Investigating experiences and perceptions of well-being during the work-capability re-assessment process

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I declare this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Statement of Total Word Count*

Section	Words
Thesis Abstract, declaration, acknowledgements and contents	**-**
Introduction	**6,809**
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Appendices	**-**
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Thesis Abstract

Previous research on the experiences of adults in receipt of welfare benefits has focussed on benefit recipients contending with health, social and economic difficulties, stigma while receiving benefits and experiences of conditionality measures. Those with ill-health or disability who have limited ability to work, or are unable to work and applying for benefits in relation to this need to go through a work-capability assessment process. Most claimants will then be subject to re-assessment of their capability to work periodically. There is existing research related to the work-capability assessment but a lack of research related to the re-assessment process specifically.

In November 2020, approximately two million people in the UK were in receipt of work-related benefits and deemed to have severe functional disability as a result of their health conditions. Since the start of the COVID-19 pandemic in March 2020, there are 363,000 more people out of work due to long-term health conditions, with a 22% increase of people with long-term sickness as a result of mental illness specifically. Therefore, further understanding of individuals' experiences and perceptions of their well-being during the benefit re-assessment process is vital, allowing potential issues to be identified and recommendations made which could improve the benefit system for those navigating it. Previous research has shown that long-term benefit recipients fear for their financial security due to anxiety around financial support being reduced or withdrawn, which impacted on their mental health and well-being. However, this research focussed predominantly on recipients of a legacy benefit that was phased out from 2008. Additionally, the work-capability assessment has been found to be detrimental to mental health and re-traumatising to military veterans.

Prior to the research study, a literature review was conducted that scrutinised how individuals experience the benefit system and their health and well-being while claiming welfare benefits. The themes derived from the literature review were: 1) Benefit recipients have to contend with health, social and economic difficulties; 2) Benefit recipients struggle with identity and stigma; 3) Benefit recipients feel negativity, mistrust and are distressed by the benefits system; 4) Benefit recipients feel the work capability assessment (WCA) is not suitable in assessing some health conditions; 5) Benefit recipients do not see work related activity (WRA) as credible; 6) Benefit recipients can benefit from volunteering or permitted work.

This thesis attempts to address the need for further research exploring experiences and perceptions of well-being during the work-capability re-assessment process. Specifically, for people who were deemed to have severe functional disability at a previous work-capability assessment (WCA) and are in the Employment Support Allowance (ESA) support group or the equivalent Universal Credit limited capability for work and work-related activity group (UC LCWRA group). The study employed qualitative methodology and 18 ESA support group or UC LCWRA group recipients participated in in-depth interviews. The narratives presented from this study portray how the re-assessment process is fraught with difficulties that can lead to stress, anxiety and depression amongst other symptoms and feelings. Moreover, it can exacerbate existing physical and/or mental health symptoms. The cycle of re-assessments for those in the ESA support group or UC LCWRA group were perceived as never-ending, harmful to health and led to social struggles including financial difficulties, food poverty and energy poverty. Despite already being found to have severe functional problems due to sickness or disability at a previous assessment, the process of being re-assessed represents conditionality, as non-compliance with the process will lead to the benefit being withdrawn despite individuals' difficulties already being known to the Department for Work and Pensions (DWP). Furthermore, participants experienced stigma during the process due to feeling judged for being in receipt of benefits, which adds to the already arduous process of navigating the re-assessment process.

The policy implications from the findings point to the need for major improvements to the re-assessment process, including:

- Ensuring there is a longer period of time between re-assessments for people who have experienced numerous re-assessments and been consistently found to have limited capability for work and work-related activity.

- The assessment provider should deliver further training for staff regarding claimants' perceptions of the re-assessment process to provide a more sensitive approach and positive experience for claimants navigating the re-assessment process

- The government and media should change how they communicate about people in receipt of benefits. This includes avoiding language that is discriminatory towards benefit claimants or will incite stigma.

Declaration

The research reported in this thesis was undertaken for the Doctorate in Public Health Programme at the Division of Health Research at Lancaster University between September 2020 and April 2023. The word length of this thesis conforms to the permitted maximum. The work presented is the author's own except where due reference is made. The research reported here has not been submitted for any other academic award elsewhere.

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Contents

Chapter 1: Introduction

The welfare state was initially designed to protect the most vulnerable people in society, ensuring a greater level of equality among all citizens (Guyard, 2020). The most vulnerable people in society are considered to include disabled people, people who are economically disadvantaged or homeless, children, elderly, those living with mental illness and ethnic minorities (Larkin, 2009). Social vulnerability and health inequalities exist as a result of inequalities in exposure to the social determinants of health. These are the conditions in which people 'live, work, grow and age', including housing conditions, working conditions, unemployment, access to essential goods, services and healthcare provision (WHO, 2008). Alongside public health interventions, the welfare state is designed to assist with reducing poverty and improving income security, helping to reduce societal and health inequalities (Joseph Rowntree Foundation, 2021).

This chapter begins by depicting the wider societal, economic and health issues in the UK and how they relate to the welfare system. This includes known links between income, health and prevalence of long-term health conditions in the UK, including the impact of the COVID-19 pandemic on the health of the population. After this initial introduction, a historical perspective of the welfare system is outlined, advancing to late twentieth century modernisation of the welfare system and benefits related to work capability. Finally, the work-capability assessment and Universal Credit (UC) for benefit claimants are considered.

The work-capability assessment (WCA) is an assessment that focusses on how an individual's health condition or disability affects them on a day-to-day basis and their subsequent capability to engage in work or work-related activity. The focus of the thesis is on people who were deemed to have severe functional disability at a previous WCA and exploration of their experiences and perceptions of well-being during the work-capability re-assessment process. The aim of the study is to understand their experiences and perceptions, provide recommendations related to the future policy of welfare benefits and potential opportunities for further research. This will be achieved through completion of qualitative, unstructured interviews, with subsequent data analysis and discussion. The methodology and methods will be covered more specifically in chapter 3. While quantitative research methods can be used to quantify how many people undertake particular behaviours, qualitative methods help us to understand how and why these behaviours take place in depth, improving our understandings of specific problems or situations (Sutton and Austin, 2015). This is important as there is an increasing number of people in the UK with long-term health conditions in receipt of work-related benefits. In November 2020, just under two million people in the UK were in receipt of work-related benefits as a result of health conditions or disability and in the category of benefit that deems them to have severe functional disability (Department for Work and Pensions, 2021a). This equates to approximately three percent of the UK population. Therefore, further understanding of their experiences during their benefit re-assessment process is imperative in ensuring appropriate provisions are in place for this population group.

There are contrasting models of disability that offer different positions on the nature of disability (Thomas, 2004). The ‘medical model of disability’ views impairment purely as a consequence of some ‘deviation’ from ‘normal’ body functioning, which has ‘undesirable’ impacts for the affected individual that need to be treated or rehabilitated (Berghs et al., 2016). However, it is widely argued that reducing disability to bodily impairment alone and an individual problem that needs to be ‘fixed’ or ‘prevented’ is conceptually weak and too medicalised, not taking into account sociological factors (Solvang, 2000). In contrast, “disability sociologists use scientific methods to develop social explanations (rather than, for example, biological, psychological or religious explanations) for social phenomena” (Carey, 2022, p. 4).

The ‘social model of disability’ distinguishes between impairment and disability, with impairment viewed as an injury, illness or condition that is likely to affect physiological, cognitive or psychological function. Whereas, disability is viewed as the limitation of opportunity to engage in functional activity or engage in society on an equal level due to social and environmental barriers

(Imrie, 1997). Disability is therefore a negative interaction between an individual with an impairment and their social environment (Goering, 2015). Finkelstein (2001) wrote of society disabling people with impairments and disabled people being an oppressed group, for example, transport or buildings not being accessible to all or negative attitudes assuming that disabled people are unable to live independently or work (Scope, 2024). Disablism can be defined as “discriminatory, oppressive, abusive behaviour arising from the belief that disabled people are inferior to others” (Council of Europe, 2024); with disablism aligning with the likes of sexism, racism, ageism and homophobia as an oppressive practice (Thomas, 2007). The social model of disability recognises that barriers make daily living harder for disabled people, with removal of these barriers offering disabled people more independence, control and choice over their day-to-day activities (Scope, 2024).

Shakespeare and Watson (2001) propose that the social model is potentially outdated, with people disabled by social barriers *and* by their bodies and embodied states. Those with impairments can simultaneously hold a belief that society is mostly to blame for their disabling experience, whilst also accepting the lived experience of bodily limitation. This proposal from Shakespeare and Watson is viewed by Thomas (2007) as an alternative model of disability or ‘medical sociological view’. Yet, the social model of disability is comprehensible as it is based on experiences of exclusion or disablement, enabling people to make a connection between removal of barriers and a fight for equality in society (Beresford, 2004). It is socially and politically located in disabled people’s movements and activism for social change (Finkelstein, 2001), with disability charities in the UK continuing to base their equality strategies on this model (Scope, 2024). This thesis aligns with the viewpoint of the ‘social model of disability’ and its aim of achieving fairer conditions and equality in society.

1.1 UK societal, economic and health issues

In the late 1990s and early 2000s, the UK had enjoyed a period of sustained economic growth. However, in 2008 there was a financial crisis when after years of cheap lending and available credit, there was a credit crisis. The credit crisis was worsened by an interrelated crash of the housing market that had built up over the previous decade (Hodson and Mabbett, 2009). This financial crisis led to a period of recession in the UK and it took five years for the UK's Gross Domestic Product (GDP) to return to pre-crash levels (Office for National Statistics, 2018). During the initial onset of the financial crisis, the economic slowdown led to job losses and falling incomes, which in turn caused reductions in consumer spending and related tax revenues. This spawned large rises in government deficits and resultantly, increased public debts. The governmental response was to introduce austerity measures, which involved reducing social spending and increasing taxation, however, these measures have been shown to more severely impact disadvantaged populations (Stuckler et al., 2017). From 2011, due to the resultant social and economic inequality, including restricted funding to local councils, public sector pay freezes and increased housing insecurity, homelessness, depression, food insecurity, hunger and foodbank use, health inequality widened and there was a national slowing of life expectancy, with some areas of the UK seeing a reduction in life expectancy (Arrieta, 2022; Jenkins et al., 2021; Marmot, 2020; Stuckler et al., 2017). Inequality in health continues to widen today, including inequalities in non-communicable and chronic diseases (Marmot, 2020). This economic backdrop relates to the thesis as the austerity measures introduced by the government are known to have had a fundamental impact on those already vulnerable, including benefit recipients, those with precarious employment, unsecure housing or with existing health problems (Stuckler et al., 2017).

In June 2016, the UK voted to leave the European Union (EU) with the exit formally occurring from the 31st January 2020. This led to a rise in inflation and added to the reduction of average income for UK households (Breinlich et al., 2017). Moreover, in February 2022 there was escalation in the war between Russia and Ukraine. This has led to a global 'cost of living crisis' whereby the cost of energy bills and everyday essential items such as groceries are rising faster than average household incomes, which further impacts societal inequalities (Webster and Neal, 2022). Therefore, further exploration of personal experiences and perceptions of well-being for those on the lowest incomes during a benefit re-assessment process is salient research.

In December 2019, there was an outbreak of coronavirus disease 2019 (COVID19), which in January 2020 led to the World Health Organization (WHO) declaring the outbreak as a Public Health emergency of International Concern (Harapan et al., 2020). The COVID-19 pandemic occurred against the background of social, health and economic inequalities described above (Bambra et al., 2020). As a result of the COVID-19 pandemic, an estimated two million people in the UK have reported symptoms of Long-COVID, meaning their symptoms have lasted over 12 weeks and 1.5 million of whom reported their symptoms adversely affect their functionality (NHS, 2023). This is in addition to the two million people who were out of the labour market due to long-term sickness in 2019 (Office for National Statistics, 2023a). Additionally, since the pandemic, an additional half a million people are out of work or 'economically inactive' due to long-term ill-health (Office for National Statistics, 2023b). Mental health issues reported to have been associated with the pandemic include stress, anxiety, depression and insomnia (MIND, 2021). Since the outbreak of the pandemic in early 2020, the number of people out of work due to long-term ill-health as a result of mental illness and nervous disorders has risen by 22% (Office for National Statistics, 2022b). Additionally, due to health service constraints during the pandemic it is estimated that 124,000 people have missed or late diagnoses, resulting in a combined 4,400 years of disability. This includes missed or late diagnoses of asthma, diabetes, rheumatoid arthritis, inflammatory bowel disease and progressive neurological disorders (Carnall Farrar, 2021).

The largest relative increase in long-term ill-health was in the age 25-34 category but over half of the working age population out of work due to ill-health is in the age 50-64 category, which is indicative of chronic health conditions and disability prevalence increasing with age (Office for National Statistics, 2022b). This increases the number of people unable to work and claiming welfare benefits, with the number of people claiming disability and work-related benefits, Personal

Independence Payment (PIP) and Universal Credit (UC) respectively, significantly increasing (DWP, 2021c; DWP, 2022f). The following section provides a historical perspective of welfare to provide a backdrop of how welfare provisions have progressed with time.

1.2 The welfare state: A historical perspective

Origins of welfare measures in the UK and Germany can be dated back to the mid-1800s, when national insurance, accident insurance and disability benefits began to be introduced (Boyer, 2007). In the United States, a national welfare system was established in the early-1900s (Kataja, 2017). However, until the UK welfare reforms of the mid-twentieth century, public services in the UK were predominantly a makeshift offering of voluntary organisations, church support and some localised government services (Slack, 1995). In 1942, Sir William Beveridge presented the 'Social Insurance and Allied Services' report, which lay the foundations of a modernised welfare state. In 1945 in the UK, when the Labour Party won the general election, the newly-formed government committed to the findings of Beveridge's report and a more formalised welfare state was introduced. This included an updated National Insurance Act that ensured everyone was entitled to unemployment benefits, old-age pensions and widows' pensions. Following on from this, in 1948 Industrial Injuries Disablement Benefit (IIDB) was introduced, which was payable in addition to individuals' earnings as a way of compensating them if their illness or disability was as a direct result of their work. The National Health Service was also introduced in 1948 ensuring free healthcare coverage for all (Burchardt, 1999; Lambert, 2022).

Prior to 1971, individuals who were unable to work due to sickness or disability were commonly not divided from the general unemployed population and received the same means-tested assistance. Invalidity Benefit (IVB) was introduced in 1971, which provided an age-related income to those who left employment specifically due to sickness or disability. In 1971, Attendance Allowance was also introduced for individuals who required significant amounts of personal assistance, followed in 1975 by Mobility Allowance for those who needed help to access the community. In conjunction with the introduction of an earnings-replacement benefit for sick or disabled non-employees, in 1976, the original Invalid Care Allowance was introduced, which ensured carers received an income (Burchardt, 1999). In 1983, statutory sick pay (SSP) was introduced, which became the primary benefit for individuals who were off work due to short-term sickness, with IVB only utilised by individuals off work due to sickness or disability beyond the short-term (Wikeley, 1995).

However, by the late 1980s, the financial needs of disabled people were still not being met by existing benefits, with Attendance Allowance and Mobility Allowance consequently replaced by Disability Living Allowance (Martin and White, 1988). Yet, in the early 1990s, the Conservative government stressed the need for ongoing welfare reforms to reduce ‘dependency’, encourage self-reliance and to improve the nation’s economic competitiveness (Lilley, 1993). The government’s view on dependency aligned with the theory of the sick role proposed by Parsons (1951), in which he viewed sickness as a form of deviant behaviour within society. Parsons felt that people who were too unwell to fulfil their normal roles were deviating away from a consensual norm, with too many people being unwell having a detrimental impact on society. Therefore, arrival into the sick role needed controlling. ‘Dependency’ focusses on assumptions that those in-receipt of benefits are dependent on these means due to personal deficit or shortcomings (Garrett, 2015). However, this fails to adequately address that people’s circumstances are not always in their control and are highly dependent on their health, social and economic resources (Mann, 2001). Yet, Invalidity Benefit was deemed as one of the main areas of benefit expenditure contributing the most to future increases in welfare spending and in 1995 it was replaced by Incapacity Benefit (IB) (Burchardt, 1999; Department for Social Security, 1993). Unlike, Invalidity Benefit, IB had tougher eligibility criteria. In Invalidity Benefit, assessments of incapacity for work could take into account individuals’ age and qualifications, however, for IB the test was more objective, focussing upon whether there was any work the claimant could perform, regardless of the likelihood of attaining a job or its suitability (Burchardt, 1999).

1.3 The welfare state: Late twentieth-century modernisation

The toughening of eligibility criteria outlined in the previous section continued in the late twentieth-century and into the twenty-first century. In 1996, Bill Clinton, then President of America, signed into law "The Personal Responsibility and Work Opportunity Act of 1996". The Act was focussed upon incentivising employment, supporting families moving from welfare into work, child support, child care and medical coverage, with the Act considered wide-ranging for welfare reform (U.S Department of Health and Social Services, 2020). Similarly, in neighbouring Canada, 'The Canada Health and Social Transfer (CHST)' was introduced in 1996, with the most significant part of this Act being the termination of automatic entitlement to welfare, which had been present since the 1960s (Karsh, 2003).

In 1997, the Labour party won a landslide majority in the UK general election. A priority of the new government was to overhaul the welfare system, with this focus heavily influenced by similar welfare reforms undertaken in the US and Canada, which had sought to incentivise employment and terminate automatic entitlement to welfare, respectively (Driver, 2018; Johnston and Pattie, 1997; Karsh, 2003; U.S Department of Health and Social Services, 2020). There was focus on incentivising work via welfare-to-work programmes, introduction of tax credits and improvement of access and funding of childcare, all with the goal of reducing poverty (Joseph Rowntree Foundation, 2004). This visible shift in welfare policy in the mid-late 1990s led to migration from Incapacity Benefit (IB) to Employment and Support Allowance (ESA) from 2008. ESA is a benefit that individuals can claim if they are unable to work because of a health condition. If an individual does not have enough National Insurance (NI) contributions and does not have sufficient money to afford day-to-day living, they may qualify for income-related ESA, which is paid if all other income coming into the household is below limits set by the government. Contribution-based ESA, on the other hand, can be awarded if an individual has paid sufficient NI contributions and is paid regardless of other income into the household (Benefits and Work, 2022).

The change from IB to ESA led to a change in the assessment that was conducted to determine whether individuals were eligible for the specific benefits. IB utilised a personal capability assessment, which focussed on what individuals could do despite their illness or disability, as well as determining if an incapacity threshold was met. If the incapacity threshold was met, individuals were exempt from any employment activity. Conversely, if individuals did not meet the threshold for incapacity, they would be advised about registering for employment. However, ESA utilised a work-capability assessment (WCA) that focussed more upon how the individual's illness or condition affects them on a day-to-day basis. There was a shift of focus away from individuals being incapacitated and completely unable to engage in employment, to individuals having a tiered ability to engage with employment activities. Individuals could be placed into what was known as the 'support group' if deemed unable to engage in any employment activities. However, individuals could now also be placed into a work-related activity group (WRAG). This would involve attending work-focussed interviews, completing training or joining condition management programmes if their illness or condition was only deemed to have a significant effect on their functional ability, rather than a more severe effect (Benefits and Work, 2022; DWP, 2010; Health Assessment Advisory Service, 2022a).

Similarly to the modernisation of work-related benefits, Disability Living Allowance (DLA), which is a benefit to support disabled people with the extra costs of disability, was largely replaced in 2013 with the introduction of Personal Independence Payment (PIP). DLA can still be claimed by children under the age of 16 or by adults who were aged 65 or over when PIP was introduced (DWP, 2015). DLA was deemed by the government to be outdated, with not enough focus on mental health or differentiation between long-term and fluctuating conditions, which gathered more understanding in the later twentieth century (DWP, 2013). In 2010, 71% of claimants in-receipt of DLA received the award for an indefinite period of time. Whereas, between April 2013 and April 2018, 18% of PIP awards were for an indefinite period of time, 82% were awarded for three and a half years or less, with recipients of PIP now subject to a more systematic process of assessments and re-assessments (DWP, 2015; Machin and McCormack, 2021). This is indicative of the government attempting to reduce welfare costs by reducing the number of people who are claiming disability benefits indefinitely. After return to government in 2010, the Conservative party introduced Universal Credit thereafter.

1.4 Universal Credit history and policy context

Universal Credit (UC) is a monthly payment to help individuals who are out of work or in low income work with day-to-day living costs, which was introduced incrementally across the UK from 2013 (DWP, 2020). UC has replaced six legacy benefits, including income-related Employment and Support Allowance (ESA) (DWP, 2022a). UC has sought to improve employment outcomes by confronting what the government perceived as a ‘culture of worklessness’ and ‘welfare dependency’, with legacy benefits alleged to trap people in poverty and dependency by failing to incentivise work (Patrick, 2017). Since the introduction of UC, benefit claimants in receipt of legacy benefits, including income-related ESA, have been gradually migrating across to UC. In March 2020 this was paused due to the Coronavirus pandemic, however, this migration was recommenced in May 2022 and now has a target completion date of 2028/29 (DWP, 2023a). There are some specific circumstances whereby individuals can still claim income-related ESA, however, the majority of new claims will be for UC (turn2us, 2021). Individuals with a health condition may be entitled to an additional amount of UC if they have a health condition that precludes them from carrying out work and work-related activity (Centre for Health and Disability Assessments, 2020). For the 2022/23 financial year, if in receipt of UC and in the limited capability for work and work-related activity (LCWRA) group, the LCWRA-element is worth an additional £354.28 per month for an individual claimant (The Benefits Training Company, 2023). When making a claim for UC, individuals are asked if they have a health condition that prevents, or limits, their ability to work. If the answer is ‘yes’ and if they continue to have limitations or an inability to work for a period of four weeks, they will be referred for a work-capability assessment thereafter (DWP, 2022b).

1.5 The work-capability assessment (WCA) process

Once the referral into the work-capability element of the UC benefit is made, individuals are sent a capability for work questionnaire called a UC50 or ESA50, dependent on whether they are in receipt of UC or ESA. If a claimant has a mental health condition that is known to the assessment provider, they can continue on the assessment journey without returning the questionnaire (Health Assessment Advisory Service, 2023a). Otherwise, there is an expectation to complete a questionnaire, which is made up of many sections titled:

- About you
- About your General Practitioner (GP) or doctor's surgery
- About other Healthcare Professionals, carers, friends or relatives who know the most about your disability, illness or health condition
- About medical or other information you may already have
- Cancer treatment
- About your disabilities, illnesses or health conditions
- How your conditions affect you: Physical functions
- How your conditions affect you: Mental, cognitive and intellectual capabilities
- Eating or drinking
- Sharing information about your health condition
- Face-to-face assessment
- Other information
- Consent to notify your GP of the outcome of the Work Capability Assessment
- Declaration (DWP, 2021d)

The information provided on the questionnaire is used to decide whether a work-capability assessment is necessary or further medical evidence can be sought to avoid this if the individual expresses severe health and/or functional problems on the questionnaire. The full work-capability element of the UC and ESA benefits can be awarded without the requirement of an assessment if:

- there is sufficient medical evidence to support that an individual has severe functional problems;
- is terminally ill with life expectancy of less than twelve months;
- is at substantial risk of physical or mental health deterioration if found fit for work and work-related activity;
- is a pregnant woman and there is serious risk to their health or the health of the unborn child if she does not abstain from work and work-related activity;
- is likely to receive chemotherapy or radiotherapy as part of their cancer treatment within six months;
- is currently undergoing such treatment, or recovering from such treatment (Centre for Health and Disability Assessments, 2022; DWP, 2022c).

However, if the severity of an individual's health condition or functional ability cannot be robustly justified from the available evidence, an assessment is required.

The letter accompanying the questionnaire contains the date that the questionnaire will need to be returned by, which is set to 28 days after the form has been received. If the form is not returned, this can lead to the specific benefit being stopped, unless a good reason can be provided for the form being late (Citizens Advice Bureau, 2023a). The work capability assessment (WCA) will usually be conducted within a few months of the questionnaire being returned (Citizens Advice Bureau, 2023a). The ESA or UC re-assessments have review periods that are usually set between 3 and 36 months, after which point a questionnaire will be sent through the post and the re-assessment process will be initiated (DWP, 2021e).

The WCA continues to be utilised in UC and ESA, however, the name for the group claimants are in post-assessment has changed, with a move away from work-related activity group (WRAG) and the support group, which are now terms specific to ESA only. The outcome from a UC WCA can be that an individual is deemed fit for work, has limited capability for work (LCW) or has limited capability for work and work-related activity (LCWRA) (DWP, 2019).

If found fit for work, individuals are expected to fully engage with Job Centre Plus to find work. These expectations are enforced using sanctions that involve the removal of a claimant's benefit income for a period of time if they do not adhere to expectations set by policy makers with respect to searching for employment (Watts et al., 2014). The behavioural expectations are enforced to condition individuals' behaviour towards extensive job searching and the potential acceptance of poor quality or insecure employment (Knotz, 2018). To have LCW means that an individual is deemed to have significant functional disability but in another act of conditionality, they are expected to complete tailored work-related activity, for example, work taster programmes or programmes related to managing health in work (Citizens Advice Bureau, 2020; Mehta et al., 2021). If a claimant in the LCW group does not engage with their work-related activity, they stop receiving this element of their benefit (turn2us, 2023). To have LCWRA means that an individual is deemed to have severe functional disability and there is no expectation to complete any work or work-related activity (Centre for Health and Disability Assessments, 2020).

The majority of UC recipients will be subject to re-assessment of their work capability unless formally diagnosed with a severe, lifelong health condition, which will not improve in the future as there is no realistic prospect of recovery (Disability Rights UK, 2017). The re-assessments can be from 3 months up to 3 years post-WCA, depending on how severely individuals are deemed to be impaired by their health condition(s). In November 2020, 2.6 million people were in receipt of ESA or UC due to their health condition(s) and 75% (1.95 million) were in the LCWRA category or equivalent ESA Support group (DWP, 2021a). For assessments completed in the final quarter of 2021, the percentage of decisions falling into the LCWRA category was 67% for new claims and 79% for re-assessments (DWP, 2022d).

A report from the Work and Pensions Committee (2018) found that failings in the WCA and secondary decision-making processes had led to a lack of trust, which threatened to undermine the WCA process. The report also highlighted difficulties for claimants before the assessment with regards to completing the benefit application paperwork, inconsistencies in the application of the WCA itself and a lack of transparency in how the outcome of the WCA is decided. A subsequent report from the Work and Pensions Committee (2023) found that many of the issues identified in the 2018 report remained and changes to improve trust and transparency in the process had not been made.

Re-assessment of individuals through the WCA has shown an increased incidence of mental health problems and prescriptions for anti-depressant medications (Barr, Taylor-Robinson, et al., 2015), with claimants reporting attending the WCA and subsequently waiting for the outcome of the assessment causing them anxiety (de Wolfe, 2012; Garthwaite, 2014). Garthwaite (2014) identified that long-term benefit recipients fear for their financial security during the re-assessment process due to anxiety around financial support being reduced or withdrawn, with this impacting on their health, well-being and mental stability. Garthwaite's study focussed on long-term recipients of Incapacity Benefit (IB), which is a legacy benefit that assessed people's capability to work via a personal capability assessment (PCA) and contained different functional descriptors and scoring criteria within the assessment compared to the WCA. The majority of the research participants had yet to undergo a WCA, which is now used towards assessing the work-related element of UC. Overall, with the use of the PCA, 17% of claimants were found to be fit for work but a year after its introduction the WCA had found 36% of claimants to be fit for work (The ME Association, 2009). This illustrates how the scoring criteria for WCA were stricter than those used in the PCA.

1.6 Universal Credit: Impact on health and well-being

UC has attracted much highly publicised attention for several reasons. Since the introduction of UC in the UK, there has been an increased occurrence of psychological distress among individuals who rely on welfare benefits (Wickham et al., 2020). Austerity measures introduced by the government in 2010 included welfare reform in the UK, which from 2010-onwards has been associated with a trend of upsurge in mental health problems, suicidal thoughts, suicide and prescriptions for anti-depressant medications (Barr, Kinderman, et al., 2015; Cheetham et al., 2019). Research focussed on the impact of the roll out of UC by Cheetham et al. (2019) identified additional worries of poverty and food insecurity due to the process of claiming benefits causing delays in benefit receipt, which led to deterioration in physical and mental health and impacted negatively upon individuals' family relationships. UC has also been found to be systematically related to the acceleration in the rise in hunger in the UK in recent years and in increased food bank usage (Reeves and Loopstra, 2020). When first applying for UC, there is a waiting period of at least five weeks from the acceptance of a claim and the first payment. This is planned to replicate monthly payment schedules as per most employed roles, however, again this gap in payment is a contributing factor to financial hardship, including going into debt as many households have been used to receiving their benefits on a weekly or fortnightly basis (Hartfree, 2014; Reeves and Loopstra, 2020). Advanced payments are available, nevertheless, these payments are then automatically subtracted from future UC payments, which merely defers the financial hardship (Reeves and Loopstra, 2020; Wright and Patrick, 2019). UC has also been found to have a negative effect on housing security and since the introduction of UC there is an increasing proportion of claimants experiencing difficulty in paying towards their accommodation (Williams et al., 2022).

Tougher measures of conditionality have been introduced with the aim of incentivising employment, enforced by the threat of sanctions, whereby benefit payments have become more transactional in nature, as opposed to being automatic or by entitlement (Mehta et al., 2021). This is a significant re-direction from people utilising a state fund of social security to assist with management of health or daily living, towards people being treated as claimants who must provide variable levels of effort in exchange for their benefits (Grover and Piggott, 2015). This re-direction represents a re-writing of the rights and responsibilities of social citizenship (Dwyer, 2016). Yet, sanctions are generally not effective: unemployment levels increase in the longer-term as work that is sourced is not secure employment or the quality of employment reduces, with earnings and job retention decreasing (Wright and Dwyer, 2022). Sanctions and related-conditionality tools have been found in many cases to lead to worsening mental health, demoralisation, financial and material hardship, food insecurity, inability to meet rent or bill payments, borrowing and debt problems, all of which can lead to benefit recipients feeling criminalised (Dwyer et al., 2020; Pattaro et al., 2022; Wright et al., 2020). Additionally, recipients of UC are less satisfied with their lives when compared to individuals who do not claim benefits and a potential reason for this is that conditionality undermines recipients' ability to do activities that they have reason to value (Thornton and Iacoella, 2022; Wright and Patrick, 2019).

Moreover, there is the longstanding yet ongoing issue of stigma. Scambler (2009, p. 441) states that "stigma is typically a social process, experienced or anticipated, characterised by exclusion, rejection, blame, devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group". Scambler (2018) wrote how stigma has always been weaponised for social and political ends and in more modern times related to governmental language when discussing benefit claimants and their dependency on 'handouts'. Tyler (2020) conceptualised stigmatisation as something received through stigmatising looks, comments and remarks, whether face-to-face or through digital encounter, adding that these encounters are entwined with wider capitalist structures of domination and social control. Baumberg Geiger (2016) breaks benefits stigma down into separate strands of stigma: 'personal stigma' which is a benefit recipient's own feeling that claiming benefits carries a cheapened identity; 'stigmatisation' which is the perception that other people will undervalue your identity; finally 'claims stigma' which relates to a lack of privacy when claiming benefits, a demeaning experience of long waits and feeling a lack of respect from staff. Gilroy (2019) stated that the only way stigma can be resisted is through unity as capitalism exploits differences and causes divisions in society by crafting hierarchies of person value and worsening class, gendered and racialised divisions. For example, there are current political campaigns focussed upon immigration, gender recognition and welfare, all of which are polarising topics and fuel discord and stigma. There is no universally accepted theory of stigma (Scambler, 2009), most approaches to reducing stigma focus on education, responding to misperceptions or negativity, self-empowerment and promotion of compassionate and dignified thinking and action (Heijnders and van der Meij, 2006).

A report from Baumberg Geiger et al. (2021) estimated that half a million people in the UK were eligible for UC during the COVID-19 pandemic but did not claim it, with 59% (approximately 295,000) citing conditionality as a contributing reason for not applying and 27% (approximately 135,000) not claiming directly due to benefits stigma. In 2022, Suella Braverman, a current Member of Parliament (MP) and leadership candidate for the Conservative Party, stated:

> *"I think we spend too much on welfare. There are too many people in this country who are of working age, who are of good health and who are choosing to rely on benefits, on taxpayers' money, on your money, my money, to get by. I don't think there's enough rigour. Universal Credit has been a brilliant thing in stamping out the culture of dependency but there's further we can go, there's more we can do" (Daisley, 2022, July 12).*

Suella Braverman spoke of benefit recipients "who are of good health and who are choosing to rely on benefits…", insinuating that some are fraudulently claiming or pretending to be unwell. There is a perception that all benefit recipients are scrutinised intensively due to media and political discussion of 'scrounging'. This risks stigmatising those with ill-health or disabilities, which will include people in the ESA Support group or UC LCWRA group respectively. This leads to further stigmatisation or negative public perception towards this population who have long-term health conditions or disability, which is damaging to their well-being and self-esteem. In qualitative research exploring individuals' experiences of stigma related to the social security system, Inglis et al. (2019) found that negative framing of benefit claimants in government and media rhetoric is to the detriment of benefit claimants' well-being.

In 2023, former Leader of the Conservative Party and current MP, Iain Duncan Smith, wrote an article in The Telegraph (2023, May 24). The heading of the article was '*Stop sick people languishing on benefits*', with a sub-heading of '*With the right incentives, they can fill vacancies and end our country's reliance on cheap foreign workers*'. In 2023, the Labour Party's Shadow Work and Pensions Secretary and current MP, Jonathan Ashworth, stated:

> *"Taxpayers will be astonished that so much cash has been lost to [benefit] fraud and blundering Tory ministers are asleep at the wheel. They need to get a grip"* (Cowburn, 2023, April 10).

These are further examples of current MPs using language that is potentially inflammatory towards benefit claimants. 'Languishing' implies failing to progress or stagnating, which is an unfair way of describing a group of people accessing welfare support due to ill-health or disability. Moreover, those who are in-receipt of benefits and in the ESA support group or UC LCWRA group are exempt from completing employment-related activities based on their health or disability. Raising benefit fraud as an issue that will leave taxpayers (working people) 'astonished' implies that people who are not in work are fraudulently claiming benefits.

This negative portrayal of benefit claimants is often reflected in media discourse. On May 25 2023, Jeremy Vine, a television and radio presenter, broadcaster and journalist, with a national platform, tweeted the following:

> *"Is it time to crack down on jobless benefits? Nearly four million people in the UK are being supported by the state without ever having to look for a job. That's because they've been deemed too sick to work. Is it wrong for taxpayers to fund them indefinitely?"* (Jeremy Vine on 5, 2023, May 25).

This comment is a further example of inflammatory language being used towards benefit claimants, who are too unwell to work. Once more, reference is made to taxpayers (working people) and how they should perceive recipients of sickness benefits. However, this is not a new topic of conversation. In 2010, Prime Minister David Cameron promised a “crackdown on benefit fraud”, with The Sun newspaper then launching a campaign against ‘scroungers’ and ‘cheats’, which encouraged readers of the newspaper to report those they suspected of over-claiming benefits to the newspaper (Aitchison, 2010, August 13). However, the fact that governmental and media communications and language related to benefit recipients continues to be inappropriate or inflammatory shows that this is an issue that continues.

1.7 My reflections and rationale for conducting this study

Prior to the commencement of this research study, I was employed by the Centre of Health and Disability Assessments (CHDA), a private company that conducts work-capability assessments on behalf of the DWP. I worked for the company from August 2015 to January 2017 as a functional assessor, assessing people’s entitlement for benefit via a work-capability assessment (WCA), before being promoted to a Clinical Standards Lead. This is a role I then did from January 2017 to February 2022, providing coaching and mentorship to new and tenured functional assessors, amongst other leadership duties. From spending multiple years working within assessment centres where WCAs are conducted, assessing thousands of claimants and leading a team of functional assessors, I have seen first-hand, claimants engaging with the benefits system. There were many positive engagements with claimants, but these were outweighed by claimants encountering difficulties in their assessments, including being sent home unseen and having to return for an assessment on a later day despite attending for an appointment as requested, having appointments cancelled late, all of which led to distress and sometimes anger for the claimants. This experience is what drove me to conduct this research and look to provide findings and recommendations that could help to improve the process for people undergoing assessment and re-assessment of their work capability. Further details related to this will be discussed in chapters 3 and 5.

This chapter has described the welfare benefits system and explained how austerity measures, and more recently the COVID pandemic, have led to widening health and social inequalities, with rising numbers of people with long-term health conditions or disability. Toughening of benefit eligibility criterion and conditionality measures enforced by sanctions have led to worsening health of benefit recipients. Furthermore, stigma remains an ongoing issue for recipients of benefits. Therefore, it is more important than ever to explore benefit recipients' experiences of being assessed for benefits.

The research outlined in the thesis utilises the Health Stigma and Discrimination Framework (Stangl et al., 2019). Martin et al. (2008) states that many existing theoretical approaches to stigma focus on health conditions in isolation, for example, obesity, HIV-AIDS and leprosy. Conversely, they focus on individual stigmatised groups such as queer or minority racial and ethnic groups. In contrast, the Health Stigma and Discrimination Framework is a crosscutting framework that can be applied across a range of health conditions and also considers stigma in relation to race, gender, sexual orientation, class, occupation and how this intersects with health-related stigmas (Stangl et al., 2019). The framework has been used to enhance research, programming and policy efforts related to engagement and adherence to receiving care and health treatments. In the context of this research, it will be utilised to magnify experiences and perceptions of the work-capability re-assessment process and how engagement with the process can be improved for those who repeatedly navigate it.

The following chapter reviews the literature on experiences of the benefit system and how benefit claimants perceive their health and well-being while claiming welfare benefits. Chapter 3 will outline the methodology and methods of the research study, while chapter 4 will present the findings from the research. Chapter 5 will discuss the findings, study limitations, a reflexive viewpoint of the research, the contribution to literature and knowledge, before offering policy implications based upon the findings and potential for future research.

Chapter 2: Literature Review

This chapter reviews the literature on how individuals experience the benefit system and their health and well-being while claiming welfare benefits. It provides a setting for the remainder of the thesis by providing a picture of welfare benefits internationally.

The review aimed to synthesise the findings from published UK and international qualitative and mixed methods studies (qualitative data only), which had explored how adults in receipt of welfare benefits describe their experience of their benefit system and their health and well-being while claiming benefits, with the aim of identifying themes across the literature within the evidence base and recommending where further research is required (Owens, 2021). Chapter 1 cited research on the welfare benefit system in the UK, including conditionality, stigma and the work-capability assessment process. This literature is predominantly quantitative research focussing upon effects of benefit systems, trends in the health of benefit claimants or impacts of the benefit system on mental health. As the current PhD literature review focuses on experiences of benefit systems and health and well-being while claiming benefits, a review of qualitative literature specifically was deemed more appropriate (Tenny et al., 2022).

2.1 Introduction

Previous systematic or scoping reviews on benefit systems have included exploration of the effectiveness of welfare-to-work programmes (Bambra et al., 2005); health, social and financial impacts of welfare rights advice in healthcare settings (Adams et al., 2006); the effectiveness and experiences of welfare advice services co-located in health settings (Reece et al., 2022); disability benefits acting as a disincentive to employment (Barr et al., 2010); the impacts of benefit sanctions on the labour market (Pattaro et al., 2022). However, none have focussed on how individuals experience the benefit system and their health and well-being while claiming welfare benefits so this area is not fully understood. This systematic review aimed to synthesise findings in relation to this, which is important as increasing understanding around the existing research for this area will highlight any areas for future research. In turn, this helped to shape the focus of the researcher's empirical study and allowed recommendations to be made in relation to benefit systems in the UK and internationally.

2.2 Method

The SPICE framework for qualitative evidence synthesis was employed as described by Booth (2006) to identify search terms, refine the review question and generate the literature search strategy. The SPICE framework was selected as it is more commonly used in qualitative research topics evaluating services, projects or interventions, encouraging exploration of wider experiences (Booth, 2006). Table 1 outlines the SPICE framework specific to this literature search:

Table 1

Table 1. SPICE Framework

Setting	High-income countries
Perspective	Adults in receipt of welfare benefits
Intervention	Benefit systems
Comparison	Health and well-being while claiming benefits
Evaluation	Experiences

The review question is as follows:

How do adults in receipt of welfare benefits in high-income countries describe their experience of the benefit system and their health and well-being while claiming welfare benefits?

A comprehensive search of five electronic databases was conducted up to 2022 using Academic Search Ultimate, the Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, PsycINFO and SocINDEX. These databases were selected specifically for their coverage of medicine, nursing, allied health professionals (AHPs), science, health and sociology. Therefore, they include research across a range of professions, health-related and sociological fields. The literature database search was initially completed between December 2020 to March 2021 and was repeated in July 2022. Databases were searched from 1996 onwards as this coincides with a visible shift in welfare policies in the United States (US), Canada and UK from the mid-late 1990s, therefore excluding papers that pre-date the welfare policy shifts. The review was also an international review and not focussed on the work-capability assessment (WCA) specifically, hence the search being conducted from 1996 onwards, as opposed from 2008 and the introduction of the WCA.

Each database was searched individually using a combination of subject headings and key search terms associated with the following concepts: 1) high income countries, 2) adults, 3) welfare benefits, 4) experiences of the benefit system and health and well-being while in the benefits system, 5) qualitative or mixed methods designs. The search was limited to high-income countries as these are the countries that have established welfare systems. Papers using mixed methods designs were only considered if qualitative data were clearly identified, with quantitative studies excluded on the basis that the review focusses upon individuals' experiences, which are not adequately explored within quantitative designs (Silverman, 2010). Two academic librarians from Lancaster University were consulted individually regarding the search strategy and key search terms were applied by the author to the title (TI) and abstract (AB) of papers to reduce the likelihood of irrelevant results. Boolean operators including 'AND' and 'OR' were utilised, in addition to truncation using the wildcard asterisk function (*) and appropriate use of individual database limiters. Table 2 outlines the inclusion and exclusion criteria.

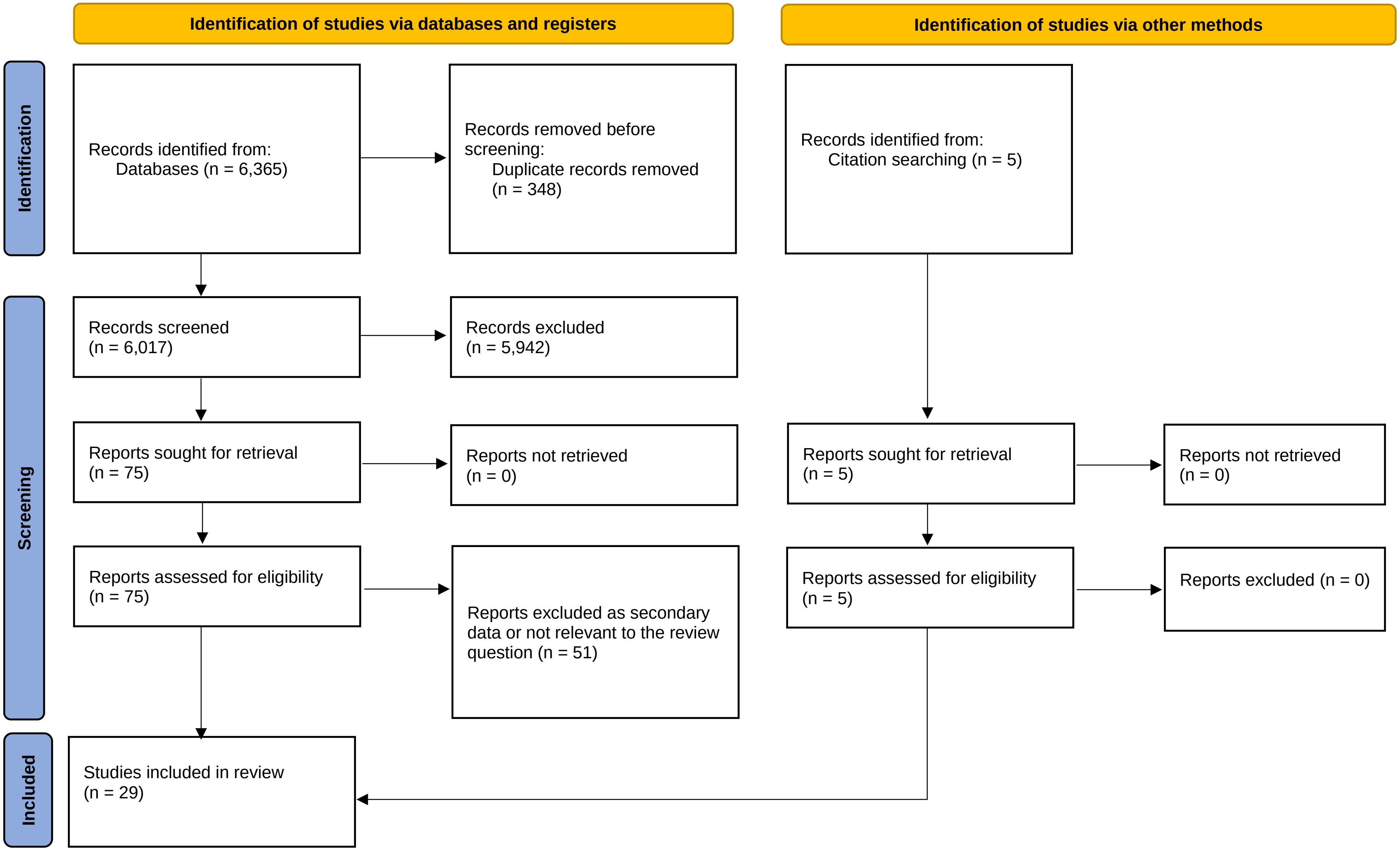
Table 2

Table 2. Inclusion and exclusion criteria

Inclusion and Exclusion Criteria	
Inclusion	**Exclusion**
High-income countries	Middle- and low-income countries
Peer reviewed articles	Papers that do not include adults' experiences of claiming welfare benefits
Adults' experiences of claiming welfare benefits	Quantitative papers
Qualitative or mixed methods papers (qualitative data only)	Pre-1996
1996-onwards	Non-English Language
English Language	Secondary research
Primary research	

Results for each database were limited to journal articles published in English language. A total of 6,365 papers were obtained from the searches. These papers were reduced to 6,017 with screening for duplicates, which was further reduced to 75 papers with application of the inclusion and exclusion criteria during screening of titles and abstracts. A hand search was conducted, which included the reference lists of the 75 papers. This hand search yielded five further papers taking the total to 80, which was reduced to 29 papers following screening of the full texts (Figure 1).

Figure 1 PRISMA flow diagram (Page et al., 2020)



2.21 Quality appraisal of included papers

There is increasing acknowledgement of the value of synthesising qualitative research in the evidence base (Thomas and Harden, 2008). Within the review, quality appraisal was utilised to provide greater context and insight to the synthesis but papers that were not considered to provide a reliable answer to the review question based on having a low methodological quality score were retained (Dixon-Woods, Bonas, et al., 2006). Exclusion of studies on the basis of quality in a qualitative review is a subjective process and studies were not excluded in recognition of this subjectivity (Hannes and Macaitis, 2012). Moreover, the exclusion of studies can adversely affect the generalisability of a review and synthesis, leading to an overall loss of conceptual richness (Britten and Pope, 2012; Carroll and Booth, 2015).

The papers underwent a three-stage process of thematic synthesis as described in Thomas and Harden (2008). The stages of this process and the rationale for using this is described further in section 2.22. Thomas and Harden (2008) utilised 'sensitivity analyses' to assess the possible impact of study quality on their review's findings, which were based on twelve criteria proposed for assessing the quality of qualitative research, principles of good practice for conducting social research with children and whether studies employed appropriate methods for addressing their review questions. Therefore, the quality assessment used by Thomas and Harden's (2008) paper in which they presented thematic synthesis was tailored to the area of research that they were working within (social research with children) and did not utilise a more generalised quality appraisal tool, which would be appropriate for many researchers following this method of synthesis. A review from Yadav (2022) pointed out that a universal or one-size-fits-all guidance or tool for evaluating qualitative research does not exist.

The methodological quality of the selected papers was appraised using a quality review form for qualitative studies based on the 'Critical Review Form – Qualitative Studies' that was originally developed by McMaster University (Letts et al., 2007). Other review papers that employ thematic synthesis have, for example, utilised the CASP qualitative checklist (Critical Appraisal Skills Programme, 2018), which has been found to be good measures of transparency of research practice and reporting standards (Long et al., 2020). However, the 'Critical Review Form – Qualitative Studies' was chosen specifically as it is a published freely-available tool, used extensively and caters for a range of research designs (Ducat and Kumar, 2015). Moreover, it uses Lincoln and Guba's (1985) concept of trustworthiness, justifying and reporting for each paper whether there is evidence of trustworthiness. Trustworthiness is a key aspect of thematic synthesis, with these trustworthiness criteria being a pragmatic choice when reporting acceptability and usefulness of research in a review (Nowell et al., 2017). Lincoln and Guba (1985) developed the concept of trustworthiness by introducing the criteria of: credibility (cohesion between the views of a papers' readers and the researcher's representation of the research participants' experiences); transferability (generalisability of findings); dependability (ensuring the research process is logical, distinguishable, and visibly documented); confirmability (whether the researcher's interpretations and findings are clearly drawn from the data, requiring the researcher to establish how conclusions and interpretations have been reached) (Tobin and Begley, 2004).

The quality review form was amalgamated with a Qualitative Assessment and Review Instrument (QARI), a data extraction tool designed for the synthesis of qualitative research (Pearson, 2004). Data extraction in qualitative synthesis is an important process with the reviewer immersing themselves in the data (Noyes and Lewin, 2011). A quality review form was amalgamated with a data extraction tool as this allowed the data extraction and quality review to be conducted at the same time, which assisted the process of 'deconstructing' and then 'reconstructing' each paper into a consistent format to facilitate the quality review and overall synthesis (Harden et al., 2004; Noyes and

Lewin, 2011). The adapted tool extracts data and reports on the quality of papers based on seventeen areas: study aim; methodology; method; setting; population; sample size; general findings; findings specific to the review question; authors conclusions; literature; theoretical perspective; sampling; consent; bias; data analysis; ethical considerations; rigour.

2.22 Synthesising the selected papers

The papers underwent a three-stage process of thematic synthesis as described in Thomas and Harden (2008), which outlined their approach and provided a worked example. The process included coding of the findings of primary studies; organisation of the codes into related areas to build descriptive sub-themes and themes; generation of descriptive themes into analytical themes. The coding, generation of descriptive sub-themes and themes, as well as subsequent analytical themes were conducted manually by electronically highlighting key text. The thematic synthesis was adopted as the review covered papers from multiple countries and different welfare benefit systems, with thematic syntheses being helpful for reducing large data sets to a manageable set of common themes (Malterud et al., 2016). Thematic synthesis has the ability to decontextualise data by systematically identifying, organising and offering themes across a data set (Thomas and Harden, 2008). There are multiple methods for synthesising qualitative research, however, the methods vary across a range of areas. Thematic synthesis does share characteristics with meta-ethnography and grounded theory, yet its use of line-by-line coding is consistent with the synthesis of primary research which is congruent with this PhD literature review (Barnett-Page and Thomas, 2009). Although thematic synthesis can be a time-consuming process, the synthesis can be structured to answer review questions directly and has been frequently used in systematic reviews exploring perspectives and/or experiences (Flemming et al., 2019; Thomas and Harden, 2021).

2.3 Results

Table 3 contains a profile of the included studies and an overview of whether trustworthiness was apparent in each study. For ease, the studies are arranged alphabetically and have been assigned a record number.

Table 3

Table 3. Profile of Included Studies

No.	Reference	Setting	Population	Objective or Research Question	Qualitative Approach (QA) and Method (M)	Concept of Trustworthiness			
-	-	-	-	-	-	Credibility Satisfied: yes (Y), no (N), partially (P)	Dependability satisfied: yes (Y), no (N), partially (P)	Confirmability satisfied: yes, (Y), no (N), partially (P)	Transferability satisfied: yes (Y), no (N), partially (P)
1	Banks, P., & Lawrence, M. (2005).	UK	606 disabled people in Scotland.	To establish the level of knowledge relating to DLA amongst disabled people in Scotland and to explore the process of application from the perspective of those involved.	(QA) not stated (M) Questionnaires (quantitative and qualitative data)	N	N	P	N
2	Bundy, H. (2022).	US	46 people with ill-health in South Carolina, who are applying for social security	To explore the vulnerabilities of people seeking disability benefits due to ill-health.	(QA) Interpretive (M) Semi-structured interviews	P	P	P	N

			disability benefit.						
3	Cheetham, M., Moffatt, S., Addison, M., & Wiseman, A. (2019).	UK	33 UC claimants with complex needs, disabilities and health conditions and 37 staff from local government, housing, voluntary and community sector organisations.	To understand the impact of the roll-out of Universal Credit (UC) from the perspectives of claimants and staff supporting them in North East England.	(QA) Thematic (M) Semi-structured interviews	Y	Y	Y	Y
4	Danziger, S., Wiederspan, J., & Douglas-Siegel, J.A. (2013).	US	52 Michigan welfare recipients.	To provide qualitative analysis of welfare program experiences a decade later (post 1996 welfare reforms).	(QA) Interpretive (M) Semi-structured interviews	P	Y	P	N

5	de Wolfe, P. (2012).	UK	23 people with ME claiming sickness-related benefits, 18 people giving their comments in emails, and five requesting an interview by telephone or in person.	To document the experience of people with myalgic encephalomyelitis (ME) in claiming sickness-related benefits in the United Kingdom.	(QA) Not stated (M) E-mail correspondence and semi-structured interviews	P	N	N	N
6	Dwyer, P., Scullion, L., Jones, K., McNeill, J., & Stewart, A.B.R. (2020).	UK	This paper presents original analysis of data generated in qualitative longitudinal interviews with 207 UK social security benefit recipients with experience of a range of mental health issues.	To explore the impacts of the application of welfare conditionality on benefit claimants with mental health impairments; and the effectiveness of welfare conditionality in supporting people with experience of mental ill health into paid work.	(QA) Temporal Analysis (M) Interviews	P	Y	P	P

7	Garthwaite, K., Bambra, C., Warren, J., Kasim, A., & Greig, G. (2014).	UK	229 long-term IB recipients in the North East of England.	To explore the health of long-term IB recipients during a time of significant change to the UK welfare state.	(QA) Thematic (M) Mixed methods: Quantitative survey and qualitative interviews.	P	Y	P	P
8	Garthwaite, K. (2013).	UK	18 key professional stakeholders & 25 IB recipients.	To explore the relationship between long-term Incapacity Benefit (IB) receipt and stigma in areas of North East England.	(QA) Narrative (M) Semi-structured interviews	P	Y	Y	P
9	Garthwaite, K. (2015).	UK	25 long-term sickness benefits recipients in North-East England.	To focus upon how individuals perceived and managed becoming ‘incapacitated’, particularly in relation to stigma and identity.	(QA) Narrative (M) In-depth interviews	P	Y	P	P
10	Garthwaite, K. (2015).	UK	25 chronically ill and disabled people (male and female).	To focus upon social networks and their relationship to stigma and identity for long-term sickness benefit recipients in the North East of England.	(QA) Narrative (M) Interviews	P	Y	P	P

11	Garthwaite, K. (2014).	UK	25 long-term sickness benefit recipients in the north east of England.	To provide a voice for long-term sickness benefit recipients to share their opinions and experiences of welfare reform in the UK.	(QA) Narrative (M) In-depth interviews	P	Y	P	P
12	Garthwaite, K. (2016).	UK	Interviews with Trussell Trust foodbank users (n=60), volunteers (n=12) and staff from referral agencies (n=8).	To explore the lived experiences of health inequalities for residents in the most and least affluent areas.	(QA) Ethnography (M) Observations, interviews, field notes	P	Y	Y	P
13	Gewurtz, R.E., Lahey, P., Cook, K., Kirsh, B., Lysaght, R., & Wilton, R. (2019).	CAN	Stakeholders including welfare recipients, welfare program and policy staff, and service providers in the community.	To unpack how fear and distrust emerge among people with mental illness who have recently entered the welfare system.	(QA) Interpretive (M) In-depth interviews	P	Y	Y	P
14	Hansford, L., Thomas, F.,	UK	Focus groups with 97 participants,	To examine the impact of increased welfare conditionality on people with mental health	(QA) Grounded Theory	P	Y	Y	P

	& Wyatt, K. (2019).		aged 18–65, from the two study sites (36 men and 61 women). 80 interviews with 57 residents (aged 18–65) who had experienced poverty-related distress.	issues claiming benefits in the UK.	(M) Focus groups and interviews				
15	Jun, M. (2022).	UK	Lone mothers across the UK who were in receipt of social assistance benefits.	To explore the social relationships of lone mothers in the UK and how these relationships are affected by the stigma attached to claiming social assistance benefits.	(QA) Interpretive (M) In-depth interviews	Y	Y	Y	P
16	Marttila, A., Johansson, E., Whitehead, M., & Burström, B. (2010).	SWE	Chronically ill people who had received social assistance for several years.	To explore in depth how social assistance recipients with chronic illness perceive and respond to the experience of living on social assistance.	(QA) Grounded Theory (M) In-depth interviews	P	Y	N	Y

17	McNeill, J., Scullion, L., Jones, K., & Stewart, A. (2017).	UK	58 disabled welfare users.	To fully understand the impact of the extension of welfare conditionality in the UK.	(QA) Not stated (M) Interviews, case studies	P	N	N	N
18	Mehta, J., Taggart, D., Clifford, E., & Speed, E. (2021).	UK	13 people in the ESA work-related activity group.	To consider the impact of processes of conditionality and sanctions on people in the ESA work-related activity group.	(QA) Thematic (M)Semi-structured interviews	P	P	P	P
19	Mitchell, E., & Vincent, E. (2021).	AUS	23 people in receipt of social security in Australia.	To explore the relationship between shame and lived experience in welfare recipients.	(QA) Ethnography (M) Interviews, fieldwork and case studies	P	P	P	P
20	Moffatt, S., & Noble, E. (2015).	UK	23 people of working age with cancer in north-east England.	To explore the connections between cancer and employment and the constraints imposed by ill health and wider structural conditions.	(QA) Narrative (M) Interview	P	Y	P	P

21	Patrick, R. (2014).	UK	15 out of work benefit claimants.	To explore how individuals directly affected by changes to the benefits system experienced and responded to these reforms.	(QA) Thematic (M) Semi-structured interviews and the use of vignettes, timelines and various task-based methods	P	P	P	P
22	Price, E., Walker, L., & Booth, S. (2020).	UK	393 subjects aged 18 to 75, resident in the UK, with a self-reported diagnosis of lupus.	To explore the experiences of people living with fluctuating long-term conditions, with a particular focus on the UK welfare benefits system.	(QA) Narrative (M) Qualitative survey	P	P	P	N
23	Pybus, K., Pickett, K.E., Lloyd, C., Prady, S., & Wilkinson, R. (2021).	UK	18 individuals experiencing mental illness who were claiming either ESA, UC and/or PIP in Leeds, UK.	To investigate the impact of functional eligibility assessments on social security claimants with mental health conditions.	(QA) Thematic (M) Semi-structured interviews	Y	Y	P	Y

24	Saffer, J., Nolte, L., & Duffy, S. (2018).	UK	4 participants with a minimum of one long-term physical health condition or disability and to have experienced changes to their disability benefits.	To document the experiences of people with a physical health condition or disability who have experienced a loss of or change in disability benefits under the welfare reform programme in the United Kingdom.	(QA) Grounded Theory (M) In-depth interviews	Y	Y	P	Y
25	Shefer, G., Henderson, C., Frost-Gaskin, M., & Pacitti, R. (2016).	UK	17 Disability benefit recipients (DBRs).	To investigate the impact of the process on DBRs whose disability was related to mental health and who won their appeal.	(QA) Thematic (M) Interviews	P	Y	N	P
26	Whelan, J. (2021).	IRE	22 people claiming and receiving social welfare.	To shed light on experiences of conditionality in the contemporary Irish welfare state and to attempt to nuance further what conditionality can mean.	(QA) Not stated (M) In-depth interviews	P	P	N	P
27	Whittle, H.J., Palar, K., Ranadive,	US	Low-income individuals living with HIV and/or	To investigate how the system of disability benefits, as well as these stigmatizing discourses,	(QA) Thematic	Y	Y	N	Y

	N.A., Turan, J.M., Kushel, M., Weiser, S.D. (2017).		type 2 diabetes mellitus.	shapes the lived experience of disabling physical illness in today's United States.	(M) Semi-structured interviews				
28	Wright, S., & Dwyer, P. (2022).	UK	141 interviews with 58 in-work benefit claimants.	To investigate how in-work UC conditionality is experienced at micro level by claimants over time.	(QA) Abductive (M) Interviews	Y	Y	Y	Y
29	Wright, S., & Patrick, R. (2019).	UK	15 single parents, jobseekers and disabled people in Leeds; 481 welfare service users in a range of circumstances.	To document lived experiences of claiming benefits and using back-to-work support services.	(QA) Phenemology (M) Interviews (from two qualitative projects).	Y	Y	Y	Y

Twenty-two of the 29 papers were from the UK, three from the US, with one from each of Canada, Sweden, Australia and Ireland respectively. Six of the papers consisted of longitudinal data collection (Dwyer et al., 2019; Garthwaite, 2016; Moffatt and Noble, 2015; Patrick, 2014; Wright and Dwyer, 2022; Wright and Patrick, 2019), while the remaining 23 papers were cross-sectional in design. All 29 papers involved self-reporting of experiences from participants, with none utilising specific health assessment tools. Sample sizes varied from two to 606 and qualitative methods utilised included: questionnaires with open-ended questions, semi-structured interviews, e-mail correspondence, observations, focus groups and case studies. Studies with over 100 participants (Banks and Lawrence, 2005; Dwyer et al., 2019; Price et al., 2020) utilised qualitative methods or longitudinal approaches. An assortment of data analysis approaches were utilised including: thematic analysis, performative analysis, narrative analysis, constant comparative analysis, grounded theory methods and one paper stated it took the approach of 'allowing the data to speak for itself'. In 'allowing the data to speak for itself' the author of this paper stated they were presenting data that placed lived experience front and centre to illustrate experiences of conditionality in the Irish welfare system. It could be argued that allowing data to speak for itself is a misunderstanding of qualitative research (Lingard, 2019) and that it is within the role of the researcher to lead the reader towards the logic arrived at from the research (Thorne, 2020). Yet, the study in question satisfied the inclusion criteria of the review and utilised a qualitative design and data collection method. As stated previously in this chapter, studies were not excluded on the basis of quality in an attempt to avoid a loss of conceptual richness in the review, therefore the study was retained.

Some of the papers included in the review are taken from the same study. A 'publish or perish' approach in academia has led to a rapid rise in the number of academic journals and publications, nevertheless, there are often accepted reasons in relation to multiple publications being produced from the same dataset. For example, if a dataset contains multiple sub-datasets or if project outputs are too large to be reported in a single publication, refraining from producing further papers from this data could potentially block access to information that is important to society. Consequently, researchers can produce more than one published paper from the same dataset if they consider the findings important for science and not disruptive to the integrity of the research (Altay and Kocak, 2021). Also, publishing multiple papers would be appropriate if the data answers different questions, requiring alternative research questions. With respect to this review, papers 9, 10 and 11 from table 3 all utilised the same dataset from Garthwaite. Additionally, papers 6, 17, 28 and 29 from table 3 all utilised a dataset from the same 'Welfare Conditionality'[1] study. However, the individual papers all addressed different objectives or research questions, hence maintaining their place in the review as they offered different findings and viewpoints.

Three of the 29 papers fully satisfied the four criteria of credibility, dependability, confirmability and transferability. 17 papers fully satisfied at least one of the four areas and nine studies did not fully satisfy any of the four areas. Additionally, 16 of the 29 papers explicitly specified appropriate ethical approvals had been gained prior to their research commencing. Five papers did not state ethical approval had been gathered but did state that ethical principles or considerations had been taken in their research. Eight papers gave no mention to ethics within their studies. It should be acknowledged that some authors have raised concerns about the use of strict adherence to universal quality reporting criteria because they do not allow sufficient flexibility to accommodate the diverse approaches and multiple interpretive practices often represented in qualitative studies (Stige et al., 2009). Furthermore, the strict word limitations that come with submission to print journals can preclude detailed descriptions in some areas (Kim et al., 2017). The goal of quality and rigor in qualitative research is always to minimise the risk of bias and maximise the accuracy and credibility of research results (Johnson et al., 2020). However, some authors follow varying paradigms that informs their qualitative research, utilising alternative criteria in how quality is achieved, which could

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[1] http://www.welfareconditionality.ac.uk/

potentially be a reason for trustworthiness criteria specifically not being fully satisfied in all studies (Birks, 2014; Ravitch and Carl, 2016). Furthermore, alterations may be made to how a manuscript is written and presented to allow publication in a specific journal, consequently, reporting of the concept of trustworthiness may not always be apparent in studies (Korstjens and Moser, 2018).

2.4 Themes

The papers underwent a three-stage process of thematic synthesis as described in Thomas and Harden (2008), whereby they demonstrated the steps involved in thematic synthesis by drawing on a review of the barriers to, and facilitators of, healthy eating amongst children (Thomas et al., 2003). It is difficult to extract key concepts or summaries of findings from qualitative research due to varying use of reporting styles (Sandelowski and Barroso, 2002), however, by taking study findings to be all of the text labelled as 'results' or 'findings', line-by-line coding (stage 1) was then conducted allowing the translation of concepts from one study to another. Codes that were similar were grouped, with new codes created to capture the sense of groups of initial codes, before organising codes into related areas to build descriptive themes.

Line-by-line coding made up stage 1 of the process, with the development of descriptive themes following on as stage 2. The development of descriptive themes (stage 2) involved categorising codes and checking the consistency of data interpretation for each code, before grouping codes and organising into individual descriptive themes. Once stage 1 and 2 of the process had been completed, a group of descriptive themes had been produced that remained close to the findings of the included studies. Stage 3 involved the generation of analytical themes by bringing the descriptive themes back to the review question. By considering the descriptive themes in narrower terms related specifically to adults' experience of the benefit system and health and well-being while claiming welfare benefits, newly generated analytical themes were tailored specifically towards answering the review question. This process had to be repeated to ensure pertinent primary findings were not lost in the generation of the analytical themes and to ensure the new themes were sufficiently conceptual to explain the initial descriptive themes, experiences of the benefit system and health and well-being while claiming welfare benefits and subsequent policy recommendations.

Six analytical themes were generated from the thematic synthesis as follows: 1) Benefit recipients have to contend with health, social and economic difficulties; 2) Benefit recipients struggle with identity and stigma; 3) Benefit recipients feel negativity, mistrust and are distressed by the benefits system; 4) Benefit recipients feel the work capability assessment (WCA) is not suitable in assessing some health conditions; 5) Benefit recipients do not see work related activity (WRA) as credible; 6) Benefit recipients can benefit from volunteering or permitted work.

Benefit recipients have to contend with health, social and economic difficulties

This theme captured how benefit systems in the UK and internationally influence numerous facets of benefit recipients' lives, not just economically but in terms of their health and social circumstances. Financial hardship was reported in several papers (Banks and Lawrence, 2005; Bundy, 2022; Cheetham et al., 2019; Danziger et al., 2013; de Wolfe, 2012; Garthwaite, 2014; Garthwaite, 2016; Marttila et al., 2010; Patrick, 2014; Saffer et al., 2018; Shefer et al., 2016; Whittle et al., 2017; Wright and Patrick, 2019). The papers show that a low income has negative implications in areas of daily living, such as not being able to afford accommodation, utilities, or sufficient nutrition. Additionally, low income can have a negative impact on health and more specifically mental health.

Aside from not always being able to afford food shopping (Cheetham et al., 2019; Garthwaite, 2016; Shefer et al., 2016), there are accounts that show even if food provisions are affordable, being on benefits does not allow for much else beyond this. Benefit recipients find themselves leading a very restricted lifestyle, being unable to buy anything beyond basic food provisions or socialise (Whittle et al., 2017; Wright and Patrick, 2019). These social and economic privations led to health difficulties. Health difficulties were evident as a direct result of benefit processes due to the physical demands of completing paper-based questionnaires, attending appointments, potentially going through an appeals process, or the mental demands that accompany being a benefit recipient and the constant threat of loss of benefit income. Moreover, pre-existing health conditions for recipients of sickness or disability benefits could be exacerbated through engagement with the benefit systems (Bundy, 2022; Cheetham et al., 2019; de Wolfe, 2012; Garthwaite, 2014).

The papers contributing to this theme show that some people are unable to afford basic meal provisions and can also feel too ashamed by this to ask for help. Additionally, they can struggle to afford accommodation costs, utilities, are unable to socialise or buy anything beyond food including new clothes, all of which can cause or compound existing health problems. Overall, this theme portrays how living on benefits can be a struggle and contributes to the health and social predicaments of benefit recipients.

Benefit recipients struggle with identity and stigma

Benefit recipients feeling stigmatised was a common theme within the UK and international literature (de Wolfe, 2012; Garthwaite, 2013; Garthwaite, 2014; Garthwaite, 2015a; Garthwaite, 2015b; Garthwaite, 2016; Jun, 2022; Marttila et al., 2010; Moffatt and Noble, 2015; Saffer et al., 2018; Shefer et al., 2016; Whelan, 2019; Whittle et al., 2017). Nine papers from the review (de Wolfe, 2012; Garthwaite, 2013; Garthwaite, 2014; Garthwaite, 2015a; Garthwaite, 2015b; Garthwaite, 2016; Moffatt and Noble, 2015; Saffer et al., 2018; Shefer et al., 2016) described benefit recipients in the UK missing being in the workplace, having difficulties accepting or adjusting to not being in work or being disabled, or suffering frustration that people felt they were somehow lucky to not be working. The idea that benefit recipients are lucky to not be in work or do not want to work was not just restricted to conversations with friends and family, but was also found to be a perception held by staff within the benefit system (de Wolfe, 2012).

UK and international papers in the review indicate others can misunderstand what brings people to be on benefits or how people feel when in receipt of benefits, which can be exasperating for benefit recipients themselves. As well as benefit recipients mourning a loss of a working identity and rejecting the identity of being disabled, the notion of stigma was captured in multiple papers within the review: firstly, how benefit recipients are depicted by government, media and the general public; secondly, how benefit recipients recognise themselves within the benefit system (Garthwaite, 2015a; Jun, 2022; Saffer et al., 2018). How benefit recipients are portrayed in the media can influence the thoughts and opinions of the general public leading to a negative perception of being in receipt of benefits. Yet, the rhetoric from government and media channels does not only influence the general public but benefit recipients themselves who can feel a need to discredit others as a way of self-legitimising their own status as a benefit recipient (Garthwaite, 2014). Alternatively, benefit recipients can "*conceal their identity as a benefit recipient as a means of avoiding being discredited by others or feeling discredited by others"* (Garthwaite, 2013, pp. 128), which may be a form of self-preservation against stigma from others. For a population group who are already at increased risk of financial, social and health difficulties, there is a threat of further exacerbating these difficulties through individuals feeling an inability to willingly talk to people and becoming socially isolated.

Benefit recipients feel negativity, mistrust and are distressed by the benefits system

Within the UK and international papers identified in the review, the theme of negativity and a deep mistrust towards the benefits system was dominant (de Wolfe, 2012; Dwyer et al., 2019; Garthwaite et al., 2014; Gewurtz et al., 2019; Hansford et al., 2019; McNeill et al., 2017; Mehta et al., 2021; Patrick, 2014; Saffer et al., 2018; Shefer et al., 2016; Wright and Dwyer, 2022; Wright and Patrick, 2019). Alterations to the welfare system were met by the study participants with scepticism and a perception of government cost-cutting, rather than the changes being implemented to support the people within the welfare system. It is not just a lack of trust in the system but how people are treated by the means of conditionality while in the benefits system that led to an overall perception of negativity (Gewurtz et al., 2019; Mehta et al., 2021; Wright and Dwyer, 2022; Wright and Patrick, 2019). Furthermore, the UK papers show that enforcing conditionality upon benefit recipients in an aim to improve compliance can be counter-productive to the aim of finding work for individuals. In imposing financial sanctions for missed appointments or a lack of engagement with the benefits agency, this potentially further compounds benefit recipients' difficulties and causes further negativity or distress.

The papers in the review show that benefit recipients can struggle with the logistics of applying for benefits and dealing with the system once within it. Manifestly, the complexity of the application paperwork can compound negativity or mistrust in the process. A constant need to apply, re-apply and justify a need for benefit receipt can lead to people no longer being able to comply with the process, or worse, no longer wanting to be alive (de Wolfe, 2012). It was also evident in the UK literature that many felt, when attending for a WCA as part of the assessment process, they were immediately at a disadvantage in terms of their benefit application as the fact they have been able to attend for an appointment was almost a sign that they are therefore well enough to engage in some form of work. Additionally, as well as a lack of trust in the WCA process, there was an evident lack of trust in the assessors conducting the WCAs and their intentions during the assessments, with people feeling the assessors' questions are targeted at attempting to steer them back into work (Hansford et al., 2019; Saffer et al., 2018).

Benefit recipients feel the work-capability assessment (WCA) is not suitable in assessing some health conditions

This theme captured how benefit recipients in the UK feel there are deficiencies to the WCA (de Wolfe, 2012; Garthwaite, 2013; Garthwaite, 2014; Hansford et al., 2019; Price et al., 2020; Pybus et al., 2021). If an individual's health condition does not functionally affect them all of the time they can be deemed fit for work in the WCA, even though a condition may potentially still affect someone regularly enough for them to be deemed unemployable to potential employers. This can lead to individuals' being 'stuck between a rock and a hard place' and in an undesirable cycle of applying and re-applying for benefit entitlement, while subsequently undergoing multiple WCAs. Another element of the theme is how stressful the WCA can be for benefit recipients who have to go through this assessment, or how stressful waiting for an outcome of the assessment can be (Garthwaite, 2013; Garthwaite, 2014; Hansford et al., 2019; Pybus et al., 2021). Additionally, the assessment process can not only cause stress but exacerbate symptoms and worsen individual's overall health (Price et al., 2020).

Benefit recipients do not see work-related activity (WRA) as credible

In the UK, since the inception of ESA and the use of the WCA, there has been an expectation on some claimants to engage in work-related activity (WRA) despite being found not fit for work (DWP, 2010). This theme captures how benefit recipients can see their benefit entitlement negatively affected due to the expectation of completing WRA, or sanctioned if they miss WRA (Dwyer et al., 2019; McNeil et al., 2017; Mehta et al., 2021; Patrick, 2014; Wright and Patrick, 2019). The literature also showed that individuals can be punished for attending medical appointments at the expense of job centre appointments, when ultimately the medical input is what will potentially put them in a position to find employment in the future (McNeil et al., 2017). Additionally, work-related activities that are conditional through Job Centre Plus (JCP) are not always seen as credible with perceptions of individuals being sent on courses that are not relevant to them and simply 'tick box exercises' (McNeil et al., 2017; Wright and Patrick, 2019). The fact that claimants can be sanctioned for having difficulty engaging with their WRA and activities provided through JCP are not viewed as meaningful, does nothing to improve trust or negative perceptions felt towards the benefits system in the UK.

Benefit recipients can benefit from volunteering or permitted work

Although the previous five themes show predominantly negative or problematic issues for adults in receipt of welfare benefits, whether in the UK or internationally, one paper in the review offered some positivity (Patrick, 2014). In the UK, some benefit recipients found engaging in volunteering, caring or parenting work external to JCP as valuable, as well as seeing some therapeutic value in work-related activity (Patrick, 2014). This is not to say these individuals did not encounter health, social or financial difficulties. However, engagement in volunteering, caring or parenting work gave some structure to their day and helped them in avoiding a loss of working identity or feeling stigma as a recipient of benefits. However, volunteering, caring and parenting are not enforced by JCP or subject to conditionality, therefore, the fact that it was these activities that provided positivity does remain a criticism of the benefits system. Nonetheless, there was a positive report related specifically to permitted work being therapeutic. It is acknowledged that the theme is derived from a single paper, which does potentially reduce the academic robustness of the theme. Table 4 includes quotations that are attributed to each theme.

Table 4

Table 4. Quotations attributed to each theme

Theme	Quotations
Benefit recipients have to contend with health, social and economic difficulties	"When you feel like, I can't feed myself, I can't pay my electric bill, I can't pay my rent, well, all you can feel is the world collapsing around you". (Participant in Cheetham et al., 2019) "He was in and out of hospital with his depression, like self-harming and that. It was just horrible … He spoke to the psychiatrist in the hospital. He was like, we've got no money, what's the point, I can't go out, can't see people, can't even eat properly" (Participant in Cheetham et al., 2019) "If you can't eat three meals a day, you'd have one meal a day and it's not good for your health. There's certainly no chance of socialising, absolutely no chance" (Participant in Shefer et al., 2016). "Mam always offers me a sandwich but I tell her I've already eaten, it's just…I feel ashamed. I fill up on cereal or yoghurts or herbal tea, things like that" (Participant in Garthwaite, 2016). "I can't remember the last time I bought anything apart from food. I don't buy clothes. We've got no internet; we've got no savings; we've got no car" (Participant in Wright and Patrick, 2019).

	“I can't go out to eat with friends. I do my book club once a month, and it’s $10 for my share for where we go, and there were a few months where I just called and cancelled 'cause it was so embarrassing that I can't afford the $10 plus the $2 tip, you know?” (Participant in Whittle et al., 2017). “‘I think a lot of people in my situation that are genuinely ill are gonna be pressurized and it’s gonna cause breakdowns, possibly even the worst case scenario y’know toppin yourself” (Participant in Garthwaite, 2014). “I ended up being treated for depression and anxiety, anyway, as well as the insomnia, still on medication now” (Participant in Cheetham et al., 2019). “A dear friend of mine … who died five years ago of pneumonia as a result of severe ME continued to have problems with benefits up to his death. It is extraordinary that someone … totally bedbound, unable to sit up, speak or tolerate speech, digest solid food or have normal bowel movements was still having to appeal the removal of the highest rate of DLA” (Participant in de Wolfe, 2012).
Benefit recipients struggle with identity and stigma	“I found it very difficult to accept that I had a disability ‘cos I’ve always been fiercely independent. I’ve never asked for help before, it wasn’t in my nature and to have to ask for it was tough” (Participant in Garthwaite, 2015a). “I bumped into a friend who I hadn’t seen for 30 years and she asked if I was working and when I said no, she was like “Oh I wish I could be a lady of leisure, I wish I had nothing to do all day” and I thought you haven’t got a clue” (Participant in Garthwaite, 2015b).

	“I was very upset to discover at a recent Jobcentre Plus interview that it was written on my notes, ‘Does not want to work.’ Certainly not my words and I have asked them to change this – it couldn’t be further from the truth” (Participant in de Wolfe, 2012). “You look at the press it’s always about the benefits. You know Channel 5 all their programmes: ‘Life on Benefit Street’, ‘Holiday on benefits’ and things like that” (Participant in Saffer et al., 2018). “It doesn’t matter if you’ve worked for the past 20 years then – bang! – It’s ‘scrounger’ and this flaming stigma. People find out you’re on incapacity benefit and you just get looked at as though they’re scraping you off the bottom of your shoe” (Participant in Garthwaite, 2015a). “People like me who’s genuine are getting stigmatised for the people who are just layabouts, you see them digging gardens or changing wheels on their car and it’s not fair…” (Participant in Garthwaite, 2014).
Benefit recipients feel negativity, mistrust and are distressed by the benefits system	“It’s hard for people to trust sort of a faceless system. There have been lot of changes to our disability system over the years” (Participant in Gewurtz et al., 2019). “By sanctioning me and cutting down on my money obviously leaves me less money to live on and if I’ve got less money to live on I can’t go for these job interviews, I can’t put credit on my phone to phone for jobs…It is hard trying to keep focused on looking for a job when at the same time you’re thinking, whoa, hang on, if I go for this interview I’ve got nothing to eat today” (Participant in Wright and Patrick, 2019).

	"You really need a blumming PhD to fill the blumming form in" (Participant in Saffer et al., 2018). "Horrible and life-wrecking though that is, it's not the ME that has finally taken away my will to want to continue living, it's the constant struggle of dealing with the benefit system and all it entails" (Participant in de Wolfe, 2012). "…it's kind of like you're in a trap where you've got to be nice, you've got to be respectful and you've got to talk, even though you feel like you just need to leave. You can't be rude because you'd get your benefits stopped. You can't not turn up because you'd get your benefits stopped and you'd lose your accommodation, but the minute you turn up, you're fit and well because you've come" (Participant in Hansford et al., 2019). "It's like they seem like they are just having a chat with you but they are not. Like everything that you say is assessed against a criteria" (Participant in Saffer et al., 2018).
Benefit recipients feel the work capability assessment (WCA) is not suitable in assessing some health conditions	"I have been told I am too healthy to claim benefit for my lupus. This is despite the fact that some days I am incapacitated by migraines, fatigue and joint pain. I do not experience these symptoms enough apparently to warrant government support" (Participant in Price et al., 2020). "…they don't realise how stressful it is, just waiting and waiting for a sword of Damocles hanging over you. They don't realise how it eats away at you and how people worry…" (Participant in Garthwaite, 2014). "All this fighting made my depression worse and the senior clinical psychologist who I still see for counselling has stated that the DWP and Capita have traumatised me by making me go through my illnesses in such detail and having to fight

	for my benefit at a time when I should have been concentrating on recovering from major heart surgery" (Participant in Price et al., 2020).
Benefit recipients do not see work-related activity (WRA) as credible	"I've tried to do things positively and it's backfired – like when I've tried to do things to address my health and help me work – then I've been penalised for that.... I think very, very few people would put themselves through this because it's horrible and it makes you feel worthless" (Participant in McNeil et al., 2017). "It's all about targets. It wasn't meaningful, it was just about literally, getting bodies into a room, so they could tick a box and then they'd get their quota … but we all have to jump through these hoops" (Participant in McNeil et al., 2017). "It is [frustrating], especially when you've been on long-term unemployed, they're doing nothing to help me at all apart from sending me on stupid courses which are absolutely a waste of time but it ticks their box" (Participant in Wright and Patrick, 2019).
Benefit recipients can feel supported and benefit from volunteering or permitted work	"It [volunteering] was good for my self-esteem really, doing something. Helping people rather than just sat at home doing nowt" (Participant in Patrick, 2014). "[The permitted work] is occupational therapy because it gets me out. It gets me meeting people and it stops me watching daytime TV. If I didn't have that then the options would be quite bleak really" (Participant in Patrick, 2014).

2.5 Discussion

This review explored how adults in receipt of welfare benefits in high-income countries describe their experience of the benefit system and their health and well-being while claiming welfare benefits. The themes found in the review provide a broad overview of experiences of the benefit system for adults in receipt of welfare benefits, including benefit recipients contending with health, social and economic difficulties, with contextual details related to identity, stigma and benefits system and processes. Palpably, the themes drawn from the evidence highlight that benefit recipients' experiences while claiming welfare benefits are mostly negative, with few positives to be drawn upon.

The review highlights across the UK and international literature that benefit recipients often cannot afford to maintain their bills or buy sufficient food for the whole family, which at times can lead to them going without meals. Monetary hardship can prevent socialising, which can lead to social isolation and an overall worsening of mental health. This is compounded by experiencing stigma associated with being a benefit recipient, which is partly driven by government and media use of discourse that supports notions of 'deserving' and 'undeserving' benefit recipients.

Although a process is needed to assess individuals' entitlement to benefits it is evident that current processes in the UK and internationally are not fit for purpose from the perspective of the claimant. The purpose of benefit assessments from a governmental perspective is to ensure the most vulnerable people in society are supported financially, however, this can involve emphasis on assessing whether people are eligible for welfare support or specific welfare benefits. If people are not eligible for welfare support or only eligible for limited support, there is also a role to assist these people back into employment (DWP, 2023b; National Audit Office, 2023). Consequently, the process is working from a governmental perspective as its purpose is being achieved in assessing people for benefit eligibility and allocating them accordingly based on an assessment outcome. Yet, it is not fit for purpose from a claimant perspective as the process is not removing health, social or economic difficulties. These difficulties are not being addressed and are potentially worsening, with claimants experiencing distress from navigating the benefits system.

Within the review, papers from the UK, Ireland, Australia, United States and Canada, evidenced that benefit recipients felt a mistrust towards the benefit system. Additionally from the review, UK and Ireland papers evidenced how conditionality compounds people's negative experiences of the benefit system, which is further exacerbated in the UK by additional financial sanctions. Recent studies have illustrated the ineffectiveness of welfare conditionality in the UK with respect to getting people back into employment, with consequences such as exacerbation of existing health problems or further ill-health (Dwyer et al., 2019; Hansford et al., 2019; McNeill et al., 2017; Patrick, 2014; Wright and Patrick, 2019). This review builds on this research, highlighting negative experiences of benefits systems and conditionality, including engagement with the benefit system undermining health and wellbeing for benefit recipients and a failure to get people back into employment via conditionality not just in the UK but internationally (Gewurtz et al., 2019; Whelan, 2020). The UK papers in the review show that benefit recipients feel the WCA used specifically in assessing work-related benefits is not suitable in assessing some medical conditions, for example in fluctuating conditions. Additionally, the WCA can worsen individuals' mental health despite the current efforts of the DWP and WCA providers. Engagement with the WCA also contributed to the themes of benefit recipients struggling with identity, with people navigating the WCA also feeling mistrust towards the benefit system. However, it is important to stress that struggles with identity and stigma and feelings of mistrust towards the system was evident across multiple countries and benefit systems, not just specific to the WCA. Furthermore, in UK papers, the expectation of WRA for some benefit recipients is largely seen as being non-specific to individual’s needs, with no credibility. There was limited reporting of voluntary work external to Job Centre Plus provided WRA as being beneficial and some WRA being therapeutic, however, this positivity was restricted to a single paper included in the review.

The main strength of this review is that it was consistent in its approach (Thomas and Harden, 2008) and had methodological rigour. An additional strength of this review is that it covers international literature. The aim of the review was to explore the experiences of benefit recipients and a qualitative framework was therefore utilised in identifying search terms, refining the review question and generating the literature search. The review methods are comprehensively documented, enhancing transparency and reproducibility in the review process and ensuring trustworthiness (Butler et al., 2016). The literature search was conducted within topically appropriate databases, subsequent studies were identified using an inclusion and exclusion criteria, with further hand searching of reference lists completed, ensuring the search process was comprehensive. A clear screening process for the studies was followed and peer-reviewed data extraction and quality review forms were utilised. Additionally, the concept of trustworthiness (Lincoln and Guba, 1985) was utilised in reporting quality within each paper identified in the review, which is widely used in qualitative research and is fundamental to the usefulness and integrity of the findings (Cope, 2014). Crucially, the whole review was conducted with the guidance of two academic supervisors, which ensured there was appropriate support offered to the reviewer.

The review does of course have limitations. The literature was predominantly from the UK, with fewer international papers sourced from the comprehensive search, however, this is indicative of where the majority of research in this area is being conducted as opposed to a limitation of the search criteria utilised in the review. It is acknowledged that by not initially excluding papers based on their methodological quality, some researchers would consider the synthesis to be covering shortcomings of the included papers in the review and risk making strong conclusions based on studies that are unreliable on the grounds of quality (Lucas et al., 2007). The majority of included papers did not satisfy all Lincoln and Guba's (1985) concepts of trustworthiness, however, this was clearly acknowledged and documented within the results section. This was done to complete the review with transparency and to offset any potential concerns related to the strength of the review findings and conclusions. Despite this there was consistency within the findings from the papers that led to the generation of themes in the review.

During the process of thematic synthesis and the drafting of final descriptive themes, there was only one reviewer involved, whereas Thomas and Harden (2008) utilised two reviewers. This is possibly a limitation within the process; having an additional reviewer involved in the generation of themes would potentially add more rigour in the process. Moreover, during stage 3 of the synthesis and the generation of analytical themes, this process is dependent on the judgement and understanding of the reviewers. Thomas and Harden (2008) completed this stage independently and then as a group, yet with only one reviewer involved at this stage of the synthesis, this is perhaps another limitation of the review as more reviewer input may have provided enhanced insights to the analysis.

The review was not registered on PROSPERO as student submissions were not being accepted at this time as a result of the COVID-19 pandemic. Additionally, the journal that the author is aiming to submit the review paper to does not require the review to be registered on PROPSERO.

2.6 Conclusion

Overall, the review highlights a need for governmental review of the benefits systems in high-income countries and policy actions that provide more favourable terms and conditions for benefit recipients. This includes policy actions to increase the monetary value of benefits, with the aim of reducing income, health and social inequality and improving well-being. A robust re-consideration of the application and ethicality of conditionality is required, taking into account whether its ongoing use is justifiable based on the negative experiences of benefit recipients. The findings specific to the UK literature call for further research focussing more in-depth upon individual benefit streams, for example, JSA, ESA, UC and Personal Independence Payment (PIP). There is a need to focus on individual benefit streams as the different benefits are designed for different populations, such as people who are out of work, low paid or those with health conditions or disabilities. Literature was identified in the review related specifically to low paid (Wright and Dwyer, 2022) and benefit claimants in the WRAG of the ESA benefit (Mehta et al., 2021). However, by further focussing on individual benefits, more specific details of population groups' experiences within individual benefits would be gathered. In the UK, further research is needed exploring experiences and perceptions of well-being during the work-capability re-assessment process for people who were deemed to have severe functional disability at a previous WCA and are in the LCWRA group or in the support group if they remain on ESA. This research is important as it will focus solely on a group of individuals with chronic physical and/or mental health problems, who have navigated the benefits system for a prolonged period of time and are in a unique position of being able to offer in-depth accounts of the re-assessment process specific to their work-related benefit. The review provides original contribution as it has systematically scrutinised international qualitative and mixed methods literature, providing themes and subsequent recommendations related to welfare systems of high-income countries internationally and specific to the UK.

Chapter two has detailed the rationale for the literature review and how it was conducted. Findings relating to how individuals experience the benefit system and their health and well-being while claiming benefits have been synthesised, which has informed the study described in chapters 3 and 4.

Chapter 3: Methodology and methods

The previous chapter addressed how individuals experience the benefit system and their health and well-being while claiming welfare benefits. This allowed recommendations to be made in relation to policy actions and future research. Based on the findings, the research question for this study was:

3.1 Research question

How do people deemed severely functionally disabled at the previous work-capability assessment perceive their well-being during the work-capability re-assessment process?

The aim of the study was to understand the experiences and perceptions of the research participants, provide recommendations related to the future policy of welfare benefits and potential opportunities for further research. This was achieved through completion of qualitative, unstructured interviews, with subsequent data analysis and discussion, all of which will be discussed further in this chapter.

People who have undergone assessment of their work capability and have been allocated to the ESA support group or UC LCWRA group are deemed to have severe functional disability. There is no expectation for individuals in these groups to complete any work or work-related activity (Centre for Health and Disability Assessments, 2020). The research question focusses on these groups and their well-being during the re-assessment of their work capability. This chapter describes the methodology and methods utilised in this study and its philosophical and theoretical approach. The study's aim, methods of sampling, data collection and analysis are described, with ethical considerations related to the study also discussed.

3.2 Philosophical and theoretical approach

The research was based upon an interpretive paradigm. This paradigm follows an ontological position of relativism, which is the interpretation that reality is subjective and varies from one individual to the next (Guba and Lincoln, 1994). The epistemological position is one of subjectivism, which is constructed on real world phenomena (Grix, 2004). This translates that to experience a phenomenon is to encounter it and become immersed in it (Heron and Reason, 1997). Willig (2016, p.7) suggested that “ontological relativism is probably not actually compatible with doing research as any account produced on the basis of a genuine commitment to ontological relativism could only tell us about the researcher’s personal world. Therefore, it would not be able to contribute to wider insights about anything at all”. Additionally, generalisations that are useful to policy makers are sometimes absent because interpretive research often produces highly contextualised qualitative data and interpretations of this data involves subjective individual constructions (Scotland, 2012). However, although universal accounts may not be possible from ontological relativism, negotiated truths are still achievable and it remains possible to attain understanding of subjective experiences of reality and truth with relativist ontology (Guba and Lincoln, 2005; Levers, 2013). Moreover, through achieving understanding of experiences in relation to morals, values, ethical standards and cross-cultural issues, this data can contribute towards public policy (Kaliyamurthi, 2021).

Within the interpretive paradigm, the study utilised a qualitative design and narrative methodology. The term ‘narrative’ can carry numerous meanings and be used in an assortment of ways, often synonymously with story-telling (Riessman, 2008). Overall, narrative research aims to impose a meaningful arrangement on what would otherwise be random and detached (Salmon, 2008). Narratives do not purely describe what an individual does in a specific circumstance but what the specific circumstances do to that individual, which allows researchers to infer what it feels like to be in the specific circumstance (Gubrium and Holstein, 2002). Narrative researchers work with small samples of participants to obtain rich dialogue, with emphasis on the storied experience, to explore and theorise human experience via in-depth exploration of the meanings individuals assign to their experiences (Salkind, 2010). However, beyond a common concept of imposing a meaningful arrangement on data, there is no specific way to conduct a piece of narrative research (Riessman, 2008). Within this research study, after some initial contextual or 'setting the scene' questions regarding the participant's age, health condition(s) that cause them to be in the LCWRA group, social history including where they live and who with, plus occupational history, the interviews comprised participants' extended accounts of their perceptions of their well-being during the work-capability re-assessment process, including the impact on their health conditions and individual circumstances. The interviewer then asked follow-up questions dependent on, or individually tailored to, the details of the participants' narratives. Riessman (2008) describes this type of narrative research as lying in the centre of the narrative spectrum, with "an extended answer by a research participant to a single question, topically centred and temporally organised" (Riessman, 2008, p. 5) at one end of the spectrum; then "an entire life story, woven from threads of interviews, observations, and documents" (Riessman, 2008, p. 5) at the opposite end of the spectrum.

A narrative methodology is appropriate for this research as it allows the participants to be the main story tellers, recounting their stories and how they make sense of events and actions in their lives (McAlpine, 2016). Within the narrative methodology, there are further methodological standpoints; sociocultural, naturalist and literary (Riessman, 2008). This research falls under a naturalist stance as the focus is on rich descriptions of the content of people's stories about a significant issue. The data is serving as a resource covering: What experiences has the individual had? What do the experiences mean to them? What evaluative aspects are being highlighted from the data? (Elliott, 2005; Pinnegar and Daynes, 2007).

The research utilised the Health Stigma and Discrimination Framework, a theoretical framework proposed by Stangl et al. (2019). This framework is relevant to the findings of the literature review, which identified that benefit recipients within the UK and internationally reported health, social and economic difficulties as a result of being on benefits. Benefit recipients also reported feeling stigmatised due to being a benefit recipient and negative media portrayals of benefit recipients led to a further divide of deserving and undeserving benefit recipients. In terms of identity, claimants not in work reported mourning a loss of work identity and rejecting an identity of being disabled. These findings from the literature review informed the selection of the Health Stigma and Discrimination Framework. Critical Disability Theory was discounted as it focusses more upon how disability is socially constructed and the social disadvantages experienced by disabled people being produced by physical and social environments failing to meet the needs of people with a specific disability (Reaume, 2014). This did not align with the focus of this study, which is based upon perceptions of well-being during a specific process for people deemed severely functionally disabled. The Theory of Social Stigma (Goffman, 1963) focusses on a specific attribute such as a health condition and the psychology of stigma relating to this attribute, without incorporating understandings of stigma and stigmatised individuals in wider contexts (Kleinman and Hall-Clifford, 2009). This was too narrow in terms of scope and what the researcher wanted to achieve from the research.

The Health Stigma and Discrimination framework focusses upon health-condition related stigmas, stigma experiences or stigma practices and how these impact upon the affected population, with the aim of guiding intervention development or policy to improve health outcomes (Stangl et al., 2019). The framework was developed with the aim to enhance research, intervention and policy. Moreover, it can facilitate research that addresses the lived realities of vulnerable populations, who have potentially complex realities in which to manoeuvre in order to protect their health and well-being (Stangl et al., 2019).

The framework was primarily proposed by Stangl et al. to address the lived reality of vulnerable populations accessing healthcare services. However, within this study, the framework was used to inform the discussion around participants' perceptions of stigma and health and/or social issues during the WCA re-assessment process. The aim was to consider stigma, health and/or social issues experienced by the participants and how current policies or practices impact upon the participants' experiences, which could then point to areas where policy makers can focus their attention to improve personal or organisational interactions with people in the ESA support group or UC LCWRA groups who are undergoing re-assessment of their benefit. Alternatively, there could be areas highlighted for policy makers to review broader policy interventions that can improve future outcomes for the study population.

Prior to the study commencing, the researcher gained ethical approval from the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University. The protocol for the research study can be viewed as Appendix 9 and the ethics approval letter can be viewed as Appendix 6.

3.3 Sampling and data collection

The study utilised purposeful sampling, which was consistent with the qualitative design and allowed the researcher to identify and choose individuals related to the phenomenon of interest (Palinkas et al., 2015). The study details were planned to be publicised using physical flyers posted up in selected Citizens Advice Bureau (CAB) offices with their consent and through the social media accounts of CAB and selected disability groups and forums with their consent. Yet, due to the Coronavirus pandemic a large percentage of CAB offices were closed and their services changed to remote offerings, with face-to-face clinics still largely reduced (Citizens Advice Bureau, 2021; Citizens Advice Bureau, 2022b). Therefore, physical flyers were not posted up as originally planned. CAB in Rochdale did consent to showing the flyers to appropriate clientele they came across at remote meetings. However, the use of social media as a recruitment tool in research has grown significantly in recent years (Gelinas et al., 2017). Subsequently, the recruitment of participants occurred in full on social media platforms, specifically Twitter and Facebook. On Twitter, the researcher posted tweets advertising the study and relied on individuals or organisations to re-tweet the post to a wider audience.

Table 5 contains Twitter handles that re-tweeted the study advert. The Twitter handles include academics, charity organisations and groups, disability or welfare groups, journals and CAB offices.

Table 5

Table 5. Twitter handles that re-tweeted my study advertising

Re-tweets from supervisor (@DrPaulaHolland); academics (@CovidRealities, @lisa_scullion, @BenBaumberg, @C_Fitz_, @McKeeverGrainne, @Sophianegus, @clindsaystrath, @Annie_Irvine); charity organisations and groups (@NRAS_UK, @spinal injuries, @HeadwayUK, @BrilLiving, @mssocietyuk, @braininjurygrp, @Mind Charity, @fmauk, @actionforme, @MEAssociation, @IFAN_UK, @NuffieldFound, @CPAGUK, @HumansMCR, @Depheruk, @FndFightback); disability or welfare groups (@johnpringdns, @WelfareTimesUK, @rightsnet, @WOWpetition, @benefitsandwork, @chronicinclude, @DisRightsUK, @DisabledGreens, @SpaEmploySocSec); journals (@JSP_Journal, @JPSJ_Journal, @JSocialSecurity); citizen's advice bureaus (@CABuryandBolton, @CalderdaleCAB, @CA_Rochdale).

On Facebook, the researcher joined a number of disability- or benefit-related groups and posted messages in the groups advertising the study. Table 6 contains the groups on

Facebook that were utilised in recruitment for the study. Advertising of the study via these groups was only done with the consent of a group moderator to ensure no group rules were contravened.

Table 6

Table 6. Disability- or benefit-related groups on Facebook that consented to study advertising

1. **WCA (work capability assessment) Benefit support group**
2. **Employment Support Allowance**
3. **PIP & ESA/Universal Credit User Support Group**
4. **A1 ESA/UC/DLA/PIP Benefit Help and Support UK ONLY**
5. **Universal Credit**
6. **Universal Credit and Legacy Benefit Advice**
7. **Disability & Benefits Big Sibling UK**

Additionally, advertising posts were posted with consent on Rightsnet and the disability equality charity, Scope, which have forums for people to use to stay up to date with social welfare developments, share their experiences of social welfare and to gather practical information related to disability equality (Rightsnet, 2022; Scope, 2022). However, no recruitment was completed via either forum and all participants were recruited via Facebook and Twitter. Any individuals who were interested in participating in the study or who wanted further details, were e-mailed a flyer, participant information sheet and expression of interest form (appendices 1, 2 and 3). Individuals responded directly to the researcher's e-mail address on the participant information sheet with any further questions, or to arrange an appropriate date and time for interview. Individuals were then e-mailed a consent form to read, sign and return prior to the interview.

The researcher did consider whether recruitment solely via social media platforms was appropriate. In the UK, 22% of the population lack basic digital skills and the likelihood of having access to the internet from home increases with income, meaning digital exclusion is often a feature of poverty (Holmes and Burgess, 2022). However, in 2022, 98% of all adults in the UK owned a mobile phone (Mobile UK, 2023), and in 2023, almost 93% of UK households have at least one working computer (Gitnux, 2023). In April 2023, there were over 48.5 million Facebook users in the UK (Statista, 2023a) and the UK is one of the biggest markets of Twitter worldwide with over 15 million users (Statista, 2023b). Therefore, although some potential research participants may not have been reached by social media advertising, given the number of individuals in the UK who own a mobile phone or computer and access Facebook and Twitter, it is likely that a large proportion of people in the LCWRA group were likely to be computer literate and have access to social media.

After approximately one month of recruitment, no participants had been recruited to the study and the researcher reflected that the lack of a 'thank you' gesture for participation was potentially a contributing factor. The UK is currently enduring a cost of living crisis and there are frequent media reports of escalating mortgage and rent payments, rising energy, fuel and grocery prices. The researcher became more acutely aware that asking individuals to give their time for free seemed inappropriate. Moreover, many people with long-term health conditions or disability have a limited resource with respect to energy for daily activities (Miserandino, 2003), consequently, research participants offering their time towards the study despite having a daily limitation of their energy resource could not be overlooked.

Therefore, the researcher needed to acknowledge the commitment from the participants in giving time and energy in agreeing to interview, which made the ‘thank you’ gesture increasingly appropriate.

This led to an amendment to the ethics application and the ethics board agreed to the introduction of a £20 voucher as a thank you for participation, with recruitment improving thereafter. This was the sole amendment to the ethics application throughout the process and the ethics approval of amendments letter can be viewed as Appendix 7. Offering a thank you for participation did initially concern the researcher, in case individuals only agreed to participate due to an incentive being on offer (Groth, 2010). However, recompensing research participants for their time is accepted practice in recognition of participants providing their time, experience and effort (Head, 2009; McKeganey, 2001; Russell et al., 2000). In addition, the researcher decided that a £20 voucher was more appropriate as opposed to £20 in cash, as receiving money for participation could have an effect on individuals’ benefit payments (National Institute for Health and Care Research, 2022).

3.4 The sample

The sample consisted of people in the UK who were deemed to have severe functional disability at a previous work capability assessment (WCA), and were due to undergo or were undergoing, re-assessment of their circumstances. All participants were able to speak fluent English language and had the mental capacity to speak on their own behalf. Mental capacity was assessed during the initial discussion regarding the research with individuals expressing interest in participating and was assessed via a two-stage test as per the Mental Capacity Act (NHS Health Research Authority, 2021). The researcher asked about their health conditions that led to them being in the LCWRA group and considered whether there was a mental health problem, learning disability, brain injury, mental or physical health condition that could cause impairment of or disturbance to, the functioning of the mind or brain. If none of these applied to the individual, they were considered to have capacity at that moment in time. If the individual did have one of the above conditions, the researcher then considered whether the impairment was sufficient that the person was unable to consent to participation or provide an accurate history at interview. The researcher considered whether individuals had the general cognition and insight to consent to participation and provide their own account during the interviews by speaking with the participants and focussing on their ability to listen to questions, understand the questions, find words, provide an appropriate answer, retain and consider information, show awareness of their personal narratives and give an accurate history (NHS Health Research Authority, 2021; Soltan and Girguis, 2017). No research participants were declined on the basis of their mental capacity or ability to provide an in-depth history.

The study initially aimed to recruit between 10-15 participants. In using unstructured, in-depth interviews, this sample size would typically allow for individual participants to have a locatable voice within the study and for intensive analysis of each case to be conducted (Robinson, 2014). It would have potentially been considered harmful or unethical to recruit further participants in a quest for thematic saturation and then not make use of the data they provided (Francis et al., 2010).

In addition, the original aim was to interview each participant on two occasions, before and after the WCA had been conducted, which would have provided 20-30 interview transcripts. This would have allowed pertinent details related to each individual's well-being in the build up to the WCA and after the WCA when the re-assessment process was complete pending an outcome from the DWP. It was felt this would enhance understanding of participants' well-being at two points in time during the re-assessment process. However, due to a combination of reasons, there were difficulties in recruiting participants who were in a position to complete two interviews. Due to the Coronavirus pandemic, face-to-face reassessments were suspended from March 2020 and only recommenced in April 2021 (DWP, 2021b). Telephone assessments were introduced, however, the Centre for Health and Disability Assessments (CHDA) who arrange and conduct work-capability assessments on behalf of the DWP produced guidance that meant many individuals were deemed not appropriate for telephone assessments, including individuals requiring interpreters, individuals with hearing difficulties or individuals with some mental health problems (Child Poverty Action Group, 2021). Yet, the decision to exclude claimants with mental health problems from telephone assessments was later reversed by the DWP as on review they determined this was an appropriate method of assessment for this cohort (DWP, 2022e). Therefore, not only were there delays in assessments being conducted but many individuals were unable to have an assessment at all for a prolonged period of time. This led to an overall assessment backlog but more specifically, the DWP prioritised initial assessments over repeat assessments meaning a reduction in the number of reassessments being conducted (Disability News Service, 2022). This had a clear effect on potential recruitment to the study, as a reduced number of potential participants were at the specific point in time whereby they could partake in interviews at two time points during their re-assessment process. Although the researcher endeavoured to conduct two interviews with participants this was not possible and single interviews with 18 participants were conducted. The recruitment stopped at 18 participants as no new themes were emerging from the later interviews. However, by gathering narratives from 18 participants who have extensive experience of this process ensured the study had attempted to gather as much pertinent detail as possible. 18 interview transcripts were taken that allowed all the participants to have a locatable voice within the study and ensured their data contributed to the study findings and subsequent recommendations (Francis et al., 2010; Robinson, 2014).

3.5 Qualitative interviews

The narrative methodology incorporated a method of unstructured interviews, which is consistent with the philosophical paradigm and methodology. This form of interviewing is suggested in conducting field work where respondents need to express their individualised perspectives in their own words, behaviours and in their own time (Jamshed, 2014). The method of unstructured interviews within the narrative methodology is appropriate where, as in the case of this research, the researcher is pursuing understanding of a specific phenomenon from an individual's perspective and the understanding can only come from the standpoint of individuals who are participating within this specific phenomenon, i.e. the work-capability re-assessment process (Cohen et al., 2007; Creswell, 2009). Unstructured interviews involved interviewing individuals in-depth to determine how they personally experienced the work capability re-assessment process and how they perceived their well-being during the process. Interviews were guided by the respondents' replies and reactions, and there were no predetermined questions for the interview beyond initial contextual or 'setting the scene' questions, rather pre-determined topics for the interviews (see Appendix 5). Furthermore, the questions were flexible from one interview to the next (Batmanabane and Kfouri, 2017). The 'setting the scene' questions were in place to gather some demographic information from the participants before the unstructured element of the interviews. When the researcher then asked the participants about their experiences and perceptions of the work-capability re-assessment process with the aim of gathering a specific narrative, interjections were only made to clarify points of their story. The participants had free rein in terms of what they wanted to disclose at interview and the topic guide was used more as a prompt to help the interviewer check pertinent areas had been covered within the interview.

Participants were invited to provide any documents or materials that gave further context to their story could potentially be analysed (personal records, diaries, copy of prescription, appointment letters etc.). The documents or materials were provided voluntarily by the individuals and any data garnered from these documents or materials acted as contributory evidence towards the over-arching narrative (McAlpine, 2016).

The interviews were initially planned to be conducted in person at pre-arranged venues that were convenient for the individual participants or alternatively conducted via telephone or video communication. However, all the interviews were conducted by telephone due to a number of reasons. Throughout 2020-2022, there were numerous variants of the COVID virus including Alpha, Beta, Gamma, Delta and Omicron, which are linked with heightened transmissibility and virulence (Aleem et al., 2022). During this time government advice was to meet in-person only if necessary. The government had enforced three main periods of national lockdowns or restrictions between March and May 2020, October 2020 and January 2021, then January and February 2021 (Office for National Statistics, 2021). Although no lockdowns or restrictions were enforced throughout 2022 when the data was collected, as the interviews were with people with long-standing health problems, telephone interviews were deemed safer than face-to-face interviews and some participants described during the interviews how they continued to self-isolate in their homes, only leaving for essential appointments or weekly shopping, which supported the decision. Moreover, research has shown that the percentage of COVID patients requiring hospitalisation was six times higher in people with pre-existing medical conditions and the percentage of people who contracted the virus was twelve times higher in people with pre-existing medical conditions (Aleem et al., 2022). This reinforced the interviews being conducted remotely as opposed to in person. The participants had a choice to conduct interviews via video communication on the Microsoft Teams platform, however, all interviews were conducted on the telephone as this was the participants' preference.

The use of telephone assessments has advantages. Rahman (2015) and Sweet (2002) found that the quantity and quality of data obtained via telephone are not affected adversely, although telephone interviews may be shorter or less comprehensive than face-to-face interviews, which can compromise quantity and quality of data (McCoyd and Kerson, 2006). Additionally, some research subjects might be more comfortable conducting interviews via telephone, as opposed to face-to-face (McCoyd and Kerson, 2006). Telephone interviews are less expensive and easier to schedule and re-schedule than face-to-face interviews if the interviewer or interviewee were to miss the appointment for any reason, which saves money and time (Musselwhite et al., 2007). However, the use of telephone interviews can potentially lead to a lack of visual cues, which could lead to data loss or distortion and subsequently data analysis and interpretation might be affected, harming the quality of research findings (Patton, 2002). Additionally, there is a potential issue of a lack of telephone coverage for some participants (Carr and Worth, 2001) and research has shown that disabled people have less access to the internet when compared with non-disabled people, mostly as a result of financial limitations (World Economic Forum, 2021). However, as previously stated, 98% of the UK adult population own a mobile phone and 93% own a computer, with 48.5 million using Facebook and 15 million using Twitter. Therefore, there was a large pool of potential candidates who were able to engage with the research study.

The researcher ensured they introduced themselves appropriately and asked each participant if they had any queries before commencing the interview. The length of the interview was dictated by the individual participant's ability or desire to maintain the dialogue (Zhang and Wildemuth, 2009). After an appropriate briefing and consent was gained from the participants, the unstructured interviews commenced. With participants' permission the interviews were all recorded using a recording application on the researcher's mobile phone and by recording the interviews, the interviewer could concentrate on the dialogue and did not feel pressured to take detailed notes, allowing for a more in-depth data analysis afterwards (Robson, 2011). The interviews ranged from 30 to 80 minutes, with the average duration of the interviews conducted being 43 minutes. Those participants who wanted to share relevant documents read them out over the telephone. This was predominantly participants utilising WCA appointment letters or WCA outcome letters from the DWP to verify timelines of their WCAs.

3.6 Data storage

The recordings were uploaded to OneDrive immediately after the interviews and deleted from the phone. Once the recordings were transcribed verbatim into Microsoft Word documents by the researcher, the transcripts were anonymised and stored on OneDrive. All personal identifiers were kept separately from anonymised transcripts to protect participants' anonymity and confidentiality of personal data was respected. Pseudonyms were assigned to research participants to maintain anonymity. The transcripts will be archived by the researcher for 10 years in Lancaster University's research information management system for publications and research (PURE). The metadata will be visible on PURE but the data will be accessible only through access requests to the Research Data Management Support Team (RDMST) (Lancaster University, 2018). After the 10-year period, the data will be permanently archived by a member of staff from Lancaster University's RDMST in a secure encrypted Lancaster University server (Lancaster University, 2018). Any personal details of the research participants and the audio recordings will be destroyed immediately on submission and dissemination of the research study.

3.7 Data analysis

The collected data was analysed using narrative analysis. This involved listening to the recordings multiple times and structuring the emergent data to build a wider, complex story of the phenomenon. After each individual interview was understood, there was cross-analysis with the other interviews to further analyse the narratives, allowing interpretations and theorising to be made by the researcher (Josselson, 2011; Kim, 2015). There are four different approaches that come under an umbrella of narrative analysis; thematic analysis of narrative, structural analysis of narrative, performance analysis of narrative and visual analysis of narrative (Riessman, 2008). The data analysis conducted was consistent with a thematic analysis of narrative, which focusses on participants' reporting of events and experiences, as opposed to how the narrative is spoken, structure of speech, localised context that can generate a narrative, or complexities during transcription; all of which align with structural, performance or visual analyses of narrative respectively (Mishler, 1995; Riessman, 2008). In conducting a thematic analysis of narrative, accounts are not fractured into thematic categories but interpreted as a whole (Williams, 1984). The researcher considered a single interview at a time, arranging relevant details regarding the participant's perceptions of the work-capability re-assessment process into a sequential biographical account. Once this had been completed for all of the interview accounts, the researcher recognised underlying assumptions from each account and coded them. The codes were then used to exemplify general patterns from the body of evidence, which contributed to the theoretical formulation thereafter (Riessman, 2008).

The narrative analysis approach was in contrast with the thematic synthesis approach that was utilised in the literature review, where the findings were analysed and organised first by theme rather than by individual (Miles and Huberman, 2009). Within the empirical study, the research participants, as individuals with ill-health who have navigated the benefit system and now navigate re-assessment of their benefit entitlement, have lived experience of the research phenomenon. The naturalist narrative methodological stance allows documenting and understanding of the distinctiveness of each participant's story, without looking to decontextualise the transcripts through mass coding and generation of common themes. Multiple views on experiences can co-exist as part of the narrative methodology, allowing a richer and more conceivable representation of the participants' lived experience (McAlpine, 2016). A thematic or narrative analysis could have been paradigmatically appropriate in this qualitative design (McAllum et al., 2019) but essentially, the researcher wanted the participants' perceptions to shine through and be the exclusive focus and did not want to break down and reconfigure the interview texts into manufactured responses (Braun and Clarke, 2006; Riessman, 2008).

3.8 Reflexivity and positionality

Having discussed the methodology and study methods, it is essential to discuss reflexivity and positionality, how they are employed within qualitative research but more explicitly, within this study. Reflexivity in qualitative research is the process of the researcher clearly describing the contextual relationships between themselves and the research participants, which deepens the understanding of the research as well as increasing the credibility of the findings (Dodgson, 2019). It should not be considered purely as a consideration in trying to get better data but should highlight complexities in the process of engaging in qualitative research (Pillow, 2010). Whereas, positionality is our understanding of ourselves, of who we are and what we bring to our research (Brown, 2022).

As identified in the literature review, the narratives of benefit recipients can include experiences that are predominantly negative, with experience of financial hardship, distress, and worsening health while in-receipt of benefits common place. These complex issues, as well as being hard for the research participants to disclose, can be difficult for a researcher to listen to and interpret. This section of the chapter will consider the presentation of the research participants individually in the study setting, including their identity and experiences.

My relationship with the research participants will be reflected upon, plus thoughts of how I felt before and during the research process and my self-identity.

3.8.1 The Researcher

Prior to the commencement of this research study, I worked for the Centre of Health and Disability Assessments (CHDA) from August 2015 to February 2022. Furthermore, before working for CHDA, between June 2013 and August 2015, I worked as a disability analyst in relation to the Personal Independence Payment (PIP) benefit, which is a benefit that provides extra money to assist people with everyday life if they have an illness or disability, which is awarded in addition to other benefits (Citizens Advice Bureau, 2022a). In the research proposal that was written prior to this study, I acknowledged how my position as an employee of CHDA would need to be disclosed to research participants prior to any interviews being conducted, as although I am conducting this research as a PhD student affiliated to Lancaster University, the research participants would need to be aware of my paid employment, as if they had concerns of the research being linked to CHDA or the DWP, they would potentially not want to engage in the study. However, this issue was negated, as I left the role at CHDA prior to any recruitment or data collection being completed and now work in a field with no direct connection to the welfare system. On reflection, I feel this was pivotal for the ongoing completion of the study, as the link between my paid employment and the research study would continually have cast a shadow over the study and my intentions would continuously have been open to question from the participants' perspective. Yet, despite the change of work role, after working for almost a decade in the industry of benefits assessments, on reflection I do feel that I may potentially be inherently biased towards the benefit claimant and hold a great deal of sympathy for people negotiating an assessment or re-assessment process. However, this potential bias is something I have had to continually self-acknowledge and reflect upon throughout the research process and effectively put to the side to ensure the data collection and data analysis is not influenced by this. Qualitative enquiry seeks meaningful, credible, valid, reliable, accurate and confirmable findings. To have a credible research strategy required I tried to adopt a stance of neutrality throughout the data collection and analysis processes (Rajendran, 2001).

3.8.2 The Researcher, research participants, and knowledge

The relationship between researchers and research participants has been a recurrent concern in the methodology literature (Raheim et al., 2016). There is often potential for a hierarchy to form between a researcher and the research participants, with the potential for an 'insider' and 'outsider' type mentality to develop (Pollner and Emerson, 2001). Nevertheless, this is a situation I have been mindful of throughout the research process and in all communication with research participants before the interviews and during the interviews, I have always spoken to the research participants on an even-footing and encouraged them to direct the flow of the conversation, as opposed to a dictatorial-type relationship from researcher to research participant based on professional expertise or affiliation with an academic institute.

I am extremely aware that defining what constitutes knowledge in a researcher-research participant relationship and what knowledge should contribute in a research process is not just the sole privilege of the researcher, as the research participants bring their own lived experience, knowledge and agenda to the research situation (Garthwaite, 2013; Karnieli-Miller et al., 2009). Several of the research participants involved in the research study expressed appreciation that somebody was researching the work-capability re-assessment process, as they felt the research gives recognition to their situation. Several also stated that they wanted to get involved in the research for the sake of others, who they thought may benefit from the study as it could potentially enact change in the process by highlighting issues with the re-assessment process to the DWP.

Chapter three has outlined the philosophical and theoretical approach to the study and how this has guided the researcher. The aim of the study was discussed and the methods of sampling and data collection were outlined, with these approaches justified. The process of data analysis and ethical considerations were considered and finally issues of reflexivity and positionality were documented. Chapter four will present the study findings.

Chapter 4: Findings

The following chapter presents the narratives of people deemed severely functionally disabled at their previous work-capability assessment. Eighteen interviews were conducted with five men and 13 women. The average age of the sample was 41. Ten of the 18 participants lived alone, seven lived with family, with one participant living with a lodger. Whether living alone or with others, most of the participants reported difficulties with activities of daily living and needing support from family or friends. Participants had experienced between one and four reassessments since being in the ESA support group or UC LCWRA group. Table 7 documents some demographic details of the research participants.

Table 7

Table 7: Participants' Demographic Details

Participant Pseudonym	Gender (Male/Female)	Age	Diagnosis/Health Condition	Number of reassessments
Alice	Female	46	Depression, generalised anxiety disorder (GAD), complex post-traumatic stress disorder (PTSD) and spinal Injury	3
Brian	Male	43	Long-COVID	1
Cheryl	Female	31	Anxiety	2
Darren	Male	43	Anxiety, depression and personality disorder	3
Elizabeth	Female	35	Anxiety and depression	2
Francesca	Female	44	Visual Impairment	2
George	Male	31	Schizoaffective disorder	2

Helen	Female	51	Long-COVID	1
Ivy	Female	32	Hearing difficulty, chronic facial pain and mental health problems	2
Jessica	Female	36	Autism, triple X syndrome, ataxia, adrenal insufficiency, asthma, osteoporosis and severe acid reflux	4
Kevin	Male	35	Anxiety and depression, and autism	4
Leanne	Female	28	Autism and obsessive compulsive disorder (OCD)	2
Mary	Female	51	Epilepsy	1
Natalie	Female	50	Ehlers-Danlos syndrome with co-morbid chronic pain and weakness, neuropathy and mental health difficulties	3
Olive	Female	55	Ehlers-Danlos syndrome, fibromyalgia, chronic fatigue syndrome, plus multiple co-morbidities	3
Penny	Female	60	Borderline personality disorder with affective instability	3
Quinn	Female	38	Borderline personality disorder, generalised anxiety disorder and chronic fatigue	3
Richard	Male	31	Severe anxiety and depression, spinal problem, abdominal hernia and chronic fatigue symptoms	1

Following narrative analysis, seven concepts were theorised: 1) stigma, 2) experience of the ESA50 or UC50 questionnaire, 3) issues with the assessment provider processes, 4) the 'luck of the draw' with the assessor, 5) waiting for the assessment outcome, 6) a perpetual cycle of assessments that is detrimental to health, 7) social and functional impacts from re-assessments. The Health Stigma and Discrimination framework (Stangl et al., 2019) was not used as part of the data analysis process but was utilised as a tool to expand the discussion by ensuring the research focus remained grounded to the research question and study aim (Grant and Osanloo, 2014). The framework achieved this by providing a lens to focus thinking during the discussion and generation of policy implications, ensuring they were tailored specifically towards addressing the future outcomes for people in the ESA support group or UC LCWRA groups who are undergoing re-assessment of their benefit. This will be discussed further in chapter 5.

4.1 Stigma

Stigma was evident in many of the narrative accounts. In these accounts, participants were often eager to express that they would work if able and did not wish to live with health problems and be reliant on the welfare system. Brian who is in the LCWRA group as a result of contracting long-COVID and has his re-assessment pending, spoke proudly about his previous work role as a freelancer with a broadcasting corporation. Over a period of 12 years he had completed numerous roles on sets and locations, including working on a few high-profile films. He also discussed how his Mum was a teacher and that he came from a proud family. He seemed eager to get across that he had worked, wanted to return to work if and when able and did not want to be on benefits. On analysis of Brian's story, there was a thread of personal stigma evident as he tried to distance himself from his current reality as a benefit recipient by focussing on his previous reality as a working man, and was keen to frame his family as a working family, as opposed to a family of non-working individuals or multigenerational benefit recipients. His comment "*no disrespect to people who are on Universal Credit 24/7*" has an underlying tone of Brian internalising stigma towards others, and feeling people who are in the LCWRA group and have never worked as a result of their health or disability have a different reality to him because he worked for a prolonged period of time before finding himself unwell.

Francesca, who is in the LCWRA group as a result of a visual impairment, spoke with authority on her previous work role. She seemed eager to relay her employment history to the researcher, which evidences personal stigma and the need to justify the receipt of welfare benefits.

> *"I was an Ofsted registered nanny for six years. I used to be a nursery manager before that and I used to be a carer as well. I became Ofsted registered so parents could have me as a nanny and then they get their discounts from the government…there's a lot of demand for that as well. I got good work as well with that but I had to stop working because it wasn't safe to be around the kids [due to the onset of her visual impairment]."*

In a similar vein, Penny, who has borderline personality disorder with affective instability, is in the ESA support group. She discussed her educational achievements, with Bachelors and Masters degrees awarded. She covered at length her teaching career, stating, *"I was a teacher for 20 years, I was an outstanding teacher who looked after everybody else's kids."* This was another example of feeling the need to legitimise being in the ESA support group, indicating personal stigma.

Helen had worked as a carer and care manager before finding herself unable to work when she was given a long-term health diagnosis. Helen reported:

> *"It's a brutal, brutal process…you are hearing people going on and on, and the government going on and on about cutting the welfare budget, and you're sitting going no wait a minute, in order to keep a roof over my head, I'm having to sell my Gran's wedding ring, and I still can't even afford to heat my house because I'm living within my means. That is not scrounging, that is not people scrounging, that is people genuinely struggling with the cost of living and with the fact that benefits haven't been kept in line with inflation for decades."*

From Helen's story it comes across that she feels stigmatised as a benefit recipient, perceiving the public and government as viewing her as a scrounger whilst living on benefits. Darren has long-standing mental health difficulties, with diagnoses of anxiety, depression and personality disorder. He has been on benefits intermittently for a number of years but has been in the LCWRA group for approximately four years. Darren discussed how he was a plant operator and civil engineer but feels he has no options with regards to potential employment due to his poor health. He feels he would be able to manage some work *"if left to himself on a machine away from everybody"* but does not feel work options are available to him.

Olive who is in the ESA Support Group as a result of multiple health problems spoke about how she continues to look for work, even if just 4-5 hours per week, which she felt would provide her with a sense of pride and improved self-esteem. However, she perceives potential employers as viewing her as "*flaky*" and wanting people with no issues with health or disability who can work full-time. Olive needing work to provide her with improved self-esteem outlines how being in receipt of benefits for her carries a level of personal stigma or shame. She also feels stigmatised by others, feeling she will be viewed as unreliable due to her health conditions and status as a benefit recipient.

4.2 Experiences of the ESA50 or UC50 questionnaire

Those applying for or being re-assessed for ESA or UC are sent a capability for work questionnaire to complete, known as ESA50 or UC50 questionnaires. The content of this questionnaire was documented in the introduction chapter, section 1.5. Experiences of receiving and completing the questionnaires were narrated in most of the accounts.

Alice has had mental health difficulties since her adolescence, with diagnoses of depression, generalised anxiety disorder and complex post-traumatic stress disorder (PTSD). Additionally, whilst a PhD student 11 years ago, she suffered a spinal injury that continues to cause chronic pain. Alice has been in receipt of benefits intermittently for the past 11 years, but in the ESA support group for the past six years. To be in the ESA support group means the claimant has no expectation to complete any work or work-related activity, while receiving an additional amount of money per month. The ESA support group is the equivalent group of the Limited Capability for Work and Work-Related Activity (LCWRA) group in Universal Credit (UC). Reflecting on the last time she received the questionnaire, she reported:

> *"The last time I got an envelope from them, I had a panic attack and couldn't open it. I called my partner and he came over and opened it for me. I can't deal with it, yeah. The first time it was difficult but I didn't know what I was doing, the second time was harder, and third time was just terrifying and honestly I don't know if I'll be able to do it again. I ended up suicidal that time."*

An interesting nuance from the above quote is the fact that Alice has found the completion of the questionnaire more and more difficult with each re-assessment process, with the latest questionnaire receipt leading to suicidal thoughts. Alice gave further detail regarding the questionnaire and how it can impact on not just the claimant:

> *"I spend hours and hours filling in the forms and it is not just the claimant who has the problem, it is everybody around them. Last time I got about half way through it and cracked, and my partner had to take it over."*

The stress that comes with completing the questionnaire is something that was also storied by Jessica. Jessica has been in the ESA support group for four years due to the combined effects of her autism, triple X syndrome, ataxia, adrenal insufficiency, asthma, osteoporosis and severe acid reflux. Jessica stated:

> *"Because I am autistic, when the form comes that then puts a lot of pressure on because I know that you've got four weeks to get it back within. You've got to write the form so it puts a lot of pressure on us, and we want to get on with it and get it done straight away, but it's not one of those forms you can do straight away, you've got to do a bit at a time because if you miss anything you'll lose your money. So it's just immediate pressure and immediate stress the moment it lands, the notorious brown envelope on the letter box floor."*

Darren has been in the LCWRA group for approximately four years. He stated:

> *"I think the questionnaire, it makes me think back on all the past and everything you know and what I'm on it for, and I find it demoralising when you send it all. You know, why it all needs to be said again?"*

Helen contracted Coronavirus in April 2020 and has seen her health decline since that time, and she now has a subsequent diagnosis of long-COVID. She has only been in the LCWRA group since April 2022, but was given a re-referral period of just three months, meaning she is awaiting re-assessment already. Helen reported:

> *"On the limited capacity form…I literally listed every single symptom and how they affected me, and gave an example, so the form that I submitted was massive, and that*

> *was all kind of anxiety based…The process of actually filling in the form was exhausting, I found it really physically exhausting, mentally exhausting, so after I had done like a couple of hours working on it, I would have to sleep and rest, and go to sleep, and be asleep for 2 to 3 hours. There was times when my energy crashed when I was downstairs in the house, and I couldn't make it up the stairs to go to the toilet, and I had to sleep before I could actually go to the toilet, and then I would have to go to the toilet and then go to my bed, and then sleep for another few hours, perhaps miss a meal because my energy was crashing so low with the effort of having to do the form."*

Richard is diagnosed with severe anxiety and depression, a spinal problem and abdominal hernia, and is awaiting further investigations related to symptoms of chronic fatigue. Similarly to Helen, he reported how completing the questionnaire was difficult due to his health problems, but also led to additional stress:

> *"It is extreme pressure and I mean the questionnaire itself is fairly straightforward if you haven't got any mental health problems, you could probably work out what to say, but my brain was completely fried just trying to think what I needed to do, so it took me weeks and weeks, and I got so close to the deadline that I thought I don't know if I'm going to be able to get this back in time, which then triggers the whole "are they going to sanction me? Are they going to cancel my claim? What are they going to do?" So it was just the worst thing that I could think to do while I was feeling so ill."*

Leanne is autistic and has obsessive compulsive disorder. A decline in her mental health has led to her being in the LCWRA group since 2020. She has had two work-capability assessments to date, the most recent being in 2022. Leanne reported how the filling in the questionnaire led to low self-esteem:

> *"I wrote everything that I possibly could, but writing all that stuff makes me feel like rubbish, and it's like, I am an absolute waste of space, like what is even the point of myself because I am having to write all this…like how am I capable of not doing so much, and it is just upsetting to have to be so negative about myself."*

In a similar vein, Elizabeth who has anxiety and depression secondary to a bereavement reported how she "*couldn't face filling it [the UC50 questionnaire] in, so they contacted me for an assessment without the form going in*."

Despite narratives about the questionnaire being predominantly negative, there was one isolated positive account from Mary who is in the LCWRA group as a result of epilepsy that developed from 2019. Mary stated, *"The questionnaire, I found it pretty straightforward that was fine."*

In summary, the findings from this section show that for some, receiving the ESA50 or UC50 questionnaire can lead to panic or suicidal thoughts. For one participant this mental impact worsened each time she had received the questionnaire as part of the re-assessment process, which is indicative of a trauma response that would be expected from symptom provocation in PTSD (van der Kolk, 2000). Contemplating filling in the form can lead to impacts on mental health, and completing the questionnaire can lead to symptoms including physical exhaustion, stress, demoralisation and low self-esteem.

4.3 Issues with the assessment provider's processes

A concept from the narrative accounts was regarding issues with the processes of the work-capability assessment (WCA) provider, or a lack of communication from the WCA provider (previously ATOS but has been the Centre for Health and Disability Assessments

(CHDA) since March 2015) (Disability News Service, 2015). This theme was evident in most of the accounts.

Brian is in the LCWRA group as he developed long-COVID secondary to contracting COVID in 2020. His re-assessment is now pending, and he reported the following difficulties regarding his work-capability assessment:

> *"Well the assessment itself had to be changed three times. It got to the morning, nothing happened, I rang the centre, I think it is based in Teesside in Middlesbrough. I explained that nobody had rang me, she apologised and said that the nurse had COVID, but again another time the same excuse being used, COVID, then luckily a third time was when I had the assessment, but you know, there was no correspondence. We had to chase the people up; a bit frustrating."*

Richard is also waiting for his next assessment, but reported the following difficulties related to his previous assessment:

> *"I was going to have the assessment early in the morning, and then by 12 o'clock nobody had called and I chased them up, and they said "oh we don't know it is with the assessor who is assessing from home, it is up to them, they might call you tomorrow, they might call you another day we don't know so leave it until Monday and then if you don't hear anything call back again." So I called back again on Monday and they said "oh we still don't know what is going on." I just left it at that and waited for someone to say your claim has been cancelled or you are not getting it and you have to come into the job centre, but I think it was a couple of weeks after that when I suddenly got the letter to say I had been assessed [on paper], but during that time I had no idea what was happening at all, I was completely out of the loop."*

Similarly Elizabeth, Cheryl and Francesca who are in the LCWRA group as a result of anxiety and depression, anxiety, and a visual impairment, and have their re-assessments pending stated the following:

> *"Last time as well, my appointment got cancelled on three occasions. I'd get myself ready for the assessment, and I'd get a call to say it couldn't go ahead. That knocked me back eight weeks. The third time it happened, I said you can't do this again, but the lady said they would give me a 9am appointment the next day so it wouldn't get cancelled, but they still only rang me at 1pm that time. I'm worrying about the same happening again already."* (Elizabeth)
>
> *"It was really stressful and I had, to be honest it wouldn't have took so long, but I had two phone assessments what they cancelled, and they wouldn't get in touch with you for months and months and months."* (Cheryl)
>
> *"So initially I had the assessment over the phone, but it got cancelled three times, and then my anxiety levels went crazy. I had to call them actually, like why has nobody phoned me, I'm waiting, and they goes like "the person is off sick". I said you could have told me, I've been waiting all morning for the assessment, but eventually when they did phone me, we did it over the phone."* (Francesca)

Whereas the above accounts focus on poor communication from the assessment provider when cancelling the WCA appointment, the below account from Darren portrays difficulties in arranging the WCA to take place at a more accessible venue. He stated:

> *"They tried to make me go to the Cardiff assessment centre, and it took me seven weeks to get that changed to an easier one for me to get to as well. To get to Cardiff is like two buses, and the assessment centre in Bridgend is about 10 miles away and it's 1 bus; and I think it's about 400 yards and I'm at the assessment centre. It took a lot of arguing and trying to persuade them [to agree to the assessment taking place*

> *in Bridgend]. Ringing up, I had to make a complaint as well. Well they put me down first as not attending, and you can guess can't you, I hit the floor with them. I told them I'm not attending because there's another centre which is easier for me to get to."*

Quinn is diagnosed with borderline personality disorder, generalised anxiety disorder and chronic fatigue. She had been in the ESA support group for three years until recent months, when a change of circumstance led to her migrating to Universal Credit. In a similar vein to Darren, Quinn reported her appointment unnecessarily being made at an assessment centre further afield from her home address:

> *"The last one was arranged for Nottingham, which would be a three hour round trip. My partner rang and said it would not be accessible for me, and they eventually changed it to Chesterfield, which is only half an hour away, but who knows why it wasn't there in the first place."*

When Quinn did attend for this work-capability assessment, a lack of communication regarding a delay to the appointment time compounded her existing anxieties regarding the assessment, making the overall experience more difficult:

> *"I had already had a panic attack but as soon as I walked in they said they were two hours behind, but they had not told anyone beforehand. It wasn't like they had rang up and said "oh we are running late, we will have to re-arrange this" or something, so I walked in…I had already had a panic attack, and then they said well you can go and walk around Chesterfield for two hours and come back, but I had already had a panic attack so I didn't want to do that, so my partner said "is there somewhere quiet we can sit?" So they just put us in this room that was off the waiting room, which was quite grubby and not very nice and had a tiny little window that didn't really open very*

> *far, so at the point when I went in for the work-capability assessment I was already in a pretty bad place mentally."*

Olive is diagnosed with Ehlers-Danlos syndrome, fibromyalgia, chronic fatigue syndrome, plus multiple co-morbidities. She has been in the ESA support group since 2015 when she migrated across from Incapacity Benefit, and continues to wait for an overdue re-assessment. Similar to the difficulties Darren and Quinn faced with arranging the WCA appointment at a more accessible venue, Olive reported the following difficulties in trying to arrange an assessment in her home:

> *"They kept insisting I went in [for a face to face assessment]. I kept saying I can't get there, my doctor also wrote a note saying she is not fit to travel and there is no ability or capacity for her to travel, why are you asking her to come in and in the end they just said we'll do it on paper. Literally the next week I was back in the support group, there was no reason to see me clearly, clearly they had all the evidence, so what was that game all about? The stress of that, having to go to my doctor, pay for a letter to say I would find that journey too difficult and beyond my capability to make that journey, let alone to make it back again, and even at the other end when you got off the bus, I don't think I'd have made it, if I'd have made it, I've have been such a mess it would have been a waste of time for everybody and I'd have been like, I can't help you because you've made me come here and it's too far, but I have told you several times, so in the end they reluctantly gave in and it just went straight through on paper."*

In summary, the findings from this section show that for many participants there were cancellations to their assessments with no warning that led to frustration, worry or stress. Claimants will continue to receive their benefit at the appropriate rate if the assessment is cancelled by the assessment provider, so there is no financial concern when the assessment is cancelled by the assessment provider (Health Advisory Assessment Service, 2023b).

However, the stress of the pending-WCA remains in situ for the claimant. Claimants can be assessed or re-assessed taking just their ESA50 or UC50 details and supporting medical evidence into account, avoiding the need for a WCA (Centre for Health and Disability Assessments, 2022). However, there were instances of participants being assessed without the need for a WCA, but sometimes this occurred without the participant's knowledge and they continued to wait for a WCA. The findings also show that claimants are at times invited to assessments that are a significant distance from their home address, despite there being nearer assessment centres, again leading to stress and the inconvenience of re-arranging appointments. This also evidences the assessment provider failing to provide reasonable adjustments as per the Equality Act 2010. Additionally, there were instances of participants arriving for their assessments and having to wait for a significant length of time beyond their appointment time due to delays, but there had been no communication related to the delay prior to them arriving for their appointment, which led to mental distress.

4.4 The luck of the draw with the assessor

The participants' perception of their assessor at the WCA was narrated in most of the accounts. This was variable from one participant to another, or even varied from one WCA to the next for some participants. Alice stated:

> *"A couple of times I have had reasonably good assessors, but last time the guy was just, he clearly didn't believe me. He was rolling his eyes, he asked me things like, "well if you're suicidal, why haven't you died yet?"*

Although CHDA provides clear guidance on what will be discussed at the WCA (Health Assessment Advisory Service, 2022b) and it is appropriate to ask about possible thoughts of self-harm or suicide during assessments where the claimant is potentially at risk (Centre for Suicide Research, 2013), Alice rightly perceived this question related to suicidal ideation as being inappropriately framed. Penny is diagnosed with borderline personality disorder with affective instability, and has been in the ESA support group since 2018. She stated the following with respect to assessors she had encountered at two different WCAs.

> *"I literally felt like I was sitting with a young person ticking a box. I didn't feel like the person was engaged in the process in anyway, and that is the truth. The person sitting next to me wasn't really there at all, whereas the first assessment, even though it felt negative and was horrible and made me feel really poorly as I felt as though I was being really scrutinised and there wasn't a lot of smiling going on in the first one… at least that person was in some way engaged in that process and luckily for me it came out with the right result."*

Similarly, Brian felt his assessor was abrupt during the WCA. He stated:

> *"With the assessor, I found them to be quite off-putting and abrupt if I'm being honest. When you are trying to remember things and trying to get your point across to the person, I had to write a lot of stuff down, which obviously I have done this afternoon just in case you forget something, but I think there was a lot of abruptness there and I think they just need to take a step back and realise that people are in these positions and they just need a little bit of support."*

While Alice and Brian felt the assessor did not believe them or that they were being abrupt, and Penny felt an assessor at one of her WCAs was disengaged from the process, Leanne described how the assessor patronised her at the outset of her WCA contributing to an already emotional situation:

> *"I took my Mum with me [for the assessment] and the first thing they asked was "is it OK for your Mum to talk on your behalf?" I was like, I haven't even spoken yet, and the first thing they had asked was, was it OK for someone else to speak on my behalf, which I found really patronising, I didn't like that at all. I hadn't even spoken, I hadn't*

> *introduced myself, so they presumed because my Mum was with me she would be the one that was speaking, and I understand that this may be common for a lot of people, but I thought that maybe…I don't know, I just didn't like it, it was bad. I didn't like how they automatically did that but then I was crying so much that my Mum had to speak for me anyway."*

Quinn reported how the assessor at one of her work-capability assessments failed to offer any emotional support despite her clearly having difficulty at the time:

> *"I just remember that I was crying, I was crying so much, I couldn't breathe properly, I got my ex-partner in there with me…there was absolutely no emotion from the person who was doing this assessment, there was no "oh do you want to take a minute" or "can I get you a glass of water", anything that if someone says they are a medical professional, you think that they would do, they didn't do. I seem to remember her saying, "I'm just here to assess you"."*

Only four participants reported good experiences with assessors:

> *"I was really worried about the assessment, but to be honest I had a really nice assessor, so I can't fault the woman that I spoke to. She was really nice and really helped with calming me down and stuff."* (Cheryl)

> *"To be honest, I can't speak highly enough of the assessor I spoke with on the phone, he's a credit to the company that does the assessments. He was really nice and put me at ease, and at the end of the assessment he said "if this was a face to face appointment, I'd be giving you a hug now"."* (Elizabeth)

> *"When eventually he did call me, the guy was really nice. He was actually really understanding."* (Francesca)

> *"The assessor was really lovely, very gentle, kind of reassuring; whereas the PIP assessor had been quite curt and not rude, but on that dividing line between being curt and being rude, being efficient and being rude…this assessor was really lovely, quite reassuring, you know, asked me not to worry, that she was just wanting to ask a few things to check, and all that she wanted to check through was to talk through my symptoms, check my medication that I was on, and by the time I had done that she said right we have got everything we need, and I think in part that was because I had gone into so much detail on the form. It was only like a 15 to 20 minute assessment, it was really short, really brief, just what she needed to do rather than double, double, double checking everything and trying to ask questions, in the PIP assessment if felt like they were asking questions in a way to almost trip me up."* (Helen)

In summary, the findings from this section show how variable participants' experiences of the WCA can be dependent on who assesses them. Some participants reported positive experiences with their assessor being nice and reassuring, but the majority of accounts portrayed negative experiences, with assessors not being supportive, lacking engagement, being abrupt or making assumptions regarding the participant before the assessment had begun.

4.5 Waiting for the assessment outcome

Feelings while waiting for the assessment outcome featured in the majority of participants' accounts. With respect to waiting for the assessment outcome, Quinn reported:

> *"Horrible, thinking about what had been said and whether anything had been missed. It is an inhumane process. Waiting for the outcome is horrible."*

Alice described how waiting for the assessment outcome was an uncomfortable time, and something that was with her constantly:

> *"Constantly, you are always wondering when is the next envelope going to come? When is the next time I am going to lose all my benefits, or have a drastic reduction and not be able to afford my life? They can do it anytime, right? You are never comfortable because you know at any moment your life could fall apart."*

Similarly, Jessica described checking the bank on the day her benefits are usually put into her bank account and expecting the money not to be deposited.

> *"Checking the bank each fortnight to see if the money had gone in, we were expecting one week the money just wouldn't appear."* (Jessica)

Whereas, Leanne described the 'horrible' process of checking her Universal Credit journal daily for an outcome:

> *"I know it was good that I had been put back into the limited capability for work and work related activities group, but like, the wait was horrible, I was checking my journal every day to find out…yeah, I don't know what else to say."* (Leanne)

The following extracts from Leanne, Darren and Olive show in further depth how waiting for the assessment outcome was not just an anxiety-inducing process, but exhausting and stressful to boot:

> *"It's such a horrible process and I was scared that I wasn't going to get it because I would have to go back to work, and how would I go back to work because I'm not in that place anymore, I'm a totally different person to who I was, and she kept referring to the fact that I used to be able to do things, and just because I used to be able to do it, doesn't mean I'm able to do it now and it was just…it made me frustrated, sad and anxious."* (Leanne)

> *"I spent 2-3 weeks in bed, having no energy at all, from the overthinking of what is going on like, and why is it taking so long [waiting for the assessment outcome]."* (Darren)

> *"After the assessment, I think there was a huge overwhelming range of emotions, I think the main one was exhaustion, a kind of relief, a kind of anger, and there was no let up because you were questioning every you said. What did I say? How did I come across? You are so exhausted that you don't need to be questioning yourself, but you can't help but question yourself, and when it is overlaid with the exhaustion, again you don't bounce back from that high level just because you've got your form in and the assessment has been, you're now questioning yourself. There is some relief, but it is not a great deal, so again it doesn't dip down low, the level of anxiety dips a bit and as the days go past obviously the exhaustion and the stress and the adrenal and everything else dips a bit."* (Olive)

Leanne made the point that she was scared that she would have to go back to work despite knowing herself that she was not in a position to do so, and this is something that was also expressed by Brian:

> *"I think it was just the waiting you know? Are you going to get accepted on this thing, when you know that you should be accepted, because you hear so many horror stories about people not getting it and having to provide more paperwork and go in for meetings."*

George has long-standing mental health difficulties, with a diagnosis of schizoaffective disorder. He has been in the ESA support group since 2010, and had his latest re-assessment in 2022. He also expressed stress at waiting for the assessment outcome despite feeling he is unable to work due to his health. Additionally, he feared losing his financial income as he felt it would lead to him becoming homeless. He stated:

> *"They said that the decision is with a decision maker and she said wait patiently, and you will be notified of the outcome, but I think the stress and the agony, the time it takes for the decision to be made, and sometimes the decision isn't in your favour, so I think it creates a lot of uncertainty, a lot of, I don't know what the word is, but a lot of anxiety starts to develop. That is the only source of income I have and without that income, I don't think that I am able to work so I don't know where I can turn to? If my money does get stopped, where am I going to turn to or where am I going to go? There is no where I can turn to and no where I can go, I would just have to live on the streets, be homeless."*

Olive had expressed how waiting for the assessment outcome had been anxiety-inducing, stressful and exhausting. However, the below exert is a powerful statement that further added to Olive's narrative:

> *"You never get back to ground zero you know, you are always up there and you stay up there until you finally get your result, and if it is the result that you want, surprisingly enough most people are then angry and the reason that they're angry is they knew they were right, they knew the award they should have got, and they know that they have just been put through three months of hell. Three months of real debilitating hell where their lives have been put on hold, and their lives have probably gone to rat shit."*

Only one account about waiting for the assessment outcome was more positive. Mary said:

> *"I know they did the best they could in the months, so I was quite happy with the process, and the outcome was a good one for me and in a couple of years when I do have to be re-assessed again, I'll deal with it then. I can't be thinking of that so early in two years' time or 18 months' time from now, but yeah it's all fine in my opinion, nothing bad to say."*

In summary, the findings from this section show that on the whole participants viewed waiting for the assessment outcome as stressful and exhausting. Although claimants remain on the appropriate benefit rate while waiting for an outcome, this does not appear to remove financial concerns as the assessment outcome can affect this, so the anticipation of benefit withdrawal or cut remains.

4.6 A perpetual cycle that is detrimental to health

Throughout the data collection and analysis processes, what was evident in most accounts, and became an overarching narrative concept, was the participants' dismay at the cycle of re-assessments which they have to adhere to or they would no longer be entitled to their ESA or work-related element of their UC. Olive reported deterioration in her health and a complete loss of functionality as a result of her latest re-assessment:

> *"I remember just eating dry bread because I couldn't contemplate trying to cook, there was no energy, there was no focus, there was just overwhelming anxiety and just eating dry bread, I didn't shop, I didn't wash, I didn't change my clothes [pauses]…for months, so the anxiety was so high and the resulting exhaustion was so high. These assessments make people so ill, so, so ill."*

Alice reported how she becomes non-functional at the time of the re-assessments, which led to a lack of self-care, yet she cannot live without the financial means of the benefit:

> *"I'm seriously panicking just thinking about being re-assessed. I just end up non-functional, last time it was for a year. I just plunged, didn't take care of my back so it got way worse. I spent around six months just in bed, I didn't get up. It is really scary, you work as hard as you can to get as functional as you can, and knowing that that might happen again, yeah it's really scary, but I don't have a choice. I can't live without it."*

Alice also described in further detail how going through the re-assessment process is to the detriment of her physical and mental health:

> *"The fatigue definitely gets worse, basically it makes pain worse, fatigue worse; it makes mental health problems worse. I get really bad insomnia when I get anxious, I tend to get very anxious, so you know if you are only sleeping three hours per night for weeks on end it is not very good for you. That makes the pain and fatigue worse, and each time it has been worse; you know the stress it gets to you, you get depressed and stop eating, stop showering, don't do the stretches and exercises I should do for my back so that gets worse; which makes me more depressed."*

Helen compared the re-assessment process to getting ready for another battle of having to prove she is unwell:

> *"It is that feeling of preparing yourself for a battle, you are constantly feeling like "oh gosh I've got to prove myself again, I've got to prove that I'm really poorly". Even though I have all this information about how poorly I am, and I've got doctors saying, you know Helen has hit a flat trajectory and remains to be severely debilitated. It's like, I'm going to have to do all this again."*

Helen also reported a decline in their physical and mental health as a direct result of the re-assessment process:

> *"Well because the anxiety…any emotional exertion also causes an increase in your post exertional malaise, it pushes up all my other symptoms, so it's making me more fatigued, my fatigue levels are really high at the minute."* (Helen)

Ivy has hearing difficulty and chronic facial pain, which has led to mental health problems secondarily. Similarly to Alice and Helen, Ivy reported exacerbation of physical and mental health symptoms during her recent re-assessment process:

> *"When I am quite stressed, and obviously it is a stressful situation, when I'm quite stressed, my pain is worse because if I get a migraine it puts extra pressure on the nerves and my pain is worse, so I have to try and not get so stressed that I get a migraine, but it's very hard when you've got all this on your mind, to remain clear minded so you don't get that additional pain and pressure."*

Jessica reported frustration that although she is diagnosed with a neurodiverse condition, which causes difficulties that are not going to change, she is expected to complete the ESA50 questionnaire annually regardless:

> *"We have both got autism, they know we struggle with managing money, words, information. It isn't going to change, but they keep sending the form every year for us to complete."*

Kevin has a diagnosis of anxiety and depression, and a more recent diagnosis of autism. He has been in the ESA support group for four years, and expressed irritation with repeated assessments:

> *"If the departments within the DWP spoke to each other, then they could compare notes and you would only need to fill in the forms once, so if you got the PIP, they could*

> *look at the PIP form; or if you got the ESA, they could look at the ESA form rather than having to do it repeatedly."*

Leanne has been through two WCAs to date, but despite being put in the LCWRA group at both assessments, she feels ongoing anxiety and is scared of being accused of fraudulent activity:

> *"I'm now scared that if I go outside by myself one day that someone will see, and that will mean that I won't get it anymore. Will I be deemed capable if I go out by myself in the garden or if I go to the local shop, because I live in a small village, and it is just things like that…not that I feel I am being watched, but I have to be really careful with everything I do so nobody thinks I am lying, even though I'm not lying, it feels like I could be accused of lying and it is just…scary and anxiety-inducing."*

Natalie is diagnosed with Ehlers-Danlos syndrome, and has co-morbid chronic pain, weakness, neuropathy and mental health difficulties. She been in the ESA support group for seven years after going through a vigorous medical retirement process with her former employer. She stated:

> *"Oh even talking about it now, it is anxiety building up, it's not fun at all. I mean even now I am thinking I'm going to have to go through all that paperwork again, and I'm going to have to detail every inch of my capability again when I have a condition that is not going to improve and is likely to get worse."*

Natalie added:

> *"I think personally that if people have been in the support group for an extended period of time, I think they should just accept that these people are not going to go to work again. Barring some medical miracle or intervention, someone that has been*

> *depressed or chronically unwell for ten years, what is the point in bringing them in for an assessment? What is the point of putting them through all of that stress and difficulty when you know that they are not going to work again? That is what bothers me about it all, the fact that I know until I get to state pension they are going to be doing this to me."*

Penny utilised a charity organisation to support her latest re-assessment, and reported she does not know how people navigate the re-assessment process without such support:

> *"God knows what people do if they are not aware of people like P3 (charity organisation who offer advice and support with benefits) because you couldn't…when you are that ill, that is how people end up homeless. You just can't cope with addressing the system, you can just about cope with getting the forms in…you don't want to, but you can just about cope with going for the assessment, but coping with the bureaucracy if you get refused, if I didn't have that charity I would be homeless now."*

Richard reported feeling his mental health initially improved after being put in the LCWRA group at a previous assessment, but the six months leading up to his latest re-assessment led to a decline:

> *"For the first six months, every day I was starting to feel better, I was getting myself back together but then the past couple of months I have started thinking every day I need to start preparing, planning, what do I need to do, and that just sends me into a spiral."*

Similarly, Alice added that given a longer period of time between assessments and the opportunity for longer-term, prolonged rehabilitation, she feels she could actually get herself in a position to consider the labour market. However, the constant cycle of assessments prevents this:

> *"I do feel I could actually get myself to a place where I could work part-time. I have scar tissue in my spinal column, failed spinal surgery and have been through the pain clinic; my chronic pain isn't going to get better. I have had mental health problems for 30 years, they are still there and aren't going away. If I didn't have to be re-assessed, I could build myself up to do some part-time work. Even if they gave me 5 or 7 years between assessments, I would have time to get myself to a better functional place. Being re-assessed every 2-3 years doesn't allow me to get better as I can write off 12 months of that time with worsening physical and mental health due to the stress of it all."*

Olive stated the following, which provides potent visual imagery of how she perceives the re-assessment process:

> *"This isn't just 'I've just been chased by a lion and I'm now up a tree and I'm fine', this is, 'I've just been chased by a lion and I'm always going to be chased by these lions'.*

4.7 Social and functional impacts from re-assessments

As well as the narratives portraying the re-assessment process being detrimental to health, there were multiple narratives fraught with other problems the participants experienced as a result of being a long-term benefit recipient and having to negotiate the re-assessment process. Darren described his financial difficulties, which are on his mind "every single day of the week" whilst he is waiting for his re-assessment:

> *"Well it's either food or warmth, I struggle for both. Sometimes it is skipping meals, or not putting the heating on. It's a massive worry. It is the gas, so it can also be choosing*

> *between washing because I worry about the cost of heating the water see, or heating the food. People just don't realise."*

Similarly, Elizabeth reported the following financial concerns and fear of losing her home whilst waiting for her re-assessment:

> *"Just feel really anxious about it. Mostly because my rent is £800-odd where I am, and I get £600-odd contributed towards this, so the extra money makes sure I can stay in my house. That is my biggest worry, the financial side of it."*

George also reported the fear of losing his benefit at his latest re-assessment led to sleepless nights, and worry about losing his home:

> *"There was a lot of stress, I couldn't sleep at night thinking what would be the outcome, am I going to get evicted from where I live as a result of that? I'd be homeless, where am I going to go?"*

George added the following related to his monetary incomings as a long-standing benefit recipient. He stated how he is not even scraping by anymore, and his income fails to cover his basic outgoings:

> *"Even like to scrape by these days, the amount of money what is being given on welfare assistance isn't enough to cover all the costs. Every month alone over the past year or so I have noticed I've been getting into an unarranged overdraft, I haven't got an overdraft on my bank account but I am not having enough income to pay out all my bills; to pay out gas, electricity, water, council tax, food…it's just I'm not even scraping by anymore, it's become so challenging and so difficult that I sometimes have to wait for my next payment to come through so that I can pay that overdraft back because I'm not able to pay it anymore. It has an impact on my financial income."*

Correspondingly, Helen gave an account of financial uncertainty as a long-term benefit recipient, adding sadly how she has had to sell a family heirloom to maintain her home:

> *"In order to keep a roof over my head, I'm having to sell my Gran's wedding ring, and I still can't even afford to heat my house because I'm living within my means."*

As a result of uncertainty related to the re-assessment process, Ivy reported having disagreements with her mother and added that people don't want to be around her as she can be in a state of agitation:

> *"Basically, my Mum is always like, since I've had the decision, "ring them up and ask them this", but because I know I won't get the answers, I'm snappy with my Mum, I'm like "well there's no point, I won't get the answers"…but then because she thinks I'm not trying to get the answers, she's like you know, short with me…but it's not that I'm not trying to get the answers, it's that I know I won't get the answers, and that it is pointless … The actual long drawn out process of it has obviously made me worry and made me anxious, and when I get anxious, it is not good for anyone really because when you're in an agitated state, you're not fun to be around and you're not great company, I don't blame them if they don't want to sit in the same room as me."*

Leanne reported that her anxiety symptoms following the re-assessment process led to her parents having to take on a bigger role in her life, which caused some frustration within the family:

> *"So when I get really anxious, my OCD symptoms get really bad, so I…it was harder for me to leave my flat on my own. I live in the same village as my parents, but around the corner, so I don't live in their house, but I couldn't leave my flat without one of them and it was affecting their life, they were frustrated because the anxiety was making*

> *everything worse, so they were having to take on a bigger role in my life, which they were frustrated by…mind you, that is just something that happens."*

Existing research specifies that family and friends can be important in helping to navigate life on a low income, usually via financial support, support with activities or emotional support (Daly and Kelly, 2015; Green and Hickman, 2010). With respect to those with health-related difficulties, this support required from others can also impact upon their ability to then source well-paid work, leading to financial distress for the wider family unit (Daly and Kelly, 2015). The above data is consistent with this research showing a need to sell family heirlooms to cover monetary shortfalls and a need for family to offer social and functional support evident.

A further circumstantial finding became apparent through the gifting of the £20 voucher to each individual as a thank you for their participation. The participants were allowed to choose where they wanted their voucher for specifically, but initially, the researcher felt participants may request this for high street stores such as Marks & Spencer or Next. However, with one exception, participants asked for vouchers for supermarkets or online businesses that deliver groceries, either Asda, Morrisons, Tesco or Amazon. When asked where she would like the voucher for, Helen who is in the LCWRA group as a result of contracting long-COVID stated *"just a supermarket, just for food…I've got an online account for Morrisons, most of my shopping comes from Aldi because its affordable, but a wee treat from Morrisons sounds nice, but you know, that is the thing that I need my money for at the minute, just for food."* When the researcher replied that all the participants up to that point had requested vouchers for supermarkets, she added, *"people claiming benefits are not greedy or looking for luxuries. The things we are looking for is money to buy food, or to have clean clothes and to be able to pay our bills."* This is the backdrop on which re-assessments are occurring, with participants already struggling to afford food or pay bills, before even considering and trying to focus on navigating the re-assessment process.

Overall, the accounts presented in chapter 4 describe how each stage of the re-assessment journey seems to be filled with angst and negatively impacts claimants’ health, finances and relationships, from dreading the arrival of the questionnaire, contemplating filling it in, actually doing so, then waiting for assessment, enduring the assessment and finally waiting for the outcome. Chapter five will summarise these areas before considering what this means in terms of answering the research question, strengths and weaknesses of the study, reflexive considerations, what the findings contribute to the wider literature and policy implications that can be derived from the study.

Chapter 5: Discussion and conclusions

This chapter focusses upon what the study contributes to the wider literature, reflexive considerations, strengths and weaknesses of the study, what the study has accomplished in terms of achieving its aim, contributions to knowledge and discussion of the findings. Finally, the chapter provides considerations for future policy implications related to welfare benefits and potential opportunities for further research.

5.1 An Overview of the Contribution to the literature

The literature review found engagement with benefit systems can lead to struggles with identity and stigma, negativity and mistrust towards the system and distress. It highlighted a need for governmental review of benefits systems or potential policy actions that would provide more favourable terms of service for benefit recipients, including an increase in the monetary value of benefits. Within the review, the findings of the UK literature called for further research into the welfare system, focussing more in-depth upon individual benefit streams, taking into account specific details of individuals' well-being and experiences of the benefit system. The empirical study contributes to the wider literature by exploring experiences and perceptions of well-being during the work-capability re-assessment process for people who were deemed to have severe functional disability at a previous work-capability assessment (WCA) and are in the ESA support group or UC limited capability for work and work-related activity group (UC LCWRA group). Individuals in the ESA support group or UC LCWRA group are not subject to conditionality measures via Job Centre Plus, nor are they expected to engage with any work-related activities. They are exempt from any work or work-related activity due to their ill-health or disability, with this group of individuals furthest away from the employment market. Previous research has focussed upon long-term claimants of legacy benefits, claimants in receipt of disability benefits not related to employment, claimants in the ESA work-related activity group, or claimants who are in receipt of UC and engaging with Job Centre Plus.

Barr, Taylor-Robinson, et al. (2015) previously found that the work-capability re-assessment process had detrimental impacts upon mental health, with the WCA associated with additional suicides and additional cases of self-reported mental health problems. However, their study was a large-scale quantitative study utilising survey data and their participants who were being re-assessed with respect to their work capability had received different outcomes from their previous WCA. Therefore, they were not specifically individuals in the ESA support group or UC LCWRA group undergoing re-assessment of their work capability. Furthermore, quantitative studies are unable to uncover deeper underlying meaning or explanation to the data (Rahman, 2016). Hansford et al. (2019) utilised qualitative data from a survey and found that the WCA is damaging to claimants' mental health and wellbeing and pushes people into further financial hardship. The current study builds on these studies by focussing on claimants already in the ESA Support Group or UC LCWRA group and undergoing re-assessment of their work capability, groups that have not been previously researched. The empirical findings are discussed below in section 5.3.

The Health Stigma and Discrimination framework (Stangl et al., 2019) aided the interpretation of the data by providing a lens to focus thinking during the discussion. Stangl et al. (2019) concentrate specifically on characteristics that can lead to stigma, which they term 'stigma marking'. This progresses to how this manifests itself through experience or practice of stigma, then how this subsequently affects populations or organisations including health and social impacts, with a view to providing recommendations that can improve future outcomes. This was adapted for this piece of research but the same principle was applied. The characteristic that can lead to stigma is being a benefit recipient but there was then a broader focus, not just related to stigma but on experiences and perceptions of well-being during the re-assessment process. How these experiences manifest through the re-assessment process was then considered, including health, social and functional impacts. In ensuring the focus was relevant to the research question, the framework acted to ground the research focus and frame the discussion and presentation of findings (Swanson, 2013; Grant and Osanloo, 2014). Furthermore, once the data had been scrutinised and findings were presented, the framework was again used as a lens to ensure that the policy recommendations were tailored specifically towards improving the future outcomes for people in the ESA support group or UC LCWRA group who are undergoing re-assessment of their benefit. Therefore, the theoretical framework had an important impact on the research outcomes, ensuring the policy recommendations are specific to identification of training for staff of the assessment provider, raising awareness to policy makers and potentially facilitating change that can improve future outcomes for the population group.

The study began with the aim of investigating participants' experiences and perceptions of well-being during the work-capability re-assessment process. It was important to unpick the reality of the re-assessment process and how participants perceive their well-being during this time as there was a gap in the literature related to this participant group specifically. The empirical study findings have achieved the initial aim as participants' narratives clearly portrayed the difficult circumstances that the re-assessment process brings with it for a population who already navigate day-to-day living with long-term health conditions or disability and the resultant social and functional difficulties. The findings (chapter four) showed that engaging with the re-assessment process, encompassing contemplation and completion of the ESA50 or UC50 questionnaire, navigating the work-capability assessment itself and waiting for the assessment outcome, was for the majority of the sample a profoundly distressing process, causing stress, anxiety and depression, whilst exacerbating existing physical and/or mental health conditions. In addition, many participants experienced stigma due to being in receipt of benefits. The re-assessment process was regarded by participants as a never-ending cycle which was harmful to their health and wellbeing, with associated impacts of financial difficulties, food poverty and energy poverty also negatively affected their households. Importantly, narratives revealed that each re-assessment has a cumulative effect on participants, bringing more and more distress with each re-assessment. The re-assessment process was also found to be counterproductive, as it reduced the ability of some participants to engage with returning to work or work-related activity. All the themes presented are linked to the participants' well-being during the work capability re-assessment process, therefore, all are directly relevant to the study's initial aim and research question. The findings will be discussed in more detail below in section 5.3, including how they have built on previous literature.

5.2 The Researcher

Throughout the research process, encompassing data collection and analysis it was important to the integrity of the research that there was a constant reflexive process conducted by the researcher. As stated previously in the thesis, the researcher's employment history related to benefit assessments and subsequent views were a potential avenue for bias within the research. To ensure a credible research strategy, a reflexive diary was documented. This was not necessarily a daily, in-depth document but somewhere where thoughts related to interview transcripts were logged, which allowed the researcher to self-reflect on their thoughts related to contextual findings during the data collection. Moreover, it ensured that these thoughts did not infiltrate the research.

By working in the benefits sector for almost a decade, many of the details brought up in the interviews were not new to the researcher. There had been many instances of seeing people struggling to engage with the assessment processes, phone conversations with people distressed and enquiring why the process was taking so long, completing work-capability assessments with people who were toiling during the assessments due to anxiety, panic, low mood or in some cases, anger. The process is filled with angst for many people who come through it, yet when interview details triggered memories of such incidences, this is when the reflexive diary was utilised to note feelings that were linked to these incidences and in ensuring there was no 'cross-pollination' between these experiences and the experiences of the research participants.

5.3 Discussion of the study themes

Stigma

Baumberg Geiger (2016) identified 'personal stigma' by which benefit recipients feel that claiming benefits is shameful and 'social stigma' whereby feeling that other people judge claiming benefits to be shameful. The research from Baumberg Geiger utilised survey data from over 2,000 people who had claimed benefits or tax credits in the year before. Pardoe (2023) found those engaging with the UC system may discuss their family members having never claimed benefits or place emphasis on the fact they met their conditions with Job Centre Plus (JCP) as a way of maintaining a 'working class' identity and considering themselves more 'deserving' than claimants that lacked willingness to engage or received sanctions. Pardoe (2023) also identified an interplay between different elements of stigma, including mental health stigma and claims stigma. The present study was consistent with the findings of Baumberg-Geiger and Pardoe, yet builds on this by focussing on the re-assessment process for those with long-term ill-health or disability specifically, with some participants feeling a need to justify that they were from working families and had themselves worked despite them now being long-term benefit recipients and being diagnosed with a long-term health problem. There was evidence of 'othering', with a reference in the findings to "*other people who are on*

Universal Credit 24/7", which is in keeping with Garthwaite (2014) who found "a distinct 'us' and 'them' dichotomy" from her participants who were long-term benefit recipients of a legacy benefit. Whereas Garthwaite's (2014) paper found stigma in 'deserving' and 'undeserving' benefit recipients, the narrative from some participants in the current study showed evidence of contrast in their mind between benefit recipients like themselves, who come from working families and had worked in the recent past but were now too unwell to work, versus benefit recipients from 'non-working' families and who have claimed benefits for longer periods of time. Patrick (2016) also referenced 'othering' of those deemed 'less deserving' in a small scale study of out-of-work claimants. The findings from the present study contribute to the literature on the wellbeing of claimants who engage with the benefits system by focussing on the re-assessment process for people who are disabled or have a long-term health condition and are in-receipt of a work-related benefit, building on previous research that focussed on recipients of UC.

Participants' narratives also revealed feelings of being stigmatised by the public and government, who they feel view them as 'scroungers' for being in receipt of benefits. This evidence is consistent with de Wolfe (2012) who also found her participants to be worried about being perceived as a scrounger or undeserving of benefits, plus others (Baumberg Geiger, 2016; Garthwaite, 2013; Garthwaite, 2014). Some participants in the current study also expressed perceptions of work not being available to them as a result of their health conditions or employers viewing them as unreliable and wanting people with no issues with health or disability. This aligns with stigma of disability or disease (Corrigan, 2014) whereby individuals are not only living with the symptoms of physical and/or mental health conditions or disability but also prejudice or discrimination, including within the employment market.

The findings from this study build on previous research focussing on benefit assessments and benefit recipients, as they reveal that stigma remains an issue for people in the ESA support group or UC LCWRA group undergoing re-assessment of their eligibility for benefits. Despite the majority of participants undergoing the work capability re-assessment process multiple times and repeatedly being found to have severe functional disability, this did not leave participants feeling validated in benefit receipt. This led individuals in this group to feel they must justify their being in the support group or LCWRA group. The re-assessment process by its nature suggests the DWP feel the need to continually check if the claimants have recovered sufficiently enough to work or complete work-related activity, which makes being in the support group or LCWRA group feel less secure or only valid for a defined period of time. Furthermore, the method of unstructured interviews allowed for broader narratives to be drawn, which exposed that this is not just stigma related to being a benefit claimant but also stigma relating to being disabled or having a long-term health condition. Using the Health Stigma and Discrimination Framework (Stangl et al., 2019), the researcher identified different types of stigma within the study data, including personal, social and perceived stigma from the government and potential employers; identified the participants' experiences or perceptions related to stigma and used this detail to produce policy recommendations to help address this, which can be viewed in section 5.6.

The ESA50 or UC50 questionnaire

Many participants described how waiting for the questionnaire was a difficult time, leading to combinations of panic, discomfort, demoralisation, stress and anxiety. This is congruous with Garthwaite (2014) who referenced '*fear of the brown envelope*' and participants panicking at the sight of the postman as they feared the repercussions from the contents of the letter, as they felt the contents could include detail of them being found fit for work. In terms of completing the form and adhering to a deadline for submission, there was a feeling of pressure for many, which when compounded by existing mental health difficulties led to increased panic, distress and even suicidal thoughts. Specifically, worry regarding the deadline for some participants led to fear of being removed from their benefits and general uncertainty around finance and housing that worsened existing health problems. For example, one participant highlighted how each time she had to complete the ESA50 questionnaire, she found it more and more difficult with each re-assessment process, with the latest questionnaire receipt leading to suicidal thoughts. This is consistent with a trauma response whereby the participant is experiencing a psychological stress reaction from a specific trigger (Substance Abuse and Mental Health Service Administration, 2014).

Research by Scullion and Curchin (2022) on military veterans with a history of trauma found the WCA process to be something to be feared, re-traumatising and to the detriment of mental health. It is known that military veterans are more likely to have post-traumatic stress disorder (PTSD) and common mental disorders (Stevelink, 2018) and re-traumatisation or exacerbation of symptoms for this population group may seem more likely from an assessment process that is known to cause stress. However, the current study goes beyond the findings from Scullion and Curchin (2022) as it revealed that individuals with a civilian background and undergoing the re-assessment of their work-capability can also be traumatised by the re-assessment process. Additionally, this can be worse with each re-assessment, producing a cumulative effect of stress and psychological reaction. This is significant, given that this is re-assessment of a welfare benefit designed to assist those with ill-health or disability. For the process to be re-traumatising and in many cases worsening individuals' overall health and/or well-being, shows that the re-assessment process is not supporting this population group with empathy, respect and dignity as would be expected by many when dealing with a vulnerable population. The 1834 English Poor Law distinguished between the 'deserving' and 'undeserving' poor, with the 'deserving' including those with sickness or disability, while the 'undeserving' poor were seen as work-shy and burdening to their communities. Although a more modern welfare system is now in-place, the previous notion that there are some in society who will always need support, seems to have been replaced with a ‘championing of tax payers’ or ‘championing of hardworking families’ and consequent tightening of benefit eligibility criteria (Golightley and Holloway, 2016). Additionally, as mentioned previously in the thesis, government views on dependency have historically aligned with the theory of the sick role proposed by Parsons (1951), within which he viewed sickness as a form of deviant behaviour within society. Parsons felt that too many people being unwell would have a detrimental impact on society, therefore arrival into the sick role needed controlling. Therefore, although a more empathetic approach to the re-assessment process may feel appropriate for many, there is an alternative view that although the welfare system is a safety net to protect potentially vulnerable populations, the re-assessment process is working from a governmental perspective as people are still being assessed with respect to their benefit eligibility and allocated to appropriate groups based on an assessment outcome (DWP, 2023b). Furthermore, although many of the participants have conditions that would not be expected to improve, for the people who could achieve improved symptom control and functionality, the re-assessment process is ensuring they are further away from achieving this and consequently individuals find themselves even further away from the labour market. This is a harmful and unintended consequence of this part of the overall process (Oliver et al., 2019).

The findings related to the ESA50 or UC50 questionnaire showed that support with the completion of the form, whether from family and friends, professional services or healthcare professionals, was often vital in ensuring the questionnaire is completed and submitted as required. Also, support was important in helping individuals with their health and functional needs at this stressful time. Again, this demonstrates how distressing the process of completing the questionnaire can be for individuals. Despite this study specifically focussing on individuals who are being re-assessed and have gone through the process at least once before, the difficulties with the questionnaire remain. This augments research from Pybus et al. (2021) who found experiences were overwhelmingly positive where claimants with mental health conditions had approached organisations for support to assist with the completion of their ESA50 or UC50 questionnaire, or with attending their work-capability assessment (WCA). However, the study from Pybus et al. (2021) focussed on individuals undergoing Personal Independence Payment (PIP) assessments, their first WCA, or navigating the appeals process having been found fit for work, plus one individual who had undergone multiple WCAs and consistently been found fit for work. None of the study group in Pybus et al. (2021) were undergoing re-assessments having been consistently placed in the ESA support group or UC LCWRA group.

A final point is related to the amount of detail some participants reported to include in their questionnaire. Many reported spending copious amounts of time completing the form to ensure they were giving a robust account of their health and functional difficulties. Some reflected on how they wrote several pages of additional information, which was largely driven by anxiety of being turned down at their re-assessment. Despite having all the appropriate medical evidence to support their re-assessment, filling in the questionnaire still led to anxiety, stress and anger. Individuals in the ESA support group or UC LCWRA group are reliant on this income for their financial survival and knowing this could potentially be withdrawn based on the re-assessment outcome causes stress at each stage of the process, including with the completion of the ESA50 or UC50 questionnaire.

Issues with the assessment provider's processes

Most of the participants' accounts referred to issues with the assessment provider processes, including difficulties communicating with the assessment provider. There were multiple examples of assessments being cancelled with no prior notice and a lack of communication from the provider in re-arranging the assessments, which then led to increased worry and frustration. Some reported being asked to attend assessment centres for their work-capability assessment in neighbouring towns or cities, despite there being assessment centres more local to them, which would involve less travel and time. When the participants attempted to change the assessment venue, this took an extensive amount of effort or even took a complaint being lodged to force through the change. Similarly, there was evidence of some participants being repeatedly asked to attend an assessment centre despite having a doctor's letter confirming they were unable to travel to the centre due to ill health. This indicates that the assessment providers were failing to offer reasonable adjustments as per the Equality Act 2010, during the re-assessment process. Furthermore, there was evidence of the assessment provider informing some participants that they could remain in the LCWRA group without need for an assessment, despite before this, asking participants to provide medical evidence to support why they could not attend an assessment centre. This led to confusion as to why there was need for the assessment in the first place, and why the assessment provider had repeatedly asked participants to attend and put them through the stress of this process when there was evidently no need.

This evidences that the stresses associated with the re-assessment process itself are being aggravated by these issues with processes and communication struggles. Previous research on conditionality of benefit recipients in receipt of JSA or UC in-work recipients (Wright and Dwyer, 2022; Wright et al., 2020; Wright and Patrick, 2019) found difficulties communicating with Job Centre Plus (JCP) and further financial or social difficulties this can lead to. Scullion and Curchin (2022) conducted a study with veterans' interactions with the social security system, which found the social security system is not trauma-informed, with veterans navigating the system not feeling physically or emotionally safe. There was a lack of trust in the social security system and the conditionality measures that are enforced led to a lack of collaborative working, which further disempowered the veterans navigating the social security system. Dwyer et al. (2018) found that feelings of disempowerment are common among people engaging with Universal Credit (UC) conditionality; there are also potential long-term negative impacts upon self-esteem (Brenner et al., 2018). The current study builds on this literature as it revealed that difficulty communicating with the work-capability assessment provider and difficulty navigating their processes is experienced by people already in the ESA support group or UC LCWRA group, who are navigating the re-assessment of their benefit. This group are under no expectation to engage in work or work-related activity and are the furthest away from the job market, unlike populations investigated in previous research who are engaging with JCP in an attempt to find work or already working and claiming UC in addition (Wright and Dwyer, 2022; Wright et al, 2020; Wright and Patrick, 2019). However, the stress associated with engagement with assessment providers each time they are re-assessed causes cumulative stress for individuals who are disabled or have long-term ill-health. Additionally, there is evidence of reasonable adjustments not being considered for individuals who are navigating the LCWRA re-assessment process with chronic sickness or disability. The additional stress caused by the communication difficulties or lack of reasonable adjustments is causing added difficulty during the re-assessment process, which is avoidable.

Conditionality

The primary condition for the receipt of welfare benefits is membership to a defined category of support, with the category people are assigned to subject to tightened or loosened behavioural requirements (Clasen and Clegg, 2007). Although benefit claimants within the LCWRA group are not subject to conditionality measures in terms of engagement with work or work-related activity, they will be removed from their benefit if they do not engage in the work-capability re-assessment process. The prospect or threat of being found fit for work or having limited capability for work (LCW), both of which would lead to conditioned interactions with Job Centre Plus, caused notable distress for people navigating this LCWRA re-assessment process. Many reported anxiety if they did not remain in the LCWRA group for a number of reasons, including knowing they were too unwell to engage in conditionality measures and fearing what would happen to them if this was forced upon them. Furthermore, the study overwhelmingly showed how participants going through the re-assessment process perceive this process to be difficult, stress-inducing and detrimental to their health and well-being. Therefore, the LCWRA re-assessment process represents conditionality in itself as it is a process people have to engage in to maintain their LCWRA group status. Those who support welfare conditionality have argued that unconditional entitlement to benefits promotes inactivity and dependency on welfare benefits (Watts et al., 2014); whereas those who oppose conditionality regard it as unethical, ineffective and causing worsening of social exclusion of disadvantaged populations (Fletcher and Wright, 2018). Dwyer et al. (2020) found that processes and secondary pressures of job searching/preparation activities, completing work focused interviews or engaging in work-related activities, which are the foundation of highly conditional “work first” benefit regimes, such as in the UK, appear to have repeated and significant negative impacts on the well-being of people with histories of mental illness and are counterproductive. The current study builds on previous research (Dwyer et al., 2020; Wright and Dwyer, 2022; Wright et al., 2020; Wright and Patrick, 2019) with people in receipt of JSA, UC in-work recipients, the ESA work-related activity group (WRAG) or UC Limited Capability for Work (LCW) group, with the current study finding deterioration of health from engagement with the LCWRA re-assessment process specifically. However, people in the support group or LCWRA group are already living with long-term ill-health or disability. In many cases this will be accompanied by, for example, reduced quality of life, chronic pain, fatigue, sensory impairment, poor mental health, all of which are existing barriers to employment. In causing further distress or worsening of health beyond the existing symptoms, the re-assessment process for many is counterproductive and moving people further away from the employment market. This aligns with Clasen and Clegg (2007) and their notion of ‘conditions of category’. ‘Membership’ into a specific group, including the LCWRA group, is socially constructed, politically managed and consequently subject to change, either more restrictively or expansively. Even where categorical groups have gatekeepers, for example a functional assessor in a WCA, the guidance provided to the assessors is subject to change in an attempt to lever the categories and impact flow into a specific benefit group. With respect to the re-assessment of work-capability, it is something individuals are exposed to repeatedly, causing a cumulative negative impact on their health and well-being.

The inability to fully engage with conditionality, for example, an individual completing insufficient job search activity or missing a work-focused interview, might be misinterpreted by some as individuals being work-shy, rather than acknowledging that their inability to fully engage is due to wider societal and social issues (Wright et al., 2020). Again, although being in the LCWRA group excludes claimants from engagement with Job Centre Plus, some of the study participants felt as though others may see them as “work-shy” or “scrounging” despite them being unable to work due to long-term health problems. The study provides original findings of the LCWRA re-assessment process being a form of conditionality that has to be adhered to despite the severe functional disability of the claimants, and the deterioration in health it causes for many cumulatively with each re-assessment process they need to engage with.

The luck of the draw with the assessor

Participants' accounts provided conflicting perceptions of the assessors but underlined how the assessor who conducts the assessment can strongly influence claimants' perceptions of the work-capability assessment. There were several positive accounts of assessors, with assessors being described as helpful, understanding or having a calming or reassuring nature during the assessment. However, most participants provided negative accounts of assessors with them described as hostile, off-putting, abrupt and disinterested. Some described how the assessor seemed to be 'completing a tick box exercise' and was disengaged from the assessment. Other accounts portrayed assessors as being unsupportive and as having dismissive attitudes towards the claimant during the assessment, such as the assessor 'rolling their eyes' or making the participant 'not feeling believed' during the assessment. The narratives related to the assessors offered varying perspectives but represented how important the relationship between the assessor and claimant is within the re-assessment process. This part of the process is arbitrary and who conducts the assessment can have a major impact on the overall work-capability assessment experience. Additionally, since 2014/15, 50% of claimants who did not have the desired assessment outcome from their WCA and appealed at a tribunal had their decision overturned (UK Parliament, 2023), further evidencing this part of the process is subjective in nature.

These findings suggest that there are inconsistencies in training of the assessors, as their working practices are evidently different when conducting assessments, with some seemingly negative towards claimants during the WCA. Pybus et al. (2021) previously found benefit claimants with mental health conditions undergoing PIP, ESA or UC assessments had a more positive experience than their preconceptions had led them to believe they would, whilst others described feeling judged and disbelieved. The current study enhances knowledge of engagement with benefit assessors as it revealed that claimants specific to the ESA support group or UC LCWRA group and undergoing re-assessment of their benefit have mostly negative experiences with their assessors which can alter individuals' overall experience of the process. This can also affect their well-being during the process. If claimants have negative experiences with assessors on multiple occasions when being re-assessed, there will be a cumulative effect on claimants' health and well-being.

The negative perceptions of claimants appear to come from negative attitudes of some assessors, which is potentially as a result of stigma. Baumberg Geiger (2016) discussed 'claims stigma', which relates to a lack of privacy when claiming benefits and the demeaning experience of long waits, plus feeling a lack of respect from staff. The current study builds on this previous research in revealing an evident negativity and lack of respect from some assessors during the work-capability re-assessment process. This is important as some participants had experienced up to four re-assessments of their work-capability, contributing to the already documented cumulative toll from the process on their health and well-being. Despite them having been through the process, on multiple occasions for the majority of the participants, they continue to encounter stigma as benefit claimants.

This theme also aligns with the concept of street level bureaucracy, which was first proposed by Lipsky (1969). Lipsky defined a street level bureaucrat as a public service employee such as a policeman, teacher or court officials, who is called upon to interact constantly with citizens in their job role. Although working within a bureaucratic structure, they have independence within their job role and the impact on citizens with whom they deal with is fairly extensive. Based on Lipsky's definition, a functional assessor in relation to welfare benefits could be defined as a street level bureaucrat. Moreover, this discretion in how they approach their work means governmental policy being delivered to citizens hinges on their behaviours and actions (Chang, 2022).

Waiting for the assessment outcome

Waiting for their assessment outcome was another burdensome episode for participants. Most participants reported feelings of stress, anxiety, agony, uncertainty, exhaustion and feeling their mind was going into overdrive thinking about the assessment outcome. It was also stated in multiple accounts that despite knowing that their health has not improved and they should remain in the support group or LCWRA group, waiting for the assessment outcome remained an anxiety provoking time, as they might still be classified as ineligible for the support group or LCWRA group. For others, although anxiety remained, there was a feeling of passive resignation while they waited for the outcome as everything they had to engage in had been completed, with the outcome now in the hands of a DWP decision maker. Feelings of anger were also reported with participants constantly questioning themselves and whether they had said the right things at the assessment to remain in the LCWRA group. There was evidence of this rumination relating to the re-assessment process causing exhaustion and subsequent anger towards the DWP for putting them through this process despite them being unwell for many years due to long-term health conditions.

Finally, one further discussion point is the length of time participants spent worrying about the re-assessment process. The stresses and anxieties described in relation to the re-assessment process are not just felt while the questionnaire is being completed, during the re-assessment or while waiting for an outcome. They are present for months or even years before the re-assessment is pending. The thoughts and fear that comes with the re-assessment process can be a prolonged issue for claimants. This uncertainty, or anticipatory anxiety (Grupe and Nitschke, 2013) about the outcome disrupts individuals' ability to avoid it or mitigate its negative impacts. Participants in the study by Pybus et al. (2021) not only spoke of the precariousness of relying on social security as a source of income but how this feeling began at the eligibility assessment stage, continuing even after financial support was in place. The current study goes beyond previous research as it demonstrated that anxiety does not just exist in the form of anticipatory anxiety for benefit claimants when initially claiming benefits and waiting for a work-capability assessment, there is anxiety throughout the whole re-assessment process for long-standing benefit claimants in the ESA support group or UC LCWRA group despite their familiarity with benefit processes. The cycle of anxiety continues with each re-assessment leading to a cumulative effect of anxiety for long-standing benefit claimants who have to undertake re-assessment of their benefits periodically and wait for the re-assessment outcome.

A perpetual cycle that is detrimental to health

In previous themes, stigma, difficulties with the ESA50 or UC50 questionnaire, difficulties with assessors, assessment provider processes and the anxiety-inducing nature of the re-assessment process were discussed. Participants then discussed how the difficulties each assessment brings repeats from one re-assessment to the next, leading to feelings of perpetuity. The narratives showed that living with long-standing health problems and having to engage in work capability re-assessments can be viewed as a perpetual cycle, an everlasting need to evidence severe functional disability. Furthermore, the cycle is detrimental to physical and/or mental health symptoms and leads to social stresses. Many participants voiced their frustration at being re-assessed every 2-3 years despite long-term health conditions which some of the participants had lived with for decades and were unlikely to improve, mostly as there was little sense of relief or peace for them in the interim period of time in-between assessments because of anticipatory anxiety waiting for the next re-assessment. Many reported feeling reassurance when receiving confirmation of remaining in the LCWRA group, yet this was short-lived and the stress and worry of being re-assessed again would soon return. This evidence suggests that re-assessment of individuals who have been through multiple assessments previously and always been allocated to the ESA support group or UC LCWRA group are being conducted in time frames that are too short. Importantly, the study also revealed that many participants were continuing to be re-assessed inappropriately as they had long-term health conditions or impairments that should have made them exempt from further re-assessments of their work capability according to DWP guidance (Centre for Health and Disability Assessments, 2022, p. 259). However, this guidance in relation to benefit recipients not requiring further re-assessments is ambiguous and assessors are consequently not consistently applying this criteria. Policy recommendations to help address this are listed in section 5.6.

There was evidence from the findings of uncertainty and constant worry about income being taken away. Additionally, despite living with health conditions, some individuals remain in a position to look for work when their health condition is in remission or a period of stability. However, having a short-term or longer-term health condition that affects one’s ability to function the majority of the time, means this group are not able to seek income via a different source. If an individual with chronic sickness or disability has their ESA support group or UC LCWRA group allocation withdrawn, they are not fit to engage in work or work-related activity and are left with no alternative avenues to source an income. This is a reason why the stress often remains in-between re-assessment processes and it is a perpetual cycle, with some participants from this study anxious at the thought of engaging with re-assessments until the time when they would be able to access the state pension, despite in some cases living with chronic, degenerative health problems.

Previous research has highlighted how third sector organisations, including charities, voluntary and community organisations, play a pivotal role in steering claimants through benefit claims-making processes (Edmiston et al., 2022). Yet, these same organisations trying to fulfil this supporting role find their capacity reduced (Adler, 2006), which can subsequently lead to them unintentionally worsening inequality in the benefit system. Black, Asian and minority ethnic (BAME) communities, the most financially insecure, people with limiting health conditions or disabilities and migrant populations are identified as those who often fail to gain organisational support due to issues with capacity or logistics (Edmiston et al., 2022).

The study findings provide a new contribution to the literature in showing a perceived worsening of physical and/or mental health, including suicidal ideation in some cases for our population group. The WCA has been commonly criticised for the inadequate consideration of mental health (Hansford et al., 2016; Maclean et al., 2017). For veterans specifically, the WCA was found to be inadequate in its ability to appropriately assess mental health issues that were attributed to service in the Armed Forces and the potential for re-traumatisation through the assessment process (Scullion and Curchin, 2022). The current study builds on the existing literature by revealing that being re-assessed for work-capability largely leads to cumulative worsening of mental and/or physical health. The resultant worsening of symptoms for many ensures that any progress made in terms of health improvement and better functionality is then reversed, evidencing that the re-assessment process for many is counterproductive in terms of their health conditions or disability, also in terms of their health improving to a point where they could eventually access work or work-related activity. The participants provided narratives that told a tale of the individual elements of the re-assessment process and how they specifically cause harm. The process in place to provide financial income for people too unwell to engage in work or work-related activity was found to cause significant harm to claimants.

Social and functional impacts from re-assessments

For many participants, their mental health worsened to the point that they became non-functional and there was a reliance on family support. One participant reported being in bed for six months due to their mental health decline, while others experienced overwhelming anxiety and resultant exhaustion leading to some not shopping, washing or changing their clothes, or maintaining their nutrition. There were multiple reports of sleep deprivation caused by stress, anxiety and low mood, but also perceptions of pain and fatigue symptoms worsening as a result of engaging in the re-assessment process. Some participants discussed potentially being able to improve their health and/or functionality and get to a situation where they could complete some part-time work if there was more time in-between re-assessments. Most of the participants discussed the re-assessment process causing deterioration to their health for varying periods of time once the process was complete. Awards of LCWRA may have been given for 2-3 years at a time but some participants reported that it can take up to 12 months to recover from the rigours of the process.

Some participants in the study discussed how they continued to look for some part-time work despite their severe problem with health and/or disability as it would give them back some pride or self-esteem. Disabled people in the UK are likely to have lower educational attainment, are less likely to be employed and are more likely to live in poverty than non-disabled adults (Hackett et al., 2020). Olsen (2022) reported that disabled people seeking employment conveyed that acquiring reasonable adjustments, which they need to be effectively employed, involves them facing barriers to sourcing the adjustments, which impacted upon their efforts to be successfully employed. This study builds on this previous research, as for the study population group, engaging with re-assessments is preventing some people from being in a position to try and access employment due to how the process causes deterioration in health and functionality. Alternatively, some participants who want to work feel that potential employers see them as unreliable due to their issue with health and/or disability, which resonates with previous studies that show there is discrimination from employers towards potential employees who are disabled and require adjustments in the workplace (Hackett et al., 2020; Olsen, 2022).

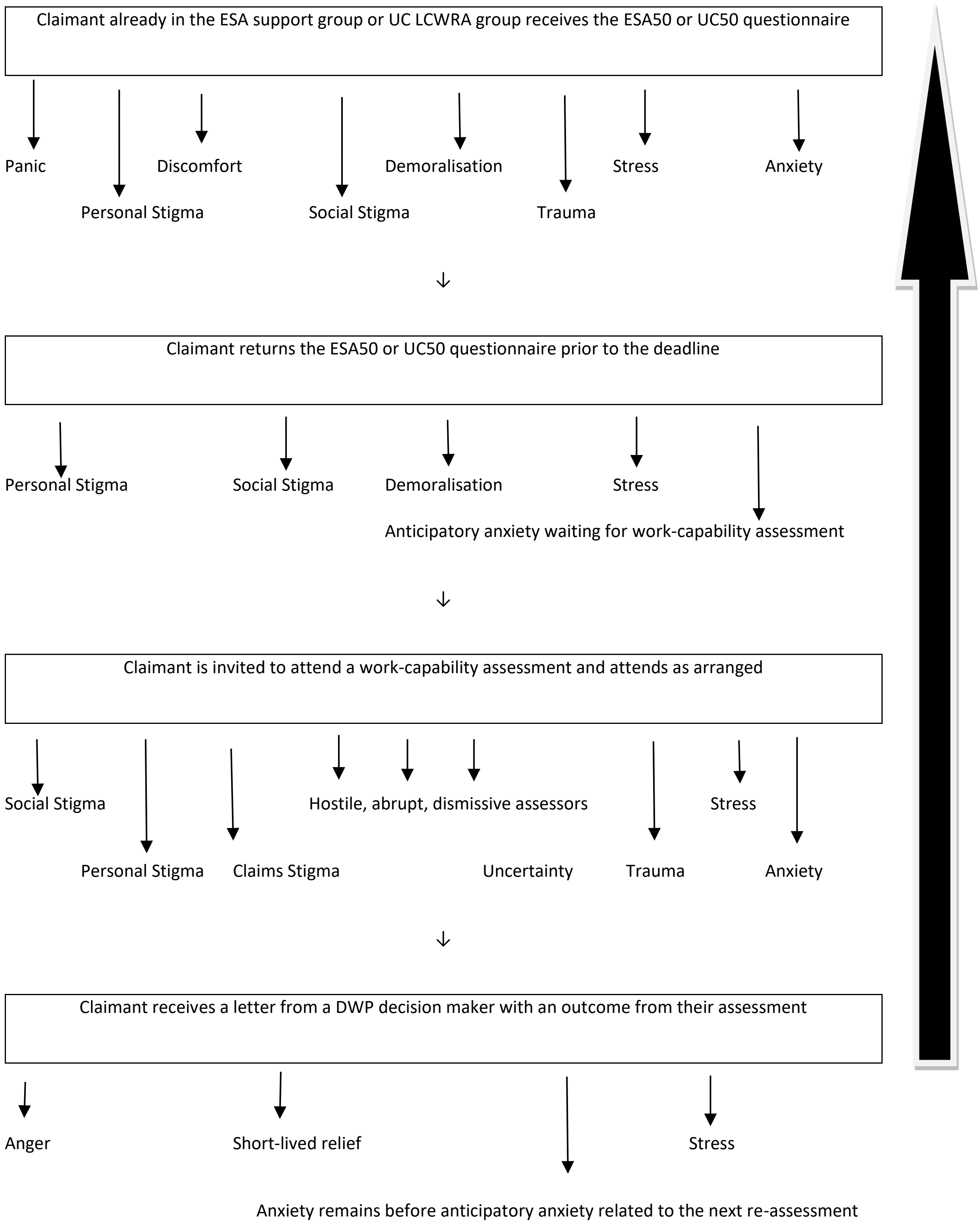
Findings from the current study suggests that the re-assessment process carries worry about financial and housing security, food poverty and can lead to a need for enhanced family support. This evidence of financial difficulties and substantial fears related to finances builds on the previous research regarding the WCA (Hansford et al., 2019) and also previous research related to the UK welfare system that highlighted economic difficulties for benefit recipients, including struggles to afford accommodation, utilities and adequate nutrition (Banks and Lawrence, 2005; Cheetham et al., 2019; de Wolfe, 2012; Garthwaite, 2014; Garthwaite, 2016; Patrick, 2014; Saffer et al., 2018; Shefer et al., 2016; Wright and Patrick, 2019).

There were reports of a need for enhanced family support secondary to a functional decline during the re-assessment process, with multiple stories of financial concerns. The financial concerns are not minor concerns but more significant worries about affording food and utilities, affording the rent and maintaining a roof over their head, with subsequent concerns over potential homelessness. There were reports of family heirlooms begin sold, borrowing money from family or unarranged overdrafts being used month after month due to financial difficulties, with the threat of benefit income being taken away or reduced compounding the fears and concerns people live with. From the participants' perceptions, it would appear that being within the perpetual cycle of assessments feeds directly into health not improving or worsening, which links to concerns related to housing and finance that in return impacts back upon health.

This study has contributed to the literature on the WCA and conditionality in the welfare system by revealing that for people in the ESA support group or UC LCWRA group, engaging with the work-capability re-assessment process is for the majority a distressing process. The re-assessment process is perceived as a never-ending cycle, which negatively affects claimants' health, wellbeing and financial circumstances. The re-assessment process was also found to be counterproductive, as it reduced the ability of some participants to engage with returning to work or work-related activity.

Figure 2 provides a flow chart of the reality of the re-assessment process based on the study’s findings. The block arrow connecting the bottom of the chart to the top of the chart represents the perpetuity of the re-assessment process.

Figure 2. A flow chart of the reality of the re-assessment process based on the study's findings



5.4 Strengths and weaknesses of the study

The study had several strengths. As documented in chapter 3, the outlined philosophical and theoretical viewpoints for the research are compatible and the methodology and method are aligned in their approach; all of which allows a broader focus from a research perspective as opposed to a narrow focus on a specific question (Neuman, 2006). There was a transparent plan in relation to sampling of participants, data collection and data analysis, all of which are attuned to a qualitative research study. The researcher was clear in their position on reflexivity and positionality and how this related to the study. The fact that the data is based on human experience is powerful and can be perceived as more compelling than quantitative data as subtleties about the research subjects are often missed with quantitative enquiries (Anderson, 2010). This has allowed influential narratives to be analysed and contribute to the subsequent results, discussion and policy implications.

Yet, the study is not without weaknesses or limitations. Although the use of social media in recruitment was justified within chapter 3, there is a potential weakness to its use in recruiting research participants. Individuals who are reviewing social media in relation to a specific topic are more likely to share posts that carry a negative message and are less engaged with positive content (Rathje et al., 2021). Consequentially, the recruitment may have unintentionally targeted participants who hold a particular viewpoint or are united in a common cause (Vladimirou et al., 2021). Future research could utilise additional recruitment methods to overcome this potential limitation.

As stated in chapter 3, the original aim was to interview each participant on two occasions, before and after the WCA had been conducted allowing for pertinent details related to each individual’s well-being in the build up to the WCA and after the WCA when the re-assessment process was complete pending an outcome from the DWP. It was felt this would enhance understanding of participants' well-being at two points in time during the re-assessment process. The impact of the COVID-19 pandemic led to delays in re-assessments being conducted, which had a clear effect on potential recruitment to the study. However, as the participants have experienced multiple WCAs and re-assessment processes, there was an abundance of experiences for them to draw upon during the interview process and an in-depth experiential understanding of the re-assessment process has been achieved. Yet, the use of a two-stage data collection could still potentially increase understanding and is a recommendation for future research related to experiences of benefit assessments. Alternatively, a diary method could be utilised for a longer-term view of participants' experiences. Furthermore, details were gathered from the participants including who they live with, gender, age, health condition diagnoses and number of re-assessments they have experienced. Future research around experiences of benefit assessments could gather further demographic details including, for example, ethnicity, marital status and educational status. All these further details could provide more data in relation to the research participants and provide further avenues for analysis or discussion.

The potential of participatory research in improving health and well-being, particularly within marginalised groups, is increasingly being recognised (Northway, 2010). This involves engaging community stakeholders in the research process, from the problem identification, identifying a research question, and dissemination of results (Duea et al., 2022). During the recruitment and data collection processes, some participants did express that they wanted to engage with the research as they wanted to make a difference to the work-capability re-assessment process and help people going through the process in the future. Taking this into account, future research with this participant group could potentially utilise a participatory approach to make the research a more collaborative and empowering piece of work for the participants, whilst ensuring the research is informed by real-world contexts (Woolf et al., 2016).

The unstructured interviews within this research study comprised some initial ‘setting the scene’ questions before covering extended accounts of their perceptions of their well-being during the work-capability re-assessment process, including the impact on their health conditions and individual circumstances. The interviewer then asked follow-up questions individually tailored to the details of the participants’ narratives. There are several ways to conduct narrative research, with “an extended answer by a research participant to a single question, topically centred and temporally organised” (Riessman, 2008, p. 5) at one end of the spectrum, and “an entire life story, woven from threads of interviews, observations, and documents” (Riessman, 2008, p. 5) at the other. How the interviews were conducted is not a weakness of the study, yet future research could potentially adopt an alternative approach to the data collection, which may gather an alternative experiential perspective from the participants.

The collected data was analysed using narrative analysis. The data analysis conducted was consistent with a thematic analysis of narrative (as outlined in chapter 3), focussing on participants’ reporting of events and experiences. In conducting a thematic analysis of narrative, accounts were not fractured into thematic categories but interpreted as a whole (Williams, 1984). The narrative analysis approach allowed documenting and understanding of the distinctiveness of each participant’s story, without looking to decontextualise the transcripts through mass coding and generation of common themes. However, a thematic analysis approach could be used in a future research study and generate differential findings from the analysis.

5.5 Contribution to knowledge

The literature review found that benefit recipients contend with health, social and economic difficulties, with stigma prevalent. It shone through from the literature review and study findings how much of a struggle being in-receipt of benefits is. There are sacrifices made day-to-day to ensure a basic standard of living is met, yet for many, even this is not being achieved with the finances offered from benefits. This subsequently leads to further deterioration of health. Stigma was rife throughout the literature review and study findings, with many participants extremely self-aware of how receiving benefits is perceived by others. Moreover, the literature review theme of benefit recipients feeling negativity, mistrust and being distressed by the benefits system also correlates with the study findings of there being issues with the assessment provider processes and the 'luck of the draw' with the assessor, whereby experiences of this part of the re-assessment process can be variable depending on who conducts the WCA as part of the re-assessment process. However, whereas the literature review findings were from multiple high-income countries, the study findings are specific to the UK setting. They also offer a unique contribution through focussing on a specific group of benefit recipients who were able to offer narratives based on in-depth experience of the work-capability re-assessment process.

The study themes related to stigma, the ESA50 and UC50 questionnaire, issues with the assessment provider's processes, the luck of the draw with the assessor and social and functional impacts from re-assessments have all added to existing literature base in relation to these concepts. Yet, they contribute a new perspective on the experiences of people in the ESA support group or UC LCWRA group navigating the re-assessment process. There are two key contributions to knowledge: the cumulative impact of assessments over time and the counterproductive nature of re-assessments. The findings showed that the re-assessments are perceived as a never-ending cycle which is harmful to health and well-being. Additionally, each re-assessment causes a cumulative effect, bringing more and more distress with each re-assessment. Furthermore, the findings showed that the re-assessment process represents a conditionality measure, in that the re-assessment process has to be completed to maintain positionality in the ESA support group or UC LCWRA group. However, this conditionality is counterproductive as claimants can be pushed even further from engagement with paid work as their health and well-being are worsened, which undermines their chances of regaining employment.

5.6 Policy Implications: Key points for policy makers

In March 2023, the then UK Conservative government announced plans to abolish the WCA in favour of an alternative method in assessing work capability. Under the new system, individuals in receipt of Personal Independence Payment (PIP), which is a benefit awarded to people with sickness or disability to help them with everyday living costs, will receive an additional 'health element', included in their UC. However, where currently being in the ESA 'support group' or UC LCWRA group means there is no expectation to engage in work or work-related activity, under the proposed system work coaches with no medical qualifications who work at Job Centre Plus will now judge whether an individual is able to engage. The changes will not come into effect until 2026 at the earliest for new claims and 2029 for existing claimants (Disability Rights UK, 2023). Consequently, individuals will continue to be assessed via the WCA for a number of years and the recommendations therefore remain current. Yet, moving forwards it appears that there is going to be a further tightening with respect to conditionality as per Clasen and Clegg's (2007) conditions of category. This will potentially lead to further distress for claimants navigating a new-look re-assessment process, knowing that work or work-related activity may be an expectation despite their long-term health condition and functional difficulties. This makes the current research even more pertinent moving forwards. However, at the time of writing there is a new Labour government following an election and the position of abolishing the WCA remains unclear.

The following policy recommendations are important in avoiding or reducing harm to claimants navigating the work-capability re-assessment process, avoiding the perpetuity of the process, improving the process, and in making the process better and fairer in its application. The policy recommendations were driven by the research findings and theoretical framework rather than the researcher's previous position working within the benefits sector.

1. *Ensure the severe conditions criteria policy is appropriately written and utilised.*

The majority of claimants in the ESA support group or UC LCWRA group will be subject to re-assessment of their work capability unless formally diagnosed with a severe, lifelong health condition, which will not improve in the future as there is no realistic prospect of recovery (Disability Rights, 2017). The DWP severe conditions criteria in the assessment providers' handbook cites examples of conditions that might meet the criteria as "Motor Neurone Disease (MND), severe and progressive forms of Multiple Sclerosis (MS), Parkinson's, all dementias, all chromosomal conditions, Huntington's, severe irreversible cardiorespiratory failure, severe acquired brain injury ... this list is not exhaustive" (Centre for Health and Disability Assessments, 2022, p. 259).

By leaving the list as not exhaustive, the criteria are open to interpretation and its application for claimants may be subjective from one assessor to another. As a result, claimants may satisfy the criterion of the severe conditions criteria (i.e. 1. their level of function would always meet LCWRA criteria, 2. their condition is lifelong once diagnosed, 3. there is no realistic prospect of recovery of function, and 4. the condition is not an ambiguous condition, and is formally diagnosed) but if their condition is not listed in the examples of conditions that might meet the criteria, assessors may be unsure as to whether the criteria can be applied, leading to unnecessary re-assessments for some claimants. For example, the list of conditions does not include sensory impairment, neurodiversity, or severe mental health conditions, all of which there were examples of in the interview data. Additionally, the wording of the criteria does not consider situations whereby a claimant may have multiple health conditions that impact upon one other, leading to severe functional disability for the claimant, again which there was evidence of within the interview data. The conditions may all be formally diagnosed, with no realistic prospect of recovery based on the length of time they have had the conditions and treatment options that have been exhausted, and they will always be assessed as being in the LCWRA group. However, again, based on the wording of the severe conditions criteria, assessors may not have the confidence to apply and justify the severe conditions criteria as an assessment outcome, and individuals may find themselves subject to re-assessments inappropriately. Therefore, there should be a robust review conducted by the DWP regarding the criteria and its wording to ensure it is appropriately and more objectively utilised and to ensure it is utilised more frequently for claimants who should not be subject to re-assessments.

2. *Longer periods of time are needed between re-assessments and a streamlined process for people who have already been through re-assessments and have limited capability for work and work-related activity.*

The DWP and assessment provider should make a co-ordinated effort to improve the re-assessment process for people in the LCWRA group who have been through the re-assessment process multiple times and have consistently been found to have limited capability for work and work-related activity based on their impairments or long-term health conditions. This study revealed that re-assessment processes are perceived by claimants as detrimental to health, so attempts should be made to improve this experience for claimants who already live with ill-health, disability and severe functional restriction. A streamlined or light weight re-assessment process could be trialled, taking away parts of the re-assessment process that lead to enhanced stress and anxiety. For example, removal of the questionnaire and work capability assessment itself, replaced with submission of medical evidence that confirms there has been no change to the individual's health and functionality, with a subsequent outcome letter confirming continuation in the LCWRA group. The individuals would still need to go through a bespoke re-assessment process, but many of the identified triggers of stress and anxiety during the process would be removed.

3. *The assessment provider should provide further training for staff regarding claimants' perceptions of the re-assessment process.*

The assessment provider gives its assessors a handbook, which is updated periodically to include updated policy. The current handbook includes the following sections related to ESA and UC, and their respective structures and processes:

- Background to Employment and Support Allowance (ESA)
- Changes to Regulations
- The Work Capability Assessment (WCA) Structure
- The financial Structure of ESA
- Overview of the ESA Claim Process
- Background to Universal Credit (UC)
- UC and the WCA
- The role of the Health Assessment Advisory Service HCP

(Centre for Health and Disability Assessments, 2022).

The handbook provides the assessors with the appropriate background information related to the specific benefits and the assessors' role. However, by making the assessors aware of claimants' wider perceptions of the process, all the assessors conducting the assessments may potentially be able to tailor their practice to provide a more sensitive and positive experience for the claimants at their assessment. Additionally, it is not only assessors who have direct communication with claimants. Management and administrative staff throughout the assessment provider staff group will have daily communication with claimants. There is a need for a review of the training offered to all staff of the assessment provider. By ensuring all staff are aware of claimants' experiences and perceptions of well-being throughout the re-assessment process, training can be provided and a policy implemented related to compassionate communication throughout the whole company to ensure every individual going through the re-assessment process, including attending for a work-capability assessment, is afforded a consistent level of care and respect. Additionally, periodic observations from clinical leaders within the assessment provider is also needed to review communication of assessors during interactions with claimants.

4. *There should be enhanced support to employers with employment of individuals with health conditions or disability.*

'Access to Work' is a government scheme that funds reasonable adjustments beyond those deemed reasonable for employers to address that are guaranteed to disabled people in the Equality Act (2010). This scheme has evidenced positive outcomes including improved wellbeing, however, it is a small programme that has not had significant marketing to a wider audience (Institute for Employment Studies, 2020).

'Disability Confident' is a government scheme developed to encourage employers to recruit and retain people with health conditions or disability (DWP, 2021f). However, the scheme has faced criticism for lacking accountability, transparency or credible performance measures to ensure employers recruit disabled people (DWP, 2022g). Additionally, the scheme has been described as focussed on process rather than outcomes (Disability News Service, 2023).

The government should conduct a rigorous review of both respective schemes, prior to their re-launch with the aim of reaching a wider audience of employers and potential disabled employees who would benefit from the schemes. This would allow claimants within the ESA support group or UC LCWRA group who feel they can work on a part-time basis more of an opportunity to do so without feeling employers will see them as unreliable or ‘flaky’ as per the study participants’ own concerns. It would also help to reduce potential barriers of discriminatory practices from employers, as the re-launch of the schemes can address any unfounded concerns employers may hold by educating them on value people with health conditions or disability can bring to their organisation.

5. *The government and media should change how they communicate about people in receipt of benefits.*

The quotations used in the introduction from current Conservative and Labour Party Members of Parliament, and a prominent journalist and media personality evidence that there is ongoing use of inappropriate or inflammatory language used when discussing benefit recipients. This is fuelling stigma within the benefits system, which was evident within the study findings in multiple accounts. There is a significant need for governmental review on how benefit claimants are discussed in private and public settings, and a need for government regulation on how benefit claimants are discussed in all means of media. This will support towards reducing stigmatisation of benefit recipients. It is acknowledged that the government and media not using inflammatory language is more of a preventative measure but it is a pragmatic recommendation that would contribute in reducing stigmatisation of benefit recipients.

5.7 Conclusion

The narratives presented in this study display lives of individuals with health problems and/or disability, alongside in many cases, social problems including the need for enhanced family support, financial concerns, housing concerns, food and energy poverty, stigma and discrimination. The study evidences how in many cases the health and/or social problems are exacerbated by the re-assessment process itself. Due to their long-term health conditions and subsequent reduced functionality, many people in the ESA support group or UC LCWRA group will likely remain in this group until they reach a state pension age and be subject to the re-assessment process on multiple occasions, which this study shows overwhelmingly is to the detriment of the health of people going through the re-assessment process. Some people in the ESA support group or UC LCWRA group feel a level of stigma as benefit claimants, be it personal, social, disability or claims stigma. There is a population within the ESA support group or UC LCWRA group who feel they could improve their health and/or functionality to an extent where they could work if not subject to such regular re-assessments, as the re-assessment process ultimately harms their health. Additionally, some feel they could engage in some form of work but feel employer discrimination leading to a lack of opportunity prevents this from happening.

This thesis outlines the need for governmental review of how the re-assessment process is conducted for people who have been through this same process multiple times and lived through the stresses that this brings. Although being in the ESA support group or UC LCWRA group in theory prevents the imposition of conditionality, having to negotiate the re-assessment process numerous times could be viewed as conditionality in itself as the benefit recipients within this group are dependent on the financial income offered by the benefit and have to adhere to the specific conditions of the re-assessment process or face losing their enhanced financial benefit income. Finally, there is a need for governmental review on how benefit claimants are discussed by politicians and in the media, as well as the need for government legislation to be introduced regarding how benefit claimants are discussed in the wider media.

The policy recommendations above remain pertinent despite the planned governmental changes to the welfare system in the coming years. Additionally, with a new government elected in July 2024, it is not known how the welfare system will be approached from this point onwards. Whatever the process in place, the need to make this a more user-friendly, compassionate and less stress-inducing journey remains important.

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Appendices

Appendix 1 Flyer

Lancaster University Research Project

Universal Credit

Are you being re-assessed for your work capability and have previously been assessed as severely functionally disabled or as having LCWRA (limited capability for work and work-related activity)?

WE NEED YOUR HELP!

Would you like to take part in this research?

- Are you in receipt of the work capability part of Universal Credit (UC) because you have previously been assessed as not fit for work or work-related activity?
- Are you in the process of being re-assessed in relation to this?
- Would you like to take part in a study that aims to improve understanding of your well-being during this process?

If so, we would like to hear from you!

What would be involved?

- Taking part in two interviews to discuss how you perceive your well-being during the re-assessment process.
- One interview before your work capability assessment (WCA), and one interview within the week after the WCA.

When and where will the study take place?

- The interviews would take place at a mutually agreed venue, or via telephone or video communication.

If you would like to express an interest in participation please complete an expression of interest form and e-mail to the below address, or ring the below number.

If you would like more details about this study so you can decide if you wish to participate please contact the researcher by email or phone:

David Fassioms d.fassioms@lancaster.ac.uk 07858281159

Appendix 2 Participant Information Sheet

Participant Information Sheet

Investigating individual perceptions of well-being during the work-capability re-assessment process for people deemed severely functionally disabled at their previous work-capability assessment

My name is David Fassioms and I am a student on the Public Health PhD programme at Lancaster University, Lancaster, United Kingdom. I am writing to invite you to take part in the following study:

What is the study about?

The purpose of this study is to explore individuals' perceptions of well-being during the Universal Credit (UC) work-capability re-assessment process. In this study, the term well-being includes:

- How you feel physically (including physical symptoms of pain and/or fatigue).
- How you feel psychologically (including evenness of temper, ability to complete activities day to day, effectiveness in completing activities day to day, maintaining relationships with other people, self-acceptance, mood).
- How you feel socially (including feeling secure in your home, financial security and control).

The study aims to understand individual perceptions of these physical, psychological and social elements during the work-capability re-assessment process. The research outcome can then be used to show what support can be offered for people in this situation.

Why have I been approached?

You have been approached because the study requires information from people who have been through the work-capability assessment (WCA) process previously; have been deemed to have severe functional disability, and are now going through the re-assessment process.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. There is no obligation to be involved in the study, and it will not impact upon your Universal Credit (UC) benefit in anyway whether you choose to take part, or not.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to be involved in an interview process. This will involve being interviewed on two separate occasions, once before attending the WCA, and once after the WCA. The interview will be conducted at a mutually agreed venue. With your permission I will audio record the interviews.

Will my data be Identifiable?

All interview data will be anonymised with use of pseudonyms, and any personal data will be kept confidential. The data collected during this study will be stored securely and only I will have access to this data.

- Audio recordings will be transferred to encrypted storage, and destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of data or relevant documents will be kept in a secure, locked filing cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected; only the researcher knows the password for the computer.
- At the end of the study, electronic copies of data will be kept securely on OneDrive for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: If what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a dissertation/thesis, and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no substantial risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Incentives/Expenses?

There will be an incentive of a £20 high street shopping voucher made to participants, and any travel expenses can be reimbursed as appropriate.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact myself, Mr. David Fassioms - d.fassioms@lancaster.ac.uk or my supervisors:
Dr. Paula Holland – p.j.holland@lancaster.ac.uk

Dr. Faraz Ahmed – f.ahmed5@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban (Research Director) Tel: (01524) 593015;
Email: f.lobban@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster
LA1 4YW

If you wish to speak to someone outside of the Public Health PhD Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

1. Samaritans

   Email: jo@samaritans.org

   Tel: 116 123

Appendix 3 Expression of Interest Form

I have read the flyer/participant information sheet regarding the study and would like to confirm my interest in participation.

Name of person expressing interest in participation:

Contact telephone Number:

E-mail address:

Appendix 4 Consent Form

Consent Form

Study Title: Investigating individual perceptions of well-being during the work-capability re-assessment process for people deemed severely functionally disabled at their previous work-capability assessment

We are asking if you would like to take part in a research project to explore individual perceptions of well-being during the work-capability re-assessment process. This will involve being interviewed on two separate occasions, once before attending your work capability assessment (WCA); and once after your WCA.

Before you consent to participating in the study we ask that you read the participant information sheet and mark next to each numbered sentence below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, David Fassioms.

Please initial alongside each statement:

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio or video recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been submitted for publication/examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my benefits being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn.

7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.

8. I consent to information and quotations from my interview being used in reports, conferences and training events.

9. I understand that the researcher will discuss data with their supervisor as needed.

10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor.

11. I consent to written transcriptions of the interview being stored securely for 10 years after the study has finished.

12. I consent to take part in the above study.

Name of Participant__________________ Signature____________________ Date ___________

Name of Researcher __________________Signature ____________________Date ___________

Appendix 5 Topics for Focus during the interviews (not restricted to)

Topics for focus during the interviews

- Condition history – what are their health conditions and how are they managed medically?
- Social history – who they live with, type of accommodation, any dependants?
- Occupational history – do they work? If so, what do they do? If they do not work, what was the main reason for them leaving work? Was this related to their health problems? How do they feel about receiving the Universal Credit benefit? How long have they been in receipt of Universal Credit?
- Individual's perceptions of physical well-being during the work capability re-assessment process, including fatigue and pain or other relevant physical symptoms.
- Individual's perceptions of psychological well-being during the work capability re-assessment process, including mood, evenness of temper and ability to complete daily living activities.
- Individual's perceptions of their ability to maintain good relationships with people during the work capability re-assessment process.
- Any specific concerns related to the work capability re-assessment process?

Appendix 6 Ethics Approval Letter

Applicant: David Fassioms
Supervisor: Dr Paula Holland and Dr Faraz Ahmed
Department: DHR
FSTREC Reference: FST21024

04 November 2021

Re: FST21024

Investigating individual perceptions of well-being during the work-capability re-assessment process for people deemed severely functionally disabled at their previous work-capability assessment.

Dear David,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Science and Technology Research Ethics Committee (FSTREC)**. The application was recommended for approval by FSTREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fst-ethics@lancaster.ac.uk

Yours sincerely,

Tom Morley,
Research Ethics Officer, Secretary to FSTREC.

Appendix 7 Ethics Approval of Amendments Letter

FHM-2022-0806-AmendPaper-1
Ethics approval of amendment

05 April 2022

FMH-2022-0806-AmendPaper-1 Investigating individual perceptions of well-being during the work-capability re-assessment process for people deemed severely functionally disabled at their previous work-capability assessment

Dear David Fassioms,

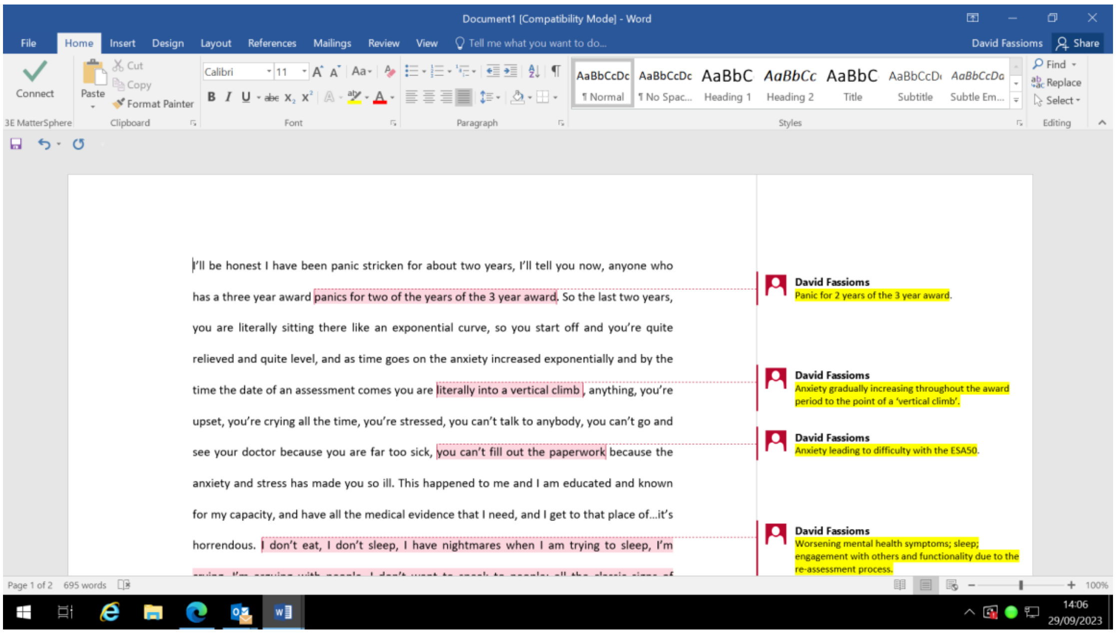
Thank you for submitting your ethics amendment application in REAMS, Lancaster University's online ethics review system for research. The amendments have been approved by the FHM REC.

Yours sincerely,

Faculty Research Ethics Officer on behalf of FHM

Lancaster
University

Appendix 8 Part of a coded transcript



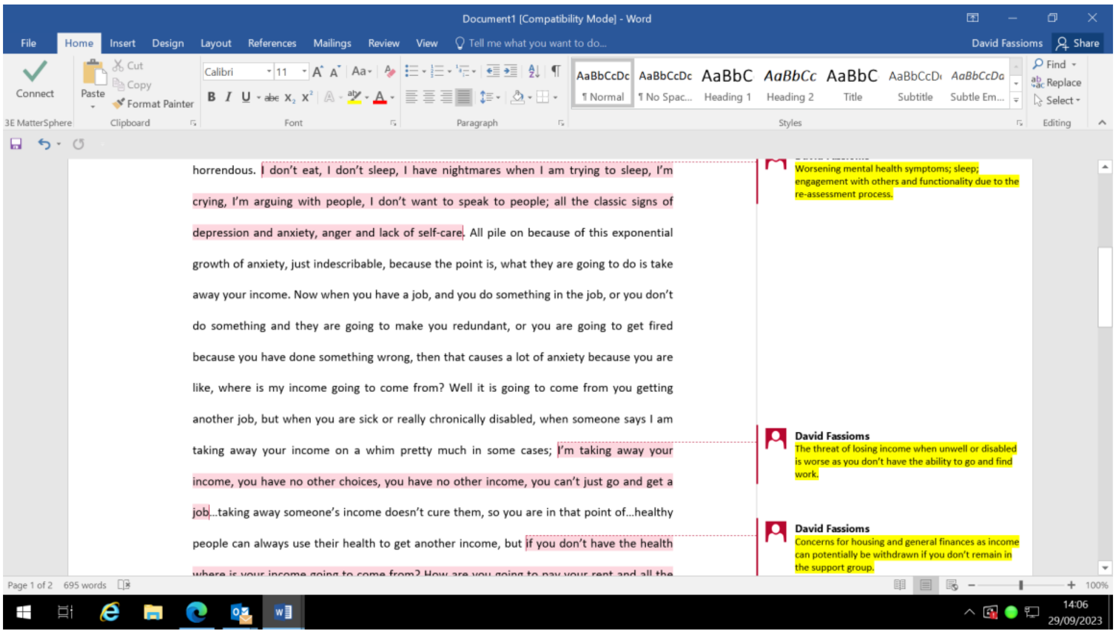
I'll be honest I have been panic stricken for about two years, I'll tell you now, anyone who has a three year award panics for two of the years of the 3 year award. So the last two years, you are literally sitting there like an exponential curve, so you start off and you're quite relieved and quite level, and as time goes on the anxiety increased exponentially and by the time the date of an assessment comes you are literally into a vertical climb, anything, you're upset, you're crying all the time, you're stressed, you can't talk to anybody, you can't go and see your doctor because you are far too sick, you can't fill out the paperwork because the anxiety and stress has made you so ill. This happened to me and I am educated and known for my capacity, and have all the medical evidence that I need, and I get to that place of…it's horrendous. I don't eat, I don't sleep, I have nightmares when I am trying to sleep, I'm crying, I'm arguing with people, I don't want to speak to people; all the classic signs of

David Fassioms
Panic for 2 years of the 3 year award.

David Fassioms
Anxiety gradually increasing throughout the award period to the point of a 'vertical climb'.

David Fassioms
Anxiety leading to difficulty with the ESA50.

David Fassioms
Worsening mental health symptoms; sleep; engagement with others and functionality due to the re-assessment process.

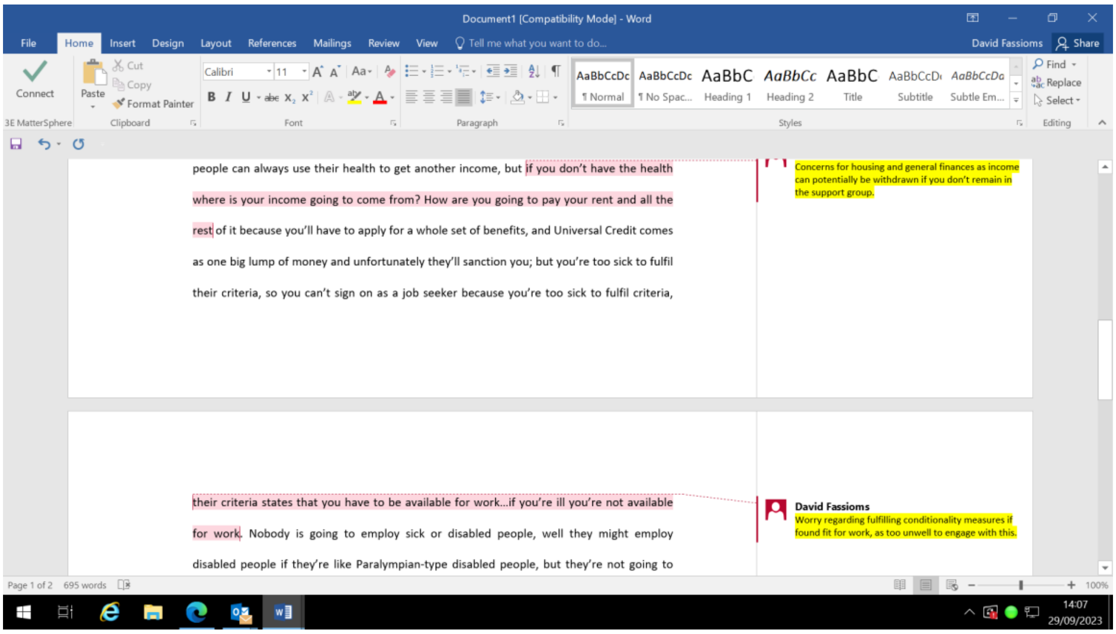


horrendous. I don't eat, I don't sleep, I have nightmares when I am trying to sleep, I'm crying, I'm arguing with people, I don't want to speak to people; all the classic signs of depression and anxiety, anger and lack of self-care. All pile on because of this exponential growth of anxiety, just indescribable, because the point is, what they are going to do is take away your income. Now when you have a job, and you do something in the job, or you don't do something and they are going to make you redundant, or you are going to get fired because you have done something wrong, then that causes a lot of anxiety because you are like, where is my income going to come from? Well it is going to come from you getting another job, but when you are sick or really chronically disabled, when someone says I am taking away your income on a whim pretty much in some cases; I'm taking away your income, you have no other choices, you have no other income, you can't just go and get a job…taking away someone's income doesn't cure them, so you are in that point of…healthy people can always use their health to get another income, but if you don't have the health where is your income going to come from? How are you going to pay your rent and all the

David Fassioms
Worsening mental health symptoms; sleep; engagement with others and functionality due to the re-assessment process.

David Fassioms
The threat of losing income when unwell or disabled is worse as you don't have the ability to go and find work.

David Fassioms
Concerns for housing and general finances as income can potentially be withdrawn if you don't remain in the support group.

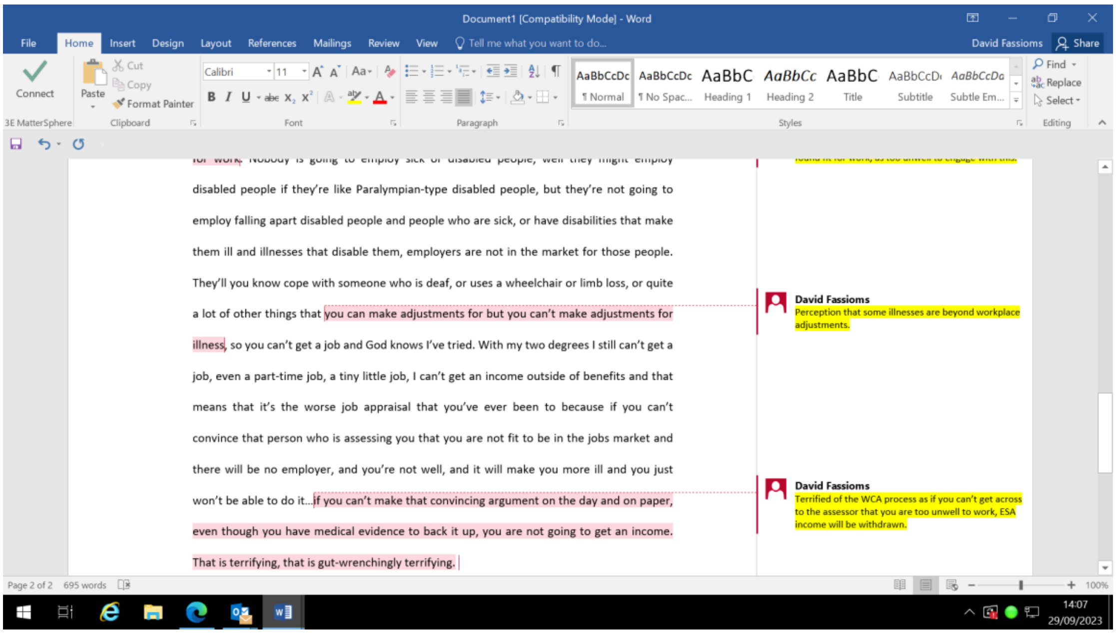


people can always use their health to get another income, but if you don't have the health where is your income going to come from? How are you going to pay your rent and all the rest of it because you'll have to apply for a whole set of benefits, and Universal Credit comes as one big lump of money and unfortunately they'll sanction you; but you're too sick to fulfil their criteria, so you can't sign on as a job seeker because you're too sick to fulfil criteria,

Concerns for housing and general finances as income can potentially be withdrawn if you don't remain in the support group.

their criteria states that you have to be available for work…if you're ill you're not available for work. Nobody is going to employ sick or disabled people, well they might employ disabled people if they're like Paralympian-type disabled people, but they're not going to

David Fassioms
Worry regarding fulfilling conditionality measures if found fit for work, as too unwell to engage with this.



disabled people if they're like Paralympian-type disabled people, but they're not going to employ falling apart disabled people and people who are sick, or have disabilities that make them ill and illnesses that disable them, employers are not in the market for those people. They'll you know cope with someone who is deaf, or uses a wheelchair or limb loss, or quite a lot of other things that you can make adjustments for but you can't make adjustments for illness, so you can't get a job and God knows I've tried. With my two degrees I still can't get a job, even a part-time job, a tiny little job, I can't get an income outside of benefits and that means that it's the worse job appraisal that you've ever been to because if you can't convince that person who is assessing you that you are not fit to be in the jobs market and there will be no employer, and you're not well, and it will make you more ill and you just won't be able to do it…if you can't make that convincing argument on the day and on paper, even though you have medical evidence to back it up, you are not going to get an income. That is terrifying, that is gut-wrenchingly terrifying.

David Fassioms
Perception that some illnesses are beyond workplace adjustments.

David Fassioms
Terrified of the WCA process as if you can't get across to the assessor that you are too unwell to work, ESA income will be withdrawn.

Appendix 9 Protocol for research study

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Title of Project: Investigating individual perceptions of well-being during the work-capability re-assessment process for people deemed severely functionally disabled at their previous work-capability assessment.

Name of applicant/researcher: David Fassioms

ACP ID number (if applicable): N/A **Funding source (if applicable):** N/A

Grant code (if applicable): N/A

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

X ☐ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM: Faculty of Health and Medicine (FHM); Public Health PhD student

2. Contact information for applicant:

E-mail: d.fassioms@lancaster.ac.uk **Telephone**: 07858281159

Address: N/A

3. **Names and appointments of all members of the research team (including degree where applicable)**

David Fassioms MSc, BSc (Hons): Principal Investigator

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health X ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here:☐ DClinPsy Thesis ☐

4. Project supervisor(s), if different from applicant: Dr Paula Holland and Dr Faraz Ahmed

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

Dr Paula Holland: Senior Lecturer in Public Health; Lancaster University

Dr Faraz Ahmed: Lecturer in Health Inequalities; Lancaster University

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'
☐

4c. If yes, where relevant has permission / agreement been secured from the website moderator? ☐

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? ☐

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? ☐

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? ☐

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. **Summary of research protocol in lay terms:** Universal Credit (UC) is a welfare benefit to help individuals financially, and individuals with a health condition may be entitled to additional finance if this prevents them from carrying out work or associated activities. There is a formal process to go through to enable individuals to receive the additional finance, which often includes attending a work capability assessment (WCA). Individuals who are deemed to have severe functional problems as a result of their health issues need to undergo periodic re-assessment of their circumstances in the majority of cases. Previous research into the introduction of UC and effects on mental health and the WCA's effect on mental health has predominantly been via secondary analysis of existing data (Barr et al., 2015a; Barr et al., 2015b; Wickham et al., 2020), and to date there is limited research into WCAs post the period of welfare reform and roll-out of UC. Additionally, the literature reviewed largely focusses upon psychological distress and mental health; whereas the proposed research aims for understanding of physical, mental and social elements of well-being for the individuals being researched. In this qualitative study, I will recruit 10-15 individuals of working age (16-65) who were deemed to have severe functional disability at a previous assessment, and complete unstructured, in-depth interviews to explore individual perceptions of well-being during the re-assessment process. Each individual will undergo an interview before and after the re-assessment to gather perceptions along the journey. Using qualitative methods to analyse the findings I aim to better understand the self-perceptions of the individual's well-being as they navigate the re-assessment process.

2. **Anticipated project dates (month and year only):**

Start date: January 2022 End date: December 2023

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. **Please describe the sample of participants to be studied:** 10-15 working age (16-65) adults (male or female) in England who were deemed to have severe functional disability at a previous work capability assessment (WCA), and are now undergoing re-assessment of their circumstances. All participants will speak fluent English language, and have the mental capacity to speak on their own behalf. The rationale for the sample size is that when conducting unstructured, in-depth interviews a larger sample size can make the process of analysis complicated. Also, it would potentially be unethical to recruit further participants and not make use of the data they provide. Additionally, as each participant will be interviewed twice, 20-30 transcripts of data will be gathered from the sample.

4. **How will participants be recruited and from where?** Recruitment will be via purposive sampling of people in England who have previously been deemed severely functionally disabled, and are now undergoing the work capability re-assessment process. Information about the study will be publicised using flyers posted up in selected Citizens Advice Bureau (CAB) buildings with their consent, and via social media accounts of CAB and selected disability groups/forums, again with consent. A flyer, participant information sheet and expression of interest form will be available to any individuals interested in participation. Those interested in taking part will contact the researcher using contact details on the participant information sheet, or send an expression of interest form via e-mail, which will give permission for the researcher to discuss the research with the interested party. The potential participant can then decide whether they consent to participation in the research, or not, and the researcher can determine whether they fit the recruitment criteria. If recruitment is low after a period of four weeks, the researcher will put out a second call for interest via social media.

5. **Briefly describe your data collection and analysis methods, and the rationale for their use:** Prior to the interviews, the researcher will need to take basic details including contact details, age, clarifying they were previously deemed severely functionally disabled and are now undergoing re-assessment of their work capability, ability to speak fluent English, and clarifying they have mental capacity to engage in the research independently. Mental capacity will be assessed during the initial discussion regarding the research with the interested party, and will be assessed via a two-stage test as per the Mental Capacity Act (NHS Health Research Authority, 2021). The test initially considers whether there is an impairment of, or disturbance to, the functioning of the mind or brain. The researcher will need to consider whether there is a mental health problem, learning disability, or any mental or physical health condition that

could confusion or drowsiness for example. If none of this applies, then the individual will be considered to have capacity at that moment in time. If the individual does have one of the above conditions, the researcher will then need to consider whether the impairment is sufficient that the person is unable to consent to participation or provide an accurate history at interview. The researcher will assess whether the individual has the general cognition and insight to consent to participation and provide their own account during the interviews with the use of a tailored mental state examination. In completing the tailored mental state examination, the researcher will consider an individual's ability to understand, retain and consider information, and ensure they can communicate their needs and an accurate history (NHS Research Authority, 2021; Soltan and Girguis, 2017). If individuals do not meet the appropriate criteria, their interest will be politely declined. Participants who have agreed to take part in the study and fit the inclusion criteria will be asked to sign a consent form to give to the researcher at their first interview, or the consent form can be e-mailed alternatively. Otherwise, if interviews take place via Microsoft Teams (video call facility) or via telephone, consent can be provided verbally and will be video or audio recorded. Qualitative data collection methods, specifically, unstructured, in-depth interviews and reading of any documents that the participants want to share that add further context to their narratives will be used. The documents could for example be a prescription that shows an increase in medication dosage, or an appointment letter showing a specific referral has been made in relation to a health condition; participants will not be asked to provide any documents, these will be volunteered and the researcher will take notes regarding this during the interview. This data collection method has been proposed as it will allow rich, contextual data to be provided by individuals who are going through the phenomena under investigation.

The interviews will be conducted at mutually agreed sites that are comfortable for the participants and safe for the researcher; or interviews will be via Microsoft Teams or telephone. All interviews will be conducted by the principal investigator, and each participant will be interviewed on two occasions; one interview prior to their WCA and a second interview after their WCA. This is to gather rich detail at different time points of their re-assessment journey, and explore perceptions of their well-being in the build up to the WCA and once this is completed. A narrative analysis (Wong and Breheny, 2018) will be applied to the interview data, and any documents or materials voluntarily provided by the participants that add context to their narratives will be analysed additionally. There will be cross-analysis between the interviews to further analyse the narratives; allowing interpretations to be made by the researcher from the context of the research question.

6. **What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)?** The interviews will be recorded using a portable audio recording device and the data will be immediately (on the same day) uploaded to OneDrive while the data analysis is being completed. Alternatively, the interviews can be recorded via Microsoft Teams and saved directly into OneDrive. Once the audio or video recorded data is

transcribed to an electronic typed format during the analysis of the data, the electronic typed data will be anonymised and stored using encrypted password protected storage. Any personal identifiers will be kept separately from anonymised data in encrypted password protected storage. Therefore, all of the participant's anonymity will be preserved and confidentiality of personal data will be respected. Any written transcripts provided by the participants will be securely returned to them once utilised for data analysis.

Electronic typed data will be archived for 10 years with the researcher in secure encrypted storage. After the 10 year period, the data will be transferred to the secure encrypted Lancaster University (LU) server where it will remain indefinitely. The researcher will destroy the data from their storage on lapse of the 10 year time frame. Any personal details and the audio or video recordings will be destroyed immediately on submission and dissemination of the research study, as these details will be transcribed and securely stored.

7. **Will audio or video recording take place?** ☐ no X☐ audio X ☐ video

a. Please confirm that portable devices (laptop, USB drive etc.) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. Recording of audio data will be done on a portable audio recording device and immediately (on the same day) will be transferred to OneDrive. The audio data will be transcribed to an electronic typed format that is anonymised and stored using encrypted password protection storage, and once the research findings are submitted and disseminated; the audio recording can be destroyed as the data will be transcribed and secured with encrypted password protection. Video recordings will be via Microsoft Teams, and this data can be stored directly into OneDrive. As per the audio recordings, once the video data is transcribed to an electronic typed format that is anonymised and stored using encrypted password protection storage, and once the research findings are submitted and disseminated; the video recording can be destroyed as the data will be transcribed and secured with encrypted password protection.

b. What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed? Electronic typed data will be archived for 10 years with the researcher in secure encrypted storage. After the 10 year period, the data will be transferred to the secure encrypted Lancaster University (LU) server where it will remain indefinitely. The researcher will destroy the data from their storage on lapse of the 10 year time frame. Any personal details and the audio or video recordings will be destroyed immediately on submission and dissemination of the research study, as these details will be transcribed and securely stored.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. **How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?**

Due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request.

8b. **Are there any restrictions on sharing your data?**

Due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request.

9. **Consent**

a**. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?** YES

b. **Detail the procedure you will use for obtaining consent?** All the participants will be asked if they have any queries about the information they will be provided with regarding the study. This information will be on a participant information sheet that can be viewed as Appendix 2 below. The participants will be informed that all the data provided will be anonymised and confidential. They will also be informed that participation in the study will not in any way compromise their benefit payments, the Department for Work and Pensions (DWP) will not be aware of their involvement, and the study is completed through Lancaster University, and is not connected to the DWP. The participants will be informed of any potential boundaries to the confidentiality, i.e. if anything is said at interview that the researcher feels alludes to the participant or a third party being at significant risk of harm, the confidentiality would have to be broken. In this instance, the researcher will need to speak to their supervisor, but the researcher will tell the participant if this was required. The participant pack will contain a copy of the flyer, participation information sheet, expression of interest form, and consent form.

The flyer can be viewed as Appendix 1, expression of interest form viewed as Appendix 3, and consent form viewed as Appendix 4.

When individuals are interested in participation in the study they will contact the researcher by e-mail or phone, or they will be provided with an expression of interest form to complete electronically before the researcher takes any personal details. The expression of interest form can be returned electronically via e-mail. After e-mail or telephone contact and on agreeing to participate in the study, a time and venue will be arranged for the first interview to take place, and the participant will be asked to bring a completed consent form to the interview or again they can return the consent form electronically via e-mail. Alternatively, the interview could take place via video communication or telephone, and the participant will be asked to e-mail their completed consent form to the interviewer, or verbal consent can be given. The researcher will ensure the participants are aware that they can withdraw from the study at any time, and will reiterate that the study is not connected to the DWP, and will have no impact on their benefits. To clarify, the participants can withdraw from the study at anytime during the interviews or in the interim period between the interviews. However, the data that has been collected up until that point can still be used towards the study. The expression of interest forms will contain individuals' name, contact telephone number and/or e-mail address. This personal information will be stored using encrypted password protected storage, and destroyed once the research findings are submitted and disseminated.

10. **What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.** The researcher does not anticipate that taking part in the study will cause participants any substantial risks or distress. However, by vocalising their perceptions of well-being during the work capability re-assessment process there may potentially be some emotional or anxiety-provoking reflections or themes. Some of the participants will have a history of mental health problem(s), and in some cases this will be the reason for them being deemed severely functionally impaired at their previous WCA. The researcher is used to working and supporting people in a sensitive and complex setting, and should any undue distress arise in the interview(s), the researcher will pause the interview and allow the participant time to debrief; and decide whether they want to continue the interview. Additionally, the researcher will suggest additional support services that will also be documented on the participation information sheet. Again, confidentiality will be preserved throughout the audio recorded data, and separation of personal details and identifiable data will ensure anonymity when the audio recorded data is transcribed into electronic typed data.

11. **What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).** There are not expected to be any specific risks to the researcher. The researcher will be conducting the interviews at pre-arranged sites, which are selected by the individual participants based on their comfort and in consideration of researcher safety; or alternatively the interviews may be conducted via video or telephone communication. Therefore, the Lancaster University Lone Worker Guidance will be adhered to when appropriate. In-particular, if conducting an interview in person the researcher will inform an associate regarding the interview venue, time of arrival and estimated time of the interview concluding; and there will always be a means of contact via telephone. On completion of the interviews, contact will be made with the associate, or if contact is not made the associate will contact the researcher to ensure their safety. In addition, no personal details for the participants will be provided to the associate to ensure there is no loss of confidentiality for the participants. The participants will be provided with contact details for the researcher, but this will be by the way of a University e-mail address and a non-personal mobile phone number. No personal addresses or contact details will be provided to the participants.

12. **Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.** There will be no direct benefit from participation in the study. Yet, some of the participants may find it a positive experience to reflect on their perceptions of well-being during the work capability re-assessment process; or may find the study a cathartic exercise.

13. **Details of any incentives/payments (including out-of-pocket expenses) made to participants:** There will be no incentive or payment made to participants, but travel expenses can be covered. The interview venues will be selected by the participants based on their comfort (as long as researcher safety can be maintained), so this is on their terms, and there is no request for them to travel. The researcher will provide refreshments during the interviews conducted in person.

14. **Confidentiality and Anonymity**

a. **Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?** YES

b. **Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.** The interviews will be recorded using a portable audio recording device and the recorded data uploaded to OneDrive on the same day as the interview. Once the audio recorded data is transcribed to an electronic typed format during the analysis of the data, the electronic typed data will be anonymised and stored using encrypted password protected storage. Any personal identifiers will be kept separately from anonymised data in encrypted password protected storage. Therefore, all of the participant's anonymity will be preserved and confidentiality of personal data will be respected. The data of any interviews conducted via Microsoft Teams (video recording) will be treated as per the audio recordings, again ensuring participant's anonymity will be preserved and confidentiality of personal data respected. Any written transcripts provided by the participants will be securely returned to them once utilised for data analysis. The participants will be informed of any potential boundaries to the confidentiality, i.e. if anything is said at interview that the researcher feels alludes to the participant or a third party being at significant risk of harm, the confidentiality would have to be broken. In this instance, the researcher will need to speak to their supervisor, but the researcher will tell the participant if this was required.

15. **If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.** The participants will not be involved in the design of the research. However, as the interviews being conducted are unstructured, in-depth interviews; the participants will have a key role in how the interviews are conducted and the details and themes that emerge from the interviews.

16. **What are the plans for dissemination of findings from the research?** The findings from the study will be submitted to the University of Lancaster as a PhD thesis, and will therefore be viewed by research supervisors during the thesis write up. On completion of the research project it is planned that the findings of the project will be disseminated by publication in a peer reviewed journal, although this is not guaranteed. Any guidance related to specific journals for dissemination will be sought from the PhD research supervisors. Additionally, the researcher plans to disseminate the findings to the Centre for Health and Disability Assessments (CHDA) who conduct the work capability assessments on behalf of the DWP for their knowledge.

17. **What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?** There are no further matters that the researcher would look to seek guidance from the FHMREC. The ethical matters for consideration in the proposed research have been addressed within the application for ethical approval for research.

SECTION FOUR: signature

Applicant electronic signature: David Fassioms Date 05/10/2021

Student applicants: please tick to confirm that your supervisor has reviewed your application and that they are happy for the application to proceed to ethical review **X** ☐

Project Supervisor name(s): Dr Paula Holland, Dr Faraz Ahmed Date application discussed 05/10/2021