause apathy".

(P2)

Despite this, there was also a sense within the team that they had a job to do and needed to get on with it regardless, and this is what kept team members motivated despite the concerns regarding impact. As demonstrated in the following exchange, team members tried to encourage others to remain both optimistic and pragmatic:

"I think we've got to...maybe it's just what I think about things, but as we go along now, work under the thought that we're gonna give it the best shot we can give it".

(P7)

"Exactly, and not worry about power".

(P1)

"And the power influence, you can't do anything about that, so try not to worry about it".

(P7)

According to my reflexive account, the teams' motivation overwhelmingly became my main motivation as the project progressed. Whilst at the outset of the project my motivations were of the worthy kind (addressing the balance of power with mental health service users), and personal (gaining an academic qualification), the team's dedication took over, and my commitment to getting everything right for the team grew. This is something I shared with the team:

"For me, the thing that really nurtured the growth of the project was that I was so inspired by you lot and so motivated. Even when things were hard at work, you would come here in the evening. It was a long way for some of you but still you came...and I appreciate people that came locally, giving up your evenings to come here. Even if I had a long day and thought, "Oh, I've got to work tonight," not not looking forward to it but thinking it's going to be a late evening, but actually I always walked away feeling really inspired, I thought if these people are motivated enough to come along to do this project that I started... and I always used to feel inspired".

(me)

In summary: the team were a highly motivated group of individuals, fuelled by both a dissatisfaction with mental health services, and a drive to bring about positive change. As the landscape of the local setting changed, the aspirations of the team actually grew, with hopes that the project would have an impact beyond the project's immediate setting. Also, as the project progressed, the team became a motivating factor in itself for us all. The next theme explores how the themes so far of power, critique and motivation came together to create a position within which the team sought to take action.

5.3.14 Hubble, Bubble, Toil and Trouble

The theme of Hubble, Bubble Toil and Trouble is the heart of the project. It connects two sets of other themes: the preceding themes that explored PAR Excellence's examination of their own position and motivations, and links them to the following themes regarding the process and outcomes of the project. It is a short theme, but powerful and highly significant, for it describes PAR Excellence's conceptual positioning of being subversive mavericks and disrupting the mental health services that they feel at most, damaged by, and at least, dissatisfied with. Within this theme there are two sub-themes: dark arts, and disruption.

5.3.15 Dark Arts

There was a notion that PAR itself was a dark art that the team were practising, as they weren't always quite sure what should or was going into the mix, or what the end result might look like. This was exemplified by Picture 17, drawn by a team member, of witches in a clearing.

Picture 17: The Witch



The team member said about this picture:

“This is a clearing in the forest rather than in amongst the woods looking at the trees. And what the witch is doing is made up of the witches body and hair. And what the witch is doing, in the forest, is tossing in to the mix, a whole series of different literatures. And thus historic ideas and all that sort of stuff, to brew up whatever it is, the concoction. And we don’t know what’s in the bottom drawer”.

(P5)

They also described how the picture showed psychiatry too as a dark art:

“Because what’s in the bottom drawer, proven alternative, um, da, da, da, da, da, da...waiting for things to give. Spare us the cutter. But I was just thinking, what is in the bottom drawer? You know? What is it? Well, we don’t know, do we? Never found out, It’s a dark art. Years ago, you

didn't have psychiatrists, I mean, all right you'd have a guy... like witch doctors and stuff. Over here, you had the exorcist. You know what I mean? You know, you're not mentally stable; you're possessed by the devil. I mean...so I mean, that's where it all starts isn't it? And its potions and ointments and...you know. The reason I didn't do a scientist in a laboratory making a concoction in a test tube is that I am constantly reminded about people all over the services that they say things like, 'Well, it's not an exact science. It's a bit of a dark art,' and stuff like that. So, that's why it's a witch making a potion. Rather than a, I don't know, calculator".

(P5)

I too was very engaged with and inspired by the witch analogy, which resonated with me on a number of levels in relation to PAR, mental health services and PAR Excellence:

"The thing I like as well about the witch analogy is it wasn't...apparently, it wasn't just women. I know we think of witches as being women but anybody that was seen as being different or an outsider who didn't conform was deemed to be a witch, man or female. So I think you're a group of people that have been seen as being different, but also you are being different by coming into a project like this, actually".

(me)

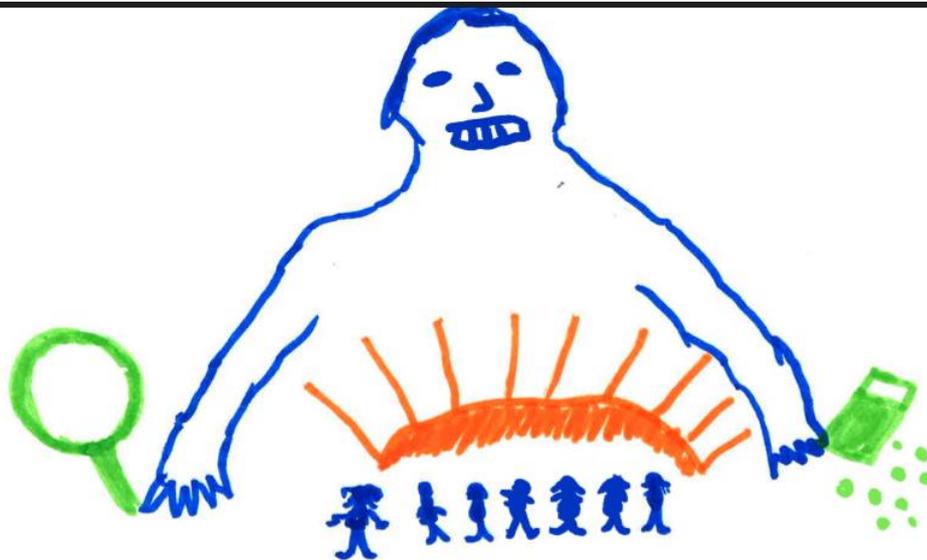
5.3.16 Disruption

Critical to this theme is the feeling of "us and them" between PAR Excellence and mental health services. There was a strong sense in the team of being on a

different side to mental health workers, and psychiatrists especially. Psychiatrists were literally seen as “aliens”.

The prevailing sense within the team was that of having to seriously challenge mental health services, and having to battle them like an enemy, in a ‘David and Goliath’ type scenario. Yet, there was hope that stemmed from the power of the collective force of PAR Excellence. Picture 18 was drawn by a team member early on in the project gave a remarkable insight into how they saw strength in the collective in the fight against the all-seeing, all-powerful psychiatrist and his medication:

Picture 18: Slaying the Psychiatrist



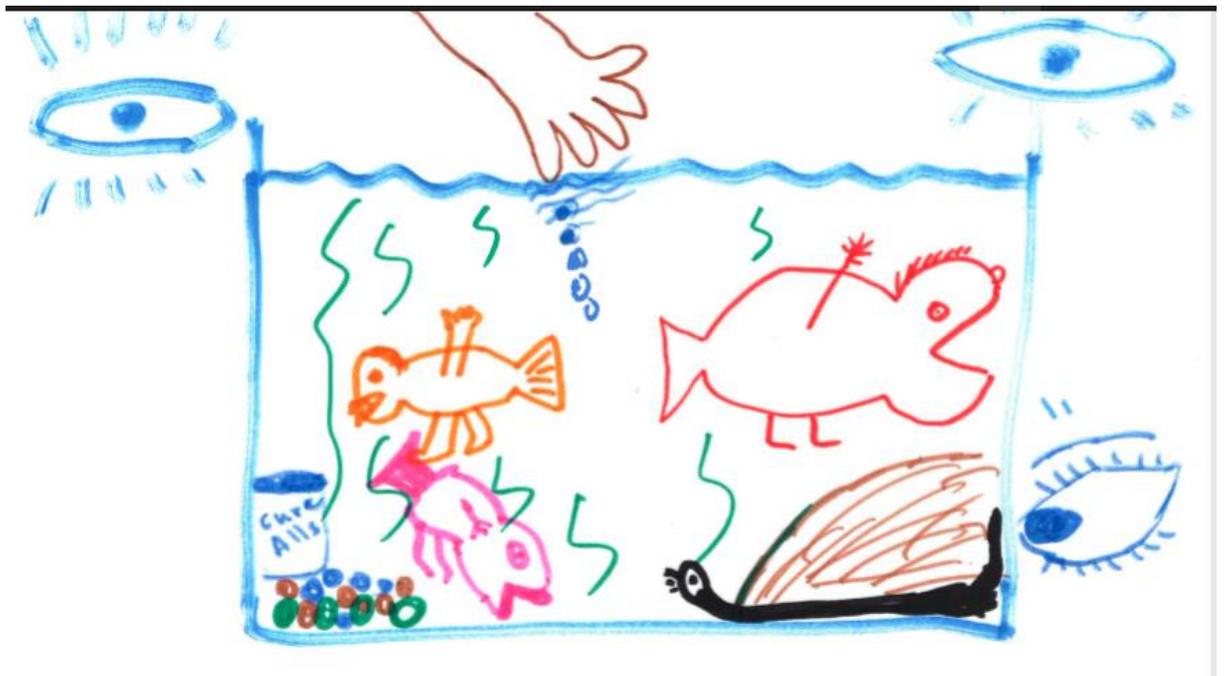
The team member said about this picture:

“I've drawn this giant psychiatrist. I was going to try and carry on and try and slay him. I was thinking about the power of the medical profession. We're trying to make things better, that's why I drew the little sunshine because we're all working together to slay this big monster”.

(P4)

Like the witches, PAR Excellence placed themselves as a subversive force, seeing their role as being to challenge mental health services through disruption and meddling. In Picture 19 drawn by the same team member later on in the project, they used an analogy of a fish tank. Now though, the team were looking in at mental health services and disrupting them by rippling the water, rather than being dominated by them and needing to attack. The picture shows how the team member felt that some of the power of mental health services had dissipated for them, by being a member of PAR Excellence.

Picture 19: Fish Tank



The team member said about this picture:

“So we are now the big people. This is a fish tank with psychiatrists in. That’s one of my old CPNs who I didn’t like very much, that slimy creature underneath. The ‘cure all’ pills that they’ve got in their little tank. We’re sort of rippling the surface now”.

(P4)

This belief that PAR Excellence were there to disrupt mental health services was shared:

“We were supposed to be sort of rising like a phoenix...it’s almost like we’ve got a jack-in-the-box, you know, like a bomb to chuck in”.

(P4)

It can be seen in this theme how PAR Excellence built on the first set of themes where they explored their situation and developed a concept of subversive meddling in response to the issues they identified. Leading on from this theme is a set of four themes regarding how the PAR process unfolded in PAR Excellence’s attempt to cause disruption and its outcomes. These are: PAR process, enablers and disablers, team, and transformation.

5.3.17 PAR Process: The Magical Mystery Tour of PARE Village

So far, rich, in-depth findings about PAR Excellence’s understanding of their situation have been revealed, and the conceptual framework of subversive “meddling and disruption” in mental health services that emerged to address some of these issues. This theme is concerned with how PAR Excellence took their anger, hope and concept of meddling and invested them in the PAR process. Within this theme there are two sub-themes: uncertainty, and choosing a research topic.

Before the sub-themes are presented, three pictures by a team member drawn across the lifespan of the project are presented. This member chose to use their adventures in “PARE Village” (PARE being an abbreviation of PAR Excellence) throughout the project to describe their experiences of the process. This series of pictures give a profound insight into the arc of the project from the perspective of someone at the centre of it, and who was one of the most

consistent and involved attendees throughout the project. They encapsulate some aspects of every one of the overall themes. Picture 20 was drawn at the first focus group early on before the research topic had been decided, Picture 21 after the research topic had been decided, and Picture 22 at the final focus group when the project was near completion. They tell a rather sad tale of initial hope, personal loss, resignation and acceptance. They also illustrate how disillusionment with mental health services and pessimism that local improvements could ever be made grew as the project wore on.

Picture 20: PARE Village First Visit



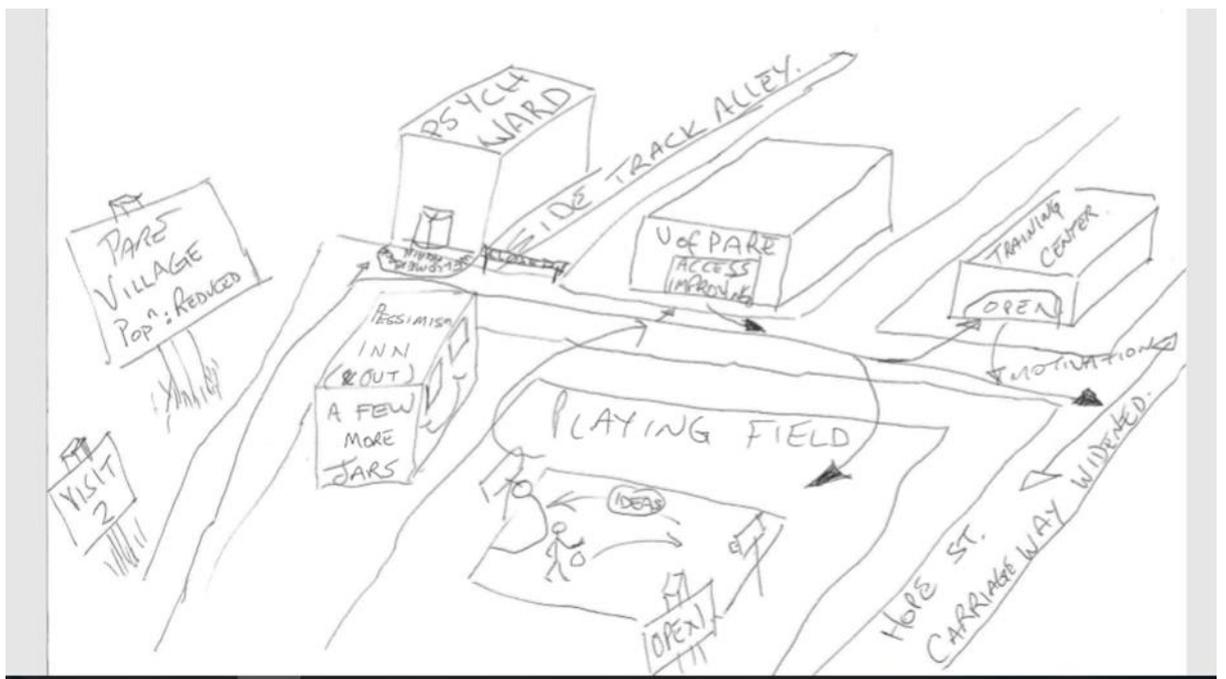
Having drawn the picture, the team member said:

“Mine is a drawing of a village and there is only one way in and it's called PARE Village. The route basically - I'm going backwards and forwards between different buildings. One of the buildings is the psych ward where sometimes I've been pulling my hair out, not knowing what I was doing exactly. That was me.

Other times for example I've been to the University of PARE where we've actually been educated in research. I have been to Peer Support House as well. I've been to Dead End Street as well and Pessimism Inn when I first came in. I got down this no through route side track alley. I think we've done that once or twice. I'm on Hope Street. Its leaning down to Hope Street, anyway. I have strong hopes that this is going to be successful and it's going to develop something that is beneficial”.

(P2)

Picture 21: PARE Village Second Visit



The team member described the picture thus:

“My picture was sort of a development of my last one, in the sense that, it’s a similar layout. But I’ve added a playing field to it. But the journey doesn’t seem as chaotic. So, you know, you can go straight to where you need to go along the roads but you’re not sort of twisting and turning

and not knowing where to go which was how it was last time. Not in the same way anyway. So, if you're going into one place, it's structured where you're coming out.

Side track alley I feel, has now been closed to the public. I don't really feel that that's open anymore. Because we seem, from my point of view, to have the direction we're going in. We know what we're after within reason. Playing fields is open to all and it's really the place where we were tossing, or we do toss forward, back and forwards, different ideas and come to conclusions and then go off to wherever we need to. But I also feel that Hope Street itself which is now a defined area is a widened carriageway. It's easier to get on and move along. I feel it's real now that hope had developed at the last forum (*focus group*), but now hope is certain as to an outcome. I think that's the best way I can say it but like, University of PARE access is improved in that.

As with training centre, but there I suppose really, the two, they're one and the same. As far as the education we've had has been really beneficial. And as much as I forget things, when I'm reminded, I understand it. Whereas before, I just didn't know it at all.

I visited Pessimism Inn quite a lot in the last place, but I now call it Pessimism Inn and out. Because it's just somewhere I visit occasionally. But when I do visit there, I have quite a few jars so that's good! And the psych ward now says, 'Welcome back, again.' Because it can be quite stressful.

(P2)

“You don’t actually put any directions on it, do you?”

(P5)

“The reason for that is, the directions are where you need to go at the time. So basically, I’m showing in effect, a circular route. I haven’t put that on there but you can go around and visit anything as you need to. And we go backwards and forwards. Brings to the fact as well that, to my way of thinking, there’s no longer the chaos that used to be there in my mind”.

(P2)

Picture 22: PARE Village Final Visit



Regarding the final visit to PARE Village, the team member said:

"I've basically drawn the start of a village. And the village started off with, as we've all said, the education, and I really enjoyed that. But as with school, is the inspiration and the camaraderie that you get from being together in a group that gels, but we moved on to that with the education at the same time came more inspiration and encouragement really. Some pictures are in Saloon Inspiration.

But before we even started we had all the problems with the funding crisis, which I put the flag there, which basically as far as I was concerned caused an absolute road crash, and every road you wanted to go down was closed. So, you know, I've got a road there - improvement way...improvement way is closed, and basically I just see as now as being on a roundabout: you either go round and round getting nowhere as far as improvement goes but the other aspect of that is that your good staff will go around so many times, lose interest, and they will just go, and then who're you going to be left with. You know, you've got no improvement and people who were totally demoralised, and that includes service users, and how can they work together in that situation. That's the way I see it.

And in myself, I just felt as we went so far down the journey, I started losing so I think it's either psychological or physical, and losing the ability to retain information. But not just that, to analyse and accept it so that I'm as absolutely relaxed as I am now. I'd be given information at the start, I'd remember a lot of it but as we went on I started losing that. But it just feels like I've had an information drain. it's not hopeless: it's hope lost for any chance of improvement...in services. So that was my journey, it's the

personal effect of a feeling that I can't hold on to information anymore and that I feel like my intellect has gone down. But I've retained enough to know that this just seems like we're on that roundabout".

(P2)

These pictures show sometimes desolate scenes. They encapsulate some of the loss felt regarding the impact on mental health services of budget cuts, restructure, and pressure on resources that made bringing about local change challenging. Included in the scenes are the personal losses the team member went through in terms of their physical and mental health. However, the hope and positives gained from being in PAR Excellence and part of the project do also shine through. "Saloon Inspiration" is a new addition to PARE Village. Furthermore, the pictures reveal a moving resilience in adversity and commitment to the project that was reflective of the whole team.

The following sub-themes now describe in more detail some of the trials and tribulations of the project, beginning with the uncertainty of the PAR process.

5.3.18 Uncertainty

In the initial stages of the project, there was a large degree of uncertainty. To be participatory, this uncertainty was wholly necessary to give the time and space for PAR Excellence to develop their own way of working and decide on the direction they wished to take:

"It's like putting a mouse on the floor and see where it goes".

(P7)

However, there was a confidence that things would eventually come together, as shown in this conversation:

“It feels like there are a lot of pieces to this kind of project. And I'm not totally clear how they are coming together yet, but I have faith that will”.

(P2)

“To me in a sense it can be like being in a pot of water and we're all just sloshing about in it. And when the water drains out we'll find out our route and knit together”.

(P1)

There was also an acceptance that there would be a level of trial and error to the process:

“In many ways it feels like a jigsaw and there are a lot of pieces loose. And occasionally when they go together afterwards I realise they don't go together and you have to pull them out and try and fit it in again”.

(P3)

However, whilst accepted, this uncertainty was not always easy or comfortable:

“I'm still a bit worried that I don't quite fully understand it, but I'll get there in the end. I got involved in the first few sessions and I thought: I don't know what I am doing here...what am I doing. And it took me quite a while to get my head around it”.

(P3)

The uncertainty was uncomfortable to people, partly because they weren't used to having so much control, leaving people feeling as if they were floundering at times:

"It was starting from us and guided and developed by us and I think that's the thing that I've struggled with. When that process is happening it can feel a bit wishy-washy, like there's no great agenda or map from A to B and what we're going to do".

(P1)

This discomfort with the unknown in some ways led to a desire for more direction, as demonstrated in the following exchange:

"I think I'd like to know what's coming, what we're doing over the process of it, what the plan is".

(P4)

"I think that also, kind of not knowing where we're going, I think that's a weakness. I think how it all jigsaws together a bit. I still think it's going to be so hard to know what to focus on. I don't know how we're going to do it".

(P3)

There was also a view that this uncertainty might be beneficial, as it might eliminate certain ideas and in doing so would help the team to get somewhere else:

“Not that Side Track Alley is necessarily a negative thing...because sometimes, a side track might not come out with what you want but at least it helps show what you don't want”.

(P2)

My own understanding also was that going down Side Track Alley might be revelatory, which I shared with the team:

“My reflection is that Side Track Alley might take you where you think you're not wanting to go but could take you somewhere really beautiful. Like...discover a lake or a forest or something”.

(Me)

Nonetheless, there was a sense of relief when some of the uncertainty had gone, and a research topic had been settled on:

“I feel better now that we've got down to shared decision making. It's like a focus now I think. It led on to Hope Street because I'd started to get some sort of structure as to where we were going. And that gave me hope”.

(P2)

5.3.19 Choosing a Research Topic

It has just been shown that a critical point in the project was the choosing of the research topic of shared decision making. This was the lynchpin of drawing all the in-depth sharing of experiences and perceptions of mental health into agreeing PAR Excellence's future direction. This sub-theme is concerned with

people's experience of the decision making process, and further reflections on why they settled on the topic of shared decision making.

It was clear that this was a significant moment for PAR Excellence, who thought this was a decision that was firmly made by the team. This was important to them:

"I think for me it was when we were deciding on what was going to be the research topic. Well, I don't think that it felt as that was led by you (*Katherine*), I always thought it was a joint decision or a collective decision. But at that point, that was us going right we're going to do something about that".

(P6)

There was also a sense that the topic had genuinely emerged from the discussion of people's experiences:

"I think to be honest our own experiences were on the table to form our shared decision the way it was. It was our experiences that made us, in the end, come up with shared decision making".

(P2)

It was believed that, although the decision emerged from people's experiences, the approach that the team took to finally agree on shared decision making was done in a rigorous manner, and this was something I had too observed and agreed with, as shown in this exchange:

"I believe we formed our decision and the path we were to go down based on logic and removed as far as we could from personal feelings".

(P6)

“That’s what I was just thinking...that the process that you used to come to the topic... it did put a robustness around it”.

(Me)

The team were pleased with the topic they settled on, as shown in the following conversation. I added my own reflection that people who hadn’t been present when the final decision was made still had input into it:

“I was really happy with the shared decision making topic”.

(P6)

“I’m quite happy with the topic as well I think even though I wasn’t here for much of it. I wanted that from the start”.

(P1)

“So your influence was present even though you weren’t?”.

(Me)

I think like when we had all the topics, I think all of them were interesting. I would have been happy with any of them, really. They were all something you wanted to delve into”.

(P6)

And, even when someone didn’t quite agree wholeheartedly with the chosen topic, they trusted the process that the team had settled on, and committed to the topic:

“I don’t think we made the decision that I wanted to make, but we made the decision that we had to make based on what we have in front of us”.

(P2)

In summary: the team experienced some turbulence and uncertainty that always wasn't comfortable at all times. However, they did keep faith that a direction would emerge, and managed to reach a consensus regarding a research topic that the whole team were satisfied with. The next theme of enablers and disablers is concerned with the team's learning around how this process happened.

5.3.20 Enablers and Disablers

PAR Excellence identified a range of features of the project that really supported the team's endeavours. This theme is concerned with the aspects of the process that really seemed to support the team's decision making and activities, as well as some of the challenges faced by us all. The length of the theme demonstrates the significant amount of learning undergone by us all. It contains five sub-themes: research education, role of the facilitator, role of the university, practicalities, and difficulties. Prior to these themes, is a mention of how important the focus groups were to the team. They found this element of reflexive practice to be a key part of the project. It gave the team space to think and this supported the decision making elsewhere:

"The first focus group was focusing on what's been going on but it actually helped to organise my brain a bit more as well. So, that was beneficial".

(P2)

The focus groups also gave some respite from the pressure of workshops and meetings to make decisions and be productive:

“If you've got poor self-confidence, the focus group in a sense is not challenging you intellectually in the same way. So, you're not feeling -- for want of a better phrase, thick”.

(P2)

5.3.21 Research Education

As touched upon in the PARE Village drawings earlier, the research education programme that was conducted by me as part of the project was deemed to have been a highly valuable and necessary element of the project:

“They've been essential, the teaching sessions and what have you”.

(P7)

“I find the research refresher at the beginning really useful”.

(P2)

The learning from the sessions carried over into other avenues of member's lives, and this greater awareness also informed member's thinking about their own research:

“I think I've got genuine great awareness of research. In everyday life, you just sort of like come across things thinking that was badly done, that was incorrect. So, it's just to be aware when we sort of carry it out to try and get over what hurdles you experience really”.

(P4)

Tailoring the research education to the needs of the team was found to be particularly valuable, and was discussed on a regular basis in team meetings:

“I think what's worked as well is like when any of us have said we like to know more about something, you like put on a workshop or an information session, so we've not just been left at a full stop with things”.

(P7)

5.3.22 Role of the Facilitator

My role as facilitator was strongly associated with the PAR process, as PAR Excellence found a number of ways in which my role impacted on the project. The team also found that an element of leadership was of benefit, as highlighted in the following conversation:

“I don't know how this process would have worked without someone sort of leading in a way or if it is someone else's project. You know, if you just got a group of people in the community together and just plonked them down and said away you go”.

(P6)

“I just think your role is like a supportive coach and obviously you've got a research background yourself. So that kind of just forms the back bone of keeping us on track, really. Otherwise we'd just be flailing around”.

(P2)

“Yeah, it did give it a drive...it would've been easy to let it flounder”.

(P6)

There was also the critical element of getting the practicalities organised:

“Obviously organisation have been helpful: brews, teas, coffees, venue, that kind of thing”.

(P4)

When PAR Excellence were asked if they would like to meet without a facilitator present, they were adamant that this would not be of use:

“I don't think it would be steered”.

(P2)

“There would just be a load of chatting”.

(P7)

In addition to the practical arrangements and direction provided by the facilitator role, there were some personal attributes that were considered crucial, including a demonstrable commitment to the project that was seen as authentic and credible:

“I think our strength is the sensitivity and sensitive guidance of the facilitator, Katherine. Without that, I think I personally would have been put off if somebody without Katherine's personality, drive and sensitivity wasn't there, it was somebody else who actually it was just a job”.

(P3)

An understanding that we were all learning about the PAR process together as we went along (including myself) and the role of the facilitator emerged. It was accepted that there was an element of both uncertainty and trust surrounding the role of the facilitator as there was in other parts of the project:

“I'd always seen it as a really fluid process. And for that reason the question about, did you do anything wrong or right or could you have done anything differently: you trust the process. Would it be wrong if we

expected you to have done something differently? Because this is like seeing it fluid and unravelling process”.

(P7)

The identity of the facilitator was crucial to some members of the team, who saw a detachment from the NHS as an enabling factor:

“We all communicate at our level which actually makes sense. If you were to bring an NHS style person, no offence to Katherine because I don't think she is, she's more of a charity person. It's different backgrounds; you're not a full time NHS are you. You're not a (NHS) lifer are you?”

(P6)

However, whilst there was general consensus that a facilitator was an essential component to the success of the project, it left a number of questions around ownership. There were some clear “giveaways” that demonstrated that at heart, the team considered it to be “my project”:

“You got to do quite a lot of work in the background haven't you? Just even preparing for each meeting. But after all that, it's your project so it's too bloody right you should!”.

(P4)

There were varying degrees of feeling responsible within the team, with one member experiencing some guilt if they missed a meeting:

“It's my responsibility to rock up and contribute as much as I could on whatever the topic was. And I did feel a sense of if I missed, which I did

miss quite a few, I felt bad and I suppose in some ways accountable that I wasn't turning up and knowing that there was perhaps only two or three people rather than the whole team there”.

(P6)

However, this for another member, accountability was firmly with me:

“I personally feel that you were accountable. I was accountable to turn up and participate and being a researcher and all, but I didn't feel any pressure like (*PAR Excellence member*) maybe did to turn up, I just felt that it'd be all right if I didn't. It's interesting though. It's the difference between participating and feeling accountable. I feel more like a participant than accountable for the work, which I don't know whether I should feel accountable. There's the main person who's got all the accountability for writing it up and doing all the hard graft and I was participating, helping. It's pretty much how I see it”.

(P7)

For another team member accountability was fluid, shifting on where we were in the project, and where they were as an individual:

“Initially, when we first go in through the training, I wasn't sure to be honest with you. I'm not sure, so I wasn't sure, but as time went on, and I got more knowledge and knew more what was happening and got a bit of a structure, yes, I felt accountable strongly. And when I was ill, then I would feel the pressure of responsibility as well. So I felt it was as much our project as yours. But as my abilities waned and time pressures

became more pressing, I realised that the accountability seemed to shift to you”.

(P2)

5.3.23 Role of the University

The supportive role played by the University’s academic supervisors (who dropped into meetings on occasion and attended some of the same conferences as the team) was seen as a vital element, demonstrating the importance of having external support. As shown in the following exchange, the team were aware of the support provided to me, but also valued the validation provided by the supervisors and the belief they had in the team and the project:

“(University supervisor) encouraged and enthused me in that he was enthusiastic, and it followed, it rubbed off. And his enthusiasm around what we were doing and how it was going really”.

(P2)

“Well, it perhaps would’ve been a support for you as well. I think having the time that we did meet him it really endorsed the project I think”.

(P6)

My reflexive account showed that for me too, the role of my academic supervisors was essential. I expressed this to the team by drawing a picture (23) myself during a focus group. I related it to my experiences of open water swimming, and the role that the safety cover plays. My academic supervisors were represented in the boat.

Picture 23: Open Water Swimming



Here is my explanation of the picture to the team:

“This makes me think about my open water swimming journey and what it is like to do distance open water swimming. And because we’re all together, there’s a bond you get when you swim with people in the sea or in the lake that you don’t get anywhere else. But still sometimes, you can feel a bit alone with it and then you realise that there’s someone there and when you’re working together, looking out for each other, it’s all going to be fine actually. But...you know the journey for me is a bit...you can’t always see where you’re going. Sometimes, the weather gets a bit bad but then sometimes the sun comes out and it’s really exciting. So sometimes, it’s quite hard work and the waves can make it

difficult. But sometimes, the waves can make it so exciting and when something comes together, it's actually the best feeling in the world.

And certainly, in terms of what I'm learning about what it means to do participatory action research, every time we get together, I learn a bit more about it. So I suppose, that's how when you come up to the top of the wave and you can see where you're going for a bit".

"And do you think (academic supervisors) in the boat would actually throw you a rope if you were starting to get into trouble?"

(P2)

"I think so. Well, they're there because sometimes, you can't always see the safety cover, when you're out there swimming, if it's choppy. You have to learn to trust them. You learn to know that they're there and sometimes, you look for them but you miss it because the waves are going up and down and you just have to carry on with the faith that they're there, really. But I do think, they do sometimes throw a lifeline to us, just in terms of their little bit of advice. The other thing that people in safety boats do is look out for things on horizon that could cause trouble. And I've put *(The Trust)* actually as this big ship in the distance. And it's just, they kind of help you manage that, really and they look out to make sure that you don't get in the way of something. Or that they don't come along and hurt the swimmers".

(Me)

5.3.24 Practicalities

There were a number of practical matters that impacted on the process. One of these was meeting attendance: there were times when attendance was low at meetings. Periods of low attendance occurred predominantly because of personal circumstances, and life events taking priority. It became increasingly difficult to schedule meetings when everyone was available, because of changing commitments particularly around employment.

However, on reflection, low attendance wasn't as problematic as envisaged. The meetings that did have low attendance could be some of the most productive. Furthermore, as is discussed in the forthcoming theme on the team, non-present members had confidence and trust in attending members making good decisions. It is probable that attendance levels may fluctuate in any project such as this, when people are not being paid, have other significant commitments and have fluctuating levels of wellness. Team members agreed that low attendance wasn't always detrimental, as shown in the following exchange:

"For one reason or another, there's not been many of us coming to the meetings and that's been a difficulty at times. But also, that's been at times a help".

(P2)

"Especially when it came to hacking the decisions to get down to the list of three and beyond that really. Two meetings have just been me, you and (PAR Excellence member) wasn't it?"

(P6)

Regular revision sessions and resources regarding both research and project progress were requested. This was in part because of the length of time between meetings: it was difficult to get the balance right between meeting enough to keep momentum and continuity up, length of meetings, and how much time was reasonable and practical to expect people to commit. There was no consensus on these matters, showing the difficulties of managing the logistics of such a project to ensure that everyone can contribute:

“I think, maybe recapping at the beginning of a meeting because sometimes we start off and I actually don't know what we're doing, but it feels almost like there's an assumption I should”.

(P3)

Trying to manage the compromise between having fixed times for meetings and being flexible to maximise attendance when people were not available presented problems and confusion:

“Regular meetings really. It is hard to remember everything and when you've had a big gap, I'm not always sure what type of meeting I'm in”.

(P3)

The following exchange demonstrated quite how challenging it is to get the practicalities right for everyone:

“I think meetings can be long at times as well. I think that's better than having lots of different meetings that are shorter though, but just feel long at times for me”.

(P2)

“I don't know, I just think that sometimes...I feel like sometimes we're just getting into it and then it...you said it's too long, but for me I feel like it's not long enough. We start getting to the point that we're supposed to be making instead of us all...and then it's like that's it, it's time to end”.

(P3)

There were also some practical aspects that, while may seem trivial, were important to the running of the project, particularly around venue. Finding the right venue turned out to be crucial, and parking. The university turned out to be the most conducive venue. Meeting in an NHS building, with all the security constraints, was less welcoming:

“I feel like I'm sub-human somehow because you've got to go through all the procedure of waiting around and ringing through and everything (*in an NHS building*). Whereas here you can just come straight up (*university*)”.

(P4)

The team also felt that meeting at the University provided some status:

“I must admit I do prefer here because it kind of validates the project we're doing”.

(P6)

Another practical consideration was the sheer time the project took. The time was much longer than first envisaged, meaning that when planning a project such as this, a number of factors need taking into account. One of the main contributory factors was that PAR Excellence were not paid members of staff. Clearly this meant that the time we could get together was limited. People had other commitments and there was a tension between not placing too many demands on people in way of time, with meeting regularly. The following exchange explored some of dilemmas around this issue:

“Should we have tried to complete the project in a shorter space of time?”.

(Me)

“How can you do that though, unless you’re doing it full time?”.

(P7)

“I think it would’ve been harder to do over a short space of time”.

(P7)

“I think the results would’ve been different, yeah. It would have unfolded differently. That is the issue that people are volunteering, aren’t they basically and have got other things to be getting on with”.

(P6)

“You know, when it was perhaps more intense was at the beginning meeting every couple of weeks or so”.

(P2)

“That’s doable. Whereas if you’re trying to squeeze that in and you’re doing an evening or even more a week, I think it’s not going to happen in terms of volunteer time”.

(P6)

The notion of creating paid posts to conduct a research project such as this was not considered to be a solution to reducing timescales, because the necessary budget limits would constrain how many people could get involved. There were further concerns though, that paying people to be involved would put a different dynamic to the project, and be detrimental to some in terms of feeling more pressure. The team concluded that a project such as this, involving people on a voluntary basis, just needs to take as long as it takes:

“But there’s also the fact that if the funding was there, you could recruit people into either part-time or full-time positions as a group to do something like this. And that takes some pressures off because they’re employed, they’ve got income, et cetera. But then that puts pressure on because if you’ve got an illness which we all have by the nature of what this is, you will feel pressured to turn up more maybe, I would. I’d feel more pressure to turn up and attend and that might make me more ill if I can’t. But if you’re employed half a week or a full week, full time or half time, something like. You’re condensing everything so you’re not...it’s more intense. For some that’ll be bad but it’s not going for as long a period of time”.

(P2)

There was also a concern that paying people could prevent their involvement if it impacted on their benefits:

“And that I’m just thinking it also limits because some people wouldn’t be able to be involved above a certain number of hours”.

(P6)

The team also discovered that there was a certain point where it would have been very difficult to include any new team members. The further along the decision making process, the harder the team envisaged it would be. This was also in consideration of the amount of research education the team had undergone by then. They therefore made a decision to not admit any new members once the topic of shared decision making was settled upon, as evidenced by the following conversation:

“I don’t think it would have worked if we’d have brought somebody else into the group”.

(P7)

“Because I think we’d gone through that journey that far that I don’t think it would have worked”.

(P6)

“It would be a lot of outside of the group work bringing them up to speed, wouldn’t it? As well as recruiting”.

(P2)

“And I think it’s worked that we’ve kept it closed at this stage because it could have just got more complicated and going off at a tangent and stuff”.

(P7)

5.3.25 Difficulties

Like any research project, a number of difficulties were encountered in delivering the project. For example, it was difficult for someone who had missed a number of sessions to get back into the flow of the project, and they felt that they would hold progress back:

“I did lose the thread in particular when you’re doing the coding. Because it was almost then it got to a point where it was, not pointless sure enough, but it kind of was really. Because I’m so far behind. You’d have been spending more time trying to catch me up and just held back the coding which was quite a big exercise anyway, wasn’t it? That was the reason I stepped back. You know, and that when we both stepped back, I actually wanted to come and do it but I felt I’d been hindering it”.

(P6)

According to one team member, there were difficulties caused by their mental health conditions, which had a negative impact on their ability to participate fully:

“I think also, a threat to the project, I suppose people’s conditions maybe. I think it happened to everybody in the team at some stage, in one guise or another that functioning meant that people can’t participate as much as they would have liked”.

(P2)

This team member had also become upset as a result of what they saw as their mental health condition, and they nearly left the project because of it:

“I think a weakness can be our own individuality and our own personalities and our own psychological difficulties. I'll give you an example; there was a time when I actually thought that when I give a point of view somebody had literally shouted me down as though they thought I was stupid. Not that I was stupid, but that it was a stupid comment to make. That happened once that I can think of and my own insecurities because of my mental health problem was such that I almost packed it in”.

(P2)

Coupled with this was a lack of confidence in people's own abilities and low self-esteem, and this caused discomfort. There seemed to be a lot of internalisation going on, when people blamed themselves and were self-critical for things they found difficult, rather than seeing the difficulties as being part of PAR:

“I always feel a lot of pressure when I've got to write something, in case I write the wrong thing”.

(P3)

There was a perception that going off topic was an issue:

“I've got a really big weakness for the group. I think sometimes we get a bit too carried away and we go off on a tangent”.

(P3)

In terms of carrying out the research activities, there were some difficulties with undertaking the data analysis, as shown in the following exchange:

"I wasn't able to identify anything meaningful. I mean it was all great and interesting but it was obviously just..."

(P7)

"Irrelevant?".

(P1)

"Just banter - just people pulling each other's legs and just chitchat".

(P7)

According to my reflexive account, the greatest difficulty I had was "letting go" of some of the control. I documented how I was not able to delegate tasks to members of the group, and then leave them to complete them. This was particularly apparent when listening to a focus group which was meant to be facilitated by a PAR Excellence member, but in fact I completely took over. This was partly because when the team member had facilitated a previous group, I had wished for more follow-up questions to probe responses from the team further.

I also felt very much in the lead when we were undertaking activities with staff. There seemed to be a reticence from team members to take on any responsibility or lead on activities, but I could have contributed to this by taking too firm a grip on proceedings. Herein lies one of the greatest challenges I found with this project: getting the balance between relinquishing power and

control, and ensuring that the project stayed on track and was conducted effectively.

My own strongest lesson learnt was around data analysis. A number of significant worries were illuminated in my reflexive account concerning this activity. When analysing the data with team members, a difficulty emerged when things people had said were considered as “facts” by team members, rather than perceptions or opinions. For example, there was debate around coding the statement that staff hold service users in contempt: should this be coded as staff contempt, or perceptions by staff? This is where I wielded my ultimate power, for I felt very compromised between PAR Excellence member’s views and the rigour required for the quality of the research.

There was also a lot of time spent by the team on criticising what staff were saying in focus groups and interviews rather than trying to interpret the data. This highlighted to me that the biggest error I made was launching into data analysis in the hope that by doing, the team would just be able to manage it. The reason for this was time constraints, at a stage in the project when it was getting increasingly difficult to get members of the team together. In hindsight, training the team in data analysis should have taken priority, for it was the most significant activity of the whole project in terms of creating findings. I shared these thoughts with the team during the final focus group:

“If I have my time again, I would have spent a day thinking about what do we mean by data analysis and what does coding mean. I kind of just threw us all into it, you know, and like, oh, we’ll just learn as we go along. I would say it was absolutely the hardest bit of the project and it’s the hardest bit of any project because that’s where you make sense of the

data you collected. Data collection is not hard is it, sit there and ask questions, but actually working out what does it mean - it was extremely difficult data to work with actually because people kept going off on tangents, they weren't talking about shared decision making. I suppose thinking about my experience, what didn't help was not being clear on the data analysis process”.

(Me)

This lengthy theme has illuminated the myriad challenges of the PAR process, and how important getting the practicalities right are. It has also shown what went right with the project: elements of the facilitator role, support from the university, and the research education programme. The following theme is concerned with the greatest strength of the project – the team itself.

5.3.26 The Team: Messing About on the Way to Hope Street

How the team developed is in essence a part of the PAR process. However, it merits its exploration as an individual theme, because it was apparent early on that the nature of the team was highly significant to the process. There was also much more to the team than the task of completing a research project. There are two sub-themes to this theme: relationships and trust, and peer support.

5.3.27 Relationships and Trust

Any team has its own dynamics, including paid, work based teams where the objectives are clear, Good team working is a component of reaching any team goals. However, the relationships that developed between team members seemed to take on a particular significance within PAR Excellence – not just as part of the effective pursuit of goals, but also in the personal gains from being in the team. A significant aspect of PAR Excellence’s experience was how the

team worked together and developed, so this theme links with both motivation and the PAR process. The team became part of people's motivation, and the development of the team a part of the PAR process overall:

"If I'm thinking about the motivation, the impact shared decision making would have, and actually what the work is about, unfortunately came secondary with to what everyone's talked about: the camaraderie and allegiance, a sense of duty to your team...that seemed to be a bigger motivator to me than being engaged on the end goal in the end".

(P2)

Feeling comfortable and able to be honest and accepted were crucial to the team:

"I can say I feel comfortable saying anything, you know, with us a group".

(P3)

This sense of openness was seen as essential to the democratic workings of the team:

"I think the feeling that we're all kind of on this journey, and we're all being pretty open with each other, all working together with is other, is fine. I think democratically, we're each able to have our voice heard, rather than people getting shouted down".

(P6)

A strong element of the team bonding was that everyone had been through the mental health system, which provided almost instant rapport, understanding and acceptance between members:

“I think some of that is probably because of what each of us has been through, that it would be fairly difficult to be shocked about somebody else's experience, I think, if you know what I mean. You'd only ever...you know, show some empathy towards what that person's been through. If it's something more extraordinary than you”.

(P6)

An important factor in the building of relationships was team members feeling safe to ask questions:

“What came out to me on the questioning was that being in a group like this where you just know, because we knew we could just be open with each other and you could ask questions, and I always felt that you can ask questions in a way that people knew you weren't being critical, you were probing, just trying to understand”.

(P2)

It was also important to the team that they had bonded, liked each other, and were likeminded:

“I think that's because we're like minded and we do things in common, but we I suppose actually like each other”.

(P1)

This like-mindedness and personal qualities were more important to team members than other types of knowing, as demonstrated in this exchange:

“I think academic knowledge isn't something we sign up for, is it?”.

(P3)

“No, no, it wasn't. It was more personal attributes and experience the kind of the desire to do various things, so, particular expertise in research didn't come into that, did it, no”.

(P1)

The diversity within the team was highly valued, not just in terms of what this brought to the activities of PAR Excellence, but also to in people's own learning and personal insight:

“But as a team, we work together, we all brought something to the party even though some of us had more experience than others. And I found that being able to apply our life or lived experiences in a way of kind of delivering the positives, something positive as an outcome of the project, you know, whether those experiences were good or bad really, we quite openly shared those and there's lots of good stories”.

(P6)

The feeling of being in a team added to the essential enjoyment highlighted earlier in the motivation theme:

“That feeling...for me that came around of participating with the team to put this project together, I just really enjoy that aspect of it”.

(P6)

This enjoyment came in part too from the camaraderie within the team, or “the banter”:

“I think it'd also though becomes part of why you come back again when you're not so good, if you get my drift, that camaraderie”.

(P2)

“I think this as well, and I don't mean this in a flippant way, the ability of the group to laugh, to have fun, to enjoy it”.

(P4)

There was also great pride taken in the achievements of the team:

“I still remember being proud of you when you went to different places in the country to do presentations and what have you. You know, taking the work nationally”.

(P7)

Another important feature was that team members felt a sense of belonging to team, even if they were not able to attend meetings for a period:

“So I'm absent but always felt included there, it's a good inclusion”.

(P7)

According to team members, trust in me was also key:

“You have to trust her to be truthful”.

(P3)

This was also recognition that trust needed to be a two-way thing, and that I was dependent on team contributions:

“She has to trust us to articulate”.

(P1)

In contrast, it wasn't always taken as a given that having a previous relationship with the facilitator (as was the case here) was necessarily a good thing. There

was reflection around the impact of the relationship I had to PAR Excellence members prior to and during the project. Whilst a trusting, established relationship was mostly considered to be a key element in keeping the project going, there were also some ruminations regarding how the dynamic might have been different had the facilitator been unknown to PAR Excellence members. It was mooted that with a facilitator unknown to the team, the research might be more objective. This viewpoint exposed a limitation in the research education programme, as it demonstrated a more traditional understanding of research rather than the immersive nature of PAR where such boundaries between the researcher and “the researched” are not necessary:

“But I wonder whether that facilitator should be – I can’t think of the word for this but somebody who in a sense is unknown to the participants because.... It is maybe suggesting bias because we knew Katherine before. Not bias but that person can then become and you can become dispassionate ...I mean, the first time I met you, I knew straight away that you cared about people and you were driven. So I might get that or other people might get that from any facilitator straightaway. But it’s more likely that unless they’re very enthusiastic, overtly so, then there will be less of a passionate engagement. And it’ll be more objective maybe”.

(P2)

However, it was also suggested that having prior knowledge of a facilitator would be more a benefit than a problem in terms of engaging people in the project:

“Maybe a facilitator that you’ve no knowledge of wouldn’t be able to enthuse you in the same way to get on board”.

(P7)

So far, there has been a description of rousing success in terms of the team dynamic. However, the team was so strong that this had a detrimental effect on one member at a certain point when they felt unable to fully contribute. Because of the closeness of the team, this led to immense pressure to not “let the team down”:

“Part of the pressure was team work and feeling that because I’m not involved, but right at the start I was involved 100% and then suddenly I started getting ill and stopped attending as much and the pressure of that was quite phenomenal”.

(P2)

Whilst the team had reached a consensus regarding the topic of shared decision making, there was an element of disappointment regarding the scope of the action the team decided to take because it was seen as limited in its scope to affect major change in staff attitude:

“So for me, the route we’ve gone down, I wonder whether it will hit people on the head or it’s just....because it’s a tool they can use, I wanted something more that would say, ‘Look, you don’t understand and this proves it so maybe you need to rethink’ So in that way, my aspirations have reduced”.

(P2)

5.3.28 Peer Support

The peer support provided by being part of PAR Excellence was another significant factor in the success of the team. The understanding that everyone had shared the experience of going through services was a powerful element of the team bond, as shown in the following exchange:

“I think it's just to know, like the basic thing, that we've all been through the system”.

(P4)

“We respect each other for that, don't we?”.

(P3)

Hearing other people's experiences gave a validation to team members' own experiences:

“My experience of the group is to hear other people's experiences of our services and see how they are all the same really, different emphasis for different people I guess. To see how my experiences were legitimate I guess, in that everyone else is experiencing and thinking it as well, which helped me to be honest in my thinking about services and stuff. So I found it quite enlightening”.

(P3)

It was interesting that, because peer support was not the ostensible objective of the project, the peer support that did occur was viewed as more effective than overt efforts at peer support:

“I keep coming for more meaningful reasons I guess, peer support. It almost surprised me -- it's almost when you have a purpose to be there,

peer support is more meaningful because it's not focus. It almost doesn't happen when it's the focus".

(P1)

This element of the team provided a space for team members to discuss their issues that they didn't have elsewhere:

"That empowered me to just be open about my difficulties, I haven't really been open with my friends about".

(P7)

The information flow between team members gave people some confidence in their own abilities to solve issues, having seen how other people had done it:

"That helped me because then you can solve it if other people are experiencing it and it's not just you. It's not you that's defected almost. It relieves that psychological burden. Well, if everyone else is experiencing it maybe I can find an answer to that little problem".

(P3)

The support found within the team addressed some of the isolation experienced by team members, and led to revelations that problems were not completely located within the individual:

"When you feel alone as well it makes you feel like you're stupid or being paranoid or you're the sick one. And when you gather that other people that have had similar types of experience, you realise that there is something more than me".

(P2)

This theme has amply demonstrated how vital the team is to the PAR process. It has also shown how the benefits of being in a team of this nature go far beyond the principle aims of the project. The personal development afforded by the PAR process through the development of the team leads into the final theme on transformation.

5.3.29 Transformation: The Wizard of Oz

Fundamental to the whole project was transformation. Transformation is a key goal of PAR, which seeks to change situations for the better. It can be seen in the earlier themes of motivation and hubble, bubble, toil and trouble that transformation was a major motivating factor for PAR Excellence, who desired to see significant change in the mental health services they had mostly had poor regard for. There are two sub-themes to this theme: impact on mental health services, and personal transformation.

What transpired is that transforming mental health services at any level was difficult, if not impossible within the scope of this project: the teams' efforts seemed to have minimal observable local impact. In contrast, the PAR process produced some significant shifts in team members in their thinking about mental health services (both positively and negatively), and some personal transformation occurred during the lifespan of the project.

5.3.30 Impact on Mental Health Services

PAR Excellence did not have the impact on local mental health services that they would have liked. This resulted in a sense of resignation rather than disappointment. However, it fuelled the teams' ambition to take their work further than the local Trust:

“I got partway through and realised with what was happening within (*The Trust*) that probably wasn't going to get adopted which is a real shame. Because for it to have been adopted and rolled out would've been a major achievement for (*The Trust*). But beyond that, I think, once I'd seen recognition from other academic bodies, the fact that we can have some published work out of it and hopefully, out of that there will be some work adopted perhaps in this country but probably more likely to be in a foreign country”.

(P6)

This does not belie that there was a sense of thwarted effort:

“So I am a bit cynical about it. It would've been great if this would've been integrated into (*The Trust*) and made a big difference to shared decision making and everything else”.

(P7)

There was hope that some minor changes occurred in staff thinking as a result of the project, although there was also scepticism about this, as demonstrated in the following exchange:

“I think for the (*mental health*) team as well, when we interviewed staff, it did make them think differently, some of them that we interviewed. So it helped a little bit on a local basis. And obviously, the next stage would've been to roll it out”.

(P2)

“But it’s whether that sticks or whether it’s just...whether on the day in that focus group they had a hygiene wash and they went back to their job. And a week later they defaulted back”.

(P7)

Disillusionment remained with the efforts to bring about change to services, and this led to a downshift in the team’s belief in what research can achieve, although aspirations stayed the same:

“But my expectations have changed with my experience. My expectations of where research would probably...it's my expectations of what research will probably do have come down. My aspirations are way up there but my expectations, they have gone down”.

(P2)

I questioned the team regarding the use of co-production with staff as an approach that might have had a bigger impact on local mental health services. However, the team were adamant that this wasn’t the answer, for they believed that this would have completely altered the dynamic of the group and inhibit dialogue. There was a belief that the staff would hold the power, and also be reluctant to adopt any changes. The strength of feeling over this is evident in the following conversation:

“No. I would not be able to be honest in front of staff”.

(P4)

“There would have been a feeling of staff power”.

(P2)

No I don't think so at all. They would just reverse back into their process and sheep dipping".

(P7)

5.3.31 Personal Transformation

One of the most significant shifts in thinking amongst team members was attitudes towards staff. For some team members, their feelings mellowed when they interacted with staff in a different capacity to being a service user:

"What helped me to some degree was that in probing somebody else, I was actually able to turn back sometimes on myself and realise that... as we're going along, we're talking about staff for example, bad staff, that my criticism sometimes was over the top on the basis of a biased viewpoint. And that was purely from trying to be objective about somebody else's thinking and viewpoint that I suddenly saw that actually...well, when you were talking about so and so and their treatment of you, then maybe you were looking at things through sunglasses rather than clear lenses".

(P2)

Being part of the project had given team members a chance to re-assess their thinking, and this at times led to a sense of understanding and forgiveness towards the services they had been so critical of:

“I think it’s probably through meeting more people. It’s a bit like this; that I’m aware that people, even psychiatrists, are in a trap, have limitations, or are sometimes trying to do what’s the best as possible with the best interest and they’re not sort of power-mad - or not completely”.

(P4)

The deeper understanding of their own position and their role in relation to mental health service staff provided by the PAR process meant that some team members started to look at their own care differently. In particular, there a recognition that to engage in shared decision making, it was not just staff who needed to change their attitudes, but service users too:

“I find it interesting that I was coming from that angle where I wanted shared decision making to be making the balance, bringing service users up to the same balance as staff, whereas actually it can be the other way around as well.

That's where I was at and actually it was staff that were urging me to do a discharge plan and to set a goal of six months and to allow it to be a shared decision rather than my decision. And after I spoke to them about it and they've explained why, I think they're right. So, what I'm saying is not just about bringing the service users voice up to the same level. It can also be about service users accepting collaboration and shared decision making with staff”.

(P7)

Another transformation occurred in PAR Excellence’s attitude towards the academic community. By interacting as peers with researchers at conferences,

some mystique and the high esteem held about researchers fell away: again, another example of the scales falling from the team's eyes. As described in the earlier sub-theme of critique of research, the team saw that research isn't always high quality – that it can be biased, or poorly conducted. This was a shock:

"I think an experience I had which I actually found was a boost to my confidence was going down to Warwick University (*for a conference*). And one of the reasons it was a boost in the confidence wasn't necessarily the taking part in the (*PAR Excellence's*) workshop, although I enjoyed that. It was the fact that I attended other people's talks on their research. And it was gobsmacking at how obvious to me it was that some of it was crap".

(P2)

According to my reflexive account, I viewed the shock that this team member felt to be a sign of a powerful transformation, for it heralded a boost in confidence in team members through their understanding that there are failings even in research conducted by well established, professional researchers. For me personally, this was particularly joyful to see: I still had vivid, and quite painful recollections of the very first research workshop I had conducted when I had provided some research papers for the team to critically appraise using CASP tools. My objective had been to demonstrate the exact point that PAR Excellence reached at the conferences: that some research is not well conducted, or is badly written about, or poorly presented. At the initial workshop, if a paper was not understood, PAR Excellence took this as a sign that they were not clever enough to understand it. So, to see the change within

team members as they felt confident to challenge researchers in a public space seemed to be a highly significant point, showing how the project had been effective in promoting a greater understanding of research, and confidence in the subject.

The research learning and development associated by members with the project could be taken into other areas of their lives:

“Everything that just made me more aware even when sort of like looking at other things and stuff in the media. It sort of opens your mind up”.

(P5)

The PAR process reinforced some personal goals of the team members:

“It’s changed in the sense that I have started to aspire now myself, although I’m not going to do anything about it for a while, but I am now thinking quite seriously about doing something myself in the research field about some of the stuff that I’ve done. So yeah, so in that sense, not changed, but just grown”.

(P1)

Sadly, some personal transformations occurred during the lifespan of the project that were less welcome, and affected the functioning of one member in particular who went through a painful process in terms of his declining physical and cognitive health. This created difficulties for his ability to engage in the project, although his determination to see the project to the end showed how meaningful the project was to him:

“In myself, I just felt as we went so far down the journey, I started losing so I think it’s either psychological or physical, and losing the ability to retain information, but not just that, to analyse and accept that I’m absolutely relaxed as I am now. I’d be given information at the start, I’d remember a lot of it but as we went on I started losing that. It feels almost like Alzheimer’s. It’s not - I’ve not had that checked but I just know it’s not. But it just feels like I’ve had an information drain and I hope it’s not hopeless: it’s hope lost for any chance of improvement”.

(P2)

A different type of transformation occurred to another team member turned out to be a mixed blessing. Being a member of PAR Excellence was credited by this team member as being pivotal to him gaining voluntary work and then employment in mental health services though the education it provided and the growth in confidence the team member experienced due to being part of the project. Going into services as a paid member of staff led to the member withdrawing completely from their service user status at one point, withdraw from the project and deciding to stop disclosing that they had used mental health services in the workplace. However, their disillusionment, disappointment and pain with services grew as the true extent of poor staff attitudes was revealed. They returned to strongly identifying as a service user, and rejoined the project with an even stronger critical voice. For this member, there was a sense of meeting the Wizard of Oz at the end of the road: that there is no great mystery to mental health services after all, and some unpleasant truths about mental health services had been revealed to them:

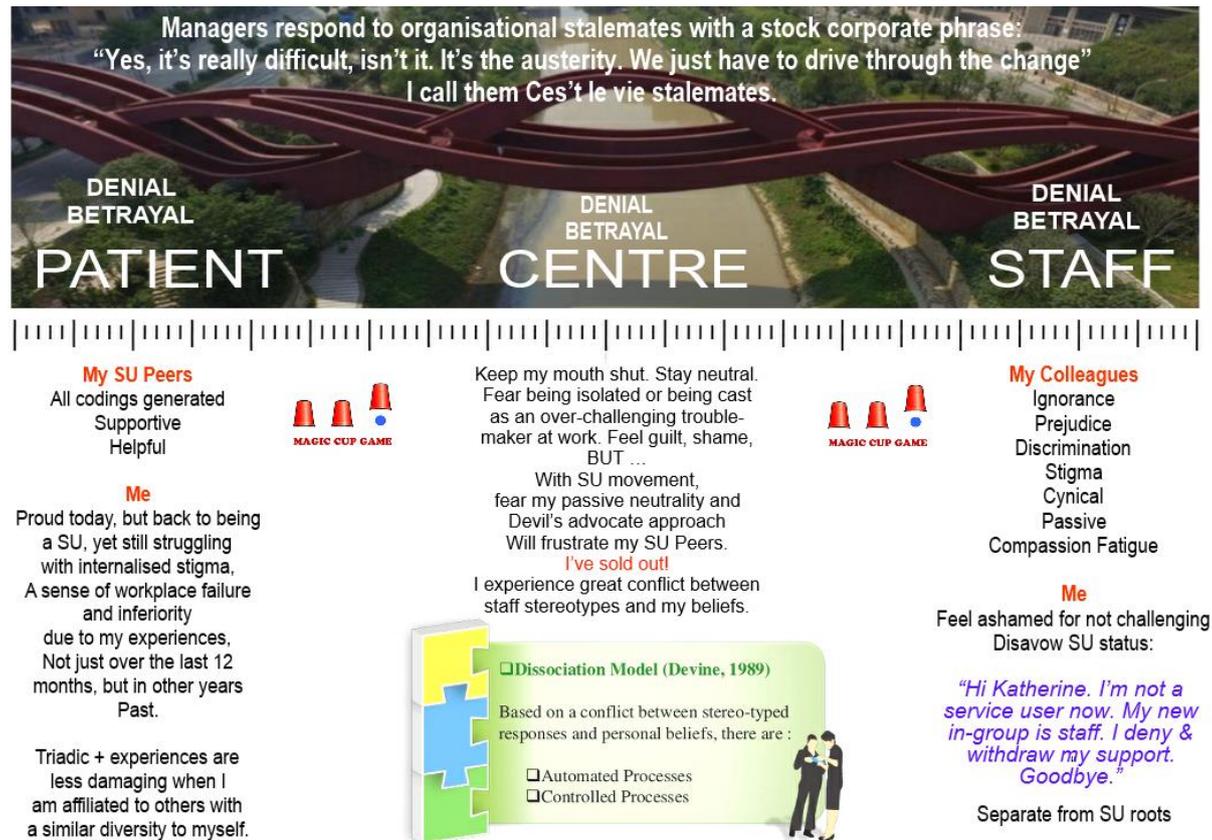
“In this job, it’s just been a real shock once you go over that other side. it is like the curtain in Oz: they pull it back and there’s a middle-aged bloke stood there with a lot of controls”.

(P7)

This team member produced two diagrams (Diagrams 3 and 4) as part of his individual reflexive account at the end of the project, which he shared at a dissemination event. These diagrams show the team member’s transformation through the various identities he held during the lifespan of the project: service user, staff member, PAR Excellence member. The diagrams show how these competing identities caused internal and external conflict, produced deep dilemmas, and finally led to even greater disillusionment and anger. They also show how meaningful some of the themes identified during the focus groups were to this member.

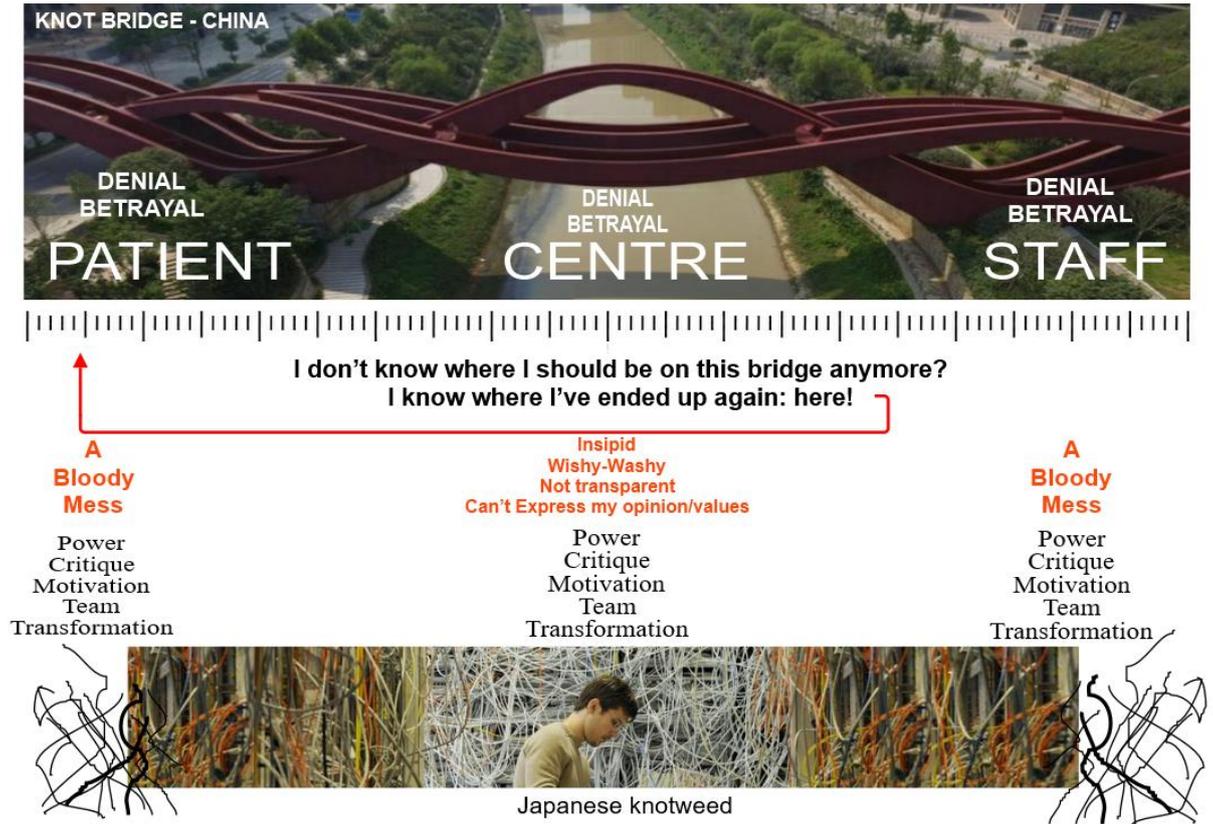
It is clear from the first diagram that the allegiances that the member built by being part of PAR Excellence went some way to limit the damage. In contrast, what is also shown is an overwhelming frustration at mental health services, somewhat away from the hope and motivation expressed earlier in the project.

Diagram 3: C'est LA Vie



The second diagram (Diagram 4) shows the complexity of trying to relate to all the findings presented concerning the experience of the participatory processes and the challenges of seeking change in seemingly impervious services, to the different identities the team member possessed in the course of the project. It shows a difficult internal grappling with the problem of identity associated with different assumed roles. The use of knotweed as a metaphor strongly communicates how insights into their own experiences were gained through the PAR process, and, crucially, the emotional turbulence and cognitive dissonance consequential on becoming a staff member with lived experience of service use. The experience of having to adapt and accommodate to different roles, values and expectations, implicit and explicit, left this person quite literally feeling tied up in knots.

Diagram 4: Japanese Knot Weed



This theme has shown that transforming mental health services in even small ways is a big ambition for a small group of people who are often swimming against the tide anyway, in a particularly challenging time for the NHS and mental health services overall. However, the team did undergo some profound personal change. Some of this was negative, and to do with personal circumstances beyond the project's control. Yet, some personal change was empowering: a greater understanding of research and the world, and the team's raised conscientiousness of their own position that PAR actively seeks to achieve. People also gained strength from working as a collective.

5.4 Conclusion to Chapter Five

PAR Excellence's central theme of Hubble, Bubble, Toil and Trouble spelt out their desire to meddle in mental health services through PAR. Shakespeare's original text was "double, double, toil and trouble. "Hubble, bubble, toil and trouble" is commonly understood as the activities of the witches in Shakespeare's Macbeth. It is argued that this error has become common parlance because it reflects the noise people imagine the witches' cauldron to make (Grogan 2017). This is in essence what PAR Excellence tried to do: make noise. It is also reflective of the common misunderstandings, myths and assumptions that become popular wisdom in mental health, which it is argued is best thought of as a mystery (Kelly et al 2010).

There are several analogies between PAR Excellence's endeavours and Shakespeare's plot. In the play there is Macbeth – the king who is willing to do anything to hold on to power, which can be seen as psychiatry and mental health services generally. Furthermore, he is disturbed by what the witches know but are not telling him, which is in line with the suspicion and mistrust that exists about people with mental health conditions, both in society and within mental health services. Macbeth seeks information from the witches but does not like everything he hears, which chimes with attempts to involve service users in mental health services. Finally, there are the witches themselves, concocting mysterious brews by throwing unexpected items into the mix. This is PAR Excellence and their activities: bringing something unusual through their own participation in both research and mental health services, and through their shared decision making resource of service users' experiences. Like the witches, they are in possession of untapped, hidden power through their knowledge.

The knotweed metaphor deployed by one PAR Excellence member depicts a set of challenging and disconcerting experiences that speak to the profound tensions of being 'in and against' the system. This positioning and identity can alter over time in relation to the different role expectations and demands. The feeling of 'selling out', or the critical accusation that this is at stake, is not uncommon in movement politics and is deeply associated with patterns of imperfect solidarity between co-workers and co-option pressures that are strongly felt, but often largely out of the control of individuals caught up in them (Bauman 2000).

This rather bleak final note encapsulates the complexity of participating in a research project in the immersive, deeply personal way expected when undertaking PAR. It also touches upon the frustration felt across the team in trying to bring about transformation and a degree of democratisation during a time when mental health services were not really receptive to the significant change sought by the team, but subject to a different, unwelcome change due to the turbulent political times and uncertainties of austerity and pressure on resources.

However, the findings still speak of hope. Interestingly, whilst hope of local change was eroded as the project setting veered further away from prioritising service user involvement in general, hope that the project could lead on to greater change elsewhere increased. Also, there was recognition that team members were making personal gains by being part of PAR Excellence. This was mostly because of the relationships they built within the team, and the peer support they gained from the process. But it was also due in some part to their development as researchers and in some instances by seeing a different, more positive side to staff whilst they conducted their research. Also, they gained

insights into their own position and standpoints, and through learning about this and research became empowered by their knowledge gains.

Essentially, this contributes to the original contribution to knowledge of the thesis by confirming that knowledge democracy can be achieved internally within a PAR project, even if the project only brings about knowledge democracy to its broader setting in a limited or unplanned way. The way PAR Excellence operated put the knowledge of team members on an equal footing with my own. It was recognised that I brought some essential research and participatory knowledge and facilitation skills that provided a strength to the team, but that their knowledge and experience (and 'fire in their belly') as service users was absolutely paramount to the project's establishment and success. Furthermore, although the project was not explicitly concerned with challenging the epistemic injustices of people who use mental health services in academia because it was not a route prioritised by the team, by becoming research active the team had the opportunity to speak at conferences alongside traditional researchers. This exemplary opportunity showed that the academic community is open to hearing non-traditional voices, and respects and welcomes the knowledge identified and created by processes such as PAR. These academic spaces gave the team priceless chances to exercise knowledge democracy not only by sharing their own knowledge alongside me, but also by challenging traditional researchers in debates.

In the final chapter that now follows, the ethical dilemmas raised by this chapter are discussed whilst all three questions set at the outset of the project are considered: can PAR be a vehicle for knowledge democracy in mental health overall?

CHAPTER SIX: OVERALL DISCUSSION AND CONCLUSION. PAR: A VEHICLE FOR KNOWLEDGE DEMOCRACY IN MENTAL HEALTH?

6.1 Introduction to Chapter Six

This final discussion and conclusion chapter considers the activities of PAR Excellence described in the previous three chapters in relation to the issues around epistemic injustice and knowledge democracy for people who use mental health services laid out in chapter two (background). Over the course of these discussions, the pertinent ethical and efficacy criticisms of PAR described in the methodology chapter are implicitly considered. In a final revisit to the tree analogy running through the thesis, this chapter is concerned with the impact the tree had on its environment, but also, how the environment affected the tree and its impact.

To return to the overall question of whether PAR can be a vehicle for knowledge democracy in mental health, this chapter is divided into four sections. Firstly, whether PAR was an appropriate choice to endeavour to bring about knowledge democracy is considered. Secondly, whether knowledge democracy was achieved internally within the project is debated. Thirdly, whether the project instilled knowledge democracy in the local setting that it set out to is discussed. This section also explores the parallels between shared decision making and PAR, and reflects on the challenges and barriers that make it difficult to achieve changes in shared decision making within mental health systems. The fourth section is the conclusion, where the original contribution to knowledge is set out. It is argued that for all its challenges and pitfalls, PAR can be a profound intervention for the individuals involved, and endeavours such as this project

needs to be seen through the lens of a broader movement that has the possibility to bring staff and service user mavericks wishing to disrupt the system together. This chapter ascertains that efforts to instil knowledge democracy in mental health services will always be threatened in the current climate, because we do not have the political environment or institutional structures required to achieve the widespread transformational change that would be required to instil true knowledge democracy. However, the PAR process can bring about significant personal transformation through the deep learning and consciousness raising in those who engage with it. This in turn means that people can contribute to the critical mass that needs to be reached in order to be part of broader transformational change.

6.2 PAR: An Appropriate Choice?

Here, we pose the question of whether the choice of PAR was appropriate to try to address some of the challenges that people who use mental health service place. The answer is yes. The justifications for choosing PAR set out in the background and methodology chapters were correct. It was evident that PAR Excellence strongly concurred with many of the issues faced by people with mental health conditions laid out in the background chapter. The team also demonstrated a fierce commitment to address these issues. This was not a surprise, as vested interest is a strong motivational factor for the impulse to participate in research (Oliver 1999). Furthermore, the staff in the project setting also identified some of the same issues.

There can be no doubt that Lukes (1972)'s analysis of three types of power resonated with PAR Excellence's experience of mental health services, as did a Foucauldian perspective on the indivisibility of knowledge and power. They identified overt tyrannical power that is exercised without consent of the

oppressed in their understanding of the dominant medical model and the government; democratic power where people are consulted but do not rule in how they are occasionally engaged by mental health services, and power executed through social institutions, customs, and discourses through their personal interactions with mental health services. The latter chimes with Foucault's insights into the enmeshment of psychiatric services with systems of governance and control, grounded in the overarching extension of power through the meta-narrative of bio-psychiatry, and Fricker's development of this view of the power of the episteme with reference to processes of epistemic injustice (Fricker 2007, Russo and Beresford 2015, Leblanc and Kinsella 2016). It was therefore wholly appropriate that PAR was chosen as a means of attempting to address these issues, for PAR is fundamentally concerned with addressing imbalances of power, and its working, inter-personal processes are commensurate with the prefiguration of alternative, more just and democratised social relations (Kemmis et al 2015).

This was cemented by PAR Excellence's chosen research topic of shared decision making in mental health, which is fundamentally about sharing power with professionals through mediating a process of knowledge exchange. It was further enforced by the team's decision to explore the use of recorded service user experiences as a shared decision making resource. By demanding that service users' voices should be heard in decision making, they were saying: we should be heard; we demand to be heard. By stating that service user experiences matter in decision making, they were saying: we matter, and our knowledge matters.

The next two sections regarding the instillation of knowledge democracy are more complex with no straightforward answers. The effectiveness of PAR in bringing about knowledge democracy within and outside of the PAR Excellence team are now considered in turn.

6.3 Knowledge Democracy within PAR Excellence

There can never be one “right way” of doing action research, and the diversity of approaches opens up a wide range of choices for its conduct (Reason and Bradbury 2008). The choices made in this project were in relation to the situation both myself and PAR Excellence members found ourselves in. However, this did mean that some compromises were required for pragmatic reasons that at times veered away from the more purist PAR approach I had hoped for, and continued to strive for throughout.

That the project was initiated by me, led by me and on several occasions, conducted by me alone rather than someone who uses mental health services meant that the project was vulnerable to being not truly participative from the outset, and therefore open to criticism. However, my position bought some distinct pragmatic advantages, and as the team discovered, it could have floundered without this kind of input. The position I held opened doors in two ways. Firstly, I was able to access a group of mental health service users with whom I had already built up a relationship with through my work role and connect them in their common cause. Secondly, I was able to quickly and easily access mental health teams to implement the project with as I was already involved with the teams in an organisational leadership position.

Klocker (2015) discusses the guilt that researchers can feel when they do take some control, and recognises that such deviation from a truly participatory

approach is open to criticism and negative judgement. However, she also identifies that the emotional wellbeing of a PAR team is the responsibility of the lead researcher/academic. Also, it has been emphasised that it is important that participatory researchers be flexible rather than purist in their understandings of what constitutes the most appropriate level of participation in a project (Kesby et al 2007). The requirements of completing my PhD in a timely fashion were never too far from mind either: as observed by Heaney (1993), students undertaking PAR need to take control of the research process in order to complete their course. But, PAR presents many challenges in practice, not least of which is working towards a realistic time scale (Walter 2009). Whilst action research cannot be for the impatient (Adelman 1993), at some point, some direction had to be used to ensure that the project was completed. But also, it has been found that the success of groups is due in some part to the facilitation and support provided by people who can draw on research and related skills to provide a safe, supportive environment (Simpson et al 2014). This is extremely important in safeguarding against some of the potential damage to participants of participatory approaches to research discussed in the earlier methodology chapter and returned to later here. This is confirmed in the findings, where there is no doubt that PAR Excellence greatly valued the role I played as facilitator. Indeed, they were of the view that the project would have floundered without that role, and the way I undertook it.

For all these internal tussles over not holding too much power and control (which at times the team thought I was over sensitive about), the motivations of those who adopt and practise participatory approaches are an important factor (Cornwall 2008), and despite the project being 'led' by me, it was participative because of my motivations for it to be so. PAR Excellence found choosing the

research topic highly participatively democratic, and were also empowered though the research knowledge they gained that deepened their critical voice. This was demonstrated throughout the relational processes of undertaking their work as well as in their attendance at and presentations at conferences as researchers, where they showed the confidence to provoke, challenge and question.

The development and maintenance of participatory relationships and implementation of participatory processes are crucial to the success of PAR (Danley and Ellison 1999). However, trying to remain true to a democratic process that respected diversity (Greenwood and Levin 1998) made some aspects of the project problematic. Some decisions were made by consensus (although this is a democratic method rejected by Greenwood and Levin), and some decisions were made that not everyone in PAR Excellence agreed with. But, at times, it seemed as if trying to remain true to a process that respected diversity was also unrealistically trying to be “all things to all people” by incorporating the views of every member of the team, even if they conflicted. This meant some compromises over more usual research robustness concerns, but also that the conceptual link between shared decision making and the shared service user experiences resource was at times muddled and confusing for both staff members and even team members themselves. For example, I regularly had to re-explain back to the team their own decision to explore shared decision making by recording service users talking about elements of their recovery. For some staff particularly in the social inclusion service, there was a real struggle to understand any element of what the team had proposed, and why.

Even within participatory practice that promotes authentic partnership, the actual practice between researchers and community members remains complex and involves making the power differences transparent, whether these differences are recognised or not. This means addressing such issues as who represents the community and university (if a university is involved), who owns the data, and who represents the research project to the external world. One of the principles of participatory approaches is the recognition that both researchers and community members have needs and agendas, which may sometimes be shared and at other times divergent or conflicting, especially if professional researchers pursue their career advancement at the expense of the community. For example, community members might be more interested in the jobs that research projects may bring to a community than in the knowledge production itself. An assurance is required that all parties will benefit from the knowledge produced (Wallerstein and Duran 2017).

Good participatory practice demands a recognition of historical or current relationships and of the potential natural scepticism resulting from historical patterns. In the mental health field, this territory is complicated by historical experiences of silencing, often on the basis of presumed 'rationality', which is a crucial consideration with regard to the interaction between knowledge and power, epistemic injustices and the sort of deliberative democratic processes that are often urged as part of a potential set of solutions (Hodge 2005a, McKeown and Spandler 2015, Young 2001). Being honest and open about these emotions is crucial. Indeed, ignoring or repressing feelings about research is more likely to produce distortion of data, rather than clarity (Lee-Treweek 2000). However, recognising the centrality of engaging with and attending to emotion throughout the research process and the potential

precariousness and chaos of research presents the challenge to work out how to resist making 'the messy' fit into a neat and tidy structure. In recognising and attending to that messiness, and in particular the emotional mess of research as a normal and valued part of participatory research processes, emotional experiences can then be seen as a valid source of data production that offers insights into the issues in question (Humble 2012).

A further, potentially more worrying element of the project is whether it did more harm than good for members of PAR Excellence. Action research gives credence to the development of powers of reflective thought, discussion, decision and action by ordinary people participating in collective research on "private troubles" that they have in common (Wright Mills 1959). However, PAR projects often fail to make a difference in a grand practical sense, and to live up to their own lofty ambitions. Failing to make the types of differences that seem sufficiently 'big' and 'important' can be deeply distressing and dispiriting. Those attempting PAR need to be prepared for the emotional pitfalls of research endeavours that seek to tangibly intervene in traumatised people's lives. Change is a messy process and any attempts to improve people's life circumstances can lead to an array of spin-off effects that are difficult to predict. These can of course, include all sorts of positive, relational benefits and improved confidence but, in some cases, change efforts may compound trauma and disadvantage rather than redressing it (Klocker 2015).

As eloquently articulated by one member in particular, the Freirean consciousness raising that occurred through PAR led this person to such an in-depth reflection on their own status and condition that by the end of the project, they felt more despondent and marginalised than they did at the outset. This

was in part because of the job they had taken up within services, which they attributed to getting because of the confidence the PAR Excellence project had given them. Once they had become an “insider”, they discovered the true extent of the powerlessness of service users in the face of the mental health system, and some of the problematic attitudes staff had. PAR Excellence had given them a platform for examining these issues on a profound level. During the lifespan of the project, two other members also gained employment within NHS mental health services. Interestingly, this shift in role did not lessen the strong critique and negative views of mental health services: in fact, it cemented them, for they had figuratively ‘looked upon’ the Wizard of Oz after their journey along the Yellow Brick Road. These roles afforded insights and theories as to why things were the way they were but did not dampen the sense of injustice felt – indeed, it reinforced it. The individual responses to this differed, however: some PAR Excellence members seemed to gradually shift further away from any service user identity and in turn the project, whilst for another, a full circle was made from rejecting the service user identity completely and withdrawing from the project for a time, to returning with an even stronger service user identity and sense of disillusionment and injustice. The PAR process, however, did support this team member to re-engage with their old allegiances, and re-affirmed their identity as an activist.

The hazard is that, by asking people to recount distressing experiences during the process of PAR, we are also promising that something good will come of it that will make the pain worthwhile. As articulated by Klocker (2015) though, there is no guarantee that the impacts of PAR projects will be unambiguously positive. This means that the risk of doing more harm than good can weigh heavily on the minds of researchers conducting PAR. PAR promises to make

research encounters 'worth the tears' (Robson, 2001), because it seeks to actively address the circumstances of participants' trauma. When PAR projects are conceived with the intent of producing long-lasting structural changes that benefit marginalised people, as this project did, there is the risk that seeming failure can become a source of great distress. When conducting research on a traumatic issue, there is a great deal of pressure to achieve something. Yet for academics who engage in PAR with the hope of achieving wide-reaching and structural reforms, 'failure' is a realistic prospect. When a deeply emotional research process is premised upon 'making a difference', apparent failure can be hard to accept and become a source of great distress in its own right (Klocker 2015). Conversely, the relational and personal gains incurred in the course of the project can be a consolation, a balm for the pain, or the spur to carry on in the pursuit of more just solutions to identified problems.

For members of PAR Excellence, what made sharing painful experiences worthwhile was what was gained from doing so within the group, rather than from bringing about any structural change. And, PAR is reliant on people engaging with difficult emotions. Emotions are central to PAR, because they motivate researchers to do something in response to apparent injustices, and emotions experienced by researchers and research participants also add meaning to research (Klocker 2015). Unfortunately, the team did conceive that the project had failed in some respects because it didn't fundamentally transform the local setting, and this caused some despondency and frustration. It is of great testament to the team that they decided to take validation from outside of the local setting instead, and were of the view at the end of the project that it was the setting that had failed, not them. They also continued to hold out hope that the project could have an impact elsewhere.

Furthermore, PAR can be concerned with personal and professional growth and empowerment, as well as knowledge generation (Herr and Anderson 2005), and it has been shown to be equitable, transformative and liberating for participants (Koch and Kralik 2006). Since the main characteristic is the communicative interaction between researchers and the traditionally researched upon, action researchers have to be experienced in handling this relationship as a minimum success factor, over and above their skills as adequate social researchers (Boog 2003). In those terms, PAR Excellence was a successful project, as it is clear in the findings that a powerful, democratised, communicative space was created. It can therefore be seen that PAR went some way in achieving some beneficial objectives to the individuals involved and as a group. Some elements of enhanced knowledge democracy were achieved: these were mostly in relation to developing research knowledge and implementation. However, I remained the person with the overall power – through my own research knowledge, and my leadership on the project. The next section considers if the project instilled knowledge democracy outside of the research team.

6.4 Knowledge Democracy Outside of PAR Excellence

The previous section argued that despite challenges, some elements of knowledge democracy occurred within in the project and that there were some positive transformations for team members. This section sets out that the project was far less impactful externally, and explores some possible reasons for this, including a reflection on the parallels between shared decision making and PAR and the challenges and barriers of shared decision making in mental health. It confirmed that implementing findings and recommendations is a key challenge (Cameron 2007). This is important, because there can be inflated

claims for PAR's impact on practice and policy and individual development can be reified whilst neglecting the organisation (Adelman 1993). Participatory approaches that use dialogue and visualisation processes to honour local knowledge to attempt local problem solving (De Koning & Martin) as was attempted in this project, can obscure the need to challenge state or global institutional policies that override local determinants of well-being (Francis 2001).

So, to the crux of the project. Did PAR Excellence's action result in knowledge democracy within the local setting where it took place? The answer is mostly no. It was clear in the findings that staff made little use of PAR Excellence's resource: "By People: For People: Shared Experiences to Support Shared Decision Making in Mental Health". There was also no medical engagement in the resource whatsoever, which is problematic as psychiatrists are the lead clinicians. However, that is not to say that there were not some useful outcomes. There were staff reports that some service users had found the resource highly beneficial, with one report of it having a profound effect on someone who used it. The biggest impact the resource had was on the staff themselves: they found that it provided insights into service users experiences that did change some of their thinking and practice. In this sense, some knowledge democracy was achieved, for the service user voice was placed centrally in staff reflective learning and practice. There was also an element of knowledge democracy in how welcomed the project was in principle because it was PAR: staff saw the project as being highly authentic, credible and important because it was driven by service users. Indeed, it was accepted into the community mental health team precisely because it was PAR, rather than a clinical researcher's project.

Why then was the implementation and impact different to what was hoped for? To try to understand this, it is necessary to look at the broader political and social context within which the project took place, and in particular the effects of the UK's version of political democracy – that is, majority rule. Greenwood and Levin (1998) argue that action research rejects the view of democracy as majority rule, and draw on Young's (1990) critique of this view of democracy as one that reduces social justice to the limited redistribution of goods to those defined as disadvantaged that is associated with the oppressive actions of welfare state capitalism. This view of democracy does not seek to enhance the capacity of the disenfranchised to act on their own behalf, but it is the one we all live within. There are implications here when trying to conduct PAR, as Mullett (2015) found. For marginalised individuals, a history of exclusion at a societal level is internalised on a personal level and transformed into feelings of irrelevance: of not being worthy of engaging in activities of the mainstream society. Devoid of this context, attempts at capacity building with knowledge are insufficient. A belief in belonging and ability is foundational. Even where participatory technologies successfully facilitate the performance of empowered agency within managed projects, more needs to be done to enable people to sustainably reperform those empowered ways of being within the very differently constituted spaces of their everyday lives (Kesby 2008). Oliver (1999) argues that there needs to be organisational commitment at all levels with clear and common goals, roles and responsibilities, resources, and shared information, decision making and accountability to achieve full participation. But, we are not living in a political system that will engender this, as it is philosophically at complete odds with majority rule governance. Furthermore, as the life world has increasingly become dominated by the systems world, people

have begun to define themselves by their roles within systems. They become objects - clients and consumers - rather than subjects or democratic members of civil society. The results of being objectified can be seen in powerlessness, poorer mental wellbeing, and the overall decline in people's belief that their participation makes a difference (Wallerstein and Duran 2017).

Although this is macro level discourse, ideals of service user participation, equality and empowerment are played out at a microlevel in the close relationships between service users and professionals (Femdal and Knutsen 2017). Power is relevant in all relationships, languages and practices, creating the structure where fields are formed, governed, and understood (McTaggart 1991). What has been abundantly clear through every element of the project and as also found by Godin et al (2007) is, in addition to the explicit and large-scale displays of force or macro-power, it is in the interpersonal relations between practitioners and service users where macro-power surreptitiously circulates, with an often implicit set of assumptions about how other people are to be identified and what they are capable of. This can manifest itself in the form of regular, seemingly innocuous gestures and utterances. Importantly, it has been suggested that this form of power is typically concerned with placing those people who use mental health services in 'the sick role', and transforming a person into a compliant recipient of treatment orders determined by the expertise of mental health professionals (Roberts 2010).

I argue that macro power and micro power are co-dependent: macro power gives credence and permission for the micro power to be exercised – and even demands it, whereas micro power provides the mechanism for macro power to continue. This project has been mostly concerned with micro power – in the

research process and in the relations between service users and service providers, and it has been found that personal transformation can occur on a micro power level. But, there will be no significant societal power shift unless macro power is challenged. PAR Excellence recognised that there is a status quo that needs challenging, and as Roberts (2010) argued and as recognised by some staff participants, staff need to challenge the status quo too if true participation is to occur. However, how possible this is in the current system that operates in a neo-liberal, capitalist political ideology during a period of austerity remains up for question. But another important question remains, and that is, how much do the macro power holders really desire a change to the status quo? By macro power holders, I am referring to policy makers, politicians, high level managers and particularly the psychiatric profession. It is argued that the language of psychiatry, and the attendant valuations or 'sense' of its diagnostic categories in particular, serve to restrict active service user involvement in mental health care (Roberts 2010). There is also political resistance to seeing service users as experts, coupled with a dominance of clinical neuroscience in journals (Faulkner and Thomas 2002). In psychiatry, the notion of service users ascending the power hierarchy is illusory and does not pay adequate regard to the institutional powers that exist within a wider society (Stickley 2006).

The other issue regarding implementation illuminated by the project was that there was no common understanding of the principles of shared decision making amongst staff, with some significant misunderstandings evident. These included the notion that shared decision making is about people "getting what they want", rather than a dialogue, negotiation and sharing of power in a partnership where different types of knowledge are respected by both parties and given equal credence. Also, a number of significant systematic and cultural

constraints and barriers were identified. Yet, can it be any wonder that staff are confused, divided and service users distrustful, and both groups disillusioned, when service user involvement comes from such polarised political ideologues: on the one hand, as part of a neoliberal, individualistic and consumerist agenda, or on the other hand as part of a rights based, emancipatory and collective one (Beresford 2002)?

These issues are relevant across both shared decision making and PAR, and what emerged is that there are clear parallels between shared decision making and PAR. These findings contribute to and take forward existing knowledge by providing insights into how shared decision making can be practised, by drawing on what can be learnt from PAR. These parallels can be sorted into three streams: philosophies, critique, and implementation.

Ostensibly, there are shared philosophies between PAR and shared decision making. Whilst the shared decision making literature review showed a divergence of philosophies on a spectrum from a compliance model to an empowerment model, most theory writing on the topic falls into the latter. This is clearly true too of PAR, which, as discussed in the methodology chapter, has its roots in empowering perceived disadvantaged groups. It is argued that participatory approaches challenge whose knowledge counts (Hall 2012), and whose ways of saying, writing and testifying count (Openjuru 2015). It should provide a mechanism to change the social power that determines what is credited as valid and useful knowledge (Macintosh 2010), and findings in PAR constitute knowledge that is lived and experienced by members of the community (Mullett 2015). All of these aspects of PAR are also reflected in shared decision making ideology on the empowerment end of the spectrum.

Shared decision making is frequently described conceptually as a challenge to mental health's traditional paternalistic model (Beitinger et al 2014, Perestelo-Perez et al 2011, Chan et al 2012, Tibaldi et al 2011, Duncan et al 2010, De las Cuevas et al 2012, De las Cuevas 2013, Drake 2009b, Simmons et al 2010), and should focus on collaboration between service users and professionals (Chong et al 2013b, Chan et al 2012, Drake et al 2010a), Duncan et al 2010, Salyers et al 2012). Service users should be seen as equal partners and experts who also bring knowledge in the decision making process (Perestelo-Perez et al 2011, Shepherd et al 2014, Curtis et al 2010, Drake et al 2009a, Goscha and Rapp 2014, Sullivan and Rae 2014). Paramount to the concept of shared decision making is ensuring that both the service user and the professional are equally and actively involved and share/exchange expertise and information to reach a consensus for which they both share responsibility (Drake et al 2010, De las Cuevas et al 2013, De las Cuevas et al 2014, Fukui et al 2015, Goscha and Rapp 2014).

Therefore, it is not surprising that there are also common themes in both the critique of PAR and the application of participatory approaches within NHS services such as shared decision making. The methodology chapter laid out criticisms of PAR, such as issues of retention of researcher control and expectations of participants to perform "appropriately" within the process (Kesby et al 2007, Cooke and Kothari 2001). Also, PAR ideals can be operationally constrained by institutions with bureaucratic goals (Mosse 2001) and the inclusion of participants runs the risk of symbolising an exercise in power and control over individuals (Cooke 2001).

These very real dangers in PAR are also threats in participatory approaches in mental health delivery such as shared decision making. Indeed, much of the discussion around shared decision making with staff concerned institutional constraints and obstructive bureaucracy, and they demonstrated a cognisance regarding their systematic power and control over service users. Furthermore, service users can become co-opted by having to adopt psychiatry's conceptual categories, diagnostic criteria and attendant valuations to be allowed to participate, which perpetuates psychiatry's 'body of knowledge' or 'discourse', along with the restrictive power that its discourse exerts (Stickley 2006). Power can be used to exclude certain voices, give legitimacy to the status quo and, in the process, reinforce existing structural power inequalities between service users and officials (Hodge 2005b). This was certainly a risk well-articulated in the findings from staff participants in this project, where they described both a power over the use of shared decision making as they saw fit, and how, when and with who to use the shared decision making resource. This resonates with Fairclough (1992)'s argument that the evaluation of the utterances of the non-powerful by the powerful can reinforce asymmetrical power relations, leading to great frustration on behalf of the service users who are unable to engage in meaningful debate about the fundamental issues that really concern them (Hodge 2005b). There too is an overlap here with PAR surrounding the discomfort that some staff expressed at the possibility that the shared decision making resource could devalue professional knowledge: this echoes Anderson (2017)'s observations about the PAR's threat to the status of traditional researchers by expanding what is known as 'expertise'.

The parallel issues across shared decision making and PAR naturally impact on the implementation of both. Fundamentally, both staff trying to practise shared

decision making and PAR practitioners are working in a political or local system that is not conducive to either. This creates practice difficulties. The democratic processes required for PAR that Walter (2009) argued can lead to competing agendas are also required for shared decision making. This causes hard ethical dilemmas, as described by the staff participants in the project. Also, as shown in the shared decision making literature review, there is a lack of knowledge about shared decision making and implementation strategies – as is true of PAR. Like shared decision making, the methods of actual PAR application can be vague, and reports of PAR implementation are presented neither in terms of specific or observable behaviours (White et al 2004).

The features that have been explored here demonstrate why there are challenges and barriers that make it difficult to achieve changes in shared decision making within mental health systems. However, whilst parallels have been described here across shared decision making and PAR, there are further complexities in the former, and the myriad of issues in shared decision making across healthcare overall identified by Légaré (2008) were reflected in the findings of the project – especially around the perceived inability to reconcile patient preferences. The further unique challenges to implementing shared decision making in mental health compared to other healthcare fields (Duncan et al 2010, Perestelo-Perez et al 2011) was also articulated by the staff participants. These include staff participants' perceptions of service users' abilities and desire due to their expectations and conditions, as well as a system that includes restrictive elements such as the Mental Health Act. The inherent power imbalance alongside providers' ability to legally override service users' preferences means that there is a different dynamic in mental health compared to other healthcare areas. As described in this project, the views of

professionals in mental health settings can continue the tradition of being provider-centric, where expertise is seen as located in the professional. The use of legal constraints, coercion, involuntary treatment, and assumptions about service users' ability or interest to participate reinforces this paternalism (Gordon and Green 2013, Curtis et al 2010). Therefore, a great deal of reflexivity to examine one's own power is necessary to eliminate elements of practice that is an expression of force (Roberts 2008), particularly considering the complex, fluctuating, and multi factorial nature of mental health conditions that can impact on shared decision making (Simmons et al 2010). Whilst such reflexivity should be a strong feature inherent any PAR project, there is not always the space for this in healthcare practice (Redmond 2006).

An overriding commonality to emerge across both effective shared decision making and PAR conduct is that activities associated with both operate on a spectrum, with a pragmatic approach required for both. The findings showed that the staff who were most articulate and confident in their shared decision making practice were the ones who could navigate the system and make it work best for them and their service users whilst understanding its constraints and limitations. This is also true of the staff who made the best use of PAR Excellence's shared decision making resource with service users. Rather than dispensing with shared decision making altogether, they did the best they could within the system. As discussed in the methodology chapter, such a pragmatic approach was also necessary in the implementation of PAR in this project. This was to ensure the wellbeing of PAR Excellence members, manage their expectations in order to avoid disappointment and even possible distress, and to ensure project effectiveness and completion. The other key commonality to emerge is the requirement for reflexivity in both. The project has contributed to

original knowledge by identifying these commonalities between PAR and shared decision making in mental health, and demonstrating what can be learnt by both areas from each other, thus strengthening the potential for practice in both.

As it is research that Lewin, Fals Borda and Freire argued could be a vehicle for the transformation required to bring about knowledge democracy, consideration too must be given to the academic community. It is clear that for knowledge democracy to occur through the use of research, some fundamental shifts need to occur. As articulated by PAR Excellence, academic language can be a real barrier to participation. The relational politics of knowledge production are also under-interrogated in participatory literature, where academic authors are largely monological, while other knowledge constituencies are typically (re)presented by knowledge elites. This thesis reproduces this trend, and is paradoxical in critiquing the epistemic privilege of academe, while centering the academic voice. This paradox is a significant limitation of participatory academic writings (Janes 2016). Fals Borda (2001) urged academics to throw away learned jargon and communicate with everyday language. Repressive power, as expressed, for example, through the use of research language that is overly technical, can inhibit how communities may respond to researchers (Wallerstein and Duran 2017). In this project I endeavoured to keep technical research language to a minimum, using easily understood, everyday life examples to explore research methodologies.

However, like psychiatry, the democratisation of research and knowledge can become a threat to academic researchers' sense of status, expertise and professional identity, and they can often recoil at the notion of expanding

expertise to the 'researched'. There are also concerns that that the long struggle to legitimise qualitative research might be undermined by participatory or action-oriented forms of research (Anderson 2017). James (2016) explored and exposed the epistemic privilege of academics and knowledge democracy ironically, by her own admission, in a highly academic paper. In doing so, she demonstrates how in reality, these discourses are almost impossible to have outside of an academic tradition. James highlights the real dilemma evident here: how can the language and the processes of participation meet the needs both of the traditional academic community, and the non-traditional community knowledge holders? Rose (2004) places some responsibility too on service users themselves to adapt, arguing that service users who wish to promote participatory types of research need strategies to give such research credibility so that it is taken seriously without diluting its political agenda. This was echoed by PAR Excellence team members themselves, who recognised that they needed to find the right way to present themselves if they were to be taken seriously. Rose acknowledges that the translation between the discourse of professionals and that of service users is not an easy one. She advises that the best of 'science' should be pursued, but always inflected with service users experiencing psychiatric services, delivering good quality research outputs with a demonstrable benefit to the academic community, practitioners and, most importantly, to service users. This was certainly something that PAR Excellence were cognisant of, in their ambition to produce "high class research".

PAR Excellence found that one of the most empowering aspects of the project was the research education programme, with the team reporting a significant growth in knowledge and confidence in research. The shift in confidence was stark, as evidenced by the team's assured and effective appearance at the

ethics committee, as well as their ability to both present and challenge at conferences. However, as James (2016) questioned: although capacity building is seen as a key activity in PAR through research training, how much can this really contribute to the emancipation of a community and self-determinism – especially considering the years it takes to become a professional, academic researcher. She also argues that it is not likely to make a difference to an individual either, with the short amount of time spent on research training. This concern was echoed regularly by a PAR Excellence member who still felt excluded from a research career despite their involvement in the project by lack of qualifications, experience, connections, and familiarity with the language. This concern played out in practice when they were discouraged from applying for a junior research post by the recruiting academic. There is clearly a difference between knowledge/understanding, and credentials/qualifications. Service users provide unique understanding about their experience of marginalisation, whilst academics provide the theoretical and technical knowledge that service users need to speak authoritatively in the academic field (Godin et al 2007). The challenge is how do we bring the two together in an inclusive, equitable way, for an overt focus on professionalism will reduce creativity (Fazzi 2016).

There also needs to be a major shift around the process for gaining ethical approval from institutions (namely, universities and the NHS), to protect against some of the quality and authenticity issues raised in the methodology chapter such as assurance that a PAR project is truly participatory and doesn't deepen powerlessness, instead of the current approaches to ethical approval that are formed on more traditional approaches. The questions asked of me by the University ethics process regarding the establishment of PAR did not

particularly address the quality and ethical issues raised by Klocker (2015) above and Khanlou and Peter (2005) as discussed in the methodology chapter. A further barrier is that of funding. In true participatory research, the research question must come from the participating community. This is difficult to achieve in a funding context where the funder decides what the subject of the tender is to be (Rose 2004).

Another issue raised by the sometimes bruising encounters that PAR Excellence members had in the traditional academic spaces at conferences is how to ensure that people who enter such spaces because of their personal, identity-based interest and emotional investment in their subject are not damaged by these encounters. While thinking through and engaging in conflict within community, it is crucial to acknowledge that conflict exists among academics too (Janes 2016). However, understandably, team members found the argument and challenge of ideas that is the “sport” of academia very hurtful at times, because the debate meant some much to them personally, on a profound level. So, whilst the team found some traditional academic encounters empowering and confidence building, they also shone a light on what some people really think of service users and the depth of stigma and discrimination they were up against. Like the team member who became more despondent once they became a staff member, these encounters provided insights that caused some distress.

In the end, it should not be surprising that the very aspects of culture and society that Marx, critical theorists and pioneers of PAR rallied against have to some degree scuppered some of the efforts of this project to bring about systematic change, even on a small, local level. Fals Borda (2001) lay the fault

for social conditions that PAR seeks to transform at the feet of capitalism. It has been argued that the process of the rationalisation of all spheres of life in modern societies does not open up the possibility of a fully emancipated society (Wellmer 2014), and that participative democracy is not a kind of societal order that can survive in small corners in an otherwise hierarchically structured world (Gustavsen et al 2008). The biggest challenge to PAR may be that, as in principle it is about the redistribution of power, the majority power holders must recognise their power, and be willing and able to share it. Unfortunately, under the current system of majority rule, representative democracy does not seek to enhance the capacity of the disenfranchised to act on their own behalf (Greenwood and Levin 1998).

However, by drawing on Peter Sedgwick's work, the necessity for discussion regarding continued strategies for provocation and challenge has been highlighted. This dialogue, if conducted with mutual understanding, could lead to more creative and sustaining strategies. It is argued that now more than ever, service user and staff mavericks and recalcitrants need to coalesce in these dialogues, however turbulent and unsettling (McKeown 2016, Spandler et al 2016, McKeown and Spandler 2015). This project has shown that PAR can be a utility to provide the Habermasian communicative action discussed by Godin et al (2007), where truths can be revealed and an unforced consensus can be reached through the provision of free open communication undistorted by the imposition of power. It is argued that this is the key to participatory democracy and emancipation. However, within the modern rational, strategy-orientated world, opportunities for open debate are limited. But that is not to say that

attempts at transformation that don't completely fulfil their grander ambitions are not worthwhile: small-scale, situated forms of participative democracy can exist as an alternative to societal norms, and prefigure larger scale initiatives or the necessary micro-relations. Nor should failures demand that we should not keep trying. "Although as Habermas acknowledges, the ideal speech situation and communicative action are ideals that only more-or-less exist in modernity's corrupted and yet-to-be-completed project of Enlightenment and participatory democracy, these ideals are worth striving for" (Godin et al 2007 p468).

On this note, I bring this discussion to a close. In keeping with the nature of personal reporting of the project, I end on an excerpt from my reflexive account, before moving on to the conclusion. I shared these reflections with PAR Excellence, and they related to them so strongly that they decided that the story should be used at two dissemination events. It is an allegorical telling that exemplifies the conclusions that we all drew from the project. It reflects the experiences of the team in their roles as people who tried to influence mental health services through being in PAR Excellence and in a number of other involvement initiatives, as people who receive mental health services, and as people who received support from me in my privileged role. It is the story of the Equatorial Guinean swimmer, Eric Moussambani – otherwise known as Eric the Eel. In keeping with the approach of using of visual material as a form of communication used in other participatory elements of the project, there are some pictures below to illustrate Eric's story.

Eric entered the 2000 Sydney Olympics as the sole swimmer from his country. He had never seen a 50m Olympic swimming pool before arriving at the Sydney pool. There were no proper swimming pools for Eric to use for training in

Equatorial Guinea. He was allowed to use a 13m hotel pool for just three hours a week.



His coach was a fisherman, not a swimmer, who taught him how to not sink in the sea. When he arrived in Sydney, it was the first time he had swum in a 50m swimming pool. He was terrified when he saw the pool for the first time.



Eric told the organisers that the pool was too big for him to swim in. He did not know how to do a dive start, or a tumble turn. He couldn't co-ordinate his breathing. He watched other teams training and tried to ask questions. People mostly ignored him, and when they saw him in the water, they questioned if he was a swimmer. However, one coach did speak to him – the South African coach. He said that he did not see a swimmer in Eric. But, he supported him, gave him some advice, and helped him to improve his technique.



When Eric got to the heat he was swimming in, he was so nervous he couldn't speak to people. He entered the pool area, and saw how many people in the audience he was going to swim in front of. He was terrified of doing something that would make people laugh at him.

Eric lined up on the blocks with two other swimmers. However, they were disqualified for jumping the starting gun. When the race was halted, Eric assumed that it was him who had been disqualified. He was told he had to swim the heat alone, but that just made things worse for Eric because he realised everyone would be looking at him only.



Eric technically won his heat because his competitors were disqualified. Much to the amusement of the swimming world, He took over twice as long to swim the 100m than other Olympic swimmers, getting from one end of the pool to the other and turning with a lack of finesse and prowess not usually associated with Olympic swimming. During that 100m swim, Eric got so tired that he couldn't feel his legs, and he felt like he wasn't moving forward at all. However, the crowd got behind him, and were cheering him on. Hearing people cheering gave Eric the strength and power to finish.

In the end, people loved Eric. He became world famous and respected for his spirit and determination despite all the odds. He came to be seen as demonstrating the true participatory spirit of the Olympics.

An uplifting story. However, there is a sting in the tail of Eric the Eel's story. Despite fairly winning his heat, he was not allowed to swim in the next heat because he was too slow. Eric never got to swim against the elite swimmers.

What happened to Eric can happen to people who have used mental health services when they get involved in research, and the NHS. They are welcomed and admired in principle, but in reality, they do not have the background or resources that would equip them to participate fully in a hierarchical world with very fixed notions of what true knowledge is. Like Eric technically winning his heat but not being able to progress any further, service user participation doesn't go as far as the top table, however much service users have the right to be there. Another commonality is the sense of self-blame: when the race was halted, Eric immediately assumed that it was because of something he had done wrong, not the other swimmers. This happened with PAR Excellence, when they first tried to understand research papers.

However, Eric's story also tells us something about the human spirit that applies to PAR Excellence members. They too decided to participate in a perceived elite field (that of research), despite knowing that the odds were mostly stacked against them, and a field that can be unfamiliar and intimidating. Also, like Eric, they found that someone who doesn't ignore you is needed, and who tries to impart some knowledge that will help you – even when they too can see really that you are quite against all the odds.

Like PAR Excellence members, through his participation Eric did undergo a personal transformation, despite never making it to the top level in swimming. And, he paved the way for the disadvantaged swimmers in his home country by using his experience and celebrity to develop the sport and get an Olympic sized swimming pool built. So, sometimes success doesn't look like we think it should, and sometimes, something small but special happens that becomes hugely significant in bringing about change.

Although PAR Excellence's impact may have been limited outside of the team, they have at the least potentially contributed to the critical mass that may one day see the societal transformation required for true knowledge democracy in mental health. Resistance movements have often had to go for decades before enough of a critical mass arrives to bring about change (Timimi 2018). It is of huge credit to the PAR Excellence team that despite feeling that they did not make the level of desired change to the mental health services locally that would have had a direct personal benefit, they still want the work to continue, and have an impact elsewhere. They have demonstrated an overwhelming generosity in encouraging me to take the work forward in my new job in a new Trust following redundancy from the Trust where the project was conducted⁵. Like Eric, they concluded that, as long as their endeavours, however painful at the time, would benefit someone somewhere, it will have been all worthwhile.

⁵ My post of service user involvement lead within the Trust was removed during the final few months of the project, resulting in redundancy. The team's final feelings towards the local Trust cannot be separated from this, as it led to despair that the Trust had no interest in their voice at all anymore, effectively making the move to disinvest in support for organised service user involvement. It also meant that they knew that the work that they had done would not necessarily be taken forward locally, or implemented as thoroughly as might be expected with a lead role in place.

6.5 Final Conclusion: A Case for Cautious Optimism

This is not our story to tell. But this is our battle, because it's no good having privilege if you only intend keeping it to yourself. Where is the value if you can't share it out? You have to be thankful first...and then make noise (Landreth 2017 p296).

At the outset, the use of an unusual structure with non-traditional chapters in this thesis was justified because it was a reflection of the non-linear nature of PAR. Through the telling of the endeavours of a team of mental health service users called PAR Excellence - their magical mystery tour through PARE Village, their meddling in mental health services with their mysterious witches brew, and their revelatory trips to The Wizard of Oz, it has been made clear that this unusual presentation was wholly necessary to communicate the complex, messy nature of the project. The background chapter established that people who use mental health services are marginalised, and explored some of the reasons why before arguing that PAR might be a solution to epistemic injustice by being a vehicle for knowledge democracy. The methodology chapter built on this argument through a discussion of PAR and its roots, its relation to critical theory, its critiques, quality and ethical matters, and the essential role of reflexivity. It then described how PAR was implemented in this project by the description of the activities of PAR Excellence. The large action chapter presented the resource created by PAR Excellence: "By People, For People: Shared Experiences to Support Shared Decision Making", and their direct research with mental health staff. They concluded that whilst the use of a library of recorded service user experiences as a shared decision making resource was generally welcomed in principle by staff and showed the potential

to be powerful for both service users and staff, in practice there was limited utilisation of the resource. Furthermore, it was found that shared decision making is a complex concept that has many different meanings amongst staff, and they work in a system where true shared decision making cannot consistently occur. However, it was also shown that staff welcomed PAR as an approach. The participation chapter established that whilst personal transformation through PAR was achievable, the potential for more general transformation was limited due to the political and economic climate within which mental health services operate, the dominance of the medical model, and the enmeshment of the two. The findings in this chapter showed that the team's motivations were rooted in a profound, collectively developed understanding of the power that mental health services had over them, distrust and dissatisfaction with services, and a deep sense of injustice. This led the team to a concept of subversive "meddling" in mental health services to address these issues. The discussion chapter concluded that knowledge democracy did occur within the team if not so much outside of it, and although the scale of transformation or level of disruption in local mental health services did not occur quite as much as hoped, the communicative space provided by the project led to personal benefits and provided the potential for the team to be part of the critical mass required for greater transformation in mental health services by holding onto a hopefulness that change may be postponed rather than completely denied. As Mullett (2015) suggests, knowledge democracy can occur on different scales. The project may not have achieved Hall (2013)'s grand social change, but it did travel some way towards equity in power over knowledge and bi-directional learning within the project through the provision of communicative space and personal capacity building and growth. It has shown

that PAR can empower individuals at a deeper level and that they are capable of constructing and using their own knowledge (Freire 1970, Reason 2005).

The project also fulfilled some of the original, essential elements of PAR. Although these methods strive to provide more influence on the functioning and decision making processes of organisations and institutions from the context in which they act, it can also be used, as was the case here, to improve capacities to solve problems, develop skills (including professional skills), and increase the chances of self-determination (Boog 2003). The project has confirmed Allam et al (2004) and Hutchinson and Lovell (2013)'s previous findings that there is the potential for transformation, connection, credible definitions of self and reciprocity for service users who collaborate in research, and Simpson et al (2014)'s findings that there are a range of significant personal gains, growth, opportunities and development for mental health service users who become involved in research: "the combination of a friendly, supportive group environment and the opportunity to engage with purposeful activities focused on generating high quality research ultimately designed to improve mental health services is a winning formulae" (Simpson et al 2014 p29). It must also not be forgotten, that despite the challenges that we all faced at times during the project lifespan both within and outside of it, that we also had a great deal of fun and enjoyment along the way. This is important, for the members of PAR Excellence had all gone through periods in their lives when there was an absence of the camaraderie and purpose that could bring such joy.

Another cause for optimism is that there were commonalities in the findings from both staff and PAR Excellence regarding discomfort at the mental health systems holding participation back. Whilst PAR Excellence members were

adamant that co-production would not have worked in this project, the way forward may be to develop a different means of bringing staff and service users together as activists to challenge the political and societal aims that are keeping service users marginalised. Anderson (2017) argues that PAR, by building an alternative power base through creating alliances, has the potential to cause the meddling that PAR Excellence sought by disrupting the pro-market and business approaches to the public sector that have created an audit culture driven by top-down, high stakes accountability and the fetishisation of data. It was clear that some staff members involved in the shared decision making element of the project were as uncomfortable about this as some service users are. But, people who go against what are considered 'standard' institutional expectations may become at risk from employers persecuting their practice (Timimi 2018). There is the potential for these people to strengthen their voice by aligning with service user mavericks looking to disrupt, and challenge these issues collectively (McKeown 2016). Linked to this is the way the project highlighted that some mental health service staff are also service users. This is an untapped fountain of hidden knowledge and resource from which everyone could benefit on multiple levels by melting away the false differentiation between service user and staff identity.

This project has made an original contribution to knowledge because despite a plethora of commentary urging more participatory ideals and use of PAR, and arguments that this promises a route to practice change and personal empowerment, there are few thoroughly documented fully fledged PAR projects in the adult mental health NHS field in the UK, where service users participated right at the outset in choosing a research topic and in all design decisions. There are examples of the adoption of participatory principles and inviting

service users to be part of research projects, and there is survivor led research that almost by definition is participatory – but a relative absence of reported PAR projects.

This PAR Excellence project is unique in the UK, having several differences in terms of focus from other uses of PAR in the mental health field. The team successfully created a tangible shared decision making resource of a multi-media library of recorded service user experiences that showed the potential to have a profound effect on both service users and staff, even if the ultimate adoption of it into routine practice was limited at this point. The project also confirmed the promise of PAR in relation to the personal creativity, growth and empowerment of the individual members of PAR Excellence. These intertwining features have produced an original analysis of knowledge democracy in the context of adult NHS mental health services in the UK. This was achieved against an unpropitious backdrop of austerity and cuts in the NHS context where the project took place, and which significantly affected some team members profoundly on a personal level outside of the project.

I end this conclusion with a return to my original motives at the start of the project. As Freire (1970) argued, to wash your hands of the conflict between the powerful and the powerless means to side with the powerful. As he advised, I have tried to practice the radical, entering into the complex and challenging territory of the psychiatric system in an effort to transform it by knowing it better. I have tried to not be afraid to confront, to listen, and to see this world unveiled, or be afraid to meet people or to enter into a dialogue with them. I have tried not to consider myself the proprietor of the history of all people, or the liberator of the oppressed, but have committed to fight at their side. Paradoxically to

Landreth's quote at the start of this section, I have been the one to tell this story in detail. But, I have sought to ensure that the authentic voices of the PAR Excellence team shine through in some way, through the presentation of their own work, words, drawings and metaphors. Finally, in response to the concerns highlighted about the risks of PAR being a path to failure paved with good intentions, I have argued that we cannot let the quest for perfection be the enemy of progress.

REFERENCES

- Adelman, C. (1993) *Kurt Lewin and the Origins of Action Research*. Educational Action Research, 1:1, 7-24
- Allam, S., Blyth, S., Fraser, A., Hodgson, S., Howes, J., Repper, J., and Newman, A. (2004) *Our Experience of Collaborative Research: Service Users, Carers and Researchers work together to evaluate an assertive outreach service*. Journal Of Psychiatric and Mental Health Nursing, 11(3), 368-373
- Anderson, G. (2017) *Participatory Action Research (PAR) as Democratic Disruption: New Public Management and Educational Research in Schools and Universities*. International Journal of Qualitative Studies in Education, 30:5, 432-449
- Andrews, S B., Drake, T., Haslett, W., and Munusamy, R. (2010) *Developing Web-based Online Support Tools: the Dartmouth Decision Support Software*. Psychiatric Rehabilitation Journal, Summer; 34 (1): 37-41
- Anthony, W A. (2010) *Shared Decision Making, Self-determination and Psychiatric Rehabilitation*. Psychiatric Rehabilitation Journal, Autumn; Vol. 34 (2), pp. 87-8
- Arnstein, S, R. (1969) *'A ladder of citizen participation'*. Journal of American Planning Association, Vol. 35, No 4, July, pp. 216 – 224
- Barr, B., Kinderman, P. and Whitehead, M. (2015) *Trends in Mental Health Inequalities in England During a Period of Recession, Austerity and Welfare Reform 2004 to 2013*. Social Science & Medicine, 147, pp.324-331
- Bar-On, A and Prinsen, G, P. (1999) *Planning, communities and empowerment: An introduction to participatory rural appraisal*. International Social Work, 42(3), pp.277–294
- Banks, M. (1998) *Visual Anthropology: Image, Object and Interpretation*, in Prosser, J (ed), in *Image-based Research: A Sourcebook for Qualitative Researchers*. London, Fulmer Press
- Baum, F., Macdougall, C., Smith, D. (2006) *Participatory Action Research*. Journal of Epidemiology and Community Health, 60, 854-857
- Bauman, Z. (2000) *Liquid Modernity*. Cambridge, Polity
- Beitinger, R., Kissling, W., and Hamann, J. (2014) *Trends and Perspectives of Shared Decision-Making in Schizophrenia and Related Disorders*. Current Opinion in Psychiatry, 27(3):222-229
- Beresford, P. (2002) *User Involvement in Research and Evaluation: Liberation or Regulation?* Social Policy and Society, Vol 1 / 2 pp 95 105

- Berkowitz, R., Shavit, N., Leff, J. P. (1990) *Educating Relatives of Schizophrenia Patients, Social Psychiatry and Psychiatric Epidemiology*, in Thornicroft, G. (2006) *Shunned: Discrimination against People with Mental Illness*. Oxford University Press
- Bentall, R.P. (2009) *Doctoring the Mind: Why Psychiatric Treatments Fail*. London, Penguin
- Biccum, A. (2005) 'Development and the 'New' Imperialism: a reinvention of colonial discourse in DFID promotional literature'. *Third World Quarterly*, vol. 26, no. 6, pp. 1005-1020
- Boog, B, W, M. (2003) *The Emancipatory Character of Action Research, its History and the Present State of the Art*. *Journal of Community and Applied Social Psychology* 13: 426–438
- Boyatzis, R. E. (1998) *Transforming Qualitative Information: Thematic Analysis and Code Development*. London, Sage
- Bracken, P., and Thomas, P. (2001) *Postpsychiatry: A New Direction for Mental Health*. *British Medical Journal*; 322 :724
- Braun, V., and Clarke, V. (2006) *Using Thematic Analysis in Psychology*. *Qualitative Research*, 3: 77–101
- Briant, E., Watson, N. and Philo, G. (2013) *Reporting Disability in the Age of Austerity: the Changing Face of Media Representation of Disability and Disabled People in the United Kingdom and the Creation of New 'Folk Devils'*. *Disability & Society*, 28(6), pp.874-889.
- Browne, T. K. (2017) "A Role for Philosophers, Sociologists and Bioethicists in Revising the DSM: A Philosophical Case Conference". *Philosophy, Psychiatry, & Psychology*, vol. 24 no. 3, 2017, pp. 187-201
- Bryman, A. (2008) *Social Research Methods*. Oxford University Press
- Cahill, C. (2007) *Participatory Data Analysis*, in Kindon, S., Pain, R., and Kesby, M. (eds) (2007) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Abingdon, Routledge
- Cameron, J. (2007) *Linking Participatory Research to Action: Institutional Challenges*, in Kindon, S., Pain, R., and Kesby, M. (eds) (2007). *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Abingdon, Routledge
- Care Quality Commission (2012) National Standards, <http://www.cqc.org.uk/public/national-standards>, accessed on 03/09/2012
- CASP (Critical Appraisal Skills Programme) (2017) <http://www.casp-uk.net/casp-tools-checklists>, accessed on 25/12/17

- Castillo-Burguete, M.T., García-Gómez, C., Castro-Borges, P. and Dickinson, F., (2015) *'I'm Not Afraid of Him; That Dog Barks But He Don't Bite'*. *PAR Processes, Gender Equity and Emancipation with Women in Yucatán, Mexico*, in in Bradbury, H. (ed) *The Sage Book of Action Research*. London, Sage
- Chambers, R. (2008) *PRA, PLA and Pluralism: Practice and Theory*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage
- Chan, K K S., Mak, W W S. (2012) *Shared Decision Making in the Recovery of People with Schizophrenia: The Role of Metacognitive Capacities in Insight and Pragmatic Language use*. *Clinical Psychology Review*, 32, 535–544
- Chesney, E., Goodwin, G. M., and Fazel, S. (2014) *Risks of All-Cause and Suicide Mortality in Mental Disorders: a Meta-Review*. *World Psychiatry*, 13: 153–160
- Chiu, L.F. (2003) *Transformational potential of focus group practice in participatory action research*, *Action Research*, 1(2), pp.165-183
- Chong, W W., Aslani, P., Chen, T. (2013a) *Multiple Perspectives on Shared Decision-Making and Interprofessional Collaboration in Mental Healthcare*, *Journal of Interprofessional Care*, May; 27 (3): 223-30
- Chong, W W., Aslani, P., & Chen, T F. (2013b) *Shared Decision-Making and Interprofessional Collaboration in Mental Healthcare: a Qualitative Study Exploring Perceptions of Barriers and Facilitators*. *Journal of Interprofessional Care*, 27(5), 373-379
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., Morgan, C., Rüsçh, N., Brown, J.S.L. and Thornicroft, G. (2015) *What is the Impact of Mental Health-Related Stigma on Help-seeking? A Systematic Review of Quantitative and Qualitative Studies*. *Psychological Medicine*, 45(1), pp.11-27
- Clements, K. (2011) *Participatory Action Research and Photovoice in a Psychiatric Nursing/Clubhouse Collaboration Exploring Recovery Narrative*. *Journal of Psychiatric Mental Health Nursing*, Dec 28
- Coffey, A., and Atkinson, P. (1997). *Making Sense of Qualitative Data*, London, Sage
- Cohen, A. (1992) *Prognosis for Schizophrenia in the Third World: a Re-Evaluation of Cross-Cultural Research*. *Cultural and Medical Psychiatry*, 16: 53–75

- Cook J A, Shore S E., Burke-Miller J K., Jonikas J A., Ferrara M., Colegrove S., Norris WT., Ruckdeschel B., Batteiger A P., Ohrtman M., Grey D D., Hicks ME. (2010) *Participatory Action Research to Establish Self-Directed Care for Mental Health Recovery in Texas*. *Psychiatric Rehabilitation Journal*, 34(2):137-44.
- Cooke, B. (2001) *The Social Psychological Limitations of Participation?* in Cooke, B., and Kothari, U. (eds) (2001). *Participation: The New Tyranny?* London, Zed Books
- Cooke, B., and Kothari, U. (eds) (2001) *Participation: The New Tyranny?* London, Zed Books
- Corrigan, P W., Angell, B., Davidson, L., Marcus, S C., Salzer, M S., Kottsieper, P., Larson, J E., Mahoney, C A., O'Connell, M J., and Stanhope, V. (2012) *From Adherence to Self-Determination: Evolution of a Treatment Paradigm for People with Serious Mental Illnesses*. *Psychiatric Services*, Feb 1; 63 (2): 169-73
- Cornwall, A. (2008) *Unpacking 'Participation': Models, Meanings and Practices*. *Community Development Journal* Vol 43 No 3 July 2008 pp. 269–28
- Cornwall, A., and Jewkes R. (1995) *What is Participatory Action Research?* *Social Science & Medicine*, Volume 41, Issue 12, December 1995, Pages 1667-1676
- Costa, L., Voronka, J., Landry, D., Reid, J., Mcfarlane, B., Reville, D. and Church, K., (2012) "Recovering our Stories": A Small Act of Resistance". *Studies in Social Justice*, 6(1), p.85
- Coulter, A. (1997) *Partnerships with Patients: The Pros and Cons of Shared Clinical Decision-Making*. *Journal of Health Services Research & Policy*, Vol 2, Issue 2, pp. 112 – 121
- Cromby, J., Harper, D. and Reavey, P. (2013) *Psychology, Mental Health and Distress*. London, Palgrave Macmillan
- Crossley, N. (1998) *RD Laing and the British Anti-Psychiatry Movement: a Socio-Historical Analysis*. *Social Science & Medicine*, 47(7), pp.877-889
- Crichton, P., Carel, P., and Kidd, I. (2016) "Epistemic injustice in psychiatry". *Psychiatric Bulletin*, Vol. 42 No. 2, pp. 65-70
- Curtis, L C., Wells, S M., Penney, D J; Ghose, S S., Mistler, L A., Mahone, I H., Delphin-Rittmon, M., del Vecchio, P., and Lesko, S. (2010) *Pushing the Envelope: Shared Decision Making in Mental Health*. *Psychiatric Rehabilitation Journal*, Summer; 34 (1): 14-22

Cutcliffe, J.R., Santos, J.C., Kozel, B., Taylor, P. and Lees, D. (2015) *Raiders of the Lost Art: A Review of Published Evaluations of Inpatient Mental Health Care Experiences Emanating from the United Kingdom, Portugal, Canada, Switzerland, Germany and Australia*. *International Journal of Mental Health Nursing*, 24(5), pp.375-385

Decision Support Centers. (2013) *APA Gold Award: Amplifying the Voices of Individuals Who Use Mental Health Services: A Commitment to Shared Decision Making*. *Psychiatric Services*, Oct 1; 64 (10): e7-9

Deegan, P E. (2010) *A Web Application to Support Recovery and Shared Decision Making in Psychiatric Medication Clinics*. *Psychiatric Rehabilitation Journal*, Summer; 34 (1): 23-8

De las Cuevas, C., and Peñate, W. (2014) *To What Extent is Treatment Adherence of Psychiatric Patients Influenced by their Participation in Shared Decision Making?* *Patient Preference and Adherence*, 8 1547–1553

De las Cuevas, C., Penate, W., and de Rivera L. (2014) *Psychiatric Patients' Preferences and Experiences in Clinical Decision-making: Examining Concordance and Correlates of Patients' Preferences*. *Patient Education and Counseling*, August, 96 (2) (pp 222-228)

De las Cuevas, C., Peñate, W., Perestelo-Pérez, L., and Serrano-Aguilar, P. (2013). *Shared Decision Making in Psychiatric Practice and the Primary Care Setting is Unique, as Measured Using a 9-item Shared Decision Making Questionnaire (SDM-Q-9)*. *Neuropsychiatric Disease and Treatment*, 9, 1045-1052

De las Cuevas, C., Amado Rivero-Santana, A., Perestelo-Pérez, L., Pérez-Ramos, J., and Pedro Serrano-Aguilar, P. (2012) *Attitudes Toward Concordance in Psychiatry: a Comparative, Cross-Sectional Study of Psychiatric Patients and Mental Health Professionals*. *BMC Psychiatry*, 12:53

Department of Health. (2013) *The NHS Constitution for England*. Department of Health, UK

Department of Health. (2011) *No Health Without Mental Health*. Department of Health, UK

Department of Health. (2010) *Equity and Excellence: Liberating the NHS*, Department of Health, UK

Drake, R E., Deegan, P E., and Rapp, C. (2010a). *The Promise of Shared Decision Making in Mental Health*. *Psychiatric Rehabilitation Journal*, Summer; 34 (1): 7-13

Drake, R. E., Deegan, P. E., Woltmann, E., Haslett, W., Drake, T., and Rapp, C. A. (2010b) *Comprehensive Electronic Decision Support Systems*. *Psychiatric Services*, 61(7), 714-717

Drake, R E., Wilkniss, S M., Frounfelker, R L., Whitley, R., Zipple, A M., McHugo, and G J., Bond, G R. (2009a) *The Thresholds-Dartmouth Partnership and Research on Shared Decision Making*. *Psychiatric Services*, Feb; 60 (2): 142-4

Drake, R E., Cimpean, D, and Torrey W C. (2009b) *Shared Decision Making in Mental Health: Prospects for Personalized Medicine*. *Dialogues in Clinical Neuroscience*, 11 (4) (pp 455-463)

Duncan, E., Best, C., and Hagen, S. (2010) *Shared Decision Making Interventions for People with Mental Health Conditions*. *Cochrane Database of Systematic Reviews*

Emanuel, E, J., Wendler, D., and Grady, C. (2000) *What Makes Clinical Research Ethical?* *Journal of the American Medical Association*, 283 (20),2701-2711, in Khanlou, N., and Peter, E. (2005) *Participatory Action Research: Considerations for Ethical Review*. *Social Science and Medicine*, 60, 2333-2340

Fals Borda, O. (2001) *Participatory (Action) Research: Social Theory: Origins and Challenges*, in Reason, P, and Bradbury, H. (eds) in *Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Fals Borda, O. (1998) *People's Participation: Challenges Ahead*. New York: Apex Press.

Fals Borda, O. (1991) *Action and Knowledge: Breaking the Monopoly with Participatory Action-Research*. New York, Apex Press

Fairclough, N. (1992) *Discourse and Social Change*. Cambridge: Polity Press, in Hodge, S (2005) *Participation, Discourse and Power: a Case Study in Service User Involvement*. *Critical Social Policy*, 25: 164

Faulkner, A., Thomas, P. (2002) *User-led research and evidence-based medicine*. *British Journal of Psychiatry*, 180, 1-3

Femdal I, and Knutsen I, R. (2017) *Dependence and Resistance in Community Mental Health Care—Negotiations of User Participation Between Staff and Users*. *Journal of Psychiatric Mental Health Nursing*; 24:600–609

Forbes, J. and Sashidharan, S.P. (1997) *User Involvement in Services – Incorporation or Challenge?* *British Journal of Social Work* 27: 481–98, in Hodge, S (2005) *Participation, Discourse and Power: a Case Study in Service User Involvement*. *Critical Social Policy*, 25: 164

Foucault, M. (1980) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. New York, Pantheon

Foucault, M. (1972) *The Archaeology of Knowledge*. London, Tavistock, in Hall, S, (1998) *Representation and Discourse*, in Smith, M J. (1998) *Social Science in Question*. London, Sage

Foucault, M. (1967) *Madness and Civilisation: A History of Insanity in the Age of Reason*. London, Tavistock/Routledge, in Smith, M J. (1998) *Social Science in Question*. London, Sage

Freire, P. (1970) *Pedagogy of the Oppressed*. New York, Herder and Herder, in Reason, P., and Bradbury, H. (2008) *Introduction*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Fricker, M. (2007) *Epistemic injustice: Power and the Ethics of Knowing*. Oxford University Press

Fukui, S., Matthias, M S., and Salyers, M P. (2015) *Core Domains of Shared Decision-Making During Psychiatric Visits: Scientific and Preference-Based Discussions*. Administration and Policy In Mental Health, Jan 42(1) 40-46

Fukui, S., Salyers, M., Matthias, M., Collins, L., Thompson, J., Coffman, M., and Torrey, W. (2014) *Predictors of Shared Decision Making and Level of Agreement Between Consumers and Providers in Psychiatric Care*. Community Mental Health Journal, May; 50 (4): 375-82

Gibbs, R. W. (1999) *The Poetics of Mind: Figurative Thought, Language, and Understanding*. Cambridge University Press, in Mcintosh, P. (2010) *Action Research and Reflective Practice*. Oxon, Routledge

Gillard, S., Simons, L., Turner, K., Lucock, M., and Edwards, C. (2012) *Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study*. Qualitative Health Research Vol 22, Issue 8, pp. 1126 – 1137

Godin, P., Davies, J., Heyman, B., Reynolds, L., Simpson, A., and Floyd, M. (2007) *Opening Communicative Space: A Habermasian Understanding of a User-led Participatory Research Project*. Journal OF Forensic Psychiatry and Psychology, 18(4), pp. 452–469

Gordon, C., and Green, M. (2013) *Shared Decision Making in the Treatment of Psychosis*. Psychiatric Times, 30(4), 11

Goscha, R., and Rapp, C. (2014) *Exploring the Experiences of Client Involvement in Medication Decisions Using a Shared Decision Making Model: Results of a Qualitative Study*. Community Mental Health Journal, July

Green, L., George, M, A., Daniel, M., Frankish, C, J., Herbert, C, J., Bowie, W, R., and O'Neil, M. (1995) *Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada*. Institute of Health Promotion Research, University of British Columbia, BC Consortium for Health Promotion Research, Royal Society of Canada, Ottawa, in Khanlou, N., and Peter, E. (2005) *Participatory Action Research: Considerations for Ethical Review*. *Social Science and Medicine*, 60, 2333-2340

Greenwood, D, G., and Levin, M. (1998) *Introduction to Action Research*. London, Sage

Grogan, I. (2017), '*Hubble, Bubble, Toil and Trouble*' is not in *Macbeth*, accessed on <https://www.alternatememories.com/historical-events/14-books/163-hubble-bubble-toil-and-trouble-is-not-in-macbeth> 20/11/17

Grundy, A.C., Bee, P., Meade, O., Callaghan, P., Beatty, S., Olleveant, N. and Lovell, K. (2016) *Bringing Meaning to User Involvement in Mental Health Care Planning: a Qualitative Exploration of Service User Perspectives*. *Journal of Psychiatric and Mental Health Nursing*, 23(1), pp.12-21

Gustavsen, B., Hansson, A. and Qvale, T.U., (2008) *Action Research and the Challenge of Scope*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Hagey, R. (1997) *The Use and Abuse of Participatory Action Research*. *Chronic Diseases in Canada*, 18 (1) in Koch, T., and Kralik, D. (2006) *Participatory Action Research in Health Care*. Oxford, Blackwell Publishing Ltd

Hall, B. (2013) *Transforming the Basis of Knowledge*. University World News, May, No. 273

Hall, B. (2012) Whose Knowledge Counts? The Emergent Knowledge Democracy Movement, Practice in Participation, <http://practiceinparticipation.org/guestcolumn/whose-knowledge-counts-the-emerging-knowledge-democracy-movement/> accessed on 17/02/17

Hall, S. (2001) *Foucault: Power, Knowledge and Discourse*. *Discourse Theory and Practice: A Reader*, Sage, London

Hamann, J., Mendel, R., Reiter, S., Cohen, R., Buehner, M., Schebitz, M., and Berthele, A. (2011a) *Why Do Some Patients With Schizophrenia Want to Be Engaged in Medical Decision Making and Others Do Not?* *Journal of Clinical Psychiatry*, 72(12)

Hamann, J., Mendel, R., Meier, A., Asani, F., Pausch, E., Leucht, S., and Kissling, W. (2011b) *"How To Speak to your Psychiatrist": Shared Decision-Making Training for Inpatients with Schizophrenia*. *Psychiatric Services*, 62(10), 1218

Hamann, J., Mendel, R., Cohen., Heres, S., Ziegler, M., Buhner, M., Kissling, W. (2009) *Psychiatrists' Use of Shared Decision Making in the Treatment of Schizophrenia: Patient Characteristics and Decision Topics*. Psychiatric Services, August 60(8):1107-1112

Hayes, JF., Marston, L., Walters, K., King, MB., and Osborn, DPJ. (2017) *Mortality Gap for People with Bipolar Disorder and Schizophrenia: UK-based Cohort Study 2000–2014*. The British Journal of Psychiatry Jul 2017

Hayter, T. (1971) *Aid as Imperialism*. Harmondsworth, Penguin

Heaney, T. W. (1993) *"If you Can't Beat `Em, Join `Em": The Professionalization of Participatory Research*, in P. Park., M. Brydon-Miller., B. Hall., and T. Jackson (eds) *Voices of Change: Participatory Research in the United States and Canada* (pp. 41-46). Westport, CT: Bergin and Garvey, in Stoecker, R. (1999) *Are Academics Irrelevant?* American Behavioral Scientist, Vol 42, Issue 5, pp. 840 - 854

Henderson, R., Corker., E., Williams, P., Rose, D., Evans-Lacko, S., Thornicroft, G., Hamilton, S., Pinfold, V., & Webber, M. (2014a) *'Viewpoint Survey of Mental Health Service Users' Experiences of Discrimination in England 2008-2012*, Social Psychiatry and Psychiatric Epidemiology, July, 49:1599–1608

Henderson, C., Noblett, J., Parke, H., Clement, S., Caffrey, A., Gale-Grant, O., Schulze, B., Druss, B. and Thornicroft, G. (2014b) *Mental Health-Related Stigma in Health Care and Mental Health-Care Settings*. The Lancet Psychiatry, 1(6), pp.467-482

Herr, K. & Anderson, G. L. (2005) *The Action Research Dissertation: A Guide for Students and Faculty*. Thousand Oaks, CA: Sage Publications Ltd

Hodge, S. (2005a) *Competence, Identity and Intersubjectivity: Applying Habermas's Theory of Communicative Action to Service User Involvement in Mental Health Policy making*. Social Theory & Health, 3(3), pp.165-182

Hodge, S. (2005b) *Participation, Discourse and Power: a Case Study in Service User Involvement*, Critical Social Policy, 25: 164

Holloway, I., and Todres, L. (2005) *The Status of Method: Flexibility, Consistency and Coherence*, in Holloway I (ed.) *Qualitative Research in Health Care*, Berkshire: Open University Press

Humble, D. (2012) *"This isn't getting easier": Valuing Emotion in Development Research*. Emotion, Space and Society, Volume 5, Issue 2, 78-85

Hutchinson, A., and Lovell, A. (2013) *Participatory Action Research: Moving Beyond the Mental Health 'Service User' Identity*. Journal of Psychiatric And Mental Health Nursing, 20(7), 641-649

Ilich, I. (1977) *Disabling Professions*, London, Marion Boyars, in McIntosh, P. (2010) *Action Research and Reflexive Practice*. Oxon, Routledge

Independent Mental Health Task Force. (2016) *The Five Year Forward View for Mental Health: A Report for NHS England*

Janes, J, E. (2016) *Democratic Encounters? Epistemic Privilege, Power, and Community Based Participatory Action Research*. Action Research 2016, Vol. 14(1) 72–87

Jones, R.M. (2017) *Mental Health Act Manual*. London, Thomson Sweet & Maxwell.

Johnson, A. (1996) *'It's Good to Talk': The Focus Group and the Sociological Imagination*. The Editorial Board of The Sociological Review, 517–538, in Chiu, L.F. (2003) *Transformational Potential of Focus Group Practice in Participatory Action Research*. Action Research, 1(2), pp.165-183

Katsikitis, M., Lane, B.R., Ozols, I. and Statham, D. (2017) *Consumer and Carer Perspectives in the Development of a Mental Health Research, Treatment, and teaching facility: A Thematic Analysis*. Journal of Psychiatric and Mental Health Nursing, Volume 24, Issue 7

Kearney, K, S., and Hyle, A, E. (2004) *Drawing Out Emotions: the Use of Participant-produced Drawings in Qualitative Inquiry*. Qualitative Research Vol 4, Issue 3, pp. 361 - 382

Kelly, B. D., Bracken, P., Cavendish, H., Crumlish, N., MacSuibhne, S., Szasz, T., and Thornton, T. (2010). *The Myth of Mental Illness: 50 years after publication: What Does it Mean Today?* Irish Journal of Psychological Medicine, 27(1), 35-43

Kesby, M. (2008) *Retheorizing Empowerment through Participation as a Performance in Space: Beyond Tyranny to Transformation*. New Feminist Approaches to Social Science, Vol. 30, No. 4

Kemmis, S., McTaggart, R. and Nixon, R., (2015) *Critical Theory and Critical Participatory Action Research*, In H. Bradbury (ed) *The Sage Handbook of Action Research*. London, Sage

Kemmis, S., and McTaggart, R. (2000) *Participatory Action Research*, in Denzin, N, K., and Lincoln, Y, S. (eds) *Handbook of Qualitative Research*. Thousand Oaks, Sage, in Khanlou, N., and Peter, E. (2005) *Participatory Action Research: Considerations for Ethical Review*. Social Science and Medicine, 60

Kesby, M., Kindon, S., and Pain, R. (2007) *Participation as a Form of Power*, in Kindon, S., Pain, R., and Kesby, M. (eds) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Abingdon, Routledge

Khanlou, N., and Peter, E. (2005) Participatory Action Research: Considerations for Ethical Review. *Social Science and Medicine*, 60

Kindon, S., Pain, R., and Kesby, M. (eds) (2007) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Abingdon, Routledge

Klocker, N. (2015) *Participatory Action Research: The Distress of (Not) Making a Difference*, *Emotion, Space and Society*, Vol: 17, Page: 37-44

Koch, T., and Kralik, D. (2006) *Participatory Action Research in Health Care*. Oxford, Blackwell Publishing Ltd

Kommana, S., Mansfield, M., Penn D L. (1997) *Dispelling the Stigma of Schizophrenia*, *Psychiatric Services*, 48 (11): 1393-1395, in Thornicroft, G. (2006) *Shunned: Discrimination against People with Mental Illness*. Oxford University Press

Landreth, J. (2017) *Swell: A Waterbiography*. London, Bloomsbury Sport

Langhout, R. D., and Thomas, E. (2010) *Imagining Participatory Action Research in Collaboration with Children: an Introduction*. *American Journal of Community Psychology*, 46: 60–66

Leblanc, S., and Kinsella, E.A. (2016) *Toward Epistemic Justice: A Critically Reflexive Examination of 'Sanism' and Implications for Knowledge Generation*. *Studies in Social Justice*, 10(1)

LeFrancois, B., Menzies, R., and Reaume, G. (eds) (2013) *Mad Matters: a Critical Reader in Canadian Mad Studies*. Toronto, Canadian Scholars Press

Légaré, F., Ratté, S., Gravel, K. and Graham, I.D., (2008). *Barriers and Facilitators to Implementing Shared Decision-Making in Clinical Practice: Update of a Systematic Review of Health Professionals' Perceptions*. *Patient education and counseling*, 73(3), pp.526-535

Levin, M. (2008) *The Praxis of Educating Action Researchers*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Lewin, K. (1948/1997) *Resolving Social Conflicts and Field Theory in Social Science*. Washington, DC: American Psychological Association. (Original work published 1948), in Wallerstein, N., and Duran, B. (2017) *The Theoretical, Historical, and Practice Roots of CBPR, in Community-Based Participatory Research for Health: Advancing Social and Health Equity*, in Oetzel, J.G. and

Minkler (eds) *Community-based participatory research for health: advancing social and health equity*. John Wiley & Sons

Lewin, K. (1946) *Action Research and Minority Problems*, in G.W. Lewin. (ed) *Resolving Social Conflicts*. New York: Harper & Row. In Adelman, C. (1993) *Kurt Lewin and the Origins of Action Research*. *Educational Action Research*, 1:1, 7-24

Lindhiem, O., Bennett, C B., Trentacosta, C J., and McLearn, C. (2014) *Client Preferences Affect Treatment Satisfaction, Completion, and Clinical Outcome: A Meta-analysis*. *Clinical Psychology Review*, 34(6), 506-517

Mahone, I H., Farrell, S P., Hinton, I., Johnson, R., Moody, D., Rifkin, K., Moore, K., Becker, M., and Barker, M. (2011) *Participatory Action Research in Public Mental Health and a School of Nursing: Qualitative Findings from an Academic-Community Partnership*. *Journal of Participatory Medicine* 3

Matthias, M S., Salyers, M P., Rollins, A L., Frankel, M. (2012) *Decision Making in Recovery-Oriented Mental Health Care*. *Psychiatric Rehabilitation Journal*, Spring; 35 (4): 305-14

Mayall, B., Hood, S., and Oliver, S. (1999) *Introduction*, in Hood, S., Mayall, B., and Oliver, S. (eds) *Critical Issues in Social Research: Power and Prejudice*. Buckingham, University Press

McIntosh, P. (2010) *Action Research and Reflective Practice*. Oxon, Routledge

McIntyre, A (2008) *Participatory Action Research*. London, Sage

McKeown, M. (2016) *Stand up for Recalcitrance!* *International Journal of Mental Health Nursing*, 25, 481–483

McKeown, M., and Spandler, H. (2015) *Solidarity Across Difference: Organising for Democratic Alliances*, in H, Spandler., J, Anderson., and B, Sapey (eds) *Distress or Disability? Mental Health and the Politics of Disablement*. Policy Press, Bristol

McKeown, M. and White, J. (2015). *The Future of Mental Health Nursing: Are We Barking up the Wrong Tree?*. *Journal of Psychiatric and Mental Health Nursing*, 22(9), pp.724-730

McKeown, M., Wright, K., and Gadsby, J. (2018) *The Context And Nature Of Mental Health Care in the 21st Century*. *Essentials of Mental Health Nursing*, London, Sage

McLaughlin, H. (2009) *What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next?* *The British Journal of Social Work*, Volume 39, Issue 6, 1 September, Pages 1101–1117

- McNiff, J., and Whitehead, J. (2009) *Doing and Writing Action Research*. London, Sage
- McTaggart, R. (ed) (1997) *Participatory Action Research: International Contexts and Consequences*. Albany, State University of New York Press
- McTaggart, R. (1991) *Principles for Participatory Action Research*. *Adult Education Quarterly* Vol 41, Issue 3, pp. 168 - 187
- Mental Health Foundation. (2017) Suicide, <https://www.mentalhealth.org.uk/a-to-z/s/suicide> (accessed on 10/08/17)
- Mitchell, J., Mackenzie, D., Holloway, J., Cockburn, C., Polanshek, K., Murray, N., McInnes, N. and McDonald, J. (London Edinburgh Weekend Return Group). (1979) *In and Against the State*. London, Publications Distribution Co-op.
- Morrow, M., and Weisser, J. (2012) *Towards a Social Justice Framework of Mental Health Recovery*. *Studies in Social Justice*, 6(1), p.27-43
- Morton-Cooper, A. (2000) *Action Research in Healthcare*, Oxford. Blackwell Science
- Moser, H. (1980) *Action Research as a New Paradigm in the Social Sciences: a Paper Presented to at the International Forum on Participatory Action Research*, Ljubjana, Yugoslavia, April, in Rahman, A. (2008) *Some Trends in the Praxis of Participatory Action Research*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage
- Mosse, D. (2001) "People's Knowledge", *Participation and Patronage: Operations and Representations in Rural Development*, in Cooke, B., and Korthari, U. (eds) *Participation: The New Tyranny?* London, Zed Books
- Mullet, J. (2015) *Issues of Equity and Empowerment in Knowledge Democracy: Three Community Based Research Examples*. *Action Research* 2015, Vol. 13(3) 248–261
- National Health Service (2017) *Public Participation Policy*. London, NHS England
- National Health Service Act (2003) Crown Copyright
- National Institute for Health and Care Excellence (NICE) (2011) *Service User Experience in Adult Mental Health Standards*, <https://www.nice.org.uk/Guidance/CG136> (accessed on 29/03/18)
- Neale, J. (2016) *Iterative Categorization (IC): a Systematic Technique for Analysing Qualitative Data*. *Addiction*, 111, 1096 –1106

Neuberger, J., and Tallis, R. (1999). *Do We Need a New Word for Patients?* British Medical Journal, 318 (7200), 1756–1758

Oakley, A. (1999) *People's Way of Knowing: Gender and Methodology*, in Hood, S., Mayall, B., and Oliver, S. (eds) *Critical Issues in Social Research: Power and Prejudice*. Buckingham, University Press

Ocloo, J. and Matthews, R. (2016) *From Tokenism to Empowerment: Progressing Patient and Public Involvement in Healthcare Improvement*. British Medical Journal, pp.bmjqs-2015.

Office of National Statistics (2015). "What do we die from?" Available at: <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2014/sty-what-do-we-die-from.html> (Accessed 10/08/17).

Oliver, S. (1999) *Users of Health Services: Following Their Agenda*, in Hood, S., Mayall, B., and Oliver, S. (eds) *Critical Issues in Social Research: Power and Prejudice*. Buckingham, University Press

Olshansky, E., Sacco, D., Braxter, B., Dodge, P., Hughes, E., Ondeck, M., Stubbs, M L., Upvall, M J. (2005) *Participatory Action Research to Understand and Reduce Health Disparities*. Nursing Outlook, May/June

Openjuru, G.L., Jaitli, N., Tandon, R. and Hall, B., (2015) Despite Knowledge Democracy and Community-based Participatory Action Research: Voices from the Global South and Excluded North Still Missing. *Action Research Journal*: 219-229

O'Sullivan, M, J., and Rae, S. (2014) Shared Decision Making in Psychiatric Medicines Management. *Mental Health Practice*, May; 17 (8): 16-22

Owen, J. (2005) *Users, Research and Evidence in Social Care*, in Burr, J., and P, Nicolson (eds) (2005) *Researching Healthcare Consumers: Critical Approaches*. Basingstoke, Palgrave MacMillian

Padilla, R. (1993) *Using Dialogical Research Methods in Group Interviews*, in D. Morgan. (ed) *Successful Focus Groups: Advancing the State of the Art*. Thousand Oaks, CA: Sage

Pain, R., Kesby, M., and Kindon, S. (2007) *Conclusion: the Space(s) and Scale(s) of Participatory Action Research: Constructing Empowering Geographies?*, in Kindon, S., Pain, R., and Kesby, M. (eds) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Abingdon, Routledge

Perestelo-Perez, L., Gonzalez-Lorenzo, M., Perez-Ramos, J., Rivero-Santana, A., and Serrano-Aguilar, P. (2011) *Patient Involvement and Shared Decision-Making in Mental Health Care*. *Current Clinical Pharmacology*, 6(2), 83-90

Perkins, R. (2001) *What Constitutes Success? The Relative Priority of Service Users' and Clinicians' views of Mental Health Services*. *The British Journal of Psychiatry*, 179: 9-10

Perkins, R. (1996) *Seen but not Heard: Can 'User Involvement' Become More Than Empty Rhetoric?* *The Mental Health Review*, 1, 16-19

Pinfold, V., Thornicroft, T., Huxley, P., Farmer, P. (2005) *Active Ingredients in Anti-Stigma Programmes in Mental Health*. *International Review of Psychiatry*, 17, 123-131, in Thornicroft, G. (2006) *Shunned: Discrimination against People with Mental Illness*. Oxford University Press

Pretty, J. (1995) *Participatory Learning for Sustainable Agriculture*. *World Development*, 23 (8), 1247–1263

Prosser, J. (1998) *Introduction*, in Prosser, J. (ed) *Image-based Research: A Sourcebook for Qualitative Researchers*, London, Fulmer Press

Rahman, A. (2008) *Some Trends in the Praxis of Participatory Action Research*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Rahman, A. (1985) *The theory and Practice of Participatory Action Research*, in O. Fals-Borda. (ed) *The Challenge of Social Change*. Thousand Oaks, CA: Sage, in Wakeford, T., Pimbert, M., and Walcon, E. (2008) *Re-fashioning Citizens' Juries: Participatory Democracy in Action*, in Bradbury, H. (2015) (ed) *The Sage Book of Action Research*. London, Sage

Read, J. (2005) *The Bio-Bio-Bio Model of Madness*. *Psychologist*, 18, 596-597

Reason, P. (2005), "*Living as Part of the Whole*". *Journal of Curriculum and Pedagogy*, 2 (2): 35-41, in Reason, P., and Bradbury, H. (2008) *Introduction*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Reason, P., and Bradbury, H. (2008) *Introduction*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage

Redmond, B. (2006). *Reflection in Action: Developing Reflective Practice in Health and Social Services*, London: Routledge.

Roberts, M. (2010) *Service User Involvement and the Restrictive Sense of Psychiatric Categories: the Challenge Facing Mental Health Nurses*. *Journal of Psychiatric and Mental Health Nursing*, 17: 289–294

Roberts M. (2008) *Facilitating Recovery by Making Sense of Suffering: a Nietzschean Perspective*. *Journal of Psychiatric and Mental Health Nursing* 15, 743–748

- Rose, D. (2004) *Telling Different Stories: User Involvement in Mental Health Research*. Research and Policy Planning, 22(2), 23-30.
- Rose, D., Evans, J., Laker, C. and Wykes, T. (2015) *Life in Acute Mental Health Settings: Experiences and Perceptions of Service Users and Nurses*. Epidemiology and Psychiatric Sciences, 24(1), pp.90-96
- Russo, J., and Beresford, P. (2015) *Between Exclusion and Colonisation: Seeking a Place for Mad People's Knowledge in Academia*. Disability & Society, 30(1), pp.153-157
- Sackett, D.L., Strauss, S.E., Scott Richardson, W., Rosenburg, W., and Brian Haynes, R. (1997) *Evidence-Based Medicine: How to Practice and Teach EBM*. London, Churchill Livingstone, London
- Salyers, M P., Matthias, M S., Fukui, S., Holter, M C., Collins, L., Rose, N., Thompson, JB., Coffman, MA., and Torrey, W C. (2012) A Coding System to Measure Elements of Shared Decision Making During Psychiatric Visits, Psychiatric Services. Aug 1; 63 (8): 779-84
- Sarantakos, S. (1993) *Social Research*. Basingstoke, Macmillan
- Sartorius, N. (2007) *Stigma and Mental Health*. The Lancet, 370; 9590, 810–811
- Sandelowski, M. (1998) *Writing a Good Read: Strategies for Re-presenting Qualitative Data*. Research in Nursing & Health, 21(4), pp.375-382.
- Schizophrenia Commission (The) (2012) *The Abandoned Illness: a Report from the Schizophrenia Commission*. London: Rethink Mental Illness
- Scott, M. (2010) *Reflections on 'The Big Society'*. Community development journal, 46(1), 132-137.
- Sedgwick, P. (1982). *Psycho Politics*. London, Pluto Press
- Shepherd, A., Shorthouse, O., and Gask, L. (2014) *Consultant Psychiatrists' Experiences of and Attitudes Towards Shared Decision Making in Antipsychotic Prescribing: a Qualitative study*. BMC Psychiatry, 14, 127
- Siddiqi N., Doran, T., Prady, S.L., Taylor, J. (2017) *Closing the Mortality Gap for Severe Mental Illness: Are We Going in the Right Direction?* BJPsych, 211, 1-2
- Simons, L., Lathlean, J., Squire, C. (2008) *Shifting the Focus: Sequential Methods of Analysis with Qualitative Data*. Qualitative Health Research, 18, 120-132, in Gillard, S., Simons, L., Turner, K., Lucock, M., and Edwards, C. (2012) *Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study*. Qualitative Health Research Vol 22, Issue 8, pp. 1126 - 1137

- Simpson, A., Bannigan, B., Coffey, M., Barlow, S., Cohen, R., Jones, A., Vřetečková, J., Faulkner, A., Thornton, A. and Cartwright, M. (2016) *Recovery-Focused Care planning and Coordination in England and Wales: a Cross-National Mixed Methods comparative case study*. BMC Psychiatry, 16(147)
- Simpson, A., Jones, J., Barlow, S., and Cox, L. (2014) *Adding SUGAR Service User and Carer Collaboration in Mental Health Nursing Research*. Journal of Psychosocial Nursing and Mental Health Services, 52(1), pp. 22-30
- Smith, M J. (1998) *Social Science in Question*. London, Sage
- Simmons, M., Hetrick S., and Jorm, A. (2010) *Shared Decision-Making: Benefits, Barriers and Current Opportunities for Application*. Australasian Psychiatry: Bulletin Of Royal Australian And New Zealand College Of Psychiatrists, Oct; Vol. 18 (5), pp. 394-7
- Social Exclusion Unit (2004) *Social Exclusion Report: Mental Health and Social Exclusion*. London, The Cabinet Office
- Spandler, H., Mckeown, M. (2017) *"Exploring the Case for Truth and Reconciliation in Mental Health Services"*. Mental Health Review Journal, Vol. 22 Issue: 2, pp.83-94
- Spandler, H., Moth, R., Mckeown, M. and Greener, J. (2016). *Psychopolitics in the Twenty First Century*. Critical and Radical Social Work, 4(3), pp.307-312
- Stratford, A., Brophy, L., Beaton, T., and Castle, D. (2013) *Recovery, Medication and Shared Responsibility in Mental Health Care*. Australasian Psychiatry, 21(6), 550-553
- Stein, B D., Kogan, J N., Mihalyo, M J., Schuster, J., Deegan, P E., Sorbero, M.J., and Drake, R E. (2013) *Use of a Computerized Medication Shared Decision Making Tool in Community Mental Health Settings: Impact on Psychotropic Medication Adherence*. Community Mental Health Journal, Apr 49 (2) (pp 185-192)
- Stickley T. (2006) *Should Service User Involvement be Consigned to History? A Critical Realist perspective*. Journal of Psychiatric and Mental Health Nursing 13, 570–577
- Stoecker, R. (1999) *Are Academics Irrelevant?* American Behavioral Scientist, Vol 42, Issue 5, pp. 840 – 854
- Stoetzler, M., and Nira Yuval-Davis, N. (2002) *Standpoint Theory, Situated Knowledge and the Situated Imagination*. Feminist Theory, 3, 315
- Streubert Speziale H, and Carpenter, D. (2007) *Qualitative Research in Nursing: Advancing the Humanistic Imperative* (4th edn). Philadelphia: Lippincott Williams and Wilkins

- Sweeney, A., Greenwood, K.E., Williams, S., Wykes, T., Rose, D.S. (2012) *Hearing the Voices of Service User Researchers in Collaborative Qualitative Data Analysis: the Case for Multiple Coding*. *Health Expectations*, 16, pp.e89–e99
- Taylor, G.W., and Ussher, J.M. (2001) *Making sense of S&M: a Discourse Analytic account*. *Sexualities* 4, 293/314, in Braun, V., and Clarke, V. (2006) *Using Thematic Analysis in Psychology*. *Qualitative Research* 3: 77–101
- Tehrani, E., Krussel, J., Borg, L., Munk-Jorgensen, and P. (1996) *Dropping Out of Psychiatric Treatment: A Prospective Study of a First Admission Cohort*. *Acute Psychiatry Scandinavia*, 94(4), 266-271, in Thornicroft, G. (2006) *Shunned: Discrimination against People with Mental Illness*. Oxford University Press
- Thornicroft, G. (2006) *Shunned: Discrimination against People with Mental Illness*. Oxford University Press
- Tibaldi, G., Salvador-Carulla, L., and Garcia-Gutierrez J.C. (2011) *From Treatment Adherence to Advanced Shared Decision Making: New Professional Strategies and Attitudes in Mental Health Care*. *Current Clinical Pharmacology*, 6 (2) (pp 91-99)
- Timimi, S. (2018) *The Scientism of Psychiatry, Mad in America, Science, Psychiatry and Social Justice*. 10th January 2018, <https://www.madinamerica.com/2018/01/the-scientism-of-psychiatry/> accessed on 18/01/18
- Torrey, W., and Drake, R. (2010) *Practicing Shared Decision Making in the Outpatient Psychiatric Care of Adults with Severe Mental Illnesses: Redesigning Care for the Future*. *Community Mental Health Journal*, Oct; 46 (5): 433-40
- Townend, M., and Braithwaite, T. (2002) *Mental Health Research – the Value of User Involvement*. *Journal of Mental Health* 11, 2, 117–119
- Trinder, L. (2001) *The Concept of Evidence Based Practice*, in Trinder, L., and Reynolds, S. *Evidence Based Practice: A Critical Appraisal*. Oxford, Blackwell Science
- The United Nations Convention on the Rights of Persons with Disabilities (2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland*
- Vaismoradi, M., Turunen, H., and Terese Bondas, T. (2013) *Content Analysis and thematic Analysis: Implications for Conducting a Qualitative Descriptive Study*. *Nursing and Health Science*, 15, 398–405

- Wadsworth, Y. (1998) *What is Participatory Action Research*. Action Research International, Paper 2, in Kindon, S., Pain, R., and Kesby, M. (2007) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*, Abingdon. Routledge
- Wallcraft, J., and Shulkes, D. (2012) *Can Psychiatry Apologise for Crimes Against Humanity?* Open Mind, January and February, pp. 12-13.
- Wallerstein N., and Duran, B. (2017) *The Theoretical, Historical, and Practice Roots of CBPR, in Community-Based Participatory Research for Health: Advancing Social and Health Equity*, in Oetzel, J.G. and Minkler (eds) *Community-based Participatory Research for Health: Advancing Social and Health Equity*. New Jersey, John Wiley and Sons
- Walter, M. (2009) *Participatory Action Research*, in Walter, M. (ed) *Social Research Methods*. Oxford University Press
- Warren, B J. (2012) *Shared Decision Making: a Recovery Cultural Process*. *Journal of Psychosocial Nursing & Mental Health Services* Dec; 50 (12): 4-5
- Wellmer, A. (2014) *On Critical Theory*. *Social Research: An International Quarterly*, Volume 81, Number 3, Fall 2014, pp. 705-733
- White, G W., Sachowierska, M., and Campbell, M. (2004) *Developing and Systematically Implementing Participatory Action Research*. *Archive of Physical Medical Rehabilitation* 85, Supplement 2
- Whyte, W. F. (ed) (1991) *Participatory Action Research*. Thousand Oaks, CA: Sage
- Wicks, P G., Reason, P., and Bradbury, H. (2008) *Living Inquiry: Personal, Political and Philosophical Groundings for Action Research Practice*, in Reason, P, and Bradbury, H. (eds) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. London, Sage
- Williams, M., and May, T. (1996) *Introduction to the Philosophy of Social Research*. London, UCL Press Ltd
- Wilson, R. (2005) *Methods, Epistemology and Consumer Involvement in Research*, in Burr, J., and P, Nicolson (eds) (2005) *Researching Healthcare Consumers: Critical Approaches*. Basingstoke, Palgrave McMillian
- Woltmann, E M., and Whitley, R. (2010) *Shared Decision Making in Public Mental Health Care: Perspectives from Consumers Living with Severe Mental Illness*. *Psychiatric Rehabilitation Journal*, 34(1), 29-36
- Wright Mills, C. (1959) *The Sociological Imagination*. New York: Oxford University Press, in Adelman, C. (1993) *Kurt Lewin and the Origins of Action Research*. *Educational Action Research*, 1:1, 7-24

Young, I. M. (2001) *Activist Challenges to Deliberative Democracy*. *Political Theory*, 29(5), pp.670-690

Young, I. M. (1990) *Justice and the Politics of Difference*, Princeton, New Jersey, Princeton University Press, in Greenwood, D, G., and Levin, M. (1998) *Introduction to Action Research*. London, Sage

Appendix A: PAR Recruitment Flyer

Help to improve the Information Exchanged between NHS Mental Health Service Users and Staff

Current and former NHS mental health service users are invited to take part in this research study to shape information exchange in NHS mental health services.

We would like to hear real stories, views and ideas from people who have used NHS mental health services. This is a chance to help those services learn from your experiences and to improve how information is exchanged with service users in the future.

If you currently use mental health services or have done so within the last two years, then we would really like to hear from you. This could be inpatient, community mental health, crisis and home treatment, rehabilitation, wellbeing, and/or counselling services.

What Will I Have to Do?

You will join other service users to form a participant research team. The team will decide on what and how information needs to be shaped. Part of the study will also look at what it means for mental health service users to be part of a participatory action research study. As a member of the team you would:

- Attend a welcome workshop
- Attend meetings
- Attend research education workshops
- Attend focus groups
- Have one-to-one interviews
- Look at data collected during the study

Travel expenses will be paid. The study will last for up to two years.

If you would like to take part in this study or require more information please contact Katherine Allen on 07507 847523 or email katherine.allen@lancashirecare.nhs.uk



Appendix B: PAR Participant Information Sheet

Title: Shaping Information Exchange in NHS Mental Health Services Using Participatory Action Research

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done, and what it involves. Please take time to read the following information carefully and discuss it with staff, relatives or others if you wish. Please ask if there is anything that is not clear, or if you would like any more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of this study?

The purpose of the study is to develop information that is exchanged between mental health service users and staff. This is because there is evidence to show that people who use mental health services do not always get enough information about services, their treatment and/or their care. This study is a particular type of research called participatory action research (PAR). In this type of research, you will be actively involved in deciding what the research should focus on, how the research is carried out, and what actions should be taken to improve information exchanged with mental health service users. You may also become actively involved in carrying out the research, and talking to people about the research findings. Part of the research will also be to find what it means for people to be involved in PAR.

Why have I been chosen?

You are invited because you have used NHS mental health services, and you are able to give informed consent. This means that you have the particular expertise and knowledge that is needed in order to develop the information that NHS mental health services exchanges with service users. There will be a small group of people taking part in the study.

Do I have to take part?

It is up to you to decide whether to join the study. We will describe the study and go through this information sheet, which you will be given to keep. If you do decide to take part, we will then ask you to sign a consent form, of which you will also receive a copy. You are free to withdraw from the study at any time, without giving a reason. This will not affect the care you receive. If you decide to withdraw from the study, any information that you have already given during the study up to that point will be used.

What will happen to me if I take part?

It is expected that you will be involved in the research for up to 24 months. You will attend meetings in Preston with the lead researcher and other participants on a regular basis, as part of a participant research team. This will be decided by the group, but initially this is likely to be once a month. The amount of time that you spend on the study may change throughout the study.

You will also attend a series of orientation and research education workshops across the 2 months to equip you with the skills and knowledge to be able to participate in this research and participate in focus groups and possibly one-to-one interviews. You will also be involved in analysing the data collected, as a member of the participant research team. You may contribute to agreeing and carrying out actions – for example, designing information and exchange methods for use by the NHS.

Some people may find it difficult or distressing to talk about their experience of using mental health services. Support will be provided through de-briefing and contact with other appropriate services. You are also able to withdraw from the study at any time if participation becomes distressing to you.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential, outside of the participant research team. However, confidentiality may need to be broken in the event that there are concerns regarding your or others' wellbeing. The researcher may have to inform your GP or professionals responsible for your care in such instances.

All records will be kept securely and only the lead researcher will have access to them. The records will be kept for no longer than five years after completion of the study. Information such as your name and address will be kept separately.

What will happen to the results of the research study?

The results will be written up for publication in professional journals and be presented at research conferences. You may decide to be involved in presenting some of the results at conferences yourself. A summary of these results will be circulated to the services taking part in the study and you can request a personal copy of this. The study will also be written up of part of the lead researcher's PhD thesis. You will not be identified in any report of the study.

Who is organising and funding the research?

The research study is organised through the School of Health at the University of Central Lancashire. The fees for this are being paid by the North West Strategic Health Authority. Katherine Allen SRASt (M) MA MSc will be the lead researcher. Katherine leads on service user involvement for Lancashire Care NHS Foundation Trust's Adult Mental Health Network, on behalf of the charity Together.

Will I get paid for participating in the study?

Reasonable travel expenses will be paid.

Who has reviewed the study?

The study has been reviewed and approved by the University of Central Lancashire's Research Ethics Committee.

Appendix C: PAR Consent Form

Informed consent form – please complete if you are happy to take part in the study.

Title of Study: **Shaping Information Exchange in NHS Mental Health Services Using Participatory Action Research**

Name of Researcher: Katherine Allen

**Please tick
the box**

1. I confirm that I have read and understand the participant information sheet for the above study.
2. I have spoken to the above researcher and understand that my involvement will be attending meetings, workshops and focus groups, and may involve attending one – to-one interviews. I have had the opportunity to ask questions.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason
4. I understand that any data or information used in any publications, which arise from this study will be anonymous.
5. I understand that all data will be stored securely and is covered by the data protection act. Data will be stored for no longer than 5 years.
6. I understand and give consent for all meetings, focus groups and any interviews to be audio-recorded.
7. I would like to receive a summary report of the study and am happy for the researcher to store my address details on a secured server in order to post the report to me when it is available.

8. I agree to take part in the above study.

Name of Participant Date Signature

Name of Researcher Date Signature

Appendix D: PAR Excellence Group Agreement

PARE - PAR Excellence Group Agreement
Introduction
<p>This group agreement was drawn up by members of PARE. The group will operate on a non-hierarchical basis. Some organisational roles have been allocated to ensure that the group is as productive as possible. It is recognised that roles will emerge and develop as the group progresses.</p> <p>Each group member will sign a copy of the group agreement and keep a copy.</p>
1. PARE Group Values and Commitments
<ul style="list-style-type: none">➤ Further the cause - of improving the treatment of people who use mental health services➤ Commitment to the mission of the group➤ Pursue excellence in participatory action research➤ Honesty➤ Dignity and respect for others
2. Meeting Organisation
<ol style="list-style-type: none">a. There will be a nominated time keeper for each meeting. The time keeper will be agreed at the prior meeting.b. Meeting notes will be taken by Katherine Allen, and circulated to group members prior to the next meeting.c. The voice recorder will be monitored by CBd. Travel expenses will be managed by CB
3. Agenda
<ol style="list-style-type: none">a. The standing agenda items are:<ol style="list-style-type: none">i. New member introductionsii. Apologiesiii. Review notes of the last meetingiv. Planning the next meeting datev. Reflection on the meetingb. The nominated time keeper will liaise with Katherine Allen regarding the

agenda prior to each meeting.

4. Quorum

The meeting quorate is 4.

5. Decision Making

Decisions will be made by those present at meetings via majority vote.

6. Attendance

If a group member misses two consecutive meetings, another group member will arrange to inform them of progress and developments.

7. Responsibilities of PARE group members

- a. Read meeting notes and keep up-to-date with developments
- b. Speak up, take part and contribute
- c. Speak one at a time
- d. Be respectful of different opinions
- e. Be respectful of different abilities
- f. Treat people with dignity
- g. Represent the group professionally
- h. Contribute to recruiting and supporting new members
- i. Be punctual

8. Conduct

- a. In the event of a group member feeling offended/upset, they should check this out within the group
- b. Behaviour that is deemed unacceptable because it is not in line with PARE's Values and Commitments will be managed within the group
- c. Any decision to ask a member to leave will be made democratically by the group

9. New Members

- a. Potential new members will be considered on a case by case basis by group members
- b. New members will receive an induction
- c. New members will be allocated a buddy, who will arrange to talk to the new member prior to their first meeting

10. Confidentiality

No personal information that is shared by group members is to be discussed outside of the group.

PARE Group Member Signature

.....

Print Name.....

Appendix E: PAR Excellence Criteria for Choosing a Research Topic

1. Is change achievable?	Yes/No/Maybe
Comments	

2. Will it be high impact?	Yes/No/Maybe
Comments	

3. Is it timely?	Yes/No/Maybe
Comments	

4. Is it able to influence?	Yes/No/Maybe
Comments	

5. Is it current?	Yes/No/Maybe
Comments	

6. Will it be out of date/obsolete?	Yes/No/Maybe
Comments	

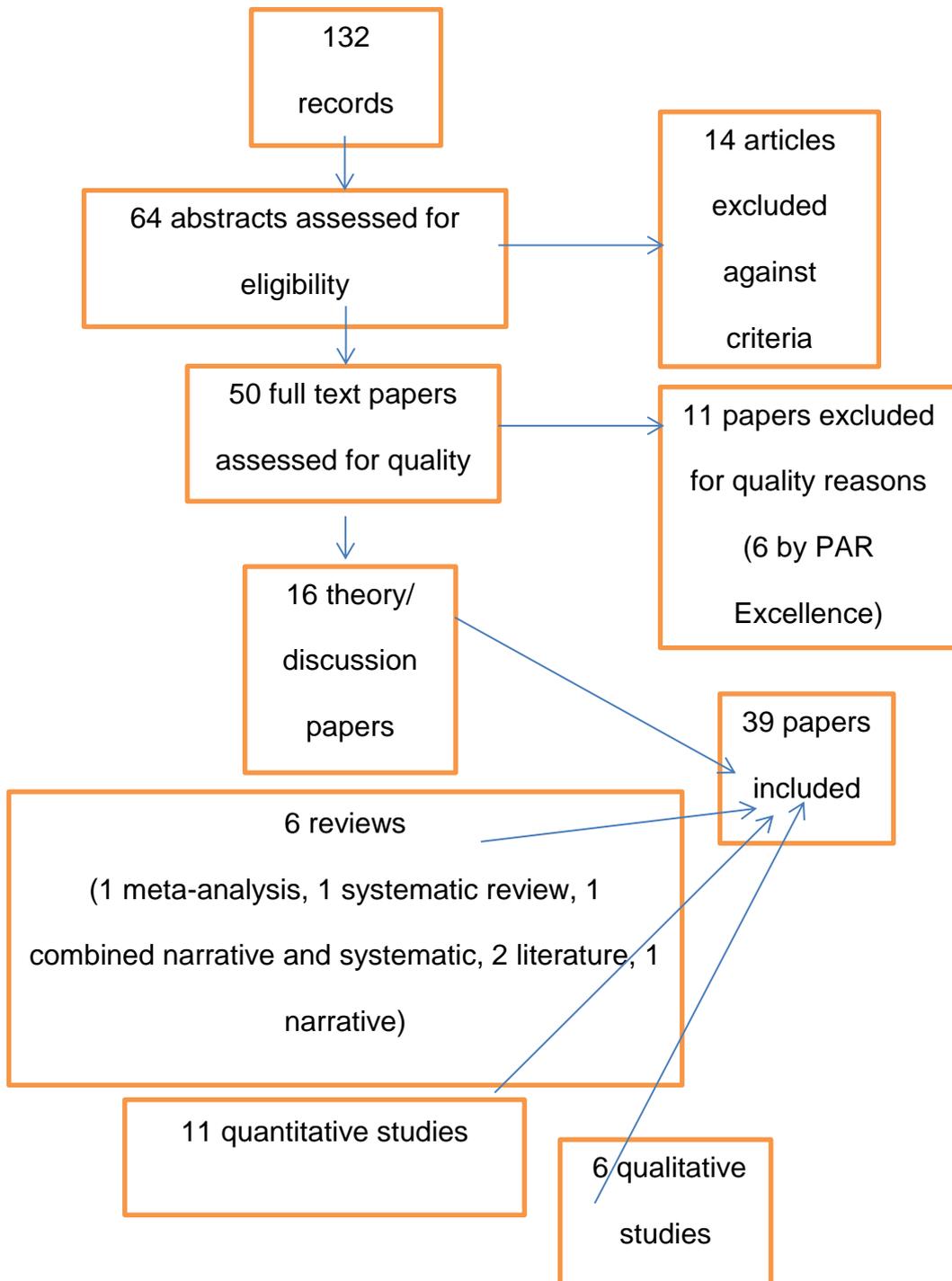
Appendix F: Integrative Literature Review Search Strategy

Databases Searched
Cochrane Sciencedirect CINAHL Medline Embase Web of Science

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Papers relating to adult mental health • Papers relating to mental health and substance misuse • Papers published since 2009. The justification for this is that the NHS Constitution (2009) was the first time that SDM as a right was made explicit in statute. 	<ul style="list-style-type: none"> • Papers relating to physical health • Papers relating to children • Papers not written in English • Papers relating to mental health in primary care • Papers relating to crisis plans • Papers relating to advanced statements • Papers relating to SDM between professionals

Search Terms	
Psychiatric* shared decision making Mental health shared decision making Psychiatric* collaboration* Mental health collaboration* Psychiatric* partners in care Mental health partners in care Psychiatric* shared care planning Mental health shared care planning Psychiatric* person centred care Mental health person centred care Psychiatric* participation*	Mental health participation* Psychiatric* service user involvement Psychiatric* patient* involvement Mental health service user involvement* Mental health patient* involvement* Psychiatric* service user* preference* Psychiatric* patient* preference* Mental health service user* preference* Mental health patient* preference* Psychiatric* personalised care planning* Mental health personalised care planning*

Appendix G: Literature Review Flow Chart



Appendix H: Integrative Review Record of Included Papers

Paper	Aim/Purpose	Methods/Type	Findings/Conclusion
Andrews, S B., Drake, T., Haslett, W., and Munusamy, R. (2010)	Discuss the development of Web-based online decision support tools intended for researchers examining the issue of shared decision making for the population of individuals with serious mental illnesses.	Description of a software platform that allows researchers and other system designers to build decision support systems.	In supporting ongoing research efforts, an online decision support tool appears to be useful for individuals facing preference-sensitive decisions and an online designer tool allows for rapid deployment of these research sites to support ongoing research efforts in shared decision making.
Anthony, W A. (2010)	Introduce SDM philosophy and developments in mental health	Editorial discussion.	SDM is a hopeful direction and compatible with the values of psychiatric rehabilitation. But it risks becoming a euphemism for persuasion or pressure, which will not support its promise of self-determinism.
Beitinger, R., Kissling, W., Hamann, J. (2014)	General overview of research on SDM in schizophrenia and related disorders	Literature review: pre 2012 narrative review; systematic review May 2012-Nov 2013	SDM is highly accepted and wanted in the treatment of schizophrenia and related disorders but more research is needed regarding how it can be implemented. Professionals need more training in dealing with difficult decisional situations
Chan, K K S., Mak, W W S. (2012)	Summarise how Metacognitive Training (MCT) and individual psychotherapy could potentially be tailored, or modified, to help consumers to develop metacognitive capacities with an end goal of facilitating the SDM process.	Discussion of the theory and concept of SDM, empirical investigations into SDM, metacognition, insights and pragmatic deficits of language in people with schizophrenia, and metacognitive obstacles to SDM.	Strategy for engaging consumers in SDM dialogue based on "where the consumers are at". Providers are advised to be cognisant of their medically driven perspective and attempt to work with the consumers in the perspective of the consumers' own recovery goals.
Chong, W W., Aslani, P., Chen, T. (2013a)	To explore the perceptions of different healthcare professionals on SDM and current interprofessional collaboration in mental healthcare	Thematic analysis of semi-structured interviews (31)	Healthcare providers appeared to have differing perceptions on the level of consumer involvement in SDM. Interprofessional roles to facilitate shared decision-making in mental health need to be acknowledged, understood and

			strengthened, before an interprofessional approach to SDM in mental health can be effectively implemented.
Chong, W W., Aslani, P., Chen, T. (2013b)	To explore mental healthcare professionals' perceptions of barriers and facilitators to SDM and interprofessional collaboration.	Thematic analysis of semi-structured interviews (31).	Changes may be necessary at several levels (consumer, provider and environment) to implement effective SDM and interprofessional collaboration in mental health.
Corrigan, P W., Angell, B., Davidson, L., Marcus, S C., Salzer, M S., Kottsieper, P., Larson, J E., Mahoney, C A., O'Connell, M J., and Stanhope, V. (2012)	To propose that the concept of self-determinism is an evolution in the explanatory paradigm of treatment adherence and non-adherence.	Literature review.	Argument that notions of adherence are significantly limited, promoting a value based perspective suggesting people who do not opt for prescribed treatments are somehow flawed or otherwise symptomatic. Two ways to promote self-determination are proffered: aiding the rational actor through approaches such as SDM and addressing environmental forces that are barriers to choice. Although significant progress has been made toward self-determination, important hurdles remain.
Curtis, L C., Wells, S M., Penney, D J; Ghose, S S., Mistler, L A., Mahone, I H., Delphin-Rittmon, M., del Vecchio, P., and Lesko, S. (2010)	To offer findings from literature and a product development process to help inform/guide those who wish to create or implement materials for shared decision making in mental health.	Literature review.	Structured SDM in mental health shows promise in supporting service user involvement in critical decision making and provides a process to open all treatment and service decisions to informed and respectful dialogue.
Decision Support Centers. (2013)	Discussion of the implementation of Decision Support Centers (sic).	Descriptive paper of a process of the introduction of CommonGround and peer led support centers.	Argument that decision making support centers enable individuals to be essential participants in the process of solving the problems they face.
Deegan, P E. (2010)	Describe an intervention to support recovery and SDM in the psychiatric medication visit.	Description of the CommonGround web application and a new role for peer staff in the medication clinic: early adopters, patterns of use and lessons learned.	Despite the constraints on the typical 15-minute medication consultation, it is possible to use technology and peer support to create an enhanced medication visit that supports SDM.
De las Cuevas, C., and Peñate, W. (2014)	To assess to what extent treatment adherence of psychiatric patients is influenced by the concordance between their preferred	967 consecutive psychiatric outpatients completed the Control Preference Scale twice consecutively before consultation, one for their preferences of	Congruence between patients' preferences and actual experiences for level of participation in shared decision making is relevant for their adherence to treatment.

	participation and their actual participation in decision making.	participation, and the other for the style they had usually experienced until then, and the eightitem self-report Morisky Medication Adherence Scale 8.	
De las Cuevas, C., Penate, W., de Rivera L. (2014)	To assess the concordance between patients' preferred role in clinical decision-making and the role they usually experience in their psychiatric consultations and to analyze the influence of socio-demographic, clinical and personality characteristics on patients' preferences.	507 psychiatric outpatients participated in a cross-sectional survey. Patients completed Control Preference Scale twice consecutively before consultation, one for their preferences of participation and another for the style they usually experienced until then, and locus of control and self-efficacy scales.	Limited concordance between preferred and experienced roles in psychiatric patients is indicative that clinicians need to raise their sensitivity regarding patient's participation.
De las Cuevas, C., Peñate, W., Perestelo-Pérez, L., & Serrano-Aguilar, P. (2013)	To measure and compare the extent to which an SDM process is implemented in psychiatric outpatient encounters and in the primary care setting, from the patient's perspective.	1,477 patients invited to complete the nine-item SDM Questionnaire (SDM-Q-9) immediately after their consultation. MANCOVA, Student's t-test, and Pearson correlations were used to assess the relationship and differences between SDM-Q-9 scores in patient samples.	The study provides evidence that SDM is a complex process that needs to be analysed according to its different steps. SDM patterns were different in the primary care and psychiatric outpatient care settings and reflect quite a different perspective of the decision making process.
De las Cuevas, C., Amado Rivero-Santana, A., Perestelo-Pérez, L., Pérez-Ramos, J., and Pedro Serrano-Aguilar, P. (2012)	To compare the attitudes of mental healthcare professionals and psychiatric outpatients towards SDM and concordance in medicine-taking, and explore the relationships of these attitudes to biological sex, age, and in the case of mental health professionals, certain variables related to their work.	A comparison the attitudes of 225 mental health professionals (125 psychiatrists and 100 psychiatry registrars) and 449 psychiatric outpatients towards SDM and concordance in medicine taking by using the self-report "Leeds Attitude toward Concordance Scale". (LATCon).	A positive attitude towards concordance in the field of psychotropic drugs prescription both in professionals and among patients is observed, but further studies are needed to address the extent to which this apparently accepted model is reflected in the daily practice of mental health professionals. Patients are clearly in favour of being informed and that their views and preferences be taken into account during the decision-making process, although they widely consider that the final decision must be the doctor's responsibility. Among mental health professionals, the broader experience provides a greater conviction of the importance of the patient's decision about treatment.

Drake, R E., Deegan, P E., and Rapp, C. (2010a)	Discussion of specific SDM information technologies.	Description of a centre for SDM, historical consumer/survivor perspectives on SDM, empirical support for SDM, and limitations.	An argument that SDM is congruent with the foundational tenets of the survivor movement and the values that inform the recovery field. Yet, there are many barriers in practice.
Drake, R. E., Deegan, P. E., Woltmann, E., Haslett, W., Drake, T., and Rapp, C. A. (2010b)	Describe a comprehensive electronic decision support system.	Discussion of comprehensive electronic decision support system. and current research.	Argument that comprehensive electronic decision support systems have the potential to improve mental health care by enhancing and connecting evidence-based medicine, client preferences, research evidence and clinical skills.
Drake, R E., Wilkniss, S M., Frounfelker, R L., Whitley, R., Zipple, A M., McHugo, and G J., Bond, G R. (2009a)	Describe an academic/community partnership to implement and study SDM.	Discussion of partnership and research activities.	Argued that the partnership offers an opportunity to develop and study current approaches to SDM.
Drake, R E., Cimpean, D, and Torrey W C. (2009b)	Describe the SDM model, reviews its current status in the mental health field, and discuss its potential impact on personalised medicine.	Discussion of SDM's current status, the doctor's role in SDM, and personalised mental health care and SDM.	Implementing SDM in routine mental health care offers considerable promise in terms of ethics, quality, informed decisions, patient satisfaction, enhanced ability for self-management, improved adherence, and meaningful outcomes. Putting these potentialities into everyday practice will be fraught with difficulties.
Duncan, E., Best, C., & Hagen, S. (2010)	To assess the effects of provider-, consumer- or carer-directed shared decision making interventions for people of all ages with mental health conditions, on a range of outcomes including: patient satisfaction, clinical outcomes, and health service outcomes.	Systematic review of Randomised controlled trials (RCTs), quasi-randomised controlled trials (q-RCTs), controlled before-and-after studies (CBAs); and interrupted time series (ITS) studies of interventions to increase shared decision making in people with mental health conditions (by DSM or ICD-10 criteria) (1890-2008)	No firm conclusions can be drawn at present about the effects of SDM interventions for people with mental health conditions. There is no evidence of harm, but there is an urgent need for further research in this area.
Fukui, S., Matthias, M S., and Salyers, M P. (2015)	Little is known about what aspects of SDM are targeted during psychiatric visits.	Secondary data analysis (191 psychiatric visits with 11 providers, coded with a validated SDM coding system) using exploratory factor	There are two factors (scientific and preference-based discussions) underlying SDM communication. Preference-based discussion occurred less. Both provider and consumer initiation of SDM elements and decision complexity were

		analysis.	associated with greater discussions in both factors, but were more strongly associated with scientific discussion. Longer visit length correlated with only scientific discussion.
Fukui, S., Salyers, M., Matthias, M., Collins, L., Thompson, J., Coffman, M., and Torrey, W. (2014)	To establish empirical evidence demonstrating factors facilitating SDM and the level of agreement between consumers and providers in psychiatric care.	Transcripts containing 128 audio recorded medication check-up visits with eight providers at three community mental health centers were rated using the Shared Decision Making scale, adapted from Braddock's Informed Decision Making Scale and analysed using Multilevel regression.	Decision complexity predicted a higher level of SDM. Consumer involvement enhances SDM and overall agreement. The provider's expectation and encouragement of the consumer's involvement should enhance SDM. Further study will be needed to build more evidence in this emerging area, incorporating longitudinal and experimental designs.
Gordon, C., and Green, M. (2013)	An argument for a collaborative style over paternalism and focus on adherence.	Discussion of challenges to SDM.	With collaborative SDM from the very start, we may bend the clinical course at least away from the alienated and polarized position in which many patients find themselves and, hopefully, find pathways that involve patients as active and empowered partners in their treatment.
Goscha, R., and Rapp, C. (2014)	Exploration of the experience of client involvement in medication decisions using an SDM model (CommonGround).	Qualitative interviews (12 clients and "most" of 15 staff).	Suggested that SDM benefits when a client has a goal that is acknowledged by the prescriber, and the identification of non-pharmaceutical ways to promote welfare, the relationship between prescriber and client, and support outside the medication consultation.
Hamann, J., Mendel, R., Reiter, S., Cohen, R., Buehner, M., Schebitz, M., and Berthele, A. (2011a)	To determine why some patients want to participate in medical decision making and others do not.	A cross-sectional survey of 203 patients participated in the study (101 with schizophrenia and 102 with multiple sclerosis for comparison). Predictors for patients' participation preferences were identified using a structural equation model.	Patients with schizophrenia exhibited lower participation preferences than patients with multiple sclerosis. Patients with schizophrenia who want to participate in decision making are often dissatisfied with care or are sceptical toward medication. Patients who judge their decisional capacity as poor or who are poorly educated prefer not to participate in decision making. Future implementation strategies for shared decision making must address how dissatisfied patients can be included in decision making and how patients who currently do not want to share decisions can be enabled, empowered, and motivated for SDM.

<p>Hamann, J., Mendel, R., Meier, A., Asani, F., Pausch, E., Leucht, S., and Kissling, W. (2011b)</p>	<p>To evaluate a new SDM intervention.</p>	<p>61 inpatients with schizophrenia or schizoaffective disorder from a psychiatric hospital were randomly assigned to receive shared decision-making training (N=32) or cognitive training (N=29, control condition).</p>	<p>Training in SDM was highly accepted by patients and changed attitudes towards participation in decision making. Patients in the intervention group became more sceptical of treatment and were perceived as more "difficult" by their psychiatrists. There were some hints that it might generate beneficial long-term effects.</p>
<p>Hamann, J., Mendel, R., Cohen., Heres, S., Ziegler, M., Buhner, M., Kissling, W. (2009)</p>	<p>To explore psychiatrists' views of shared decision making in schizophrenia treatment.</p>	<p>A structured questionnaire given to psychiatrists (352) and principal component analysed.</p>	<p>51% reported regularly applying SDM, but decision making styles were tailored to individual patients and decision topics. SDM was seen as useful for well-informed and compliant patients and for those who currently dislike their antipsychotic, but it was not seen as useful in cases of potentially reduced decisional capacity. Psychosocial matters (for example, work therapy, future housing, and psychotherapy) were considered more suitable for SDM than were medical and legal decisions (for example, hospitalisation, prescription of antipsychotics, and diagnostic procedures).</p>
<p>Lindhiem, O., Bennett, C B., Trentacosta, C J., and McLearn, C. (2014)</p>	<p>Focus on focus on several testable hypotheses surrounding potential measurable benefits of client preference. Specifically, we expect that client preferences are associated with greater satisfaction, higher completion rates, and better clinical outcome. In addition, we expect that preference effects might be moderated by one or more variables including type of choice (informed versus uninformed), setting (inpatient versus outpatient), and diagnosis.</p>	<p>Meta-analysis on the effects of client preferences on treatment satisfaction, completion, and clinical outcome. 34 empirical articles found describing 32 unique clinical trials that either randomized some clients to an active choice condition (SDM condition or choice of treatment) or assessed client preferences.</p>	<p>Findings highlight the clinical benefit of assessing client preferences, providing treatment choices when two or more efficacious options are available, and involving clients in treatment-related decisions when treatment options are not available.</p>

Matthias, M S., Salyers, M P., Rollins, A L., Frankel, M. (2012)	To explore how consumers and providers make decisions in medication management consultations.	40 medication management appointments were observed, audio recorded and transcribed. Emergent thematic analysis was used to characterize decision making processes.	Whilst a high degree of person-centeredness was observed, SDM was not prevalent.
O'Sullivan, M, J., and Rae, S. (2014)	Discussion of increasing recognition that SDM should be routine in all areas of health care, but is not yet standard practice.	Implementation of Shared Involvement in Medication Management Education training sessions (SIMME), focus groups and telephone interviews (53 staff and service users).	Early findings are where mental health staff and service users have received training in SDM, they have identified a positive effect on the service users' quality of life and unmet needs, and increased satisfaction with care. Clients have reported greater involvement in decision making, more agreement about treatment goals and increased ability through using decision aids to decide whether to stop medication. Practitioners have become more confident, developed a better understanding of service users' requirements and been more concordant with treatment guidelines.
Perestelo-Perez, L., Gonzalez-Lorenzo, M., Perez-Ramos, J., Rivero-Santana, A., and Serrano-Aguilar, P. (2011).	Present the current state and the future perspectives of SDM in mental health.	Provide an overview of research in mental health treatment decisions.	It is argued that there is controversy over the viability and plausibility of applying SDM in mental health. However, it appears that its positive effects are comparable to those found in non-mental health groups.
Salyers, M P., Matthias, M S., Fukui, S., Holter, M C., Collins, L., Rose, N., Thompson, JB., Coffman, MA., and Torrey, W C. (2012)	To assess the application and usefulness of a scale to measure the presence and extent of SDM in clinical decisions in psychiatric practice.	170 audio recordings of medication visits were rated with a scale, which was tested for interrater reliability.	The rating scale appears to reliably assess SDM in psychiatric practice.
Shepherd, A., Shorthouse, O., and Gask, L. (2014)	To explore the attitudes and experiences of consultant psychiatrists relating to SDM in the prescribing of antipsychotic medications.	26 semi structured Interviews with psychiatrists were analysed using a directed analysis method.	Participants expressed support for the SDM model, but also acknowledged that it was necessary to be flexible as the clinical situation dictated. A number of potential barriers to the process were perceived however: The commonest barrier was the clinician's beliefs regarding the service users' insight into their

			mental disorder, presented in some cases as an absolute barrier to SDM. In addition factors external to the clinician - service user relationship were identified as impacting on the decision making process, including; environmental factors, financial constraints, societal perceptions of mental disorder in general and antipsychotic medication in particular.
Simmons, M., Hetrick S., and Jorm, A. (2010)	To provide an overview of the skills required to implement a SDM model and the resources currently available.	Description of the process of SDM and the use of decision-making tools, an overview of the evidence to support such models, and discussion of the main challenges and barriers.	Despite the growing interest in SDM for psychiatric disorders and the recent increase in studies reported, little work has been done overall in this area.
Stein, B D., Kogan, J N., Mihalyo, M J., Schuster, J., Deegan, P E., Sorbero, M.J., and Drake, R E. (2013)	Examination of the impact on psychotropic adherence of a decision support centre and computerized tool (CommonGround) designed to empower and activate consumers prior to an outpatient medication management visit.	1,122 adults receiving psychotropic medication from community mental health centers over a two-year period from community mental health centers. Multivariate linear regression models were used to examine if tool users had higher rates of 180-day medication adherence than non-users.	Using the computerized tool did not affect adherence to psychotropic medications.
Stratford, A., Brophy, L., Beaton, T., and Castle, D. (2013)	To explore a recovery orientation when introducing, prescribing, administering and monitoring medication as part of treatment in psychiatry.	Discussion of challenges in current practice	Argued that a recovery-oriented position does require the adoption of an enabling and empowering approach to the use of medication. The cornerstone of this is shared decision-making that respects the person's own lived experience and choice as well as the practitioner's professional expertise.
Tibaldi, G., Salvador-Carulla, L., and Garcia-Gutierrez J.C. (2011)	To meet an urgent need to identify major determinants of adherence and non-adherence through specific interventions aimed at facilitating optimal use of medication and through a different approach to	Narrative review of purposive sample of scientific papers and official reports, and authors' expert knowledge of research, practice, training and public policy consultations.	Patient and family members need guidance and balanced decision support rather than paternalism. SDM is a highly complex process requiring new skills and decision support tools, and a person-centred attitude that focusses on empowerment and the patient's subjective perspective.

	decision making which involves patients, family members and professionals.		
Torrey, W., and Drake, R. (2010)	Describe current structural obstacles to collaborative psychiatric care and envision a redesigned office visit process that facilitates active informed patient involvement.	Discussion of challenges and a vision of a redesigned office visit that facilitates active informed patient involvement.	It is argued that a transformational psychiatrist office visit process that weaves together all the elements that are needed for efficient evidence-based psychiatric practice could be designed, tested, packaged, and implemented widely.
Warren, B J. (2012)	Discussion of SDM and relation to recovery.	Editorial.	Psychiatric nurses can be instrumental in the promotion of recovery processes and SDM.
Woltmann, E M., and Whitley, R. (2010)	Investigation of consumer decision-making preferences and understanding of construction of decisions in community mental health	People living with severe mental illness being treated in the public mental health care system (N=16) participated in qualitative interviews which were cross-case thematic analysed.	Mental health consumers may have a different view of decision making than the literature on SDM. Mental health consumers may consciously decide to at least verbally defer to their case managers, and remain silent about their preferences or wishes.

Appendix I: Recruitment Flyer for Service Users Recording Their Experiences

(Overleaf)



Shared Decision Making in Mental Health: You Could Shape Our Future!

We are people who use mental health services and we have formed a research team called PARE (Participatory Action Research Excellence).

We are inviting people who are using or have used mental health services to record their experiences of recovery or of meeting a goal. **You are invited to a workshop on Tuesday 31st May from 1-4pm at the University of Central Lancashire, Preston, or Wednesday 1st June from 1-4pm at Woodlands, 155 St Andrews Road South, St Anne's.**

We decided that shared decision making in mental health is a very important topic. So, we have designed a research study to explore the use of a shared decision making resource.

Are you over 18 and able to contribute in English?

If you take part, you will be able to choose how you would like to record your experience of recovery or of meeting a goal. We can film you, audio record you, write down what you tell us, or you can write it yourself. You will see the final version and decide then if you are happy for us to share it.

We are inviting you to a workshop to help you think about what experience you would like to share. Then, your recording will form part of our shared decision making resource. We are going to give the resource to service users and staff, and research if it supports shared decision making.

If you are interested in making a recording, want to attend a workshop or require more information please contact Katherine Allen on 07507 847523 or email katherine.allen@lancashirecare.nhs.uk. Or, please let a member of staff know that you are interested and they will ask Katherine to contact you.

Appendix J: Guidance for Service Users Recording Their Experiences

A Guide to Sharing Your Experience

We are encouraging people to share positive recovery experiences for other mental health service users to hear and/or read about. We think that this could give other people hope and inspiration, and help them to identify their own life goals. This in turn could help people to engage in shared decision making with staff from mental health services about what treatment and support would be right for them in order to meet their goals.

What might be useful for me to talk about?

We would like people to talk about a success in their lives, to give hope to others.

You can use the story board to help you to piece your experience together.

You might find it helpful to think about a success that you want to share, then go back to where you were before you achieved that success. Then, use the following questions to fill the story in.

My success/achievement/positive outcome.....

*Employment? Voluntary work? Travel? Goals? Relationships? Making friends? Socialising?
Education? Housing? Meaningful occupation? Children? Physical health? Going to the shops? Dealing with bills? Managing finances? Going to the gym? Cooking good meals?
Getting out of bed? Getting in touch with family? Answering the door? Opening post? Using the internet? Using the telephone? Looking after appearance? Making a life changing decision?*

1. What was your starting point?
2. Significant events getting to where you are now
3. What did you do and why?
4. What made a difference?
5. Who helped and what did they do?

6. Why was it meaningful to you?

What are your key “take home” messages (up to three) of what you have learnt?

1.

2.

3.

Tips

I have made progress, but wouldn't consider myself completely “recovered”

That is perfectly ok. You may still be using mental health services, experience symptoms, and feel that you have some way to go before you think of yourself as “recovered”. We are looking for examples of when something has gone right for you. Your achievement might be a stepping stone which has improved your quality of life.

What if I haven't had a good experience of mental health services?

We are not asking people to “endorse” or “recommend” mental health services. If you think that played a big part in supporting you to achieve your goals, then you are very welcome to talk about the role they played. But if they haven't, you can still talk about how you met your goal. The most important message is how you achieved something, or how you got to where you are.

What might be less useful to talk about?

We are really hoping that people's experiences of how they recovered in an aspect of their life will send out positive messages to others about what they too could become in future. So, if you have had a bad experience of mental health services in the past, this isn't the place to share it. For this project, we are looking for positive experiences only. Please talk to Katherine if you have had bad experiences of mental health services that you wish to discuss. Her details are below.

How can I share my experience?

You can share your experience via video recording, audio recording, by narrating it to us, or by writing it down.

What will happen after I have shared my experience?

We may need to do some editing to ensure that we can fit your experiences into the shared decision making resource we are developing. We will show you this first and will not use it if you are no longer in agreement for us to share it with service users and staff in our research project. Once your recording has been shared with other service users and staff in the research project, we will not be able to withdraw it. When the project is over, you will be invited to a final event to share the findings of our research project.

Further Questions?

Please contact Katherine Allen if you have any further queries, and she will be very happy to help. She is the lead researcher for this project. You can call her on 07507 847523, or email her: katherine.allen@lancashirecare.nhs.uk

PARE would like to give you a huge thank you for helping us with our research project!

Appendix K: Service Users Recording Their Experiences Information Sheet

Title: Using Mental Health Service Users' Experiences as a Shared Decision Making

Resource: A Participatory Action Research Project

We are mental health service users like yourself, and we have formed a research group called PARE (Participatory Action Research Excellence). Participatory Action Research (PAR) is a special type of research, where service users design and conduct their own research. We have decided to research Shared Decision Making.

We are inviting you to help us to conduct in our research study. We want to record mental health service users' experiences of recovery journeys and then share these with other service users and staff as part of a shared decision making resource. We then want to research if the resource supports service users and staff to engage in shared decision making. We think that by hearing from people like you, other service users will be able to think about what goals they could achieve, and this will help them to decide what care and support they need to achieve them. We would like to record your experience either by video, audio, write it down, or you could write it yourself. The choice is yours.

Before you decide to take part it is important for you to understand why we are doing the research, and what it involves. Please take time to read the following information carefully and discuss it with us, staff, relatives or others. Please ask for clarification if there is anything that is not clear, or if you would like any more information. Do take time to decide whether or not you wish to take part.

A separate part of the study is for us to discover what it is like to conduct PAR. We are working as co-researchers with a PhD student and this study is part of her student project.

What is the purpose of our study?

The NHS Constitution states that shared decision making in healthcare is a right. Also, the Department of Health states that the NHS should get better at involving patients and empowering them to manage and make decisions about their own care and treatment. This means that people should receive information that is accessible to support them to participate in shared decision making. However, there are challenges and barriers in implementing shared decision making in practice – particularly in mental health services. The purpose of our study is to explore the use of mental health service users' experiences as a shared decision making resource for service users and staff.

Why are we inviting you?

You are invited because you are or have been a mental health service user and we would like to record your experience of recovery or meeting a goal.

Do I have to take part?

No. It is up to you to decide if you would like to record your experience. We will describe the study and go through this information sheet, which is yours to keep. If you do decide to take part, we will then ask you to sign a consent form, of which you will receive a copy.

You can decide that you do not wish to record your experience at any time, without giving a reason. This will not affect the care you receive. If you decide that you do not want us to use your recording once it has been made and before we have shared it with other service users and staff, we will not use your recording.

We may edit your recording. We will share the final edit with you, and if you wish to withdraw the recording at this stage you can.

However, once we have shared your recording with other service users and staff as part of our research study, we will be unable to withdraw your recording until the end of the study.

What will happen if I take part?

We will invite you to attend a three hour workshop to support you to decide what parts of your experience you would like to record, and how. We will then arrange to meet you to record your experience in a way that you chose – video, audio, or you can narrate it to us. Or, you could write it down yourself. We may have to edit the recording, and you will be invited to see the final edit. It is expected that you will be involved in the research for two months. You will be invited to see the final edit of your experience recording, and you will be able to withdraw your recording from the project at this stage, without giving a reason.

We do not anticipate that there will be and adverse effects for you from recording your experience. However, some people may find it difficult or distressing to talk about their experience of using mental health services. Support will be provided through de-briefing and contact with other appropriate services if necessary. You are also able to withdraw from planning or recording your experience at any time if it becomes distressing for you. You will also be invited to an event at the end of our study, where you will be offered the opportunity to discuss any distressing or difficult feelings that may have arisen as a result of taking part.

What is the time commitment?

The time commitment will be six hours, over no longer than a two month period. After the three hour workshop where we will support you to develop your experience recording, we will arrange to meet you at your convenience to record your experience. Doing the recording will take no longer than two hours. You will then be invited to see your recording after we have edited it. This meeting will take no longer than one hour.

Are there any benefits to taking part?

You may find that there is some therapeutic value in recording your experience. Shared decision making has the potential to improve people's recovery, engagement with services and experience, and ensure that they get the treatment and support that is right for them. It is an essential component of person care centred planning, and also has the potential to improve self-management and self-care.

Will my recording be kept confidential?

If you choose to record your experience via video or audio, you will be identifiable to the service users and staff that we share the recording with. If you choose to narrate or write your experience, this will be anonymised. You will be able to withdraw your recording at any time before we circulate it to the research participants without giving a reason, including after you have viewed the final edit.

If you tell us about anything that might involve harm to yourself or somebody else, anything about criminal acts, or anything about malpractice. In these circumstances we are obliged to pass this on to the relevant manager, care co-ordinator, or your GP. If we feel we have to do this we will discuss it with you first where possible.

What will happen to the results of our study?

The results will be written up for publication in professional journals and be presented at research conferences. A summary of these results will be circulated to you if you wish, as well as Lancashire Care NHS Foundation Trust staff. You will also be invited to a closing presentation once the study has been completed. The study will also be written up as part of the lead researcher's PhD thesis. You will not be identifiable in any report of the study.

Who is organising and funding our research?

Our research study is organised through the College of Health and Wellbeing at the University of Central Lancashire. The fees for this are being paid by the North West Strategic Health Authority. Katherine Allen SRAsT (M) MA MSc is the lead researcher. Katherine leads on service user involvement for Lancashire Care NHS Foundation Trust's Adult Mental Health Network.

What if you have a complaint about our study?

If you have any concerns about your involvement in this research, in the first instance, please raise them with Katherine Allen, lead researcher: katherine.allen@lancashirecare.nhs.uk, 07507 847523. If you wish to make a complaint, you can do so by contacting Nigel Harrison, Dean and Head of School, UCLan School of Nursing, NHarrison@uclan.ac.uk, 01772 89 3700, or Lancashire Care NHS Foundation Trust Customer Care Department, customer.care@lancashirecare.nhs.uk, 01772 695315.

Will you get paid for recording your experience?

Reasonable travel expenses will be paid by Lancashire Care NHS Foundation Trust.

Who has reviewed our study?

The study has been reviewed and approved by the North West - Lancaster Research Ethics Committee: a Research Ethics Committee established by the Health Research Authority.

Thank you for reading this information sheet. We would like to remind you to contact us if you want to discuss any part of our study.

Appendix L: Consent Form: Service Users Recording their Experiences

Title of Study: Using Mental Health Service Users' Experiences as a Shared Decision Making Resource: A Participatory Action Research Project

Name of Researchers: Katherine Allen, PARE Team

	Please i n i t i a l e a c h b o x
<p>9. I confirm that I have read the information sheet for the above study, have had the opportunity to ask questions, and understand what taking part will involve (having my experience recoded in writing or video or audio for the sole use of a shared decision making resource and strictly for no other purposes).</p>	
<p>10. I understand my experience recording will be shared with other service users and staff so it is not confidential. I understand that if my recording is video or audio, I will be identifiable, and if it is recorded in writing it will be anonymised.</p>	
<p>11. I understand that all personal data will be stored securely and is covered by the Data Protection Act (with the exception of my experience recording, which will be shared with service users and staff).</p>	
<p>12. I understand that if I tell the researchers anything that might involve harm to myself or somebody else, and/or anything about criminal acts or malpractice, the researcher has a duty of care to pass this on to my GP or other relevant professionals, but this will be discussed with me first where possible.</p>	
<p>5. I would like to receive a summary report of the study and am happy for the researchers to store my address details on a secure server in order to post the report to me when it is available and invite me to the closing presentation.</p>	

**Appendix M: Staff Recruitment Flyer
(Overleaf)**



Shared Decision Making in Mental Health: You Could Shape Our Future!

We are people who use mental health services and we have formed a research team called PARE (Participatory Action Research Excellence).

We are inviting Fylde Community Mental Health Team and/or Social Inclusion Service staff and service users to take part in our research study on shared decision making.

We decided that shared decision making in mental health is a very important topic. So, we have designed a research study to explore the use of a shared decision making resource.

If you take part, you will be invited to attend an initial focus group to tell us your thoughts about shared decision making, then afterwards to share your experiences of using our resource.

Then, you will be given our shared decision making resource, which includes recordings of service user's experiences. You will be invited to use the resource in your conversations with service users over months.

If you are interested in taking part in our study or require more information please contact Katherine Allen on 07507 847523 or email katherine.allen@lancashirecare.nhs.uk.

Appendix N: Staff Participant Information Sheet

Staff Research Participants

Title: Using Mental Health Service Users' Experiences as a Shared Decision Making Resource: A Participatory Action Research Project

We are mental health service users, and we have formed a research group called PARE (Participatory Action Research Excellence). Participatory Action Research (PAR) is a special type of research, where service users design and conduct their own research. We have decided to research Shared Decision Making.

We are inviting you to take part in our research study. Before you decide to take part it is important for you to understand why we are doing the research, and what it involves. Please take time to read the following information carefully and discuss it with us or others. Please ask for clarification if there is anything that is not clear, or if you would like any more information. Do take time to decide whether or not you wish to take part.

A separate part of the study is for us to discover what it is like to conduct PAR. We are working as co-researchers with a PhD student and this study is part of her student project.

What is the purpose of our study?

The NHS Constitution states that shared decision making in healthcare is a right. Also, the Department of Health states that the NHS should get better at involving patients and empowering them to manage and make decisions about their own care and treatment. This means that people should receive information that is accessible to support them to participate in shared decision making. However, there are challenges and barriers in implementing shared decision making in practice – particularly in mental health services. The purpose of our study is to explore the use of mental health service users' experiences as a shared decision making resource for service users and staff.

Why are we inviting you?

You are invited because you are a member of staff in the Fylde and Wyre Community Mental Health Team or Social Inclusion Service. There will be a group of people who use these services taking part in the study, as well as other staff members of the services.

Do I have to take part?

No. It is up to you to decide whether to join our study. We will describe the study and go through this information sheet, which is yours to keep. If you do decide to take part, we will then ask you to sign a consent form, of which you will receive a copy.

You can withdraw from the study at any time, without giving a reason. If you decide to withdraw from the study, any information that you have already given as part of a group during the study will still be used. This is because your information may have already been combined with information given by others and anonymised.

What will happen if I take part?

You will be given a shared decision making resource by us. The resource was designed and developed by us. It includes different types of recordings of mental health service users' experiences of their recovery journey, and some information about shared decision making. You will be invited to a one hour information session about shared decision making and our resource. You will also be invited to attend an initial focus group to discuss your views and experiences of shared decision making. We will then ask you to make use of our shared decision making resource when you have contact with service users where appropriate over a three month period. We are also going to provide an information session for service users about shared decision making and resource, and invite them to make use of the resource when they have contact with you. We will then invite you to another focus group to discuss your experience of using our shared decision making resource.

We do not anticipate that participating in this study will have any adverse effects for you.

What is the time commitment?

The time commitment is five hours over a four month period. This is a one hour information session, a two hour focus group before you use the shared decision making resource, and a two hour focus group after you have used the shared decision making resource. We will be inviting you to make use of the shared decision making resource as part of your usual contact with service users over a three month period. There should be no additional time commitment when you are making use of the resource with service users.

Are there any benefits to taking part?

We anticipate that our shared decision making resource will support you to do your job. Shared decision making has the potential to improve people's recovery, engagement with services and experience, and ensure that they get the treatment and support that is right for them. It is an essential component of person care centred planning, and also has the potential to improve self-management and self-care.

Will my taking part in this study be kept confidential?

The nature of focus groups means that you will be sharing information with other participants. At the beginning of each focus group we will discuss confidentiality and establish a group agreement.

No information that can identify you will be passed on to anyone outside of the research team or the people who are supervising the research at the University of Central Lancashire, or be contained in the final report or any other publication. Data will be securely stored at Lancashire Care NHS Foundation Trust and any information that is put on a computer will be protected with a password known only to the lead researcher. Only the research team and supervisory team will hear recordings of focus groups, or read transcripts of the recordings, and the recordings will be erased once the study has been completed. The anonymised data set will be kept for five years.

The only exception to this will be if you tell us about anything that might involve harm to yourself or somebody else, anything about criminal acts, or anything about malpractice. In these circumstances we are obliged to pass this on to the relevant manager. If we feel we have to do this we will discuss it with you first where possible.

What will happen to the results of our study?

The results will be written up for publication in professional journals and be presented at research conferences. A summary of these results will be circulated to you if you wish, and service users will also receive a copy. You and the service users participating in the study will also be invited to a closing presentation once the study has been completed. The study will also be written up as part of the lead researcher's PhD thesis. You will not be identifiable in any report of the study.

Who is organising and funding our research?

Our research study is organised through the College of Health and Wellbeing at the University of Central Lancashire. The fees for this are being paid by the North West Strategic Health Authority. Katherine Allen SRAsT (M) MA MSc is the lead researcher. Katherine leads on service user involvement for Lancashire Care NHS Foundation Trust's Adult Mental Health Network.

What if you have a complaint about our study?

If you have any concerns about your involvement in this research, in the first instance, please raise them with Katherine Allen, lead researcher: katherine.allen@lancashirecare.nhs.uk, 07507 847523. If you wish to make a complaint, you can do so by contacting Nigel Harrison, Dean and Head of School, UCLan School of Nursing, NHarrisonion@uclan.ac.uk, 01772 89 3700.

Will you get paid for participating in the study?

No.

Who has reviewed our study?

The study has been reviewed and approved by the North West - Lancaster Research Ethics Committee: a Research Ethics Committee established by the Health Research Authority.

Thank you for reading this information sheet. We would like to remind you to contact us if you want to discuss any part of our study.

Appendix 0: Staff Consent Form

Consent Form: staff research participants

Title of Study: Using Mental Health Service Users' Experiences as a Shared Decision Making Resource: A Participatory Action Research Project

Name of Researchers: Katherine Allen, PARE Team

	Please initial each box
1. I confirm that I have read the participant information sheet for the above study, and have had the opportunity to ask questions and understand what taking part will involve (using a shared decision making resource with service users and attending an information session and focus groups)	
2. I understand that the nature of focus groups means that I will be sharing information with other participants, so is therefore not confidential within the focus group members.	
3. I understand and give consent for focus groups to be audio-recorded and transcribed.	
4. I understand that any data or information used in publications and presentations which arise from this study will be anonymised before use.	
5. I give permission for any anonymised data set to be kept for 5 years.	
6. I understand that all data will be stored securely and is covered by the Data Protection Act.	
7. I understand that if I tell the researchers anything that might involve harm to myself or somebody else, and/or anything about criminal acts or malpractice, the researcher has a duty of care to pass this on to my manager or other relevant professionals, but this will be discussed with me first where possible.	
8. I would like to receive a summary report of the study and invite to the closing presentation.	
9. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason	
10. I agree to take part in the above study.	

Name of participant

Signature

Date

Name of researcher

Signature

Date

Job title _____

Work address Woodlands

Email _____

**Appendix P: Service User Participant Flyer
(Overleaf)**



Shared Decision Making in Mental Health: You Could Shape Our Future!

We are people who use mental health services and we have formed a research team called PARE (Participatory Action Research Excellence).

We are inviting people who use Fylde Community Mental Health Team and/or Social Inclusion Service and staff to take part in our research study on shared decision making.

We decided that shared decision making in mental health is a very important topic. So, we have designed a research study to explore the use of a shared decision making resource.

Are you over 18 and able to contribute in English?

If you take part, you will be given our shared decision making resource, which includes recordings of other service user's experiences. You will be invited to use the resource in your conversations with mental health staff members over 3 months.

Then, you will be invited to attend a focus group or interview with us, or keep a written diary according to your preference, to tell us about your experience of the shared decision making resource.

If you are interested in taking part in our study or require more information please contact Katherine Allen on 07507 847523 or email katherine.allen@lancashirecare.nhs.uk. Or, please let a member of staff know that you are interested and they will ask Katherine to contact you.

Appendix Q: Participant Information Sheet: Service User Research Participants

Title: Using Mental Health Service Users' Experiences as a Shared Decision Making Resource: A Participatory Action Research Project

We are mental health service users like yourself, and we have formed a research group called PARE (Participatory Action Research Excellence). Participatory Action Research (PAR) is a special type of research, where service users design and conduct their own research. We have decided to research Shared Decision Making.

We are inviting you to take part in our research study. Before you decide to take part it is important for you to understand why we are doing the research, and what it involves. Please take time to read the following information carefully and discuss it with us, staff, relatives or others. Please ask for clarification if there is anything that is not clear, or if you would like any more information. Do take time to decide whether or not you wish to take part.

A separate part of the study is for us to discover what it is like to conduct PAR. We are working as co-researchers with a PhD student and this study is part of her student project.

What is the purpose of our study?

The NHS Constitution states that shared decision making in healthcare is a right. Also, the Department of Health states that the NHS should get better at involving patients and empowering them to manage and make decisions about their own care and treatment. This means that people should receive information that is accessible to support them to participate in shared decision making. However, there are challenges and barriers in implementing shared decision making in practice – particularly in mental health services. The purpose of our study is to explore the use of mental health service users' experiences as a shared decision making resource for service users and staff.

Why are we inviting you?

You are invited because you use the Fylde and Wyre Community Mental Health Team or Social Inclusion Service. There will be a group of people who use these services taking part in the study, as well as staff members of the services.

Do I have to take part?

No. It is up to you to decide whether to join our study. We will describe the study and go through this information sheet, which is yours to keep. If you do decide to take part, we will then ask you to sign a consent form, of which you will receive a copy.

You can withdraw from the study at any time, without giving a reason. This will not affect the care you receive. If you decide to withdraw from the study, any information that you have already given as part of a group during the study will still be used. This is because your information may have already been combined with information given by others and anonymised. Any information that you give during an interview can be withdrawn if you wish.

What will happen if I take part?

You will be given our shared decision making resource, either by us or a member of staff. You will be invited to a one hour meeting about shared decision making and our shared decision making resource. The resource was designed and developed by us. It includes recordings in different media of mental health service users' experiences of their recovery journey, and some information about shared decision making. You will be invited by us and staff to make use of our shared decision making resource when you have contact with staff, over a three month period. You will then be invited to attend a focus group and/or interview depending on your preference to discuss your experience of using the shared decision making resource. It is expected that you will be involved in the research for seven months.

We do not anticipate that there will be any adverse effects for you from being part of our study. However, some people may find it difficult or distressing to talk about their

experience of using mental health services. Support will be provided through de-briefing and contact with other appropriate services if necessary. You are also able to withdraw from the study at any time if participation becomes distressing for you. You will also be invited to an event at the end of our study, where you will be offered the opportunity to discuss any distressing or difficult feelings that may have arisen as a result of taking part.

What is the time commitment?

The total face-to-face time with us is three hours over a three month period. There is an introductory one hour meeting at the beginning, then a two hour focus group at the end. The time you take looking at the shared decision making resource, and if you choose, writing a diary about your shared decision making experiences is up to you. It could be as little or as long as you wish. We expect that you would use the shared decision making resource as part of your usual contact with your mental health workers, so there will be no extra time commitment in terms of your time spent with mental health services.

Are there any benefits to taking part?

Shared decision making has the potential to improve people's recovery, engagement with services and experience, and ensure that they get the treatment and support that is right for them. It is an essential component of person care centred planning, and also has the potential to improve self-management and self-care. You may find our shared decision making resource helpful, and you may find it beneficial to share and hear about other people's experiences of using mental health services.

Will my taking part in this study be kept confidential?

The nature of focus groups means that you will be sharing information with other participants. At the beginning of the focus group we will discuss confidentiality and establish a group agreement.

No information that can identify you will be passed on to anyone outside of the research team or the people who are supervising the research at the University of Central

Lancashire, or be contained in the final report or any other publication. Data will be securely stored at Lancashire Care NHS Foundation Trust and any information that is put on a computer will be protected with a password known only to the lead researcher. Only the research team and supervisory team will hear recordings of focus groups and interviews, or read transcripts of the recordings, and the recordings will be erased once the study has been completed. The anonymised data set will be kept for five years.

The only exception to this will be if you tell us about anything that might involve harm to yourself or somebody else, anything about criminal acts, or anything about malpractice. In these circumstances we are obliged to pass this on to the relevant manager, care co-ordinator, or your GP. If we feel we have to do this we will discuss it with you first where possible.

What will happen to the results of our study?

The results will be written up for publication in professional journals and be presented at research conferences. A summary of these results will be circulated to you if you wish, as well as Lancashire Care NHS Foundation Trust staff. You will also be invited to a closing presentation once the study has been completed. The study will also be written up as part of the lead researcher's PhD thesis. You will not be identifiable in any report of the study.

Who is organising and funding our research?

Our research study is organised through the College of Health and Wellbeing at the University of Central Lancashire. The fees for this are being paid by the North West Strategic Health Authority. Katherine Allen SRAsT (M) MA MSc is the lead researcher. Katherine leads on service user involvement for Lancashire Care NHS Foundation Trust's Adult Mental Health Network.

What if you have a complaint about our study?

If you have any concerns about your involvement in this research, in the first instance, please raise them with Katherine Allen, lead researcher: katherine.allen@lancashirecare.nhs.uk, 07507 847523. If you wish to make a complaint, you can do so by contacting Nigel Harrison, Dean and Head of School, UCLan School of Nursing, NHarrison@uclan.ac.uk, 01772 89 3700, or Lancashire Care NHS Foundation Trust Customer Care Department, customer.care@lancashirecare.nhs.uk, 01772 695315.

Will you get paid for participating in the study?

Reasonable travel expenses will be paid by Lancashire Care NHS Foundation Trust.

Who has reviewed our study?

The study has been reviewed and approved by the North West - Lancaster Research Ethics Committee: a Research Ethics Committee established by the Health Research Authority.

Thank you for reading this information sheet. We would like to remind you to contact us if you want to discuss any part of our study.

Appendix R: Consent Form: Service User Research Participants

Title of Study: Using Mental Health Service Users' Experiences as a Shared Decision Making Resource: A Participatory Action Research Project

Name of Researchers: Katherine Allen, PARE Team

	Please initial each box
1. I confirm that I have read the participant information sheet for the above study, and have had the opportunity to ask questions and understand what taking part will involve (using a shared decision making resource, attending focus groups, individual interviews, and/or keeping a written diary as I choose).	
1. I understand that the nature of focus groups means that I will be sharing information with other participants, so is therefore not confidential within the focus group members.	
2. I understand and give consent for focus groups and interviews to be audio-recorded and transcribed.	
3. I understand that any data or information used in publications and presentations which arise from this study will be anonymised before use.	
4. I give permission for any anonymised data set to be kept for 5 years.	
4. I understand that all data will be stored securely and is covered by the Data Protection Act.	
5. I understand that if I tell the researchers anything that might involve harm to myself or somebody else, and/or anything about criminal acts or malpractice, the researcher has a duty of care to pass this on to my GP or other relevant professionals, but this will be discussed with me first where possible.	
6. I would like to receive a summary report of the study and invite to the closing presentation and am happy for the researchers to store my address details on a secure server in order to post the report to me when it is available.	
7. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason	
8. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
9. I agree to take part in the above study.	

Name of participant

Signature

Date

Name of researcher

Signature

Date

Address: _____

Email _____

Telephone: _____

Appendix S: Staff Focus Group Guide

1. Think of an example of when you have done shared decision making with a service user
2. What might the benefits of shared decision making be?
3. Think of an example when shared decision making hasn't worked with a service user
4. What are the barriers to SDM?

Possible follow up question....

5. *Do service users always make choices appropriate to the problem identified?*
6. Does the role of service users' families' impact on shared decision making?
7. Do service users want to engage in shared decision making?
8. Is there a power dynamic between you and service users?

Possible follow up question....

9. *Do relationship dynamics and service user behaviour impact on shared decision making?*
10. Do you have any fears about shared decision making?

Possible follow up question....

11. *Do you have any hopes for shared decision making?*

Appendix T: Staff Post-Resource Interview Guide

1. How easy to use was the shared decision making resource?
2. How confident were you about using the resource?
3. Was the shared decision making information session useful?
4. Is there any way that the resource could be improved?
5. Did it help you in your job?
6. Did it empower people to make informed choices?
7. Did it alter the power dynamic between you and service users?
8. Has the project being service user led made you think about anything differently?

Appendix U: PARE Focus Group No 1

Semi-structured Guide

- 1. Introduction: agree time management?**
- 2. What are the strengths of the group? (good bits!)**
- 3. What are the weaknesses?**
- 4. What are the experiences of the group?**
- 5. What benefits people in the group?**
- 6. What motivates people in the group?**
- 7. Are there any negative impacts of being in the group?**
- 8. What are the aspirations of the group?**
- 9. Where is the power in the group?**
- 10. Where is the knowledge in the group?**
- 11. What do we need to know about each other?**
- 12. How do we identify our skills?**

Appendix V: PARE Focus Group No 2

Semi-structured Guide

- 1. Introduction: agree time management**
- 2. What have been the experiences of the participants?**
- 3. What has worked?**
- 4. What hasn't worked?**
- 5. Have aspirations changed? (including Katherine's)**
- 6. What are the benefits of being in the group?**
- 7. What motivates people in the group?**
- 8. Where is the power in the group?**
- 9. Where is the knowledge in the group?**
- 10. How do we think others perceive us?**
- 11. What skills are needed for the next part of the project?**

Appendix W: PARE Focus Group No 3

Semi-structured Guide

- 1. Introduction: agree time management**
- 2. What have been the experiences of the participants?**
- 3. Are all the participants happy with the decisions made?**
- 4. What has worked?**
- 5. What hasn't worked? (Is there anything that can be done for people to attend more?)**
- 6. Do we need to recruit more members?**
- 7. Have aspirations changed? (including Katherine's)**
- 8. Have the benefits of being in the group changed?**
- 9. Have the motivations of people in the group changed?**
- 10. Is there a centre of power in the group, and has it changed?**
- 11. Where is the knowledge in the group?**
- 12. How do we think others perceive us?**
- 13. What skills are needed for the next part of the project?**

**Appendix X: By People, For People: Shared Experiences to Support Shared
Decision Making in Mental Health**

Text only: final version was in A3 booklet form.

(Overleaf)

By People, for People: A library of written, video and audio shared experiences

Shared Experiences to Support Shared Decision
Making in Mental Health

www.sharedexperiences.online



Shared Experiences...

**“I never thought I would be here....”fear is the cheapest room in the house. I would like to see you living in better conditions”
(Hafiz)**

“Do you know just how valuable your lived experience is to yourself and others? I think we’re all amazing!”

“My partner and I felt much more informed and therefore more confident in asking questions and actively being part of the decisions being made about my care”

“I have got there as a result of the support from my family, friends, peer support, organisations, and sheer chance!”

“I was able to accept and move forward with the diagnosis”

“I am now enjoying a life that I feel is rewarding and pleasurable, in many new ways”

“I have found an ease and freedom to be myself in life which to me is priceless”

Contents

	Page
Introduction: Our Hopes for You	5
How to Use the Shared Experiences Library.....	6
About Shared Decision Making.....	6
Who We Are	7
The Shared Experiences Library	8
The Experiences at a Glance	8
Lyn-Rosamund.....	10
Chris	11
Alyssa	13
Ermintrude.....	13
Chris	14
Christopher	15
J.....	17
Background to Our Project	
What is Participatory Action Research?	18
About our Research Project.....	18
How to Contact Us	20

Shared Experiences to Support Shared Decision Making

Introduction

A very warm welcome to our shared experiences library. We are PAR Excellence, a team of mental health service users who have developed this resource for other mental health service users. In here you will find a collection of shared experiences from people who have all used mental health services. Each experience describes things that have helped people to achieve something in their lives – big and small. You can also watch video clips or listen to an audio clip by visiting our website: www.sharedexperiences.online. You will find all the experiences and information in this booklet on the website. This booklet also contains information about us, shared decision making, participatory action research, and our research project. To go straight to the shared experiences library, please turn to page 8.

Our Hopes for You

You matter. We want to empower you to be a partner in deciding about your care. By hearing from other people who have been where you are, we hope that these experiences will help you in your recovery. We also hope that they will support you to share decisions with your mental health workers. We think that the experiences will give you ideas, inspiration and hope for the future, and might help you to talk about what would be the right thing for you. They show what is possible, and that you are not alone. We hope to enable you to take control of your own recovery.

Our Research

This project is part of a research study. The study is using participatory action research (PAR). This means that we as a team of mental health service users chose to do a project about shared decision making between service users and their mental health workers. So, we decided to create this shared experience library. We would like to hear your feedback about the library, and shared decision making in mental health generally. You can find out more on pages 18. Please contact us via the details on the back page or via our website.

Our Partners and Supporters

We are doing this project at the Fylde Community Mental Health Team and Social Inclusion Service at Woodlands. We are working in partnership with Lancashire Care NHS Foundation Trust's Adult Mental Health Network, and the University of Central Lancashire.

www.sharedexperiences.online

Page 5

How to Use the Shared Experiences Library

In this booklet from page 8 you will find experiences written by people who have used mental health services. They describe the difficult things they have faced, and discuss what helped them to achieve their goals. These have not always been easy journeys, but each experience describes a positive outcome in the end.

You can also watch videos and listen to an audio clip from more people talking about their mental health experiences and what has helped them in their recovery. You will need to contact us or a member of staff for a simple password to watch the videos online. Details of how to do this are on the back page.

We hope that these experiences will help you to share decisions about what would be best for you with your mental health workers.

About Shared Decision Making

“no decision about me, without me”

You have the right to be involved in discussions and decisions about your health and care, and to be given information to enable you to do this (NHS Constitution). Shared decision making allows you to be an equal partner in your health care, working with your health care workers to make an informed decision about your treatment.

The NHS wants to become dramatically better at involving service users and their carers, and empower them to manage and make decisions about their own care and treatment. This means giving people the knowledge, skills and confidence to manage their own health so that they can actively participate with their healthcare workers in making choices about their care and treatment.

In mental health, some people think that shared decision making can help people to recover. This is because it gives you the power to set the right goals for you, and also supports you to manage your own health. You are an expert with knowledge about your values, preferences, goals and support. Your health workers have knowledge about conditions, evidence, interventions, risks, benefits and alternatives. Shared decision making ensures that you and your workers are equally and actively involved, sharing expertise and information to reach an agreement which you all hold responsibility for.

Key to shared decision making is information that is understandable. That is why we have put this library together – so that you can find

www.sharedexperiences.online

Page 6

out from other people who have used mental health services what has worked for them, and so that you know you are not alone.

Who We Are

"We hope that this project will inspire and motivate more service users to have a voice and lead on improving services"

PAR Excellence team member

We are all people who have all used mental health services in the past or present. We got together because we were invited to form a research team where we would decide what to research, how to research it, and carry out the research. We called our team PAR Excellence. Together, we decided to create this library, and find out if it supports people in shared decision making. We have done research skills training to ensure that we carry out our project well.

The team is facilitated by Katherine Allen, who works for Lancashire Care NHS Foundation Trust as service user involvement lead. She is also a student at the University of Central Lancashire, and this is part of her PhD study.

"I set up this project because I thought it was important to find a way of giving power to people who use mental health services to take control of their own research, and give them an equal voice amongst traditional researchers and professionals. I believe that we do not hear enough from people about what are the most important and meaningful aspects to their lives and the care and treatment they receive, and what should be researched in relation to these things. I also believe that people who use mental health services have a vast amount of knowledge and experience but this is not always recognised or made use of. I hope this project goes some way to redressing this balance. Being part of this project has been brilliant – I have been completely in awe of the commitment and passion the team have shown to improving things for others – and of the people who have so kindly and generously shared their experiences so candidly".

Katherine, project facilitator

The Shared Experiences Library

The Shared Experiences at a Glance

Lyn-Rosamund Page 10

Read Lyn's story of living a life in a "self-imposed prison", until a support worker persevered and encouraged her to try something new. There, Lyn found a friend, and her life changed beyond recognition through the support they give each other. Her key message is to never give up: there will be something right for you in your recovery.

Chris Page 11

Chris writes about how recovery hasn't been a 'pathway', more Pan-American Highway. He describes how he developed his confidence through service user involvement, which led to voluntary work. He then got a job in health care, which changed his view of himself and mental health workers. He discovered just how important and valuable lived experience is.

Alyssa Page 13

Alyssa describes an excellent example of shared decision making during a period of being very unwell. Through conversations with Alyssa and her partner, her care co-ordinator and psychiatrist agreed on a medication change and involved a pharmacist to advise and monitor progress. Alyssa's case was a complex one, because of her physical health condition and the medication she also takes for this. Both Alyssa and her partner felt fully involved throughout, which meant that they felt confident to ask questions.

Ermintrude Page 13

Ermintrude shares how she moved from a transient life with many hospital admissions to a secure home, job and meaningful activities. Her highlights are fulfilling her ambitions to travel, and her passion for nature. She recommends remembering that you are the expert in your own life.

Chris Page 14

Read a snapshot of how, through talking to his care co-ordinator, Chris found someone to speak to about his mental health diagnosis, and come to terms with what it meant for him. This has helped him to move forward with his life with greater understanding and control. He highlights the importance of trust and talking.

Christopher..... Page 15
Christopher has written about once being homeless and isolated, penniless and scared. Now, he has a rewarding and pleasurable life. A chaotic lifestyle - including drug and alcohol misuse and experiencing delusions and disordered thoughts - left Christopher living behind a wall of silence. By taking positive steps and ownership over his future, including engaging in mental health services, he rebuilt a new life, developed his confidence, formed a social network and found full-time work.

J..... Page 17
J shares how she overcame the devastation and losses of becoming unwell as a young adult. Though by no means taking an easy path, she decided that change lay within herself, and took control of how she viewed her situation and her relationship with mental health workers. J now lives a rich life of her choosing, with an ease and freedom that is priceless.

Shared experiences online: please contact us for easy steps to watch our videos

Janet

Janet talks about the impact of a distressing childhood on her life - at times, an upsetting account. But, Janet also tells us about how learning to trust a social worker who never gave up on her turned her life around completely. Through this relationship, Janet agreed to give therapy a chance, and it gave Janet a life she never thought she would have. She passionately believes that however painful your childhood is, please try to confide in someone as early as you can. Childhood and growing up is a precious time and is when we learn how to deal with people, with life. Try and trust someone as early as you can, accept help and don't give up - however hard: it is worth it in the end.

Richard

Richard discusses his experience of bi-polar disorder and his journey to wellness and recovery. Key relationships with a support worker and psychiatrist led Richard to make some major life decisions. A combination of mindfulness, cognitive analytical therapy and medication helped him to come to terms with his condition and make helpful lifestyle changes. He tells us about the role of voluntary work in his life, and how supporting others has given him an immense sense of value and purpose. Richard also tells us about some excellent practice in shared decision

www.sharedexperiences.online

Page 9

making between him, his family and his psychiatrist about medication.

Brian

Brian talks about the vital role volunteering has played in his life, and others. He has observed how it can develop social contact, confidence, and self-esteem, as well as opening doors to further opportunities. He discusses how rediscovering, or finding something you love and are passionate about can be key to making a recovery – even from a point where things seem hopeless. He also found talking therapy helped him, and showed him that you may think you are on your own, but you are not.

Joy

Joy tells us about her journey to recovery after some significantly bad life events and six months in hospital. She talks about the roles her care co-ordinator and occupational therapist played in getting Joy out of the house and getting used to people again. Through voluntary work, her confidence grew and she eventually became a mental health advocate, supporting service users in meetings. This in turn led to a paid role.

Neil (audio)

Neil talks about how difficult school days were followed by depression which led to distressing psychotic episodes. He describes his symptoms and social isolation in detail. Following a hospital admission, he received intensive support from mental health services and accessed therapy. Although Neil remained despondent to begin with, his workers always had hope for him and believed in Neil's recovery. Gradually he started to talk to people, made friends, and completed the degree he started before his psychosis. Life is a lot more livable, after several hard years.

Lyn-Rosamund

"Fear is the cheapest room in the house. I would like to see you living in better conditions". Hafiz.

I am 63 years old and have been (off and on) a service user for 56 years. That may seem a negative outcome but I have seen a lot of positive changes in 'the system'.

In the 60s patients had little or no say in their treatment. Support after discharge was practically unheard of. Relapses were viewed as a failure of the patient. We were patients, not people. Now service users (a much better form of address than "patient") are given care packages and staff involve them in their ongoing care and support.

www.sharedexperiences.online

Page 10

A big turning point for me was my last support worker, who was brilliant. She kept persevering with my negative attitude of "been there - done that and nothing worked". She came armed with information on various courses and I would go once or twice and then retreat back into self-imposed isolation and sink back into agrophobic depression. I couldn't go out alone, couldn't even go shopping, couldn't make friends. Finally though, I realised the "safe place" was actually just four walls that were in fact imprisoning and suffocating me. I found out that walls are not safe. I was in a self-imposed prison that I needed to get out of. You don't have a life when you just have walls, and I had nowhere to be me. This realisation made me more open to going to yet another course. I was dragged kicking and screaming to an art course, and I just wanted to go home.

At the course I met someone who I could talk to. We started meeting up outside of the course, which was a breakthrough. We became best friends and she has helped and supported me ever since. The friendship I formed made the difference to me spiralling. She is someone I can text, have a chat with, and she takes me to places where I wouldn't go alone. She opened up my world.

Also, she could give me support when my family couldn't, as she understood. And, I think it has done the same for her.

If I were to give one piece of encouragement to someone it would be to keep trying because there is something that will be the right thing for them to help their recovery. Don't give up on doing something: keep trying, and something will click. I didn't think it would work for me, but it did.

The system is not perfect but it is improving and changing all the time. I never thought I would be here.

Chris

My name is Chris. I'm not far off 50. My recovery hasn't been a 'pathway', more Pan-American Highway. It's been a 35 year long 'Forest Gump' run in the wilderness without Asics trainers or a Sat Nav! Until a few years ago, I was a passive recipient of health-care. I definitely saw the interaction between the professional and me (the patient) as 'them and us'. I thought that 'they' were problem-free and flawless and I was just disabled and inferior. I did what they said, and that included at least some compliance with every psychiatric drug from every class known to man. And I accepted

each new label that came along with the latest locum I saw.

When I was no longer needed as a Carer (yes, I had more than one person piggy-backing me on that highway), I joined the Involvement group Experts by Experience. I started to feel valued and my confidence grew. Health professionals came to our meetings and asked for my input. We got involved in training and redesigning services. I didn't go the other way and start over-challenging, but I definitely became less servile in the presence of the 'top bods'. I developed loads of transferable skills and it felt like shared decision making to me, even if the 'tokenistic' cynics raised an eyebrow to the process. Maybe health professionals did need to tick the involvement box initially, but our input did affect change and that's all that matters. I realised that I had something professionals want. I still thought that it was because I had something they'll never have (lived experience of mental health problems). However, this opinion was set to change.

I became an NHS volunteer in the workplace. This led to a paid post with Lancashire Care. My lived experience was gold-dust to other service users and my years of socially anxious, disorientated failure were no longer defined by myself or others as "what a waste". Now 'staff-side', the massive curtain in OZ was drawn, revealing to me that professionals are just as anxious, depressed and 'stuck' in their own common and specific dung as I am! I felt guilty for a while, as I recalled all the times I'd emotionally drained them in sessions. I'd never given their welfare much thought. I just assumed they grew up in validating environments with a perfect genetic code, were nurtured to be emotionally resilient, Stepford-like robots, and if they did malfunction or run out of steam, they just plugged themselves into the national grid when they got home to recharge! Now I know that, just like service users, health professionals are human beings too.

'Physician, heal thyself' isn't much different to 'Physician heal me', or even 'Physician, help me to heal me, even if you can't heal yourself'. That's why I hope this project narrows the gap between professional and patient. I know from how I work that health professionals can maintain boundaries in a therapeutic relationship without putting an ocean between themselves and their 'client'. Compassionate mutuality is great. Shared Decision Making is the new God! We're all human beings is my message, and to my fellow 'Experts by Experience', think about your answer to this question: Do you know just how valuable your lived experience is to yourself and others? I think we're all amazing!

www.sharedexperiences.online

Page 12

Alyssa

While already involved with Community Mental Health Services, my mental health deteriorated significantly and my capacity to make a decision about my care became limited. During an appointment with the psychiatrist, my Care Coordinator, my partner and me to discuss my deteriorating mental health, it was suggested that a permanent medication change might be able to improve and stabilise my symptoms.

Due to also having physical health problems that require many different medications, and as such many potential interactions, it was decided that the team's Clinical Pharmacist should also be present in the meeting. Having the Clinical Pharmacist there meant she could not only get a fuller picture of my particular presentation and symptoms at that time but also could more fully present the challenges and possible options going forward. The Clinical Pharmacist asked questions and gathered information directly from my partner, and where possible me, to get the most accurate picture possible, even considering which potential side effects would be most unbearable to me. As per my care plan, my partner was entirely included in the decision-making process, particularly when my input was limited. As such I felt my needs were taken into consideration even when I wasn't fully able to express them myself. After the implementation of my medication change, I continued to see the Clinical Pharmacist for the next three months while the medication was gradually increased. During these appointments, she monitored my symptoms and any side effects, as well as doing physical health checks due to the type of medication and answering any questions relating to my medication that my partner, Care Coordinator or, as my health improved, I asked. The outcome of this meant that my partner and I felt much more informed and therefore more confident in asking questions and actively being part of the decisions being made about my care. This meant that not only my health improved but also that my partner and I felt we were both a part of that process.

Ermintrude's Experience

My first contact with mental health services was twenty years ago. Since then, I have had a number of hospital admissions, and have lived in supported accommodation. I lived a transient life, moving around frequently. I now live in a secure home of my own, and am working part time.

My largest achievement has been to start travelling the world. I fulfilled some lifelong ambitions of going to China to see the giant pandas, the Great Wall, and the Terracotta Army. I have also visited Turkey, Italy

www.sharedexperiences.online

Page 13

and Bruges, plus trips in the UK. I have a trip planned to Croatia. I have also followed my passion for nature, volunteering regularly for a nature reserve. The feelings of awe and wonderment are so different to the feelings that I have when I haven't been well - about my life being a waste. The memories remind me of what I am really capable of, and that things can change on an hour or day by day basis.

I have got there as a result of the support from my family, friends, peer support, organisations, and sheer chance! I have learnt to take opportunities as they arise – my travelling started with a free coach trip to Blackpool.

I have worked hard to do the external, day to day things, and the internal follows. You need to persevere. I often don't feel that I want to do things, but mostly feel better when I have done them. As far as services go, I have tended to work best with people like occupational therapists, art therapists and psychotherapists who are creative, "outside of the box" professionals. I found the WRAP course very valuable (wellness action recovery planning), as it places you at the core of your wellbeing and recovery, and puts you in the lead. I have also accepted that I might always need some support in the background, however much I progress.

As far as my job goes, I am trying to learn from what went wrong before, and what could make me unwell again. I am open about my mental health condition with my employers, and they have been very supportive. For example, I have been able to be honest about what hours I can work, that fit in with my medication times.

My advice to others would be:

- Live for each day or even each hour if that seems too much
- You know yourself how you feel more than any expert
- Talk to who you feel comfortable with

Chris

I have suffered with mental health problems most of my life and had struggled with it for as long as I can remember. Having spoken to many GPs I was told to take my tablets and see how I feel.

Four years ago whilst dealing with the distress of my grandmother passing away (someone who I was very close to), I found myself being sectioned and kept in a psychiatric unit. I struggled with this at the time

as it felt helpless and powerless at first.

After a few weeks I was discharged with the diagnosis of "Emotionally unstable personality disorder" This both confused and angered me as it felt like I was broken somehow.

I decided to speak to my care coordinator about my diagnosis and we decided I needed to talk to someone in detail. So, I met with a therapist. This was the part where I took control of my diagnosis and found out which part I agreed with and which parts I didn't. Through this process I was able to accept and move forward with the diagnosis. If I hadn't have spoken with my care coordinator and mutually deciding I needed to go through this process I think I would still be struggling with this today. Decision making is scary and daunting and often seems too much. However having someone I could trust and talk to helped me make the right decision for me.

Christopher's Experience

I became ill after having worked in London for a few years, due to a combination of very high stress levels, and a lifestyle which exposed me to poor diet, excessive alcohol and recreational drug use too. Having left my employment I quickly became isolated and although I had some family and friends there, they could not really cope with my constant references to religiously based conspiracies, and deluded beliefs that I had a role to play as a peacemaker in the Irish Troubles.

Returning home to live with my parents, I began to feel there was a wall of silence building up around me, directly by psychiatry, and thus my isolation increased, and accordingly did my alcohol and drug misuse. I maintained a very poor medicines compliance and began to blame others for not only the conspiracy against me, but for failings to address the situation in the world that I felt were the problems that threatened us. It was, with hindsight, when I was told I had delusions of grandeur by the medical services, that I withdrew from them almost completely, and began to live a life that I felt was basically in the "Underground", and I stopped talking and discussing any issue at all regarding politics or situations that would be thought of as news worthy.

After some years of this approach to life, I began to think that I needed to fix the situation myself, as no-one else understood. I decided that if I had a positive plan for my own life, then others may see me as more normal, and after asking a friend, who had maintained some faith in me,

www.sharedexperiences.online

Page 15

I put together a plan to train and get experience in horticulture, which obviously pleased my family, and they began to offer encouragement. The booze and the drugs continued, and so frankly did the isolation to an extent, but I did have a focus, and around that built some structure to my days.

I considered that I was moving forward well, until around the millennium, when I suddenly felt that I had lost all friends, and had wasted a life's opportunity to succeed, and that at the age I was, my life had been a complete failure. To this day, I still put this down to the fact that conversations about how I felt, and the experiences I was having, were not possible due to the wall of silence built and maintained by the mental health services, and friends who were frightened of being considered similar to myself when and if they talked about things. Thus around the time of the millenium, I decided I needed to do something more romantic with my life, a romance was missing, and also a change of scenery and possibly a fresh start with jobs, where the stigma of mental illness might not be so severe.

I set off for Europe, and essentially, surviving in terms of living outside, and eating what could be found, I had an adventure. I ended up with work, and a number of temporary addresses, and met people, who were polite on the whole, and who would offer help in terms of finding suitable "acceulis", which are a kind of centre with accommodation, food and medical advice.

I felt that whatever had been missing beforehand, I found some of whilst abroad, and eventually decided to give up drugs, and began yoga. I quickly stopped using them, as I had a new focus, and soon after I felt I had a new found confidence, and decided to return home, knowing that I had achieved things myself, and had understood that even though I could still believe in the experiences I had had, it would be better served to me to keep them to myself.

I came back home and summoned the courage to apologise for everything to my parents, and then began to engage with the mental health services. I took the medication prescribed and stability and some reduction in anxieties ensued.

Building on this I bought a bike with my disability benefits, and some earnings from a part-time job in a local hotel kitchen. I worked as a volunteer with a local health focused charity, and slowly but surely my

confidence grew until I was able to apply for a number of jobs, whilst doing more voluntary work utilising the skills I had learnt as a younger man.

I secured a part-time job with the social inclusion service, and that, essentially has grown into full-time work. I now have a new and enjoyable social life, and have also seen olive branches be held by older friends, and am now enjoying a life that I feel is rewarding and pleasurable, in many new ways.

I take care of my own physical and mental health as best I can, by using alcohol in a very moderate way now, and have stopped smoking cigarettes. Advised by professionals I also now use some supplements for general mental health care, such as fish oils, and vitamins, plant based products from health food stores, as well as any medication my GP now prescribes.

I sometimes look back at how low my situation was, homeless and isolated, penniless and scared, but today I know that I have left that behind. I do not suggest that it is a way of approaching mental health and wellbeing, as each individual is different. What I would see as the essence of the time I spent like that, was in fact the ability to decide to work at health myself, which we are fortunate to be able to do when we understand what is involved, and thankfully, we have the time and space to make those choices in relative comfort.

J's Experience

Becoming unwell has been the best and worst thing that has happened in my life. It's a devastating thing to happen to a young adult, but it is also an opportunity to take the path less travelled which leads to a far richer life experience in my view. The losses are real (friends you thought you had, life you had planned) but in their place I learned who my real friends are and I have gained insights about myself and others that enrich my daily life. Prejudices I had myself were strongly challenged for example allowing me a clarity of vision I did not have previously, and I have discovered a strength and resourcefulness in myself of which I had not previously been aware.

It is known that at times people become well despite the services rather than because of them. In the early days I certainly realised quickly that my attitude needed to change from grieving for my lost 'friends' to appreciating the ones I had. I needed to switch on and learn. No one else was going to get me out of hospital. Consequently I 'ditched'

my psychiatrist and 'doctor shopped' until I found a kind professional empathic GP who actually spoke to me like a human being. Pretty soon I was also allocated a superb CPN and new psychiatrist. I had not had a personality transplant, and I was prepared to work hard to become well but I needed the help, support (and respect) of my team in order to do that.

Decades on and I still need some support every now and then, but don't we all? Having people to talk to who understand the stigma and discrimination I have faced being 'out and proud' about my condition has helped hugely and learning practical techniques and skills for everyday life has also empowered me to live the life I choose. When asked to write this I have had to dig deep to remember some of the early days which were not easy (to say the least) but I have found an ease and freedom to be myself in life which to me is priceless.

What is Participatory Action Research?

Participatory action research (PAR) is research that is done together with or led by people who would usually be people that research is carried out on. It is research that focuses on changing things for the better – not just finding things out. PAR is especially interested in people who traditionally have not had a voice in what research takes place, or how. In this project, that is people who have used mental health services. PAR is used to find out what people really want to be researched. People choose the research topic, and decide how the research will be carried out. They also actively carry out the research themselves, and talk to others about their research at conferences.

About our Research Project

“learning to be researchers and breaking down language barriers”

Through our own experiences of the journey through mental health services, we chose the topic of shared decision making together as the research area we think is the most important to focus on. We reached a consensus by looking at the path people take through mental health services. We developed our own criteria for choosing our topic. We wanted to make sure that we chose a topic that would mean something to other people who have used mental health services, and had the potential to change things for the better.

We looked at lots of literature on shared decision making in mental health. We found that mental health services need to provide accessible information that is easy to understand for people to be able to share in

www.sharedexperiences.online

Page 18

decisions with their mental health workers. We decided that we want to find out if it is helpful if this information comes from people who have used mental health services themselves. This is why we have put together this shared experiences library. We are asking people who use mental health services and their workers if the library helps in any way, and about their experience of shared decision making overall. We have spoken at conferences about our project, and will be sharing our findings at the end of the project.

How to Contact Us

You will need to contact us to get a simple password if you would like to look at the online videos.

If you have any queries at all, or need help to look at the shared experiences videos online, please do not hesitate to contact us. We can arrange to meet you for you to look at the shared experiences videos online.

Katherine Allen, project facilitator

Telephone: 07507 847523

Email: katherine.allen@lancashirecare.nhs.uk

www.sharedexperiences.online

You can also find lots more information about mental health on the Lancashire Care NHS Foundation Trust website:

<https://www.lancashirecare.nhs.uk/Information-Leaflets>

© Lancashire Care NHS Foundation Trust. All rights reserved. Not to be reproduced in whole or in part without the permission of the copyright owner.

Data Protection

Lancashire Care NHS Foundation Trust adheres to The Data Protection Act 1998. The Trust will endeavour to ensure that your information remains secure and confidential at all times. For further information regarding data protection please visit the Trust's website or ask a member of staff for a copy of our leaflet entitled "Sharing Information With Us".



LAN291 - A library of written, video and audio and shared experiences