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Doctoral Thesis

Social Justice is the Best Therapy: Exploring Lived-Experiences of Welfare Reform in the United Kingdom

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Word count

Thesis Section	**Abstracts**	**Text**	**Tables, References and Appendices**	**Total**
Thesis Abstract	-	290	-	290
Literature Review	250	7997	7645	15,892
Research Paper	162	8000	5758	13,758
Critical Appraisal	-	3998	896	4894
Ethics Section	-	4971	2324	9387
Totals	***412***	***25,256***	***16,623***	***44,221***

Thesis Abstract

This thesis consists of a literature review, a research paper and a critical appraisal. The focus of this thesis is to understand the impact of welfare reform and austerity on individuals, with particular focus on mental wellbeing.

In attempt to explore the impact of stigma on individuals who claim benefits a qualitative metasynthesis of 18 papers was completed. Findings demonstrated that individuals experienced multiple levels of benefit stigma, that stigma had social and emotional impact, individuals adopted various strategies to manage their stigmatised identity and that benefits stigma created an atmosphere of distrust and suspicion within communities.

The research paper specifically explored the impact of applying for Personal Independence Payment (PIP) on mental wellbeing. PIP is a form of disability benefit introduced under the Welfare Reform Act. Thematic analysis of qualitative data yielded from 16 interviews led to the development of six related themes: 1) PIP is ‘gruelling’ throughout: designed to frustrate?; 2) ‘Treated like a criminal’ - a dehumanising, criminalising process; 3) ‘It’s life threatening for some people’ - impact of PIP on mental health; 4) ‘It feels like they’re trying to cull the weak’- lacking a sense of belonging and worth in society; 5) ‘They need to make improvements’ –how PIP could be improved. These findings captured the distressing nature of the PIP process.

Finally, the critical appraisal provides a reflective stance on a central issue underlying many of the recommendations made within the literature review and empirical paper- the role of Clinical Psychology in politics and social justice. It is argued that psychological thinking can offer unique insight into some of the most pressing issues society faces. Therefore we have a responsibility to contribute our research findings and our theoretical understandings to public, social and political debates.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from July 2018 to May 2019. The work presented here is my own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Charlotte Thompson

Date:

Signature:

Acknowledgments

Firstly and most importantly, I wish to acknowledge and thank the participants of this study whose contribution was entirely selfless. They gave their time and shared their stories to help a researcher whom they did not know and they asked for nothing in return. I can only promise to dedicate my research and my career to tackling the injustices they and many others face as a result of austerity. I will stand alongside you in saying *‘enough is enough’* and use the knowledge you shared with me to help others to navigate a safe path through austerity. I will not deny my privilege or power, but endeavour to use it wisely.

I would like to express my gratitude to my supervisors- Dr Pete Greasley (Lancaster University) and Dr Hayley Higson (Lancashire Care NHS trust). Both have been generous with their time, resources and guidance. They showed great patience and compassion when I experienced difficulties, as well as commitment and passion towards this work. Thank you also to the 2016 Lancaster University Doctorate in Clinical Psychology cohort who provided friendship, laughter and support throughout the past three years. I would like to thank Charlie, for his encouragement, words of motivation and his unwavering belief in me. My parents, without whom I would not have been fortunate enough to be in a position where I was able to complete this research. In particular I’d like to thank my mum- for always offering a final spelling and grammar draft read!

Finally, I am grateful to Psychologists for Social Change for inspiring me to pursue research into social justice and for showing me the role that clinical psychologists can play in generating social change. In particular I would like to thank the members of Psychologists for Social Change North-West. They provided a space where I could reflectively discuss this project and some of the difficult feelings that research in this area can provoke.

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Section One: Literature Review

Benefit stigma in the UK during a period of economic recession, austerity policies and welfare reform: a qualitative metasynthesis

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Word count- 7997

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Abstract

It has been suggested that stigma towards benefit recipients has increased in recent years. This is likely due to the current political and economic climate in the UK as well as prominent neoliberal ideologies which present benefit claimants as ‘scroungers’. This synthesis explores qualitative research investigating the experiences of receiving benefits in an era of economic recession, austerity and welfare reform to understand the impact and reach of ‘benefit stigma’. A systematic literature search was conducted over four databases. This lead to the identification and inclusion of eighteen qualitative papers within this review. Analysis led to the development of four themes: 1) Multiple levels of benefit stigma experienced 2) The emotional and social impact of stigma 3) Workers not scroungers- Coping with a stigmatised identity and 4) Impact on communities- Creating a climate of distrust and suspicion. These findings show that many individuals who receive benefits experience stigma in their day-to-day lives. This impacts not only individual wellbeing but interpersonal relationships and community tensions.

Key Practitioner Message:

- Professionals who work with individuals who receive benefits should ensure that they operate in ways which do not perpetuate stigma.
- Professionals and professional training programmes should ensure that competence is developed in speaking to clients about issues of social and political injustice in a way which is empowering and does not contribute to self-blame.
- Services should acknowledge that benefit stigma may present as a barrier to accessing psychological services and find ways to address this.

Keywords

Stigma; Austerity; Welfare reform; Mental Health; Qualitative; Benefit Stigma

In 2008 the UK spent roughly £500 billion on a bank rescue package in response to an ongoing financial crisis. This contributed to a period of economic recession in the UK (Dagdeviren, Donoghue & Meier, 2016). Economic recessions are often followed by what has been described as ‘a crisis in social policy’ as they can provide justification to review welfare spending (Saffer, Nolte & Duffy, 2018). Accordingly, in 2010 the UK government initiated their austerity programme - a fiscal policy intended to curb public spending. Austerity measures describe a deficit reduction programme which consists of sustained reductions in public expenditure and tax increases. The purpose was to reduce the government budget deficit and reform the role of the welfare state in the UK. In 2012 the Welfare Reform Act was initiated (Welfare Reform Act, 2012). Benefit reforms introduced under this act can be seen in box 1.

[INSERT BOX 1]

The UK austerity measures and welfare reform have received widespread criticism. This has come from a variety of politicians and economists, as well as anti-austerity movements forming among citizens generally (e.g. UK uncut [www.ukuncut.org.uk] and the occupy movement [www.occupywallst.org]) and among professional groups (such as Psychologists for Social Change [www.psychchange.org]). It has also been argued that austerity policies and welfare reforms have disproportionately impacted individuals with disabilities (Garthwaite, 2014).

These reforms are a product of neoliberal ideologies and are accompanied by a rhetoric which portrays benefit claimants as ‘lazy’ and ‘scroungers’ and the welfare state as promoting ‘welfare dependency’. These discourses focus on individual behaviours/ characteristics (e.g. lifestyle choices and motivation) as a determinant of benefit claimant status and portray claimants as responsible for their circumstances. These discourses are prominent within national newspapers, with sensational articles about claimants cheating the system, e.g. "*75% of incapacity claimants are fit to work*" (Peev, 2010) (despite the DWP's [Department for Work and Pensions] own statistics estimating fraud levels at two percent [DWP, 2018]). There has also been a surge of British television programmes such as 'Benefits Street' (Channel 4) and 'Saints or Scroungers' (BBC one), which attempt to depict life on benefits. These have been accused of demonising working-class people and contribute to an environment where benefit claimants feel increasingly stigmatised (Saffer et al., 2018). This rhetoric has been reinforced by former Prime Minister, David Cameron, who asked '*why has it become acceptable for many people to choose a life on benefits?'* (as cited in Patrick, 2017) and former Chancellor of the Exchequer, George Osborne, who linked the crimes of Mick Philpott (British father who received benefits and was found guilty of causing death by arson) to welfare dependency stating that the welfare system was guilty of *'subsidising lifestyles like that'* (Wintour & Dodd, 2013). These quotes are reminiscent of the wider perception that receiving benefits is a lifestyle choice and efforts to demonise welfare recipients based on the actions of a minority.

The media is a powerful means to promote this discourse and is often blamed for increasing levels of benefit stigma (Lister, 2004). In considering the power of the media in shaping public attitudes it is useful to consider the 'agenda setting function of the mass media' theory (McCombs & Shaw, 1972; Carroll & McCombs, 2003). This suggests that the media sets the public agenda as it has the power to influence what people think about. In the majority of media portrayals of benefit claimants, systemic causes of welfare need are neglected. Instead the focus is on individual pathways to poverty e.g. unemployment, family breakdown, substance use and debt (HM Government, 2014). This demonstrates how neoliberal ideologies can result in the individualisation of difficulties and shift focus from unjust systems to the individual (Hansen, Bourgois & Drucker, 2014). Briant, Watson and

Philo (2011) conducted a large scale content-analysis of articles relating to disability and benefits between 2004 and 2011 using five newspapers: The Sun, The Mirror, The Express, The Mail and The Guardian. They found a reduction in articles portraying individuals with disabilities in sympathetic terms and that individuals with mental health difficulties or hidden disabilities were particularly likely to be portrayed as ‘undeserving’. This research also used focus group discussions where individuals were asked to talk about their reactions to media portrayals of benefit claimants. These discussions revealed that participants estimated that up to 70% of disability benefit claims were fraudulent, they justified this belief by referencing articles they had seen in newspapers. Beliefs regarding fraudulent benefit claimants may well be influenced by media representation such as the Sun’s ‘beat the cheat campaign’ which was launched in 2012 to encourage people to report suspected ‘benefit cheats’ by reporting them to the ‘National Benefit Fraud Hotline’ (Newton-Dunn, 2012). In fact, a case study of the Sun’s publications on disability revealed that articles published in 2012 had a strong moral focus which presented claimants as undeserving of support (McEnhill & Byrne, 2014). This was achieved through: disproportionate coverage of benefit fraud comparative to other types of fraud, generalisations made using individual benefit fraud cases and politicians speaking against benefit fraud and supporting the ‘beat the cheat’ campaign. Another analysis of media coverage found that the majority of newspaper articles about benefit claimants were negative (Baumberg et al., 2012). This analysis found that, in comparison to previous years, articles about benefit claimants were increasingly likely to focus on lack of reciprocity (the idea that we must contribute in order to receive e.g. contributing to the labour market in order to receive financial payment). The researchers concluded that *‘stigmatising newspaper coverage is likely to raise personal stigma*’ (p. 54). These examples support the notion that the media influences public perceptions of benefit claimants. However, the media is not the only perpetuator of negative attitudes; personal experiences (e.g. knowing people who they believe are claiming fraudulently) and welfare reform itself have contributed to people feeling that claimants are undeserving.

Cuts to benefits, rising cost of living and the negative discourses that have dominated political debates during this period of recession, austerity and welfare reform have created a *'perfect storm'* (Pemberton, Fahmy, Sutton & Bell, 2016, p. 30) - intensifying the lived reality of poverty. The British Social Attitudes survey has demonstrated that attitudes towards the unemployed and the role of the welfare state in supporting them are currently less sympathetic than they were prior to this current period of economic instability (Clery, Lee & Kunz. 2013). In addition, quantitative research conducted by Baumberg (2016) found through a survey of 2,601 individuals (of whom 1,123 had claimed benefits) that 12% of participants felt ashamed to claim benefits, whilst up to 19% of participants felt that others should feel ashamed to claim benefits. Qualitative researchers have also found that benefit claimants report experiencing the current narrative around benefit claimants as stigmatising (Baumberg et al., 2012; Garthwaite, 2014).

Stigma

The concept of 'stigma' was first articulated by Erving Goffman in the 1960's. Goffman viewed stigma as a process based on the social construction of identity and argued that individuals who become linked to a stigmatised attribute shift from a 'normal' to 'discredited' social status which becomes internalised and shapes behaviour (Goffman, 1963). Since this early definition understanding of stigma has developed and expanded to include considerations of how society, communities and relationships are influenced by stigma (Parker & Appleton, 2003). Some have argued that stigma can be understood as a social process involving the rejection of human difference as a form of social control (Phelan, Link & Dovidio, 2008). This definition is particularly useful as it addresses both the psychological and social aspects of stigma, recognising that stigma has micro and macro-level consequences. Research has primarily focused on the micro-level impact of stigma, such as impact on the individual and their interactions with others (Link & Phelan, 2001). However stigma categorises an entire group of people and thus there are systemic implications. In light of this it has been argued that the stigmatisation of certain groups or behaviours is an imperative mechanism in enforcing social norms or ‘social capital’ by stigmatising non-normative behaviour (Blume, 2002).

Stigmatisation is a complex and dynamic process with several levels (e.g. interpersonal, individual and structural) and perspectives (e.g. objective versus subjective) which operate at various levels of severity (e.g. hate crime, discrimination and negative judgements) (Meyer, 2003). The socio-ecological model (Baral et al., 2013; Link & Phelan, 2006) operationalises stigma according to the levels and means through which it is experienced; these are - structural, interpersonal and individual. This is a useful model to apply in understanding the reach of benefit stigma. Structural stigma describes the societal norms and policies which constrain access to resources. Structural stigma can be seen in the processes underlying claiming benefits and the way policies are enacted at a personal level. This is similar to what has been described as ‘institutional stigma’ (Corrigan, Markowitz & Watson, 2004). Examples of this level of stigma include: feeling looked down on by DWP staff, lack of privacy in jobcentres and being treated as underserving (Finn & Mason, 2008). Baumberg et al. (2012) argue that institutional stigma is the most powerfully felt stigma that claimants experience. Interpersonal stigma describes direct or enacted stigma, such as violence, hostility and verbal harassment. Several disability charities have stated that they are regularly contacted by individuals who have been subject to harassment from members of the public in which they have been accused of faking their disabilities in order to claim benefits (Walker, 2012). Finally, at the individual level, stigma involves the internalisation of stigmatised attitudes. This level refers to the feelings and beliefs that a stigmatised individual holds about themselves, the beliefs they feel others hold about them and how this might shape their behaviour. This was observed in Garthwaite’s (2015a) qualitative research where participants spoke about feeling ashamed of their claimant status and this leading to social withdrawal. These categories overlap and contribute towards each other, for example experiencing interpersonal and structural stigma can lead to individual stigma.

Stigma has both internal and external components in that individuals internalise a stigmatised identity through responding to and feeling external forces of stigma and exclusion. In addition, in an attempt to manage stigmatised identities, individuals who receive benefits will often engage ‘othering’ processes, whereby they stigmatise others who receive benefits and they view as less deserving than themselves (Chase & Walker, 2013). This can lead to divisions within communities (Patrick, 2014) and create an atmosphere of distrust (Saffer et al., 2018) which is likely to lead to increasing withdrawal and isolation. This could have a negative impact on individual mental wellbeing (Lauder, Sharkey & Mummery, 2004).

In exploring why benefit stigma exists, the idea of social norms of reciprocity and the perceived deviation from this in receiving benefits is a dominant viewpoint (Stuber & Schlesinger, 2006). This is of interest given research which shows that media representations of claimants have increasingly focused on lack of reciprocity (Baumberg et al., 2012). This may contribute towards our understanding of why benefit stigma has reportedly increased since the 1970’s (Clery, Lee & Kunz, 2013). Furthermore the extent of stigma appears to be influenced by whether claimants are viewed as ‘deserving’ or not. Certain groups of claimants are often portrayed by the media as ‘less deserving’ than others, for example individuals who have never worked, immigrants and individuals with substance use difficulties (Wincup & Monaghan, 2016). Evidence suggests that people make ‘deservingness judgements' based on their perceptions of individuals' need and whether they are seen as to blame for their circumstances (Oorschot, 2000).

The Impact of Stigma

In considering benefit stigma from a psychological perspective it is important to explore the impact of stigma on individuals and communities. In the field of mental health research stigma has been linked to a range of negative consequences such as reduced self-efficacy, hope and empowerment (Hackler, Cornish & Vogel, 2016; Firmin et al., 2017). This has also been observed in poverty-stigma with research suggesting that participants experienced heightened feelings of guilt, humiliation and shame and reduced self-esteem as a result of stigma (Sutton, Pemberton, Fahmy, & Tamiya, 2014).

Stigma can influence personal identity through creating a discrepancy between the given identity (by those stigmatising) and actual identity, meaning that feelings of tension and vulnerability can be provoked (Lister, 2015). Benefit stigma can also impact the day-to-day lives of those who claim benefits. Airey (2003) argues that stigma can result in 'neighbourhood incivilities' and that this can influence sense of well-being as well as lead some individuals to engage in 'distancing strategies', such as social withdrawal, in order to resist the potentially harmful impact of stigma on wellbeing. Stigma can also influence how comfortable claimants feel when speaking to others in the community (Garthwaite, 2015a) and has been linked to increases in hate crimes against individuals with disabilities (Roulstone, Thomas & Balderston, 2011). This increased sense of disconnect is likely to perpetuate low self-esteem, lack of 'belonging' in society and feelings of worthlessness, which can be detrimental to positive mental wellbeing (Hill, 2006). It is also likely that in order to avoid feeling the full impact of stigma individuals withdraw from society, increasing vulnerability to isolation and loneliness which are also linked to poor mental wellbeing (Holt-

Lunstad, Smith & Layton, 2010). It has also been argued that the political/economic climate and the dominant rhetoric regarding claimants has led to internalised humiliation and shame for many benefits recipients (Garthwaite, 2014). Unfortunately this increase in shame has a negative impact on mental health (Zavaleta, Samuel & Mills, 2014). Benefit stigma is likely to evoke feelings of shame and humiliation and perpetuate withdrawal, isolation and loneliness - all of which are consistently linked to poor mental health. It is also possible that stigma might lead to people not applying for benefits to which they are entitled to which may impact them financially. Polls demonstrate that a very small number of individuals felt that they would not apply for benefits even if they needed them due to shame (4%) (Baumberg et al., 2012). This might suggest that stigma does not lead to individuals making the decision not to apply for benefits. However the experience of stigma may be under-reported as feeling stigmatised is stigmatising in itself (Chase & Walker, 2013). This may explain why some non-recipients make a decision not to apply for benefits even after being told they are eligible (e.g. Bauld, Hay, McKell & Carroll, 2010) and why Garthwaite (2014) found that claimants' experiences of not feeling eligible appeared to be linked to stigma.

Rationale for Review

Within the literature exploring the impact of austerity and welfare reform a key theme which emerges is the impact on mental health (Pemberton, Sutton, Fahmy & Bell, 2014). Within this, stigma and the negative portrayal of individuals who receive benefits have been highlighted as factors which negatively impact wellbeing (Garthwaite, 2016). Therefore, as clinical psychologists working in therapeutic settings it is essential that the impact of benefit stigma is considered and discussed. To ensure that issues are not located within the individual, clinical psychologists must remain aware of these processes and the effect that they can have on mental wellbeing. Failure to do so may result in worsening mental health (Goodman, Pugach, Skolnik & Smith, 2013). Furthermore lack of attention to the impact of benefit stigma also means that other stressors associated with claiming benefits may be missed and it may perpetuate the stigma by sending the message that claiming benefits and stigma should not be discussed.

Behavioural and individualised explanations of poverty and welfare use have been part of British political discourses throughout history (Chase & Walker, 2013) embedding the deserving/ undeserving poor dichotomy within cultural consciousness. Views towards the welfare state have fluctuated at various points in history (Welshman, 2002) and are impacted by political and economic circumstances. Research outlined above suggests that empathy and compassion for individuals receiving benefits has steadily eroded. Individuals are becoming increasingly stigmatised and the economic and political context the UK is currently situated within has amplified this. With this in mind, this paper will identify and synthesise qualitative research exploring the experience of stigma in individuals who receive benefits in an era of economic recession, austerity and welfare reform. The aim of this review is to explore and understand individual experiences, in terms of how benefit stigma impacts a person’s sense of identity, how they manage this and how it might impact communities during a period of economic instability and welfare reform.

Method

The research findings from published qualitative studies exploring benefit stigma in the UK in a period of economic recession, austerity and welfare reform will be systematically examined and interpreted. This review will use the metasynthesis approach put forward by Noblit and Hare (1988) this is discussed below.

Search Strategy

The databases PsycArticles, PsycINFO, PubMed and SOCINDEX were searched in January 2019 using the search terms in Box 2.

[INSERT BOX 2]

These terms were selected to capture the range of austerity measures and welfare reforms in places. Where possible additional filters were applied in each database in order to filter out papers which did not meet the inclusion criteria. The following Inclusion/ Exclusion Criteria were applied:

1) Research papers with a primarily qualitative component or a significant component of mixed-method design related to review question – stigma and benefits
2) Included the experiences and/or beliefs of participants receiving benefits
3) Included benefit stigma as a central concept of the research questions and/or findings
4) Papers published between 2008-2019. Papers will only be included if data was also collected within this time frame.
5) Related to the UK and published in English
6) Published in peer-review journals, thus excluding unpublished theses.

Table 1 shows which filters were applied within which database search and figure 1 provides a flow chart of the selection process.

[INSERT TABLE 1]

[INSERT FIGURE 1]

In total, 18 papers were included in this review, these can be seen in table 2. All included papers were conducted in the UK. Sample sizes ranged from 15 to 73 participants. Data was obtained via 1:1 interviews (n=17) and focus groups (n=1). Data was analysed via differing methods which included: thematic analysis (n=12), grounded theory (n=1), case studies (n=1) and ethnographic fieldwork (n=3), three papers did not state how their data was analysed.

[INSERT TABLE 2]

Papers by Patrick (2014 & 2016) used the same data set, however different results and themes are discussed. Therefore both papers were included. Pemberton, Fahmy, Sutton and Bell (2016 & 2017) also used the same data set, however different results were discussed, thus both were included. Finally, Garthwaite (2014, 2015a, & 2015b) and Garthwaite, Bambra, Warren, Kasim and Greig (2014) used data from a wider study (Warren et al., 2013) which employed a mixed-methods approach to explore the experiences of 229 individuals receiving disability benefits. Of this larger participant group 25 participated in qualitative research and these are the experiences discussed within the papers included in this synthesis. All papers discuss different aspects of the data and develop different themes, therefore they were all included.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP, 2017) research checklist was used to appraise the quality of the included studies. Papers were rated by the researcher and another trainee clinical psychologist. Table 3 provides the scores from both ratings. Scores were generally agreed, where there were differences these were discussed until a final rating was agreed. Eight areas were used for assessing the quality of papers, including methodology, design, data collection and analysis. A rating system developed by Duggleby et al. (2010) was used in conjunction with the checklist to quantify the quality of each paper. Duggleby et al.'s (2010) rating scale assigns a score of one to three for the eight CASP items with a maximum score of 24. A score of one point is awarded when little or no justification or explanation is provided, two points when the issue is addressed but not fully elaborated on, and three points when extensive justification and explanation is given.

[INSERT TABLE 3]

The CASP shows that the all of the papers were of good quality. The main areas in which papers received a low score were in outlining how ethical issues were addressed and in not considering the relationship between the researcher and participants. This is important to bear in mind when interpreting the results as transparency is regarded as a fundamental component of sound qualitative research and allows potential sources of researcher bias to be identified (Yardley, 2000). Three papers did not state how they had analysed their data. This is reflected in their comparatively low scores.

Analysis

Based on previously published descriptions of the process (Noblit & Hare, 1988) this metasynthesis involved three steps:

1) Identifying papers for inclusion

2) Quality appraisal and data extraction and

3) Summarising and synthesising data.

The aim of this method of synthesising data was to explore the contribution of a collection of similar studies as a whole to produce higher order themes using the interpretations of the participants' original accounts. All papers were read several times to identify the central concepts with particular attention given to the 'results' and 'discussion' sections. Relevant quotes, interpretations and emerging themes were extracted verbatim. The key points noted from the individual studies were compared which allowed overlap and similarities to be seen between the papers. Schutz's (1971) notion of first, second and third order constructs was applied to this review. First order constructs (participants' understandings and direct quotes), second order constructs (the interpretations of the authors of the papers) and third order constructs (the researchers' synthesis of first and second order constructs) were added to a table and initial codes were generated using these. Following this it was possible to identify recurring themes. Figure 2 demonstrates the codes used to generate each theme. This allowed the key themes from each study to be compared to the emerging themes across the studies. Formulation of final themes were developed in discussions between the researcher and supervisors.

[INSERT FIGURE 2]

Results and Discussion

The results of this synthesis revealed four themes: 1) Multiple levels of benefit stigma experienced 2) The emotional and social impact of stigma 3) Workers not scroungers - Coping with a stigmatised identity, and 4) Impact on communities - Creating a climate of distrust and suspicion.

There were several instances in which relationships between different themes and subthemes were observed in the data. These are show in figure 3 which demonstrates the different levels at which benefits stigma operates, how this stigma impacts the individual, their responses to this and the ways in which these responses impact communities.

[INSERT FIGURE 3]

This diagram shows the link between these multiple levels of stigma and the emotional and social responses to this. Starting from the broader political level stigma and filtering down through institutional stigma experienced within the processes of applying for benefits, to interpersonal stigma within communities and relationships all of which contribute to internalised stigma.

Theme 1: Multiple levels of benefit stigma were experienced

As discussed in the introduction, stigma can operate at various levels (Baral et al., 2013). In this synthesis four levels of stigma were identified: political stigma, institutional stigma, interpersonal stigma and internalised stigma.

Political stigma

The broadest level in which participants experienced stigma was at a political level. Participants often described feeling *‘tarred with the same brush’* (Saffer et al. 2018, p. 104) by politicians and the media due to the use of the term ‘scrounger’ to generalise benefit claimants: "*...when David Cameron says there's a lot of scroungers . . .' 'it's generalization and it's just upsetting."* (Garthwaite, 2014, p. 790). Participants hypothesised that *'disabled people are scapegoated'* (Saffer et al., 2018, p. 133) as a means to justify welfare reform. Thus some felt that they were stigmatised due to the Government's need to reduce welfare spending and a perceived ease in targeting those who are vulnerable: "*If they could cut a penny in half they would. I think if they could bring euthanasia in, they would'... 'Take all the lame ones out, just like a sick animal"* (Garthwaite, 2014, p. 788). Others suggested that stigma was a result of Conservative party ideologies such as: *'every man for himself'* (Saffer et al., 2018, p. 132). One participant drew comparisons between UK political parties:

> *I feel under the Labour government they were more sort of friendly towards people with social problems and disabilities but I think the Tories have come in at a difficult time and it's an easy group of people to target* (Garthwaite, 2014, p. 790)

This suggests that stigma may be more intensely felt in the current political climate, either due to the ideology of the party in power or, as the quote above alludes to, the *'difficult times'* of economic recession. One participant discussed how they felt that this political stigma will be enacted via institutions such as the DWP: *"I expect that the government through the DWP will go for the low hanging fruit first, that is the bad back and CFS* [Chronic Fatigue Syndrome] *malingerers' brigade which is pretty much me."* (Saffer et al., 2018, p.133). This quote also highlights an internalisation of the stigma as this participant refers to herself as belonging to the *'malingerers' brigade'*- devaluing her condition and accepting the narrative as opposed to rejecting it.

Institutional stigma

Participants reported feeling that *"[Job Centre staff] do look down at you..."* (Patrick, 2016, p. 248) that they are treated like *"a different species ..."* (Wright, 2016, p. 11) by benefits system staff, and the process of applying for benefits *"makes you feel guilty for being disabled"* (Shefer et al., 2016, p. 839). Others discussed lack of care given to claims paperwork, including errors on forms and paperwork going missing. This highlights the devaluing and dehumanising nature of engagement with benefits processes. In addition, the presence of security guards at Job Centres was seen to reflect that benefit claimants were treated and managed as a threatening population by benefits system staff (Patrick, 2016). These examples communicate to claimants that they are of low-status and served as a *"constant reminder that to them, you're scum"* (Smith, 2017, p. 127).

Interpersonal stigma

Participants discussed examples of interpersonal stigma within their communities and relationships. Pemberton et al. (2017) reported that many of their participants had experienced verbal abuse which was framed within the rhetoric of 'hard workers versus benefit claimants'. Across the studies interpersonal stigma appeared to stem from perceptions made regarding claimants 'deservingness' and resulted in many feeling the need to justify their use of welfare support to others (e.g. Garthwaite, 2015a). Participants felt that they were looked down upon by others in the community and that they *"just get looked at as though they're scraping you off the bottom of your shoe"* (Garthwaite, 2015b, p.7). Comments about perceived 'wellness' were a common experience (e.g. Garthwaite, 2015a). Individuals with unseen illnesses were more likely to experience interpersonal stigma as outwardly they do not look unwell (e.g. Garthwaite, 2015b).

Internalised stigma

Pemberton et al. (2017) concluded that the stigma participants in their research had endured had become internalised. This was observed across several of the studies included in this review. Many participants adopted self-stigmatising language such as *"scrounger"*

(Garthwaite, 2015b, p. 7), *"layabouts"* (Macdonald et al., 2013, p. 201) and *"dole dosser"* (Giuntoli et al., 2015, p. 406) highlighting an internalisation of the dominant rhetoric. Participants described feeling that: *"people like me have no worth because I'm not producing"* (Saffer et al., 2018, p. 127) and: *"I'm a piece of shit'…'I'm one of the dregs of society, I'm one of the ones wasting your tax"* (Garthwaite, 2015b, p. 6). In many of the participants' accounts it was observed that the stigmatising rhetoric was intensified by the process of claiming benefits and interpersonal interactions demonstrating stigmatising attitudes. For many this resulted in internalised stigma. In this respect it can be argued that several levels of stigma operate simultaneously to entrench benefit stigma. This can lead to deepening feelings of shame, humiliation and exacerbated emotional strain, which is explored in the next theme.

Theme 2: The emotional and social impact of stigma

As a result of the multiple levels of stigma it is not surprising that an internalised stigma was observed e.g. *"I really am ashamed… it's like a rope around your neck"* (Garthwaite, 2015b, p. 6). This internalisation appeared to inform self-perception and resulted in negative impact on self-esteem (Pemberton et al., 2017) and negative 'social emotions' (Smith, 1993). Social emotions are evoked through the experienced, anticipated, or perceived thoughts, feelings or actions of others. This can include embarrassment, guilt and shame which emerged as common emotional responses to the stigma which participants endured (Shefer et al., 2016; Smith, 2017; Garthwaite, 2014; Garthwaite, 2015b). For many participants it was clear that the impact was psychological and relational harm (Patrick, 2016). One participant expressed that: *"I've been poorly through depression every time I've been on benefits"* (Patrick, 2016, p. 253) and attributed this to her internalised belief that she should work hard for her money and the stigma associated with deviating from this. For many participants these feelings were a motivating factor for pursuing a life without benefits as this was seen as a way to no longer feel ashamed and thus be ‘alright’, for example:

> *The main thing I want to change about my current situation is get off benefits and go and get a job . . . Onto a job and then I can get that feeling of being ashamed off me and them I’m all right then . . .* (Partick, 2014, p. 710).

Participants also described under-claiming benefits; this linked to the emotional impact of benefit stigma, which left some doubting their eligibility: *“Even though I’m entitled, I don’t think I should be entitled.”* (Garthwaite, 2014, p. 790). Others adjusted the ways in which they lived their lives as a result of the shame felt in spending money which was not felt to be truly ‘theirs’: *“when you work for your money it’s a lot different from receiving benefits, because you can kind of feel better to spend that money because you’ve earned it”* (Patrick, 2014, p. 720)

Garthwaite (2014) highlighted that some participants felt that as benefit recipients they were not entitled to enjoy luxuries such as cars and holidays (a perspective emphasised by political and media rhetoric). This is reminiscent of Patrick’s (2014) findings that participants in their study felt that they were *“existing but not living”* (p. 709) and suggests that stigma might contribute to this.

Social withdrawal also emerged as a significant aspect of this theme as the stigma experienced and the fear of stigma encouraged people to withdraw from their existing social networks (Garthwaite, 2015a). For some participants this meant avoiding social interactions due to a fear of stigma:

> *I make any excuse to not to go a party, not that I’m invited to many, but at church it might be someone’s golden wedding anniversary and if I go and there’s people I*

> *don't know and they ask me what I do, what do you think I say?* (Garthwaite, 2015b, p. 6)

In several instances participants hid their claimant status from others expressing that it was easier to *"deliberately keep meself to meself"* (Garthwaite, 2015a, p. 205). This was linked to feelings of shame and guilt due to receiving benefits as well as lived experience of stigma.

These extracts illustrate the impact of benefit stigma which lead to increased shame and resulted in the increasing isolation of many benefit claimants. In attempting to manage their experiences of shame and embarrassment participants would attempt to hide their stigmatised identity through withdrawal.

Theme 3: Workers not scroungers - Coping with a stigmatised identity.

Participants appeared conscious to describe themselves as 'workers' and emphasise that they would rather be working then receiving benefits. Comments such as *"I have a very strong work ethic. I would love to work rather than lay in bed all day*" (DeWolfe, 2012, p. 626) were common. This is perhaps reflective of a desire to distance themselves from the dominant narrative of 'work-shy' benefit claimants. By rejecting the dominant rhetoric it is possible that participants were able to protect themselves from internalised stigma. Many provided examples of how they were not a 'stereotypical' benefit claimant, with comments such as: *"I knew I had already paid tax when I had worked before so I felt entitled to it"* (Formby, 2017, p. 8) and *"I'd rather be out working, having my own money. But then, everybody says, 'well, you've worked all your life', which I have"* (Moffatt & Noble, 2015, p. 1200).

Some participants went beyond simply stating that this narrative was incongruent with their values and thus did not apply to them and gave examples of other 'types of people' who this narrative was better suited to. This was described as 'othering' by Partick (2014) and was common within the studies synthesised. In fact one participant felt that welfare reform was a good thing as it might alleviate some of the stigma she felt in being associated with others that she felt were undeserving:

> *People like me who's genuine are getting stigmatized for the people who are just layabouts, you see them digging gardens or changing wheels on their car and it's not fair . . . it'll separate the wheat from the chaff, definitely* (Garthwaite, 2014, p. 792).

Participants stated that they *"hate being associated with them no hopers"* (Garthwaite, 2014, p. 793) with some implying that certain sub-groups of claimants were less deserving. Some participants questioned the deservingness of immigrants: *"it does make people angry 'cos how we see it is these people are coming into our country, taking our jobs and a lot of them are doing two identities and taking our benefits as well"* (Patrick, 2014, p. 711); others felt that *"alcoholics and druggies, they shouldn't get [benefits]"* (Patrick, 2014, p. 711) and some felt that those who had not contributed previously (e.g. worked or paid taxes) were less deserving – *"If you haven't put nowt into country you shouldn't get nowt off country"* (Patrick, 2016, p. 255). Interestingly these views fit with wider perceptions that claimants 'deservingness' is determined by reciprocity (e.g. having paid 'into the country' previously) and whether or not their benefit claimant status is a result of poor lifestyle choices (a common belief attributed to addiction). This process of 'othering' certain sub-groups of claimants whilst portraying themselves as more 'deserving' is inherently divisive and may contribute to discord and feelings of distrust within communities.

Theme 4: Impact on communities - Creating a climate of distrust and suspicion

As discussed in the previous theme many participants responded to the stigma they experienced by distancing themselves from the stigmatised identity and in turn stigmatising 'others'. Some participants discussed the divisive nature of this:

> *It has got really bad. Some neighbours opposite they are in exactly the same situation as you are, but they still stick their nose up at you. You are just fighting a dead battle… It has got worse, it has got really bad now, wherever you go now you hear people say look at these 'dole bums'* (Pemberton et al., 2017, p. 13)

Patrick (2014) suggested that these discourses of a 'deserving us' and 'undeserving them' exacerbated existing fault lines within communities. Participants felt that they were judged by others in their communities with several reporting negative language from others such as *"benefit scum*" (Saffer et al., 2018, p. 113). In addition, several participants felt that neighbours were watching them and reporting their activities to benefits services: *"I think that most of the information that social security get isn't from some great detective skills, but from neighbours ringing up"* (DeWolfe, 2012, p. 624). This illustrates an atmosphere of distrust and even paranoia within communities – *"It's the paranoia. That somebody's gonna dob you in, somebody's gonna, that they'll be watching you"* (Saffer et al., 2018, p. 115). Participants highlighted their fears that periods of activity might be interpreted by neighbours as an indicator that they were well enough to work:

> *"Neighbours judged me unkindly and when I was well enough to walk short periods I felt I was being judged when I went out and that I was being secretly videoed to show the authorities I was well enough to work and I was a con artist."* (DeWolfe, 2012, p. 624)

Interestingly some participants also noticed themselves engaging in these thought process in that they doubted the 'genuineness' of other disability claimants illnesses: *"…when you walk into an assessment office you see people on crutches and you think this guy has crutches but does he, is he putting this on when I really have a disability?"* (Saffer et al., 2018, p. 129). Again, this points to an overall atmosphere and distrust, suspicion and division within the communities in which benefit claimants live. Unfortunately, this environment also contributes to the withdrawal discussed in the previous theme and is a consequence of the stigma outlined in theme one and the distancing strategies individuals use to ‘shift’ the stigma away from them discussed in theme three.

Summary

This synthesis explores the experiences of benefit stigma during a period of political and economic instability in the UK. Through a thorough analysis of qualitative studies into benefit claimants experiences it became clear that many individuals who receive benefits experience stigma in their day-to-day lives through various levels and means. This impacts not only individual wellbeing but interpersonal relationships and community tensions.

The inflammatory and pejorative media and political coverage of benefit claimants presents a ‘deserving/undeserving poor’ dichotomy identifying benefit recipients as ‘undeserving’. This distances those who receive benefits from the rest of society (Chauhan & Foster, 2014). This distancing and creation of a demonised ‘other’ contributes to benefit-recipients experiencing interpersonal stigma, e.g. verbal abuse and ‘undeserving’ assumptions from others. Furthermore the processes involved in applying for benefits are inherently stigmatising. The processes of welfare reform, austerity measures and changes to benefit entitlement have been experienced as dehumanising and humiliating - deepening and extending the reach of benefit stigma. It is therefore unsurprising that these social discourses become internalised, resulting in an ‘imposed identity’ (Anspach, 1979) which is in line with stigmatising narratives yet in contrast to individuals’ values and self-identity. This internalisation can result in low self-esteem, depression, anxiety, embarrassment, stress and humiliation as was demonstrated in this synthesis (and in other papers not included in this review e.g. Warr, 2005; Reutter et al., 2009; Sherman, 2013; Broussard, Joseph & Thompson, 2012). Goodman et al. (2013) argued that these ‘social injuries’ lead to a sense of powerlessness and lack of control. This review highlighted that to manage these feelings and perhaps to claim back some power and control, participants’ endeavoured to reject and resist negative discourses. However due to the entrenched, insidious and relentless nature of benefit stigma their attempts had individual costs (e.g. withdrawal, isolation and loneliness) and held the potential for considerable negative impact on communities.

Unfortunately, through engagement in ‘othering’ as a response to being ‘othered’ benefit claimants re-circulated and further deepened the reach of the ‘scrounger’ rhetoric projected against them. By creating *‘phantom others’* (Garthwaite, 2015a, p. 209) as a method to alleviate their experiences of stigma participants externalised blame and deflected stigma by projecting it onto others. This strategy to protect identity is consistent with Bourdieu’s (1984) understanding of social inequality which suggests that people distance themselves from those perceived as ‘below’ them in the social hierarchy, or as Garthwaite (2015a) suggests, create positions in the social hierarchy for those who are ‘worse off’. Self-identity can be protected as long as it is not aligned to the ‘othered’ group. This process of ‘othering’ is inherently divisive and puts the focus on the benefit claimants rather than on the unjust system with which they are struggling. It was seen to create an atmosphere of distrust, suspicion, isolation and ‘social disorganisation’ (Halleröd & Larsson, 2008). Effectively this means that the capacity and opportunity for benefit claimants to unite and demonstrate the solidarity, social cohesion and force necessary to challenge Government policy and rhetoric is limited. Thus the status-quo remains unchallenged and unchanged.

Finally, while Government and media discourses have frequently alluded to a ‘culture of worklessness’ (MacDonald, Shildrick & Furlong, 2014) and suggested an underclass of welfare recipients who have never worked, or do not wish to work, and whose families have never worked, it has been suggested that this powerful idea may have little basis in fact.

Research has consistently failed to provide any evidence to support the notion that cultures of worklessness exist within families or that benefit claimants would rather receive benefits than work (Gaffney, 2015; Jensen & Tyler, 2015). Accordingly, this synthesis found that in the majority of studies participants spoke of their history of work and their hopes to get back into work. Unfortunately these inaccurate Government and media discourses have directly influenced policy, for example 'Universal Credit' (the UK Governments flagship welfare reform) was introduced in order to tackle the problem of children *'growing up in homes where no one works'* and unemployment is repeated *'through the generations'* (DWP, 2010, p. 3). This highlights a crucial need for the discourses to be refuted and challenged.

Clinical Implications

This review highlights how social context can be stigmatising and considers the impact of this on mental wellbeing. With this in mind professionals who work therapeutically with individuals who experience benefit stigma should ensure that they operate in a way which does not contribute to it. Research has indicated a tendency for therapists to avoid discussions about social and political context (Smith, Li, Dykema, Hamlet & Shellman, 2013; Appio, Chambers & Mao, 2013; Boyle, 2011) creating an over-emphasis on individualised determinants of distress (Reid, 2010). This is likely to impact therapeutic alliance as it could result in 'blind-spots' in therapy whereby salient factors regarding distress are ignored (Smith et al., 2013). It is likely that this avoidance of engaging with social context stems from uncertainty in how to manage these issues and familiarity with models which focus on cognitions and behaviours. With this in mind clinical psychologists and clinical psychology training programs should ensure that competence in this area is developed. Whilst these issues cannot be changed in therapy the way in which a person views themselves as a result of them can be discussed. Their distress can be validated and the way that they respond to unjust treatment can be considered. In this respect, therapists who are competent in discussing social and political injustice are better placed to empower clients (Goodman et al., 2013). This could lead to a therapeutic intervention whereby an individual's internalised guilt could be replaced with more empowering thoughts and feelings.

The reach of clinical psychology expands beyond the therapy room, however this is seldom utilised. Clinical psychologists are well positioned to address benefit stigma from a service level through developing strategies to 'shame-proof' mental health services (Lister, 2015). This might be done by taking steps to address the isolation that benefit claimants might experience through developing support groups for those who are distressed as a result of the benefit-system. This could act as a 'safe-space' for people to meet others in similar positions. Services which are set up to be mindful of the isolation, fear, stigma and precarious financial security benefit claimants may experience could reduce benefit stigma. In addition, acknowledgement of the barriers that being a benefit claimant might present in accessing psychological services and attempts to address these barriers would be advantageous. For example, if a client's benefits are reduced it may become difficult for them to continue attending sessions, in which case home-visits may provide a suitable alternative.

Benefit stigma can result in individuals feeling ashamed of not only their status as a benefit claimant but also the life-circumstances that led them to claim benefits in the first place. This has been described as 'no legitimate dependency' (Peacock, Bissell & Owen, 2014) - meaning that people allocate a disproportionate level of self-blame and personal responsibility for their circumstances. This can result in individuals feeling that they should be able to manage their situation by themselves due to it being their fault, thus presenting as a barrier to seeking support. This idea of 'no legitimate dependency' and self-blame as a barrier to seeking support may explain why researchers have established that those from poorer socioeconomic backgrounds are less likely to engage with mental health support (Falconnier, 2009). This could be a difficult barrier to overcome as traditionally in order to address self-blame an individual would need to attend the service. Thus clinical psychologists need to look towards alternative strategies to manage this. This could involve speaking-up against benefit stigma, the ‘scrounger’ rhetoric and stigmatising Government policies and aligning themselves with benefit claimants. Clinical psychologists should look towards creative, inclusive approaches which promote acceptance, reduce stigma, encourage unity within communities and tackle the social injustices that maintain poverty. Further discussion regarding how this could be achieved, the potential barriers to achieving this and suggestions for overcoming these barriers are disused in section three of this thesis.

Strengths and Limitations

This is the first review to synthesise papers exploring benefit claimants experiences of stigma during a period of economic instability and welfare reform in the UK. The individual studies in this review did not focus on benefit stigma yet this featured heavily in their findings. This review allowed these stigma specific experiences to be extracted and understood in further depth than the individual papers provided. In addition, the focus on a period of economic instability, austerity measures and welfare reform sheds some light on the impact of wider contextual factors on benefit stigma.

However, conclusions drawn from the findings of this review must be made within the context of the following limitations. Firstly, whilst an exhaustive search strategy was applied to identify relevant papers it is possible that some were missed. Secondly, as is inherent in qualitative methodology interpretation bias may have impacted theme development, however themes and codes were reviewed by the researcher’s field and academic supervisor to ensure integrity. Thirdly, it is not possible to draw firm conclusions as a result of the diversity within the studies in terms of focus, participants, methodologies and epistemologies. Whilst common themes were identified it is possible that another researcher might identify different themes, although it is envisaged that they would be similar. Finally, the CASP highlighted some areas of concern regarding the quality of some of the papers, in particular the lack of transparency and failure to report sufficient detail regarding how data was analysed. While some researchers (Walsh & Downe, 2006) advocate the exclusion of studies which are methodologically flawed in order to protect the reliability of the synthesis, studies in this synthesis were not be excluded due to quality appraisal scores. This is because poor quality reporting does not mean that the papers findings are not useful (Sandelwski, Docherty & Emden, 1997). In addition, failure to provide information is likely due to journal word-count guidelines as opposed to author oversight (Walsh & Downe, 2006).

Future Directions for Research

There is a need for larger scale qualitative and quantitative studies in order to sufficiently depict the impact and experience of benefit stigma as well as increase understanding into the experiences of welfare reforms more generally. These studies should consider how applying for or receiving welfare benefits during periods of economic instability impact individual mental wellbeing, relationships and communities.

Conclusion

This synthesis demonstrated that benefit stigma is a central feature of claiming benefits for many individuals. It is vital that academics and professionals advance understanding of the psychological and social harms caused by benefit stigma and develop strategies to remove stigma within services. Clinical psychologists in particular should endeavour to utilise their skill set, psychological knowledge and privileged position to mobilise professional and public consensus to tackle this enduring issue.

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Box 1: Benefit Reforms Introduced Under the Welfare Reform Act

- Reduced adequacy of some out-of-work benefits (e.g. not adjusting due to inflation and increasing cost of living).
- A cap on the amount of benefits a family can receive.
- Reductions in housing and council tax benefits
- Work Capability Assessments (WCAs) for those claiming Employment Support Allowance (ESA).
- The removal of the Independent Living Fund in England and Wales.
- Increased conditionality (behavioural conditions attached to certain benefits enforced through penalties or 'sanctions' that reduce, suspend or end access to benefits).
- And replacing Disability Living Allowance (DLA) with Personal Independence Payments (PIP).

Box 2. Search Terms Used

MeSH terms/ thesaurus terms

austerity OR auster* OR “welfare reform” OR "welfare policy" OR neoliberal* OR benefit* OR "Disability Living Allowance" OR "Employment Support Allowance" OR "Personal Independence Payment" OR "sickness benefit*" OR "Incapacity Benefit*" OR “welfare claim*” OR “Independent Living Fund” OR WCA* OR work capability assessment* OR poverty OR “universal credit” OR conditionality OR sanctions OR “benefit cuts” OR “tax credit*” OR “housing benefit*” OR jobcentre

AND

stigma*

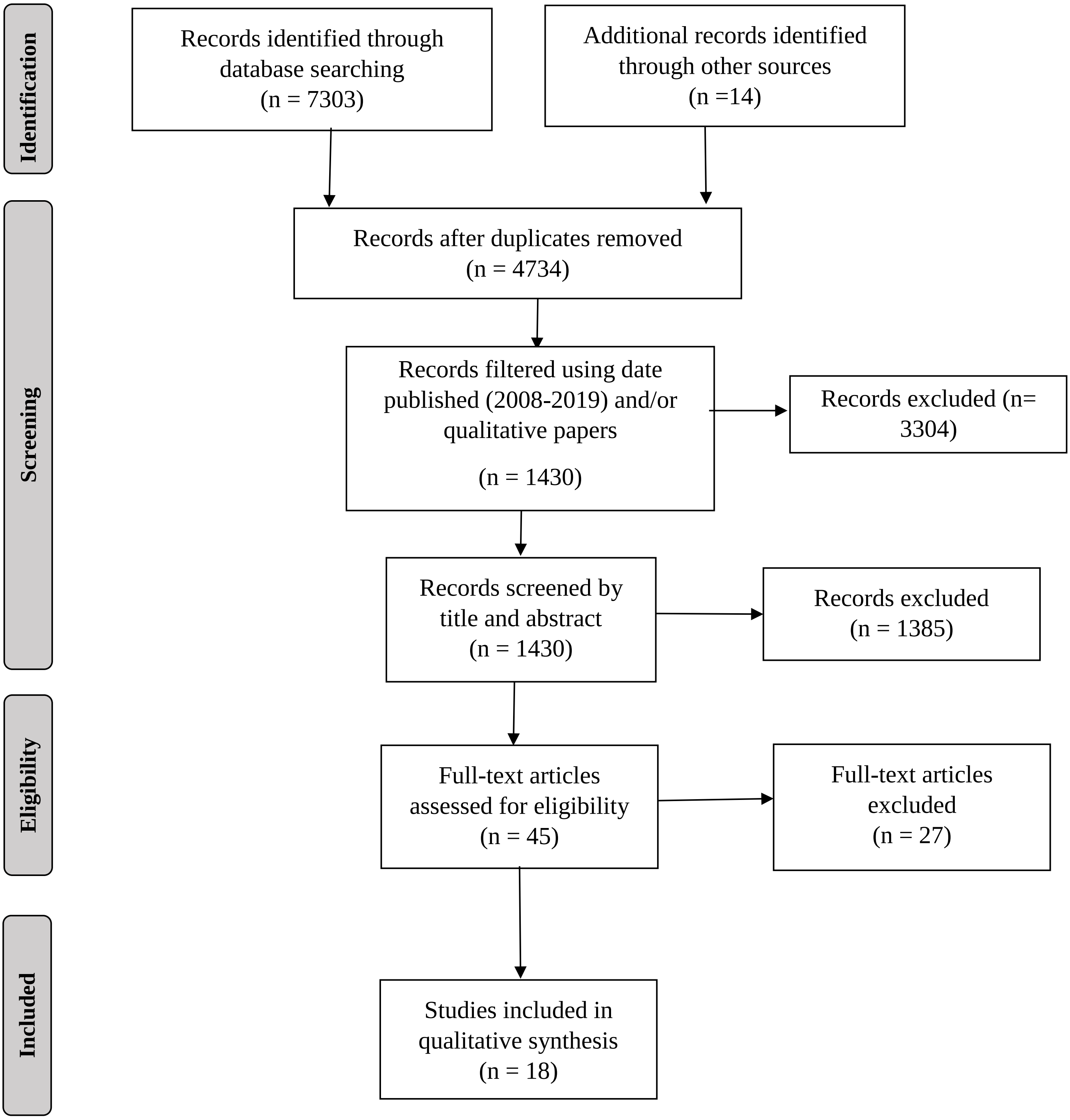
Free Text Terms

“claims stigma*” OR “benefit stigma*” OR “benefits stigma*”

Table 1: Filters Applied to Each Database

PsycArticles	*PsychInfo*	*PubMed*	*SOCINDEX*
- Publication date: 2008-2019	- Publication date: 2008-2019 - Methods: ‘qualitative’ and ‘interviews’ - Search terms: in abstract and title	- Publication date: 2008-2019 - Participants: human	- Publication date: 2008-2019 - Sources: academic journals - Language: English - Geography: Great Britain

Figure 1: Search Strategy



Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram (Moher, Liberati, Tetzlaff, Altman & PRISMA group 2010).

Table 2: Papers Included in the Review

Authors	***Title***	***Year***	***Participants***	***Aims***	***Data analysis***
De Wolfe	Reaping the benefits of sickness? Long-term illness and the experience of welfare claims.	2012	23 participants with myalgic encephalomyelitis (ME). 17 in receipt of disability benefits	To explore the experience of people with ME in claiming sickness-related benefits in the United Kingdom	Not stated
Formby	'Got a degree… all of a sudden I'm in a Jobcentre': The role of 'stigma' in 'precarious' graduate transitions	2017	26 graduates.	To explore how graduates respond to different aspects of 'benefit stigma'	Not stated
Garthwaite *	Fear of the Brown Envelope: Exploring Welfare Reform with Long-Term Sickness Benefits Recipients.	2014	25 chronically ill and disabled people in receipt of disability benefits	To explore long-term sickness benefits experiences of welfare reform in the UK	Thematic analysis
Garthwaite *	'Keeping meself to meself' How social networks can influence narratives of stigma and identity for long-term sickness benefits recipients'	2015 a	25 chronically ill and disabled people in receipt of disability benefits	To explore social networks and their relationship to stigma and identity for benefits recipients	Thematic analysis

Garthwaite *	Becoming incapacitated? Long-term sickness benefit recipients and the construction of stigma and identity narratives.	2015 b	25 chronically ill and disabled people in receipt of disability benefits	To explore how individuals perceived and managed becoming ‘incapacitated’, particularly in relation to stigma and identity.	Thematic analysis
Garthwaite Bambra, Warren, Kasim & Greig*	Shifting the goalposts: a longitudinal mixed-methods study of the health of long-term Incapacity Benefit recipients during a period of substantial change to the UK social security system.	2014	25 chronically ill and disabled people in receipt of disability benefits	To explore long-term sickness benefits experiences of welfare reform in the UK	Mixed methods: qualitative = Thematic analysis
Giuntoli, Hughes, Karban & South	Towards a middle-range theory of mental health and well-being effects of employment transitions: Findings from a qualitative study on unemployment during the 2009–2010 economic recession.	2015	16 focus groups with a total of 73 people who lost their jobs as a result of economic recession.	To explore the impact of job loss and involuntary unemployment on participants mental well-being during the 2009–2010 economic recession.	Thematic analysis

Macdonald Shildrick & Furlong	In search of 'intergenerational cultures of worklessness': Hunting the Yeti and shooting zombies	2013	47 people across twenty families, participants were receiving a range of welfare benefits	To investigate whether 'cultures of worklessness' are passed down the generations.	Case studies
Moffatt & Noble	Work or welfare after cancer? Explorations of Identity and Stigma	2015	23 people of working age with cancer	To explore how cancer impacts on welfare, employment and returning to work	Thematic analysis
Patrick**	Working on welfare: findings from a qualitative longitudinal study into the lived experiences of welfare reform in the UK.	2014	15 out of work benefits claimants who were experiencing at least one change to their benefits	To explore how individuals affected by changes to the benefits system experienced these reforms.	Thematic analysis
Patrick**	Living with and responding to the 'scrounger' narrative in the UK: exploring everyday strategies of acceptance, resistance and deflection	2016	15 out of work benefit claimants who were experiencing at least one change to their benefits	To explore how out of work claimants respond to the 'scrounger' narrative.	Thematic analysis
Pemberton, Fahmy, Sutton & Bell***	Navigating the stigmatized identities of poverty in austere times: Resisting and responding to	2016	62 individuals experiencing poverty in England and Scotland (52 were not in paid work).	To explore the impacts of current discourses on participants.	Thematic analysis

	narratives of personal failure.				
Pemberton, Fahmy, Sutton & Bell***	Endless Pressure: Life on a Low Income in Austere Times	2017	62 individuals experiencing poverty in England and Scotland (52 were not in paid work).	To explore the impacts of current discourses on participants.	Thematic analysis
Saffer, Nolte & Duffy	Living on a knife edge: the responses of people with physical health conditions to changes in disability benefits	2017	15 participants who had made claims for disability benefits	To explore the experience of people with physical disabilities in living as a benefit claimant	Grounded theory
Shefer, Henderson, Frost-Gaskin & Pacitti	Only Making Things Worse: A Qualitative Study of the Impact of Wrongly Removing Disability Benefits from People with Mental Illness.	2016	17 individuals with mental health difficulties receiving disability benefits	To investigate the impact of benefits cuts on disability benefits recipients whose disability was related to mental health.	Thematic analysis
Shildrick & MacDonald	Poverty talk: how people experiencing poverty deny their poverty and why they blame 'the poor'	2013	60 participants caught up in 'the low-pay, no-pay cycle'	To investigate the dynamics of poverty over the life-course.	Thematic analysis
Smith	'You don't own money, you're just the one who's holding it': Borrowing,	2017	Number not stated – all were working age adults and receiving some	To explore the practice of borrowing and lending money between	Ethnographic fieldwork

	lending and the fair person in North Manchester.		form of state welfare.	neighbours in times of financial precarity and social stigma.	
Wright	‘conceptualising the active welfare subject: welfare reform in discourse, policy and lived experience’	2016	16 individuals claiming benefits	To explore differing conceptualisations of the ‘active welfare subject’ in relation to users’ perspectives on the lived experience of receiving benefits.	Not stated

*used the same data set **used the same data set ***used the same data set

Table 3: Application of the Critical Appraisal Skills Programme (CASP) to Papers Included in the Review.

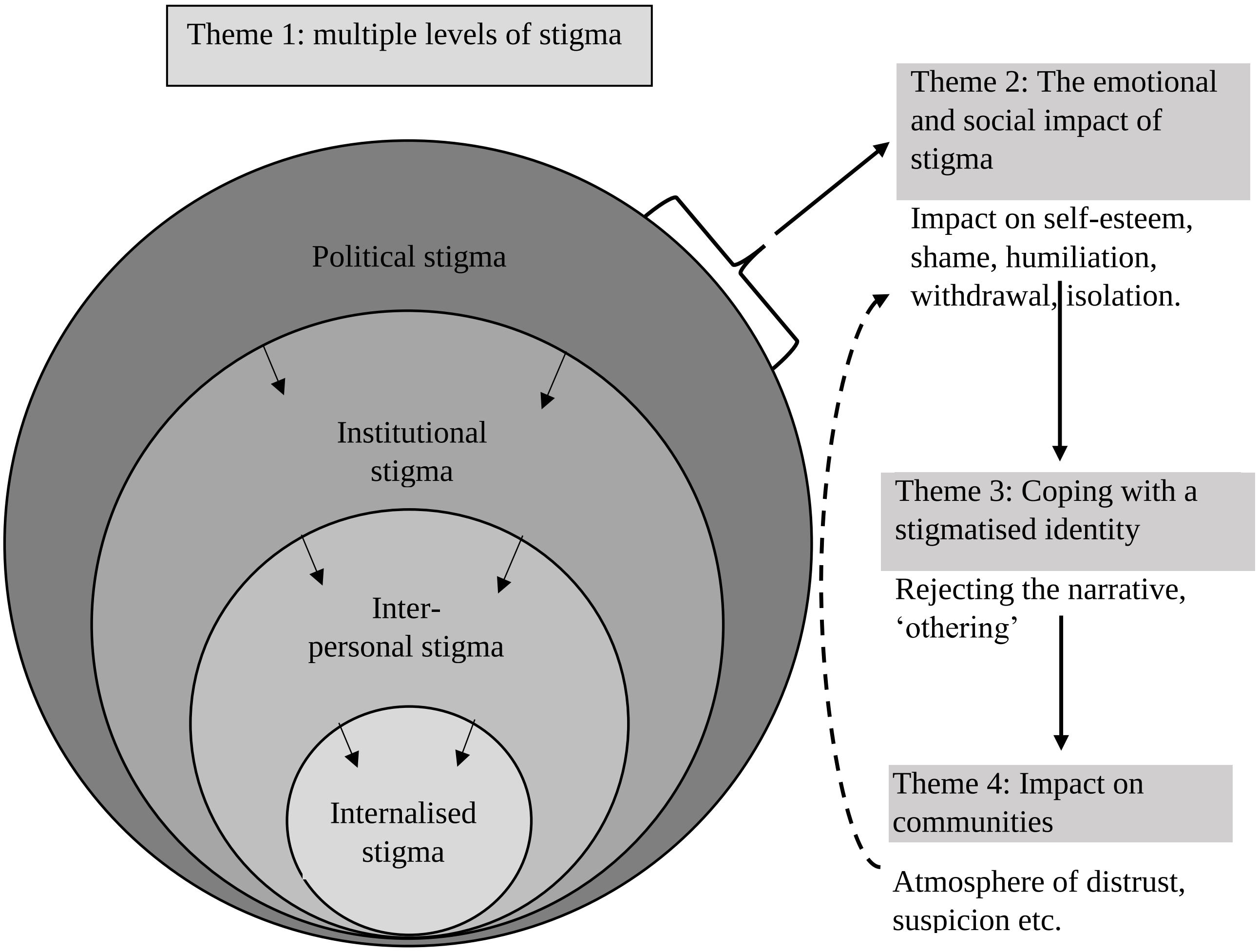
Study	***Research Design***	***Recruitment Strategy***	***Data Collection***	***Reflexivity***	***Ethical Issues***	***Data Analysis***	***Findings***	***Value of Research***	***Total***
De Wolfe (2012)	1	3	2	1	1	2	3	3	**16**
Formby (2017)	1	2	3	1	1	1	3	3	**15**
Garthwaite (2014)	3	3	3	1	3	3	3	3	**22**
Garthwaite (2015a)	3	3	3	1	2	2	3	3	**20**
Garthwaite (2015b)	3	3	3	1	1	2	3	3	**19**
Garthwaite, Bambra	2	2	2	1	3	2	3	3	**18**
Giuntoli, Hughes, Karban & South (2015)	3	3	3	1	3	3	3	3	**22**
MacDonald, Shildrick & Furlong (2013)	2	2	2	1	3	2	3	3	**18**
Moffatt &Noble (2015)	3	3	3	1	2	3	3	3	**21**
Patrick (2014)	2	2	2	1	1	2	3	3	**16**
Patrick (2016)	3	3	3	1	1	2	3	3	**19**
Pemberton, Fahmy, Sutton & Bell (2016)	3	3	3	1	1	2	3	3	**19**
Pemberton, Fahmy, Sutton & Bell (2017)	3	3	3	1	1	2	3	3	**19**
Saffer, Nolte & Duffy (2018)	3	3	3	3	3	3	3	3	**24**

Shefer, Henderson, Frost-Gaskin & Pacitti (2016)	3	2	3	1	3	3	3	3	**21**
Shildrick & MacDonald (2013)	3	3	3	3	1	2	3	3	**21**
Smith (2017)	2	2	2	3	1	1	3	3	**17**
Wright (2016)	1	3	3	3	2	1	3	3	**19**

Figure 2: Theme Development

	Theme 1: Multiple levels of benefit stigma.	***Theme 2: The emotional and social impact of stigma.***	***Theme 3: Coping with a stigmatised identity.***	***Theme 4: The impact of stigma on communities.***
Codes	Internalised stigma; Interpersonal stigma; Stigmatised by the media; Stigmatised by politicians; The process is stigmatising; Welfare reform is stigmatising; Jobcentre staff judge; Errors made by staff	Guilty; Shame; Low self-esteem; Not living; Humiliated; Embarrassed; Questioning own eligibility; Impacting mental health; Stigma is a burden; You feel like a burden	Rejecting narrative; Stigmatising others; Highlighting eligibility; Want to work; Othering; Drug users not deserving; Immigrants not deserving	Feeling watched by neighbours; Judging others; Suspicion; Distrust; Isolation; Withdrawal; Divisive

Figure 3: Thematic Map



Political stigma:	***Institutional stigma:***	***Interpersonal stigma:***	***Internalised stigma:***
Media representation of people receiving benefits, comments from politicians, welfare reforms themselves	Use of security at jobcentre, feeling judged by jobcentre staff, lack of care over claimants paperwork	Comments from friends and family, comments from strangers, social media	Self-stigmatising language e.g. 'scrounger', questioning own eligibility

Appendix 1-A

Author Guidelines: Clinical Psychology and Psychotherapy

Sections

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Submissions which fall outside of Aims and Scope, are not clinically relevant and/or are based on studies of student populations will not be considered for publication and will be returned to the author.

2. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Research articles: Substantial articles making a significant theoretical or empirical contribution (submissions should be limited to a maximum of 5,000 words).

Reviews: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

Assessments: Articles reporting useful information and data about new or existing measures.

Practitioner Reports: Shorter articles (a maximum of 1200 words) that typically contain interesting clinical material. These should use (validated) quantitative measures and add substantially to the literature (i.e. be innovative).

3. PREPARING THE SUBMISSION

Parts of the Manuscript
The manuscript should be submitted in separate files: title page; main text file; figures.

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For more information about APA referencing style, please refer to the APA FAQ.

Reference examples follow:

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Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with

maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry, 159,* 483–486. doi: 10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from *http://www.youtube.com/watch?v=Vja83KLQXZs*

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Endnotes should be placed as a list at the end of the paper only, not at the foot of each page. They should be numbered in the list and referred to in the text with consecutive, superscript Arabic numerals. Keep endnotes brief; they should contain only short comments tangential to the main argument of the paper.

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Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

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3. Numbers: numbers under 10 are spelled out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
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Section Two: Research Paper

Experiences of Individuals Claiming Personal Independence Payment for Mental Health Difficulties

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Abstract

Concerns have grown that applying for Personal Independence Payment is a potentially harmful process. This study aimed to explore these concerns through interviews with 16 individuals who had applied for PIP due to mental health difficulties. Thematic analysis was applied and five themes were identified: 1) PIP is ‘gruelling’ throughout: designed to frustrate?; 2) ‘Treated like a criminal’ - a dehumanising, criminalising process; 3) ‘It’s life threatening for some people’ - impact of PIP on mental health; 4) ‘It feels like they’re trying to cull the weak’- lacking a sense of belonging and worth in society; 5) ‘They need to make improvements’ –how PIP could be improved. The findings captured the distressing nature of the PIP process. The overriding message is that the process is currently not fit for purpose for individuals with mental health difficulties. Thus implications and recommendations for clinical practice, service design and policy are discussed.

Key words: PIP, mental health, welfare reform, austerity, disability benefits, social policy, qualitative

In 2008 the UK entered a period of economic recession following the collapse of the global financial market and the banking crisis in 2007 (Gamble, 2009). This impacted many countries worldwide. Several of these countries, including the UK, implemented ‘austerity measures’ - a fiscal policy which aimed to restore economic stability through decreasing public expenditure and increasing taxes (Seidman, 2012). Thus, in 2010 the Conservative-led coalition government introduced large-scale cuts to local budgets (HM Treasury, 2010). Then in 2012 ‘welfare reform’ (The UK Government, 2012) was introduced to reduce expenditure on ‘out-of-work’ benefits by reassessing the eligibility of 1.5 million benefit claimants.

Alongside these reforms there has been a prominent neoliberal discourse within British media and political platforms which emphasises the free market and anti-dependency policies (Bochel, 2011). Researchers have argued that this discourse has promoted intolerance and hostility towards benefit-recipients by creating a narrative whereby those who are in receipt of benefits are seen as lazy, lacking in aspiration and engaging in poor lifestyle choices (Garthwaite, 2014 & 2016).

Welfare reform and austerity measures have been positively correlated with increases in suicides and adverse mental health outcomes in the UK (e.g. Barr, Taylor-Robinson, Scott-Samuel, McKee & Stuckler, 2012; Hawton et al., 2015; Spence, Roberts, Ariti & Bardsley, 2014). This pattern has also been observed in other European countries (Greece, Spain and Portugal) that adopted austerity measures (McKee, Karanikolos, Belcher & Stuckler, 2012). Interestingly, this is not the case for European countries that protected their welfare state e.g. Germany and Iceland (Karanikolos et al., 2013). These patterns do not necessarily provide evidence that austerity leads to poor mental health outcomes. However it is worth noting that negative mental health patterns during economic crisis trends typically reverse once economic recovery begins to show (Biddle, Brock, Brookes & Gunnell, 2008).

There are several possible mechanisms through which mental wellbeing may be impacted during periods of economic hardship. It has been argued that austerity policies disproportionately impact those with mental health difficulties (Garthwaite, 2014). Individuals with mental health difficulties are more likely to have their benefits cut and receive sanctions (Barr et al., 2016). This places them at increased risk of severe poverty (Loopstra et al., 2015) which is a well-established a factor contributing to poor mental wellbeing (Melzer, Fryers, & Jenkins, 2004). Researchers have argued that this will negatively impact mental health through increasing social comparisons and that social inequality heightens social evaluation anxieties by increasing the importance of social status (Wilkinson & Pickett, 2010). This can impact mental wellbeing through fostering low self-esteem and triggering social emotions e.g. humiliation and shame (Rodgers & Pilgrim 2005; De Botton, 2004). Humiliation and shame have been highlighted as key emotions linked to receiving out-of-work benefits (Mills, Zavaleta, & Samuel, 2014; We Are Spartacus, n.d). These are powerful emotions which can impact our relationships, our view of ourselves as well as our psychological and physiological states (Cacioppo & Patrick, 2008). Thus, it is suggested that wellbeing is highly dependent on our capacity to monitor and respond to how we exist in the minds of others (Gilbert, 2009a).

Unfortunately, the negative discourses surrounding benefit claimants restrict their abilities to control how they are perceived by others. Interestingly, this narrative is lacking in evidence and researchers have consistently failed to find a reduced work-ethic among benefit claimants (e.g. Macdonald, Shildrick & Furlong, 2014). This suggests that benefit claimants may be subject to an ‘imposed-identity’ (Brantlinger, 2009) which is not in line with how they view themselves. The implications for this are significant and link back to feelings of humiliation and shame as allocated group membership that is stigmatising can lead to internalised shame, humiliation and self-criticism (Pinel, 1999). Understanding of these internal experiences is imperative in order to inform how mental health services approach and support this population. For example, Gilbert (2009a) has put forward the argument that compassion is a powerful antidote to shame and humiliation. This suggests that ideas from compassion focused therapy (Gilbert, 2009b) could be beneficial in supporting benefit claimants who present with these difficulties.

It is also important to discuss mental health service provision within this period of economic instability and the psychological ramifications presented. In conflict to Governmental reassurances to create equality between mental and physical healthcare (Department of Health [DoH], 2014) budget-cuts have been significantly higher for mental health services than physical health services (NHS England, 2013). As a result services have attempted to make efficiency savings and meeting targets has become a priority (DoH, 2012). This has exacerbated difficulties in an already underinvested sector (Docherty & Thornicroft, 2015). One consequence of this is a reduction in practitioners’ abilities to provide flexible and person-centred care. Unfortunately the delivery of flexible and person-centred care have been consistently highlighted as approaches which help to mitigate some of the psychological and practical barriers that restrict individuals under financial strain from accessing mental health services (e.g. Kim & Cardemil, 2012; Pugach & Goodman, 2015). Thus austerity policies have placed vulnerable individuals at increased likelihood of requiring mental health support. However as a result of austerity related cuts to mental health services their needs are unlikely to be sufficiently met.

Personal Independence Payment

In 2012 the UK coalition Government’s Welfare Reform Act replaced Disability Living Allowance (DLA) with Personal Independence Payment (PIP) (Department for Work and Pensions; DWP, 2015). Atos and Capita (private companies who employ PIP assessors) have held the contracts for PIP assessments since its inception. Box 1 outlines the key features of PIP, including the eligibility criteria, the components to PIP and the difference between the standard and enhanced rates (source: Citizens Advice). Figure 1 provides a diagrammatic representation of the PIP application and dispute process (source: www.parliment.uk).

[INSTERT BOX 1]

[INSERT FIGURE 1]

PIP and Mental Wellbeing

Statistics show that 55% of new PIP claims and 38% of DLA reassessment claims are rejected (DWP, 2018). Of these rejections 9% are appealed (DWP, 2018a) – with 65% of these appeals being ruled in favour of the claimant (Grey, 2017). A cursory view of these statistics might imply that the majority of individuals (91%) are happy with their PIP outcome as they choose not to appeal. However, according to data published by the DWP the decision not to appeal is typically based on the anticipated stress of appealing (37%), feeing too unwell (20%) or a belief that it would not be effective (20%) (DWP, 2018b). It is important to consider the potential psychological impact of this high appeals-overturn rate. Claimants experience a reduced income whilst appealing. The appeal process puts them under emotional strain and having claims rejected is likely experienced as invalidating. The overturn rate alone suggests systemic ineptitude in the assessment of PIP eligibility and the way that the criteria are interpreted. In addition, the number of applicants who do not appeal the decision due to anticipated emotional strain suggests that the PIP process is unnecessarily stressful.

The PIP process has been found to be particularly difficult for individuals with cognitive difficulties, mental health concerns and learning disabilities. Research conducted by

Allen, Hale, Seton and Newton (2016) suggested that PIP claimants found the process complex and difficult to understand. Participants also reported that PIP assessments did not allow them to adequately explain how their condition impacted them. This was found to be particularly difficult for those with fluctuating symptoms or invisible illnesses (e.g. mental health). Furthermore, Varshini (2016) revealed that inconsistencies and intimidation were experienced by participants in face-to-face assessments, raising concerns regarding the level of psychological stress claimants may be experiencing.

The statistics and research findings outlined here reflect long-standing concerns around PIP and suggest that the current system is not only failing individuals with mental health difficulties but is actively working against them. This highlights the importance of research into the experiences of applying for PIP and the potential impact on mental wellbeing.

The Role of Mental Health Services and Clinical Psychology

Those who receive welfare benefits (including PIP) are more likely to experience mental health difficulties and report higher rates of suicidal thoughts, suicide attempts and self-harm than those who do not receive welfare benefits (e.g. mentalhealth.org, 2016; Ford et al., 2010). Thus a significant number of individuals who attend mental health services will likely be affected by PIP (Roulstone, 2015).

Many mental health services will offer individual therapy, medication or a combination of both. These interventions prioritise a reduction in ‘symptoms’ as a measure of success. Many individuals will be offered support via the Improving Access to Psychological Therapies (IAPT) model and will be offered Cognitive Behavioural Therapy (CBT). The focus within CBT is on identifying and changing ‘faulty thinking patterns’ and ‘maladaptive behaviours’ (Enright, 1997)- as well as how the individual can manage their experiences differently, how they can change and how they can see things from an alternative perspective. This reflects a misplaced assumption that the causes of distress are located within the person which can perpetuate the self-blame that benefit claimants can often feel, by placing their issues internally as opposed to externally, i.e. as a result of social injustice.

It has been argued that clinical psychology is overly concerned with changing the individual and that many psychological theories are ignorant of social context (Boyle, 2011). This avoidance of social context can be argued to maintain the social status-quo and protect the interests of the powerful (Ferraro, 2016). This has led to criticism that psychological theories can and have been used support a neoliberal political agenda (Teghtsoonian, 2009).

In order to prevent social issues being reframed as an individual issue it is vital that clinical psychologists have an understanding of the social factors which contribute to mental distress. Whilst the majority of psychologists are no doubt aware of this, it is important that understanding extends beyond awareness and thought is given to how this can be mitigated in the context of a profession where there is an element of one-to-one work. Failure to do so may result in individuals as viewing themselves as responsible for their social context which could lead to increased distress and self-blame (Goodman, Pugach, Skolnik & Smith, 2013).

The Power Threat Meaning (PTM) Framework (Johnstone et al., 2018) may be a useful model to consider in moving away from these individualising narratives. The focus is on contextualising distress and replacing diagnoses with individual narratives focused on issues of power, threat and meaning. Through this framework the social origins of distress are recognised and thought is given to how social narratives can impact wellbeing. The PTM framework can be applied to understanding distress due to experiences with the benefit system by demonstrating how *power* is held unequally through policies which maintain individuals’ circumstances and the stigmatising rhetoric. The *threat* is caused by austerity policies and welfare reform (e.g. Higson, 2016) and the *meaning* that individuals attach to this could be self-blame, guilt and a sense of worthlessness as individuals are left feeling at fault for their benefit claimant status and, by extension, the life circumstances that led them to claim benefits. Applying this framework could help to move away from existing narratives (e.g. scroungers vs deserving) and help form more useful narratives.

Given the impact of welfare reform and PIP on mental wellbeing it is important that clinical psychology focuses on developing knowledge, understanding and research into the social origins of distress. Clinical psychologists must take the lead in moving beyond the therapy room and look towards ways to address social inequalities, utilising their position of power and privilege to facilitate social change. This notion has led to the development of groups such as psychologists for social change[1] who aim to apply psychological theories to policy and political action.

Rationale for Current Research

It is important that research in this area progresses for three reasons. Firstly, it is vital that those supporting individuals with mental health difficulties have a comprehensive understanding of the challenges likely to impact this population. Secondly, there is currently little empirical research to support concerns that PIP may cause distress (e.g. Mattheys, Warren & Bambra, 2018; Shefer, Henderson, Frost-Gaskin & Pacitti, 2016); anecdotal evidence seen across the media is easily influenced by the political stance of the media outlet and surveys commissioned by charities are influenced by the interests of such charities, thus peer reviewed empirical papers are of particular benefit. Thirdly, before research can be translated into action there needs to be a relative degree of confidence regarding its accuracy, therefore, increasing research may facilitate reformist action.

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[1] www.psychchange.org/

Aims of the Study

The aims of the study are therefore: 1) to gain an understanding into individuals' experiences of applying for PIP due to a mental health difficulty and 2) to develop understanding around the impact that applying for PIP might have on mental wellbeing.

Method

Design

Interviews were used to explore participants’ experiences of applying for PIP due to mental health difficulties. The interview questions were developed collaboratively between the researcher and their supervisors following familiarisation with literature and discussions with individuals who had claimed PIP. The full interview schedule can be seen on page 4-34 and further information regarding the interview can be seen under ‘procedure’ in this paper.

Reflexivity Statement

I grew up in a predominantly working-class area of the UK with an above average number of people living below the poverty-line. I also have first-hand experience of claiming out-of-work benefits. Professionally I have worked within substance-use services, homelessness charities and foodbanks before beginning clinical psychology training in 2016. Through these roles I have direct experience of working with individuals whose mental wellbeing was impacted by welfare reform and austerity. These experiences have shaped my attitudes towards welfare reform, my beliefs about the social determinants of distress and will have inevitably influenced the theoretical and epistemological frameworks which underpin this research.

A critical-theorist stance is taken which considers the social, political, historical and ideological structures which shape society. The assumption that countries, such as the UK are unproblematically, democratic and free is questioned and the competing power interests between groups in society are considered (Kincheloe & McLaren, 2011). Critical-theory assumes that those in powerful positions have a vested interest in maintaining the status-quo. The dynamics of these efforts as well as issues of power and justice are central to critical research. In this respect critical-psychology is an underlying perspective within this research.

In recognition of the researcher’s own biases and the inherent challenges qualitative research can face in terms of bias management, several strategies were utilised to manage this. The use of supervision enabled the researcher to reflect on any emotional or biased responses and avoid incorporating them into the data analysis. In addition supervisors viewed interview extracts, initial coding and theme development throughout the research process. During the interviews the schedule was strictly adhered to and the researcher was conscious to not share their own opinions so as not to influence participants. Finally findings were compared to other research findings in this field as significant deviation from previous findings could indicate researcher bias.

Inclusion/ Exclusion Criteria

To be eligible to participate participants had to be aged 18-70. This reflects the age based eligibility requirement of PIP (16-64) and allowed additional years for older adults who may have received PIP previously. Those under the age of 18 were excluded due to issues in obtaining informed consent. Participants must have applied for PIP primarily due to mental health difficulties; individuals with physical difficulties or cognitive difficulties were included if mental health difficulties were a significant contributing factor. This was decided by the participant - if they felt their mental health difficulties were a primary influence in their decision to apply for PIP they were eligible to participate. Participants must have made the application within the past 3 years to ensure that participants had taken part in an up to date PIP process.

Recruitment and Participants

Initial recruitment began by contacting various Facebook groups which offered support to individuals applying for welfare benefits and asking them to share the recruitment poster (p.4-36) on their page. Unfortunately Facebook group administrators did not respond to these requests. This meant that the research was not as visible as the researcher had anticipated through this platform. Thus, this strategy resulted in no participants being recruited. However, the Twitter ‘hashtag’ and ‘sharing’ functions served as a useful means to overcome this barrier and provided the research with higher visibility on this platform- resulting in all participants being recruited via Twitter. O’Connor, Jackson, Goldsmith and Skirton (2014) provide a useful summary of how Twitter can be used in health-based research recruitment and detail the various functions that can facilitate wide sharing of research and thus recruitment. Their research also demonstrates that Twitter can enable engagement with individuals who may not be accessing services and provide a transparent, anonymous and accessible means to research participation.

Twenty-seven people expressed an interest in participating and were contacted to arrange an interview. This led to the recruitment of 14 participants: 11 took part in the interview over the phone and three took part via skype. The researcher was contacted by two individuals who expressed interest in participating yet did not find the research accessible due to their mental health difficulties. This led to the development of a qualitative “online-questionnaire”. Through the online-questionnaire the interview questions were displayed on-screen and a free-text option to respond was provided. This led to the recruitment of two more participants (see procedure section for details).

Table 1 provides details of the participants’ PIP applications and outcomes. This table has been included as it is important to consider the participants’ context when interpreting the results. Thirteen participants were receiving PIP at the time of the interview and three were not. Out of the 13 participants receiving PIP, six received reduced benefits following their reassessment from DLA to PIP. Eight participants had applied for “mandatory reconsideration” (see figure 1) following the outcome of their assessment and three participants had attended tribunals. Twelve participants had attended face-to-face physical assessments and four were awarded PIP with no face-to-face assessment. No further information (such as age, gender, location or ethnicity) was collected in order to protect the anonymity of participants.

[INSERT TABLE 1]

Ethics

Ethical approval was provided by the Lancaster University Faculty of Health and Medicine Research Ethics Committee on 05/10/2018. Requested amendments to send an online-questionnaire to participants was granted on 21/10/2018. See section four of this thesis for ethics application forms and approval letter.

Procedure

Recruitment began with an advert posted to Facebook and Twitter. This provided a link to the participant information sheet (p.4-26) which participants read before responding to a screening-survey (p.4-30) which ensured that they met the inclusion criteria. At the end of the screening-survey they were asked to provide their preferred method of contact. Finally, they were asked to view and sign a consent form (p.4-31). Following this, participants were contacted to arrange an interview.

The interviews lasted between 15-50 minutes, in which the researcher asked a series of questions related to applying for PIP. The interview was semi-structured, allowing for follow-up questions to be asked based on responses. The interview began with an open-question asking participants to describe their experience of applying for PIP. They were then asked about how the process made them feel and whether the process had any impact on their mental wellbeing. They were also asked about what support they received when applying for PIP and if this was experienced as helpful. Towards the end of the interview they were asked about what changes they would like to see regarding PIP. Finally they were asked if there was anything regarding their experience of applying for PIP which they had not discussed and would like to share with the researcher. During the interview the researcher asked follow-up or clarifying questions where appropriate. The interviews were recorded onto an encrypted audio-recording device and transcribed verbatim.

Individuals who had requested to participate via an online method were contacted once the required amendments had been approved in order to facilitate this. The researcher then provided these participants with a link to the online-interview where they read the same participant information sheet and consent form and completed the same screening survey as the other participants. Once these were completed the online-questionnaire was presented on-screen.

The online-questionnaires took between 13-35 minutes to complete, this was recorded via a function on the online survey tool (Qualtrics). For the online interview participants were presented with the questions from the interview schedule. This meant that these interviews were structured rather than semi-structured as the reviewer was not able to ask follow-up questions based on participants' responses. Implications of this are discussed within the results and discussion section.

Data Analysis

Thematic analysis (TA) was used to explore common themes within individuals' experiences (Clarke & Braun, 2014). A theme captures something salient within the data and represents a level of patterned response. TA often combines elements of inductive/ deductive analysis (Rohleder & Lyons, 2014). Pure induction is never possible because standpoints, epistemology and theoretical frameworks will influence how data is interpreted (Braun & Clarke, 2006). However, this research aimed to ground observations in the data rather than in prior theory, so in this respect, it was an inductive TA.

A number of steps were taken to analyse the data in this way as suggested by Braun and Clarke (2006). This involved familiarisation with the data set through reading and re-reading the transcripts. Following this, initial codes were generated. Appendix 2-B shows the initial codes extracted from each participant’s interview. Codes were then examined and arranged into common themes; this is demonstrated in appendix 2-C. This was done through examining the prevalence of certain codes and through arranging the codes into groups of similar/ related codes. The researcher’s supervisors examined interview extracts and initial codes. Discussions regarding emerging themes were held between the researcher and their supervisors. Following this the key themes were reviewed, defined and named.

Results and Discussion

Five themes emerged from analysis of the interviews documenting the experience of applying for PIP due to mental health difficulties:

1. PIP is ‘gruelling’ throughout –Designed to frustrate?
2. ‘Treated like a criminal’ - A dehumanising, criminalising process
3. ‘It’s life threatening for some people’ – Impact of PIP on mental health
4. ‘It feels like they’re trying to cull the weak’- Lacking a sense of belonging and worth in society
5. ‘They need to make improvements’ – How PIP could be improved

Information regarding participants represented in each theme can be seen in table 2. This table demonstrates that 15 participants found PIP to be a gruelling process (theme one) and found it negatively impacted their mental health (theme three). All participants felt that improvements to PIP were needed (theme five). However, only 10 participants felt that the process was dehumanising/ criminalising (theme two) and only six participants commented on impact on their sense of belonging in society (theme four). This might suggest that themes one, three and five are more robust than themes two and four and therefore they may be more generalisable. This should be held in mind when interpreting the results.

[INSERT TABLE 2]

Theme One: PIP is ‘Gruelling’ Throughout - Designed to Frustrate?

Participants discussed the gruelling and challenging nature of the application process. As Robin stated: *“Each stage has been gruelling…it slowed my heath recovery massively*.”

Six participants discussed difficulties in completing the form. This was experienced as stressful due to challenges in fitting mental health experiences into the layout of the paperwork which appeared to be more applicable to physical health. Some felt that the forms were intentionally complex in order to deter potential claimants from applying e.g: *"The form is very puzzling and it makes you think that it's been done in that way on purpose so that you'll give up time filling it in and they've got less people to pay for then."* (Jamie).

In terms of reducing distress this highlights the potential advantages of claimants receiving support with their PIP paperwork. In fact several participants reflected that support received from family, charities or mental health professionals eased some of the stress associated with making PIP applications e.g. *"I wouldn't have got my PIP without my mental health workers. They helped me with the forms, I was going to give up. Like I imagine most people do"* (Frankie). The benefits of support in filling in claims paperwork has been demonstrated in research into the use of welfare-advisors in primary care settings (e.g. Greasley & Small, 2005; Wise, 2015).

When discussing the assessments it was evident that many participants experienced discomfort in being expected to share their mental health experiences with a stranger. This highlighted the exposing nature of discussing mental health difficulties with those who may be feared and who may not have established a trusting rapport. As Robin described: *"It's definitely upsetting especially if you have to go through to the physical stage of meeting with someone and having to expose all that darkness to some stranger.*" This quote also highlights the experience of shame that many feel as a result of the stigma surrounding both claiming benefits and mental health difficulties (e.g. Kim, Thibodeau & Jorgensen, 2011). For some, the difficult nature of discussing mental health difficulties resulted in distressing experiences during the assessment; Billie stated: *"I started hearing voices and became dissociated and couldn't answer very well"*. This suggests that the assessment has the potential to be so difficult that claimants experience distressing mental health difficulties within the room. It was noted by one participant that this presents a safeguarding concern: *"There's a complete* *lack of care, even safeguarding to make sure people who are walking out of the appointments aren't going to kill themselves before they get home"* (Rudy). Here, Rudy observed that distressing topics are brought to the surface in assessments which are not managed safely and that this could result in an individual taking their own life. In fact, Barr et al. (2016) found that assessments for out-of-work benefits were linked to increases in suicide rates. Whilst the Government has argued that these findings are misleading (Buchanan, 2015) there are many reported instances in which individuals have taken their own life as a result of welfare reform driven assessments (Calum's list, 2019; Spartacus Network, 2015). In light of this it is somewhat surprising that neither Capita nor Atos assessors are required to undertake any training in suicide intervention (PPRproject, 2018). Evidence points to a link between these assessments and increased risk of suicide. A systemic failure to safeguard against this is arguably violation of individuals' human rights under Article 2 of the Human Rights Act- 'a right to life'. This outlines individuals' rights for their life to be protected as well as the Governments' responsibility in safeguarding against threat to life (Human rights Act, 1998).

Theme Two: 'Treated Like a Criminal': A Dehumanising, Criminalising Process

Feelings of being criminalised and dehumanised by the PIP process were expressed by 10 participants. This was summarised succinctly by Robin who stated: *"I just felt dehumanised";* this is reminiscent of how each participant represented in this theme described feeling, thus fewer quotes are provided in this theme in order to avoid repetition. The psychological impact of feeling dehumanised impacted mental wellbeing, e.g:

> *I just felt completely dehumanised and I felt beaten down, after each tribunal I went into a spiral, a mental health spiral that lasted a couple of months because of just how, almost surgical and unfeeling the whole thing is* (Robin).

Participants also discussed the fact that tribunals are held at Magistrates courts and the criminalising impact of this; as one participant expressed *"the psychological side of it…you're in a criminal court, where people go because they've done wrong"* (Jamie). As Jamie points out there are psychological processes at play here, as the implication of being in court is that you are a criminal, that you are lying or guilty and that you need to defend yourself. This led to a heightened state of anxiety which holds the potential to impact the proceedings as well as their overall psychological wellbeing.

The experience of criminalisation and dehumanisation has been highlighted in Von-Sommaruga-Howard's (2016) recent review exploring the current neoliberal narrative and its consequences where the dehumanising aspects of austerity were discussed. This was regarded as a means of maintaining 'the other' (the disadvantaged) in positions of low power. In the USA, Wacquant (2009) has suggested that welfare claimants are portrayed as deviant and argues that this allows claimants to be transformed into *"cultural similies of criminals who have violated the civic law of wage work"* (p.60).

Theme Three: 'It's Life Threatening for Some People' - Impact on Existing Mental Health Difficulties

For all but one of the participants the process of applying for PIP had a negative impact on mental health. Examples included: increases in self-harm, anxiety, voice-hearing, difficulties eating, dissociation and a flare up in a physical health condition triggered by stress. One participant disclosed that they had attempted suicide as a result of PIP: *"after getting the letter I started self-harming more, my mental health got worse and worse to the point that I was sectioned and nearly killed by a train"* (Billie); and two stated that they been sectioned under the Mental Health Act as a result of PIP: *"my anxiety worsened significantly and the stress led me to being sectioned"* (Alex) and *"it was mostly to do with this PIP form* *that I was sectioned"* (Billie). In fact, a total of eight participants (50%) discussed an increase in suicidal thinking and planning as a result of PIP, highlighting the potentially life-threatening nature of the PIP application process.

In addition to the direct impact of PIP on mental health, five participants discussed the financial implications of being denied PIP and the impact this had on their mental health with one participant explaining: *"the immediate loss of half your income, it made me suicidal"* (Lee). Participants explained that concerns about financial insecurity had an impact on their mental health. This appeared to be a result of a threat to stability and security. *"I worry… Am I going to lose my home?"* (Jamie). This threat to stability and security is likely to have significant impact on mental wellbeing.

It is important to note that one participant (Daryl) reported that their mental health was not negatively impacted by PIP. They attributed this to the fact that they had not been asked to attend a face-to-face assessment following recommendations from a healthcare professional to the DWP. This suggests that one way mental health professionals may be able to support benefit claimants is by contacting the DWP to recommend against a face-to-face assessment if it is felt that this would put an individual at significant risk[2].

Theme Four: 'It Feels like They're Trying to Cull the Weak'- Lacking a Sense of Belonging and Worth within Society

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[2] It is important to state that several participants' healthcare professionals also made this recommendation. However it was inconstantly adhered to by the DWP. Therefore this support does not guarantee exemption from a face-to-face assessment.

This theme discusses participants’ sense of belonging and worth within society, participants’ perception of the relationship between themselves and those in power, and the impact of stigma. For some participants their sense of belonging in society had been deeply impacted by the PIP process, as well as the wider rhetoric around benefits claimants. This theme focuses on social and institutional stigma (Baumberg et al., 2012). Social stigma refers to a perception that others have regarding benefits-claimants and institutional stigma refers to stigma that arises from the process of claiming benefits. Baumberg et al. (2012) found that institutional stigma was the most common form of stigma reported by benefits claimants followed by social stigma.

In the UK various media outlets and politicians have contributed to the increasingly negative attitudes towards benefits claimants (Pemberton, Fahmy, Sutton & Bell, 2016). Jamie explained how this led to an increase in withdrawal and fear of being identified as a benefit claimant whilst in the community: *“Now you just don’t want anyone else to know that you might be claiming PIP because you hear quite a lot of the way people are verbally abused out in public so it makes you become more withdrawn”* (Jamie). A similar finding was seen in Garthwaite’s (2015) research on stigma and identity in long term sickness benefits recipients. The potential psychological ramifications of this are increased loneliness and isolation. Isolation and loneliness have been linked to increased risk of mental health difficulties (Bhugra & Arya, 2005; Cornwell & Waite, 2009). Thus policies which increase isolation and loneliness directly threaten mental wellbeing.

Comments from participants, in particular those which reference the dominant ‘benefit scrounger’ narrative, highlight a profound disconnect between those in power and those who are struggling to make ends meet as a result of increased difficulty in accessing welfare support. This points to one of the most contentious narratives associated with austerity - the idea that a person who receives benefits is worth less to society. Unsurprisingly this was seen to generate feelings of ‘worthlessness’ among participants: *“It just makes you feel worthless and it makes me feel like I’m a burden and the government would rather I ended up as a suicide statistic because it’d cost them less money.*” (Rudy). This feeling was even echoed by Dylan who had been awarded PIP with no face-to-face assessment. This highlights that even for those who are spared face-to-face assessments, rejections and tribunals, the rhetoric that surrounds PIP and welfare recipients more generally can be emotionally damaging. Dylan had attended a judicial review regarding the mobility component of PIP and stated:

> *I’ll never forget what it felt like to have lawyers paid by the government standing up in court and arguing in favour of policies that are clearly there to discriminate against people like me. It makes me feel so unsafe, on such a deep foundational level that the government hate you that much, that they’ll pay all this money to all these lawyers just to take away the things you need.*

Another participant described how they felt that the process of applying for PIP was intentionally difficult and frustrating in order to put people off applying and to refuse as many people PIP as possible: *“It almost feels like they’re trying to cull the weak, the things that they’re doing. I know it sounds extreme but a lot of people have ended up killing themselves over these assessments.”* (Morgan).

Participants’ comments speak volumes about the impact of social and institutional stigma on well-being and sense of belonging within society. It would therefore be unwise to underestimate the profound impact that the negative portrayal of those receiving benefits can have on an individual level. This theme suggests that for those who have prior vulnerabilities and see themselves as being subject to relentless public vilification at the hands of elected politicians and the media there is more than likely going to be a significant impact on sense of worth, self-esteem, self-respect and mental health.

Theme Five: ‘They Need to Make Improvements’–How PIP could be Improved

Every participant expressed that improvements need to be made to the PIP process to make it a more manageable experience and to make it suited to assessing the needs of individuals with mental health difficulties. Key areas highlighted for improvement were: a) to make the process (the forms and assessments) more mental health focused; b) for assessors to increase their knowledge of mental health difficulties and; c) for greater emphasis to be placed on evidence provided by healthcare professions at the decision-making stage.

Many participants felt that the PIP forms and the questions they were asked in assessments did not allow them to accurately portray the nature of their mental health experience and how it impacted them on a day to day basis. For example Charlie explained that *“a lot of the questions are totally irrelevant to mental health”.* Furthermore, some questions could be argued to be discriminatory against mental health. This is due to a failure to recognise the fluctuating and complex nature of such difficulties which are unlikely to be captured within a simple ‘yes/no’ response. Bobbie provided the following example:

> *Take a simple example is a question like…do you have a bank card? Yes or no… from that they make assumptions about your ability to manage your own spending and stuff. Now obviously bipolar, common symptom… problems managing money, so you should score a point, but because you’ve got a bank card and it’s yes or no.*

The focus on physical health and the lack of opportunity to adequately express mental health difficulties left some participants feeling that their mental health difficulties were not seen as important, as Rudy described: *“it implicitly invalidates the reality of my mental health experiences”*. This raises the question of whether mental health difficulties are being intentionally devalued in these assessments and if so, how does this fit with the government's promise to create a parity of esteem between mental and physical health? (HM Government, 2011).

Participants also expressed concerns regarding the assessors' limited mental health knowledge with several highlighting that *"there needs to be more understanding from the people who are doing the questioning about exactly what mental health is"* (Jo). For Morgan this lack of knowledge resulted in inappropriate questions regarding depression: *"I think there could be a lot less invasive questioning… like 'why haven't you killed yourself yet?"*. Similar experiences were reflected by several participants whereby lack of mental health knowledge resulted in insensitive and invasive questioning. This line of questioning is highly inappropriate, particularly as the individual is offered no therapeutic support within or following the assessment and would lose their benefit entitlement if they opted to end an assessment. This raises concerns regarding risk of harm and whether assessors are working within their remit. These concerns are explored in further detail later in 'professional issues'.

Finally, participants felt that greater focus on the evidence provided by their healthcare professional would be advantageous. Taylor argued that *"evidence sent in from the mental health teams should be given far more weight"*- suggesting that this would be a more reliable assessment of difficulty. However, as Jordan expressed: *"They sometimes completely disregard what your mental health professional says".* In fact several instances were noted whereby participants felt that medical evidence was ignored by the assessors.

Strengths and Limitations

This is one of few studies considering the impact of the PIP process on mental wellbeing using a participant group who experience mental health difficulties. In-depth accounts of participants’ experiences were beneficial given the relative lack of research in this area. The results of this research are consistent with findings from similar studies in the area of welfare reform and mental wellbeing (e.g. Garthwaite, 2014; De wolfe, 2012; MacDonald, Shildrick & Furlong, 2014) suggesting that these feelings are experienced widely amongst people applying for PIP.

It is also acknowledged that individuals may have been more likely to volunteer to participate in this research if they had a negative experience of their PIP application. Therefore potential bias within the sample must be taken into account when considering the generalisability of these findings. However, the majority of the participants were successful in their PIP applications, suggesting that unsuccessful applications was not a factor which motivated participation. In addition, recruitment via Twitter meant that individuals who were active in speaking about benefits claims or mental health on Twitter were more likely to see the recruitment advert and thus participate which could have increased bias within the sample. It also excluded individuals who did not use Twitter.

Two participants took part via the online-questionnaire. This enhanced the inclusivity and accessibility of the research. Whilst this is seen as a strength to the research it is equally important to acknowledge the limitations it presented because less data was collected via the online-interview as follow-up questions were not asked. If this research were to be repeated e-mail would be considered as an alternative way to collect this data (e.g. McAuliffe, 2003). This would allow for follow-up questions to be asked.

The use of phone and Skype interviews allowed participants from various geographical locations to participate without the need to travel. It also allowed participants to speak to the researcher in a location they have chosen themselves - thus they are more likely to feel at ease (McCoyd & Kerson, 2006). However, it is important to be mindful that relying on technologies such as the internet, skype, phones and e-mail for interviews has limitations. Use of these strategies excludes those who do not use or do not have access to these technologies (Morris, 2013). In addition, some researchers have argued that important visual cues are absent when phone or skype is used (e.g. Garbett & McCormack, 2001). However the lack of visual cues in phone interviews may have mitigated against researcher bias as feedback cues (e.g. nodding to indicate agreement) were not seen by participants.

Finally, it is important to consider limitations of using TA to analyse the data. Using TA meant that emerging themes could not always be sufficiently explored with participants as the interview schedule remained the same throughout the interviews. Thus themes such as 'Theme 4: Lacking a Sense of Belonging and Worth within Society' were not developed in as much depth as they might have been had Grounded Theory (Glaser & Strauss, 2017) had been used.

Professional Issues

PIP assessments are carried out by healthcare professionals registered under professional bodies with strict codes of professional standards from the Health and Care Professions Council (HCPC) and the Nursing and Midwifery Council (NMC)therefore they must comply with their codes of conduct.

However, in the current study several instances are highlighted where this may not be the case. The HCPC state that: '*you must keep within your scope of practice by only practising in the areas you have appropriate knowledge, skills and experience*' (HCPC, n.d. p.6). There is no requirement for staff employed by Capita to have any previous experience in mental health (www.capitapipjobs.co.uk). This raises the question of whether it is appropriate for staff with no training to assess the needs of individuals with mental health difficulties.

The HCPC also state that: *’you must not do anything, or allow someone else to do anything, which could put the health or safety of a service user, carer or colleague at unacceptable risk’* (HCPC, n.d. p. 8). Given that participants in this research discussed worsening mental (including suicide attempts) as a result of their face-to-face assessments it is likely that this standard is not consistently adhered to.

These regulatory bodies have a responsibility to evaluate whether professionals are causing harm to individuals and are no longer in compliance with their professional codes of conduct. It is suggested that other registered healthcare professionals urge their professional bodies to address this concern.

Recommendations

On the basis of this research and other research in this area, several recommendations have been made. It is acknowledged that many of the recommendations made in this section are not novel and have been suggested by others within the mental health profession. However, time and resources need to be allocated to allow progression from recommendations to practical change and tackle any barriers which restrict abilities to do so. Debates around this are covered in more depth in section three of this thesis.

Mental health services

Mental health services should ensure that discussions around benefits and ongoing claims are incorporated into assessments. In doing so, practitioners should ensure that distress around benefits claims is treated empathetically and individuals are made aware that they are not alone in experiencing this. Practically, services should encourage practitioners to provide supporting evidence to the DWP and consider how this additional task may impact caseloads. Furthermore mental health services should develop links with community groups offering support around benefits claims and ensure that relevant individuals are signposted accordingly. If local groups are unavailable it is suggested that services consider providing this.

Clinical psychologists

Clinical psychologists should emphasise approaches which take into account social context and openly explore this. For example, through narrative therapy (which views people as separate from their problems) a contextualised understanding of an individual's difficulties can be developed through externalising distress (Epston, 1992). In fact, it has been suggested that narrative therapy acts as a form of activism by challenging and resisting dominant cultural truths (White, 2004). Through this approach therapist and client can deconstruct unhelpful narratives which contribute towards distress.

Psychologists could also work more broadly, within communities and wider social systems in order to respond to the distress caused by changes to the welfare system. Through community psychology (Levine, Perkins & Levine, 1997) an active role can be taken in identifying and challenging the welfare reforms, political narratives and social contexts which can lead to distress. This could be through researching the impact of welfare reform, using the findings to inform assessment, formulation and treatment as well as disseminating findings with policy makers, politicians and services. Finally, clinical psychologists are encouraged to use their position to urge the Government to overhaul the PIP assessment process to ensure that it is fit for purpose.

Policy makers

During the interviews participants made several suggestions regarding improvements that could be made in the implementation of PIP. Most participants reflected that if assessors had specific knowledge related to their condition this would make the assessments less daunting. Whilst this may not be feasible, one suggestion may be to employ individuals who can act as consultants to DWP/ Capita staff who are not familiar with the condition they are assessing. In addition, as Grey (2017) recommended in the second independent review of PIP assessments, rigorous quantitative and qualitative evaluation should be undertaken which prioritises focus on the effectiveness of PIP for mental health. Finally, steps should be taken to address the stigma associated with claiming benefits. Increased awareness on the reality of experiencing mental health difficulties and claiming benefits may help to address this. This might involve providing training to politicians and assessors.

Future Research

Discussions with participants yielded interesting suggestions for future research. One participant felt that their diagnosis of autistic-spectrum-condition (ASC) created additional challenges in claiming PIP and suggested that this should receive some research attention. Research into the impact of PIP on individuals with ASC (and neurodiversity more generally) would be of benefit due to recent statistics have showing that almost a quarter (24%) of individuals who listed some form of learning difficulty or neurodiversity as their reason for applying for PIP had their benefits cut between 2016 and 2018 (DWP, 2018). As a ‘hidden disability’ the impact on an individual’s ability to manage with day-to-day life may not be apparent in in assessments. Another participant expressed their fear of Universal Credit (a new form of welfare benefit being gradually introduced across the UK) and how this might impact their mental health. Further research might consider exploring this. This would be beneficial as concerns have been raised that Universal Credit is likely to significantly impact mental wellbeing in those who receive disability benefits (Mind, 2017; Dwyer & Wright, 2014).

Conclusions

This research suggests that PIP is not a suitable or safe method of assessing the needs of individuals with mental health difficulties. The process of applying for PIP had a negative impact on all but one of the participants' mental wellbeing and several discussed thoughts of suicide or suicide attempts. This highlights the severely distressing nature of PIP and brings to light a significant risk issue which, if unmanaged, could have devastating consequence to individuals, families and communities. This impact on mental wellbeing indicates that clinical psychologists and mental health professionals should play a role in attempting to mitigate some of the psychological ramifications of PIP. This could be done through ensuring services are designed in a stigma free way and that difficulties with the welfare system are openly discussed. Beyond this professionals are encouraged to urge the Government to re-evaluate the current welfare system as the overriding message from this research is that PIP is not fit for purpose and urgent overhaul is needed.

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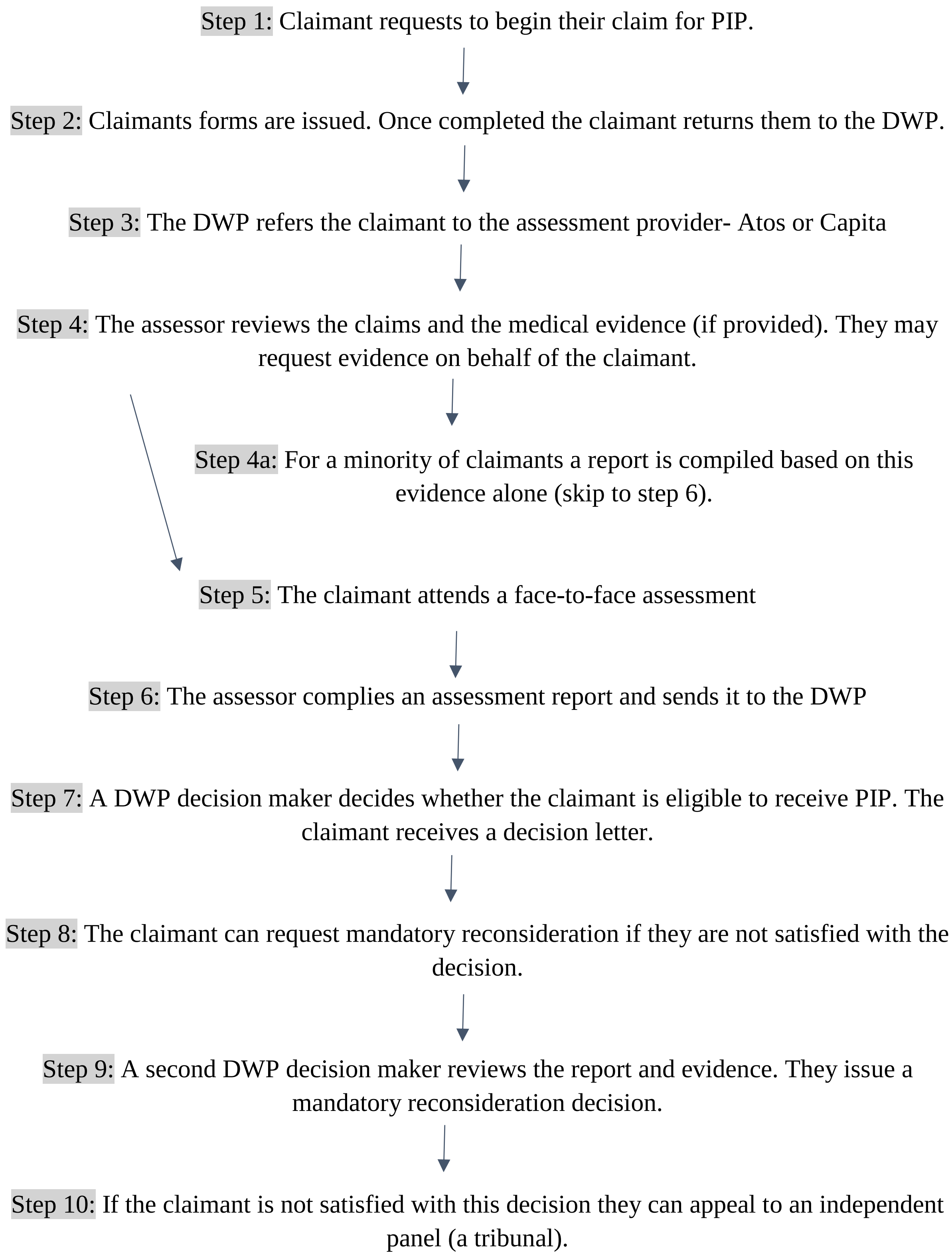
Box 1: Key Features of PIP

- PIP is a form of welfare benefit awarded to individuals who need extra money to support them with everyday living due to illness disability or mental health conditions. Eligibility requires that individuals must:
    i. be aged 16-64
    ii. need support with everyday tasks
    iii. have needed this support for three months and expect it to continue for a further nine months
    iv. have been living in England, Scotland or Wales for at least two years
- PIP is made up of two components, a daily living component and a mobility component.
- PIP is paid at either a standard or enhanced rate depending on level of need
- The standard rate for daily living is £57.30 a week and the enhanced rate for daily living is £85.60. The mobility standard rate is £22.65 and the enhanced rate is £59.75.
- Individuals who apply for PIP are assessed by a health professional (usually a GP, nurse, occupational therapist or paramedic).
- Assessors send a report to the DWP where a decision maker will decide whether an individual is entitled to PIP, which components they are entitled to, the rate which they are entitled to and for how long they should receive it.

When PIP is due to end an individual will be reminded to make a new claim and will be asked to repeat the above process to make a new claim (the length of the claim varies according to the individual and is based on the likelihood of their condition changing)

Figure 1: PIP Assessment and Dispute Process



Step 1: Claimant requests to begin their claim for PIP.

Step 2: Claimants forms are issued. Once completed the claimant returns them to the DWP.

Step 3: The DWP refers the claimant to the assessment provider- Atos or Capita

Step 4: The assessor reviews the claims and the medical evidence (if provided). They may request evidence on behalf of the claimant.

Step 4a: For a minority of claimants a report is compiled based on this evidence alone (skip to step 6).

Step 5: The claimant attends a face-to-face assessment

Step 6: The assessor complies an assessment report and sends it to the DWP

Step 7: A DWP decision maker decides whether the claimant is eligible to receive PIP. The claimant receives a decision letter.

Step 8: The claimant can request mandatory reconsideration if they are not satisfied with the decision.

Step 9: A second DWP decision maker reviews the report and evidence. They issue a mandatory reconsideration decision.

Step 10: If the claimant is not satisfied with this decision they can appeal to an independent panel (a tribunal).

Table 1: Outcome of Participants PIP Applications and Processes

Participant	***Receiving PIP***	***Not receiving PIP***	***Receiving less PIP following DLA***	***Attended a face-to-face assessment***	***Did not attend a face-to-face assessment***	***Applied for mandatory reconsideration***	***Attended a tribunal***
Robin		X		X		X	X
Charlie			X	X		X	
Bobbie	X			X			
Jo		X		X		X	
Daryl	X				X		
Jamie			X	X		X	X
Frankie	X			X		X	
Morgan	X			X			
Rudy		X		X		X	
Stevie			X		X		
Taylor			X	X			
Billie	X			X		X	
Jordan	X			X			
Dylan	X				X		
Lee	X			X		X	X
Alex	X				X		

Table 2: Participants Represented within each Theme

Participant	***Theme 1: PIP is ‘gruelling’ throughout: designed to frustrate?***	***Theme 2: ‘Treated like a criminal’ - a dehumanising, criminalising process***	***Theme 3: ‘It’s Life Threatening for Some People’ - Impact on Existing Mental Health Difficulties***	***Theme 4: ‘It feels like they’re trying to cull the weak’- lacking a sense of belonging and worth in society***	***Theme 5: ‘They need to make improvements’ –How PIP could be improved***
Robin	X	X	X		X
Charlie	X		X		X
Bobbie	X	X	X		X
Jo	X	X	X		X
Daryl					X
Jamie	X	X	X	X	X
Frankie	X	X	X		X
Morgan	X	X	X	X	X
Rudy	X	X	X	X	X
Stevie	X	X	X	X	X
Taylor	X	X	X	X	X
Billie	X	X	X		X
Jordan	X		X		X
Dylan	X		X	X	X
Lee	X		X		X
Alex	X		X		X

Appendix 2-A

Journal of Mental Health- Author Guidelines

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Appendix 2-B

Initial Codes Identified in Each Participants' Interview

Participant	*Initial codes*
Robin	worrying, criminalised, lack of empathy, stressful, negative impact on mental health, anxiety, uncertainty, cycle of reassessment, dehumanising, clinical, unfeeling, uncaring, unprofessional assessors, focus is on physical health, feeling judged, cold, unfeeling, lack of emotion, lack of compassion, trapped, stuck
Charlie	financial impact, negative impact on mental health, less anxiety due to not having a face-to-face assessment, focus on physical health, biased against mental health
Bobbie	cycle of reassessments, emotional process, stressful wait, uncertainty, insecurity, negative impact on mental health, treated like a liar, questions not suited to mental health difficulties, mental health team involvement
Jo	lack of knowledge about mental health, insensitive questions, poor organisation of DWP, dehumanising, anxiety, not suitable for mental health, fear of being seen as a liar, guilty, negative impact on mental health, stress, lack of humanity, scrutinised
Daryl	focus on physical difficulties, reduced stress due to no face-to-face assessment, questions not suited mental health, not accessible, fear of reassessment, cycle of reassessments
Jamie	confusing, self-doubt, criminalised, inaccuracies in report, vulnerable, draining, treated like a liar, lack of warmth, negative impact on mental health, suicidal, complex form, fear of losing home, stability, uncertainty, unfair, cruel, negative media portrayal, stigma, negative perception of claimants, withdrawn
Frankie	anxiety, inaccuracies in report, degrading, lack of empathy, questions not suitable for mental health, portrayed as a liar, criminalised, suicidal, financial impact, negative impact on mental health, fear of reassessment, self-doubt
Morgan	DWP poor organisation, stressful, long waits, ashamed, lack of compassion, dehumanising, questions not suited to mental health, degrading, insensitive questions, fears of universal credit, suggested improvements
Rudy	risk, safeguarding, hostile, assessor lack understanding of mental health, worthless, unwanted, burden, stigma, worthless, shame, invalidates mental health, focus on physical health, degraded, cycle of reassessment, fear, suicidal thoughts, not suited to mental health difficulties, traumatic, suicide, targeting vulnerable people, interrogated, criminalised
Stevie	negative expectations, focused on physical health, unsympathetic, questions not suited to mental health, lots of paper work, difficult to write about

	mental health difficulties, less stress due to not having a fact-to-face assessment, negative portrayal in the media, stigma, feeling like a fraud, stressful
Taylor	designed to be hard, vulnerable, upsetting, judged, looking for inconsistencies, discriminated against, made to feel like a liar, negative impact on mental health, cycle of reassessment, fear of reassessment, medical evidence, questions not suited to mental health, insensitive, stressful, designed to take support away.
Billie	life threatening, judgement, security, negative impact on mental health, self-harm, lack of respect towards gender diversity, fear of reassessment, support needed to fill in forms, traumatic, questions not suited to mental health, assessors unaware of how to manage mental health difficulties, psychological difficulties in the assessment, suicidal, paranoia, sectioned
Jordan	negative impact on mental health, anxiety, feeling useless, focus on negative, stressful wait, lack of control, negative impact of the forms, fear of reassessment, medical evidence,
Dylan	humiliating, cruel, unsafe, hated, unwanted, mental health professionals need to be involved, medical evidence, suicidal, humiliating, waste of space, reminder of weaknesses, long waits, cycle of reassessments
Lee	feeling worthless, ashamed, overwhelming, uncertainty, made to feel like a liar, traumatic, long process, felt stupid, feelings of worthlessness, stress, self-hatred, shame, financial difficulties, exposing, withdrawn, isolated, fear of reassessment, fear of being seen as a liar, fear of been seen as a fraud, scrutinised, judged, vulnerable, traumatic, threat to stability, suicidal
Alex	need for mental health professionals to be involved, not suited for mental health, focus on physical health, medical evidence, responsibility, cost, long process, fear, cycle of reassessments, anxiety, stress, long waits, uncertainty, negative impact on mental health, sectioned, lack of support from mental health team

Appendix 2-C

Initial Codes Used to Develop Each Theme

PIP is 'gruelling' throughout: designed to frustrate?	*'Treated like a criminal' - A dehumanising, criminalising process*	*'It's life threatening for some people' –Impact of PIP on mental health;*	*'It feels like they're trying to cull the weak'- Lacking a sense of belonging and worth in society*	*'They need to make improvements' – How PIP could be improved.*
not suited for mental health, focus on physical health, designed to be hard, traumatic, complex form, confusing, made to feel like a liar, financial difficulties, support needed to fill in forms, cycle of reassessment, reminder of weaknesses, negative impact of the forms, risk, safeguarding	fear of being seen as a liar, felt judged, fear of been seen as a fraud, lack of empathy scrutinised, clinical, unfeeling, uncaring, degrading, cold, unfeeling, lack of emotion judged, vulnerable, exposing, humiliating, unsafe, lack of respect towards gender diversity, hostile, interrogated, criminalised, dehumanised	fear, anxiety, stress, uncertainty, negative impact on mental health, self-doubt sectioned, life threatening, fear of losing home, stability, uncertainty threat to stability, suicidal, paranoia, feeling worthless, ashamed, overwhelming, withdrawn, isolated self-hatred, shame, self-harm, less stress due to not having a fact-to-face assessment	hated, unwanted, waste of space, worthless, designed to take support away, negative portrayal in the media, stigma, hostile, burden, targeting vulnerable people, negative perception of claimants	need for mental health professionals to be involved medical evidence, long waits, not accessible, cancellations by DWP, not suited for mental health, focus on physical health, assessor lack understanding of mental health, DWP poor organisation

Section Three: Critical Appraisal

Critical Appraisal

Charlotte Thompson

Trainee Clinical Psychologist

Lancaster University

Word count- 3998

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This critical appraisal involves three distinct sections. The first section provides an overview of the thesis findings and the contribution to the existing literature base. The second section explores methodological issues, with focus on the potential for researcher bias and reflections in managing this. I will also reflect on areas that I could have explored further and discuss my hopes for how this research may influence services and policy. In the third section I reflect upon a debate which underlies the clinical recommendations made in the empirical research and literature review - the political, personal and professional intersections of psychology and social justice. This will involve a critical exploration of the role of clinical psychologists in either maintaining the status quo or being a driving force for social change.

Section one

The literature review demonstrated that stigma is a common experience in the day-to-day lives of individuals' who receive benefits and that this is experienced through several levels, meaning that stigma is entrenched to such an extent that it not only impacts individual wellbeing but also relationships and communities. This literature review drew attention to the process of 'othering'; this has been discussed in several papers regarding benefit claimants experiences, however this literature review acted as a means to pull these papers together and highlight that this is a common phenomenon discussed by participants. This review expanded discussion of stigma from focus on the individual impact to give greater consideration to the wider social reach and impact of stigma, highlighting the way in which stigma can serve to maintain the status quo and justify oppressive policy.

The empirical component to this research highlighted the distressing nature of Personal Independence Payment (PIP) applications and the significant impact PIP can have on mental health, self-esteem and self-worth as well as its potential to be 'life threatening' for some individuals. This finding generated important clinical recommendations regarding risk management in relation to individual mental health and ongoing benefit claims. It also explored the impact that claiming benefits can have on individuals' sense of worth and belonging in society which has received limited attention in previous research. This research drew attention to a consensus that as it currently stands PIP is not a sufficient method of assessing mental health need.

This thesis adds to the current literature base by drawing attention to the distressing, detrimental and damaging impact that welfare reform policies and benefit stigma can have on individuals, society, relationships and communities. This is explored from a psychological perspective, thus the role of clinical psychology in alleviating distress is explicitly considered and important recommendations for clinical practice in light of the findings are made.

Section two

Researcher bias

Yardley (2008) states that researcher bias is inevitable in qualitative research. It was therefore important to remain aware that my experiences, background, theoretical opinions and way of seeing the world could have impacted how I viewed and interpreted data. Yardley (2008) argues that biases can be useful in exposing hidden meanings within data. In addition, I reflected that if I had not witnessed suffering, pain and distress as a result of austerity and welfare reform I would not have developed a bias against these policies and ultimately I would not have pursued this research. Therefore I began to question whether it is not only is impossible to remove bias from qualitative research but if in some instances biases could generate and inspire research.

In acknowledging this it was important to hold biases in consciousness throughout the research process and to be open-minded to the possibility that they may be inaccurate. The use of supervision and reflective logs facilitated this through providing time dedicated to exploring biases. In addition, the inclusion of a reflexivity statement and an overview of my epistemological stance within the method section of the empirical paper will hopefully allow readers to place the findings within the context of the researcher.

Perhaps the most influential source of bias was in the way that I viewed and related to those who participated. I saw the participants as legitimately in need individuals who were being systematically let down, silenced and denied their rights. I felt that they were being simultaneously victimised and villainised by the media and those in power. I was therefore conscious of my desire to portray my participants as anything other than ‘scroungers’, ‘lazy’ or ‘undeserving’. I hoped to generate a more compassionate narrative. This alliance with the participants can be understood as embracing ‘insider status’ Le Gallais (2008) which may have facilitated more open and honest interviews with participants.

Due to these biases the research component of this thesis can be most accurately viewed as a partial representation of the experiences of applying for PIP as it is influenced by the contexts of the participants, the researcher and the research supervisors.

Exploring stigma in more depth

Following the development of themes in the research component, I wondered if I should have explored stigma within the interviews. Stigma was discussed by several participants without it being explicitly inquired about. This implied that stigma was a common experience and may have impacted the wellbeing of participants. In fact, I felt it myself as I deliberated whether or not to disclose my own experience of claiming out-of-work benefits in my reflexivity statement.

Perhaps the neglect to ask about stigma was due to viewing it as a result of the neoliberal discourse around claimants rather than as directly relevant to the experience of

PIP. In this respect I wonder if my focus at the start of this process was too narrow. I focused on how individuals perceived the experiences of PIP (the paperwork, the assessments, the tribunals etc.) but did not consider how wider contextual issues and narratives might have impacted wellbeing. I wonder also whether this is a reflection of the criticism that clinical psychology can neglect the social determinants of wellbeing in research and in therapy (Harper, 2016). In recognising that stigma may have been experienced by some of the participants and a retrospective desire to explore this further, I made this the focus of the literature review.

Hopes for this research

I hope that this research will draw attention to the impact that claiming benefits can have on mental wellbeing. I hope that if mental health practitioners are aware of this they will: ask about difficulties with ongoing claims in initial assessments, normalise distress as a result of difficulties with claiming benefits, take appropriate steps to safeguard against risk and incorporate their understanding of distress, in response to benefits claims and benefits stigma, into their understanding of the individual. In this respect I hope that practitioners can help to prevent this distress from becoming internalised and clients can be empowered to see the system as the problem as opposed to themselves.

I hope that services might develop in response to increasing understanding that reforms to social policy are leading to distress. Possible developments might include: exploring benefits claims in risk assessments, the development of benefits support groups and allocated time for practitioners to support clients with benefit claims.

Finally, I hope that this research will encourage professionals to use their position to encourage those in power to urgently review the suitability of PIP in assessing the needs of individuals with mental health difficulties. Ideally, this would extend to questioning the ethics of Health and Care Professionals Council (HCPC) and Nursing and Midwifery Council (NMC) registered professionals carrying out assessments for benefits.

Section three: clinical psychology and politics

In both the empirical paper and literature review in this thesis several recommendations were made. These predominantly centred on a need to apply psychological theory beyond the therapy room and work towards addressing issues of social injustice through integrating psychology with policy and politics. Many other researchers have made similar recommendations, and the professional debates and barriers restricting ability to implement these recommendations have received little discussion within this thesis. This is largely due to the limited word-count which would not have enabled the in-depth discussion these recommendations deserve. Thus this section of the thesis explores these in more detail.

I believe that mental health difficulties exist, at the extent to which they do, because social inequalities are tolerated. Mental wellbeing is impacted by a range of social factors, such as housing, employment, poverty, environment, policy, stigma and education (Marmot, 2015). I feel that all of these factors are shaped by politics and the powerful elite, thus I believe that the integration of psychology and politics is logical. If psychology ignores the influence of politics on the context and systems in which our clients live we only scratch the surface in alleviating distress. If we purely focus on thoughts, feelings, behaviours and relationships we reinforce an individualistic understanding of distress and risk blaming people for their circumstances. If psychologists only work within individualised approaches systemic issues are ignored, in which case we contribute to forces of oppression (Gergen & Ness, 2016).

Prilleltensky (2014a) distinguishes between micro, meso and macro-level ways of working. Micro-level work takes place with individuals, meso-level work takes place within families, schools and work places and macro-level work involves communities and wider society. Currently macro-level of working is relatively unexplored within clinical psychology. Prilleltensky (2014b) also draws a distinction between levels of change – amelioration (targeting the 'symptoms' of the problem rather than the problem itself) and transformation (targeting the conditions which give rise to the problem). Relating this to clinical psychology individual (or micro) interventions can be seen as ameliorative, particularly if distress is routed in social injustice. Smail (2005) encourages understandings of psychological distress to consider the role of 'distal power', referring to the wider contextual influences on mental wellbeing (e.g. economics, politics, culture and ideology). He asserts that, whilst individual therapy may be beneficial for some individuals and for some circumstances, increased focus on tackling issues routed in distal power is a necessity.

Psychological professional bodies also highlight the importance of macro-level work. The British Psychological Society (BPS) code of ethics states that a standard for competence is sensitivity to developments in our social and political contexts (BPS, 2019) and the American Psychological Association (APA) committee on accreditation (APA, 2009) stated that the future of clinical psychology should focus more on advocating and prevention work. In addition, professional groups such as Psychologists for Social Change (PSC) argue that we have an ethical responsibility to speak out about the effect of social injustices and that we should apply psychological theory to policy and political action (PSC, 2015). Finally, The World Health Organisation asserted that a focus on social justice *"... may provide an important corrective to what has been a growing overemphasis on individual pathology*" (Friedli, 2009, p.V).

Unfortunately, whilst acknowledging a need for more macro/ transformative level interventions the path towards this is currently unclear for clinical and community psychologists (Thompson, 2007). Prilleltensky (2014b) stated that: *"we [community psychologists] do mostly ameliorative work, we hope to do transformative work, and in some* *instances we even fall prey to co-optation"* (p.153) (co-optation refers to the idea that some professionals may inadvertently become aligned with social forces that maintain the status-quo). Targeting intervention in this direction is complex. It raises many concerns, questions and debates and may require clinical psychologists to acquire additional competencies.

Thompson (2007) interviewed trainee clinical psychologists about their thoughts on the relationship between clinical psychology and community psychology and found that the majority positively endorsed the idea that clinical psychologists should tackle socio-political issues. However, they did not see how this could be done practically. Some discussed how issues within the system created barriers to bringing community psychology ideas into clinical psychology practice, they suggested that it may be naïve to think that we can challenge the systems we work within and queried the extent to which a professional group can oppose the Government policy. They also highlighted the pressures in the day-to-day work of a clinical psychologist as a barrier to action, in that long waiting-lists and increases in referrals mean that there is too much work to be done within clinical psychology's traditional remit to allow time for psychologists consider working at macro-levels. Other participants questioned whether clinical psychologists have the power to influence and incite real social change and suggested that this attitude maybe idealistic and unrealistic. Finally, some participants expressed concerns that if clinical psychologists were to become involved in politics that the integrity, objective stance and neutrality of the profession would be threatened. These participants questioned whether it is within our role to become involved in political discussions and if in doing so, we may risk alienating clients and straying from the core purpose of the profession. Some of these barriers were also highlighted by Fleming and Burton (2001) in their article exploring trainee clinical psychologists' reactions to socio-political teaching. Feedback suggested that there was a lack of practical techniques outlining how clinical psychologists could work at a macro-level. The authors reflected that the idea of psychologists tackling socio-political issues may have conflicted with trainees' experiences and professional identities and that there may also have been too great a contrast between the teaching materials and placement activities. It is possible that the trainees interviewed in both studies are a reflection of the feelings and understandings of the wider profession. With this in mind it is unlikely that teaching input alone will influence the status of macro-level work within clinical psychology. Thus we need to move beyond teaching new ideas, but consider changing the current way of thinking.

Drawing upon the above literature and my own experiences as a trainee clinical psychologist, I wonder if the two overriding concerns which prevent psychologists becoming involved in macro-level interventions are *'should we do this?'* and, if 'yes'- *'how can we do this?'*. If we are to consider working at a macro-level we must first critically reflect upon our professional values and biases and consider how they may serve the status quo and perpetuate social inequalities. We must also engage with questions regarding professional integrity, challenge the assumptions which underlie these concerns and openly navigate a path towards consensus. We then must progress from asking *'yes- but, how?'* and dedicate real time, resources and effort into answering this question and developing more socially just interventions. I believe that this is firmly located within the remit of a clinical psychologist.

'Should we do this?'

It is important to consider the argument that promoting social change and challenging political structures is a predominantly 'liberal' goal. If psychology pursues this route it may contribute to what some argue is a problematic bias against Conservative viewpoints within the field (Duarte et al., 2015). This has led some to wonder if psychology involvement in socio-political issues could negatively impact the open-minded, neutral and non-judgmental stance of the field and thus damage professional integrity (Thompson, 2007). In addition

Redding (2001) argued that this political bias may threaten the validity of the conclusions drawn within psychology. It has been well documented that both professional and academic psychologists hold significantly more 'liberal' views than other professions (e.g. Tetlock & Mitchell, 2015; Funder, 2015). This has led to some asserting that the findings of psychological research are 'perfectly predictable' based on the dominant political views of the profession (Hatch, 1982).

There are many possible factors which contribute to this lack of political diversity within psychology, discussion of which are beyond the scope of this appraisal. However, it is important that psychologists attempting to work at a macro-level are aware of their biases. On the other hand, it is also worth questioning whether the overrepresentation of liberal opinions in psychology might reflect a collective acknowledgment that some Government policies are incompatible with positive mental wellbeing in the clients psychologists most frequently encounter.

Aside from the issue of showing political bias, others have suggested that focusing on structural oppression and injustice is not the role of a clinical psychologist and may be better suited to those in the fields of sociology, public health, gender or race studies and political activism (Rosenthal, 2016). Yet the extensive literature which provides evidence that oppression, stigma, inequality and social policy can have detrimental impact on a range of adverse consequences related to mental health and psychology (e.g. Hatzenbuehler, Phelan, & Link, 2013; Lewis, Cogburn, & Williams, 2015; Logie & Gadalla, 2009) would suggest that these issues are well within the realm of clinical psychology. In addition the APA states its aim is to *"to advance the creation, communication, and application of psychological knowledge to benefit society and improve people's lives"* (France, 2015, p.1). This suggests that promoting social justice and engaging in socio-political issues should be part of a clinical psychologists work.

Furthermore, Smith (2009) argues *"silence regarding injustice ultimately contributes to its perpetuation"* (p.89). With this in mind, if we accept that social injustices contribute to poor mental health outcomes, I question how we can ethically maintain a stance of neutrality given our core role in alleviating distress. In remaining silent on social and political causes of distress I fear that as a profession we inadvertently engage in what Grimes and McElwain (2008) term *"discrimination by negligence"* (p. 2).

'How can we do this?'

A key idea in how clinical psychologists can achieve macro-level work is by taking ideas from other areas of psychology, namely critical psychology and community psychology. Community psychology emerged in the USA in 1965 at the Swampscott Conference (Rickel, 1987) and during the Civil Rights Movement, Martin Luther King Jr addressed the APA to stress that behavioural scientists not only should, but could support citizens fighting for their fundamental rights - amplifying interest in community psychology. This is still relevant today as we experience economic crisis, austerity, right-wing populism, neoliberal rhetoric and political instability and see the impact of these socio-political changes on mental wellbeing. This idea that behavioural sciences can support those experiencing injustices is the key to community psychology (Cromby et al., 2006).

Community Psychology is well established in the USA, Canada and Australia (Burton, Boyle & Kagan, 2007; Burton, Kagan, Boyle & Harris, 2007; Orford, 2007) yet is comparatively underdeveloped in the UK with the BPS only establishing a community psychology division in 2010. Burton and Kagan (2003) attribute this to differing social policy contexts and a lack of community-based workers in the UK. Therefore one suggestion in how UK based clinical psychologists can work towards more macro-level work may be to draw inspiration from overseas. For example, the American Counseling Association have developed 'social justice counselors' who promote social justice through the empowerment of individuals and communities and active confrontation of injustice and inequality. In addition, the American Counseling Association have introduced placements related to social policy and social injustice into all their doctoral courses (Burnes & Singh, 2010).

Despite community psychology being less established in the UK there are several examples of UK-based psychologists identifying social and political issues which impact mental health and developing macro-level interventions to address these. Notably, Orford (2008) was successful in reframing gambling addiction from a difficulty based on personality (and therefore treated through individual intervention) to understanding gambling as social issue (requiring macro-level intervention). Through campaigning against fixed-odds betting machines and for a review of gambling policies he was able to drive national policy change (Wardle, Griffiths, Orford, Moody & Volberg, 2012). This suggests that one way clinical psychologists can use their expertise to incite social change is through sharing their perspective, challenging individualising narratives and campaigning for policy change.

In this respect psychologists can be activists and adopt the role of 'activist-practitioner' (Williams & Zlotowitz, 2013) through campaigning, raising awareness, lobbying and collective action. There are several examples of clinical psychologists mobilising and driving social change. The development of groups such as PSC and their involvement in community projects is one way in which clinical psychologists are becoming more involved in macro-level work and engaging more with community psychology principles. Clinical psychologists have also campaigned, lobbied and taken part in collective action to raise awareness about the impact of socio-political issues. For example, in 2015 the 'Walk the Talk[3]' campaign involved clinical psychologists who aimed to raise awareness about the impact of welfare reform, homelessness and food poverty. In addition the 'Beyond the

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[3] www.walkthetalk2015.org

Therapy Room[4]' conferences discuss the importance of macro-level work and ideas for how this could be implemented. This suggests that disseminating ideas for macro-level work among ourselves, other healthcare workers and policy-makers at conferences may be a step forward. In 2015 the BPS spoke of their commitment to expanding their policy department and increasing their impact on issues of social justice (The Psychologist, 2015). The BPS has also taken a stance against 'gay conversion' therapies, lobbied for greater investment in preventative mental healthcare and pressured the DWP to address failings of Work Capability Assessments (Kinderman, 2017). Furthermore, research exploring the experiences of clinical psychologists involved in macro-level work highlighted that participants had achieved this through putting themselves in positions where they could increase their influence, such as sitting on committees and commissioner meetings, engaging with health boards and increasing involvement with the BPS (Browne, 2017). Thus clinical psychologists could aim to become more involved in macro-level work through seeking out opportunities and roles which would increase their influence.

The examples outlined above point towards a changing viewpoint within the profession and increased recognition that engaging with macro-level interventions is important. They also address many of the concerns regarding whether working at a macro-level is possible by demonstrating how it can be done.

However, in acknowledgement that current commissioning and NHS structures do not always facilitate macro-level work and that this is often completed within the professional's own time it is also useful to consider how we can work to address social inequality in the traditional therapy room setting. Primarily this can be done by asking *'does this individual need therapy or do they need help accessing and applying for benefits/ housing?'* and acting accordingly. In this instance it is important to avoid the assumption that support with benefits

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[4] www.psychologyfringe.com

applications is ‘another professional’s job’ as this could lead to no one offering support in this area. Watts (2018) has provided a useful summary outlining how professionals can support an individual to make a successful benefits claim. Professionals should encourage an open dialogue regarding the impact of benefit applications on mental wellbeing, in particular- do benefit assessments present a risk to their client? If so, how can the risk be minimised? Furthermore therapists should be mindful to adopt approaches which avoid internalising distress. For example, compassion focused therapy- which encourages self-compassion and has been found to be beneficial in reducing shame, guilt and self-stigma (Gilbert, 2009) or narrative therapy- which focuses on externalising difficulties (White, 2004)). These may be a useful alternative to cognitive behavioural therapy where the onus is on the individual to make behavioural and cognitive changes (this can be difficult for those whose behaviours are restricted by oppressive systems).

Conclusion

Clinical Psychologists (both individually and collectively) need to engage more assertively with threats to welfare, austerity policies, increasing inequality, divisive political rhetoric and humanitarian principles. The core function of clinical psychology is to understand human behaviour and use this understanding to reduce distress. Psychologists are therefore uniquely qualified to offer insight into some of the most pressing issues society faces and understand how these issues may contribute to poor mental wellbeing. Therefore we have a responsibility to contribute our research findings, our theoretical understandings and our values to public, social and political debates. Ethically we have a duty to speak up about social, economic and political issues that impact our clients and to share our expertise with politicians and policy-makers. In conclusion, as Clinical Psychologists we occupy a relatively powerful and privileged professional position. We have a responsibility to use this power as a driving force for change and not allow ourselves to maintain forces of oppression.

As writer and equality activist Ijeoma Oluo states: *‘when we identify where our privilege intersects with somebody else's oppression, we'll find our opportunities to make real change’* (Oluo, 2018).

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Section Four: Ethics application

Ethics Section Ethics Application for Research Paper: ‘Experiences of Individuals Claiming Personal Independence Payment for Mental Health Difficulties’.

Charlotte Thompson

Trainee Clinical Psychologist

Lancaster University

Word count- 4971

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FHMREC Application Form

Highlighted yellow = amendments requested by FHMREC
Highlighted green = amendments requested to add an online interview

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Guidance on completing this form is also available as a word document

Title of Project: Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties.

Name of applicant/researcher: Charlotte Thompson

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

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**

☒ 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

2. Contact information for applicant:

E-mail: c.thompson11@lancaster.ac.uk **Telephone**: XXXXX (please give a number on which you can be contacted at short notice)

Address:

Furness College, Lancaster University, Bailrigg, Lancaster LA1 4YW

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

Dr Pete Greasley – Research staff member of the Lancaster University Doctorate in Clinical Psychology

Dr Hayley Higson- Dclinpsy. Clinical Psychologist based at Brookside retirement village (Ormskirk)

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 ☐ 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:

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**: Pete Greasley-based at Lancaster University

Dr Hayley Higson- Dclinpsy. Clinical Psychologist based at Brookside retirement village (Ormskirk)

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)

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' no

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

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? no

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 the Data Protection Act 1998.

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

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? yes

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 (indicative maximum length 150 words):

Concerns have grown that that the process of applying for personal independence payment (PIP) may be unfairly biased against those with mental health difficulties and that it is an ongoing cause for concern and distress among applicants. Despite this this there is currently no research which attempts to explore this in individuals' claiming due to mental health difficulties. This research aims to investigate this through interviewing 12-16 individuals who have been through the PIP application process due to a mental health difficulty. These interviews will then be analysed to uncover common themes in individual's experiences.

Step 1: All participants will read the PIS (provided either online, via email or via post).

Step 2: All participants will complete the short screening survey

Step 3: Participants will view the consent form and will be given the option to consent or withdraw from the study (those who do not consent following the survey will have their information deleted)

Step 4: Participants who meet the criteria and filled in the consent form will be contacted via their agreed method of contact to arrange an interview

Step 5: The information (including consent forms and contact details) of those not participating in an interview will be permanently deleted.

Participants who opt to take part in the research via the online survey option will read the participant information sheet and sign the consent form before the survey allows them to answer the questions. They will be presented with a short debrief at the end of the survey reminding them of the researchers contact details.

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

Start date: 01/11/2018 End date 05/19

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 (including maximum & minimum number, age, gender):

The research will include 12-16 participants who have been through the process of applying for PIP due to a mental health difficulty in the past three years. Individuals will be included regardless of whether their application was successful or not. There will be no restrictions on participant's gender and they will be aged between 18-70 years old. The age range reflects the age restrictions in making a PIP application (16-64) whilst ensuring participants are over the age of 18 and allowing 6 additional years due to the length of time that PIP has been implemented, this means that individuals can take part if they are no longer in receipt of PIP, as long as they have made an application at some point in the past three years. Participants will be restricted to English speaking individuals only due to the limited time and funding.

- Inclusion criteria: age 18-70, individuals who have applied for PIP primarily due to a mental health difficulty. Participants must have made the application within the past 3 years.
- Exclusion criteria: under the age of 18 or over the age of 70. Individuals who did not apply for PIP as a result of a mental health difficulty. Individuals who applied for PIP over 3 years ago will not be included.

Potential participants will fill in a brief survey online which will determine whether they are eligible to take part in the research. If individuals are unable to fill in the survey online (for example if they do not have access to the internet) they will have the options to answer the screening questions over the phone with the researcher, through post or via email.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

As an initial step to recruit participants I will contact support groups who specialise in offering advice, support and guidance in PIP applications; this will be done via email. I will ask them if they would mind sharing an advertisement of the study along with a link to the screening questionnaire to members of their group. Support groups that will be contacted include:

- Fight back for justice (an independent community interest group based in Bury offering support and advice around PIP, ESA [employment support allowance], DLA and UC [universal credit]).
- The admin of ESA/ DLA/ PIP support and advice public Facebook group
- The admin of ESA, DLA, PIP support/ info group “resources library” Facebook group.
- The personal independence payment help group based in Wales, Pontyclun. Providing specialist support in PIP and ESA.
- The admin of PIP/ ESA assessments advice and support Facebook group
- The admin of DWP DLA PIP, carer allowance benefit information support Facebook group
- The admin of ESA/DLA/ PIP advice and support (UK only) Facebook group
- A1 benefit support- for people with mental health and hidden illnesses- peer support group

Details of the study, including a poster with the aims and brief overview of the inclusion criteria and what will be involved as well as a link to the screening survey will also be posted on social media sites.

If individuals would like to participate they will be asked to fill in a brief survey which will be supplied online through an online survey provider such as qualtrics. If individuals are unable to fill in the survey online they will have the option to answer the screening questions over the phone with the researcher or via email. They will be asked to leave a method of contacting them e.g. phone number, address or email address if they would like to take part in the research.

All those who volunteer and meet the criteria will be included. Once a sufficient number of participants has been reached the online survey will be removed. Participants who do not meet the criteria will be informed that they are unable to take part through whichever method of contact they expressed a preference for.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Participants will be interviewed using a semi-structured interview schedule and a series of open ended questions. This will allow the individuals who are participating to tell the story of their experience in a way that explores it at a more personal level than quantitative research or a structured interview would. The data from these interviews will be analysed using a thematic analysis. This will allow for rich, detailed and complex description of the data and patterns across individuals experiences to be identified.

Participants will also be given the option to answer the questions via an online survey. Whilst face-to-face, phone or skype would be the preferred method of communication it is likely that a number of individuals will see this as a barrier to participation due to their mental health difficulties. Individuals who highlight that their mental health difficulties are preventing participation (e.g. social anxiety) will be provided with an electronic link so that they can answer the questions online. This will be provided via Qualtrics.

6. What plan is 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 the Data Protection Act 1998.

Research data will be stored on the university H drive and accessed via the VPN, this is a secure and password protected way to store the data. All identifiable information will be encrypted. Individual documents (e.g. transcripts or recordings) will each be password protected as well. The only exception is the brief period in which the audio recorder will store the interviews before being moved onto an encrypted medium. The data will be transported as quickly as possible and will be deleted from the audio recording device as soon as it has been moved. In the meantime it will be kept in a secure location. Whilst the study is ongoing the data will be stored on the university H drive. The data will be accessed by the researcher via the VPN who will not keep any of the data on a personal laptop when the data is not in use (for example when transcribing or coding). Data will be stored on the H drive until the time when the thesis has been submitted and a pass has been achieved. The information will then be retained on a secure university server for up to 10 years. The research supervisor is data custodian for the research and the data is stored by the research co-ordinator after it's been submitted for long-term storage (Sarah Heard). The encrypted data with be shared with the research co-ordinator through box. This data will then be stored on a secure area on the university network until it is ready to be destroyed.

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

Any identifiable data such as audio recordings and participant contact details will be stored on encrypted devices (laptops and memory sticks). Audio recordings will be deleted from the audio recording device as soon as they have been moved onto a secure encrypted and password protected laptop or PC. The audio device will be securely stored in the meantime. Contact details for participants will be stored separately from audio recordings and transcripts. Any documents containing identifiable information (e.g screening survey answers and consent forms) will be encrypted. Encrypted transcripts will be stored for 10 years on a secure device at Lancaster University.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

The data, including participant information, signed consent forms, audio recordings and transcribed interviews will be stored on an encrypted device for the duration of the study (until it has been submitted to the university for examination and a pass has been achieved). Following this the transcribed interviews will be kept for up to 10 years on a secure, encrypted Lancaster University server. The data is stored by the research co-ordinator after it's been submitted for long-term storage (Sarah Heard). The encrypted data with be shared with the research co-ordinator through box. This data will then be stored on a secure area on the university network until it is ready to be destroyed.

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?

Data will be held, managed and preserved on Lancaster University's PURE data repository for 10 years

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 with genuine researchers (for example those with an 'ac.uk' email address). Access will be granted on a case by case basis by the research co-ordinator.

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?

Participants will read the participant information sheet and then fill out the short screening survey. Following this they will then be asked if they provide consent to participate. This way potential participants will know what information they have provided on the online survey and will be able to make a more informed choice about whether or not to consent. Those who do not consent will not have their information saved. Consent will be taken prior to the interview taking place. Participants who do not have access to the online survey will be sent a consent form to either their email address or an address provided (depending on their preference) either through the researchers' university email or post. They will be asked to return the signed consent form, via email or post to the researchers university email or to the university address. Interviews will not take place unless consent is received (either through the online survey, post or via email). Participant's capacity will not be assessed as part of the consent process and capacity will be assumed.

10. What discomfort (including psychological eg 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.

Participants will be asked questions about their mental health and mental wellbeing in relation to a time when they completed an application form for PIP. Speaking to someone that they have not met before or may be speaking to over the phone about their mental health may be difficult may be a difficult experience for participants. They will be advised at the start of the interview that they can take a break or end the interview at any time. If the researcher feels that the participant is becoming distressed in the interview they will check-in about how they are feeling and remind them that they can take a break if they wish. The interviewer will also draw upon their own clinical skills and clinical supervision which can be accessed through the researcher's field supervisor. Participants will be provided with a participant information sheet which will provide possible sources of support following the interview. Participants will be able to withdraw from the study before or during the interview and up to 2 weeks following their interview. After this time audio recording are likely to have been transcribed and analysis may have began meaning that it would be difficult to extract an individual's 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).

Where possible interviews will take place face-to-face, however as this study is aiming to participate nationwide it is unlikely that all participants will be able to attend a face-to-face interview. Therefore to make the research more accessible to a wider participant group and to avoid any unnecessary stress by asking participants to travel to face-to-face interviews some will take place over the phone or via skype. If a participant is having a face-to-face interview the lone working policy will be utilised. The researcher will book a room on campus and let the research supervisor (or another member of the academic or clinical dclinpsy team) know where the interview is taking place and when it has finished. For interviews taking place via phone or skype email addresses and contact numbers provided to participants will be university email addresses and a non-personal phone will be used for the interviews.

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 may be no direct benefit to participating in this study. However, people may find it a positive experience to participate in the study due to the opportunity to share their story and experiences. There may be some benefits in terms of any recommendations that might come as a result of the study to mental health services and advice to mental health professionals in working with individuals who are claiming PIP which might benefit others.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

N/A

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.

There might be situations in which confidentiality needs to be breached, for example if a participant discusses plans to harm themselves or others. In this situation I would speak to my academic and field supervisors and take any action necessary following these discussions. Participants will be informed of the limits to confidentiality at the start of the interview and if confidentiality needs to be breached they will be informed of who the information is going to and why wherever possible.

Direct quotes from participants will be used in the analysis; however these will be anonymised through the use of a pseudonym allocated to each participant. No identifiable information will be published.

Interviews will not be transcribed or listened to by anyone who is not on the research team.

A professional skype account and a research phone will be used for this research or the universities' Web Ex system would be used. If this is not possible and skype is used participants will be reminded that the internet cannot be guaranteed to be a completely secure means of communication.

If participants opt to participate via the online survey there will be no way to identify them (i.e. they will not provide a contact method or their name) this means that confidentiality cannot be breached in cases of disclosure of safeguarding concerns. The participant info sheet and consent form will be modified to reflect this).

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

An individual who has been through the process of applying for PIP for a mental health difficulty has been involved in aspects of this project. This included thinking about what questions to ask in the screening survey and in the interview itself and providing advice/ ideas around recruitment and giving feedback on some of the forms used such as the consent form and participant information sheet.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The research data will be seen by the primary researcher, academic supervisor and field supervisor. As a student the submission of the thesis will be a form of dissemination. The research may also be presented at university conferences and events, for example all third year DcClinPsy students will present the results of their thesis to other trainees, staff and members of the Lancaster university public involvement network. Results of the research may be submitted for publication in an academic/professional journal.

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?

Participants may feel distressed during the interview through discussion about their mental health. This would be difficult to manage as some of the interviews will take part over the phone; however they would be told that they can take a break or end the interview if needed and would be reminded of this if it seemed appropriate to do so during the study. They would be provided with sources of further support on the participant information sheet.

If participants were recruited through word of mouth e.g. through a friend telling them about the study or through sharing it on social media it may be possible for individuals who know the person to identify some of their quotes if they referred to specific situations. However every effort would be made to ensure that the quotes used do not allow participants to be identified.

SECTION FOUR: signature

Applicant electronic signature: charlotte thompson Date 14/05/2018

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 ☒

Project Supervisor name (if applicable): Pete Greasley Date application discussed 01/05/18

Submission Guidance

1. **Submit your FHMREC application by email to Diane Hopkins (**d.hopkins@lancaster.ac.uk) as two separate documents:
    - i. **FHMREC application form.**
      Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    - ii. **Supporting materials.**
      Collate the **following materials for your study, if relevant, into a single word document:**
        - a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
        - b. Advertising materials (posters, e-mails)
        - c. Letters/emails of invitation to participate
        - d. Participant information sheets
        - e. Consent forms
        - f. Questionnaires, surveys, demographic sheets
        - g. Interview schedules, interview question guides, focus group scripts
        - h. Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    - i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to **Diane Hopkins by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

   a. existing documents/data only;
   b. the evaluation of an existing project with no direct contact with human participants;
   c. service evaluations.

3. <u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>

Research protocol

Title: Exploring the Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties.

Applicant: Charlotte Thompson

Research supervisor: Pete Greasley

Field Supervisor: Hayley Higson

Introduction

Since the coalition Government's Welfare Reform Act in 2012 replaced the Disability Living Allowance (DLA) with Personal Independence Payment (PIP) concerns have grown that PIP is unfairly biased against those with mental health difficulties and that it creates an unfair, discriminatory and potentially harmful process for individuals attempting to access financial support. Various mental health and disability charities, activists and advocacy groups have campaigned against several aspects of the PIP assessment process and assessment criteria (Mind, 2017) arguing that the PIP application process is an ongoing cause for concern and distress among applicants. PIP has received attention within the media and mental health charities which have provided a vast body of anecdotal evidence affirming the significant and often severe impact that PIP applications are having on individuals' wellbeing. Despite this there is currently no research which attempts to explore this impact on individuals' claiming due to mental health difficulties. Given the impact of undertaking a stressful and time consuming application process, the outcome of which presents significant financial and lifestyle implications affecting an individual's well-being, it is important that knowledge around this is extended as much as possible. Therefore this research will explore individuals' experiences of claiming PIP for mental health difficulties. Qualitative interviews, which will allow participants' to tell their story in a way which they choose will be used to generate in-depth data using a personal and human approach.

An independent fact checking charity (Full Fact) have stated that between 2013 and 2016, 22% of individuals claiming DLA for mental health difficulties had their benefits reduced following the introduction of PIP (Full Fact, 2017). A survey by the mental health charity Mind indicated that 90% of individuals' who had been in receipt of out-of-work benefits reported a negative impact on their mental health (Mind, 2017). A large scale survey conducted by the DBC (Disability Benefits Consortium) provided evidence that the PIP process is particularly difficult for individuals with sensory impairments, cognitive difficulties, mental health difficulties and learning difficulties (DBC, 2014). The survey found that many respondents (48%) struggled to complete the form in the time allowed. The majority of respondents highlighted the PIP process as a stressful experience; 73% found the face-to-face interviews stressful and 51% found that it had a negative impact on their mental health. A small number reported finding the PIP process so stressful that it caused them to have suicidal thoughts. These findings are consistent with those of the Welfare Rights Advisors Survey (DBC, 2014) which revealed that 72% of respondents felt that the PIP assessment negatively impacted claimant's well-being. These statistics reflect long-standing concerns around PIP and suggest that the current benefit system is not only failing individuals with mental health difficulties but that it appears to be actively working against them.

It is important that the social origins of distress receive attention. Research into the social determinants of health demonstrate the impact of social inequality on health, including emotional wellbeing (e.g. Marmot, 2010 and Wilkinson and Pickett, 2010). Research has shown that mental health difficulties are linked to low income and socioeconomic status in all developed nations (Melzer, Fryers, & Jenkins, 2004). Furthermore the application of austerity policies has coincided with a significant rise in prescriptions for antidepressant medication

(Spence, Roberts, Ariti, Bardsley, 2014) and increasing GP appointments for mental health difficulties (Insight Research Group, 2012). In the UK and in other European countries that have adopted austerity policies (Greece, Spain and Portugal) the rate of suicides has increased; this is not the case for European countries which have protected their welfare state (e.g. Germany and Iceland) (Karanikolos, 2013 and McKee, Karinokolos, Belcher, Stuckler, 2012).

Social constructs, for example ideas of 'status' and social comparison, can have huge impact on mental wellbeing, through fostering low self-esteem and triggering social emotions such as humiliation and shame (Rodgers and Pilgrim 2005; De Botton, 2004). In fact humiliation has been highlighted as a key experience in those affected by disability benefits changes (We are Spartacus. n.d). This is exacerbated by the current benefits rhetoric which actively blames individuals for their own need by promoting the idea that those who access welfare benefits are 'shirkers' whereas those who work are 'strivers' (George Osborne, Conservative party speech, 2012). The potential impact of this rhetoric is far reaching and thus may be costly on both an individual and a societal level.

It is therefore vital that there is increased recognition and understanding of the psychological cost that government policies, reforms and programs (e.g. changes to disability benefits, bedroom tax, universal credit and cuts to social services and NHS budgets) have on those who access services. Crucially, it is important to recognise that these changes are detrimentally impacting the most vulnerable members of our society and communities. Clinical psychologists occupy a relatively powerful professional position whereby, through access to the theory and research above, there is a professional ethical responsibility to speak up about wider social issues. The British Psychological Society's (BPS) code of ethics states that part of the standard for competence as a clinical psychologist is sensitivity to developments in our social and political context (BPS, 2009). This suggests that there is an increased need for research into the psychological impact of social issues thus allowing clinical psychologists and others who work in mental health to better support their clients and act as a voice against discriminatory policies.

Aims of the study

The aims of the study are to 1) gain an understanding into individuals' experiences of applying for PIP due to a mental health difficulty by identifying common themes within the dataset and 2) to develop understanding around the impact that PIP applications might have on individuals' mental wellbeing.

Method

A qualitative approach will be adopted to explore participants' experiences in depth and elicit a rich and comprehensive understanding of the processes involved in applying for PIP for individuals' with mental health difficulties and the impact that the processes have on individuals wellbeing. As the overriding function of this research is to explore individuals' experiences, a personal approach (qualitative thematic analysis) was deemed to be the most appropriate research methodology. This research will use thematic analysis to explore common themes within individual's experiences (Clarke and Braun, 2014).

Participants

The research will include 12-16 participants who have been through the process of applying for PIP due to a mental health difficulty in the past three years. Individuals will be included regardless of whether their application was successful or not. There will be no restrictions on participant's gender and they will be aged between 18-70 years old. The age range reflects the age restrictions in making a PIP application (16-64) and allows 6 additional years due to the length of time that PIP has been implemented, this means that individuals can take part if they are no longer in receipt of PIP, as long as they have made an application at some point in the past three years. It also excludes individuals under the age of 18, due difficulties obtaining informed consent from this population. Participants will be restricted to English speaking individuals only due to the limited time and funding.

- Inclusion criteria: age 18-70, individuals who have applied for PIP primarily due to a mental health difficulty. Participants must have made the application within the past 3 years.
- Exclusion criteria: under the age of 18 or over the age of 70. Individuals who did not apply for PIP due to mental health difficulties (primarily). Individuals who applied for PIP over 3 years ago will not be included.

All potential participants will fill in a brief survey online which will determine whether they are eligible to take part in the research. Prior to this they will read the participant information sheet. At this stage agreeing to continue to the survey after reading the information sheet will act as consent. If individuals are unable to fill in the survey online they will have the option to answer the screening questions over the phone with the researcher or via email, provided that they have signed the consent form and viewed the participant information sheet (arrangements will be made for these to be sent via email or post if required). At the end of the online survey participants will be provided with a consent form, providing the consent form at this stage means that potential participants will know what information they have provided and be able to make an informed decision about whether or not they are happy to share this information and continue to the interview stage of the research.

Recruitment Procedure

Participants will be approached through social media and through making contact with relevant mental health advocacy or support groups e.g. Fight back for justice (an independent community interest group based in Bury offering support and advice around benefits applications). They will be asked to view the participant information sheet. They will be asked to complete a short online survey (or answer the screening questions over the phone with the researcher or via email) which will assess whether they meet the research inclusion criteria. Following this they will be asked to sign the consent form. Any individuals who do not meet the criteria will be sent a short email or letter thanking them for volunteering their time but explaining that they did not meet the study's criteria to participate. Those who do meet the criteria will be contacted to see if they would still like to participate. Following this, an interview will be arranged with the participants, this will take place either face to face, over the phone or over Skype. If individuals live locally and are able to attend an interview at Lancaster University then arrangements can be made for a face to face interview.

Interviews

The interviews will last approximately one hour and will be semi-structured in style. Questions will be centred upon the aims of the study to gain understanding of experience and impact of applying for PIP on mental wellbeing. The specific form of the questions will be ultimately decided between the primary researcher, field supervisor and an expert through experience. Interviews will be recorded using an audio recording device and moved onto an encrypted laptop where they will remain stored whilst they are used for the study.

An option for participants to answer the interview questions via an online survey will also be included. This is in order to make the research more accessible for individuals who find that their mental health difficulties are a barrier to participating.

Ethical considerations

Data protection and storage: Data from the interviews will be stored on an encrypted laptop and deleted from the audio recording device as soon as it is transferred to the laptop. Data will be transcribed within a two week period following the participant's interview; after this is complete the audio recording will be deleted and only the interview transcript will remain. The transcripts will remain on the laptop and on an encrypted memory stick as back up until the write up of the data is complete and the research has been submitted to the University for marking. After this point the data will be moved from the memory stick onto a secure university system where it will be stored, along with the scanned copies of the consent forms for 10 years. Throughout analysis both the laptop and memory stick will be stored in a secure locked draw in the researchers' home.

Consent and rights to withdraw: The participants will be provided with study information sheets and consent forms prior to participation in the interview. When the forms are returned an interview time will be scheduled. Participants will be informed of their rights to withdraw consent at any time before or during the interview. Following the interview participants will be informed that they have 2 weeks to withdraw consent; after this time data will have been transcribed and analysis may have taken place meaning that it would be difficult to fully extract an individual participant's data.

Confidentiality: To protect participants rights to confidentiality participants will be allocated a pseudonym which will be used in the write up of the data. No identifiable information will be used or published. All data will be stored on a secure, password protected and encrypted device at all times.

Proposed analysis

The interviews will be transcribed and analysed using thematic analysis (Clarke and Braun, 2014). Thematic analysis will be used because the aim of this project is to explore any common themes 7 across experiences among to gain a better understanding of the impact of making a PIP application on mental wellbeing. The primary researcher will develop initial codes following familiarisation with the data recordings, then search for themes. The researcher will then identify themes within the data, these will be reviewed with the researchers field and academic supervisors. These will then be compared with those identified by the primary researcher, this will involve discussion about the themes identified, and the themes will then be refined and expanded. Practical issues Cost: there are no cost issues anticipated, the researcher will use an audio recording device provided by the university and participants will not be paid to participate.

Timescale

- June-October 2018: ethics application
- October-December 2018: recruitment and interviews, intro and method write up
- December 2018: data collection complete
- February 2019: Analysis complete
- March- April 2019: write up results and discussion and submit draft
- May 2019: Submit thesis

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Appendix 4-1

Participant Information Sheet

Exploring the Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties

My name is Charlotte Thompson and I am conducting this research as a trainee on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the experiences of people who have applied for personal independence payments (PIP) within the last 3 years due to a mental health difficulty.

Why have I been approached?

You have been approached because the study requires information from people who have applied for PIP within the last 3 years due to a mental health difficulty.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

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 arrange a time to meet with the researcher either face-to-face or via skype. During this meeting you will be asked questions about your experiences of applying for PIP and about any impact the process might have had on you and your mental wellbeing. It is important to note that interviews which take place via skype cannot be guaranteed to be wholly secure.

If you are unable to participate via face-to-face interview, phone or skype but would like to share your experiences please get in touch with the researcher (see contact details below). We will be able to discuss an alternative way for you to participate.

Will my data be Identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and deleted once the project has been submitted for publication/examined
- All files containing identifiable information will be encrypted (that is no-one other than the researcher will be able to access them) and the computer used to view the data will be password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised 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 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, is 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. (The underlined sentence will be removed in the online survey option as there will be no method to breach confidentiality)

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection.

What will happen to the results?

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

Are there any risks?

The researcher will ask a series of questions around your mental wellbeing at the time of applying for PIP. This may be experienced as distressing. The researcher will use their clinical skills to attempt to minimise distress. However, if you experience any distress during or following participation you are encouraged to inform the researcher and/ or 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.

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 the main researcher:

Charlotte Thompson at c.thompson11@lancaster.ac.uk or on ***

Or,

Dr Pete Greasley at p.greasley@lancaster.ac.uk or 44 (0)1524 593535

Or

Dr Hayley Higson at …

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:

Dr Bill Sellwood Tel: (01524) 593998
Title; Email: b.sellwood@lancaster.ac.uk
Division of Clinical Psychology
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
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. .....

SANEline:

- SANEline is a national out-of-hours mental health helpline offering specialist emotional support, guidance and information to anyone affected by mental illness, including family, friends and carers. They are open every day of the year from 4.30pm to 10.30pm on 0300 304 7000.

Samaritans:

- Samaritans are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and self-harm. Their national freephone number is 116 123, or you can email jo@samaritans.org.

CALM:

- If you're a man experiencing distressing thoughts and feelings, the Campaign Against Living Miserably (CALM) is there to support you. They're open from 5pm–midnight, 365 days a year. Their national number is 0800 58 58 58, and they also have a webchat service if you're not comfortable talking on the phone

The Silver Line:

- If you're an older person (over the age of 55), the Silver Line is there 24 hours a day, 365 days a year to provide information, support and friendship. You can call them from anywhere in the UK on 0800 4 70 80 90 (freephone).

The NHS:

- This page provides advice and information about a range of mental health difficulties. www.nhs.uk/livewell/mentalhealth/Pages/Mentalhealthhome.aspx

Money advice:

- This website contains information about what you can do if you are experiencing difficulties with PIP, for example what you can do if you disagree with a decision that has been made regarding your benefits.

  www.moneyadviceservice.org.uk

The citizens advice bureaux:

- The citizen’s advice bureaux is a registered charity (charity number 279057) where you can get advice online, by phone or in person. This includes advice on benefits and tax credits if you are working or unemployed, sick or disabled, a parent, a young person, an older person or a veteran. There is also information about council tax and housing costs, national insurance, payment of benefits and problems with benefits.

  www.citizensadvice.org.uk

Appendix 4-2

Screening survey

Are you aged between 16 -70? Yes/No

Have you applied for Personal independence Payment (PIP) during the last 3 years? Yes/No

Was the reason you were unable to work, and therefore made a PIP application, primarily due to a mental health difficulty? Yes/No

Are you interested in taking part in a research study that hopes to explore individual's experiences of applying for PIP due to a mental health difficulty and the impact that the process has on mental wellbeing? Yes/No

In order for the research to contact you could you please provide some contact information (you only need to provide your preferred method of contact):

Phone number:

Email address:

Address:

Do you give consent for the researcher to contact you via your preferred method of contact to discuss your participation in the research? Yes/No

Appendix 4-3

Consent Form

Study Title: Exploring the Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties.

We are asking if you would like to take part in a research project exploring the experiences of individuals who have applied for personal independence payments (PIP) within the last 3 years due to a mental health difficulty.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box 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, Charlotte Thompson.

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 recorded and then made into an anonymised written transcript. ☐ This statement will be reoved for the online option
4. I understand that audio recordings * (changed to *data for online version) will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that as I am participating online it will not be possible to withdraw after the data is submitted (online version) ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐

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 will need to share this information with their research supervisor. This statement will not be included in the online version as it will not be possible to breach confidentiality. ☐

11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

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

Please initial each statement

Name of Participant__________________ Signature____________________ Date ___________

Name of Researcher __________________Signature ____________________Date ___________

By signing this consent form you confirm that:

- You have read the information sheet and understand what is expected of you within this study
- You confirm that you understand that any responses/information you give will remain anonymous
- Your participation is voluntary
- You consent for the information you provide to be discussed with my supervisor at Lancaster University

- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Appendix 4-4

Interview Schedule

The interview will begin with an open question, after which various prompts may be used to obtain specific information relating to the aims of the study.

- Open introductory Question:

Can you tell me about your experience of applying for PIP?

Prompts

- *Support*

Did you receive any support when applying for PIP? If so, from who?

If you’re under the care of a mental health team what was there involvement in supporting you with your PIP application?

- *Process*

How did the process of applying for PIP make you feel?

Were there any parts of the process that you found particularly stressful?

Were there any parts of the process which you felt were not stressful?

- *Impact on mental health*

Do you feel that the process of applying for PIP impacted your mental health in any way? How?

How would you feel if for some reason you had to apply for PIP again?

- *Views about changes/improvements to the process*

What changes would you like to see to the PIP application process?

Do you feel like you were treated fairly throughout the process? If so, why? If not, why not?

Do you feel like the PIP application process is a good way of assessing the needs of people with mental health difficulties?

How do you think the process of applying for PIP could be changed to better support people with mental health difficulties?

How do you think that mental health services or mental health professionals could be involved in supporting people with PIP applications?

Appendix 4-5

Recruitment poster

Experiences of Claiming Personal Independence Payment (PIP) for Mental Health difficulties

Looking for participants aged 16-70 who have applied for PIP in the last 3 years due to a mental health difficulty.

My name is Charlotte Thompson. I am researching the experiences of people who have applied for PIP due to mental health difficulties as part of my study at Lancaster University Doctorate in Clinical Psychology. I am hoping to explore what the PIP application is like for people with mental health difficulties and what (if any) impact the application process has on mental wellbeing.

What will I have to do? If you are interested in participating then you will need to fill out a quick online survey to assess whether you meet the studies criteria or not (see below). If you do meet the criteria the researcher will get in touch to arrange an interview. This will take part either over the phone, face-to-face or on skype and will last approximately 40 minutes to an hour. The Researcher will ask you questions about your experience of applying for PIP and your mental wellbeing throughout the process.

If you are interested in participating please fill out the online survey at *insert web address*. Alternatively you can contact the researcher on c.thompson11@lancaster.ac.uk or by phone on *add research phone number*if you would prefer to answer the questions by phone, post or email or if you have any questions about participating.

Appendix 4-6

FHMREC Approval Letter 05/10/18

Lancaster
University

Applicant: Charlotte Thompson
Supervisors: Pete Greasley and Hayley Higson
Department: Health Research
FHMREC Reference: FHMREC17096

05 October 2018

Dear Charlotte

Re: Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties.

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, 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.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

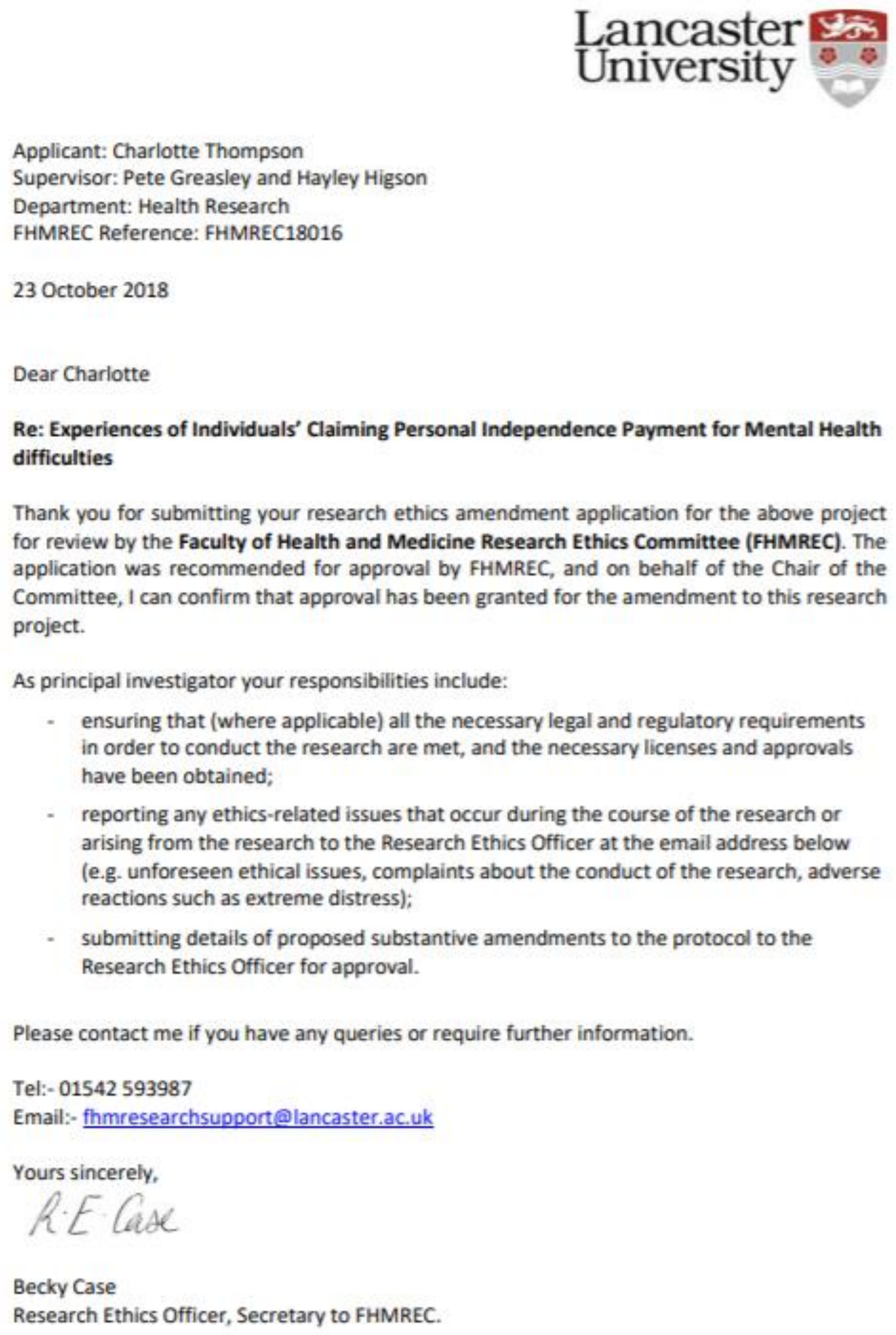
Yours sincerely,

R.E Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

Appendix 4-7

FHMREC Approval of Requested Ammendments 23/10/18



Lancaster University

Applicant: Charlotte Thompson
Supervisor: Pete Greasley and Hayley Higson
Department: Health Research
FHMREC Reference: FHMREC18016

23 October 2018

Dear Charlotte

Re: Experiences of Individuals' Claiming Personal Independence Payment for Mental Health difficulties

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

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.