# Submitted in partial fulfillment of the Lancaster University Doctorate in Clinical Psychology, April 2018

# **Doctoral Thesis:**

The experience of living in poverty, the role of stigma, and mental health: A qualitative analysis

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# **Word Counts**

	Main Text	Appendices (including tables, figures and references)	Total
Thesis abstract	242	-	242
Literature Review	7,973	3137	11,110
Empirical paper	7,999	6,431	14,430
Critical Appraisal	3,870	243	4,113
Ethics Section	5420	1740	7160
Total	25,504	11,551	37,055

#### Thesis Abstract

A systematic search of electronic databases was conducted, identifying 14 qualitative papers for the meta-synthesis. Four themes were identified including: Awareness of stigma, The personal impact of the imposed identity, Stigma management and Acceptance. The theme of Stigma management comprised of two subthemes; create safety in an unsafe world, and the coping paradox. Findings highlight how identity is formed in relation to social narratives and the strategies that are employed to manage poverty stigma, may not always be the most helpful. Implications for clinical psychology are discussed and findings from anti stigma campaigns are examined to inform future practice and service design.

The second section of the thesis is the empirical paper. The aim of this research was to understand the experiences of people with mental health conditions and their Work Capability Assessment (WCA). Ten people were interviewed about their experiences and a narrative approach was used to analyse the data. Themes captured the story of the assessment encompassing before, during and after the WCA. The research provides an insight in to the detrimental impact of the WCA on mental health and suggests implications for the development of services and clinical practice.

Finally, the critical appraisal is a reflective piece describing the journey throughout this research. It follows that same structure of the empirical research encompassing before, during and after the research. The impact of the research on the author's identity will be discussed, while attending to the use of similar stigma management strategies that the literature review uncovers.

**Declaration** 

This thesis records work undertaken for the Doctorate in Clinical Psychology at

Lancaster University from August 2016 to April 2018.

The work presented here is the author's own, except where otherwise stated. The work

has not been submitted for the award of a higher degree elsewhere.

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# Acknowledgements

Firstly, I would like to thank my husband and children for their immeasurable support throughout and for your understanding, patience and unwavering belief in me.

To my supervisors who have been completely supportive and encouraging during this extended research process. For always answering emails and providing telephone support and, on most occasions, much needed humour. I really do feel lucky to have had supervisors that have gone above and beyond their role to help out and to just be around.

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Running head: STIGMATISED IDENTITY OF POVERTY

# **Section One: Thesis Literature Review**

Understanding the stigmatised identities of people living in poverty: a review of qualitative studies.

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#### Abstract

In recent years, people living in poverty have been the subjects of derogatory media representations. The association between poverty and mental health conditions has been documented extensively, with both positions holding negative connotations and preconceptions that can reinforce stigmatising beliefs, in society and within the person. A systematic search of electronic databases including PsycINFO, PsycARTICLES, CINHAL, Academic Search Ultimate and Sociology Index, was conducted. Fourteen papers were identified for metasynthesis. Four concepts emerged from the review: Awareness of stigma, Personal impact of imposed identity, Stigma management, and Acceptance. Findings capture the complex nature of the stigma experience and examine the coping mechanisms that are employed to manage poverty stigma. Implications for future clinical practice, service design and anti- stigma work is proposed.

Keywords: qualitative review, poverty, stigma, psychology, mental health.

In the United Kingdom, poverty is calculated by measuring household income as 60% of the median income in that year (Tinson, Aryton, Barker, Born, Aldridge, & Kenway, 2016). It was reported in 2013 that 21% of the population lived below the government's official poverty line (Duffy, 2013) thus, representing one-fifth of the population. The rate of children and pensioners living in poverty is on the increase. In 2011/12, 27% of children lived in poverty, compared to 30% in 2017; while 13% of pensioners in 2011/12 lived in poverty, rising to 16% in 2017 (JRF, 2017). Child poverty is set to increase, with an additional 400,000 children set to fall in to poverty due to changes in tax and welfare reform (Hood & Waters, 2017).

The voices of people living in poverty seldom feature in current debates about poverty and are instead dominated by media narratives and political rhetoric, locating an individual as responsible for their current status (Lister, 2004; Broussard, Joseph & Thompson, 2012; Pemberton, Fahmy, Sutton & Bell, 2016). People living in poverty are, therefore, excluded from policy and intervention development, and are ultimately excluded from mainstream society. Fourteen million people in the United Kingdom currently live in poverty (JRF, 2017), which is a significant number of people excluded from crucial discussions and debates, regarding future policy design and development.

The economic recession of 2008 and the rise in poverty levels, compounded by negative media portrayal, have together created a 'perfect storm' (Garthwaite, 2016). Poverty manifests itself as material deprivation, but is more than simply a lack of income or resources to meet ones needs (Walker, Kyomuhendo, Chase, Choudary, Gubrium, Nicola, Lodemel, Mathew, Mwiine, Pellissery & Ming, 2013); it is also associated with social exclusion.

## **Poverty Stigma and Mental Health**

Poor mental health has been associated with poverty, debt and social deprivation (WHO and Calouste Gulbenkian Foundation, 2014). During the economic recession, there was an increase in the number of people experiencing difficulties with their mental health, and in 2013 the suicide rate reached a thirteen- year high, despite economic recovery (Barr, Kinderman & Whitehead, 2015). A systematic review examining mental health outcomes in times of recession (2004- 2014), across 27 European countries, reported that people with mental health conditions were more vulnerable to loss of employment, compared to those without such conditions (Fasquilho, Matos, Salonna, Guerreiro, Stroti, Gasper and Caldas-de- Almeida, 2016).

The steady increase of people living in conditions of poverty, in addition to mental health conditions, warrants serious investigation, particularly in the field of psychology and its intersections with sociology and public health. The context of poverty in relation to mental health suggests a link between deprived geographical areas and poor outcomes for recovery from mental health conditions (Smith, Li, Dykema, Hamlet & Shellman, 2012; Delgadilo, Asaria, Shehzad & Gilbody, 2015). Although this relationship is complex, and potentially mediated by a variety different constructs, it is essential that clinical psychologists are able to understand presenting issues and remain open to the potential social causes of their clients' difficulties. There is a risk that in viewing each client's presenting difficulties in isolation of their social context, could result in the cause and responsibility of such difficulties being located within the individual.

This individualised, pathologising approach is unhelpful (Beresford, 2005), and has been criticised as the psychologization (Howell, 2011) or psychiatrization (Mills, 2015) of distress consequential to social context.

This has the potential to result in individuals developing a view of themselves as being responsible for their social position and feeling as though they are unable to move beyond it, which could potentially exacerbate and prolong distress. This process of blame and internalisation can lead to shame through social comparison with others regarding their social position (Peacock, Bissell & Owen, 2014). Psychologisation, therefore, allows for structural, economic, and political causes to remain overlooked, and subsequently, disregarded, and those occupying marginalised sections of society can be easily ignored and forgotten. It is the responsibility of clinical psychologists and researchers to capture these ideas, move beyond the therapy room, consider them in the context of current systemic changes in service provision and to determine if services are responsive and tailored to the specific needs of the client group. Swarbrick & Stahl, (2009) state "poverty may be the most pervasive, significant, and debilitating barrier to achieving recovery and full participation in the community for people with psychiatric disabilities." (p. 335).

Remaining ignorant to the implications experienced by people attending services and also living in poverty, will not promote recovery, social justice or a detailed and nuanced understanding of mental health issues. The potential exists for services, and therefore clinical psychologists working within services, to stigmatise service users by locating the problem as something attributable to the individual.

Lack of attention or acknowledgement of this issue, means to ignore the experience of stigma that service users will in no doubt, have experience of already.

## Stigma

Shildrick (2016) reports that empathy for people living in poverty has eroded over the last 30 years, with a vilification and stigmatisation of people claiming out of work payments (Patrick, 2014). This, coupled with extensive media coverage dubbed 'poverty porn', objectifying people in poverty, perhaps gives rise to a change, or intensification of the stigma associated with being poor, and evidence that negative media coverage is linked to stigma (Baumberg, 2012).

The study of stigma receives considerable attention from the social sciences but less so from psychology, in particular, clinical psychology. However, the impact of stigma upon the individual psyche suggests that its influence can have a lasting and detrimental impact. Different variations and definitions of stigma exist according to each theoretical orientation (Link & Phelan, 2001), operating at different levels and taking several forms. While there is variability surrounding the definition of stigma, Goffman's (1963, p.12-13) definition of stigma as "an attribute that is deeply discrediting" is most often quoted. The dynamic nature of stigma denotes how its definition can change, depending on who is stigmatising, and where responsibility for the 'problem' is located (Sayce, 1998). Stigma can create stigmatising distinctions between 'the poor' and 'the non-poor' (Lister, 2015), and can influence personal identity, because the given identity (by those stigmatising) is in contrast to the actual identity. The discrepancy between the two identities can lead to feelings of vulnerability and tension. Specific devalued characteristics are applied to social identities, inducing relations of power (Reutter, Stewart, Veenstra, Love, Raphael, Makwarimba, 2009), resulting in identity incongruence and discrepancy.

<sup>&</sup>lt;sup>1</sup> The origins of the term 'poverty porn' is uncertain but it has been used critique the negative representation of people living in poverty in numerous televised documentaries (Jensen, 2014).

The impact of stigma and its association with mental health conditions, offers some insight into the personal impact of the pejorative labels, of which people have little or no control. Mental health stigma has been associated with a range of negative consequences (Hackler, Cornish & Vogel, 2016), resulting in reduced self-efficacy, hope, empowerment and symptom severity (Firmin, Luther, Lysaker, Minor, McGrew, Cornwell & Salyers, 2017). Poverty related stigma can also have a similar affective impact, such as feeling guilty, humiliated, embarrassed and reduced self esteem (Sutton et al, 2014). Underlid (2005) suggests that economic problems or financial concerns can also exacerbate a person's sense of guilt and shame.

The emotional load attributed to living in poverty, and the stigma associated with both poverty and mental health conditions, warrants further examination and attention. As clinical psychologists providing individual work in therapeutic settings, the extent to which this issue is attended to could vary according to clinical setting, therapist and approach. While it would be irrational to always consider poverty as a precursor to distress as this too could lead to 'pathologising poverty' (Hansen, 2014), it is essential to consider the influence of poverty and associated stigma in therapeutic services.

#### The Involvement of Clinical Psychology

To prevent the location of social problems to the individual psyche, clinical psychologists require an awareness of social contributory factors to mental health. Reluctance to do so could result in more harm and self-blame (Goodman, Pugach, Skolnik & Smith, 2013). Despite the association between living in poverty and the development of mental health conditions, services remain underutilised by this population (Smith, Li, Dykema, Hamlet, & Shellman, 2013).

Access to therapy may be determined by practical barriers, such as transport fares to appointments, changes in work schedules, and childcare costs (Appio, Chambers & Mao, 2013). People can also be sensitive to whether a therapist can empathise and understand their situation given the difference of perceived social status. In doing so, they may be unwilling to share personal experiences, assuming that the therapist is unable to understand and relate to their situation wholeheartedly (Goodman, Pugach, Skolnik, & Smith, 2013). People living in poverty can encounter significant mental health risk factors but are less likely to attend services for support. The need to be prepared for this challenge in service provision, in addition to the design and accessibility of services, requires attention and thoughtful consideration. Lack of attention to the impact of poverty within mental health services, risks the ignorance of the multiple stressors associated with living in poverty (Appio et al., 2013), and can in turn, perpetuate the stigma associated with it. Boyle (2011) suggests that psychiatry and psychology perhaps unconsciously avoid the social context contributing to emotional distress. Communicating social values and making assumptions within therapy, can replicate unhelpful dynamics within the therapeutic relationship. For these reasons, clinical psychologists need to be able to understand and reflect on the potential for discrimination within the therapy room.

#### **The Current Review**

The increase of people living in poverty and the association between poverty and mental health difficulties, suggests that the number of people attending mental health services experiencing poverty stigma may also be on the increase. This review aims to highlight and synthesise qualitative literature exploring the experience of stigma in people living on low incomes.

The primary aims of this review are to understand the individual impact of living in poverty and conceptualise individual experiences, in terms of how poverty stigma influences a person's sense of identity, and what coping strategies are used to respond to the impact of poverty stigma. Given the dynamic nature of stigma and its presentation throughout individual and systemic/structural experiences, the external influences upon identity will inevitably require attention. It is hoped that the areas of work identified can be incorporated into future service design and can be implemented to ensure that this, arguably significant and vulnerable client group, will receive attentive and inclusive services and support.

#### Method

## **Search Strategy**

The Joseph Rowntree Foundation defines poverty as "when a person's resources (mainly their material resources) are not sufficient to meet their minimum needs (including social participation)" (JRF, 2014). On this basis, in the UK poverty is measured by an income threshold of 60% of median income (Poverty and Social Exclusion, 2016). However, this measure is relatively arbitrary (Field, 2010), and instead, measures of deprivation may be a more foundation for understanding the consequences of poverty. The aim of this review is not to scrutinise definitions of poverty but to understand the implications and effects of it; therefore, all papers including the terms poverty, deprivation, low income and financial insecurity were included. Given the cultural sensitivity of this terminology, the focus of the review was limited to research published in Western countries according to a list published by Organisation for Economic Co-operation and Development (OECD, n.d.).

A systematic review of the literature was performed in December 2017 using the following electronic databases: PsycINFO, PsycARTICLES, CINHAL, Academic Search Ultimate and Sociology Index. An exhaustive search strategy of titles and abstracts, combining free text search and thesaurus terms, was conducted. The search strategy combined the following key words and related words to identify articles with the relevant content and methodology: stigma\* OR identit\* OR self concept OR self perception AND poverty OR low income OR financial strain OR social deprivation OR disadvantage\*. For search strategy, see appendix 1-A.

#### Inclusion and Exclusion Criteria

#### Inclusion criteria:

- Primary empirical qualitative research or mixed-method design
- Included the experiences and/or beliefs of participants living in poverty
- The effect of poverty was a central concept
- Included stigma as a central concept of the research questions and/or findings
- Included working age adults (age16-64)
- Related to Western countries
- Written in English

#### Exclusion criteria:

- Studies including views of people not subjectively experiencing poverty such as professionals, or public attitudes.
- Studies involving developing/low and middle income countries
- Studies reporting stigma but did not have this as a substantial focus of the research aims or findings.
- Studies of children, young adults or older adults.

#### **Selection of Studies**

Articles were identified as appropriate if they qualitatively explored how people experienced stigma as a result of living in poverty. Search parameters were chosen to provide a relatively homogenous sample allowing us to obtain a coherent picture of the stigmatised identities of people living in poverty. Figure 1. provides a flow chart of the study selection of the initial 1088 papers.

Fifty seven papers were excluded as they were either not available in English or were duplicates, the title and abstract of 1031 papers were read to determine their relevance to the topic. If relevance could not be determined, abstracts and full texts were read for more information. A hand search of the reference section of articles was used to identify further relevant and suitable papers yielding three extra papers. These were also reviewed to determine eligibility for the review.

#### **INSERT FIGURE 1**

From the initial search, 14 papers were identified for meta-synthesis. Seven of the studies were conducted in UK, five in USA, one in Canada and one in Australia. The studies included issues associated with poverty and stigma such as housing, welfare benefits, food bank use and disability. No restrictions in terms of dates were applied to the search yet all studies were published between 2005 and 2016, perhaps indicating particular attention to this issue in recent years. Three papers considered for inclusion appeared to involve the same sample for data collection and analysis (Garthwaite, 2014a, 2014b & 2015). One of these studies was excluded (Garthwaite, 2015) due to a lack of substantial reporting on stigma, the remaining two were included having met all the required criteria. For an overview of the study characteristics of included papers, see Table 1.

#### **INSERT TABLE 1**

## **Quality Appraisal and Data Extraction**

The Critical Appraisal Skills Program (CASP; Critical Appraisal Skills Program, 2017), comprising a checklist of 10 questions, was used to appraise the studies, providing a guide to the rigour of the research, e.g. 'was the data analysis ...'

- 'yes' (3), 'cant tell' (2), 'no' (1). The appraisal tool and scoring system, was used as a guide, the maximum being 30. The authors do not recommend a cut off for inclusion (CASP, 2017), and it was therefore used as an information tool to explore rigour and credibility, and not to exclude papers. The final selection of papers were independently screened and quality assessed by the lead author and an academic.

Table 2. provides the agreed scores from both raters. Scores were generally agreed and where there were differences, this was discussed until a final rating was agreed.

From the table, we can see that generally, all of the included studies were of good quality and therefore, equal attention was given to each study.

#### **INSERT TABLE 2**

#### **Data Analysis**

Noblit and Hare's (1988) seven steps of meta-ethnography was used to produce the synthesis. All papers were read several times to identify the main concepts and key findings, and to aid familiarisation with the data. Relevant information, including metaphors and emerging themes, were extracted from each study to provide a context for key information included in the final analysis. Data was extracted verbatim to reduce the risk of losing important details. Many published examples of metasynthesis use Schutz's (1971) notion of first, second and third order constructs, and this method was followed for this review.

A table was developed and the extracted information was used to populate the table, see Table 3. First order constructs incorporated the language used in the studies referring to everyday understandings of participants, followed by second order constructs using the language and interpretation of the researcher. Third order constructs involved the synthesis of both first and second order constructs. This data set was grouped together using constant comparison between studies and understanding the relationship between them. At this point it was possible to identify similar reoccurring themes; these were clustered together and notes were made about how these themes related, or did not relate, to other themes. A line of argument could then be established and overarching themes were identified.

#### **INSERT TABLE 3**

Stigma was a main concept in the review, and therefore the majority of papers were written up describing and using the language of stigma, such as othering, internalisation, concealment of the truth etc. potentially simplifying the analysis. However, in synthesising the data, attempts were made to go beyond the commonly used stigma terms to prevent repetition and description of an already well-argued topic.

#### **Results**

Four themes were identified from the metasynthesis: Awareness of stigma, The personal impact of the imposed identity, Stigma management and Acceptance. The theme of Stigma management comprises of two subthemes; create safety in an unsafe world, and the coping paradox.

#### Theme 1: Awareness of Stigma

There was an acknowledgement across the majority of the papers that people were aware of the existing social narratives or had a 'stigma consciousness' (Reutter, Stewart, Veenstra, Love, Raphael & Makwarimba, 2009). Social class position (Broussard, Joseph, Thompson, 2012), negative media representation (Garthwaite, 2016) and stigma within institutions (Reutter et al. 2009; Hansen, Bourgois & Drucker, 2014; Whittle, Palar, Ranadive, Turan, Kushel & Weiser, 2017) were also explored in the studies. The awareness of negative representation from institutions was mentioned particularly in the research examining food bank use and welfare reform, (Garthwaite, 2014a, Garthwaite, 2014b; Purdam, Garratt & Esmail, 2016; Patrick, 2016), highlighting a sense of blame and attribution for their poverty position. These papers described strict welfare reform regimes, humiliating experiences attending food banks, and stigmatised encounters with welfare staff:

"Sometimes they're kind, sometimes they're rude. And it's hard when they're rude....and like, social workers and people constantly talk down to you. And you're angry, but...if you speak out or speak up, you just make it worse for yourself so you just go along with things you definitely don't like." (Broussard et al., 2012, p.196).

An awareness of pejorative labels was also evident in the data. People were considered 'shirkers', 'lazy' and 'immoral' (Whittle et al., 2017), 'scroungers' (Purdam, et al., 2016), 'outsiders with deeply discredited attributes' (Warr, 2005), having a sense of 'undeservingness', and being a perceived 'burden on society' (Reutter et al., 2009). A conscious awareness of these negative external judgements led to further negative consequences and exacerbated the existing stigma experience (Whittle et al., 2017).

The impact of these narratives influenced individuals differently. How society viewed poverty and poor people depended on how people coped with and managed their situation. Reutter et al. (2009) stated that some people understood poverty as a deliberate, personal responsibility and an individual choice. Viewing poverty as a result of poor money management, poor choices, and having unhealthy spending habits, denies social responsibility for inequality. This coupled with negative media coverage and stricter welfare regimen bears heavily on people living in poverty. Social interactions with others serve to reinforce negative self-belief and personal identity was then created in line with these collective beliefs and assumptions (Garthwaite, 2016).

# **Theme 2: Personal Impact of Imposed Identity**

Given the level of social awareness evident from the literature, it comes as no surprise that these messages become internalised. Reutter et al. (2009), Sherman (2013) and Whittle et al. (2017), described the internalisation of these deeply ingrained discourses. People endeavour to reject and resist these negative perspectives (Patrick, 2016) but it seems as though the insidious and persistent nature of the stigma experience not only makes this difficult, but had a considerable negative impact and individual cost.

The internalisation and absorption can inform self-evaluation (Pemberton et al., 2016), and lead to low self-confidence and esteem (Pemberton et al. 2016; Warr, 2005), depression, anxiety, self-hate, embarrassment, humiliation (Reutter et al, 2009; Sherman, 2013), and stress (Broussard, 2012). In an attempt to manage the associated shame and embarrassment, people tried to hide and disguise their stigma (Warr, 2005), and became increasingly concerned with external reactions from others (Garthwaite, 2015b). Broussard suggested that people supress their true emotions for fear of negative consequences: "...if you're nasty to me, you know, I want to tell you where to get off. But I can't you can't tell welfare people that, you cant tell doctors and nurses that... you have to bite your tongue" (2013, p.196).

Avoiding humiliation would also come at a cost as people would chose deprivation rather than ask for help and support. This seemed to arise as a response to manage further stigma by association; for example, people would only ask for help if no other option was available: trying to manage without food was more preferable than accessing a food bank or seeking financial support such as welfare payments.

The fear of further stigma of having to ask for help and the negative association associated with this, reduced the likelihood of asking for help (Sherman, 2013), maintaining the emotional cost and burden.

The 'imposed identity' part of this theme relates to individual identity being influenced or imposed upon by society, and people feeling less able to reject this or form a more favourable identity easily. When people found themselves living in poverty, and this was in contrast to their original self-identity, it resulted in identity incongruence. This occurred when the identity imposed by society ran in opposition of the identity that a person originally identified with.

Hansen et al. (2014) described participants identifying as hard working but found themselves unable to secure employment, and therefore became a 'scrounger' in the eyes of society. Alternatively, people defined themselves according to their disability, but then had to prove this to justify support (Patrick, 2016); without proof, they were labelled 'lazy'. This then contributed to the emotional cost, leading to further negative self-images "Sometimes I think, yeah. Get looked down on sometimes and things like that. Thinking I'm not worth nothing" (Patrick, 2016, p. 250).

The constant self-comparison and falling short of the rest of society, having to hide your true identity and feelings for self-preservation, having feelings of failure for not being able to provide for their families (Purdam et al., 2016), and the emotional burden and negative self-evaluation, are a constant reminder of the low rank that people living in poverty occupy in society. Strategic and effective coping mechanisms are therefore required to navigate and manage these difficulties and social pressures.

# **Theme 3: Stigma Management**

# Create safety in an unsafe world.

In order to feel safe in a world that may be making negative judgements, people tried to create their own sense of security and protection. People were mistrustful of the motives of others and would avoid social contact, through fear of negative appraisal, personal cost or being 'found out' (Warr, 2005). People became mistrustful of those who stigmatised them (Broussard et al., 2012), and projected this to those around them in the social hierarchy.

This forced them closer together creating 'out groups' or 'phantom others' (Garthwaite, 2015), alleviated any threat to their existing social identity (Hamilton, 2012), and externalised blame for their position or status (Hansen, 2014). In order to maintain this position, people needed to work hard to continually deflect stigma, would stigmatise other groups, and create an undeserving 'them' and deserving 'us' (Patrick, 2016). The difference and distance that was created, contributed to an atmosphere of separation and stigmatisation across groups. Managing their stigma in this way, in the context of other themes, including social narratives and internalisation, highlighted a need for positions to be created at the bottom of the social hierarchy for those considered 'worse off' (Garthwaite, 2015a; Garthwaite 2015b). As long as self-identity was not aligned to membership of this created group, one could retain and protect their self-identity and keep it elevated and intact.

The process of 'othering' as a method of stigma management was identified across the literature. People would align themselves with people who held similar beliefs and an understanding of each other's difficulties, resulting in intense socially homogenous relationships (Warr, 2005). This also had the consequence of creating less favourable, stigmatised groups:

"...there's people like Zara from next door and she's from a different country, she's from Pakistan and she's a lovely, lovely woman but she gets free gas, free electric and Home Office pay her shopping. She gets everything for nowt..."

Patrick (2016, p 255.)

Reviewing the literature highlights the utility and function of stigma management strategies but it also suggests that while the strategies employed may be helpful in the short term, they may actually maintain and contribute to further negative evaluation in the long term.

## The coping paradox

Stigma management strategies can often have a paradoxical effect and have adverse, and perhaps unexpected consequences. In an attempt to manage stigma and negative appraisal, people would deny their poverty and conceal it from others (Sherman, 2013; Reutter, 2009; Patrick, 2016; March McDonald & Schroeder, 2013; Hansen, Bourgious & Ducker, 2014, Garthwaite, 2014, Garthwaite, 2015). To cope with this concealment, people would avoid social interactions thus reducing the opportunities for risky social disclosure (Warr, 2005), and preventing shame and social disapproval (Sherman, 2013), which in turn, alleviated any threat to their social identity (Hamilton, 2012), and avoided feelings of pity (Reutter et al., 2009): "Well if I meet people I don't tell them that I'm on assistance...that I'm in subsidised housing...that my cupboards are empty. I don't tell them this stuff coz it's embarrassing" (Reutter et al., 2009, p. 305)

Another strategy used to conceal their poverty was to deny the truth and overcompensate. Despite insufficient funds available, expensive items were purchased to ensure social acceptance (Reutter et al., 2009) and some would impulse buy regardless of the consequences (Hamilton, 2012). This helped to protect from the dissatisfaction of their situation and poverty status.

Marsh-McDonald and Schroeder (2012) described how people overcompensated by presenting themselves in a positive light to avoid negative judgement, while Hamilton (2012) argued that people would consume to facilitate and project a positive identity, in an attempt to disconfirm negative stigma.

The consequences of consuming more to mask poverty and avoid stigma, resulted in the development of 'chav' culture, that in itself presents negative judgements, and the initial strategies employed to protect against stigma, and disconfirm the stereotype, actually maintain it. This is also true for the strategy of avoiding social contact to conceal poverty. As people withdraw for self-protection, to avoid negative judgement, and align with same for safety, the consequences foster more problems. These stigma management strategies can lead to further social isolation and loneliness. Loneliness and isolation are significant factors continuing throughout the studies describing the limited opportunities available to engage in and develop social networks. Warr (2005) described loneliness as a critical health issue, and it excludes people from mainstream society (Patrick, 2016). Social isolation presents barriers to community involvement (Warr, 2005; Reutter et al., 2009), leading to exclusion from potential support (Reutter et al., 2009), and reduced and undermined social solidarity and community support.

The stigma experienced and the fear of stigma, encouraged people to withdraw from their existing social networks (Garthwaite, 2015), such as the family. The role of the family was crucial when considering support available to protect against isolation and loneliness, although people also felt excluded from their family if their poverty situation did not fit with their wider family values (Patrick, 2016). Studies suggested that shame could prevent disclosure of their poverty status to friends and family (Warr, 2005; Garthwaite, 2014b; Purdam, 2016), due to feeling stigmatised and misunderstood by them (Reutter et al., 2009). Changes in identity associated with poverty such as job loss, food bank use, or inability to pay bills; also impacted upon these relationships (Garthwaite, 2015; Hansen, 2014).

The role of family and friends either provided support or was considered unhelpful, leaving people to cope by excluding themselves from the family unit (Hansen, Bourgios and Ducker, 2014; Garthwaite, 2014b). The perception and availability of support from family and friends was crucial when considering how conceivable it was for people to navigate the consequences of stigma.

The paradoxical strategies employed to manage stigma, resulted in people feeling re-stigmatised and maintained the feeling of social isolation and exclusion. When this theme is considered in line with an awareness of stigma, and is combined with the human and emotional cost, it becomes clear how people living in poverty can feel isolated and alone in their plight, and almost disempowered to move beyond their current predicament or believe that progress beyond this is possible or attainable.

#### Theme 4: Acceptance

A level of acceptance was required for people to feel able to move forward, and if necessary, accept help and support. In managing stigma and wider social discourses, people found ways of accepting their position. This could present as a coping strategy in itself, or it could be considered a process that one has to go through in order to find satisfaction with their sense of acceptance. Sherman (2013) described how people traded stigma for survival and were faced with a choice between the shame associated with asking for help, and the need to accept help in order to receive support. To acknowledge and accept help from others meant a process of letting go of existing moral and gender identities such as 'hard working' or 'male provider'.

When people found themselves in difficult positions, and clung to particular identities for survival or esteem, the process of acceptance was difficult:

"It's hard for me. You know? And – but I have to be okay with it because um, I can't say, "no, you can't help us." Because she's helping us with – at this point in time, you know, she's helping us with things that we need."

(Sherman, 2010, p. 425).

When people found resolution through the process of acceptance, it helped to increase their self-esteem and their sense of independence (Reutter et al., 2009; Hamilton, 2012). While the catalyst for this acceptance was unclear, Pemberton et al. (2016) concluded that the maintenance of a positive identity meant an active rejection and an opposition to negative social discourse. Reutter et al. (2009) and Broussard et al. (2012) found involvement in voluntary work was a way of making this difference. People derived a sense of empowerment through helping others with whom they identified as in greater need than themselves. Helping with emotional and practical support enhanced their feelings of being able to make a positive difference (Reutter et al., 2009). Alternatively, experiencing an accepting environment was also a factor in personal acceptance. Garthwaite (2016) and Purdam (2016) found that after accepting the need to seek support and attend a food bank, the accepting and welcoming environment there was crucial in allowing them to begin to move beyond, and alleviate their personal feelings of stigma. Feeling valued and less isolated, and being able to connect and share experiences with people in similar positions, seemed to counteract the emotional and personal cost experienced.

#### **Discussion**

This meta-synthesis aimed to explore and understand the impact of poverty stigma and its influence on identity. The synthesis resulted in four concepts, which captured the core elements of those experiences.

Firstly, the awareness of stigma emanating from social and media narratives is unsurprising given the availability and frequency of often inflammatory media coverage (Beresford, 2016; Feltwell, Vines, Salt, Blythe, Kirman, Barnet, Brooker, & Lawson, 2017), presenting a 'deserving' and 'undeserving' poor, to create distance between those in poverty and the rest of society (Chauhan & Foster, 2014). This research highlights how this experience can result in the creation of an identity that is in line with these discourses, exacerbating the stigma experience. These social narratives then became internalised and people began to adopt and incorporate the identity that had been 'given' to them, despite it being in contrast to their self-identity. Over time, these experiences lead to 'social injuries' (Pemberton, Fahmy, Sutton & Bell, 2016) such as shame, embarrassment, low self-esteem and feelings of inferiority, leading to powerlessness and lack of control (Goodman et al., 2012).

In addition to this process of internalisation, the second theme of the personal impact of imposed identity also incorporated individualisation. People described feeling blamed, ashamed and responsible for their poverty and avoided social contact to protect their identity. Peacock et al. (2014) described this process as 'no legitimate dependency', whereby people felt disproportionately personally responsible for their situation. People were expected to be able to cope with what was happening to them and, therefore, would not seek help in the fear that this would be viewed as a sign of weakness or dependence, presenting as a barrier to seeking support.

All of the studies reviewed described stigma management strategies. People tried to conceal their identity or poverty status, in fear of further stigma, making it unlikely for a person to identify as 'poor' or admit this in public (Lister, 2004). Barriers to seeking support were also a consequence of the paradoxical nature of the coping strategies developed to protect identity and keep stigma at bay. In their endeavor for self-protection and elevation, people remained excluded and isolated.

Another common strategy employed was the othering of people considered less worthy, or lower down the social hierarchy. People protected their identity by denigrating and creating a less favourable 'other' to elevate their current position and identity. In the creation of the 'other', people sought out those in similar circumstances, aligning with them, investing in the relationships, and helping to create a separate group. The process of social comparison enabled the maintenance of a positive social identity, however, people were reluctant to cross boundaries into other groups, perhaps through fear, threat, or potential rejection. This can be explained using Social Identity Theory (Tajfel & Turner, 1986). Similar status groups are more likely to compare themselves to each other increasing the potential for alignment with groups considered 'higher'. Conversely, considerable differences in social status reduced the opportunity for social comparison and therefore, developed negative social identity, hence people were less likely to venture towards anything considered too different. The work of Wilkinson and Pickett (2009) offers an explanation, in countries of greater inequality; the upward comparisons made are seen as unobtainable and perhaps fuel negative selfidentity. The papers included in this review consisted of Western countries according to OECD, and these are also considered countries with greater inequality (Wilkinson & Pickett, 2006).

This process of comparison not only occurred from above (by media, society etc.) but was also enacted by those at the 'bottom'. By separating themselves from perceived less favourable others, this protected their identity and the identity of their group. This is consistent with Bourdieu's (1984) explanation of social inequality, and how people identify with those 'above' the social ladder, and distance themselves from those 'below'.

The research reviewed highlights the need for people to manage poverty stigma and overcome potential barriers. People sought help when they believed there were no suitable alternatives, and were 'forced' to accept their stigma in order to access support e.g. from a food bank (Sherman, 2013; Garthwaite, 2014; Purdam et al., 2016). When support was accepted, the outcome was usually positive and issues such as a welcoming environment and friendly faces were beneficial, and aided the destigmatising process. It is essential, therefore, that when accepting support, people have a positive experience, as negative experiences could reinforce stigma and damage identity.

The strategy of social comparison can be successful in protecting identity and can have also a positive outcome. Social comparison can be employed to enable people to see commonality in their experiences. In comparing themselves to those they perceive as similar or less fortunate, people can empathise with their situation and offer help and support. Craig and Richeson (2016) described how stigmatised groups can either identify with other stigmatised groups, or can view their discrimination experiences as unique to them. This review suggests that being able to identify with others and engage in voluntary work (Reutter, 2009) can help to form a new, more favourable identity that is preferable to the stigmatised identity.

Reutter et al. (2009) argue that the nature of poverty stigma is complex, as individuals need to manage the threat of stigma in addition to the hardships of poverty, potentially leading to detrimental health implications, and leading to further social exclusion.

#### **Reimagining Mental Health Practice in the Context of Poverty**

The stigma experience of people living in poverty allows for careful consideration of the potential impact on mental health and in mental health services. It is, therefore, important to consider the impact of these findings and how they may, or may not, present in mental health services and inform future service delivery. This review suggests that the coping strategies employed by people living in poverty can present problems in the long term, making it essential for services to be aware of this when considering their expectations of those utilising services.

Research with therapists working in the context of poverty, suggests that without previous contact or training, there was a potential for therapist bias. This could result in blind spots that could be played out within therapy, influencing the therapeutic alliance (Smith et al., 2013), or by making assumptions about poverty (Appio et al., 2013). Service users can also be cautious and sensitive to a therapist's understanding of their situation (Goodman et al., 2013). In relation to clinical psychology, practitioners who developed competency and awareness of poverty related issues, could be better placed to empower service users to address the issues themselves (Goodman et al., 2013). Reid (2010) proposes some clinical psychologists "adopt an equally individualised, contextless approach to research and clinical practice", and Boyle (2011) suggests that clinical psychology could be in fear of social context and therefore, avoid it in clinical work.

Although clinical psychologists must not be expected to experience every issue potentially impacting upon a person's presentation, it could prove beneficial to consider the impact of the social context in therapy to prevent further marginalisation of service users. Teaching the importance of the social context and in particular, the impact of poverty, in all practitioner training schemes would help to bring any assumptions made about poverty and privilege, into awareness. Teaching could include service users in the teaching of trainees to reflect on how social issues can influence the course of therapy or interfere with therapy, to consider what enabled access therapy such as practical support, time set aside to complete paperwork for benefits applications and bus passes. Teaching could also encourage clinical psychology trainees to train staff and raise issues on placements.

Finding places that were welcoming and approachable were experienced positively among the studies and helped to manage stigma. Services ought to be aware of this issue and provide approachable and welcoming environments, as people may have had to overcome substantial barriers and stigma to attend. This could also help to prevent a mismatch between the needs of services users and the limited scope and reach of mainstream services. The consultation and involvement of the public in the design and set up of services, could help to promote more inclusive environments and could identify potential barriers before they actually impede or prevent attendance.

Loneliness and isolation was a consistent theme presented in the literature, which is consistent with Shevellar et al. (2014) who suggest that how people relate to each other is crucial for a sense of belonging. This sense of belonging can be encouraged by providing space for people to regain a sense of a valued identity, by sharing the dilemma, consider relationships, and to foster acceptance within the therapeutic relationship. Designing services with loneliness and isolation in mind, may help to counter the stigma experienced, and develop a more positive and valued identity, one that is chosen and not simply attributed by society. Linking people with local community groups and services would help to develop relationships within their community.

This could address isolation, provide volunteering opportunities, and hopefully provide welcoming environments where people can create and develop a sense of belonging and purpose. Clinical psychologists can learn from and liaise with colleagues outside of the discipline to identify and make links within local communities.

To help reduce the stigma associated with particular groups, it is helpful to reflect and learn from other related campaigns. The extensive work of Holmes (2010) aimed to address the negative impact of stigma in mental health services by developing psychology in the real world. This idea was underpinned by principles of collaboration between socially valued and socially devalued people in society, to help create unity, and accept their differences, the recognition that each person's experiences are unique, and the faith that people have the ability to develop their own understanding of the world they live in. *Psychology in the real world* is based on the principle of "If we all see each other as part of the human race, categorisations...will lose their power and prejudice against people who have been assigned to socially devalued groups, such the 'mentally ill', may lessen", (Holmes, 2010, p. 137). Shared interest groups were developed such as 'Understanding ourselves and others', 'Toxic mental environments' and 'This is madness'. All groups sought to develop self- awareness, build relationships and reduce stigma. Similarly, Seager (2017) described an emphasis on the 'human condition' and stated that stigma reduction could begin if attention was diverted away from treating mental conditions, and instead moved towards meeting the needs of the human condition. Tailoring environments and honoring the needs of people in this way could take positive steps towards reducing the stigma associated with mental health dependency.

Stigma reduction strategies have been noted in the development of services for personality disorder. The document 'Personality Disorder: No Longer a Diagnosis of Exclusion' (NIMHE, 2003) highlighted institutionalised stigmatisation and how people with a diagnosis of Personality Disorder (PD) found it difficult to access services, were blamed for their condition, and were met with prejudice from staff (Snowden & Kane, 2003). Since the publication of this document, there have been developments in service provision, specialist staff training, government policy and collaboration between different organisations, contributing towards stigma reduction (Evans, Sethi, Dale, Stanton, Sedgewick, Doran, Shoolbred, Goldsack & Haigh, 2017). However the Consensus Statement for people diagnosed with personality disorder suggest that people with this diagnosis experience complex social and systemic failures suggesting that work in this area requires further attention and focused effort (MIND, 2018).

In relation to psychosis research, emphasising the psychosocial explanations of psychosis, to allow for a more nuanced and humanised understanding, can help to reduce stigma. Focusing on biological etiology and, therefore, locating the 'illness' in the individual, only serves to perpetuate stigma in creating social distance and internalisation (Longdon & Read, 2017). Additionally, the recent introduction of the Power Threat Meaning Framework (Johnstone & Boyle, 2018) may help to divert attention away from individualising and blaming narratives, towards a more detailed, and resourceful one. The framework recognises the role of social factors involved in mental distress such as poverty, inequality and discrimination, and how social narratives can influence identity. For example, the PTM Framework relates to this research by providing an understanding of how *power* could be attributed to state mechanisms and policies perceived by people to maintain poverty, the *threat* could be remaining in poverty, unable to move away from it, or a threat of ill health, the *meaning* for those concerned could be how people individualise and locate blame for their poverty status and in turn, their 'illness'.

Although in its infancy, using the framework in this way could help to form a counter narrative, one that people can understand their current positions and feelings of powerlessness. If incorporated into services, the framework could help people to create more hopeful narratives, instead of viewing themselves as to blame or defective.

As clinical psychologists it is essential that the depth of peoples experiences and the impact of poverty are attended to as a continuation of a narrow, reductionist understanding of poverty and mental health, will only serve to prolong the distress already experienced. Given the paradoxical coping strategies employed when trying to manage stigma, it may not be easy to identify in clinical work. Offering constructive alternatives to services is therefore required, to move away from the location of social issues being attributed to an individual. Designing services with the aim of reducing the stigma experience, and developing *real world* groups so that people can share their experiences with a view to attaining and sharing skills, can provide valued roles and accord greater power.

This research can be used to negate the myths and misconceptions that perpetuate stigma and negative social identity. Clinical psychologists therefore need to be sensitive and in tune to how people understand their social identity and their need to maintain this identity amidst the threat of stigmatisation from external sources.

# **Strengths and Limitations**

This literature review synthesised qualitative experiences of poverty and stigma in Western societies. Findings revealed similar processes already identified in the wider stigma literature and this review sought to apply these findings to consider the multiple disadvantages in relation to mental health.

A limitation of the review centers around the complex and dynamic nature of both stigma and poverty. Both concepts encompass substantial research areas consisting of a wide range of sub topics, making it difficult to find a homogenous sample to review. In the future it may be helpful to review literature focusing on one area such as the stigma associated with welfare payments or food bank stigma.

The review did not specify gender, one paper included single mothers only and one paper included families of both mothers and fathers in the sample. There could be a difference in how gender influences the management of poverty and families cope. Further reviews could also focus on one particular country as not only the experience of poverty could differ, but the social and media narratives and negative discourses could be different according to countries and cultures.

### **Conclusion**

This review aimed to explore the experiences of people living in poverty and the coping mechanisms employed to manage poverty stigma. The synthesis of 14 articles highlighted four themes encompassing and determining the extent of poverty stigma, and how the stigma management strategies employed may prolong stigmatising experiences. Understanding these experiences presents questions and opportunities for clinical psychologists, services and communities.

To acknowledge the role of clinical psychology in particular, means to acknowledge the role psychologists could potentially play in stigmatising poverty. A failure to evidence awareness of the social context can maintain stigma, and result in people feeling their stigmatised identities do not belong, and therefore, *they* do not belong, perpetuating the marginalisation already experienced. Clients also could present the same stigma management strategies they use to manage their poverty status such as concealment, creating distance, and social comparison to therapy; perhaps unconsciously influencing the therapeutic alliance.

Social comparisons could also be made between the client and the therapist, reinforcing difference and otherness, and ultimately, negative social identity.

Clinical psychologists need to be aware of the social context and the experiences of clients, to provide services that are in touch with and led by them, rather than services controlled by individualistic, stigmatising models and practices. Practical limitations of clients attending services should also be catered for by working assertively, and proactively with an awareness of the local socioeconomic conditions of the area so that services can be designed with the needs of the service user at the core.

The need for a fundamentally different approach to services is perhaps required. Learning from other disciplines and agencies that have strived to reduce stigma and prioritise solidarity with service users as citizens, will be of benefit for clinical practice. Being creative and working towards approaches that are inclusive, foster a sense of belonging to minimise stigma, while addressing the root causes of poverty and developing stronger communities is necessary. As clinical psychologists, we should utilise our skill set, theoretical knowledge and privilege, and live up to our social responsibility to endeavour to find, and be a part of, the solution.

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Figure 1: Flow chart of study selection

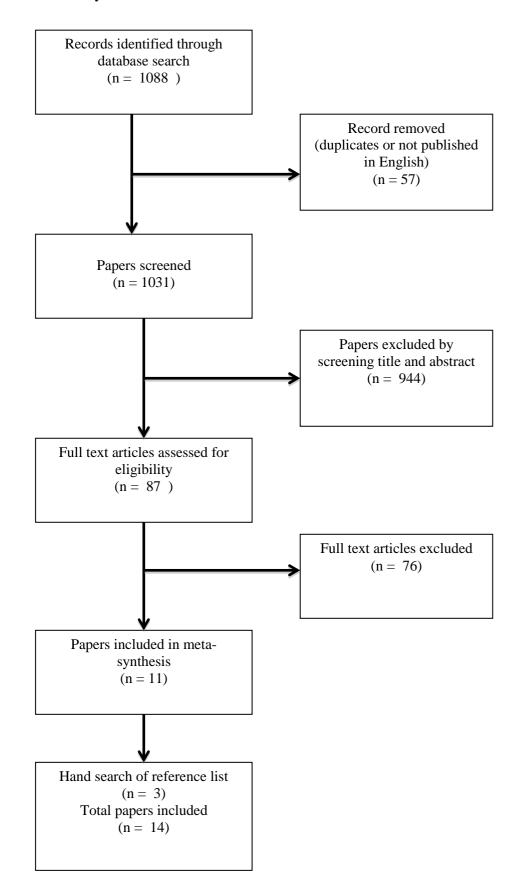


Table 1. Study Characteristics

Author and country	Sample size	Aims/research question(s)	Data collection	Main findings
Broussard, Joseph & Thompson (2012) USA	n = 12 female, single parents >18	Problems caused or exacerbated by poverty, perceptions of poverty by non poor individuals, personal experience of stigma, personal stressors and coping strategies	Interviews and narrative analysis	Impact on physical and mental health Stigma related to poverty and public assistance Impact on childcare Coping strategies and support
Garthwaite (2015a) UK	n = 25 people on long term sickness benefits	Experience of receiving sickness benefits, notions of stigma and identity, perspectives on welfare reform	Interviews and grounded theory	Constructing new dimensions of the self, validating their illness, pursuing aspirations
Garthwaite (2015b) UK	n = 25 people on long terms sickness benefits	How stigma is co- constructed, how people receiving benefits are aware of stigma in everyday social interactions.	Interviews and thematic framework analysis	Importance of social networks, fractured relationships, stigma, networks and community, social apect of working.
Garthwaite (2016) UK	<100 interviews	Stigma, fear and embarrassment of food bank use.	Ethnography - interviews, field notes and observations	Stigma, shame and embarrassment, food bank use and 'othering'

Hamilton (2012) UK	<ul><li>n = 30 families,</li><li>24 females and</li><li>6 males</li></ul>	Everyday life, budgetary strategies, hopes for the future, financial circumstances	Interviews	Paradoxes of coping with poverty, Stigma avoidance and keeping up appearances, empowerment and single motherhood.
Hansen, Bourgois, Drucker (2014) USA	n = 4 psychiatric diagnosis qualifying them for disability benefits	Whether being mentally ill is experienced as stigmatising, how structures and stigma shape one another	Case study Thematic analysis	Stigma of joblessness versus disease, Medicalised subjectivities, the balance of masculinity and dependency, punitive neoliberal reaction.
Marsh- McDonald & Schroeder (2012) USA	n = 10 females	Whether women with impoverished childhoods would have raised their social class status as adults.	Interviews Grounded theory	Women recognised the importance of education but changes continued as a result of having children, women had to be 'ready' for change, task was an obstacle and a challenge.
Patrick (2016) UK	Out of work benefits claimants n = 22 & n = 15 for longitudinal follow up	Exploration of internal and external aspects of stigma and stigma of benefits.	Interviews	Stigmatisation, personal stigma, managing the 'scrounger' narrative, and 'othering'.
Pemberton, Fahmy, Sutton & Bell (2016) UK	n = 62 people experiencing poverty	Identify behavioural discourses and adaptive responses to stigmatising	Interviews Thematic framework analysis	Behavioural discourses, rejecting the discourse, permission to denigrate, internalising, adaptive responses

Purdam, Garratt & Esmail (2015) UK	n = 34 food bank users	Identify underlying patterns of food insecurity	Interviews and case studies	Costs of coming to a food bank, stigma and embarrassment, household budgets and food sacrificing.
Reutter, Stewart, Veenstra, Love, Raphael & Makwarimba (2009) Canada	n = 93 low income people	Participants perceptions of belonging and isolation, participation in community life, causes and effects of poverty,	Individual and group interviews	Labels and stereotypes, sources of stigma consciousness, perceptions of personal identity, responses to poverty stigma
Sherman (2013) USA	n = 55 low income populations	Thematic areas: History in the community, family history, political interests	Interviews and ethnographic fieldwork Grounded theory	The great recession and employment struggles, growing need and stigma of aid.
Warr (2005) Australia	n = 26 public housing residents	Thematic areas: History of the area, things they like best and least about their neighbourhood, community contacts, hopes for future	Interviews	Local social networks, social isolation and loneliness, people within the community, stigma of living there.
Whittle, Palar, Ranadive, Turan, Kushel & Weiser (2017) USA	n = 64 people in a community project	Guide: financial situation, food security, physical health, engagement in care	Interviews	Challenging interactions with social institutions, experiences with stigma, beurocracy and stigma in the American neoliberal state.

Table 2: CASP Quality appraisal scores

Study	Valid results	Method	Research design	Recruitment	Data collection	Relationship	Ethics	Data analysis	Statement	Valuable	Total
Broussard et al. (2012)	3	3	2	3	3	2	3	1	1	3	24
Garthwaite (2015a)	3	3	3	3	3	1	3	2	3	3	27
Garthwaite (2015b)	2	3	3	3	2	2	3	1	3	1	23
Garthwaite (2016)	1	3	3	3	3	1	2	1	3	3	23
Hamilton (2012)	3	3	3	3	3	3	2	2	3	3	28
Hansen et al. (2013)	3	3	3	1	1	1	3	3	1	1	20
Marsh- McDonald et al. (2012)	3	3	3	3	3	3	3	3	2	2	28
Patrick (2016)	2	1	3	3	3	1	2	2	3	1	21
Pemberton et	3	3	3	3	2	1	2	2	3	3	25

al. (2016)											
Purdam et al. (2015)	3	3	3	2	3	1	2	2	3	3	25
Reutter et al. (2009)	3	3	3	3	3	1	2	2	3	3	26
Sherman (2013)	2	3	3	3	3	1	2	3	3	2	25
Warr (2005)	2	3	2	3	3	1	2	1	1	2	20
Whittle et al. (2017)	3	2	2	3	2	1	3	3	3	3	25

Table 3. Data analysis

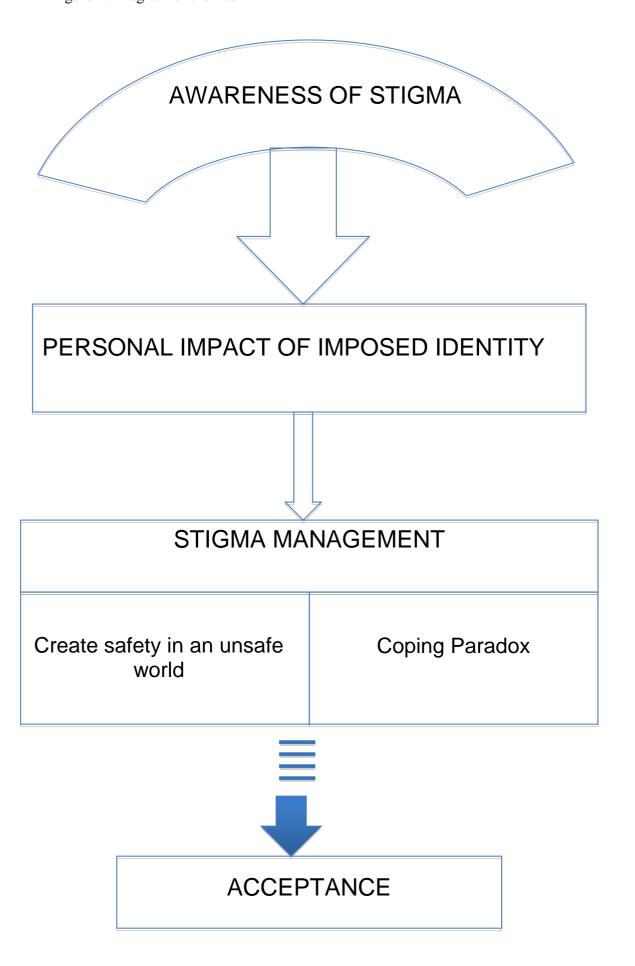
Papers contributing to	1 <sup>st</sup> order constructs	2 <sup>nd</sup> order constructs	3 <sup>rd</sup> order	Overarching
the theme			constructs	theme
Broussard et al., 2012;	Awareness of negative view of others – scrounger, lazy, immoral	Awareness of	Awareness of	
Garthwaite, 2015a;	shirkers/malingerers, deserving and undeserving	negative labels	social narrative	
Garthwaite,	Misunderstood by family and friends	Stigma = social		
2015b;	Negative social identity - result of enacted/felt	identity		Awareness
Garthwaite, 2016; Hamilton, 2012; Hansen et al., 2013; Pemberton et al., 2016; Purdam et al., 2016; Reutter et al., 2009; Sherman, 2013; Warr, 2005; Whittle et al., 2017.	stigma Social interactions reinforce underlying beliefs Strong sense of stigma consciousness Identity created in line with self definition & social discourses Stigma is complex, dynamic, insidious, evolves	Stigma conscious Family - help and hindrance Identity created in line with society Nature of stigma	Complex nature of stigma	of stigma
	Hidden costs come with accepting help	Conceal stigma at	Cost	
Garthwaite, 2015a;	Embarrassment and acceptance	cost		
Garthwaite, 2015b;	Psychological cost	Cost of change		
Garthwaite, 2016;		Cost of acceptance		
Hamilton, 2012; Hansen	Negativity projected by others		Impact of	
et al., 2013; Marsh-	Reminded of 'differentness'	Individual	imposed	Personal
McDonald et al., 2012;	'Forced' into roles - threaten identity	responsibility and	identity	impact of
Patrick, 2016;	Identity is disbelieved (institutions)	choice		imposed
Pemberton et al., 2016;	End in demote an enough	Change identity for		identity
Purdam et al., 2016;	Feel inadequate as a result	acceptance		
Reutter et al., 2009; Sherman, 2013; Warr,	Self blame Internalise negative	Internalise blame	Internalisation	

2005; Whittle et al., 2017.	Negative self evaluation	Detrimental to sense of self		
	Cautious in relationships Emotional cost - humiliation, embarrassment, burden, worthless, shame, stress, Impact on self esteem Shame is embedded Personal failure	Human and emotional cost Failure Internalise	Personal cost	
Broussard et al., 2012; Garthwaite, 2015a; Garthwaite, 2015b; Garthwaite, 2016; Hamilton, 2012; Hansen et al., 2013; Marsh- McDonald et al., 2012; Patrick,	purchase items to avoid looking 'poor' = impression management present as more favourable to avoid negative judgement consume to avoid social exclusion impulse buy regardless of consequences emotionally cope - internalise ideology of consumer society consume to disconfirm negative stigma	Buy expensive items despite funds disconfirm negative identity Justify self worth Avoid judgement Consume Produce accepted identity	Compensation strategies	Stigma management
2016; Pemberton et al., 2016; Purdam et al., 2016; Reutter et al., 2009; Sherman, 2013; Warr, 2005; Whittle et al., 2017.	Coping strategies employed undermine social solidarity perpetuates the stereotype of individualistic attributions for poverty reduced solidarity but increase activism perpetuate difficulties - further marginalisation/stigmatisation	Paradox of 'coping' Strategies unhelpful Further stigma Avoidance	Paradox of coping	

	Avoid risky self disclosure Conceal truth/identity Social withdrawal Shame	Disconnect Conceal	Self protection	
	People select their identity Careful management of information Present idealised self	Manage presentation to manage stigma	Stigma management	
	Multiple stigma Cognitive distancing Stigma hierarchy Deflect stigma Locate blame elsewhere	Othering Projection Hierarchy Social comparison Multiple disadvantage	Create distance and hierarchy	
	Socially homogenous relationships Align with same for protection, safety, comfort Rely on valued others - reciprocity	In group networks Reciprocity within	Safety within groups	
	Social isolation Loneliness Withdraw from support or cant get to it	groups Discredit others  Loneliness and	Loneliness and isolation	
	Excluded from society	isolation		
Broussard et al., 2012; Garthwaite, 2015a; Garthwaite, 2015b; Garthwaite, 2016;	Stigma as a barrier to support Lack of available resources Go without to reduce stigma Accept poverty to move forward	Presentation of barriers	Help seeking	Acceptance

Hansen et al., 2013;				
Patrick, 2016;		Stigma forces		
Pemberton et al.,		sacrifice		
2016; Purdam et al.,	Deconstruct the stigmatised identity	Accepting help	Moving	
2016; Reutter et al.,	Reject individualised attributions of poverty to	is toxic	beyond	
2009; Sherman,	cope Look beyond stigma		the label	
2013; Warr, 2005;	Tacit acceptance to move forward			
Whittle et al., 2017.	Feel empowered through helping	Narrative		
	others Try to resist stigma to see the	reconstruction		
	real me	Stigma as		
		motivation		
		Sacrifice is		
		resourceful		
		Reject		
		negative		
		identity		

Figure 2. Diagram of themes



### 1-55 Appendix 1-A: Search Strategy

	Search ID#	Search Terms	Search Options	Actions
0	S14	S7 AND S8 AND S13	Search modes - Find all my search terms	Q View Results (574)
0	S13	S9 OR \$10 OR \$11	Search modes - Find all my search terms	☐ View Results (977,548)   ☐ View Details   ☐ Edit
0	S12	(AB AB "qualitative" OR "interview"" OR "focus group"" OR "case stud"" OR "grounded theor" OR "narrative" OR "thematic" OR "experience") AND (59 OR S10 OR S11)	Search modes - Find all my search terms	Wew Results (0)
	S11	AB AB 'qualitative' OR "interview" OR "focus group" OR "case stud" OR 'grounded theor" OR 'narrative" OR 'hematic' OR 'experience"	Search modes - Find all my search terms	Wew Results (849,095)
	\$10	Ti Ti "qualitative" OR "interview" OR "focus group" OR "case stud" OR "grounded theor" OR "narrative" OR "thematic" OR "experience"	Search modes - Find all my search terms	Wew Results (148,962)
D	S9	DE "qualitative" OR "interview" OR "locus group" OR "case stud" OR "grounded theor" OR "narrative" OR "thematic" OR "experience"	Search modes - Find all my search terms	□ View Results (\$39,178)      □ View Details      □ Edit
0	S8	S1 OR S2 OR S3	Search modes - Find all my search terms	
	87	S4 OR S5 OR S6	Search modes - Find all my search terms	☐ View Results (92,152) ☐ View Details ☐ Edit
0	S6	AB (((AB "identity Formation") OR (AB "Self-Concept")) OR (AB "Stigma")) OR (AB "Self-Perception")	Search modes - Find all my search terms	☑ View Results (38,727) ☑ View Details ☑ Edit
0	SS	Ti (j[Ti "identity Formation") OR (Ti "Self-Concept")) OR (Ti "Stigme")) OR (Ti "Self-Perception")	Search modes - Find all my search terms	© View Results (15,575) ☑ View Details ☑ Edit
	S4	[3] ((DE "Identity Formation") OR (DE "Self-Concept")) OR (DE "Stigma")) OR (DE "Self-Perception")	Search modes - Find all my search terms	© View Results (72,804) ☑ View Details ☑ Edit
0	S3	AB (((((AB "Poverty")) OR) OR (AB "Social Deprivation")) OR (AB "Lower Income Level")) OR (AB "Financial Strain")	Search modes - Find all my search terms	© View Results (19,528) ☑ View Details ☑ Edit
Û	S2	Ti ((((Ti "Poverty")) OR) OR (Ti "Social Deprivation")) OR (Ti "Lower Income Level")) OR (Ti "Financial Strain")	Search modes - Find all my search terms	© View Results (4,116)
	S1		Search modes - Find all my search terms	🖳 View Results (22,665) 😰 View Details 🥁 Edit

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# Section 2: Empirical Paper

"It's like fighting an invisible army": An Investigation into the Impact of the Work Capability Assessment on People with Mental Health Conditions

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Prepared for submission to: *Disability and Society (See appendix 2-C for journal guidelines)* 

### Abstract

The introduction of the Work Capability Assessment (WCA) in the UK in 2008 resulted in the reassessment of everyone claiming out-of-work benefits. This assessment has generated controversy but despite criticism, the WCA continues to be the only way for people who are unable to work to be assessed for out-of-work benefits. In this study, ten participants with mental health conditions and experience of being sanctioned, were recruited and interviewed. Findings examine the personal experiences of the assessment process and how current methods of assessment can have a detrimental impact. The WCA and the threat of reassessment was viewed by participants as having a negative influence on wellbeing and often resulted in deterioration in mental wellness. Participants described becoming more 'ill', feeling responsible for their circumstances, and some considered suicide. Mental health services need to be aware of the socio-economic policies that could be influencing and exacerbating psychological difficulties.

Key words: mental health, work capability assessment, disability, narrative enquiry/analysis, psychology, qualitative, benefits.

Providing a generous and inclusive welfare state has become increasingly more difficult due to harsh spending cuts, service restructuring and the continual introduction of private provision across the state sector (Taylor-Gooby, 2012). This includes providing additional support to those claiming benefits by introducing job search training and preparation, and skills development groups. In 2011 Iain Duncan Smith, the then Secretary of State for the Department of Work and Pensions (DWP), stated that the aim of this welfare reform was to make sure that it pays more to be in employment than to "sit on benefits" with a statement that "if there is work to do, we expect you to do it" (Duncan Smith, 2010).

The Work Capability Assessment (WCA) was introduced as part of the Coalition government's Welfare Reform Act in 2012 and aimed to make distinctions between those who are fit to work (or able to with support), and those who are not fit to work due to health related issues (Litchfield, 2014), the assumption being that there are individuals in receipt of benefits who should in fact be in the workplace. The assessment was introduced to assess not only new ESA (Employment Support Allowance) claims but to re-assess 1.5 million people considered at the time to be eligible and receiving benefits, in the hope that more people could be considered fit to work (DWP, 2014). Despite initial hopes of enabling people struggling with mental health difficulties to re-enter the workplace, welfare strategies have now become associated with the exacerbation of such difficulties. While this has been captured in some quantitative studies (Barr, Taylor-Robinson, Stuckler, Loopstra, Reeves & Whitehead, 2015), there is a limited exploration of the qualitative components of people with lived experience of both the mental health system and the benefits system.

Perhaps most indicative of the uncertainty surrounding the WCA, is the amount of successful appeals against the removal of welfare payments.

The number of disability benefit claims for mental and behavioural health reasons steadily increased between 1999 and 2014 (Hood & Norris Keiler, 2016) making up almost half of people claiming disability benefits. In December 2014, 40% of fit to work decisions were successfully appealed (DWP, 2014) and new claims for disability benefits were wrongly removed from more than 114,000 people over 4 years (Shefer, Henderson, Frost-Gaskin & Pacitti, 2016). This figure, however, only considers new claims and not existing claims for people already in receipt of benefits. Adding to this controversy are the accusations that the assessment focuses on blaming narratives (Cross, 2013; Garthwaite, 2011) and concerns have been raised about the application of the assessment (Yates & Roulstone, 2013; Cross, 2013; Roulstone, 2015). Specifically with regard to claimants with mental health difficulties, the process is criticised for being unsuitable for the assessment of mental health issues (Barr et al., 2015; Shefer et al., 2016), because despite the initial hope of enabling more people to return to work, it would appear that the WCA has a strong potential to have a detrimental and counterproductive impact (Shefer, et al., 2016).

### Mental health and the benefits system

With one in six adults experiencing common mental health issues and around 20% of days lost from work attributable to mixed anxiety and depression (McManus, Bebbington, Jenkins & Brugha, 2016), the economic impact of mental ill health can be high, both for the individual and employers. For those not in current employment, an application for financial support is often required. To apply for this, an ESA50 form is completed and people will then be required to attend a WCA to have their eligibility assessed using a functional checklist.

This assessment will determine which group a person is most suited to; for example, if a person is considered able to work or can with support, they are placed in Work Related Activity Group (WRAG), where they will be expected to attend job interviews, take part in work related activities, and work experience programmes.

People with mental health conditions can find it difficult to meet tougher restrictions and conditions required from WRAG and are therefore at risk of being sanctioned – part or complete cessation of payments. Regular assessment, reassessment, the anticipation of the 'brown envelope' containing correspondence from the DWP (Garthwaite, 2014), can also have damaging and lasting consequences. Barr, Taylor-Robinson, Stuckler, Loopstra, Reeves et al. (2015) suggest the lack of availability to a secure income could be one reason that welfare reform is influencing mental health in addition to people facing sanctions. Furthermore, in geographical areas where a greater proportion of the population was exposed to the reassessment process, there was an increase in suicides, mental health problems and prescriptions for antidepressants.

In their analysis of people with disabilities in receipt of benefits, Shefer et al. (2016) argue that considerable harm is inflicted upon people who are wrongly considered able to work and is therefore one of the most severe forms of social exclusion. Given the level of inaccuracy in the assessment outcomes (as witnessed by the number of appeals discussed above), a high proportion of claimants are potentially open to both a fiscal and emotional impact. This impact is clearly demonstrated in the suicide statistics; in the UK it is estimated that the recent recession has led to 1000 excess suicides, locating an increase in male unemployment as associated with two fifths of these suicides (Barr, Taylor-Robinson, Scott-Samuel, McKee and Stuckler (2012), and 66% of people aged 16-64 in receipt of ESA have expressed suicidal thoughts and 43% attempting suicide (Adult Psychiatric Morbidity Survey, 2014).

Although the causality of these statistics is unclear, and should therefore not be overemphasised, the research highlights a trend of an increase in suicide rates alongside economic and financial changes.

### The role of mental health services

People with mental health conditions are two to three times more likely to be unemployed and around half will receive a disability based benefit (OECD, 2012). As a consequence, a substantial group of people attending mental health services and meeting with health professionals have been through the WCA and will be in receipt of out-of-work benefits.

People present to mental health services for a variety of often complex and dynamic reasons, and services are designed with individual therapy as the main focus for 'treatment'. People are assessed, diagnosed and allocated a 'treatment' plan under the direction of National Institute of Clinical Excellence (NICE) Guidelines. These guidelines recommend a combination of medication and psychological therapies according to the diagnosis given. Therapeutic approaches can have 'recovery' as their focus utilising principles of maintaining hope, building resilience and regaining control of life, primarily focusing on managing symptoms differently in the hope that that this leads to long term change and prevent relapse.

While the scope of this thesis does not allow for a more critical discussion of the evidence surrounding treatment pathways, it is worth noting the lack of acknowledgment of the influence that socio-economic determinants of health can have on mental distress (Wilkinson & Pickett, 2007). Boyle (2011) argues that, as a discipline, psychology is concerned with changing the person rather than their world and theories of individual behaviour are often ignorant of their 'social context'. This avoidance of social context can help maintain the social and economic status quo (Ferraro, 2016).

An inability to address social issues could stem from either the clients beliefs or the psychologists beliefs and behaviour in the therapy context. Perhaps the client feels that these issues do not 'belong' in therapy; perhaps the psychologist is unaware of the relationship between such societal influences and mental distress.

The individualised approach to therapy has been criticised for being part of a neoliberal, political agenda. Definitions of neoliberalism centre on the promotion of marketization where competitiveness and inequality are valued positively (Davies, 2014). Peacock, Bissell and Owen (2014) suggest that individualised language of therapy aligns with these neoliberal discourses, as therapeutic language can often emphasise individual responsibility and agency. This can be noticed in the role of psychology as an explanation of unemployment and in the delivery of mandatory job training courses (Friedli & Stearn, 2015) and in the overreliance on medication and individual therapy, focusing solely on the individual, rather than social or preventative factors (Harper, 2016). Psychology could therefore, be at risk of inadvertently promoting individual responsibility discourses, disregarding and ignoring evidence of the extent to which socioeconomic influences contribute to mental health difficulties. Consistent with this argument, and importantly from a service user perspective, Recovery in the Bin (2016) have criticised the extent to which the language of recovery has been forced to fit a model in which a normal life is restored when an individual learns to adequately manage their symptoms.

# Stigma

Allocating blame to an individual for their struggles is argued to be a principal precursor of stigma towards that individual or the social group to which they belong (Link & Phelan, 2001). In the case of benefits claimants more generally (including people with mental health difficulties), the media is a key source through which stigma is propagated.

It will also provide an understanding of how mental health services could tailor interventions and bring awareness to social issues that either in whole, or in part, precipitate the need for mental health interventions. Given the recent welfare reforms, and the controversy surrounding the efficacy of the approaches used in these regimes, this research will highlight the socio-political context in which people with mental health difficulties find themselves.

'Poverty porn' often depicts individuals in poverty as being responsible for their social position, along with the reinforcement of particular stereotypes (lazy, scroungers), encouraging judgemental responses (McEnhill & Byrne, 2014). This negative rhetoric perpetuates the stigma associated with being unemployed (Baumberg, 2012; Patrick, 2017).

Garthwaite (2011) identified a 'dual stigma' including the stigma of receiving out-of-work benefits *and* being disabled. People are stigmatised and disabled by society according to their disability and are stigmatised for being in receipt of benefits. This stigma is compounded by cultural narratives and subsequent stigmatisation of those in society who are considered "deserving and undeserving poor" (Garthwaite, 2011, p.370). This, coupled with the increase in a 'dependency' narrative of welfare recipients (Roulstone, 2015), serves to reinforce negative self- image and outlook (Henderson, Corcker, Hamilton, Williams & Pinfold et al, 2014). Internalisation of these wider discourses can lead to shaming social comparisons (Peacock, Bissell & Owen, 2013) and self blame (Peacock, Bissell & Owen, 2014). The consequences of internalised stigma can include increases in symptom severity, reduced daily functioning, and poorer treatment outcomes (Pearl, Forgeard, Rifkin, Beard, & Bjorvinsson, 2017).

<sup>&</sup>lt;sup>1</sup> The origins of the term 'poverty porn' is uncertain but it has been used critique the negative representation of people living in poverty in numerous televised documentaries (Jensen, 2014).

# **Current study**

This research takes place in the backdrop of a socio-political climate focusing on cost reduction, value for money, and austerity measures. Its aim is to explore the impact of the WCA in order to make recommendations for mental health services in their endeavour to provide adequate and effective support.

### Method

### **Design**

Qualitative narrative research methodology was used to explore the personal experiences of WCA of people claiming out of work benefits because of a mental health condition. Due to the political and social nature of the research, a narrative approach was chosen to guide the interview procedure.

Murray (2003) suggests two types of narrative interview: life-history interview and episodic interview. This study aimed to understand the journey throughout the WCA, therefore episodic interviews were used to focus on this particular point in time.

Individual interviews were used to provide a rich and unique perspective, which generated a depth of understanding. The narrative approach enabled detailed insight into individual experiences, and examined how identity was constructed and understood. This approach provided the flexibility required to capture and investigate details and stories that participants or the researcher considered useful. The aim was to offer a framework through which detailed narratives could be produced, as opposed to responses to specific questions. In this context, a narrative approach enabled an assessment of the relationship between the self, identity, and culture in relation to the WCA, in order to highlight participants' story throughout the assessment process.

### Inclusion/Exclusion criteria

To allow for some degree of coherence across the stories that participants would share, inclusion and exclusion criteria were set.

Inclusion criteria included: (i) aged between 18-64 years; (ii) claiming benefits primarily for a mental health condition; (iii) had their benefits changed as a result of attending WCA. Benefits changes constituted what participants regarded as a sanction or reduction in payments, for example, moving on to a different benefit such as JSA or ESA WRAG, or appealing a decision (mandatory reconsideration), and returning to the original benefit. Participants were also assessed using the following exclusion criteria: (i) were in receipt of benefits for a physical health condition; (ii) had been diagnosed with a mental health condition, secondary to their physical condition, or as a result of the WCA.

## **Participants**

Ten participants were recruited to the study through opportunity sampling (1 female and 9 males), ranging from 26 - 55 years of age. No statistics are currently available from the DWP about the gender of people undertaking the WCA; however, there was clearly a gender imbalance towards male participants in this sample, which may not be representative of the general population.

Table 1 provides participant characteristics and demographic information including age, mental health diagnosis, and the outcome of the WCA. Thirty-six people expressed an interest in the study. Fourteen people either declined to take part or ceased to reply to correspondence. Four people made contact on behalf of others, and twelve participants were omitted according to the exclusion criteria. Ethical approval was granted by Lancaster University Research Ethics Committee (Appendix 4-E).

### **INSERT TABLE 1**

#### **Procedure**

Initial discussions took place with service user representatives from a charity. All service users had previous experience of WCA. This helped to ensure that potential questions were framed in a way that would encourage open discussions and were attentive to the difficult nature of the topic. Involvement in this way contributed to the robustness and transparency of the research process.

Participants were recruited through social media (Twitter), and by directly emailing various charities and organisations (Disabled People Against Cuts, MIND, Trussel Trust), local food banks and Citizens Advice Bureaus (CAB). For a copy of the recruitment email, see Appendix 4-A.

Participants were directed to the participant information sheet by either attaching it to an email, or by following an online link to the university research website, see Appendix 4-B for the participant information sheet. If participants were interested in taking part, they were invited to contact the researcher.

Participants were given the opportunity to ask questions about the study and were offered a convenient and suitable time for an interview. Participants were then reviewed to ensure they met inclusion and exclusion criteria.

Confirmation of mental health condition was taken from participants. Two interviews were face to face interviews and eight were via Skype.

At the beginning of each interview, participants were invited to re-read the information sheet, and were given the opportunity to ask questions about the study. Consent forms were signed during face to face interviews. For Skype interviews, verbal consent was obtained from participants and this was recorded and transcribed. For a copy of the consent form see Appendix 4-C. Demographic information was also collected (Appendix 4-D). A semi- structured interview took place using an interview template, see appendix 4-E, following a format encompassing before, during, and after the assessment, to enable a coherent narrative. The interviews lasted between 52 - 103 minutes.

#### **Analysis**

There is no agreed method of conducting narrative analysis; therefore, guidance was taken from a number of previous narrative studies (Crossley, 2007; Reissman, 2008; McAdams, 2008; Howitt, 2010; Weatherhead, 2011).

Each interview was listened to, transcribed, and read 5/6 times to achieve familiarity with the text, and to identify emerging themes and significant moments for data extraction (Crossley, 2007). Pseudonyms were used to protect the anonymity of the participants and transcriptions were kept simple to avoid unnecessary detail (Howitt, 2010). During the research process, a detailed account of the data collection development was recorded and discussed in supervision to discuss patterns of interpretation (Yardley, 2000) and to aid with the final analysis.

Crossley's (2007) analytic method for narrative analysis, comprising of six steps, was incorporated to identify narrative tone, the use of imagery, and key themes. Particular attention was paid to how participants viewed themselves, their self construct (Weatherhead, 2011), and their identity. The language and metaphors used were also noted to offer depth, and to promote ideas as to the formation of identity (Crossley, 2007). The concept of autobiographical reasoning (MacAdams, 2008), and how people use episodic knowledge to merge this into their self view, was included in order to offer insight into how people make meaning of themselves in relation to society and their social world. Focusing on 'what' was being said, in contrast to 'how' it was said, meant that narrative analysis was preferable to discourse analysis. This approach enabled a broad description and understanding by drawing on different themes from which interpretative constructions of emotional experience of the WCA journey were formed. Therefore, thinking about how the topic (WCA) and dominant discourses influenced a person's notion of self, were integrated into the analysis. Using these principles as a guide, transcripts were reviewed individually, and data were extracted and integrated into a table of core elements of participants' narratives, see Appendix 2-A.

Shared experiences and similarities across the narratives were noted to present a shared common narrative identity and experience, situated within a broader social context.

Summary stories of participants are included in Appendix 2-B to provide context to the findings.

## **Reflexivity Statement**

The epistemological position of the researcher is of central importance in qualitative research. Narrative analysis acknowledges, and considers the influence of, the researcher and their interactions with the participant to produce rich and useful data. Narratives can be influenced by a person's cultural, political, and social beliefs and experience, and therefore considered a co- creator of meaning (Reissman, 2008). It is therefore essential in this co-creation that my position as a researcher is attended to. The framework of narrative analysis pays particular attention to 'what' is being said, within the content of narratives, in contrast to 'how' it is being said. As such, the narrative framework adopted was informed epistemologically by a critical realist position, whereby language is seen as a route to truth and meaning. Additionally, the possibility of objective knowledge or reality is accepted, while maintaining that many different meanings and interpretations of a phenomenon can co-exist (Barnett-Page & Thomas, 2009). Therefore, the participants that were interviewed, gave personal accounts of their experience and meaning of the WCA, this was their truth.

#### **Results**

Eight of the participants involved in the research had been in paid employment for extended periods of time prior to accessing the benefits system. All of the participants expressed a desire to work but were concerned about the impact on their mental health. The fear of rejection from potential employers when they discovered their mental health condition, or being forced into roles that could be detrimental to their recovery, appeared to drive these concerns.

In line with the narrative structure of the research interviews, the results will follow the same procedure capturing before, during and after the WCA. Each narrative section is separated into storylines, for an overview, refer to figure 1.

#### **INSERT FIGURE 1**

### Part one: Setting the scene – naïve anticipation of the WCA

There was variation in how participants approached the WCA, with some holding quite a naïve position, expecting it to be a simple and positive process: "I thought the WCA would be good coz I've got everything written down, they (staff) know everything about my illness, but they hadn't, you're a blank canvass and I didn't know this" (Marge). Others were more intimidated: "There's been so many horror stories constantly...its like oh my good god, you see it everywhere" (James).

The physical environment of the government building also influenced people's experience. Phil described it as "the most unfriendly environment and unsupportive place I've ever walked in to in my life." He felt the environment was similar to his previous employment, the latter of which he believed triggered his mental health difficulties. Making this link perhaps illustrates a similarity between his experience of work and now the government building.

Damon described the encounter as "pure conflict" and how he believed he could "see the stress levels". Charlie drew parallels between his experience of the assessment environment, and his experiences of dealing with the police and prison service. He described the extent to which he felt under surveillance: "there aren't a load of cameras but there are mirrors...they check on claimants from behind mirrors."

Most of the participants described their life before the WCA, and how they believed the stigma of their mental health condition could complicate finding work; for example, Paul said: "nobody would employ me coz my depression is active. I could get the job, last 2 to 3 weeks and then not turn up, get fired and lose benefits and then I wouldn't be able to re-apply [for benefits] for months". This was based on his previous experience of being "fired on the grounds of ill health", and was also shared by James, who described how his manager had to "let him go" after a period of sickness: "I was fine but everything all got overwhelmed and my brain broke."

The overall impact of these initial forays into the benefits system led to feeling further rejected by society. After working in the armed forces for over 30 years, Peter described his life as: "proud... that you have stood up and done your bit." He later described his experience of WCA: "...it's designed to make you feel less of a person, therefore you have less value in society's eyes." His identity shifts from one of feeling proud to feeling deficient in some way in comparison to others in society, perhaps highlighting how one can only be of value to society through paid employment and if you are mentally 'well'.

Part two: the WCA process

### Storyline 1: Vulnerability is (consciously) overlooked

The WCA is a functional assessment and participants believed that assessors are asked to make judgements on their appearance. While positive feedback about appearance is generally viewed as positive, here it is inverted. A smart, well kempt appearance denotes an ability to look after themselves and is considered evidence of 'wellness' by assessment staff. The consequence of this perspective is that participants can be considered fit enough to work, something the participants to do not believe they are capable of. Marge gave an example: "I went [for assessment] in shorts and a t-shirt, it came back on the form 'this woman was smartly dressed' can you imagine going to a party dressed like that (laughs) ...you can be absolutely depressed to the hilt and still put make up on and wash your hair." Phil also described his experience "...on my form it said I was well groomed and tidy which was bullshit...if you look at it this way, Ted Bundy was well groomed and look what he done." Other participants also referred to this point, and felt a sense of frustration, and at times bemusement about how they had been regarded as 'well dressed' or 'well kempt' when they did not believe they presented in this way.

These discrepancies in perspective gave a sense that assessors were only looking at fragments of information, without fully attending to the depth of applicant's struggles:

"...you're trying to push me back in to that game [work] with vulnerable people, young and old, when I'm vulnerable myself. Now if they'd have pushed me into the care game (takes a deep breath) you know, they might as well have had a mannequin there instead of me coz I wouldn't have been able to function, but yet they (raises his voice) were persistent in that and I thought, do they care or what?" (Phil)

Phil made links to his vulnerability, which is in contrast to his earlier description of himself as a "normal working man all my life." To accept this level of vulnerability indicates that his identity has been updated to incorporate his constructed understanding of his new reality. Throughout his story, he describes his motivation to return to work, but acknowledges that he needed time. He became quite agitated when describing his experience of the WCA and said: "I was sat there, rocking backwards and forwards, hands sweating, clutching at my trousers with obvious signs of anxiety...when I saw what he'd written down...and I failed each one...(shouts) you liar!" Again, there is evidence that people want to fail the assessment as any positive attribute or change can be used as evidence against them.

### Storyline 2 – "Finding the energy to fight"

James was the only participant who believed he did not have the power needed to appeal the decision. He described feeling "powerless" and "hopeless" and on 'bad' days he described being "...not human on those days."

The appeals process was a difficult experience: "...I don't know what I'm gona do. I'm like a 40 year old man and ...at 40 you're meant to have your shit together aren't you?" - perhaps highlighting the level of responsibility he felt for his situation. It seemed that going through the WCA process required resilience, determination, and knowledge. Ken described his experience of the appeal: "I applied for ESA and I never got it, it took a year of going to high Court and everything to appeal it but my anxiety was too much for me to go into Court and go through the stress of it all." Paul also relates to this explanation: "I've been through it, I've appealed, I've been through it, it's a battle ...they hope you will give up so you just wont get anything, but I wont give up, I'll probably have to appeal again."

In an attempt to navigate this process, participants sought help from professionals or people in similar positions. Those without this support used their anger as motivation to "fight" the decision, or did not attempt the "fight".

For those choosing to "fight", this can be viewed positively by the DWP, and is evidence of being fit enough to work. This is counter productive for participants; for example, Shaun: "If you turn up on your own you have really failed on mental health grounds coz apparently depressed people don't do things on their own." He described how he felt he had no option but to "fight" alone. When this is used as positive evidence by the DWP, he becomes angry and upset:

"It's a catch 22 situation. I can't do anything other than by myself...it didn't help that I found out my mother was dying from cancer having gone through it a few years earlier whether my sister would die from cancer...its just horribleness all the time (he begins to cry), sorry, and its all because of bureaucracy, you're being made to save money and the way to save money is to not have people on their books anymore."

## Storyline 3: "Am I really to blame?"

Participants described feeling they had personally failed the assessment, as if it was something they did not do 'right'. It therefore becomes something that only they alone can remedy. When talking about the sanctions he experienced, Ken stated: "... you are responsible to do it all without help. Again the responsibility is thrown on to the service user when they [DWP] are failing you based on points."

Perhaps in an attempt to rationalise their situation participants begin to externalise this blame. An awareness of socio-political issues and negative media coverage enabled them to look to other claimants to blame. Participants sought to create distance between what they perceived to be genuine claims i.e. themselves, and other fraudulent claimants 'spoiling' the process for them. In making these comparisons, they can maintain and protect their identity of being 'deserving' and 'genuine' claimants.

#### Storyline 4: "Pushed and forced into submission"

Participants felt the WCA process did not allow time to understand and manage their mental health conditions. Pressure to provide additional evidence of their mental health condition, and evidence of job searches, applications, interviews, and to be available for work despite feeling incapable of work, was particularly challenging. Marge spoke about feeling forced to 'lie' in this situation, as she believed that by signing on to JSA meant that she was admitting being fit-for-work, something that was in contrast to how she felt: "I said I'm not signing JSA coz I'm not fit for work and if I sign that then I'm being fraudulent coz I'm saying I'm fit when I'm not".

This experience resulted in her attending her GP in "such a state" indicating a decline in her mental wellbeing due to feeling "forced" to make commitments that she did not feel comfortable to make. Marge explained the depth of her mental health condition: "...when I'm really low it's like I'm fatigued, I'm like zombie-fied and my body shuts down, it's like I've got a space helmet on, like a numbness throughout." Here, she describes an almost 'disconnect' from the world and how she would not have the physical capability to work.

All participants believed that being forced back into work before they felt able to would have a significant negative impact on their recovery; for example, Phil: "you can sort your mental side, I don't want to be like this forever, as soon as I get treated right I'll be going back to work". Charlie also found the lack of time difficult and described feeling "forced" to apply for jobs. After applying for over 5000 jobs he described how the redundancy and rejection "hurts brilliantly". Charlie went on to describe feeling "pushed" into work "regardless of how suitable it was", and drew parallels between his experience of WCA, similar childhood experiences, and being in prison:

"...you queue up one after the other, in front of everyone, you strip down to your underpants, get searched, get swabbed... you remove your underpants, put the prison suit on...all the time they are watching you and it felt exactly like exactly the same process, its designed to make you feel a lesser part of society."

The assessor then reinforced his experience when she said "you are free to go."

The use of this language, he believed, suggests that he was not free beforehand.

Some of the participants discussed feelings of survival, to have the "basics", and did not feel as though they were given time to survive; for example, Ken: "constantly you were just scraping the barrel...trying to make ends meet, just surviving". He later uses the same terminology to discuss trying to manage his mental health, "again it was a scrape and a struggle, survive, do what you could." Using similar language in this way could suggest similar themes of survival underlying both the challenge of having mental health difficulties and trying to navigate the WCA.

Describing their mental health as "dark lands" (Paul), "the shutters coming down" (Marge) and "weaker...a hammer to your head" (Damon) coupled with feeling pursued and trapped by the DWP, and as though they were not believed or taken seriously, impacted on participants negatively.

#### Part three – after the WCA

#### **Storyline 5: Running out of options: considering suicide**

With few exceptions, the most frequent adaptive response amongst the participants was suicide. A sense of hopelessness and powerlessness seemed to provide a foundation for suicidal thoughts. Presenting for a WCA, and feeling unheard or disbelieved, feeling ashamed discussing their mental health conditions, managing the upset at the perceived unfair decisions made on their behalf, seemed to perpetuate these feelings. Feeling "forced" and "hounded" by the DWP and employment agencies also seemed to add to feelings of powerlessness and hopelessness.

Mark discussed how he felt when faced with the possibility of JSA, as though he was: "running out options, it's not good to think about really (laughs)...I don't know what I would have done if that [support] didn't happen." Damon related his experiences to media reports. When talking about his "mission impossible" in dealing with DWP, and how his depression made him "weaker", he made reference to another case: "...like the guy found in his flat with 6 tea bags, CV's by his bed, and he'd committed suicide cos he couldn't see a way forward." Later in the interview he adds context to his sense of weakness: "...you're never quite the same as you were 10 years ago and you were happy, carefree, no job pressures, you're a different person now. You avoid conflict now."

For the participants who made reference to suicide, they attributed deterioration in their mental wellbeing to pressure from the DWP, and feeling their mental health conditions were not taken seriously. Tom described his "meltdown" after being declared fit-to-work: "...I knew I was gona die coz I was gona lose my benefits, lose my housing benefits, lose your flat and I thought there's no point." He went on to describe wanting to "go off somewhere and die". When asked how he coped with being declared fit-to-work he replied: "Erm, you very nearly commit suicide is how you cope." When asked the same question, Marge replied "Seriously? (pause) I probably wouldn't be here", and described her sense of hopelessness. She later became upset thinking about the consequences of her thoughts:

"I start to think of my son and that he is better off without me...I know it's awful to say and I love him absolutely more than the world itself, but the thought that depression sometimes gets a hold of me that I feel it could beat the love I have for him, could mean me doing something silly..."

Peter's narrative suggests how being accused of fraud by the DWP is at odds with his self concept. Throughout the interview, he described being a soldier, serving his country, and how this gave him a sense of identity to feel proud of. His 'new' identity of being a fraud is in contrast with this, and is connected with his suicide attempts, resulting in a 12 week hospital admission,

"If I didn't have the means to support myself when I came out of hospital, if there were no finances in place, you and I would not be having this conversation right now, no doubt about that whatsoever, I would have killed myself no doubt about that, sorry"

## Storyline 6: "Left with no choice but to become the label".

After being refused ESA, Tom's need to acquire further medical evidence with a different diagnosis to fit the requirements outlined by the DWP, resulted in deterioration in his mental health.

"...cos you're not allowed to claim ESA on the same condition that you failed on your appeal, coz that makes sense! So I went back to my GP and got a sick note that said 'worsening depression', so they [advisor] said right, now you can reapply for ESA, so I did."

He described "a bit of a meltdown" wanting to "go off somewhere and die".

The meltdown he described from experiencing the process would indicate that his depression did actually become worse and so he ultimately became his new label.

Charlie described successfully appealing his decision, and when he received confirmation of this he reported: "...so I'm bouncing around the room shouting yay, I'm still insane!" In order to be successful in his appeal, he became the label, proved it and celebrated his 'insanity'.

Conversely, Paul struggled incorporating the new label into his identity. During the WCA, he became frustrated when he believed he was not being listened to and tried to walk away. Staff viewed this negatively, and he was advised to return or risk sanction:

"I think she was scared coz I'm a big guy, when I get anxious they see it as threatening behaviour, body language, but I don't mean it, I won't do anything but it gets taken the wrong way. People get nervous...so I've not been going out, I try to keep myself to myself."

Later, when discussing his experience of the Tribunal: "...the minute I said I get violent, I can tell people think I get right aggressive sometimes, the judge said right you've got it, you've got 15 points". At this point, Paul had a different relationship with his identity. Although he was initially ashamed, he recognised its usefulness. His anger was positively reinforced, as he had to present the part of himself that he was ashamed of, and so he too becomes his label. This was confirmed by Peter: "when you get the label as being different...it's very easy then for that label to become more and more detrimental, so therefore you become a shirker, ... nobody would insure me to work, you're caught in a vicious circle..."

#### **Discussion**

Patrick (2014, p.707) claims there has been an "intensification of the vilification and stigmatisation of benefits claimants," and a mismatch between wider political rhetoric and the reality of people's lived experiences. In this study, individual stories were explored to understand how participants made sense of their personal context, how relationships were shaped, and the impact this had on their identity. Reviewing the narratives of participants demonstrated how the WCA process had a detrimental impact on mental health. The anticipation of the assessment, the physical environment, staff interactions, the decisions made, and the anticipation of further and continual reassessment, all had a lasting influence and exacerbated distress. The emotional intensity and upset was clear during the interviews, which took place, in some cases, 3 years after the initial assessment.

With few exceptions, the most common adaptive response of participants was thoughts of suicide. The constant cycle of assessment, rejection, and appeal is a circuitous process with vulnerable people at the core. The constant threat of reassessment, the risk of not being believed by staff or taken seriously, coupled with the external threat and blaming media narratives, led to feelings of hopelessness, disempowerment and vulnerability, contributing towards a sense that no alternative exists. The requirements necessary to appeal decisions placed huge burden on the applicant that would appear to exacerbate distress and prolong recovery.

Participants described concerns that the assessment was deficient in understanding the nuances consistent with minimisation of mental health experiences.

Attempts to minimise the seriousness of mental health difficulties manifests itself in the interactions between claimants and the system in several ways.

Reported power differentials experienced by participants in their contact with WCA assessors and invalidations from staff, left people feeling embarrassed, humiliated, and feeling at fault. Not being clear enough, or not having the 'right' paperwork, during the assessment left people internalising blame for their situation.

It could also be argued that making individuals personally accountable for their application and appeal implicitly blames them, as opposed to acknowledging potential errors in the system. Being placed in the 'wrong' category had a financial impact, but feelings of not being believed, heard, and valued were perhaps more devastating than any loss of income. More damaging than the refusal of welfare benefits was the denial of the validity and identity that they are 'ill' and 'deserving' of help and support.

The involvement of external stigma and indeed, the self-stigma that this can give rise to, reinforced why people must present at their worst in order to be viewed as genuine and worthy claimants, which Garthwiate (2015) described as adopting the 'disabled role'. Participants were driven to be defined by their diagnosis, or had to develop a 'worse' label to be considered as valid and worthy of support. Roulstone (2015, p. 674) attributes the need to present at one's worst as a "shrinking of the disability category" based upon a fixed bio-psychosocial model of disability, with no allowances for anything falling outside of these categories. Ramon (2008) states that encouraging disabled people to enter the employment market is typical of a wider neoliberal agenda, focusing solely on the evaluation of people based upon their economic value.

People can feel incurable and hopeless, or have to at least occupy this position to be allowed time to feel 'work ready'. Therefore, in their efforts to feel better, they are viewed as fit to work when they perhaps do not feel ready or confident enough to do so. Being regarded by the DWP as 'coping' can be viewed as fraudulent, proving that people have been 'cheating' (Cross, 2013). Both of these explanations can have a negative impact on identity and hope for recovery.

The State, public policy, and media narratives can insidiously dominate sense of self and become incorporated into a person's self construct. Evidence of the adjustment of people's self concept, in line with public discourse is represented in the findings from disability studies. Thomas (2007) developed the concept of 'psycho- emotional disablism', referring to the management of the pejorative views of others, in conjunction with internalised oppression and invalidating experiences. These experiences can also re-enact previous trauma or abuse (Reeve, 2006) increasing mental distress (Reeve, 2015). Reeve (2015) described disablist hate crime as an extreme form of psychoemotional disablism based on assumptions about a person's invalidity and less-thanhuman identity. It could therefore be argued that participants in this research are describing examples of psycho-emotional disablism in terms of social and media narratives. In applying this theory to the current research, it is proposed that the WCA is a form of institutional disablism. Not accurately assessing people's mental health conditions, reliance upon psychiatric diagnosis, and rejecting the validity of their presentation, could result in institutional psycho-emotional disablism. While the WCA aims to move people into employment, for some, it could actually result in moving people further away from it.

In their study of people living in poverty, Pemberton, Fahmy, Sutton and Bell (2016) found that people rejected their pejorative labels and positioned themselves opposing others in similar situations. This finding is in contrast to the findings of this study as participants found themselves forming alliances with others in the hope of support and sense of direction, suggesting that both coping responses occur.

The concept of 'dual stigma', involving the stigma of being disabled *and* receiving out-of-work benefits (Garthwaite, 2011), can also be related to the present findings. Having a mental 'illness' is an additional intersecting stigma in this study. People are stigmatised and disabled by society, are stigmatised in their receipt of welfare benefits, *and* are stigmatised further by their mental health condition. A holistic conceptualisation of multiple sources of stigma can be understood using Link and Phelan's (2001) five component model (Figure 2.). The model proposes ways in which individual cognitive processes can cause the production of stigma while social processes and power relationships can form patterns of disadvantage. The model can be applied in this research to explain how the WCA can result in people feeling ostracised, oppressed, and at a social disadvantage.

#### **INSERT FIGURE 2.**

Given the extent to which the WCA process induces mental distress, minimises those most vulnerable in society, and forces the alignment of self constructs according to neoliberal discourses and governmental policy preferences, calls for its revision (Shefer et al., 2016), or indeed it abandonment, need to be made loudly and in unison. Appeals by people denied ESA were at a three year high in 2016 (House of Commons Work and Pensions Committee, 2018), and since 2013, 60% of ESA appeals have been won by claimants (Ministry of Justice, 2017).

This suggests that, at best, the WCA is flawed in identifying mental distress, and at worst, is placing people with mental health difficulties at an even greater detriment, presenting further barriers to recovery.

#### **Practical recommendations**

Current mental health services commissioned for individual work and promoting individualised self-management interventions, can precipitate mental distress and ignore the social context of which distress occurs. Therefore, the emphasis of the impact of social variables on mental health difficulties requires attention from Commissioners. In relation to the WCA, mental health services could consider ways of supporting people in their care as they navigate the WCA process by:

- Encouraging people to form a collective identity around the issue of being affected by welfare reform to empower people and provide a social network for those feeling isolated and alone in the WCA process. This could be in the form of local service user groups in primary and secondary mental health settings, coming together to share their experiences. These groups could be encouraged to collectively advocate for changes in policy, legislation and the design of mental health services.
- Thinking proactively about including WCA and benefits appeals in mental
  health assessments and including this information in formulations and care
  plans may be beneficial. This could include specific dates for the
  assessment or Tribunals as the anticipation of such can act as triggers for
  further distress.
- Providing supporting information for people as they prepare for WCA and/or reassessment.

- Being aware that any positive sign of improvement in mental health can be viewed in WCA as 'fit-to-work'
- Attributing more value to existing community services that can provide additional help and support with finances, social crises, welfare advice, housing etc. to signpost accordingly.

## Implications for the continued development of clinical psychology

Given the knowledge base of the profession, there is scope for psychologists to advocate for policy changes that could enable services users to experience fairer practices governing access to resources.

The individualised focus and design of mental health services may inadvertently reinforce patters of individualisation. This focus, for example, comes in the form the Government investment in short term individual therapy aimed at helping people find employment. The individualised language of therapies that encourage self-management as a route to recovery, in addition to the individualised language of WCA, may reinforce in people a feeling that they are responsible for their predicament. This could lead to feelings of hopelessness and invalidation reducing the likelihood of a person believing in their ability to move beyond their current circumstances (Harper, 2016).

Consistent with clinical psychologists' professional capacity to adapt to peoples needs in society and beyond the therapy room, perhaps there is also scope for clinical psychology to become involved in generating a more holistic plan to enable the wellbeing of all individuals collectively as opposed to a practice that confines dealing with mental distress to an individual basis (Smail, 1998).

When people are exposed to political systems that isolate and blame them, it can result in feelings of powerlessness and hopelessness, while exacerbating the experience of mental health difficulties (Shefer et al., 2016). Clinical psychology could work with other related professionals to minimise unnecessary power differentials that generate feelings of shame in individuals for perceived failings, and promote socially inclusive practices.

Individuals and groups who feel isolated can have a weaker collective identity (Peacock et al. 2014). The testimonies of participants reported feeling separate from their families, peers and the wider society, resulting in them withdrawing and feeling excluded. Without support, people felt less able to fight and appeal the decisions made. This is consistent with Mikucka's (2013) suggestions that people would benefit from support systems where they can share experiences, and prevent further social isolation. If clinical psychology is to continue its focus on: 1) nudging policy in healthier directions; 2) becoming more involved in societal wellbeing strategies and 3) enabling peer support within mental health settings, then the profession surely stands the greatest chance of delivering the greatest good to those most in need.

### **Strengths and Limitations**

This is the first study to consider the WCA at a particular point in time paying specific attention to people with mental health conditions and considers the implications for mental health services. However, as with most qualitative research, the sample size is small and therefore, cannot be considered statistically representative.

The participants in this study were motivated to appeal decisions while only one participant felt he could not appeal the decision made by the DWP.

It is therefore important to consider the voices that were not included.

Specific charities and social media were used to recruit participants and perhaps only those upset with their outcome were motivated to participate in the study, meaning that people satisfied with the WCA did not volunteer.

#### Conclusion

This research has highlighted significant limitations of the WCA process and the impact of the assessment on people experiencing mental health difficulties.

Existing media narratives, stigma and individualisation of the 'problem' absolves responsibility of government policy and leaves people feeling alone and isolated in their plight. Both issues serve to protect government policy and perpetuate oppression of the most vulnerable in society.

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Table 1. Participant demographic information

Participant	Age	Mental health condition	Changes to benefits
Charlie	48	Personality disorder	Benefits changed from ESA* to JSA** – appealed and ESA SG *** reinstated
Damon	44	Depression	Missed appointment at Job Centre
James	40	Anxiety and panic attacks	Benefits changed to JSA  – appealed and ESA  SG reinstated
Ken	39	Depression	Benefits changed from ESA to JSA- appealed and ESA SG reinstated
Marge	46	Anxiety, depression, Bipolar	Missed appointment due to illness. Later assessed and she refused to accept JSA
Mark	26	Anxiety	Missed appointment at Job Centre
Paul	36	Anxiety and depression	Missed appointment at Job Centre
Peter	55	Personality disorder, PTSD, schizophrenia	Benefits stopped and investigated for fraud
Phil	53	Anxiety, depression, psychosis	Benefits changed from ESA to JSA – appealed and ESA SG reinstated
Tom	48	Depression	Benefits changed from ESA to JSA - failed appeal — re- appeal — ESA SG reinstated

<sup>\*</sup>Employment and Support Allowance \*\*Job Seekers Allowance

<sup>\*\*\*</sup>Support Group

Figure 1. Illustration of storylines and themes

## **BEFORE the WCA**

Part 1: Setting the scene Naïve anticipation of the WCA

## **DURING the WCA**

Part 2

Storyline 1: Vulnerability is (consciously) overlooked

Storyline 2: Finding the energy to fight

Storyline 3: Am I really to blame?

Storyline 4: Pushed and forced into submission

## **AFTER the WCA**

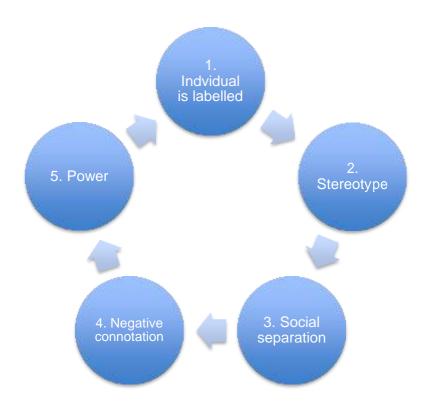
Part 3

Storyline 5: Running out of options: considering suicide

Storyline 6: Left with no choice but to become the label

Figure 2. Five components of stigma development (Link & Phelan, 2001) and its application to this research

- 1. Individual is labelled or branded in a way as a member of a specific group e.g 'lazy', 'shirkers' and 'scroungers'
- 2. An association forms between the labels and corresponding stereotypes. Can be stereotyped as 'chav', 'work shy'.
- 3. The association between the label and the stereotype results in social separation and categorises people as 'us' and 'them'.
- 4. Negative connotations about mental health/welfare support leads to affective and behavioural consequences such as social distancing and discrimination, at both individual and institutional levels.
- 5. People who label, stereotype and discriminate against groups must also have the power to produce real social disadvantage e.g. less legal rights, negative media treatment, increased difficulty in finding employment and housing.



Appendix 2-A. Core elements of participants' narratives

	Grand narrative  I have had a close escape (from suicide) "I am doing my best" "I really want to work"		
1. Mark			
Psychological reality	Images/metaphors used		
I could have been one of these (suicide) I am qualified enough and I want to work I am trying my best – this isn't recognised – I feel unheard – punished – powerless My mental illness is my justification	It is supposed to be a safety net but doesn't feel like it Not treated as a human		
How self/identity is created	Language/discourse (connects individual to social context)		
I've been to University, I have skills and knowledge to use I am better than others (self protection?) I will try anything to work Lied to parents – shame, embarrassment? I am a genuine person	Need to fight Feel betrayed I must do as I'm told Pushed (used frequently throughout) Shoved from pillar to post Narrow escape (suicide) Powerless Guilty till proven innocent		
Themes	Relation to society		
I would rather have nothing than return to JSA  Not treated as humans Forced to make choices It made my mental health and anxiety worse Embarrassed Assessment isn't suitable Pushed	Awareness of 'stories' in the media Aware of statistics and unemployment figures Feeling power-less in society Feels the need to live up to the expectations of others (society and DWP) Implicit awareness of the pressures on DWP staff, targets to meet and how they could also feel powerless within the system Could be personalising the inadequacies presented by others e.g. job agencies		

	Grand narrative I am a fighter Ashamed of true self so needs to hide		
2. Paul			
Psychological reality	Images/metaphors used		
I have a problem (MH), I don't know why (seems confused by MH) I cant help it, it's the way I am I need help Nobody understands me Anger/ aggression	We are not all scumbags like you see on the tv  Its like a game Jump through hoops like a trained monkey Push you intentionally An invisible army People fall through the cracks		
Forms his own identity in relation to the plight of others (social comparison)  I am a worker, I have always worked  Its my mental health - seems disconnected from it -? responsibility  "I'm a fighter, I want to help others" I don't fit in/belong (repeat his	Language/discourse (connects individual to social context)  Fight and battle I feel like giving up – I cant have what everybody else has It is tiring (appealing and fighting) Fighting is my work now I cant walk away (from DWP) coz I need to fight – risk losing benefits and get		
pathology?) Illness' is separated from the self	nothing I fight everyday		
Themes	Relation to society		
Impact of the appeal – uncertainty – difficulty of having to tolerate this uncertainty I have to hide my 'true' self Wants to work Feels misunderstood You made me ill	They want us to die – we are easily expendable – we have no purpose or impact in the world  Society makes negative judgements		

### Grand narrative 3. Charlie The system is re-traumatising It beings back bad memories Psychological reality Images/metaphors used Difficult tot untangle identity from Pushing you to get a job offending history - ? enmeshed Stab in the dark Makes direct links to his situation Like being interrogated by Police with WCA and previous traumatic Its like being in prison – makes experiences direct, explicit links "I am the lowest" (re offences) – has greater consequences for him How self/identity is created Language/discourse (connects individual to social context) Makes a "nuisance" of himself to be heard (does this repeat his pathology and I am strong internalise his identity) You win or lose, simple as that You cant hurt me, I'm the lowest of Live to the expectations of others the low anyway Lowest in society Need to prove 'weirdness' to get support **Themes** Relation to society Powerful – powerless Links changes in government to change of social response and negative Oppressor – oppressed judgement and condemnation I am the lowest in society Aware of social attitudes changing People don't like me Power – cant have an option or a choice Brings back bad memories (trauma) - must do as you're told and know your Layers of oppression Cycle of rejection Power – Has to take sanction to 'avoid' being found out (offence history). (he could not apply for a job due to his previous offences, did not want to disclose this info to DWP and risk shame, so takes sanction instead)

#### **Grand narrative** It makes you worse, psychologically 4. Ken demoralises you Psychological reality Images/metaphors used I want to understand myself more so I am a fighter, I will survive I can help myself I am a better person, I have ad good I am solely responsible for what iobs happens The 'wrong' people It takes luck to get you through Constantly scraping the barrel (living I am at rock bottom on a meagre existence) Like being questioned by the police, in a witness box Fight for survival Language/discourse (connects How self/identity is created individual to social context) Uses positive affirmation to cope (fighter, I will survive) Pursued by DWP You withdraw and lose confidence Controlled by ATOS Responsibility for situation is located Stuck in the loop of appeal and with the individual fighting Its not my fault Thrown in to houses I am intelligent and have had good Trapped don't know what will happen in the future jobs Messed around with ESA Has to fight process but it is difficult In the support group you are "left alone" but they will pursue you again Forced to apply for jobs it haunts you and It comes for you Have to watch your back, it makes you paranoid Themes Relation to society Improvement in mental health is used feels powerful enough to raise issues against you with MP I have no control of my life felt supported by Sikh community, I am alone worked for them in return for help. Want to "give back" to society and make Any positivity is attributed to luck. a contribution Lack of control WCA creates more problems in society Need to withdraw to cope Awareness of others in similar positions Locates control externally as himself

### **Grand narrative** Being sanctioned/JSA is worse than 5. James having nothing at all" "I am lost" "I need protection" **Psychological reality** Images/metaphors used Struggling to cope (anxiety/money) My brain broke This isn't seen by others or believed I was a wreck Real people – "I am genuine/need Helpless, lost, cant fight help/cared for" DWP are faceless – no consequences "stuck" even if I seek help, this could Its like waiting to be shot be used against me Worry about the future I am a 40 year old man, I am supposed to have my shit together" How self/identity is created Language/discourse (connects individual to social context) I feel blamed, unheard, vulnerable, unsafe, devalued - therefore I need Treated less then human by society, protection they (society) don't care about you He cant fight so he gives up Its deliberate Too overwhelming so he opts out Othering – I'm real, genuine I an terrified Fewer support services available I'm not human on a bad day Themes **Relation to society** Anti-welfare rhetoric can What it means to be a man in this society maintain/perpetuate fear or (should, coulds, oughts) DWP/WCA Feels angry and helpless at the same time Staff don't care Rather have nothing than JSA If you are honest and truthful, you get nothing Wants to hide for protection

### **Grand narrative** 6. Peter Feel ostracised, pushed away, excluded from society Your best is never good enough Just existing, not living Psychological reality Images/metaphors used Try to better yourself but this isn't A parasite good enough Pushed until you hit a brick wall I need to improve myself (to have Dark lands – depression value) Explode in your face Good or positive things are attributed Tip of the iceberg to luck "Sword of Damocles" I must clear my name Your world in gona collapse again Strips you of your dignity Waste of energy Bad nightmare How self/identity is created Language/discourse (connects individual to social context) I am a soldier, proud, strong, Army language used throughout – independent "Cost to the country" Now have little value It will break you Having to admit to and rely on others detrimental Its about survival I am controlled, at fault, guilty Chipped away and chipped away until there is nothing left **Themes** Relation to society Have to exaggerate your symptoms Excluded from society Want to give up but you have no Have no value in society's eyes choice – you have to deal with DWP or Awareness of socio-political context e.g. risk getting nothing NHS funding, Government structures. It is difficult to access support Has to improve himself to be socially You cant fight the system and have accepted (to were he once was?) good mental health Desperate to get back to society

	Grand narrative		
7. Damon	I must hide because I am scared		
Psychological reality	Images/metaphors used		
I am invisible Under threat, paranoid, hyper vigilant I switch off and withdraw I am powerless I don't stand a chance against DWP  How self/identity is created  I am better than the jobs on offer Identifies with being excluded (not believed) by media/society Shifts in identity – I'm not the same person	They hound you (job sites) being chased, pursued.  In a pinch position, stuck between systems  Depression makes you weaker "hammer to the head"  (going to the DWP) is like going through the pain barrier  It's a bad nightmare  You are pushed into a system that will hurt you  Language/discourse (connects individual to social context)  Only the 'lowest' jobs are available "push you"  Parked off the figures (hidden)  They push you to your lowest denominator  Targets are more important than peoples lives		
Themes	Relation to society		
Intentionally avoided DWP to avoid further harm  Wants to be able to hide The process is ridiculous It will hurt you intestinally Social exclusion, left behind	People have ulterior motives Tries to communicate with those in more powerful positions (local MP) Is politically aware Awareness of oppression – DWP, Gov. media, sanctions Feels 'done to' by Government Excluded by society Society does not take this seriously		

	Grand narrative		
8. Phil	Work caused my MH problem and now I am forced to return to work  Images/metaphors used  If you look smart you will be eaten alive Someone will go berserk in there (in JC+) They will eat you alive		
Psychological reality			
Angry and frustrated with the system I have lost my true self Makes you doubt yourself Doubt who you can trust, cant trust self.  I receive 'coded' letters – I don't understand – more paranoid Feel powerless – paranoid = MH deteriorates I feel paranoid			
How self/identity is created	Language/discourse (connects		
Fantasises acting out his rage Alienated as I don't understand procedures Normal working man all my life Makes threats to DWP (to feel powerful?)	Uses the stories of others to explain his situation, explain his own narrative Push it out, get it off (people on benefits)  Feels protective of others Staff should show more mercy		
Themes	Relation to society		
Need time to heal Was naïve about process and new I was unprepared Assessment isn't accurate Hostility of the environment Has to remain vigilant Cant trust self/own judgement, lost confidence	DWP have the power – I don't have any There's no humanity anymore Nobody cares		

	Grand narrative		
9. Marge	I am a good, kind person – they don't see that. I am hidden		
Psychological reality	Images/metaphors used		
Inferior to others Compares self to others No self confidence WCA – I feel like a fraudster, belittled, wrong – then forced to lie and become fraudulent My life is hard enough with the sanctions I was naive	Hit rock bottom – this is difficult to accept  Mental 'illness' the shutters come down, I am zombified  Depression - Like wearing a space mask  Its like having a canvass and there's nothing, just grey  Like opening a fridge and there's nothing inside		
How self/identity is created	Shutters coming down  Language/discourse (connects		
I am not a full person – measures the value of herself to others I am emotionless and numb Embarrassed about situation I am trying to get better, I want to help others I have nothing to offer the world Shame Good mother	I am not a full person I help others, I fit their life but where is my life? She believes the social narratives of those deserving/undeserving — I am genuine — others are not. (staff) are brutal and rude "pushed' to do things I cant do		
Themes  I would rather have nothing than go	Relation to society  I am not part of society		
to the food bank – this is rock bottom  Thoughts of suicide v's love or her son  I will never belong  Spoils it for genuine people (like me)	I am on the outside looking in, disconnected, don't belong They (DWP) are only concerned about 'pushing' you into work. They are not bothered about your illness, only about statistics She identifies a macro narrative "everyone is out for themselves"		

Grand narrative		
Stuck /Juxtaposition "there is no point, might as well die"		
Images/metaphors used		
Trapped Pressure Im not a fill person anymore Punished for helping myself I had a meltdown		
Language/discourse (connects individual to social context)		
We are numbers, not people It's a beurocracy Was protected by job coach – he felt believed and valued. Dramatic and powerful language used throughout Falls between services		
Relation to society		
We should help the vulnerable in society Unless you can work and contribute to society, you don't belong. Lost and isolated		

## **APPENDIX 2-C: Participant summary stories**

Mark is a 26 year old man. He says he will do anything to find work and despite living in the North East he applied for a job in London and was willing to relocate but was unsuccessful. He has a university degree and since leaving university he has been unable to find work. He later developed symptoms of anxiety, depression and panic attacks. He applied for ESA after being diagnosed with anxiety and depression by his GP and felt that the WCA process was unfit for purpose, didn't ask specific MH questions and that he was considered 'guilty until proven innocent' by staff. He directly relates his experience of WCA with a worsening of his panic attack symptoms and had a panic attack at the job centre offices. He was sanctioned for not attending an appointment at the Job Centre but did not receive an appointment letter until 2 days after the scheduled appointment. He lives with his parents and hid from them the fact that he was out of work as he felt ashamed and embarrassed about his circumstances.

**Paul** is a 36 year old man. He has had various jobs including a postman and in security and believes he has had mental health difficulties for most of his adult life. He says that he can become angry and aggressive in certain situations and although this is a problem for him he is certain that he would never hurt anyone. He has been diagnosed with anxiety and depression and he also has some physical limitations. He is worried that people can judge him negatively because they never get to see and experience the real person behind the anger and frustration. He views his mental health difficulties as potentially hereditary (his uncle has similar 'problems').

Charlie is a 48 year old man with a forensic history. He has served time in prison and before the conviction was in stable employment. He believes that he finds it difficult to work because of his previous convictions and his mental health difficulties. He believes himself to be the 'lowest' in society and experiences negative comments from people in his area. He lives in a rural community and finds it difficult to get involved in social activities due to the remote geographical location. He sees himself as a physically strong person and laughs about his mental health diagnosis. He reports to have applied for 5000 jobs and says the amount of rejection 'hurts brilliantly'. It seems as though because he places himself (or is placed) at the bottom of society he has come to expect nothing.

**Ken** is a 39 year old man who worked previously as a data analyst and in technical support. He began to use alcohol to cope with the demands of what he considered to be a difficult and stressful job and subsequently had to leave his employment. Since then his mental health difficulties have progressed and he was unable to pay his bills. He has lived with several people whom he believes are "unsavoury characters" and his main aim was to keep a roof over his head. He considers himself lucky to have a tenancy now but is concerned about the very short term nature of this. He locates a lot of what happens to him as his 'own fault'. He makes direct links between WCA and his mental health deteriorating. Survival is his main priority.

**James** is a 40 year old man who previously worked as a chef. He described an accumulation of stress and a release of unpleasant memories from when he was a child and his 'brain broke'. This resulted in him having to take some time off work due to symptoms of anxiety and panic and he was therefore fired from his job.

He began to use alcohol in an attempt to manage the symptoms of his anxiety and depression. He was reassessed under WCA and was declared fit-to-work. He does not believe he has the ability to adhere to the expectations of JSA and his partner 'signs on' on his behalf and appealed the original decision. He does not feel able to continue in this way for much longer and does not have the ability to 'fight'.

**Peter** served in the armed forces for 30 years and has worked continuously since leaving. He believes he was 'fine' but his work colleagues began to notice some changes. This resulted in a hospital admission and his driving license was revoked by his psychiatrist, leaving him unable to work and earn a living. Peter decided that a positive way forward would be to re-train so that he could return to work as soon as possible. He believes that he spoke to the DWP on numerous occasions about different education courses and after one year of being at university, he was accused of fraud by the DWP. Peter believes that this accusation was one of the factors in him having another hospital admission. He accrued debts from unpaid bills whilst in hospital and is still trying to rectify this and "clear [his] name".

**Damon** used to work shifts until the "work dried up". He was later diagnosed with depression and after WCA was declared fit-to-work and was advised to claim JSA until he secured employment. He has since applied for many jobs all of which have been unsuccessful. He describes the difficulty of applying for jobs that he believes either don't exist or won't employ him anyway but he feels as though he has to apply for them to comply with DWP. He also described feeling "hounded" and "pressured" by different recruitment agencies, is "scared" of job websites and worries about the pressure he believes he is put under. He was sanctioned for missing an appointment at DWP as he was attending a careers interview organised by the DWP on the same day.

**Phil** is a 53 year old man. He has had various jobs throughout his life and found himself out of work in 2011. He then began working in young peoples homes as a support worker, something that he valued dearly but felt unprepared for, not knowing the demands or the backgrounds of the young people he was to come into contact with. Some of the issues the young people faced reminded him of his own background and experiences. The demands of the job, the self harm and suicides of the young people and what he perceived to be "injustices" against them, contributed to what he called a "breakdown" and he became increasingly paranoid and suspicious of others. He believes that the WCA was unhelpful for him and contributed to his mental health difficulties making him more paranoid and worried about getting things 'perfect' to avoid a potential sanction. He would lose sleep and spend long periods of time ruminating about the 'brown envelopes' [letters from DWP] he received.

Marge is a 46 year old woman. She believes she has had mental health difficulties for most of her life and also suffers with chronic and persistent pain. She believes that she approached WCA from a naïve position, as she was sure that she would meet the criteria for ESA. She was declared fit-for-work and was advised to sign for JSA. She declined to do this, as she believed that she would be lying, as she did not believe herself to be able and fit enough to work. While she appealed this decision she decided not to apply for JSA and relied on financial support from her family. She makes direct links between the refusal for ESA and her depression becoming worse and her mental health nurse discussed bipolar disorder as a potential diagnosis.

She had previously completed work experience in the DWP and believes that she heard derogatory and unprofessional comments made by staff about claimants. This knowledge led her to believe that the staff could be making derogatory about her.

**Tom** is a 48 year old man who worked as a nurse until he had to take time off due to feeling depressed and low in mood. He was dismissed from the NHS because of this and did not appeal this decision at the time. He did not apply for support for the first 12 months due to being 'too depressed'. He did eventually apply for financial assistance and had a WCA. He received short sessions of CBT and does not believe that this worked for him. He was on a waiting list for therapy for over 12 months and failed an appeal (against DWP) during this time due to lack of additional medical evidence. He believes he could not get the additional evidence required as he was on a waiting list and not actually in contact with services. He is currently in therapy and recognises a pattern of being independent and never wanting to ask anyone else for help as something that can be detrimental for him. He believes that this 'independence' was viewed as fitness-to-work by DWP. Tom admits that he is able to complete paperwork and attends interviews at DWP alone as he has nobody else to attend with him. His mother has terminal cancer and his sister has also had cancer and lives far away. He has no choice but to attend appointments alone. He states that ironically, the Job Centre have been the most helpful in helping him with his mental health needs rather than NHS services.

# **Appendix 2-C: Author Guidelines for Journal**

## **Disability & Society**

#### **About the Journal**

The first thing authors should do is to click on the link below to the language policy document. It is essential that all submissions reflect awareness of the journal's policy on language.

Editorial on Language Policy

Disability & Society is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Disability & Society accepts the following types of article:

- Article
- Current Issues
- Student Perspectives
- Doctoral Theses

#### **Peer Review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

## **Preparing Your Paper**

#### **Article**

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, research process, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
  - Should be no more than 8000 words (excluding references).
- Should contain an unstructured abstracts of 150 words.
- Should contain Points of Interest 100 to 150 words (maximum) describing in plain English the importance of your work for lay readers in 4 or 5 bullet points.
- Between 2 and 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

## **Student Perspectives**

## **Doctoral Theses**

#### **Guidelines for the Doctoral Theses section of the journal**

We have agreed to provide within the journal a list of completed theses in the field of Disability Studies. This will be an important resource for readers to follow through as well as provide the names of colleagues who are new entrants to the discipline. This is an open invitation for theses completed from 2013 which fit with the Aims and Scope of Disability & Society.

Please provide the following information:

- · Name of the author
- Title of the thesis
- University awarding the degree (please state degree awarded and year)
- A 200-word synopsis of the thesis
- · Email address

.

## **Style Guidelines**

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

# **Formatting and Templates**

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

A LaTeX template is available for this journal. Please save the LaTeX template to your hard drive and open it, ready for use, by clicking on the icon in Windows Explorer.

If you are not able to use the template via the links (or if you have any other template queries) please contact authortemplate@tandf.co.uk.

#### References

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2

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Please use this reference guide when preparing your paper.

An EndNote output style is also available to assist you.

#### **Checklist: What to Include**

**Author details.** Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named coauthors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

**Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.

**Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

**Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artwork document.

**Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

**Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

7 **Units.** Please use SI units (non-italicized).

**Section Three: Critical Appraisal** 

A reflective approach to the research story

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# Critical appraisal

This critical appraisal describes the research process following the same narrative structure as the research paper, capturing the temporally ordered story throughout the thesis process. The appraisal encompasses my own personal stigma management strategies experienced, such as internalisation, acceptance and creating distance, similar to the concepts described in the literature review. I have taken the direction of offering a more personalised approach, as it seems fitting given that the empirical research attends to issues of inequality, power and oppression. The appraisal therefore includes critiques of my own position of power and experience of similar constructs to those described by participants, including changes in identity and self throughout the research process. A critique of my experiences of the persistence and paradoxical nature of self-care and academic writing will be presented.

Consistent with the narrative approach, and as a consequence of hearing poetry written by service users, I include a poem. I hope this provides the reader with a deeper understanding of the broader, social context to the research.

## An initial review of the research process

One of the strengths of the review is reliant upon the depth and detail in the accounts given by the participants. Participants explained their experiences relatively independently of the prompts used. A particular limitation of the research could be the lack of opportunity to meet and interview more participants in person. While the timescale and financial budget of the research could not allow for this to take place, it may have supported the validity of the research if transcripts and interpretations could have been revisited collaboratively with participants to check interpretations, and to reflect on and add to what was originally expressed.

Future areas of research could seek to separate parent's experiences from people without children. The emotional burden, sense of shame, responsibility and failure as a parent, could be expressed differently between the two groups. Shildrick, MacDonald and Furlong (2016) discuss discourses surrounding families and how these can reinforce particularly punitive responses to poverty and social exclusion. Furthermore, Jensen and Tyler (2015) describe how narratives can be culturally and politically crafted to reinforce mechanisms of control and power. Future research could investigate any potential differences between the experiences of families and the more general experience.

This research focused on people with diagnosed mental health conditions but it would be interesting to examine more closely the experience of WCA with those who may have had little contact with mental health services. Focusing on recruitment in this area could provide valuable insight into how participants may find it more difficult to provide the additional supporting information required by DWP. Comparisons could be made between these two groups in both primary and secondary care services.

The participants in this research often highlighted frequent attendance at their GP, not only in an attempt to monitor distress, but also to attain correspondence as proof of mental health diagnosis in preparation for WCA. It would be pertinent then to understand the impact on GP's, the additional time taken to accommodate an increase in requests of supporting letters as evidence, how this is managed in different practices and to what extent a GP can influence the WCA process.

Finally, and from a clinical psychology perspective, research could focus on interviews with clinical psychologists, therapists, and mental health practitioners in mental health services who assist, or do not assist, the people they work with through this process. It would be helpful to see if, and how much, practitioners are influenced by media narratives, service pressures etc. and to see how this is incorporated or supported in their clinical practice and experience.

# The presence of context in choosing a research topic

The broad idea for the research had been generated before clinical psychology training. While working in a Crisis Resolution and Home Treatment Team, nurses would return from assessments attributing distress to social issues such as poor housing, loss of benefits, and lack of employment. This was interesting to me and I drew parallels to my previous experience of working in forensic services and therapeutic communities.

I believe that psychologists are drawn to certain topics for specific reasons which are either consciously or unconsciously acknowledged. Clinical work can provide the opportunity to work through unresolved issues (Obholzer & Zagier-Roberts, 1994), whether we are consciously aware of it or not. The same applies to research, and I now find myself wondering why I had a chosen this topic. Was it because I was interested in it? Or had my past experience led to me this decision? Perhaps in choosing this as my research topic, I am seeking resolution by defending against and preventing my own return to poverty.

I consider myself working class. I was the first person in my family to go to university and I did so with little help or support from my parents. I have often felt in conflict with academia, and what I often consider an elitist nature and language, and way of working. I fought the need to give in to the perfectionism required; would this make me a bad clinical psychologist? I struggled to understand how this attention to detail and reliance upon evidence and truth within academia could help me to become a 'good' clinical psychologist.

I took comfort from Billig (2013, p. 40); "No one is born with the ability to produce the convoluted sentences that academic social scientists regularly write". He goes on to suggest that academic writing is like learning a foreign language occurring and improving over time and something that works best using ordinary terms where possible. These reassurances provide the basis for a change in identity and one that can be incorporated into my self-concept.

While I may never be fluent in the language of academia, I might just have learnt enough words to get by in a way that I can communicate and make recommendations that make sense to people beyond the island of academia.

All of these experiences have formed how I viewed the world and what I considered important. Working as a social therapist and in a therapeutic community for 11 years, I have always been encouraged to consider and value social influences in health and wellbeing, and it is with this context that I approach this research.

# The Self-Care Paradox and Identity Shift

The promotion of self-care is featured throughout training and during the research process, but I found this a difficult concept to incorporate. I reflect on some of the reasons why I may have barriers to take the principles of safe care fully on board.

Self-care can be defined as engagement with any practices that promote wellbeing (Myers, 2012). I struggled throughout training with this concept; while I could conceptually perceive its value and importance, it was not something that came easily to me, and actually, I often viewed it as yet another task that I 'should' be doing.

Cognitive and emotional awareness, and work-life balance are clear benefits and positive outcomes of self-care (Zahniser, Rupert, Dorociak, 2017), but for me, it could at times, become a contradiction or paradox, another item on a long list of things to do and something further to feel guilty for not doing. While being advised to self-care, we also have to balance other roles and duties that perhaps do not combine easily with self-care. We may encounter times when self-care is the only option but is this really self-care? I reflected on how difficult this paradox was to manage emotionally, and how this was expressed by the research in the literature review, the paradox of coping. Trying to find ways of coping that don't actually help us to cope. The strategies I employ are similar to the strategies employed and expressed in the research. Regardless of the issues at play, as humans we try and cope in the best way that feels comfortable, even though this may not ultimately be the 'right' way.

When life deals an unhelpful blow and we are forced to stop, but the lingering residual feeling brings nothing but guilt, this is not self-care. Admittedly, persevering in spite of these unexpected circumstances would not help either, but having to stop and 'self care' could feel like a burden, leading to resentment and perpetuating distress.

This research has made demands of me. It has forced me to work harder, to think clearer and to not take knowledge for granted. I have made sacrifices to complete these demands and it has made me question my stamina, my integrity and if I should be even trying to meet these demands at all. I have had to invest in life less, just to finish a piece of work. I have read articles on the touch line of my sons football matches, I have made notes sitting on the floor next to my dad in his hospital bed, I have worked at the computer before the children wake up, but worst of all I have missed so much. I therefore find myself asking the same questions I have tried to answer in my research: what is the impact of 'x'? How does this experience influence my identity? How can this information be used to inform my future practice?

I resented my single, childless colleagues who could sit at a computer for hours as they were in charge of their own time. This felt like a luxury to me, I felt angry inside at their complaints of having no time for yoga or to go to the gym. They had no idea. Perhaps my self care became letting the resentment go, accepting my position and working within the boundaries of this.

## **A New Identity Approaching**

Perhaps I have now developed an identity of a clinical psychologist. This sits uncomfortably with me at times and is again, a paradox. I never wanted to be a clinical psychologist. To my mind clinical psychologists were elitist, eloquent, privileged, clever, and confident. My original identity is in contrast to this as someone who is lacking in confidence and full of self-doubt. This new professional identity means that I am now part of a different group, but I must not believe in its specialness or I could become complacent and elitist too, and I have then lost my original identity.

My identity has changed so much, but I cannot speak about this in my close relationships or I could risk rejection from them. I conceal my truth to keep the opinions of others at bay and for self-protection. I see similarities between myself and the research. I cannot move too far beyond my original identity or I too, may face rejection. This felt close to coming to fruition in my close, personal relationships. Fear that my identity could evolve into something others could not compete with, and in turn, have the potential to threaten masculinity. Another paradox developed, if I was not a clinical psychologist at one point, the outcome could have been different, maybe involving a mental health crisis team or worse, hospital. My identity was a protective factor as well as both a precipitating and perpetuating one in this relationship.

My sense of identity changed with the death of my grandma, the very person who, unknowingly, gave me the components of my self, my outlook, and my foundations. I cling to these fragments of my core identity. Approaching the end of training, already disadvantaged and behind my peers, the unthinkable happened.

My dad arrived at my house distressed, he was worried that the there were people having a party in his house, that he had waited for the plane to take him to Tokyo but it hadn't turned up. He wanted to jump off a bridge but couldn't manage it. I take all of the knives from his house, calm him down, ground him, attend university and present my half completed thesis research. My truth remains hidden, not through fear of stigma, but through fear of pity or remarks or comments that just don't work, reassurances that fail to reassure. Intensive care for seven weeks, one week on a ward, then it's over. This happened during my penultimate week of training. My identity fractured, I start my first job as a (almost) qualified clinical psychologist, two weeks after the funeral.

I consider self-care at this point but it does not feel as though there is enough time, I have to keep moving forward, there is little choice or any suitable alternative. I reflect on the research and the experiences of participants. They described feeling hopeless and oppressed by life events that they had no control over. At some level I can share this feeling but I had the privilege of knowledge, social support, and an abundance of caring others within the profession to support me. I reflect on how it must feel to have these experiences in isolation of support, and I think about the role of clinical psychology. Tolerating the feelings of others and offering containment. Perhaps we manage the anxiety in others in order to manage and contain our own anxieties (Obholzer, 1994).

Maybe if there was greater emphasis on reflection and less time learning steps, models, technical language, interventions, and making recommendations, perhaps we could be more present and available in clinical practice.

The world continues to move and perhaps my self-care becomes simply moving at a pace that feels comfortable. I need to finish the thesis but I doubt my energy, capacity and stamina to move forward as quickly as I 'should'. I don't feel capable of anything else. I have to come to terms with what I would like to do and what I am actually capable of. Surely, I am supposed to end this process wiser and stronger, more knowledgeable and enthusiastic. Instead I am weak, critical and questioning. I have less confidence and I feel exposed to everything that I do not know, that I am not good at and that I can't do. Even motherhood is something that I feel I was once good at but am now failing. Being a clinical psychologist has meant that at times (so many more than I would have liked, or would care to admit to), I have had to put work first. I hate this about the course and myself.

I think about the stigma experience and struggle of the participants during the interviews and I reflect on my own difficult experiences and the impact this has on my outlook and my ability to cope.

I consider the difficulty in discussing this with a stranger and I feel even more grateful for the participants who came forward to provide their stories as part of the research.

Considering the structure of stories and narratives of others, while reflecting on my own, adds to the ethical credibility of the narrative approach employed, knowing that no researcher is completely separate to the research and analysis.

#### "I Must Self-Care"

Packenham and Stafford- Brown (2012) suggest that clinical psychology training leaves little time for self-care activities. Betteny (2017) argues that self-care teaching could help to develop resilience, and cope with the demands of working in current NHS structures. This comes from the assumption that people *need* to build their resilience. Just because one is forced to adopt the role of 'student' or 'trainee', does not mean that one is a blank slate with little experience, skill or pre-existing resilience, and arguably, the demonstration of these skills enabled acceptance on to clinical psychology training. Bettney (2017) moves on to suggest an action orientated approach to self-care, and proposes that trainees could take the initiative to develop skills to maintain wellbeing, rather than simply discussing it or raising awareness. While, I would agree with an action-orientated approach, it could also add to an already long list of trainee duties. If this action-orientated approach involved group work, it could serve another process, one that is perhaps absent from my experience of training. Understanding the role of processes of group work, under the guise of self care, could present unintended and unplanned group work skills, drawing parallels to the processes involved in daily clinical work in the NHS. The effectiveness of groups can depend upon clear boundaries, clarity of task, the size of the group, preparation required, inconsistent attendance etc. Indeed, how a group is constituted and managed is of central importance (Obholzer & Vega-Roberts, 1994).

Staff meetings and group work with clients can present issues such as containment, facilitations skills, and group membership, dynamics and processes that can be explored and learnt from during training, fostering skills for future practice. Group dynamics are perhaps an overlooked issue and skill in clinical psychology training.

In order to rise to challenges, think clearly and offer containment, we must be able to function and practice efficiently. We have professional guidance to adhere to (British Psychological Society, 2009; Health and Care Professions Council, 2015), we have regular clinical supervision, we are meant to recognise times that we are fit to practice, and the times when we are perhaps finding it more difficult. All of this requires the ability to reflect upon and think critically of ones own thoughts, feelings, and limitations, and be emotionally present for clients. Something about clinical psychology training though ran counter to this. The constant assessment, evaluation, meetings, essays, reports, changing placements, different supervisors etc., for me, meant that there was little time for much else. Personally, the lack of time to reflect was another paradox for me as time spent reflecting and understanding the impact of training meant that my self-care had to be avoidance. While I accept this can be an undesirable trait and not entirely professional, it was my self-care. Perhaps if I had stopped and considered my position, the enormity and complexity of the task, and the reality of my personal life, I might have thought that it was not possible, and this was not an option. Had I been in my early 20's I might have allowed negative self-doubts to creep in, but over the years I had managed to internalise some helpful and nurturing narratives. While I may have minimised and avoided the complexity at times, I had also held on to encouraging and hopeful thoughts, and believed them. It had taken years and a potential doctorate for me to begin to internalise this.

I continue to struggle with the concept of self-care and disagree with its flippant use at times. Maybe I have used self-care, or at least been consciously aware of it, perhaps this is enough.

# **Incorporating a 'Softer' Approach**

After attending a conference and listening to poetry written by service users, I felt inspired and motivated to write my own poem. The following section includes a poem written to try and capture and explain my experiences in the hope that this can move beyond and reach further than the academic word. This is consistent with Gee (cited in Reissman, 1993), who states that poetry builds on what we do all of the time and helps to fossilise what is in everyday speech.

Still doubting the appropriateness of including a poem as part of an academic assessment, I sought academic support. Koelsch (2015) proposed how the creation of poems can emotionally engage the reader or audience beyond a single linear narrative. Poetry has been used to understand dementia diagnosis, helpful to capture meaningful experiences and enable a clearer understanding of self-construct (Clark-McGee & Castro, 2015). Lodge (2003) takes a literary approach to the understandings of consciousness and suggests that poetry is the most distilled form of qualia (from the Latin quale, meaning the specific nature of our subjective experience of the world), and is mans best effort to describe the individual experience of human beings in a specific point in space and time.

"In a world where nothing is certain, in which transcendental belief has been undermined by scientific materialism, and even the objectivity of science is qualified by relativity and uncertainty, the single human voice, telling its own story, can seem the only authentic way of rendering consciousness."

Lodge (2003).

When discussing the human condition, Seager (2017) describes how science often outweighs art. Both are 'split' into separate distinctions, with science being a 'hard' discipline and art as a 'soft' discipline in comparison. In my attempt to introduce qualia and include a 'soft' approach into a 'hard' academic field, I include a poem.

# **Greatest expectations**

I sit in my now familiar place in my study uniform, and mourn the life I had, "Look after yourself," "self care is essential" but they have no clue, I am the bottom of the list, I have to, nothing else will do.

So much time spent thinking, rethinking, cognitive overload, brain power, memory flexing, thought processing, neurons firing, networks igniting, pages read, words stored, references written, correctly now, don't forget the apostrophes, the commas, the difference between 'that' and 'which', the semi colons, is it 'and' or '&', the bold, the underline, the indentations, the uniformity, the adherence, the conformity, we all need to be the same and apply these rules to tick the boxes to feel able to move onto the next boxes but wait...

What am I doing in a world of adherence, failure, solitary confinement and constant refinement, Perhaps I should have been stricter, slicker, more organised, to keep things ship shape, make fewer mistakes.

It's taking more than I've got, I knew this before but I still wanted more, or I thought I did. There's no more left, its gone, I'm spent, I have to relent and refill my pot but I forgot, that damn apostrophe again.

I fail, then I am bereaved, it's a huge loss, it stings, I knew it would,
But there's a test to get through, I wait for it to pass (God I hope it will pass) coz I need to pass,
and tick the next box, but wait...

There comes another loss, it's different this time, it stings but it is confusing, debilitating, draining,

But I head back to the thinking and processing and checking and rechecking, I remember the times I could connect to my soul with relative ease,

but now I must check my semi colons and margins, and count my words but wait...

This is too much now, the machines, the bleeps, the visits, the updates, we just wait

And see what happens.

He's too brittle, he's poorly, we need to consult and take time

but I don't have time,

Don't they know I have diagrams to draw and statistics to locate, spelling mistakes, how long will this take?

I need to get back as there's deadlines and draft reads and places to be and people to see.

Who needs balance or self care, so I take my things there,

And read papers and highlight and try and absorb the things I must do, by this hospital bed,

Amid the blood and the bags and the swelling and the turning and alarms and the psychological

harm

And then the confusion and the illusion of personality and what was not meant to be or happen to me, not yet, not now.

So I get back to it, there is no time to sit and take it all in

There's commutes, plans and formulations, and models and letters to make it all better

Then there's the call.

Everything stops.

But now there is absolutely no time at all

To understand or comprehend or deliberate, make no mistakes, just keep moving forward.

There are celebrations to be had, and good things planned by everyone else,

but I am not part of it.

What do I know about epistemology, philosophy, neurology and cognitive tests, mediation analysis, meta synthesis?

No time now, just got to keep moving and ticking and completing and finishing and ending.

Good things will come, have faith, back to basics, just strip it all back to what matters most, I knew the answers, I knew all along,

It's so simple you see, there is no theory or complexity, just human connection.

And care and love and passion and genuine giving a shit.

It's so easy to forget this under the cloak of demands and expectations.

Simply belonging, belief, hope, connection, prevention, justice, community and unity, The being human, the getting it wrong, the reparation, the communication, the walking alongside, the strength to not hide.

So it's time to fill the emptiness, its time to take things back and reconsider what matters, Time to reconnect and rekindle and make it count and to let the guilt go.

The intimidating, lurking, heavy breathing of the unmitigated guilt, constant, incorporating, consuming guilt. You have engulfed me for long enough.

1 can get back to sunsets, dog walks and 10p mixes, to music, singing, and baking, Just time to fill, be thankful for, be grateful in, to share, to ponder, to just be.

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ETHICS SECTION 4-1

**Section Four: Ethics** 

Helen McGauley

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count (excluding references, appendices, tables & figures): 5420



**FHMREC Application** 

# Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

## **Application for Ethical Approval for Research**

for addi(onal advice on comple(ng this form, hover cursor over 'guidance'

**Title of Project**: The Psychological Impact of Benefit Sanc8ons Following the Work Capability Assessment (WCA)

Process for People with a Mental Health Diagnosis

Name of applicant/researcher: Helen McGauley

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 exis8ng documents/data only, or the evalua8on of an exis8ng project with no direct contact with human par8cipants. **Complete sec@ons one**, *two* and four of this form

Includes direct involvement by human subjects. Complete sec@ons one, three and four of this form

# **SECTION ONE**

1. Appoi	ntment/posi@o	n held by applicant and I	Division withir	<b>r FHM</b> Train	nee Clinical Psychologist	
E-mail:	ct informa@on fo	To	elephone:		(please give a number on which yo	ou
Address:						
3. Name	s and appointme	ents of all members of th	e research tea	ım (includi	ng degree where applicable)	
	<b>3. If this is a stu</b> e appropriate: (ple the procedures	ease note that UG and takes set out on the <u>FHMREC was</u>	cate what type ught masters p	ch, Lancast e of projec rojects sho	er University  t by marking the relevant box/deleaded	_
	PG Diploma	Masters by research	PhD Th	hesis	PhD Pall. Care	
						July 2016

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

DClinPsy SRP [if SRP Service Evalua8on, please also indicate here: ] DClinPsy Thesis

- 4. Project supervisor(s), if different from applicant: Pete Greasley
- 5. Appointment held by supervisor(s) and ins@tu@on(s) where based (if applicable): Teaching Fellow

#### **SECTION TWO**

Complete this sec@on if your project involves exis@ng documents/data only, or the evalua@on of an exis@ng project with no direct contact with human par@cipants

1. An8cipat ed project dates (month and year) Start date: End date:

2. Please state the aims and objec8ves of the project (no more than 150 words, in lay-person's language):

## **Data Management**

For addi+onal 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 evalua8on to be undertaken. I
- 4a. How will any data or records be obtained?
- 4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'
- 4c. If yes, where relevant has permission / agreement been secured from the website moderator?
- 4d. If you are only using those sites that are open access and do not require registra8on, have you made your inten8ons clear to other site users?
- 4e. If no, please give your reasons
- 5. What plans are in place for the storage, back-up, security and documenta8on of data (electronic, digital, paper, etc)? Please ensure that your plans comply with the Data Protec8on Act 1998.
- 6a. Is the secondary data you will be using in the public domain?
- 6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for addi8onal later use of the data.

Please answer the following ques8on *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 publica8ons for at least 10 years e.g. PURE?
- 7b. Are there any restric8ons on sharing your data?

## 8. Confiden@ality and Anonymity

- a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publica8ons?
- b. How will the confiden8ality and anonymity of par8cipants who provided the original data be maintained? All
- **9.** What are the plans for dissemina8on of findings from the research?

10. What other ethical considera8ons (if any), not previously noted on this applica8on, do you think there are in the proposed study? How will these issues be addressed?

#### **SECTION THREE**

## Complete this sec@on if your project includes direct involvement by human subjects

Summary of research protocol in lay terms (indica8ve maximum length 150 words):

The aim of this research is to interview people with a pre-exis8ng mental health condi8on who have been receiving welfare benefits because of this and have therefore been through the WCA assessment process. If they have been subject to benefits sanc8ons as a result of this assessment, I would like to discuss the psychological and social impact that this has had.

Par8cipants will be recruited via conferences on a similar subject area and via Twiler using a research account specifically set up for this project. The research will aim to recruit and interview between 8 to 14 par8cipants. The interviews will be semi structured and will last for around one hour. They will take place at various public loca8ons and via Skype.

People with any mental health diagnosis will be included as long as the par8cipant has been receiving benefits as a result of their inability to work because of this condi8on.

The interviews will be transcribed and analysed by the principle researcher.

2. An@cipated project dates (month and year only)

Start date: November 2016 End date: June 2017

#### Data Collec@on and Management

For addi+onal 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 par8cipants to be studied (including maximum & minimum number, age, gender):

Males and females aged 18 to 64.

Minimum number 8 and maximum number 14.

Will have a pre-exis8ng, self reported mental health diagnosis

Will be (or have been) in receipt of disability benefits, will have experienced the WCA assessment process and faced sanc8ons because of this process.

4. How will par8cipants be recruited and from where? Be as specific as possible.

Informa8on sheets will be distributed at conferences (Psychologists and the Benefits System), adver8sed on Twi I er (using a separate account for the purpose of this research only) and organisa8ons such as Trussel Trust, Mind, Rethink Mental Illness and Disabled People Against Cuts (DPAC).

Par8cipants will contact principle researcher via university email or university approved telephone for more informa8on about the study. The research will be discussed in more detail and informa8on packs (including PIS, demographic sheet and consent form) will be sent out.

An appointment for an interview will be arranged and at this mee8ng the informa8on sheet and consent forms will be discussed before the forms are signed by both par8es. Interviews will take place in person and as a last resort, Skype will be considered. As Skype is not a secure network, par8cipants will be made aware of this before hand. Only if the par8cipant remains happy to con8nue with a Skype interview will it then take place. If the par8cipant would prefer not to use Skype then an alterna8ve method will be discussed (either interview in person or telephone call).

Recruitment will stop when the maximum number of par8cipants has been reached (14).

5. Briefly describe your data collec8on and analysis methods, and the ra8onale for their use.

Interviews will be conducted and recorded using a dictaphone and transcribed by the principle researcher.

These qualita8ve interviews will take place at a mutually convenient loca8on such as public libraries, GP Prac8ces, Mind centres, Community centres. This is to ensure that par8cipants are able to chose a loca8on that is suitable and accessible for them. Home visits will not be considered.

This research will use narra8ve analysis based on interpre8ng stories and how people construct meaning and iden8ty through their narra8ves. This approach fits well with the research topic as narra8ve analysis a lends to social context and considers this context at one par8cular point in 8me. Stories can also mobilise social change and can be persuasive in their nature. For these reasons narra8ve analysis is the most appropriate method of analysis (Riessman, 2008). Thema8c analysis will be used in conjunc8on to iden8fy any themes from the data.

6. What plan is in place for the storage, back-up, security and documenta8on of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protec8on Act 1998.

A Dictaphone will be used to record the interviews. The recording will be transferred to a computer file immediately amer the interview by the principle researcher. Time will be allocated to do this amer each interview has taken place.

Once the audio file has been encrypted, password protected and uploaded onto Lancaster university server the original recording will be deleted from the dictaphone.

Hard copies of data such as transcripts, consent forms and demographic informa8on will also be uploaded onto university server and the original hard copies will be destroyed by the principle researcher.

Data will be stored at the University for 10 years and the Research Co-ordinator at Lancaster University will be responsible for the storage and dele8on of data amer comple8on of DClinPsy.

Confiden8ality will be explained to the par8cipants individually before the interview including limita8ons to confiden8ality such as risk of harm to self or other, where their data will be kept and how they can withdraw from the research.

All interviews will be transcribed by the principle researcher and any quotes used in the write up will remain anonymous with the use of pseudonyms.

- 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 iden8fiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. To protect data, any auto recordings will be uploaded directly to the Lancaster University server amer each interview and will be deleted from the dictaphone immediately amer the successful transfer of data.

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 computer files will be encrypted, password protected and stored on the Lancaster University VPN. at this point, audio recordings on the dictaphone will be destroyed amer each interview. All completed paperwork (transcripts, consent forms and demographic informa8on) will be scanned and uploaded onto university server, once uploaded hard copies will be destroyed by principle researcher. Anonymised transcripts will only be used during analysis and will be destroyed amer analysis is complete.

Please answer the following ques8ons *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 publica8ons for at least 10 years e.g. PURE?
- 8b. Are there any restric8ons on sharing your data?
- 9. Consent

- a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospec8ve par8cip@ft(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representa8ve in accordance with applicable law?
- b. Detail the procedure you will use for obtaining consent?

  Interviews in person by principle researcher Consent forms for the research will be completed if the par8cipant agrees to take part in the study. This will be before the interview takes place. Signed consent forms will be collected, uploaded to university server and hard copies destroyed by the principal researcher.

  Interviews via Skype The par8cipant informa8on sheet, demographic informa8on sheet and the consent form will be posted or emailed to the par8cipant to read before the interview takes place. Consent can then be discussed before the interview and verbal consent will be recorded in the transcript of the interview.
  - 10. What discomfort (including psychological e.g distressing or sensi8ve topics), inconvenience or danger could be caused by par8cipa8on in the project? Please indicate plans to address these poten8al risks. State the 8mescales within which par8cipants may withdraw from the study, no8ng your reasons.

Discussing poten8ally distressing events surrounding their assessment and talking about their mental health diagnosis could be psychologically sensi8ve issues to consider during this research. Par8cipants will be assured that they can withdraw from the study at any 8me up un8l the stage of data analysis. When data analysis has taken place it would be difficult to retract any informa8on as themes will have been iden8fied.

At the end of each interview, par8cipants will be given details of suppor8ng organisa8ons such as Ci8zens Advice Bureau (CAB), Samaritans and Mind.

If at any point par8cipants feel uncomfortable they will be offered a break and will be allowed to discon8nue if they wish.

11. What poten8al risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, no8ng the support available to you; counselling considera8ons arising from the sensi8ve or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Interviews to take part in person - In line with LCFT lone working policy, supervisors and colleagues (buddy system employed) will be aware of each planned interview (start 8me, loca8on and expected finish 8me). The principle researcher will call buddy amer each interview to inform them that the interview is over. The buddy will have the loca8on and 8me of the interview and will be asked to open this envelope and contact principle researcher if no contact has been made at an agreed 8me (at the expected 8me of the comple8on of the interview) the buddy will contact principle researcher and follow LCFT lone working procedure if no contact is made. Interviews will

will only take place in public spaces such as libraries, community centres, or churches. As per LCFT lone worker policy, if at any point principal researcher feel unsafe, they are to remove themselves immediately. No home visits will be accommodated.

12. Whilst we do not generally expect direct benefits to par8cipants as a result of this research, please state here any that result from comple8on of the study.

There may be no direct benefit in taking part in this study.

- 13. Details of any incen8ves/payments (including out-of-pocket expenses) made to par8cipants: Par8cipants will be offered their travel expenses reimbursed if they a ¶ end an interview for thesis research up to the value of £20.
- 14. Confiden8ality and Anonymity
- a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publica8ons? Please include details of how the confiden8ality and anonymity of par8cipants will be ensured, and the limits to confiden8ality.

Interview data (demographic sheet, consent form and transcrip8on) will be numbered for iden8fica8on purposes and iden8fiable informa8on with then be removed. Pseudonyms will be used during the write up of the research. The limits of confiden8ality will be explained to par8cipants before an interview takes place - if a par8cipant discloses any inten8on to harm themselves or others then I would have to discuss this with my supervisors and break confiden8ality. I would discuss this with them beforehand if possible.

If an interview takes place using Skype then a professional account will be set up by the Principal Inves8gator and will not be used for any other purpose. At the beginning of the interview, par8cipants will be reminded that the internet is not secure and I can therefore not ensure confiden8ality. Par8cipants will be advised to conduct the interview at a 8me and place that is convenient for them and when they will not be interrupted. If an interview takes place in a public setng such as GP prac8ce or room in another health/community centre, then confiden8ality cannot be fully ensured.

15. If relevant, describe the involvement of your target par8cipant group in the *design and conduct* of your research.

In my spare 8me I am involved in groups such as a Community Psychology Group and Psychologists Against Austerity. As part of these group discussions I have spoken to people with significant lived experience in this area. Although no target par8cipants have been involved directly in the design of the research I have frequently spoken about these issues with them. (pilot study removed)

16. What are the plans for dissemina8on of findings from the research? If you are a student, include here your thesis.

To write up the results as part of DClinPsy Doctorate thesis.

Results of the research will be submiled for publica8on in an academic and/or professional journal. The professional journal will be targeted at social workers and/or nurses to reach as wide professional base as possible.

A shortened report will be produced and disseminated at relevant mee8ngs (Psychologists Against Austerity and Community Psychology groups) and will be sent to those organisa8ons that have helped to adver8se the research.

17. What par8cular ethical considera8ons, not previously noted on this applica8on, do you think there are in the proposed study? Are there any malers about which you wish to seek guidance from the FHMREC?

Par8cipants could be concerned about any repercussions for discussing this topic in the fear that it could impact nega8vely on their rela8onship with Department of Work and Pensions (DWP). Par8cipants will be reassured that this research is independent of any DWP involvement and any current appeals they may have ongoing.

#### **FHMREC Application**

**SECTION FOUR: signature** 

**Applicant electronic signature**: Helen McGauley Date 28.08.2016

Student applicants: please 8ck to confirm that you have discussed this applica8on with your supervisor, and that they are happy for the applica8on to proceed to ethical review

**Project Supervisor name** (if applicable): Pete Greasley Date applica8on discussed 16.08.2016

You must submit this applica(on from your Lancaster University email address, and copy your supervisor in to the email in which you submit this applica(on

#### **Submission Guidance**

d.

1. Submit the following materials for your study if relevant:

a. Your full research proposal (background, literature review, methodology/methods, ethical considera8ons).

b. Adver8sing materials (posters, e-mails)c. Le I ers/emails of invita8on to par8cipate

Par8cipant informa8on sheets

e. Consent forms

f. Ques8onnaires, surveys, demographic sheets

g. Interview schedules, interview ques8on guides, focus group scripts

h. Debriefing sheets, resource lists

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

- 2. Submit the FHMREC form and any relevant materials listed above by email to Diane Hopkins d.hopkins@lancaster.ac.uk. The submission should be as a SINGLE all achment in PDF format. Before conver@ng to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing show markup>balloons>show all revisions in line.
- 3. Submission deadlines:
- a. Projects including direct involvement of human subjects. The *electronic* version of your applica8on should be submiled to Diane Hopkins by the commi8ee deadline date. Commilee mee8ng dates and applica8on submission dates are listed on the <a href="FHMREC">FHMREC</a> website. Prior to the FHMREC mee8ng you may be contacted by the lead reviewer for further clarifica8on of your applica8on. Please ensure you are available to a lend the commilee mee8ng (either in person or via telephone) on the day that your applica8on is considered, if required to do so.
- b. The following projects will normally be dealt with via chair's ac8on, and may be submiled at any 8me. Those involving:
- i. exis8ng documents/data only;
- ii. the evalua8on of an exis8ng project with no direct contact with human par8cipants;
- iii. service evalua8ons.

The Psychological Impact of Benefits Sanctions Following the Work Capability Assessment (WCA) Process for People with a Mental Health Diagnosis

The Work Capability Assessment (WCA) has been operational since 2008 and was a crucial part of the out of work benefit reforms established by the Welfare Reform Act 2007. It intended to make distinctions between those who are fit to work (or able to with support), and those who are not fit to work due to health related issues (Litchfield, 2014). Part of the proposed welfare reform introduced Universal Credit (UC) and aimed to increase movement into work through improved financial incentives, making the process of application more simple and transparent and to bring more people into 'conditionality regimes' and sanctions (DWP, 2015). Another part of the reform was premised on the notion that a health condition or a disability should not be a barrier to finding suitable work (Kennedy, 2012) and that too many people had wrongly entered the disability category (Roulstone, 2015) thereby claiming Disability Living Allowance (DLA). The cost of benefit payments to disabled people was also considered unsustainable with expenditure in far in excess of the estimated costs (McVey, 2012). Therefore, in 2010 the government initiated a programme to reassess all claimants of disability payments using the WCA (Barr, Taylor-Robinson, Stuckler, Loopstra, Reeves et al, 2015). As a result of this assessment process, people considered unable to work were then entitled to the Personal Independent Payment (PIP), which replaced DLA.

The introduction of these reforms has been controversial and disability rights organisations have voiced serious concerns about the application of the new assessment process (Yates & Roulstone, 2013; Cross, 2013; Roulstone, 2015). The conduct of staff completing the assessments on behalf of the DWP has also been criticised; for example 40% of people deemed 'fit to work' have had this decision overturned through appeals (Barr, Taylor-Robinson, Stuckler, Loopstra, Reeves et al, 2015).

## The impact of WCA on people with mental health conditions

Economic difficulty and recession have impacted upon suicide rates and the mental health of a population (Barr, Taylor-Robinson, Scott-Samual, McKee & Stuckler, 2012). One hypothesis for this relationship from Barr, Taylor-Robinson, Stuckler, Loopstra, Reeves et al. (2015) suggests the lack of availability to a secure income could be one reason recent reforms are influencing mental health in addition to people facing sanctions if they do not meet the requirements from job centres to engage in job searches and unpaid work. This, coupled with the increase in the narrative and current rhetoric of welfare recipients claiming benefits

2015) has also increase the stigma associated with this (Henderson, Corcker, Hamilton, Williams & Pinfold et al, 2014) and reinforce negative self image, mental health and outlook.

## The relationship between poverty, unemployment and mental health

The relationship between low income or poverty and mental health problems has been widely debated (Fitch, Hamilton, Bassett & Davey, 2011; Wright, 2014; Ljungqvist, Topor, Forsell, Svensson & Davidson, 2015) yet the direction of the relationship remains uncertain. In their study of suicide rates during 2008-10, Barr et al. (2012) state that although the link between suicide rates and the economic recession and subsequent lack of employment can not be considered causal, the strength of the effect size, consistency and coherence with previous research and the lack of any other robust explanation suggest that there is a valid link.

Van Haal (2015) contributes to the evidence of a potential link between economic crisis and mental health problems and suicides stating that similar patterns can be identified across countries in crisis such as Greece, Spain and Portugal. The author also argues that social protection measures should be invested in to protect and reduce the mental health of their population. This research is supported by the organisation Psychologists Against Austerity (PAA) who released a briefing paper that called for "a social security system that empowers and supports, rather than punishing people in times of need" (Psychologists Against Austerity, 2015). The paper proposes five ways in which policies impact upon mental health: humiliation and shame, fear and distrust, instability and insecurity, isolation and loneliness, being trapped and powerless.

Research has also shown that there has been a shift in emphasis on individual and personal attributes responsible for ill health and less emphasis on socio-political factors. Morrow (2013) argues that the increase in prescriptions for antidepressants (Barr et al, 2015) is indicative of people feeling unable to cope, and reflects the dominant discourses around mental health in which social determinants are not considered focusing, instead, on individual responsibility. This is supported by Friedli and Stearn (2015) who consider this to be an unhelpful narrative; the use of psychology and the focus on the self in the delivery of WCA links unemployment to a psychological 'deficit' and does not take into consideration the wider social influences or barriers. This is supported by Wheeler (2015) who argues that unemployment is being 'rebranded' such that those who do not present a 'positive' outlook must undergo training to alter this outlook, and if they do not they could face benefit sanctions. He goes on to suggest that claimants are interviewed to assess their 'psychological resistance' to work, and that the focus is

ETHICS SECTION Research Protocol

no longer on what you must do to get a job but how you must think and feel about work. Friedli and Stearn (2015) refer to this as 'psycho-compulsion'.

Existing research shows that shame, social comparison (Peacock, Bissell & Owen, 2014) and discrimination (Henderson et al., 2014) are also associated with inequality, poverty and receiving welfare benefits which could all contribute and impact upon wellbeing.

## **Proposed Research Project**

The former President of the BPS, Jamie Hacker-Hughes (2015) also states, "We in the BPS have become increasingly concerned about benefits sanctions and a number of other issues concerning the psychological welfare of those on benefits...there are approximately 250,000 people receiving the benefit ESA who need the support primarily because of their mental health." Additionally, Rycroft-Malone (2010) calls for new and innovative ways of implementing evidence-based practice in an age of austerity to improve the patient experience.

A review of the literature highlights recent developments in the field examining the impact of benefits sanctions and unemployment on people with a mental health condition but as yet no research focuses on the lived experiences of the people affected. Therefore, this proposed research will seek to examine the psychological and social effects of benefits sanctions on people with a diagnosed mental health condition.

#### Method

## Design

The study will follow a qualitative design using semi-structured interviews to collect the data (Interview schedule, Appendix E) and will include areas such as before and after the reassessment and participants' understanding/experience of the assessment. A qualitative approach will be used in this study to gain insight onto the experiences of the participants and will use narrative analysis and thematic analysis to uncover stories and themes from the data.

## **Participants**

**Inclusion Criteria:** 

- Adults aged 18-64 years. These ages are included as this is the age people can receive Personal Independence Payments (PIP) which this project is specifically focusing on (PIP replaced Disability Living Allowance). The age of 65 is considered pensionable age and people would therefore not receive PIP/DLA.
- Participants will have a pre-existing mental health condition and will have been receiving or have received benefits as a result of this.
- Participants will have had their benefits sanctioned.
   Exclusion Criteria:
- Participants will be excluded if they have been diagnosed with a mental health condition *after* they have been assessed via WCA.

The study aims to recruit between 8 and 14 people. Narrative analysis will be used to capture the stories of the participants and thematic analysis will be used to develop themes across the data set. In accordance with the aim of the study, patterns of the psychological impact of sanctions will be explored by identifying themes but also the participant stories are a significant part of the research.

Recruitment will take place directly from local upcoming conferences discussing the impact of benefits sanctions and poverty. Charities, specialist organisations and social media will also be used to recruit participants. Purposive sampling will be used to generate a list of participants based on the inclusion criteria.

Participants will be offered their travel expenses up to the value of £20 if they chose to take part.

#### Recruitment

Participants will be recruited by distributing flyers at local conferences including, 'Psychologists and the benefits system: time to get off the fence' and 'Welfare Reforms and Mental Health'. The participant information sheet will be available at the events for people who would like more information about the research. Details of the research will also be advertised on social media, and recruitment emails (Appendix B) will be sent to organisations such as Mental Health Foundation, Disabled People Against Cuts (DPAC), Refuted, Mind, Church Poverty Action Group, Trussel Trust, Child Poverty Action Group and Rethink Mental Illness.

Interested participants can then contact the Principle Investigator (PI) for more information. Contact can be made by either university telephone or email address. PI will check that the participant fulfils the research criteria and if so, the participant information sheet (Appendix C), demographic information sheet (Appendix F) and consent form (Appendix D) will be posted to the participant including a stamped addressed envelope (of PI university address). The participant can return the signed and completed consent forms to PI. Participants and PI will discuss a convenient time and place depending on the participants preference such as a room in a GP surgery, community centre, local library, university campus etc.

#### **Procedure**

Consent will be discussed and forms signed before the interview takes place. Participants will be assured that any information discussed will remain anonymous and any quotes used will also be used anonymously so that their experiences cannot be traced back to any one individual. Participants will be invited to ask questions about the study.

(pilot interview deleted)

Each interview will last for around 1 hour. If participants wish the interview to continue for longer this will be allowed as narrative methods benefit from extended accounts from participants and the PI will be conscious of welcoming these accounts rather than brief answers.

Interviews will be recorded using a Dictaphone and the PI will transcribe verbatim all data and will be responsible for storing the data. After each interview the audio recording will be uploaded onto password protected file space Lancaster University server (refer to data storage section for more detail).

ETHICS SECTION
Research Protocol

## **Proposed Analysis**

Narrative analysis will be used to learn more about how individuals negotiate the challenges of sanctions and integrate these in to the story of their lives. Thematic analysis will also be used to identify any common themes and differences across the sample.

The PI will collaborate with supervisors to check and discuss themes.

### **Practical Issues**

Interviews will take place at a location that is suitable and accessible for both participant and PI and is suitable in terms of confidentiality and quiet enough for an interview to take place. No home visits will be considered. Locations such as private rooms in community centres, church's, libraries, university campus, GP surgery or health centres will be used. These will be booked as and when required.

Lancashire Care Foundation Trust and Lancaster University lone working policy will be adhered to. Lone working is defined as "any situation or location in which someone works without a colleague nearby; or when someone is working out of sight or earshot of another colleague." In line with this policy, staff (supervisors and admin) will have access to a list of appointments (including location address, telephone number and expected start and finish times). The PI will keep in regular contact with colleagues replicating a 'buddy system'.

## **Data storage**

A Dictaphone will be used to record the interviews and the audio recording will be encrypted, password protected and transferred to the Lancaster University server. Hard data (including consent forms, transcripts and demographic information) will be scanned and uploaded on to Lancaster University server. Only anonymised transcripts will be shared, if applicable, with research and field supervisors for validity of analysis.

# **Ethical Issues**

The duration of the interview will be flexible and time will be allocated for full descriptions of narratives. At the beginning of the interview consent will be reiterated to ensure that participants are aware of this and that they are free to withdraw their consent at any time up until March 2017, as the analysis and write up will be completed at this point. Before this time, the interviewee will be free to withdraw their data without giving reason and without negative consequences.

ETHICS SECTION Research Protocol

Participants will be informed that they can have a break during the interview and they will be given a short debrief at the end of the interview. This will comprise of me asking the participant about their experience of the interview and I will give them the opportunity to ask questions about the study and the information collected. Contact details of the PI and supervisors will be on the participant information sheet and participants will be reminded to make contact if they have any questions or concerns after the interview. Details of the Samaritans, Citizens Advice Bureau and Mind will also be provided.

There is a potential that participants could feel emotional during the interview and this will be important to discuss beforehand. It is hoped that any concerns about the research, use of information, confidentiality etc. can be discussed openly.

# **Dissemination Strategy**

A report summary will be sent to the organisations contacted to advertise the research. The research findings will be submitted for publication in Disability and Society and Mental Health Review Journal. A Social Work and/or Nursing Journal will also be considered in order to reach a wider audience.

Dissemination of the research will also take place through various media outlets.

#### **Timescale**

September - apply to FHMREC

October - attend conference and distribute flyers. Advertise research via social media. October to December - Data collection, transcription and commence literature review. Discuss early findings with supervisors. Lit review draft 1 to research supervisor.

January – Continue with analysis. Meet with supervisors. Draft lit review 2 to research and field supervisor.

February – Draft research paper 1 to research supervisor

March – Draft research paper 2 to research and field supervisor.

April – Draft critical review to research and field supervisor.

May – Draft critical review 2 and submit.

July - Summary of the research findings to participants.

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Appendix 4-A: Recruitment email



# Do you have a diagnosed mental health condition? Have you experienced the Work Capability Assessment? Have you had your benefits stopped or sanctioned?

At Lancaster University we are developing a project hoping to understand the psychological impact of benefits sanctions following the Work Capability Assessment process and what impact this had, if any, on your mental health and outlook. You will be invited to discuss your experiences of this process in an interview.

If you would like to take part in the study have answered yes to the above questions, please express your interest with Helen McGauley.

email: h.mcgauley@lancaster.ac.uk Twitter: @helen\_thesis

Please share this with anyone else who you think might be interested in taking part.



# Do you have a diagnosed mental health condition? Have you experienced the Work Capability Assessment? Have you had your benefits stopped or sanctioned?

At Lancaster University we are developing a project hoping to understand the psychological impact of benefits sanctions following the Work Capability Assessment process and what impact this had, if any, on your mental health and outlook. You will be invited to discuss your experiences of this process in an interview.

If you would like to take part in the study have answered yes to the above questions, please express your interest with Helen McGauley.

email: h.mcgauley@lancaster.ac.uk Twitter: @helen\_thesis

Please share this with anyone else who you think might be interested in taking part.

Appendix 4-B: Participant Information Sheet



## **Participant Information Sheet**

# The Psychological Impact of Benefits Sanctions Following the Work Capability Assessment (WCA) Process for People with a Mental Health Diagnosis

My name is Helen McGauley and I am conducting research as part of my DClinPsy Doctorate at Lancaster University, United Kingdom.

### What is the study about?

The purpose of the study is to understand the psychological impact on people who have been sanctioned as a result of the Work Capability Assessment (WCA). I would like to know more about what the process was like for you and what impact it has had on your mental health, if any.

## What is the purpose of this study?

The study forms part of my Doctoral thesis. The study aims to understand participants experiences of the assessment and how they have been able to cope as a result of being sanctioned. The study will focus particularly on the psychological and social experiences of each participant.

# Who are we looking for?

I am hoping to interview anyone between the ages of 18 and 64. You will need to have a mental health diagnosis and have had your benefits sanctioned in some way as a result of the Work Capability Assessment process.

## Do I have to take part?

It is entirely up to you whether or not you take part. If you do decide to take part then you will be given this information sheet to keep and will be asked to sign a consent form. Please remember that you are free to withdraw from the study at any time without having to give a reason.

#### What will be required of me?

You will be invited to be interviewed for around one hour. I can meet at a location that is convenient for you or we can use talk using Skype but please note that due to the nature of the internet, Skype is not considered a secure network. I am able to reimburse any travel expenses up to the value of £20.

## Will my data be identifiable?

The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study and your name will never be attached to them. There are some limits to participant 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 inform you if I

Appendix 4-B: Participant Information Sheet

have to do this.

## What will happen to the results?

The results will be summarised and reported as part of my thesis and may be submitted for publication in an academic or professional journal.

# Your rights as a participant

If at any time during or after the research you decide that you no longer want to participate, you are free to withdraw at any point. You may also decline to answer any questions. All data obtained will be kept strictly confidential and any information used will be anonymised.

## Are there any risks?

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

## 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.

**Contact Details** - If you require any further information and/or have any questions about this study, please feel free to contact me:

Helen McGauley – email: h.mcgauley@lancaster.ac.uk

or my supervisors, Dr. Pete Greasley email: P.Greasley@lancaster.ac.uk or

Dr. Ste Weatherhead email: s.weatherhead@lancaster.ac.uk

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

can contact: Helen McGauley – email: h.mcgauley@lancaster.ac.uk or my supervisors, Dr. Pete Greasley email: P.Greasley@lancaster.ac.uk or Dr. Ste

Weatherhead email: s.weatherhead@lancaster.ac.uk

## **Complaints**

If you wish to make a complaint of raise concerns about any aspect of this study and you do not

want to speak to the researcher you can contact:

Professor Bill Sellwood

Course Director.

Clinical Psychology Doctorate,

**Furness Building** 

Lancaster University

Bailrigg

Lancaster

LA14YG

Tel: 01524 593998

email: b.sellwood@lancaster.ac.uk

## Appendix 4-B: Participant Information Sheet

Professor Roger Pickup, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University,

Lancaster LA1 4YD

Tel: 01524 593746

email r.pickup@lancaster.ac.uk

# **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:

Samaritans 24 hour helpline: 08457 909090 Citizens Advice Bureau: 03454 04 05 06 Mind infoline: 0300 123 3393 or text: 86463

# Appendix 4-C: Consent From

Study Title: The Psychological Impact of Benefits Sanctions Following the Work Capability Assessment (WCA) Process for People with a Mental Health Diagnosis

We are asking if you would like to take part in a research project about the impact of benefits sanctions on people with a pre-existing mental health condition

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, Helen McGauley.

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.	
4.	I understand that audio recordings 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, without my medical care or legal rights being affected.	
6.	I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, 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 any information I give will remain strictly 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 her research supervisor.	
10.	I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	

11. I consent to take part in the above study.				
Name of Participant	Signature			
Date				
Name of Researcher	Signature			
Date				
Please provide a suitable email address if you would like to receive a summary of				
the research findings and				

# Appendix 4-D: Demographic Information sheet

	1. Name		
	3.	How long have you been in receipt of benefits because of your mental health	
	condition?		
	4.	Highest level of parental education.	
<b>5</b> .		How would you describe your socioeconomic status?	
thinking about: economic capital = income, savings, house value; social capital = the number and status of people you know; cultural capital = the extent and nature of your cultural interests and activitie			

- **Elite** the most privileged group in the UK, distinct from the other six classes through its wealth. This group has the highest levels of social, cultural and economic capital
- **Established middle class** the second wealthiest, scoring highly on all three capitals. The largest and most gregarious group, scoring second highest for cultural capital
- **Technical middle class** a small, distinctive new class group which is prosperous but scores low for social and cultural capital. Distinguished by its social isolation and cultural apathy
- **New affluent workers** a young class group which is socially and culturally active, with middling levels of economic capital
- **Traditional working class** scores low on all forms of capital, but is not completely deprived. Its members have reasonably high house values, explained by this group having the oldest average age at 66
- **Emergent service workers** a new, young, urban group which is relatively poor but has high social and cultural capital
- **Precariat, or precarious proletariat** the poorest, most deprived class, scoring low for social and cultural capital

Appendix 4-E: Interview schedule

## **Diagnosis**

Can you tell me a bit about when you first received a diagnosis? How did it feel to receive this diagnosis?

# Applying for financial support

How did you feel the first time you applied for financial support for your mental health condition? (Stigma, shame, embarrassment, relief?)

What was the process like?

Did you get any help from professionals to do this?

How did it feel having to apply for support?

### **Before reassessment**

Thinking about what life was like when you were receiving DLA/ESA/JSA, how were you at this time?

In terms of your mental health, how were you feeling? In terms of your life in general, how were you?

#### Reassessment

When you found out that you would have to be reassessed, how did you feel?

What did you know about the new process?

Had you seen anything in the media about the process at that time? How do you think this might have influenced your approach/outlook?

Can you talk me through your experience of the WCA process? What was the assessment interview like?

What support did you have from professionals? What were your expectations?

#### **Being sanctioned**

In what way do you think the sanctions impacted upon you? Your finances? Your mental wellbeing? Your relationships? Your outlook?

What was your experience? Did you get any support?

Did you know what to do next and how to go about it? Please explain.

How do you think this has affected you in the short-term/long-term?

What has changed as a result of these sanctions? (your relationships with self/others,) Did you get any help/support from people? If so who? If not, who do you think could have helped?

On reflection, how do feel about the process now?

What stands out for you? What have you learnt?

What would your advice be to anyone else going through this process?

Do you think this assessment is helpful?

What, if anything, could be done differently?

Appendix 4-F: Review letter

## **Faculty of Health and Medicine Research Ethics Committee**

Our ref: FHMREC16007

20 September

2016 Helen

McGauley
Division of Health Research
Faculty of Health and
Medicine Lancaster University

#### Dear Helen

Re: FHM Research Ethics Committee application for project titled: 'The psychological impact of benefits sanctions following the Work Capability Assessment (WCA) process for people with a mental health diagnosis'.

Thank you for sending in the paperwork for your application. We appreciated reading about the project. We have a few minor concerns, and ask that you address the following in revising your application materials:

#### General

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Your application currently lacks detail, and has been marked-up with detailed feedback by the lead reviewer. Please address these comments in amending your application. In addition, please address the points outlined below.

Please use the correct logo (included at the end of the email in which this letter was sent)

You query to the chair regarding the dissemination film you hope to make was raised at the committee. It was noted that reference to the film has been removed, and should be included again, since this will ensure it is given thorough consideration. As you are currently at the planning stage, it is acceptable to also note that you will seek further permissions as needed. You may wish to discuss this further with the lead reviewer of your project, Dr Heather Robinson, who will be able to advise you on this.

#### Application section 3.2

Amend the start date to take into account the timescale for ethical approval.

#### Application section 3.6

Since you are putting in place means by which participants' data can be withdrawn at any point, clarify where the participant personal/identifying details will be kept, in what manner and for how long. Note that personal details should be kept separately from data, in a secure locked cabinet in locked office or in a separate file on the password, encrypted server. They should be deleted once the thesis has been assessed.

Please note here that your reason for earliest possible upload or your audio recordings is that it is not possible to encrypt your portable devices. If it is possible to encrypt them, please state this here.

Please indicate in this section who will be responsible for the storage and deletion of data once you have completed your course.

#### Application section 3.9b

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You may wish to consider using verbal consent, gathered via Skype and recorded in the transcript. Please discuss this further with your supervisor.

#### Application section 3.15

It is not clear whether the DPAC representative is running the pilot interview, or being interviewed. Please clarify.

You use the term 'pilot interview' in this section, whilst you refer to a 'pilot study' in your protocol. Please clarify which is correct, and amend as required.

#### Participant Information Sheet

Where can I obtain further information about the study if I need it? Please add your and you supervisor's contact details here.

Add a new section entitled 'complaints' and include Prof Sellwood's details here. Amend his title to 'Professor', and add his telephone number

**Complaints section:** Please add Prof Roger Pickup, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University, Lancaster LA1 4YD (email <a href="mailto:r.pickup@lancaster.ac.uk">r.pickup@lancaster.ac.uk</a>, Tel: (01524) 593746) as an additional contact for complaints

Ensure consistency between the application form, the Research Protocol and the supporting materials in line with the changes requested above.

Please use Lancaster University letter-headed paper for all participant materials
We ask that you attend to these in writing by (re)submitting to the FHMREC via Diane Hopkins
(d.hopkins@lancaster.ac.uk) the application document and materials with any changes
highlighted. If your responses to the above are satisfactory then approval will be
recommended on Chair's action. If you have questions, please feel free to contact me.

Yours sincerely,

Prof Roger Pickup

Chair of the Faculty of Health and Medicine Research Ethics

**Committee Lancaster University** 

R. W. Pakup

## Appendix 4-G: Approval Letter

Applicant: Helen McGauley

Supervisors: Pete Greasley and Ste

Weatherhead Department: Health Research

FHMREC Reference: FHMREC16007

12 December

2016 Dear Helen

Re: The psychological impact of benefits sanctions following the Work Capability Assessment (WCA) process for people with a mental health diagnosis

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.

This is approved with the caveat that anonymised data will be stored separately from demographic data and consent documents.

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 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC.