DProf thesis

An exploration of the experience of women with mental and physical health issues

Lambert, N.

___

Title: 'An Exploration of the Experience of Women with Mental and Physical Health Issues'

Nicky Lambert - n.lambert@mdx.ac.uk

Doctorate in Professional Studies

Module code: DPS 5360

Nicky Lambert: M00475648

Submission date: Sept 2023

Contents

Abstract

Aim: To explore the experience of physical health issues in women with mental distress, in order to support best practice and improved care.

Rationale: Attempts to improve the physical health care of people with mental health difficulties are ongoing, with women's experiences within this field frequently overlooked and underserved. The study's focus is gender-specific in order to better understand women's experiences and to contribute to improved practice in this area.

Objectives:

- To understand if and when women with mental health issues seek help for their physical health concerns
- To explore what their experience of accessing and receiving support for those physical health needs are.

Methodology: This is phenomenological research shaped by a service user advisory panel and working from a feminist, activist standpoint using coproduced focus groups and an online survey disseminated via social media to facilitate open participation.

Conclusions: The knowledge jointly created from this coproduced project demonstrates that women from marginalised communities are able to come together to voice their concerns and demonstrate their strength in challenging orthodox thinking around complex practice issues

Recommendations: More self-referral pathways are needed to a broader range of primary care health staff. Radical innovation is required around the processes for raising concerns and supporting women's health. Lastly service users need to commission projects that meet their needs and requirements and research bodies should reward innovation in coproduction and activist work.

Summary:

This study is a coproduced, phenomenological, feminist and participative investigation of the experience of women with mental and physical health issues. It is designed to increase insight into the needs of women with both physical and mental health issues – sometimes called 'complex need'.

It explores the ways that women understand their own mental and physical health concerns and how they perceive the response of health services to their needs. It seeks to establish how, if and when women with mental health issues elicit help for their physical health concerns and what their experience of accessing and receiving support for their health needs are.

Introduction (Terms of Reference and Objectives)

In this first chapter I introduce the topic chosen for my study and define my Terms of Reference.

The title of this work is:

<u>'An Exploration of the Experiences of Women with Mental and Physical Health Issues when Accessing and Receiving Care'</u>

and this study seeks to better understand the experience of physical health issues in women with mental distress, in order to support best practice and improved care.

The physical health of people with mental health difficulties is a troubled area of professional practice that is still in expansion. Physical health checks are part of measurable outcomes for the National Health Service (NHS) which means that health services need to skill staff up to perform and record them. In turn Higher Education Institutes (HEIs) need to provide initiatives supporting skills acquisition for both undergraduate and as part of Continuing Professional Development (CPD). It is important that teaching and practice are rooted in an evidence base and it is vital to ensure that physical health - a relatively new field of expertise within mental health nursing is practiced holistically and with personalisation in mind. It is against this backdrop that each year more than 26,000 people with severe mental illness continue to die prematurely each year from preventable physical illnesses (Office for Health improvement and Disparities, 2023)

Focussing in, women's specific health needs are highlighted by the reviews of service provision that provide a constant backdrop of change within health and social care; and are at the mercy of poor resourcing and bewilderingly frequent

policy change. A previous version of the current Women's Health Strategy for England was launched in July 2022 and withdrawn in August of that year. These changes of policy direction are not new and the guidance paper 'I Am More Than One Thing' (2014) from the Women's Health & Equality Consortium observes the historical dimensions of the ongoing challenges.

Introducing another dimension, Van Den Tillaart et al (2009) noted the increased medicalisation of social problems such as poverty, crime, and societal marginalisation and that they affect women's health outcomes more severely. This tension is best encapsulated in Keating et al's (2003) seminal work on around trauma-informed practice which noted that services fail to meet women's needs by asking 'what's wrong with this woman?' instead of 'what's happened to this woman?'. Since Covid and with lockdown, the referrals system has had to prioritise urgent need, at the same time many women's support services closed, or reduced their provision. This was especially problematic for women already facing disadvantage and at greatest risk of poverty. (Voices from Lockdown, Agenda, 2021).

In addition, the experience of illness is one which can reach into all aspects of a person's life (social, physical and psychological) and the nature of health care has changed from addressing single issues to working with long term complexity – bringing with it a need to build a new evidence base of effective interventions. The Health Foundation (2023) expect the number of people living with illness to increase by a third by 2040, most of whom will be over the age of seventy. With women living longer and accruing a wider range of complex issues it is imperative to understand more about the relationship of women with multiple need to services.

Aim: I designed this research project as a partnership to explore the experience of physical health issues in women with mental distress, in order to support best practice and improved care.

Objectives:

• I wanted to understand if and when women with mental health issues seek help for their physical health concerns
• I wanted to explore what their experience of accessing and receiving support for those physical health needs are.

Terms of Reference:

I defined this final topic broadly in the first instance because I wanted to understand the breadth of experience that could have presented. It is an 'exploration' as I felt that if I focused too specifically at an early a stage of the research, I risked shaping the findings instead of following the data and being guided by it.

I define 'women' within this study as those who self-identify as female. I have not made any provision to purposely seek out the experiences of trans-women as that is specific perspective due to the nature of their physical and emotional health needs. However, I have not sought to exclude them either, as the experience of being a woman or indeed female cannot be disentangled the other forms of intersectional disadvantage. In order to be transparent, it is important to be clear though that whilst the focus groups were accessed through a women's centre who had no records of trans-women in their membership, the online survey data appears to contain that viewpoint.

I use the separated terms 'mental' and 'physical' health issues for exactness. I have been careful when using the term 'complex' in this work because the human experience of wellbeing is by its nature an embodied one. To have, for example, a long-term physical health issue like diabetes is likely to result in emotional and physical issues and may be co-occurring with other health diagnosis. However, the term is widely and popularly used and to some extent inevitable.

Likewise, multi-morbidity, (that is the co-occurrence of two or more long-term conditions) is not an unusual presentation and most people have factors alongside ill health such as low income or carers duties that can make access to services more challenging. I have tried throughout this research to assert that people whose health status is the norm should not be labelled as 'complex' in the sense that they are unusually demanding of services in some way when people with multiple need are the majority.

I have separated the experiences of 'accessing' and 'receiving' care as some people who seek care from health services do not always receive it in any meaningful way. It should also be noted that the locus of control for the participants in this study varies and that some people express less agency and are more 'directed' than others when accessing care. Whilst all the participants wished to receive help for their health needs, some also were given services that they did not request.

Rationale: I chose this topic because I saw an unmet need and on further exploration I felt that previous research could not yield the necessary information to move practice forward. I was initially interested in clarifying the impact of physical and mental health needs on individuals and the implications of service provision mismanaging unmet complex need. I anticipated being able to add value in my specialty by undertaking an original piece of work to

build the case for the creation of an evidence base that will support better outcomes for women with complex need.

My research focus evolved over time as I concentrated my interest on the physical health of service users in a more gender-specific way. I wanted to hear particularly from women about their experiences and ask them about their suggestions for improvement. This study aimed to address some of the gaps in previous research, professional practice, methodology and ethics (particularly in regards to participants with health issues). I hoped to develop the literature in this field by adding specificity to what have been to this point generic and unsuccessful attempts.

Whilst research has provided clarity around the inequality of mental health service users' access to physical health care and the poor outcomes they experience in terms of ill health and early death (Lambert, 2012); there is little that is gender specific either in primary research or systematic reviews. If a problem is not fully understood and the issues that complicate it are not appreciated, it is unlikely that effective solutions can be found. This study was designed to increase insight into the experience of women with both physical and mental health needs – a circumstance often described as multi-morbidity and which is often seen as anomalous when it is routine and should be treated as such.

It is challenging to get current statistics with the disruption to data sets wrought by Covid but the Department of Health (2014) had predicted that the number of people with comorbidities was set to increase in England from 1.9 million in 2008 to 2.9 million by 2018. If the impact of Long Covid and missed and delayed treatment is factored in the numbers can only be higher than that. A report from the Health Foundation (2023) estimates that by 2040 one in six of the adult population will be experiencing ill health.

Certainly, the majority of GP consultations involve a patient with more than one pressing health need (Kim-Dorner et al 2022). A series of valuable studies by Shiner, et al (2020) and Salter et al (2020) consider this phenomenon and some of the issues that my own project does but from the opposite viewpoint - that of the professional. They also note that GPs find the lack of resources, especially that of time, a struggle in consultations. They state that these factors can result in the GP dominating the interaction in order to manage their workload. Interestingly the GP's whose interactions are studied are nearly all male and those coming to the surgery for support are predominantly women. However, like much of the literature in this field the implications of this interface are not recognised, let alone addressed, despite there being a number of hierarchical and power dynamics which are likely to be relevant.

At the beginning of my career I assumed that things were going to continue to automatically improve for women and for marginalised people more generally, however I have not seen the equality of representation, pay and reduction of sexual violence that I had anticipated. This continues to impact women's physical and mental wellbeing. Despite many excellent initiatives and the hard work of dedicated staff and service users even the mental health services that I have worked in over the last twenty-five years have consistently failed to deliver safe, responsive and effective services for women (Lambert, 2018). This has shaped my professional choices and those that impact my research methodology.

In addition to the topic itself I was also clear in my mind about the way that I wanted to undertake the research itself. I wanted to establish how, if and when women with mental health issues seek help for their physical health concerns and what their experience of accessing and receiving support for those physical health needs are. This necessitated partnership working and the expectation of change indicated the need for an explicitly feminist and activist stance. Part of my rationale for this project was to ensure that any knowledge creation was done in ways which were respectful and collaborative.

The field of mental health has a long and problematic history of mismanaging power dynamics with people – especially women experiencing vulnerability (Showalter, 1987). I wanted to exercise care in the ways that this project took shape and be certain that I did not cause iatrogenic harm when collecting, and seeking to understand women's stories.

From the 'Still Sane' exhibition in Vancouver in 1984 - a pivotal moment for women speaking out about their experiences of misogyny and abuse from psychiatric services (Morrow, 2017) to work by Tollan and Magnus (2018) the title of whose work 'Misogyny – a silent epidemic in the health service' speaks clearly of the dangers of misused power. This is an area of concern that is rarely explicitly approached within health research but it is fundamental as a driving force for this project. My own professional and personal life experiences combined with these factors to draw on research that was explicitly feminist and to incorporate that standpoint into my own work (Lafrance and Wigginton, 2019).

I used coproduction as a fundamental principle of my research study design because coproductive approaches necessitate service users and practitioner allies collaborating together and this partnership can disrupt the restrictive power dynamics within traditional research (Lambert and Carr, 2018). The construction of this project was as important as the potential findings would be from the start and this necessitated a specific approach.

I assumed that this piece of research would be a self-contained, relatively straightforward and reasonably quick process. However, it has grown with me over a lengthy period and has permeated my working practices and other projects. In turn those activities have nourished my thinking on the issues that are central to this D.Prof. Rather than having discrete functions, I have found that my research has shaped my pedagogic and nursing practice, and my learning from all these activities have encouraged me to become an activist.

This iterative cycle has reinforced my commitment to women's wellbeing and has shaped both my rationale for and construction of this research.

Informed by my research activities and my professional duty of care I began and am still working on national projects to ensure basic standards of health care for women. For example, I am part of the Expert Reference Group for the Sexual Safety Initiative with the National Collaborating Centre for Mental Health (NCCMH) in partnership with the Care Quality Commission (CQC) and the Royal College of Psychiatrists (RCPSYCH) to ensure that people – most usually women, do not experience sexual violence whilst in services (CQC, 2018). Unfortunately, this remains a very real issue for many people in inpatient settings, it is both a crime and it negatively impacts the wellbeing of all. I wanted my methodology to reflect my concerns for the wellbeing and safety of women and this has shaped my approach to participation and to constructing an ethical approach to research (which I will expand on in my methodology).

This work has also changed my understanding of how to create a transformation of standards of care on a national scale as I have fed my experience and research results into the project. It has increased my ambitions for what can be achieved in terms of person-centred care whilst it also frustrating me with the glacial pace of quality improvement. The back-and-forth between conducting research to understand a phenomenon and to build an evidence base for practice improvement has shaped my relationship to this work over the past few years and reinforced my belief in the need for this project and others like it.

This research is also informed by my work with gender-specific services over the course of my career as I have generally found them more flexible in terms of individualised care provision. I anticipated that this would make providing physical health care for women more straightforward and hoped to find evidence for ways to ensure best practice. Most women and certainly those interviewed for this project did not receive gender specific care and both they

and I continue to encounter unacceptably low levels of understanding and indeed care provision around women's health.

This is the case for even the most common female health experiences like menopause; as a result of my this and as another branch of my research journey I have worked with the Royal College of Nursing on national guidance for Mental Health and Menopause (2019). My experiences from practice and those formed whilst undertaking this research suggest that what is needed most urgently, is a step change in professional expectations around our caring obligations. The malleability of female bodies and the changes that they undergo across the lifespan are often problematised, marginalised and ignored. Until all health professionals are equipped to appreciate how to provide holistic and compassionate care for women – their physical and mental wellbeing will continue to be underserved. It will take a tranche of gender-specific research to build the evidence base in order to establish best practice and to make widespread change. I hope that this project can go on to be a part of that work. In this first chapter I have introduced the topic chosen for my study - the exploration of women's care experiences. I have defined the Terms of Reference used within this project and clarified the need for a project of this kind and been explicit about my personal rationale for working in this way.

In the next chapter I situate this information within the context of the current literature in order to provide framework to understand how previously established knowledge has influenced this study

Chapter 2 Literature Review

In this second chapter I present the literature that provides the framework underpinning the crux of this work, that is women's access to services. I consider how previously established knowledge has influenced the study and what the next steps might be. In the next chapter I will explore the methodology used to investigate my question and offer a rationale for the choices that were made.

Method

The aim of this research is to understand the experience of women with multiple health needs in order to support best practice and improved care. The focus of this literature review is on investigating what is known from the peer reviewed literature about women's experience of accessing and receiving support for those health needs.

Literature reviews are commonly used to establish an understanding of what is already known in an area of practice in order to build from it and to identify gaps in what is known for future study. They can be undertaken at the start of a wider study or as a stand-alone work. In health research they frequently take the form of a Systematic Literature Review (Lim, et al., 2021). However, I have not undertaken a systematic review as the initial scoping search showed that there was not enough published for this to be a feasible strategy. Instead a purposive review was used as it offers the flexibility to engage more broadly with studies that intersect with the topic, although it has its limitations (Cook, 2019).

Intersectional Boundaries

Coproductive studies, especially where their subject matter crosses boundaries in terms of methodology, practice, subject and discipline lend themselves less well to systematic reviews in health which often delineate a hierarchy of research and privilege quantitative studies. The information needed to provide background to this topic is largely found across qualitative research into women's experiences. In terms of nursing literature - mental health and physical health are separate fields of inquiry and primary care is a specialism in its own

right so all have different cultures and audiences. In addition, work by practitioners and service users in the field which would be helpful, is often confined to the 'grey literature' and not included in most health-related bibliographic databases.

However, peer reviewed research germane to this topic can also be found in journals and databases spanning health, medicine, social care, social work, gender studies, feminist activism, theory and policy, midwifery, health visiting, and health and social policy. In addition, many of these fields of knowledge, despite having shared concepts in common remain siloed in research and rarely overlap in terms of disciplinary expertise and joint academic practice.

It is due to these factors that I have focussed this purposive review on women's experiences of accessing health services I will bring in both grey and peer reviewed literature to the wider conversation in the discussion chapter where they are a better fit. Lim, et al., (2022) note there can be contradictions between 'the process' - the way a review is conducted, 'the type' – systematic, narrative conceptual etc. and 'the value' of literature reviews – which is how they are seen in terms of academic standing. Traditional expectations are that reviews, like other aspects of research process should conform to conventional patterns. I would argue that the criteria that give a literature review value, should be based in utility.

There is precedence for this pragmatic approach as Brockbank and McGill, (2006) state the purpose of the review is to serve the projects' need and they reframe the idea of reviewing the literature, into the "use' of literature. Van de Ven, (2007) describes the ongoing tension between rigor and relevance as being at the heart of practitioner methodologies heart of practitioner methodologies. There are no straightforward choices in work-based learning approaches to enquiry, and finding academically acceptable ways to produce knowledge that is useful to everyday practice is a balancing act.

Certainly, for a review to have worth, it must have a formal, clearly articulated structure that is logical and justified. I would argue that it is crucial for the review to be credible as not only is it one way to support the need for the for further research, but also to credit people who have contributed to this field in the past and note who is missing. In the case of coproduction, it is especially important to do this, as many of the first people writing in this area were Experts by Experience and may have been overlooked and underappreciated previously. Being aware that my literature may miss some key texts by Service Users and practitioners I kept the literature review open during the length of the project and have purposively included some key texts that resulted from extensive reading across these fields.

A Note on Missing Data

Another issue that complicates literature search on this topic is the idea of women's health itself. It seems a straightforward search term but frequently it is conceptualised in opposition to 'Health' as a universal idea. I use a capital letter here because this generic category is often used to describe any aspect of health that is not to do with gynaecology or fertility. Bagenal et al (2022) capture the essence of this thinking in relation to the recent National Women's Health strategy (2022). Human issues that affect women are included like diabetes, but they are only discussed in terms of polycystic ovary syndrome. Mental health issues the most prevalent of which are depression and dementia are seen through a 'female' lens in terms of menstruation. This means that health concerns that are responsible for most female deaths like cardiac problems, are not adequately covered and so called 'bikini medicine' with its focus on reproduction and breast care (Future of Sex and Gender Medicine Working Group et al, 2023); whilst an important part of the picture, are over-represented in the literature.

Therefore, women's wellbeing, is still considered largely in relation to traditional expectations around reproductive and childbearing roles in society. The female body is understood and explored in terms of its 'purpose' but the experiences

of being a woman within the world that shapes their health from social issues like domestic violence, poverty and medical misogyny are often overlooked and less likely to be incorporated into the bigger picture formed by research. Interestingly, Bagenal et al. who offer a critique of the current health policy for women in the U.K. note this regressive and reductive approach to thinking about women and what they need from health provision '*will not help women to be listened to'* (2022, p.1570). This is important because feeling heard emerges as a key theme of this literature review.

As was noted in the introductory chapter, the problems arising because of women's exclusion from medical research studies (due in part to hormone fluctuation and potential for pregnancy) have already resulted in a dearth of information on women's health but what research has been undertaken on women's health appears to be inadequate. Hallam, et all (2022) found that in 2020 almost half of articles about women's health were about reproductive health – this over representation means that a huge amount of women's experience is missing and we do not have comprehensive picture to draw from. Women have complex health needs but they are not being researched with regard to complexity and with the urgency and scope they deserve.

Another way of shifting this focus would be to consider women's wellbeing with a life course approach - as women live longer with rates of disability in old age it would make sense to focus on illnesses affecting women that are more prevalent in later years. However, again the trend is for a focus on pregnancy and reproduction and it is only recently that more attention is being paid to menopause and other issues of aging. This pervasive and limited way of conceptualising women's health becomes an issue for literature searching primarily because it appears that research on women's health is flourishing when in fact there is a preponderance of information in a few select areas and taken as a whole the overall picture is incomplete.

Search Strategy

This literature search establishes a historical and current context for this shared study. Having a general understanding of the experiences of women accessing health provision and comparing the similarities and differences that exist between the data drawn from the literature review and the specific experiences of women participating in the focus groups and the survey will inform the discussion chapter and provide context for the findings.

I initially searched for access taking place within primary care as that is where most U.K. health journeys begin and helpfully it is also the area most frequently referred to in the study data. I have also included research from areas where women's experiences or novel approaches have a bearing on understanding this interaction in order to gain a more fully rounded perspective.

Based on the purpose outlined previously, the following database search was undertaken

Prisma Diagram (Page et al. 2020)

Identification of studies via databases and registers

- I searched EMBASE, MedLine, CINAHL and PsycInfo separately, then combined their findings

- I used combinations of the following search terms: woman, female, General Practitioner, GP, primary care:

  Terms related to women: Women, female, woman and I included the experiences of female service users where they occurred but weren't specified by gender.

  Terms related to healthcare or primary care: healthcare, primary healthcare. General practitioner, G.P. surgery.

- Excluded: Experiences of health professionals (without lived experience). Experience of under 18's, Experience of men only,

Identification

Records identified from*:
Databases: Medline, PsycInfo, BNA, Cinahl

Records removed *before screening*:
Records removed for being duplicate, no relevance, not being in English, not peer reviewed (n = 1541)

Screening

Records screened
(n = 57)

Records excluded** (n = 45)

Reports sought for retrieval
(n =12)

Reports not retrieved
(n =0)

Reports assessed for eligibility
(n = 12)

Reports excluded:
None

Included

Studies included in review
(n = 12)

An international literature search was done at the start of the project in 2016. The search was rerun again in 2023 to identify any research across the fields of women's wellbeing and coproduction, to be included in the discussion chapter. This search revealed a dearth of studies.

Relevant literature was selected from searches of bibliographic databases covering health research (Medline, CINAHL, and PsychInfo). Searches were restricted to English language journals published between 1950 and 2016. Studies were included in the review if they included findings on the experience of adult women aged over 18 in accessing health settings. Reference lists of relevant studies examined for the review were also searched for other relevant literature.

Analysis

I used an integrative review approach to draw together information from a wide range of research using multiple methodologies (Cowell, 2012). Following Whittemore and Knafl's strategy (2005) I conducted a database search and drew on literature that added value to the project and reviewed the studies. Key information from each the studies relating to author, year, setting, method, and findings were extracted and tabulated (Appendix iii). I used Caldwell et al's (2011) framework to assess study methodology and although some of the methodologies were more effective than others, none needed to be excluded due to any scholarly irregularity.

The studies were reviewed and themes were extracted from the literature following the process described by Whittemore and Knafl (2005). There are methodological issues raised about the use of integrative review. It is suggested that using this variety of primary sources could lead to reduced rigour, bias, or other types of inaccuracy (Hopia et al., 2016). Whilst this is a concern it is important to balance it with the issue that there is little in the way of literature that directly addresses the topic of women's interaction and access to primary

care, particularly when they have complex needs and a certain amount of creativity and pragmatism is needed until this situation is resolved.

Key themes

The international literature reviewed has several clear connecting themes. The papers reveal that are similarities throughout in the way women of all different backgrounds find themselves at odds with service providers and struggle to be heard. It is difficult to comprehend how to approach such widescale issues, but it is helpful to be able to situate this small-scale localised project conducted in North London to the wider issues arising from the literature review findings.

Five themes were identified and are summarised in the diagram below.

```
                    ╭─────────────────╮
                    │  Understanding  │
                    │ Patient Satisfaction │
                    ╰─────────────────╯
                             │
  ╭───────────╮              │           ╭───────────────╮
  │ Innovation │──────╮  ╭───────────╮  ╭──│ Women's Lives │
  ╰───────────╯      ╰──│ Themes from │──╯  ╰───────────────╯
                        │     the     │
                        │  Literature │
                     ╭──╰───────────╯──╮
          ╭──────────╯                 ╰──────────╮
    ╭──────────────╮              ╭──────────────────╮
    │ Satisfaction │              │  Marginalisation  │
    ╰──────────────╯              │  & Disadvantage   │
                                  ╰──────────────────╯
```
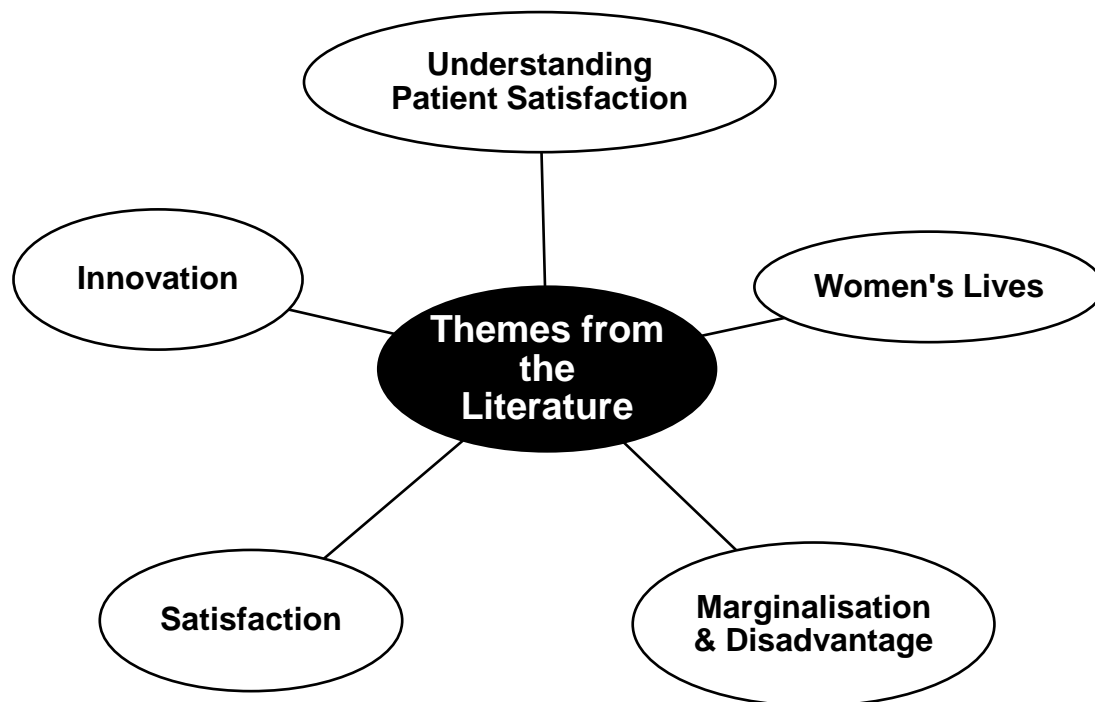
Theme one: Understanding Patient Satisfaction

Trying to understand and measure levels of patient satisfaction using research is nothing new - it usually takes the form of exploring a specific intervention certainly, the fact that women attend surgeries more frequently and are intimately connected to their health systems through the burden of fertility management and by being caregivers, and that they generally report less favourable interactions is broadly agreed in the research (Alexander, 2004). This basic understanding has been established for some time and is recognised as an ongoing issue – where there is difference is in how best to respond to these circumstances.

Mead and Bower (2002) conducted a basic literature search to scope the issue patient-centred consultations and related outcomes in primary care. It seems obvious that any individual going to see their General Practitioner (GP) should have the care offered to them based on their specific personal needs. It is easy to see why an approach like this would seems to be a solution as it removes the necessity of looking at care from a gendered perspective altogether.

However, the researchers encountered problems because investigating this issue generically opens up a very wide field. The idea of what constitutes good care and what is a reliable measure greatly varied across the studies included in their review. Mead and Bower noted that much of evidence is unclear as to whether patient-centred consulting results in better outcomes, and that research findings are inconclusive. Much of the research they reviewed (none of which was coproduced) had quality assurance issues. However, Mead and Bower's study is important to this review because it takes a traditional approach to addressing the issue of understanding the experience of accessing primary care. It is clear that 'who' is doing the accessing is important to understand, and once that information is understood their personalised care needs become apparent as does the need for specific tools and approaches to gathering data.

A very different approach was taken by Alexander (2004) who used a series of focus groups to explore experiences of primary care patient interactions. From the perspective of the hierarchy of evidence (Wallace et al. 2022) the syntheses of many peer-reviewed projects should provide clearer answers than small studies based around focus groups. Nevertheless, they can provide detailed insights on patient experience, even though the focus group method has its limitations (Smithson, 2000). Alexander suggests that the design of the study itself (critical theory participatory-action research) made space for women to recognise problems themselves and that they will be able to go on and find solutions. She transparently described her practitioner/activist stance and her underpinning (Freirean) ethos. The work was not coproduced but was ethically and participatively undertaken with methods and processes carefully detailed.

Alexander found that participants were able to identify both good practice and issues of concern - a lack of caring was noted, women described not being listened to, and treated with indifference. They noted a lack of trust and disrespect and at times, prejudice, which are common experiences. There is one example given in the narrative of a women undergoing a painful intimate procedure. She indicated that she was in pain, and then asked the staff member to stop and they did not. This acts as an illustration of the difficulties associated with this theme - firstly it is not a women's job to make professionals behave professionally – with compassion and expertise. It is the professionals who need to act within their codes of conduct and behave respectfully and safely.

It might be assumed that 'access to health care' is about issues such as booking appointments. whereas Alexander's study shows that women experience unacceptable behaviours from practitioners in positions of which range from discourtesy to assault. These are the very definition of 'personal' and despite the fact they are recorded persistently in the research, very little indication is given about personal impact or the cost to the individuals sharing instances which may feel exposing or shaming. It also raises questions about the ethics

processes for ensuring support to vulnerable people sharing personal information that affects their health and safety.

Theme two: Women's Lives

Research suggests that women are not unaware of, or passive towards the potential impacts of stigma on their care. Birch et al (2005) used semi-structured interviews to gather data from six women, which was member-checked by study participants. The women in her study had multiple health needs, in this case mental health issues alongside a need for physical care. Whilst they reportedly felt positive about receiving general physical health care in comparison to receiving mental health care, they had challenges when this was combined with expectations of their life course roles around pregnancy and motherhood. It is of note that they experienced multiple stigma when these identities intersected, and their experiences suggest that mothers can access care and specific support in their role as patients but that the combination of the two roles, and their inherent contradictions prove problematic.

Birch notes that she has a feminist standpoint and began her work with an expectation that it was unlikely that the participants holistic healthcare needs would be well served however, it was clear that participants held similar expectations. Mental health services have a long history of exerting excessive control over people it deems lacking in capacity. It is not a surprise to hear women preferring to be given agency and valuing the feeling of being 'nurtured' when presenting with physical symptoms. The 'sick role', when it pertains to physical illness is universally comprehensible and motherhood usually elicits sympathy.

However, in this study it was when the women's mental distress became known they experienced stigma. Troublingly, the women in the study spoke about having to present themselves to the best advantage to gain access to bias-free care by downplaying stigmatised conditions and displaying behaviours to appear rational and competent to health care providers in order to be heard.

This is another theme that appears across a range of data. Similar stories of women with multiple disadvantages struggling to access regular health care occurred in focus groups conducted with women at rural psychosocial clubhouses (Lyon and Parker, 2003) This study highlighted a range of discrimination and poor communication from health professionals, particularly around supporting women with the co-existence of multiple health needs occurring with the frameworks of women's lives. It suggests again that professionals struggle to respond to harm occurring to women's health outside of biomedical causation - that is a result of societal injustice such as poor housing or crime like domestic violence.

Theme three: Impacts of Marginalisation and Disadvantage

Miller et.al. (2004) used thematic analysis of open-ended interviews to assess the experience of women with chronic ill health who were financially marginalised in a feasibility study for 'Group Medical Visits' (GMV's) which takes places in the USA. This is a markedly different response to the injustice that multiply-disadvantaged women receive poorer healthcare. Instead of looking to find a remedy, Miller's study offers a suggestion to organise care as well as can be expected in a system with privatised healthcare. Miller describes the GMV model as 'well tolerated' by patients, noting that it is cost effective. Findings suggested that participants were pleased to get access to personalised attention, although sharing their consultation time with around seven other unknown women, but were unsurprisingly negative about the loss of confidentiality. It is not clear how a woman who wanted to report a condition such as a prolapse would be expected to gain assistance in a group setting whilst maintaining their dignity.

Given this, it appears that GMV is an insensitive and inappropriate approach to addressing the heath needs of poor women. The study emphasises fiscal

benefits of providing care to women who have no other alternatives, being cast as willing participants. It is troubling that the data collection for this research by interview offered more privacy and dignity than the supposed health intervention.

Ewart et. al's (2016) research also contain worrying narratives about the lengths that people need to go to at times, to gain access to basic health care. They used a qualitative exploratory design and unfortunately, a gender breakdown of study participants. Although some men are included the study is pertinent because of the findings on 'survival strategies' used to overcome barriers to care. This concept of using stratagems to enable access, includes the tactics previously described as 'presenting oneself' as a compliant and willing patient and reappears in the chapter on findings.

Theme four: Satisfaction

Women with medically unexplained long-term fatigue were asked about their experiences with Norwegian GPs in a study by Lian and Hansen (2016) that offers a complex statistical analysis of survey data from 431 women recruited through a patient organisation. Both doctors and patients reported being left unsatisfied by a lack of resolution. The main themes that were found from this data centred on the importance of shared decision making, being respected and taken seriously. The study showed that continuity of care and the experience of being in a partnership with a specialist who understands the patient's experience fostered higher levels of satisfaction. It may also be possible that the quality of interaction of women with the specialist which increased satisfaction by a factor of six times, is not just that the doctor has specialist knowledge but that a relationship is built over time where they are not under the same kind of time pressure as generic services are.

Anderson et al (2001) worked with focus groups to ask 137 women from diverse local communities about their satisfaction levels with women's health centres. Staff who showed that they respected women's own perspectives of their health, who were knowledgeable, non-judgmental, trustworthy, and listened well

received positive feedback. Unfortunately, there were disparities in experience reported. It would have been helpful to understand which women encountered these barriers and in which localities; because overall this work echoes themes from the others in the review but doesn't provide any way to link them to wider societal patterns or inequalities.

A telephone survey of 1,205 women was conducted by O'Malley and Forrest (2002) to follow-up a series of focus groups with women living in Washington, DC. This sample was predominantly African American women on restricted incomes. They found that despite all of the participants having the same expectations of their primary care, (that is that staff must be trustworthy, caring, respectful, and patient to provide good quality care) women who were poorer were more likely to have negative care experiences compared with their richer neighbours. O'Malley and Forrest posited that structural and theoretical barriers to obtaining care resulted in reduced satisfaction.

Anderson et al (2007) worked with over a thousand female participants at primary care centres connected to American universities. They surveyed the participants pre and post visit using tools including the Primary Care Satisfaction Survey for Women instrument (PCSSW), and a global satisfaction rating to compare how they felt about their visit and their health care over the past 12 months. They found that retrospective comments were connected to continuity or care and quality of care coordination and the day-of-visit ratings were related to 'communication'. Continuity of care speaks of a relationship over time and the role care coordinator can contain within it a therapeutic value and professional intimacy that has value in itself. The idea of feedback on the day being about positive communication potentially downplays the skilled and complex work that forms part of establishing a therapeutic bond, of building trust and connection.

As a study its findings that short and long-term factors influence the way women feel about their health access is reasonable, it is included in this review because

it demonstrates the issues that can occur when research methods are used despite, rather than because of the nature of the questions being asked. Anderson notes that a limitation of the study is that it was carried out with women who had completed at least one additional visit over the last year which meant that women with health conditions that require ongoing support were overrepresented in his sample. However, this is helpful for exploring the experience of women with complex needs.

The PCSSW (Scholle et. al. 2004) has a number of components that make it helpful in terms of its use in Anderson et al's study. Scholle and her team used focus groups and intensive statistical testing to create a comprehensive survey instrument that can be administered by 'phone or in person. It has questions specific to a woman's physical experience of visiting a health professional and their understanding of care needs as well as some less tangible ones about the emotional and psychological aspects of receiving care. These are sensitively worded and include aspects of communication that might get overlooked on generic service review forms like 'being taken seriously', having a health professional who 'demonstrates interest in you and in what you are saying'. It also has a question about feeling able to get dressed after intimate examination before the conversation restarts. This is very important in order to maintain a sense of equality between care giver and patient. However, the sensitivity in the PCSSW tool does not successfully translate into Anderson's study analysis where it is designated as 'privacy' which is too general to give a detailed understanding.

Theme five: Innovation and Patient Experience

Edge and MacKian (2010) worked with a purposive sample of twelve Black Caribbean women using in-depth interviews about risks for perinatal depression and women's models of help-seeking. They developed the concept of 'reflexive communities' rather than putting the onus on individuals to have an awareness that they should seek help and have the confidence to approach services. In terms of study conduct, there was no coproduction but researchers took special

care with service user involvement and postulates that the model developed in study could improve focus on the quality and effectiveness of health encounters more generally.

Jobling et al's 2016 Australian study was developed through work with indigenous peoples. Forward thinking in the mental health sphere especially, has often come from Australia and New Zealand whose indigenous cultures can provide a holistic counterpoint to biomedical thinking. The researchers conducted focus groups and interviews with nineteen Aboriginal people who accessed services due to multiple health needs. They reported that access was supported by GPs who provided continuity of care and relationships which were based in respect and cultural competence.

Jobling's study is included because like Edge and MacKian's work, it demonstrates an understanding that health needs are most effectively considered in a social-emotional context. For Aboriginal people in Australia that must include cognisance of historical oppression, current racism, cultural and environmental factors as well as an understanding of the individual's psychological and physical ill health. Likewise, a consideration of context proved vital for understanding women's experience in this shared study.

Summary

This literature review identifies five themes: understanding patient satisfaction; women's lives; impacts of marginalisation and disadvantage; satisfaction; and innovation and patient experience. Another reoccurring subject across all these findings is how little women are asking for to deem a service encounter a successful, and how often services are failing to meet even basic standards of social norms – like eye contact and civility.

Overall, it suggests that mainstream health research has not investigated the impact of factors such as structural racism and sexism, yet it is vital to understand such broader influences on women's heath in order to improve equal health access and quality care - professionals need to be mindful of structural inequalities and their impact on people's experiences and choices. In this second chapter I presented the literature that provides the framework to underpin the central issue of this work – that is women with multiple needs' access to healthcare. I have explored how previously established knowledge influenced the study and in the next chapter I will explore the methodology used to investigate my question and offer a rationale for the choices made.

Chapter 3 Methodology

Chapters one and two offered a rationale and context for this research and clarified its purpose and scope. This third chapter explores the methodology I used to investigate my question and offers a rationale for the choices made. I will give context to the decisions made by considering my positionality and reflexivity and then discuss the epistemology and theory, research design, research methods and tools, I will touch on ethical considerations, data collection and analysis where they are relevant to understanding methodological choices but have explored them in more depth in their application as part of the next chapter in project activity.

Context: If I were to begin this project again I would dare to be more creative and work with less fear in terms of methodology. I learned what I needed to have understood about methodology from the start only by undertaking and completing the project. My conceptualisation of this research project began when I was in the role of nursing practitioner and that perspective shaped the way that I initially considered the issues I faced. I was working as a ward manager in a busy acute mental health service and stopped to talk to a female service user who had visited her GP and had been treated brusquely. She had been given leave to attend her GP for physical health support, which her psychiatrist had not felt equipped to give. However, despite seeing two well-qualified professionals she had returned not with a tailored and effective care plan but feeling unheard and in tears.

At the time it lodged in my mind as problem to be solved and I addressed it as such - although I recall wondering how it was that a personable, capable person had been so underserved. When I looked for research focus for this project, this remembrance informed my choice. I wanted to explore of the experience of women with multiple health issues, and had a clear goal of using my resulting learning in order to support best practice and improved care.

As I have become more considered in my practice - something which occurred as a result of new life experiences, for example a move into academia which brought some emotional distance and a chance to read and think more widely. I reconsidered my underlying assumptions. Why should a service user have to present in a certain way to receive basic care? I also benefitted from continued exposure to wise colleagues and friends with lived experience of health concerns. I realised that I had focussed on how to support individual service users to better access existing services, rather than considering the structural issues that create these access issues. I misperceived the impact of stigma and social and structural inequalities as the responsibility of vulnerable individuals which was an error resulting from being task-focussed rather than approaching problem-solving with a holistic perspective. I misunderstood the nature of the issue and because of my faulty assumptions I asked the wrong question.

My initial plan

I look back at the choices I made at that time and am disappointed by my implicit assumptions. I accepted without question that personal qualities like 'likeability' would result in a better experience of services without considering the implications of that assumption. Which is that a wide range of the most vulnerable people will be poorly served and their health and indeed their lives will be negatively impacted. I also demonstrated an expectation that an individual had to have skills and 'capability' to obtain the quality care she should have received as a fundamental right.

At that time, I assumed that the service user's experience was unusual, but rather than seeing how systems can privilege some voices over others I thought that the solution in this instance was to leverage my own social capital to make up the 'deficit' in her own. I regret this. It is not the responsibility of a person needing care to perform a complex dance to receive it - it is the job of professionals to ensure that the system they work in, meets the needs of the individual - respectfully, compassionately and effectively. This realisation and

the altering of my response to structural inequalities and my research question are just some of the things that continue to evolve as part of my learning journey.

I note this experience here, (rather than as part of my critical reflection) as the knowledge and understanding I possessed at the time of beginning the formulation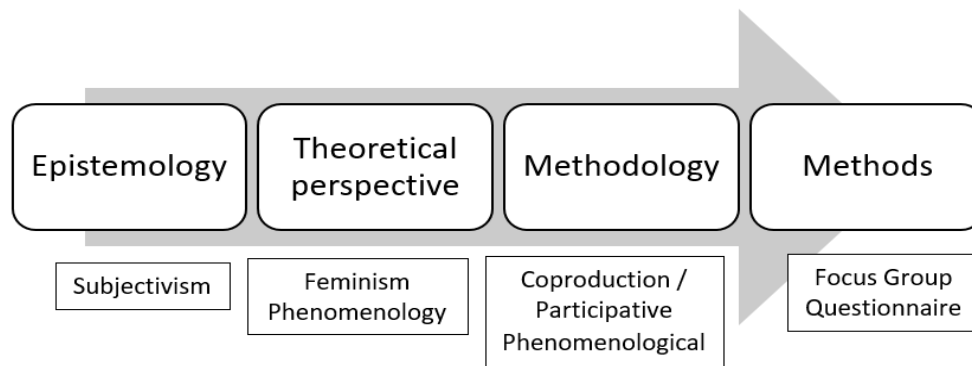 of this research limited my later choices in constructing this methodology. The beginning of my learning journey has had a fundamental impact on the projects' later trajectory and circumscribed the potential it contains for providing meaningful and useful findings.

My Original Plans:

VALUES – ethics as structural device not bolt-on OPEN PARTICIPATION: informed consent and checks at the different stages

MOTIVATION FOR STUDY – gaps in literature, poor evidence base (Cochrane) pressing need

LITERATURE – small patchy quality not offering solutions. Prompts collaborative working to establish need.

RESEARCH QUESTION: *'An Exploration of the Experience   of Women with Mental and Physical Health Issues'*

RATIONALE: **We are not meeting success in supporting complex need, we have tried top down methods and joint working may give a fresh perspective on women's experience of complex need which could help us understand the experience of women and define best practice and improve care.**

HYPOTHESIS: An overview establishing the experience and understanding of women with complex need could offer new insights into best practice and help identify unhelpful interventions.

AIMS: to engage in evidence-based research to form a better understanding of the experience of women with mental and physical health concerns, in order to inform education and health providers to develop inclusive practice and to develop a sound evidence base for improving women's' health.

RESOURCES

PARTICIPANTS: I have strong connections to service user groups and to women's networks in the locality.
SOCIAL MEDIA: I have a strong professional presence in terms of social media and mental health and have used survey monkey via twitter recently to gather quality data on issues affecting women. I have free access to both.

OBJECTIVES: to work participatively with female mental health service users in creative ways to develop an understanding of their experience of physical and mental health issues. This project seeks to establish how, if and when women with mental health issues seek help for their physical health concerns and what their experience of accessing and receiving support for those physical health needs are.

THEORY – feminist (concerned with supporting women to enjoy improved circumstances), phenomenology (paying attention to experience).

CONCEPTS

I have been given time and can bid for internal funding for this project as needed.

DATA COLLECTION: 3 steps
 LOCAL PARTICIPATIVE: Focus groups,
GENERAL PARTICIPATIVE: Survey monkey,
STAKEHOLDER: In depth interviews to clarify.

RESEARCH DESIGN

FOCUS GROUPS: purposive sample of women with service user expertise from locality to form ethics oversight group, to generate themes (to counter gaps in literature) and as a reference group (May contribute to stakeholder interviews to clarify as needed).

SOCIAL MEDIA SURVEY MONKEY: open access, disseminated through social media, exposes the ideas and concepts to wider scrutiny and engagement. Supports access to people to volunteer for in-depth interviews.

INTERVIEWS: stakeholder interviews, purposive sample to clarify themes raised via initial focus groups, more widely exposed through the survey monkey and interview participants

SAMPLING: **Purposive initially to gain local expertise, then open via networks of interest, social media, professional links to support a' crowd sourced response'.**

RELIABILITY: multiple perspectives open participation, clarity, thick description.

DATA ANALYSIS: IPA

FINDINGS:

IMPACT: women co-producing research and active in meeting their own health needs. Study brings women's experience of complex need to the forefront locally in terms of education and provision and more widely through academic dissemination.

OUTPUT: A collaborative presentation of the findings between participants and the researcher. A 'user friendly' guide to physical health for women with mental health problems to help them to know their rights to screening, access and complaint as needed. Teaching sessions/materials will be developed for use in the undergraduate nursing curriculum and offered to local NHS trusts who have expressed an interest. Conference presentations and academic paper are also expected as a result of the study and the learning that accompanies it.

VALIDITY: member checking, exposure of concepts and themes to wider comment using different methods over time and recognising the expertise of participants.

33

The Final Research Design

| Epistemology	Theoretical perspective	Methodology	Methods
Subjectivism	Feminism Phenomenology	Coproduction / Participative Phenomenological	Focus Group Questionnaire

This research is structured as a phenomenological, feminist and participative investigation of the experience of women with mental and physical health issues. It was conducted with the principles of coproduction guiding the research design choices.

Positionality: Positionality is formed by the social and political constructs that blend to shape an individual - it also describes how that identity influences, and potentially prejudices your understanding and perspective. Undertaking self-reflexive praxis requires self-discipline and support (Rix et al. 2013) but it can facilitate researchers to note areas of tension in their research practice that need further consideration (Olukotun et al. 2021). I was very influenced by Rix et al's (2013) approach to working sensitively and justly as a white nurse researcher with Aboriginal people. She describes levels of reflexive practice: situating the self in the research, considering interpersonal relationships with participants, and critiquing wider health systems. Keeping a journal was key to her exploration of insider/outsider roles, as were having regular helping conversations with the Aboriginal advisory group to better understand issues like researcher positioning, power and unequal relationships. The clarity of these working practices (which I emulated) and the boldness of naming social issues as part of health inequalities was very helpful to me as I was beginning to make my own research choices.

Being open about one's own positionality facilitates those reading the research to see how the data has been collected and represented and whether those choices are academically credible (Finlay, 2002). This disclosure can be one way to add validity to research; although It is a complex undertaking in that the circumstance that the researcher seeks to expose, may be hidden from them through a lack of insight. Positionality is also something that shifts with time and by interacting with the research processes themselves.

I adapted Jacobson and Mustafa's (2019) social identity mapping exercise as part of my early attempts to be reflexive and explicit throughout this work about how my world view and experiences impact my work (Day, 2012). This was my first attempt to understand how my identity and experiences impact the research I undertook, and I have used it to structure my thoughts in this section.
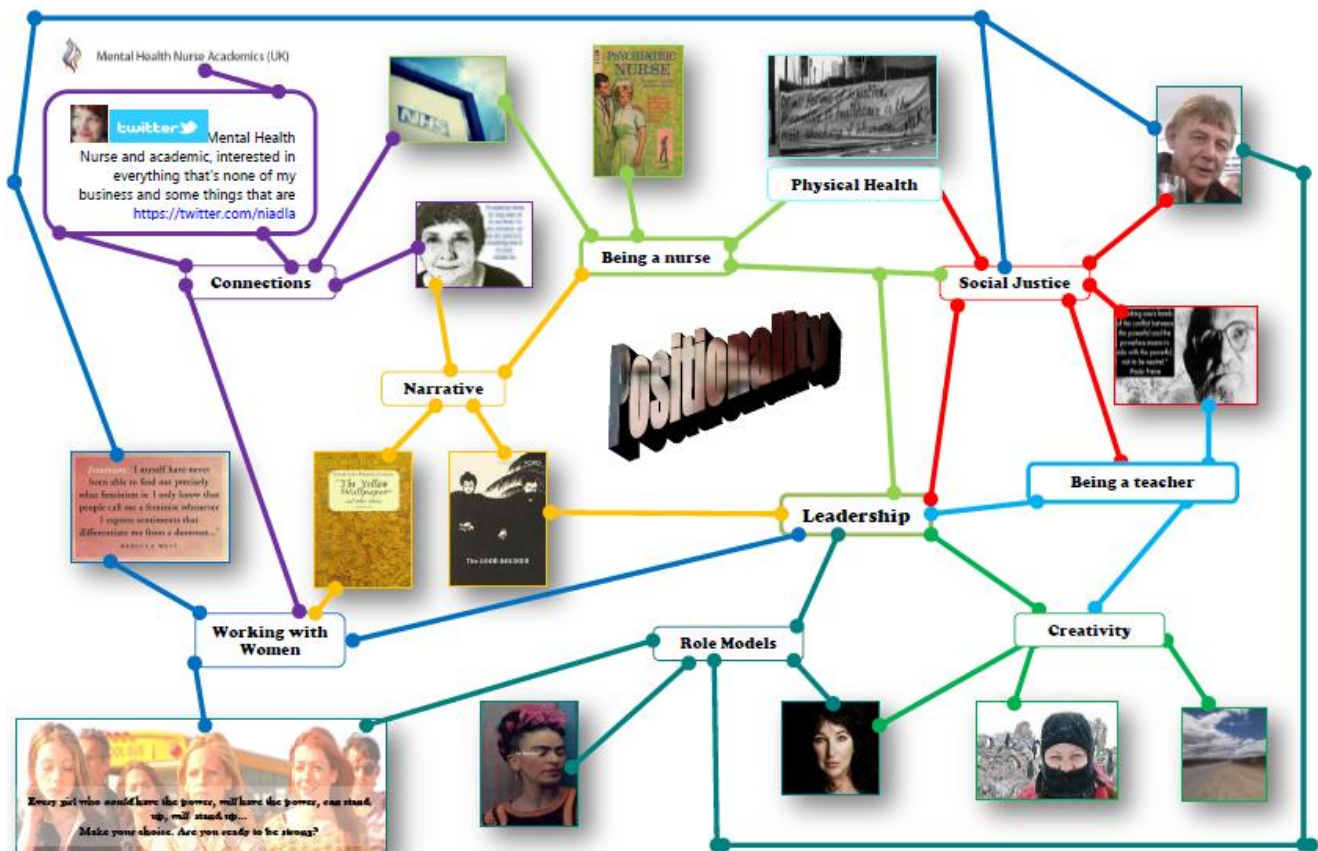
Finlay (2002) defines reflexivity as continuous awareness of the self and the ways our positionality impacts the way we perceive the world. Kezar (2002) develops this concept suggesting that researchers have a range of 'selves' and Berger (2015) suggests that in addition to offering a range of perspectives shaped by experience, 'who' a researcher is central to an understanding because it shapes their access to participants and what those sources are comfortable to share. The role and status of a researcher molds their worldview and their social capital, impacts what they choose to study, what questions are deemed important, how they are phrased and the analysis and write up of the findings.

For example, having an insider status in your field of study might yield you access, rapport and a more intimate understanding of your subject (Hayfield and Huxley, 2015). Arguably though having an outsider stance might give your work emotional distance and perspective, this of course depends on the type of data you are attempting to produce. Beresford (2003) cautions against uncritically assuming that distance' and 'neutrality' are enough to yield quality research. As researchers always interact with their research methodology and activity and therefore will inevitably shape and change it, it is important to understand the ways in which who you are and what you value, will shape your work.

As my nursing and teaching practice are person-centred and recovery-orientated, it seemed logical that I would research similarly (Mason-Bish, 2019). I have been a mental health nurse for 25 years, I am from a family of nurses and it is something which shapes the ways I see myself, the world and my place within it. I had an Anglican upbringing and imbibed an expectation that I would support others and I expected to work with people and to volunteer from a young age. I moved from nurse leadership into nurse education as part of a desire to see better practice and to support recovery working on a wider scale.

I am also affected by my own experiences in learning. Reading Freire consolidated my belief that knowledge - through formal and personal learning can prove a way to be free. Free to make or at least understand your choices, and to make enough money to live meaningfully. I research using this emancipatory idea as a guiding principle and what power I have accrued, I use in ways I hope will support others to increase their knowledge and in turn their autonomy (Nussbaum, 2011). It is because of this, that I use research methods where learning is shared and reciprocal and where the creation of a joint understanding enriches both participants and researcher.

As my nursing and teaching are influenced were shaped by emancipatory theorists like bell hooks, and research practice that shares power and promotes social justice seems logical to me. One such idea that impacted my understanding of positionality is the way hooks (1990) uses the concept of 'marginality' as way to consider role boundaries and shifting identities afresh. In much scientific discourse, clarity is seen as a valuable aspect of rationality and blurred boundaries are considered to be a place of confusion and thus problematic. However, hooks (1990) describes marginality as a useful viewpoint, if we are at the outside but still a part of the whole we can see our own hidden perspective as well as knowing the dominant one. hooks states that those at the centre know little about those at the margins but that the very survival of those at the edge is dependent on their understanding of dominant culture. The margin offers a place that is open to possibility and provides opportunity to critique ideas that can otherwise be taken for granted.

My positional and ethical stance informs all my work and my research is an extension of it, not a separate issue. My style is facilitative rather than didactic and again my drive for engaging with learning and teaching is to 'make things better'. This is a pattern that has continued throughout my career and what has made it personally satisfying. This sense of who I am and what I want to do has shaped my research in turn and it is the reason this study is participative and activist.

Working in a person-centred and recovery-orientated way as a mental health nurse and educator is an expectation of my professional codes. Person-centred care means supporting people in ways that affirm their dignity by being compassionate and respectful, offering caring responses that are tailored to the individual's needs (Ohlen, 2017). Recovery working is supporting people to recognise their own strengths and make independent and hope-filled choices about their own futures (Lambert, 2019). However, it is still unusual for research to be explicitly framed in this way. There are tacit assumptions around what research is for and what it should look like and a pressure to perform research that is acceptable to academic peers, professional journals, and doctoral assessors. Coproduction can necessitate a different set of standards and priorities, and it is key to be clear about the purpose of the research in the initial stages as it is easy to find projects becoming diluted. Papoulias and Callard (2021) go further describing coproductive approaches as often separate to other traditional products of research partnerships, using the image of a limpet on a ship's hull to describe its peripheral, easily overlooked yet tenacious nature.

I underestimated the personal and professional impact of researching in this way and came to realize that in fact my focus was initially on undertaking research that would be acceptable to my academic peers, to professional journals and future assessors. The type of research I wanted to undertake necessitated a different set of standards and priorities. Coproductive approaches can challenge the 'myth of the disinterested researcher' (Lambert and Carr, 2018) and research that is 'messy' or 'personal' can be perceived as less valuable within in the traditional hierarchy of evidence. Reading feminist researchers helped me to consider why this may be and I found a balance by naming these tensions and drawing on work by Daly et al (2007) who created a hierarchy of evidence for practice in qualitative research. Indeed Lewin et al. (2015) cite the importance of qualitative methods in Improving women's and promoting gender equity by providing rich, contextual data, that can drive policy and social change and as part of quality improvement.

I maintained the integrity of my research but where I could strengthen it by implementing their suggestions for creating a higher quality of research data I did. For example, I made sure my sampling was focused by theory and the literature and that I located it in the literature to assess its relevance to other settings. I took steps to capture a diversity of experience and ensured my analytic procedures were comprehensive and clear. That said there is an inevitable tension between doing research that 'looks right' to others and that which 'feels right' on a personal level.

It is hard to resist the pressure from the machinery of ethics approval, publication and conference systems that 'reward' traditional research; and to learn from, but not be unduly shaped by influential peers that mandate that 'good' mental health research must reflect academically respected methodology or medical models, and that any diversion from these approaches inevitably jeopardizes objectivity and impairs research quality and reliability. As an early career researcher, I feel the need to be 'approved' of whilst at the same time feeling that old methods cannot in this instance, yield new perspectives. I felt pressure to change my methodology to give a more conventional appearance to the project but I felt that would be inauthentic to do so, like putting a white lab coat on it and creating the 'theatre' of Scientism.

It was suggested that my research would be more 'valid', if I compared specific physical and mental health conditions – for example if I looked at diabetes and depression. However, that would not allow women to express their experience freely and participate on their own terms. I was also asked why I did not interview health staff particularly GP's and compare the two perspectives; but the purpose of the study was to understand women's experiences. I asked experts with lived experience directly and I have their data, and it is not necessary to 'fact-check' it. In a reverse study, few people would suggest interviewing service users to check the accuracy of a medic's testimony. Although on one occasion where that was done, an 80% discrepancy between

what medics asserted Service Users thought and what Service Users actually said was found (Rose, et al 2003).

When someone is denied the capacity to share their knowledge or to interpret their own experiences it is known as an epistemic injustice. It does harm to that person 's sense of self and their agency (Crichton et al. 2017) it can also lead to undertreatment of pain symptoms specifically that of minority communities (Keogh, 2021) and can result in higher death rates as we still see in the House of Commons report into Black Maternal Deaths (2023). Crichton et al (2017) posit this injustice occurs where there is a difference between a service user's personal lived experience of illness and a professionals' formal understanding of the issue. The professional will often prioritise their own flawed or partial conceptualisation of events over what they are told by the Expert by Experience. This interpersonal prejudice can be repeated on a larger scale in situations (such as the one described by Rose et al's, 2003 work), where Evidence Based Practice - best practice established through research is preferred over the testimony of those with lived experience. With an awareness of such power imbalances and with an understanding of epistemic injustice informing the ethics of this research it proved more methodologically sound to seek validity through a clear articulation of rationale and a transparent account of positionality rather by than diluting the approach and so that was the path taken. I was also guided by the need to keep this project readily accessible for the people engaged in it and who may wish to read the findings.

Best (2003) warns against convoluted theories that are impenetrable to all but a few scholars. I support her position that if narrative feminist research is committed to engaging with others to tackle, not just understand social our work must be comprehensible and communicated in a straightforward manner. It was here that a commitment to coproductive working proved invaluable, with Williams et al (2020) questioning academic hierarchies by asking why academics are rewarded more highly for publishing in high impact journals than working directly with people to improve their communities.

EPISTEMOLOGY

In terms of the ontological position of this research, I pragmatically assume that whilst the nature of reality is best treated an objective fact, our understanding of our everyday experience is subjective and socially constructed. Harding's (2004) Standpoint Theory states that knowledge is produced from one's experience of power within society and that different and unequal opportunities shape particular ways of knowing and being. It follows then, that women from different backgrounds and with their own experiences of ill health will have a useful, if less explored perspective.

In addition, Reed (2022) notes that Standpoint Theory has much to offer nurse researchers in particular. In critically appraising the objectivity that underpins a biomedical understanding of nursing science, a recognition of the human, environmental factors and values support a more holistic approach. Epistemologically, as both observable phenomena and subjective meanings form acceptable types of knowledge within this research and its meaning is co-created, it seemed that qualitative methods within a pragmatic paradigm would serve the research purpose most effectively.

The experience of women was the focus of this study for many reasons. Firstly, demographically they are likely to experience multi-morbidity and secondly, they are likely to have their health needs exacerbated by socio-political constraints like poverty, sexism and violence (Changing Lives, 2018). Neubauer et al (2019) describe phenomenology as being distinctively positioned to help health to learn from the experiences of others. If an insight can be gained into ways of supporting this group with their challenging and evolving health needs it is possible that some good practice can be transferred into more general interventions. It was key that the methodology used in this project was consciously selected to be responsive to women's lives and be likely to yield helpful data.

I sought to explore how women understand their own mental and physical health concerns and how they perceive the response of health services to their needs. It was important to me not to conceptualise 'women' as a single category, as the groups of women in this study are different in many ways from each other even whilst they share some characteristics and experiences. I needed to find a way of working that allowed for that and indeed celebrated it. Stanley and Wise (2013) go further seeing problems in defining oneself as the 'researcher' in opposition to study participants, which can lead to a privileging of the researcher's perspective and voice over that of the other women giving their labour to help to create knowledge as participants. A balance is required and a methodology that allowed for dialogue and iterative processes seemed better placed to provide that. This research is intended to be 'for' all of the women involved, not 'on' them.

I chose to use qualitative methods as there was (Field and Morse, 1985) and indeed still is, little established knowledge about this area. Whilst there is an academic prestige associated with quantitative research (Hoffman et al. 2013), it was not suitable for producing the kinds of knowledge I was seeking to co-create. Beresford (2004) has long questioned the conventional preference for positivist assumptions, asserting that Experts by Experience are disadvantaged by the valuing of concepts like 'distance', 'neutrality' and 'objectivity' - concepts which are themselves open to question. He states that the information is likely to be more accurate and reliable if there is a shorter the distance between direct experience and its interpretation. This is an important tenet for this project and one that proved key to the analysis of the findings. I could not find a way to coproduce research with the volunteers using quantitative methods or locate a successful example of this being undertaken elsewhere at that time and keep to principles that underpin this work focussed on coproduction and emancipatory practice.

In addition, I wanted to understand personal, embodied experiences and quantitative methodology with its focus on direct, statistical relationships over

narrative, experiential accounts would be unable to provide me with the richness of information needed. The research design had to situate women's experience at its core, and in particular the experience of having a female body is one of embodied knowledge which entailed working phenomenologically (Merleau-Ponty,1962).

In order to keep the lived experience of women with multi-morbidity central to the research and in an attempt to work collaboratively in a non-exploitative fashion I recruited a paid steering group by means of an independent small grant fund. It is fundamental to coproductive working that lived experience is recognised morally and valued professionally, paying for expertise is one way to do that. I then worked in partnership with a service user organisation which consisted of women who themselves had a combination of health needs and who formed an advisory panel. They gave feedback on the project protocols and helped form the questions for the focus group and questionnaire. I will in later chapters explore how the methodology was encountered and seen by the women I worked with as their perspective on ways of working was understandably not an academic one and they placed little importance on theoretical models.

However, an understanding of women's experience remained the central focus of the research and my methodology drew on both phenomenology and grounded theory; as the findings are generated inductively. In terms of phenomenology Husserl (1965) wrote about the importance of focusing on the meanings people give to their experiences. He assumed that we are all shaped by our experience of our personal 'lifeworld'- that is that we cannot experience a phenomenon without referring back to our own context.

Hermeneutic phenomenology, then, offers a way to investigate the phenomena beneath our surface awareness and how our understanding of context influences our understanding (Ashworth, 1996). This approach is important as it offers an approach to offset the impacts of a system that often seems to

prioritise its own functioning and needs over those of the people it is created to serve. It was essential that the women who participated in the project should have their voices were placed centrally and honoured as expert evidence (Lopez and Willis, 2004).

Van Manen (1984) described phenomenological research as a 'caring attunement', a 'wondering' about being alive which spoke to ethos of my own nursing practice. On a personal level it was essential to me to have my personal beliefs and professional ethics in alignment with my research methodology as these different lenses over lap and inform each other. More broadly though it is important for service providers and commissioners to better understand how their services appear to, and are experienced by women attempting to access their support. There is value in itself in working with women to present this information in an accessible way (Peer Researchers for the National Commission on Domestic and Sexual Violence and Multiple Disadvantage, 2018) and phenomenological inquiry is an accessible and coherent way to explore the perspectives of women with physical and mental health needs as it addresses the nature and meaning of human experience (Van Manen, 1990).

Initially the data was to be analysed using Interpretative Phenomenological Analysis (IPA) which was selected because it has a provenance within nursing research. Pringle et al, (2011) describes its use in providing a greater understanding of experiences in healthcare and illness in order to improve service provision. My study has similar aims and they note that to influence health behaviour and lifestyles the nurse researcher must establish shared meaning. Larkin (2008) notes the fundamental requirement of phenomenology and feminist research to not only hear the experience of participants; but the importance of being able to contextualize and 'make sense' of these claims and concerns from a psychological perspective.

Smith (2004) describes the process of IPA as the participant trying to makes sense of their personal and social world from within it – Heidegger's (1962)

concept of 'Dasein'. Alongside the researcher who is in parallel experiencing Dasein attempting to make sense of the participant trying to make sense of their personal and social world. Smith makes an important point in favour of using IPA, suggesting that some other qualitative methods exclude marginalised groups because they carry within them requirements of reflexivity and eloquence on the part of research participants. I was aware that some of the participants would be participating in a second language and so accessibility was a key consideration. I hoped that by using IPA the richness of the account would support a positive experience and facilitate participation. This turned out to be the opposite in practice

When using IPA was suggested to the women working with the data and looking at the analysis it was rejected as 'too complex' and was seen as imposing an unnecessary layer of meaning on the experiences they and their groups had shared. I will discuss this in more detail in later chapters. I note it here as an explanation as to why a straightforward form of grounded theory was used to explore and understand the data.

A cyclical process

Data Collection

Coding

Theoretical sampling

Theory

How grounded theory was used to move from data to theory:

- **Collect data** – review it and find repeating themes.
- **Code** the themes with keywords and phrases
- Grouping the codes into concepts and then categorise the concepts by identifying relationships.
- Categories created through this process, as well as the links between them, are used to develop **new theories**

Corbin and Strauss (2008) highlight the utility of grounded theory to investigate social issues and to move from description to an understanding of the processes. It was also helpful that they encourage researchers to be pragmatic and to "… use the procedures in their own way" (2008 p.x). If the project was to be a shared endeavour then the participants had to be able to see their words represented rather than have a preselected way of working forced on them. The participants responded intuitively to Grounded Theory and as it lent itself as an approach to the type of work being undertaken it was adopted. The fact that the ideas discussed and concepts we created proceeded directly from the participants words, kept the link between data and theory explicit. In addition, having distinct phases during the process of analysis made shared working straightforward and lent the process itself clarity.

No theory remains static though and there are later differences around how to approach Grounded Theory between Glaser and Strauss. Firstly, over whether verification should be an outcome of this type of analysis - so a clear description of how coding was undertaken is included to clarify that concern. Secondly. the initial premise of a wholly neutral observer and themes being 'emergent' can be problematic as they are not in alignment with current ways of thinking. That said, more recent publications have acknowledged the importance of the activity of the researcher. Cooney, (2010) suggests that this is evidence of an acknowledgement of social constructivist ontology and postmodernism as it is allowed that theories are constructed by researchers out of stories made from the data shared by research participants. Again, this is in alignment with the research project and was a positive factor in its use.

One unexpected issue that arose though was a participant independently reading about Grounded Theory who came across an article talking about excluding 'dross' from analysis. They were understandably offended that experiences shared freely by potentially vulnerable people could be seemingly disparaged in this way. The idea of 'dross' in this sense refers to removing

information that is unrelated to the topic – however in everyday usage it is defined as rubbish or something worthless. It was explained as an issue of terminology but it is a point to note that as the world of research becomes more transparent to both participants and the public there will need to be many more changes in approach and attitude. Rose (2017) describes how what attempts there have been in tackling stigma, silencing and disrespect in the academic arena have largely been made by service user/survivor researchers. This is something all practitioner / researchers should be aware of and take steps to both support this important work and ensure that their own work is not dismissive or oppressive.

As part of the methodological approach taken to strengthen the credibility and trustworthiness of this research I provide thick description and seek to enhance transparency throughout. Cucciniello et al. (2016) found that strategies to support transparency helped to increase participation with research and ethical behaviours in researchers. I drew on Arguinis and Solarino's (2019) summary of recommendations for enhancing transparency and replicability in qualitative research and to ensure best practice. As part of that transparency I note that I felt drawn to this way of working from my own preferences, as much as the project dictated it as the best fit for the research question.

Having had experiences from my practice days with research where participants were treated in a high-handed manner I knew that I wanted to work in ways that expressly value equality (Kagan et al. 2010). Following on from my love of nursing philosophy I wanted to draw on a work like Carper's (1978) ways of knowing. These experiences and resulting beliefs shaped my responses towards the kind of information I find persuasive and meaningful, and in turn the kind of work I wanted to produce.

There were instances though where my identity as a nurse researcher has shaped and perhaps flexed the methodology. Certainly, the theories and values that inform my research are the same as those underpinning my professional

identity and practice and what Leslie and McAllister (2002) describe as "nursedness" - which is the way that a nurse presents themselves – often unconsciously, can lead to heightened levels of trust from participants and result in different outcomes like increased disclosure. Nelson and Mee (2018) describe instances where her expertise as a nurse jars with her novice status as a researcher noting that whilst the activity of research had begun her identity had not had time to adjust and shift focus. Dreyfuss (1991) suggests Heidegger's theory of 'readiness-to-hand' offers a way to understand this discomfort. For many nurse researchers the 'ready-to-hand' skill set is that of nurse, and it is so ubiquitous it is unseen to them, unlike the present-at-hand skill set of the researcher that is needed but can still feel unwieldy.

My nursing background helped me to be comfortable with creating space to manoeuvre within methodology. I am aware that for some non-clinical researchers having a fixed plan at the start of their project offers them a sense that their work will have rigour, however in part due to my professional practice and familiarity with the philosophy of nursing I saw value in having some flexibility and responsiveness within the project design.

 As Munhall (1983) notes, another way of 'knowing' within nursing is "unknowing", it is not uncommon to hold a 'watching brief' as for example, symptoms develop or results come back on tests so attentive waiting as a plan unfolds was a familiar stance for me. The position of openness she advocates, facilitated me as a nurse-researcher "to be authentically present' and to 'interact with full unknowingness about the other's life" (p,125). Being able to sit with a certain amount of ambiguity at the start of the project enabled me to more freely respond to the data generated by and the guidance from women with lived experience. I was also able to make some change in my initial plans when I could see that they were having a negative impact on research participants and was clear about my remit and duty to do so.

THEORETICAL PERSPECTIVE

Feminism and Activism:

My personal and political beliefs impact my choices in all aspects of my life - including my research (Sarter, 1988). Planning a project requires thoughtful and deliberate choices and I am explicit about my positionality in order to provide context for this project throughout this dissertation. Knowledge is created within a social ‑ political context and that it is shaped by an ever-evolving dynamic between the dominant culture and individual personal experience.

Danieli and Woodhams (2005) note that participatory and emancipatory research is open to critique because it selects to use of the works of feminist researchers and contains within in it the tension between epistemological requirements to produce valid results and emancipatory processes to re-centre marginalised voices. I would argue that you cannot explore the experiences of women with multiple health needs without doing just that, but working with an explicitly feminist perspective also carries a possibility of marginalising other protected characteristics – like race and disability. This is an issue that is pertinent to this study as it seeks to explore the experience of having both physical and mental health needs and the research participants are from a range of social and cultural backgrounds. However, if knowledge can be generated and shared through coproductive methods and with an awareness intersectionality (Crenshaw, 1991) that process can lead to a clarification of overlooked issues and some measure of self ‑ emancipation.

Intersectionality can provide a tool to consider how structures of dominance and oppression in society. The power dynamics of forces like racism, misogyny and capitalism privilege certain groups or identities over others (Overstreet et al., 2020); and using this concept helped me to understand the ways in which women with mental and physical health issues seek help and to explore what their experiences of accessing and receiving support were in order to seek improvement. This necessitated partnership working and the expectation that my findings could result in identifying potential improvements indicated the need

49

for an explicitly activist stance. My own professional and personal life experiences combined with these factors to draw on research that was explicitly feminist and to incorporate that standpoint into my own work (Lafrance and Wigginton, 2019).

Richter et al (2020) work with an understanding of themselves as "tempered radicals", seeing themselves as working from activist "homeplaces" (hooks, 1990). That is using the academic space to nurture resistance practices and to protect activism. They note a discomfort that I share, experienced between the desire to use my skills to support social justice practices, whilst navigating the neoliberal culture of modern universities. Although it should be noted though that universities whilst welcoming to some, are not universally experienced that way and Faulkner and Kalathil (2012) observe the importance of using 'non-elite' spaces when undertaking coproduction. The idea of "tempered" radicalism, captures the experience of being privileged and marginalised at the same time (Case et al., 2020). It is a circumstance that brings with it, responsibilities to support others and recreate higher education as a space of liberation rather than one that can be exploitative. At the same time, it is important to remember that scholar activism is a form of praxis that can jeopardise those same hard-won benefits.

I was drawn first towards nursing philosophy and research which (despite being one of the few areas of thought that is dominated by women) has a complicated history with scholarly activity, feminism and gender theory. There is an anti-intellectual stream that runs through nursing (Allen, 1992 and Foth et Al. 2018) and nurse researchers are often conscious of being dismissed, first by practitioners for being detached from 'real world' issues and then again by the research world as 'applied theorists' and thus second-class citizens intellectually.

Nurses in frontline practice face their own negative social stereotypes as part of what the Chicago Tribune (2005) described as the 'Pink Ghetto' of

traditionally overlooked women's work. The Royal College of Nursing (RCN, 2020) note that nursing is the most underpaid profession in health and that even when nurses do get access to senior positions of influence and power, these are disproportionately taken up by their male nursing colleagues. Although women make up around ninety percent of all nurses (NHS Employers, 2019), they fill less than one third of senior positions. In addition, there are deeply embedded inequalities around wages (a common measure of vocational prestige) which have not changed in decades despite their being a high demand for nursing care and a perilous number of vacant posts.

Even television programmes routinely represent the relationships around power and respect between women in health as oppositional, with offence often being taken by female medics who are mistaken for nurses and competent nurses being 'complimented' by being told they are 'good enough' to train as doctors. Summers (2010) in her article 'The image of nursing: Not good enough for a feminist?' – introduces further levels of confrontation around intellectual and social standing when she describes medics who are women, seeking to distinguish themselves from female nurses who are seen as 'a surly, uneducated servant class' (p.24).

The issues that can stymie female collaboration and participation within health settings mirror those in wider society. Indeed Fagin (1987) went so far as to claim that second wave feminism raised women's aspirations so 'high' that it nearly wiped out nursing as an option for young girls and rendered it an 'invisible profession'. This is rather a sweeping argument, but it encapsulates something of the problematic nature for women of operating successfully and collaboratively in the spheres of health and academia. It may also go some way to shedding light on the question as to why, in a health service whose workforce is comprised largely of women – so many women both staff and service users are not getting their needs adequately met whether they are in regards to pay and conditions or personalised care.

It is also worth noting the dominance of male academics in higher grade posts, even across the female-dominated nursing fields. The Higher Education Staff Statistics: UK, 2020/21 noted that whilst there are 23,495 professors in the UK, only 6980 are female and of that minority only 45 are black women. There is a further gendered disparity between teaching and research, with research seen as more prestigious. When research is seen as the gold-standard of academic and intellectual performance (and is economically rewarded) it becomes increasingly hard for women to move away from pastoral care and teaching – areas to which they are often allocated and into highly-paid and highly-valued leadership position in research. If you are not at that table you are restricted in the ways you can influence research agendas.

A feminist approach to my work has given me ways to think about the nature of the issues I faced theoretically and the practical approaches I might select - it also yielded the impetus and expectation that action will result as part of the research process (Case, 2017). This was something I had not experienced before having been part of research studies that had purely theoretical expectations. I felt that my research practice could align with my personal inclination and professional expectations for the first time. As Maynard (1994) states there are many different ways to research from a feminist perspective but there are some commonly shared expectations. Ideas of gender and power are of prime consideration within feminist studies, and there is an intention to identify, interrupt and transform the structures and associations that oppress people along intersectional lines (Cole, 2009; Barker, 2015).

Working with Intersectionality brings a number of dilemmas, firstly like coproduction it is both a theory and a method. Secondly as Collins (2015) points out, it forms part of the power dynamics that it seeks to describe, although it is this attribute that renders it so helpful to professionals who can engage with it as a form of critical praxis when addressing social inequalities.

Being mindful of these power differentials, feminist research must begin with an intention to 'respect, understand, and empower women' (Campbell and Wasco, 2000: 778). This entails valuing the experience of research participants by being mindful of the potential power dynamics between the researcher and participant (Walters, 2020). Riaño (2016) theorises that this often leads to collaborative approaches being preferred within feminist research processes. Which again positions female researchers away from the recognised profile of 'superstar' professors – people (usually older white men) who can front a bid because of their recognisability and build the kind of profile needed to shape larger or groundbreaking projects. However, Thompson et al. (2018) raise concerns around the absence of some participants' first-hand experiences in recent debates of agency and resistance (Saukko, 2008) and so I formally address this matter though the use of Coproductive methods.

The UN General Assembly Human Rights Council Report of the Special Rapporteur (UNHCR, 2017) described the use of co-production in mental health as a transformation of power and control between service users and practitioners in the mental health system. It should follow then that the same emancipatory approach applies to co-production in mental health research (Lambert and Carr, 2018), however genuinely radical approaches are still rare and coproduction is something which frequently falls short of expectations and hopes for both parties.

Williams et al (2020) describe a list of potential issues from discourteous and dangerous practice to researchers being thought less of for working in this way and finding it hard to have their academic outputs published and professionally valued. Indeed, Rose and Kalathil (2019) go further saying that because of the power differentials genuine coproduction cannot occur between researchers and people who have experienced mental distress, especially if they are people of colour. I will return to explore this premise in the discussion chapter.

A recent blog for NSUN (The National Survivor User Network) by a service user activist Amy Well (2023) whose title 'I don't want a seat at your table' reveals the disillusionment and anger felt be many around this increasingly missed opportunity. Activism and ally-ship are already complex positions to hold in relations to professional practice and academic expectations of politically neutral research (Rose, 2017). When co-production and involvement opportunities turn out to be compromised, tokenistic and not underpinned by genuine power sharing whilst paradoxically being demanding and unfulfilling to participate in, it is not surprising that Experts by Experience, who are knowledgeable researchers themselves are wary. Indeed Carr (2020) offers a timely warning about allies, people who began with good intentions to support the centering of marginalised voices who then go on to stray into becoming 'experts of experience' and begin talking over or on behalf of others.

At the same time service users who have not had exposure to this way of working may well have lived experience but find the strictures of formal research baffling and be uninterested in them. Coproduction carries an expectation service users and patients understand and want greater power and control - certainly some do but many others just want the problems they face identified and fixed. It is quite the contradiction to require that some of the most vulnerable, stigmatised and resource-stressed people in our communities should work for little or nothing to fix issues of fair access and social justice that should not exist in the first place, but left unresolved can prove potentially fatal for them. I have not found an answer to this dilemma with this research but I what I can do to address this issue, I will do.

This call to action links into the second theme of feminist research - activism. That means working with an awareness that feminist research has the potential to empower women in ways ranging from consciousness-raising, to establishing an evidence base and organising and protest. Lafrance & McKenzie-Mohr (2014) describe this activist stance within feminist research as the mobilisation of personal stories of opposition and resistance to enhance collective wellbeing.

Foucault however flagged concerns with the impulse to craft a 'singular adventure' into 'a general phenomenon in the name of science" (Foucault,1973, p.8).

I found Hopkins et al's (2016) work on finding equipoise between the interrelated dimensions of phenomenological practice helpful. Being able to visualise continuums between a focus on the general context and the specific aspect, between interpreting meaning and describing particulars and when to practice reflexivity and to apply reduction was helpful. Utilising the 3+1 framework helped me to make decisions within the hermeneutical cycle about when to focus on particular aspects and when to pull back to achieve balance. The framework posits that developments in theory or policy are influenced by the interests of those involved, current ideas, and by the systems and institutions that provide their context. A checklist of questions is included to help practitioners understand the impact of their choices and help navigate their way to the best result.

For Fraser and MacDougall (2017) though, the purpose of feminist research is not one rooted in the macro and in finding broadly generalisable themes but like qualitative research to offer a counterpoint perspective. They also note the gendered customs that shape expectations around the construction of evidence and Fine (2011) describes variations in who gets to speak and is deemed worthy of an audience. In these circumstances the activism is in challenging the way that research expectations limit possibilities for a broad range of understandings rather than in the findings themselves. This has proved to be the case for this study.

Feminist research at its best is characterised by critical reflection, an emancipatory stance, connecting the fields of theory and practice as equals and it is a collaborative enterprise with a sensitivity around power dynamics. It is by necessity intersectional and should include a recognition of differences in race, class, and sexuality and other dimensions that further strengthen it ethically; but

as Regan and Burton (1992) suggest, feminist research is less about the method used and more importantly the positive intentions with which it is undertaken. Kagan et al (2010) write that nurses working within their professional codes of conducts and human rights law naturally find themselves through praxis in alignment with this way of working. The Nursing and Midwifery Council Code of Conduct (2018) is explicit around respect of difference, using the best quality current evidence base and working within firm ethical boundaries and provides a useful steer when making choices that impact others.

I was helped to think about how to navigate practice that spans boundaries of identity and power by reading Anzaldúa's (2012) work Borderlands/La Frontera. The approach she describes and the imaginal space of borderland methodology helps people who position themselves mutably within multiple power relations (which can include gender, race, sexuality etc.) supports us to better understand ourselves and our work as internally whole. Rather than dividing oneself up into two sides as my training and the culture of professionalism within nursing itself expects - one 'professional' and the other 'personal' we can pursue knowledge as people without the clearly constructed distinction. The boundaries between personal and professional and academic and lay identities are often monitored with penalties for transgression.

A borderland methodology expects us to assess our approaches according to their value to multiple communities, but not to automatically prioritise formal structures.   I was challenged by the requirement to develop ethics of cooperation unbounded by 'loyalties' to ideas like capitalism, professionalism or indeed institutions. I hadn't considered that I did that but on reflection elevating boundary considerations, even inflating them outside their worth or utility can easily be part of traditional academic research structures. The structure of the D. Prof itself and hooks (2019) work on the 'margins' being places of power gave me 'permission' to be creative but I was always mindful and concerned to tread a fine line to avoid accusations of a lack of academic rigour.

Sandra Harding's (1995) theories of 'strong objectivity' and her critique of traditional positivist scientific research as being sexist and androcentric also shaped how I developed this methodology. which compromises claims to objectivity and biases the research – the feminist argument that research cannot be 'value-neutral.' Another theoretical influence on this methodology particularly in regards to activism is the work of Freire (1970). I first encountered it as a nurse educator and was impressed by the unabashed description of a moral obligation to express 'love in action' and the right to be freely and fully human (p. 45). Freire defined praxis as 'reflection and action upon the world in order to transform it' (p. 36) which spoke to me as a practitioner working with marginalised people. It was a stance reinforced by hooks' work in Teaching to Transgress (1994) on the concept of education as a practice of freedom. I took much from its themes around the importance of thinking critically and challenging oppressive practice and explore how these concepts work together in the discussion chapter.

Returning back to the start of this chapter, I always tried to consider my previous learning about identifying when an issue is systemic rather than a collection of individual problems and I reflected on it when making choices in this area. Once I understood how to look for it I came up against systemic issues throughout my mental health and educational practice. They also shaped this research; one reason less is known about this topic is that the questions I am asking have not really impacted people making decisions about commissioning and funding research before. Indeed, I have been very fortunate to be supported in this project but there are few women in positions of authority with the capacity to offer support or guidance around this topic even now.

METHODOLOGY

Coproduction:

As previously discussed coproduction can be both a theory of practice and a methodology in itself, I used coproduction as a fundamental principle of my

research study design because finding answers the research question necessitated a collaborative approach. It also afforded me a way to work with experts by experience in a way that was removed from the restrictive power dynamics within traditional research (Lambert and Carr, 2018). It was important that coproductive expectations ran through this project from the planning stages, to gathering data, interpreting findings, and sharing them. I wanted take care to avoid circumstances like those described by McSpadden, (2011) who described being unable to recognise their own memories within a after they had been repurposed by a researcher for their own narrative.

It is a familiar experience for marginalised people and as hooks poignantly writes 'No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still the colonizer, the speaking subject. and you are now at the centre of my talk' (hooks, 1989 p.208). I feel a weight of responsibility as a researcher. It is an anxiety for me that given access to the stories that participants tell about who they are and what they have experienced that I might let them down. It is one thing to be ignored by people with who you have no relationship, but I imagine it to be more painful to trust someone to share your message and your hard-won learning to see it appropriated and misused.

Part of a researcher's role is to interpret findings and it is important to me that I do that ethically, effectively and transparently. I was also aided by reading qualitative health researchers whose scholarship is informed by critical and postcolonial feminist epistemologies particularly that of Olukotun et al (2021) which offers examples and questions to ask oneself about bias towards research participants. This was an especially important consideration for me as I have no shared cultural background with most of the women in this study. They also note the importance of thinking about historical and political issues with an

expectation of pre-emptively addressing them. It is not enough to observe difference or separation when there are things we can do to bridge gaps and connect.

I am heartened though by hooks's description of marginal space as a site of resistance, of 'radical openness and possibility' … and as 'a site of creativity and power' … an 'inclusive space where we recover ourselves, where we move in solidarity' (hooks, 1989 p.209). Ally-ship can prove easier to lay claim to, than to meaningfully and consistently deliver as it requires a constant focus on maintaining equality within a research context. (Tew, et al 2006). Many conventional research structures can skew towards hierarchical and exploitative, however choosing to prioritise partnership can lead to exciting and inventive research.

Coproduction originated from American public management theory during the 1980's to describe the symbiotic connection between citizens and public institutions in resource administration (Ostrom, 1996); and it was Cahn's (2000) book 'No More Throw-away People' that progressed ideas of coproduction into the sphere societal and social justice concerns. Cahn used his own lived-experience of being a patient to conceive of coproduction as being 'a fight over being declared useless' (Cahn 2000 p. 5) and to articulate the importance of a move from dependency to equality in terms of receiving healthcare. This resonated with my understanding of stigma resulting from 'spoiled identities' (Goffman, 1963) and my observations around the experiences of women with a range of health needs. A respectful, valuing stance was a quality I wanted to explicitly underpin my own research.

The idea that power could and should be shared began to change health and social care in England slowly (HM Government, 2007 and Stephens et al. 2008) and the mental health system began to restructure in ways which were more inclusive however inconsistently and unequally (Slay & Stephens 2013). Even today despite the expectation of recovery-focused practice becoming

mainstream, the reality for people using services often falls short as the latest reforms to the Mental Health Act demonstrate. Sharing the ability to define your own reality and tell your own story is a fundamental part of understanding yourself and being human. Coproduction offers a way to recognise the individual inside the research data and to recognise people as the 'point' of ethical research, rather than problematising them as a hindrance. The data belongs to the research participants as it is their narrative and their gift to the process of creating knowledge. Their closeness to it adds a particular value as does the perspective of someone external to the process who uses their emotional distance to work on analysing its meaning – neither is better, they are different options for difference needs.

As coproduction in health care necessitates a sharing of power within the system to improve experience and outcomes, it seems logical that the same principles should apply to coproduction in mental health research. Service user involvement in research in UK are dominated by the agenda of generic 'patient and public involvement' (PPI) (INVOLVE, 2012). It is important to be clear that PPI does not automatically alter the power and control dynamics that impact mental health practice and research (Roseet al. 2018) and a specific aspiration for equality must be present as a foundation for transformative coproduction and emancipatory research (Carr, 2016).

Whilst I have aimed to coproduce this study, I am careful to recognise the places where the work is best described as participative rather than fully coproduced - for example it was not commissioned by service users but initiated by me. Williams et al (2020) note that the current enthusiasm for participatory research practice has led to a phenomenon they name 'cobiquity'. This is the misappropriation of the term 'co-production' for technocratic rather than egalitarian motives, so it is important to be precise with terminology. The term coproduction can be used to suggest that work has legitimacy when in reality it is not radical in its approach to redistributing power and control (Needham and Carr, 2009).

Ethics (relating to methodology – see Appendix i.): The design of this study is coproductive and its ethos is active and participative however its participants could be considered vulnerable as they experience a range of multiple health needs and may at times need support and protection. These seemingly contradictory drivers need to be acknowledged in order to clearly present the ethics strategy for this research project. I had to balance my expectations towards participants (that they would actively participate in shaping the research, gathering the data and establishing its meaning), with their wellbeing so my ethical stance was envisioned as a flexible ongoing process rather than a single action - something discussed in greater depth in the chapter on project activity.

All researchers have an obligation to uphold good ethical practice when working in partnership with research participants (Department of Health, 2005); both the Council for International Organizations of Medical Sciences (CIOMS) and the World Health Organization (WHO) (2002) stress the importance of ensuring that potential participants have appropriate information to facilitate decision making around consent. They provide guidance as do the ICH (2006) as to what this procedure should look like; and recognise that special provision must be made in the case of vulnerability or the inability to protect one's own interests. However, there can be moral dilemmas as it is not always clear who should make that decision with some professional backgrounds being more confident in this area than others - and confidence not always being correlated to competence.

In addition, as a nurse researcher I have responsibilities around duty of care which fall under the Code of Conduct (Nursing Midwifery Council, 2008) and within its' first tenet 'make the care of people your first concern' (NMC, 2008). As a profession nursing has historically been positioned as prioritising others rather than being self‐regarding. This might suggest that research with potentially vulnerable populations should be avoided to uphold the principle of

non-maleficence. Indeed Ashley, (2020) describes the dangers of research fatigue in participants – particularly those with marginalised identities as needing a special sensitivity. She describes this phenomenon as a risk to both individual participants and minority communities and as an opportunity cost for future research. It is important though when walking the fine line between beneficence and Duty of Care not to become paternalistic and to have freedom for participants to make decisions about whether, and to what extent they wish to engage.

Another perspective on this issue comes from Kagan et al. (2010) who describe nurses as also having an ethical responsibility to promote social justice and they call on nurses to address this explicitly within the fields of practice, education, and research. This impacts research design choices around ethics because whilst a duty of care can be conceptualised as protective, the principle of justice means working in ways to include the voices of people who are marginalised in research. These principles are not always in alignment and the nurse researcher must find an equitable balance.

Chinn and Kramer (2007) build on Carper's 'Ways of Knowing 'framework (Carper, 1978) with the concept of Emancipatory Knowing. They define it as a critical awareness of the social-cultural context in which nursing takes place, with nursing having an inherent obligation to tackle equalities and injustices. Peart and MacKinnon (2018) note that whilst social justice forms part of the normative discourse within nursing practice it is not often well-articulated. Small (2019) argues that the concept of social justice is addressed in the NMC's (2008) Code of Conduct within the sections requiring nurses to ensure personalised care which implies nursing involvement in seeking justness within healthcare.

D'Antonio (2018) highlights the value of Chinn and Kramer's work in recognising nursing scholarship as being innately political. In doing this the production of nursing knowledge receives legitimacy to comment and act as part of its ethical

mandate. This has encouraged many nurses (myself included) to engage with matters which are pertinent to wellbeing but which fall outside of the traditional biomedical sphere because of their ethical duty not despite it. In this case it gives license to conduct research which is organised to include marginalised voices rather than excluding them without justification.

It may be that lengthy protocols, complications with ethics review boards or potentially negative outcomes for individuals cause anxiety for those designing ethics protocols (Moor and Miller, 1999). Whatever the reasons, certain underserved populations have long been designated by others as 'vulnerable' and underrepresented in the literature which in turn weakens the evidence base and is unethical. The idea of vulnerability is in itself a shifting and complex concept and it is notable that it is one more frequently bestowed on others than self-selected.

Arguably researchers have an ethical responsibility not just to avoid personal harm (Polit and Beck, 2013) but to actively promote the public 'good' (Butts and Rich, 2013). It was a central concern that voice of women with multiple needs was honoured and their needs and perspectives prioritised. The ethics protocol of this research was designed to respect the characteristics that made their voices vital (their experiences of mental and physical ill health) whilst making participation as personalised, equitable and accessible as possible.

In this third chapter I explored the rationale for the choices made around research methods, ethos and design and in the next chapter I clarify the project activity.

Chapter 4 Project activity

In chapter three, I described the overarching principles that helped to shape the methodology of this project. I discuss and reflect on activity and process evolution using co-productive approaches (ceding control, sharing power and ownership) within both of these chapters. This is because the theory and the application of this way of working do not divide neatly and artificially. It is important to acknowledge this and to be clear that the work of exploring the necessary 'messiness' of this process, is central to research transparency and ethics (Moravcsik, 2020).

This chapter is concerned with the workstreams of research activity (Figure 3). that generated the data. I have structured this chapter by giving a brief overview and then focussing on the key areas in more detail.

This is a diagram of the Workstreams that comprised the research activity itself.

Activity 1. Literature scoping review	Purposive literature review	
Activity 2. A service user-led research advisory group	Group who coproduced the methodology. (n=6) Also present was a skilled researcher with lived experience to act as a critical friend and co-facilitator	A service user-led research advisory group was paid from an independent small grant to support the formulation the methodology for this work. Also present was a senior colleague from a service user organisation who is both an academic researcher and an expert by experience who acted as a critical friend and helped share the facilitation to enable me to be present and make notes for this project. It was via this process that the rationale for the research was developed and the aims, objectives and methodological framework were decided jointly though discussion after i explained my research question and its purpose.
Activity 3. Four service user Focus groups Appendix iv.	Stakeholders from the focus groups findings Asian Women's group - group of 8 with 15 attendees 59 mins Somali Women's group - group of 8 with 10 attendees 1hr 17 mins Irish Women's group - group of 8 1 hr 19 mins recorded	Four service user focus groups were formed from a purposive sample of women who share the same locality so as to better be able to compare their experience of their health provision. Throughout the planning stages adaptions were made where service users and research participants contributed ideas. This was done because of a commitment to coproducing this research. A staged approach was used so participants could choose what aspects of the research to engage with and to allow a number of different levels of participation with regular opportunities to consent or withdraw according to preference or need. The groups were held in a familiar and informal community setting so that it would be accessible for

	YoGa+ Women's group A group of 7 40 mins The focus groups partcipants' preferred not to have theor general personal characteristics formally noted	people with restricted mobility and people with prams etc. There were childcare facilities available if needed. I also used this female-only space to ensure participants had open access to the research findings as they were being generated and typed up
Activity - online survey Appendix iv.	33 responses: 32 cis-female 1 preferred not to say . 24 - white uk, 5- white other. 1 – Bangladeshi 1 - Asian (other) 1 - Dual Heritage.	The survey was open for two months initially to provide access for people unable to access the focus group but also to provide a counterpoint that was not bounded be geographical location.
Activity 5 open source feedback and comments from the centre members	Member Checking group - 2 representatives from each focus group An open 'sense-making' event with participants and interested parties- up to (n=110)	Self-selected representatives from each of the focus groups also scrutinised the results of all the groups and were able challenge any mistakes, misrepresentations and we worked together to co-create meaning from the findings. These findings were also shared back with the groups at a later point for final comments. Faulkner et al (2019) have written on the importance of participants having control over their own data as an important strategy in reducing harm and ensuring that research is trauma informed. I wanted the people who created the data to have ownership over it and i made a display where women with an interest in the research were able to comment on the findings from the interviews, the survey and the rough draft of the analysis. This was done by inviting them to write, draw, and leave post-it notes on it over the course of two weeks when they were displayed on a prominent wall in a shared space; or to contact me directly to share their thoughts

Activity 1. Literature Review

I described the process of the literature review and summarised the way that it impacted this research process in chapter two.

Activity 2. The Advisory Group (see Appendix ii.)

The advisory group consisted of six of women, representative of the population of London. They ranged between 22 and 68 years old and had varied social and cultural backgrounds. They were all experts by experience and agreed to partner in scoping the topic, determining the research questions and focusing the investigation. We worked together in an accessible location belonging to a service user organisation to ensure 'neutral' ground'.

We worked collaboratively around a big table, having jointly set the agenda for the day. We stopped for breaks as they were needed and to share lunch together. The group members had all got lived experience of the topic being researched and in order to provide a trauma-informed, safe working environment I was joined by skilled researcher with lived experience. She participated as part of the group and as a critical friend and co-facilitator – although it should be noted that the hierarchal structure in the group was not a pronounced one.

The group helped me to design interview schedules, look at drafts of documents, etc. to ensure that the research was useful, accessible and encouraged participation. They were also to act as an advisory group in the case of any ethical concerns arising however that proved a precaution only.

From the start the advisory group demonstrated a seriousness of purpose and had an obvious expertise on a wide range of experiences of physical and mental health issues. They were eager to work together, and had read the preliminary paper-work, and prepared their contributions. They raised many key issues from their lived experience that the literature review had not identified. Most

importantly, they confirmed that this topic was of interest to them and an issue of practical concern more generally. After we had talked about the expectations of the research and the processes, I expected them to think like I did, as a practitioner researcher. However, they had many pertinent questions about the suitability of the established research process and were extremely direct in dismissing research conventions that the felt had no relevance to coproduction.

I thought that coproduction would give my research a form of legitimacy and credibility, and expected to come out with my planned output complete. I was put right early on about the fact that this study had coproductive elements but did not meet the standards for full coproduction and because of the demands and outcomes of co-productive processes employed, I had to remain flexible with my methodology and research activity throughout. I spent a lot of time anxious and distressed thinking about how to deliver this part of the project; constantly feeling like I was failing both the participants and expectations of academic research integrity but I have come out with a far better understanding of the research topic and of the commitment needed to work in this way. However, as a result of my time with the advisory group, I gained a completely altered perspective on the workings of conventional health research approaches for coproduction and some very practical suggestions to improve the study as well as my research practice.

 In light of my research question it was apparent that much of the traditional research framework was ill-fitted to the real-world requirements of transforming power and control needed for co-productive practice. So, I sought help to draw on previous best practice and expertise by experience. I recruited to the group by circulating a flyer stating the research purpose and the pay and conditions that I could offer and I circulated it via London-based service user and advocacy groups and online using social media. I had applied for funding through a small grant scheme previous to this so I had a revenue stream and that group members would not have to wait to be paid. I found coproductive studies to be a challenge to independently fund for a number of reasons.

Firstly, the process is complicated by the necessity for a shared, iterative approach to research design. The fluidity of this method can cause operational difficulties within traditional research frameworks whose structured application forms do not readily lend themselves to this type of design.

Secondly, it is important to value people's expertise by paying fairly for it. Unfortunately, the welfare system as it stands disadvantaged some women who wanted to contribute but who could not do so without jeopardising their benefits. This meant that people had to be remunerated in different ways - for example some women pooled and donated their payments back to other community projects and some women declined payment altogether. I was able to provide refreshments but not to give gift vouchers or anything that might be considered a payment. Whilst there was no evidence that these differences created problems with the data that was collected, it is fair to assume that important data could be missing from women who quite reasonably chose not to participate because of these systemic inequalities.

I asked for women with experiences of having multiple needs in regards to their physical and mental ill health to join the project so that they could offer support as a reference group for other women with similar experiences and to help to generate themes to counter gaps in the sparse literature. A group of seven self-selected after meeting that criteria and came forward to share their own expertise. One person had to drop out due to ill-health. I made efforts to accommodate her health needs but she preferred to withdraw and later informed me that she had participated in the survey when she had felt better. I was pleased to hear that, as it suggested that the flexibility and autonomy built into the design was serving its purpose.

It was made clear to all members of the advisory group that they could contribute to the other workstreams if they wished to. It was important to me to make the process as open as possible and to allow members to share their

expertise as they saw fit as experienced specialists and as autonomous members of society. In the event, whilst a couple of the advisory group completed the survey - the majority decided not to, stating that they had said all that they wanted to in their role as advisory group members.

The option to allow the advisory group to participate in the study if they chose to raised queries. However, the decision was informed by Faulker's (2004) writing where she states that research where participants have power and control leads to further empowerment. For my part I felt that if someone met the criteria as having lived experience and relevant testimony, they should be able to share their hard-won knowledge unimpeded. This work was constructed with the emancipatory expectation that knowledge production is not an end in itself, but should lead to empowerment and change and this decision is another example of that stance (Rocha, 1997)

Activity 3. Focus Groups.

When focus groups were initially used as part of research they were seen as suspect in terms of data gathering as they were considered unreliable and lacking generalisability (Graffigna & Bosio, 2006). However, they are shared expert discussions (Kamberelis & Dimitriadis, 2005) and when approached in ways which are equitable can share considerable 'cultural wealth" (Ginsberg & Wlodkowski, 2009, p. 23). The focus group members self-selected from a purposive sample. In order to ensure that the women had experienced a similar range of services I contacted a women's centre that drew its membership from a city centre locality. This meant that their health provision was also local and that the study's participants often shared the same GP practice although I took care not to collect unnecessary data. I wanted the focus to stay on the women and their stories not be a review of the services themselves.

I explained the aim of the research again at a women's day celebration when many of the centre members were present. I also used posters to invite any

members who met the criteria (of having multiple needs in regards to their physical and mental ill health), to form focus groups of between 6-8 people. Eventually four groups formed. Three with distinct ethnic identities based around groups that already existed within the centre and one which was formed of women who knew each other from activity sessions. The groups self-selected and named themselves: Somali, Irish, Asian and YoGa+ (yoga /gardening/crafts).

It was important that both the advisory and focus group participants should be representative of the women who might benefit from the findings generated by this type of research (Pratt and Loff, 2011). By benefits I include the process as well as any output, as Madriz (1998) writes:

'Communication among women can be an awakening experience and an important element of a consciousness raising process, because it asserts women's right to substantiate their own experiences. The discovery that other women face similar problems or share analogous ideas is an important tool…in women's realization that their opinions are legitimate and valid. (p. 116-117)'.

It is key to note though that an environment like this where everyone is sharing simultaneously about personal topics, confidentiality and anonymity can be potentially problematic areas (Sim and Waterfield, 2019). In these focus groups I was conscious of having scant influence over what participants said within and without the group. It was possible that harm could occur during the discussion of sensitive topics so time was taken to talk about this and the groups agreed to be thoughtful of this possibility and to work with compassion.

Focus Groups
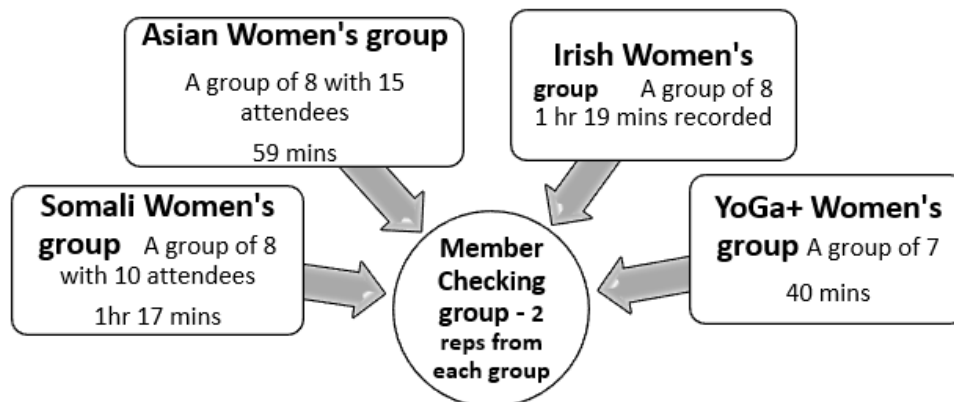
Ethical considerations - From an ethical perspective and in accordance with the principle of justice, the benefits and risks of taking part in a research project should be shared equally. There is a balance to be negotiated between the obligations of accessibility and shared participation, care and protect of participants - especially where vulnerability is indicated. It was of interest that questions were raised in regards to the fact that the women choosing to participate in this might have mental distress but notably less concern was registered about the impact that their physical health issues might have on their ability to make autonomous decisions.

There is still a public assumption that people with lived experience of mental distress and / or service users are a homogenous group who are dependent and or who are in hospital settings and unable to consent to participate in research. However most mental health concerns are dealt with via GP's and people carry on working, being parents and living their lives whilst receiving mental health input. A significant proportion of people experiencing mental distress don't approach services at all. If a research project was being undertaken with people with asthma, diabetes or any other long-term physical health condition, whilst their health status would be a point of interest from a research perspective, it would not automatically reduce their potential for participation in the eyes of others.

The participants in this research were not recruited from hospital settings but their own communities. If an adult is well enough to drive, vote and use a credit card arguably that person can decide whether to fill in an online survey or attend a focus group with their friends and it is not for the researcher to screen them out. That said, Walter et al (2018) make a distinction between the capacity to consent to treatment and the capacity to consent to research participation and I was careful to respect this. It is important not to assume a lack of capacity in one area, is a lack of capacity in all areas.

For example, within a research setting a participant who would not be able to participate in an hour-long focus group should not be excluded when they may be able to offer an informed opinion on a single important question. This principle informed the decisions to break participation in this research project down into smaller sections and to support flexible involvement and remote contributions. I wanted to ensure throughout this process that the expectations of the 'way' that research should be structured did not take priority over the people most able to share their expertise and that their perspective and right to have a voice on this topic always came first.

Slade et al (2014) notes a common barrier to co-researching with people mental health issues is the low expectations by professionals. This infantilising response may come from a lack of nuance when considering vulnerability in terms of research participants or a lack of knowledge about the experience of mental health issues (Bashir, 2017). Arguably this has been compounded by a lack of imagination and flexibility on the part of research communities, however as coproduction and Patient and Public Involvement (PPI) have become commonplace funding requirements that attitude is fast disappearing. As a result, I made every effort to cede control to participants and to act as a resource for them as we worked on this project.

The issues that beset funding in coproduction also affected ethics. Ethical approval for coproduction is needed to ensure that research is safely

conducted, rather than for a specific agreement that a set research itinerary should proceed (Kingston, 2020). Until an advisory group meets, questions cannot be generated or research documentation completed, and it is challenging to get clearance for what can appear to be a speculative project where the outcomes are undetermined. These systemic issues can prevent genuinely coproductive work being undertaken and best practice would be to reshape the ethics process so it is fit to review co-produced projects.

However, I surmounted these issues by approximating the expected scope of the research and submitting it with the proviso that an advisory group will rework the submission once details are decided. As all parties agreed to this unwieldy procedure I was able to get provisional ethical clearance for the advisory group to undertake their work and afterwards, I resubmitted a final iteration back to the ethics committee. This two-stage process took time and needed to be understood by all parties. It is also not a pure coproduction rather an approximation of coproduction in order to secure funding and ethical clearance in order to circle back around and then attempt to undertake coproductive research.

Interestingly, though this process, which resulted in comprehensive discussion at the start of the project, produced such detailed documentation that it did not require any changes on resubmission. Initially, advice was given to concentrate on a more empirical question and select a discrete target population like 'women with cancer and depression' or 'schizophrenia and diabetes'. However, there is little evidence to suggest that any specific combination of physical and mental health issues would be any more relevant to explore than any other for the women concerned. Structuring the work in this way would make it look more 'recognisable' as research which might make others more comfortable with it but would not result in a better way to gather the data to needed to explore the question. As soon as the process of coproduction started, women spoke about the impact of wider social, economic, and political issues as well as individual

health-based ones and using coproductive methods ensured that their experience shaped the discourse rather than artificially applied constraints.

This complexity echoes reality in a way that predetermined questions cannot and whilst complexity is another challenge inherent to co-production, developing a methodology to address complexity can be better placed to investigate to 'wicked problems' (West Churchman,1967). As a result, the research scope was extended and the study conducted with the recognition that processes and methodologies need to be flexible.

Traditionally, services have acted as gatekeepers to potential research participants who may be vulnerable. In this case though, as I contacted the service user groups directly and used social media to access contacts for the survey meant the decision to participate or not was with the women themselves. This mean that not only was the research process was devised by women with multiple needs but also that women who wanted to address this issue found the study by themselves and requested to participate. As previously stated support was offered to participants if needed and the advisory group were stood by in case any participants wanted it however it proved unnecessary.

This change from a research 'recruitment' and screening mind-set to one where meaningful participation is actively supported requires thoughtfulness on the part of the researcher as there is still a moral requirement to protect people who may experience vulnerability and throughout this process I am was aware of my identity as a 'nurse researcher' rather than a 'researcher'. I am molded by over 20 years of professional identity and working within my Nursing and Midwifery Council Code of Conduct (2018). I have previously explored positionality but note this aspect of ethics here as it is relevant to my research practice. The first tenets of the Code I follow are that the care and safety of others must be my main concern; it is followed by the expectation that people's dignity is preserved and their needs are met. In research terms this involves working creatively to support engagement at different levels and in phases, by interested parties,

rather than working to 'screen' people out of involvement. This approach worked well for the advisory group but it caused some challenges when it came to working collaboratively with the focus groups who each had very different ways of conceptualising shared working.

As a practitioner committed to social justice I used the work of Rodriguez et al (2011) especially their guidance on being a 'Culturally Responsive Researcher'. I needed to consider the participants' social and cultural identities and preferred ways of communication. It was important to hold the groups in an environment that they had 'ownership 'of so it was a safe and comfortable space (Hennick, 2008). I spent time reflecting on my own positionality and ways I could make it easy for participants to share their experiences if they chose to without feeling pressured or exploited.

I spent time going through the paperwork with the advisory group and the participant focus groups all of whom disliked it. I am aware that very few people enjoy this part of the research process but it is usually just taken for granted as a necessary step. I was surprised because this aspect of research that for me, that is so ubiquitous it has become unremarkable was seen as not only unnecessary by lay participants - but also potentially problematic.

The advisory group wanted to simplify and redesign the documents and whilst I agreed with the points they made about accessibility it was a challenging moment when I had to explain that it was not within my power to do that. They accepted my rationale – I was candid that it was essential university paperwork and that unfortunately neither the study nor the small grant monies could proceed without it. I ensured that the participants in the focus groups read and understood the forms - using interpreters where needed. In general, the participants in the focus groups showed little interest in the proceedings and did not disguise the fact that it was seen as 'red tape'. There were no issues fed back about the process through the online survey. I wondered if this antipathy to the expectations of traditional research processes came from an unfamiliarity

with scientific principles or whether it might be because the shared aim of the research was applied rather than theoretical and this encouraged participants to look on it as a problem-solving exercise that belonged to them, rather than a 'pure' research project that it was not their place to comment on.

Interestingly Benson et al (1985) found that the majority of participants in a study with depression gave consent to participate before they had received the necessary information to make an informed consent. This could be used to suggest that people with a diagnosis of mental ill health are not interested or able to make informed choices. However, this is comparable to Penman et al's (1984) finding the same for people with cancer patients who enrolled in clinical trials who reported that the consent forms did not inform their decision making. It suggests rather that people make up their mind using circumstantial factors – whether they like or trust the researcher, are interested in the topic etc. rather than by weighing up detailed information and responding logically in their best interests. That does not mean that giving clear information is not important, but rather that researchers need to appreciate Gillon's (1985) work on autonomy.

Gillon (1985) identified three categories of autonomy: the ability to think for oneself (capacity) or the ability to act to one's own deliberations (informed consent); and freedom to act as one wishes. These three aspects of autonomy were given careful consideration as part of the ethics process within the study and were explained separately to ensure that participants understood what they were agreeing to. Arguably giving information about ethics is the same as giving information about anything else, confusing, long and inaccessible wording will lead to non-engagement or unthinking assent, neither of which are desirable. The MacArthur Competence Assessment Tool for Clinical Research has been used to assess capability and I looked at it for this research because of feedback from the ethics panel.

I expected that that language differences were more likely to be an issue looking at the demographics of the potential participants and as Kirk and Bersoff (1996)

rightly complain the test is inequitable as it sets the standard of consent higher for people who have not experienced mental distress than for those who have. This is discriminatory and limits service users' autonomy and right to participation. Coproductive research requires a pragmatic approach using an active process of advocacy (Miller and Weijer, 2009). Observing ethical standards should be a process rather than a singular opportunity to participate, which has been designed to meet researchers' legal obligations rather than their moral ones.

Within this protocol vulnerability was accepted to be situational and a state which can fluctuate (Kapp and Mossman, 1996). The most practical way to acknowledge this was to address the inherent power imbalance in all aspects of the research process and to use coproduction throughout.

Whilst ethics committees are still coming to terms with agreeing best practice in this area, service user researchers have established useful protocols. I used the 4Pi National Involvement Standards (NSUN, 2015) which was developed and produced by a collaborative group of mental health service users and survivors. I also benefitted from Tew et al's (2006) 'Mapping out the value base for social research in mental health' which identifies five helpful themes. They are 'Partnership' which focusses on the ways in which participants meaningfully co-create research. 'Standpoints' which identifies rigour as being produced by a combining the 'insider' (experientially based) knowledge with analytical frameworks. 'Holism' appreciating the impact of the wider social context on the individual and 'Emancipatory purpose' being explicit about wanting to have positive outcomes as a result of research projects.

These themes offered ethical guidance for the principles underpinning the research and connected up to the nursing philosophies and feminist ethics to help me to consolidate a concept of my own expectations for ethical research practice. Many approaches to research ethics have an implicit expectation that a chilly distance is a way to demonstrate that a clarity of purpose is being upheld

and that emotional detachment is the best way to ensure 'untainted data'. That said, whether the researcher likes it or not as soon as researcher and participant come into in contact there is an implicit bargain struck and a relationship of some kind has formed.

The project aim was to explore the experience of women with multiple health needs. So, a logical approach seemed to be to ask representatives of that population and be guided in this process by them. However, getting ethical clearance to approach people who self-identified as having physical and mental health needs who were willing to contribute on this topic was problematic not just from an ethical perspective.

As Warner (2004) writes, people's participation in research is built on the expectation that by sharing their private information – something which has personal value as well as being of academic interest with a researcher something positive will occur. This was a challenge for me in this study as the timescales were longer than even I had first anticipated. If you are working with participants who share information and move on this is less of an issue. This study however involved coproduction and I initially envisaged a team of us as researchers working through to the end. This was quickly stymied by service user researchers who were more experienced and realistic than me and my final approach was shaped by feminist approach to ethics. Something that Lindemann (2005) describes as a way of 'doing' ethics rather than a type of ethical practice.

On reflection I should have been clearer about what research is, about what it can do and about the practicalities like potential timescales for the participants as these were the issues that they had questions about. The activity of consent, whilst important to the study's integrity and to me as a researcher looking for approval - was of much less importance to the participants and I could have spent my time more usefully had I borne that in mind.

Reflections on co-production and focus group conduct

In order to be transparent and provide a rationale for the methodological decisions that were made in the moment, I have drawn on elements of thick description in this section (Ponterotto, 2006).

Women from the centre formed themselves autonomously into focus groups after hearing of my request for help with this project. They named themselves and contacted me to arrange the sessions at time that suited their members. The groups associated with ethnicity and culture were already established and undertaking shared activities from creative writing to trips out. Whilst they shared broad characteristics of identity, they were personally diverse in age and languages. For example, whilst Hindi was the main language spoken in the Asian Women's group, four other languages were in active use and there was a range of religious belief represented with some members fasting for Ramadan during this time. The Somali Women's group spanned the age range from 19 to 82 years and the Irish Women's group had members from both the north and the south of Ireland as well as second-generation / born in London.

None of the groups were keen on having their individual characteristics like age, sexuality etc. recorded although they were extremely free in discussing intimate matters conversationally. I worked hard to respect their preferences whilst attempting to accommodate the expectations of the ethics forms – this was another area of conflict between research processes and the values of coproduction.

Another point of note was that whilst sex and gender were considered acceptable topics in the focus groups - sexuality was only referred to obliquely despite it being my having personal awareness of there being a range of sexuality in the groups. It was not clear if that is because participants felt it would be unacceptable or because it was considered unremarkable in groups who were familiar with each other. However, the anonymity of the survey did give space for comments regarding this feature of wellbeing and personhood.

The YoGa+ group was different in that it comprised of women from across the activity groups – namely Yoga and Gardening, with people attending from Pilates and crafting. This group whilst containing some racial diversity was mainly white British and its members were from populations with access to higher social capital with most having or having retired from professional work and holding positions of civic authority. I explained the participation payment structure and each group independently came back to me with the suggestion that any payment be donated to the groups to help support shared activities. This communitarian mindset was typical of their approaches to participation in all aspects this activity.

There were similarities in attitude and approach across all the groups, the most striking differences, in terms in of working practices, were between me and the participants. I had worked coproductively on many other occasions and had a wide range of community engagement experience so I was not expecting to meet anything new. I anticipated that that because I had explained how focus groups are 'done' that the participants would work within the expectations of a research framework. I assumed that because I had described my 'requirements': that there would be 6-8 participants in a closed group, that we would go through the semi-structured questions in order, that we would end after about 40 minutes and that there would be a baseline of understanding and acceptance of this process.

This was not to be the case, I initially fell into what Clandinin and Connelly (2000) call the "Hollywood plot" error - where the researcher believes that if they follow the expected 'script' the result will be 'perfect' research. The experience of the focus groups was challenging for me as a new researcher, and it was my experience as a nurse having run therapeutic and clinical groups that helped me to be confident that I was getting an important understanding of the research question and should keep going.

One thing that all the groups had in common was that all of the women took the task of coproducing knowledge extremely seriously and set about it in the ways that they would normally collaborate to achieve a common goal. They were much less passive in terms of process than any other groups I had worked with before. The subject clearly interested and engaged them – they were clear about what they wanted to achieve and they readily took ownership of it This was very positive in some ways, however not only was there understandably little in the way of working knowledge of research methods within the focus groups and there was very little acceptance of conventional research processes as the best way to achieve their shared goals – however this was more of a concern to me than it was to anyone else!

When I explained the process of focus groups it was roundly dismissed as being unnecessary and impractical. In fact, the only group that followed my initial expectations was the last one that I undertook - the YoGa+ group. It was a group of 7 who were in the main white British and at the higher end of the spectrum of social capital found within the centre. Most of the had been part of focus groups before and were used to consultation exercises and similar experiences as part other professional working lives. They made little comment about the process and confident in their role within it. I will explore this more fully within the discussion section.

I attended all the groups according to when they could fit me in and it was important to me that I went to them at their convenience, rather than summoning them at my own. I visited the groups over the course of three months, meeting them on their home ground at the women's centre.

Somali Women's group

My first experience was with the Somali women's group, when I arrived I found 18 women there and ready to attend. I explained that 8 was the most I could manage. I explained about research protocol, transcribing and all of the reasons I had been taught to limit focus groups in this way and I was met with laughter.

The group said that they had been looking forward to sharing their thoughts and had already met previously to discuss their ideas so they could tell me what they thought I needed to know. I was embarrassed to find that when it came to shared, egalitarian working practices I was the person lagging behind. I fast realised that I need to adjust my expectations and my working practices if I was seriously committed to sharing power and working co-productively.

I explained aims of the focus group again, eight people sat in a ring and I gained informed consent and began the questions. The other members of the group then sat down and began to contribute. I paused the activity, got everyone to consent and we started again. We were a short way into the questions when a point was raised and the group universally agreed that a member of their group who was not present had the required information. I was momentarily taken aback when a member of the group called her on a mobile to hear her thoughts and make sure her insights were included.

Five minutes later that woman arrived at the group shopping bags in hand, ready to help. I had not expected to need a management protocol for an incident of this kind, but I had a set of baseline collaborative principles we were working to. I had asked this group of women for help to understand an issue, and they had mobilised all of their resources to creatively and unstintingly supply it. So, I paused the group again to ensure that the new participant understood the situation, and with group members agreement, she signed a consent form, joined us and contributed her specialist knowledge.

I am aware that some of my academic peers may feel that data gathered in this way is 'tainted' because the accepted collection process had been disrupted. However, I feel that if you ask people to collaborate in a structured information gathering exercise which is what this type of research essentially is and they endeavour to share that process fully; you cannot then recoil and assert control when they collaborate on their own terms.

There is much written about so-called 'hard-to-reach' populations, but perhaps it is researchers who sometimes create this distance. I found the OPHELIA principles (Kinsman et al 2020) - particularly around prioritising local wisdom, culture and systems - echoed my own practice here. For example, in half of the focus groups, multiple languages were spoken. I asked the group members how they wanted me to manage interpreters joining us. They felt that this was unnecessary and a waste of resources. They came up with their own solutions, advising that they would interpret as a group as we proceeded, so that a collective understanding could be established. It was rare that a participant made a statement that was not discussed by all and incorporated as part of the group meaning.

When I describe group meaning I am not referring to a quiet, shared acquiescence - I mean that people vociferously agreed, disagreed, questioned each other, translated for each other across a number of languages and then assembled an agreed understanding at the end. I was concerned that individual differences would be edited out in the process, but we discussed this and planned how to address this should it occur. As the focus groups understood more about research processes, it stopped being a question of me extracting data from them and then deciding its relevance. There was a shift to deep discussion with focus group members around gathering the data and making sense of it 'in action', as a shared process. This led to a change in the way that the data was eventually analysed, the rationale for which is discussed later.

We gradually moved as a group from the position of having little understanding of what research could achieve, (illustrated by a comment where one woman in the Asian Group explaining to another 'if you tell her what the matter is, she will tell the government and it will be fixed'!). To a point where the focus group members checked their data and explored and thoughtfully commented on the results across the different groups. They collaborated in disseminating the findings to be scrutinized by other women in a range of communities; from women's events to health conferences, and they have continued to speak up

about research and use their knowledge as health activists for their communities.

Asian Women's group

The second group I worked with was the Asian Women's group. After the anxiety and complexities of conducting and transcribing a large focus group I reiterated the cap on numbers I had previously requested and was met with assurances it would be met. However, on arriving for the group the participants had arranged themselves with an inner ring of the eight nominated focus group - senior women, with an outer ring of people who had ostensibly come to watch and support. I consented everyone in the event as it soon became clear that the 'audience' was passing comments forward to the nominated 'speakers' and translating and commenting on everything that was being said anyway. Like the Somali group, it was a joyful occasion with much laughter, loud commiseration and agreement. Both groups had a leader who maintained order when it needed to be reasserted and the participants by shushed each other if they had trouble hearing or being heard.

Despite the noise level in this group I noted at one point an older member, on the outskirts of the group had fallen asleep. She was just covered up by a coat by the other group members as we carried on talking and listening to each other's stories. It is also the only group I have been in which served and ate a full meal whilst in session. It did not impact on the data collection and when I remarked on it being unusual to the group I was met with mild surprise as it hadn't been legislated against and was standard hospitality for guests.

Irish Women's group

The third group consisted of six women of Irish heritage, they were a small group in numbers which in turn yielded a smaller focus group with a more flattened hierarchical structure. They were open, thoughtful and engaged, a distinct variation in this group was that their use of language was more psychologically literate and more bio-medically minded. I attributed this to the

fact that at least one member had received a formal diagnosis of mental ill health and another had been a nurse. They also were the only focus group to explicitly articulate the stigma that of diagnostic overshadowing (Shefer. et al. 2014) – where a diagnosis of mental ill health can be assumed to render you an unreliable witness to your own body in the eyes of some.

It was notable that no other group described their experiences with mental distress using psychiatric jargon. The other groups preferred vague non-medical phrases like 'bad nerves' despite the fact that I was aware that some individuals were on medications only dispensed for mental ill health indicating that they were formally recognised as psychiatrically unwell.

I found this group challenging despite their small numbers because I was shocked by the casual racism and stigma they encountered as part of their health provision and work lives. I expected to hear that women of colour might be disadvantaged and was more prepared but I was taken aback at the extent of unacceptably poor care offered to this often-unseen minority. I did not comment on this at the time but I was disturbed by it.

This group structured themselves as a discussion over pots of tea and cake. I felt we had reached a point of data saturation after around forty-five minutes and I attempted to close the session. However, I was informed that they had not finished but that they understood if I had to go. I initially wondered how to manage being exited from my own focus group, then realised it was our group and quite capable of generating data without my 'permission'.

We paused the discussion and discussed the issue - at the participants request I continued to record data for an hour and nineteen minutes - around the same time as the Somali group to ensure parity and then formally stopped recording because of the issues of getting a longer session transcribed. The group had suggested they continue to make their own notes to send to me in case anything important to them came up which seemed a sensible way forward. As it was no

further data was added, but it was a valuable reminder that as I researcher I can be instrumental rather than collaborative if I don't maintain my self-awareness. I was there to co-construct meaning out of hearing the stories from the group and what might be helpful in answering the research questions - not milk data out of people and make an autonomous decision about what I 'needed' from their accounts and what was not 'useful' to me.

YoGa+ Women's group

The last focus group was the YoGa+ group who were the most conventional in terms of research procedure. They kept scrupulously to time and met the set expectations in regards to numbers and ran their group more like a business meeting working through the questions more like agenda items. As previously noted they had a markedly higher level of social capital as demonstrated by their conversations about home ownership, gardens, holidays, workplaces, roles and previous exposure to research activity. The most telling difference of all was that the women in this group, despite sharing the same pool of GP's and health facilities because of their shared locality had a different perspective of the accessibility of those services and described a different experience of care. In addition, they were the group most surprised to hear about the experiences of the others and unaware of issues reported as common by their peers.

'Member checking' process / Quality assuring the focus groups

As Creswell and Miller (2000) state the trustworthiness of research data is important for a number of different audiences - the researcher, the participant and for future readers. I would also add that it is also key to the wellbeing of those the findings pertain to, as whist the research itself might not be of personal interest to that population – it is possible it could affect their care and their future experiences. With that in mind I took a number of strategies towards implementing quality assurance processes which support the validity of this research.

Firstly, the findings generated by all these groups were member checked and shared widely within the centre for comment during 'Open feedback' and 'Sense-making' events.

I used member checking initially because it was described as crucial to establishing credibility by Lincoln and Guba (1985), something I later found to be questionable and I was influenced here by hooks' (1989) work on 'choosing the margin as a space of radical openness'. I was aware of women's voices being marginalised and especially those of women of colour (Prodan‐Bhalla, and Browne, 2019); and that people experiencing health issues are sometimes seen as having less to offer (Williams et al. 2020). This in combination with the fact that research processes, even those which aim to be collaborative end, can be experienced as exclusive, made me determined to keep this project as permeable as possible. I attempted to keep ownership of the project shared and ensure that the people invested in sharing their stories to create the findings remained close to them as the data was collected, analysed and shared back.

One way that this was undertaken was by 'participative member checking' (Doyle, 2007) which is an intentionally proactive approach where participants are able to see the data to confirm its accuracy and feedback on the interpretation of the findings (Carlson, 2010). Regular opportunities for open feedback were offered to participants and women attending the centre at each key stage of the work. With the findings displayed on a notice board and post-it notes and pens kept beside it to enable comments. There was also information about the research and Its aims, invitations to comment and questions on the board asking things like 'is this the same or different to your experiences?' etc. I adapted this approach from Curtin & Fossey (2007), however whilst I noticed many women reading the information on the boards and talking to me and each other about the research - few formally commented using this method.

Anecdotally the responses I got when I asked about it were that the women 'didn't want to mess the display up' or that it was interesting and they agreed

but they hadn't anything to add. Whilst this approach helped keep participants informed, and some interesting feedback was collected this is an area that I would address differently if undertaking studies like this in the future. It was an excellent way to share information and to initiate informal conversations but less successful at garnering formal comment.

In terms of managing the accuracy of the transcripts I recorded on two devices and had a transcriber from the centre. I then checked the transcriptions against the recordings and referred back with the groups where clarification was needed or when languages other than English were used. I also shared back the transcripts and recordings to each of the groups to check that it represented their stories and viewpoints accurately.

During my M.Sc. I sent transcripts verbatim to participants who I realise now were unprepared and it impacted them negatively. They had been part of a study looking at involvement by auxiliary staff in health education and a recurrent theme was anxiety around appearing uneducated or being judged inarticulate by others. When this group were presented with a verbatim transcript including filler words, paralanguage and repeated phrases they reported feeling embarrassed and wanted to edit the transcripts – something my supervisor at the time was opposed to. I was very inexperienced in terms of research generally with no real understanding of participative research methods and I found myself trapped between the two expectations. It was one of the first occasions I felt conflicted between my own moral compass, professional expectations and the expectations of 'sound' research processes.

Even at the time I could see that if I had worked more coproductively and had explained the process and set expectations more openly - the situation would not have occurred. During my training and early professional life my main exposure was to the types of research which did not prioritise or address the relational side of the endeavour. Embarrassingly it had not occurred to me that member checking which seemed a basic but essential task, might only not

necessarily improve validity, but that it might even be hurtful or harmful. I used my Code of Conduct (NMC, 2018) to manage the contradiction rather than look at research practice at the time and prioritised the wellbeing of participants because it was an emotive experience and I initially reverted to old strategies. I used my skills of critical reflection to explore the issues and difficult emotions and owned the error. Like Hallett (2013) I didn't realise how common or complex an issue member checking could be was until I had the emotional distance to look for other researchers accounts after encountering it.

I place a high value on trustworthiness in all aspects of my professional life and think that in that circumstance I incorrectly used accuracy as a proxy for being truthful and trustworthy.   Candela (2019) notes the importance of positively managing the procedure of member checks and notes that trustworthiness in research is best demonstrated through mindfully and ethically handling data at all stages of the research process. Undertaking this research, I was more prepared and had a strategy which included the service user panel who helped me to understand the experience of research from the participant perspective. I also leaned more on person-centred research techniques and the practice of researchers whose approaches I found admirable.

I better understood the tension and balance to be found between Kohler Riessman's (1993) prioritisation of readability in transcripts and Tilley & Powick's (2002) advocacy a full transcription to ensure nothing is missed. I explained the research process with participants using written and visual aids and flagged up what to expect at each stage from the start of the project. I offered the full transcript, the audio and an 'easy read guide' to the focus group participants and gave them the choice of what suited them better. They went through the material without me and then I met with two representatives from each group to confirm accuracy and start the process of analysing the data. As Candela (2019) notes member checking is not merely a procedure to enhance validity and but can be an emotional experience, an opportunity for reflection (Koelsch, 2013) and a gateway to beginning data analysis.

Reflections on the use of visual body mapping

Whilst there was some diversion from the initial plans for running the focus groups they were successful in terms of gathering data. This section describes a collection tool that was less successful in this environment – Body Mapping. During the planning sessions the advisory group and I talked about making sure all members of the focus groups were able to participate whether they might be cautious to talk in front of others or whether they might be engaging in a second or even third language. We found a visual technique for collecting qualitative data in the shape of body mapping. Body-mapping has its roots in activist practices where it foregrounds disadvantaged perspectives and the embodied or sensory aspects of phenomena (de Jager et al, 2016). DeMello (2014) describes body mapping as especially useful when exploring concerns around embodied experience; in this case though an arts-based method proved to be tonally incongruent with the way of working that was established within the focus groups by the members.

It was not intended to generate its own distinct data but it was thought it might be useful as another way for people to feedback answers to the focus group questions and act as an ice breaker. At the start of each session different shaped outlines were put on the table with coloured pens and pencils for anyone who wanted to use them. There is excellent guidance for anyone wanting to use these as a primary data capture source in work from Coetzee et al (2019) and they are very helpful in generating qualitative data from participants about their subjective experiences of bodily experiences. They were not generally used by the participants of these groups though.

As the groups knew each other they did not need activities to bond them and whilst some speakers did not have any English they were aided by their fellow participants until a general agreement was established over the point that was being made. There was in the Somali and Asian groups a sense - although I cannot be sure, that the exercise was thought to be rather childish. In retrospect I added this activity without a good enough rationale and out of a generalised

anxiety about how the groups would go. If my concerns were around access or atmosphere I should have taken steps to address these issues directly. If I did choose to introduce body mapping with a firmer purpose, however informally, I should have done so with more explanation and in a more rigorous way. It is some comfort that whilst their presence did little that was positive, at least they did no apparent harm.

In fact, only one elderly lady used them after the session where she had enthusiastically participated, she had a younger woman with her who explained that she had a question about her hands. She showed me a body map untouched but for red zig zag lines around the knuckles of the hands. She wanted to know the right word for it, I looked at her hands and we established the issue was arthritis – I asked if she needed support and she said not. She got me to write it down and folded up the paper neatly and took it away satisfied to put in her purse. In that sense the body map worked well - it just was unnecessary in this project.

Activity 4. Survey

I first thought of using a survey in order to make participation more widely accessible for those not able to attend the focus groups or who might want to venture their thoughts more anonymously. I suggested it to the advisory group who approved it and helped shape the questions. Having an online survey also met with enthusiasm and approval by the four focus groups who were interested to hear what people outside their immediate groups thought of the research topic. The survey design was qualitative and used open ended questions based on findings from the literature review and the work done by the advisory team to develop the focus group questions. There were twelve questions based on those from the focus groups to allow for some comparison. It was primarily qualitative data and there was an opportunity for participants to give personal details if they wanted to.

This strategy offered an opportunity to triangulate a number of methods and sources of data to develop a more comprehensive overview (Patton, 1999 and Bans-Akutey et al, 2021). Triangulation can be used as a research strategy to increase the validity of research findings – particularly those with cross-specialty research areas like those found in nursing (Cowman, 1993). The study made use of 'Method Triangulation' which involves the use of multiple methods of data collection – in this case a survey and focus groups addressing the same phenomenon (Polit & Beck, 2012). It is thought that if information from different sources and perspectives converges it suggests that the data collected has more validity (Carter et al, 2014).

This idea comes partly from triangulation's origin in surveying and navigation, and that when applied to qualitative research suggests empirical measurement and positivist ideas of rigour. Arguably this confirmation is unnecessary if you are looking to create a different type of knowledge; and indeed, a common issue with this quality enhancement strategy is that researchers state that triangulation is being used but are not clear about how the findings of this activity are interpreted and incorporated (Varpio et al. 2017). In this study the focus group transcripts and the survey data were analysed separately and then brought together with participant representatives to explore how the two data sets are similar and different from each other and how that informs the study's conclusions.

I used an online survey to collect the data which through my university departmental account. The survey was open for two months, over the same period I was conducting the focus groups. It was an open access survey, disseminated through social media (Twitter) and 33 people completed it. It was not intended to produce a big pool of data but to allow interested parties from the women's centre who were not able to be part of the focus groups (which I had intended to be capped at 8 participants!) a chance to have their views recorded. It had the added benefit of exposing the ideas and concepts generated in the advisory and focus groups to wider scrutiny and engagement.

I had not anticipated much detail from the survey data as previously stated it was an option to increase participation for would-be participants unable to access the focus groups due to illness, childcare issues etc. Braun et al (2020) note that qualitative surveys are a misunderstood collection strategy and many researchers hold mistaken assumptions about survey data of this kind lacking depth. Qualitative surveys, like the ubiquitous interview or focus groups can also yield complex accounts of respondents' subjective experiences, and beliefs (Braun & Clarke, 2013).

There are some concerns around using online methods and social media as there is an expectation of digital literacy which may exclude some women who may have otherwise met the inclusion criteria – in this case of having lived experience of multiple need (Hafford-Letchfield et al 2017). This is balanced by the fact the very local and personal nature of the focus group data can be explored alongside information that is geographically varied and from individuals with diverse backgrounds.

Activity 5. Data Analysis (focus group and survey data)
Thematic analysis is a way of exploring the meanings that can be found within a set of qualitative data, such as focus groups or interview transcripts. The researcher engages thoroughly with the data to identify common ideas and patterns of meaning that reoccur. Out of that they create themes and use those themes to better understand the information that the research has yielded. There is no one preferred method of analysis and different approaches are more suited to certain types of data (Burnard, 1981). The resulting data from this study was originally to be analysed using Interpretative Phenomenological Analysis (IPA) which was selected because it has a provenance within nursing research. Indeed, Pringle et al, (2011) describes its utility in providing a greater understanding of experiences in healthcare and illness in order to improve service provision.

Unexpectedly, the participants roundly rejected this approach when we began to try and work with it finding it to obscure rather than reveal the meaning that they had expressed. I felt that I should have been able to explain the purpose of thematic analysis in a way that made it seem desirable. To the participants, like some other aspects of the research process analysis evidently felt like an unnecessary step and it was clear that a more accessible approach was needed – something that would enable the participants to maintain control over the meaning ascribe to the data they generated – something that would be meaningful to them.

In retrospect this event was if not inevitable, at least very likely to occur. I had worked for so long around research and did not question its' inherent expectations and procedures and the participants wanted to take a practical approach to collecting and presenting the data and were not aware of research methodology in any detail. We were keen to work together and coproduce this project but whilst we shared an end vision and endless goodwill towards each other and achieving our goal, we had little shared understanding and agreement about how to get there. In order to keep the project coproduced we needed to keep in dialogue and to compromise.

Initially, I was taken aback by this research moment but tried to keep in mind Willig's (2008) description of qualitative research is an adventure and Braun and Clarke (2017) stating that for research to be feminist it must be creative and innovative by its very nature. Things were not proceeding to plan again but I knew the kind of work I wanted to engaged in and I was influenced in this by Oakley's (1981) paper which takes a different approach to the relationship between researcher and participant, one based on empathy and respect between women

Fortunately, Pringle et al, (2011) also describes the importance of the nurse researcher establishing shared meaning. Larkin (2008) notes the fundamental requirement of phenomenology and feminist research to not only hear the

experience of participants; but the importance of being able to contextualize and 'make sense' of these claims and concerns from a psychological perspective. So, I went back to the literature and found an option which whilst allowing 'sense-making' of the data did not reimagine its meaning or reshape it in a way that made it unrecognisable to the participants who created and shared it. It was important to me that the stories that were being explored were acknowledged to belong to the people who shared them and that any learning created by engagement with their lived experience was respected.

Eventually I found Braun & Clarke's (2006) work on thematic analysing in qualitative research. It was a method developed out of those described in the literature of grounded theory (Glaser & Strauss 1967; Strauss 1986). I wanted to use something that was accessible and clear and from a pragmatic standpoint we needed to maintain project momentum. I was familiar with their work from nursing literature and the practical staged approach to analysis reassured me as much as it did the participants. We followed a six-step process (Familiarization, Coding, Generating themes, Reviewing themes, Defining and naming themes and Writing up) and because of the shared way of working, dialogue and course correction occurred throughout:

Flowchart for the Analysis Process

| Representatives from the focus groups confirmed for accuracy via member check and shared initial group thoughts on the data from the focus groups | Researcher shared to the focus group representatives initial thoughts on the data from the survey and literature review |

← **Iterative discussions** →

Preliminary analytic framework developed by the researcher drawing on data and discussion from the focus group, the survey and literature review

Iterative discussions

Adapted analytical framework used to code the separate qualitative data sets

Iterative discussions

Qualitative data sets explored in dialogue with each other.

Iterative discussions

Cycles of writing and discussion to produce final analytical narrative, research findings, and make recommendations

Iterative discussions

- Stakeholder feedback was elicited throughout process via conversations and an interactive display of the research progress and emerging themes to participants and the expert reference panel with opportunities for comment and question.
- Feedback was also elicited more generally by presenting this work for comment via publications and at Conferences

Familiarisation

I kept a reflective diary, noting moments of learning and uncertainty and used it to support the discussion section of this work. I had made notes in it after each focus group and on my first reading of the survey data so I re-read everything and then I began the process of data analysis by sharing the transcripts with the groups. I also sent the plan for analysis so they could work alongside me if they wanted to - the information was also available on the noticeboard in the

centre along with research updates. It was important to me to maintain transparent working processes throughout as I have been involved in research where the results were surprising to the participants at the end and that experience suggested to me an issue somewhere in that knowledge production process. Mauthner and Doucet (2003) are clear that the methods you use carry epistemological and ontological assumptions, nothing done in a research process is 'neutral' so it is key to be open about values and assumptions underpin those choices

Coding

I immersed myself in the data, listening to the transcripts repeatedly as I went about my day listening first for content, then for structure and connections. I noted the themes and issues that I identified as carrying meaning, then updated the groups and began coding. I worked my way through all the focus groups and then the survey data. As I went I tagged any features of the data sets that I thought provided useful or interesting information that could shed light on the research questions with a coding label. I was aware that my own positionality would shape these choices and I tried to be reflexive in my approach and shared my work back with the women at the centre.

Working with the themes

I generated themes by seeing where codes were linked by concepts or experiences. I described each theme, I gave them interim names (only to aid ease of discussion) and reviewed them firstly with women at the centre through a small group process of two representatives from each group and talked about them with my supervisor. The work was taken back to each focus group by their representatives and they let me know the wider group feedback. After this some themes were considered to be aspects of the same thing and merged others were separated out to recognise nuance.

Writing up

I wrote up a final draft of the agreed themes, my first draft of notes for the findings chapter and an update for the message board and through these iterative and discursive processes the themes were created and finalised. The themes did not 'emerge', they were the result of our joint thoughts, experiences and choices (Orr and Bennett (2009). As Bevir and Rhodes (2003, p. 23) note "we have experiences only within a prior discourse" we constantly form our research in our own image and knowledge cannot help but be linked to society and to forms of power (Hardy and Clegg, 1997).

Final reflections

Many research papers talk about the importance of reviewing with sceptical peers to provide the analysis with a respectable cloak of reliability and I was keen to avoid researcher bias. Indeed, I began with an expectation that this was the key purpose of this stage and without doubt, the rich dialogue and contrasting perspectives have improved this section of the work. That said, I increasingly feel it is not for participants to have to prove to external commentators the truth of their perspectives. Whilst I want this work to be of the best quality, I am doubtful that these attempts to 'prove' the worth of this joyful and contentious experience can actually make this categorising method any more or less valid that it is.

I have endeavored throughout the pressures of designing and delivering a working methodology to maintain transparency. This availability of research activity to outside scrutiny is part of quality assurance but an equally important part of working coproductively is ensuring that the process of knowledge generation is clear to those within the project. I have worked to clarify the aims, objectives and all the steps of taken accurately. The approaches and methods used have had to be changed – at short notice on occasion, because they must be appropriate to the task in hand, and managed ethically and with due care to all participants.

I have attempted to share information relevant to the study in accessible ways. I was guided by Pawson et al's (2003) caution that no one must be excluded by verbose or overly technical presentation of research information. I have provided a rationale for decisions although this has been a challenge at times because of the numbers of people involved, differences in written and spoken English language confidence and very varied levels of interest. Where decisions have been taken I have clarified who instigated change and why and when there have been differences of opinion I have articulated their resolution. The guidance principle though out this work is a wish to work coproductively and we have all tried to keep within the conceptual framing informing these choices.

In this chapter I have described the research activities that generated the data for the project and in the next chapter I present the findings from these workstreams with discussion and interpretation.

Chapter 5 Project findings

In chapter four, I described the workstreams of research activity that generated the data and how they were applied in practice. In this chapter I present the findings and have structured this information by giving a brief overview of the themes and then focussing on the key areas in more detail.

An overview of the themes
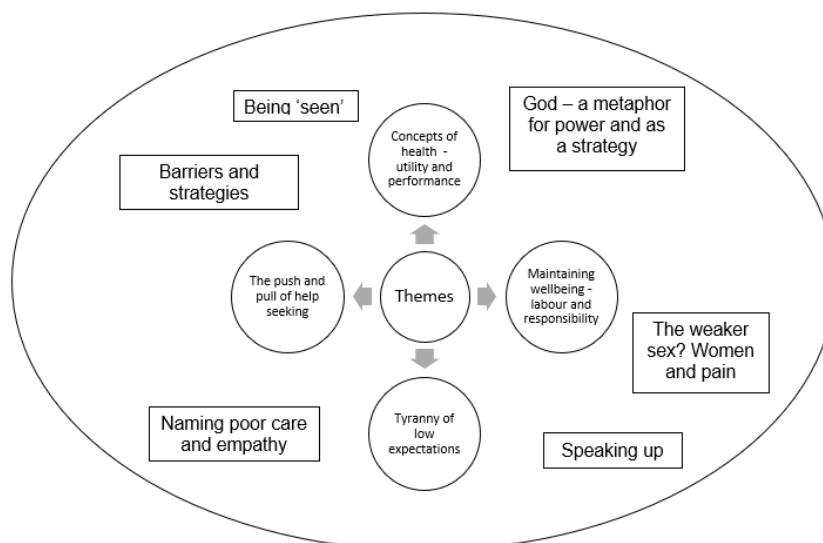
Theme - Concepts of Health:

The first theme to be identified was around the different ways that good health was conceptualised there was some consensus between the groups around health as utility and performance of women's work.

> *(Participant, Asian Women's Group) Everything in balance - If you can cope with every day's chores then that is also healthy so I think – then you can be mentally as well as physically fit - because you can be physically but if you're mentally upset you're not going to function well so for me it's the combination of the two*

(Participant, Somali Women's Group) - When I am moving, when there's nothing wrong with me. My body is carrying me to do my activities, my tasks, I feel that I'm healthy but if there is for example I cannot do my day to day tasks and that time I know there is something wrong with me and that time I need help from my GP or something

The Somali Women's Group were the first to speak about the emotional impact of feeling impact of physically ill and the vulnerability and self-doubt it can engender.

(Participant, Somali Women's Group) - Sometime you don't have energy, so you can't do things … Yeah lack of energy

(Participant, Somali Women's Group)- For me when I want to do something and I cannot I'm scared and worried, that's when I know I'm not the person I used to be so that makes me very worried

The Irish Women's linked independence, happiness and health together and they added in a conceptualisation of health with an allowance for age related deterioration:

(Participant, Irish Women's Group) - "Being physically and mentally mobile. Even if mobility is slow, being able to do things for yourself, things that you could do when you were younger, still being able to do them now for yourself."

(Participant, Irish Women's Group) - "Being able to do things for yourself makes you feel happy and gives you a little boost of confidence to make you feel that you can actually overcome those bumps along the way."

They were explicit about the value they placed on their wellbeing:

(Participant, Irish Women's Group) - My health is more valuable to me than materialistic things and money".

The Yoga & Gardening Group were the only focus group to equate weight with health and happiness, although physical appearance was considered as part of

health by the Survey the other group of participants who were mainly while, western women.

> (Participant, Yoga & Gardening Group) - "I felt I was really big. I was much bigger. I was eating the right foods, but just too much of it."

> (Participant, Yoga & Gardening Group) - "Being good about eating the right things and being happy

The Survey Respondents also described being in good health as a form of autonomy – with freedom of movement and freedom of pain – this is similar to the ideas of health as bodily utility but it is distinct in that it is an end in itself, it is not goal orientated as previous statements – particularly not towards housework:

> *Survey Respondent - Being able to live my life in the way that I choose without restriction.*

> *(Survey Respondent). - Able to move freely and without pain or breathlessness and with the energy to do so.*

The women from the survey took a holistic approach to describing good health:

> *(Survey Respondent). having the energy and motivation and physical wellbeing to actively participate in life, maintain my own lifestyle (i.e. cook and clean for myself), leave the house, enjoy activities/hobbies, spend time outside, participate in social relationships with friends/family/lovers*

> *(Survey Respondent). - having a 'fit healthy positive mind that also helps the body to heal'*

They were more likely to site their concept of health within bodily and social/cultural contexts particularly in regards to a lack trauma-informed understanding.

> *(Survey Respondent). - women's health 'may include some different needs specific to our reproductive biology and also our experiences of feeling pressure to look beautiful/shame for not doing so and our experiences of feeling unsafe around men due to experience of sexual*

harassment, abuse and rape. I feel this aspect of my health is not considered at all when accessing physical health services'.

When the survey group spoke about health in terms of bodily utility they did not explicitly relate it to women's work, but a lack of pain was a common thread. They also linked health to stereotypical ideas of beauty linking happiness and enjoyment.

(Survey Respondent) - Feeling able to go about your day without being impeded by pain, fatigue, discomfort, unhelpful thoughts or behaviours. Looking good means: glowing skin, shiny full hair, having the body/physique/weight you want to have, standing taller, smiling, happy.

They also expressed how they visualised a woman in good health – to my mind, in terms that sounds like a model from a skincare advert:

(Survey Respondent) - Awake not sluggish, good skin complexion, bright eyed, good hair condition

(Survey Respondent) - She's confident, she's independent, she looks well in herself (healthy complexion etc.

The focus groups had within them women who had mobility and pain issues, mental health diagnoses and who took medication regularly and some who used wheelchairs and other mobility aids but only the survey group was explicit about the ongoing impacts of physical and mental distress, perhaps because the survey allowed more privacy to be open:

(Survey Respondent) - Having a meaningful life that is led by my goals, values and aspirations. A healthy woman, would be able to move independently and not be in chronic pain due to moving (I'm a wheelchair user or crutches for shorter distances).

(Survey Respondent) - I wish it could mean that I would have not had to have psychiatric medication and treatment for the last 40 years since the birth of my son

(Survey Respondent) - I have cerebral palsy and recurrent depression. I think the recurrent depression has been misdiagnosed at times … I feel my depression has been caused by cerebral palsy and this has not been recognised previously. Stiffness and muscle spasms can affect my mental health as I get frustrated by the limitations it places on me as up to 6 months ago I was very active.

Women from the survey gave very full and detailed responses, they showed an advanced level if understanding how their health issues intersected and were open about the ongoing ways wish having multiple health issues impacted their lives.

(Survey Respondent). - I have ME/CFS and while it is a biomedical illness it affects my mood hugely when I am in pain or very fatigued. I also have food intolerances that can cause my mood to dip … I also have complex PTSD and it can trigger my fatigue because it is so draining to live with. I am also more likely to have trauma symptoms when my ME is bad. I'm seeing how linked they are physically and mentally and trying to balance them is exhausting.

(Survey Respondent). - I have medication that has side effects so they counteract with the symptoms of my mental health chronic conditions when I'm ill physically it can have an impact on my mood vice versa if I have steroids for my asthma that makes my mental health worse I have chronic pain and UTI infections which can affect my mental health also can affect my physical health with pain … it's hard to sleep than also can affect my stomach condition vocal cord condition and my enlarge thyroid so I don't have a peaceful sleep so I'm tired some days.

(Survey Respondent). - I have Ehlers Danlos which means if I don't do much I decondition really quickly and my physical health gets worse. This is such a vicious cycle and I feel constantly trapped by this. It takes only a week of lying down depressed to make my EDS a lot worse. And then when I try to do stuff that's good for my mental health my fatigue and pain stop me from being able to do them. I was working full time until 2014 and then this cycle has prevented me from recovering enough to work at all since then.

Of particular note were women talking about poorly-managed heart conditions. I will expand on this in the Discussion Chapter but for clarity - health issues for women are often articulated around breast cancer and diseases that have popular awareness campaigns targeting women, what actually ends the lives of many women is heart disease. The cardiovascular risks of ill health and death are higher in women and treatment is less accessible and effective (Möller-Leimkühler, 2022). So, hearing of casual responses to cardiac issues in women is concerning:

> *(Survey Respondent) - If my anorexia worsens I get cardiac arrhythmias.*

> *(Survey Respondent) - I came off an antidepressant abruptly and suffered cardiac disturbances which were treated inappropriately with a pacemaker which has ended up being permanent. This has had a significant MH impact as the withdrawal symptoms which manifested as mental illness relapse were treated with further MH drugs causing further withdrawal problems later on.*

Again, the focus groups had within them women at all stages of the life course, some who were nursing mothers, others who were menopausal but again the survey was the only place where the impacts on one's health of having a women's body were distinctly expressed.

> *(Survey Respondent) - But, I am a breastfeeding woman with two young children and this means that my own health and wellbeing is harder to achieve. The experience of pregnancy, breastfeeding, maternity leave and child raising can make health and wellbeing significantly different for men and women*

> *(Survey Respondent) - Some physical health issues like HRT needs do lead to mood swings and imbalances. I'll be trying to sort those with my Gynae team. It's all a bit trial and error.*

> *(Participant, Yoga & Gardening Group) - So much of women's health is about the monthly cycle and the longer cycle, going to the menopause, having children. We have all those other complications which affect our moods, affect our bodies so fiercely.*

Theme - Maintaining wellbeing

Labour and responsibility: Considerable discussion took place around the work that goes into maintaining health, from overall responsibility for preventing ill health, to managing health interactions for themselves and others and shouldering the bulk of caring duties. It was clear that for most women – no matter what their background, responsibility for wellbeing fell on their shoulders. When they are part of families they often prompt and manage the wellbeing of others, particularly children and parents. When living as solo women, whilst they were motivated and managing their own health well, they had little in the way of support and were often more concerned about inadvertently burdening others. This is a picture that is supported in other research I have been involved in (Reilly et al 2020, Lambert et al, 2018).

> *(Participant, Asian Women's Group) - Well I look after me because I left my husband and literally I have to look after myself because I don't want to be burden to my kids. Because I decided I don't want to be begging for attention from anybody so I mentally make a note every day to say: no, you can do it and stop fussing and get on with it. Even though I think sometimes that deep down I am so lonely that I need someone to talk to or shower me a bit of extra care but then I think...is that what you're asking? Is it fair? Because I'm a mum and I think mum's terms because I have two daughters and I ask myself what do I want from them? At times I have a little cry.*

> *(Participant, Asian Women's Group) - Nobody look after us [Laughter] Nobody there to look after us we are alone…so we have to*

> *(Participant, Somali Women's Group) - No one I look after myself*

> *(Participant, Somali Women's Group) - I mean to be honest with you for me I'm not that type of human who is seeking help, it's not that I'm so strong, no, but I think that none can fulfil my needs and I don't want to be a burden on other so that's why wherever my needs is I'll keep it to myself, it's a bad thing but I think that if I share with it others, people will show*

> *support and everything but even showing it's quite difficult for me personally*

The women who were surveyed said they looked after themselves, some described asking partners for their opinion when it came to the wellbeing of shared children or if they felt their own judgement might be compromised by ill health. The survey group were also the only groups to say that they checked their symptoms on the internet (although none of them thought this was a particularly reliable source of help). This is perhaps less surprising as they were all recruited through social media so technological literacy would be congruent with that.

> *(Survey Respondent). - I make my own decisions about my health. Sometimes I seek advice from friends and family. And the internet (but that's bad because usually the internet tells you that something is seriously wrong)!*

> *(Survey Respondent). - My partner and mum informally look out for my wellbeing as I have had issues with bpd in the past leasing me to self-harming and self-destructive behaviours*

The survey respondents   were much readier to talk about the types of support they received from the professional health sector and described a range of experiences from positive and co-produced plans to support wellbeing through to encounters that were managerial and hierarchal.

> *(Survey Respondent). - when you have a "rare" physical health illness (I have to travel 2+ hours to see Consultant) and mental health illness, fortnightly or monthly GP visits in my case I have ended up feeling very "medicalised" and if I'm honest I resent this.*

> *(Survey Respondent). - I have a consultant psychiatrist who I am now to see every six months. A CPN who I see am responsible for my health, although sometimes a friend will intervene and talk to my GP if they feel I am unwell and either don't have the insight or ability to ask for help.*

> *(Survey Respondent). - I am the key holder to my own health but I reach out to GP's and mental health support when required.*

(Survey Respondent). - I live alone and decisions on my day to day health are made by me and longer term in what I can negotiate with my GP and NHS. I often have no say in my physical health which is poor and remains untreated on the NHS. My mental health is supported by my paid private therapist which is reassuring and collaborative.

One woman from the Somali Women's Group   shared a distressing experience that encapsulates many of the challenge's women face in managing their everyday health needs - it touches on many of the previous themes and in this case has been amplified by cultural expectations around 'modesty' and self-sufficiency.

(Participant, Somali Women's Group) - I got pregnant and I got… bleeding, they told me that the baby is out we need to do cpu [note: she may mean an ERPC here – which is a surgical evacuation of the retained products of conception] *and at that time my husband was there and my kids were there but I never told anyone. I went to my GP they transferred me to a day clinic they sedate me, they cleaned me and everything, I left my car I took a cab I went there they did all the procedures, I came back out and I was in bed for 2 days doing everything and I never told anyone. It's not that I just want to hide, it's like if I told them what would they do for me? I did tell my son who was 10, that I'm going for a procedure, I told him where the money is and everything because I might not come back and I went to the procedure.*
To this day I don't know why I did that. For me sometimes I don't bother to tell or to show someone or to ask the reason behind this is I don't feel anyone would for me how I want. And also, I'm not feeling comfortable. All my life, as far as I can remember, I have been by myself. I don't ask, whatever situation I am I try to be by myself. Maybe it's inherited from our mothers because they used to keep the pain and the everything to themselves…

It stood out to me that the participant describes herself as being 'by herself' when there is at least one other adult present. This led to other women in the group offering sympathy and trying to make sense of their cultural drivers around self-reliance even in extremis.

(Participant, Somali Women's Group) - *I had caesarean with one of my kids, but I remember the morning after I took a shower and I didn't need anyone, and they were shocked they asked excuse me how did you come off the bed? Who helped you? Nobody. Are you okay? You …mentally fit? I say yes, I am fine. Maybe it could be culture… I don't know what it is.*

Participants talked to general agreement about the role modelling around health and self-sufficiency they had received from their own mothers. They noted how that impacts the relationships they have gone on to have with their own daughters, who as second-generation Somali-Londoners see the world very differently.

(Participant, Somali Women's Group) - *It's the things that they've put into our mind, like they make us think so what its nothing, get up and do something. I mean on of my daughters if she has a headache she needs someone to carry her and I am concerned how will she go through life and I really wanted to be there for her because she's just a poor child but for me the way that I've been bought up by a gigantic human being and mum who was so strong maybe I have adapted that from her. I think its culture.*

(Participant, Somali Women's Group) - *This is how I raise my child, especially my daughter, this morning she was saying she's pain and I said that's nothing go and dress up and prepare for school. She say, why you not make me appointment with the doctor, I said for what, what is he going to do? This is the life, you just have to get on with it.*

This sense of fatalism and inevitability concerning pain and discomfort as the lot of women is a recurrent theme as is the idea of God as comforter and as health strategy.

(Participant, Somali Women's Group) - *Allah is looking after us*
(Participant, Somali Women's Group) - *Only mighty God looks after us*

The importance of faith was also echoed in the Irish group, who clearly also valued each other's practical companionship and support:

(Participant, Irish Women's Group) - With my faith, God helps me. I have a very strong faith, also my friends.

(Participant, Irish Women's Group) - That's why I am glad to be in this group, because people listen to me and that gives me confidence to express myself a bit more. …. We care!

It was noticeable that other than as part of initial assessments, religion isn't part of many health interventions but all of the focus groups spoke about their faith or God directly as part of their understanding of health both as a metaphor for power and as a strategy for coping:

(Participant, Asian Women's Group) - The hardest part I think is after you live with family… with your spouse…and suddenly you're faced with old age and having to look after yourself. Praying that nothing happens.

.

(Participant, Irish Women's Group) - With my faith, God helps me. I have a very strong faith, also my friends.

Even with the groups that were more secular in outlook there were echoes of Victorian-type beliefs about health, religion and morality.

(Participant, Yoga & Gardening Group) - *"I think cleanliness is next to godliness. If you are very clean and your house is tidy then it is good for your health. If you are dirty that creates ill health and depression*."

Another coping mechanism that was particularly notable in the survey group was that of managing distress through food: and diet, which bought with its secondary issues.

(Survey Respondent). - Yes - when I'm down I over eat, drink and then feel more down for over indulging

(Survey Respondent). - . Medication makes me fat & makes me tired which makes me unfit and depressed.

(Survey Respondent). - I have osteoarthritis and also experience depression and anxiety. When I am struggling with depression I am more

likely to stay indoors and I comfort eat. I've had a really difficult time with depression over the last 12 months and have gained two stone in weight.

Theme - Managing ill health

In addition to finding ways to cope with ill health, women also deployed a broad range of strategies to promote their own health and many relied on non—medical and traditional approaches to secure their wellbeing.

(Survey Respondent). - I use hiking to manage my mental health issues, but currently have issues with foot pain - but it's going to take months to get that looked at.

(Survey Respondent). - … time for exercise, getting out in sunshine, eating well, sleeping well. . . Anxiety reduction, feeling stronger. . . Virtuous circle

(Participant, Somali Women's Group) - *… if it is a simple problem like cold, fever or this …paracetamol, honey, water, garlic… that we will not even think to go to the GP for.*

Across the groups it was clear that the role of carer was seen as women's work - hard work and because of the emotional toughness and practicality needed just to cope, in some way, the challenge was status giving:

(Participant, Irish Women's Group) - That's a part of women's health isn't it. Having children and taking care of other people. We've all done that haven't we, taking care of other people."

(Participant, Irish Women's Group) - I take care of my 3 on my own and one of them has Asperger's. He is 20 now. … I got cancer, so I had three children, one with Asperger's and my mother was dying, so I was caring for her too. I was just wrecked. So yeah. I thought I was going to have a nervous breakdown and I often still feel on the verge of one, but I'm still putting it off.

(Participant, Irish Women's Group) - When my mother was ill, I actually said I don't want anybody coming in doing another assessment, because I had so little time and these people would come in to do an assessment

and tick so many boxes and then they went and then there was no help. I realised after a while that I wasn't going to get any help from any place."

Relationships with mothers ran through all the discussions that addressed this sense of responsibility:

(Participant, Yoga & Gardening Group) - Nobody asks me if I need to go to the doctor - With my mum dead, it's all on me."

*(Participant, Yoga & Gardening Group) - That links with what ***** is saying, maybe we've become more involved because we are the ones generally speaking, of course it's not 100% of the time, if the children need feeding, it's the women who are managing the budget who are buying the food, who are preparing the food, who are making the choices about what food they can afford which isn't always going to be fresh organic fruit and vegetables. So, we take care of our own health but we also take care of the children if we have children.*

Theme - The weaker sex? Women and pain:

There was also a lively debate on gender differences and how they impact peoples understanding of health and responsibility for the health of others. One woman from the Asian Women's Group speaking through her friends felt that men might have strong bodies but that women had strong minds which enabled them to take a lead in managing health, this was echoed in health beliefs across the groups:

(Participant, Asian Women's Group) - I got a strong will – strength [Flexes arm - outbreak of group discussion] … She thinks a woman is born much stronger than men

(Participant, Asian Women's Group) - Ladies deal with the crisis or difficulties or with the children or with the family life…they manage better than men…they've got patience, that's what I think

(Participant, Somali Women's Group) - We are a lot stronger than them, I mean, in a way like taking pain I feel that women are stronger in these aspects. More capable- our threshold of pain is

more than theirs. I mean I can see that with my partner, if he has a slight headache he would lay down on the bed for days and maybe if I have the same thing I'll still do what I have to do - I'm buzzing like a bee

(Participant, Somali Women's Group)   - Last night my husband had some pain and the way he was screaming…it's like he was going to die I was like excuse me I have 24/7 pain, honestly, on top of knee there's a crack on my bone and I have to use chronic pain killers which I don't do because my tongue swells and tonsils swell and my mood changes so I stay away. I live with the pain, now even when I'm talking to you I feel sharp pain. A little pain he's crying … I say excuse me I live with this and I never complain, so please….

The Irish Women's Group built on this suggesting that society shapes and rewards women for being the guardians of family health and that they benefit from being socially sanctioned to have emotionally open, discursive support networks.

(Participant, Irish Women's Group) - "I think men tend to go a lot less for these check-ups and things. They tend to put it off until something really serious happens, or pain or something, whereas women tend to go for mammograms and cervical smears etc.".

(Participant, Irish Women's Group) - "I think men tend to neglect their health. Whereas women are a lot more social and more prepared to talk about things, sort of generally with any sort of health problem, we will actually talk with our friends about the problem as well as different things."

The scope of the Yoga & Gardening Group's discussion quickly moved outside of family and friends' networks and started to explore the effects of gender on wider society and the wider health needs of women. They noted a broad range of issues from the ways that childcare is assigned, the gender pay gap, epistemological injustices, diagnostic overshadowing, to medicalisation of women's fertility.

(Participant, Yoga & Gardening Group) - I don't know if it's that there are different ways of being healthy, but that those things really impact the state of mind and also, it's different because men have privilege in society so there's this whole other realm of things we have to deal with that affect our wellbeing. Domestic abuse, single parenthood. If a family breaks apart, the overwhelming majority of the time it's the women who takes care of the children. All those things have a huge impact I think mentally and physically. Also, we still don't get paid as much for doing the same amount of work. So, I think there's huge difference. I don't even know about access to health, you know, that example that you gave, would that have been the same if it was a man who went in and said he had a twisted ankle. We are kind of stigmatised as being whatever… mental health issues maybe."

(Participant, Yoga & Gardening Group) - "I don't think men are as consciously aware of or take as much interest in their health as women do. Whereas, women are also concerned about other people. I think men just focus on getting on and I don't think they go to the doctor as often as they should. They don't go and have check-ups. They just think everything is fine. They don't address the fact that they may or may not need attention. That was the impression I got. They just go on and think it's all fine

Theme - The push and pull of help seeking:

Another area of debate across the groups were the triggers and barriers seeking help as women with multiple health needs. The NHS has been attempting to pivot to a health promoting model of care, rather than waiting for people to come for help when their treatment options have become limited and prognosis worse. This ambition has been stymied by the waiting lists being exacerbated by Covid and the ongoing staff shortages. Certainly, in the groups whilst people took care to stay well. attending the GP in particular seemed to only occur when things had become desperate.

(Participant, Asian Women's Group) - I think most women just go when they just can't bear it, you know it is the last resort they go to the GP …

(Participant, Asian Women's Group) - Some GPs are very intimidating … Some GPs are like I'm here what do you want and you just go and you think do I say or not they might think I'm a nuisance. Because of this I have to be dying of pain before I go to the GP

(Participant, Yoga & Gardening Group) - you've got this culture of don't go to A&E now unless you're practically dying.

Theme - Barriers and strategies

Building on the concerns voiced above many women spoke about challenges for them in getting good quality care. These issues begin with the complications of trying to get through on the phone to book an appointment but the whilst the participants were often inconvenienced attempting to gain access to services they proved tenacious and resourceful.

(Participant, Asian Women's Group) - Getting an appointment is difficult you know, we can't get appointment by phone. If we phone we have to phone like 8 o'clock in the morning even then they say oh we are full up, then we go stand outside the door half past 7 in the morning and they open the door 8 o'clock and we go inside and then we can get the appointment. Getting appointment is very difficult

(Participant, Asian Women's Group)- Even when you want to make appointment over the phone you have to hold phone for 10…15 minutes some of the GPs are so busy you know and for pensioners it's very difficult you know…it is you know… because we are using our money from limited income… its going after the telephone you know… so that's the main problem when GPs are very, very busy or receptionist it takes 10 to 15 minutes

(Participant, Somali Women's Group) - You have to go there and make the appointment, because on the phone is hard and they finish the appointments. But by the time you reach they say appointment is full

One situation that raised particular concern was that of a lady from the Participant, Asian Women's Group who was elderly, disabled and had limited English. The group helped her to tell her story:

(Participant, Asian Women's Group) *- she's had 5-6 operation on her hip and leg. She is disabled. She's had an awful time because she's had to call doctor again and again and again and sometimes they would just ignore her. She calls A&E calls an ambulance goes to the A&E sometimes they will see her and treat her and sometimes they will just send her back, last Saturday she was in such a pain that she went out in her wheelchair and there were some boys playing in the street and she asked them to call the ambulance they called the ambulance and the ambulance staff took… looked at her, looked at her sugar level and all that and told her she's not serious enough so they won't take her to the hospital.*

She was not the only woman who had difficulties understanding how to navigate access and understand staff instructions. It is no surprise when people who are worried and want to speak to a health professional try and find other ways into the system and may attend already overstretched emergency departments.

(Participant, Somali Women's Group) *- They say make a proper appointment, not an emergency, make it a proper doctor appointment …make a double appointment and you cannot find it.*

(Participant, Somali Women's Group) *- GP would be the last thing to go to, because it will be hard from the beginning to get access to. I cannot get up 6 o'clock to be in line by 8 and I don't know by 6 o'clock how much queue will be in front of me. I'd rather go to the A&E, after hours, especially after-hours call is much easier and it is GP services. It's an emergency I will go after hour's services.*

The Irish Women's Group, who had experience of all sides of the health world, as patients, carers and sometimes staff, were clear about the informal rationing of services by overwhelmed staff and articulated the importance of knowing what you are entitled to, standing your ground and being an effective self-advocate*.*

(Participant, Irish Women's Group)*: I know about people being discharged from hospitals. I know somebody who was discharged from hospital where his toilet is upstairs and he's on a Zimmer frame. They said I'm sure you will be alright. His toilet is upstairs and he can't get up the*

stairs." If the question you're asking is "is your toilet on the ground floor"? That's very different from "can you manage". Because being asked if you can manage is going to make you feel guilty isn't it. … Because there's a tendency for people to say oh, I'll be okay. Because they don't want to be a burden and create work for other people

The Irish Women's Group were the most explicit about the way that not just gender but class, culture and nationality intersect to make access to services more challenging for certain groups.

(Participant, Irish Women's Group) - *If you can speak - class plays a part and being sent off to write out forms in the hope they won't come back*

(Participant, Irish Women's Group) *"Unfortunately, I've seen this happen. I'm not just playing the victim, it's happened to me repeatedly and other Irish friends in the mental health service. I've felt that good nature was being exploited. I've felt that people from the Irish community who had mental health issues, either in the hospital or in the community, like myself are being taken advantage of. good nature being exploited."*

(Participant, Irish Women's Group) - *I'll just ignore all the physical stuff and I needed to feel as though I had to get feedback from other people to kind of remind me that actually, there's a problem here and I didn't know what it was. Then I would feel that sort of emotional thing about not wanting to bother anybody. It's like I needed an English friend to remind me that I need to go to the GP and then it's alright and you just do it. There's something about being an Irish female, you feel as though you don't deserve things and you shouldn't ask and you just go on and don't complain."*

(Participant, Irish Women's Group) - *"We are one of the communities. Is it, Irish women and Caribbean women who are way down in the system as regards to going for medical appointments and we always wait until the last minute and that's not just about mental health problems, it's actually about all problems. As a general rule we are way down the other end of the scale which is quite interesting."*

(Participant, Irish Women's Group) - *"There's a lot of people who can't speak very well about their condition and I've often noticed that 'these kind of people' seem to get shoved off very quickly, even from reception who*

send them off to fill in the forms somewhere else. It's like go away and don't come back is kind of the message you get."

 (Participant, Irish Women's Group) - *"I've known a few Irish people who have likened it to black racial abuse."*

 (Participant, Irish Women's Group) - *"Just in respect of the Irish health, there was a report done in 2006 and I've just remembered that the Irish were the only immigrant group who came here whose health did not improve, it got worse after they came here"*

There were other women on the survey who had also experienced stigma relating to multiple aspects of their identities or and were disadvantaged as a result. It had happened to some because of classism, some because of prejudice towards mental ill health, and others because of racism. It should be noted here that discriminating against anyone because of protected characteristics (including race, disability and gender) is illegal (Equality Act, 2010).

 (Survey Respondent). - I think I am quite passive (which I put down to my working-class upbringing! My middle-class friends are often excellent at fighting for the services and care they feel they deserve.

 (Survey Respondent). - They do not listen to me about my symptoms of my physical [health] they are just going on about my mental health their attitude towards me is biased

 (Participant, Somali Women's Group) *- I think the assumption that we have as a community, seeing you like this they will say first of all she doesn't speak English, she doesn't know what she's talking about, I don't think she will complain, we don't know nothing so no one- because I believe if I complain and the rest complain people will look at you, you have to make noise for them to look at you. That's the problem that we have, for how long we have to make noise why? if there is services that other people are getting it why not me. Why you have this stereotype, I'm having a hijab or I'm a Muslim lady or something like this no one will hear me, no one will even look at me, this is bad.*

The Somali Women's Group articulated a number of access issues relating to communication, firstly they experienced feeling unwelcome because of who they are and secondly, they often had unreasonable requests made of them around translation. To note the NHS has an online / phone translation service and if there are any difficulties that is available both to book and as an emergency. Records of any translation needs should be on patient records so not only is it against recommended guidance to ask family members to translate it should be unnecessary.

(Participant, Somali Women's Group) - *There is no effective communication we need them - even if there is I mean from the BME community as a receptionist as a something like this and we need them to be more welcoming. Right now, GP is like a horror for me, it's a horror,*

(Participant, Somali Women's Group) - *One more thing most of our community their English is limited and the thing is when I want to send a message you if the is no effective communication can't tell you and there is no support from the GP*

(Participant, Somali Women's Group) - *They will tell you bring family to translate, how can't I bring when it's a private thing, honestly, it's absolutely ridiculous my children don't speak very good Somali and is mistranslation.*

(Participant, Somali Women's Group) - *We have no effective channel of communication with the GP even if you take your kids that will translate wrong and it will be embarrassing.*

(Participant, Somali Women's Group) - *I feel NHS neglected Somali community, either the GP or the hospital, I feel the NHS department has neglected the Somali people health, I don't know the reason so I have to hear if they have the same problem that we have to see if NHS have a problem or it's only Somalians that have this problem, for me now I feel we are not important in this society we are not part of this community of such a great country - Great Britain.*

It is not a surprise to encounter systemic racism in any large structure in society but I find it especially disappointing in the NHS – I was not expecting though to

hear some of the most blatant examples of both systemic and individual practitioner racism from the Irish Women's Group.

(Participant, Irish Women's Group) - *She said to me when I left the surgery "a lot of people didn't like you because you were from Northern Ireland". I'm not lying about that, she actually said that to me in the surgery. I was a bit taken aback at the time because you know, we were in a vulnerable situation, I was a single parent family with a psychiatric history. I didn't make a fuss or talk about it until now, I just left it*

(Participant, Irish Women's Group) - *There was also of course the political aspect. Because with the political thing, because you were Irish, you were a terrorist or a drunk and Catholic, so you were dirty and had HIV or whatever*

(Participant, Irish Women's Group) - *Someone else from Northern Ireland who is not here today, she told me that her doctor said to her that she seemed to do very well with the alcohol. She said "what". He said we have recorded you here as an alcoholic. She said I've never had a problem with alcohol. I don't drink and I haven't done in the past. But that was there on the record and had been passed on to other professionals.*

One example from the Irish Women's Group was a woman who after receiving abuse at work about her heritage took time off sick and had to visit a GP for a sick note and received a bewildering and offensive response:

(Participant, Irish Women's Group) - *I was being bullied about being Irish and it was kind of little things at first, like she won't be able to do this or that task. it had got so bad that one morning I just got up and walked out and then I had to come back in and explain myself. … I was listening to people saying things like "oh yeah, he did get the money to pay for his TV license, … Oh, he was Irish, he probably drank the money." You know just imagining things all the time about Irish people. They all had this prejudice. I thought this is not just about me, it's about them. So, I couldn't really go back from that and I just couldn't really go into work and I needed to have some time off."*
"I went to the GP to ask for time off and just explain the situation. He was really unsympathetic, he just thought it was hilarious. He said to me it says here that you live in RC Street, because I live in a place called Royal College Street. Obviously also RC stands for Roman Catholic and he was

> *thinking Roman Catholic equals Irish. He said do you think someone's done that on purpose to upset you as well? At the time when he said it, I didn't really know what he was talking about and then afterward it kind of hit me. … But he clearly thought it was just a joke and it didn't happen and I'm sure it must have happened to loads of people because there is loads of prejudice and you don't know when you're going to hit it, then if you hit it and it upsets you then you're going to need time off work. You know you'd think doctors would be more understanding of these issues."*

One aspect of the discussion around racism occurred in the smaller group of representatives from the focus groups who collaborated together on analysing the data. Issues of discrimination related to race came up in the Somali, Asian and Irish Women's Groups and as the quote below shows there was interest in talking about this subject across the groups:

> (Participant, Somali Women's Group) *- I will be very happy for other communities to sit down together like we are sitting down together and hear them out, if the other people share with us this problem or is it just alone for us.*

However, when the topic came up, first brought up by the Irish Women's Group representatives, there were sighs, and nods from the Somali and Asian Women's Group representatives. The Yoga & Gardening Group representatives were understandably shocked and said so, they had not got that experience themselves and it brought the conversation to an abrupt end and moved on before I could intervene.

Despite some very difficult, unfair and in some cases, illegal situations, most women accepted the challenges and instead employed a range of creative responses to get their needs met: The ranged from being strategic, being charming through to being to being resolute. Whilst the strategies involved were impressive I found it very disheartening to hear of women with multiple needs having to contort themselves to receive a basic service that they have already paid for.

(Participant, Asian Women's Group) - I have more than one thing, I make a list so I don't waste the doctors time, if they see the paper the ask what you have written, so when they see that they seem to be okay That's what I do, sometimes I write it on a paper … Just put it on a table like a shopping list like here fix these

(Participant, Irish Women's Group) - You need to prep yourself don't you, so you remember. Sometimes I have forgotten one or two important things which I of course remember as soon as the appointment is finished. Because I am concentrating at the time on expressing myself about one issue and I forget to mention the other issues."

(Survey Respondent) - Use the internet to find out more information so that I can be very specific about what I ask them and don't waste anyone's time.

(Survey Respondent). - Once I find a good professional I try to return to them

(Survey Respondent). - There are times when I do declare the previous jobs I have had in the NHS

(Participant, Asian Women's Group) - *If I'm sick I always go to **** or **** for emergencies, I always take my kids there because I know I'm not going so see the doctor I want or they're not going to give me an appointment its usually oh we are fully booked, I have a 4 year old and 6 years old they say it's will take until next week of they say you have to go to emergency which will take another 2-3 hours.*

(Participant, Somali Women's Group) – *save some money and go to the private insurance. Now you have to take to Germany or the private doctors*

(Participant, Irish Women's Group) - *Thankfully, I have a sister who is a nurse, so I can defer to her. But the difficulty in getting an appointment here just sort of amplifies the situation for something that could be a fairly minor ailment, but the waiting just makes it worse."*

Some women described being extremely polite or deferential to get heard, and this went beyond the normal social courtesies expected in a social interaction:

(Participant, Asian Women's Group) – *She is polite …* [does an impression of being 'sweet'] *'Dr can you please help me'?* [group laughter]

(Participant, Asian Women's Group) - *if I'm worried about any situation at that time then I read that problem…question and then I say doctor' I'm really worried about it can you please help me' so I get answers*

(Survey Respondent). - I say thank you when I get the help I need. I think it is important that doctors know you appreciate them when they have done their best to help you.

(Survey Respondent). - Being respectful and asking questions about treatments and what I can do to improve my health.

(Survey Respondent). - Try to be clear. Speak clearly (a bit teacher voice) Take in notes. Not try to jam too many issues into a single GP visit. Look them in the eye wherever possible. Use appropriate terminology (without sounding like a Wikipedia doctor).

Women describing their strategies for accessing care via the survey noted the importance of being clear but some felt they had to moderate their presentation of self so as not to appear too confident or pushy which they felt would go against them. Others describe hard cognitive labour in terms of preparation, planning and rehearsing just to be heard and attended to. It was clear that women were managing their presentation, tone and trying to present themselves as rational help seekers and good 'patients' to be heard. Others brought friends or carers to add weight to their requests – unfortunately despite their best efforts, these strategies were not always successful.

(Survey Respondent). - Try to be assertive and know subject matter although this can again go against you....

(Survey Respondent). - Stand my ground and not leave an appointment without a solution if I felt something hadn't been resolved.

(Survey Respondent). - I'm persistent, polite and address any concerns immediately. Unfortunately, I probably come over as defensive.

(Survey Respondent). - I'm quite articulate and can usually explain the problem clearly and give an idea of what I need to happen.

(Survey Respondent). - I write a tiny list on my phone or notepad of 3 things I need to say or want from the mtg. If it's a crucial apt e.g. about an op or treatment then I may rehearse it with friends or family. Often my family have good tips on how to be diplomatic and yet direct. It's tricky in appointments as they are time pressured. So, you don't want to appear like one of those hyper fast-talking people on a pay go phone. I also have learnt to embrace a silence. Smile more and let the Dr or Nurse think. And to try and start off v positively even if I feel in pain so I'm not judged as being depressed when I'm not. I also write a list of meds I'm on. And re read any side effects before. I always thank the person for their time. If I don't get what I believe I need I also negotiate a follow up plan of some kind so we can revisit and review a different approach or med. That makes me feel better like the door is still open

(Survey Respondent). - I don't mention having ME or mental health issues if possible. I find if I am on my own I get less good care so an ally helps.

(Survey Respondent). - I make notes to prepare for appointments, I prepare written info for professionals as required, I bring an advocate...makes zero difference.

Some women found themselves in situations where their surgery had decided there was a rule of 'one problem per consultation'. This immediately disadvantaged women with complex interrelated concerns, it is of interest that some of the Yoga & Gardening Group (made up of predominantly white women with social capital) had heard other people speak about this 'rule' but did not encounter it.

(Survey Respondent). - One of the things was that you have complex needs… so sometimes you have physical health issues that effects how you feel emotionally and you all are say you can only tell him one thing at the time or her one thing at a time. So how do you manage that? So how do you get care if you're in a situation where you have physical and emotional things at the same time, what do you do then?

(Participant, Asian Women's Group) - *Most troubles we can't tell you know, we have to let it go …So you pick the worst one and go with that [Laughs]*

> (Participant, Irish Women's Group) - *Sometimes my doctor says one thing at a time, if you want something else, you need to make another appointment."*

> (Participant, Irish Women's Group) - *"Other ones don't actually say the time is up, but they start looking at their watch. But I never need a double appointment, when I go in, I get the time I want."*

> (Participant, Yoga & Gardening Group) - *"Yes I've heard a couple of friends talking about that. One issue per appointment. But they allow you to book twice or three times, which is absurd. A total waste of time and they don't allow you to use the same appointment for different issues, I would just try to string it all into one sentence."*

Most women found the idea of this rationing nonsensical, it is rare that someone who is unwell has just one thing and a discrete set of symptoms happening in their life. As ever the women described tactics from finding new surgeries to repeat booking and standing their ground.

> (Participant, Asian Women's Group) - *Doctors have some limits So you have to take another appointment [Question - So what if you had more than one problem? What do you then?] That means you have to go all the time to see him*

> (Participant, Irish Women's Group) - *After five minutes I asked him if we could talk about another problem. I had to put my foot down and say I was entitled to ten minutes and I wanted to talk about the other issue. I didn't like his attitude. But when I left I was very nice and polite and I even shook his hand even though I felt very angry inside. He was really sort of obnoxious.*

The difficulties that are presented to anyone attempting to access services are multiplied for women with multiple health needs. Who in addition may already be experiencing symptoms which make the practical and cognitive efforts involved in access health service more problematic. It is a concern to hear of people putting off help-seeking or emotionally disengaging as a result.

> (Survey Respondent) - *My mental health means I find it extremely hard to access physical services. Esp. Intimate exams e.g. Smear tests, but it*

is more than this and often people don't understand how hard this is. It also makes it difficult for me to attend regular physio appointments so I get discharged. But my physical health is still bad so I reduce activity and my mental health gets worse.

(Survey Respondent). - sometimes I put off seeing my GP as it's a hassle getting an appointment & the Drs in my surgery aren't v good and dismiss a lot of problems so you have to visit 3 times to get taken seriously or referred which takes up physical and mental energy to pursue something.

(Survey Respondent). - In regards to my mental health, I've had four or different diagnoses from psychiatrists and to be quite honest, I don't believe any of them. I just don't listen to them, because I'm not there to listen to either "jog on" or medical format, because I'm a lay person

Theme - Speaking up

Many women were aware that the treatment they had received or the way that they their case was dealt with was substandard - there were a number of responses to this. The most prevalent was one of silence, very few women from the Asian and Somali Women's Groups for example felt that they could complain for fear of reprisals and a feeling that it would make no difference. They expressed a firm belief as a group that the 'system' was against them.

(Participant, Asian Women's Group) - We can't do anything, sometime some nurses and doctors make mistakes you can see with your own eyes you can say give me some report or write some complains, you know, but they don't do anything sometimes we can't help

(Participant, Somali Women's Group) - To be honest with you we absolutely have a problem, we never being heard, they don't have the time for it or they have a stereotype that this people don't know nothing they are taking us for advantage thinking we will not complain. When someone slaps you, and you take that slap and then next time they will keep on doing it, it's like bullying, the more you will be submissive that's it. If I were to complain next time they will be like you know what don't talk to the GP, you know they are the ones that will give you the medicine you know what they are the one who will tell the hospital. You will get scared -

And they are against you. Do you guys agree with that? [Chorus of Yes] I agree totally

There were some cases where women did seek support to complain but it came at a great price in terms of their wellbeing and energy levels.

(Participant, Somali Women's Group) *- I will go to the tribunal and I will say the advisor or representative who was handling this case is absolutely incompetent and I will complain about it and it was within 15 minutes that lady who had disappeared gave me a call and said I will take it from here I was trying to call this I was trying to call that but what I'm saying is why should I fight every now and then for my voice to be heard I have to fight with my GP I have to fight with the welfare I have to fight with the housing, for how long? How many battles do I have to go through? It's hard.*

(Participant, Somali Women's Group) *- it's a burden on me because what it is I was discussing it with my colleague why we should fight every now and then for simple things, if people will do their work perfectly, you won't have a fight. If I do my job, I have to fill in forms, I have to liaise and this and that I'm doing it perfectly, or hopefully perfectly, but the other people making your life miserable you have to complain you have to do this you have to that, which is unfair.*

(Participant, Somali Women's Group) *- I will complain, if there is a serious matter I always tell my people to complain because the idea itself that this people they will never go so far*

(Participant, Asian Women's Group) *- I took some action against the GP, I said look here now I went to some organisations and they helped me and after that the date was coming for the hearing very soon, all the GP was coming … Mrs **** do not go for that, I will get the problem* [solved].

Understandably many women choose to' vote with their feet' and just leave a service without saying anything. Others when they tried to complain, met an ineffective complaints procedure. This was especially the case for members of the Somali Women's Group who often describe tactical withdrawals from poor service. It is important to note though that the tone within the group was not

defeatist – it was described in pragmatic and energy-saving terms. The women were generally exasperated rather than angry, although one member of the Somali Women's Group memorably referred to her ex-GP as a '*servant of hell'*.

(Participant, Somali Women's Group) - *What can we do? We cross our hands and sit down because we are not important. For me … I never went back to that GP what so ever, they gave me with another GP,*

(Participant, Somali Women's Group) - *Always she rude to me. 3 times, and my form need my GP to sign she lost it. When I was complaining to a manager she says I already sent you a form for housing, and housing call and say you time is finish and I say my GP they didn't send you the form, they said sorry no, so again I apply and I never make appointment here they are so difficult to sign. When I wanted to complain, she said I will call you, she called me the manager and she said sorry if you want to you need to register with another GP. I was here 15 years and it's across my place, how can I change it. My doctor is too rude to me and I don't want to see them, they say if you don't want to see you have to change to different GP.*

(Participant, Somali Women's Group) - *They never let you talk, if you want to talk they keep you silent.*

(Participant, Somali Women's Group) - *We never complain anything because if we do we will lose the doctor*

(Participant, Somali Women's Group) - *What it is, the culture of the complaint we always have the concept of - this complaint no one will back you up so that's why we are leaving it, that's our mentality because if even if you want to complain someone, even you friend, with say no stop. If I complain, it's going to be a problem for me because next time I go they may give me the wrong medicine.*

(Participant, Somali Women's Group) - *I'm not saying that everything will be in a pink flowery things but at least a slight change that the GP can be accessible to us that is what we want and I am scared- to be honest with you- I'm scared if I go with a serious matter to my GP or to the hospital I am reluctant to go there and tell them about the situation and that's unfair, that's absolutely unfair and I don't know to whom else I will go to.*

In the Irish Women's Group, the situation was very similar, with the women feeling both resigned and convinced that a complaint was a best, a waste of time, and at worst potentially risky.

> (Participant, Irish Women's Group) - *I didn't like his attitude at all. But I wasn't going to let him know, because I didn't want to make the situation worse and I don't do things like that in life anyhow. Also, because we depend a lot on medical people. After that I changed my GP."*

> (Participant, Irish Women's Group) -*…. so much for trying to be proactive and look after yourself. So, I think it's time I change my GP."*

> (Participant, Irish Women's Group) - *"It's also having the time to do that and whether it would be a futile exercise. I weigh up the time I use to do something like that and what the end product is going to be and whether it is going to improve my life. Nine times out of ten complaining about a health professional you are just wasting your time."*

> (Participant, Irish Women's Group) - *"If everybody made the effort to do it, rather than just a small section of people it might actually have some effect. But if a lot of people do it, it might not change overnight but it might change something."*

Some women made the decision to try to effect change out of necessity or if they had the emotional headspace or energy to spare.

> (Participant, Irish Women's Group) - *"It's definitely about having the time. I would be very reluctant to do something formal, but I would try to do something."*

> (Participant, Irish Women's Group) - *But I always stick to my guns, if I go in and there is a problem, I will not leave until it is sorted. It might be the prescription, if they have left something out, I won't leave until I get it.*

It was a markedly different picture from the Yoga & Gardening Group the majority of whom went to a GP situated in a more affluent area. They hadn't really had to complain about anything because all seemed to get timely and proactive care.

(Participant, Yoga & Gardening Group) - At my GP, they've got the forms sitting there for you to fill out if you're not happy with anything."

(Participant, Yoga & Gardening Group) - "I do, but I have been very lucky! As I say I went in for peeling lips and came out with everything. Loads of checks and tests and a follow up appointment."

The women in the survey group who had higher levels of complex need, including formal diagnoses of mental health issues had similar experiences to women in the Somali, Irish and Asian Women's Group. Whilst a few women from the survey felt confident to raise concerns there was that same calculation and weighing up of whether complaining would be a worthwhile use of their time They recognise the process as a drain on their resources with uncertain outcomes but they were more open to complaining online or via other secondary means.

(Survey Respondent). - I would be hesitant to do anything at first but I would put a complaint in/request to see someone else.

(Survey Respondent). - I would like to complain and force change, but realistically, as a depressed and anxious person, the energy expended by making + attending an appointment absolutely exhausts me, so I do not have the capacity to make complains and advocate for myself

(Survey Respondent). - I find it a huge struggle to get my views across face to face. I tend to go along with the HP and sometimes will complain or send a letter to feedback later. Often, I get little response though.

(Survey Respondent). - Maybe leave a review on NHS Choices. Complain if serious enough but usually it isn't. If just an insufficient service might just end up ignoring the problem or going back again months later.

(Survey Respondent). - I would intend to complain (although I often haven't in the past), and nowadays I would also consider posting a review online

(Survey Respondent). ..., generally, ...I find one who is competent to deal with both physical health and mental health without dismissing, I make appointments only with that person

(Survey Respondent). - Often, I bite my lip. Rant to friends and family and make sure I avoid that GP. If it's a consultant or something more serious that has had an impact on me getting treatment I may lodge a complaint direct to that team. I find PALS slow. I tend to stick up for friends and family more than myself.

(Survey Respondent). - Well, I'd recognise and remind myself that I am powerless, and that if I tried to challenge it, I would lose. When I was younger, a doctor broke my confidentiality in the most blatant way, which damaged my life for several years ... Medical professionals have power, and I do not, so there is no point in fighting them - the safest way is to stay away from them.

(Survey Respondent). - I have learnt that once you are "known to the system" it is best not to complain as it won't be taken seriously and you might receive worse treatment because of it

If an individual has not had this experience personally it can be hard to credit how frequent the experiences of being poorly served is for certain populations. There is a marked similarity in their narratives - of feeling unable to complain, being too exhausted or unwell to take on the system, being afraid of punitive action and disengaging and moving away from poor care. One piece of testimony that was particularly sad to hear was that of a woman who did everything to change the system by giving up her time to work with a service provider only to hear disparaging comments made about other women who were trying to be heard. It is not surprising that service users often take such a jaundiced view of poorly constructed attempts to coproduction quality improvement.

(Survey Respondent) - I used to sit on the Complaints and Compliments committee as a service user at the award-winning mental health provider (*******) and will never forget the Chair of the meeting describing a person who had complained and we were reviewing it, as a "serial complainer".

Not one member of staff, challenged this Band 8 mental health manager; this is the manager who to your face would describe a complaint as a "gift", the sheer hypocrisy was scary.

Theme - 'Being Seen':

Another key theme that arose across the groups was the concept of 'being seen', not just in terms of getting in to see a GP but in terms of actually being acknowledged with personalised attention and actually looked at. Making eye contact with someone in western culture is a fundamental act of respect and an expectation of basic social contact. However, this social courtesy was often withheld from the study participants.

(Participant, Irish Women's Group) - *I've had this experience and I can't stand it when you walk in to see the doctor and they're not even looking at you, they're on the screen and I say don't you want to have a look at me? You know, you can read so much. Medicine is an art, you look and you see if your patient is like this, they might be a bit down but you can't tell that if you are just looking at the screen scrolling through your notes. I do need to see my doctor and I'm making a little list and I'm bracing myself.*

(Participant, Asian Women's Group) - *She's saying …because she goes to the hospital…GP a lot… as soon as they see her face they are like oh you're back again*

(Participant, Asian Women's Group) - *I just want to you to see me I'm in pain please look at me – my advice would be pay attention to the patient, smile when you are there – it is very important that you are smiles and you are kind.*

(Participant, Asian Women's Group) - *So, there's a problem there is there… we aren't being heard or seen properly. now I'm waiting for the surgeon to see that is my hope, otherwise seeing a GP who doesn't even look at you… I mean you have to look at it… you have to see or research even if you don't know exactly what is happening in the body*

The Somali Women's Group   agreed and one woman (who was accompanied by her young son) told a of a bizarre encounter with a GP who during her brief

appointment ignored her, took a personal call and physically chased after her when she decided that she had had enough and left.

> *(Participant, Somali Women's Group) - The GP sometimes not look at you, they don't look at you they just …*

> *(Participant, Somali Women's Group) - Always it's like is it like this okay here is the medication, they will never even look here, they will never even listen*

> *(Participant, Somali Women's Group) - he doesn't have his glasses at that time, and instead of being busy with me he was busy with the keyboard. My son was with me, I was so scared I was telling my condition he was banging the keyboard like this and he was talking to his wife, and then all of sudden he went from the room, and then I told my son lets go, let's run away. I took my son and I went. Like who knows what medication he would have given me, I didn't feel confident I went to the reception, I said listen I was seeing that doctor - room number 3- I am not confident to see him I have concerns and can I see someone else, and he was coming running after me COME, COME I'm back, I said no I'm not coming to you.*

Another woman from the same group who had been sent to her surgery by the emergency department with high blood pressure who was threatened with the police being called after fainting in her surgery after waiting hours without food.

> *(Participant, Somali Women's Group) - She has very horrible story regarding, she is a hypertensive patient and high cholesterol and she went to the hospital as an emergency, she was diagnosed with high blood pressure, what it is, they were there overnight sleeping in the hospital and the hospital said they cannot keep you long and I think what it is was day emergency and they said you should go out we need the bed go back to your GP let them control or monitor it or something like this. She went back straight from the hospital to the GP, GP said we will not see you today, although she showed them all the letters from the hospital they said now will not see you have to come early in the morning wait in the queue and then we'll see you. The next day she was there since 6:30 waiting in the queue. And when she was inside they told her no we will not see you because the appointments have finished. And then she fainted, and one of the staff management she came and said you are pretend these things,*

if you do not move out we will call the police and we'll take you off the register with us.

There were similar stories from the Irish Women's Group around being unnecessarily hurried and unacknowledged although they were able to bring some experiences of positive practice.

(Participant, Irish Women's Group) - One time when I saw my GP, he looked at me and said everything was fine. He was really, really rushing me. He never really looked at me. He looked at my back, he looked at my face and for whatever reason, I just didn't like him at the beginning

(Participant, Irish Women's Group) - rather than going to see a doctor or psychiatrist, where you feel as though you are talking to a computer rather than an actual person. Because when you go to see them, they are just tapping away and barely notice you are there. It feels as though there is a big breakdown in communication between doctors and patients. I understand that there is a lot of pressure on doctors but I think sometimes people's body language and the way they answer, tells you a lot more than what they are actually saying. That's been my experience anyway

(Participant, Irish Women's Group) - …she actually looks at you. She actually turns her chair around to ask you a question. So, she needs that extra time because she's actually looking at the person as well as taking down the details. I find other doctors, they don't look at you, they are just looking at something on the computer and it makes you feel as if they don't care as much."

The Yoga & Gardening Group had not experienced these phenomena but one participant (below) talked about the campaign for compassionate care launched by the late Dr Kate Granger (Granger, 2013). Dr Granger was a medic who was diagnosed with cancer and found that none of her colleagues introduced themselves when giving care – she set up a campaign to challenge this poor practice. Notably one of its key components is 'See Me - See me as a person first and foremost before disease or bed number'.

(Participant, Yoga & Gardening Group) - *"I think they should look at their patient. I think that's really fundamental. It bothers me so much that they look at the screen when I walk in. I think they should look and observe their patient. I think this woman* [Dr Kate Granger] *who did this amazing work, hello my name is the doctor rather than the stranger, I think that's what she was getting at. We are all so immersed in the screen and we have lost something absolutely critical, observing the patient. If they say, "my name is…, how can I help you today", put the pen down, observe and be mindfully present for the patient."*

Despite the poor care the groups highlighted they were still able to offering some empathy for overburdened staff:

(Participant, Asian Women's Group) - I think the doctors themselves are under stress. They have to meet their target… certain things like that

(Participant, Asian Women's Group) - there is a lot of paper work now, more than before but those paperworks are necessary now a days, what can be done about it? Less paper work maybe

(Participant, Somali Women's Group) - They are working in hours and they have a short time for you and they have running late or other people to see, that's the first thing. Secondly, I think referring you - GP to refer you to the hospital it's very difficult I think maybe it's getting taken out from their budget. Yeah, it's getting taken from their budget and that's why they don't want to refer you.

(Participant, Irish Women's Group) - "I think he has got worse over the years. I think he feels the pressure as well that he doesn't have the resources to refer people and things like that.

There was also a narrative than ran across groups that somehow members of the public were recklessly wasting resources – from taking medication they do not need, to misusing appointment time. This is something that is a common media narrative but there were no real-world examples forthcoming from the participants.

(Participant, Somali Women's Group) - 'People going for nothing'

(Participant, Irish Women's Group) - "There are also a lot of other people who don't keep their appointments. At my GP, there's just less than 1000 people a month that don't show up for their appointment and that's only in one GP. And they're under such pressures, but that's just bad management and something has to be done about it, people not turning up for their appointments

(Participant, Irish Women's Group) - "I think there's more and more pressure being put on everybody, particularly in the health service. I'm not complaining about my GP, but when I see "go and see your GP" every point of contact is your GP and I'm thinking how do they cope!"

Theme - The tyranny of low expectations

The participants had clear ideas of how they wanted services to be and what they felt was good care. What struck me was how low-level their expectations were. When I go to a GP I have high expectations of professionalism, expertise, and efficiency. I will have checked the service and the professionals beforehand online, I will have researched and know what I want to happen and I would complain to the highest levels if my needs were not met.

The majority of women across this study are just hoping to be greeted politely and be listened to and describing it as a 'fantasy'. Women did describe behaviours that they felt indicated good practice when they saw them and throughout the pressures on staff was noted.

(Participant, Somali Women's Group)   - I mean this it's in a fantasy world, it's not in the real world, in a fantasy world when I'm going to my GP I will find a welcoming greeting staff… frontline staff and I want an understandable GP, someone who could listen to me, I need him to listen to me about my concerns which I don't have it with my GP and I cannot even get access to it, for the past 6 months I'm leaning on the medication of others to continue my life. I'm getting from other shops, other patients because I cannot get access to my GP and I cannot get appointment with him

(Participant, Asian Women's Group) - It's good to be recognised…to be acknowledged by the receptionist you know even if you're ill if they smile a little it's good My GP she smiles, whenever I enter the room she smiles

(Participant, Asian Women's Group) - And also to have at least 15 minutes per client, because now they have 8 minutes, in my surgery its 8 minutes per patient. So, they are very conscious of the time and always looking at the clock or the watch so you don't go on and on and on, but you have been waiting three weeks for this appointment you want them to listen to you so I think my advice would be pay attention give them time also look at what their life style is before you prescribe them medication. Do you take walks? do you eat meat? Are you a vegetarian? Have you got any allergies? no, no questions. And treat them like a human being, that's important to treat them like human beings not rubbish

(Participant, Somali Women's Group) - *I mean the thing is, first of all they should make them accessible more often to us, I need my GP to be more accessible. I mean easy access. I need them to listen to us about our complaint- and we need them to have the time, the thing is when you are inside there you have 5 minutes and you cannot talk to someone who is looking over his watch, you cannot talk. I mean whatever you want to express you won't say and they will say excuse me if you will say I have a back ache, my knees is hurting me, excuse me keep you knee outside talk about your back*

(Participant, Irish Women's Group) - Her doctor came along to her and he had a team of trainee doctors and he kept talking in medical terms, but then he went into lay terms which was very good because Phil was blanking because she did not understand the medical terms. But then he does it in lay person's terms and I thought that was wonderful. She said he was so nice, he actually explains things clearly and for her in that situation it was very good. I thought that was very nice to see the fact that he did it in both ways.

(Participant, Irish Women's Group) - "I think it's good in hospitals now that they have a big board on each floor that says who is in charge that day and other information about the unit. I think that to me is a big improvement." "I think we need to manage our expectations. But yet, we're getting more things now infections and things."

(Participant, Irish Women's Group) - *I actually found it very nice and her to be a very nice doctor. If you actually asked at reception at the time of*

your appointment, if you needed extra time, then they would give it to you. It made me feel supported

(Participant, Irish Women's Group) - "My GP gives me as long as I want. There is a problem though, she's always running late. Sometimes you might have to wait for as much as 2 hours to see her. So, when I make an appointment usually, unless it's an emergency, I usually take a book or something. When I get to see her, she's very, very good and she listens to what I have to say. If she wants to prescribe you something and you don't agree with her, she'll say it's okay, I'll put it in the drawer and the next time you come, you can let me know what you want to do."

The women from the survey had strong opinions about what constituted good care and placed a particular emphasis on not being rushed. Like the others the interpersonal dimensions of the therapeutic relationship were what was expressed as being of highly value. More so than efficient treatment and symptom reduction.

(Survey Respondent). - feeling valued, listened to and respected. my GP is always running at least 30 minutes late, but I don't mind because I know that I will be listened to and treated kindly when I am seen

(Survey Respondent). - When a health professional really listens to you about your physical and mental health symptoms acts accordingly to help with this shows you respect treats you with dignity kindness compassion empathy and good care

(Survey Respondent). - They LISTEN, and take seriously any concerns. They do not assume that how I seem to function for a ten min appointment is how I function most of the time. They probe a little deeper, or make sure what they think/assess/will write in their notes is true for me too, or say that I disagree in the notes. They will understand my history of past abuse and trauma and difficulties with being in areas with lots of men, or being undressed/less dressed where there are others around.

(Survey Respondent). - Somebody who will listen to you and does not judge. Somebody who is compassionate.

(Survey Respondent). - Timely. Friendly and welcoming. Feel that they take me and my concerns seriously. Feel that they want to get to the root

of the problem not brush it off. Feel that they understand how things might be connected. Feel that they are going to look after me not that I'm on my own after that appointment is over (if it's something ongoing).

(Survey Respondent). - Validation of my ill health and acknowledging that my chronic pain impacts on my mental health. My GP is fabulous at seeing me as a whole person and acknowledges that sometimes he can't help solve everything, e.g. last visit "I'm sorry I haven't been able to help much". Compassion.

(Survey Respondent). - Three things, listening, caring and doing what they can to help you without judgement. I have a lovely General Practitioner who treats me this way.

(Survey Respondent). - I've rarely had this experience. However, a few gold star Drs and Nurses do exist. I'd say they all have in common: empathy, good listening skills, good EQ, ask probing questions, involve me in creating a plan or solutions & ask what I'd like to happen, arrange follow ups so I'm not left in limbo, also ask about me if I'm caring for others, prescribe or refer me instead of faffing around for months. Treat me as an individual, don't rush me, don't dismiss me. They seem to have some life and health experience of their own and relate well with health issues.

(Survey Respondent). - When they listen, don't write me off as a fool, or fat, or middle aged, or female, and manage to remember more than the last sentence I said (that last one is engaging for anyone with a complex problem).

(Survey Respondent). - I don't know - I've never had a good experience. I think it would involve not being patronised or talked down to, not having assumptions made about me based on nothing more than my age and sex, having the professional use an evidence-based approach rather than the latest directives from the top of the NHS (e.g. "Oh, we have just recently decided that everyone's problems are due to a Vitamin D deficiency, so we won't look any further than that", which has been the experience recently of several of my friends who do still go to the doctor) and for the professional not to feel threatened and insulted that I am clearly at least as intelligent and as well-informed as s/he is, and that I refuse the role of passive and grateful recipient of care.

(Survey Respondent. - Being listened to is important. Feeling as though I am the expert in my own body - knowing when things are not right. Being

given time to explain - especially when the issues relate to my mental health.

(Survey Respondent). - Looks at your Dx or label then treats you with bias making an ill-informed judgement doesn't listen when you tell them you do not drink or smoke or take illegal drugs because you have mental health unhealthy attitudes towards you because they think you want to self-harm and don't listen to you when you have physical symptoms and have chronic illness they use their powerful position to put you down bully you

(Survey Respondent). - Somebody who feels like you are wasting their time. It makes it less likely that you will go back. These experiences put me off accessing healthcare that I need. Also, the amount of bureaucracy in healthcare is astounding. Even to join a GP surgery is not an easy task.

(Survey Respondent). - Awful - degrading, fail attitude and ignorance towards you - I get quite upset by these experiences and will return to my car and sob

(Survey Respondent). - Rushed, stereotyping, false assurances, arrogance/male creepiness

(Survey Respondent). - Not listening and understanding that I live in my body and know it well and that I am not there for attention. I would rather get things sorted quickly than drag it out as I don't want to waste my time or theirs. The 'wait and see' approach always sounds like them saying 'it's all in your head' and showing a lack of trust in me.

The survey group reported experiences of feeling harmed by their interactions with staff and again it is a different picture from that shared by the Yoga & Gardening Group. The Yoga & Gardening Group seem to have markedly more positive encounters and they were the only group who were proactively phoned. They also went with agendas (which were met) and then double- checked the health advice given, there seemed to be less of a power imbalance in these interactions.

(Participant, Yoga & Gardening Group) - I have to say, they picked it up and I almost wish that they hadn't done that. It caused me a lot of

141

unhappiness and distress. But then actually, there was nothing there. I mean, they were very on the ball but it just caused me loads of distress for no reason.

(Participant, Yoga & Gardening Group) - I've found my GP has been very responsive and they do take things seriously. I was going away on a long-distance flight. My GP must have read something on my file and there was a concern that I might get DVT on the plane. I got a telephone call first and I explained my concern, so they said to come in. Then they said it wasn't anything to worry about and they were able to reassure me

(Participant, Yoga & Gardening Group) - "So, I wanted to check about this issue. So, I went online because I knew it takes so long to get an appointment when it's not something life or death. So, I went online and got an appointment and it's never the same doctor. But he was excellent! He checked everything and tested everything, blood pressure and all of that. He even checked out a mark on my face."

(Participant, Yoga & Gardening Group) - "He asked me if I wanted my cholesterol checked. I couldn't fault him."

Lastly women from the survey offered some sound advice back to professionals:

Survey Respondent - Be compassionate, non-judgmental, listen to what the patient is saying. Try to leave your own views aside and understand where the patient is coming from. Recognise that the person may be telling you something that is really hard for them to say and that seeking help is an enormous step for them. Don't blame people if they are not immediately getting better: it's not easy and it might not be their fault. Usually they are trying their best. Blaming makes things worse and they might be likely to disengage.

Survey Respondent - Please understand how different things are connected and that it's really frustrating when it feels like only one thing is being looked at in isolation. Follow up with us a while after treatments for a long-term issue (e.g. Mental health issues or physio) as the problem might come back and it's so frustrating having to start again at square one.

Survey Respondent - To listen and take time, acknowledging the expertise of the person they're supporting. If they're so overworked and

over-stretched, with lack of resources, and that's impacting on care quality, then join a Union and start fighting for the NHS before it's too late.

Survey Respondent - Try to remember that if someone is being difficult it may be a result of being mentally unwell or in pain. Try not to take it personally. It may be, that you will get an apology from a mortified patient once they have recovered from their illness. Remember, we are dependent on you to help us get well and need you to know that we are sorry for being a nightmare when we are ill. Please understand it is the illness, not the person making things difficult. We need you to be in our corner when we are unwell, especially mentally unwell as we may have alienated our friends and family in our unwell state.

(Survey Respondent). - Most of all, listen with empathy and without judgement. I know it is a lot to ask, especially with the time pressures of general practice. If there is not enough time to listen properly, schedule another appointment when there will be. If there is another colleague better suited to dealing with the issue pass the patient on to this person or collaborate with them. If you are good to your patient they will appreciate it and they will appreciate you enormously. Also, forgive yourself for the times you get it wrong. You are human and we all make mistakes. Say sorry to your patient. They will appreciate it. In summary, listen without judging, do what you can to help and if it is beyond your capabilities refer. Forgive your patient for bad behaviour that is a direct result of illness. When they are better they will probably say sorry and if they don't, it's not you at fault.

(Survey Respondent). - Try and put yourself in the patient's position. Try and treat people how you'd like to be treated. Or ask the patient how to. Be human. You can smile or joke appropriately or even say you don't know but you'll find out. I hate blaggers and fobber-off-ers. Be sincere and authentic and honest. Don't try to put me in a box or label a physical issue as mental or vice versa. I'm not a fool and I know the body is complex and linked. Positively encourage me to do well. Suggest other ways of helping myself. Don't become robotic if I'm in a hospital gown I'm still human. Ask me how I feel. Ask what plan of action I'd like. Oh, and stay up to date on new research and findings. I hate Drs and Nurses that don't and fudge stuff. Watch the news read Nature and The Lancet. Cos guess what some of your patients do. And remember if your patient has a long-term health condition they may know more about it than you from networks forums and Twitter. So, ask me for info or what I'd suggest. Give me eye contact and make me feel heard.

Survey Respondent - Summarize what the patient has said back to them before reaching a decision and ask them of that is correct. Believe people who say they have pain: particularly women, particularly children, particularly people of colour. Don't stop seeing a patient as a whole person because they look fat, or look poor, or are over 50.

Survey Respondent - Treat a patient as part of your team … Accept that your patient is the true expert!

In this chapter I have presented the findings that were produced from the analysis of the data. There are clear themes around access issues, poor communication, women having to work hard to be heard, and fearing to complain and in the next chapter I will discuss them in the context of the literature review.

Chapter 6 Discussion

In the previous chapter the research findings were thematically analysed. Following on, in this chapter the data gathered though the literature search, the focus groups and the survey are considered critically in order to understand what has been learned.

The Literature Review - Under Feeling and Over Claiming

It could be assumed that 'access to health care' would be a prosaic topic to research and primarily be dealing with everyday issues like booking appointments etc. However, multiple data sources, from the literature review to the survey, show that women are detailing emotive responses to troubling behaviour from authority figures that ranges from discourtesy to outright assault. It seemed likely from the planning stage that sensitive issues would be arise in the course of this project but even with twenty-five years' experience as a nurse, I found myself saddened and angered at times, coming to appreciate the disregard with which some women were treated. I was surprised on multiple occasions by how little comment there is about this from researchers. There is usually no indication that they have noted the personal impact on, or the cost to the individuals sharing instances of poor care which may feel exposing or shaming.

Most of the papers in the literature search noted failures in communication and in the therapeutic alliance including incivility, minimising or disbelieving reports of pain and other symptoms which could lead to health deterioration. Some women reported serious breaches of care such as being left uncovered – an offence to dignity (Hadland and Lambert, 2014) and others recounted illegal actions, like being purposefully hurt. What is striking about this was the lack of recognition of this from some the researchers. These occurrences were reported in the same tone that requests for nicer decoration in the waiting room were noted.

Even whilst formal academic writing structures have scant space for emotion, there was little acknowledgement of women's experiences being problematic. These experiences seemed to occur with greater frequency to women with marginalised identities. Indeed, in some cases like Miller et al (2004) idea of 'group medical visits' (which I would imagine would be unthinkable for the researchers themselves) are described as 'well tolerated' and 'acceptable' for low income women. This is hardly a ringing endorsement and a low bar by any standards in terms of quality.

As discussed in the Methodology chapter, a certain emotional distance between researchers and subjects is encouraged in most traditional approaches to academic writing. However, the articulation of problems without incorporating the skill of empathy can lead to a deficiency in ethical consideration. Arguably scientific voices that are lauded for truth telling with an impartial, objective and neutral voice, are actually just recording events like a camera – unheeding, callous and disregarding. It is in speaking about an issue from a standpoint with knowledge and understanding that value is added. I was moved by Livia's (1996) resonant point that as a feminist writer she expected to be held accountable for what she created but that it only dawned on her much later that she was also responsible for what she left out. What is left out from many of these accounts is an acknowledgement that these socially unjust practices are unacceptable.

From my perspective as a human first - as well a practitioner with a feminist activist stance, I experienced a range of emotions that shaped my thinking and responses to this emotionally raw data. I would argue that there is a moral imperative to respond when something is unprofessional, and a legal one where actions mean that other people are unsafe. I contend that when thinking and feeling fall out of balance, with thought unmoored from responsibility - the quality of the knowledge is itself damaged and our ability to safely create useful information is diminished.

Although I have felt disadvantaged at times by having a practice rather than academic base to my research approach, it also gives me a structured ethical stance to think from – I posit that as transdisciplinary and practice- based researchers we need to be braver in bringing in different 'ways of knowing' (Carper, 1978) to our research. Carper describes personal knowing as '*standing in relation to another human being… unmediated by conceptual categories or particulars abstracted from complex organic wholes"* (p.18). Thorne (2020) builds on this and states the importance of maintaining a vigorous critique of empirical science - warning of an over-reliance on undue standardisation and the 'depersonalization' of knowing. It is important that when we are in a position of privilege to create and put out information into the world that we take responsibility for its impact.

It is as easy to under-empathise with experience of the participants; as it is to over-emphasise the possible impact of one's own research. When researchers develop and implement their own methodology it takes on a personal importance that may make it harder to hold the reality of others in our heads. Alexander (2004) created an exemplary study and drawing on her theoretical understanding of Freire, she suggests that being part of a research study of this kind changes the material aspects of participants lives. Technically it is possible – but this assertion takes emancipatory practice and instead of using it to 'free' people's minds it inappropriately places the burden of systemic change on the shoulders of the already multiply-disadvantaged. Ahmed (2000) sees this approach as stemming from a western perspective of positioning societal harms like racism and socio-economic disadvantage as individual concerns and trying to address them on the micro-level instead of considering the cultural factors facilitating them.

Frye's (2019) work on oppression sheds further light on this phenomenon and her theory links to questions about why some vulnerable people can struggle to complain or speak up in health care settings; (which is another aspect that we will look more closely at later in this chapter). Frye's ideas help shift our critical

focus from why one woman does or doesn't do something and helps us think about the impact of being a member of a category of people who are systematically reduced and silenced in society. Consideration of issues of this kind demonstrate the importance of conducting research on women's experiences that is trauma-informed. Planning to avoid harm, to reduce inequalities and increase safe working practices needs to become a fundamental prerequisite for work in this area.

Rolfe (2016) describes nursing as a deeply human praxis necessitating a nursing researchers to use their professional values and integrity to reshape the academic agenda around what is researched and how. His call to foreground the 'nursing imagination' (p.525) has its merits but we can be more ambitious and draw on ideas of coproduction and from the findings of the focus groups and survey to proceed more usefully here.

Working Coproductively – Voices and Choices

Regardless of someone's initial place in society becoming a patient or receiving health care places you at a disadvantage. A classic example of this being Dr Kate Granger (2013) who is referred to by one of the focus group participants. She was a successful doctor who became ill with cancer, the minute she was in the role of the patient she found that she became excluded from social norms. Staff no longer greeted her and introduced themselves, it led her to set up the campaign #HelloMyNameIs encouraging staff to remember and recognise that patients using services are people first.

The 'sick role' (Parsons, 1951) is by its nature always placed in a deficit position - the patient is in inferior relation to the 'expert' who advises you, and in some cases makes decisions for you. One of the most disturbing parts of women's testimony in the survey and the focus groups were the number of women who described being wary or frightened of their health care provider. Women spoke about trying to behave in ways to meet the approval of staff, of fearing to complain and being worried about reprisals if they did.

It is discomfiting to admit that in all my practice years I never anticipated that I might be an object of fear for people. I would also be surprised if the majority of staff, (particularly those who are apparently paying the scantest attention to people coming to see them) think of themselves or of routine health appointments as causes for alarm. However, this is yet another reason that peer researchers and coproduced studies are essential to explore issues of inequality. Wilkinson & Kitzinger (1996) concur, noting their disquiet concerning research presented without reflection on the power inequalities fundamental to the formal processes of knowledge creation.

To undertake meaningful research in to situations that need to change you have to know what to ask, who to ask and how to ask. This again strengthens the case for working with and for people with lived experience who can prioritise issues that white middle class researchers have no knowledge of. Another issue that indicates a need for devolving and sharing responsibility across research projects is something that Buetow (2019) calls apophenia. Which is a type of cognitive bias occurring when researchers perceive patterns in unrelated information due to their own experience, the remedy for which is discursive reflection within communities of practice to find and remove the impact of unconscious bias.

It is here I must thank again the women in the steering group for helping define the research and identifying my blind spots, and the women in the focus and analysis groups particularly those who were in insistent about not 'over-interpreting' findings (Sandelowski and Barroso, 2002). At the time I felt deflated that I was 'doing it wrong' and that I wasn't following the initial plan – as things have turned out - they were right and following coproductive methods has resulted in a more meaningful research experience.

To be able to conceptualise potential bias and blind spots, critical self-reflection is needed (Finlay, 2002) as well as the ability to consider oneself through the

eyes of others (Hunt and Sampson, 2006). In terms of human capital, I am in a privileged position. I am a white, professional and as a researcher - I am the one 'asking the questions' (Cannon et al. 1988). It is easy to consider one's own position as default – for example to see whiteness as a neutral or default identity that black and brown women are seen as 'different' from.

When I began this project, I thought hard about how I could work with women from minority backgrounds in ways that were respectful and just. I came to realise through the deliberate practice of undertaking this work and critically reflecting that it is a perspective that goes both ways and that I also needed to think about aspects of my whiteness as well as how my identities intersect.

For example, I see myself still as working class but my job and life experiences have put me in a position where many of the women I researched with on this project definitely see me as middle class. This was key for me to appreciate as the effects of class identity were something I was not expecting to be so clearly voiced by participants. Again, I see myself as sharing the concerns of women because of my feminist stance but not all the women in this study relate to or welcome that - indeed Aziz (1997) is just one of many people clarifying that if feminism is not intersectional, it is by default 'white feminism' and if it is not actively challenging discriminatory power structures it becomes part supporting them.

Agyeman (2008) says that when attempting to undertake research with marginalised people it is essential for the researcher to be frank with participants about who they are and what their intentions are, as this type of work is in essence a 'political' process. Owusu-Bempah and Howitt, (2000) continue asserting that if research into a marginalised experience different to your own is undertaken without the engagement of participants in the process, it can result in the pathologisation of minority experiences of mainstream culture (or approaching the subject without nuance as either a homogenous entity or from a deficit stance.

Wilkinson and Kitzinger (1996) contribute to this concept by bringing Marx's ideas on Vertretung and Darstellung. Vertretung roughly translates as representation - in the sense of articulating the needs of people who are struggling to be heard or acting as an ally and Darstellung conveys a meaning of representation as 're-presentation', taking someone's space, talking on their behalf and performing their story with your meaning. Braun and Clarke (2019) pick up on issues with the idea of 'giving voice to' saying it is a term used in conjunction with marginalised women, and in opposition to the critical approaches taken to privileged women's experiences. It has a condescension to it, a presumption of incapability as if without a white researcher to save them from their mute acquiescence black and brown women would just be sat waiting, something which has never been the case.

There are many circumstances that divide researchers from the people they research which can feel insurmountable but De Marco et al (1993) are explicit about the need for research by nurses to be ambitious in creating positive change. They note with hope that points of difference are places where contradiction and inquiry can be found, they are places not just of divergence but where new understanding can be co-constructed.

Working on this project with women who organised themselves along lines of their own interests and ethnicities threw these standpoints, differences and possibilities into sharp relief. I will explore some of the ways these different perspectives manifested themselves in the findings in the next part of this chapter.

Working with Marginalised Women

One of the first decisions that impacted the ways that women were able to make themselves heard was the way that data could be shared. I have described the evolving methodology of the focus and survey in earlier chapters but the nature of information shared was conspicuously different. In the survey women were

151

explicit about their diagnosis, their fears, and generally they shared more personal information and in greater depth. The data that was given had the quality more of a confessional or personal diary. In the focus groups whilst the tone of the groups and the individuals they consisted of was very different each time, the testimony was more narrative with shared space to share stories and experiences. It was co-constructed but at the same time by its circumstance it had an element of shared performance.

The idea of presentation of self – but with a different purpose was something that reappeared across the data. It was described in literature as 'survival strategies' (Ewart et al. 2016) which it absolutely is for some women. Women described themselves as walking a tightrope between cajoling, kowtowing, strategising, charming, and letting staff know that they shared similar knowledge or experience to make links across this invisible boundary to secure good care.

At the same time women expressed vulnerability about getting this finely calibrated performance correct, and being painfully aware of when their best efforts seemingly failed. This masking and performance, of hiding stigmatised mental health diagnosis or medically unexplained symptoms, the fear of being too knowledgeable or too confident, of understanding that 'inciting' a staff members displeasure is a punishable offence is as exhausting as it should be unnecessary.

It is reminiscent of seminal work by Stockwell (2002) on the concept of the '*unpopular patient'*. Essentially Stockwell stated that staff respond more favourably to patients who make them feel good about themselves and competent in their practice. This means that someone coming in with one simple problem, that is not 'their fault', who gets better preferably with medication and is grateful; is treated more favourably. Exhausted and overstretched staff are less welcoming and responsive to someone with a complex case that is challenging to make headway on and who is understandably dissatisfied with their health encounter. Stockwell's research found negative staff responses

were visceral, she noted that 'unpopular' patients were even smiled at less frequently. I note this research for two reasons, firstly it caused outcry at the time of publication because it was as true then, as it is now. Secondly, because it is consistent with the narrative's women are telling about their experiences throughout this research.

This brings the focus on to one of the most professionally concerning aspects of the strategy's women used to manage negative experiences of seeking help. Many women described using a silent retreat from services and just finding another GP when they had had an unpleasant experience. It is absolutely the individual's choice about whether to complain or not. Indeed, many women made rational and strategic decisions about this aspect of care. Some used technology to complain at a remove and maintain their anonymity. Others decided that the cost to their wellbeing and emotional safety was not worth the risk - others decided to do it if they felt not taking action would place someone else at risk.

The net result is that a great deal of bad practice is continuing - staff who seem to be unofficially (and unequally) rationing services, behaving (whether purposefully or not) in racist, misogynistic and other unprofessional ways. In addition to this the burden of poor care appears to be falling unequally across the different groups of women participating in the study. Notably white women from the Yoga and gardening focus groups reported having access to complaint forms but no need to use them, white women from the survey were the ones most likely to use anonymous, online feedback options. It was women from the marginalised groups who seemed to have the greatest cause for complaint and most frequently articulated concerns that complaining would result in negative personal outcomes for them.

Without feedback about problems arising with staff and information about ongoing access issues, unintended difficulties cannot be remedied and it means that practitioners who should be retrained, remanded or removed are continuing

to cause distress. I will explore potential solutions to this challenging issue in the concluding chapter.

Responding to Discrimination

As Sim, et al (2021) points out it is no secret that racism and unconscious bias are negatively impacting people's interactions with the health system. It formed a main theme of the findings and there was an incident that took place during the group analysis, that underscored the context that makes identifying and addressing this widespread issue such a challenge.

The Somali and Asian women's group varied in their confidence and willingness to pinpoint incidents of racism that impacted their care. This could be because the reasons for failures of care can be complex and nebulous and if you are entering a hierarchical space with an identity where multiple marginalised experience co-exist it might be hard to say which is being offended against - are your needs not being met because you are from another faith, because you were born overseas, because your first language is not English, because you are old, because you are a woman etc.

However, the Irish women's group were much more definite. This could be because many were second generation and they feel less exposed or because they had survived being in London from the time of the Troubles when discrimination was even more blatant. When the representatives from this group brought up the amount of racism experienced there was a moments recognition from the Somali and Asian Women's Group representatives, before the Yoga & Gardening Group representatives responded with shock.

They said they hadn't seen anything like that, which I am sure was the case and it was like a door to a possible discussion shutting. There was a tacit response unilateral from women with marginalised experience and the conversation was redirected. I had been caught by surprise as I was expecting a full discussion about this topic and considered intervening but the moment had passed. I felt

at the time that the women whose experience this was had chosen not to discuss it and I could empathise why they felt disinclined to justify themselves. Equally I could see that the women who had such marked privilege were discomfited by it and no doubt were shaken by the thought of their friends experiencing that pain.

I am unsure in retrospect what I could have done differently. I felt that it wasn't my story to tell and the information had been given clearly already. Although I am mindful of Cannon et al (1988) talking about social realities being constructed to epitomise white and middle-class experiences and with issue pertaining to minority group interest consigned to the margins of consideration (Zinn et al. 1986)

It was a recurrent theme across the data that many of the white and privileged participants articulated ideas around access issues but they often spoke theoretically. A number of the Irish women had been staff and patients were in a position to describe the situation from both perspectives and acutely noted the subtler forms of service rationing. Such as using leading questions to play on patients sense of guilt 'you'll be alright to go home' or concern about 'being a burden'.

The Irish Women's Group were the most explicit about the way that not just gender but class, culture and nationality intersect to make access to services more challenging for certain groups. The survey group (who were majority white) spoke about class differences between them and their care providers impacting their ability to be heard. In contrast to this the Yoga & Gardening Group seem to have markedly more positive encounters but what was notable was that they assumed priority services like being honed at home were standard expectation and the experience of all.

Womanhood and Wellness

There were interesting differences about the ways in which wellness and health were thought about across the focus and survey groups. The way some of the white participants visually described health - talking about their weight, having shiny hair and clear skin were almost like an advertisement. Especially when compared to the other groups descriptions of functionality and being independent - which is incidentally much more in alignment with health professional's perspective. The measurement of an individual's ability to undertake the Activities of Daily Living (ADL's) is a common measure of functionality - for example whether you can attend to your own self-care etc. The idea that 'looking' healthy is as important and valued by some participants as 'being' healthy, is likely to surprise many staff involved in assessment.

Health as work was an idea that crossed all groups whether you are talking about domestic labour or maintaining a conventionally 'attractive' body. Something Foucault talked about as 'biopower' - which is the way that individuals can feel societal pressure to regulate their bodies - through diets and exercise for example to meet collective expectations. There are social rewards available for being healthy and docile - just as there are sanctions for dissenting and being ill. As Beresford (2019) writes the very of experience of having unmet or multiple health needs puts individuals out of step with the everyday expectations which in turn shapes your interests and values. He goes further continuing that this marginalised experience can mark them out to the extent that their very existence is felt by some as a criticism.

Another theme that was unevenly found across the different groups were the ways in which ideas of womanhood impacted the participants expectations of pain and hardship. This is a separate topic in its own right but it is relevant to this study to note Werner and Malterud's (2003) work on women with medically unexplained symptoms being met with incomprehension and suspicion by their doctors. The research focused on the gendered dimensions of the experiences and women's struggles to be recognised as credible by staff are familiar.

This project adds a new and different perspective to this narrative by bringing in the lenses of culture and class. Whilst everyone's experience is individual it is interesting to see how shared discussion in the focus groups led to greater depth around specific points. From the Somali women's exploration of their desire for self-sufficiency and to be strong which they described being passed down like an inheritance from mothers to daughters. To the Asian women's discussion around subverting stereotypes by 'performing' compliance and gratitude. To the Irish women's clarity around race and class discrimination, which was echoed in the survey findings and the Yoga and Gardening groups conversation broadening initial understandings of health maintenance as gendered work to include beauty as well as functionality.

New Ideas

Despite the fact that the methodology for this project has been resource intensive, its' structure has remained porous despite external pressures. Taking an innovative approach has allowed women to contribute when and how they wanted to. None of the data or processes have been hidden away or moved outside their control and decisions have been made collectively. This is novel and hopeful, it also links with other new approaches being undertaken.

Blignault et al's (2021) study is called "You can't work with my people if you don't know how to" and it is a positive step forward. It is a well-funded project prioritising ethical and trauma-informed approaches to working with people whose needs and identities have been long overlooked. It is an evaluation for accessing primary care which led by and for Aboriginal Australians with complex need. It is heartening to see research protocols taking the principles of self-determination and equity of Experts by Experience seriously and using a strengths-based and appreciative inquiry approach,

Like the women in this study, the research participants working with Blignault's (2021) research team have experienced different forms of injustice and a loss

of trust. Where these innovative types of study add extra value, is that not only do they provide opportunities for services to understand how to improve their quality but they can also help begin to repair some past damage.

In this chapter I have explored the data gathered as part of this project. In the final chapter I offer conclusions and make recommendations for future practice.

Chapter 7 Conclusions and Recommendations

In this chapter I offer conclusions and make recommendations for future practice. The conclusion is structured by returning to the initial questions posed in this research and reviewing what novel information has been learned and how it is relevant to academic and practice areas. Then in the second part the recommendations are considered in light of changes that can be made both in practice and in research.

This research set out to understand if and when women with mental health issues seek help for their physical health concerns and to explore what their experience of accessing and receiving support for those physical health needs might include. The questions around women's encounters with health systems whilst initially seeming straightforward, soon led to the crossing of domains of practice between activism, scholarship, teaching and research. It required knowledge that was in part professional and in part personal to be valued equally and to do that it was essential to use coproductive methods and work with a transdisciplinary approach (Maguire, 2015).

A review of the literature highlighted the widespread nature of the problems faced by women, (particularly those facing multiple-disadvantage), when attempting to successfully access healthcare. Concerns about the type of research undertaken were noted, there was a lack of coproductive techniques which suggest only a partial understanding of the challenges are being made available. There were also queries around the limitations in the ethical frameworks being used to work with marginalised people. There was little formal recognition of women's distress and no articulation of trauma-informed or activist values were noted.

In this study the findings that were produced bring together multiple women's voices that whilst valuing individual stories, also shed light on the ways that different cultural and activity-based groups conceptualise their health and wellbeing. The narratives also highlighted the ways that poor experiences of

care impact current and future wellbeing and how the current reporting systems are not fit for purpose and are not effective in advancing quality or patient safety.

However, the most novel aspect of the project was the methodology was used. Whilst it was not commissioned by women using services, I strove from that point on to seek out women with lived experience of multiple need to offer insight via an advisory group. This group of specialists collaborated to create the research agenda from the questions to the ethics and participant guidance. The focus groups who self-selected and who worked in egalitarian and creative ways to create their own findings and member-check them; also nominated members to help analyse the findings thematically. This coproduced approach also incorporated feedback via and open survey and input from community members using the women's' centre and participating freely.

The knowledge that has been jointly created from this project shows ways in which women from marginalised populations who are often seen as 'hard to reach' are able to come together to voice their concerns and demonstrate their strength in challenging orthodox thinking around complex practice issues. With their permission and through working coproductively I have been able to publish and present these ideas and take them forward into national strategy documents. For example, the complexities around managing ethics in respectful and trauma-informed ways have been published in a paper urging practitioners and service users to be radical in critiquing their use of power in coproduced research. This call to use emancipatory and applied research methods to find solutions to areas of practice has had academic impact with the paper already having 50 citations (Lambert and Carr, 2018).

Another advantage of using this innovative approach has been to support my development as a practitioner working across heated political environments and needing to find solutions to issues which have conflicting agendas and have required innovation. I have detailed a reflexive account of my personal learning and professional journey in Chapter 8, but to give an example here I am a

founder member of a team that set up an open-access mental health podcast and vodcast to help create communities of learning that have been nominated for national awards. The constant call back to critical self-appraisal and reflection has benefited me in being part of national work on sexual safety in inpatient units. I was enabled by the learning from this project to work with Experts by Experience alongside professionals from the police to architects to share my academic knowledge into real world solutions.

Undertaking narrative, emancipatory feminist research has enabled me to integrate different aspects of my practice into a whole. I am much braver about what I say now professionally and have found a strength in my academic voice. Orr and Bennett (2009) also noted the subsequent enrichment of their work as the knowledge from their academic and practice-based professional identities became successfully fused.

Completing this research, using this particular way of working and seeing the impact on women of inadequate healthcare access has foregrounded the responsibility of professionals to change this situation. Braun and Clarke's (2019) description of the pressures inherent in neoliberal university systems was helpful in encouraging me to identify and resist the urge to conform to traditional methodologies or to depoliticise the data we collected. This research is hopeful in the strength and resourcefulness of the participants but the current picture of practice it depicts is a complex and disappointing one. There is a demonstrable need to change our focus from re-recording the same issues of disenfranchisement and publishing off of them, to actively start working on solutions

Recommendations

In this final section, using learning from this project I note the main findings from this research process and make links between them to targeted recommendations with the intention of improving care outcomes. This project was co-designed as a partnership to explore the experience of physical health issues in women with mental distress, in order to support best practice and improved care. My objectives were to understand if, and when women with mental health issues seek help for their physical health concerns. I also wanted to explore what their experience of accessing and receiving support for those physical health needs are. To aid a clear understanding of how the data gathered has shaped the findings, I have provided cross-references to demonstrate those links between findings and recommendations by page and paragraph.

The context of this work is important, with women's wellbeing being poorly served historically in biomedical settings. With the focus on reproductive health there is little consideration of women as independent citizens within their wider communities; or of other aspects of embodied womanhood (p106, para.4). With more women living longer as members of an aging population we need a health service that is able to support their long-term, multiple health needs (p.105, para.2).

The literature review highlighted issues with repetitious research studies which are not responsive to service-user need and which rarely result in meaningful service improvement. In addition, the data collected from the focus groups and online survey highlighted the multiple ways good health is conceptualised (p,101, para.2). It also identified concerns with a lack of accessibility to services (p.116, para.4), and women's unseen labour in maintaining their own and others wellbeing (p106, para.1). There were worrying accounts of women being ignored, dismissed, treated with incivility, (p.119, para.5) as well as experiencing

racism and poor care (p.102, para.2). These occurred alongside insufficient safe pathways to offer feedback or to complain (p.132, para.4).

The following recommendations are designed to relate to each of the issues highlighted by the project and indicate the bodies and organisations who may be assisted by the project's findings.

The first set of recommendations come from the need to better understand women's health and wellbeing indicated in the literature search and by the respondents. It is aimed at policy makers, educators and other stakeholders

The Women's Mental Health Taskforce Final Report from the Department of Health and Social Care and Agenda (2021) noted that services were still not flexible enough to meet women's needs especially when these are multiple or cross 'jurisdictional' boundaries. I contributed to this and nothing has changed except that this is now superseded by the Women's Health Strategy for England (2022). There was a call for evidence which 100000 individuals responded to and more than 400 responses from experts and organisations - including myself.

However, demographics of those with the social capital to hear about it, understand its importance, find the energy and time to respond were unsurprisingly and overwhelmingly: white, cisgender women. They were mostly from the south of England, of working age and those with certain types of disability or previous condition were over-represented. This is not representative of the experience of marginalised voices who should have been supported to shape this policy.

As a result, key information is missing and there are no concrete or measurable priorities attached to improving communication or meaningful participation– just

a vague aspiration to increase the 'representation of women's voices and experiences in policy making". This is despite the fact that 84% of respondents said that they didn't feel listened to by health staff - clearly a fundamental issue and one which if it is not addressed undermines all other aspects of a consultation. As Bagenal et al (2022) note there are many countries that are ahead of us who have excellent policies that could have offered some inspiration. It is telling that despite this policy's remit that the words misogyny and sexism are not present at all.

There is an All-Party Parliamentary Group on Women's Health which is a backbench cross-party group of MPs and Peers in the UK Parliament of Westminster. They should have a systematic reporting structure to inform their actions and shape their priorities that is drawn from women from diverse backgrounds who are facilitated to report in and also to commission service users to give feedback on particular issues (p.132, para.5).

In addition, everyone needs clearer understandings about how all human bodies work and from school age onwards there needs to be openness and clarity about traditionally taboo topics like menstruation and menopause. Without it we will continue to experience issues as a society with shame and stigma around the natural bodily processes of half of the population resulting in period poverty, lack of policy and support for people undergoing menopause and continued mismanagement of women's pain (p.103, para.4).

These educational expectations need to be explicit for all health professionals and formally embedded within curricula. More broadly we need to facilitate conversations about what it means to be well and be able to seek help appropriately, which leads on to the next set of recommendations.

The second set of recommendations aim to enable better access to services by utilising Communities of Health as indicated by previous

studies and in the feedback from both survey and focus group respondents. It is for service providers, professionals and policy makers; providers:

One way to address the loaded and unsatisfactory relationship that women have with access to primary care would be to shift away from the biomedical model which pushes so much power into professionals' hands. Participants in the project identified many ways to be healthy – for some people it was about their body's functionality for others it was about the way they look or feel inside.

These different conceptions of health could be supported by a range of services or groups; and there are small but positive moves to design, and evaluate crowdsourcing activities for promoting health (p111, para.2). From dementia-friendly communities, architecture built to support wellbeing, community gardens and access to green and blue spaces, to peer support projects and digital innovations to make services themselves more porous.

It is crucial that the systemic underfunding of social care, housing and community projects ceases. Much of the pressure on primary care is caused by underperformance in other parts of the systems designed to nurture society. For example, GP's cannot 'solve' homelessness or a poor police response to domestic violence and this lack of help in other parts of social care is resulting in the public attempting to get all its various needs met through the health service (p.114, para.6). This is resulting in a worrying correlation between poverty, marginalisation and high rates of inappropriate antidepressant prescription as well as overwhelming the GP services.

If the Australian Women and Digital Health Project is compared to the troubled NHS App, the gap between what is possible and what is happening is laid bare. The Australian project highlights the expertise by experience that women demonstrated in understanding and using health information, it also celebrates the role many women have in mediating access to health to others.

Where some groups' knowledge is underestimated, others can feel poorly prepared as agendas evolve. This project suggests that staff do not all have the training, skills or qualities to confidently offer holistic care to women (p.136, para.3) – health staff need open access to training and information in order to deliver trauma informed care that is gender specific and based in the realities of women's' lives (Lambert, 2018 and Lambert, 2023).

Staff training needs to be reconsidered by care providers and universities so that staff who are shift workers, and who frequently have carers responsibilities on top of a hectic work schedule can access updated information. Few health staff are able to commit to off-site day long training sessions but a blend of online or app-based training with personalised coaching gives staff the flexibility to build a personalised learning plan.

Another option is for apps or online health website to encourage members of the public to input their own health priorities and receive back a personalised plan or links to web resources or local support groups. This has happened in the private sector for health issues ranging from weight loss to addressing mental distress. If it were replicated with a local emphasis, it could help create health communities that reinforce connection. In addition, it could empower individuals who want to address their health needs without having to go to their GP as a sole access point and offer feedback anonymously (p.131, para.7). It could also alleviate some of the unseen labour of women if they were not automatically being assigned to manage their both own and their wider family's health (p110, para.1). This leads onto the third set of recommendations.

The third set of recommendations are to alleviate some of the pressure on GP services – a need indicated in the findings and discussion It is intended for NHS commissioners and may be of interest to those using services:

Since the pandemic GP surgeries are providing half a million appointments more every week (NHS Digital, 2023) and the need for them to act as triage services is growing as the population ages and requires more professional support to manage complex and interrelated health needs. It is likely that people will have better experiences if there is less pressure on this service (p.115, para.4).

One recommendation is to enlist more professionals who can aid GPs - if practice nurses, therapists and social prescribers were more accessible through self-referral pathways and those services offered from community centres, pharmacies and other community spaces then patients could select who they wanted to see. This access could happen via web or app access or even through touch screens in libraries, chemists or the surgeries themselves.

At the moment most people start ringing their GP at 8.30am in the hope that they will get an appointment in the next month and this unsatisfactory situation is only worsening. There has been recent review to explore primary care issues - the Fuller Stock take report (May 2022) and whist there are some excellent suggestions being considered, the strategy to involve people who use primary care is not clear. A twitter/'X' hashtag was created and nearly 1,000 (unspecified) people were involved through workstreams, but this seems haphazard and one of the main groups of people who need to be consulted are the people for whom the system is not working, who may be fearful about coming forward and who are unlikely to access a twitter/'X' hashtag.

There are many citizens who have to access GP's regularly who have experience and can offer valuable suggestions if they are given the opportunity. It would make better sense to let service users lead their own review and feedback independently, which leads on to the fourth set of recommendations.

The fourth set of recommendations aim to radically innovate the process of getting direct feedback from services users and to facilitate ways for them to raise concerns that are safer and effective. This need is highlighted from the research participants and in the discussion. The recommendations could be utilised by service providers, professionals and academic institutions/educators:

Berzins et al, (2018) found that 77% percent of service users and carers they spoke to reported finding it very difficult or difficult to raise concerns with health providers (p.127, para. 5), this is not an issue that will go away by itself. Instead of putting the onus on individuals to report issues, an automatic request to ask everyone to rate their health service interactions anonymously each time by phone or email could improve care. People do it all the time in other parts of their lives, and encouraging real time feedback, good or bad to GP surgeries normalises investing in this crucial relationship (p.119, para.5).

The World Health Organization and UNICEF (2018) have written guidance on crowdsourcing in health and health research and with a service-user led paper from that same year – there is best practice guidance on how to commission local communities to find a solution to the problems. Berzins et al, (2018) reported patients being ignored, worried about retaliation to complaints and found the process overwhelming (p.129, para.5) - especially when they were unwell, the current processes are not yielding improvements.

Universities, employers and governing bodies need to come together to agree on best practice guidance for staff responding to feedback and start educating staff to learn positively from feedback rather than fearing it. The NHS complaints policy should also be redesigned to make it an 'easy-read' document so anyone can understand it. It would also help to have links to an online reporting system with prompts, so helpful information can be shared and people can report the data that it's needed anonymously without fear of retribution. The NHS has a long history of supporting public health and the public have had pride in it. The

continued success of the NHS has to come from the people using it contributing to it – by understanding its purpose, when and how to use it and being able to shape and feedback to it freely.

The last set of recommendations come from the need to coproduce research that has meaning for its participants and which results in better care experiences. Its need is generated from the findings and discussion chapters and could be helpful for academic institutions, researchers and research funders.

It is a common trope that researchers always recommend further research be done in their chosen area. This is one case where we do not need any more research of the kind that has been previously produced. There is already much repetition that is not leading to any noticeable quality improvement.

Universities and councils could set aside funding for local communities to commission or vote for research that benefits their localities priorities and/or to award prizes to projects that result in improvements to an area or group. Funders can support service users to commission projects that meet their specific needs and requirements and find ways to start rewarding innovation in coproduction and activist projects.

All research projects should embrace guidance by service users on coproduction and ethical methodologies and to facilitate people with lived experience to have secure careers as researchers seeing their dual perspectives as a benefit rather than a potential issue. After an initial burst of enthusiasm around coproduction, many research plans are reverting back to lip service and diluting their commitment to ethical working practices. If innovation and tangible benefits were able to be recognised and rewarded by the populations the research impacted it could reinvigorate this commitment.

As Belone et al., (2016) assert, research questions and design need to come from the people being researched, coproducing findings about the issues that materially shape their lives, in the same way policy development should be centred around their input rather than having the bloodless ambition to increase 'representation of their voices'.

To conclude, this project has been resource-intensive but it has resulted in new ways to understand the problems women face when seeking support and care from their health service and methodological innovation. At the start of this project one of the outcomes was intended to be joint publication. When this was suggested to the participants the suggestion was politely declined, what was wanted was for me to leverage my contacts and provide female professionals to the women's centre who could be guests in Q and A sessions. One of the women's groups organised a monthly group where members suggest a topic that interests them, they compile questions and over a shared lunch and the relevant health professional answers their questions. The information is précised and turned into health and wellbeing information that is distributed via a community calendar.

It could be seen an insignificant outcome compared to something tangible like a large research grant but it is a hopeful sign to me. I am seeing women organising themselves to meet their needs, gathering, celebrating and sharing their knowledge. For the first time for some of them, a health professional has had to make an appointment to come to them, is in their space, answering their questions, they are hosting and they are being heard.

Chapter 8   A reflexive account of your personal learning and professional journey

My initial understanding of my positionality, this was written at the start of my research

I look back on this journey with very mixed feelings. I started optimistically and with a sense of positive purpose and whilst I still care greatly about the topic and the experience of women with multiple needs, I feel very differently about my own capacity to effect change and to be the possessor of knowledge. Learning to learn in this way been a bruising experience and most of my understanding has come though recognising limitations and making mistakes. It is a different journey to the one I initially envisioned.
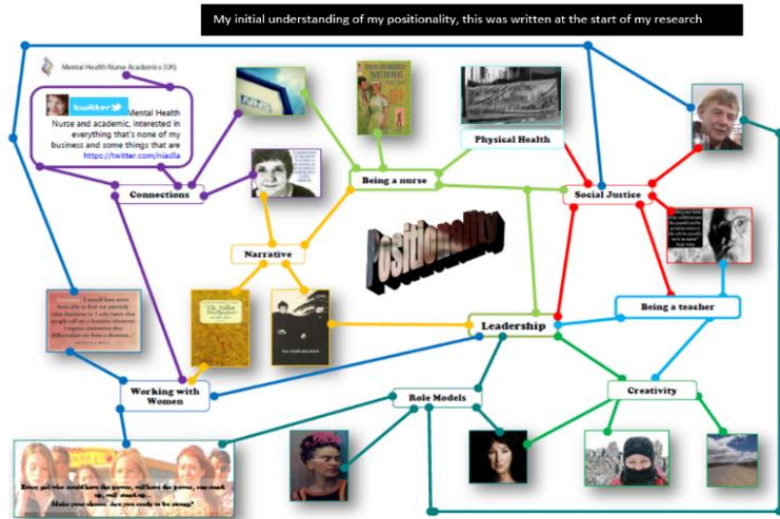
Adapting Brookfield's (1994) activities of critical reflection, I have considered my underlying assumptions, the context of the choices I made, I have used my imagination to explore possibilities and attempted to be sceptical and questioning about my recollection and personal narrative. Rather than a retrospective timeline I have considered key events and their ramifications, acknowledging the emotional components of critical reflection and learning.

<u>Reflecting on finding my voice:</u> I came to this project having been a nurse

Beginning to speak publicly about my own thoughts and positionality

manager and as a lecturer. I was able to talk about the things that mattered to me professionally in protected spaces but in retrospect I was hesitant about saying what i really thought about key matters in the public sphere and I worried about being

171

controversial. I equated neutrality to professionalism but i was also afraid of being wrong in public and to some extent being unlikeable.

I think now that power isn't power, if you are afraid to use it and it was through this work and by focussing on issues that were too important to stay quiet about that I gradually changed.

I was encouraged to use my voice creatively through listening to Kate Bush, and encountering work by Frida Kahlo and Charlotte Perkins Gilman taught me to consider a women's perspective on what constitutes a good life. I wanted to be able to talk about 'messy' subjects like 'pain', and explore controversial subjects like control and self-determination. Reading hooks, Freire and Rich encouraged me talk about social justice as part of health, wellbeing and education. It took time for me to become confident in my professional sense of self to speak openly about the lack of social justice in our society causing ill-health, sexual and domestic violence as part of a public health crisis.

I began speaking at conferences about my passion for mental health practice, then nurse education and then going on to tackle more controversial subjects. I still find publishing anxiety-provoking be it a blog, an editorial or an article. The feeling of having a permanent record made of your ideas – fixing them in stone so they are no longer capable of growth and charge still alarms me. I was speaking about the importance of person-centred, trauma-informed care at an international conference and I was quoted on a tweet on the ineffectiveness of the biomedical model in addressing the public health crisis of domestic violence.

Dr Sarah Carr @Schre... · 12/05/2017

"If I'm sending a woman home to domestic violence, no amount of Prozac is going to stop her getting hurt" @niadla

Getting bolder at an international conference talking about this work and on non-medical approaches to women's wellbeing

⟲ 53   ♥ 76

I still stand by what I said, but I don't know that i would have said it so baldly in an open setting at that time. I can still remember the anxiety i felt seeing my idea which had been expressed in the relatively sheltered environment of a health conference escaping and entering the public sphere. I recall that visceral feeling of dread but still I don't know who I thought I would get into trouble with.

I made professional connections to talk about women's wellbeing in more diverse forums and have since collaborated with the museum of domestic design and architecture through a podcast talking about the yellow wallpaper by Charlotte Perkins Gilman and the impact of the misuse of professional power and misogyny on women's health. I built on this productive relationship to co-host an open conference on health, wellbeing and the built environment which explored the impact of gender and class on health. It is important to me to bring ideas about health and coproduction to the widest audience.

I wrote editorials and parts of the nursing curriculum at my institution always making sure to bring in issues related to women's health and trauma-informed care. I have since spoken internationally on project related issues to many people, from introducing initially bewildered Mongolian nurses to trauma-informed practice and to clarifying the importance of co-production to Italian psychologists. I began work with period dignity projects and organised and hosted podcast/vodcasts on the important of period dignity and awareness in mental health settings and went on to work with the RCN's menopause specialists to produce national information packs about menopause awareness for staff when those subjects were still uncomfortable for some people to discuss openly.

Because my learning journey was based around hearing from people with lived experience and supporting others to speak up about what is important to them, this project has impacted my work in unexpected ways. I developed modules that cross the three years of the nursing degree and support students to consider their identities, make choices about their learning and see themselves as health activists and people whose voices and opinions are important contributions to their communities.

I was able to take learning from coproductive research into the planning of the curriculum

This is an open learning group at the Tate exploring the NMC guidance on modern slavery by looking at art and history.

The youngest person is 9 months students are encouraged to bring families and the older was 72 and a local who joined when they saw the invitation online.

and find ways to facilitate flexibility and inclusion by having the course online well before Covid and including options and critical reflection.
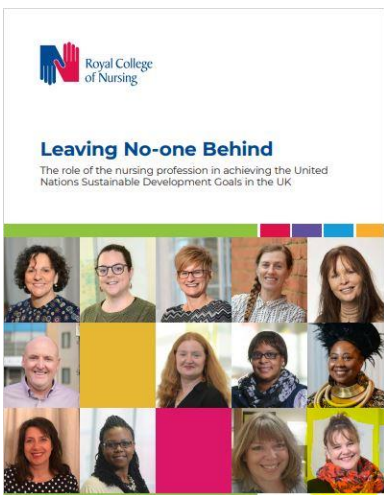
This work on expansive learning has been presented at numerous conferences and was recognised by the RCN as of national importance and used as an example of one of the ways that nursing can help meet the united nations sustainable development goals. Coproduction and learning from my D. Prof is central to its success.

The way I participate in debate around women's issues has been revolutionised by my time on this project. At the start I wanted to be able to speak out – now I want to co-create spaces to hear others. An

example of this change is that in 2020 when Covid struck I worked with the lead for mental health from Unite and a colleague who specialised in social media and we produced #mhTV – it is a podcast/vodcast that has live input from listeners and gives space to experts by experience and by learning to present issues that impact on health and nursing. It is coproduced and discursive.

There are over 130 episodes freely available via Facebook, YouTube, stitcher and Podbean and we were finalists in the RCNI awards for 2021. One of the things that this project has impressed upon me that I use in my work on #mhTV, is the

I am proud that we have been able to host so many different perspectives and enable access to presentations, conferences and discussions on a wide range of key topics

importance of knowing when not to speak and using what power you have to witness other people's stories and support space for them to tell them.

Reflecting on my professional sense of self: the learning I have accrued from this project has made me reconsider at lot of my assumptions about my own expertise. I have worked hard to take the skills i do have to areas where I can be of service. I was a trustee for West Hampstead Women's centre from 2014-21 and for the Bridge (a women's health charity) since 2021, I have participated in lots of nationally important work around women's wellbeing, safe practice and making coproduction central to quality improvement. For example, I was part of the group who worked on mental health nursing competency and career framework from skills for health and HEE. I authored the RCN public mental health pages, was part of the CQC sexual safety collaborative. I worked on London HEG: project Cureate and contributed official supporter of the 'ask and take action' project for Agenda.

I worked with dedication and enthusiasm to change services for the better and to make sure that women in particular would get the care they deserve. Locally I am a member of Camden and Islington women's strategy group: sexual safety work and policy writing. Nationally my work is used as a good practice example in 'No Wrong Door' a report by Centre for Mental Health and NHS confederation to create a vision for mental health, autism and learning disability services in ten years' time. I was also a member of the expert reference group for National Collaborating Centre for mental health's sexual safety standards and guidance.

Over the course of this project I have presented key ideas from this work from everywhere from America where I was part of meeting of nurse activists with Peggy Chinn to Malta where I spoke to a very traditional audience on politically engaged nursing practice. I enjoy new ideas and meeting people with shared passions but I am prouder that I have been able to take ideas across-interdisciplinary boundaries. The value for me in this way of learning is freedom I have had to investigate and create. It has been a significant gift to me personally and professionally and is something that helps to mitigate disappointments.

I worked in the NHS for 10 years before academia, and both institutions taught me about the difficulties of making change. I am glad (but obviously can't take personal credit!) that coproduction and women's health are mainstream topics now but am still frustrated by the slow pace of change. I think that at the back of my mind I naively assumed that if people were given information they would want to change and that systems would evolve to be kinder, more inclusive and better able to meet the needs of the people who pay for them.

I had the usual discouragements of working twice on national strategies for women's health - one was scuppered by a change of government and priorities. The second came to fruition and was released … and promptly ignored. Unless services are mandated to make changes and held to account, staff are so overwhelmed with necessary priorities they cannot summon the energy to

transform embedded working practices. I still help with projects on this scale whenever I am asked but I am more reserved in my expectations. It has been my experience that major change comes slowly and then with sudden tipping points because society and people's expectations change. It is because a requirement for change is needed before energy is put into reconfiguring systems that I have used my skills to facilitate women coming together to express their needs.

Along with local work connecting experts by experience and subject experts and mentoring. I worked on the women's marches after Trump's election, the processions project and for the 50:50 parliament. I used my organisational skills and health knowledge as a steward and led the disability access part of the project. This may seem unrelated to this project but it felt important to me that women with complex health needs were able to safely participate and are a recognised part of the community of women demanding respect and access to power.

I began to use my skills in health and organisation to support other women to make themselves heard and was the health and disability coordinator for the women's marches in London and the 50:50 parliament demonstration

However, it was the personal impact of a loss of a close friend to suicide was the main challenge I had to valuing my professional voice. I had been a mental health nurse for 20 years and a nurse educator for 8 when i said goodnight to an old friend going through a tough time only to hear that they had killed themselves the next night. I was the last person to have seen them and testified at the coroner's court as well as being central to cleaning and clearing their belongings.

Being a mental health nurse was so central to my identity at that point I hardly made a distinction between my personal and professional selves. I had lost service users to suicide as a nurse and felt it deeply. I had attended coroners court before but not as an individual. I was heartbroken and filled with grief, shame and guilt. I felt that I had missed clear signs of distress and did not know who I was, if I wasn't good at keeping vulnerable people safe.

I don't think that you do recover from losing someone you love – especially in that manner I think it is a pain you live around, I went to counselling and through the milestones of anniversaries I fought a battle to come back to that role. I really felt that I had no right to speak about mental health when I clearly knew nothing and the first time I taught students about suicide and risk assessment I was shaking and I cried in the toilets afterwards because I felt like a fraud. It took me a year to come back to feeling that I had any right to write or speak on this subject of mental health and I came back to the project a different, humbler student.

Despite the anxiety I have communicating my ideas and the doubts i have about the value of my expertise; presenting and writing have been a comfort at times when 'top down' change has brought little in the way of results. I have had people thank me for something I have written or said and being part of a community of learning has made a difference to my continued commitment to stand for things I believe are crucial to public health and wellbeing. It something that I value and now always make attempts to do for others.

Hi Nicky,

My name is [redacted] and I'm an academic/researcher at [redacted] cam across your paper today, written with Sarah Carr and I just wanted to write and tell you how much I loved it.

My PhD looked at power relationships and stigma for people living with mental illness admitted to general adult ICU – and now in my post doc, I want to undertake some participatory action research as a co-production. Your writing just really spoke to me, particularly about addressing power and centering the interests and needs of the participants, not the researchers.

I had been despairing post PhD because my findings were not that ICU nurses need more education (they do, but they can access that anytime) but that social change was needed. I had been reflecting at length about how to engage with co-production in a way that wasn't performative or tokenistic, god forbid the creation of a workbook or something. My goal is social change and the only people who can really drive that or know what is needed are those who have experienced the pointy end of these formidable power structures.

I'm not looking for anything particularly, I just connected with the paper so strongly that I wanted to say thank you – it has validated my own reflections and also articulated how I need to move forward.

If you are the type who likes to chat about your work, I would love to have a conversation with you – but if not, please just accept my thanks and complements.

I would really like to say the same to Sarah but cant see a current email for her. If you are in contact, are you able to pass this on?

Have a great day and thanks again for your work – it is really brilliant.

I concluded that as a senior practitioner one of the most useful things that I can do is to publicly acknowledge the problems and failures that are part of learning and researching and role model ways to move forward. I have done this though seminars writing and informal support. The independence of learning through a D. Prof is exciting and rewarding but it is simultaneously exposing as any errors are yours alone.

The world of academia is a place of ego and relies on the successful presentation of self to achieve success. To open yourself up to criticism and to be vulnerable is a risk. Especially if you don't have a secure contract or are still forming your academic reputation. One presentation I gave that people really responded to was called 'how not to be a mental health researcher' where I talked about the things that hadn't worked. I talked about how to avoid pitfalls and how

Enhancing Mental Health and Emotional Well-Being: The Impact of the Professional Doctorate

Middlesex University London

Nicky Lambert: Assoc. Prof. (Practice) at Middlesex University, and Dir. of Teaching and Learning for Mental Health and Social Work.
I am registered as a Specialist Practitioner (NMC) and a Senior Teaching Fellow (SFHEA). I am also co-director of the Centre for Coproduction in Mental Health and Social Care

This poster explores how working on a D.Prof has redefined the ways that I envisage my role and purpose as a nurse.

Academic productivity is often seen as the 'point' of learning at this level - arguably it is just one aspect of the journey. Outputs that impact practice are another outcome and one of ways that D.Profs are differentiated from other types of programme. My own work has generated tangible benefits to the health and wellbeing of others and in addition, it has also supported my professional development and this has linked symbiotically to personal growth which has occurred over the timespan of this project.

This poster was adapted from a talk which contends that in terms of wellbeing, recognising and celebrating the personal changes generated by the programme are equal value to the traditional outputs.

Getting through the bleak times

Developing your critical resilience and understanding your strengths and learning needs is key to any successful professional career. These are skills often honed from the rigours of a long term applied project.

- Build links to your community of learning and get a support team in place.
- Expect there to be low points and plan for them. Learn from other people's coping strategies.

Finding your voice.

- **Engage with your research community.** Try to go to conferences (in person or follow along online), attend workshops, special interest groups... go anywhere practitioners from your area of interest meet.
- **Write whenever possible:** Blogs, articles, journalistic articles as well as peer reviewed work.
- **Say yes !** Present your work as often as you can, and for as many different audiences as possible - talk to the public as much as to your peers - use podcasts, festivals, talks.
- **Use Social Media:** link your tweets/Instagram etc. to your blogs, use infographics to make your ideas accessible, use platforms like The Conversation to connect your work to current concerns.
- **Don't be afraid to speak up on your topic** ... you have earned your expertise!

Evolving alongside your D.Prof.

My D.prof journey began with a chance encounter with someone crying in a hospital corridor and is still unfolding. My research looks at the Experiences of Women with Mental and Physical Health Issues in Accessing and Receiving Care - a topic well within the remit of a mental health nurse.

However, my learning quickly removed me from my comfort zone and took me onto a journey with many new roles: as an educator, a writer, a broadcaster, a trustee, a spokesperson, and an activist. All of which have been equally valuable outputs.

Nicky has worked across a range of mental health services both in the UK and internationally supporting staff and practice development in acute and mental health trusts, councils, businesses and charities. She is also a Trustee for West Hampstead Women's centre.

Nicky has a professional Twitter feed: https://twitter.com/niadla (@niadla) and is keen that all people with an interest in mental health engage together as a community to support good practice and challenge discrimination.

She has teaching and research interests in women's health, physical and mental health, co-production, social media and health education
(ORCID ID: 0000-0001-8785-4719)

193

to recover from them. I want my learning to support people to thrive and not to undercut their self-confidence. To do that I have to be honest about my experience and challenge negative learning environments.

Reflecting on learning by experience: I was committed to coproductive processes from early in my career and to working with people living with mental distress. I had a technical and professional understanding of the importance of lived experience. In terms of women's health though that knowledge was technical rather than visceral. I grasped that it was important for service improvement and to ensure quality but I hadn't truly appreciated the cost to of involvement to service users. Although my commitment to wellbeing remained during lockdown as it was an emergency this project was temporarily set aside.

I provided teaching and learning support to nursing students and university staff through an online series on mindfulness and relaxation. I worked with NHS England & NHS improvement to host wellbeing sessions for nurses, coproduced free online resources with my care academy to support staff who needed to learn new skills to offer care after death for patients suspected or confirmed covid-19. I worked with NCL in mind / Tavistock/Portman NHS trust to connect and support the North Central London Health and Social Care Workforce during the coronavirus outbreak.

180

I worked with service users via my local recovery college order to deliver short courses on healthy relationships for local communities who were experiencing loneliness and isolation. I wrote editorials, blogs and articles and when the situation had eased and lockdown ended I caught Covid.

It wasn't bad, just a couple of weeks however I didn't bounce back. During my working life to this point I had had 8 days off over 25 years, I have always loved my work and found it a pleasure. I couldn't settle or focus and was constantly tired. Eventually I was persuaded to see my GP on a Wednesday and was signed off with suspected long Covid. I was shocked and I felt humiliated to be off sick, it took me until the Friday to admit I was ill and it happened because i was struggling to write a blog on self-care that I had agreed to do as a favour. I was sat at my laptop and I realised I could not form a sentence. It was terrifying. My symptoms worsened quickly and I soon stopped being able to talk fluently, I could not breathe or walk and my memory and focus were poor. I was off for four months and then had 6 months of a phased return to work. It has been a year since then and I am still slow. I wake with anxiety and tire easily. I have physical limitations and mentally, my processing and recall are still problematic.

However, I learned some hard lessons that feed into this work. This experience has been devastating but the forced shift in my perspective from professional to patient has made me more passionate about ensuring women get trauma informed, person centred care. I had years of knowledge about how the NHS works and was able to negotiate the system. I was able to understand what was happening to me and to describe my symptoms. I had a reputation and professional standing that meant I was attended to when I spoke and was believed. I knew how to complain – although I never needed to because my care was good but with all of that there were no answers for me. I had banks of blood tests and medical support but none of it helped with any of the symptoms. I self-isolated at first because I didn't want my friends and family to see me. I didn't want to worry them or for them to feel sorry for me.

What really changed things was having friends who had long-term health conditions and who had already grappled with illness themselves. People with anxiety and chronic fatigue generously gave advice about managing my energy levels. People with depression spoke to me about motivation and managing emotion. Others spoke about navigating appointments and contact with professionals. When I couldn't focus to read, I had guidance on how to begin again and helpful book recommendations.

That store of knowledge got me to a space where I could write myself a nursing care plan and start building back. I started to share my experience with friends and work colleagues and was overwhelmed by their support. I went to community choir for breathlessness and had physical rehab. Eventually i was mobile and back in front of an online classroom, it is a challenge still but I have a new perspective on my work and purpose.

I understand the cost of personal knowledge in a way that I didn't appreciate previously and recognise the emotional component of ill health. My negative response and stigma toward my own vulnerability made me question my assumptions about illness. I have been a mental health nurse all my adult life and would never think negatively about someone else who was sick. I assumed that I was exempt from this life experience – in any case it took me a while and more counselling to process my fear and to recognise my own internalised stigma. I did not think there was any shame in needing help but I had a subconscious hierarchy in my head that I only discovered when I became a patient myself.

There is an element of ego in being a professional and making decisions about other people's options, there is a social ranking to being a lecturer. If your power comes from having power over others even if you try consciously not to use it, it still impacts what you see and how you are seen. I only want to have power over myself and that has proved illusory but it is important to me to keep a check on how well I think of myself and my gifts and abilities and also to be

realistic about my limitations. I still think that whatever power anyone has they are obliged to use it to help the next person.

My personal learning has been that I turned out not to be as good as I thought I was, or as bad as I feared I was. Professionally I try to gather myself and come back to my first principles - what is important to me remains kindness and compassion, I have different skills to offer now and the way I offer them is to genuinely 'do with' others rather than 'do to' them. It is that shift from thinking I know to asking, and waiting listening instead of talking – it does not always come naturally to me but it is the kind of researcher, teacher and nurse that i want to be.

The things that give me pleasure now are about being part of the whole, being made a fellow of the mental health collective and accepted as part of that community was moving. Being recognised by people whose skills you value is affirming. I am still not in a place to celebrate all of my learning journey, there are aspects which are very painful but I do appreciate it.

MHC_UK
@MHC_UK

This New Year's Day, we are delighted to announce that Nicky Lambert FMHC has been recognised as a Fellow of the Mental Health Collective. #FMHC @niadla

I still support work on wellbeing but from a more open and vulnerable place. I collaborated on the "I'm fine" project with paintings in hospitals designed to improve nurses' mental health and wellbeing. I worked with NHS England / NHS improvement on wellbeing conversations and I think that whilst I have completed my research and published and presented it the products of this learning that will have the most significant and lasting value for me are not ones that will end up in a repository.

Subject: Talking Heads – Video attached

Dear All,

I want to take this opportunity once more to thank you all for helping making this work possible. Without you I could never have gotten this great piece of work off the ground. The link below will take you to the wellbeing conversation package that will be available tomorrow. Thank you also for sharing your experiences and your vulnerability as well. You are all truly magnificent. It is a pleasure to be able to call you all my colleagues. If anyone needs a chat at anytime, please don't hesitate to contact me.

https://people.nhs.uk/projectm/wellbeing-conversations/

Best wishes and stay safe.

Staff Health and Wellbeing Team
Staff Experience and Engagement, People Directorate
NHS England and NHS Improvement
Follow us on Twitter: @NHSImprovement
#CaringForOurPeople

References

Agenda Alliance (2021) Voices From Lockdown: One Year On: A Way Forward For Women And Girls Full Report Https://Www.Agendaalliance.Org/Documents/15/Voices_From_Lockdown_Report.Pdf Last accessed 29/8/23

Aguinis, H. and Solarino, A.M., (2019.) Transparency and replicability in qualitative research: The case of interviews with elite informants. Strategic Management Journal, 40(8), pp.1291-1315.

Agyeman, G.S., (2008). White researcher-black subjects: Exploring the challenges of researching the marginalised and 'invisible,'. In Proceedings of the 7th European Conference on Research Methodology for Business and Management Studies: ECRM2008 (p. 267). Academic Conferences Limited.

Alexander, I.M., (2004) Characteristics of and problems with primary care interactions experienced by an ethnically diverse group of women. Journal of the American Academy of Nurse Practitioners, 16(7), pp.300-310.

Allen, D., (1992). Anti-intellectualism is stifling the nursing profession. Nursing standard (Royal College of Nursing (Great Britain): 1987), 7(3), pp.14-14.

Anderson, R.T., Barbara, A.M., Weisman, C., Hudson Scholle, S., Binko, J., Schneider, T., Freund, K. and Gwinner, V., (2001). A qualitative analysis of women's satisfaction with primary care from a panel of focus groups in the national centers of excellence in women's health. Journal of women's health & gender-based medicine, 10(7), pp.637-647.

Anderson, R.T., Weisman, C.S., Camacho, F., Scholle, S.H., Henderson, J.T. and Farmer, D.F., (2007) Women's satisfaction with their on-going primary health care services: a consideration of visit-specific and period assessments. Health services research, 42(2), pp.663-681.

Anzaldúa, G. (2012) Borderlands/La Frontera: The New Mestiza. Fourth Edition Ed. San Francisco: Aunt Lute Books. Latin American And Caribbean Ethnic Studies 21

Ashley F. (2020) Accounting for research fatigue in research ethics. Bioethics. 2020;00:1–7. https://doi.org/10.1111/bioe.12829

Ashworth, P., (1996). Presuppose nothing! The suspension of assumptions in phenomenological psychological methodology. Journal of Phenomenological Psychology, 27(1), pp. i-25.

Bagenal, J., Khanna, R. and Hawkes, S., 2022. Not misogynistic but myopic: the new women's health strategy in England. The Lancet, 400(10363), pp.1568-1570.

Bans-Akutey, A. and Tiimub, B.M., 2021. Triangulation in research. Academia Letters, 2. https://www.researchgate.net/profile/Benjamin-Tiimub-2/publication/355425953_Triangulation_in_Research/links/616fd0f1b148a924b8013beb/Triangulation-in-Research.pdf Last accessed 29/8/23

Belone, L., Lucero, J.E., Duran, B., Tafoya, G., Baker, E.A., Chan, D., Chang, C., Greene-Moton, E., Kelley, M.A. and Wallerstein, N., 2016. Community-based participatory research conceptual model: Community partner consultation and face validity. Qualitative health research, 26(1), pp.117-135.

Beresford, P., (2005) It's Our Lives: A short theory of knowledge, distance and experience https://shapingourlives.org.uk/report/its-our-lives-a-short-theory-of-knowledge-distance-and-experience/ Citizen Press Last accessed 29/8/23

Beresford, P., (2005). Developing the theoretical basis for service user/survivor-led research and equal involvement in research. Epidemiology and Psychiatric Sciences, 14(1), pp.4-9.

Beresford, P., 2019. Public participation in health and social care: exploring the co-production of knowledge. Frontiers in Sociology, 3, p.41.

Berzins, K., Louch, G., Brown, M., O'Hara, J.K. and Baker, J., (2018). Service user and carer involvement in mental health care safety: raising concerns and improving the safety of services. BMC health services research, 18(1), pp.1-8.

Best AL (2003) Doing race in the context of feminist interviewing: Constructing whiteness through talk. Qualitative Inquiry 9(6): 895–914..

Bevir, M. and Rhodes, R.A.W. (2003), Interpreting British Governance, Routledge, London

Birch, S., Lavender, T. and Cupitt, C., (2005). The physical healthcare experiences of women with mental health problems: Status versus stigma. Journal of mental health, 14(1), pp.61-72.

Booth, A., Garside, R., & Rashidian, A. (2015). Using qualitative evidence in decision making for health and social interventions: An approach to assess confidence in findings from qualitative evidence synthesis (GRADE-CERQual). PLoS Med,12(10): e1001895. https://doi.org/10.1371/journal.pmed.1001895

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. Sage.

Braun, V., Clarke, V., & Gray, D. (2017). Innovations in qualitative methods. In B. Gough (Ed.), The Palgrave handbook of critical social psychology (pp. 243–266). Palgrave Macmillan.

Braun, V., & Clarke, V. (2017). Reflecting on qualitative research, feminist methodologies and feminist psychology: In conversation with Virginia Braun and Victoria Clarke - Glen Jankowski Psychology of Women Section Review, 19(1), Reflecting on qualitative research, feminist methodologies and feminist psychology_ACCEPTED.pdf (auckland.ac.nz) Last accessed 29/8/23

Breitbart, W. Rosenfeld, B.D. Passik S.D. (1996) 'Interest in physician-assisted suicide among ambulatory HIV infected patients' Am J Psychiatry, 153 pp. 238–242

Brockbank, A and McGill, I (2006) Facilitating Reflective Learning through Mentoring

Brookfield, S., (1994). Tales from the dark side: a phenomenography of adult critical reflection. International journal of lifelong education, 13(3), pp.203-216.

Buetow, S., (2019). Apophenia, unconscious bias and reflexivity in nursing qualitative research. International journal of nursing studies, 89, pp.8-13.

Burnard, P., (1991). A method of analysing interview transcripts in qualitative research. Nurse education today, 11(6), pp.461-466.

Caldwell, K., Henshaw, L. and Taylor, G., (2011). Developing a framework for critiquing health research: an early evaluation. Nurse Education Today, 31(8), pp. e1-e7.

Candela, A.G., (2019). Exploring the function of member checking. The Qualitative Report, 24(3), pp.619-628.

Carlson, J.A., (2010). Avoiding traps in member checking. Qualitative Report, 15(5), pp.1102-1113.

Candia, P. C.; and Barba, A.C. (2011) 'Mental capacity and consent to treatment in psychiatric patients: the state of the research' Current Opinion in Psychiatry Vol 24 (5) 442–446

Cannon, L.W., Higginbotham, E. and Leung, M.L., (1988). Race and class bias in qualitative research on women. Gender & Society, 2(4), pp.449-462.

Carnrike CL, Jr, Cherry R. (1984) 'Informed consent for investigational chemotherapy: patients' and physicians' perceptions. J Clin Oncol. 2(7):849–855

Carper, B. (1978). Fundamental patterns of knowing in nursing. Teachers College, Columbia University

Carr, S. (2020) Opening the doors of the Machine Room – Evidence & Policy blog https://www.mricg.info/single-post/2020/10/09/opening-the-doors-of-the-machine-room Last Accessed 29/0/23

Carter, N. Bryant-Lukosius, D. DiCenso, A. Blythe, J. and Neville, A.J. (2014) The use of triangulation in qualitative research. In Oncology nursing forum (Vol. 41, No. 5, p. 545).

Carver, L., Morley, S. and Taylor, P., 2017. Voices of deficit: Mental health, criminal victimization, and epistemic injustice. Illness, Crisis & Loss, 25(1), pp.43-62.

Case, K. (2020) Intersectional patterns of prejudice confrontation by White, heterosexual, and cisgender allies. Journal of Social Issues, 76(4), 899–920.

Cavanaugh, S. (1995),'Depression in the medically ill: Critical issues in diagnostic assessment' Psychosom Bull, 36 pp. 48–59

Chinn PL, Kramer MK. (2018) Knowledge Development in Nursing. Theory and Process. 10th ed. St Louis, MO: Elsevier;

Clandinin, D. J., & Connelly, F. M. (2000). Narrative inquiry: Experience and story in qualitative research. San Francisco, CA: Jossey-Bass.

Clarke, V. and Braun, V., (2019). Feminist qualitative methods and methodologies in psychology: A review and reflection. Psychology of Women and Equalities Section Review, 2(1), pp.13-28.

Coetzee, B., Roomaney, R., Willis, N. and Kagee, A., (2019). Body mapping in research. https://philpapers.org/rec/COEBMI Last accessed 29/8/23

Coghlan, D., & Brydon-Miller, M. (Eds.). (2014). The SAGE Encyclopaedia of Action Research. SAGE.

Collins, P.H., (2015). Intersectionality's definitional dilemmas. Annual review of sociology, 41, pp.1-20.

Cook, D.A. (2019). Systematic and Nonsystematic Reviews: Choosing an Approach. In: Nestel, D., Hui, J., Kunkler, K., Scerbo, M., Calhoun, A. (eds) Healthcare Simulation Research. Springer, Cham. Department of Health and Social Care (2020) Independent Medicines and Medical Devices Safety Review report, published July 2020

Cooney, A., 2010. Choosing between Glaser and Strauss: an example. Nurse researcher, 17(4).

Corbin, J. and Strauss, A., 2008. Qualitative research. Techniques and procedures for developing grounded theory, 3.

Council for International Organizations of Medical Sciences (CIOMS) and World Health Organization (WHO) (2002) International Ethical Guidelines for Biomedical Research Involving Human Subjects www.fhi.org/training/fr/retc/pdf_files/cioms.pdf   Last accessed 29/8/23

Crenshaw, K. (1991) Mapping the margins: Intersectionality, identity politics, and violence against women of color. Stanford Law Review, 43(6), 1241–1299. https://doi.org/10.2307/1229039

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. Theory into Practice, 39(3), 124-130.

Crichton, P., Carel, H. and Kidd, I.J., (2017) Epistemic injustice in psychiatry. BJPsych bulletin, 41(2), pp.65-70.

Cucciniello, M., Porumbescu, G.A. and Grimmelikhuijsen, S., (2017). 25 years of transparency research: Evidence and future directions. Public Administration Review, 77(1), pp.32-44.

Curtin, M., & Fossey, E. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. Australian Occupational Therapy Journal, 54, 88-94.

D'Antonio P. (2013) Working on the "jagged edge": reflections on Thorne and Chinn. Can J Nurs Res;45(2):23.

D'Agincourt-Canning, L. and Ells, C. eds., (2019). Ethical Issues in Women's Healthcare: Practice and Policy. Oxford University Press.

Danieli, A. and Woodhams, C., (2005). Emancipatory research methodology and disability: A critique. International Journal of Social Research Methodology, 8(4), pp.281-296.

Day, S. (2012). A reflexive lens: Exploring dilemmas of qualitative methodology through the concept of reflexivity. Qualitative Sociology Review,8, 60–85

DeMarco, R., Campbell, J. and Wuest, J., (1993). Feminist critique: Searching for meaning in research. Advances in Nursing Science, 16(2), pp.26-38.

Department of Health (2005) Research Governance Framework for Health & Social Care (2nd Edition) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962   Last accessed 29/8/23

Department of Health (2014) Comorbidities A framework of principles for system-wide action https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/307143/Comorbidities_framework.pdf   Last accessed 29/8/23

Department of Health and Social Care (2020) Report of the Independent Inquiry into the issues raised by Paterson, published February 2020

Department of Health and Social Care (2022) Final report of the Ockenden review, published March 2022 doi.org/10.1111/scs.12327

Department of Health and Social Care (2022) Women's Health Strategy for England: August 2022 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100721/Womens-Health-Strategy-England-web-accessible.pdf Last accessed 29/8/23

Doyle, S. (2007). Member checking with older women: A framework for negotiating meaning. Health Care for Women International, 8(10), 888-908.

Dreyfuss HL (1991) Being-in-the-world: A Commentary on Heidegger's Being and Time, Division 1. Cambridge, MA: MIT Press

Edge, D. and MacKian, S.C., (2010). Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among Black Caribbean women in the UK. Ethnicity & health, 15(1), pp.93-111.

Ewart SB, Bocking J, Happell B, Platania-Phung C, Stanton R. (2016) Mental Health Consumer Experiences and Strategies When Seeking Physical Health Care: A Focus Group Study. Global Qualitative Nursing Research. 2016;3. doi:10.1177/2333393616631679

Fagin, C.M., (1987). The visible problems of an" invisible" profession: The crisis and challenge for nursing. Inquiry, pp.119-126.

Faulkner, A., and Kalathil, J. (2012). The Freedom to Be, the Chance to Dream: Preserving User-led Peer Support in Mental Health. London: Together for Wellbeing.

Faulkner, A., Carr, S., Gould, D., Khisa, C., Hafford-Letchfield, T., Cohen, R., Megele, C. and Holley, J, (2019). 'Dignity and respect': An example of service user leadership and co-production in mental health research. Health Expectations.

Field, P. A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches, Rockville, MD: Aspen.

Finlay, L., (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. Qualitative research, 2(2), pp.209-230.

Flaskerud, J.H. and Winslow, B.J., (1998). Conceptualizing vulnerable populations health-related research. Nursing research, 47(2), pp.69-78.

Foth, T., Lange, J. and Smith, K., (2018). Nursing history as philosophy— towards a critical history of nursing. Nursing Philosophy, 19(3), p.e12210.

Fraser, H. and MacDougall, C., (2017). Doing narrative feminist research: Intersections and challenges. Qualitative Social Work, 16(2), pp.240-254.

Fricker, M. (2008) "Epistemic Injustice: Power and the Ethics of Knowing": Précis Theoria: An International Journal for Theory, History and Foundations of Science, SEGUNDA EPOCA, Vol. 23, No. 1(61) pp. 69-71

Frye, M., (2019). Oppression. In Ideals and ideologies (pp. 411 - 419). Routledge.

Ganzini, L. Lee, M.A. Heintz, R.T. Bloom, J.D. and Fenn, D.S. (1994) 'The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy' Am J Psychiatry, 151 pp. 1631–1636

Gilligan, C., Spencer, R., Weinberg, M.K. and Bertsch, T., (2003). On the Listening Guide: A voice-centered relational method.

Gilligan, C.,(2015). The Listening Guide method of psychological inquiry. England: Pearson Education.

Ginsberg, M. B., & Wlodkowski, R. J. (2009). Diversity and motivation: Culturally responsive teaching in college (2nd ed.). San Francisco: Jossey-Bass.

Goffman, E. (1963). Stigma: Notes on a spoiled identity. New York, NY: Simon and Schuster.

Goodey, J., (2005). Victims and victimology: Research, policy and practice. Pearson Education.

Graffigna, G., & Bosio, A. C. (2006). The influences of settings on findings produced in qualitative health research: A comparison between face-to-face and on-line discussion groups about HIV/AIDS. International Journal of Qualitative Methods, 5(3), 55-76.

Granger, K (2013) Hello My Name Is: A campaign for more compassionate care https://www.hellomynameis.org.uk/ Last Accessed 29/8/23

Griffin MG, Resick PA, Waldrop AE, Mechanic MB. Participation in trauma research: is there evidence of harm? J Trauma Stress. (2003) Jun;16(3):221-7. doi: 10.1023/A:1023735821900. PMID: 12816333.

Hadland, R. and Lambert, N., (2014). The challenge of dignity in mental health. British Journal of Mental Health Nursing, 3(3), pp.132-136.

Hafford-Letchfield, T., Lambert, N., Long, E. and Brady, D., (2017). Going solo: Findings from a survey of women aging without a partner and who do not have children. Journal of Women & Aging, 29(4), pp.321-333.

Hallam, L., Vassallo, A., Pinho-Gomes, A.C., Carcel, C. and Woodward, M., (2022). Does journal content in the field of women's health represent women's burden of disease? A review of publications in 2010 and 2020. Journal of Women's Health, 31(5), pp.611-619.

Hallett, R. E. (2013). Dangers of member checking. In W. Midgley, P. A. Danaher, & M. Baguley (Eds.), The role of participants in education research: Ethics, epistemologies, and methods. (pp. 29-39). New York, NY: Routledge

Hankivsky, O., (2012). Women's health, men's health, and gender and health: Implications of intersectionality. Social science & medicine, 74(11), pp.1712-1720.

Harding, S., (1995). "Strong objectivity": A response to the new objectivity question. Synthese, 104, pp.331-349.

Hardy, C. and Clegg, S. (1997), "Relativity without relativism: reflexivity in post-paradigmorganization studies", British Journal of Management, Vol. 8 No. 2, pp. S5-S17 (special issue).

Health Foundation (2023) Health in 2040: projected patterns of illness in England July 2023 https://reader.health.org.uk/projected-patterns-of-illness-in-england Last Accessed 29/8/23

Heidegger, M. (1962). Being and Time. Oxford: Blackwell Publishing.

HESA (2021) Higher Education Staff Statistics: UK, 2020/21 https://www.hesa.ac.uk/news/01-02-2022/sb261-higher-education-staff-statistics Last Accessed 29/8/23

HMSO (2010) Equality Act. London: " https://www.gov.uk/guidance/equality-act-2010-guidance Last Accessed 29/8/23.

Hoffman, T., Bennett, S., & Del Mar, C. (2013). Evidence-Based Practice: Across the Health Professions (2nd ed.). Chatswood, NSW: Elsevier. Last Accessed 29/8/23

hooks, b. (1994) Teaching to transgress: education as the practice of freedom / Bell Hooks Routledge New York

hooks, b. (1990) Yearning: Race, gender and cultural politics. Boston, MA: South End Press.

hooks, b., (1989) Choosing the margin as a space of radical openness. Framework: The Journal of Cinema and Media, (36), pp.15-23.

Hopia, H., Latvala, E. and Liimatainen, L., (2016). Reviewing the methodology of an integrative review. Scandinavian journal of caring sciences, 30(4), pp.662-669.

Hunt, C. and Sampson, F., (2018). Writing: Self and reflexivity. Bloomsbury Publishing.Parsons T. (1951). The social system. Tavistock Publications.

Husserl, E. (1965). Phenomenology and the crisis of philosophy. (Z. Lauer, Trans.). New York: Harper & Row.

Jacobson, D. and Mustafa, N., (2019). Social identity map: A reflexivity tool for practicing explicit positionality in critical qualitative research. International Journal of Qualitative Methods, 18, p.1609406919870075.

Jeste, D.V. Palmer, B.W. Shahrokh, G. Eyler, L.T. Dunn, L.B. Meeks, T. Glorioso, D. Fellows, I. Kraemer, H and Appelbaum, P.S. (2009) 'Multimedia Consent for Research in People with Schizophrenia and Normal Subjects: a Randomized Controlled Trial' Schizophrenia Bulletin 35(4): 719-729

Jobling, K., Lau, P., Kerr, D., Higgins, R.O., Worcester, M.U., Angus, L., Jackson, A.C. and Murphy, B.M., (2016). Bundap Marram Durn Durn: Engagement with Aboriginal women experiencing comorbid chronic physical and mental health conditions. Australian and New Zealand Journal of Public Health, 40, pp. S30-S35.

Kamberelis, G. & Dimitriadis, G. (2005). Focus groups: Strategic articulations of pedagogy, politics, and inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (3rd ed., pp. 887-908). Thousand Oaks, CA: Sage.

Kapp, M.B. and Mossman, D. (1996) 'Measuring decisional capacity: Cautions on the construction of a "capacimeter." Psychology, Public Policy, and Law, Vol 2(1), 73-95.

Keogh, E., (2021). The gender context of pain. Health Psychology Review, 15(3), pp.454-481.

Kim-Dorner, S.J., Schmidt, T., Kuhlmann, A., Graf von der Schulenburg, J.M., Welte, T. and Lingner, H., (2022). Age-and gender-based comorbidity categories in general practitioner and pulmonology patients with COPD. NPJ Primary Care Respiratory Medicine, 32(1), p.17.

Kingston, A.K., (2020) Feminist Research Ethics: From Theory to Practice. Handbook of Research Ethics and Scientific Integrity, pp.531-549.

Kinsman, L., Radford, J., Elmer, S., Ogden, K., Randles, S., Jacob, A., Delphin, D., Burr, N. and Goss, M., (2020). Engaging "hard-to-reach" men in

health promotion using the OPHELIA principles: Participants' perspectives. Health Promotion Journal of Australia, pp.1-8.

Kirk, T and Bersoff, D.N. (1996) 'How many procedural safeguards does it take to get a psychiatrist to leave the light bulb unchanged? A due process analysis of the MacArthur Treatment Competence Study'. Psychology, Public Policy, and Law, Vol 2(1), 45-72.

Koelsch, L. (2013). Reconceptualizing the member check interview. International Journal of Qualitative Methods, 12, 168-179.

Kohler Riessman, C. (1993). Narrative analysis. Thousand Oaks, CA: Sage.

Kutcher, A.M. and LeBaron, V.T., (2022). A simple guide for completing an integrative review using an example article. Journal of Professional Nursing, 40, pp.13-19.

Lakeman, R., (2010). Epistemic injustice and the mental health service user. International Journal of Mental Health Nursing, 19(3), pp.151-153.

Lambert N (2019) Nursing care plans in mental health. Mental Health Practice.

Lambert, N. and Carr, S., (2018). 'Outside the Original Remit': Co-production in UK mental health research, lessons from the field. International Journal of Mental Health Nursing, 27(4), pp.1273-1281.

Lambert, N. Hafford-Letchfield, T. Khan, H. Brady, D. Long, Clarke, L.(2018) Stories of intimacy and sexuality in later life: solo women speak Sexuality, Sexual and Gender Identities and Intimacy Research in Social Work

Lambert, N., 2018. Supporting women with mental health issues. Mental Health Practice, 21(7).

Lambert, N., 2023. Supporting people who are experiencing domestic abuse. Mental Health Practice, 26(3).

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), pp.59-78.

Lewin, S., Glenton, C., Munthe-Kaas, H., Carlsen, B., Colvin, C.J., Gülmezoglu, M., Noyes, J., Booth, A., Garside, R. and Rashidian, A., (2015). Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). PLoS medicine, 12(10), p.e1001895.

Lian, O.S. and Hansen, A.H., (2016). Factors facilitating patient satisfaction among women with medically unexplained long-term fatigue: A relational perspective. Health: 20(3), pp.308-326.

Lim, W.M., Kumar, S. and Ali, F., (2022). Advancing knowledge through literature reviews: 'what', 'why', and 'how to contribute'. The Service Industries Journal, 42(7-8), pp.481-513.

Lincoln YS, Guba EG. (1985) Naturalistic Inquiry. Beverly Hills, CA: Sage Publications

Livia, A. (1996) "Daring to Presume". In Kitzinger, S. and Wilkinson, C. (eds) (1996) Representing the Other. London: Sage.

Lopez, K.A. and Willis, D.G., (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. Qualitative health research, 14(5), pp.726-735.

Lyon, D. and Parker, B., (2003). Gender-related concerns of rural women with severe and persistent mental illnesses. Archives of psychiatric nursing, 17(1), pp.27-32.

Maguire, K., (2015). Transdisciplinarity as translation. Transdisciplinary professional learning and practice, pp.165-177.

Mason-Bish, H., (2019). The elite delusion: reflexivity, identity and positionality in qualitative research. Qualitative Research, 19(3), pp.263-276.

Mauthner, N.S. & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. Sociology, 37(3), 413-431.

McKenzie-Mohr, S. and Lafrance, M.N. eds., (2014). Women voicing resistance: Discursive and narrative explorations. Routledge.

Mead, N. and Bower, P., (2002). Patient-centred consultations and outcomes in primary care: a review of the literature. Patient education and counseling, 48(1), pp.51-61.

Merleau-Ponty, M. (1964). The primary of perception, (J. Edie, Trans.). Evanston, IL: Northwestern University Press. Moccia

Miller, D., Zantop, V., Hammer, H., Faust, S. and Grumbach, K.,(2004). Group medical visits for low-income women with chronic disease: a feasibility study. Journal of women's health, 13(2), pp.217-225.

Miller, P. B. and Weijer, C. 'Trust and Exploitation in Clinical Research' In Corrigan, O. McMillan, J Liddell, K. Richards, M. And Weijer, C (Eds) (2009) The Limits of Consent: A Socio-Ethical Approach to Human Subject Research in Medicine Oxford University Press

Möller-Leimkühler, A.M., (2022). Gender differences in cardiovascular disease and comorbid depression. Dialogues in clinical neuroscience.

Moravcsik, A., (2020). Transparency in qualitative research. SAGE Publications Limited.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont report: ethical principles and guidelines for the protection of human subjects of research. In: Sugarman J, Mastroianni AC, Kahn JP, (eds.) (1998) Ethics of research with human subjects. Frederick, MD: University Publishing Group, Inc :19–30.

Nedelsky, J., (1990). Law, boundaries, and the bounded self. Representations, 30, pp.162-189.

Nelson, L. and Mee, S., (2018). Risk of role confusion for nurse researchers: a reflective account. Nursing Times, 114(2), pp.43-46.

Neubauer, B.E., Witkop, C.T. and Varpio, L., (2019). How phenomenology can help us learn from the experiences of others. Perspectives on medical education, 8, pp.90-97.

NHS Digital (2023) Appointments in General Practice, January 2023 https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice Last Accessed 29/8/23

NHS England and NHS Improvement (2022) Next Steps for Integrating Primary Care: Fuller Stock Take report https://www.england.nhs.uk/wp-content/uploads/2022/05/next-steps-for-integrating-primary-care-fuller-stocktake-report.pdf Last Accessed 29/8/23

Nowotny, H., Scott, P. and Gibbons, M., (2003). Introduction: 'Mode 2' revisited: The new production of knowledge. Minerva, 41(3), pp.179-194.

Nursing & Midwifery Council. (2018). The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates.

Nussbaum, M.C., 2011. Creating capabilities. Harvard University Press.

O'Malley, A.S. and Forrest, C.B., (2002). The mismatch between urban women's preferences for and experiences with primary care. Women's Health Issues, 12(4), pp.191-203.

Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), Doing feminist research (pp. 30-61). London: Routledge & Kegan Paul.

Office for Health Improvement Disparities (2023) Fingertips Public Health Data – Severe mental Illness https://fingertips.phe.org.uk/profile-group/mental-health/profile/severe-mental-illness/data#page/4/gid/1938133369/pat/159/par/K02000001/ati/15/are/E92000001/yrr/3/cid/4/tbm/1/page-options/tre-do-1 Last Accessed 29/8/23

Official statistics, Experimental statistics https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/january-2023 Last Accessed 29/8/23

Ohlen, J., Reimer-Kirkham, S., Astle, B., Hakanson, C., Lee, J., Eriksson, M., & Sawatzky, R. (2017). Person-centred care dialectics—inquired in the context of palliative care. Nursing Philosophy, 18(4), e12177. https://doi.org/10.1111/nup.12177

Olukotun, O., Mkandawire, E., Antilla, J., Alfaifa, F., Weitzel, J., Scheer, V., Olukotun, M. and Mkandawire-Valhmu, L., (2021). An analysis of reflections on researcher positionality. An Analysis of Reflections on Researcher Positionality (up.ac.za) Last Accessed 29/8/23

Orb, A. Eisenhauer, L. Wynaden, D (2000) 'Ethics in Qualitative Research' Journal of Nursing Scholarship 33 (1) 93-96

Orr, K. and Bennett, M., (2009). Reflexivity in the co-production of academic-practitioner research. Qualitative Research in Organizations and Management: An International Journal, 4(1), pp.85-102.

Overstreet, N., Rosenthal, L. & Case, K. (2020) Intersectionality as a radical framework for re-envisioning our disciplines, social issues, and the world. Journal of Social Issues, 76(4), 779–795.

Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA (2020) statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Papoulias, S. and Callard, F., (2021). 'A limpet on a ship': Spatio-temporal dynamics of patient and public involvement in research. Health Expectations, 24(3), pp.810-818.

Parsons, T. The Social System. (1951). Glencoe, IL: The Free Press

Patton, M.Q., (1999) Enhancing the quality and credibility of qualitative analysis. Health services research, 34(5 Pt 2), p.1189.

Paul, J., Lim, W. M., O'Cass, A., Hao, A. W., & Bresciani, S. (2021). Scientific procedures and rationales for systematic literature reviews (SPAR-4-SLR). International Journal of Consumer Studies, 45(4), O1–O16.

Penman DT, Holland JC, Bahna GF, Morrow G, Schmale AH, Derogatis LR, Carnrike CL, Jr, Cherry R. (1984) 'Informed consent for investigational chemotherapy: patients' and physicians' perceptions '. J Clin Oncol. 2(7):849–855

Petrovic, S., Lordly, D., Brigham, S. and Delaney, M., (2015). Learning to listen: An analysis of applying the listening guide to reflection papers. International Journal of Qualitative Methods, 14(5), p.1609406915621402.

Pettitt, B., Greenhead, S., Khalifeh, H., Drennan, V., Hart, T., Hogg, J., . . . Moran, P.(2013). At risk, yet dismissed: The criminal victimisation of people with mental health problems. Retrieved from https://www.mind.org.uk/media/187663/At-risk-yet-dismissed-report_FINAL_EMBARGOED.pdf   Last Accessed 29/8/23

Ponterotto, J.G., (2006). Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. The qualitative report, 11(3), pp.538-549.

Prodan-Bhalla, N. and Browne, A.J., (2019) Exploring women's health care experiences through an equity lens: Findings from a community clinic serving marginalised women. Journal of clinical nursing, 28(19-20), pp.3459-3469.

Pylypa, J., (1998). Power and bodily practice: Applying the work of Foucault to an anthropology of the body.

Reed, P.G., (2022). Standpoint epistemology and nursing science. Nursing Science Quarterly, 35(1), pp.41-45.

Reilly, E., Hafford-Letchfield, T., & Lambert, N. (2020). Women ageing solo in Ireland: An exploratory study of women's perspectives on relationship status and future care needs. Qualitative Social Work, 19(1), 75–92.

Richter, J., Faragó, F., Swadener, B.B., Roca-Servat, D. and Eversman, K.A., (2020). Tempered radicalism and intersectionality: Scholar-activism in the neoliberal university. Journal of Social Issues, 76(4), pp.1014-1035.

Rix, E.F., Barclay, L. and Wilson, S., (2014). Can a white nurse get it?' Reflexive practice' and the non-Indigenous clinician/researcher working with Aboriginal people. Rural and remote health, 14(2), pp.240-252.

Roberts, L.W and Roberts, B. (1999) Psychiatric research ethics: an overview of evolving guidelines and current ethical dilemmas in the study of mental illness Biological Psychiatry Vol. 46, Issue 8, Pages 1025-1038

Rocha, E.M., (1997) A ladder of empowerment. Journal of Planning Education and Research, 17(1), pp.31-44.

Rodriguez, K.L., Schwartz, J.L., Lahman, M.K. and Geist, M.R., (2011). Culturally responsive focus groups: Reframing the research experience to focus on participants. International Journal of Qualitative Methods, 10(4), pp.400-417.

Rolfe, G., (2016). Exercising the nursing imagination: Putting values and scholarship back into research. Journal of Research in Nursing, 21(7), pp.517-527.

Rose, D., (2017). Service user/survivor-led research in mental health: epistemological possibilities. Disability & Society, 32(6), pp.773-789.

Rose, D., Fleischmann, P., Wykes, T., Leese, M. and Bindman, J., (2003). Patients' perspectives on electroconvulsive therapy: systematic review. Bmj, 326(7403), p.1363.

Royal College of Nursing, RCN (2020) Gender and Nursing as a Profession Valuing nurses and paying them their worth https://www.rcn.org.uk/professional-development/publications/pub-007954 Last Accessed 29/8/23

Sandelowski, M. and Barroso, J., (2002). Finding the findings in qualitative studies. Journal of nursing scholarship, 34(3), pp.213-219.

Scholle, S.H., Weisman, C.S., Anderson, R.T. and Camacho, F., (2004). The development and validation of the primary care satisfaction survey for women. Women's Health Issues, 14(2), pp.35-50.

Shefer, G., Henderson, C., Howard, L.M., Murray, J. and Thornicroft, G., (2014) Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms–a qualitative study. PLoS One, 9(11), p.e111682.

Sim, J. and Waterfeld, J. (2019) Focus group methodology: some ethical challenges Quality & Quantity (2019) 53:3003–3022

Smith, K., (2015). Stories told by, for, and about women refugees: Engendering resistance. ACME: An International Journal for Critical Geographies, 14(2), pp.461-469.

Smithson, J., (2000) Using and analysing focus groups: limitations and possibilities. International journal of social research methodology, 3(2), pp.103-119.

Sorsoli, L. and Tolman, D.L., (2008). Hearing voices: Listening for multiplicity and movement in interview data.

Stockwell, F., (2002). The unpopular patient. Exemplary research for nursing and midwifery. London: Routledge, pp.23-41.

Tew, J., Gould, N., Abankwa, D., Barnes, H., Beresford, P., Carr, S., Copperman, J., Ramon, S., Rose, D., Sweeney, A. and Woodward, L., (2006). Values and methodologies for social research in mental health. Bristol/London: National Institute for Mental Health in England and Social Perspectives Network in collaboration with the Social Care Institute for Excellence.

The International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH), (2006) Guideline for good clinical practice E6 (R1) www.ich.org/fileadmin/Public_Web_Site/ICH_Products/Guidelines/Efficacy/E6 _R1/Step4/E6_R1__Guideline.pdf   Last Accessed 29/8/23

Thompson, L., Rickett, B. and Day, K., (2018). Feminist Relational Discourse Analysis: putting the personal in the political in feminist research. Qualitative Research in Psychology, 15(1), pp.93-115.

Thorne, S., (2020). Rethinking Carper's personal knowing for 21st century nursing. Nursing Philosophy, 21(4).

Tilley, S. A., & Powick, K. D. (2002). Transcribing other people's research. Canadian Journal of Education, 27(3), 291-310.

Tutton, R 'Person, Property and Gift: exploring languages of tissue donation to biomedical research'. In Tutton R and Corrigan. O. (Eds) (2004) Genetic Databases: socio-ethical Issues in the Collection and use of DNA Oxford University Press

Van de Ven, A.H., (2007). Engaged scholarship: A guide for organizational and social research. Oxford University Press, USA.

Van Manen, M., (1984). Practicing phenomenological writing. Phenomenology+ pedagogy, pp.36-69.

Varpio, L., Ajjawi, R., Monrouxe, L.V., O'Brien, B.C. and Rees, C.E (2017). Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. Medical education, 51(1), pp.40-50.

Wallace, S.S., Barak, G., Truong, G. and Parker, M.W., (2022). Hierarchy of Evidence Within the Medical Literature. Hospital Pediatrics, 12(8), pp.745-750.

Walters, R., (2020). Relinquishing control in focus groups: the use of activities in feminist research with young people to improve moderator performance. Qualitative Research, 20(4), pp.361-377.

Warner, DN (2004) Towards a queer research methodology. Qualitative Research in Psychology 1(4): 321–337.

Wells, A (2023) I don't want a seat at your table: co-production in mental health services - blog for NSUN https://www.nsun.org.uk/i-dont-want-a-seat-at-your-table-co-production-in-mental-health-services/   Last Accessed 29/8/23

Werner, A. and Malterud, K., (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. Social science & medicine, 57(8), pp.1409-1419.

Whelan, P.J.P Oleszek, J. Macdonald, A. and Gaughran, F (2009). 'The utility of the Mini-Mental State Examination in guiding assessment of capacity to consent to research.' International Psychogeriatrics, 21, pp 338-344

Whittemore, R., Knafl, K. (2005). The integrative review: Updated methodology. Journal of Advanced Nursing, Dec, 52, 546–553.

Wilkinson, S. & Kitzinger, C. (Eds.) (1996). Representing the other: A Feminism & Psychology reader. London: Sage.

Williams, O., Sarre, S., Papoulias, S.C., Knowles, S., Robert, G., Beresford, P., Rose, D., Carr, S., Kaur, M. and Palmer, V.J., (2020). Lost in the shadows: reflections on the dark side of co-production. Health Research Policy and Systems, 18, pp.1-10.

Willig, C. (2008). Introducing qualitative research in psychology: Adventures in theory and method. Maidenhead, UK: Open University Press

Winick, B. J. (1996). 'Foreward: A summary of the MacArthur Treatment Competence Study and an introduction to the special theme'. Psychology, Public Policy, And Law, 2(1), 3-17.

World Health Organization and UNICEF, (2018). Crowdsourcing in health and health research: a practical guide (No. TDR/STRA/18.4). World Health Organization

Zinn, M.B., Cannon, L.W., Higginbotham, E. and Dill, B.T., (1986). The costs of exclusionary practices in women's studies. Signs: Journal of women in culture and society, 11(2), pp.2

Appendices

Appendix i. **A sample of ethics paperwork to demonstrate coproduced ways of working within academic systems**

MIDDLESEX UNIVERSITY - SCHOOL OF HEALTH AND EDUCATION

HEALTH AND EDUCATION ETHICS SUB-COMMITTEE

APPLICATION FOR ETHICAL APPROVAL OF CATEGORY A3 PROPOSALS

This form must be completed for all research projects carried out by staff or students of the School that conform to the Category A definitions.

Title of proposed study:

'An Exploration of the Experience of Women with Mental and Physical Health Issues'

Name(s) and qualifications of supervisor(s) / principal investigator (s):

Nicky Lambert: Senior Lecturer MSc Clinical Health & Education, PGCHSCE, RMN

Name(s) and qualifications of researcher(s):

Nicky Lambert: Senior Lecturer MSc Clinical Health & Education, PGCHSCE, RMN

Permanent contact details (address, email & telephone number):

Nicky Lambert 3rd Floor, Hendon Town Hall Annexe, Senior Lecturer - School of Mental Health, Social Work & IPL Middlesex University, The Burroughs, Hendon, London, NW4 4BT, United Kingdom Email: n.lambert@mdx.ac.uk Tel: 02084115302

Is the proposal linked to a programme of study? If so, please identify:
D.Prof - Module 4561

Indicate the start and end date for the proposed study:
Sept- 2014 – Sept 2015

Is the proposal externally funded? If so, name the source of the funding:
Funding has applied for through the departmental small grants.

Have you applied to any other sub-committee to the School of Health & Education?   No

If yes, which one...N/A

Identify under which of the criteria in Category A of the guidelines this proposal can be classified:

A1   ☐ **For information only** (e.g. External NRES application)
          (If yes, *please state the name of the external ethics committee*)..

A2   ☐ (pre/post student questionnaire)   A3   ✔)
A4   ☐   A5   ☐   A6   ☐

NB: If A6 is ticked you will also need to tick A2, A3, A4 or A5 as appropriate

PARTICIPANT INFORMATION SHEET

Project title: '**Exploration of the Experience of Women with Mental and Physical Health Issues**'

You are being invited to take part in a research study. Before you decide if you want to proceed, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

- **What is the purpose of the study?**

Little is known about the experience of women with physical and mental health needs. This study aims to find out more about the needs and circumstances of women who have experienced these issues. This study is responding to identified gaps in the research literature about what is known about women with this experience and the overall aim is to consider the implications of findings in relation to future health and social care provision.

- **Why have I been chosen?**

You have identified yourself as a woman with experience of mental and physical health needs; we hope that you may be in a position to share your understanding or experience around this subject.

- **Do I have to take part?**

No, you don't. It is up to you to decide whether or not to take part. We will be inviting you to take part in an online survey and/or some focus groups with a researcher. You can participate in either of these methods and this will not have any effect on any other part of your life or be traced back to you. You may also choose to withdraw at any point if you wish to. Any data collected from a survey or a focus group will be anonymised so it cannot be traced back to you or make you identifiable in any way.

- **What would I have to do if I decide to take part?**

SURVEY: You are invited to complete a short online survey. It is assumed that you consent to take part in this research if you complete it. The survey will not take more than 10-15 minutes to do.

FOCUS GROUP: We would ask your consent to record you in a group discussion with 4 other women about the experience of having mental and physical health issues using a digital voice recorder.

- **What are the possible disadvantages and risks of taking part?**

There are no known risks in participating in this project except the giving of your valuable time.

• **What are the possible benefits of taking part?**

Potential benefits of this research include helping to gain a clearer understanding of the needs of women with physical and mental health needs.

• **Will my taking part in this study be kept confidential?**

All data will be made anonymous after collection. Your survey or digital recording of focus groups will be given a number and anonymised. The data will be stored on a password protected computer and stored, analysed and reported in compliance with UK Data Protection Legislation. The data will be kept for 24 months after the study has been completed after which it will be destroyed.

• **What will happen to the results of the research study?**

The results of this research will be published in a way that identifies general themes, not traceable to individuals taking part. It may be published in the form of a short report, journal article or conference presentation, generally within academic forums and with audiences such as policy makers or practitioners working in the area of supporting successful ageing. You will also be offered a copy of a short summary of the research findings. If you would like to see the results of this study please contact the researcher, Nicky Lambert for this information using her details below..

• **Who has reviewed the study?**

The committee is the Middlesex University, School of Health and Education Ethics sub-Committee

• **Contact for further information**

Nicky Lambert, Senior Lecturer in Mental Health
Dept. of Mental Health, Social Work and Integrative Medicine, Middlesex University, The Burroughs, Hendon, London, NW4 4BT, United Kingdom
Email: n.lambert@mdx.ac.uk   Tel: 02084115302
Thank you for your time. At the time of the interview, you will be invited to sign a consent form which is kept as a record of your informed consent.

'An Exploration of the Experience of Women with Mental and Physical Health Issues'
Name of Researcher: Nicky Lambert

1.   I confirm that I have read and understand the information sheet dated ....for the above study and have had the opportunity to ask questions.
2.   I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3.   I agree that this form that bears my name and signature may be seen by a designated auditor.
4.   I agree that my non-identifiable research data may be stored in National Archives and be used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers.
5.   N/A
6.   I understand that my participation in this focus group may be taped and subsequently transcribed.
7.   I agree to take part in the above study.
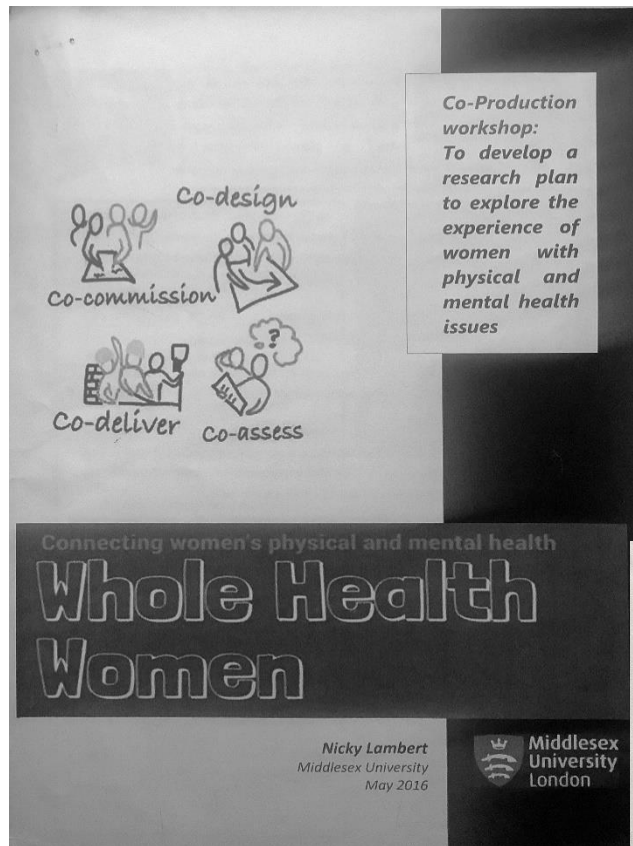
Name of participant _____ Date: _____ Signature: _____

Name of person taking consent _____ Date: _____

Signature (if different from researcher): _____

Researcher: _____ Date: _____ Signature: _____

1 copy for participant; 1 copy for researcher

Appendix ii. **A sample of ethics paperwork to demonstrate coproduced ways of working during the initial workshop**

Co-Production workshop:
To develop a research plan to explore the experience of women with physical and mental health issues

Connecting women's physical and mental health

Whole Health Women

Nicky Lambert
Middlesex University
May 2016

Middlesex University London

The plan: A workshop with women who have experienced both mental and physical ill health to co-produce a research plan - I'd like to come up with a number of ways to gather information about women's experiences of having multiple or complex care needs.

Output from the day

- I'd like to consider the ways women access health care, to identify any issues / gaps and understand how they would define good practice. I want to be creative in this process so people to can join in on their own terms.

- I want to develop an online survey and hold some focus groups, so I need to look at questions and information for women taking part.

- I also want to include visual and shared ways of gathering/sharing this information. I'd like to use body mapping (see attachment)

- This process would be part of my research project so I'll need to record the process in some way: record key discussions and take pictures of notes pages etc. (all the data is anonymised). If there are any academic outputs from the day I'll co-credit any participants as co-authors who want to be.

Project description: As part of my D.Prof I want to look at the experience of physical health issues in women with mental distress so that we can identify good practice and understand what works.

- Research shows that people with mental health issues have more problems with poor physical health than others in society. We don't know how this affects women though.

- So we want to ask how women about their mental and physical health concerns and how they think about how health services respond to their needs.

  o *How / when do women with mental health issues seek help for their physical health concerns?*

  o *What is their experience of accessing and receiving support for those physical health needs?*

Appendix iii. Literature search

Mead Reference	What was done	What was found	Notes on Quality/Utility
1. Alexander, I.M., 2004. Characteristics of and problems with primary care interactions experienced by an ethnically diverse group of women. Journal of the American Academy of Nurse Practitioners, 16(7), pp.300-310.	Study recruited 14 women. Of these 14 participants, 6 never attended a single meeting, 4 had time conflicts, and 2 withdrew from the study. Thus, 8 women participated. – well described focus group process	Staff interactions were main issues - a lack of caring was noted —a lack of concern, women described not being listened to, a lack of trust and disrespect and prejudice.	Excellent research process. Study 20 years before this one, in the US practically the same results.
2. Anderson, R.T., Barbara, A.M., Weisman, C., Hudson Scholle, S., Binko, J., Schneider, T., Freund, K. and Gwinner, V., 2001. A qualitative analysis of women's satisfaction with primary care from a panel of focus groups in the national centers of excellence in women's health. Journal of women's health & gender-based medicine, 10(7), pp.637-647.	Each centre conducted up to three focus groups of women recruited from the community, for a total of 137 women participants. In order to include diversity in healthcare experiences and access, the focus groups were composed of both CoE and non-CoE patients. The groups were stratified by age (ages 18–34, 35–54, and $55) and race/ethnicity (Latina, African American, Asian, Caucasian). Each group included between 5 and 9 women.	Qualities like being non-judgmental, trusting, and a good listener were central themes for women participants. Participants expressed a positive evaluation of providers who respected the woman's own view of her health, who showed knowledge of women's health issues pertinent to her age or life stage, and who could have empathy, encouraging the patient to discuss complex and personal issues bothering her	Well conducted study which highlighted key areas of concern and areas of strength that women perceive and value about their healthcare. The wide variation in experiences in healthcare reported by the participants, both concurrently and retrospectively, does suggest that woman-focused healthcare may be uneven and, sometimes difficult to get Echoes themes from this study but doesn't link them to wider societal inequalities.
3. Anderson, R.T., Weisman, C.S., Camacho, F., Scholle, S.H., Henderson, J.T. and Farmer, D.F., 2007. Women's satisfaction with their on-going primary health care services: a consideration of visit-specific and period assessments. Health services research, 42(2), pp.663-681.	1021 patients attending a primary care visit with at least one prior visit were consented on site, enrolled in the study They were surveyed at two time points: pre- and immediately post visit. The pre-visit survey included demographics, self-rated health, visit history and expectations for health care; the post visit survey focused on patient experiences	The data suggests that patients weigh different pieces of information differently when formulating judgments about health care quality over a period of time. Despite the fact that all ratings were collected at the same point in time, women focussed more provider communication, and less on care coordination occurring over past visits.	A limitation of the study is that it was with women who'd completed at least one additional visit in the past 12 months to the study practice site. This criterion likely selected patients with health conditions that needed periodic management while excluding generally healthy patients with few health concerns.

	during the visit, assessment of health care quality using the Primary Care Satisfaction Survey for Women instrument, and global satisfaction with visit and health care over the past 12 months	Like other studies patient participation in decision making and perception of provider interpersonal behaviour most important to attendees.	This is helpful to me as I ws exploring women with complex need.
4. Birch, S., Lavender, T. and Cupitt, C., 2005. The physical healthcare experiences of women with mental health problems: Status versus stigma. *Journal of mental health*, *14*(1), pp.61-72.	6 women - The study used a cross-sectional, within group design, with a semi-structured interview. The qualitative methodology of Interpretative Phenomenological Analysis (Smith, 1995) was used to analyse the data	Women found general physical healthcare positive in contrast to their experiences of MH, but in relation to life-cycle issues were stigmatizing due to stigma of mental ill-health and motherhood, healthcare.	Well executed study – issues raised about being seen as bad mothers due to started MH issues. In this study women spoke about 'hiding' MH diagnosis to improve chances of 'good' care.
5. Edge, D. and MacKian, S.C., 2010. Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among Black Caribbean women in the UK. *Ethnicity & health*, *15*(1), pp.93-111.	In-depth interviews were undertaken with a purposive sample of twelve Black Caribbean women selected from a lager sample (n=101) to examine prevalence and psychosocial risks for perinatal depression among this ethnic group. The study also sought to explore women's models of help-seeking.	Concept of 'reflexive communities' rather than individual patients as one way to explore relationships around help seeking and self-awareness of depression. The model developed from this study could improve focus on the quality and effectiveness of health encounters.	Followed qualitative research - expectations small sample of only twelve women, selected for their '- could be said to be representative within the cases reviewed. No coproduction but especial care taken over Service user involvement.
6. Ewart SB, Bocking J, Happell B, Platania-Phung C, Stanton R. Mental Health Consumer Experiences and Strategies When Seeking Physical Health Care: A Focus Group Study. Global Qualitative Nursing Research. 2016;3. doi:10.1177/2333393616 631679	Qualitative exploratory design was utilized. Semi structured focus groups were held with 31 consumer participants	Troubling stories of the lengths that consumers go to for barely minimal standard physical health care were shared. Participants recounted that on the fortuitous instances where access to physical health services was gained, the diagnosis of "mental illness" was a major barrier to providers	This is included because although it is a mixed group - gender breakdown not included! It notes what they call 'survival strategies' used to overcome barriers to care – very similar
7. Jobling, K., Lau, P., Kerr, D., Higgins, R.O., Worcester, M.U.,	19 participants - Focus groups and interviews were conducted with	Barriers included cost of private healthcare, long waiting times ack of	Aboriginal people, need the concept of health needs to be approached

Angus, L., Jackson, A.C. and Murphy, B.M., 2016. Bundap Marram Durn Durn: Engagement with Aboriginal women experiencing comorbid chronic physical and mental health conditions. Australian and New Zealand Journal of Public Health, 40, pp.S30-S35.	Aboriginal people who had comorbid health conditions and were accessing Aboriginal and/or mainstream services.	culturally competent healthcare practitioners, high health staff turnover as well as systems failures and the provision of effective follow-up care planning. Identified service

Enablers included established, positive relationships with general practitioners and access to staff who could provide cultural brokerage to appropriate services and culturally competent health care practitioners. | in the social-emotional context, which includes history of oppression, racism, environmental circumstances, cultural competence, psychological processes and physical ill health

That seems likely for women in this study – mainstream health is not talking about ideas of structural racism, sexism etc in order to improve the care for all. It will refer to structural inequalities but struggles to speak openly and in ways seen as political. |
| 8.   Lian, O.S. and Hansen, A.H., 2016. Factors facilitating patient satisfaction among women with medically unexplained long-term fatigue: A relational perspective. *Health:*, *20*(3), pp.308-326. | Statistical analysis of survey data collected from a net sample of 431 women recruited through a patient organisation for people suffering from ME in 2013. Participants were asked about their experiences with general practitioners in the Norwegian national health system in two different phases: shortly after illness onset, and current regular general practitioner last 12 months. The questions evolved around themes concerning shared understanding and decision making, being taken seriously, being paid due respect and being treated as an equal partner | Found continuity, congruence in doctor–patient views and being seen by a specialist, = patient satisfaction. X6 higher in women who were referred to specialists, compared to those who were not. Continuity of care and experiences of being in a partnership - a shared understanding of the patient's illness – foster patient satisfaction | Unusual approach - sound but odd not just to use qualitative methods

Could these methods also suggest that it's not just the specialist but the fact that a relationship is built that isn't under the same kind of time pressure? |
| 9.   Lyon, D. and Parker, B., 2003. Gender-related concerns | Focus groups to investigate the perceptions of rural | Many of the participants noted difficulties in obtaining regular health | A bleak study that speak of multiple disadvantage |

of rural women with severe and persistent mental illnesses. Archives of psychiatric nursing, 17(1), pp.27-32.	women with severe and persistent mental illness (SPMI) about their gender-related health concerns. In a series of five focus groups conducted with 16 women at rural psychosocial clubhouses	services and in communicating with (non-MH) health care professionals.	and discrimination – not least from services
10. Mead, N. and Bower, P., 2002. Patient-centred consultations and outcomes in primary care: a review of the literature. Patient education and counseling, 48(1), pp.51-61.	Basic literature search – they have had issues because the behaviour they are trying to measure is so disparate that the studies they are looking at often have little in common outside the title and vague theme	Their findings are that patient-centred consulting leads to better patient outcomes in primary care is ambiguous to date because of the quality of the research – none of which is coproduced.	This is included because it represents scientism asking the wrong question of the wrong source. Incidentally they don't measure the damage a lack of patient care causes.
11. Miller, D., Zantop, V., Hammer, H., Faust, S. and Grumbach, K., 2004. Group medical visits for low-income women with chronic disease: a feasibility study. Journal of women's health, 13(2), pp.217-225.	The intervention consisted of six GMV sessions cofacilitated by a physician/nurse practitioner team. Participants included 28 women with at least one chronic disease diagnosis (71% Latina). Thematic analysis of open-ended interviews assessed participants' experiences in the GMV. Patient charts and provider logs provided information on health service utilization patterns and provider productivity.	In this inner-city clinic setting, the GMV model was well tolerated by patients, did not alter provider productivity, and may have encouraged participants to avoid more expensive urgent care services. The results of this pilot study suggest that GMVs represent a cost-effective ambulatory care alternative that is acceptable to low-income women with chronic disease.	Aghast at the premise of this - women reported positivity about being able to have personalised attention but were unsurprisingly negative about the loss of confidentiality - 7 women who were strangers in most sessions!
12. O'Malley, A.S. and Forrest, C.B., 2002. The mismatch between urban women's preferences for and experiences with primary care. Women's Health Issues, 12(4), pp.191-203.	A community-based telephone survey of 1,205 urban women is a follow-up study to a series of focus groups of women from the same areas in Washington, DC.15 In the focus groups, women identified their priorities for specific features of primary care. This follow-up study determines, via a population-based sampling methodology,	The study found that women of lower socioeconomic status had poorer primary care experiences compared with higher income counterparts, despite similarly high preferences for primary care. The poorer primary care experiences of lower socioeconomic status women were attenuated by better access to primary	A limitation of this study is that these data may not generalize to women under age 40 or to persons without telephones or in rural areas. They did not validate patients' attainment of primary care via provider surveys, they focussed on patients' perceptions of and experiences with

	whether women receive the types of primary care that they desire. The sample was predominantly African American (82%), and had a wide range of incomes with over half at or below 200% of the federal poverty guidelines.	care. Differences in primary care attainment are not solely a matter of personal preferences; rather, they appear to be more strongly related to barriers to obtaining care. How important are the personal aspects (trust, caring, respect, patience) of your physician? – rated highest – matches this studies data.	their primary care providers. I did the same thing – same barriers reported, the same valuing of interpersonal connection.

Appendix iv. Survey Questions adapted as a loose Topic Guide for focus groups: - codesigned with advisory group.

- What does being well and healthy mean to you?

- Who looks after your health? (for example, how are decisions made about healthy living or seeing health professionals in your household?)

- What does a good experience of visiting a health professional feel like?

- What does a bad experience of visiting a health professional feel like?

- What kinds of health support do you find most helpful?

- Do your physical and mental health issues impact on each other?

- What would you do if you received a service from a health professional that you weren't happy with?

- Do you feel confident to complain to health professionals if you have had a bad experience?

- Do health professionals listen to you and respect your needs when giving care?

- Is there anything that you do to make sure you get good care from the professional you're seeing?

- What advice would you give to health professionals wanting to do a good job of supporting your health and wellbeing?

- Is there anything you'd like to tell me about your experience of accessing and receiving support for your health needs that I haven't asked about?

Appendix V. A summary of contributions to practice related to this work

Over the course of my studies I have grown in confidence and developed skills that enabled me to support a variety of activities, I have grouped these outputs and provided explanatory notes where needed show what part of my research journey shaped the output (research outcomes, methodology, skills acquired or learning and reflection etc.):

In summary:

- *I have contributed to women's wellbeing on a community level, strengthening bonds between local women and their access to health, and shared research and activist practices. I have disseminated my learning in this area through conferences, social media and publications.*
- *I have shared my knowledge of women's health needs in national policy making fora, through publication, conferences and teaching sessions.*
- *I have developed as a mental health nurse academic and have contributed to my discipline at a national and international level.*
- *As a researcher I have explored new ways of working coproductively and offered practical solutions to navigating the challenges that this process can pose. I have taken these principles into my work in social media and teaching to ensure a variety of voices are heard.*

Contributions to Knowledge Transfer and Professional Practice

2022- current: External panel reviewer for HEE accredited courses – *I use the skills and learning developed during my D. Prof to ensure that I the courses I examine include sound practices around coproduction and good practice.*

2022 – Work shaped by this learning was used as a good practice example in No Wrong Door a report by Centre for Mental Health and NHS Confederation to create a vision for mental health, autism and learning disability services in ten years' time. - *I used the skills I developed through undertaking this project and research outcomes here*

2021- current: Trustee for The Women Health and Wellbeing Charity - the Bridge. *– I use the skills and learning developed during my D. Prof to advise around women's wellbeing and coproductive practices.*

2021: I was a member of the Expert Reference Group for National Collaborating Centre for Mental Health's Sexual Safety Standards and Guidance *– I became involved because of concerns that were heightened reading the literature around women's complaints about services and used skills and learning from the project*

2020 - 2022: I co-produced and ran courses for Camden and ISLINGTON recovery college which were well attended and reviewed. - *These sessions*

provided a template for shared, open-access learning and were informed by my methodology.

2020: I taught on the Mongolian Mental health Nurse Training project specifically about the importance of trauma informed care esp. when working with women. – *This was informed by learning from the project*

2020: I co-hosted the #mhnr2020 conference and the Eileen Skellern Awards celebrating good practice and helping researchers get their voices heard. – *This is informed by findings from the project*

2020- current: I am a founder member of [#mhTV](#)- a coproduced series of vodcasts addressing issues current in mental health and for nurses more generally. *It is coproduced, it highlights the voices of people with lived experience and helps share good practice, it comes from the project methodology.*

2020: I was part of the group who worked on Mental Health Nursing Competency and Career Framework from Skills for Health and HEE. *I took the opportunity to champion coproductive approaches to care as essential skills – again informed by the methodology.*

2020 - current: I authored the RCN Public Mental Health Pages – this highlights the importance of managing personal wellbeing as well as that of Service Users.- *This is shaped by my personal reflection and learning*

2019 - 2021: I was part of the CQC sexual safety collaborative   - again this work was to tackle issues particularly impacting women's experience of care.

2019 – I was an Official Supporter of the 'Ask and Take Action' Project - [Agenda](#) supporting women's safety – *see above.*

2019 – I collaborated with MoDA – through a podcast and by co-hosting and open conference on Living Well: health, wellbeing and the built environment. *These coproductive outputs focussed heavily on women's wellbeing and were shaped by refection and personal learning from doing the research.*

2018 - **current:** I am a member of the RCN Mental health forum representing Mental Health, public health and Menopause **–** *again I use these opportunities to promote women's wellbeing and they are informed by my refection and learning from this project.*

2018: Host for a MHNA session On Period Dignity in Mental Health Services https://www.youtube.com/watch?v=40gWIwtIwTc - *My ability to speak up on topics that can be sensitive is a skill honed by this project.*

2018- **current:** Member of Camden and Islington women's strategy group: Sexual Safety work and policy writing. *I use these opportunities to promote women's wellbeing because of reflection on my learning from this project.*

2018: Organiser for disability/extra support needs access for the London branch of PROCESSIONS, a mass artwork celebrating 100 years of women voting https://www.processions.co.uk/ - *I skills developed in this project to*

enable access for people with complex needs who may have been prevented from participation otherwise.
2018: Consultancy for Fulfilling Lives - South East *Skills developed in coproductive working were part of the methodology practiced in this research*
2017: Chair of Policy-UK's Revolution in Mental Health conference. *Speaking up and supporting other professionals to use their voices was part of my learning in this research.*
2014- 2021 Trustee for West Hampstead Women's centre – *my work here was promoting women's wellbeing prompted by my experience on this project.*

I wrote/cowrote the following articles during the time I worked on my D.Prof. They are varied but all share the same range of goals: to raise awareness of good practice esp. when working with women and when using coproduction and to encourage nurses to use their voices to express their professional opinions and to improve services.

Public Output: ORCID ID 0000-0001-8785-4719

- Lambert, N., (2022) Supporting people who are experiencing domestic abuse. Mental Health Practice 25 (5)
- Lambert, N., (2022) Editorial for *Mental Health Nursing* 'Moving Forward to Meet the Challenges of 2022'
- Lambert, N., (2021) #mhTV - standing together in tough times *Journal of Community Nursing* https://www.jcn.co.uk/journals/issue/02-2021/article/mhtv-standing-together-tough-times
- Lambert, N (2021) Editorial for *Mental Health Nursing* 'Caring for yourself is not an indulgence'
- Lambert, Reilly, E., Hafford-Letchfield, T. and Lambert, N., (2020) Women ageing solo in Ireland: An exploratory study of women's perspectives on relationship status and future care needs. *Qualitative Social Work*, *19*(1), pp.75-92.
- Lambert, N., (2019) Nursing care plans in mental health. *Mental Health Practice*, *23*(3).
- Foley, L., Dadzie, L.K., Pezzella, A. and Lambert, N., (2019) Exploring the educational experience of culturally and linguistically diverse students in Higher Education. Preliminary findings from a small-scale project. – conference paper
- Reilly, E and Hafford-Letchfield, T and Lambert, N (2018) *Women ageing solo in Ireland: an exploratory study of women's perspectives on relationship status*

and future care needs. Qualitative Social Work ISSN 1741-3117 (Published online first)

o   Lambert, N. and Carr S. (2018) 'Outside the Original Remit': Co-production in UK mental health research, lessons from the field *International Journal of Mental Health Nursing*

o   Kirton, C., Lambert, N., Matheson, H. and Connell, S. (2018) Exploring the experiences of trainee mental health workers: moving from theory to practice. *The Journal of Mental Health Training, Education and Practice*, 13(3), pp.137-147.

o   Khan, H T. A. and Hafford-Letchfield, T and Lambert, N (2018) Single women living alone in later life: a short review; understanding society. In: Sexuality, Sexual and Gender Identities and Intimacy Research in Social Work and Social Care: A Lifecourse Epistemology. Dunk-West, Priscilla and Hafford-Letchfield, Trish eds. Routledge, London. ISBN 9781138225879 (Accepted/In press)

o   Lambert, N. (2018) Supporting women with mental health issues. *Mental Health Practice*, 21(6).

o   Aceijas, C., Waldhäusl, S., Lambert, N., Cassar, S. and Bello-Corassa, R., (2017) Determinants of health-related lifestyles among university students. *Perspectives in Public Health*, p.1757913916666875. *http://rsh.sagepub.com/content/early/recent*

o   Hafford-Letchfield, T. Lambert, N and Long, E. and Brady, D. (2016) *Going Solo: findings from a survey of women ageing without a partner and who do not have children.* Journal of Women and Ageing pp. 1-27. ISSN 0895-2841 (Accepted/In press)

o   Hafford-Letchfield, T. Lambert, N. & Long, E (2015) '*Solo women - a new agenda for ageing?'Journal of Fertility Counselling*, 1 (22). pp. 10-12. http://eprints.mdx.ac.uk/16943/

I am aware that many people find academic writing challenging to access so I work to present my ideas in a range of formats.

Book Chapters, Podcasts, vodcasts, blogs etc.

o   Lambert, N., (2023). Co-Production   *Introduction to mental health nursing -* third edition *(in press)* Callaghan, P and Renwick, L. (Ed).

o   Lambert, N., (2022). Mental distress and cultural diversity- second edition. *Diversity and Cultural Awareness in Nursing Practice*, Brathwaite, B. (Ed).

o   Lambert, N., (2022). Collaborated on the "I'm Fine" Project - Zoom work with Paintings in Hospitals designed to improve nurses' mental health and wellbeing.

- Lambert, N., (2021). MDX Minds blog: #mhTV – a podcast series launched during COVID-19 pandemic https://www.mdx.ac.uk/news/2021/02/mhTV-mental-health-nursing
- Lambert, N., (2021) Lunchtime Sessions: 3 wellbeing sessions focussed on breathing and mindfulness: Experiences of Stress and Breathing Exercises - https://www.youtube.com/watch?v=jjceveFGIXc&feature=youtu.be Mindfulness and Meditation - https://www.youtube.com/watch?v=HaDwXFeAvPc&t=1292s and Celebrating the moment - https://www.youtube.com/watch?v=7YJkT7k88JA&feature=youtu.be
- Lambert, N., (2020). How working on a Doctor of Professional Studies has redefined the ways that I envisage my role and purpose as a nurse Middlesex University Work Based Learning e-journal http://wblearning-ejournal.com/uploads/text_with_images/9.2.a1607430635.pdf
- Lambert, N., (2020). Mental distress and cultural diversity. *Diversity and Cultural Awareness in Nursing Practice*, p.154. Brathwaite, B. (Ed).
- 2019- current Mental Health Podcasts Mental Health Nurses Association https://podcasts.apple.com/gb/podcast/the-mental-health-podcast/id1473978950
- Cunningham, S. and Lambert, N., (2020) Inclusive Learning, Diversity and Nurse Education. In *Dimensions on Nursing Teaching and Learning* (pp. 65-81). Springer, Cham.
- Lambert, N., (2020) Navigating your way as a student nurse Podcast - Together in Mind / Tavistock and Portman Trust https://togetherinmind.nhs.uk/in-mindcast/nicky-lambert-navigating-your-way-as-a-student-nurse/
- Lambert, N., (2020). Home (Dis)Comforts Podcast Museum of Domestic Design & Architecture https://moda.mdx.ac.uk/conversations/home-discomforts/
- Lambert, N., (2020). MDX Minds blog https://mdxminds.com/2020/05/21/mentalhealthawarenessweek/
- Lambert, N., (2020). British Educational Research Association blog: Ensuring students achieve, thrive and survive their educational journeys: Using creative ways to support learning and resilience
- Lambert, N (2019) Editorial for *Mental Health Nursing* 'Time to consider women's health'
- Lambert, N., Hafford-Letchfield, T., Khan, H.T., Brady, D., Long, E. and Clarke, L., (2018) Stories of intimacy and sexuality in later life: Solo women speak.
- Lambert, N. (2018) Informed Gender Practice in Acute Mental Health: When Policy Makes Sense in Eds: Beresford, P. and Carr, S. Social policy first hand: An international introduction to participatory social welfare
- Lambert, N., (2017) A spotlight on student mental health in UK universities The Mental Elf. https://www.nationalelfservice.net/mental-health/spotlight-student-mental-health-uk-universities/

o Lambert N, & Connell, S. (2016) Promoting Recovery in Mental Health Nursing. Trenoweth, S. (Ed.) Chapter: Promoting Social Inclusion Sage Publications

o Lambert, N (2016) Dec 16th - Blog post on: *Violence and Women's Mental Health* for Mental Elf https://www.nationalelfservice.net/social-care/safeguarding/violence-and-womens-mental-health-new-review-summarises-the-evidence/

o Lambert, N (2016) Editorial for *Mental Health Nursing* 'Academic Year Starts in Uncertain Times'

Conference Presentations:		
MAR 2023	HORATIO European Festival of Psychiatric Nursing, Malta	#mhTV Coproduced, collaborative learning
MAY 2021	RCN Education Conference and Exhibition 2021	Expansive Learning: online nurse education that is co-produced, creative and critical'
MAR 2021	Trauma and Complex PTSD	Coproduction and trauma - Case studies from social work and mental health.
2021 MAR	#EVERYDAYCOURAGEIWD21 NHS England & NHS improvement	Two wellbeing sessions for Women's Day in collaboration with practice colleagues.
2021 FEB	City University - Disability and Social Inclusion seminar	Co-production in mental health and social care
2020 DEC	Bright Start Conference: 'Parenting Engagement and best practice'	Young People's wellbeing: Adverse Childhood, Covid impacts and Critical resilience
2020 SEPT	Annual Learning & Teaching Conference,' Supporting our Students' London	'Supporting Social Work and Nursing students to learn and thrive during lock down'
2019 JUN	BERA - Education and Mental Health	The role of animals in supporting students to achieve, thrive and survive the educational journey! And Using arts and culture to support students learning and resilience
2019 MAR	RCN Education Forum National Conference	Improving the educational experience of Black, Asian and Minority Ethnic student nurses
2019 MAR	CULTURES OF HEALTH AND WELLBEING CONFERENCE	Supporting student nurses to become thoughtful, compassionate professionals using art and culture
2018 Sept	Philosophy and Theory of Higher Education Conference: London	- Symposium: Student freedom and responsibility; academic citizenship and societal engagement: politics, professionalism and practice.
2018 Nov	White Ribbon Day 2018 4th Annual event: International Day to Eliminate Violence against Women and Girls, London	"A University Perspective".
2018 Jul	The Joint World Conference on Social Work, Education and Social Development Dublin Ireland.	- "Ageing solo in Ireland": an exploratory study of women's perspectives on relationship status and future care needs.
2017 Sept	23rd International MHNR Conference 2017, Cardiff	"Outside the original remit": Working creatively to co-produce qualitative mental health research with service users: reflections from two studies.
2017 May	4th HORATIO European Festival of Psychiatric Nursing, Malta	- Politically Engaged Nursing Practice.

2017 May	4th HORATIO European Festival of Psychiatric Nursing, Malta	- Symposium: Exploring best practice in co-producing qualitative mental health research
2017 Mar	UCL Qualitative Health Research Symposium 2017 Making Research Accessible to Marginalised and Vulnerable Groups	- "Working Creatively to Co-Produce Qualitative Mental Health Research: Reflections from Two Studies.
2016 Nov	RCN International Centenary conference, London	- Women's experiences of mental and physical health issues in accessing and receiving care.
2016 Sept	International Psychiatric Nurse Conference (NPNR) Nottingham	- Going Solo: providing support to women ageing without a partner and who do not have children
2016 Sept	International Psychiatric Nurse Conference (NPNR) Nottingham	- The Time of Their Lives? Lifestyles and the Experience of Health among UK Undergraduate University Students.
2016 Sept	International Psychiatric Nurse Conference (NPNR) Nottingham	- How does the role of Trainee Mental Health Workers in clinical practice compare with expectations prior to starting the programme?
2016 June	Joint World Conference on Social Work, Education & Social Development. Seoul, S. Korea.	- What is my life for? Exploring the experiences of SOLO women in later life
2015 Sep	International Psychiatric Nurse Conference (NPNR) Manchester	- Survey into Attitudes Regarding the Potential Changes to Nurse Education
2015 July	Department of MH, SW & IM Annual Conference, London	- SOLO Women Future Directions *and* TMHW
2015 Mar	London Assoc. of Mental Health Nursing Practice Conference	- Gender and Physical Health
2015 Mar	Compassionate Health care conference, London	- Dignity and Compassion in Practice
2015 Feb	Centre for Research on Families & Relationships: Emotions seminar series, Edinburgh	- Researching stigmatised experience Loneliness: the 'L' worse than leprosy.
2015 Jan	Ageing without children conference, London	- Going SOLO: future research priorities
2014 Dec	Middlesex Early Evening Seminar, London	- Exploring the intimate and broader relationships of SOLO women and the implications for their support needs in later life
2014 Nov	European Festival of Psychiatric Nursing, Malta	- Symposium Taking Objective Structured Clinical Examinations (OSCE's) to the Next Level in MH Nursing
2014 Nov	Conference of ESREA's Network on the Education & Learning of Older Adults, Malta	- Learning in later life: SOLO women
2014 Sept	Transformative feminist methodologies conference, Durham	- Consider a birdcage … reflecting on potential vulnerability and recognising expertise.
2014 July	WhitCAT Compassion Seminar, London	- Compassion & Dignity