“It feels like they're constantly looming”. A pluralistic, qualitative exploration of how UK health-based welfare systems are experienced by those living with chronic unseen health conditions.

William Benjamin Day
Doctor of Philosophy
Aston University
September 2023

“It feels like they're constantly looming”. A pluralistic, qualitative exploration of how UK health-based welfare systems are experienced by those living with chronic unseen health conditions.

William Benjamin Day
Doctor of Philosophy
Aston University
2023

Thesis abstract.

Often framed as a ‘response’ to the growing numbers of individuals living with chronic health conditions, many countries have introduced policy instruments for promoting the employment of individuals with chronic illness. Within the UK, the two main ‘health-based’ welfare policies are Employment and Support Allowance (ESA) for individuals who are unable to work due to sickness or disability, and Personal Independence Payments (PIP). PIP aims to support individuals with the costs incurred due to illness or disabilities. Access to both PIP and ESA rest on processes of assessment and conditionality; processes that have been found to lead to feelings of marginalisation and stigmatisation. These feelings may be felt more keenly by individuals whose health conditions lack a visual signifier of disability.

The work of this thesis aims to address the absence of psychological knowledge on the topic of health-based welfare. This was achieved through a pluralistic exploration of individuals' experiences, whilst considering how knowledges around welfare have been constructed. A Foucauldian-inspired Media Framing Analysis aided an understanding of how stigmatising discourses were rooted in the creation of these policies, as well as the subject positions ‘made available’ for claimants of health-based welfare benefits. The empirical studies within this thesis made use of a longitudinal qualitative design. A dual focus analysis, applying Interpretative Phenomenological Analysis and Foucauldian Discourse Analysis to the same data set, enabled by an exploration of participants' interview data in a way that illuminated how discourses around welfare are lived *through*.

Amidst the disruption of a global pandemic, participants shared photographs that represented their day-to-day experiences. Through the rupture of the pandemic, participants were able to find new ways of being-in-the-world; lines of flight that enabled authentic ways of living. The results of these studies were used to make recommendations for changes to health-based welfare policies.

Key words: welfare, PIP, ESA, phenomenology, Foucauldian Discourse Analysis, Interpretative Phenomenological Analysis, pluralism, qualitative, psychology

Personal acknowledgements.

Although not *directly* comparable, I feel as though the proverb “it takes a village to raise a child” can be a useful way to explain how a PhD is *actually* completed. It is only through the help, guidance and support of everyone around me that I have been able to finish this not-insignificant piece of work.

Firstly, I would like to thank the participants who committed to being a part of this research. Without your dedication, effort and time, none of this work would have materialised. Thank you for sharing your experiences.

To my supervisory team, thank you so much for all the support and encouragement. To **Professor** Rachel Shaw, I wouldn’t have found myself on this path were it not for your guidance and encouraging enthusiasm. You are my academic role model, thank you for all that you have done for me. Dr Michael Larkin: I’m so glad that your years of ‘unofficially’ supervising me now get to be recognised. Thank you for introducing me to concepts and ideas far beyond my horizons. To Dr Dan Shepperd, I’m sorry that your circumstances meant you couldn’t be as involved as we’d originally planned. Thanks for sharing your discursive knowledge(s)!

This thesis builds on the rich history of qualitative research in psychology. I’d like to thank all those qualitative researchers that have gone before me, for winning all the ‘battles’ and academic skirmishes that needed to be fought. Closer to home, I would like to thank every member - past, present and future - of Aston’s Phenomenology of Health and Relationships group (PHaR). In particular: Tiago, Shioma-Lei, Katharine, Gemma, Jo, Caity, Valeria, Kisane, Emma, Miko, Nicola, Rosa and Julie. I’m so proud of the genuine community we’ve managed to build. Long may it continue!

Being able to complete this research alongside learning how to teach (and all the things that go alongside working in a university) has only been possible because of my colleagues and all the students I have taught. To everyone within Aston’s School of Psychology: thank you for the belief that I could do ‘it’ and for the interest in my work. To Kate, thanks for being such a fantastic colleague and friend, and for enabling me to think creatively about teaching. One day, we will do that ‘immersive theatre’ lecture. More recently, I’d like to thank the PUGs team for reassuring me that academic work can be carried out in a collegial way; full of humour and persistence, even when things get tough. Thanks in particular to Rob, Sarah, Jason, Lottie and Chanelle for helping me to understand the never-ending complexities of academic admin.

It’s impossible to capture how important being part of a supportive team of likeminded GTAs has been. Nikki, Tom and Sam, it has been so great to share this experience with you. I know we’re all at different stages, but we’ve all achieved so much already. I’m going to include Niyah as an honorary GTA here: those afternoons we (Nikki, you and I) lost to discussions of *everything* were completely worth it. It’s been so great to watch you make academia work for you. Nikki, you and I were the first Psychology GTA ‘experiments’ and it’s been amazing to work our way through this world together. I’m always astonished at everything you’ve accomplished, and it’s such a nice synchronicity that we get to submit our theses at the same time. Well done us!

Thank you to my Mam, Dad and Nan for a lifetime of support, and for encouraging me to be curious. I'm very glad I've been able to live up to your prediction that I would "never leave school". Here's hoping. To Edward and Rich (and Ralph and Russell): thanks for the LOLs, drag discussions and for listening when I go off on a ramble. Lynn and Barry; Carol and Roy: thank you for being so interested in what I'm up to even when we're separated by distance and time zones. Maybe now I'm done, we can come and visit.

Thank you to Ana and Njazi for being such great in-laws. Thank you for all the food and the DIY training. Rais, thank you for, intellectually, keeping me on my toes. To the London-Merko crew, it's been so great to be a part of your lives. Jason, Mason and Eilisa: you are all an inspiration. I can't wait to see everything that you are going to do and achieve.

To all my friends, who've endured years of me talking about similar things or disappearing when work got in the way, thank you for your understanding and empathy! To Elliot; Esther and Rich; George; Josie; Matt and Gina (and Emily and Jacob); Rhiannon and Alex (and Wren): thanks for being there. Thanks in particular to Samuel as I can trace a lineage between some of the more 'out there' ideas in this thesis to when we first started dabbling in philosophy at the age of thirteen. Philosophy: just say no?

A few more unusual thank-yous. I would like to thank the city of Birmingham. A truly underappreciated place: full of green spaces, abandoned industrial areas, amazing food and unique people. I'll gladly stay here, wander your streets/canals and give my accent over to you. I'd also like to thank the following record labels who (unbeknownst to them) released music that soundtracked the writing of this thesis: Hyperdub, Shall Not Fade/Time Is Now, Comatonse, Scissor & Thread, Other People, CloudCore, Hessle Audio, Warp and many (many) more.

Last but by no means least, I would like to thank my wife, Françeska. You were there at the start of this journey and it's fantastic to think how much things have changed since then. Thank you so much for the reassurance, humour and understanding you bring to our lives. It would have been extremely difficult to finish this project were you not so supportive. This PhD has been a big part of our time together: I'm so excited to see what we can do next.

Table of contents.

Table of acronyms.

Acronym	Acronym meaning
BPS	British Psychological Society
CFS	Chronic Fatigue Syndrome
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ELCI	Energy limiting chronic illness
ESA	Employment and Support Allowance
FDA	Foucauldian Discourse Analysis
GP	General Practitioner
IB	Incapacity Benefit
IPA	Interpretative Phenomenological Analysis
ME	Myalgic Encephalomyelitis
MFA	Media Framing Analysis
MR	Mandatory Reconsideration
NHS	National Health Service
PIP	Personal Independence Payment
UC	Universal Credit
WCA	Work Capability Assessment
WRAG	Work Related Activity Group

List of tables.

List of figures.

Chapter 1. Introduction and background.

The 'rise' of chronic conditions.

From 2011 onwards, after decades of steady improvement, increases in UK life expectancy began to slow (Raleigh, 2022). Then, during the COVID-19 pandemic, life expectancy in the UK dropped sharply (Raleigh, 2022). Several studies attributed this slowdown in life expectancy to be a consequence of austerity-driven constraints on health, social care and other publicly funded services (Loopstra et al., 2016). Prior to these declines, and as a result of the world experiencing dramatic epidemiological change, mortality rates had steadily declined from the 19th century onwards (Raleigh, 2022). People were living longer but they were living with increased rates of chronic illness. As a result of globalisation, improved medical technology and disease management one of the largest 'challenges' now faced by healthcare systems in the 21st century is the increasing prevalence of chronic illness (Murray, 2012). Chronic illness, or rather chronic health conditions, can be typified as being slow in progression, long in duration with a need for continued medical treatment (Megari, 2013). Vickers (2005) characterises chronic conditions as being physical, emotional or cognitive in manifestation: variable conditions that may or may not be treatable. The encompassing nature of these definitions is reflected in examples of potential chronic conditions: for example heart diseases, diabetes, bowel diseases, renal diseases or central nervous system disorders could all be considered chronic conditions.

More than one in four of the adult population in England now lives with two or more long-term conditions (Imison, 2021). This means that 25% of England's adult population now meet the definition of "multimorbidity"; where several conditions co-exist but there is no single focus of attention on one condition over and above the others (The Academy of Medical Sciences, 2018). In a systematic review of the links between chronic conditions and comorbid mental health, Cimpean and Drake (2011) found that at least 30% of all individuals with a chronic condition in England were also diagnosed with a mental health disorder; a figure that becomes more striking when compared against the general UK population rates of mental health problems (17%; McManus et al., 2016). Such figures tend to include those living with certain cancers and HIV/AIDs; diagnoses that would not traditionally be considered chronic conditions. However due to advancements in available treatments, these conditions are increasingly experienced as such (Deeks et al., 2013; Tritter & Calnan, 2002).

These shifts in categorisation, with experiences of conditions ‘as lived’ informing population level data, neatly demonstrate the malleable nature of the classification and organisation of chronic conditions (a ‘construction’ of illness); concepts that are themselves salient to the focus of this research project.

The growing numbers of individuals living with chronic health conditions, particularly those experiencing multiple conditions, is regularly discussed within health research and wider media reporting it as a ‘challenge’; a problem for the cost and quality of care in both health services and social care (e.g. Iacobucci, 2017; Vogeli et al., 2007). Models of health behaviour propose targeted interventions as a response, a way to prevent or lessen the future ‘burden’ of estimated further increases (Kingston et al., 2018). Such problematisations of chronic conditions are bolstered by an ever-increasing number of epidemiological studies which provide statistical evidence to support links between (‘bad’) behaviours and chronic conditions (Galvin, 2002). Moral theories of illness have existed across cultures and time. However health and illness have increasingly become redefined and understood as matters of individual responsibility: illness as a deviation from the ‘norm’ of health (Galvin, 2002). These lines of intervention negate the overwhelming evidence of the influence of socioeconomic status on both development and prevalence of multimorbid chronic illnesses (Mair & Jani, 2020). A continued concentration on individual behaviour change strategies, whilst ignoring the social determinants of health, will be insufficient to address the epidemic of chronic illness (Mair & Jani, 2020).

Chronic conditions and UK welfare systems.

Against these backgrounds of an increased prevalence of chronic conditions and an affirmation of health as a reflection of an individual’s choices, the consequences of increasing experiences of chronic conditions have moved beyond the worlds of health and care providers. Individuals living with chronic conditions are more likely to be out-of-work than other groups (Holland et al., 2016). Often through a framing of ‘response’ to these statistics, many countries have introduced policy instruments for promoting the employment of individuals with chronic illness, assessing working capability and re-evaluating the personal costs incurred due to illness or disability (Gjersø, 2016). Within the UK, these changes have manifested as two major welfare reforms: the introduction of Employment and Support Allowance (ESA) in 2008 (1.7 million claimants as of August 2022; DWP), replacing

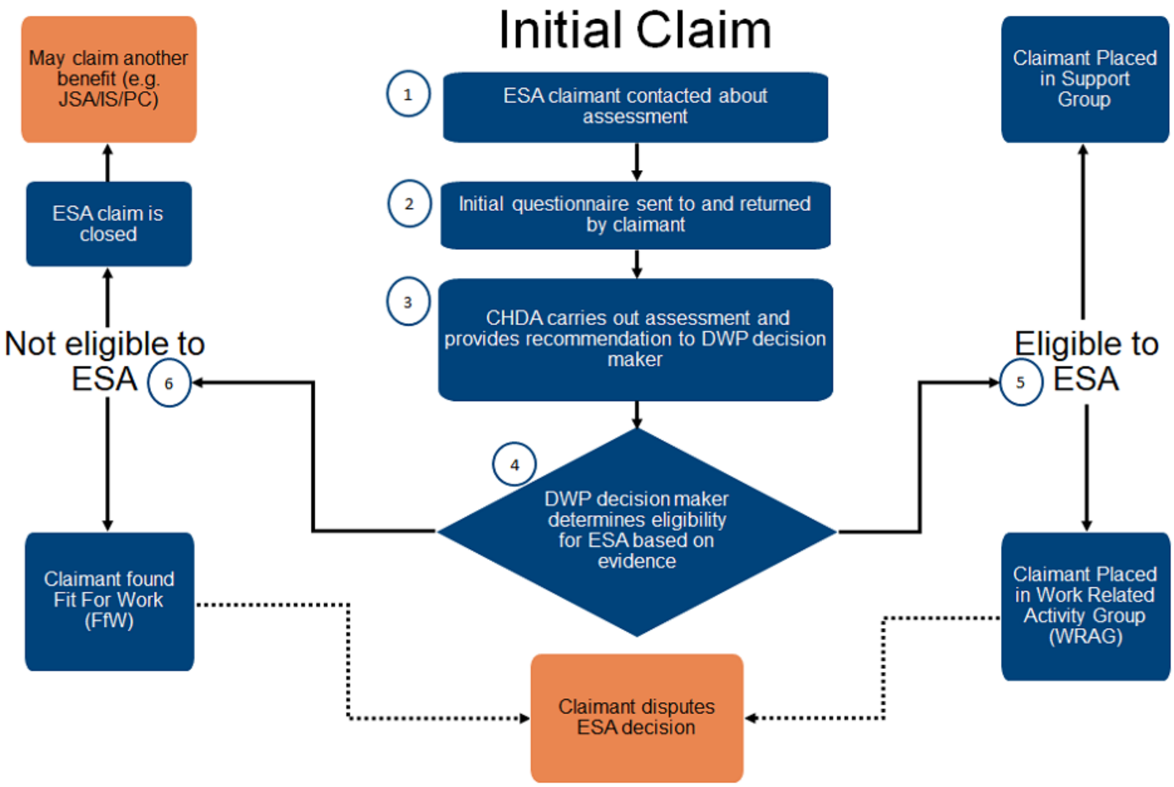
Incapacity Benefit (IB) for individuals who are unable to work due to sickness or disability, and Personal Independence Payments (PIP) in 2012 (2.8 million claimants; August 2022, DWP). The policy intent behind PIP is to support individuals with the costs incurred due to illness or disabilities; supplanting Disability Living Allowance (DLA) and Incapacity Benefit with an “objective assessment” (Gray, 2017) of individuals’ needs, with outcomes that are “fixed term awards” (Gray, 2017) rather than the indefinite award decisions of the DLA (Roulstone, 2015).

Universal Credit (UC), an overarching welfare reform that seeks to combine six specific welfare benefits into one monthly-made payment, is gradually being ‘rolled out’ across the UK’s local authorities. As of January 2023, 4.2 million households had been moved into the UC ‘track’ (DWP, 2023). However, 2.5 million households have yet to be moved over to UC and remain claiming “legacy” benefits and tax credits (DWP, 2023). ESA, but not PIP, is now one of the six benefits absorbed into Universal Credit: ESA claimants living within areas in which Universal Credit has been implemented remain within the ESA ‘system’ (going through assessment processes etc.) but receive payments through the Universal Credit routes. Both ESA and PIP fall into the category of “health-based welfare policies” and this term (or variations of it) will be used throughout this thesis.

How are ESA and PIP benefits accessed?

The Department for Work and Pensions (DWP) makes use of ‘health assessments’ to determine if welfare benefits can be accessed (House of Commons Work and Pensions Committee, 2023). A process known as the Work Capability Assessment (WCA) is used to determine an individual’s eligibility for ESA. The WCA comprises of two stages: claimants complete a 28-page questionnaire (the ESA50; DWP, 2021) prior to the face-to-face ‘medical test’ of the WCA, which is outsourced to an American private healthcare company, Maximus (Stewart, 2019). Medical evidence, for example from a treating doctor, can be submitted alongside the initial questionnaire. However, the collation and submission of any evidence is claimant driven and not an automatic stage of the ESA ‘journey’ (shown in Figure 1.1).

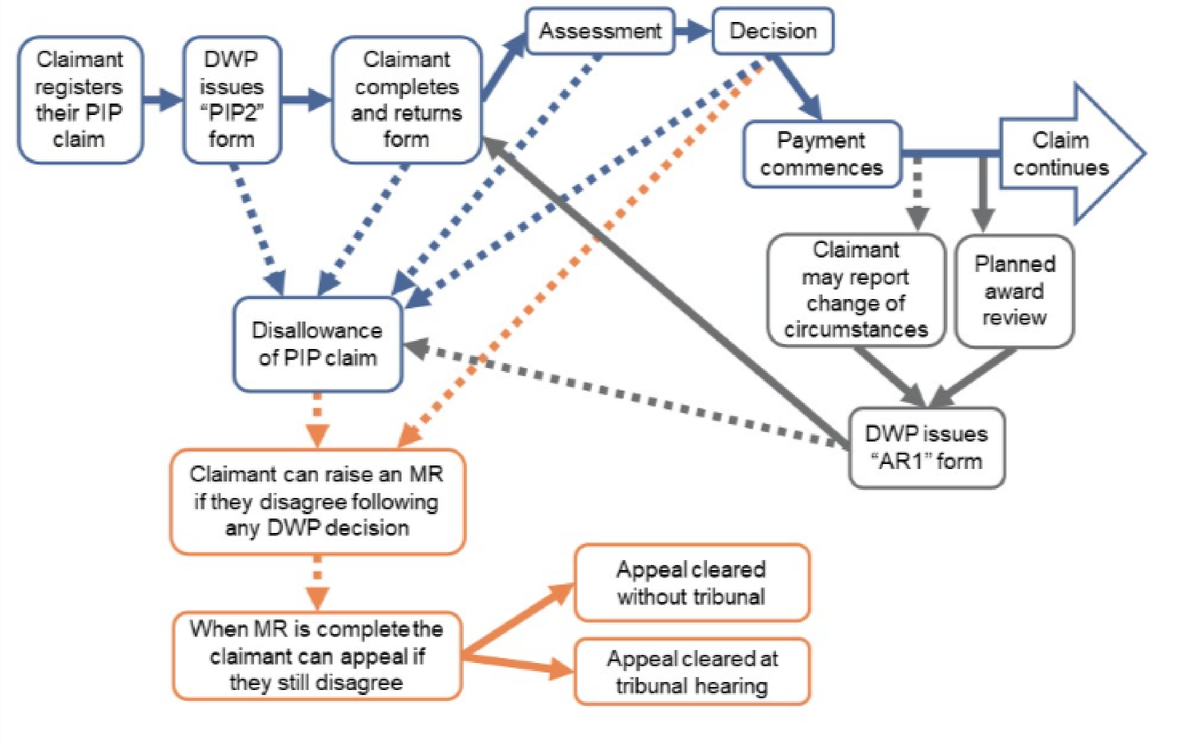
Figure 1.1. *Employment and Support Allowance new claims customer journey (DWP, 2021).*



The ESA50 questionnaire seeks to assess an individual's physical and mental limitations against 17 specific activities, known as descriptors (Gjersø, 2016). The first 10 descriptors focus on physical health (e.g. "Can you pick up and move a litre (2 pint) carton full of liquid using your upper body and either arm?"; DWP, 2021). The last seven descriptors aim to assess mental health (example question: "can you manage to plan, start and finish daily tasks?"; DWP, 2021). Each descriptor carries a number of points, linked to the three possible responses ("no, yes, it varies"; DWP, 2021). The sum of these scores determines if ESA can be awarded at this point or whether a face-to-face assessment is required. Face-to-face WCAs entail a discussion between a healthcare professional (employed by the outsourcing company carrying out the assessment) and the claimant around the responses given in the ESA50. With permission from the claimant, a WCA may also involve a clothed physical examination, such as raising an arm or walking a certain distance (Citizens Advice, 2020).

Both the ESA50 questionnaire and report documenting the medical test are used by non-medically trained civil servants within the DWP to make a decision on ESA eligibility. The decision is time-limited with claimants being reassessed after a period of months or years. The length of award (e.g. the time from the first application and a future reassessment) is determined and stated within the decision. ESA is a two-tier system, with successful claimants being assigned to one of two groups. In an example of the conditionality of ESA, claimants placed in the Work Related Activity Group (WRAG) are expected to engage in paid work at some point in the future (but not in the present moment), with payment of the benefit dependent upon attendance at mandatory employment training or workfare schemes. Failure to comply with these conditions may lead to withdrawals of benefits, through a process known as 'sanctions' (Geiger, 2017). Those placed with the Support Group receive a higher level of benefit payment and are not expected to engage in work-related activity. Alternative welfare systems available to individuals who are found ineligibility for ESA is the 'new style' jobseeker's allowance, which is paid at a lower rate than ESA, and is dependent on previous national insurance contributions (Gov.uk, 2022), or Universal Credit.

Figure 1.2. *Diagram showing the PIP "customer journey" (House of Commons Work and Pensions Committee, 2023).*



The PIP claim process closely mirrors that which is undertaken to access ESA. If initial eligibility conditions are met (claimants must be aged 16 to 64, living with a health condition or disability which has created difficulties for daily living and/or mobility, alongside an expectation that these difficulties will continue for at least 9 months; Gov.uk, 2023), individuals must first contact the DWP via a phone call to request an application form. The questions of this 20-page form (titled "how your disability affects you") fall into one of two components; through focussing on "daily living" (10 descriptors) or "mobility" (two descriptors) claimants are instructed to "tell their story" of how their condition affects them (DWP, 2018). Each question has a (different) Likert-like list of potential responses. The number of potential responses ranges from question to question: the lowest being four and the largest, seven. Depending on which region of the country claimants are living in, healthcare professionals working for either ATOS or Capita (private healthcare companies) assess submitted questionnaires, deciding whether a face-to-face consultation is required or whether a 'paper based' decision can be made. Before the COVID-19 pandemic, a "significant majority" of PIP assessments were completed face-to-face (Gray, 2017). This has now fallen to 7.7%; 72.6% conducted remotely (via telephone or video) and 19.7% of assessments being completed via the paper-based route (Pursglove, 2023). Claimants who score 'highly' on each component (e.g. mobility and daily living) receive a higher rate of welfare: for example, as of April 2023, the standard weekly rate paid relating to mobility is £26.90 (Gov.uk, 2023). This rises to £71.00 per week for the 'enhanced' rate, paid to those who are severely limited in their ability to move, plan a journey or follow a route (Gov.uk, 2023). Similar to ESA decisions, PIP awards are time-limited with individuals usually being reassessed after two years.

ESA and PIP decisions can be appealed. Decisions can be challenged by the two methods. The first is a "mandatory reconsideration" (MR): where the DWP looks again at the initial decision. A secondary recourse is available by appeal to His Majesty's Courts and Tribunals Service. When decisions are challenged, the percentage of overturned decisions is high. Tribunals have overturned over 50% of ESA and PIP decisions since 2014/15, with a peak of 77% for both in 2019/20 (House of Commons Work and Pensions Committee, 2023).

Criticisms of the post-2008 health-based welfare policies.

Access to both PIP and ESA rest on processes of assessment and conditionality (i.e. the meeting of state set conditions in order to continue to claim welfare). Embodying, as it does, the new processes of assessment required in order to access welfare, the WCA has been subject to increasing levels of public and academic criticism (Gjersø, 2016). The initial focus of media and public dissatisfaction was on the 'medical' test. The test is perceived as too technically driven with little human interaction; claimants reporting feelings of a lack of respect and empathetic understanding (Harrington, 2010). Drawing on the experiences of 50 participants who had been through the WCA or PIP assessments, Porter et al. (2021) see these reforms attempting a form of “procedural objectivity”; through which objectivity is regarded as a function of methodological neutrality and disinterestedness. This has implications for how claimants are treated in assessments and the marginalisation of provided medial evidence (dismissed as untrustworthy compared to the more ‘objective’ assessments administered by the state) (Porter et al., 2021).

Using aggregate routine population survey data for 149 local authorities within England, Barr et al. (2016) found that for each additional 10,000 people reassessed through the WCA there exists an association of 6 additional suicides, 2,700 cases of reported mental health issues and the prescribing of an additional 7,020 anti-depressant items. These associations were independent of baseline measures in the area and followed (rather than preceded) the process of reassessment. However due to the nature of aggregate data, it cannot be determined that those who experienced adverse mental health outcomes were the same individuals who had undergone the WCA reassessment (Barr et al., 2016). Whilst not making claims of causality, when combined with the findings of McManus et al. (2016) it is possible to grasp how potentially vulnerable those, as a group, who claim ESA can be: two thirds (66.4%) of people in receipt of ESA had thought about taking their life, with 43.2% having made a suicide attempt.

In a survey of 1,056 General Practitioners (GPs), 91% of those surveyed said that ESA had increased their workload within the last 12 months (Iacobucci, 2017). Despite this increase, 52% of GPs felt that the medical evidence supplied was “often” or “usually” ignored by those involved in the assessment of claimants (Iacobucci, 2017). In interviews with GPs, Hansford et al. (2019) found themes of GPs being overwhelmed by a situation in which, to support their patients, they were forced to engage with an uncompassionate welfare system – a system within which they had no power to affect change. Given the role that healthcare professionals have in the assessment of welfare claimants, Barr et al. (2016) highlight the ethical issues raised by these findings: can the commitments made through the Hippocratic Oath be reconciled with an involvement in welfare systems which have adverse consequences for mental health?

Bambra and Smith (2010) argue that the shift from Incapability Benefit to ESA marks a movement in UK welfare systems towards ‘workfare’: signalling a break with the previously voluntary nature of participation in employment interventions. Rights to accessing benefits have now been firmly established as being conditional; people with a disability or long-term condition must fulfil defined obligations, such as taking part in training programmes, work experience (often unpaid) or community services (Bambra & Smith, 2010). These ‘tougher’ measures are often framed by the UK government(s) as being a mechanism to improve the employment rates of people with chronic health conditions or disabilities whilst simultaneously reducing expenditure on benefits (Barr et al., 2015). Considering the effectiveness of improving employment rates, Barr et al. (2015) investigated if people out-of-work with chronic health conditions experienced a greater increase in the chances of moving into employment in local authority areas where a greater proportion of the population had been through the WCA process. There was no substantial impact on claimants moving into employment and some indication that it might have had a negative impact for some groups (such as people living with a mental health condition) (Barr et al., 2015).

Moving further beyond the specifics of the WCA, utilising thematic analysis following interviews with 25 ESA claimants, Garthwaite (2015) saw themes of fear and trepidation over ongoing welfare reforms; with media coverage of benefit “scroungers” leading to greater stigma and struggles with personal identifications of “disability” for those within the ESA system. Patrick (2014) found a mismatch between the substantial efforts needed by disabled individuals to ‘get by’ on benefits and government rhetoric of welfare as a ‘lifestyle choice’. Considering the impact of capability assessments on doctor-patient relationships Wainwright et al. (2015) interpreted themes of heightened tension due to changed definitions of “fitness for work”. Cooper and Whyte (2017) suggest that these reforms should be talked about and thought of as “institutional violence”; the ordinary and mundane bureaucratised violence that makes up the lived experience of austerity. Support for this characterisation can be found from the United Nations: in 2013 the UK became the first country to be investigated by the Committee on the Rights of Persons with Disabilities (Machin, 2017). The committee inquiry concluded that there was reliable evidence of systematic violations of rights for those claiming welfare (United Nations, 2016) with five of committee’s eleven recommendations related to the administration of disability benefits (Machin, 2017).

Psychology missing (in)action.

In 2016, the British Psychology Society (BPS) produced a briefing document that called for further reforms of the WCA (BPS, 2016). The call focuses very much on querying the reliability and validity of the ESA50 and the WCA, making the case that psychometric measures – when administered by appropriately qualified assessors (i.e. psychologists) – could be “extremely valuable” tools for assessing individual’s capability for work (BPS, 2016). The Society lobbies for the introduction of specialist assessors, supervised by qualified clinicians, who have knowledge of the effect of mental, cognitive and intellectual difficulties. The appropriateness of reassessments for people living with long term conditions is called into question, as is the lack of referral routes for those needing specialist support (BPS, 2016). Given the wealth of research evidence around the problems of the WCA, it is appropriate that the BPS made this call to action. However, taking a critical perspective to the intended aims and foci of the briefing document, it reads more as an appeal for psychology’s greater involvement in these welfares systems; perhaps with the implicit aim of creating more employment opportunities for its own members, rather than considering how psychological knowledge could help improve these systems for claimants. This absence is particularly notable, given that through the use of a mediation analysis it has been found that the conditionality of Universal Credit negatively indirectly affects life satisfaction by increasing psychological distress (Thornton & Iacolla, 2022).

Friedli and Stern (2015) further problematise the relationship between psychology and UK government workfare programmes. Examining the conditions welfare claimants need to comply with, it is made clear how psychological explanations for unemployment underpin activities designed to modify attitudes, beliefs, dispositions or personalities of those who are unemployed (Friedli & Stern, 2015). The ‘cosiness’ between the Behavioural Insights Team (the government’s ‘nudge unit’) and psychological sciences legitimises a reading of social problems through an understanding of the individual. For some, the achievement of psychology’s involvement within the administration of welfare policy is complicated, but something that is ultimately to be celebrated and encouraged (Weinberg & Doyle, 2017). We see this interest filter through the small amount of psychological research which engages with health-based welfare benefits. One such example is Purdie and Kellett’s work (2015) which evaluates a psychoeducational programme designed to improve return to work rates for claimants of ESA and its precursor, Incapacity Benefit. The intervention was theoretically grounded in Williams' 'five areas' approach to enhanced psychological well-being (2006a). Williams' 'five areas' is a self-help approach to overcoming anxiety. Clients are encouraged to identify life/situation and practical problems; condition-related unhelpful cognitions; condition-related altered emotions; condition-related altered physical feelings/symptoms; and unhelpful behavioural patterns (Kellett et al., 2013). In Purdie and Kellett's (2015) intervention, sessions covered ways to improve mood through increased activity, managing anxiety, improving sleep, healthy lifestyle and pacing. Contrary to the study's hypothesis, participants living with mental health conditions were found to be more likely to return to work across the short and long term, compared to those with physical health conditions. In the longitudinal data, 12-30 months post-intervention, Puride and Kellett found a return-to-work rate of 28-30%, for physical and mental health conditions, respectively. The paper concludes that cognitive-behaviourally-based intervention can be thought of as a "useful catalyst" for those claiming health-based welfare (Puride & Kellett, 2016).

In recent years, and from the more critical perspectives of health and social psychology, there has been some increased interest in what psychology can offer to the topic of welfare. Critical approaches to health psychology developed as a response to the positivist assumptions of traditional psychology and its lack of engagement with broader social and political issues (Morrison et al., 2019). Critical psychologists tend to use qualitative and participatory methods of research with the aim of improving the conditions of life for socially marginalised individuals. Within critical approaches, there is a broad commitment to deepening social analysis for social justice purposes (Morrison et al., 2019). One such example of a critical psychological approach to welfare systems comes from Goodman and Carr (2017). Using a discursive psychological approach, Goodman and Carr (2017) explore how the concept of a "just world" is rhetorically drawn upon by individuals to support their position on claimants of unemployment benefits. The just world hypothesis (Lerner, 1965) is understood as an erroneous explanation for negative events: people getting what they deserve. Their analysis unpicks the sophisticated and nuanced ways in which talk (situated in TV documentaries about welfare claimants) draw on notions of fairness.

Prior to the start of this PhD programme, completed as part of an MSc. in Health Psychology, I sought to explore individuals' experiences of the WCA, deploying phenomenological perspectives in a critical manner (Day & Shaw, 2022). Making use of Todres et al.'s notion of ‘life-world led care’ (2007) I examined how participants experienced the WCA: as an extension of the medical model of health. Participants described strong feelings of a lack of autonomy. However, this loss of independence was not due to the restrictions of their conditions, but rather through lengthy battles for diagnosis, effective treatment and recognition by the WCA process (Day & Shaw, 2022).

However, the majority of research looking at how health-based welfare policies have been experienced comes predominantly atheoretical perspectives: from sociology and social policy (e.g. Baumberg, 2016; Patrick, 2014; Patrick, 2016; Patrick, 2017); human geography (e.g. Garthwaite et al., 2014; Garthwaite, 2015); and independent researchers with lived experience (e.g. Stewart, 2018; Hale et al., 2021). Little attention has been paid to the psychological effect of claiming welfare; or how discourses around welfare claimants may impact on processes of meaning making. This absence of engagement by psychologists becomes notable when considering the theoretical model that under-pins the WCA and PIP assessments; that of the biopsychosocial model of health. Shakespeare et al. (2016) argue convincingly that a flawed application of the model has been used as a way to justify stigma through a failure to genuinely consider macro socio-economic factors.

‘Unseen’ chronic conditions.

The difficulties associated with claiming health-based welfare may be more keenly felt by those living with ‘invisible’ or unseen chronic illnesses: those conditions that are not directly perceptible, not noticeable or visually evident to others (Vickers, 2001). Here it is worth noting that within the literature there is a tendency to favour the term ‘invisible’ over ‘unseen’. However, that which is invisible cannot be seen whilst what is unseen can be seen but is/was not seen. What I mean by this distinction is that the challenges faced by individuals living with chronic unseen health conditions can be chosen to be acknowledged, whilst a label of ‘invisibility’ potentially renders the experiential qualities of a health condition unknowable. In aiming to do so, this thesis will, therefore make use of the ‘unseen’ label.

Having a chronic unseen illness subjects a person to possible stigmatisation (Joachim & Acorn, 2000). For those whose conditions lack a visual element, coping with potential stigmatisations involves an element of decision making: do we disclose our condition and potentially face stigmatisation or do we conceal our health circumstances and hope to ‘pass’ as ‘normal’ (Joachim & Acorn, 2000)? The dilemmas and practices of these disclosures within the workplace are understood as opting into a state of vulnerability (Norstedt, 2019). Considering the experiences of chronic unseen illnesses within the workplace, Vickers (2003) found themes of a definitive lack of certainty, fragmentation and chaotic narratives; for individuals with chronic illness a life of “predictability” becomes a distant memory leading to feelings of judgement and perception of misunderstandings from colleagues.

Looking at unseen chronic health conditions within a workplace context is a theme within the literature (e.g. Godard et al, 2022; Bend & Fielden, 2021; Dolan, 2021; Thompson et al., 2019). Other research focuses on younger people’s experiences of disclosure (Kaushansky et al., 2017) or on the transition into university life (De Beer et al., 2022; Chu et al., 2020; Giroux et al., 2016). A common ‘thread’ that runs through this line of enquiry is around identity management: how individuals make sense of their own (sometimes contested condition) within the social contexts they find themselves. The ‘gulf’ between outward appearance and embodied experience lead to dismissive appraisals from friends, family, acquaintances or representatives of the state (e.g. “you don’t look sick”; Hale, 2018). Such remarks actively negate and trivialise the impairing impact chronic conditions can have.

Further marginalisation can be experienced through battles for representation: traditionally individuals with chronic illnesses have either not seen themselves as part of the disability movement or have been effectively excluded from it (Duffy, 2018). The boundary between disabled and non-disabled is less clear for those living with unseen health conditions (Hendry, 2022). Indeed, the majority of academic research critiquing welfare reform draws upon the experiences of those who identify as ‘disabled’. What of those living with fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), inflammatory bowel disease, lupus, chronic pain or medically unexplained symptoms? Those whose experiences defy easy categorisation may find themselves at risk, at odds with the understandings of society. A useful way of conceptualising the shared experiences of these conditions comes from the Chronic Illness Inclusion project; a participatory research group organised by and with people living with physical chronic illnesses (Hale et al., 2021). Hale et al. (2021) talk of “energy limiting chronic illness” (ELCI) as a means of capturing the debilitating mixture of physical fatigue, cognitive fatigue, and pain experienced by individuals living with chronic illness. Moving beyond cultural expectations of disability that require a visual difference, or binary understandings of capacity, ELCI focuses on the impact of fluctuation in symptoms and environmental stressors (Hale et al., 2021).

Overview of this thesis.

This PhD aimed to investigate how chronic unseen health conditions are experienced within the wider context of UK welfare reform, from a critical perspective. Addressing the absence of psychological knowledge around the topic, I aim to do so by taking innovative approaches to what can be considered data, alongside a pluralistic approaches to data analyses. The epistemological and methodological foundations (and consequences) of this body of research are outlined in the second chapter. Having established these positions, the ‘contemporary’ contexts of welfare are explored. Building on a Media Framing Analysis methodology, Chapter 3 develops a systematic method for collating a data corpus suitable for discursive analysis. Looking at three time points in the history of the UK’s employment and support allowance health-based welfare policy, a Foucauldian-inspired discourse analysis is deployed to examine relevant news media and policy documents. Such analysis aims to illuminate which pre-existing discourses are drawn upon, or which ‘new’ constructions are developed, in relation to the contemporary landscapes of UK welfare. What discursive resources might be available for those living with chronic health conditions who are claiming welfare? How might the subjectivities of people living with chronic health conditions be shaped by these constructs? During the Media Framing Analysis, Ken Loach’s 2016 film *I, Daniel Blake* was identified as an important discursive resource. Reflecting the methodological commitment made to different forms and types of data, within chapter 3, I commit to a novel multimodal discourse analysis (which contains ‘spoilers’ for the film), to examine the ‘immaculate construction’ of fictional ESA claimant Daniel Blake; specifically considering the implications for ‘real life’ ESA claimants.

Chapter 4 begins the empirical research of this thesis. Taking a longitudinal approach to data collection, eight individuals living with chronic unseen health conditions who had engaged with UK welfare systems, were recruited as participants. In Chapter 4, I use both Interpretative Phenomenological Analysis and Foucauldian Discourse Analysis to pluralistically explore these eight individuals’ experiences of living with chronic unseen health conditions. The dual focus analysis is presented in an integrated manner, to reflect the ‘cojoined’ nature of individuals’ lifeworlds, which take place in discursively rich contexts.

Chapter 5 marks the first piece of data collection that took place within the ‘rupture’ of the COVID-19 pandemic. Given the research focus on chronic health conditions, it is perhaps unsurprising that the pandemic had a significant impact on participants’ lives. Following the first interviews (analysed within chapter 4), participants were invited to take photographs that represented their daily experiences of chronic illness and/or instances of claiming welfare. The incorporation of participant created photography was initially conceptualised within an interview framework, that participant created photographs would function as interview stimuli. However, in a continued commitment to treating multimodal data as distinct, the visual data was first phenomenologically analysed away from (and separate to) participants’ interview data. The later analysis (chapter 6) of the photovoice interview data seeks to bring participants’ meaning making to the foreground: what do the shared photographs mean to them? How do these attempts at representation bridge the gap between experience and expression? Within the discussion and conclusion of this thesis (chapter 7), I consider the theoretical contributions made by this research, whilst also working with participants who took part in the longitudinal study to curate a list of recommendations for policy and practice. Framed in terms of ideas for welfare reform, I also consider the wider changes needed for a holistic (re)understanding of what it is like to live with chronic unseen health conditions in the present-day United Kingdom.

Chapter 2. Epistemologies, methodologies and methods.

Introduction.

This thesis aims to make use of both phenomenological and discursive methodologies to explore two distinct but inseparable phenomena: participant experiences of claiming welfare whilst living with a chronic, unseen health condition. Historically, within qualitative psychological research, these two approaches to analysis have been seen as epistemologically incompatible, as they seek to produce different types of knowledge. This chapter aims to explore these 'mismatches' of epistemology; how the limits of each approach can be met by the other; and how a genuinely pluralistic approach to data analysis can be conceptualised. Beginning by exploring relevant aspects of phenomenological inquiry (Heidegger [1889-1976], Merleau-Ponty [1908-1961]), I will then consider how the writings of Michel Foucault (1926-1984) might compliment phenomenological thought. Building on the hermeneutic writings of Gadamer and Ricœur, alongside the work of contemporary qualitative psychological researchers, enables the application of these schools of thought to formulate a pragmatic and theoretical framework for this thesis.

Phenomenology.

Phenomenology can mean many things to many different people; an often-disputed tradition that is nonetheless tightly policed within philosophical circles. Within this section I will aim to outline and define those phenomenological concepts that are most relevant to the focus of this thesis. Despite varied methodological adaptations, phenomenological analysis can be broadly characterised as the study of human experience, with a particular emphasis on appreciating how meaning is understood within the context of our lives as lived.

Ontologically, phenomenology is underpinned by a foundation that there exists a 'real', tangible, world. The world beyond ourselves is experienced through our sensory perceptions. Collapsing the Cartesian divide between mind and body, Husserl's use of the term 'intentionality' describes the nature of consciousness: when we are conscious, we are always conscious *of something*. Our consciousness is turned out towards the world; we orientate our awareness towards objects. One of the ways in which psychology can be 'phenomenological' is through an interest in this orientation: what is experienced and how is it experienced? This 'phenomenological attitude' is distinct from the usual way we engage with the world: where we 'take-for-granted' an everyday, unexamined, way of perceiving the world. In his earlier writing, Husserl believed that a transcendental phenomenology was possible: that, through a series of reductions, we would be able to get to an understanding of the content of conscious experience; the specifics and essential features of pure consciousness (Moran, 2000).

Heidegger, perhaps Husserl's most well-known critic and student, is often attributed with leading the existential turn in phenomenological philosophy. However, this turn was prefigured by Husserl's concept of the lifeworld. Centralised in Husserl's later writing, the lifeworld is the world as concretely lived: the 'taken-for-granted' everyday that forms our natural attitude. The sharpest divide between Husserlian thought and the proceeding existential phenomenologists is around the natural attitude. Husserl believed it possible to bracket off, totally, the natural attitude in order to reach the essences of experiences. For Heidegger, all people are inseparable from the worlds they inhabit. If we are unable to transcend beyond our lives, being able to fully bracket our own pre-understandings becomes an impossibility. Instead, Heidegger embraced the inextricable link between individuals and the world. The concept of Dasein ('there-being') can be roughly defined as the subjective qualities of being human. The coining of a new term (i.e. Dasein) is both indicative of Heidegger's inventive approach to language, whilst also an attempt to reinvigorate considerations of what it means to exist. For Heidegger, a core tenet of Dasein is the pre-existent nature of the world we are 'thrown' into. We cannot meaningfully detach ourselves from the world of objects, people, language that we find ourselves existing in (Smith, et al., 2022).

The key features and structures of Dasein present us with existential foci; ways to investigate the complexity of worldly existence. How time is experienced; temporality, is one such feature. We are projecting ourselves towards future possibilities; whilst a continuity between the past and present is always there. However, due to the predated world we are thrown into, the possibilities we have access to are limited: this is the 'facticity' of our existence. Being-towards-death marks the limit of these temporary possibilities. Being-towards-death, for Heidegger, reflects the finitude of human nature. We are all directed towards death and this momentum shadows all our projects and engagements (Moran, 2000). Disruptions to our lives (such as the "biographical disruption" of illness (Bury, 1982), unemployment or bereavement) make us aware of this being-towards-death.

The feature of ‘mood’ highlights the pre-reflective way we experience the world. In Heideggerian terms, a mood is not a transient and contingent psychic state, but instead a structure of our existence (Trigg, 2020). Mood is the mode in which we find ourselves in the world. Mood is lived through first, but only understood through later reflection. Heidegger argues that when we become aware of our finitude (e.g. our being-towards-death), this brings into focus the most fundamental of moods: angst, or anguish. We are reminded of the need to make life meaningful, against the ontological limit of our existence. One of ways that meaning can be experienced is through the concept of being-with. For Heidegger, we are social beings. The intersubjective way we share the world (that is, our experiences are overlapping and relational to others) necessitates concern or care for things in the world.

Of all the post-Heideggerian phenomenologists, it has been argued that Merleau-Ponty has made the greatest contribution to phenomenological psychology (Langdridge, 2007). Merleau-Ponty saw human experience as an immensely complex weave of consciousness, body and environment. His emphasis on the body is what, in part, distinguishes his thinking from his contemporaries (such as Arendt, De Beauvoir and Sartre). Merleau-Ponty makes use of the phrase ‘body-subjects’ to describe the primary experiences of embodied human existence (Moran, 2000). For Merleau-Ponty, the world is made to be discovered by, and to respond to, our sense organs. The body is not an object in the world, rather the body is a means to communicate with the world. The world is revealed to us through our body, we speak and think from our body. However, this communication is not just in one direction: the body is both perceived *and* perceiver. Through the concept of ‘the flesh’, Merleau-Ponty overcomes the traditional subject/object dichotomy. Just as the body is part of the fabric of the world, the world is encrusted in the flesh of the body (Moran, 2000).

This focus on embodiment has a number of important consequences for phenomenological psychology. One such consequence is that, given the primacy of our embodied perspective, our relation to others will always come from a position of difference (Smith et al., 2022). We can never fully share another’s experience because this experience is shaped through *their* embodied position in the world. This quality of ‘mineness’ contained within the body-subject has implications for the phenomenological reduction. Merleau-Ponty’s philosophy is always a philosophy of immersion in the world (Moran, 2000). A “God’s eye view”, which may produce incontrovertible truths about our experience of phenomena, becomes an impossibility (Langdridge, 2007). For Merleau-Ponty, our history can be understood in similar terms; a rejection of an absolute system of knowledge, history as a single stream of meanings. There is no position from which we can view the course of history from 'outside': we cannot have the view of a house as "seen from nowhere" (Moran, 2000). Instead, and contrary to Sartre, Merleau-Ponty argues that the freedom of freedom is historically conditioned, a unique product of historical forces. History can be understood in terms of motivations whereby external conditions are internalised (Moran, 2000). For this thesis, when hoping to understand how specific welfare policies and systems have been experienced, it is therefore important to map out the corporeal *and* historical situatedness that individuals find themselves in.

Within the context of health and social care research, modern approaches to phenomenology apply phenomenological concepts to qualitatively understand how experiences have been made sense of, at an idiographic level. The research of collaborators Todres, Galvin and Dalberg (2007; 2009; 2014) provides particularly useful ways of thinking about how we might use key features of Dasein; both in terms of ways of understanding, but also as means to inform caring practices. Todres et al. (2007) outline the intertwined nature of life as lived, illustrating how lifeworld concepts can provide a foundation for humanised care. For example, considering how an individual's experiences of temporality, intersubjectivity, spatiality, embodiment and mood might be impacted by illness can have an effect in immediate healthcare settings, but may also encourage new ways of political thought (Todres et al., 2007). These models for care provide a useful resource for this thesis, both as a practical tool to highlight potentially relevant aspects to engage with in the analysis of data, but also for generating new ways of thinking about how illness can be (de)humanised by political systems.

Hermeneutics.

These ways of existentially exploring how life is experienced have had a direct influence on phenomenology as a research endeavour. Yet phenomenological psychology is rarely aiming to provide purely descriptive accounts of experiences in their appearing. In the move away from transcendental phenomenology, Heidegger's approach to phenomenology can be thought of as a *hermeneutic* phenomenology. Historically rooted in the interpretation of biblical texts, hermeneutics is the art, or theory, of interpretation. The notion of fore-conception becomes relevant here. In Heideggerian terms, our fore-conceptions may include our assumptions, prior experiences and preconceptions. These fore-conceptions cannot be fully bracketed away, so form the foundation of any ‘new’ interpretations (Finlay & Gough, 2008).

The writings of Gadamer and Ricœur further expand on the role of hermeneutics within phenomenological research. Gadamer’s work will be discussed in this section; we will return to Ricœur’s hermeneutics of suspicion when exploring the pluralistic framework taken in this thesis. With an increased focus on the role of language, Gadamer stressed the historically and culturally situated nature of interpretation; we always speak from a position that is situated within a specific context. Our pre-understandings, for Gadamer, both enable and limit our understandings. But for Gadamer, speech is the essential way in which understanding emerges. Gadamer’s concept of horizons, and particularly the *fusion* of horizons, is indicative of this emphasis. Rather than the ‘every day’ use of the term, Gadamer builds upon Husserl’s definition of horizons: that horizons demarcate what can be directly sensed but doesn’t limit this perception to what can be directly sensed (Vessey, 2009). Husserl’s use of the term is bound up in perception. Gadamer broadens the metaphor towards intelligibility through language (Vessey, 2009). A horizon is not a boundary, but something that invites us to advance further. Our horizons mark both what is significant for understanding, but also what our current limits are. A fusion of horizons between people (for example, in a qualitative interview setting) is not simply an opportunity to arrive at a mutual agreement but is an expansion of understanding; an openness to move beyond our current fore-conceptions. But what may have shaped these fore-conceptions (Shaw, 2010)? When we talk of current limits of understanding, where may these have been imposed from?

Foucauldian Discourse Analysis.

The relationship between language and subjectivity emerged from very specific historical and cultural conditions. In an attempt to understand why the French Communist Party failed to succeed in the 1968 period of civil unrest, Michel Foucault sought to redefine how ‘power’ operationalises. Rejecting the Marxist focus on the effects of ideology on the working class, Foucault sought a more flexible and differential model of power.

Rather than solely repressive, for Foucault, power is, above all, productive. Power: “induces pleasures, forms of knowledge, produces discourse” (Foucault, 1982 cited in Bloom, 2018, p. 126). Power does not function to repress individuals but rather *produces* them through practices of subjectification and action. In Foucauldian terms, a ‘discourse’ can be defined as a body, or system, of knowledge; a way of understanding. Under Foucauldian terms, language, alongside practices, are constitutive parts of discourses. Discourses produce social and psychological life (Willig, 2021). By way of an example, Bloom (2018) argues that in the present day, rather than the suppression of identities and ideas, power is actively manufacturing these subject positions. We are, for example, encouraged to live freely; expressing our identities in a responsible and enterprising manner. Through this lens, a discourse of ‘freedom’ represents a form of subjection. Subjection is not just social overdetermination, it involves the investment in a culturally provided identity; a ‘taking up’ of the subject positions which are discursively offered. But what happens when that identity (e.g. a welfare claimant) is constructed as being undesirable? And what if other identities, or positions, are not available (as a result of poor health, for example)?

Foucault conceives our social worlds as constituted by the term “power/knowledge”. For Foucault, knowledge is never separate from the dynamics of power (Newman & Clarke, 2017). Instead, power creates, guides and enacts knowledge (Bloom, 2018). In comparison to positivist portrayals, under Foucauldian terms ‘knowledge’, and what we can claim to know, becomes something far less fixed. Dominant discourses may become so entrenched and legitimised that they may be considered ‘common sense’ or that they reveal fundamental ‘truths’ about the nature of our world. Yet, alternative constructions are always possible (Willig, 2021). By exploring the historical construction of discourses, we are potentially able to delegitimise established knowledge; to strip back the layers of institutional practice that organise and regulate social life (Willig, 2021). The epistemology of such a genealogical approach is therefore an epistemology of critique, rather than an epistemology of truth (Hook, 2005).

Foucauldian inspired discourse analysis was introduced into Western qualitative psychological research in the late 1970s (Willig, 2021). Foucauldian Discourse Analysis (FDA) is concerned with language and its role in the constitution of social and psychological life (Willig, 2021). An underlying epistemological foundation of FDA is that knowledge is socially constructed. That is not to (necessarily) suggest there isn’t a world that exists pre-language. Instead, taking a Foucauldian approach requires taking up an epistemological position that acknowledges our knowledge of the world is unavoidably produced through the organisation of language. Discourses facilitate and limit, enable and constrain what can be said by whom, when and where (Parker, 1994). As a tool of analysis, FDA enables researchers to focus on the availability and genealogy of discursive resources within a culture, something that can be considered the discursive economy. FDA, with its foundations in post-structuralism, aims to examine how objects (things) and subjects (people) are constructed through language use. Foucault's later writings on governmentality (how reality, from the micro to the macro, is rendered governable) and biopower (the ability to observe, measure and to 'know' the biological details of a population) become particularly pertinent in critical psychological studies of health and well-being (Galvin, 2002). FDA enables considerations of the potential affects and effects of these discursive constructions: what are the implications for individuals living within these discursive economies (Willig, 2021)? What can be felt or done? What can neither be done nor felt?

Phenomenology and language.

Having outlined how FDA treats language (as discourse), in this section I return to phenomenology to consider how phenomenological thought 'makes sense' of language. For Heidegger, the world (and our being-in-the-world) is made intelligible through discourse. This importance of language is captured in one of Heidegger's most well-known quotes: "language is the house of Being. In its home human beings dwell" (Moran, 2000, p. 216). Heidegger's considerations of language hones in on instances when language becomes 'fixed'. Drawing on the distinction between scientific discourse and poetry, Heidegger argues that, in its attempt to create unambiguous representations of the world, scientific language becomes 'dead' as soon as meaning is fixed (Langdridge, 2007). Creative and novel uses of language, in poetry, are able to reveal more about the world than language that is fixed. Those who are able to creatively engage with language are highly thought of: "those who think and those who create with words are the guardians of this home" (Moran, 2000, p. 244).

It can be argued that there is a potential naivety at play here. Heidegger considers how the meanings of language can become fixed (and equally, the revelatory power that creative language may have). He reflects on those who are able to construct language, and who can create new meanings. Those who can, the philosophers and poets, are understood as being able to guard the essential nature of Being. This power, the ability to construct new meanings, becomes concentrated in particular people, within a binary of the scientific and the poetic. Here, language becomes a tool of communication: there is the assumption that there is a representational validity to language. That by using language we are able to represent, or get close to representing, the essences of an experience. Even though meanings *can* change, there exists an implicit failure to recognise language as one the dynamic features of the world we are thrown into. Language becomes conceptualised as a tool carried by the thrown person, rather than a feature of world we find ourselves thrown into.

‘Dead’ language, language that is fixed, powerfully communicates scientific knowledge. Perhaps more so than poetic language, as it is language that is fixed that is commonly considered to hold truth values. For Heidegger, meanings can and do change, but the specifics of how language may transmute is framed in purely technological terms and does not consider the *constructive* power of language. To return to the ‘home’ metaphor oft used in phenomenological writing, what are the walls that form the structure of our ‘language houses’? Who has created the language homes we find ourselves thrown into? Are we all living in the same house? What happens when this home is made to feel unhomely? To answer these questions, a hermeneutical approach coupled with a social constructionist perspective is needed. Here, the availability of particular ways of talking about an experience, or phenomenon, is shaped by the language we have available. Merleau-Ponty suggests that the other is already within us when we use language (Moran, 2000). Who put the other in there? *What* is put there?

This is not to say that phenomenological philosophy is lacking in its considerations of language. For Merleau-Ponty, language is an ‘interworld’: it consists of cultural rules and resources which are shared by a community (Crossley, 1993): thought is achieved through shared language. The exploration of the public institution, of language, is therefore crucial for both subjectivity and intersubjectivity. Perhaps this critique is best understood in Gadamerian terms: the analysis of discourses as being just beyond the horizon of phenomenological investigation. Language was evidently a concern for phenomenologists, but through taking a discursive approach in addition to a phenomenological one allows us to traverse into this horizonal openness. Foucauldian thought offers a way in to examining how these structures come to be and, crucially, what the implications of the power/knowledge nexus may be understanding experience.

Pragmatic pluralism.

The wider research project is informed by a pragmatic pluralistic theoretical framework (Frost, 2011; Willig, 2017). Underpinning pragmatism is the assumption that research occurs in social, historical, cultural and political contexts (Creswell, 2009). As such, what we may consider to be a ‘truth’ is contingent on these contexts. We, as researchers, are therefore free to choose techniques and methods that best enables us to explore these truths. This thesis will make use of different methodologies and methods of analysis. Dependent on the research question, methods with differing epistemological ‘aims’ will be deployed. Discursive methods (such as FDA) will be made use of; in other contexts, phenomenological methods (such as Interpretative Phenomenological Analysis) will be used. In practical terms, each chapter in this thesis will outline the method of data collection and analysis used. These methods sections will link back to, and be informed by, the epistemological explorations made in this chapter. In one study, a *dual focus* methodology will be used to enable the researcher to apply two methodologies that previously would have been considered epistemologically incompatible on the same set of data (Willig, 2017).

Given the project’s focus on the micro and the macro, an array of different types of analysis are necessary to explore the influence (or not) of contingent external relations on internal meaning making (Hood, 2016). With its emphasis on the careful examination of human experience, through an accessing of the meaning and texture of subjective experience, phenomenology is an appropriate methodology to explore the lived experiences of participants (Smith et al., 2022). Foucauldian Discourse Analysis, which examines the role of language in the facilitating, limiting, enabling and constraining of social and psychological life, is an equally suitable methodology for examining how ‘knowledge’ of welfare claimants is constructed (Willig, 2021).

Chapter 3 of this thesis will discursively examine how health-based welfare reforms have been constructed by UK media and policy documents; exploring the potential knowledges produced about those who are chronically ill and who claim welfare. The later empirical research of the thesis aims to explore the interplay between the two dimensions and two methodologies: deploying both phenomenological and discursive methods of analysis to data sets to examine how discourses are potentially *experienced.* My research inquiries can therefore be understood as being underpinned by an abductive approach to data and theory (Shaw et al., 2018): considering the data generated alongside existing theoretical concepts of phenomenology and discourse analysis; to help explain these analytic approaches further whilst better understanding the phenomenon of living with chronic unseen conditions within the wider context of UK welfare reform.

However there exists epistemological mismatches between phenomenology and FDA: language in phenomenological analyses describes the meaning of an experience (there exists a perceivable reality) whilst for FDA, born from social constructionism, language both mediates and constructs our understanding of reality (Willig, 2021). This is not to say that phenomenological approaches are uncritical, for example the interpretative stance inherent in Interpretative Phenomenological Analysis (IPA; Smith, 1996) involves an interrogation of interviewee accounts, ways by which meanings of experience can be “drawn out” (e.g. Larkin, et al., 2006). Within IPA, language used by participants isn't taken to be an unproblematically direct reflection or representation of that reality; instead, it is treated more as an attempt at giving meaning or interpretation to their worlds as lived. A deepening of this interpretative stance is present in critical phenomenology, which aims to be attentive to social and political norms of our lifeworlds (Stanier, 2022), but envisages a challenging of these structures through a process of continuous co-creation, rather than a committed turn to language. Such a commitment to a relativist epistemology (more pronounced within FDA) doesn’t entail a position of ontological relativism (the existence of multiple realities; Willig, 2016). Instead, deploying FDA alongside phenomenological perspectives potentially broadens how we can understand what meaning is and the resources made available to those ‘making meaning’ whilst acknowledging the presence of a material and social reality (Baboulene & Willig, 2023).

Willig (2017) proposes three ways of conceptualising combining FDA and IPA; ways in which we can reconcile the epistemological incompatibilities of the approaches. The first is a language dominant view: the social constructionist approach. Here discourse ‘comes first’ and constructs experience; experience is defined as the product of subject positions. A phenomenological conceptualisation posits that experience pre-exists discourse but that discourses constrain how experiences can be talked about. The middle position suggests that discourse shapes experience by providing a context: that multiple meanings will always be available. Whilst considering which of these three conceptualisations might be the most generative for this research project, the importance of the pre-reflective and embodied way we experience the world seemed to entail a ‘taking up’ of the phenomenological conceptualisation.

Pre-reflective self-consciousness can be understood as the immediacy of experience and sensations: we have a sensation - such as pain - before reflecting on it and making sense of it.

Particularly relevant in the study of health and illness, pre-reflective features can also be apparent when reflecting upon the experience of 'everyday' sensations (such as the experiential-ness of eating chocolate; Gallagher & Zahavi, 2008). These, and all, experiences are characterized by a quality of 'mineness' or 'for-me-ness', the fact that it is I who am having these experiences (Gallagher & Zahavi, 2008). Within the tradition of phenomenology, from Husserl to Merleau-Ponty, there is close to unanimous agreement that the experiential dimension always involves such an implicit pre-reflective self-awareness (Gallagher & Zahavi, 2008). I posit that because of the importance of pre-reflective self-consciousness within phenomenological thought, when considering how to conceptualise the ontological 'ordering' of pluralism we must make use of the phenomenological conceptualisation: i.e. experience exists prior to discourse, but that discourses shape how experiences are made sense of. The phenomenological conceptualisation of pluralism will inform how methods of analysis are made use of. When a dual focus is used within the analysis of data, data will be initially approached through a phenomenological 'lens'. Following a phenomenologically informed reading of the data, FDA will be used to consider what discourses are used within the text. Continuing the camera metaphor, FDA perhaps represents a 'zooming out'; adjusting the focus of the lens to get the widest possible view of the politico-cultural landscape participants are living in.

In work that takes an 'affective turn', Margaret Wetherell (2013) highlights the limitations of discursive approaches taken in psychological research. Wetherell (2013) notes that many areas of discursive research are not well suited to investigating the affective nature of embodiment. Affect, that is an emotional reaction or state, is often reduced down to a product of our subject positions. That, through the anti-essentialism foundation needed to explore the constructive nature of language, detailed investigations of embodied states become closed off (Wetherell, 2013). There is the potential for FDA work to become overly deterministic when theorizing the affective quality of 'available' subjectivities: e.g. because of how this position has been constructed, and how *x* has been positioned as a subject within this construction, the following emotions become available for *x*. Such a determination negates the ways discourses are lived through, e.g. language and discourse are a part of Dasein that we cannot step outside of. This is in contrast to some areas of contemporary phenomenological thinking (Ratcliffe, 2019; Carel, 2021), which explore how emotions are experienced through our bodies and through our bodily disruptions. This horizonal limitation of discursive thought illustrates the divide between discourse analysis (understanding can be gained through the analysis of how language is used) and existential phenomenology (primacy of embodiment, partially expressed through language).

The hermeneutic writings of phenomenologist Paul Ricœur can, to some degree, reconcile these differences and provide further justification for the use a phenomenological conceptualisation of pluralism. Phenomenology, as practised within research contexts, is interpretating the understandings of a participant. This is achieved through a hermeneutic of empathy; demythologizing through empathic engagement as we (the researcher and the participant) move towards a fusion of horizons (Langdridge, 2007). This can be contrasted, or complimented, by a hermeneutic of suspicion: where we seek to identify the meaning hidden below consciousness (Langdridge, 2007). Ricœur advocates Freud, Marx and Nietzsche as the "masters of suspicion": providing us with tools (psychoanalytic, economic and the will to power) to unmask the meaning below the surface (Langdridge, 2007). Ricœur does not suggest that it is necessary to incorporate these *particular* hermeneutics into phenomenology. However, he argues for including a hermeneutic of suspicion that is appropriate to the social phenomena under investigation (Langdridge, 2003). FDA allows us to consider the function, construction and variation of discourses as lived. Using Foucauldian notions of power/knowledge enables a research project that simultaneously captures the phenomenological meaning of data, whilst recognising the vital role of language in mediating our access to participants' lifeworlds (Langdridge, 2003).

Unlike other examples of pluralism within qualitative psychological research (Johnson et al., 2004; Colahan et al., 2012; Spiers & Riley, 2018; Dempsey et al., 2019), rather than presenting analyses as distinct and separate, in the writing up of a dual focus analysis I aimed to reflect the enmeshed conceptualisation of how these two methodologies can create complementary insights: analyses is intertwined, rather than carefully delineated, as a commitment to illuminating the complexity that pluralism entails.

A pragmatic pluralistic framework also has implications for what constitutes data. While the semi-structured interview is the traditional form of data collection in qualitative research (Smith et al., 2022), I advocate, as others have done (see for example Boden et al., 2019; Burton et al., 2017; Kirkham et al., 2015; Boden & Eatough, 2014; Shinebourne & Smith, 2011), that moving beyond the spoken word to engage and elicit subjective experience visually and creatively, can support more nuanced understandings of phenomena. Similarly, discourse, under Foucauldian terms, is understood as social knowledge. As such it would be reasonable to include texts that may contribute towards the constructions of what is socially 'known' within the thesis as data.

Reflexivity.

Making use of a pluralistic framework also has consequences for reflexivity. An integration of both FDA and phenomenological approaches to research can engender a deeper engagement with reflexive practices. One example of this is considering the role of pre-understanding. As researchers, we engage in regularly asking questions. However, in *Being and Time*, Heidegger highlights that we rarely examine what is involved within questioning itself: "every seeking gets guided beforehand by what is sought" (Moran, 2000, p. 236). Applying these considerations within the context of this research, there was a purpose 'behind' the posed research questions. There was a 'fore-conception', or an 'average understanding' of what we might find: broadly speaking, the negative effect welfare systems have on individuals living with chronic health conditions. Considering where these fore-conceptions arrive from, I arrive at my own experiences; experiences that mirror the two distinct phenomena (welfare and chronic health conditions) under investigation through two distinct methodologies (phenomenology and discursive). Following a complex and disruptive period of illness, I – at the age of 15 – found myself facing life with a chronic health condition. In later years, prior to my 'leap' into academic work, I was employed to audit the very welfare systems that this thesis seeks to explore. My life uncannily duplicating, or reflecting, the doubling that is present throughout the thesis: two methodologies, two phenomena, lived experience of both.

My average understanding is, in part, also informed through a critical engagement with the available literature examined in chapter 1. FDA allows us to explore *other* (potentially more readily available) average understandings: what are the predominant understandings constructed, and held, by our culture? In a commitment to the social constructivist perspective that underpins FDA, the analyst critically considered, recorded and examined their own assumed knowledges. This becomes particularly pertinent as I progress through the research stages of the thesis. For example, following a Media Framing Analysis of data specifically looking at the formation of post-2008 welfare policies, how might these findings inform later analysis? What might be expected to be 'found'? What language might I have anticipated to be used? From a Foucauldian perspective, *all* forms of knowledge are considered to be constructed through discursive practices (Willig, 2021). Anything produced by the researcher is a further construction of knowledge. It therefore becomes important to consider the 'visibility' of the researcher (Kitzinger, 1987). How was, and is, the analyst positioning themselves? What implications might this have for the types of knowledge being produced?

Alongside these approaches, and within the traditions of interpretative approaches to phenomenology, through the strategies of introspection, meaningful reflection and monitoring of one's own reactions (recorded within a reflexive log), I was able to make sense of my own fore-conceptions and presuppositions, minimising their affect through these processes of active monitoring. It was not the intention to completely restrain my pre-understandings (if such a thing could even be possible), rather Dahlberg's (2006) conceptualisation of "bridling" becomes a meaningful way to engage with these reductions: a way to reflexively dwell with my hermeneutic reflections (Shaw, 2010). Bridling is the 'restraining' of one's pre-understandings (Dahlberg, 2006). We can think of what may fall into a definition of pre-understanding in broad terms: personal beliefs, theories, other experiences may all disrupt, distort or shape our attempts to understand the meaning of a phenomenon. Bridling, as a variation of bracketing, was developed from Dahlberg's (2006) time on a horse ranch. It is useful to hold this origin in mind when consider how bridling can, or should, function within a research context. Bridling is an acceptance of the intentional threads that tie us to the world (Merleau-Ponty, 1995 cited in Dahlberg, 2006). In contrast to Husserlian notions of reduction, we do not want to cut these ties: as a metaphorical equestrian we do not want to lose our connection with the horse. However, we want to loosen these ties, to create distance that enables a stance of "active waiting", a dwelling for the phenomenon and its meanings (Dahlberg, 2006). In practical terms, this means first a meaningful engagement with the ties that bind us to the phenomena under investigation. These ties may be multiple and complex but gaining an understanding of what these ties are becomes pertinent. In Heideggerian terms, understanding of our 'fore-conceptions' may only be realised during or *after* interpretation. Within this research process, these understandings were therefore considered as an iterative process: not a 'one off' period of reflection, but rather an ever-present scrutinizing of how intertwined, embedded and embodied my pre-understandings may be, and how they may have shaped the research process.

Concluding remarks.

Within qualitative psychological research, we have reached a stage of innovation whereby we can bring together approaches or mindsets which previously may have been considered incompatible. There are, undoubtably, tensions in bringing these methodologies together. This chapter has attempted to offer ways these tensions can be navigated. Similarly to the justifications offered by de Visser and McDonnell (2013), who used mixed methods to explore how discourses around masculine identities shaped experiences of health behaviours, being deterred by this tension would lose the benefit of a broader understanding of how discourses shape individual experience. Being a methodological purist, that is engaging with and maintaining methodolatry, can be restrictive practice: a stance that limits our potentiality for understanding through a prioritising of coherence and consistency (Chamberlain, 2000). In contrast to this, the pragmatic pluralistic framework outlined in this chapter, will inform and guide the research of this thesis in an abductive manner that is motivated by the complexity posed by the research topics.

Rather than avoid questions of epistemology and methodological incompatibility, this chapter has aimed to engage with these issues. Phenomenological concepts such as intentionality, the features of Dasein and body-subjects have been defined. Drawing on the work of Willig (2017), these concepts form the foundational basis of the phenomenological conceptualisation of pluralism. The hermeneutic writings of Gadamer and Ricœur help us to understand both the horizonal limits of our chosen methodologies, but also provide a mechanism through which Foucauldian Discourse Analysis can be applied alongside phenomenological readings as a hermeneutic of suspicion. Taking up this pragmatic pluralistic framework has implications for the types of data I will seek to include, alongside methods of analysis and reflexivity.

It is hoped that by broadening out how these phenomena can be explored, it will also allow a demonstration of what a critical approach to health psychology can contribute to topics such as welfare, traditionally the focus of sociology or social policy disciplines. A closer pairing between critical health psychology and critical social psychology may also reveal that the divides between the branches of psychological study are institutionally maintained, rather than by some ‘naturally-occurring’ difference in research endeavours. Cumulatively, I aim to apply these methodological ideas to show what might be necessary to improve health-based welfare systems for those living with chronic unseen health conditions in a holistic and meaningful way. This thesis aims to illuminate new ways of understanding and talking about those who claim welfare whilst living with chronic unseen health conditions. To return to the metaphor favoured by phenomenologists, that of language as the house of Being, we may not be able to get *outside* of the house, but could it be possible to rebuild from within?

Chapter 3. A Foucauldian-inspired discursive multimodal Media Framing Analysis of the UK's Employment and Support Allowance welfare benefit.

Introduction and background.

Having outlined the pragmatic epistemological and methodological framework of this thesis, we can now begin to explore the phenomena under investigation; namely, living with a chronic unseen health condition within the wider context of health-based welfare benefits. In the introductory chapter of this thesis I examined the mechanisms of these health-based welfare benefits: how they are administrated and how they are accessed by potential claimants. These health-based welfare policies were examined critically through the available literature. Problems of "procedural objectivity" (Porter et al., 2021) and the conditionalities of workfare (Bambra & Smith, 2010) were highlighted; as was the impact of the WCA on GP workloads (Iacobucci, 2014) and adverse trends in claimants' mental health outcomes (Barr et al., 2016). I questioned the lack of psychological research on this topic and the complex relationship between psychological theory and UK government policy. This chapters aims, in part, to readdress this lack of contribution from a critical perspective.

The introduction of ESA, accessed through the WCA, heralded the UK's shift towards health-based welfare policies that are firmly rooted in conditionality (Bambra & Smith, 2010). In order to access state support, claimants must now be 'actively' involved in labour market programmes. Failure to comply with these expectations can led to a loss of financial support, through the process of benefit sanctions. Within the UK, ESA can be thought of representing the 'end point' of a "creeping conditionality" that has come to shape many European welfare states (Dwyer, 2004; Milton et al., 2015, p. 144). Such conditionality establishes that access to welfare is dependent on individualised behavioural actions rather than an implicit part of the social contract of citizenship (Dwyer, 2004). But how is shift in consensus, from "basic social right" (Conover et al., 1991) to a contingency on the fulfilment of responsibilities, established?

Considering how welfare is spoken about, Milton et al. (2015) notes a distinction between welfare benefits that are seen as a taken-for-granted reward, owed by the state to its citizens (such as pensions, free travel), and those that are contingent on economic or needs-based conditionality. The latter are more often framed as 'benefits' and, in interview data with UK pensioners, constructed through discourses of deservingness and undeserving others (Milton et al., 2015). These findings, in part, mirror those found by Goodman and Carr (2017) whose analysis illuminated the ways in which the concept of a "just world" is complicatedly drawn upon in televised discussions about welfare claimants. In a given example, it becomes simultaneously 'just' that welfare claimants are personally responsible for their unemployment, yet it is 'unjust' that those who are employed must contribute to their upkeep (Goodman & Carr, 2017). Given that health-based welfare policies, such as ESA and PIP, would – through this lens – be perhaps discursively framed as a 'benefit' rather than a justified entitlement, it is important to consider how this discursive economy has been constituted. How are these 'common sense' views of welfare conditionality entrenched within health-based welfare benefits?

Within this chapter, I aim to critically explore discourses around contemporary UK welfare policies. Specifically, I want to explore the way in which these health-based welfare reforms have been reported within UK media; answering the research questions of what sort of cultural landscape has been made 'available' for those who live with chronic unseen health conditions whilst claiming welfare?

Methods.

Design.

Given the analytical focus on what is socially known, it was considered reasonable to include analysis of any texts that may contribute towards the constructions of what modern welfare is or the types of human subjects created by these discourses. However, within the discursive literature, there is scant guidance on how data can be systematically gathered. A key criterion for including data within a discursive data corpus is that choices should be guided by the research question, but methods papers (e.g., Goodman, 2017; Willig, 2021) are reticent to prescribe *how* data should be collected and collated. To avoid the potential critique that included data were selectively curated (for example, to present certain discursive outcomes that align with the overall aims of the project), I looked to other, more systematic, methodologies that could act as a broad framework for secondary analysis of this type of data. To that end, a Media Framing Analysis (MFA; Giles & Shaw, 2009) combined with PRISMA reporting guidelines was developed and conducted. The MFA aimed to look at how the UK's employment and support allowance (ESA) was initially introduced and subsequently reformed.

Media Framing Analysis.

MFA is a procedure for conducting analyses primarily of news media texts. MFA draws on elements of existing framing research from communication exploration alongside an incorporation of features relevant to psychology, such as narrative and characterisation (Giles & Shaw, 2009). The first stage of a MFA is to identify a screening process. The novel approach taken within this analysis is detailed below. The second stage of a MFA is to identify specific units of time that could be regarded as the source or origin of a story. Known as ‘news pegs’, these can be specific incidences on which the search strategy can focus (Giles & Shaw, 2009). News pegs can be multiple, enabling the analysis to capture a news story as it ‘evolves’ or to consider a topic from a longitudinal perspective. The analysis presented here is shaped by three news pegs.

This first news peg revolves around the reporting of the introduction of the Work Capability Assessment (WCA), as part of wider welfare reforms by the then Labour government via the green paper “No one written off: reforming welfare to reward responsibility” (published 21st of July 2008). This second news peg considers how, in 2010, the then recently formed Conservative and Liberal Democrat coalition government sought to broaden the scope of the WCA. Further reforms aimed to ‘reassess’ all two million recipients of Incapacity Benefit, placing these claimants into the Employment and Support Allowance (ESA) system. For the third news peg I considered further reforms proposed by the Conservative Party government in September of 2016 which suggested removing reassessments for individuals living with chronic illness. However, within this data set, the intended news peg was ‘overshadowed’ by discussions around a fictional portrayal of an ESA claimant. Ken Loach’s *I, Daniel Blake*, which tells the story of the titular character’s battle through the ESA process, was released in October 2016. It was identified as a significant discursive object and as such, I made the decision to shift analytical focus to consider the counter-discourses presented within the film. Details on the analysis of the film are given in the below section.

An important feature of a MFA is the identification of key individuals, those figures who recur frequently in the data set. Within the analysis, key characters were noted throughout. In the presentation of the analysis these characters, and the salient aspects of their inclusion, are identified within a table prior to the analysis of each news peg. A MFA also asks the analyst to consider who the audience is and who they are invited to identify with. The developed search strategies sought to include *all* UK newspapers, from broadsheets to tabloids, rather than excluding papers with particular ideological perspectives. As such, cumulatively, the audience was considered to be – potentially – representative of a broad section of society.

Data sources and search strategy.

To further illuminate and systematize what data were included in the MFA, we adopted the PRISMA reporting guidelines (Liberati et al., 2009), traditionally used in the process of systematic reviews, as a screening procedure. Searches for UK news media articles around the three news pegs (time periods significant in the history of ESA) were done via LexisNexis databases. The search terms used were "employment support allowance" or "ESA" or "work capability assessment" or "WCA" or "welfare". The search parameters included all UK newspapers that contained any of the search terms in any of their text. Custom date ranges were used; a monthly window 'after' each defined news peg (e.g. 14 July 2008 to 14 August 2008).

Screening procedure.

All search results were screened for inclusion within the data corpus. In order to be eligible for inclusion, news articles needed to focus on ESA welfare policy from UK based newspapers. These could be in the form of news reports but also commentaries on policy reform. Following the identification of duplicate articles, headlines were screened for relevancy. A large number of articles were removed at this stage. Remaining articles were then read for eligibility. Reasons for exclusions of articles read for eligibility were recorded and included within PRISMA flow diagrams (one per news peg; see figures 3.1 and 3.3).

Additional records.

The PRISMA process enabled the inclusion of 'additional records'; material relevant to the research question, but that may be unobtainable through the developed search strategy. Relevant documents, referred to within the screened data, were identified and included within the analysis. Information on what these documents were is addressed within the introduction of each news peg's analysis.

Referencing.

In order to improve readability of the analysis, a deviation from discipline norms was needed. A significant number of news articles failed to state who the text's author was. Rather than ‘clutter’ the analytical write-up with lengthy (and overlapping, as years of publication are all the same) in-text citations, each quoted source from the data corpus was allocated a superscript number. Two tables at the end of this chapter link texts cited to those text citations. These tables (3.4 and 3.5) also provide information on the newspaper/publisher, the date of publication, author(s) (if stated), the document type and the article’s headline or title.

Analysis.

Crucially, MFA does not tie us to a specific analytic or conceptual epistemology: MFA was used to guide and structure the identification and collation of data, but I selected the method of qualitative analysis based on what was appropriate to answer the research questions. As the initial research question looks at the effects of language; Foucauldian Discourse Analysis (FDA) was selected as our method of analysis. FDA enables a tracing of the genealogy of ideas – how things we consider to be common-sense, or knowledge, come to be (Willig, 2021). Foucauldian Discourse Analysis enables us to examine the productive nature of these knowledges through practices of subjectification and action. How are the contemporary social and psychological lives of welfare claimants produced (Willig, 2021)?

Analysis of a film.

Coincidentally (or perhaps not) within the third of the news pegs initially covered within the MFA, Ken Loach’s film *I, Daniel Blake* was released. *I, Daniel Blake* tells the story of a widowed carpenter’s journey through the ESA system. Dan befriends Katie and her children Dylan and Daisy; a family who have been relocated to Newcastle-upon-Tyne from London due to a lack of available council houses. Through the experiences of these main characters the audience explores the consequences of modern approaches to welfare: Jobcentre sanctions are received and bustling food banks become relied upon. Within the MFA’s data corpus, *I, Daniel Blake* became a significant discursive object: regularly used as a ‘shortcut’ to combat dominant narratives around welfare claimants. I felt it important to ‘spotlight’ the film within the MFA, albeit with a slightly more specific research question: what discursive implications did the popularity of *I, Daniel Blake* have for ‘real life’ ESA claimants?

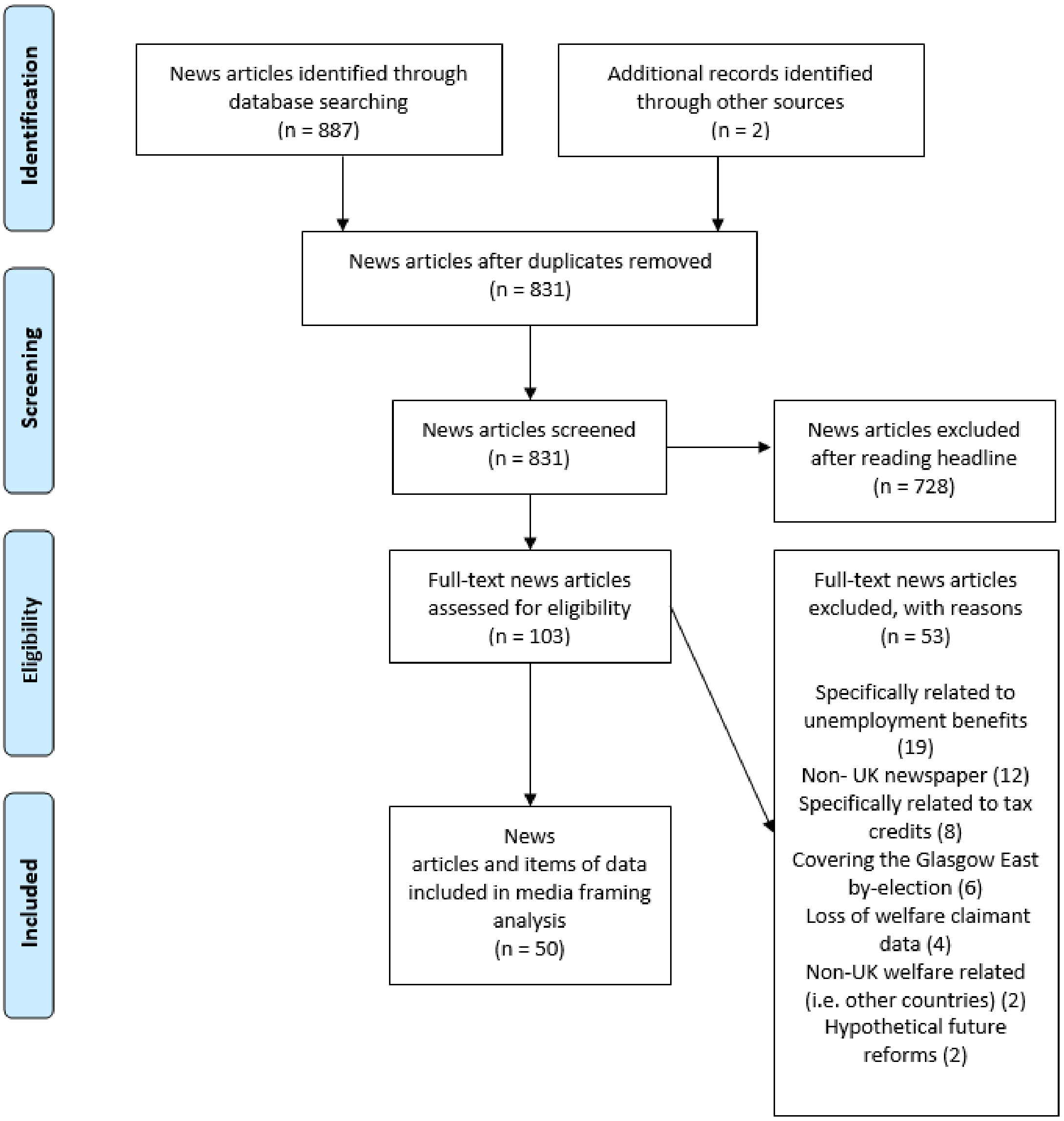
Despite the innovations imagined by Ian Parker and the Bolton Network (1999), film has remained an underexplored data source for discourse analysts in psychology. As suggested by Durmaz (1999), this may be due to the difficulties of *presenting* the data: unlike drawings or a painting, it is not possible to put ‘the text’ (i.e. a film) on a page. Discourse analysis’ focus on more traditional sites of meaning, such as interviews or "naturalistic data sets", have done much to 'establish' qualitative research as a rigorous method within the discipline of psychology. Perhaps, were discursive approaches to routinely include film and less 'accepted' media as data, this would have been perceived as a 'step too far' for the psychology departments of the 1990s as an embarrassing hindrance in their battles for a place within the scientific hierarchy.

However discourse, under Foucauldian terms, is understood as social knowledge (Willig, 2021). As such, we thought it reasonable to include analysis of any texts that may contribute towards the constructions of what is socially 'known'. We were encouraged by the sense of opportunity and potential present in modern qualitative psychology research, particularly emboldened by the inclusions of radio (Carr et al., 2018) and televised debates (Goodman & Carr, 2017) as data, we began to consider how to approach *I, Daniel Blake* as a text. A concentration solely on the language spoken in a film seems to wilfully disregard the production choices made in the creation of a film; a decision that would make for an easier, but incomplete, analysis. Instead we drew upon a method of multimodal discourse analysis (MMDA; Kress, 2011). In MMDA the materially diverse textual 'threads' (gesture, speech, image, music) are brought together into one textual/semiotic whole. This drawing together is conceptualised as a 'weaving' of threads, implying a weaver who provides a sense of coherence to the text. Within the production of a film the weavers would be many. For *I, Daniel Blake*, we consider our primary weavers as being director Ken Loach and screenwriter Paul Laverty. In order to add further structure to our foray into film analysis, we drew upon the design aspects of mise-en-scène to assist in an identification of salient visual choices and modifications of space (Monaco, 2009). Lighting, composition, acting, set design and filmstock were all examined for discursive meaning, enabling us to weave together a new text: this analysis.

Findings.

First news peg.

Figure 3.1. *PRISMA diagram showing the different phases of the systematic reviewing of the first news pegs material.*



Following the search strategy described within the methods section and detailed in Figure 3.1, the first data corpus consists of 48 articles published in UK national and regional newspapers over a month-long news peg (14th of July 2008 to 14th of August 2008). This first news peg revolves around the reporting of the introduction of the Work Capability

Assessment (WCA), as part of wider welfare reforms by the then Labour government via the green paper "No one written off: reforming welfare to reward responsibility" (published 21st of July 2008). Many of the included news articles referred to the published policy documents. As these documents provided useful context to the news articles, both the green paper (a consultation documents produced by the Government) and the press release issued by the Department for Work and Pensions (DWP) were identified as relevant additional items for inclusion within the analysis (shown in figure 3.1). As such the total number of records included within the analysis was 50. Four main discursive constructions were identified and are discussed at length below: constructions of illness and disability; expectations and responsibilities; a discourse of 'reform' and consensus, and preconstructed opposition.

Cultural context.

The notion of 'context' is a key differentiating factor in approaches to discourse analysis (Delprete & Tarpey 2018). Given the macro, Foucauldian approach taken by this analysis, it is important that we first briefly explore the wider cultural context in which these reforms were proposed, and the included data collected from.

In July 2008, the UK was in the midst of what has since been termed the "great recession" (Rich, 2013). As a result of the 2007-2008 financial crisis, the UK experienced the deepest recession since the Second World War. Northern Rock, one of the country's top five mortgage lenders, had been nationalised four months previously and the impact of recession would make a prolonged impact on the country's economic growth. Gordon Brown had served a year in office as prime minister and leader of the Labour party following his succession from Tony Blair in June 2007.

Characters.

Table 3.1. *Key individuals (and events) identified from the first news peg.*

Character	Biography (as of the time of the news peg)
James Purnell	Secretary of State for Work and Pensions between January 2008 and June 2009. Touted as "future Labour leader" (Daily Mail, 2008[5]).
Chris Grayling	Shadow Work and Pensions Secretary (Conservative Party)
Gordon Brown	Prime Minister (Labour government)
David Cameron	Leader of the opposition (Conservative Party)
Polly Toynbee	Columnist at The Guardian
Jeremy Corbyn	Labour backbench MP for Islington North
Glasgow East by-election	Held on 24th of July 2008, 3rd safest Labour seat in Scotland. Positioned as referendum on the proposed welfare reforms and the Brown Labour government. Won by the Scottish National Party with a 22.5% swing from Labour.

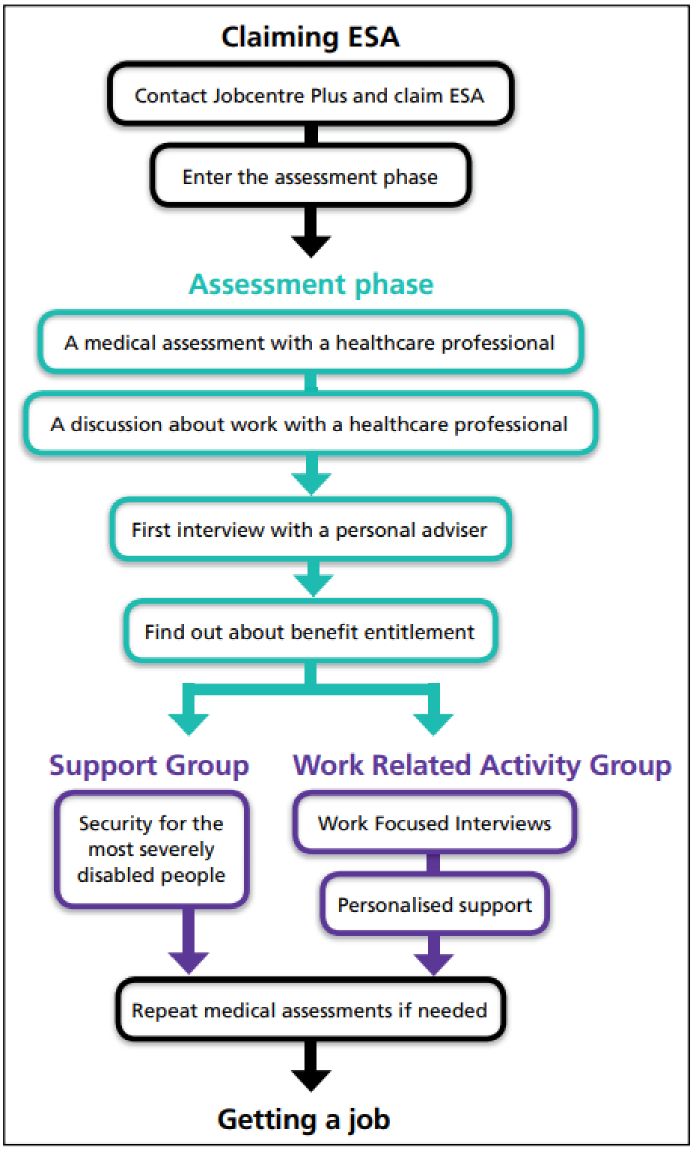
Constructions of illness and disability.

Throughout the corpus of data illness and disability are constructed in definitive terms. Within the green paper, employment and support allowance (ESA) is definitively portrayed as a "temporary benefit for the majority" (DWP, 2008[25]). The green paper proposes that:

> *Many people leave benefit during the first three months of a claim because they have recovered or adapted to their illness or disability*
> *DWP (2008[25]).*

In order for the benefit to be a temporary benefit, illness and disability themselves must also become temporal states, experiences that will be overcome. Within this discourse, health becomes an obtainable, tangible goal. Through the deployment of appropriate support and resources illness can be timetabled, regimented and predicted: a return to employment as an inevitable conclusion. This is perhaps best illustrated by the included diagram (figure 3.2) which illustrates the "ESA customer's journey" with all paths leading to "getting a job".

Figure 3.2. *Claimants' ESA journey as proposed by the "No one written off" green paper (DWP, 2008*[25]*).*



What subject positions are made available for individuals whose experiences fall outside of this discourse? In terms of welfare, discussions of those that could, or would be, 'genuine' claimants are left implicit and thoroughly unexplored by the data. Extreme case exceptions to the proposed journey are offered to those "badly crippled by disability" (The Sun, 2008[1]); "incapable of doing anything" (The Daily Telegraph, 2008[2]); "the most severely disabled" (DWP, 2008[25]) or "with severe disabilities" (Daily Mail, 2008[3]). These conceptualisations categorise illness and disability firmly within the biomedical model of health: health is either present or absent. Linking health with welfare, the presence of health becomes synonymous with capability, specifically a capability to work and the need to gain employment. Those who subjectively experience health or illness in ways different to these constructions are limited to a small number of available actions: to become “subject[ed] to the ESA regime” (DWP, 2008[25]), move on to jobseeker’s allowance (understood as an admission of health) or finding suitable employment.

In a further demonstration of a commitment to the medical model of health, the green paper firmly separates mental health out from other conditions and disabilities. This dualism allows a further reductive categorising of health, a separation of physical health and mental health. In this distinction, the DWP is able to compartmentalise mental health as its own distinct ‘problem’, one that has traditionally been less responsive to return to work schemes. The green paper suggests the need for a separate strategy to respond to the “employment changes faced by people with mental health conditions” (DWP, 2008[25]); a shifting of responsibility away from the reforms of welfare. However, ESA does take into account ‘mental functionality’, and it is probable that individuals claiming would have a comorbidity of conditions (for example, not just physical in classification) and experiences. As such, talk of individuals’ worlds, within the context of welfare, may become restricted in practice.

Through a focussing on illegal drug use and work “sickies", media constructions of illness both introduce a discourse of ‘choice’ and compound constructions of temporarily. Talk of “Sicknote Britain” (Daily Star, 2008[4]) and “sicknote culture” (Daily Mail, 2008[5]) lead or permeate through many of the newspaper articles reporting the proposed reforms. This is despite the relatively small focus on drug users and work sicknotes within the green paper.

> *Heroin and crack cocaine addicts will be forced to seek treatment or lose their benefits […] under the most radical reform of the welfare state in more than 60 years.*
> *The Independent (2008)*

In this example, the premise that drug users should be forced to engage with treatments in order to receive benefits ‘frames’ all subsequent reporting of the reforms. Single mothers, drug addicts, the long-term unemployed and those “unable to work” are all spoken of collectively (The Independent, 2008[6]). This ‘muddying’ of different types of welfare claimants has the effect of creeping dehumanisation. If all ‘types’ of welfare claimants can be collected together and successfully ‘othered’, the need for reform becomes unavoidable. To oppose the treatment of one group would be to oppose the reforms as a whole. As we shall explore further when looking at the discourse of consensus, this minimises the availability of positions for opposition.

With illness and disability constructed as a temporal experience, the solution of the proposed problem becomes issues of accessibility and resources. Previous welfare systems are constructed as dangerous: systems that have abandoned and actively discourage people from looking for work (DWP, 2008[25]). Those unable to work are offered the position of victim, an absolution for circumstances that were not entirely their own fault. In response, the proposed reforms enable an assumption that barriers to work caused by health difficulties can be overcome by a supportive and 'active' welfare state.

Support is spoken of often within the Green Paper, usually deployed as a balancing 'carrot' to the implicit 'stick' of responsibility. However what support may include is not fully explored. Rather 'support' becomes an uncommitted term, constructed as a potential future solution: "supporting claimants to better manage their medical condition" (DWP, 2008), but rooted firmly as part of a pathway to work and *not* as support or care from the National Health Service (NHS), or any other agency of support such as charities, family, etc.

Work itself becomes a form of treatment: a way in which employment can empower through a "reaching of potentiality" (DWP, 2008[25]). However individuals' potential is constructed in purely economic terms: potentiality remains unfulfilled if an individual remains unemployed. Similarly, discussions of workplace equality are evoked within the context of support, rather than the rights one may assume them to be. Here 'empowerment' becomes a cursory term used specifically to highlight the importance of employment for those living with illness or disability. This construction allows the reform to appear progressive whilst actually *limiting* practices available for the individuals it will affect: namely that only through employment can you become empowered.

In contrast, individuals that do not work are chastised for "slowing down" the economy (Daily Mail, 2008[7]); constructed as "people who get all the benefits of our society, but put nothing back" (The Independent, 2008[8]). Taking these constructions together, we see the individual reduced to a commodity, a purely economic reading of the individual: what contributions can they make to the economy. If no contributions can be made, the individual is positioned as a drain on the economy, which allows, or even normalises, a justification for the previously identified process of othering.

It is through these constructions, and the positions that they offer, we are able to consider the implicit reasons for these reforms being introduced at this period in time. Scattered through the data corpus there are references to the late 2000s financial crisis and subsequent recession being experienced by the country as these reforms were presented. However, when the recession is spoken of, it as a potential barrier for the implementation of these reforms, never a reason *for* these reforms:

> *Getting people off benefit and into work will be much harder now than it would have a few years ago when the economy was booming*
> *The Daily Telegraph (2008)*

But beyond the bottom-line argument of the Prime Minister's foreword to the green paper ("And in a globalised world, we simply cannot afford the high price of large numbers of people on benefits", DWP, 2008[25]), little consideration is paid to why these reforms are *needed* now. Instead, the truth presented is one of support and responsibility; the individual empowered through making contributions to the country's economy, a focus on this process of empowerment and being freed from a previously dangerous welfare system and not the economic outcome (increased employment and reduction of welfare costs).

Expectations and responsibilities.

Building upon these constructions of illness and commodification, a discourse of responsibility becomes the method by which the reforms exercise power. Having constructed illness and disability as temporary, against the background of the individual defined through their economic contribution, a discourse of responsibility allows a cultural policing of those claiming ESA benefits. The very title of the green paper introduces this concept of responsibility:

> *No one written off: reforming welfare to reward responsibility*
> *DWP (2008[25]).*

Rather than 'handouts', benefits become a commodity in which access is gained through a 'meeting of' responsibilities. Like the customer journey in figure 3.3, all responsibilities relate and lead to finding employment. Writing in The Guardian (2008[9]), James Purnell talks of responsibility in solely individualistic terms: that the attempts of previous Labour policies to “help the poor” neglected the need for “individual responsibility” (The Guardian, 2008[9]). Instead, individuals must instead bear responsibility for their actions and circumstances. Implicit here is an absence of *state* responsibility; a neoliberal reaffirming that circumstances such as illness, poverty or unemployment are matters for the individual (Galvin, 2002).

This notion of individual responsibility is filtered through collectivist language, whereby those who are claimants should be subjected to expectations: an active reinforcement of their responsibilities. Here public opinion, driven by expectations constructed from responsibilities, becomes an indiscriminate tool for maintaining subjective positions. As James Purnell explains:

> *This is already working […] because the government wants to use the collective power of our citizens to galvanise individual responsibility*
> *The Guardian (2008[9]).*

Individual responsibility becomes a construct that can be enforced by power. Power is constructed as embedded within citizenship alongside a further othering of those claiming benefits (who are instead defined as ‘disabled people’ or ‘the unemployed’ rather than included within the discourse of citizenship). Through this signifying practice the concept of “reasonableness” allows citizens (those of the population who have not been othered) to participate in these power dynamics:

> *It is perfectly reasonable to expect those looking for a job, and receiving benefits to do a month’s community work after a year, and do full-time voluntary work after two years if they have not found a job. Those receiving incapacity benefit should have to prove they are incapable of any work.*
> *The Independent (2008[15]).*

To go against what is reasonable would be potentially illogical, perhaps even at the risk of removing yourself from the position of ‘citizen’. Discursive constructions of citizens, who are defined foremost through their taxpaying status before being collectively linked through a sense of patriotic duty to other citizens, expect a reaction of relief to these reforms:

> *His [James Purnell’s] assertion that a life on benefits should no longer be an option for those able to work will be welcomed by most taxpayers*
> *The Daily Telegraph (2008[2])*

Within these different ways of problematizing welfare, an opening up of a larger array of potential positions of support occurs. A concurrent construction of welfare as an issue of morality allows non-claimants to take a position of care and concern whilst remaining within the reform-welcoming citizen discourse. Writing in The Independent journalist Johann Hari appeals to a suppression of "your gut reaction" to the proposed reforms (The Independent, 2008[8]). His own experiences of a welfare system, growing up in Glasgow East, which leaves people "in a rut", trapping those into a life of "lost potential", who "shrug with heartbreaking indifference" constructs an appeal for reform that is distinct from government rhetoric and rooted in authenticity.

Other constructions escalate the moral emphasis towards that of a holy war. Reform is conceptualised as a "crusade" (Mail on Sunday, 2008[10]). War is declared on "sicknote Britain" (Daily Star. 2008[4]); a "welfare blitz" awaits those impervious to shame (Mail on Sunday, 2008[11]). A metaphorical physicality appears: "giving it [the reform] muscle" (The Daily Telegraph, 2008[12]) whilst benefits will be "stripped" (Mail on Sunday[11]; Daily Mail[13], 2008). Within the construction of a moral crusade, these actions and our high expectations become a necessary motivation.

A consequence of these power infused expectations is an erosion of privacy, and right to a private life, for those who do claim. Due to the moral need for individuals to prove their incapacity, they must become "subject[ed] to the ESA regime" (DWP, 2008[25]). With clear links with previous moral constructs of welfare, the regime here is a militaristic show of force. In a demonstration of individual responsibility, the onus is on the claimant to "undergo a stringent medical examination [the WCA]" (Daily Mail, 2008[13]). The assumption of illness temporality justifies a continual process of reassessment until some capability is found (The Times, 2008[14]). A series of binaries becomes constructed: one can be wholly well or wholly ill. If individuals are wholly well, they are capable of work. Incapacity is only possible through a state of complete ill-health. For the claimant this closes down experiences of health in practice: that subjective experiences of health should be confessed within an assumption of capability.

Discourse of "reform".

The nature of the reform is constructed in changing, at times almost paradoxical terms. From James Purnell's ministerial foreword to the green paper onwards, reforms are positioned as either ‘revolutionary’ or a ‘return’ to the ethos of the 1942 Beveridge report which founded the welfare state in the United Kingdom. This disparity between one construction, the revolutionary, which would entail a complete, possibly disruptive, change for those individuals currently claiming Incapacity Benefit and a compassionate ‘return’ allows an ambiguity which can be explored through different action orientations. Within a revolutionary discourse, against the backdrop of economic turbulence, the government is able to present reform as a “tough” innovation. Whilst appeals to a return suggest an approach that is rooted in historical consistency and aligned with the true intentions of the Beveridge report.

For example, in a comment article titled “A welcome return to the principles of Beveridge” published in The Independent (2008[15]) the day after the green paper was formally announced, reform is constructed firmly as a discourse of return:

> *It may be politicians’ hype to describe this as the biggest shake-up of the modern welfare state since the Beveridge report of 1942, but it restores an important principle of that settlement. One of its key principles was that the welfare state should not stifle incentive, opportunity and responsibility.*

Here the return discourse extends towards a restorative orientation. Pre-empting any dismissals that may arise in response to the “hype”, we are presented with a re-reading of the 1942 report: a re-focussing on key principles that have been overlooked by both recent policies and public opinion.

Writing in the Mail on Sunday (2008[16]) the day prior to the publication of the green paper, James Purnell constructs reform as both restorative, a resetting of a system that would “simply not be understood” by its founding government, *and* radical:

> *There may be some who think this is a radical step from a Labour Government. But there is nothing Left-wing about sentencing people to a life on benefits or expecting everyone else to pick up the bill for people who simply don’t want to work.*

Any inconsistency in these constructions can be mediated by the distanced stance rhetorically taken by Purnell: he himself is not suggesting that these reforms are radical, however they may appear radical to others. However, the effect of this distancing is diminished when considering the opening line of the DWP issued press release which defines the proposals as “a radical overhaul of the welfare state” (DWP, 2008[26]).

When considering these differing constructions of the reform, it is hard to overlook the *intentionality* of the discourses in action. What function do these different constructions serve? We, the citizen reader – who is not the “other” – are being sold a programme of reform. With regards to responsibility, and the cultural expectations that enforce these responsibilities, the general public ‘buying’ the reform is an essential act. We are those being afforded the power from government to intersubjectively communicate these expectations. As such, the appeals to either revolution or return serve a significant function: they allow the possibility of an individual to take up a stance of support regardless of their position on the political spectrum. For those on the left, a purposeful return is to the original intentions of welfare. Whilst for individuals on the right ‘revolution’ can address the ‘problems’ of welfare in a fundamental and transformative manner.

Consensus and preconstructed opposition.

Green papers are “consultation documents” produced by the government, with the aim of allowing those within and outside of parliament to provide feedback on proposed policies (Parliament, 2010). However, this definition is not embodied by the “No one left behind” document. Instead the importance of and need for reform become taken-for-granted, and transcend political tribalism. The “radical” proposals “thrilled” David Cameron (The Guardian, 2008[17]) and this consensus reaches the print media, with newspapers accepting the argument regardless of their usual political leaning.

Despite this widespread consensus, opposition “from the left” becomes anticipated and pre-emptively constructed. News reports set out characterising the positions that these counter discourses may take:

> *But the government faces a challenge from some of its own backbench MPs over the radical measures which seek to stop individuals spending a “life on benefits”.*
> *The Guardian (2008[18])*

Here resistance becomes equated to a condoning of a life on benefits. The various different problematisations of welfare all reinforce the need for reform; opposition by its mere appearance is constructed as regressive (“which would take Britain back to the 1970s”, The Sun, 2008[19]). As in the discourse of restorative reform, specific time points in the UK’s history become signifiers of media templates (Kitzinger, 2000), key events which offer explanatory power to new events. “The 1970s” here used to negatively reconnect the reader to times of high unemployment and economic stagnation.

Concerns around budgeting and the cost of implementing these reforms are pre-emptively explored through the implicit treatment of welfare administration as a ‘business’. This construction allows us to address concerns about how such systems could be established in a period of recession, whilst also drawing upon the ‘innovations’ of the private sector. The country’s budget is constructed through the simplistic metaphor of a household budget (The Daily Telegraph, 2008[20]). Reform is the only available action of investment, with future positive outcomes ensured for the country (The Independent, 2008[20]). Private firms are “called up” (Daily Mail, 2008[13]) to bid to provide services, evoking a sense of patriotic duty to a government strongly skilled in business negotiation. The process of outsourcing democratically obtained power allows for a further disruption of individuals’ experiences of illness and disability: private service providers would now have a greater say in deciding and defining individuals’ capability for work, over and above the decisions of doctors.

Opposition is always expected to appear from “backbench Labour MPs” (The Guardian, 2008[18]). Despite the minimisation of these responses (the ‘backbench’ discursively symbolising an insignificance and distance from any position of power) and from within the position of political consensus, James Purnell is praised for being “quite brave” for introducing such reforms (The Guardian, 2008[21]). The reason for this bravery is the Glasgow East by-election which in some reports becomes a referendum on the proposed reforms. In doing so, the electorate of Glasgow East, of which many are constructed as being “reliant on state handouts” (Daily Mail, 2008[5]) are put on moral trial: either able to accept the “lifelines” of workfare and ESA, proving themselves to be “the salt of the earth” or an admission of a culture unwelcoming to reform, instead continuing with:

> *Creative accounting for maximum benefit accrual […] having enough dosh to follow Celtic football club with all the expenses that involves – particularly for matches played abroad.*
> *Daily Mail (2008[22]).*

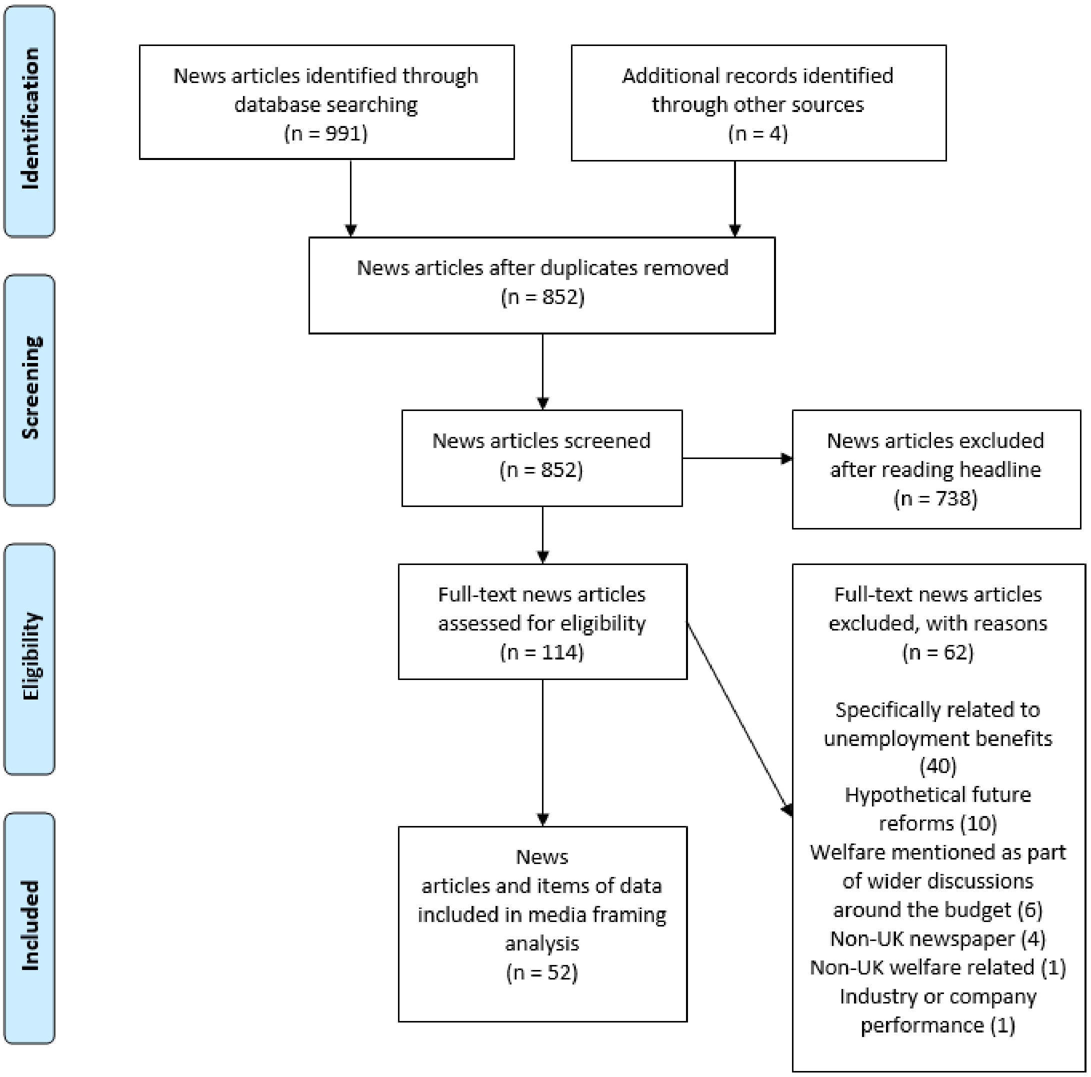
However, the first critiques do not come from the left, but rather appear from the right. Constructions of political distance between the two main parties first focus on ownership, with Chris Grayling, the shadow Work and Pensions minister, claiming the plans were a "straight lift" of those previously proposed by the Conservative party (Daily Mail, 2008[13]). A second wave of criticisms suggests that reforms should go further: that tests of capability, such as the WCA, will always be able to be cheated by "highly talented code breaking claimants" intent on "monkeying around" (The Times, 2008[23]). In this construction of the welfare claimant we see a nefarious juxtaposition; a highly talented individual wilfully wasting their potential. Such an extreme case formation is deployed as justification for more punitive measures.

The Wisconsin Works system is jointly constructed as being a beacon of individual responsibility and potential model for future, truly "radical" reforms. The American state Wisconsin introduced the Wisconsin Works welfare reform in the 1990s. Claimants were able to claim welfare for two years in one stretch, or five years across their life. After that, further state support became unavailable. Wisconsin Works is presented as an unequivocal economic success due to the reduction in benefit costs (Daily Mail, 2008[5]). Conversely the system is also used as justification from the left for accepting the green paper proposed reforms: Wisconsin Works is perceived as an example of how "brutal" reform under David Cameron would be (The Independent, 2008[8]). Here the consensus and limited alternatives (which seek to extend rather than retreat) limited further opposition in practice.

When counter discourses from the left do appear, relatively small in media coverage, they make use of the previously mentioned media templates to take a position of opposition to the construction of individual responsibility. Jeremy Corbyn constructs the reform as going "even further than Thatcher" (the 1980s here symbolic of social diversion through individualism) and, challenging the restorative reform discourse, one that bears no "resemblance to the principles of the Labour Party" (Morning Star, 2008[24]). Political consensus becomes a queasy "chumminess" rather than an example of necessity. Corbyn attempts to 'rehumanise' the construction of a welfare claimant through removing of the individual responsibility discourse and presenting a counter discourse of "cycle[s] of poverty and deprivation" (Morning Star, 2008[24]). Attempting to slip the already disempowered characterisation of 'Labour backbench MP', and operating within the implicit reasons for reform (i.e. the recession), Corbyn points to a column written by Polly Toynbee ("by no means on the left of the Labour Party", Morning Star, 2008[24]) for an alternative solution: would these reforms be necessary if "tax loopholes on foreign earnings" were closed (Morning Star, 2008[24])? These counter discourses illustrate well Foucault's conceptualisation of resistance (1980); resistance as never external to power, alongside the need for multiple points of resistance.

Second news peg.

Figure 3.3. *PRISMA diagram showing the different phases of the systematic reviewing of the second news pegs material.*



This second news peg considers how, in 2010, the then recently formed Conservative and Liberal Democrat coalition government sought to broaden the scope of the Work Capability Assessment (WCA). Further reforms aimed to 'reassess' all two million recipients of Incapacity Benefit, placing these claimants into the Employment and Support Allowance

(ESA) system. The search strategy described within the chapter's methods section identified 48 articles published in UK national and regional newspapers over a month-long period (13th of May 2010 to 13th of June 2010) in which this news peg 'occurred'.

In addition to the found articles, four items were identified as relevant to the focus of the analytical enquiry and, as such, were included as data (see Figure 3.3). Published on May 20th, "The Coalition: our programme for government" gave an overview of the policies that had formed the basis of the coalition government's agreement to govern which included a focus on welfare reform. These policies were subsequently outlined by Queen Elizabeth II during the state opening of parliament on May 25th 2010. A press release, detailing the specifics of the proposed Welfare Reform Bill (introduced within the Queen's speech) followed, preceding the opening of parliament. On 27th May 2010 the Rt Hon Iain Duncan Smith delivered his first speech as Secretary of State for Work and Pensions: the published version of this speech, the programme for government, the Queen's speech and Welfare Reform Bill press releases are included within this data corpus. Through these records, we see how the coalition government 'sets the agenda' for welfare reform; in some examples, building upon the discourses examined in the previous news peg, whilst other constructions seemingly seek to modify knowledge about welfare and welfare claimants.

Cultural context.

In January 2010 UK unemployment levels had decreased by 7,000 to 2.46 million, the first monthly fall in two years (BBC News, 2010). Statistically no longer in a period of recession, economic issues nonetheless dominated voter concerns: respondents of the British Election Study rating "the economy" (41%); "government debt" (11%) and "unemployment" (7%) as amongst the most important election issues (Dunleavy, 2012). The general election took place on 6th May 2010, with campaigning focusing on the economy, the deficit, parliamentary reform and immigration. For the first time since February 1974 no single party achieved the 326 seats required for a parliamentary majority (Thompson, 2010). After five days of talks, and following the resignation of Prime Minister Gordon Brown, the Conservative-Liberal Democrat coalition took office, marking the end of 13 years of Labour governance.

<u>*Characters*</u>.

Table 3.2. *Key individuals, events and organisations identified from second news peg.*

Character	Biography (as of the time of the news peg)
"The Coalition"	The first full UK coalition government since the Second World War. Formed following the outcome of the 2010 general election (a hung parliament), consisting of the first and third parties in terms of votes and seats won (the Conservatives and the Liberal Democrats respectively).
Iain Duncan Smith (IDS)	Appointed as Secretary of State for Work and Pensions (DWP). Former leader of the Conservative Party from September 2001 to October 2003.
Danny Alexander	One of five Liberal Democrat MPs to serve in the Coalition cabinet; initially for two weeks as Secretary of State for Scotland before taking the role of Chief Secretary to the Treasury.
David Cameron	Prime Minister, leader of the Conservative Party.
Nick Clegg	Deputy Prime Minster, leader of the Liberal Democrats.
Anne Begg	Labour MP for Aberdeen South.

The spreading scope of individual responsibility: worklessness and the deficit.

Throughout the data corpus, both implicitly and explicitly, is the 'problem' of government debt. Continuing the electoral campaign themes of how best to mend the UK's economy following the 2007-2009 'great recession', the 'structural deficit' becomes a construct in relation to which *all things* are structured and understood. As this analysis will show, economic concepts both undefined and ill-defined are frequently deployed, seemingly to constrain and close down potential experiences at macro and micro levels. Instead of being presented as a solvable problem, the problematising construction of government debt is used to 'set the agenda' for welfare reform; reforms that are grounded in stark economic constructions which appear commensurate to the electorate's concerns.

Writing in the foreword of "The Coalition: our programme for government", David Cameron and Nick Clegg characterise their approach to "tackling the deficit" as:

> *We both want to build a new economy from the rubble of the old.*
> *HM Government (2010[1])*

Here the economy is constructed as collapsed, broken beyond repair in its current form. However, the focus is on the fertility of these “ruins”: the emphasis shifts to growth (which is “essential for our future”; HM Government, 2010[1]), on how an economy can be rebuilt, rather than examining the causes for the collapse.

Just as analysis of the deficit construction will be ever-present through this write-up, so does the deficit “loom” throughout the data. In conceptualising the deficit as “looming” (The Guardian, 2010[2]) a sense of presence, almost omniscient, is created. The looming deficit becomes a physical entity which has an effect on all policies and overshadows the mood of the country. The sense of rebuilding, in response to the “monstrous deficit the coalition has inherited” (The Telegraph, 2010[3]), allows an urgency for reform: necessitating action orientations of policies which will reduce the deficit.

With the pressing need for reform established, welfare policy reform is positioned as humane and morally ‘correct’. Within these constructions the previously explicit reasons for reform (to “tackle the deficit”; HM Government, 2010[1]) become backgrounded; the emphasis instead on extending notions of individual responsibility. An example of how this is done can be seen through examining the introduction of the neologism ‘worklessness’. The term itself seems to have been first coined by work psychologists aiming to understand the detachment from the formal labour market experienced by particular socioeconomic groups in particular geographical areas as part of research commissioned by the Department for Work and Pensions (Ritchie et al., 2005). However, when used within our current data set, it is done so without an accompanying definition; initially appearing in Iain Duncan Smith’s (IDS) first speech as DWP’s Secretary of State, before being unexamined by the reporting media:

> *The team refined the work into five pathways to poverty – family breakdown, educational failure, addiction, debt, and the fifth, worklessness and economic dependency.*
> *Department for Work and Pensions (2010[4])*

> *IDS identified these causes today as including educational failure, family breakdown, debt, addiction and worklessness. He is quite right. The Tories should be brave and abandon Labour's failed "sticking plaster" approach.*
> *The Telegraph (2010[3])*

In presenting an ambiguous concept in such definitive terms (as a *pathway* to poverty nonetheless) the speech act itself becomes a demonstration of power. To question, or examine the positions made available by such a construction would go some way to reveal the potential intentions behind the use of the term. Such a critical approach is not taken by the reporting press who, as we see from the accompanying extract, accept the term and seemingly call for comprehensive action based on its validity.

Creating a notion of worklessness distinguishes between unemployment and a choice *not* to work. In practice, doing so becomes an act of apportioning and limiting blame. The discourse of 'unemployment' traditionally is within the remit of governmental bodies: employment rates are measured, organised and compared by the state. Economic policies are underpinned and informed by employment theories, which in turn signify commitments to wider, distinct economic systems (for example the 1981 budget of Margaret Thatcher's Conservative government represented a break with the Keynesian theories of employment which had become post-war consensus [Bean & Symons, 1989]). Inherent within these discourses of economic policy is accountability: that governments' policies can and will affect the employment status of individuals. Much of the embodied distress felt by individuals during the 2007-2009 recession was a result of job loss and the slow recovery of the labour market (Sherman, 2013). Constructing a concept of worklessness allows the state to drastically minimise its role within these outcomes. Instead, the worklessness discourse requires that jobs *are* available (suggesting an economy that is 'on the mend'); and that rather, behind unemployment figures lies an element of *individual* choice.

Growing out from this construction of worklessness, whereby welfare claimants appear to have *chosen* their othering via an opting out of employment, we see a notion of individual responsibility stretched beyond 'the individual'. Instead consequences take on a generational aspect.

> *How […] can it be right for generations in families to live and die without ever holding down a regular job?*
> *Department for Work and Pensions (2010[4])*

Poverty and worklessness are both constructed as inherited problems. The inequalities of one generation become passed to the next. However, because of the concurrent construction of "worklessness", the element of choice, allows blame to be apportioned. In contrast, and in an example of how blame can be constructed differently, local news reports of confidential WCA outcomes being posted to the wrong individuals (stories which always remain reported at a local level) there is “error” and “mistake” (Derby Evening Telegraph, 2010[5]) and “human error” (Evening Chronicle, Newcastle, 2010[6]). Such constructions neutralise any potential accusations of blame whilst minimising the impact of any error (for example, medical notes become “health documents”, shielding the reader from considering what personal information has been mishandled).

Conceptualising action without blame is a privilege not afforded to benefit claimants. Those who claim welfare, who *choose* to live their whole life outside of ‘regular’ experiences (being employed), are not just condemning themselves but their children and their children’s children. This positioning is achieved through inflating the importance of individual responsibility; individuals claiming welfare are positioned in a manner which entails a limited number of available practices, all of which rest on the assumption of ‘choice’: individuals either choose to claim benefits (with generational consequences) or ‘choose’ employment (regardless of whether or not this can be achievable, in personal and wider economic realities). The importance of making the morally ‘right’ choice becomes heightened for those who could be categorised as descendants of intergenerational worklessness: the obligation to step outside of your lineage, to ‘transcend’ the sins of the father, and to turn instead to employment. An extreme case formation, resulting from the muddying of a claimed link between death and the previous incapacity benefit, seems to await those who ‘choose’ not to remove themselves from the welfare systems:

> *He [IDS] claimed that anyone on incapacity benefit for at least two years is more likely to die than work again.*
> *The Daily Mail (2010[7])*

As such, the previously explicit drive for reform (the deficit) now becomes implicit: the focus instead becomes a concern for the well-being of those claiming welfare. In order to save individuals who claim (and their proceeding generations) “radical reform” (The Western Mail, 2010[8]) is necessary (in contrast to the first news peg, here reform is always constructed as ‘radical’). Continuing the ancestral narrative established by intergenerational worklessness, ‘roots’ become a discursive object. Firstly through symbolising the central link between welfare usage and poverty: *the* root cause of poverty becomes welfare dependency. This established ‘root’ then becomes the rhetorical impetus for “root and branch reform”:

> *He [IDS] will argue that endemic poverty and intergenerational worklessness can only be tackled by a root and branch reform which ends the "absurd situation" where some of the poorest faced huge penalties for trying to get off benefits and into work.*
> *The Western Mail (2010[8])*

"Root and branch reform" is not defined in specific terms. However, its metaphorical function seems to suggest a thorough *uprooting* of current situations. The evoking of a tree's anatomical features, combined with the *intergenerational* aspect of worklessness, can be understood as to symbolise the *family tree*. This construction suggesting (or entailing) the likelihood of "root and branch reform" targeting the family unit: that future welfare reforms should, and could, regulate interpersonal relationships in a more thorough and disruptive manner, 'up-rooting' those family structures which fall into the category of being morally incorrect.

Even in comparison with the first news peg, the number of subject positions made available to individuals living with chronic illness who claim welfare has become limited. Building upon notions of responsible citizenship, discourses now sharpen onto generational responsibility. Medical discourses around the role of genetics in chronic illness and disability implicitly talk of the "personal tragedy" of illness or disability (Shakespeare, 1999). In a similar way, and by apportioning intergenerational blame to those claiming welfare whilst living with chronic conditions, unique feelings of shame and fear are made available: a responsibility for *future* events (be it illness or the consequences of unemployment); that actions now, as well as genetics, will inevitably condemn or lead to these personal tragedies. Individual responsibly becomes a responsibility to one's family, or future families; with the construct of 'blame' as a mechanism to keep the responsibility at an individual, micro, level. The only morally 'right' action available is to remove yourself from the benefits system, to avoid becoming 'the root'.

Established within these constructions, and indeed within the focus of this analysis of 'intergenerational worklessness', is the normality of family discourse: that one does or has practised within family social structures. However, extreme case formations of the relationship between claiming welfare and death appear to reinforce and emphasise individual consequences. In doing so, discourses gravely assert a hastened morality that seems to operate independently of an individual's personal experiences of illness. The implicit assumption is that finding employment, that is choosing to lessen your personal contribution to the looming structural deficit, is the only way to avoid dangerous subject positions.

Implications of counter discourses.

Having considered the economic discourses which position and restrict experience for individuals who claim welfare (focussing on those living with chronic health conditions or disability) the analysis now turns to consider how these individuals are constructed within the data set. Seemingly as a reaction to the constructions explored within the analysis of the first news peg, as well as the widespread use of the WCA and continued 'roll-out' of ESA, counter discourses which focus on the humanisation and personal histories of ESA claimants begin to emerge. Such constructions can be characterised as 'bottom-up' in approach; as opposed to the more 'top-down' design seen in the previous section (whereby newspaper reports were often unquestioning accounts of governmental policies). Instead, counter discourses can be seen to initially come from the margins of media commentary; from the local press, the letter pages of national broadsheets or sympathetic one-off profile features of ESA claimants. At first these counter discourses appear to give 'voice' to the previous faceless individuals living with chronic conditions. However, such counter discourses also offer their own restricted constructions of 'illness' and available subject positions, whilst also limiting possibilities for action.

> *FEARS were growing last night that children and the disabled are to be hit by well over £12billion worth of welfare cuts.*
> *The Mirror (2010[9])*

Talk around ESA claimants constructs a narrative of collected victimisation; of individuals that have been subjected to aggressive actions perpetuated by the state. Doing so, independent of sympathetic motivations, nonetheless *reinforces* the power present within predominant discourses. Metaphors of "firing line[s]", "chainsaw[s]" construct a deadly, violent notion of the state's welfare reform (The Mirror, 2010[9]). Individuals become at risk, positioned as inherently vulnerable and infantilised through a combined positioning with children, whilst the state exists as reckless and truly dangerous. By characterising power as a violent and dangerous actor, counter discourses minimise the potential self-efficacy of individuals existing within the benefit system: how can someone 'resist' such manifestations?

> *DISABLED TARGETED*
> *The Mirror (2010[10])*

Claimants are often categorised and positioned as “disabled” (The Mirror, 2010[10]). Such constructions take up and perpetuate the difficulties of the medical model of disability. For individuals living with chronic illness, in order to be included within (and benefit from the social outcomes of empathetic counter discourses) they must first identify themselves within the discursive construct of being ‘disabled’. Reflecting, or indeed informed by, the lay-person’s understanding of disability, the medical model of disability problematises an individual’s body (Goering, 2015). As a consequence, treatment or care is needed to ‘empower’ the individual to reach ‘normal functioning’. Here we can see parallels with how chronic illness and disability are constructed by the policy documents analysed within the first news peg: that ‘health’ becomes an achievable goal through choosing and selecting the appropriate support and resources. Within these counter discourses the same constructions become apparent: limiting the way in which individuals can talk about their illness experiences. What positions are available for individuals who do not see themselves as disabled? Chronic conditions, many of which are without a cure or complete symptom relief, stand markedly outside of these constructions. In doing so their legitimacy is called into question.

Within profile pieces and newspapers’ letter pages, there are more nuanced constructions of illness which move beyond the ‘disabled or not’ dichotomy. These pieces emerge after statistics about the number of successful ESA appeals are re-addressed by the media, seemingly following Danny Alexander’s appointment to cabinet. Once a vocal critic of the ESA assessment process, his initially passionate critiques become more ‘factual’, more closely linked to his role as a Liberal Democrat MP. Such reports aim to position Danny Alexander as someone who has abandoned his principles upon entering the coalition government: either as an example of the corrupting nature of political power or that the Liberal Democrats can now be understood as lacking integrity. However, in doing so, these rhetorical exercises raise questions around the discursive object of ‘genuineness’:

> *The fact is that the process isn't working and that genuinely vulnerable people are being denied money as a result.*
> *Danny Alexander MP quoted in The Daily Telegraph (2010[11])*

The question, and construction, of ‘genuine claimants’ becomes implicit within the data corpus. There is an assumption that a number of genuine claimants, those “seriously ill and disabled [people]” (The Herald, 2010[12]) will be supported by a health-related benefit. However further discussions of what are the necessary and sufficient conditions of ‘genuineness’ remain unexplored. Instead, the health experiences of individuals become lost behind both the successful appeal statistics and the unexpected number of ESA claimants found ‘capable for work’:

> *Under the new employment and support allowance, 50 per cent of applicants were expected to be deemed unfit for work and in need of support. In practice, it was only 32 per cent.*
> *Sheila Gilmore MP quoted in Edinburgh Evening News (2010[13])*

The idea of genuineness as a potentially knowable entity becomes eroded: the disparity between governmental expectations (which suggests intentions to reduce welfare expenditure) and actualities presents a split in the discourse. For some, this mismatch represents a justification of the “rigorous medical assessments” (Daily Mail, 2010[7]) that must be undertaken by ESA claimants: the exceeding of expectations as evidence of fraudulent claims. Within this construction, genuineness is known to be a *rarity*. Once established this allows, or necessitates, deepening suspicion of ESA claimants as well as further cuts to health-related illness benefits.

However, counter discourses instead consider and humanise those whose genuineness is seen as self-evident. In a demonstration of Foucault’s (1980) notion of recovering disqualified knowledge, we can see how these presentations of reported lived experience (which could be classified as “low-ranking knowledge”; Foucault, 1980) undermine dominant discourses.

> *Mary Hodgson could not believe her eyes when she read that she had been judged fit to work after an ESA work capability assessment. Hodgson, 42, from Annan, Dumfries and Galloway, formerly a support worker for people with learning disabilities, had to give up work when an operation to correct a prolapsed disk resulted in nerve damage and other significant health problems.*
> *The Herald (2010[14])*

Using a case study of a named person, who is locally located (to the area in which the newspaper was published), has the effect of humanising a would-be ESA claimant. Mary is positioned as a hard worker, someone who is patient and resilient, but who has been let down by the system. Implicit here is a positioning *apart* from those who don't want to work; revealing the internalisation of discourses that state claimants have chosen not to work. Instead, because of her health conditions, the emphasis is on a *lack* of choice: on tasks that can no longer be performed. The decision of the DWP mismatches with Mary's reality; her practice has exceeded the positions made available to her by the predominant discourses. Here the notion of 'resistance as never exterior to power' becomes evident (Foucault, 1980): the availability of counter discourses always exists within power relations.

However this case study also exemplifies the subject positions that are made available by counter discourses. Mary's story, and the stories of others, follow the narrative construction of biographical disruption (Bury, 1982). An illness event (for Mary the prolapsed disc) disrupts the structures of everyday life, forcing her to re-establish her capability within this context. However, this story is told within the specific socio-historical context of discourses regarding ESA claimants and due to its function (obtaining through interview, with the intention of publication in a newspaper) there is a performative aspect to the narrative. In doing so, such counter discourses which focus on performative narratives construct specific discursive objects of 'illness'. An emphasis on 'an event' negates other possible practices, instead conceptualising health as present until disruption occurs.

> *As a result, many thousands of seriously sick and disabled people in Scotland have been put under pressure to find work or lose their benefit. […] including clients who are suffering from conditions like Parkinson's disease, multiple sclerosis, terminal cancer, bi-polar disorder, heart failure, strokes, severe depression and agoraphobia.*
> *Press Association (2010[15])*

> *CRIMINALS are forced to do community service as a punishment, so making the jobless do demeaning work is treating them like law-breakers. […] The real spongers feign backache, stress or addictions to dodge work.*
> *Letters, The Mirror (2010[16])*

Conditions, or experiences, that fall outside of these constructs aren't afforded the protection offered by the counter discursive constructions. Accounts of unseen illnesses (chronic medical conditions that show no outward, visible, symptoms) or medically unexplained symptoms (bodily complaints without a specified aetiology) may lack the availability of a clear narrative structure: a method by which humanisation becomes lost. Instead, as evident from the two extracts above, conditions that fit within the counter discourse are privileged over those that don’t. The lack of a visual component in backache, stress and addiction automatically, firmly, positions those living with these conditions within the predominant discourse: as “spongers”; those that have chosen unemployment, who ‘soak up’ resources, and as such should be treated as law-breakers.

Whilst those making use of counter discourses aim to refute the dominant knowledge around welfare claimants, these counter discourses also offer their own restricted constructions of ‘illness’ and available subject positions. In order to participate within the available counter discourses, individuals must either position themselves within the medical model of disability or ascribe to a hierarchy of conditions that privileges practices which possess a clear narrative structure or visual component.

The power of ‘knowledge’ in uncertain times.

Contextualised by the reporting press as a historically significant achievement, the formation of a coalition government is constructed as a unique event within the history of British politics. Due to the novel nature of the election’s outcome, a sense of *uncertainty* becomes prevalent; constructions of ‘the coalition’ which emphasise the uniqueness of joint government by definition are unable to appeal to historical points of reference. In comparison to the first news peg, media templates which may offer explanatory power to new events are few and far between. The ‘vacuum’ created by uncertainty appears to entail a relief, or solace, in discourses that can be easily understood as ‘known’: truths become a solid ground in from which the unpredictable future can be built. Through our interpretative work we are able to see how establishing ideas of ‘truth’ appear to be more easily done in times of political uncertainty. A sense of optimism, buoyed by the change of government, also appears to prioritise the ‘new’; that is ideas, reforms or policies that can be characterised as distinguishable from the Labour party. Combined, these constructs minimise the relevancy of the subjective experiences of those affected by reform, whilst also reducing the *suitability* of resistance.

One such example is considering the language used to construct and cultivate the public image of Iain Duncan Smith, the newly appointed Secretary of State for the DWP.

> *Since his well-documented Damascene conversion during a visit to the neglected Glasgow housing estate of Easterhouse in 2002, Duncan Smith has recreated himself as a passionate social reformer, respected by some for the vigour of his commitment to tackling poverty*
> *The Guardian (2010[17])*

Positioned here (in the first of many profile pieces) as a "passionate" reformer, the evocations of religious zeal create a sense of fulfilling a destiny. Iain Duncan Smith's 'conversion' to social reformer is not one borne of shifting political ambition, but instead is the culmination of a journey; a summation of experiences. Positioning Iain Duncan Smith in such a way suggests that his proposals for reform will be informed by, and seek to drive, social reform which will 'tackle' poverty. The initially explicit context of reducing welfare expenditure again shifts into the background. Instead, reforms will be made from a commendable and 'known' moral standpoint: a proposed return to "pro-marriage, pro-family, often faith-based solutions" (The Guardian, 2010[17]) are presented with curiosity, as potentially an effective, novel, idea. The lack of counter discourses around these approaches to policy has the effect of condoning othering positions that would occur for individuals outside of heteronormative, Christian practices.

The idea of novelty becomes entwined within the construction of 'Iain Duncan Smith'. He is portrayed as being a maverick within the Conservative party, needing to convert others. Doing so reaffirms his commitment to a morally 'just' approach to welfare reform, whilst confirming his lack of political posturing. Despite the political turmoil (the previously unknown newly found "common ground" (Press Association, 2010[18]) between the Conservative and Liberal Democrat parties) Iain Duncan Smith's principled, experientially-informed, approach can be counted on. For his "bravery", he is to be wished "good luck" (The Telegraph, 2010[3]); welfare reform becomes entangled with a permissive cult of personality and to oppose such a principled stance would be to reject such rare certainties.

It is curious that Iain Duncan Smith is able to be positioned as an outsider of a party he once led. Within the data corpus, the reader is often reminded of Iain Duncan Smith's history as "former Tory leader" (The Express, 2010[19]). This positioning of people by a role is a common practice. Doing so appears to appeal to 'shortcuts' to knowledge; that 'knowing' an individual's position can either legitimise their claims (consistent with the construction of Iain Duncan Smith) or seek to pre-emptively neutralise objections.

> *Wheelchair-using MP to study benefits change […] Ms Begg, who uses a wheelchair, will also have to lead scrutiny on other welfare reforms as the Conservative/Liberal Democrat coalition attempts to cut the cost to the taxpayer of benefits.*
> *The Scotsman (2010[20])*

Here we see how the Labour MP for Aberdeen South, elected to the position of chairwoman of the work and pensions select committee, is defined first and foremost through her wheelchair use. Anne Begg's work of "scrutiny" is pre-emptively constructed: there exists an incompatibility between her wheelchair use and the potential of an objective critique of welfare reform, despite these being reforms being constructed as a cost saving exercise. In this example the power of knowledge, and its effect on individuals, becomes evident: 'known' positions, determined by disability, limit what actions are made available. Anne Begg's stance on welfare reform will always be understood through the prism of her wheelchair use: her contributions always defined in relation to her positioning. This appears to be symptomatic of the disempowerment made available for individuals living with disability or chronic illness; with opposition to the ESA system seemingly always understood in relation to an individual's positioning.

Demonstration of the power of 'knowledge' is similarly prevalent as the coalition's aims and intentions for reform are discussed. "Simplification" of the welfare system is constructed as an essential, common sense, tool for reform:

> *The tax and benefit system will be made fairer and simpler.*
> *The Stationery Office (2010[21])*

> *The purpose of the bill:*
> - *to simplify the benefits system in order to improve work incentives.*
>
> *Prime Minister's Office (2010[22])*

Introduced by Queen Elizabeth II, the discursive object of 'simplification' is persistently maintained as a known required first step in welfare reform. It forms the basis of an act of parliament (Prime Minister's Office, 2010[22]): simplification becomes a notion which can be legislated into existence. Simplification becomes a priority within the Queen's speech, second only to (and linked with) a commitment to "reduce the deficit and restore economic growth" (The Stationery Office, 2010[21]). Yet no definition of what simplification would mean, in practical terms, is provided.

Underlying the notion of simplification is that simplicity is *always* the better approach; conversely, that complexity will allow for ambiguity and uncertainty (undesirable traits). This notion is embedded within both the categorisation of ESA claimants by the WCA (who either cannot work, need support to work, or who should be working) and counter discourses (the hierarchy of 'included' conditions which privileges narratively consistent conditions). Simplicity also becomes indicative of the coalition's approach to policy: the Queen's speech opening the houses of Parliament is "shorn of the political rhetoric often deployed by New Labour during its 13 years in power" (The Guardian, 2010[23]). Apparent is the rhetoric of *no rhetoric*. By being positioned in opposition to "New Labour" (by May 2010 now symbolic of untrustworthiness), the coalition is able to benefit from the uncertainty surrounding its style of government. In place of political 'spin' comes statements of intent. The 'lack' of rhetoric implies a truthfulness which *should* be exempt from critique. Even if political writings were able to be free of rhetoric, through a discursive analysis we are able to see what is constructed by the language used: what institutional patterns of knowledge emerge.

> *The research shows that social mobility in Britain is worse than in the USA, France, Germany, Spain, Sweden, Canada, Finland and Denmark, and a higher proportion of children grow up in workless households in the UK than in any other EU country.*
> *Press Association (2010[24])*

From this research, published by the DWP, there is a conflation of two (distinct) constructs. Social mobility is the economic measure of the change of individuals' social statuses: the 'Great Gatsby' curve suggests a positive relationship between a country's inequality and intergenerational social immobility (Kruger, 2012). However, through a mere conjoined presentation of two distinct 'facts', the DWP seeks to explain the UK's comparatively low social immobility through worklessness, and "welfare dependency" (The Western Mail, 2010[8]). Rather than focus on potential economic causes (social immobility as an inevitable phenomenon of free market capitalism where determination of wages by a market in recession precipitates a downward pressure on wages), 'knowledge' instead looks to a lack of individual responsibility for explanation. Doing so, again, shifts any potential blame away from policy makers on to those who claim welfare.

When analysing the talk deployed around concepts of 'poverty' and 'power' we are able to see a government *engaging* with discursive practice. Knowledge around what 'poverty' is, and therefore which children within a population would be considered as *affected by poverty*, is deconstructed:

> *He [IDS] also discloses that he is looking at widening the definition of child poverty to include other measures besides the previous government's definition of poverty, which he says was a measure of inequality. "You get this constant juddering adjustment with poverty figures going up when, for instance, upper incomes rise.*
> *The Guardian (2010[25])*

An acknowledgement of the social construction of poverty here destabilises previous knowledge (the prior construction attributed to the Labour government). The *power* of talk becomes evident. How the categorisation of individuals' experiences of 'poverty' is called into question: a re-addressing of what was previously known becomes necessary. By creating *uncertainty* a need for knowledge is created: 'poverty' must be able to be categorised to be spoken of meaningfully. Creating uncertainty paves the way for future discourses: a hole that must be filled.

In an interesting parallel to this Foucauldian inspired analysis, within David Cameron and Nick Clegg's introductory "programme for government" document (HM Government, 2010[1]), much is made of 'power'. Unlike Foucault's conceptualisation, power seems to be constructed as a tangible resource:

> *it is our ambition to distribute power and opportunity to people rather than hoarding authority within government.*
> *HM Government (2010[1])*

The resource of power is to be given away, but also an acknowledgement that governmental 'power' is being eroded by advances in technology and the "decentralisation" of information (HM Government, 2010[1]). By constructing 'power', as a (perhaps dwindling) resource that is the government's to give, a certain irony occurs: the state alone has the power to control where power can and cannot go. Diffusion of this political construct of power would therefore always be conditional; dependant on the agreement of the government and, perhaps, given the decentralised nature of information presently, is power even desirable? Instead the esoteric significance of the Queen's speech suggests the *true* nature of power: power as a divine right. Closing, as is tradition, with the Queen's prayer that the "blessing of Almighty God may rest upon your counsels" (The Stationery Office, 2010[21]) the policies introduced as a programme for government take on greater significance. Against the historical backdrop of the divine right of kings, and despite the established sovereignty of parliament, through the language used the monarch is constructed as a conduit between God and her counsels. What has been spoken is not just politically legitimate but is the *will of God.* There now exists two constructions of 'power', two certainties, which can be deployed to legitimise knowledge; one divine, the other resource-based.

Those living with chronic conditions and disability are not afforded the luxury of experiencing 'power as a resource'. Empowerment through a receiving of political power is only available to citizens. Those who claim welfare are instead positioned as outside of society.

> *Ministers complained that entire communities were existing at the "margins" of society, trapped independency and leaving disadvantaged children to become disadvantaged adults.*
> *Coventry Evening Telegraph (2010[26])*

Society becomes a physical location, that individuals, and families, can be on 'the edge of'. Despite being recognised by Iain Duncan Smith as "some of the most vulnerable members of our society" (DWP, 2010[4]) claimants are to remain outside of it. They are there through their own refusal to work; employment as the only, literal, pathway into society.

Within these constructions we have been able to examine the interplay between 'knowledge' and power. During a specific period characterised as being politically uncertain, the power of knowledge became greater. Certainties about the character and suitability of Iain Duncan Smith positioned him as a highly suitable DWP Secretary; seemingly allowing the opening up of possible practices. 'Rhetoric free' polices that sought to simplify welfare mirrored the classification of illness and disability whilst economic 'facts' were conflated to further discourses of intergenerational worklessness. Discursive practices undertaken by the coalition deconstructed notions of poverty and power either creating vacuums for further discourse to fill or limiting the practices available to those living with chronic conditions who claim ESA.

Third news peg: I, Daniel Blake.

The third news peg aimed to consider further 'common-sense' reforms proposed by the Conservative Party government in October 2016. Following the search strategy outlined in the methods section, 60 documents were identified for inclusion within the data corpus. Analysis was conducted, however it became clear that within this data set, the intended news peg was 'overshadowed' by discussions around a fictional portrayal of an ESA claimant. Ken Loach's *I, Daniel Blake*, which tells the story of the titular character's battle through the ESA process, released in October 2016, was identified as a significant discursive object. Attentive to the data collected, the focus of the third news peg shifted to concentrate solely on the Ken Loach film: what discursive implications did the popularity of *I, Daniel Blake* have for 'real life' ESA claimants?

Cultural context.

In the wake of the June 2016 Brexit referendum, the then prime minister David Cameron resigned. The Conservative Party appointed a new Conservative leader and Prime Minster, Theresa May. May appointed Damien Green as Secretary of State for Work and Pensions in July 2016. That year's Conservative Party conference took place in Birmingham, UK (2 October – 5 October). Speaking at this conference, Damien Green announced an intention for further reforms to the WCA process: stating that there needed to be an end to "punitive" reassessments for individuals living with chronic illness. Against this backdrop, Ken Loach's film *I, Daniel Blake* was released in UK cinemas.

Characters.

Table 3.3. *Key individuals (and events) identified from* I, Daniel Blake.

Character	Biography (as of the time of the news peg)
Ken Loach	British film director and director of *I, Daniel Blake*. Loach's films fall within the genre of "social realism"; films that aim to realistically depict working class life
Paul Laverty	Screenwriter and lawyer. Screenwriter of *I, Daniel Blake*
Daniel Blake	(Fictional). A widowed carpenter living in the Northeast of England. Dan has been declared unfit to work by his doctor. Played by comedian Dave Johns
Katie Morgan	(Fictional). A single mother to two children who is befriend by Dan. Katie and her family have been moved from London to Newcastle due to the unavailability of council housing. The role of Katie is played by Hayley Squires

Analysis of I, Daniel Blake.

We begin our analysis by examining the 'immaculate construction' of the character Daniel Blake. Dan is a responsible and caring individual, both to his community (shown through his exasperation with his neighbours' rubbish and anger at a nonchalant owner of a defecating dog), friends (particularly the quasi-paternal role he takes up in relation to Katie) and family (having cared for his wife before her death). The construction of Dan is extremely precise, bringing about a character who is hard to find 'fault' with.

The audience never sees Dan smoke, drink or gamble: he has no 'vices'. This is in direct opposition to the discursive construction examined within the first two news pegs: the 'negative' positions made available to welfare claimants, through their individual behavioural choices, are not taken up by Dan. When invited to the pub by an ex-colleague, Dan declines, justifying his choice through a responsible approach to his health:

> *DAN: Thanks Joe… got to keep off the sauce*
> *(Laverty, 2016)*

In doing so, Dan is moved away from what is 'known' about welfare claimants: that, through belief, in the "just world hypothesis" claimants are in need of support because of a fault of their own (Goodman & Carr, 2017). Instead Dan is positioned within a construction of 'responsibility': where his decisions, made in relation to his well-being and work, are informed by his health. Despite the importance of individual responsibility, fostered by policy and media documents, Dan's responsible actions (or absence of *irresponsible* actions) is not 'rewarded'. Instead Dan finds himself entangled within a tension between medical advice (not to return to work) and the Department for Work and Pensions who find him 'fit for work'.

Alongside these narrative choices, the casting of Dan (played by Dave Johns) has a significant impact on the character's construction. Dave is a stand-up comedian from Byker, Newcastle-upon-Tyne (UK) and prior to *I, Daniel Blake* was considered 'unknown' as an actor. Talking about this casting choice, director Ken Loach draws upon the traditions of stand-up comedy, that of a man or woman "rooted in working-class experience" (Laverty, 2016). Made explicit is the ontological significance of comedic timing: "their timing is absolutely implicit in who they are" (Laverty, 2016). Despite the subject matter of the film, there are elements of dark humour throughout, the effect of which is amplified through the comedic abilities of Dave Johns. An authenticity sought by Loach is partially realised through the background of Dan's character, made 'real' through auditory and linguistic semiotics namely his accent (situating him from Newcastle) and good-natured, cynical, spirit (the type of humour used). These aspects of Dan's character are established in the opening scenes of the film: against the 'blank slate' of a black screen the audience listens to Dan's Work Capability Assessment. Before we have seen Dan (within the film; notwithstanding the socialist realism styled film posters), these characteristics have been established through Dave Johns' delivery of the dark comedic script, as Dan's experiences buffet against the, almost immediately, 'Kafkaesque' responses of his assessor:

> *DAN: Listen… I've had a major heart attack and nearly fell off a scaffolding… I want to get back to work too… now, will you please ask me about my heart and forget about my arse which works like a dream (Laverty, 2016)*

Other early scenes add to the construction of Dan's character. One such example is made through a rare, diegetic (i.e. the source of sound is visible) use of music. The distinctive tune of "Sailing By" followed by the sounds of names and sounds of the shipping forecast make use of the aesthetic resonance evoked by the forecast. First broadcast by the Meteorological Office in 1911, the shipping forecast has developed a peculiar status within British culture. Far beyond the likely anticipated audience, the shipping forecast has become ingrained as part of British culture and a "signifier of Englishness" (Carolan, 2011): a semiotic shortcut to the 'fuzzily' defined, but oft used, notions of English identity.

Figure 3.4. *Scene 6, Dan's flat (night).*

[Image removed from open access version for copyright reasons]

As seen in Figure 3.4, we see a lighting arrangement that through the deployment of established film lighting conventions (the practical light of the desk lamp remaining in frame), allows for sense of time to be established: that this broadcast of the shipping forecast is 'live' and happening in the present of a late night/early morning. This, combined with the intimate feel of the short scene, in which Dan woodworks silently, suggests the chance recording of a nightly ritual. In doing so the film's weavers position Dan firmly within this discourse of English identity. This positioning is echoed by Dan's name: a consideration that was "very very important" for the script's writer Paul Laverty (Buder, 2017). For Laverty, the surname Blake is "quintessentially English" (Buder, 2017), presumably drawing upon the lineage of William Blake; that of 'Jerusalem' arranged to music and fervently beloved as "the second national anthem of England" (Ferber, 2000).

These constructs cumulatively establish Dan as a 'cultured everyman': English working class, 'refined' of taste. However the film is keen to 'protect' Dan from the actions made available by those discourses that may, in the perceptions of the audience, follow from conservative constructions of 'Englishness'. Within a globalised world, there does exist the potential 'danger' of asserting a national identity: the opening up of isolationist discourses and practices (Robins, 2005). Dan escapes these ideological positionings. He is well liked and respected by his younger neighbours, China and Piper, who treat him as a friend. As shown in Figure 3.5, this respect and fondness is mutual. Dan’s amazement at China’s business links with “Stanley from Guangzhou” (Laverty, 2016) and their video-telephonic conversation suggests a marvel with the modern world which goes far beyond the potential actions made available by isolationist discourses.

Figure 3.5. *Scene 16, China’s flat (night).*

[Image removed from open access version for copyright reasons]

The variances between the script and the finished text can be understood as choices made to preserve this ‘immaculate construction’ of Dan. Differences occur through a variety of ways; where what was shot deviates from the script or scenes that were cut early in the editing process are easiest to identify. One such example is the CV workshop which Dan is required to attend following a ‘formal direction’ from the Jobcentre. The Dan constructed within the script becomes more defiant as the scene progresses; mocking the farce of the system, as opposed to the bemused compliance seen in the film. These extra scenes were filmed but were removed from the final edit and are available as ‘deleted scenes’. The audience may have considered the reactions of the ‘script Dan’ as reasonable: ‘cheeky’ but justified acts of contempt. However, such is the discursive power of the individual responsibility rhetoric that compliance with all demands of the welfare system is expected. Had the additional dialogue remained in the film, Dan would have been open to criticism through his failure to accept his responsibilities as a welfare claimant. As we see in the film, the power inherent within these demands operates independently of the effectiveness or applicability of such requests. As such, to preserve the immaculate construction of Dan, these scenes become removed.

Another example of divergences between the script and film occurs within the relationship between Dan and Katie. The script seems to play with notions of an unspoken intimacy which go beyond the quasi-paternal dynamic that appears in the film. In removing any potential romantic overtones, Dan's position as a widower remains 'untarnished' preserving the subjectivities that such a positioning entails (the dignity by which he seems to have experienced caring for, and eventually losing, his wife Molly). Instead Dan takes up the position of 'the man of the house': the action of repairing the council property allocated to Katie signifying the fulfilment of 'traditional' gender roles. This father-figure position taken by Dan extends to Katie's children, Dylan and Daisy, who Dan teaches resourceful ways to combat the cold. In one small demonstration of how considered the construction of Dan's character is, we see a difference in the practice of Dan's 'fatherly' responsibilities. In the script Dylan is encouraged by Dan to light the candles used to heat the dinner room and kitchen, exposing Dan to potential blame (allowing a young child to play with matches, violating the discourse of responsibility inherent within constructions of parenting). Instead, within the film, we are shown Dan lighting the candles: the responsibilities of a father fully formed and demonstrated through practice.

Having explored the level of considerations made by the weavers of the text in order to construct the near faultless character of Dan, it is important to consider why such lengths have been taken. Why is Dan constructed in such, almost martyr-like, terms? It is possible to conceive of how, if 'pushed' too far or perhaps directed in more 'dramatic' style, that these constructions would have become unbelievable (such as the contested concept of the "Mary Sue": an idealised fictional character (Chander & Sunder, 2007). Within the writing, direction and making of the film, a balance appears to have been intended: in providing a counter-discourse to prevailing discourses around welfare claimants, achieved through a character that is constructed in a palatable and agreeable manner. The reasons for this careful construction reveal the subjectivities of the intended *audience*, as well as the power relations between those that the characters 'represent' and those anticipated to watch.

Figure 3.6. *Scene 14, city centre.*

[Image removed from open access version for copyright reasons]

Loach makes regular use of deep focus shots, from a static camera. In doing so the 'importance' of the audience is enforced (Stam, 1999). Such shots establish the viewer as omniscient, observing an "objective point of view" (Stam, 1999). We are seeing a lived experience: Dan's lived experiences of welfare in modern Britain. The emphasis is on documenting this experience in an almost 'apolitical' manner. The effect of which is eroded by the auteur status of Ken Loach; whereby he is positioned firmly within a leftist political and cultural discourse: synonymous with the genre of 'social realism', which can be characterised as seeking to 'expose' the consequences of prevailing ways of organising society (Stafford, 2017). With Loach's dedication to shooting on film (thereby making use of the film's 'grainy' quality as a semiotic shortcut to realism) *I, Daniel Blake* initially appears to continue this tradition. However, I suggest that *I, Daniel Blake* can be better understood through Deleuze's (1989) conceptualisation of "neo-realism". Neo-realism produces shots that dwell on its characters' subjectivities, physicality and presence outside of dramatic narrative. As seen in Figure 3.6, the audience often views Dan walking through Newcastle, one of a crowd of people 'going about' their daily lives. Such positioning visually reinforces the construction of Dan as an 'everyman' through his physical presence, but also suggests a commonality to Dan's experiences: how many 'Dans' may be amongst us?

Unlike *Cathy Come Home* (Garnett & Loach, 1966), a realist drama that sought to highlight Britain's homelessness crisis, the audience is not directed to statistics or specific governmental policies. Within *I, Daniel Blake* individuals seen as culpable are identified by the film's characters. During the Jobcentre graffiti scene specific members of government are *named* by the "Scotsman". The Scotsman speaks to the effects of welfare reforms: the UK's income inequality remains "rhetorically absent" repressed within a historical construction (Billig, 1997a). The deployment of the Scotsman seems to be in the tradition of the "Greek chorus" (Weiner, 1980). Plays of ancient Greek theatre tended to include a chorus of 12 to 50 individuals whose function was to collectively comment on the dramatic action: to bring the passions of the characters into sharp focus, so that the audience can consciously accept, or reject, the ideas presented (Weiner, 1980; Brecht, 1964). Within this scene we, the audience, are observing this action at a distance. Members of the public stop and watch as Dan makes his statement via spray can. Our view is occasionally obscured by passing buses and other comings and goings of city life, reminding us of our positioning as a passing member of the public: we are Dan's (and the Scotsman's) audience.

Figure 3.7. *Scene 38, outside the Jobcentre.*

[Image removed from open access version for copyright reasons]

Understanding the cumulative effect of these choices reveals subjectivities that are expected by the weavers of the film to be held by the audience. The intended audience is likely not from this 'world' of welfare and as such that class structures are integral for understanding the divide between the characters and the anticipated or expected audience. The ‘us’ and ‘them’ of class relations based on commodities, practices and lifestyles imagined by other social classes, rather than known through lived experience (Day et al., 2017). Other social classes only have socially constructed knowledge available to them about Dan’s world. Through the setting and decors of *I, Daniel Blake* the film first confirms these understandings before attempting to subvert the *practices* assumed to follow from such constructions of class. Considering this assumptive lack of lived experience goes some way to understanding why the construction of Dan is done so precisely. In order to combat the ‘truths’ examined within the earlier news pegs, for example those prevailing discourses around responsibility, choice and “worklessness”, a character was required whose motivations and behaviours would be beyond reproach. Such a construction is therefore both a site of resistance *and* a testament to the dominating effects of these discourses.

The tension between socially constructed knowledge and lived experience of class is mined for dramatic effect through the actions of Katie. Katie isn’t afforded the same ‘immaculate’ construction as Dan and looking at the differences between the script and what is shown in the film, we see how changes made play on the expected audiences’ reactions. Within the script, we see her shoplifting sanitary towels ‘as it happens’. Whilst in the film, the act of ‘theft’, and what has been taken, is hidden from the audience. The audience learns of the theft at the same time as the shop’s manager: in the moments between the accusation and the reveal, the sense of drama propagates from class relations and the practices available to those positioned within the ‘working classes’. Instead, in the reveal, Katie’s theft of hygiene products affords her sympathy; a clemency felt by the audience and granted by the manager. In her ‘crime’, Katie is not afforded luxury: she is beholden to the audience’s moral standards in order to maintain our sympathies. Were Katie to shoplift any product that could be considered ‘non-essential’, discourses of responsibility that revolve around an individual’s behavioural *choices* would allow moral judgements to be passed on her character and her family. In the earlier food bank scene, Katie is shown to ask for sanitary towels: her lack of available actions is firmly established. The audience, much like the shop’s manager who considers the items paid for, is encouraged to feel sympathy for Katie; a sympathy that rests on the items needed as well as the belief that all other ‘options’ have been tried and exhausted.

It is through Katie's family, and the other support characters, that we see the wider effects of austerity. China and Piper's 'entrepreneurship' is shown as a result of unreliable available work; the 'reality' of zero hour contracts. Recalling the notions of 'uprooting' discussed within the analysis of the second news peg, Katie's family has experienced this metaphor literally: moved from London to Newcastle due to a shortage of council properties. We see the consequences of this disruption perforate through their family, culminating in Katie's uncontrollable hunger at the foodbank and her subsequent 'descent' (as thematically constructed within by film) into sex work. The former is understood through the prism of the construction of Katie's identity as a mother. The quiet desperation of the foodbank scene, in which Dan joins the audience as an observer, making her hunger (previously alluded to) unavoidably explicit. It is implied that this public reveal becomes known throughout the area, as it becomes a part of the bullying 'repertoire' of the children at Daisy's school. Such repercussions seem to disrupt available constructions of motherhood: Katie's sacrifice, of going without meals, in turn becoming a cause of her child's suffering.

Figure 3.8. *Scene 35, Suburban road and flat.*

[Image removed from open access version for copyright reasons]

In the latter situation, which can perhaps be considered as the 'climax' of Katie's narrative, Kate's turn to sex work is shown through the prism of her and Dan's relationship. In one of the few examples of explicit 'body language' direction contained within the script, the quasiparental construction of their relationship is heightened: "she suddenly crosses her arms across her chest, as if confronting her father" (Laverty, 2016). Dan's reactions of disappointment and sadness are practices made available to him through this fatherly positioning and because of his construction as a 'cultured everyman', the crafting of a bookcase comes to be symbolic of a better future; that the bookcase will hold her Open University books, and that this education will be a way out of poverty.

Through this semiotic work, we see a 'trade-off' between the basic needs of the *now* and an ideal(ised) future. Katie's sex work is constructed as being an immediate method by which she is able to fulfil her role as a mother. Prostitution as enabling a form of responsible economic survival, even success. In Marxist terms, Katie's sex work is shown as an inevitable consequences of capitalist practice, as if it were another social institution alongside wage labour or 'the family' (Ericsson, 1980):

> *KATIE: I've got three hundred quid in my pocket... I'm going to buy the kids fresh fruit*
> *(Laverty, 2016)*

In contrast, Dan's fatherly subjectivities seem to stem from a discourse of conventional moralism: prostitution understood as an example of sexual immorality. Foucault argues that such an approach to sexuality is not innate but rather is the effect of historically specific power relations, which control and determine actions available to women (McNay, 2013). However through his loss of words and visible distress we see concern in Dan's actions. These actions again evoke a paternalistic practice, whilst also reinforcing what is and what is not 'acceptable' (Lux, 2009). Heightening the intensity of the scene, this myriad of discourses is explored rapidly: the scene is relatively short taking place within the spatially confined environment of the brothel, or amongst the back alleys. As shown in Figure 3.8, when situated within the brothel, the audience sees Katie 'in person', but also her reflection in the mirror behind is shown within the camera shot. As these discourses (which all pertain to Katie's body and her positioning within the ethical complexities of sex work) swirl around the room, Katie finds herself visually exposed to the audience. Both her 'choices', and the consequences of these choices, are 'laid bare'.

Given the focus of the film (and this analysis) on Katie's experiences, it is perhaps easy to conceive of an alternative story, one titled *I, Katie Morgan*. Potentially a 'spiritual successor' (Carreker, 2012) to *Cathy Come Home*, the impact of decreased social housing availability would have formed the main plot of *I, Katie Morgan*. Dan's battles with the DWP's bureaucratic obscurities would have been repositioned as the film's subplot. However, as shown in this analysis of the discursive discrepancies between the characters of Dan and Katie, if the priority of the plots were to be inverted, *Katie* would need the immaculate construction previously required for Dan. Through our considerations of who the audience is, and the socially established 'knowledge' available to them, cumulatively we can understand the *intention* of the film weavers. A number of different social issues (housing, workforce casualisation) are seen, however the 'function' of *I, Daniel Blake* is to promote activist-type engagement specifically with the welfare system. Narratively, there appears to only exist room for one wholly sympathetic portrayal. As the issue for reform is welfare, it is Dan who needs to be constructed immaculately in order to counter the predominant discourses around ESA claimants. These social 'truths' are understood by the audience, who are assumed to be 'middle class' and without lived experience of claiming welfare. The middle classes are therefore presumed to possess power, and that this power can be used to force a wider re-examining of the discourses around welfare or further reforms of policy. Although the impact is now disputed (Garnett, 2016), such an affect would mirror the role of *Cathy Come Home* in establishing public awareness of the 1960's UK housing crisis and the founding of the charity Shelter.

Visually this intent is realised in the final scenes of the film: at Dan's funeral. As Katie begins to read her eulogy, the camera fixates on two groups of individuals we have not met before (four men, one woman and a second group of five women). The length of these static camera, long take shots is notable; held whilst Katie speaks Dan's 'last words', originally written for his appeal. Implicit here is a 'call to action', that we (the audience), who like Dan are citizens, are *allowing* these the events shown in the film to happen. Through our collective inaction and acceptance of constructed knowledge we are complicit in these outcomes and in the death of 'Dans'.

Figure 3.9. *Scene 43, crematorium.*

[Image removed from open access version for copyright reasons]

However, complicity is not the same as being responsible for such outcomes. The film's weavers are keen to not blur these boundaries. Despite its emergence from analysis of media coverage of humanitarian crises, the work of Höijer (2004) can be helpful in understanding how such distinctions are maintained. Through interpretations of audience reactions to televised distant suffering, Höijer (2004) identifies four forms of compassion. Tender-hearted compassion focuses on the suffering of the 'victims' and the entailing responses of pity and empathy. Considering *I, Daniel Blake*, it is possible to see this as an appropriate audience response to the experiences of Dan, Katie's family and (to a lesser extent) supporting characters: that this response would be intended by the film's weavers. Although Daniel Blake would not fit Höijer's (2004) definition of an "ideal victim", a position normally made available to children, women and the elderly, through Dan's immaculate construction (where no blame can be apportioned) the subjectivity of tender-hearted compassion becomes available to the audience.

The tension between the fictional lived experiences shown through the film and the previously held social knowledge likely may lead to reactions of shame-filled compassion: the act of watching of others' suffering whilst being in (relatively) more comfortable and cosy environments (Höijer, 2004). In the funeral scene we see this being semiotically suggested to the audience who, emblematically and literally, are embodied as the mourners of Dan. However the intention is not to produce all-encompassing subjectivities of shame: doing so may led to a third categorisation of compassion described as “powerlessness-filled”, where the audience’s potential actions become limited by an awareness of the limits of their abilities to affect change (Höijer, 2004). Instead through the infrequent use of ‘fade-outs’ during intensely emotive scenes, a sense of the audience being ‘spared’ becomes apparent. At the conclusion of the foodbank scene, as Katie sobs into a handkerchief provided by Dan whilst being watched bemusedly by her daughter Daisy, a slow fade-out removes the helpless audience from its voyeurism. The same occurs following Dan’s fatal heart attack: in amongst the claustrophobic rush of calls for medical assistance and Katie’s distress, the inactive audience experiences the scene through a static camera shot; Dan’s lifeless body firmly kept in focus, until the scene is faded away. These scenes, if lived, would have continued. However the characters, and audience, are both afforded dignity rather than an emphasis on explicit subjectivities of shame for the audience and (further) humiliation of the characters.

The culmination of these types of compassion lead into the fourth Höijer (2004) defined category: blame-filled compassion. Dan and Katie and entirely ‘worthy’ of our sympathies; the audience itself is not entirely to blame for their situations. However actions can be taken that would prevent future ‘Dans’: our anger is to be directed solely at the DWP. Throughout the film the DWP remains impenetrable and unseen. Both the audience and Dan interact with those who ‘represent’, in a removed manner, the DWP: job centre staff, ‘healthcare professionals’, security staff, the CV workshop manager and call centre staff are conduits for messages from the DWP. The DWP themselves, especially the decision maker (who remains intangible even to the call centre staff), remain absent; hidden behind the ideology of professionalism through the methods of technology. Contrasting against the loss of time, space, place and selves experienced by Dan, Katie, Dylan and Daisy; the DWP’s ability to remain unobtainable yet omnipotent represents a performative display of power.

The semiotic representation of this distinction between the powerful and the powerless can be seen through the metaphor of analogue and digital technologies. Dan is firmly an ‘analogue’ individual. His CV is handwritten, the radio analogue, his craftsmanship requires pencils and wood. These physical objects come to symbolise a life understood in ‘rich’ terms, not just binary choices offered by ‘digital by default’. The most evocative of these is shown through the music/muzak distinction.

> *DAN: The music helped her [Molly]… but sometimes she hit the rocks… we used to play it at night before going to bed, help her calm down, stop her mind racing… find sleep if she could… 'Where will we sail tonight Dan?' That was her little joke*
> *(Laverty, 2016)*

Molly's taped recording of "Sailing By" has meaning for Dan in a multitude of ways: the piece of music itself but also the cassette as an object. The audience, and Katie's family (see Figure 3.10), come to know Molly through these artefacts and Dan's descriptions of Molly. Molly is known through Dan's terms, rather than the positions made available by revealing diagnoses (in the script Daisy, drawing upon her experiences of living in hostels, correctly deduces that Molly had manic depression). Understanding Deleuze's neo-realism considerations of objects and settings can reveal how this knowing is achieved: objects take on a material reality for which it is essential that the audience and the characters invest these realities with their gaze before action takes shape in it (Deleuze, 1989). We are shown the cassette and have previously heard the music in the night woodworking scene. Once combined, we are able to appreciate the almost *therapeutic* role of the music. The significance of "Sailing By" to Dan is reflected by its treatment within the film, the song as an auditory 'thread': it is one of the very few times we hear music (either diegetically or not) within the film. In contrast, the 'tinny' sounding, synthesized version of Vivaldi's "Four Seasons" which is used as repetitive hold muzak by the DWP affronts Dan so much he includes changing it within as part of his spray painted 'demands'. Through this musak/music contrast positions of 'authenticity' become available to Dan; whilst symbolising the 'remoteness' of bureaucratic systems, which practise a denial of humanity (Morris-Jones, 1949).

Figure 3.10. *Scene 25, Dan's flat.*

[Image removed from open access version for copyright reasons]

The pathos of the 'mouse' scene (in which Dan physically lifts a computer mouse up the screen) further embeds this notion of analogue-ness within the construction of Dan. He is not a reluctant Luddite but is instead intending and trying to learn. This is driven by a necessity, perpetuated by the bureaucracy made 'necessary' by the DWP, Dan finds himself on the wrong side of the 'digital divide': alienated further by a lack of digital skills despite his willingness to seek support and help from those around him:

> *DAN: I'm pencil by default… What happens if you can't do it?*
> *(Laverty, 2016)*

Discussion.

This multimodal Foucauldian-inspired discourse analysis has examined the genealogy of discourses around a modern day, health based, UK welfare policy. This analysis allows us an understanding of the subject positions ‘made available’ for those living in the UK with chronic unseen health conditions who claim welfare. In some ways, these identified discourses share a lineage with the same rhetorical histories as the 1834 English Poor Law: that there can be a distinction between the ‘deserving’ and ‘underserving’ poor (Golightley & Holloway, 2016). However, conditions or disabilities that once may afford an individual the protection of being positioned as the “underserving poor” have been eroded through a neoliberal lens of individual responsibility. Instead, individuals who need to claim state support are likely to be understood as an economic burden; that through their chosen avoidance of work they may be accelerating the economic difficulties of the country.

We have seen how temporal and dualistic discourses of illness and disability focus and synonymise ‘health’ with a capability for employment. These discourses limit and constrain available positions for experience. Within media and policy discussions, ‘genuineness’ is ‘known’ to be a rarity and avoided only those who are categorised as being severely ill or disabled. As such, and against the backdrop of recession, discourses of citizenship and othering allow an enforcing of responsibility through cultural expectations and multiple problematisations of welfare. Participation in these power dynamics is facilitated through differing discourses of reform, allowing an individual to take up a stance of support regardless of their position on the political spectrum. Constructions of consensus and preconstructed opposition further limit opposition in practice and illustrate the need for a multiplicity of points of resistance.

Set against a ‘looming’ structural deficit, this analysis of the second news peg has shown how discourses perpetuate the need to find employment. Deepening notions of individual responsibility require claimants to ‘choose’ employment and avoid subject positions which would be dangerous for both themselves and their familial connections. The societal protection offered to individuals by emerging counter discourses requires either a self-positioning within the medical model of disability, or agreement to a hierarchy of conditions which privileges practices which possess a clear narrative structure or visual component. Discursive practices undertaken by the coalition government, reveal the interplay between malleable ‘knowledge’ and the diversities of power; legitimatising further ‘othering’ of those simultaneously positioned as the “most vulnerable members of our society” (DWP, 2010[4]).

Collectively, these socially constructed discourses of illness negate the complexity of chronic conditions, focusing instead on temporary notions, and the responsibilities of citizenship. In an alignment with the findings of Galvin (2002), we can see how chronic illness is increasingly understood as a moral failure. That to be unable to contribute to economic life is to clash with the image of a “good citizen” (Galvin, 2002). As such, submitting those who have failed in their individual responsibilities to the technologies of governance becomes a morally just practice. Here we see an example of the power of citizenship; a complex and debated notion (Andreouli, 2019). What recourses are available for those who find themselves positioned in ways that are at odds with citizenship?

The film *I, Daniel Blake* potentially represents the growth of counter discourses; notions that push back against established constructions of who welfare claimants are. Within the MFA we see how these counter discourses emerge: from the margins of media commentary, the letter pages of national newspapers; to sympathetic one-off profile features of ESA claimants; towards a film that held a position in the cultural zeitgeist. Through the multimodal analysis of the film *I, Daniel Blake*, I explored how through the careful construction of Dan, created not just through the script but all the mise-en-scène decisions made, the intention of the film’s weavers can be understood as a ‘call to action’. This call rests on a number of assumptions which position the assumed audience as middle class, who lack a direct lived knowledge of welfare. In order to discursively counter socially constructed knowledge about those who claim ESA, the narrative focus on the impact of ESA systems requires that Dan be immaculately constructed. Such positions are less available for those characters experiencing the consequences of other austerity informed policies.

Through considerations of the different forms of compassion it is possible to see how these constructions ‘lead’ the audience to a source of blame: the opaqueness and unknowability of the DWP position the department as the film’s antagonist. Yet power is not understood as purely politically obtained: instead power is available to those watching, and it is the film makers’ intention that this power is used to gain “administrative justice” for those ‘Dans’ that walk amongst us in our towns and cities (O’Brein, 2018). However such compassions rest on the notions of an ‘ideal’ welfare claimant. In confronting the problems of the ESA and welfare processes, counter-discourses presented by *I, Daniel Blake* also legitimises a *certain type* of welfare claimant. ‘Daniel Blake’ becomes a semiotic reference point that threatens to cement criteria about who is a genuine claimant; an example of how the availability of counter discourses always exists within pre-existing power relations (Foucault, 1980).

What recourses are available for claimants who do not match such a perfect construction? Like the case studies explored within the second news peg, Dan’s condition neatly fits within a narrative of biographical disruption (Bury, 1982). An illness event (Dan’s heart attack) disrupts the structures of everyday life, forcing him to re-establish capability within this context. As heard in Dan’s closing statement (and communicated implicitly through the declarative, legal-like, statement of “I, Daniel Blake”), Dan sees himself as a *citizen.* This role, for Dan, seems to have been earnt through previous years of work and financial contributions to the country. This conceptualisation of citizenship constructs welfare as an earnt support that should be available for those who are citizens. Access to welfare is less related to the conditionalities of the Work Capability Assessment, but rather the conditions required for ‘citizenship’. Although not fully explored within the film, these citizenship conditions seem to be tied to periods of previous employment and a sense of neighbourly responsibilities. Can the counter-discourses within *I, Daniel Blake* ‘protect’ all ESA claimants or do individuals need to ‘share’ the characteristics of an ideal welfare claimant? Are these characteristics interrelated with Dan’s gender, class status, age, ethnicity or cultural background? What of those experiencing conditions that cannot be understood or communicated through a simple narrative? Or conditions without physically presenting symptoms? How much employment is needed before one can be considered a citizen? The work of Ken Loach and Paul Laverty goes a significant way in highlighting the problems of dehumanisation seemingly experienced by ESA claimants. However, in doing so, the film raises these questions that may further problematise constructions of who (and who is not) able to be considered as ‘genuinely’ deserving of welfare.

Reflecting on the analytical procedures undertaken in this chapter, this research has contributed a practical way to systematically collect data for discourse analysis. The use of PRISMA reporting guidelines, set within a media framing analytical approach, has enabled the transparent collation of a data set that is thorough and, potentially, replicable. The addition of a transparent screening process improved the quality of the study (Yardley, 2000). Having detailed *how* data were collected, it is hoped that readers are likely to find the resultant analysis and synthesis of the data more enlightening. However, there are some limitations to the decisions made. When considering where social knowledge resides within the 21st century, it is increasingly commonplace to consider data from social media contexts. For example, van der Bom et. al (2018) analysed tweets to examine the discourses and representation of social class drawn upon in public reactions to the TV program "Benefits Street". 73% of UK survey respondents accessed news via online sources (Ponsford, 2022). Although the news articles included within this analysis were made available online, to concentrate an analysis on the content of the articles rather than, for example, social media comments or reactions, may have limited the opportunity to consider counter discourses or sites of resistance.

Taking this systematic approach to data synthesis allowed me to engage with a varied data set. But, in doing so, the research was not bound to inflexible constraints. Here it is worth considering why the analysis has been (retrospectively) framed as being "Foucauldian-inspired", rather than a more straightforward characterisation of a Foucauldian Discourse Analysis. Having reflected on the analysis produced, it could be said that I have 'stretched' the analysis method to its limits: specifically, in regard to intention. The dimensions of power/knowledge that have been explored within the analysis, despite retaining an insight into their complexity, converge on an identifiable source of power: the UK government. We have seen how a temporal variability is present, how these power/knowledge relations operate within different periods and within different disciplinary regimes (Arribas-Ayllon & Walkerdine, 2019). However, there is (potentially) an implicit direction within the analysis, that points to a continuity by design. That these are examples of political power, rather than Foucauldian conceptualisations of power. However, the consideration of a range of different media goes some way to reconsider how power is dispersed across regimes of truths (Foucault, 1991) rather than a solely singular sovereignty (such as through government policies). Through this consideration of power/knowledge, with an (unintended) emphasis on state production, we can see the machineries of stigma power in action (Tyler, 2020): the central role that UK media and government policy have in producing stigma. Link and Phelan (2014) define stigma power as the role played by stigma in the exploitation, control or exclusion of others. As evident in this analysis, citizens who don't claim welfare are invited to participate in stigma power dynamics which enforce the responsibilities claimants need to meet. This has been achieved through a *successful* stigmatisation of welfare. Looking at social attitudes to welfare, Hills (2014) found a demonstratable 'hardening' of public attitudes towards working-age welfare claimants. This was contrary to what had occurred in previous recessions, where public support for welfare provisions had increased as hardship became more visible (Hills, 2014).

In conclusion, the methodologies chosen encouraged an exploration of data (news media reports) that traditionally may not have been conceptualised as qualitative data suited to psychological enquiry (such as film). The analysis of *I, Daniel Blake* has uniquely examined the production choices made in the creation of a film. Only through moving *beyond* what was said, interpreting the cumulative effects of lighting, sound, camera shots etc., was I able to understand how these discursive constructions were achieved. I believe this multimodal approach to analysis shows *how* the stories and narratives we consume can inform how we make sense of contested phenomena, such as welfare. However, as is common with Foucauldian Discourse Analysis, the subjectivities of these discourses is – at this stage – theorised. Subject positions, for example, can be 'taken up' by individuals; but they can also be resisted (Willig, 2021). Making use of the epistemological flexibility of this thesis (outlined in chapter 2), the next stages of this PhD will examine if such discourses constrain or facilitate how individuals feel they can talk about their *own* experiences of welfare and chronic conditions.

Table 3.4. *References of those data included within Media Framing Analysis (first news peg) and included within the write-up of results.*

Reference	Newspaper/publisher	Date of publication	Author(s) (if stated)	Document type	Headline/title
2008[1]	The Sun	July 19, 2008	George Pascoe-Watson	News article	The end for sicknote UK
2008[2]	The Daily Telegraph	July 22, 2008	N/A	Feature	Courage is needed to put benefits plan into action
2008[3]	Daily Mail	July 19, 2008	Benedict Brogan	News article	Bounty for private firms to find benefit claimants a job
2008[4]	Daily Star	July 19, 2008	Anthony Walton	News article	Sickie pay to be axed
2008[5]	Daily Mail	July 21, 2008	Michael Lea	News article	Get clean or lose your benefits, junkies told
2008[6]	The Independent	July 19, 2008	Ben Russell	News article	Get treatment or lose benefits, addicts to be told
2008[7]	Daily Mail	July 16, 2008	Graham Grant	News article (front page)	The teens stressed to work: outrage as 11,000 youngers claim £26m in sickness benefits because of anxiety issues
2008[8]	The Independent	July 21, 2008	Johanni Hari	Comment piece	Yes, for welfare you must be made to work
2008[9]	The Guardian	July 21, 2008	James Purnell	Opinion piece	Comment & Debate: Only we can help the poor: The Tories still don't get it. They believe tackling poverty is all about individual responsibility
2008[10]	Mail on Sunday	August 3, 2008	Simon McGee	News article	One million sickies each year…at the Ministry leading blitz on workshy
2008[11]	Mail on Sunday	July 20, 2008	Simon Walters	News article	Addicts who lie to get benefits could face jail in welfare blitz
2008[12]	The Daily Telegraph	July 21, 2008	Janet Daley	Comment piece	The Tories must show they'll get tough with fraudsters on 'the sick'; with both parties saying roughly the same thing about Incapacity Benefit, voters will to decide who really means it
2008[13]	Daily Mail	July 22, 2008	Michael Lea and Ian Drury	Comment piece	Work – or lose your handouts; Jobless will have to pick up litter to earn benefit
2008[14]	The Times	July 22, 2008	Philip Webster	News article	Tighter system to remove option of 'life on benefits'
2008[15]	The Independent	July 22, 2008	N/A	Comment piece	A welcome return to the principles of Beveridge
2008[16]	Mail on Sunday	July 20, 2008	James Purnell	Comment piece	There is nothing Left-wing about expecting everyone else to pay for people who simply don't want to work; Work and Pensions Minister JAMES PURNELL sends a tough message on benefits – which will enrage many in his party
2008[17]	The Guardian	July 21, 2008	Patrick Wintour	News article	Benefits clampdown on heroin and crack users
2008[18]	The Guardian	July 21, 2008	N/A	News article	Drug users set to lose benefits if they refuse treatment
2008[19]	The Sun	July 21, 2008	George Pascoe-Watson	Comment piece	Warning to lefties
2008[20]	The Daily Telegraph	July 21, 2008	Philip Johnston	Opinion piece	Billions are wasted and they just shrug it off; I am heartily sick of seeing my hard-earned cash squandered on an almost daily basis without anyone responsible feeling any pain
2008[21]	The Guardian	July 19, 2008	Patrick Wintour	News article	Labour's work for dole plan leaked to website: Unemployed would carry out community tasks: Tories claim credit for Purnell's green paper
2008[22]	Daily Mail	July 21, 2008	Katie Grant		Time to halt this £12bn gravy train
2008[23]	The Times	July 22, 2008	Frank Field	Feature	The radical way to beat benefit culture
2008[24]	Morning Star	July 23, 2008	Jeremy Corbyn	Feature	Punishing the poor; Jeremy Corbyn explains how James Purnell's welfare reform programme goes even further than Thatcher

Reference	Newspaper/publisher	Date of publication	Author(s) (if stated)	Document type	Headline/title
2008[25]	Department for Work and Pensions	July 21, 2008	DWP	Green Paper	No one written off: reforming welfare to reward responsibility
2008[26]	Department for Work and Pensions	July 21, 2008	DWP	Press release	21 July 08 - No one written off: reforming welfare to reward responsibility

Table 3.5. *References of those data included within Media Framing Analysis (second news peg) and included within the write-up of results.*

Reference	Newspaper/publisher	Date of publication	Author(s) (if stated)	Document type	Headline/title
2010[1]	HM Government	May 20, 2010	Cabinet Office, The Rt Hon David Cameron, and The Rt Hon Nick Clegg	Programme for government	The Coalition: our programme for government
2010[2]	The Guardian	May 26, 2010	Peter Beresford	Opinion piece	Society: Second thoughts: Peter Beresford on the coalition's contradictory plans for social care
2010[3]	The Telegraph	May 27, 2010	Neil O'Brien	Blog	This is why welfare reform is a massive task
2010[4]	Department for Work and Pensions (DWP)	May 27, 2010	Department for Work and Pensions and The Rt Hon Iain Duncan Smith	Speech	Welfare for the 21st Century
2010[5]	Derby Evening Telegraph	May 21, 2010	Kate Liptrot	News article	Medical details sent in error
2010[6]	Evening Chronicle, Newcastle	May 21, 2010	Phil Doherty	News article	Concern as notes go to wrong man
2010[7]	Daily Mail	May 27, 2010	N/A	News article	Nine out of ten on incapacity are fit to return to work
2010[8]	The Western Mail	May 27, 2010	N/A	News article	Radical reform of welfare system planned
2010[9]	Daily Mirror	May 19, 2010	Bob Roberts and Danny Buckland	News article	Osborne's pounds 12bn 'chainsaw' threatens vulnerable
2010[10]	Daily Mirror	May 28, 2010	James Lyons	News article	Disabled targeted
2010[11]	The Daily Telegraph	May 27, 2010	Simon Johnson	News article	Welfare reforms may 'force sick back to work'
2010[12]	The Herald	May 26, 2010	N/A	Feature	Benefits system requires to be fine-tuned for genuine claimants
2010[13]	Edinburgh News	June 10, 2010	N/A	News article	MP hits out at party's record in first speech
2010[14]	The Herald	May 26, 2010	N/A	Case study	I can walk, but I can’t feel my foot
2010[15]	Press Association	May 27, 2010	Scott Macnab	Newswire	Ill people being pressured to go to work - Citizens Advice
2010[16]	Daily Mirror	May 31, 2010	Fiona Parker	Letters	Don't punish jobless; your letters
2010[17]	The Guardian	May 14, 2010	Amelia Gentlemen	Feature	The new government: Ministers: Welfare: Duncan Smith: the contradictory social reformer with a 'huge job'

Reference	Newspaper/publisher	Date of publication	Author(s) (if stated)	Document type	Headline/title
2010^{18}	Press Association	May 20, 2010	James Tapsfield	News article	Cameron and Clegg to unveil details of coalition agreement
2010^{19}	The Express	May 25, 2010	N/A	News article	Welfare
2010^{20}	The Scotsman	June 11, 2010	N/A	News article	Wheelchair-using MP to study benefits change
2010^{21}	The Stationery Office	May 25, 2010	N/A	The Queen's speech to both houses of parliament	Her Majesty's most gracious speech to both Houses of Parliament
2010^{22}	Prime Minister's Office	May 25, 2010	Prime Minister's Office	Bill	Queen's Speech: Welfare Reform Bill
2010^{23}	The Guardian	May 25, 2010	Nicholas Watt	News article	Queen's speech 2010: Coalition announces school, welfare and budget reforms
2010^{24}	Press Association	May 27, 2010	Matt Dickinson and Alan Jones		
2010^{25}	The Guardian	May 27, 2010	Patrick Wintour	News article (front page)	Duncan Smith starts welfare revolution: Minister says benefit system 'bust' and people who take jobs seen as 'morons'
2010^{26}	Coventry Evening Telegraph	May 28, 2010	Alan Jones	News article	We'll make work pay; Government's vow on benefits reform

Chapter 4. Living with chronic unseen health conditions and claiming welfare: a dual focus analysis of younger people's experiences.

Introduction.

In chapter 3 of this thesis, I explored how the UK's 'post-2008' health-based welfare reforms and chronic illness have been constructed by news media, policy documentation and film. This analysis provided an understanding of the subject positions 'made available' for those living in the UK with chronic unseen health conditions who claim welfare. It became possible to see how temporal and dualistic discourses of illness and disability focus and synonymise 'health' with a capability for employment. Through a deepening of rhetoric around individual responsibility, claimants were required to 'choose' employment and avoid subject positions which would be dangerous for both themselves and their familial connections. The Ken Loach film, *I, Daniel Blak*e, provided useful counter discourses which 'pushed back' against the dominant knowledges around claimants of ESA. However, in an example of how counter discourse always exist within pre-existing power relations (Foucault, 1980), I was made to show how these constructs legitimised a *certain type* of welfare claimant: 'Daniel Blake' becomes a semiotic reference point that threatens to cement criteria about who is a genuine claimant. Cumulatively, the effect of these discourses appeared to be a successful reinvigoration of welfare stigmatisation. The only apparent way out is by avoiding a 'dependency' on the state through becoming a personally responsible individual.

Thinking about the potential effect of these discourses on an individual level, I wish to draw on Foucauldian concepts of the technologies of the self, technologies of subjectivity and practices of the self. Foucault defines technologies of the self as the active process by which an individual shapes their own conduct in specific ways; in ways that accord with what is proposed, suggested and imposed on them by the cultural context in which they live (Foucault, 1993). This is an example of the productive function of power: through processes of governmentality a new subject is produced. Hook (2007, cited in Yates & Hiles, 2010) teases out a distinction between technologies of the self and technologies of subjectivity. For Hook (2007, cited in Yates & Hiles, 2010), technologies of subjectivity refer to regulative practices which bring governmental ambitions and intended social norms into alignment with an individual’s own ideals. Hook suggests that there is a gap between these different forms of technologies, a chance for agency and resistance that can be enacted through *practices* of the self. This is an opportunity for an individual to have some ‘degrees’ of freedom. However, what can be done and said by the subject will always stake place against the background of a culture’s discursive economy (Yates & Hiles, 2010).

To apply these concepts to this thesis, in chapter 3 I identified the discursive resources and knowledges that are available when discussing Employment and Support Allowance (ESA), a health-based welfare policy. However, the Foucauldian-inspired analysis could only go so far. There was a wide range of subject positions made available; it therefore becomes difficult to appreciate the extent to which discourses would translate into technologies of subjectivity. Would, or had, these technologies of the self constituted certain types of subjects? Rather than concluding that the offered subject positions will be simply taken up, it becomes important to understand the material reality of these discourses. What implications do these discourses have for the ways in which the world is experienced by those within health-based welfare systems? Are, for example, these stigmatising discourses felt within the body?

This study aims to empirically explore the lived experiences of these phenomena. As noted in the introduction to this thesis, previous studies which have explored the experiential qualities of claiming health-based benefits have tended to come from disciplines other than psychology. One such example is by Machin and McCormack (2021). Approaching Personal Independence Payment (PIP) from a social care perspective, Machin and McCormack (2021) sought to explore how the transition from Disability Living Allowance (DLA) to PIP had been made sense of by 12 claimants who self-identified as having mental health problems. A thematic analysis explored three perfunctory themes: outlining the problems of claiming PIP, the problems of conveying mental health problems and the positive experiences associated with the transition to PIP (Machin & McCormack, 2021). Looking further into their analysis it is possible to see how the uncertainty of time-limited awards heightened feelings of anxiety. Participant worries centred around a perceived, or anticipated, lack of understanding and disaffection with communication received from the DWP. Yet the transition to PIP did bring about feelings of strength through adversity as participants forged links with others in their local communities who were also experiencing problems with social security benefits (Machin & McCormack, 2021).

The findings of Machin and McCormack (2021) compliment those of Clifton et al. (2014), who looked at how the Work Capability Assessment (WCA) is navigated by mental health service users. Using a combination of a questionnaire and focus group, their findings portray an inaccessible cyclical system which makes claimants more ill and financially poorer. Looking specifically at the experiences of ESA claimants having to engage with the conditionalities of the Work Related Activity Group (WRAG), Mehta et al. (2020) describe processes of workfare which led to feelings of devaluation; undertaking self-negating activities to avoid the omnipresent threat of sanctions. Similarly to Machin and McCormack (2021), a sense of connectedness is reported by participants: peer support or feeling of solidarity with others trapped in "perverse and punitive" welfare systems (Mehta et al., 2020).

There is a tendency within the experiential research around health-based welfare policies to focus on how mental health conditions are (mis)treated by the procedures and processes of assessment. This is, in part, due to the perception that the assessment of eligibility focuses overwhelmingly on physical health (e.g. Pybus et al., 2020). Such a focus is also justified by the rates of successful applications. When transferring from DLA to PIP, claimants living with a psychiatric condition are 2.4 times more likely to have their claims rejected, compared to claimants with some non-psychiatric conditions (Pybus et al., 2019). However, the inability of assessment processes in capturing the episodic and variable nature of mental illnesses is potentially mirrored in the assessment of chronic health conditions. This may be particularly true for conditions that lack a visual element. Looking at the experiences of individuals living with energy limiting chronic illness (ELCI), Hale et al., (2021) found that the WCA fails to account for energy impairment, fluctuation and the cumulative impact of activity. Such oversights lead to misleading decisions which give no indication how many hours an individual may be able to work (Hale et al., 2021).

Hale et al.'s (2021) work also considers the climate of stigma experienced by people living with ELCI. They suggested that stigma and prejudice is rooted within the assessment processes themselves. As a result, the discounting of lived experiences serves a systematic function: stigma cannot be displaced without a fundamental reform of how health-based benefits are accessed (Hale et al, 2021). Using a heterogeneous sample of parents affected by changes to Income Support, disabled people being migrated from Incapacity Benefit to ESA and young jobseekers, Patrick (2016) examined how dominant stigmatising narratives around welfare reform were navigated by out-of-work claimants. Utilising a longitudinal design, 15 participants were interviewed at three time points. Participants spoke about the impact of stigmatisation on their lives, highlighting the relational nature of processes of stigmatisation (Patrick, 2016). Participants perceived their interactions and relationships with others (family, friends and broader society) being harmed by the negative associations of being a benefit recipient (Patrick, 2016). Over time, claimants adopted strategies to manage stigma, most notably via an 'othering' of those deemed less deserving (Patrick, 2016). Here the potential for social support and solidarity seen elsewhere (e.g. Mehta et al., 2020; Machin & McCormack, 2021) is absent. Patrick (2016, p. 255) found that participants living with a disability were likely to talk of undeserving claimants who weren't "*really* disabled". In data extracts, this distinction between those who are undeserving and deserving seems to rest on the perceptibility of a claimant's disability: "walking normal", for example, as a preclusion to an authentic eligibility (Patrick, 2016, p. 255).

Reflecting on the collection of data from individuals over different time points, Patrick (2016) concludes that it became possible to generate dynamic pictures of benefit stigma. Although not new, qualitative longitudinal enquiry is an evolving methodology (Neale, 2021). Qualitative longitudinal work enables an engagement with the temporal dimensions of experience: how are personal or social changes made sense of? Given the 'active' underpinnings of health-based welfare policies, how might an individual manage a continual engagement with processes of assessment, reassessment and workfare? Within the context of chronic unseen health conditions, this continual engagement would occur alongside the day-to-day management of a health condition. What role or function might stigmatisation discourses have in how these experiences are made sense of? Younger people living in the UK have been the most affected by 'austerity informed' policies (Mckee & Stuckler, 2013): how might their experiences be shaped by the discursive economy identified in chapter 3 of this thesis?

This study will focus specifically on the experiences of younger individuals aged 16 to 29: living with chronic unseen conditions who have applied for either PIP, ESA or the ESA component of Universal Credit – those who will have 'grown up' within the cultural contexts explored in chapter 3. What shaping role might the discourses explored in the MFA have had on young peoples' experiences? Previous work looking at how 'modern' welfare systems have been navigated (Day & Shaw, 2022) saw how older participants would make sense of their engagement with these new processes through their experiences of previous welfare regimes. There was always a potential that the previous ways of doing things may come back; that these systems (such as Incapacity Benefit) might return; the ‘new’ approaches to health-based welfare seen as temporary. How might contemporary health-based welfare systems be navigated by those who have no experience of previous ways of administering health-based welfare? This study aims to explore how these young people living in the UK experience life with a chronic unseen health condition. How have these individuals navigated the processes of claiming welfare? What role do wider discourses around welfare, welfare claimants and chronic health conditions play in participants’ sense making?

Method.

Design.

Two distinct but inseparable phenomena are the focus of this study. Specifically, these are the experience of living with chronic unseen health conditions, within the wider context of the UK’s health-based welfare policies; the impact that societal knowledge about welfare claimants may have on idiographic experiences. Beginning from a pragmatic approach, I considered which methodological approaches would best facilitate understandings of these two phenomena. As explored in chapter 2, the wider programme of research is informed by a pluralistic theoretical framework (Frost, 2011; Willig, 2017). Deploying a pluralistic framework enables us, as researchers, to make use of methodologies that previously would have been considered ontologically and/or epistemologically incompatible.

As outlined in chapter 2, the present study is underpinned by this theoretical framework: a pluralistic ‘phenomenological-first’ approach to exploring how individuals make sense of living with chronic unseen health conditions whilst claiming welfare. The pluralistic framework outlined in chapter 2 enables me to take a dual focus approach to data analysis. Interpretative Phenomenological Analysis and Foucauldian Discourse Analysis will be used to analyse the same data sets.

This study also functions as the first time point in a longitudinal qualitative enquiry. It was hoped that by taking a longitudinal approach to data collection, ‘staying with’ the same participants over different time periods, I would be able to explore individual trajectories that change, evolve or formalise within and between time-points (Farr & Nizza, 2019). As explained in chapter 5, initially planned time-points were disrupted by the COVID-19 pandemic.

Participants.

Informed by the study's 'phenomenological-first' pluralistic framework, my aim was to have a homogenous sample of participants. This was achieved through purposeful recruitment. Eligible participants were aged between 16-29 years old; were living with a chronic unseen physical health condition and had had some experience of applying for UK welfare – specifically 'post-2008' forms of health-based benefits (ESA, PIP or Universal Credit). The study excluded individuals who experience chronic illness but had not applied for welfare, and those whose conditions were related *solely* to mobility or mental illness.

Charities that supported those living with chronic health conditions, welfare rights organisations and relevant public figures were contacted and asked if they were able to assist with the promotion of the study via social media posts. The use of Twitter proved to be particularly effective: the original tweet advertising the study was 'seen' over 25,000 times. Poster advertisements were displayed in local public spaces such as supermarkets, post office notice boards, galleries and local libraries as well as on Aston University's campus. 12 potential participants contacted the researcher. All potential participants were provided with an information sheet which explained the study in greater detail. Discussions which occurred after potential participants read the information sheet reduced the number of potential participants. Potential participants were unable to take part in the study due to their age (being over 30 years old), health conditions (mental illness) and lack of interest. Eight eligible participants were recruited. Participants had a range of health conditions, however there were certain shared characteristics: the reasons for their welfare claims were predominately related to a physical health condition, which was chronic in duration and lacking in a visual signifier of illness (e.g. their condition could be considered 'unseen'). Participant biographical information is included within table 4.1.

Table 4.1. *Participant biographies using pseudonyms.*

Denise’s conditions include severe irritable bowel syndrome (IBS), asthma and an undiagnosed musculoskeletal genetic disorder which causes pain, difficulties walking and fatigue. Denise, who is autistic, went to a residential school from the age of 15. Now aged 27, Denise is a keen artist and voluntary employment advocate. Denise was previously successful in an application for Disability Living Allowance (DLA), a precursor to PIP. More recent applications for PIP and ESA were eventually awarded after appeals overturned the original outcomes.
Diane has lived with Myalgic Encephalomyelitis (ME) since the age of 11. Interviewed at the age of 21, Diane had recently completed an undergraduate degree and was due to begin a master programme in the upcoming academic year. After appeal, Diane’s second application for PIP was successful.
Alongside childhood asthma, **Lucy** has been living with idiopathic chronic back pain for eight years. Lucy was in training to become a chef before her pain forced her out of work, into a period of unemployment. Now aged 26, Lucy works as part of a professional services team at a UK university. All of Lucy’s applications for welfare were all unsuccessful.
Following a bout of pneumonia in the middle of her teenage years, **Margaret** never fully recovered. For the past 10 years, Margaret (26 years old) has been living with ME/chronic fatigue syndrome (CFS), before being more recently diagnosed with fibromyalgia. After a lengthy battle with her employer around “reasonable adjustments”, Margaret is now able to continue her work as an engineering technician. Margaret’s original application for DLA was successful; however when transferred onto PIP, Margaret needed to go through the appeals process in order to be (re)awarded. Margaret was also successful in an application for a “blue badge”, a parking permit that allows access to disabled parking spaces.
As a result of a benign tumour growth in his femur, **Phillip**, aged 29, has been living with arthritis in his hip for a number of years. Due to a series of surgical treatments, Phillip was unable to continue working in either of his previous careers: as a personal trainer or retail assistant. Phillip applied for Universal Credit however his application for the ESA component was unsuccessful. Phillip is now a postgraduate student.
Richard was diagnosed with multiple sclerosis (MS) at the age of 23. Previously a health care assistant in mental health services, Richard, now 26, works as a laboratory technician.

In-between employment, Richard had claimed Universal Credit, however his applications for ESA were not awarded.
Sarah, aged 26, was studying remotely and part-time for an undergraduate degree. Sarah had previously been a waitress, until her health prevented her from further work. Around the ages of 19/20, Sarah was diagnosed with fibromyalgia. Two years later, she received a diagnosis of Borderline Personality Disorder (BPD). Sarah was successful in an initial application for ESA (but later lost her entitlement due to her partner's increased income) and PIP.
Shelly was working full time as a marketing analyst, leading a busy and active life before becoming ill overnight. Diagnosed 10 months later, Shelly (now aged 28) has been living with ME for 4 years. Both her PIP and ESA applications were awarded, but only after going through the full appeals process.

Data collection.

The project received ethical approval from Aston University's Life and Health Sciences Ethics Committee (see Appendix 1). I designed an interview schedule which outlined topics of discussion relevant to answering the study's research questions (see Appendix 2). I structured the interview schedule in a way that expanded 'outwardly', from the micro to the macro; questions moved from individuals' experiences of their chronic unseen health conditions to the contexts of their lives in which these experiences took place. Later questions sought to explore interviewees' experiences of applying for welfare, before examining participants' perceptions of how welfare claimants are discussed within wider society. The schedule was not prescriptive, instead it acted as a guide to facilitate a semi-structured interview. Ordering of questions and examined topics were adapted to accommodate the specific contexts, emotions and chronological relevancies of each interviewee (Willig, 2021).

Due to the potential impact of chronic illness on energy levels and mobility, significant consideration was paid to offering a comprehensive and flexible array of interview methods: face-to-face at any convenient location, via telephone or synchronous/asynchronous online media. The choice of which medium would be most appropriate was made entirely by the participant. Half of the interviews (*n* = 4) were conducted in-person onsite at Aston University. Two interviews were conducted synchronously via WhatsApp's messaging; one through a mixture of telephone conversation and follow-up emails; one was carried out asynchronously via email. The length of interviews ranged from 57 minutes to four hours; those interviews taking place via online media tending to continue over extended periods of time.

Consent was taken after participants had read the study's information sheet. The information sheet described the exact topics that would be covered by the interview. A number of questions taken from the interview schedule were included as part of the information sheet (see Appendix 3). This enabled participants to be informed of interview topics prior to giving their (fully informed) consent, with the aim of reducing the potential for anxiety. Consent forms (see Appendix 4) were either completed and signed in-person or signed digitally and returned via email.

Interviews that were conducted face-to-face were audio recorded and later transcribed. All participants were given a pseudonym which reflected their gender and ethnicity. This pseudonym was used on all study documentation, as a way to underhold participant anonymity; reducing the risk of participants being identified by anyone apart from the principal investigator. Any other potentially identifying information discussed within the interview (such as town names or the names of friends or family members) were coded or omitted from transcripts.

All data, both audio recordings and transcripts, have been stored according to GDPR guidance: securely saved on the principal investigator's password protected laptop computer and online cloud storage account with servers based in the European Union (box.com). To ensure participant anonymity, only the principal investigator had access to the audio recordings. These audio recordings will be destroyed upon completion of the principal investigator's PhD. Physically signed consent forms were stored in a locked set of drawers in an office at Aston University with only the principal investigator having access to these drawers. Digitally completed consent forms have been stored within a password protected Aston University owned online cloud storage account (box.com).

Analysis.

The use of a pluralistic framework entails a 'dual' methodological approach to analysis: applying two methods of analysis to data sets (Willig, 2017). The move away from 'good health' could be considered an extended, transitional episode in an individual's life: a significant experience (Dilthy, 1976). The use of Interpretative Phenomenological Analysis (IPA; Smith, 1996) was therefore considered an appropriate phenomenological 'tool' for understanding the lived experiences of participants. As a method, IPA allows us to look in detail at how the affective qualities of the transition are made sense of by someone who is currently experiencing the phenomenon under investigation.

Both pragmatically, and as a consequence of the phenomenological conceptualisation of pluralism ascribed to, the process of analysis began with IPA. It felt important to first attempt an empathetic understanding of participants' experiences: the analyst attempting to make sense of how participants had made sense of their experiences (the 'double hermeneutic' that underpins IPA). Informed by Smith, Flowers and Larkin's (2009) iterative steps, analysis initially began with the reading and re-reading of each transcript idiographically. Each transcript was then annotated into a series of descriptive summaries describing participants' narrative accounts. These explanatory comments were analysed to identify emergent themes, reflecting both the participant's original words and the analyst's interpretation. Identified themes were further explored and organised into tentative, idiographic, superordinate themes. As a way of engaging at a more 'conceptual level' with the data, an interpretative account of each participant's narrative was written. This acted both as a summary of the overarching patterns of meaning, but also hoped to capture the felt 'sense' of each data set (Gendlin, 1986): what, interpretatively, were the most 'resonant' qualities of the participant's account? These processes were repeated for each transcript. Themes from the eight transcripts were compared and recurrent superordinate themes identified and discussed within the research team and other research settings. Following these refinements, the resultant superordinate themes came to form the foundational basis of this study's findings.

Data were then re-examined through a discursive 'lens'; an appropriate metaphor as the analyst began a process of 'honing' – or focussing – in on narrative elements identified as being discursively important. Foucauldian Discourse Analysis (FDA; Willig, 2021) was deployed to explore which discursive resources were being made use of by participants. Willig's (2021) guidelines to 'doing' FDA added structure to the process of analysis. Particular emphasis was placed on the ways in which participants were positioned by (or how they positioned themselves within) wider discourses, as well as considering how these positions could be, or were, experienced: examining which subjectivities became available or inhibited through wider discourses. In a further commitment to a dual focus approach, it became apparent that to ‘untangle’ these methods of analysis in the writing-up of our findings (i.e. presenting each analysis separately) would weaken their exploratory power. Instead the analysis was thought of as a collection of Matryoshka dolls: each methodology enabling an examination of the nested layers of an individual’s lifeworlds. FDA allowed the analyst to ‘re-examine’ the thematic findings of the Interpretative Phenomenological Analysis; a further hermeneutic of suspicion. As such, the analyses have been interwoven; written in a manner that is rooted in a phenomenological understanding, but which foregrounds relevant discursive constructions when appropriate.

Reflexivity was approached in a similarly pluralistic manner. Within the traditions of IPA, through the strategies of introspection, meaningful reflection and monitoring of one’s own reactions (recorded within a reflexive log), I was able to make sense of my own presuppositions, minimising their affect through these processes of active monitoring. It was not the intention to completely restrain my pre-understandings (if such a thing could even be possible), rather Dahlberg’s (2006) conceptualisation of “bridling” became a meaningful way to engage with these reductions: a way to reflexively dwell with my hermeneutic reflections (Shaw, 2010). In a commitment to the social constructivist perspective that underpins FDA, the analyst critically considered, recorded and examined their own assumed knowledges. This became particularly pertinent following the completion of the Media Framing Analysis: what might be expected to be ‘found’? What language might I have anticipated to be used? Within the context of the research and beyond, how was and is the analyst positioning themselves? What implications might this have for the knowledge being produced?

Findings.

Table 4.2. *Themes and discourses explored within the analysis.*

Themes	Predominant discourses
1. Gathering tools and resources: responding to the ‘event’ of chronic illness	Commodification of the self: medical power
2. Haunted by halted lives	Discourse of failed expectations
3. Please let me be understood: observed but rarely known	Rationality and legitimacy: under observation
4. The other others: on the edges of out-groups	Not like us: escaping the identity of ‘welfare claimant’

Gathering tools and resources: responding to the ‘event’ of chronic illness.

The first theme speaks to the biographical ‘event’ of a chronic health condition (Bury, 1982). Despite the array of conditions which participants live with, there existed similarities in how these illnesses were first experienced. The ‘chronic’ element of individuals’ conditions, the ways in which illness would temporally stretch into their imagined futures, required a response; a prolonged period of sense-making or a gathering of tools and resources that would enable autonomy and coping.

> *Shelly: I was working full time and I was busy pretty much most nights of the week doing various hobbies I like was part of choirs I was learning French I did um circus as well […] and then like one night like one morning I woke up and I just felt awful mm and I haven't been able to do anything like that since*

For Shelly this illness event occurred overnight. An immediate change that came and never left. An instantaneous event, but one that required a period of consideration and realisation before it could be known and understood. Comparable to a seasonal flu, in terms of the encompassing cognitive and mobility effects of symptoms experienced, Shelly began to suspect she had ME once the ‘chronic’ aspect of the condition became apparent. The usually time-limited affective states of tiredness and isolation becoming her norm; leading to a knowledge about herself prior to, and independent of, diagnostic confirmation:

> *Shelly: I didn't know a bit about it but at first I didn't want it to be that because I knew how bad it could be so I was like oh it must be something else it can't be that (.) erm and then kind of […] I knew it was before I got diagnosed*

Others found it more difficult to locate a specific time or origin-point to the onset of their condition. Instead, a diagnosis became a complicated event; in part, a reassurance that their symptoms could be 'contextualised', a diagnosis of a chronic health condition also signified the scarcity of potential medical interventions:

> *Margaret: It's a relief to find out that you're not dying but then after a little while you realize (.) okay I'm not dying but they're not telling me that I'm going to be better and they're not giving me any like medicine or anything to help me I'm still the same so (.) it's useful in the way that you know what you have but I after getting the diagnosis I found a support group*

At the time of her diagnosis, Margaret was bedridden, having exhausted several alternative explanations through a trial-and-error approach to prescribed medication. Diagnosis came at the bottom of a steady decline, a place where the severity of her symptoms had "stopped" life for Margaret. Margaret's gradual ascent from this stasis came not from a cure, nor specific medicines, but rather through a bricolage of resources learnt from a local support group. Taking the same trial and error approach used by doctors, Margaret was able to learn how changes in diet, rest and pain management could help provide her with more energy. Although the condition is not spoken of by name in the interview (the persistent absence of which creates a sense of a potentially hazardous 'incantational' quality) Margaret's diagnosis of ME/CFS gave her a label which was used to access a support group. In turn, this group provided her with condition-specific knowledge; tools with which she was able to overcome 'blocks' on the paths she envisaged herself progressing along: towards becoming "a valuable member of society". A number of participants drew upon a discourse of 'value' that was rooted in a commodification of the self. A desire to prove their worth through contributing to household incomes, but also wider economic systems, was apparent. To do so would enable individuals to position themselves outside of the discourse of 'welfare claimant'; individuals positioned as a 'drain' on the country's economy.

Learning the mastery and application of 'tools' to manage conditions and symptoms was a common experience for participants. Techniques were often devised through an attunement to embodied sensations; a developed, personalised, understanding of what actions could enable feelings of wellness, or allow a ‘reconciliation’ with pain. Speaking about both the importance of staying active through employment, and avoiding the “numbing” consequences of painkillers, Lucy personifies her back pain as a nagging pet:

> *Lucy: It's like ignoring your dog you know the more you ignore it the more it wants your attention and I think […] in a silly way that's kind of how it works I think the more I try and take it off my mind the more the worse it is or at least sort of when it does rear its ugly head it's worse because I feel like you know with distractions it's great but it's still there and I can still sort of feel it whereas I think if I was to block it out completely when I've actually did relax or try and get to sleep I feel it would be a lot worse […] I don't want to feel numb*

Although metaphorically externalised, here pain is understood as an ever-present *internal* presence; one that can, and will, intrude without warning. A type of vigilance is required by the pain’s owner. A constant state of staying active, rather than masking over the pain through rest, relaxation or sedation. Lucy evokes this metaphor for a number of potential reasons; as a way to explain how she conceptualises her back pain, but also as a justification of her desire to subvert the expectations of her partner and family – to remain employed in her physically active job as a cleaner whilst simultaneously being “in pain”. Within the Media Framing Analysis, we examined how ‘work’ is constructed as the only way in which individuals living with chronic health conditions could become empowered. Lucy is able to position herself within this wider discourse of responsibility; her avoidance of pain requires her to be a responsible social actor, to remain ‘active’ through employment.

More mechanistic metaphors are deployed by Phillip as he makes sense of his post-diagnosis life:

> *Phillip: At that point I knew going into the first operation that it wasn't gonna fix anything it was purely just kind of a it was like scaffolding you know sort of just building it up so that we can actually fix the main problem so um yeah (.) so I knew that it wasn't going to improve during that time and so going back to work was was always going to be a problem*

Prior to experiencing skeletal-muscle difficulties, Phillip trained and worked as a personal trainer. Deploying this, richly detailed, physiological knowledge base Phillip understands the causal chain his body exists within. We are able to see how Phillip perceives the ‘process’ of becoming well: a construction project, that requires a number of distinct stages that build upon one another, leading towards an endpoint. In doing so Phillip comes to terms with the length of time a slow and incremental recovery may take, whilst also minimising the sense of control that he may have over the situation. Progress is a group effort, however Phillip's body (specifically his femur) is the site of construction; the surgeons and medical teams are the site's builders and engineers. In comparison to Lucy's previous account of tool use, Phillip's narrative retains a sense of inevitability: actions that were done to him, rather than by him, casually leading to specific, unavoidable, outcomes.

> *Diane: A doctor told me not to look up my condition online. And because they're a doctor and they're supposedly an expert and an authority figure you trust that. So I went years before I really researched it. And then it turned out all these symptoms I'd been having that I didn't truly understand, were actually my ME […] Because it's in the guidelines as a psychosomatic disorder that you don't suggest symptoms to them […] So all the hypersensitivity symptoms I was having, I didn't know what that was. For example I used to get disorientated in supermarkets from the sensory overload. And I just thought there was something wrong with my brain like I was crazy*

Contrary to the experiences of other participants and through the actions of her doctor, Diane was denied the chance to gather resources, or even fully make sense of her condition. Implicit in the above extract are the consequences of ME's "psychosomatic" construction. The doctor able to justify the withholding of knowledge; Diane, the patient, positioned as naïve and vulnerable. To be granted more knowledge around her condition would worsen her symptoms: the doctor's actions towards Diane become 'well meaning' and responsible; 'protective' rather than an exertion of power. As a consequence of this authoritative, 'medical model' approach to knowledge, Diane is unable to make sense of her symptoms. A fearful sense that experiences of sensory overload were symptoms of a disorder of the mind.

In this theme we have seen how participants reconciled their understanding of the self in response to the biographical disruption of chronic illness. Their fluctuating inability to contribute to society throughout employment drew upon a discourse of commodification of the self: a reduction of the self down to its economic value. As such personal vigilance is needed, to keep symptoms (such as pain) at bay. Through these displays of individual responsibility and understandings of how their bodies are affected by their conditions, participants aim to take control of their progress towards health.

Haunted by halted lives.

Within this second theme we see the complex ways in which loss is experienced by participants. Individuals' narrative accounts were imbued with a felt sense, a mood, of losses. For some, the unpredictable nature of their own physical capacity was understood through an almost Cartesian dualism; a separation between mind and lost bodily function. Other losses were more existential: futures that were once anticipated, almost-tangible, now slipping away. The presence of these once future destinations remained, gaining a haunting quality as participants resigned to newly rearranged and readjusted hopes.

> *Lucy: I just finished an apprenticeship and I was so eager to get into work and I was really looking forward to it but I found that once I got into I suppose a real chef job I found that I couldn't handle it and that was that was really difficult 'cause at the time it was something I really wanted to do and I still like cooking now but I've had to face facts can't stand for 14 hours*

Lucy's back pain began at a transitional period in her life. Having completed an apprenticeship and begun a role as a chef, the physical limitations of her emergent condition forced Lucy to confront her ability to continue along this career path. Lucy describes this self-confrontation as if being "railroaded"; being forced off-track through a mixture of her own physical struggles and the unsympathetic actions of her employer. Lucy's analogous use of rail tracks evokes a notion of fixed direction; of progression and forward movement. 'Down the line' are the hardships of her apprenticeship, but these hardships were full of purpose as they led ahead to a "wanted" career. The sense of 'peak' potentiality present when discussing this period in her life ("I was really excited about something for the first time ever") collapses: the train cannot be returned to the tracks.

Sarah's health caused her to leave university and paid employment. Against the backdrop of Sarah's role within her family's history, and their perceived hopeful expectations, having to claim welfare compounded Sarah's feelings of personal failure:

> *Sarah: I think the feelings of failure are because of the pressure that I've always put on myself. The only thing I had going for me as a child was that I got good grades. My family were always so proud of my grades and I was the first person in my family to go to university. When I had to drop out I felt like such a failure, and like I'd let my family down (although they continued to support me). My whole family work too, so when I had to stop working it was hard as well*

Sarah interprets her feelings of personal failure in a number of different ways. Although coming from ‘within’, a pressure that she exerts upon herself, Sarah entangles her trajectory with the seemingly gentle hopes of her family. As a child, Sarah’s sense of self-worth is attributed solely to her educational achievements. However, rather than linking her self-worth to her family’s feelings of pride, Sarah appears to keep these emotions independent of each other. When later having to “drop out” of university, the consequences are felt by Sarah in distinct ways: first as a personal failure (based on her own pressures and self-expectations), before a perception of having disappointed her family, through a reneging of her role as the first in her family to attend higher education.

Sarah’s wanting to make her family, in particular her father, proud reoccur throughout her account. That she once held a role through which familiar hopes of a better life were channelled:

> *Sarah: I grew up on a council estate and I think my dad always hoped I'd end up somewhere a bit nicer. Although, my dad has always said that as long as I tried my best, then that's good enough. It's something I try to live by, but I always want to make him proud, even now that I'm an adult*

As hopes are readjusted, Sarah is unable to shake the frustrations of her lost independence. Needing to rely on her partner for financial assistance, and additionally having to ‘open up’ her partner’s finances to examination by the DWP as part of her application for ESA collectively serves as a reminder for Sarah of how things might have been; how different her and her family had hoped things would be.

In the below extract we can see similarities between Lucy and Phillip’s occurrences of illness; both beginning at a potentially transformative period in their lives:

> *Phillip: Ironically when I was doing the personal training I was kind of just at the point where I was like okay I've got enough money to kind of look elsewhere and thankfully it happened when it did 'cause otherwise if I kind of well I was literally at the point of right let's let's get a flat or get somewhere that I can call my own and then I would have had to cancel everything and lost an awful lot of money and so yeah I was living with my mom which wasn't the easiest thing given everything that was going on she was very (.) […] we had a few arguments 'cause um I was very much trying to be positive about it and at that point in time I was very much right I want to go back and return to personal training and not just get back to a*

> *normal sense of life and um she was very "oh what if you can't do this?" "what if you can't do that?"*

For Phillip there is a sense of relief; that the ‘jump’ to living in a flat of his own didn’t happen and that the associated financial difficulties that would have been incurred were subsequently avoided. However, the likely impossibility of continuing with his profession becomes more difficult for Phillip to resign himself to:

> *Phillip: I keep being tempted back into personal training especially 'cause people keep asking me and I'm like ohhhh like I just don't want to do anything that would jeopardize [his studies]*

Driven by a ‘core’, fundamental need to help others, Phillip had developed a sense of purpose and identity around the job of personal trainer. Uncertain he will ever be able to return despite persistent-present hopes, ghostly temptations and desperations, he becomes a trainer of one: a self-trainer, using these skills and expertise to train himself, to develop the muscle strength that will enable him to manage the arthritis.

> *Richard: So the numbness had got that bad that it was completely detached […] you know I would look at it and my hand would be completely straight but my brain would be telling me “actually your hands doing this” and I'd look at it and you know*

Richard’s losses are symptomatic of his MS: an embodied loss of function, a creeping numbness that is experienced as a significant detachment between his body and mind. But Richard’s account also reveals the way in which *time* is lost for those living with chronic health conditions and claiming welfare. In accounts similar to those shared by other participants, routine and days of good health are lost to the bureaucratic processes enforced by the state, employers and healthcare providers:

> *Richard: I did ask for office work and then she just didn't chase it up she just ignored me to the point where I just had to carry on I had to just stop and go on the errr Universal Credit and I just hope that I'd find something on the other end (.) so it wasn't the best [laughs] it wasn't the best you know like you dealing with this I didn't need to deal with bad management*

This theme examines the ways in which lost futures are experienced by participants. Their hopes and intentions for their future lives lost, or forcibly readjusted, by chronic illness.

Finding themselves temporally ‘out of joint’, participants are haunted by reminders of what could have been, instead having to grapple with the label of being perceived of as a ‘failure’.

Please let me be understood: observed but rarely known.

The third theme explores the ways in which chronic illness is experienced relationally; how the lack of a visual component for many participants (the ‘unseen’ aspect of their condition) regularly led to feelings of being intersubjectively misunderstood. Individuals often felt ‘vulnerable’, exposed – or at the mercy of – a wide range of organisational power structures.

Many participants found that being young and unwell presented an ‘incompatible’ picture for the outside world. To be ill and young violates a ‘natural order’ of how things should be. As a consequence of this ‘violation’, many participants experienced mistrust, suspicion and discrimination. These responses came from a wide variety of sources: family members, friends, employers, schools, members of the public, healthcare professionals and the DWP.

> *Shelly: I think I've been lucky in that my parents have been really good like I think I think unless you've lived it up you can't understand it but they try to understand it and they believe me which I know some people don't have that some people their family don't believe that they're really sick*

For Shelly, an empathetic understanding must first be grounded in belief: a belief that her condition and symptoms are real. This belief can then enable degrees, or proximities, of understanding. It isn’t possible to reach a state of full understanding, to understand completely what Shelly has experienced. However, like her parents, it is possible to *try*. Understanding here is a show of support, a validation of her experience. The stress and hurt of being found ‘fit for work’ by the DWP exacerbated her health condition, partially through by a misplaced sense of having been understood. Within the time and space of her work capability assessment, Shelly felt as though the assessor had attempted to understand her; that the existence and effects of her condition (ME) had been believed. However, a reoccurring motif within participants’ accounts was that of receiving “zero points” in post-assessment reports used by the DWP to determine ESA or PIP eligibility. Participants interpreted receiving zero points as an indication that their condition was thought to have no impact on their lives or ability to work. This quantitative lack of acknowledgement served as a revelation for Shelly; an upsetting realisation that she had misplaced her sense of being understood, that her low expectations of empathy and monetary award were not met:

> *Shelly: I still remember the way it felt to see that they had just completely not believed anything I'd said and thought I was fit to work it was quite upsetting I sort of expected to not get the full amount I expected but I didn't expect to get nothing [laughs]*

This revelation leads Shelly to re-reflect on her assessment. Recontextualising what was initially thought of as an attempt by the assessor to understand her experiences; on further reflection becomes known as a successful attempt at manipulation. The assessor's words now retrospectively understood as being "put" into Shelly's mouth to actively construct a narrative that did not match her lived experience.

> *Shelly: During the assessment I thought like maybe I kind of she maybe like kind of she was understanding and um (.) then when err at times there were times when I was struggling cognitively and she was putting words in my mouth and then afterwards I sort of realized well actually that's not actually true*

Richard experienced similar levels of hurt at receiving zero points. Richard's pain was made sense of through a different conceptualisation of 'understanding', one that focusses on the external validation of his currently invisible symptoms:

> *Richard: At the end of the day and I think it's because you know everything I tell them I've got is a symptom there are no signs err you know unless you (.) […] because I look okay I look healthy I look like everything's fine it was none it's just zero nothing absolutely nothing for them nothing wrong with them just let them get on with it and carry on with whatever it is that they're dealing with (.) and I was a bit of a (.) a kick because it came as soon as it came through the post […] you know only need 5 points for mobility and I'm looking at it's like I'm a total nothing a zero like I wouldn't even need any of those things but the the zeros the zeros hurt a lot and it's like you could have put them somewhere*

Symptoms, such as fatigue, that lack a visible 'signifier' of illness become open to ontological dispute. That which cannot be seen, or inferred, becomes likely to be disbelieved. Here we see how the assessment process is perceived by participants to draw on a discourse of rationality: the objectivism that is inherent within the system. An observable entity is needed to corroborate an individual's claims. Richard understood the DWP's lack of validation (shown, again, by the zero points received in the WCA report) through the unseen nature of his condition. By not needing to use a crutch or a wheelchair, Richard expresses both frustration at being considered "not unwell" but also a sense of despondency; that by not having these signifiers, the possibility of receiving support from the DWP becomes impossible. Instead, he will be left to “carry on”. This sense-making, however, does not remove the hurt that these zeros cause: the felt ‘nothingness’ of state positioned invalidation.

Richard’s account reveals the limiting practices made available by the DWP. Access to support (e.g. to be found ‘incapable’ of work) relies on the ways in which potential claimants align with specific constructions of illness or disability; illness as temporary and disability needing to be “severe”. Participants spoke regularly of medical evidence from healthcare professionals being ignored; all that was salient was how they presented within the context of their assessment; what could be observed and recorded by the assessor. The assessments faced for PIP and ESA beginning from this epistemological stance of disbelief, with almost illogical thresholds for what could be considered knowledge. Given the lack of a foundational belief, the assessment process becomes incapable of ‘understanding’, rendering both the process and outcomes unable to be understood by those whose lives the reports purported to reflect. Participants often spoke about the dehumanised ways in which they were treated; feeling as if they were being observed and processed by “robotic” assessors:

> *Phillip: It was very automated almost you know robotic it wasn't it wasn't any kind of personal care or you didn't feel valued […] just feels like they've got targets to meet let's just rush through [laughs] on to the next one sort of thing*
>
> *Richard: I can't have been in there longer than 10 minutes so it wasn't a thorough “we’re really going to get to the bottom of what's wrong with you what help we can give you” it's just in you’re done off you go really robotic is genuinely how you'd have to describe it […] it felt like they that didn't want you there like you're a burden on their day like it's their job but they want you out you know you’re in and they’re like “oh I can’t be bothered to deal with this let's just send you on your way and then afterwards I’ll write up that everything’s fine”*

Through the sense of dismissal present in both Richard and Phillip’s descriptions of their assessments, these accounts reveal the complex ways in which welfare assessment processes appear to dehumanise. However, dehumanisation is present in myriad ways. It is not just a dehumanisation of those who are being assessed, an understanding that may match the more ‘traditional’ applications of the medical gaze. Instead, the assessment process has created workers (proximally employed by the state) which are functioning as target-driven robots. In turn, these robotic entities devalue those who are being assessed. Participants’ accounts of living with a chronic health condition are reduced down into burdensome tasks; there is little desire, need or capacity to engage ‘humanely’ with these stories, instead fictional accounts can be processed and written up at a later date.

The lack of visible signifiers of illness left participants vulnerable to comments and judgments beyond the formal assessment setting. The following extracts from Margaret’s interview demonstrate the ways in which presumptions of ‘wellness’ manifest in daily life:

> *Margaret: It is some people would just do it jokey and be like “oh you’re a young young woman you should take the stairs” um but other people would err be very unpleasant about like tutting and huffing at you and you'd just be like (.) what (.)*
>
> *Margaret: And it's weird when you get um say other people using the disabled bays who might be in a wheelchair or whatever and them looking at you funny or comments like (.) “are you more disabled than me?” How do you feel (.) right to say that you deserve it and I don't*

The ways in which Margaret needs to spatially interact with her surroundings becomes a point of contention. Strangers assume that she is making choices: using an elevator at work to go up one floor, parking her car in a disabled bay. To them, the way that Margaret is outwardly ‘presenting’ allows judgement or overt questioning of her actions. Based on her age, mobility and lack of signifier of disability, Margaret is presumed to not meet the criteria necessary to use the spaces in the way she needs to. Such reactions reveal the ways in which people living with both chronic unseen health conditions *and* more visible disabilities are policed: that their ‘being-in-the-world' becomes contingent on matching constructions of what it is to be unwell or less able.

Margaret makes sense of these instances of public objectification in a number of ways; initially as a stark reminder that although some progress has been made in raising awareness of unseen health conditions, more “education” is needed. The historical construction of her health conditions (ME/CFS) also becomes pertinent:

> *Margaret: So I know that the illness that I have (.) probably when I was a very young child they used to call it was it yuppie flu […] from what's been explained to me that means that posh privileged people who were pretending that they were ill so that they don't need to work*

Although, because of her age, she is able to position herself as outside of when these constructs first developed, Margaret is entangled within the legacy of the questioned legitimacy of ME: a ‘contested’ condition, one that is rooted discursively in class privilege. Despite feeling able to distance herself from these discourses around ME, Margaret is able to make sense of her encounters through an engagement with how her condition has been constructed. In doing so, Margaret shifts her intentionality of potential blame; the reactions of strangers become understood as an available subjectivity. As a consequence of the ways both ME and welfare claimants have been constructed by “programs on TV or newspaper articles”, ‘jealousy’ is the subjective experience made available for those who are not unwell and not claiming welfare. A jealousy towards people like Margaret, who appear to be healthy and young individuals who are seemingly receiving money and state support for no apparent reason. Within this discourse of ‘legitimacy’, the observation and questioning of individuals becomes a readily available practice; an almost civic duty, a way of making sure that no one is ‘getting away’ with anything they shouldn't be.

> *Sarah: I have visible self-harm scars so quite often I feel like there isn't much point in pretending that I'm not mentally ill. Fibromyalgia is harder I think, as when I do go out I often put makeup on and I look healthy so people assume that there's nothing wrong with me. They don't see how much I struggle on my bad days, which are far more frequent than my good days.*

When discussing the intersubjective ways in which her conditions are experienced, the ‘duality’ of her conditions (one physical, one mental) creates a paradoxical presentation for Sarah. Sarah’s self-harm scars make her mental health visible and observable, bringing about an openness to her mental health. Whilst her fibromyalgia is often misunderstood: with the application of make-up she will look and present as “fine” until the brain fog descends and she is embarrassed to be discovered as “ill”.

Like Margaret, Denise had experienced instances of receiving unprompted comments from people they did not know. For Denise, however, the greater concern was feelings of being observed by the DWP, outside and beyond the context of an ESA or PIP assessment:

> *Denise: The only time i go out alone is when i have a good day, and it always makes me anxious that the dwp will be spying on me or something* 😂 *Like if they can go out today they can do it all the time or bs idk [bullshit I don’t know]*

This sense of potentiality present within “good days” of health becomes tainted by the mood of being observed: the DWP always possibly spying, waiting to make inferred generalisations about what Denise ‘*really*’ can do. These weather-like moods extend into Denise’s virtual lifeworld: their social media presence becoming “locked down”, viewable only to those friends they know can be trusted. Cumulatively these responses to feeling observed create a sense of opportunities for freedom becoming ‘closed down’. Later in their interview, Denise specifically identifies David Cameron (British Prime Minister from 2010 to 2016) as a “dredger” of discourses around welfare claimants. Denise views Cameron as exhuming Victorian conceptualisations of the deserving and undeserving poor; an unwelcome past returned to the present. These positioning discourses are understood by Denise as leaving them directly vulnerable to assumptions of fraud. However, despite the pervasive, ‘top-down’ construction of this divisive rhetoric, Denise asserts the individualistic ways in which people may choose to ‘take up’ available practices and subjectivities; that swallowing and regurgitating such discourses tells us something meaningful about that person’s character.

Diane’s account of becoming ill whilst within the UK school system illuminates the ways in which power can shape and subjugate experience. Her incapacity to attend lessons regularly impacted on the school’s overall attendance metrics. A consequence of this was that Diane was treated hostilely; as a likely truant who had been successful in manipulating the sympathies of her parents. Diane’s actions at school were observed and recorded by teaching staff and school administrators, in a manner tantamount to the collecting of evidence. Justified feelings of paranoia forcing Diane to intersubjectively ‘disconnect’ from the social worlds around her:

> *Diane: They claimed that I was an 'active girl who they saw playing football with the boys'. I remember the occasion. My friend's were playing football. I was having a good day and frankly could have lightly joined it. But I was paranoid that they were watching so I sat out and held everyone's phones*

Diane’s response to these accusatory misunderstandings was to “prove them wrong”. Education, and succeeding within educational systems, became a way for Diane to become ‘known’. Getting good grades, and exceeding expectations, emerged as a complex motivational drive for Diane:

> *Diane: And then funnily enough they stopped giving me a hard time when I got As in the mock exams*

Diane initially revels in demonstrating how wrongly she had been judged. When learning in a more supportive environment (university), education for Diane becomes less ‘goal-orientated’, and more about the meaningful journey she finds herself on. The potential, alternative life she may have had akin to being lost, directionless, in a gentle breeze: “otherwise I'd just be floating along doing very little”. This sense of purpose is imbued with a desire to reach her potential, to be able to ‘contribute’ to a wider society through her academic abilities. PIP assessments do little to alleviate Diane’s feelings of being a burden. However, being able to access support and welfare empowers Diane to feel hopeful for a burgeoning independence.

This theme has shown how attempts to ‘objectively’ record the effects of illness actively dehumanise and reject participants’ embodied knowledge. Participants report feelings of disbelief that come from a range of powerful, observing, sources, ‘shutting down’ or inhibiting ways to be in the world.

The other others: on the edges of out-groups.

Within the final theme, I explore the ways in which participants make sense of being a welfare claimant; the ways in which the value-laden label of ‘claiming benefits’ is negotiated. For some participants the identity is to be embraced, a shared experience that entails solidarity. However, for many others it becomes difficult to reconcile their own experiences with the label that is put upon them. Through feelings of being more fortunate than imagined others or finding it impossible to relate with ‘stereotypical’ welfare claimants against the cultural backdrop of wider discourses, there is a sense of not wanting (or being unable) to belong.

> *Denise: I was sat in a waiting room with other people […] Everyone else seemed upset too*

Whilst in the waiting room prior to his ESA assessment, Denise felt a commonality with those present. A shared mood of waiting in purgatory, before the ‘confession’ like assessment begins the decision process: are they to be the deserving or underserving poor? For Denise, resisting these further divisions was salient, an illustration of their collective conceptualisation of the struggles faced by those living with chronic health conditions.

However, for many participants, the discursive construction of ‘welfare claimants’ problematised notions of solidarity. What they saw, heard and felt within assessment centres acted as a confirmation of stereotypes; wishing to position themselves outside the group identity of ‘welfare claimant’. In the following extract, we are able to see the ways this is achieved interactionally, between Richard and the interviewer:

> *Richard: So you go in and it's full of old people and as much as you don't want to be prejudiced chavs [laughs]*
>
> *I: [laughs] Okay yeah*
>
> *Richard: It’s old ladies and then really angry chavs who are getting annoyed that it's taking 20 minutes more and all this kind of stuff and they're all there and they're making sure that they're getting their bus tickets claimed and everything is yeah they get in as much from the system as they can and I'll just sat there like I didn’t know I could claim my bus pass back no one told me this*

Describing his arrival at an ESA assessment centre, Richard constructs an account of fellow claimants that is discursively rich. In an attempt to ‘disclaim’ any accusations of prejudice, Richard acknowledges (at a distance, the switch to second person affording him a position of generality) the use of classist language. A term that first appeared within post-millennial UK vocabulary, “chav” has become understood as a “ubiquitous term of abuse for white working-class subjects” (Tyler, 2008). The chavs in Richard’s account are angry, inpatient and know how to ‘play the game’ of welfare; seemingly with an intricate knowledge of what expenses can be claimed. Drawing upon these discursive resources enables Richard to linguistically distance himself. Lacking this knowledge distinguishes Richard from the chavs; they may share the same space (and are presumably hoping for the same outcome) but cannot be considered ‘the same’. Richard’s age and gender precludes his inclusion as part of the other group type of welfare claimant present (“old ladies”); the only possible position left is that of a group of one.

Richard’s construction remains unchallenged by the interviewer. Wanting to retain my role as an empathetic ‘researcher’, my acknowledgement nonetheless permissively perpetuates a construction of welfare claimants that draws upon a number of stigmatising discourses (such as claiming welfare as a ‘choice’). Shared commonalities between the interviewer and

Richard (in terms of gender, race, class and educational background) are later evoked by Richard as a means to further position himself away from other welfare claimants:

> *Richard: When they do report on this kind of stuff I don't they pick people that you I think they do give you that preconceived notion like they pick those people that you look like they expect them to as horrible as it sounds like you look at them and you go yeah that person looks like they're claiming benefits and then it's like they actively seek people that (.) aren't bucking the public opinion on it you know they're not picking people like us because we don't look like we're the type of people that you're expected to we're not the kind of old people we're not the the young moms we're not you know that the people that kind of have that image that you would then go oh yeah*

Discussing media representations of welfare claimants, Richard separates himself and the interviewer away from those people who "look like" they claim welfare. Those individuals are not "people like us". The implications of this orientation are numerous: Richard and the interviewer become bound together, collectively critically examining the ways in which they have been mispresented, and disempowered, by the media. However, this struggle is not one built on a wider solidarity for *all* welfare claimants: instead the validity of these stereotypes is reinforced. Richard distinguishes himself further by drawing upon a discourse of responsibility: he *wants* to be able to work; his claiming of benefits is born from a need, rather than the result of a choice. Later in the interview, Richard explores his hopes of avoiding the practices and subjectivities available to those who can be understood as stereotypical welfare claimants. In doing so, he makes use of the metaphor of being tarred "with the same brush". His hopes are to avoid the brush; the shameful staining that comes from being positioned as a recipient of welfare.

The metaphor of welfare as being stain-like is also present in Phillip's account:

> *Phillip: You almost felt like a criminal like you felt very (.) [sighs] dirty I don't know like yeah [...] just wanting help and I mean I could see it wasn't like I imagined you know I can sympathize with them they obviously get a lot of people that are perhaps not true cases but I mean they could see I had an operation it wasn't as if there was no cause for what was going on*

Here welfare becomes a dirt that sticks to, and marks, Phillip: a felt consequence of wider discursive constructions. A level of stigma that feels comparable to being convicted of a crime; the act of seeking support from the state entailing a loss of rights or claims to citizenship. The objective 'facts' of his case, medical evidence that shows he was recovering from an operation, is ignored. Instead he receives practices afforded to prisoners; suspicion and dismissal. These responses occur despite his sympathies towards the process and policy; positioning himself away from potentially fraudulent 'other' claimants.

As previously explored within the study's third theme, having applications for ESA or PIP rejected brought about feelings of hurt, anxiety and in some cases exacerbated health conditions. The discursive ideas explored above offer some insight into why some of these subjectivities became available for participants. The demarcation of group membership; that they were not legitimate or genuine claimants led to feelings of shame, embarrassment or further stigmatisation:

> *Lucy: I wasn't eligible for benefits either so how useless did I feel then?*

Lucy's experiences of rejection (which came swiftly after her initial application), compounded feelings of 'uselessness'. Forced to give up her job, unable to contribute to her and her partner's household costs, whilst also unable to access state support, Lucy renders herself of no use. Here use appears to be understood in economic terms; what Lucy can (or cannot) provide, and the autonomy that some level of financial recompense would provide. Lucy describes the desperation with which she wanted the independence that a small amount of money could buy. Despite these initial feelings of helplessness, the act of rejection is later re-understood by Lucy as a welcome "push":

> *Lucy: I do feel like you know I was fairly upset that I didn't get it […] but I understand now that actually it was a push in the right direction for me […] it helped me get back into work and it made me more determined to try and you know not get better but manage it better*

Conceptualising rejection in such a way mirrors the discourse of individual responsibility explored within the Media Framing Analysis; that individuals have a responsibility to find employment (and that citizens should be *expected* to do so). Constructing welfare as a limited resource, Lucy reasons that her financial and emotional difficulties were a worthy, almost sacrificial, contribution: "I don't want benefits to be cut for everybody 'cause one extra person's got it you know what I mean?". Within this discourse to receive support is to take from someone who may be in greater need - a potentially irresponsible action. Making further use of concepts from behavioural economics, Lucy expands her “push” to a “nudge” that could be applied to all welfare claimants; a way of checking in, ensuring that their health circumstances are the same, and confirming (crucially) that welfare is not ‘hindering’ claimants’ lives. For other claimants, could being forced into activity be the same welcome “nudge” that was experienced by Lucy?

Burdened by the continued bureaucratic requirements of claiming welfare (collecting medical evidence, attending regular appointments at Jobcentres etc.), the accounts of all other participants suggest they would not welcome further nudges from the DWP. The pervasive looming threat of future reassessments culminate in a specific fear for Sarah: the fear of losing more of her already diminished independence:

> *Sarah: I think what makes me nervous is the insecurity of it all. It feels like they're constantly looming, looking for an excuse to reassess you*
>
> *Diane: I'm dreading going through it in 3 years again*

For Sarah and Diane, the looming dread of reassessments functions almost as a ‘saturation’ of their daily lives, a felt mood that clouds their senses of security. Sarah has heard stories of loss from other claimants: having the amount of money received reduced; finding themselves housebound through the loss of mobility support. Reassessments reveal the unpredictabilities of the system (decisions that illogically change reports created just 2 or 3 years previously) whilst also illuminating the precarity that participants could be considered as ‘genuine’ claimants. Coupled with the panopticon-like levels of observation, participants’ accounts illustrate the ease in which their awarded claims could be removed. Unable to work, but ineligible to claim welfare, such delegitimization would expose individuals to the positions of the *other* welfare claimants; the close-to-hand constructs of chavs, shirkers or scroungers. This is an unwanted group membership, complete with the staining subjectivities of shame, embarrassment and (further) stigma.

Other forms of social comparison occur between participants and the imagined other welfare claimants. Reflexively considering their “luck” gives way to feelings of guilt or acknowledgements of privilege. In some accounts, these comparisons are financial in focus; others consider the social support they have access to or the fluctuating impact of their conditions on their well-being. There are always others, often unknown but existing 'out there', who have been less fortunate than themselves:

> *Diane: But I also felt sort of guilty because though by no means rich, I have my lower middle class, not in poverty family as a safety net*

Having family finances that could potential act as "safety net" is, for Diane, a source of guilt. These feelings of guilt are understood relationally; she is aware that this is a privilege unafforded by many people living with chronic health conditions. The presence and support of her parents puts her in a position that other PIP claimants cannot occupy. Discursive constructions of welfare as a 'safety net', which appear within policy documents and political speeches, are not present in Diane's account. The state cannot be relied upon; the significant costs and 'burdens' of illness can only be shouldered through social support.

This theme explores the complex ways the construct of 'welfare claimant' is navigated by participants. For some what was seen, heard and felt acted as a confirmation of stereotypes, problematising notions of solidarity. The position of welfare claimant is to be avoided, the potential associated stigma acting – for some – as a motivating push into paid work or as a threat to their own legitimacy. For other participants other welfare claimants remain only imagined; impossible to know directly.

Discussion:

This dual focus analysis has considered participants' experiences of claiming health-based welfare benefits whilst living with a chronic unseen health condition. Guided by the epistemological and methodological framework outlined in chapter 2 of this thesis, the analysis of this data took a 'phenomenological-first' approach: initially applying Interpretative Phenomenological Analysis to data, before using Foucauldian Discourse Analysis to 'hone in' on data considered discursively rich.

Such an approach enabled an analysis that illuminated how discourses around welfare, and welfare claimants, are lived *through*. Constructs of individual responsibility, citizenship and legitimacy are regularly made use of by participants, as they position themselves in – or outside – of these discourses. Participants' lived experiences often came into conflict with these dominant ideas. Conditions that lacked visual signifiers of disability were open to ontological dispute. This position of dispute was particularly notable for ME/CFS as its biopolitical genealogy as a ‘contested’ illness, symbolic of economic privilege, was used to contradict how the condition was experienced. Such dismissals add to the body of research around how ME/CFS is perceived by others: regular occurrences of invalidation which are rooted in disbelief, rejection and suspicion from health professionals and social networks (Williams et al., 2019).

Discourses of expectations and legitimacy were understood as justification for why participants were subjected to panopticon-like levels of observation. Phenomenologically, we can make sense of this continual observation as a felt mood. Drawing on Heideggerian terms, we can conceptualise mood as both disclosing and concealing the structures of the world. Mood is not something that we necessarily give attention to, rather it is the ground from which our affective states are thematized (Trigg, 2020). The looming dread of reassessments saturating participants’ daily lives, is a powerful example of the pre-reflective nature of mood. For some participants, the insecurity and certainty fostered by reassessment processes structured their everyday contexts.

A secondary mood is present within participants’ accounts, that of being haunted by lost futures. Unlike the discourses of illness as a temporary state seen in the Media Framing Analysis, for participants the chronic nature of their conditions disjointed temporary experiences. Traditionally used within the analysis of film, music or literature; or of the historical contexts underpinning geo-politic perspectives, I wish to make use of Mark Fisher’s (2012) expansion of Derrida’s notion of hauntology to further explore how these losses were experienced. Participants found that what they had imagined their lives to be, their future hopes and intentions, were radically altered by chronic illness. In some cases, these losses compounded feelings of failure or of becoming a disappointment. In doing so these future plans retained a spectral quality: they were neither fully present (i.e. materialised realities) nor fully absent. Hauntology is not to do with one’s belief (or not) in ghosts, but rather a consideration of this present absence; the interplay between past, present and future (Tseliou & Benozzo, 2022). Derrida’s categorisation as a post-structural thinker may suggest that this present absence would benefit from a discursive consideration. However, due to its *felt* nature, I want to approach it from a phenomenological perspective. Could phenomenology, a study of experience, offer an understanding of experiences that can no longer happen yet are still evoke some features of 'an experience'?

The experience of being haunted by a changing sense of how we imagined our lives to be are surprisingly common. Due to the choices and decisions we make, biographical futures that we anticipated, or imagined may occur, no longer feel possible or within our grasp (Neale, 2021). Everything is possible only on the foundation of a whole series of absences, which precede and surround us (Fisher, 2013). Scott (2020) contextualises these negative social phenomena within a broader sociological theory of nothingness: the phantom forces, things that we have not done, had, or become. For Scott (2020) narratives of nothing aren't necessarily sad and sorry tales. Instead, lost futures may give rise to dignity, acceptance and peaceful pain relief (Scott, 2020). However these 'positives' are another absence in this data. Within the context of chronic illness, the disruption of illness upending taken-for-granted assumptions (Bury, 1982), may offer a reason why these positives are missing. A lack of autonomy may explain why participants' losses have a heightened affective quality to them: the absent is more present because it was taken rather than given. Temporality has been a consideration of phenomenological research into experiences of chronic illness (Toombs, 1990; Todres et al, 2007; Jowsey, 2016). An avenue for future work in this vein could be into the moods produced by the discontinuities of time; by futures that can no longer come to be.

The unnerving, robotic approach taken by assessors is indicative of the attempts at procedural objectivity. Termed by Fine (1998), procedural objectivity refers to the ideal of a method which regards objectivity as a function of neutrality, detachment and disinterest (Porter et al., 2021). The assessments faced for PIP and ESA began from an epistemological stance of disbelief: the assessor distrusting the individual's perspective. In doing so, assessors actively rejected the potential to humanely, empathetically, understanding the lived experience of a condition. Instead, assessors foreground their own empirical observations and conclusions: becoming arbitrators of knowledge (Porter et al., 2021). Such an approach to illness has parallels with rational, task-driven care practices, whereby impersonal technological progresses increase the distance between hand and world (Todres et al., 2007). Ritzer (1993) writes convincingly about how concerns for rationality, speed and efficiency encapsulate the "McDonaldization of society". Exemplifying this line of thought through health-based welfare policies, like McDonalds' restaurants, the administration and processing of welfare systems are designed to be standardised, moving claimants/customers quickly through rational assessments. This privileging of rationality is at odds with an existential understanding of what it is like to be human or, more specially, the complexity and 'messiness' of being ill. In the emotional repercussions experienced by participants following these 'rational' assessments, we can see the dehumanising consequences of these decisions: how the materialisation of objectification leads to the "hurt" of being awarded zero points or being found fit for work.

Through the final theme we see how the complicated relationship participants had with the label of 'welfare claimant'. In many accounts encounters with other welfare claimants take place in specific spatial contexts: whilst waiting in rooms ahead of assessments. In some instances, these encounters evoke feelings of solidarity similar to those reported elsewhere in the literature (e.g. Mehta et al., 2020; Machin & McCormack, 2021). However, in other circumstances, talk of undeserving claimants is common. As seen in Patrick (2016), some participants are keen to distance themselves from underserving welfare claimants. An application of the social identity theory can help, in part, to understand these reactions. An individual's social identity is that part of the self-concept that derives from these group memberships. If a group is socially devalued, individuals will prefer to dis-identify and attempt to leave the group (Ellemers et al., 1993). However, throughout this thesis, we have seen how the group boundaries of being a welfare claimant are impermeable: it is extremely different to avoid the stain-like stigmatisation of welfare. Corrigan, Watson and Barr (2006) suggest that such circumstances may lead to the paradox of self-stigma: personal reactions which may either decrease self-esteem for some, whilst others are energized by experiences of prejudice and are able to express righteous anger. A third group is also conceptualised: individuals who neither lose self-esteem or become angry; they remain able to ignore the effects of stigma (Corrigan et al., 2006). The most common response by participants is in this study is a resigned frustration. Yet this frustration is directed towards other members of the social group they find themselves in, it is turned towards the chavs and old people, who represent the underserving welfare claimant. Why might this have occurred?

Chapter 3 explored the successful (re)stigmatisation of those who claim health-based welfare benefits. Within this dual focus analysis we have seen the implications of this stigmatisation. The social group of 'welfare claimant' is now so loaded with stigmatised constructions that membership is to be negotiated or, ideally, avoided. To some extent this renders the social identity of 'welfare claimant' as being a socially 'dead' category (Králová, 2015). To be a welfare claimant is to become a ‘non-person’: someone not worthy of social or cultural protection (Králová, 2015). When thinking about other welfare claimants, participants were either keen to separate any connection between them (either through age, appearance or socioeconomic background) or reflect on their own fortune or privilege that they weren’t the same as them. Due to this lack of social connectedness feelings of solidary were rare. These techniques seem to protect participants’ self-esteem, through frustration towards those they would be perceived to be grouped with.

This study has a taken a novel approach to analysis. By deploying a dual focus analysis it has been possible to depict the lived experience of interpretive repertoires. This approach to analysis showed how discursive resources can facilitate or restrain sense making. To choose one approach over the other would have limited the insights that this data set can provide. A conscious decision was made to present these two analytical approaches in an intertwined manner; rather than a presentation of one methodology’s findings before another, as has been common in some pluralistic analyses (as seen in Clarke et al.’s 2015 meta-study of analytical pluralism in qualitative research). In doing so, I have been able to show how participants live through a discursively constructed sense of reality, whilst attending to each methodology in a rigorous manner. In some examples, the discourses identified in this analysis align with those identified in chapter 3. In other circumstances, ‘new’ discourses are drawn up or refined through participants’ lived experiences.

As explored within the analysis, there were instances where my positionality – how I was positioned by participants – had an interactive effect on the data produced. I was afforded the status as an insider, as one of them, at the expense of ‘other’ individuals (the ‘other’ welfare claimants). Despite the discomfort this made me feel, I was happy to accept this position for the perceived benefits this had on data collection. In some ways, this a testament to the pervasive power of dominant discourses around welfare claimants. Through the analysis presented in chapter 3, I had critically considered the constructions of these discourses prior to the interviews. Despite this the availability of subject positions, which reinforce a dichotomous binary of genuine/illegitimate claimants, meant it was easy to uncritically ‘take up’ these in the moments of an interview. I was reassured by the longitudinal nature of this research project; these encounters would not be my only time to speak with participants. How would my own identity and skills as a researcher change or shift across the length of the project?

Due to the energy-limited potential of participants' chronic health conditions, participants were offered a range of ways to conduct interviews: face-to-face at any convenient location, via telephone or synchronous/asynchronous online media. The choice of which medium would be most appropriate was made entirely by each participant. This worked well, enabling an inclusive approach to research, whereby participants were able to share their experiences of illness in ways that accommodated the effects of illness into the research process. However, the inconsistent ways in which data was collected did have an impact on how data was viewed within the analysis. Rather than a distinction between in-person or 'remote' methods of data collection, I found the difference between synchronous and asynchronous methods had a bearing on the resonate qualities of interviews. Those that were conducted with some element of temporal urgency, whether by interviews that happened face-to-face or via messaging apps, were remembered as having greater depth or 'richness'. I was able to challenge these assumptions in the analytical process; forcing myself to put aside these feelings of what had gone well, in order to reengage with the data from a more open perspective.

Beyond intentions to increase accessibility, by providing participants a choice of interview method it was hoped that this would go some way to shift the power balance of the typical researcher-participant dynamic. However, the researcher still retained a significant amount of control over the interactional elements of the interview: what was spoken about, for example, was guided by the topics pre-determined by the interview schedule. Despite data being collected across different media, the emphasis remained on the linguistic: what could be communicated via language. As we have seen, what can be communicated is often restricted or shaped by the discursive economies participants are living within. Creative methods of data collection, those that draw on artistic approaches, have been recognised as holding significant potential for increasing human understanding, adaptation, and acceptance of health conditions (Smith, 2002). Could a focus on more creative methods of data collection empower participants to 'take control' of the research process; to offer insights into their experiences which go beyond what can be verbally articulated? The next chapters in this thesis will explore how moving beyond the spoken word can, through an engagement with visual and creative methods, support more nuanced understandings of living with a chronic unseen health condition whilst claiming health-based welfare benefits.

Chapter 5. Creative phenomenology: how can photographs be used to represent day-to-day experiences of claiming health-based welfare whilst living with chronic unseen health conditions?

Introduction.

In previous chapters of this thesis, I have explored the discursive economy available for claimants of health-based benefits who are living with chronic unseen health conditions. In chapter 4 a dual focus methodology was applied to participant interview data. In doing so it was possible to see depict the lived experience of interpretive repertoires; how stigmatising discourses around welfare, and welfare claimants, had been lived through by participants. After data had been collected, analysed and a draft write-up created, the COVID-19 outbreak emerged as a pandemic. The full impact of the pandemic will be explored in chapters 6 and 7, but it is within this context that this study was completed.

One of the conclusions of chapter 4 was around the analytical emphasis on the linguistic: despite a dual focus approach, analysis had been bound to what could be communicated by participants via language. As have been seen through this thesis, what can be communicated is often restricted or shaped by the discursive economies participants are living within. Could there be other ways 'into' understanding lived experience?

The semi-structured interview is the default, or 'traditional' form of data collection in phenomenological research (Smith et al., 2022). Creative methods of data collection, those that draw on artistic approaches, have been recognised as holding significant potential for increasing human understanding, adaptation, and acceptance of health conditions (Smith, 2002). Growing numbers of researchers working within phenomenological psychology have advocated a 'moving beyond' the spoken word (see Boden et al., 2019; Burton et al., 2017; Kirkham et al., 2015; Boden & Eatough, 2014; Shinebourne & Smith, 2011). This is not necessarily a rejection of the spoken word or linguistic forms of communication, but rather an argument that deeper exploration of participants' lifeworlds can occur through a supporting of visual articulations. Eliciting and engaging with subjective experiences through visual and creative methods can support more nuanced understandings (Day et al., 2023). This can become particularly pertinent when exploring sensitive or stigmatised topics, for example, those relating to identity, illness and distress (Day et al., 2023).

Creative approaches to phenomenology aim to explore new ways of seeing and expressing. It is additionally hoped that, in providing participants with different platforms of expression, a shift in the power balance of the ‘standard’ researcher-participant relationship can occur. Rather than the ‘predetermined’ roles of an expert researcher controlling the participant’s environment, greater feelings of autonomy and self-direction can be experienced by participants and that this, in turn, can empower them to step outside of their ‘rehearsed narratives’ (Boden et al., 2019). However, creative approaches to phenomenological data can often require participants to be skilled or motivated in data creation - such as having the ability to produce artwork (Craythorne et al., 2020; Craythorne et al., 2023) or drawings (Nizza et al., 2018; Boden et al., 2019). Such skills may be perceived as a barrier to research participation, particularly for a person experiencing pain or reduced self-esteem (Fancourt et al., 2020). Given the integration of smart phones into our daily lives, digital photography can be a method that requires less skill, is ‘close to hand’ and familiar for participants, but that still has the potential to produce data rich with meaning.

Photovoice and photo-elicitation are two common methods of participant photography used in health research (Murray & Nash, 2017). Compared to photo-elicitation (the method of including visual material into an interview setting), photovoice aims to place participants and their image creation at the centre of the research process (Brunsden & Goatcher, 2007). Brunsden and Goatcher (2007) suggest that making use of photovoice within a framework of Interpretative Phenomenological Analysis (IPA; Smith, 1996) could be particularly generative. That, through the combination of the visual and verbal, an opening up of new potential routes to understanding becomes possible through a fusing of horizons. Drawing upon Gadamer’s conceptualisation of hermeneutics this illustrates how the combination of visual and verbal data can enable more centralised understandings of others’ lived experiences.

Within photovoice research, participant-created photographs can act as data in and of themselves but can also be used to facilitate and drive a discussion that produces verbal data (Brunsden & Goatcher, 2007). In studies that situate photovoice within phenomenological explorations of experiences of illness, the analytical focus is often on the interview data produced, rather than the interpretative potential of the created visuals. This may be for a number of reasons or restrictions (such as the confines in which academic research is published), however a privileging of one data set over the other can undo the empowering commitments that underpin creative approaches to phenomenological investigation. For example, when looking at longitudinal experiences of caregiving, Morrison and Williams (2020) embedded IPA within a photovoice methodology. Their findings revealed the changing and myriad ways caregiving as a 'consuming' act were made sense of by participants. However, the evocative photographs created by participants are excluded from the authors' analysis and published work; relegated to the paper's online supplementary materials. Photographs produced by Norwegian participants living with medically unexplained long-term fatigue are included within Lian and Lorem's published study (2017). Yet the images only serve to illustrate the analysis of the interview data, despite being powerful illustrations of participants capturing their altered ways of being-in-the-world (Lian & Lorem, 2017). Photographs here represent a way for the researcher to "visit" places that are a part of participants' daily lives (Lian & Lorem, 2017, p. 484) but how might we, as researchers, interact in a more meaningful way with participant efforts of self-representation?

Other studies find a better balance between the inclusion of photographs within processes of analysis. One such example is Papaloukas et al.'s, (2017) research around marginalisation and chronic illness. Photographs taken and captioned by participants are not only used to illustrate analytical points made within an Interpretative Phenomenological Analysis but the photos also structure and drive the focus of the study's analysis. Inductive coding and categorisation are applied to participants' photographs in a way that positions the visual data in an "equal locus" with the in-depth interview data (Papaloukas et al., 2017, p. 419). A similar approach is taken by Wilde et al. (2020) in their exploration of men's experiences of living with ME/CFS; integrating the verbal and visual data into the analytical process of IPA. Papaloukas et al. (2017) celebrate the necessity for approaches to research that are designed in a flexible manner. However, they remain committed to the notion that participant-created photographs cannot and should not be separated from the individual narrative text of which they are part (Balmer et al., 2015; Papaloukas et al., 2017). But in doing so, I suggest, one form of data will *always* take priority over the other. This is similar to the problems faced by mixed-methods research, where data collected through different epistemological positions can cause difficulties when a reconciliation towards a conclusion is attempted (Shaw et al., 2018). Where there is ambiguity, or a tension, between how a photograph can be viewed and how it is spoken about by its creator, which account would shape our understanding of the image? Given phenomenological psychology's reliance on the semi-structured interview format, the verbal account would likely take precedence over a photograph's more aesthetic qualities. Within the setting of a photovoice study, treating photographs in this way renders them as tools of intended elicitation: ways to produce more, or richer, interview data. Treating participant-created photographs as efforts of self-representation, open to interpretation away from the context of an interview, may enable us as researchers to explore these potential tensions between what was said (meaning of the photographs for participants) and what was seen (how photographs could be interpreted). Against this back-drop, and as part of the longitudinal study running through this thesis, I sought to understand how participants used photographs to represent their day-to-day experiences of living with chronic unseen health conditions and claiming health-based welfare.

Methods.

Data collection and ethical considerations.

The project received ethical approval from Aston University's Life and Health Sciences Ethics Committee. As part of the longitudinal study that forms the central empirical work of this thesis, participants were invited to take photographs between the first and second interviews. Beyond the ethical issues discussed below, participants were given little direction as to what these photographs could, or should, contain. Participants were provided with an additional information sheet (see Appendix 5) towards the end of the first interview which invited participants to take images that represented their day-to-day experiences of living with a chronic unseen health condition and/or their experiences of claiming health-based welfare benefits.

The photovoice element of the longitudinal study was optional. Six of the eight participants chose to share images they had taken. Participants had autonomy over how and when they shared their images, however the aim of the second interview was to explore what the chosen photographs meant to participants. The initial timeframe for the study anticipated the second interview to occur six months after the first. However, due to the disruptions created by the COVID-19 pandemic (both for participants and the researcher), the second interviews took place between a year to two years after the first. Two participants (Margaret and Phillip) chose not to engage with the photovoice element but did want to remain part of the longitudinal project: their second interviews occurred without the photographic element (see chapter 6). Table 5.1 gives an overview of the participants who took part in the photovoice element; showing how many images were taken and when these photographs were shared.

Table 5.1. *Details of photovoice engagement.*

Participant pseudonym	Health conditions	Month of first interview	Month of second interview	Number of photographs shared	When photographs were shared
Denise	IBS, asthma, undiagnosed musculoskeletal genetic disorder	June 2019	March 2021	3	At the end of the first interview
Diane	Myalgic Encephalomyelitis	June 2019	April 2020	9	Throughout the period between the first and second interview; during the second interview
Lucy	Asthma, idiopathic chronic back pain	July 2019	April 2020	8	During second interview
Richard	Multiple sclerosis	March 2019	February 2021	10	During second interview
Sarah	Fibromyalgia, Borderline Personality Disorder	July 2019	March 2021	3	During second interview
Shelly	Myalgic Encephalomyelitis	July 2019	April 2020	7	Throughout the period between the first and second interview; during the second interview

In order to preserve the anonymity of participants (and other individuals), participants were asked to avoid taking photos that contained identifiable information (such as faces, addresses, unique locations etc.). Photographs were screened by the researcher during analysis and any potentially identifiable content was obscured in a way that reduced the risk of identification but still retained the visual content of the images. Participants gave consent for their photographs to be used in any written reports, publications and academic presentations.

Analysis and reflexivity.

The incorporation of participant created photography was initially conceptualised within an interview framework, e.g. that participants would talk through the meaning of the images chosen during a second interview and the analysis of this data would include an exploration of the photographs. Here the photos would become interview stimuli, more ways 'in' to the lifeworlds being studied but would ultimately be subservient to the interview data: the meanings foregrounded by the participants in the interview would have shaped our understanding of the images. However, in a continued commitment to treating multimodal data as distinct, the visual data was first analysed away from (and separate to) the participants' interview data.

The research of Brown et al. (2020) and Boden and Eatough (2014) inspired the approach taken to the visual data. In their reflections on the use of photo-production to explore the material spaces of mental health units, Brown et al (2020) reveal the complex relationship that exists between interview and visual data. Rather than a presumption of, or striving towards, triangulation (the photographs providing a clarification or a means to elaborate on the interview data), once viewed as distinct but interconnected types of data, photographs and interview extracts may not be necessarily complementary (Brown et al., 2020). I argue (like Guillemin, 2004; Boden & Eatough, 2014) that the photographs created by participants produce meaning outside of a verbal narrative and can be considered as a rich source of meaning in their own right. Treating the photographs created by participants as efforts of self-representation, open to interpretation, allows us researchers to explore these potential tensions between what is said (the meaning of the photographs for participants) and what is seen (how the photographs can be interpretated). As such, this chapter focuses on the analysis of the visual materials created by participants. Later analysis (chapter 6) will (re)consider the photographs within the context of participants' verbal accounts.

Adapting Boden and Eatough's (2014) framework for the analysis of drawings (see table 5.2) provided the researcher with a phenomenologically informed 'toolkit': a way to explore and make sense of the visual data.

Table 5.2. *Framework for the analysis of drawings (adapted from Boden and Eatough, 2014).*

Framework for the analysis of drawings
1. Contents: Describe each of the distinct elements of the image.
2. Composition: How are the elements spatially laid out on the page? Are they sparse or dense, are there areas of blank page, do the elements overlap? Is there a sense of repetition, 'rhyme,' or pattern?
3. Balance: How do elements interplay? Is there a sense of equilibrium or disequilibrium? Is there symmetry or pattern?
4. Geometry: What shapes are used? How do these interplay together?
5. Materials: Which material has been used for each element?
6. Texture: What are the textural characteristics of each element?
7. Colour: How have hue (colour), saturation (vividness), and value (lightness/darkness) been used?
8. Depth/Perspective: What spatial depth and perspective have been created through space and colour?
9. Temporality/Dynamism: Is there a sense of rhythm or movement? Does the image suggest a snapshot, continuity or duration?
10. Focus: What is the visual focus of the image? What is your eye drawn to?
11. Expressive content/Empathic reaction: What is the emotional tone of the image? What feelings does the viewer have in response (bodily, emotional, memories, images)?
12. Signs/Symbolism: Are there any overt symbols or cultural references included?
13. Style: Does the image 'shout' or is it 'quiet,' or something in between? Does the drawing seem to imitate or reflect a particular trend or style, e.g., cartoonish, child-like, modern, romantic, pop-art, etc.?
14. Text: Has any text been included, for example a title? Where has this been placed? In what way has it been included? What style, font, capitalisation, etc., is used?
15. Distraction/Noise: Do any elements draw your attention away from the main focus? Is there a sense of confusion or clarity in the image?

The framework enables the analyst to explore how an image was made, how it is composed and what meanings it may convey. As the framework was created to be used alongside participants' created drawings, some elements of the framework were less relevant than others (i.e., "material"). However, the framework encouraged the researcher to 'look carefully': paying attention to how the image resonated, bodily, within the analyst.

Interpretative Phenomenological Analysis (IPA; Smith et al., 2022) was deployed as a method of analysis; a means to 'structure' and guide the use of the framework. The analytic process of IPA complimented the framework for the analysis of photos (Boden & Eatough, 2014): describing the contents of each image mapped onto the exploratory noting stage of IPA. The content of each image was initially described in detail. The remaining elements of the framework allowed the researcher to move towards a more interpretative stance. In line with the construction of experiential statements; the volume of the detail was reduced while maintaining a commitment to understanding the complexity expressed within each photo. After all of the photographs were analysed, the experiential statements were used to develop group experiential themes (GETs). These themes formed the findings of this chapter.

In a divergence from IPA, the *photographs* were explored in a separated manner, rather than exploring the photographs produced by each participant collectively. There was, by effect, an attempt to temporarily 'lose' the agency inherent within the photographs as texts; as artifacts separated from those who created them. This shift came as a result of (for this analysis) prioritising the interpretation of the visual. The researcher attempted to strip the images of their wider context. The analysis was shaped by the research question (considering these photographs as representations of life with a chronic health condition and/or experiences of claiming welfare) rather than exploring who took these images or how participants had communicated the meaning of these images in their second interview. Instead, there was a concentration on the affective qualities of the images: how were these affects achieved through the creation and presentation of these photographs? How might these affects be phenomenologically understood? Reflexively, this was a significant task. Rather than the bridling approach (Dahlberg, 2006) used in chapter 4, the analyst actively attempted to engage in the phenomenological psychological reduction (Giorgi et al, 2017). This reduction was towards the photographs as representations of 'being in the world', expressions of lived experiences. However, there was an attempt to bracket what was said about these images by participants in their interviews (and therefore known by the interviewer, who is also the analyst). Doing so allowed the analyst to consider how the photographs present themselves to the consciousness of the experiencer. For the purpose of presenting the data, and to enable a continuum between this chapter and the later second stage interview analysis (wherein photographs were idiographically 'reattached' to participants), images are attributed to their creator's pseudonym.

Collages.

To briefly step outside of the types of writing one may expect to see in the methods section, I thought it would be appropriate to write in a more reflexive manner about the later stages of this study. Following the write-up of the analysis, feedback was sought from a number of sources. Nothing 'out of the ordinary' or beyond the confines of academic practice: I presented my work at a phenomenological research group based at Aston University (Phenomenology of Health and Relationships; PHaR); my main supervisor provided feedback on a draft; and I spoke to peers and colleagues about my work. Two 'themes' that came from these sources of feedback was around the novelty of the methods taken and the potential for generating impact via visual pathways. Within this context 'impact' was spoken about in terms of the visual being an effective medium for communicating and drawing attention to the plights of individuals living with unseen health conditions. Could the analysis produced capture some of the essences of participants' representations of experience? Could this be done in a way that further expands the innovative approaches taken? Would it be possible to align these attempts with this study's commitment to the visual, rather than just simply through the text of the analysis?

Following these discussions, I turned my attention to the idea of collages. Collage is the art of making a new whole through an assemblage of different forms (Gerstenblatt, 2013). In 2018, I had attended a series of seminars funded by the Sociological Review (Jensen et al., 2018). Titled "Welfare Imaginaries" each season contained a 'zine' making element where, guided by artist Jean McEwan, we were invited to capture our reflections on the past, present and future of welfare. I found this seminar series to be a transformative experience for me. This was due, in part, to the knowledge and experiences shared through the more traditional academic means (such as talks and discussions). However, the zine making had a significant impact on how I thought about the relationships between academic work, arts-based practices and activism. Doing collaging was never planned as a part of this PhD. However, the waves of inspiration I had felt after having the opportunity to be creative in an academic context had remained with me; coming back to shore as I turned over considerations of how best to communicate findings of a visual analysis.

Within a research context, collaging has been used a form of therapy for children who refused to attend school (Takata, 2002); a means to explore adolescent perceptions of health (Borraccino et al., 2019); as part of an arts-based intervention that aimed to reduce emotional and behavioural problems (Amjad & Jami, 2020); and a visual tool to motivate at-risk children (Cho, 1996). Within all of these contexts, collaging is deployed as a methodological tool, a technique used to change behaviour; the success (or not) of which can be measured. One study (Gerstenblatt, 2013) presented a method of creating collage portraits which supported a narrative thematic analysis around African American women's experiences of living in a rural American town. Beyond this example, I was unable to find other instances of collages being used to display the results of an analysis or as an attempt to represent the findings of an analysis.

I found myself enthused by the potential communicative power of collages. I envisaged putting together collages in an attempt to capture and express the interpreted ‘essences’ of each experiential theme. The term collage originates from the French word “collé”, which means “glued” (Gerstenblatt, 2013). With this in mind I got to collaging the only way I knew how. Each participant-created photograph was printed at its original size. Photographs were then moved into their group experiential themes. The written analysis of each GET was read and reread. Holding the experiential qualities of each theme in mind, I began to cut portions of the images out. Through these acts of cutting and deconstruction, the objects of intentionality (as interpreted by the analyst) were focused on. These were arranged and rearranged onto a blank piece of A4 paper. The more descriptive analytical insights gained through engagement with Boden and Eatough’s framework (2014; see table 5.2) helped guide the placement of these objects. The visual descriptions, which addressed the components of the framework, were drawn upon to determine how the meaning within each GET could be communicated through the collage. For example, could the recontextualised geometry of objects within a collage be used to represent the patterns of meaning across the GET? How might representations of movement be captured, or recontextualised in affective ways? Sections of images were added, taken away, overlapped, trimmed in an iterative manner. At this stage, the aim was to create a new image. This new image, the collage, aimed to capture and reflect the affective ‘mood’ of each GET. Once I felt this had, in some ways, been achieved, the selected portions of images were glued in place – creating a visual representation of a group experiential theme. This process was repeated across each theme. The GET collages were shared with colleagues before being digitalised. These scanned versions of the collages are included at the end of each thematical write-up as a visual ‘summary’ of the interpretative commentary

Findings.

Towards productivity: signs and symbols of daily management.

This theme explores the multiple ways in which individuals manage their condition. From the more typical (e.g., pill routines) to the more 'drastic' signs of medical intervention (i.e., the photo of an intravenous line (IV) line, figure 5.4). As viewers of these photographs, we can see symbols of illness-management: means to achieve comfort, support or autonomy. The 'typical' illustrations of medical management show the routine and regime required for good health. A reoccurring image was that of the storage and organisation of medication, pills and tablets.

Figure 5.1 *by Sarah.*

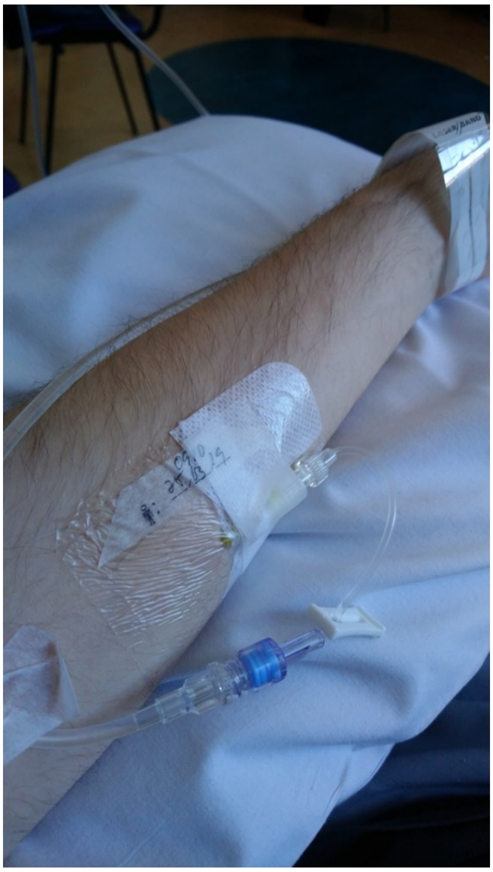
Figure 5.2 *by Shelly.*

The first two images are markedly similar in composition and focus. The viewer is to see the medication in deliberately arranged ways. What is contained within these bottles and boxes, the pills, or tablets themselves, are mostly not visible: instead, the story of these photographs is the time and preparation needed to organise treatments. The images act as a display of medication regimes. The amount and volume of medication feels potentially overwhelming. As the viewer, we are unaware as to how long these pills and tablets would last (although the colour coded tablet boxes run from Sunday to Saturday). As such the necessity of having a routine in place becomes apparent: organisation and management becomes paramount. Within Shelly's image we are able to see the names and labels on the containers. The medication captured in the image is not strictly pharmaceutical, rather it appears to be a mixture of supplements (such as "Vegepa", an omega 3 supplement) alongside prescribed medicine. This, potentially, more holistic approach to 'treatment' illuminates how Shelly may conceptualise her understanding of her health, an understanding that goes beyond the purely 'medicalised'. We are reminded of the limitations of medication and the symptoms that may escape management.

Figure 5.3 *by Lucy.*

In contrast, the focus of Lucy's image seems to be the tablets that have already been taken. Against the stark, black background, the bright blue tablets arranged towards the top half of the image initially draw the viewer's attention: two blister packets of tablets, both packets are 'face down' so that the pills are visible. However, the angle of the camera directs the viewer to the emptied blister packs: what has been rather than what is yet to come; the regimes that have been passed through; evidence of an adherent patient. The emoji sticker 'brings in' a playful sense of humanity. Displaying an emotion of annoyance or mild anger, the sticker potentially acts as a proxy for what can't be shown: the instructions participants received asked them to avoid including anything that may lead to identification of themselves or others. The frustration or annoyance shown by the emoji-sticker is at odds with the organisation of the pills: a possible display of control; that Lucy is calmly in control of her pill management.

Figure 5.4 *by Richard.*



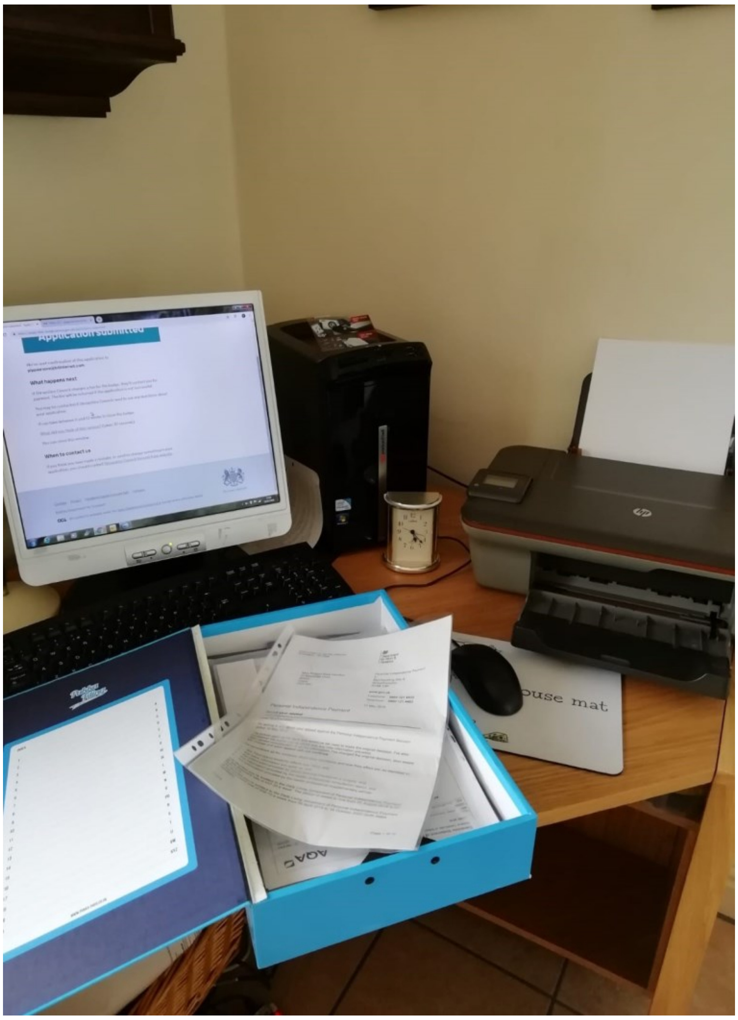
An image taken by Richard demonstrates the intertwined nature of treatment and the body. A portrait of an arm, on top of a white hospital pillow. Halfway up the inside of the arm there is a cannula attached to the skin. The arm acts as a diagonal divide through the image, from bottom left to top right. In this framed snapshot, the cannula and IV act as symbols of medical care. The arm becoming seen as a detached part of the body: an object that is in receptance of treatment. The careful framing of the image seems to draw attention to the interdependent nature of the treatment: the ‘man-made’ cylindrical, shapes of the intravenous tubes contrasting – but also running concurrent to – the shape of Richard’s arm. Despite forcing the viewer to confront these entanglements, there is a stillness present in the image: a calm, potentially patient, acceptance of the treatment.

Figure 5.5. *Shelly's new bathroom.*

Other images within this theme explore the permanent nature to some of the pragmatic methods taken by participants in the management of their health conditions. Amendments to physical spaces that will remain present. One such example is the presence of 'grab handles' in bathrooms, a practical solution to mobility problems. The handles present a stylised, but significant, interruption to what feels a detached, sterile, impersonal living space. The handles offer a 'way in' to thinking about who lives here, as does the splash of colour that arrives via the shampoo bottles – a small 'marker' of who makes use of these amenities.

Through other images, we are also able to see the more mundane, less 'medical' steps utilised: reminders on smart watches, cushions, desks; all parts of (potentially overwhelming) daily routines to make life manageable. It becomes apparent how much time and effort are taken by participants to 'be', to live with their conditions. Yet management of these conditions is not just through a knowing of their own bodies. Understanding stretches out from the body towards how the body is known by *others*. Implicit within many of this theme's photographs is how management is displayed. There exists a tension between management to enable comfort and relaxation and management as a means to productivity. For individuals living with chronic health conditions, what forms of productivity are actually possible; which will be deemed 'acceptable'? As many images were taken during the first year of the COVID-19 pandemic, we see how laptops come to symbolise the meshing of home and work lives: the content of the screen, or position of the laptop itself, indicating to the viewer whether 'rest' or 'work' is occurring.

Figure 5.6. *Diane's PIP application.*



We see a PIP application, with all the visual signifiers of an administrative office job. The image shows a desktop computer and a full box file next to a ready-to-be-used printer. The screen connected to the computer is on and showing a webpage. The webpage is mostly white, with black and blue text. It is confirming that a PIP application has been received. The page gives summaries of what will happen next and who to contact. Presenting the application process in this manner serves as a reminder of the effort and management needed to access state support: a process that resembles a job, both visually and in practice. Although the application is complete (as shown by the website on the screen), there is the sense that this is just the beginning of a much longer process. As a mirror image to the administrative job the scene signifies towards, applying for PIP is not a one-off task: instead, it will be a continual, ongoing series of tasks – something more akin to a job role.

Figure 5.7. *Collage 1. Towards productivity: signs and symbols of daily management.*

Homeliness: the quiet joy of authenticity and potentiality.

Within this theme we see images that serve as displays of identity; displays of a comfort with who participants *are*. Within, and through, the images created we are able to see how participants have developed their sense of self, within (or alongside) the 'dis-ease' of living with chronic health conditions.

Here 'home', and the feeling of being at home, exists not just through the physical rooms we see but the spaces that reflect an authentic 'being'. Where participants can, and do, dwell. One such example is shown by Diane:

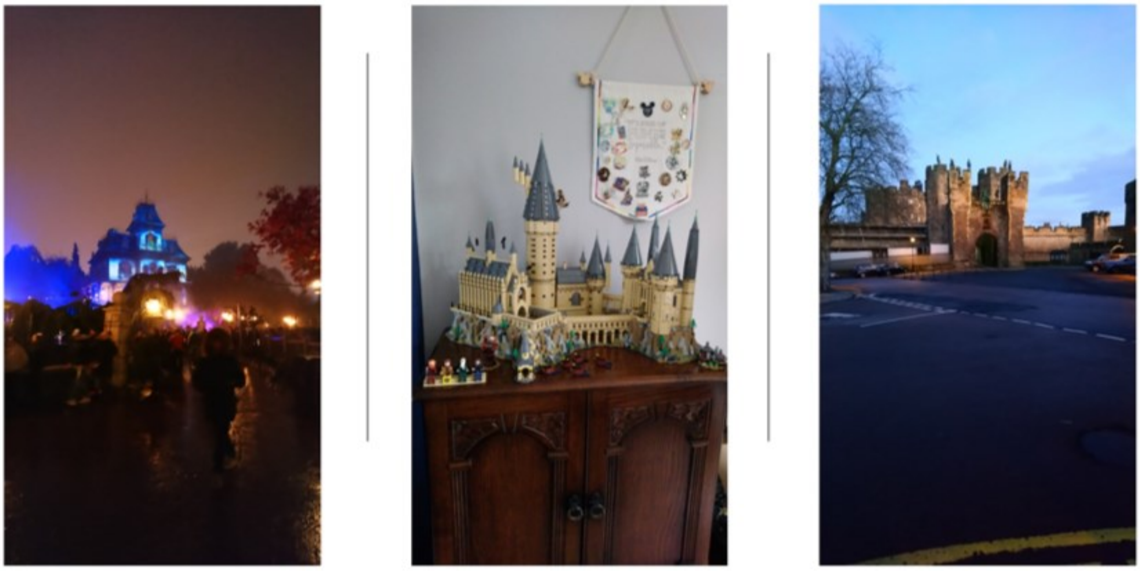
Figure 5.8 *by Diane.*

Two shadows are shown on a country lane. The shadows stretch into the middle of the lane. On the right we see the shape of a man, presumably the photographer as his right hand seems to be holding a camera or smartphone to his chest. A woman is to the left of him – seemingly gazing up at his face. The woman seems to be either in a wheelchair or using a walker. The depth within the image is striking: many elements 'stretch' into the further aspects of the photo. The country lane and the shadows being the most prominent aspects. The parallel lines of the hedge and grass line lead the viewer to 'look ahead', down the lane to the eventual unknown: it isn't possible to know what is around the bend. The expressive, emotional content of the image is complex. There is a sense of potentiality, heading towards a future together, alongside feelings of peace and tranquillity (communicated through the stillness and the vitality of the surrounding countryside). Despite not being able to see Diane's facial expressions, her shadow (on the left) seems to be expressing love. Cumulatively, the image portrays 'home' as an emotional state, an expression of security that is rooted in companionship.

Figure 5.9 *by Richard.*

Home is embodied in a more concrete example provided by Richard. The image shows a window, three panes, looking out onto to a row of houses. On top of the windowsill are 10 "new home" cards of various different designs. The bottom half of the image feels deliberately obscured: the darkened lighting drawing the viewer's attention to the row of "new home" cards. The focus of the image seems to be the middle card, which is itself a card that shows a complete house, a home that is sitting within a home. There are houses and homes within many parts of the photo: explicitly expressing the tangibility of homeliness, but also that this feeling of being 'at home' is a novel sensation. This view from the window is perhaps a new one. However, similar to Diane's image, there is a sense of stillness: the symbols of suburbia creating a mood of security and safeness.

Figures 5.10-5.12: *Richard's castles.*



In a series of distinct images (which were curated as a triptych by the analyst) Richard further explores expressions of homes. The first is in darkness, a gothic style mansion lit in dramatic blue and purple light. The second image shows a castle constructed out of Lego. The third image shows an actual castle, set against a cold-looking blue sky. Bringing to mind the idiom "an Englishman's home is his castle", Richard captures the differing ways that homes can be conceptualised. However, the shapes and locations of each castle are distinctly different. For example, the first castle, which resembles more a gothic mansion, has a peaked tower surrounded by two roofed elements. In comparison, the Lego castle (from left to right) has a cloister-type building facing the front-right of the picture. To the right of this is the largest turret, which reaches up to the middle of the background tapestry (hanging on the wall). What is visible of the final castle seems to be the gatehouse – an entry point surrounded by two watchtowers of equal height. In addition, the differences in perspective and temporalities (e.g., the sense of moving through a crowd in the first compared with the solitary, almost solemn, movement *towards* the final castle) present within each image potentially challenge the decision to consider these images as a triptych. However, I argue that – collectively – the photos seek to evoke feelings of adventure, wonder and grandeur. Reflecting on the dedication needed to create the Lego castle, these teleological considerations extend to the other two sites. That these castles, or mansions, represent an endpoint: a historical marker of the labour required to create a castle (and/or home). Within the context of living with chronic unseen health conditions, we are reminded of the disrupted nature of 'progress', or life as a project: that the creation of comfortable and safe environments cannot be taken for granted. But that these feelings of awe (wonder, grandeur etc.) brought about by historical sites can act as a catalyst to realising potentiality, whether this be the creating of a Lego castle within a home or the development of feelings of 'homeliness'.

Figure 5.13 *by Diane.*

A realisation of potentiality is celebrated by Diane in an image showing a scene from graduation. Against a backdrop of greenery, the flung mortarboard 'cuts through' the less-defined shapes of nature (the trees and dome-shaped bushes; full of leaves and a deep, dark, green). The image itself is fleeting, a brief snapshot to capture a symbol of academic achievement. The trajectory of the mortarboard, extending away from the thrower's arm, recalls a 'line of flight', or escape (Deleuze & Guattari, 1987). That graduation enables the opening-up of a new identity: that of 'a graduate'. With the fulfilment of this potentiality, new possibilities become available: new job roles, or further study, for example. These new opportunities function, perhaps, as ways of moving towards further new identities. However, the appearance of a second mortarboard (to the left of the image, lower than the mortarboard in focus) reminds us of the competition that is implicit within neoliberal job markets and academia itself. It is necessary for some individuals to do better than others; achievements may always entail comparison.

Other images show the comforts of homemade food, wild gardens and shared restaurant meals. It is within these widening contexts of homeliness, that allow authenticity to flourish, we see the practices of care for the self: an illustration of Foucault’s notion of self-liberation through secular or non-theistic spirituality (White, 2014). That is, that in these ‘quiet’ – often still – moments of peace, participants find themselves able to (temporarily) escape the subjectifications imposed on them. Instead, these moments provide moments of meaning and reveal future templates for a continued project of authentic living.

Figure 5.14. *Collage 2. Homeliness; the quiet joy of authenticity and potentiality*

Liminality and the world outside.

Images within this theme speak to the 'other side' of homeliness: the unease that is present in some photographs. We see a world that exists outside, but it is one that remains at a distance to participants. This can be specific, shown, physical places (where comfort becomes more akin to confinement or a 'waiting') but also the political world that is experienced as an 'outside' but also in an affective, embodied sense.

Figure 5.15 *by Sarah.*

The stillness present within the image is different to the sense of ease contained in the photographs in our second theme. A portrait images showing a curtain-drawn across a window. Light is visible through the curtains. The desk in front of the window is very 'busy', cluttered, and barely visible. Stacked on it are plastic boxes, bottles, nail polish remover, cleaning sprays, pink desk files, books, boxes, a biscuit tin – topped with a Coca-Cola can on the right-hand side of the image. The viewer's focus is immediately drawn to the hanging skeleton, looming over the stacked and cluttered items in the foreground. It may feel reductive to draw attention to the symbolism of death and mortality; what may be more appropriate is a sense of resignation. A feeling of that nothing can be done, of waiting away from the world. The outside daylight is being kept at bay: the colours become drab and indistinct. The cluttered desk is not dirty or unclean. It does, however, add to the expressive content of the photograph: an oppressive feeling of being shut away, alone.

Figure 5.16 *by Shelly.*

The presence of the outside world is felt in figure 5.16 taken by Shelley. The image shows what appears to be a chair, enclosed in a material 'shell'. It looks as though someone would sit in the chair and 'zip' the shell around them. The grey of the shell-chair brings to mind foil, an almost spacesuit type design. This contrasts with the flowery curtain, which acts as a symbolic conduit to the natural world. Despite the potential for the shell-chair to be moved, it seems rooted there as a place to sit and watch the world. The mixture of the clinical confinement and protection adds to the mood of liminality: of being between worlds. One pictures the participant as a solitary figure, a separated observer.

Figures 5.17-5.19. *Painted triptych by Denise.*

What may be on the outside is explored in a series of paintings created by Denise. Through shifting the medium from photography to photographs of created artwork, Denise is able to present their fears in a more abstract manner. The first individual shown seems to be a reoccurring character within the triptych. Potentially a self-representation, the figure displays an expression of extreme worry and upset. Eyes are filled with tears, which stream down the figure's face. The second painting replicates the same portrait style. However, the expressive content is vastly different. Against a dark red background (that seeps into the woman's hair), a new character is introduced. A small nose leads down to large, grimacing, mouth. Her mouth is open, revealing a full set of teeth. On each tooth, from left to right, there is a letter. These letters spell "austerity".

The final image is different in scope: the first character seemingly returns, although they have their back to the viewer. The character is facing a white set of disjointed, uneven, stairs. Their arms, a fleshy pink colour, are stretched to the right, as if gesturing in an uneasy way. Attached to their left leg, but moving to the right of the painting, is a large ball and chain. Written on the ball, in white paint, is the acronym "DWP" (i.e., the Department for Work and Pensions). A sign is hanging at the base of the stairs: it states that the stairlift is out of order indefinitely.

Taken together, this evocative set of images seems to tell the affective story of the subjectification of claiming welfare. The first and third paintings are saturated with sadness: feelings of being held back, of being upset and isolated. The character is at the mercy of someone who has power. The woman who features in the second painting seems to be an embodiment of the state, or the DWP. Here austerity literally ‘has teeth’: a display of power and aggression. The DWP conceptualised as a metaphorical ball and chain, is in very concrete terms adding to the structural difficulties faced by the character. Unable to access a stairlift, the attached chain makes any sort of ascent an impossibility. There seems to be no hope of resolution, just an exasperation (shown by the character’s arms, flailing in disbelief).

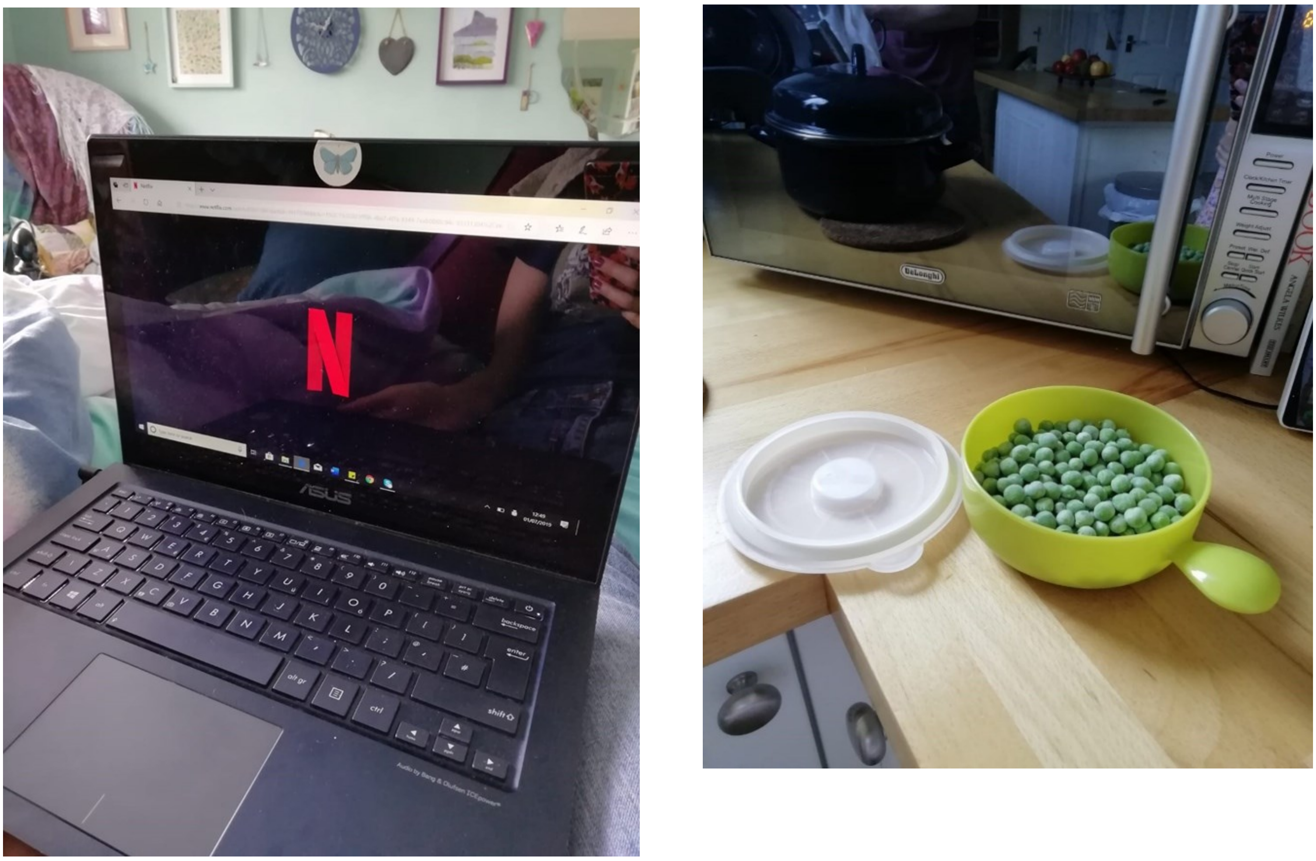
The images that form the basis of this theme express moods of horror, frustration and isolation. Spaces that are ‘between’: liminal in physical space, but also in their affective dis-ease. Feelings of limitation or restriction may arise through the limitations brought about by poor health. However, they also serve as an important statement on the role of *autonomy*. Without having a choice over their living situations, constrained by both their bodies and by being at the mercy of governmentality, the affective moods of day-to-day life become constrained and isolated.

Figure 5.20. *Collage 3. Liminality and the world outside.*

Invisible presence: photographs and the limits of horizons of understanding.

Given the project's focus on 'unseen' conditions, this theme explores how the photovoice method captures that which isn't present. We consider photovoice as a means for participants to share meaning, whilst also exploring a metatextual reading of photovoice as a method of data collection. At first impressions, this theme may resemble more of a methodological reflection. However, I suggest that it provides a means through which to explore the phenomenology of analysing photographs through a phenomenological lens: what is it *like* to analyse these photographs? How can we make sense of the limits – or horizons - of our understandings?

Figures 5.21 and 5.22 *by Diane.*



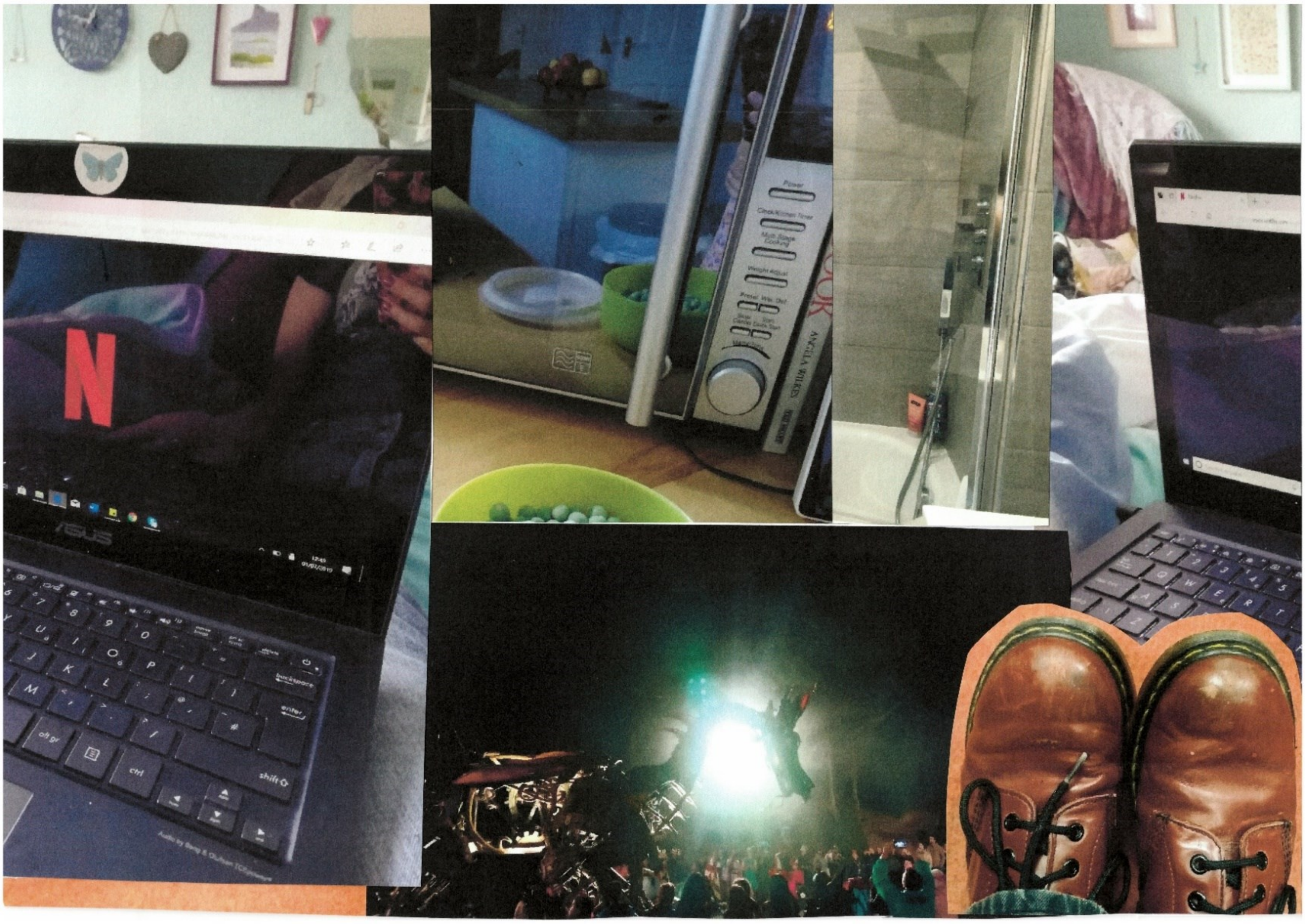
One of the ways in which these horizons of understandings are materialised is through the glimpses we catch of our photographers. As in the example images above, taken by Diane, these appearances are often very faint: just enough to be aware of the participant's appearance. Mirroring the unseen nature of participants' heath conditions, the glimpses of individuals resemble a disclosure of sorts: they have chosen how much, or how little, to reveal. These appearances come to the viewer via reflective surfaces. Laptop screens, shower panels, microwaves draw our attention to what is *behind* the camera. In doing so, we – as viewers and interpreters – move beyond the intentionality of the participants. Participants were asked to take images that captured their day-to-day experiences of living with a chronic health condition and/or their experiences of claiming welfare. As such, images are directed towards scenes or objects that are filled with some degree of meaning for the photographer. In an attempt to broaden our understanding of participants' lives, through the process of analysing these images (as 'standalone' attempts at representation), the analyst neglects, or moves away from, this intentionality. Instead, there can be a focus on what is not present; or the aspects of the image that are *barely* present. Despite what we can see, there is so much more 'out there'.

Figure 5.23 *by Richard.*

Notions of intentionality are embedded within the temporalities of the images. The images given to the research process appear on a continuum between one-off snapshots, brief moments in time, to more posed demonstrations of 'something': an image for an intended audience. Those that are snapshots reminds us of the temporal limits of the photograph, as a medium: a snippet of a life that is imbued with meaning through the act of capturing it as an image. What has come before, or the future events that have followed, remain an unknown. This can give images a sense of mystery. Figure 5.23 by Richard is one such example; a crowd of people are stood either side of a pathway (or road). The image is taken 'back' from the closest row of people. Passing through the road, through the middle of the pathway, there is a large metallic looking dragon. There is a dreamlike quality to the seemingly metallic, hollow, dragon parade. Devoid of the wider context, of what happened next or before, more questions remain.

Collectively these insights illuminate the limits of our understanding. Both in terms of the methods used (that the images are stripped of the meaning given to them by participants) but also as a reminder of our horizons of understanding. We, as researchers, may attempt more than most to reach as far as possible towards these horizons. However, it is also apparent that figures of authority (healthcare professionals, representatives of the state; assessors, DWP staff etc.), as well as friends, family members and strangers, may regularly and actively refuse or resist an *attempt* at fusing horizons. This is not to pass a moral judgement, favouring a 'virtuous' researcher, but rather illustrate the difficulties associated with communicating meaning: that a holistic understanding of the impacts of poor health is inherently complex. Deploying differing ways for participants to show the effects and affects of their condition (within the context of their lives) becomes salient, if an attempt at understanding is to be made.

Figure 5.24. *Collage 4. Invisible presence: photographs and the limits of horizons of understanding.*



Discussion.

Within this study I have aimed to understand how participants used photographs to represent their day-to-day experiences of living with chronic unseen health conditions and claiming health-based welfare. Inspired by creative approaches to phenomenology, as well as being motivated by the belief that participant-produced photographs can communicate meaning outside of a verbal narrative, I adapted Boden and Eatough's (2014) framework for the analysis of drawings to phenomenologically explore and make sense of participants' visual data. I then took a novel approach to the communication of these findings, using collages to illustrate my analytical points. Through taking an approach to participant-created photographs which foregrounds visual data, I have offered an analysis which expands a complex understanding of how chronic unseen illnesses are experienced within the context of health-based welfare systems. The use of collaging provides a new way of communicating the meaning of each theme whilst also opening up potential pathways for dissemination of findings which goes beyond an academic or researcher-focused environment (Papaloukas et al., 2017).

While temporarily 'losing' the person taking the photograph, images showed the complexity of these illness experiences. Chronic unseen health conditions require self-management routines that resemble regimes: an intertwining of personal time and body through the medication, procedures and applications engaged with. Phenomenological considerations of temporality and embodiment can be useful here. Husserlian notions of lived time, as distinct from objective time, conceptualise this difference as inner and outer time (Toombs, 1990). Through the images explored within the first theme we can see how this distinction is captured through the creation of photographs. Images capture the outer time of routines, behaviours or treatments needed to regulate time as lived through. Clock alarms, the measured infusions of IV treatments, pill routines: all of these symbolise the way outer time can interrupt or impinge on inner time in discrete incidences. These occasions can remind us of, in the context of health and illness, how interdependent these distinct types of time are. Adherence to self-management patterns is a crucial part in the management of chronic illnesses (Audulv, 2013). The inner time of individuals living with chronic illness must organise and comply with these interruptions defined by outer time to avoid more detrimental, embodied, disruptions to their lived experiences of time (namely, through poor health outcomes).

Other images explore the meaning of homeliness and the different ways that potentiality can be experienced. Sometimes these are through grand 'life events' (such as graduation) but are more regularly shown through quiet moments of authenticity and domesticity. Within these photographs, 'home', and the feeling of being at home, exist not just through the physical but through spaces that reflect an authentic 'being'. Where participants can, and do, dwell. In these images there is a sense of 'rootedness', a peaceful attunement (Galvin & Todres, 2011).

In later works, Heidegger theorised that living an authentic life (our "ownmost" being; Moran, 2000) relies on a sense of mobility: a movement towards this wholeness. This existential route towards an authentic homecoming is through an ontological certainty; individuals with a stable sense of self who are able to engage with society in ways that feel meaningful (Shaw et al., 2016). Galvin and Todres' (2011) theory of well-being develops these concepts into a lattice of dwelling-mobility which aims to demonstrate the different kinds and levels of well-being (shown in Figure 5.3). The given experiential domains (such spatiality, mood) function as distinct examples of how well-being can be expressed. These domains are informed by lifeworld constituents found in the phenomenological tradition (Galvin & Todres, 2011). Their value is in asking us to think about well-being in distinct ways: how could, for example, mobility be emphasised in some experiences of well-being? Different variations will become more relevant at different times. What may at first appear to be paradoxical unity (between dwelling and mobility), the framework aims to illustrate the ways embodied experience can hold multiple qualities at the same time: the ways in which mobility and dwelling can become intertwined (Galvin & Todres, 2011).

Table 5.3. *''Dwelling-mobility'' lattice (adapted from Galvin & Todres, 2011).*

Experiential domains	Mobility	Dwelling	Dwelling-mobility
Spatiality	Adventurous horizons	At homeness	Abiding expanse
Temporality	Future orientation	Present-centredness	Renewal
Inter-subjectivity	Mysterious inter-personal attraction	Kinship and belonging	Mutual complementarity
Mood	Excitement or desire	Peacefulness	Mirror-like multi-dimensional fullness
Identity	I can	I am	Layered continuity
Embodiment	Vitality	Comfort	Grounded Vibrancy

Qualities of rootedness, peace and possibility are present throughout the second theme's photographs. A calm acceptance of what is 'now' but also a hope for what can be in the future. The potential limiting aspects of illness (and the stigma of claiming welfare) are pushed far into the background. Instead the possibilities of well-being are foregrounded. Whilst not being used to guide the analysis deploying this conceptual framework helps to further how these analytical insights can be understood.

Deleuze and Guattari's concept of deterritorialisation may be a useful addition to discussions of dwelling-mobility. Deterritorialisation is the process where there is a break from the rigid territories of 'the major' (Deleuze & Guattari, 1987). For the post-structuralist thinkers Deleuze and Guattari, 'the major' are all things that have status and significance at any given time (Barlott et al., 2020). The major codes and creates hierarchies, organising binaries and oppositions. Examples relevant to this thesis could be the distinction between healthy/ill; legitimate/illegitimate; or deserving/undeserving. There are parallels here that can be drawn between the major and Foucauldian notions of power (see chapter 7, discussion), however one distinction lies in the notion of resistance. For Deleuze and Guattari, a break from the rigid territories of the major is possible through a 'line of flight'. Lines of flight refer to the paths or trajectories that individuals or groups can take to break free from the constraints of dominant social structures and power relations. These lines of flight are not predetermined or fixed, but rather emerge through the experimentation and creativity of individuals who seek to escape from the limitations of their current situation (Barlott et al., 2020). Within the analysis of participant created photographs, there are examples of individuals embracing lines of flight; taking trajectories of escape from the constraints of the status quo and reimagining their existence. These lines of flight can offer a complimentary insight into how the dwelling-mobility attunements are achieved – through the mobility of movement towards change.

In contrast, within in the third theme, the stillness present in images is interpreted as displays of 'dis-ease': a fear of the physical spaces and reminders of displays of power that may exist 'outside'. The images here illustrate how illness can be experienced as a state of disharmony, disequilibrium, dis-ability and dis-ease (Toombs, 1993). These qualities represent a loss of a once familiar world; a distant change in how one can be in the world. Although taken after many years of living with chronic unseen health conditions, these images represent the long-lasting nature of these changes. A mood of isolation is present within these photographs. Isolation within experiences of illness can be all the more acuate because the familiar world continues on as normal (Toombs, 1993). The images within this theme seem to capture this aspect of isolation through their representations of liminality. Liminality as an existential state is where individuals do not fit into a space, classification or definition (Sanders et al., 2019). Participant generated photographs illustrate how illness can leave participants stuck between what is familiar yet unobtainable. Feelings of existential well-being (seen in earlier themes) may be displaced or disrupted by the fluctuations inherent within chronic illness. The uncertainties fostered by looming health-based welfare systems (seen in chapter 4) may further contribute to these feelings of liminality. Knowing that the 'genuineness' of their claims are only ever temporary (as per the discourses identified in chapter 3), and could be revoked with little notice, undermining ontological certainties needed for authentic living such as a stable sense of self.

This study was driven by the desire to treat participant-created photographs as efforts of self-representation, open to interpretation away from the context of an interview. It was hoped that in doing so, I may have been able to explore potential tensions between what was said (meaning of the photographs for participants) and what was seen (how photographs could be interpreted). This was in contrast to other phenomenological photovoice studies which are often underpinned by a methodological decision that participant-created photographs cannot and should not be separated from the individual narrative text of which they are part (Balmer et al., 2015; Papaloukas et al., 2017). In some ways, the approach taken in this study (and indeed, the photovoice design of the study) entailed that this chapter would be inextricably linked to the next: that the analytical points could only go so far. The limits of that approach represent a starting point for other opportunities for analysis, and I reflect further on the interconnected relationship between these studies in the final section of chapter 6. However, within the context of this chapter, the final theme of this analysis is where these limits were met. Here I considered the limitations of the treatment of images, as separated from their creators. Notions of intentionality become useful for understanding the mystery and 'unseen' elements present within photographs, which acted as reminders of our horizons of understanding. Future analysis, exploring the accompanying second interview data, may well recontextualise these images as we aim to understand the meaning and significance of the images for those who captured these moments.

Chapter 6. How do participants use photographs to tell their stories of living with chronic unseen health conditions during COVID-19 whilst claiming health-based welfare benefits? A photovoice study.

Introduction and background.

This chapter will continue the longitudinal empirical work of this thesis by analysing the interview data that accompanied the photographs shared by participants. We have already encountered the photographs created by participants: these were treated as distinct, multimodal data in chapter 5. The analysis interpreted the participant created images as showing the multiple ways in which individuals manage their health conditions, towards an aim of becoming 'productive'. A second theme explored displays of authenticity and homeliness: how participants have displayed their sense of self or identities. A third theme captured the liminality of illness; the sense of unease that can be experienced through a world that remains 'outside' for those living with chronic health conditions. The fourth theme highlighted the limits – or horizons - of our analytical understandings: our best attempts at understating life with a chronic health condition, of claiming welfare, will always reach a threshold.

A threshold of understanding was reached, in part, due to the methodological restrictions of the previous chapter. By temporally 'losing sight' of the participants during the analysis, it became impossible to infer potential meanings represented by some of the shared photographs. Photovoice, the methodology that informed the design of these inter-connected studies, is rooted in values of human creativity and participation whilst being informed by a critical pedagogy (Donnelly et al., 2021). With its focus on creating a visual record of a community's concerns and problems, photovoice is an appropriate means of studying unseen chronic illness as photographs may illuminate the everyday realities and hidden conditions of people's experiences (Donnelly et al., 2021; Skoy & Werremeyer, 2019). Photovoice has the potential to cultivate interview data that is greater in depth by offering participants another way of expressing aspects of life that may be difficult to articulate (Balmer et al., 2012). However, in order to reach these potential depths, it becomes essential to ask participants what these images meant to them. As such, this study explores how participants spoke about the photographs they created and shared. Specifically, this chapter seeks to answer the research question how do participants use photographs in an interview setting to represent their experiences of living with a chronic health condition and/or claiming welfare?

Cultural context.

As referred to in the previous chapter, this period of data collection, analysis and write-up was affected by the COVID-19 pandemic. The COVID-19 pandemic had a profound effect on all aspects of society, including mental health and physical health (Holmes et al., 2020). In the 'first-wave' of research around the psychosocial effects of COVID-19, having a pre-existing chronic illness was associated with increased psychiatric distress (Chiaravalloti et al., 2021). Specifically, individuals living with a chronic health condition had increased rates of stress, anxiety and depression in population-level surveys (e.g. Ozamiz-Etxebarria et al., 2020). Some research suggested that this was due to concerns around a heightened vulnerability, alongside wider-spread worries around the effects of social isolation on well-being and apprehension about the practical implications of government responses to the pandemic, such as an increase in financial difficulties (Holmes et al., 2020).

One such response from the UK government was a series of 'lockdowns' between March 2020 and July 2021. The first lockdown required the closure of all 'non-essential' businesses; the population were ordered to stay at home, only permitted to leave for essential purposes such as buying food or for medical reasons (Brown et al., 2021). Those who were identified as being clinically extremely vulnerable were identified through the NHS and advised to 'shield'. Shielding involved a number of actions to decrease the risk of exposure to the coronavirus, most notably those who were shielding were advised to not leave their homes or gardens (except for medical appointments) and to physically distance from other household members (Sloan et al., 2021).

During the periods of lockdowns, there were no face-to-face assessments for Employment Support Allowance (ESA) or Personal Independence Payment (PIP). New claims were decided on the basis of paper-based assessments (considering the evidence that had been provided within the application forms) or carried out over the phone (Social Security Advisory Committee, 2020). Reassessments of current claimants were suspended and end dates of awards were extended. When ESA and PIP assessments did return, from May 2021 onwards, there was a significant shift away from face-to-face assessments to telephone or video assessments (House of Commons Work and Pensions Committee, 2023). As the longitudinal research of this thesis had begun prior to the COVID-19 pandemic, I was well positioned to explore the how participants had made sense of the new worlds they found themselves in.

Methods.

Design.

The project received ethical approval from Aston University's Life and Health Sciences Ethics Committee. As part of the longitudinal study that forms the central empirical work of this thesis, participants were invited to take photographs between the first and second interviews. The approach that informed the creation of photographic materials was photovoice methodology (Wang & Burris, 1997). Photovoice can be categorised within the field of participatory action research (PAR; Migliorini & Rania, 2017). PAR is underpinned by a commitment to community and social change. In an alignment to the idiographic approach of Interpretative Phenomenological Analysis, PAR treats individuals as the experts of their own lives. Despite this study being informed by the photovoice method, it cannot be considered to have strictly adhered to the necessary processes and procedures required within photovoice. Due to the disruptive nature of the COVID-19 pandemic, the group and community element of photovoice studies – whereby participants receive training on photography and may share and explore photos with each other – was not possible. It was also considered that this collective approach would undermine the anonymity and confidentiality promised to participants. The method taken can therefore be more accurately described as a phenomenologically-focused adaptation of the photovoice method: an approach that retains a fidelity to the intentions of the original method but a version that foregrounds individual perspectives whilst grappling with what could be pragmatically done during a pandemic.

Participants were provided with an information sheet (see Appendix 5) towards the end of the first interview which invited participants to take images that represented their day-to-day experiences of living with a chronic health condition and/or their experiences of claiming welfare. Participants were given little direction as to what these photographs could, or *should*, contain. Due to the integration of digital photography within smart phone technology, participants were invited to use their 'ready to hand' smartphones to capture scenes that represented something important to them. Earlier in this thesis (chapter 5), these images were analysed as distinct visual data. Within their second interview, participants were invited to talk about the meaning of the photos they had taken. This chapter explores the interview data of these second interviews.

The second interview was intended to be less structured than the semi-structured approach taken in the earlier interviews. The photovoice element offered an opportunity to create a shift in power dynamics between the researcher and the interviewees. By enabling participants to shape the focus of their second interview, to choose which photographs and topics were discussed, it was hoped that participants would feel an enhanced sense of control over the research process and that this, in turn, would enable greater levels of self-reflection, self-awareness and empowerment (as has been noted in other photovoice studies; Foster-Fishman et al., 2005). As such, the researcher took a less structured approach to interview preparation. The transcripts of participants' first interviews were reread to enable a 'refamiliarisation' with participants' lives. Any photographs shared prior to the second interviews were also viewed. However, in a commitment to the potentials of a more equally balanced interview, the researcher did not create specific questions or an interview schedule.

Participants.

All participants recruited to the longitudinal project took part in the second interview. The photovoice element of the research was optional and six of the eight participants chose to share images they had taken. Two participants (Margaret and Phillip) opted not to engage with the photovoice element but did want to remain part of the longitudinal project: their second interviews occurred without the photographic element. Table 6.1 gives an overview reminder of who the participants are, how data was collected and when photographs were shared.

Table 6.1. *Details of photovoice engagement.*

Participant pseudonym	Health conditions	Month of second interview	Format of second interview	Number of photographs shared	When photographs were shared
Denise	IBS, asthma, undiagnosed musculoskeletal genetic disorder	March 2021	WhatsApp messages	3	At the end of the first interview
Diane	Myalgic Encephalomyelitis	April 2020	WhatsApp messages	9	Throughout the period between the first and second interview; during the second interview
Lucy	Asthma, idiopathic chronic back pain	April 2020	Microsoft Teams video call	8	During second interview
Margaret	Myalgic Encephalomyelitis	March 2021	Microsoft Teams video call	0	N/A
Phillip	Arthritis	April 2020	Zoom video call	0	N/A
Richard	Multiple sclerosis	February 2021	Microsoft Teams video call	10	During second interview
Sarah	Fibromyalgia, Borderline Personality Disorder	March 2021	Email	3	During second interview
Shelly	Myalgic Encephalomyelitis	April 2020	Telephone call	7	Throughout the period between the first and second interview; during the second interview

Data collection.

The initial timeframe for the study anticipated the second interviews to occur six months after the first. However, due to the disruptions created by the COVID-19 pandemic (both for participants and the researcher), the second interviews took place between a year to two years after the first. Further effects of the pandemic were felt in how interviews were conducted. In the first round of interviews, half (n = 4) of participants chose to be interviewed in person. Due to the continued restrictions around physical distancing, prior to each interview all participants were given the choice of how they would like to remotely engage with the interview process. Those who conducted their first interviews via remote methods all chose to use the same platforms or media (email, phone call, synchronous WhatsApp's messaging). Participants who had been previously interviewed in-person chose video conferencing platforms, using either Microsoft Teams or Zoom.

Once the scheduled interview began, participants were reminded of the consent they had previously provided and asked if they had any concerns or queries about taking part in the research. Participants gave consent for their photographs to be used in any written reports, publications and academic presentations. Interviews that were conducted via video conferencing platforms were audio recorded and later transcribed. All participants retained the same pseudonym that had been given following the first interviews which reflected their gender and ethnicity. In the time between the first and second interview, the participant given the pseudonym 'Denise' had changed their name and gender identity (now using they/them pronouns). Their initial pseudonym, which reflected a more masculine gender identity, was used when writing up the analysis of the first interview. Following our reconnection as part of the process of arranging the second interview, this pseudonym was retrospectively changed, across the entire thesis, to reflect the change in how they represented their gender.

In order to preserve their anonymity (and other individuals), participants were asked to avoid taking photos that contained identifiable information (such as faces, addresses, unique locations etc.). Photographs were screened by the researcher during analysis and any potentially identifiable content was obscured in a way that reduced the risk of identification but still retained the visual content of the images.

Analysis.

As outlined in chapter 2, the pluralistic approach taken to data analysis within this thesis also has implications for what can and could constitute data. Previous chapters have made use of a variety of different types of data. This study continues this tradition by taking a pluralistic approach to data: participant created photographs that became intertwined with (and informed) the interview data. As the research question sought to explore how participants used photography to represent their experiences, the focus on the experiential entailed an analysis that was committed to understanding these representations of phenomena on participant's own terms. Due to the method's utilisation of hermeneutics and emphasis on sense-making, I made use of Interpretative Phenomenological Analysis (IPA; Smith et al., 2022) in the analysis of the interview data. In the time period between the analysis presented in chapter 5 and the interview data explored in this chapter, a new edition of Smith et al. (2009) was published. This new edition (Smith et al, 2022) updated and revised some of the analytical terminology while retaining the underlying principles of IPA. The researcher considered the new terminology to more accurately reflect the process of 'doing' IPA. As such the analytical process and terminologies outlined by Smith et al. (2022) were followed.

Each transcript was printed and engaged with as a physical object. Handwritten scribbled notes were made in the wide margins of the pages; highlighted colour codes were developed, abandoned and recalibrated throughout the analytical process. First, I immersed myself in each transcript, in a case-by-case and idiographic manner. Rereading each participant's account, I noted my emotional responses to the text: what feelings or moods were evoked by the data? I then began the process of making exploratory notes: comprehensive and detailed notes on what was said by participants. Once this was completed, I returned to the start of the interview transcript and – in considering the most salient features of the explanatory notes – began to construct experiential statements. These experiential statements aimed to focus directly in on participant's experiences: what statement can I, the analyst now very familiar with the data, make about how a participant has made sense of their experiences? What role has the photograph created by participants had in this sense making? The next step was to consider potential connections between these experiential statements. How can these statements be organised together? How might they best 'sit' together? This drawing of connections was done in a literal sense: initial groups were written out onto a blank page of paper. I then drew connecting lines between statements, using a pen to group and delineate more defined and convincing groups of statements. Once the statements had been clustered together, I gave the groupings a title and a brief description which aimed to capture the 'essence' of each clustering. This step of the process proved to be particularly iterative. Within the restraints of naming a 'title', a process of back and forth playing around with words was undertaken to try and find the phrases that best reflected the data as analysed.

Once these named clusters were tentatively decided, they became defined as the study's personal experiential themes (PETs). The process of moving from exploratory noting to PETs was completed for each participant's interview transcript. All participants' PETs were then written onto post-it notes. Post-it notes were chosen to be able to move PETs around, to create a dynamism needed to cluster PETs across participants. This comparing and contrasting of PETs aimed to understand and explore areas of convergence and divergence, whilst grouping themes across cases. Grouped PETs took the form of group experiential themes (GETs). These were refined, reshaped and titled so that they both illustrated the broad patterns of meaning, whilst leaving room to explore specific instantiations. These GETs form the basis of the results of this chapter. In the interest of transparency, the PETs that shaped the GETs are included within the table that starts this chapter's findings section.

Reflexivity.

As the images had already been analytically engaged with earlier in the thesis, I took efforts to 'divest' myself of these earlier analyses. Temporal distances between the writing-up of the previous chapter and the undertaking of this analysis did help this process. The distance was created, in part, by a disruption in my employment situation. A fixed term contract as a graduate teaching assistant had come to an end, but I was successful in applying for a new role in Aston University's school of psychology. This new role is predominantly teaching-focussed with significant additional administrative responsibilities. On a steep learning curve, I was having to peel through the layers of university policies and procedures. I had always known these structures to be present, but now it was part of my responsibilities to *understand* them. Alongside increased teaching commitments, I found myself distanced from my ongoing research. Despite the negative connotations such a distance may conjure, being taken away from my research came at an opportune time. As I 'settled' into my new role, as teaching terms wound down, I found myself able to return to these interviews with a weary yet refreshed perspective. The more evocative images had left an affective residual. But I was keen to remember how *participants* had interpreted these images. The data had captured a global moment of transition and upheaval from idiographic perspectives. Given the historical specificity of when these interviews occurred, the interview data came to feel like a haven, a retreat that was isolated from exterior time. At my distanced time of analysis, and despite the disruption, horror and worries of living through a still-ongoing pandemic, the mood captured within this interview data is a nostalgic one. Being able to acknowledge, talk and write about, these affective qualities enable me to slacken the threads that tied me to these various worlds (Dahlberg, 2006).

Findings.

Table 6.2. *Structure of the group experiential themes.*

Group experiential theme	Personal experiential themes (by participant)
Potentialities, empathy and growth: secret joys during the pandemic	Pandemic as an affective revelation/disruption (Shelly) Changing tones: knowing how and when you've been understood (Margaret) Being precariously lucky in unkind systems (Shelly) Letting the outside in: routines transformed through the pandemic (Lucy) Potentialities as a source of hope (Diane) Knowing the self: ontologically an outsider (Diane) Emboldened by shared values, identities and experiences (Richard) The secret joy of the pandemic: more energy, more autonomy (Margaret)
Limited autonomy in an uncertain, new, world	Prioritising through uncertainty (Sarah) The autonomy to understand pre-determined choices (Richard) Responsibilities of unguided autonomy (Sarah) Looming threats to the potential of an easy life (Denise) Little control in an uncertain world (Phillip)
Coping strategies for unruly bodies	Facing the facts (unemotionally) (Denise) Controlling pain through a calm understanding (Lucy) Stress as the antithesis of joy (Richard) Unrealised hopes; the unruly body and shifting baselines of health (Richard) Keeping the psychological at bay (Phillip)

Potentialities, empathy and growth: secret joys during the pandemic.

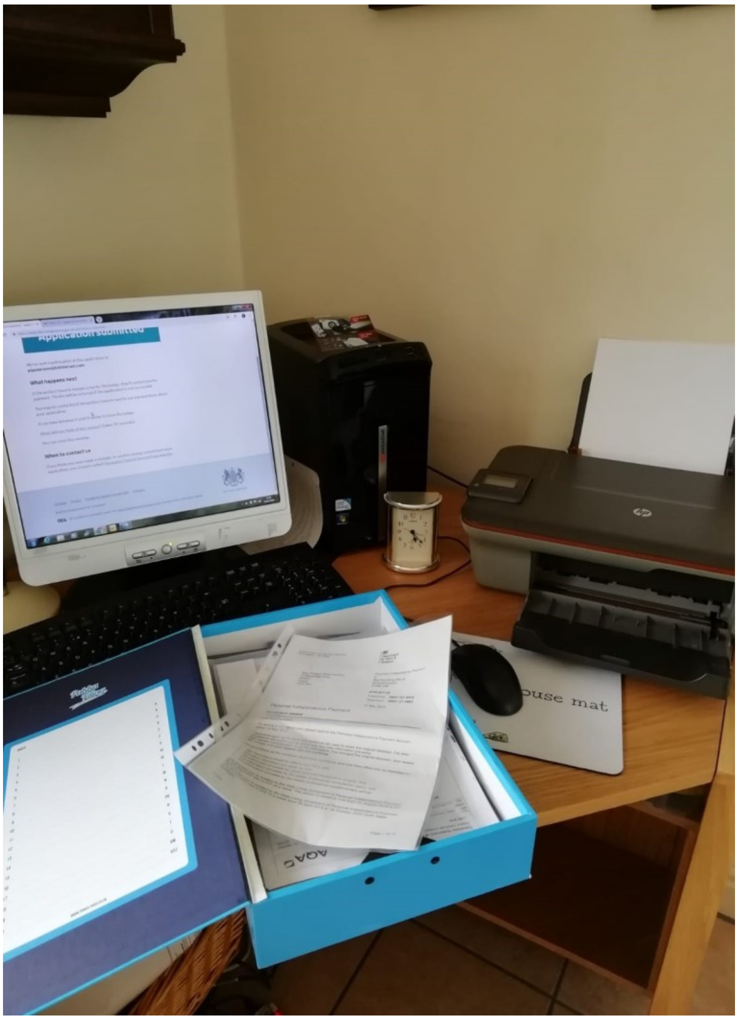
Perhaps unsurprisingly, the COVID-19 pandemic had a significant impact on participants' lives. However, rather than a furthering restriction to daily life, the 'rupture' created by the pandemic enabled new ways of engaging with the world. For many, this mood of potentiality was rooted in an increased empathy from others:

> *Shelly: Some people are definitely like coming out and being like, "oh, I have a lot more understanding now for what you go through", which is quite nice. Yeah, I mean, it's interesting to see how much people are struggling with it and it's been my reality for so long*

There is an intersubjective nature to these feelings of validation. The public health policies of 'lockdown' have been understood by healthy individuals (participants' colleagues, family and friends) as an approximation of what it must be like to live with a chronic health condition: namely, a constrained reality that is to be struggled with. Despite this characterisation, participants appreciated the transformative potential of the pandemic; the circumstances creating an opportunity for others to develop empathy and understanding for what they had experienced.

For some, these new attempts at empathetic understanding filtered through to the Department for Work and Pensions (DWP). All participants reported a 'shift' in how their access to welfare was mediated by the DWP. This ranged from reassessment decisions that were shaped solely by medical evidence (so-called "paper-based reviews"); an increased choice in whether assessments were done face-to-face or via a telephone appointment; or an abandonment of reassessments, extending the time that participants were deemed to have eligibility:

Figure 6.1. *Diane's PIP application.*



> *Diane: I looked back at those pictures and realised I've had an amazing break from paperwork recently […] I think this is the longest I've gone in a while without having some kind of disability related paperwork. And it's wonderful! […] All the actually productive things I can do without it*

> *Sarah: It was a COVID extension I think, but it's such a relief. I get so anxious about the assessments, like I have to prove myself to a stranger, that I really do need the benefit. It feels like begging, if that makes sense*

Beyond these procedural empathies, which gifted participants greater autonomy or respite from the 'looming' nature of reassessments, those who had experienced a reassessment found the interaction to be markedly improved. For Margaret this was reflected in her PIP reassessment:

> *Margaret: The last assessment I had, it was someone who came to the home, my house […] and it was a completely different experience to the one I'd had previously where I had to go into […] their offices, yeah. So this lady came to my home and I think all of the questions were very similar but*

> *she was more (.) Like she was more engaging, so she was looking at me in my eye when she was asking questions […] I felt like she was prompting me to answer in the way that it needed to be answered for her form, to get what I needed because I mean, I don't know for certain but I think they probably have specific phrases or sentences or words that they need and I think she was encouraging me to say them. It didn't feel as difficult*

Margaret's account initially foregrounds a humanity that was absent in previous assessments. The assessor understood as a guest, someone who has come into her home. In comparison to the 'robotic' style of interaction (explored in participants' first interviews), attempts at a connection are made through an acknowledgement of Margaret as an individual. This, more humane, engagement creates a shared foundation between Margaret and her assessor. Together they navigate the assessment; the assessor actively willing the necessary responses from Margaret.

Beyond the intersubjective interactions of the pandemic, participants found their daily routines and ways of managing their conditions becoming derailed and transformed. Responses taken by workplaces and the government, such as making working from home the 'default', disrupted routines. For some, these routines were beloved; providing a structure and certainty that was thought as a necessary way to exist peacefully alongside their health conditions. A number of photos shared by Lucy aim to show how these routines are structured and adhered to throughout her day. Figure 6.2 shows an Apple watch with alarms and reminders that repeat throughout the week.

Figure 6.2: *Lucy's Apple watch.*

However, Lucy's experiences during the pandemic – specifically her job becoming homebased – presented a welcome challenge to the 'rigidity' of the routines she lived within:

> *Lucy: I know that I can be a bit more flexible in the way I work. Whereas, before I was very rigid, you know, I was always, I'm a creature of habit, so I'd always get up at the same time and I'd always, you know, I'd do exactly the same things, I've had the same breakfast. You know, I tend to do the same, if not very similar, work and I have very strict patterns and I'd always have lunch at the same time and then I'd leave at the same time every day and I'd get on the same bus. Whereas this is just, this is just nice and it's kind of nice to mix it up and make my own patterns, which I've never done before […] I'm quite rigid in my habits and I love my routine but I've found that doing things a bit differently has actually made me feel better. I feel like it's been really good for me to do things a little bit differently. So I think I'd like to try and continue that. And actually I'm feeling a lot happier than I was when I was at work with my routine. Because before, I felt like everything was just sort of passing me by and, you know, I've tried to do things, I've tried to do things all the same because, you know, migraines like routine and pain likes routine. And, you know, when you do things a bit differently, your body lets you know. But I've found in these last few weeks, it's been really, really nice to sort of mix up my routine and not, you know, not have to do things in exactly the same way.*

Here routines are appreciated and acknowledged as a fundamental part of Lucy's identity: she is a proud creature of habit. This "love" of routines is also, in part, rooted in their protective nature. Routine functions as a protective shield against pain and migraines. The embodied threat posed by pain illustrates the almost Cartesian-like divide that Lucy uses to distinguish between her 'self' and the anthropomorphised pain she experiences. These pains can be placated by living a life that is regimented, a life that can be known and anticipated by her body. But this certainty comes at a cost. Lucy talks of the feeling of remaining static, being rigidly bound by these routines, and having "everything" pass her by. A chance to break from these routines, initially by the disruptive force of the pandemic, creates an opportunity for freedom whilst avoiding the feared negative health effects. Lucy achieves this through an increasing engagement with the outside world. From long walks with her partner, to using her laptop to work in her garden, these chances to "mix up" the restrictive (but helpful) routines come through letting the external world 'in'.

Many participants spoke about the rejuvenating role that the pandemic's restrictions had had on them. For Margaret, this is shown through being given the 'gift' of more energy. Through being able to work from home, Margaret is able to make use of the energy that would usually be expended by her commute:

> *Margaret: Like for everyone they'd have their commute but for me, that commute would mean I get to work and feel like exhausted already so I'd need a morning break and then from being at work and the commute home, as soon as I got home I'd need a rest then as well, so to remove them, it (.) Yeah, it's definitely a positive change for me […] it is quite nice. It almost makes me feel a bit like this is what probably most people feel like, like if I've got (.) Like previous, if I had say half an hour, I would play a meditation tape and like lie down and like almost forced relaxation. But now it's like, well I could like potter around and water my plants or I could paint my nails or I could like read a magazine, read a book, do a jigsaw, even though they're not things that take loads of energy, like I have enough energy to be able to do that rather than have to just do absolutely nothing*

The resource of energy, prioritised by Margaret as a tool that enables her to work, becomes untethered from productivity. Instead, the removal of a commute has opened up new ways that she can enjoy her free time. The potential possibilities become abundant and are far from her earlier available option of doing "absolutely nothing" to recuperate the energy spent throughout a day of work and commuting. Margaret, Diane and Denise speak about the happiness that these new ways of being brings. However, they find themselves unable to share how incredible these changes feel. Finding themselves surrounded by friends and family who are struggling with the unfurling trauma of the pandemic, they are unable to share their joy.

> *Margaret: The first one [lockdown] I absolutely loved and it's like the best I have felt in years […] And I didn't feel like I could. (.) I couldn't really say that to my friends because they were all having an awful time. But what I really liked was my friends or like not even friends, just people I follow on*

> *like Instagram or Facebook and them not posting things on evenings and weekends because I (.) Is it FOMO? […] I get that because if I’ve actually like been working and needing to rest on the weekend, it would all just feel unfair but when everyone can’t do anything I was like, this is quite nice but I can’t tell anyone!*

For many participants, the responses to the pandemic acted as a ‘levelling’ of the playing fields of their social worlds. The ‘feeling of missing out’ (FOMO), exacerbated by social media sites bringing what exactly was being missed to individuals’ consciousnesses, becoming notably absent. However, in a parallel of what participants had found themselves facing pre-pandemic, they are still unable to become involved: their subjectivities are to be hidden away, mismatched as they are with the wider world.

The mood of growth and potentialities present across this second set of participants’ interviews can be understood as not only as a causal consequence of the pandemic, but as a ‘capturing’ of the personal growth that has happened through this time period. It only became possible to capture this growth through the longitudinal design of the research. Returning to participants after a number of years, aided by the reflections within the photovoice exercise, encouraged participants to take a reflective stance: where they were now compared to the first interviews.

Diane made sense of this discontinuity between their past and present self through a greater understanding, or accepting, of themself as an ‘outsider’. For Diane, this seemed to be an ontological acceptance: an ownership of a fundamental truth about who she is. Diane had made sense of how this outsideness (inextricably linked to her living with a chronic health condition) manifested in her social interactions. Explaining how she had experienced meeting course-mates on a master’s programme, Diane seems to understand her actions as a “compensation” for her perceived deficiencies:

> *Diane: It all feels a lot easier if I can charm people before asking things from them in relation to my disabilities. Or almost to be like, yes it's worth being friends with me IN SPITE of all the things I can't do […] it sounds pathetic, but proving your worth. It's oddly made me more extroverted in social groups. Because I feel I have to compensate. Or maybe that's just my excuse for not shutting up 😂 […] I seem to have developed more of a sense of humour and an outgoingness in social situations. Even at times when I'd rather just sit back and watch. But when I don't get to spend as much time with people, there's a sense of needing to make an impression […] It's not extreme enough that I'd be the dominant voice in a group, more that I think I'd be more quiet if I didn't have ME*

Her actions, and projected personality, go beyond what she would prefer to do: for example, becoming more of a passive observer in social settings. Yet, this doesn't seem to make Diane feel uncomfortable, or evoke concerns that this a disingenuous performance. The value she deserves from proving some sort of social worth seems meaningful to Diane; one that is rooted in confident ease with who she is.

Similar expressions of ownership are present in Richard's narrative. In the time that passed, he and his fiancée intertwined, more closely, their lives together. Significant life events, such as getting engaged whilst buying (and decorating) a house together, have enabled a sharpening of their shared identities. Discussing the role that 'pop culture' (such as Disney characters and the Harry Potter stories) has had on their lives together, Richard binds these interests (and defences of these interests) to his relationship:

> *Richard: This is our relationship really. This kind of personifies me and [partner] really well. We are kids at heart, we're both in jobs that are […] we're professionals but this is us behind closed doors. We're building LEGO, we're playing video games and board games and playing D&D and… […] you get people and they're always like "ah why do you spend so much time playing games?" […] there are some people who this kind of stuff really upsets them that you still do it as an adult and, but we're just kind of like "no, this is us, this is how we are"*

Richard is keen to pre-empt objections that might be received. Instead, this ownership of who – and how - they are speaks to a wider enmeshing of their shared identities, identities that can be expressed through their interests and hobbies. LEGO Harry Potter castles that are built together are proudly displayed in their new living room and photographed for this project (see Figure 6.3).

Figure 6.3. *The LEGO Hogwarts built by Richard and his fiancée.*

These identities entail or align with wider values that have become authentically threaded throughout their shared lives. A consistent dedication to the preservation of the environment leads to a garden that has been cultivated to attract bees; Richard embraces his partner's vegetarianism in order to ensure that their shared experiences can be equally enjoyed:

Figure 6.4. *Richard's vegetarian anniversary meal.*

Richard: She's vegetarian with as many days in the week she can do vegan as well. And these were all vegetarian things because I'm not vegetarian but I eat vegetarian at home because it's easier and when we go out I tend to check for the vegetarian things on the menu because […] means we can share and try each other's bits and bobs, you know. If I'm sat there with a steak she can't have any of it and I'm not going to say, you know "your thing looks really nice, let me have it"

Within this theme, we have seen the myriad ways in which potentialities and personal growth have been fostered throughout the pandemic. Greater levels of empathy and understanding, alongside new working environments, have empowered participants to feel rejuvenated. However, not all of these experiences of growth are as a result of the pandemic. Through an 'ownership' of their identities, participants have discovered and engendered authentic ways of living.

Limited autonomy in an uncertain, new, world.

Through this theme we see the how the new world of the pandemic, combined with additional caring responsibilities and limited social support networks, has affected participants. For some, the isolation and ongoing uncertainty cultivated during the periods of lockdown drew attention to the limited autonomy they had over, and within, their lives.

For Phillip, who was living alone at the time of the interview, becoming 'housebound' during the first lockdown brought back memories of extended periods of recovering from operations.

> *Phillip: I've had good practice of it and definitely it's easier than that purely because, as you say, like I've got my mobility now so if I do want to go outside I can. But, yeah, very much, very similar. Very similar, it's sort of, yeah, it's a prolonged period of time where you can't necessarily do what you want and you're, kind of, a prisoner in your own home.*

The lack of options, in terms of what can be done, is similar to his previous experiences of illness. However, compared to these previous times, Phillip has greater mobility but is limited in how he is able to *meaningfully* use this mobility. As a result of this restriction, and shrinking of his lifeworld, the 'homeliness' of Phillip's home has been lost. He is imprisoned, facing a prolonged period of restriction.

Elsewhere in the interview, Phillip talks about the worry of being able to access food during the first months of the lockdown. Phillip, like all participants enrolled in the study, found himself outside of the category of individuals advised to 'shield'. During the first period of 'lockdown', the NHS contacted people who were deemed as "clinically extremely vulnerable" to COVID-19; they received advice and guidance on how to protect themselves by not leaving their homes and minimising all face-to-face contact. One of the ways that this support was operationalised was through a prioritising of supermarket home deliveries to individuals who were shielding. Considering himself at greater risk, but falling outside of the official categories of vulnerability, left Phillip reliant on friends to bring him food supplies. Hearing stories of 'panic buying' increased Phillip's feelings of frustration:

> *Phillip: Certainly within my friendship group there have been people that have just overbought and then have had to throw stuff away, which is just such a shame. You're just kind of baring your teeth kind of thing […] Kind of heart-breaking to hear. You're like… ahh!*

Despite being, relatively, well Phillip finds himself reliving his experiences of illness. A prisoner of limited choices, trapped in his own home, receiving little contact with the outside world.

Richard experiences limited autonomy in a different context. Exploring the changes he has experienced to his medical care, Richard often understands decisions that have been made *for him* as a choice.

> *Richard: It’s this kind of case of they won’t let me have it at the moment because it hasn’t actually gone to the team meeting so they’ve not discussed it. There’s two I’m allowed. Ocrevus is one of the top three and then there’s this fourth one which isn’t as good, which is a tablet forever kind of thing, which, you know, that would probably be a bit better because it’s easier to take […] But yeah, so once they’ve discussed it and I’m offered one of those two*

Richard has amassed a wealth of knowledge about the potential treatments he can access. Treating his health as though it were a research project, he has engaged with a number of sources of information (peer reviewed studies, support forums, conversations with healthcare professionals). This collection of knowledge is drawn on to shape the telling of his treatment narrative. Numerous treatments have been attempted, with various successes. In the recanting of these experiences, Richard rationalises the decisions made, foregrounding his role in choosing the outcome. Outcomes are always informed by the knowledge he has and potential costs and benefits that have been weighed-up. In doing so, Richard is able to retain a sense of autonomy and control over his treatment plans. Even when these plans become disrupted by the COVID-19 vaccine rollout (Richard finds himself forecasting when certain treatments may become an option based on when he is able to complete his vaccination regime), Richard is able to see himself as an active agent, even the options presented represent a number of decisions that have already been made for him.

Figure 6.5. *Sarah’s medication.*

In contrast, Sarah is able to experience greater levels of autonomy over her medication regimes. Finding the side effects of a number of pain medications (some of these captured in Figure 6.5) to be more of a “hindrance” than helpful, Sarah undertook a process of withdrawing from a number of prescriptions. Although done with her GP’s approval, Sarah received little guidance or support. The result was a series of “horrific” withdrawals that were managed in a ‘trial and error’, ad-hoc, manner:

> *Sarah: I know that I need some of it to help me to function, but on the other hand do some of the side effects impact that too? It's a difficult decision sometimes, I can't say I've had much helpful advice from GPs*

Figure 6.6. *Sarah’s bedroom.*

Sarah spoke about the difficulty of balancing different priorities, such as finishing a part-time undergraduate degree, the emotional challenges of caring for her dad and having to reengage with the PIP process on his behalf. For Sarah, this was captured in a photograph (Figure 6.6), showing the necessary deprioritising of decluttering her bedroom, a Halloween decoration becoming a permanent ornament. Unlike Richard, she was unable to dedicate time to developing a knowledge base around her medications. As such, the process of removing medications became driven by her embodied knowledge: her own understandings of the bodily effects certain prescriptions (such as Tramadol) are having on her. Being given the autonomy to take these choices is beneficial for Sarah, but the lack of support and guidance is understood as a dismissal by her GP; being 'left to it' to solve the problems herself.

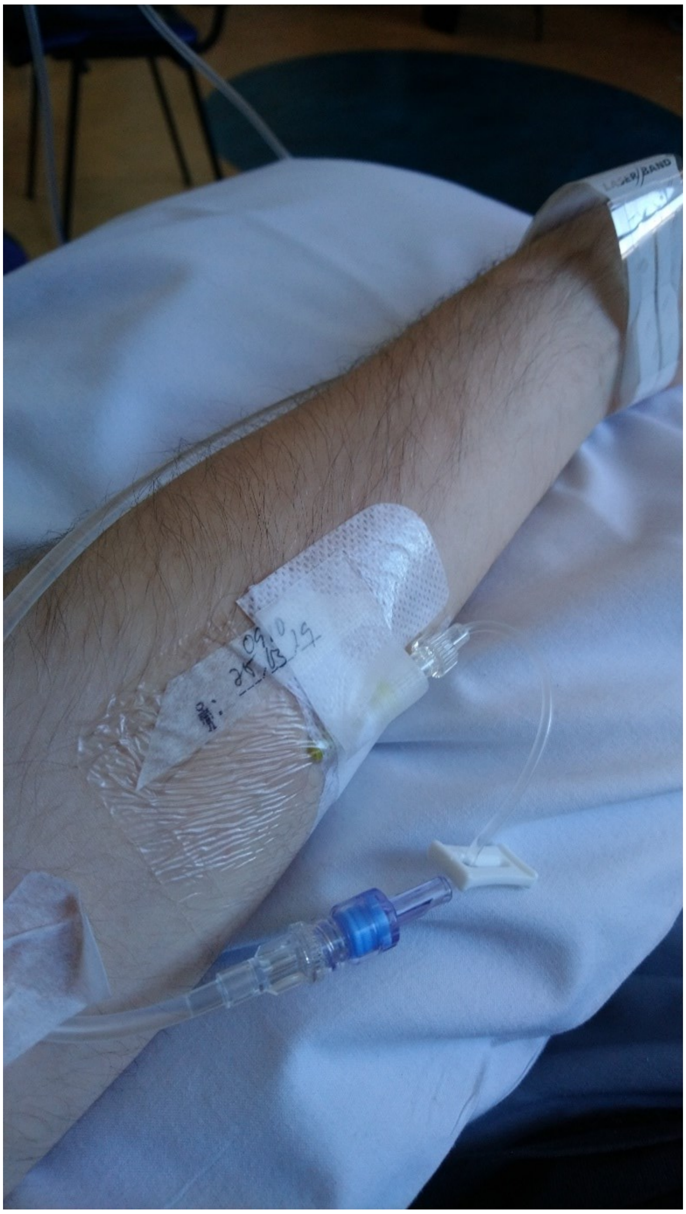
Through this theme we have been able to see the complex ways that limited autonomy has been made sense of by participants. The uncertainties of the pandemic are sources of frustration and worry: a reminder of times of ill health. Choices around medication and treatments are strived for but are either pre-emptively limited or unsupported.

Coping strategies for unruly bodies.

How participants reacted and responded to their health conditions extended beyond choices made around medication and treatment. Within this theme we can explore how participants make sense of continual embodied and affective uncertainties produced (predominantly) by illness. As the time spent living with their health conditions has increased, participants have found new ways to cope with – and challenge – bodies that defy predictability.

For Richard, the photovoice element of this study brought about reflections around unrealised hopes. Looking at a photo (figure 6.7), Richard considered how the significance of the image had shifted since the creation of the photograph:

Figure 6.7. *Richard's infusion.*



> *Richard: So it wasn't the best but, you know, like I said at the time lots of hope that I wouldn't have to go through any more treatments and all that kind of stuff, but I look at it now and it's like oh you just didn't work […] this was, um, this failed*

Between the first and second interview, Richard had undertaken a number of new, intensive infusion treatments. The first of these new regimes required Richard to be a day patient in hospital (once every six months) alongside monthly blood tests, supplementary tablets and increased protection against infection. These demands weren't, initially, thought of as a burden. The photograph taken by Richard during his first infusion aimed to capture the feelings of hope associated with the treatment: that it would be able to halt the progression of his MS and decrease the impact symptoms were having on his daily life. However, in the present day of the interview, these hopes for the future are realised as dashed: the infusions hadn't worked as they should have done; what might have been a respite was now understood as a failed venture.

Richard's capturing of these changing meanings was part of a larger narrative around his experiences of declining health. What had started as an unseen condition had begun to become more visible. MS symptoms had started to affect his walking and stamina. Richard seems to make sense of these changes as if they were a shifting baseline: what has been lost being quickly assimilated as a new normal. Any emotions attached to these losses of function are sublimated, or outsourced, to his consultant and other health care professionals.

> *Richard: I mean he's, my specialist is absolutely brilliant but he got so annoyed that I'd had a relapse though because the meds are supposed to be really good and he was just sat there and he was like "this really shouldn't have happened as quickly" […] And then when I speak to the nurses and they were like "he hates it when his patients relapse because he's kind of, he's told them that it shouldn't happen and it's just going against him"*

The potential emotions associated with his declining health (such as annoyance or hate) are only spoken of through the subjectivities of others. These are emotions experienced by his specialist consultant. Yet these emotions are directed towards Richard's body; anger that it has not responded the way it should have. In Richard's retelling, he and the nurses are witnesses and interpreters of these emotions. Instead, the emotions that Richard himself feels are kept at a distance throughout the interview. Avoiding an association with these stronger emotions, Richard focuses instead on "frustration" as a more placated emotional explanation of how he is coping with an unruly body.

A similar concentration on keeping the psychological at bay is taken by Phillip and Denise. Denise's interview is underpinned by a mood of acceptance: facing the facts of the pandemic and their varying health in an unemotive yet vaguely hopeful manner. There does exist potential threats to Denise's 'easier life': PIP reassessments loom, despite being five years in the future; a less flexible employer, should their zero hours contract be changed; new medications. Yet Denise seems able to protect their well-being against these dangers.

Wrapped up in a world of creativity, Denise has been able to develop new means of self-expression:

> *Denise: i have 😊 been filling in a sketchbook recently […] I've been doing more writing than art lately but both are good 😋 […] I've been writing some poetry and some of a self help book 😊*

The use of different forms of expression, from art to self-help writing (based on Denise's own experiences of illness) create a lifeworld in which uncertainty is a source of creative inspiration rather than of anxiety or worry.

Despite the isolation experienced throughout the first lockdown, Phillip maintains a coping strategy that is rooted in a Cartesian divide between mind and body. For Phillip, the physiology of the body is an almost unending source of exploration. Three years on from a series of operations to correct damage created by a non-benign tumour, Phillip is continuing the process of understanding how his body can be controlled and shaped by exercise routines. His body becomes known as an object, something that is – at times – seemingly fully independent of himself but still within his control. This exploration offers a way out both in terms of escaping the impacts of arthritis, but also as a means of proactively avoiding and succumbing to a negative outlook:

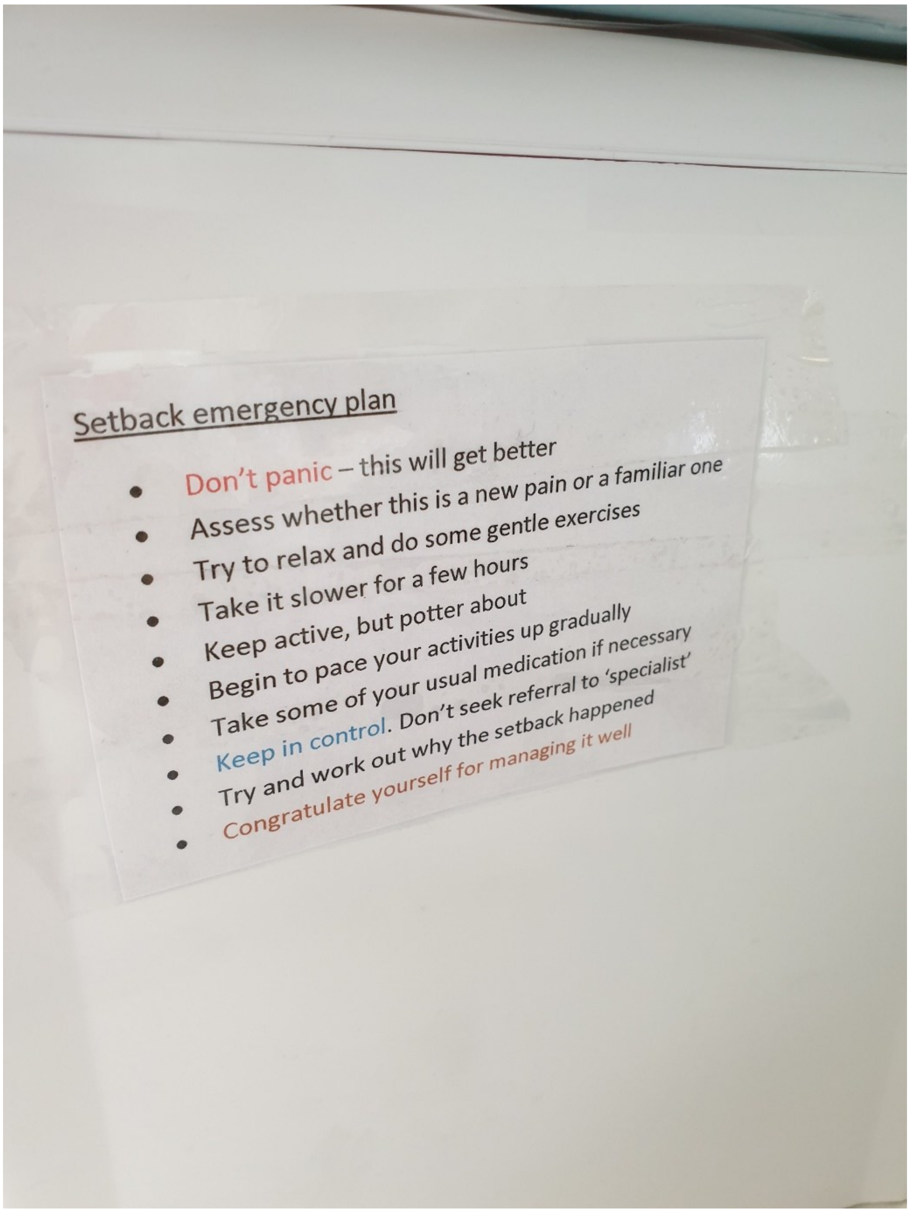
> *Phillip: For someone like me having my livelihood taken away from me, like I really struggled with that, whereas the anatomy side of things I was like 'well, yeah, I can do the exercises no problem.'*

Many of the photographs taken and shared by Lucy explore her ways of coping with pain. As described in the first theme, Lucy regularly anthropomorphised her pain. However, her previous ways of managing this pain have been identified as dangerous:

> *Lucy: there was a point where I couldn't get a dose high enough and I was taking, you know, I was taking Tramadol five times a day because I couldn't physically get enough painkillers into my body and I was still having pain. You know, they'd wear off really quickly. But supposedly, that's like a sign that you're starting to get addicted to a painkiller, which I didn't know at that point […] Because the painkiller's smart and it wants you to take more.*

In the above quote, the anthropomorphism extends to painkillers (such as Tramadol): they desire their consumption and use their intelligence to convince you to take more. But this overconsumption accidentally reveals something to Lucy; that she is on the precipice of addiction. In a response to this, Lucy finds a ‘shame’ in taking medication. The avoidance of these feelings of shame, lead her to committing to the lessons she learnt during a functional restoration programme (captured in figure 6.8).

Figure 6.8. *Lucy’s pain response.*



Setback emergency plan

- Don’t panic – this will get better
- Assess whether this is a new pain or a familiar one
- Try to relax and do some gentle exercises
- Take it slower for a few hours
- Keep active, but potter about
- Begin to pace your activities up gradually
- Take some of your usual medication if necessary
- Keep in control. Don’t seek referral to ‘specialist’
- Try and work out why the setback happened
- Congratulate yourself for managing it well

> *Lucy: But sort of, now and again, I will kneel on the floor and I will not be able to get back up, so I’ll need to pull myself up on something because I can’t lift my, my body won’t, sort of, lift me that way because I’ll either get like a twinge of pain or. Basically I just don’t feel like strong enough to do it.*

> *So it’s good now that I know that there’s nothing wrong with me, so when these things sort of happen, I don’t like have a panic moment now. So the first thing on this flare-up management is keep calm. So now, when I sort of twinge something, so, you know […] I know it’s not bad for me, so I can sort of get over the twinge and then I’m not worried about it. But that’s something I’ve had to learn to do because, you know, I’m a worrier.*

Lucy’s new ways of coping are rooted in a calming acknowledgement of the temporal nature of pain. For Lucy, pain will always appear and be disruptive. But it will also always disappear: Lucy’s pain is temporary but her reactions to pain can be fixed. The calmness of accepting the temporality of pain is rooted in an embodied confidence. Lucy is now able to know how she can cope with pain.

This theme has illuminated the different ways participants coped with unpredictable bodily realities. For some, an avoidance or sublimation of emotion served as a useful tool. Avoiding the affective qualities of illness seemed to enable participants to see their bodies as solvable problems or as sources of creative inspiration. A repeating of a self/body dualism opened up new ways of understanding the impact of pain medication on bodies. Situating pain within a temporal framework engendered new ways of calmly responding to misbehaving bodies.

Discussion.

This chapter explores interview data from a photovoice study. These interviews were the second time I met with participants enrolled in the longitudinal study; 1-2 years after their initial interview. In the time between the first and second interviews, the world experienced a pandemic: COVID-19. Unsurprisingly, the effects of the pandemic featured dominantly in participants’ narrative accounts.

For all participants, the pandemic brought about changes to work situations, health conditions, welfare assessments and their connections to others. Changes to working environments, with a shift to working from home becoming the default, enabled participants to redistribute how they ‘spent’ their energy resources. A feature of many chronic health conditions is that of fatigue or energy impairment (Hale, 2021). By being able to avoid commutes into work settings, participants were able to use this unspent energy in ways that invigorated them: spending time exploring potential new ways of being. The pandemic seemed to go some way to 'level' the social worlds that participants found themselves in. Participants found themselves no longer disadvantaged by being unable to socialise, as everyone they knew was facing the same (or similar) situation. Participants reported increased levels of empathy as friends and family equated their experiences of lockdown with how participants had had to cope previously with flare-ups of their illnesses. However, participants felt unable to verbalise these joyful experiences. The prevalent cultural atmosphere around the lockdowns could not easily accommodate the improvements that participants had experienced. The uncertainty, the feelings of being trapped away from family and family that dominated popular consciousness during lockdowns wasn't experienced negatively by these participants; instead, it brought everyone else into the same space that they had inhabited for some time.

The process of being reassessed for welfare eligibility brought about similar, but distinct, positive emotional affects. Decisions either became extended by default; shaped solely by medical evidence or participants were given an increased choice in whether assessments were done face-to-face or via a telephone appointment. These greater levels of autonomy alongside the 'relief' from the stress and worries associated with engagement with the DWP acted as a reprieve for participants. The oppressive mood created by the "looming" nature of reassessments (explored in chapter 4) abated. Similarly, the "robotic" approach to how assessors communicated with participants seemed to have been upended and rehumanised. For those that did go through the process of being reassessed, there appeared to be a change in how assessments were conducted: with assessor and claimant working together to access what was needed.

Many participants experienced other forms of personal growth. Increased understandings and ease with who they were can be understood through existential concepts of authenticity and belonging. The 'otherness' of illness can often be experienced as an unhomelike being-in-the-world (Svenaeus, 2011). What was once taken for granted, the background transparency of health, can be radically disrupted by illness. Much of this disruption was explored in participants' first interviews as they discussed their journeys through health towards the 'obstruction' of illness. Yet, in the photovoice interviews, there is a sense of momentum towards homelikeness: of finding belonging in what has become a potentially unhomelike world, an external world thrown into pandemic-created uncertainty. This belonging came, for some, through an intertwining of their lives with loved ones. Whilst for others, this was achieved through an authentic embracing of who there were: not defined by their illness but accepting how their lifeworlds had been inextricably shaped by illness. Rather than the haunting of how their lives could have been, lost futures gave rise to acceptance, dignity and peaceful pain relief seen in Scott's (2020) exploration of negative social phenomena.

Despite these significant experiences, the period between the first and second interviews cannot be considered as entirely 'positive' for participants. Shifting baselines of health led to dwindling options for treatment, whilst finding themselves outside of potential means of support during the pandemic left some with increased feelings of vulnerability. Limited support and guidance from healthcare professionals further illuminated how 'unempowered' participants saw themselves. Perhaps in part due to a response to these continuing feelings of restriction, in the final theme we saw how participants developed and refined coping strategies that assisted in their sense-making: methods and techniques that helped master the continual embodied and affective uncertainties produced (predominantly) by illness.

Some participants achieved this through the evoking of a dualistic understanding of self and body. The body as an object that can be understood and tested; or the body as containing anthropomorphised multitudes, distinct entities (e.g. pain), that have their own wants and desires. These ways of understanding seem to have helped participants protect their emotional well-being: carving out opportunities for autonomy that are rooted in embodied understandings. Through this prioritisation, it becomes possible to sublimate or avoid potential subjectivities; the effects of ill health becoming mechanistic problems to be solved. Given the extended history of philosophical engagements with mind–body dualism, there is a certain irony here. For participants, this metaphysical divide is just a useful a tool used as a positive coping strategy rather than a philosophical problem to be overcome.

The photovoice element of this study worked well. Difficulties with the photovoice method, such as participant anxieties around what could be a suitable or 'proper' photograph (Ronzi et al., 2016) were not experienced here. Participants didn't struggle with the photovoice element and seemed to value the opportunity to share visual insights into their lives. The photographs were effective as conduits to discussing topics that an interview schedule wouldn't have necessarily sought to explore. The addition of the photovoice approach also worked as a way of keeping participants engaged with the longitudinal research project. Participants mentioned how the prompt to take photographs that represented their experiences of living with a chronic health condition and/or claiming welfare stayed with them: keeping the study in their thoughts throughout the time between interviews. By design, participants were invited to share photographs whenever convenient for them. This led to a disparity in when images were first seen by the researcher and the amount of time spent being 'aware' of these photographs. Photographs shared outside of the interview setting were made available with little, or no, context. An intriguing preview to future discussions. However, in this analysis, the meaning of these images to *participants* was foregrounded. It was in the context of the interview in which these understandings were made known. In some instances, the temporal distance between the images' creation and their sharing led to a triple hermeneutic: the researcher making sense of a participant making sense of how sought to represent an experience. This is best illustrated by Richard's photograph of the infusion: what represented hope now was understood as a failed venture. These unique, reflexive, insights were made possible through the flexibly designed study and the longitudinal scope of the wider body of work.

The photovoice method does, however, require a sustained commitment from participants. Not all participants enrolled in the longitudinal study chose to take part in the photography element. It was important to respect this decision whilst also ensuring that they remained part of the research process. As such, their interviews were conducted in the same unstructured manner just without the photographic element. The data collected from these two participants was not significantly different from those interviews that did contain discussions of photographs: it was gratifying to be able to honour participants' ongoing commitment to the research by ensuring that *all* of their experiences were included within the analysis.

As outlined in the design subsection of this chapter's method section, the approach taken to photovoice could be more accurately described as a phenomenologically-focused adaptation of the photovoice method: an approach that retains a fidelity to the intentions of the original method but a version that foregrounds individual perspectives whilst grappling with what could be pragmatically achieved during a pandemic. The community element of photovoice, whereby participants attend a structured series of sessions; learn about the photovoice methodology and develop frameworks to guide the creation of photos (Migliorini & Rania, 2017) was not within the scope of this study. This was due to practical restraints brought about by the disruption of the pandemic, but also the limitations in which this research took place. These are, in part, financial (access to research funds was brokered by the head of school two years into my PhD) but also ethical. I have made an ethical commitment to preserve participants' anonymity. Although anonymity can be managed in group settings (such as focus groups; Sim & Waterfield, 2019) it felt challenging to increase the risks associated with eroding participants' individuality in order to preserve methodological fidelity.

In some ways these limitations point towards the limitations of photovoice as a method. Photovoice has been criticised for being under-theorised (Cooke & Kathari, 2001). As such, much consideration was given to how to ground this photovoice study within phenomenology. Across these two chapters, we have seen how this was achieved. A 'splitting apart' of the visual data from the interview data was needed in order to meaningfully engage with each of the data sets. To approach the data as a whole would entail prioritising one over the other: what participants said about the photographs rather than the potential meanings present in the images themselves. Differences in the way participants provided their account added depth and complexity to them; enabling an insight into the multifaceted nature of experience (Williamson et al., 2021). Rather than making a claim to have reached triangulation, there are some potential convergences of understanding between the analyses. This is most notable in the themes of "homeliness; the quiet joy of authenticity and potentiality" from chapter 6 and theme of "potentialities, empathy and growth: secret joys during the pandemic" explored within this chapter. Both themes speak to participants' experiences of dwelling-mobility. With the focus on displays and discussions of management of health conditions, the themes of "coping strategies for unruly bodies" (from this chapter) and "towards productivity: signs and symbols of daily management" (chapter 5) also dovetail nicely. These connections go some way to illustrate how consistency can be achieved through a photovoice study underpinned by a theoretical position, whilst also demonstrating how nuances of different data can be lost when one medium is prioritised over the other.

Perhaps these complimentary findings, instead, represent moments of reflexive self-awareness. This study acts as a demarcation of how I had grown as a researcher through the time of this PhD. I was eager to embrace a new approach to interviewing; hoping that the unstructured format would empower participants whilst also creating new challenges for me as an interviewer. I was attentive to my own feelings in relation to the data, being particularly alert to the myriad ways I had engaged with the data. For the analysis presented in chapter 6, I had then attempted to engage in the phenomenological psychological reduction: bracketing what I knew about how participants had described their photographs, considering how the photographs present themselves to the consciousness of the experiencer. As outlined in the methods section of this chapter, I then sought to bridle my own anticipations and preconceptions around the interview data. Despite these efforts, I still see some of my experiences of the pandemic refracted through the analysis. Two years later, the sense of optimistic potentiality present in participants' accounts, the feeling that 'once this is all over' we would find ourselves in a world ready for transformation, now bears a sharp sting of melancholia. Worlds we had been told would be impossible to achieve had occurred overnight. Welfare eligibility was opened up; claimants' medical records were prioritised and trusted; reassessments were deemed unneeded. To paraphrase Marx and Engels (1975), all that was solid *had* melted to air. But the hopes that this would lead to permanent changes, or even an appetite for long lasting change, have since been lost in a rush back to the old normal. It is hoped that the concluding recommendations of this thesis can build upon the affective potentiality of having lived through a pandemic. Is it possible to harness these lost hopes to foster different ways of thinking about chronic unseen illness and UK welfare systems?

Chapter 7. Discussion.

Introduction.

Often framed as a 'response' to the growing numbers of individuals living with chronic health conditions, many countries have introduced policy instruments for promoting the employment of individuals with chronic illness. These policies either assess working capability or aim to compensate the personal costs incurred due to illness or disability. Within the UK, these changes manifested as two major welfare reforms: Employment and Support Allowance (ESA) was introduced in 2008 for individuals who are unable to work due to sickness or disability, and Personal Independence Payments (PIP) in 2012. Both policies make use of assessments to determine if welfare benefits can be accessed. Both PIP and ESA require claimants to undergo some form of 'medical test', such as the Work Capability Assessment (WCA) in order to determine eligibility.

In the introductory chapter of this thesis, I undertook a review of pre-existing literature around the topic of health-based welfare policies (e.g. ESA and PIP). I found critiques of the 'medical' tests which determine eligibility; perceived as being too technically driven with a lack of empathetic understanding from assessors (Harrington, 2010). Beyond the mechanisms of assessment, research illustrated how vulnerable those, as a group, who claim ESA can potentially be (Barr et al, 2016; McManus et al., 2016). Other research highlighted the additional strain these reforms had on General Practitioners (Iacobucci, 2014; Hansford et al., 2019) and their relationships with patients (Wainwright et al., 2015). Evaluating the effectiveness of the WCA process in improving ranges of employment for people living with chronic health conditions, Barr et al. (2015) found no substantial impact on the numbers of claimants moving into employment and some indication that it might have had a *negative* impact for those living with a mental health condition. Following a consideration of the literature around certain types of chronic health conditions, I surmised that the difficulties associated with claiming health-based welfare may be more keenly felt by those living with 'invisible' or unseen chronic illnesses: those conditions that are not directly perceptible, not noticeable or visually evident to others.

Much of our understanding about the welfare state has been the preserve of disciplines beyond psychology (e.g. sociology, human geography, social care and independent researchers with lived experience). When psychological research has turned to considerations of health-based welfare policies, it is often with the intention to increase levels of involvement of psychologists within the administration or reform of policy. I took a critical stance to a call for reform of the WCA produced by the British Psychology Society, suggesting that it had the implicit goal of increasing employment opportunities for its *own members* rather than directly aiming to improving the conditions of those going through processes of welfare assessment. Little attention has been paid to the psychological effect of claiming welfare; or how discourses around welfare claimants may impact on processes of meaning making. Addressing the absence of psychological knowledge around the topic, this thesis aimed to explore how chronic unseen health conditions are experienced *within* the context of the UK's health-based welfare policies.

Given the project's focus on the micro (experiences of health conditions) and the macro (knowledge around welfare claimants), an array of different types of analysis are necessary to explore the influence of contingent external relations on internal meaning making (Hood, 2016). With its emphasis on the careful examination of the meaning and texture of subjective experience, phenomenology was determined as appropriate methodology to explore the lived experiences of participants (Smith et al., 2022). Foucauldian Discourse Analysis (FDA) which examines the role of language in the facilitating, limiting, enabling and constraining of social and psychological life, was decided to be an equally suitable methodology for examining how 'knowledge' of welfare claimants is constructed (Willig, 2021). However, within qualitative psychological research, these two approaches to analysis have been seen as epistemologically incompatible, as they aim to produce different types of knowledge. In chapter 2 of this thesis, I formulated a pragmatic pluralistic theoretical framework that would enable the use of both phenomenological and discursive methodologies. Focusing on how each methodological approach makes sense of language, through an exploration of these mismatches of epistemology I reasoned that the limits of each approach can be met by the other. A commitment to this pragmatic pluralistic framework had additional implications for the types of data included within the thesis, alongside methods of analysis and reflexive considerations. However, the overall aim of defining such a framework was to create a means by which holistic understanding could occur. What might be necessary to improve health-based welfare systems for those living with chronic unseen health conditions in a meaningful way?

Overview of findings.

This programme of research offers a significant contribution to psychological and experiential understandings of UK health-based welfare systems. Summarising the findings in a holistic manner, in this section I hope to neatly capture the complexities and nuances of the knowledges created through this research.

By using a Foucauldian-inspired analytical lens, I was first able to deconstruct the discourses ‘built into’ Employment and Support Allowance welfare policies. Through a genealogical approach, I showed how discourses were developed and refined over time. Notions of health became interwoven with capabilities of employment. Claimants of health-based benefits were positioned as not only economic burdens, but as outside of societal constructs of citizenship. The importance of individual responsibility became centred; the conditions that citizens could expect claimants to adhere to. This disempowerment of welfare claimants had been achieved through a *successful* stigmatisation of welfare. By taking an analytical focus on news media, it was possible to reveal how these discourses became established through a consensus between political power and machineries of news communication. Potential counter-discourses, ways of ‘reknowing’ welfare claimants, were explored through the cinematic lens of *I, Daniel Blake*. An analysis of this fictional account showed how counter-discourses both challenged and paradoxically reinforce preconceived notions. While the film pushes back against prevailing stereotypes, it inadvertently cements an ‘ideal’ claimant archetype, which holds the potential to mould societal perceptions.

Mindful that the subjectivities of these discourses could only be theorised, I explored whether such discourses constrained or facilitated how individuals felt they could talk about their *own* experiences of welfare and chronic conditions. In chapter 4, I used a dual focus analysis to delves into claimants' experiences, casting light on the profound impact of living with chronic unseen health conditions. Constructs of individual responsibility, citizenship and legitimacy are regularly made use of by participants, as they positioned themselves in – or outside – of these discourses. Participants’ lived experiences often came into conflict with these dominant discursive ideas. Marked by temporal disruptions, my analysis explored participants’ poignant feelings of loss and the unsettling ‘haunting’ of unrealised futures. Discourses of expectations and legitimacy were understood as justification for why participants were subjected to panopticon-like levels of observation. Phenomenologically, I was able to make sense of this continual observation as a felt mood: the looming dread of reassessments saturating participants' daily lives. For some participants the insecurity and certainty fostered by reassessment processes structured their everyday contexts. The mechanistic nature of welfare assessments, grounded in scepticism and robotically devoid of empathy, further deepening the sense of detachment and disempowerment amongst participants.

In the latter half of my empirical work, I was able to uniquely explore the unforeseen positives ushered in by the COVID-19 pandemic. Disrupting established routines and attitudes, the pandemic becomes an unexpected catalyst for movements towards authentic experiences of well-being. Newfound remote work arrangements, coupled with increased empathy from friends and family, reinvigorate many participants' lives. Greater levels of autonomy over how participants could engage with processes of reassessment acted as a reprieve. The oppressive mood created by the "looming" nature of reassessments abated. The 'McDonaldization' of welfare assessments had become eroded; instead, some forms of rehumanisation practices had emerged. However, for some participants, shifting baselines of health led to dwindling options for treatment. Finding themselves outside of potential means of support during the pandemic left some with increased feelings of vulnerability. Limited support and guidance from healthcare professionals further illuminated how 'unempowered' participants could find themselves.

Cumulatively, this intricate interplay of discursive and experiential perspectives underscores complexity of how health-based welfare policies are experienced. By intertwining historical discourses, personal narratives and unexpected pandemic-driven shifts, I was able to weaves a comprehensive tapestry that illuminates the intersection of policy, media, identity and lived experiences. Through this thesis I have been able to show how political decisions are lived through. How decisions made, often 'at a distance', shape and form discursive economies at a societal level. This thesis is a story of how these policies are lived through; how the political is navigated in participants' day-to-day life.

Epistemological and methodological contributions.

This PhD has made a number of significant contributions to how qualitative research can be conducted within psychology. Building on the sense of creativity, potentiality and playfulness present in modern qualitative psychological research, I developed and expanded upon pre-existing methods. However, these innovations were not just done for the sake of novelty. The intention behind these decisions was to create methods that enhanced understandings of experience and subjectivities.

In chapter 3, I designed a practical way to systematically collect data for discourse analysis. The use of PRISMA reporting guidelines, set within a media framing analytical framework, enabled the transparent collation of a data set that was thorough and, potentially, replicable. This builds on the bodies of work that describe how do discourse analysis (such as Goodman, 2017; Willig, 2021), guides which can be reticent to prescribe *how* data corpora should be collected and collated. This way of systematically showing how data was collated directly addresses notions of transparency. Transparency is a general quality criterion that we can use to assess qualitative research (Yardley, 2000). As qualitative researchers, we should make visible the choices we have made in the research process. Procedural rigour should be developed in a way that enables researchers to explicitly describe how their research was conducted (Yardley, 2000; Moravcsik, 2019). The inclusion of a more rigorous screening process was done in a way that ensured methodological coherence whilst ensuring this research met the standards needed for high value qualitative health research. A discursive commitment to understand how social knowledge is constructed would entail the potential inclusion of many different forms (and types) of texts. The use of PRISMA's "additional records" process allowed for the inclusion of material that was relevant to the research question. One such example was the inclusion of a film within the analysis. This inclusion of a film creates an analysis that, in part, meets the hopes around what a 'text' can be considered to be; the broad view and approaches introduced by Ian Parker and the Bolton Network (1999). Within a discursive approach, this commitment to rigorously collating different forms of text seems essential if we, as discursive analysts, want to make claims about social knowledge.

Chapter 4 took a dual focus analytical approach: applying Interpretative Phenomenological Analysis (IPA) and Foucauldian Discourse Analysis (FDA) to the same data set. Although not the first time this has been done (e.g. Black & Riley, 2018), an analytical process was designed and articulated in a way that aimed to minimise any threats of incoherence or inconsistency whilst avoiding the reifying of methods over potential findings (Chamberlain, 2000). Instead, an approach to analysis was taken that rigorously 'respected' each methodological approach but in a way that promoted flexible thinking and engagement with the collected data. The analysis was thought of as a collection of Matryoshka dolls: each methodology enabling an examination of the nested layers of an individual's lifeworlds. FDA allowed the analyst to 're-examine' the thematic findings of the Interpretative Phenomenological Analysis as a further hermeneutic of suspicion. The writing up of dual focus, or wider pluralistic qualitative analyses, can experience the same difficulties that befall mixed method research: how can different types of data can be reconciled, or 'merged', into overall conclusions (Shaw et al., 2018)? Through the establishing of transparent, and rigorous, pluralistic theoretical framework I was able to navigate these potential limitations. The presented, intertwined, analysis enabled a more comprehensive understanding of the dynamic interaction between discourses and the situatedness of participants' embodied experiences. By doing so, I illustrate the strengths in moving beyond concerns around methodolatry. I was, instead, able to fulfil my intentions to create an analysis that was both pragmatic and rigorous. Through my commitment to a philosophically established, pluralistic framework I was able to produce inquires that were rich and impactful. To commit to one form of knowledge over another would have meant losing many of the insights produced by this body of work. Like the pragmatic approaches taken to mixed methods psychological research (Yardley & Bishop, 2017), this thesis serves as a testament to the understandings made possible by qualitative research that is genuinely pluralistic. Given these conclusions, I suggest that the future of qualitative research should give meaningful consideration to whether pluralistic approaches to data and analysis are actually always *needed* in order to gain more comprehensive understandings of human experience.

Informed by creative approaches to phenomenological research, in chapters 5 and 6 I sought to incorporate the use of participant-created images into the research project. There are examples of critical health research making use of a phenomenologically informed approach to photovoice. However, I identified a tendency for the privileging of verbal accounts over a consideration of what a photograph may represent through the aesthetic choices made in its creation. Instead, I posited that the photographs created by participants produce meaning outside of a verbal narrative and can be considered a rich source of meaning. Doing so enabled another perspective on the data to be produced; a way in to thinking about how the complexities of human experience can be captured through representations. This was achieved through a creative method that didn't require specific skills or technical knowhow from participants – namely the taking of digital photographs. Considering the socio-political, power-related and emotional risks (Corbin & Morse, 2003) of research, I used an approach that shifted power from the researcher to participants. Participants were empowered to direct the research process; choosing what was spoken about in their second interviews and which images they created were shared.

Collaging was made use of as a means of displaying the analytical findings from chapter 5. It is hoped that these collages may meaningfully reverberate and affect an audience. Representations of experience, particularly the visual, can be effective mediums to communicate and draw attention to the plights of individuals living with health difficulties (Day et al., 2023). By potentially taking these new ways of displaying qualitative analysis into spaces outside of the academy (such as art galleries; online media; or public spaces; e.g. Langdridge, et al., 2019) there is an increased potentiality to create empathy and meaningful change through research practices. Often the ways in which academic research is evaluated comes from external bodies, through processes such as the Research Excellence Framework. Through collaging, and the wider project of taking creative approaches to phenomenological research, novel ways of demonstrating (and creating) impact from qualitative research become possible. This programme of research functions as a call to diversify the types of data qualitative researchers can, and should, engage with. I have been able to demonstrate the deeper levels of understanding made possible through creative methods. Future qualitative research should look to routinely include different types and forms of data within analyses. What insights can be learnt from encouraging, and fostering, creativities?

The main empirical studies of this PhD took place within a longitudinal setting. Participants were interviewed at two different time points, and many shared photographs and brief ‘catch-ups’ with the researcher between formalised research points. Through the use of longitudinal data collection, I was able to see how participant experiences dynamically changed within and between study time-points. When the rupture of the COVID-19 pandemic occurred, I was well positioned to explore the how participants had made sense of the new worlds they found themselves in. From a practical perspective, the photovoice element kept participants engaged and interested in the research process. This has implications for how we can approach qualitative longitudinal research. Designs that include aforementioned creative approaches to data have the added benefit of retaining participants and participants’ investment in the research programme. The empirical work of this thesis stretched across four years. Despite this length of time (which encompassed a global pandemic), all recruited participants remained committed to the project. Incorporating creative forms of data collection within a longitudinal paradigm had additional implications for how participants’ made sense of their own experiences. Taking photographs over a period of time created multiple hermeneutic circles in which participants remade sense of photographs they had shared at an earlier stage of the research process. These convergences and divergences of meaning within, and across, participant accounts were attended to in the resulting analysis; a quality indicator for IPA research (Nizza et al., 2021). Doing so enabled a further capturing of the changing meanings of participant experiences (Farr & Nizza, 2018), whilst also providing participants with an unexpected reflexive insight into their own journey.

Epistemological and methodological limitations.

The methods used within this thesis are not without their limitations. Study specific limitations have been discussed in their respective chapters but in this section I wish to take a critical perspective on methods used *across* the thesis. One such example is around the longitudinal design of the research. Participants were already in welfare systems by the time they had been recruited. All had been through a process of assessment and some had experienced the process of getting these decisions overturned. It may have been beneficial to consider how welfare systems are made sense of as participants moved through them. A pre/post type design could have been deployed; participants interviewed at time-points that were fixed more rigidly around their assessments. How did people feel about their how their health conditions were perceived prior to a health-based welfare assessment? How might these understandings change over time, as they moved through the assessment and reassessment processes? This may have caused difficulties in finding relevant participants; although not easy, as outlined in the methods section of chapter 4, there were pathways for finding people who had already engaged with welfare systems. Given the lack of standardised awareness around what benefits individuals can access, it would have been more difficult to catch people as they 'became' welfare claimants. Within the setting of this PhD, had I planned the longitudinal work in this manner, the defined time-points would have always been disrupted by the effects of COVID-19. However, future work could consider how the journey of becoming a welfare claimant is experienced by people living with a chronic illness.

Another potential limitation of this work is around the inclusion criteria for participant recruitment. Participants who were recruited took part on the basis of them living with a chronic unseen health condition. Recruited participants were living with a wide range of chronic health conditions. This produced a participant pool that potentially threatened the homogeneity needed for a phenomenological study. However, it is apparent from the findings of this study that there were many commonalities in how these conditions were lived through. Both the ‘chronic’ and ‘unseen’ aspects of their illnesses shaped how participants were intersubjectively treated. In a commitment to the convergence and divergence needed for quality IPA work, I was mindful to attend to the similarities and differences between participants (Nizza et al., 2021).

Making use of a pluralistic theoretical framework has created a thesis which resembles an analytical movement from telescope to microscope. The use of macro, Foucauldian-inspired, analyses in chapter 3 metaphorically taking shape as a telescope, used to look out on society: what knowledge is out there? The dual focus analysis of chapter 4 marks the beginning of a movement towards the microscope. In examining the lived experience of participants, this was an attempt to understand the idiographic, micro, ways discourses were lived through. However, this was done in a phenomenology-first manner: considering how lived experience, or discussions of experience, were shaped by discourses. In doing so the potential ‘thread’ from chapters 3 to 4 was frayed. The dual focus analysis was not done in a ‘top down’ manner: the questions created for the interview schedule did not ask about the specific discourses that had been identified in chapter 3. As such there is no direct correlation between identified discourses and individuals’ experiential accounts. What is captured is far more complex: subject positions are taken up; new discourses are drawn upon whilst other previously identified discourses are not present within the data. A more positivist approach, of attempting to see (for example) the causal link between language and effect was not the aim of this thesis. Nonetheless, it is useful to highlight how the ‘pluralism’ was conceptualised (i.e. phenomenology-first) and the interpretative impact this had. Had other conceptualisations been made use of (for example, a language-dominant framework which proposes that discourse constructs experience; Willig, 2017) different analytical insights would have been produced. The research work undertaken in this thesis, and the epistemological frameworks explored, can act as the foundation for future explorations of ways to enact pluralistic qualitative research.

Theoretical contributions.

Within this PhD, I developed a philosophically sound argument for the use of a pluralistic theoretical framework. This framework aimed to establish a methodological ground for the thesis: one that entailed pluralistic uses of methodologies (i.e. phenomenology and

Foucauldian Discourse Analysis) alongside a pluralisation of the forms of data that would be made use of (e.g. news articles, policy documents, film, interview data, participant-created photographs). Through this framework I intended to establish an abductive approach to data and theory (Shaw et al., 2018): considering the data generated alongside existing theoretical concepts of phenomenology and discourse analysis; to help explain these analytic approaches further whilst better understanding the phenomenon of living with chronic unseen conditions within the wider context of UK welfare reform. In each empirical chapter of this thesis, there have been explorations of the two-way explanatory relationship between theory and data. Within this current section I wish to foreground, and expand upon, occurrences which seem to be the most generative.

Foucault's concept of governmentality can be understood as the ways in which populations are rendered thinkable and measurable (Galvin, 2002). Rose (1996a) situates governmentality within a neoliberal context by concentrating on the notion of political rationalities: the intellectual machinery needed to create governable subjects. In chapter 3, through a Foucauldian-inspired analysis, it was possible to see this machinery in action. Through a consideration of power/knowledge, with an emphasis on state production, the central role that UK media and government policy play in the production of stigma was shown. However, this was only possible through a 'stretching' of the Foucauldian analytical approach. Foucault (1991) suggests that we think of power as being dispersed through regimes of truth rather than a result of a directed, singular sovereign entity. In the presented analysis there were aspects that provided an insight into how power was dispersed. This was most notable in how citizens who didn't claim welfare were positioned. Individual responsibility became a practice that could be enforced by and through the power that they had access to. It was 'reasonable' to expect welfare claimants to comply with the conditionalities of welfare. However, the majority of the analytical focus was on the how political power – from UK governments – produced and subjectivised claimants of health-based welfare benefits.

This unintended focus on political power arose partially due to the design of the Media Framing Analysis; by targeting searches to explore how changes to government policy were communicated through news media would tighten a focus on where power was being directed from. Had the types of data collected been broader in scope, it is likely that more examples of how power is dispersed throughout society would have been found. However, the analytical findings of this study perhaps tell us something about how power has become more concentrated within the top echelons of UK political systems: a creeping consensus, capitalist enclosure that preserves inequalities through the production of stigma (Tyler, 2020). There are few ways out. We see this through the repercussions of stigmatisation in the dual focus analysis: the ways in which participants use frustration and identity distinction to disavow a connection with other welfare claimants. There is little room for solidarity or connection with those in similar circumstances to yourself; lest you be tarred with the same brush. Understanding the act of claiming welfare as like a stain, or dirt, tell us something about the embodied nature of incorporeal discourses: stigma can be felt as a mark on the body (Tyler, 2020). These understandings are only possible through the previously mentioned 'stretching' of Foucauldian concepts. However, rather than an inconsistency to be admonished, this innovation enabled a greater understanding of contemporary forms of political culture. A more dogmatic reading of Foucault's work would have restricted the types of insights produced by this thesis, perhaps yielding a commentary that lacked relevancy. Instead, the analysis produced was attentive to the rigorously collected data and offered detailed exploration of the discursive complexities of health-based welfare systems.

Despite (or because of) the disruptive nature of the COVID-19 pandemic, for many participants new ways of engaging with the world were made possible. Across the two time periods of the longitudinal research, I was able to see how feelings of living authentically were achieved by participants. This 'seeing' was, at times, literal in manifestation through the viewing of photographs shared by participants. These developments speak to the movement towards a "potential-to-be-whole" as conceptualised by Heidegger and developed further by Galvin and Todres (2011). Exploring these findings through Galvin and Todres' "dwelling-mobility" lattice (2011), a greater understanding of the ways existential well-being is possible. Looming moods of anxiety and uncertainty created by threats of reassessments abated during the pandemic. Participants found greater incidences of empathetic understanding and new routines that enabled a present-centredness. An interaction between temporality and identity meant the ghosts of lost futures (as seen in the first interviews) became less present. Instead, participants became at ease with who they were and what they could be capable of. Lost futures gave rise to acceptance, dignity and peaceful pain relief seen in Scott (2020). In dwelling-mobility terms (Galvin & Todres, 2011), this represents a mobility *across* existential kinds of well-being: a mobility away from the past (temporality) to a state of identity that is both mobile ("I can") and dwelt within ("I am"). The pandemic offered a pause for participants, a chance to authentically engage with the projects of Dasein.

This programme of research was able to capture this significant period of history; how the pandemic was lived through by this group of participants. It was experienced as reconstitution, a decommodification, of their worlds: their 'worth' or value being no longer based on their capability to earn money or contribute to society.

We may not live through another global pandemic. But does this limit the opportunities for welfare claimants living with chronic unseen health conditions to experience possibilities of well-being? As introduced in chapter 5, Deleuze and Guattari's concept of deterritorialisation is a useful addition to discussions of dwelling-mobility. Deterritorialisation is the process where there is a break from the rigid territories of 'the major' (Deleuze & Guattari, 1987). For Deleuze and Guattari, a break from the rigid territories of the major is possible through a 'line of flight'. Lines of flight refer to the paths or trajectories that individuals or groups can take to break free from the constraints of dominant social structures and power relations. These lines of flight are not predetermined or fixed, but rather emerge through the experimentation and creativity of individuals who seek to escape from the limitations of their current situation (Barlott et al., 2020). Within the analyses of the final two chapters, there are examples of individuals embracing lines of flight; taking trajectories of escape from the constraints of the status quo and reimagining their existence. Against the cultural context of restrictive discursive economies (which can also be thought of as 'the major'), the concept of lines of flight can offer an insight into how the dwelling-mobility attunements can be achieved – through the mobility of movement towards change. This is in contrast to resistances to discursive power as conceptualised by Foucault; that resistance can never be external to power (1980). Within the analysis of *I, Daniel Blake* (2016) this asymmetrical set of relations between power and counter discourses was present: the character of Dan was only made worthy of our sympathises through his immaculate construction, which in turn reinforced discourses of legitimacy. In contrast, lines of flight have an inherent exteriority to them. By embracing lines of flight, individuals may find the mobility and openness necessary to move towards authenticity. The creative exploration and willingness to challenge established structures can pave the way for a more authentic existence through a cultivated deeper sense of self.

The discursive economies identified in chapter 3 (which are lived through in subsequent data sets) can be potentially thought of through the phenomenological lens of mood and atmosphere. Trigg (2020) defines atmosphere within phenomenological models of shared emotion. An atmosphere can serve as a common ground between people. It is our pre-reflective orientation towards a specific affective register: the ways we can find ourselves caught up in meanings which are not of our own making (Trigg, 2020). An atmosphere is therefore diffused through a world in a porous way; it becomes difficult to pinpoint where an atmosphere is located but an atmosphere is always experienced in and through the lived body (Trigg, 2020). To apply this concept to the findings of this thesis, it could be that that stigmatising discourses are experienced as atmospheres, a public sphere, that we are all subjected to. Although related, moods are distinct from atmosphere. For Heidegger, moods both disclose and conceal structures of the worlds we are in. Moods act as the interpretative lens through which the world is revealed to us (Trigg, 2020). So the stigmatising atmosphere may be felt as an interpretative mood by individuals claiming welfare. Identifying how the mood of, for example, the anxieties created by reassessments are shared by many welfare claimants, may go some way to draw attention to the shared grounds of atmosphere. This anxiety could be re-understood as not just an individualistic response but is a material condition diffused in the air and grasped under the skin (Trigg, 2020). It is a force, rather than an individual failing. Sharing the affective qualities of atmospheres may create new opportunities for connection and solidarity between and within welfare claimants.

Implications for practice and the future of health-based welfare.

This PhD was completed on a part-time basis. Since the start of my PhD programme in January 2017, the UK has experienced periods of vast political turmoil. During this time the UK has had four different prime ministers, all as leaders of Conservative governments. The Department for Work and Pensions (DWP), the government department responsible for the administration of welfare policies, has had six secretaries of state. With each new Secretary of State comes a new shift in focus, alongside new ideas for future policies. Petticrew (2007) notes that the public are frequently ‘enrolled’ in real-life policy experiments, often without consent or the prospect of anyone learning anything substantive about the effect of these interventions (Barr et al., 2016). Alongside other forms of assessing welfare eligibility, one such experiment is the WCA. The findings of this thesis can add to the overwhelming body of research that show how attempts to ‘objectively’ determine an individual’s capacity for work or assess the impact a health condition would have on day-to-day life have failed.

In some ways the most recently prosed changes to health-based welfare benefits acknowledge these failings. In March 2023, the Government published a white paper stating that “fundamental changes” to the design of these systems was needed (House of Commons Work and Pensions Committee, 2023). The most radical of these proposals is to remove the WCA and introduce a new health component to Universal Credit. This new component would be linked to PIP. Those found ineligible for PIP would be unable to receive benefits related to unemployment. From their own figures, the DWP estimate that 516,000 claimants across England and Wales would see their benefits eroded were the proposals enacted (Pring, 2023a). If such reforms were put into legislation, it is estimated that the rollout would be completed by 2029 at the earliest (DWP, 2023). Labour, the UK’s main opposition party, has indicated an intent to reform the WCA, with the objective of increasing the numbers of disabled people who are in employment (Pring, 2023b). As the assessment processes of PIP share the same procedures as the WCA, even if the WCA does get scrapped or reformed – its spirit will seemingly live on.

The findings of this thesis show the complex ways stigmatising welfare systems are experienced by claimants living with chronic unseen health conditions. Given the sense of existential well-being felt when these welfare systems were disrupted by the pandemic, it seems prudent to suggest that removing *all* forms of health-based eligibility assessments would be transformative for significant numbers of the UK population. The political realities we find ourselves living in would likely deem such a proposal as unthinkable. As such, the following recommendations for reforms to health-based policies were devised. Their design was informed solely by the findings of this thesis. In a continued commitment to critical research which aims to be participatory (e.g. working *with* participants), these recommendations were shared with participants and revised based on their feedback.

Recommendations for changes to health-based welfare policies:

1. Constant reassessment causes avoidable distress and uncertainty. Reassessments for all chronic illnesses should be no longer required. There should be a movement towards a model of trust, in which benefits are awarded indefinitely until claimants report a change in their health. These changes in health could be an improvement or a decline in health and could lead to a reassessment to determine if levels of financial support are still appropriate.

2. Following the possibilities experienced during the pandemic, when assessments and reassessments do occur there should be an increased use of paper-based assessments and a greater engagement with provided medical evidence.
3. Following the possibilities experienced during the pandemic, claimants should have greater choice and autonomy about how and where assessments and reassessments are carried out.
4. When assessments and reassessments do occur, they should be rooted in an empathetic attempt at understanding by assessors. Acknowledging their roles as healthcare professionals, assessors should work with claimants to try and understand how health conditions are lived through.
5. Processes of assessments and reassessments should attempt to take into account the ways individuals living with chronic illness learn to adapt to how illness affects their bodies.
6. The dynamics between people living with chronic unseen health conditions and health care professionals can be complex. Although medical evidence should be engaged with by assessors, it should not take precedence over a claimant's own self-reports.
7. The language around health-based welfare often actively reinforces stigmatisation. In political communications and discussions around health-based welfare claimants, a new vocabulary should be used. Welfare should be established as an unconditional right and any language that seeks to stigmatise welfare claimants should be relegated to the past.
8. There should be creative and news ways of portraying a diversity of welfare claimants. How have people living with chronic illnesses been able to thrive and flourish while claiming welfare?

Future research.

In this discussion chapter, I have written about several opportunities for future research that arise from the findings and limitations of this thesis. One such example was a consideration of a longitudinal study that explores the 'becoming' of a welfare claimant; e.g. how is an individual's sense-making effected by going through welfare assessments? In this section, I wish to expand on these ideas whilst presenting new ideas for future research.

Long COVID is the patient-coined term for a seemingly 'new' chronic disease experienced by at least 10% of people who were infected by the COVID-19 virus (Altmann et al., 2023).

Long COVID is a multisystem condition with a range of debilitating symptoms (Altmann et al., 2023). As a condition, Long COVID shares much in common with Hale et al.'s (2021) definition of an energy limiting chronic illness, with fatigue, post-exertional malaise and cognitive dysfunction reported as the most prevalent symptoms. Half of the people living with Long COVID in the UK have reported having to reduce their working hours as a result of their symptoms (Hale et al., 2021). Lived as a chronic unseen health condition, with implications for employment, it seems as though Long COVID may emerge as the next significant 'problem' for health-based welfare systems. How will these systems be experienced by people living with Long COVID? What sort of knowledges of Long COVID welfare claimants are being produced? Future research may want to explore the social contexts of this evolving condition.

Future work on health-based welfare benefits may wish to incorporate the perspectives of stakeholders beyond those directly living through the assessment processes. Previous work (Mehta et al., 2020; Machin & McCormack, 2021) has shown the importance of peer support; how participants forged links with others in their local communities who were also experiencing problems with social security benefits. Within the findings of this thesis, participants experienced empathetic support within a much closer proximity: from friends, family and colleagues. The use of multiple perspective designs could be useful in understanding the relational aspects of being a welfare claimant (Larkin et al., 2018). A theme across the findings of this thesis is around the process of assessment; the potential for this interaction to be a dehumanising or invalidating experience. Similarly designed, multiple perspective research may wish to explore the dyadic nature of the assessment process for health-based welfare policies. Between claimant and the healthcare professional acting as an assessor: what are the shared and distinctive features of this interaction?

Considering the complexities of stigmatised identities, there may be value in exploring how the individualising consequences of stigma can be overcome. Developing a sense of collective identity has been identified as a key aspect for the emergence of solidarity between workers (Simms & Dean, 2015). However, opportunities for the development of solidarity often comes through the sharing of a physical space (Tassinari & Maccarrone, 2020). Participants had few physical encounters with other health-based welfare claimants. Within the analysis of interview data in chapter 4, we saw a glimpse of the potentiality of these interactions: the sharing of spatiality, in a waiting room prior to their assessments, was a chance to see others experiencing the same difficulties as participants. In a brilliantly insightful study, Tassinari and Maccarrone (2020) explore how precariously employed food delivery platform couriers make use of the ‘common delivery waiting points’ outside or within restaurants to share emerging feelings of reciprocity with other delivery drivers. Ethnographic designs could be used to explore the potential to nurture social relations within the brief meetings between welfare claimants in physical environments.

In the final study of this thesis, I was able to capture the significance of changes in work practices during COVID-19 restrictions. Participants found that their resources of energy became untethered from productivity. Removing the need to commute opened up new possibilities and ways to enjoy their free time. Recent research has considered the flexibility in post-pandemic work policies, suggesting that mandatory office presence can be considered a discriminating policy (Smite et al., 2023). UK employers seem, anecdotally, keen to roll back the opportunities for flexible working created by the pandemic. Careful considerations need to be paid to the impact on well-being this will have for individuals living with chronic health conditions.

One of the recommendations for changes to welfare policies glanced over notions of a new vocabulary needed for political communications and discussions around health-based welfare claimants. Future research could engage with the practicalities of this. Could it be possible to harness the increased levels of empathy experienced by participants during the early stages of the pandemic to establish new discourses? What would be linguistically necessary to roll back the machineries of stigma?

Across this thesis my work has made both methodological and theoretical contributions to the field of qualitative psychological research. It may be beneficial to develop these contributions in research contexts beyond the specific phenomena focussed on in this thesis. For example, from the discussion section of chapter 4, could a phenomenological account of the spectral yet experiential qualities of lost futures prove insightful? Would it be fruitful to apply the concept of atmosphere as a shared affective ground, felt through mood, to other political phenomena? Might the links between Deleuze and Guattari’s work on deterritorialisation and phenomenological concepts of dwelling-mobility be valuable to other critical health or social settings? Would an expansion of creative approaches to phenomenological data collection, through the use of collaging for example, provide participants with new ways to represent meaning? How might a pluralistic approach to psychology knowledge enable deeper understandings of how other political decisions (such as economic policy, immigration or responses to climate collapse) are lived through? I would welcome the chance to work with colleagues in psychology, and other disciplines, to explore all of these questions.

Reflexive considerations.

Within the method and discussion sections of each chapter of this thesis I have demonstrated the ways in which I have engaged, meaningfully, with reflexive processes. As mentioned earlier in this discussion, my PhD has been completed part-time, over a six (plus) year time period. This stretching temporality has created plenty of opportunities for meaningful reflexivity! I have seen myself, in some ways, thoroughly and authentically transformed by the process. It has become difficult to separate the work of this thesis from my developing identity as an academic 'in training'. As explored in the reflexive account shared in the methods section of chapter 6, this PhD was initially linked to my employment as a graduate teaching assistant. I found myself learning 'on the job' how to do many roles: to be a postgraduate researcher, to develop a teaching identity, to find a place within academia. None of this was particularly 'straightforward'. I learnt to balance the demands of a role that was meant to be an equal 50/50 split between research and teaching, but which never was. I learnt the realities of academic work; that everyone is doing the same performance of a balancing act. I learnt that if you spin your plates well enough, you are given more plates to look after. But I love it. I often find myself telling friends, family members and strangers how lucky I am to have found a job that provides me with such meaning. However, I know I am fortunate to have experienced academia in this way. It's only through the support of a truly nurturing supervisor and colleagues who seemed to genuinely encourage my growth that I was able to find spaces of 'mobility-dwelling' (Galvin & Todres, 2011).

In the above paragraph, I state that I was "in some ways" thoroughly transformed by this process of research. How can I be transformed in both a thorough but partial way? My shared connection to the phenomena under investigation acted as an anchor to my personal past, a reminder of why I found myself on *this* research path. Prior to my PhD, I had completed a Master's degree in health psychology. Whilst being its own thing, the research project designed and completed during this programme also functioned as a 'pilot' study to the approaches and ideas which inform this thesis. These preconceptions shaped an understanding of the topic under investigation. In some ways, I anticipated the types of responses I would receive. I *knew* how health-based welfare systems were experienced. The pain that could be caused and the shadows that were cast across peoples' lived experiences of illness. To bridle these things I felt I knew, I was mindful to engage with reflexive practices, such as writing down my thoughts and impressions, throughout the length of this body of work.

A research interest in how chronic illnesses were handled by health-based welfare policies had also been informed and shaped by my life experiences before these opportunities in academic work had opened up. To pay for my Graduate Diploma in Psychology conversion course (and subsequent master's in health psychology) I had taken a job auditing the very welfare systems that this thesis has explored. Looking at how the assessment processes for PIP were administrated, how decisions were reached, I could see a system that clashed with how *I* had experienced chronic illness. At this stage in my life, I was ten years on from being diagnosed with ulcerative colitis, an inflammatory bowel disease. I found the procedures of diagnosis, condition management and personal sense-making of this chronic unseen health condition to be disruptive and complicated. Yet I had experienced many years of good health, and as these experiences and interests converged around this PhD, the circumstances felt full of synchronicity.

As we have seen in interview data extracts, sharing some of my experiences with participants seemed to ease the connections between myself as a researcher and those who took on the role of interview participant. I was highly attuned to the social contexts of these relationships between myself and my participants (Yardley, 2000). There are instances where I am explicitly positioned as 'one of them'. Where my insider status helps establish a shared connection. Despite not having been through the assessments and processes of health-based welfare systems, my own lived experiences of chronic unseen illness served as a foundation for a shared understanding. Some participants initially were suspicious of why I was researching this topic. Was I reporting back to the DWP? I felt a strange sense of pride to be able to distance myself clearly from these worries. No, that wasn't me; I was more so one of them. However, there were times when what was said in interviews shook and surprised me. As explored in chapter 4's theme "the other others: on the edges of out-groups", participants' lack of solidarity with other welfare claimants caught me by surprise. Naively, I had assumed that were my preconceptions 'correct', all participants would want to improve health-based welfare systems for everyone who was affected by them. I didn't anticipate hearing participants replicating and reproducing stigmatising discourses; a firm line between us, the legitimately ill, and those chavs looking to swindle all they could. In those moments my insider status held me firmly in place. All I could find myself doing was to let the judgements pass without comment or critique. Had I positioned myself as an outsider to the phenomena, how might these encounters have been different? Had my desire to forge a connection with my participants unintendedly emboldened those discourses my PhD sought to challenge? In the write-up of those encounters I was keen to reflexively acknowledge these discrepancies between my expectations and the realities of research. Doing so drew attention to the power invested in these discursive constructs whilst also, potentially, serving as penance for my role in their co-construction.

As the longitudinal aspects of this research continued, I felt an increased sense of responsibility and diligence towards ‘my’ participants and their stories. This intensified during COVID-19; many of the second interviews taking place in the strange and uncanny times of the first lockdown. I often found myself in awe of how participants were dealing with their ill-health. I couldn’t see myself being so resolved and filled with self-knowledge. I began to worry if these connections were based on a misconstrued shared understanding. Chronic illness had become a present-absence for me. I had been generally well for so long, my identity as a chronically ill individual felt deceptive. Especially given the tribulations and worries participants were stoically going through. Then I caught COVID-19.

I’ve only knowingly had the COVID-19 virus once. I caught it in between the first and second vaccinations in August 2021. Unfortunately, a deeply unpleasant few weeks of illness led to longer-term consequences. Following some regular (but overdue) check-ups on the status of my colitis, heightened levels of inflammation were found. A local enthusiastic GP seemed to think that given the pathways between COVID-19 and gastrointestinal systems, this re-emergence could be explained by my encounter with the virus. As I had now lived with colitis for a significant period of my life, I was at an increased risk of developing certain types of cancer. To reduce the levels of inflammation I was prescribed an indefinite series of infusion treatments, a biologic medicine given in hospital via infusion every two months. I found myself thrown back into a medical world: the hours lost waiting for blood tests, for appointments, for time to just pass; the checklists and metrics hurriedly worked through by empathetic and funny nursing staff, teetering on the edge of burnout.

During one of these infusion appointments, I had taken the time to work on the writing-up of this thesis. Glancing over at my right-hand, I was struck by the similarity between what I saw and an image Richard, a participant of this research, had shared with me (see Figure 6.7 of chapter 6). I quickly snapped a photo (Figure 7.1). Later I shared this with Richard. The context of the photograph, taken while I was working on parts of this thesis, felt like an authentic summation of my feelings towards the research I had undertaken and how the research process had reflexively shaped me. My role as a researcher moulded not by my health, but by an authentic want to understand how these systems and conditions had been experienced by others. To use my position and fortuitousness to try, in some small way, to see how these experiences could be improved. These are intentions and realisations that I will take with me as I look - hopefully - towards a future career in academia.

Richard reacted with a heart emoji.

Figure 7.1. *The researcher's infusion.*

Concluding remarks.

This thesis has pluralistically explored individuals’ experiences of claiming health-based welfare benefits whilst living with chronic unseen health conditions. A Foucauldian-inspired media analysis aided an understanding of how stigmatising discourses were deeply rooted in the creation of these policies, as well as the subject positions ‘made available’ for claimants of health-based welfare benefits. The use of a dual focus analysis enabled an exploration of interview data in a way that illuminated how discourses around welfare, and welfare claimants, are lived *through*. Against the backdrop of a global pandemic, participants shared photographs that represented their day-to-day experiences. Through the rupture of the pandemic, participants were able to find new ways of being-in-the-world; lines of flight that enabled authentic ways of living. The results of these studies were used to make recommendations for changes to health-based welfare policies.

References.

Altmann, D. M., Whettlock, E. M., Liu, S., Arachchillage, D. J., & Boyton, R. J. (2023). The immunology of long COVID. *Nature Reviews Immunology*. https://doi.org/10.1038/s41577-023-00904-7

Andreouli, E. (2019). Social psychology and citizenship: A critical perspective. *Social and Personality Psychology Compass, 13*(2), e12432. https://doi.org/10.1111/spc3.12432

Amjad, Z., & Jami, H. (2020). Reducing Emotional and Behavioral Problems by Improving Life Skills and Self-Esteem of Institutionalized Children: Effectiveness of an Art-Based Intervention. *Pakistan Journal of Psychological Research, 35*(3), 595–616. https://doi.org/10.33824/PJPR.2020.35.3.32

Arribas-Ayllon, M., & Walkerdine, V. (2019). Foucauldian Discourse Analysis. In C. Willig, and W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (2nd ed., pp. 110–123). London: SAGE Publications Ltd. ISBN:9781526405555

Audulv, Å. (2013). The over time development of chronic illness self-management patterns: A longitudinal qualitative study. *BMC Public Health, 13*(1). https://doi.org/10.1186/1471-2458-13-452

Baboulene, K., & Willig, C. (2023). Benefits of a dual focus methodology utilising IPA and FDA in understanding meaning-making around the experience of psychosis. *QMiP Bulletin, 1*(35), 36–46. https://doi.org/10.53841/bpsqmip.2023.1.35.36

Balmer, C, Griffiths, F & Dunn, J 2015, ‘A “new normal”: exploring the disruption of a poor prognostic cancer diagnosis using interviews and participant-produced photographs’. *Health (United Kingdom), 19*(5), pp. 451–72.

Bambra, C., & Smith, K. E. (2010). No longer deserving? Sickness benefit reform and the politics of (ill) health. *Critical Public Health, 20*(1), 71–83. https://doi.org/10.1080/09581590902763265

Barlott, T., Shevellar, L., Turpin, M., & Setchell, J. (2020). Destabilising social inclusion and recovery, and pursuing “lines of flight” in the mental health sector. *Sociology of Health & Illness, 42*(6), 1328–1343. https://doi.org/10.1111/1467-9566.13106

Barr, B., Taylor-Robinson, D., Stuckler, D., Loopstra, R., Reeves, A., Wickham, S., & Whitehead, M. (2015). Fit-for-work or fit-for-unemployment? Does the reassessment of disability benefit claimants using a tougher work capability assessment help people into work? *Journal of Epidemiology and Community Health, 70*(5), 452–458. https://doi.org/10.1136/jech-2015-206333

Barr, B., Taylor-Robinson, D., Stuckler, D., Loopstra, R., Reeves, A., & Whitehead, M. (2016). “First, do no harm”: Are disability assessments associated with adverse trends in mental health? A longitudinal ecological study. *Journal of Epidemiology and Community Health*, *70*(4), 339–345. https://doi.org/10.1136/jech-2015-206209

Baumberg, B. (2016). The stigma of claiming benefits: A quantitative study. *Journal of Social Policy*, *45*(2), 181–199. https://doi.org/10.1017/S0047279415000525

BBC News. (2010, January 20). *Unemployment falls to 2.46m*. Retrieved from: http://news.bbc.co.uk/1/hi/business/8469648.stm

Bean, C., & J, Symons. (1989). Ten years of Mrs. T. In O., J. Blanchard & S. Fischer (Eds.), *NBER Macroeconomics Annual 1989, Volume 4* (pp. 13-72). MIT Press.

Bend, G., & Fielden, S. (2021). I see you but you don't see me: The "two-way mirror effect" of gender and disability in employment. *Gender in Management: An International Journal*. https://doi.org/10.1108/gm-03-2019-0049

Billig, M. (1997a). The dialogic unconscious: Psychoanalysis, discursive psychology and the nature of repression. *British Journal of Social Psychology, 36*(2), 139–159. https://doi.org/10.1111/j.2044–8309.1997.tb01124.x

Black, S., & Riley, S. (2018). Active ink: Analysing the experience and construction of tattoos as therapy using dual-focus methodology. *Qualitative Methods in Psychology Bulletin, 25*, 24-28.

Bloom, P. (2018). *The Bad Faith in the Free Market*. Springer International Publishing. https://doi.org/10.1007/978-3-319-76502-0

Boden, Z., & Eatough, V. (2014). Understanding more fully: a multimodal hermeneutic phenomenological approach. *Qualitative Research in Psychology, 11*(2), 160–177. https://doi.org/10.1080/14780887.2013.853854

Boden Z., Larkin. M., & Iyer, M. (2019) Picturing ourselves in the world: drawings, interpretative phenomenological analysis and the relational mapping interview. *Qualitative Research in Psychology, 16*(2): 218–236.

Borraccino, A., Pera, R., & Lemma, P. (2019). "What being healthy means to me": A qualitative analysis uncovering the core categories of adolescents' perception of health. *PLOS ONE, 14*(6), e0218727. https://doi.org/10.1371/journal.pone.0218727

Brecht, B. (1964). Brecht on Theatre, ed. *John Willett, London: Methuen*.

Breeze, R. (2011). Critical discourse analysis and its critics. *International Pragmatics Association*, *21*(4), 493–525.

British Psychological Society (BPS). (2016). *Call to action on Work Capability Assessment reform*. Retrieved from https://www.bps.org.uk/news-and-policy/bps-call-action-reform-work-capability-assessment

Brown, J., Kirk-Wade, E., Baker, C., & Barber, S. (2021). *Coronavirus: A history of English lockdown laws.* House of Commons Library. Retrieved from https://commonslibrary.parliament.uk/research-briefings/cbp-9068/

Brown, S. D., Kanyeredzi, A., McGrath, L., Reavey, P., & Tucker, I. (2020). Reflections on a photo-production study: practical, analytic and epistemic issues. In Reavey, P. (Ed.), *A handbook of visual methods in psychology: using and interpreting images in qualitative researc*h (2nd edition, pp. 113-132). Routledge.

Brunsden, V., & Goatcher, J. (2007). Reconfiguring photovoice for psychological research. *Irish Journal of Psychology, 28*(1–2), 43–52. https://doi.org/10.1080/03033910.2007.10446247

Buder, E. (2017, January 9). *'I, Daniel Blake' writer Paul Laverty on climbing the 'enormous mountain' of a screenplay*. Retrieved from https://nofilmschool.com/2017/01/paul-laverty-interview-i-daniel-blake

Burton, A., Hughes, M., & Dempsey, R. C. (2017). Quality of life research: a case for combining photo-elicitation with interpretative phenomenological analysis. *Qualitative Research in Psychology, 14*(4). pp. 375-393.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167-182.

Carel, H. (2021). Pathology as a phenomenological tool. *Continental Philosophy Review*, February. https://doi.org/10.1007/s11007-021-09538-9

Carolan, V. (2011). The shipping forecast and British national identity. *Journal for Maritime Research*, *13*(2), 104-116.

Carr, P., Goodman, S., & Jowett, A. (2018). ‘I don’t think there is any moral basis for taking money away from people’: Using discursive psychology to explore the complexity of talk about tax. *Critical Discourse Studies, 0*(0), 1–12. https://doi.org/10.1080/17405904.2018.1511440

Carreker, D. (2012). *The game developer's dictionary: a multidisciplinary lexicon for professionals and students*. Cengage Learning.

Chamberlain, K. (2000). Methodolatry and Qualitative Health Research. *Journal of Health Psychology*, *5*(3), 285–296. https://doi.org/10.1177/135910530000500306

Chander, A. & Sunder, M. (2007). Everyone’s a superhero: A cultural theory of ‘Mary Sue’ fan fiction as fair use. *California Law Review*, 597–626. https://doi.org/10.15779/Z389X3M

Chiaravalloti, N. D., Amato, M. P., Brichetto, G., Chataway, J., Dalgas, U., DeLuca, J., & CogEx Research Team. (2021). The emotional impact of the COVID-19 pandemic on individuals with progressive multiple sclerosis. *Journal of neurology, 268*, 1598-1607.

Cho, M., M. (1996). Using visual art to motivate at-risk children. *Teaching pre k-8*, *26*, 54-55.

Chu, L., Fuentes, L. R., Marshall, O. M., & Mirin, A. A. (2020). Environmental accommodations for university students affected by Myalgic Encephalomyelitis/Chronic

Fatigue Syndrome (ME/CFS). *Work (Reading, Mass.), 66*(2), 315–326. https://doi.org/10.3233/WOR-203176

Cimpean, D., & Drake, R. E. (2011). Treating co-morbid chronic medical conditions and anxiety/depression. *Epidemiology and psychiatric sciences*, *20*(02), 141-150.

Citizens Advice. (2018). *How much PIP you can get and for how long*. Retrieved from https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/before-claiming/how-much-you-get-and-how-long/

Citizens Advice. (2020). *Preparing for your ESA medical assessment*. Retrieved from https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/employment-and-support-allowance/help-with-your-esa-claim/esa-medical-assessment/

Clarke, N. J., Willis, M. E. H., Barnes, J. S., Caddick, N., Mcdermott, H., Wiltshire, G., Clarke, N. J., Willis, M. E. H., Barnes, J. S., Caddick, N., Cromby, J., Mcdermott, H., Wiltshire, G., Pluralism, A., Clarke, N. J., Willis, M. E. H., Barnes, J. S., Caddick, N., Cromby, J., & Wiltshire, G. (2015). Analytical Pluralism in Qualitative Research: A Meta-Study. *Qualitative Research in Psychology, 12*(2), 182–201. https://doi.org/10.1080/14780887.2014.948980

Clifton, A., Reynolds, J., Remnant, J., & Noble, J. (2014). The age of austerity: the impact of welfare reform on people in the North East of England. *Mental Health Nursing, 33*(6), 30-32.

Conover, P. J., Crewe, I. M., & Searing, D. D. (1991). The nature of citizenship in the United States and Great Britain: Empirical comments on theoretical themes. *The journal of politics, 53*(3), 800-832.

Cooke, B., & Kathari, U. (Eds.). (2001). *Participation: The new tyranny?* London: Zed Books.

Cooper, V., & Whyte, D. (2017). *The violence of austerity*. Pluto Press.

Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative inquiry, 9*(3), 335-354.

Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self–stigma of mental illness: Implications for self–esteem and self–efficacy. *Journal of social and clinical psychology, 25*(8), 875-884.

Craythorne, S. L., Shaw, R., & Larkin, M. (2020). Using artwork and Interpretative Phenomenological Analysis to explore the experience of coping with body dysmorphic disorder. *Qualitative Methods in Psychology Bulletin, (30),* 18-27.

Craythorne, S. L., Shaw, R. L., & Larkin, M. (2023). Visual representations of coping with body dysmorphic disorder: a multimodal hermeneutic phenomenological approach. *Arts & Health,* 1-23.

Creswell, J. W. (2009). Mapping the field of mixed methods research. *Journal of mixed methods research, 3(*2), 95-108.

Crossley, N. (1993). The politics of the gaze: Between Foucault and Merleau-Ponty. *Human Studies, 16*(4), 399–419. https://doi.org/10.1007/BF01323025

Dahlberg, K. (2006). The essence of essences – the search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health and Well-Being, 1*(1), 11–19. https://doi.org/10.1080/17482620500478405

Day, K., Rickett, B., & Woolhouse, M. (2017). Towards a critical social psychology of social class. In Gough B. (Ed.), *The palgrave handbook of critical social psychology* (pp. 469-491). London, England: Palgrave Macmillan.

Day, W., Craythorne, S-L., Moutela, T., Slade, K. & Heath, G. (2023). Creative phenomenology within health and social care research: bridging the gap between experience and expression. In Tseliou, E., Demuth, C., Georgaca, E. & Gough, B. (Eds.), *The Routledge International Handbook of Innovative Qualitative Psychological Research*.

Day, W., & Shaw, R. (2022). When benefit eligibility and patient-led care intersect. Living in the UK with chronic illness: Experiences of the work capability assessment. *Journal of Health Psychology, 27*(2), 456–469. https://doi.org/10.1177/1359105320953476

De Beer, C., Isaacs, S., Lawrence, C., Cebekhulu, G., Morkel, J. M., Nell, J., Mpisane, N., Van Tonder, W. P., Mayman, Y. R., Thobenjane, L. Z., & Pedro, A. (2022). The subjective experiences of students with invisible disabilities at a historically disadvantaged university. *African Journal of Disability*, 11. https://doi.org/10.4102/ajod.v11i0.932

De Visser, R. O., & McDonnell, E. J. (2013). "Man points": Masculine capital and young men's health. *Health Psychology, 32*(1), 5–14. https://doi.org/10.1037/a0029045

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*, *382*(9903), 1525–1533. https://doi.org/10.1016/S0140-6736(13)61809-7

Deleuze, G. (1989). *Cinema 2: The time-image*, trans. Hugh Tomlinson and Robert Galeta (Minneapolis: University of Minnesota Press, 1989), *77.*

Deleuze, G., & Guattari, F. (1987). *A Thousand Plateaus*. New York: Bloomsbury Publishing.

Delprete, D., & Tarpey, T. E. (2018). Text and Context: The Role of Context in Discourse Analysis. *Working Papers in Applied Linguistics and TESOL, 10*(2010).

Dempsey, M., Foley, S., Frost, N., Murphy, R., Willis, N., Robinson, S., Dunn-galvin, A., Veale, A., Linehan, C., Mccarthy, J., Robinson, S., Dunn-galvin, A., Veale, A., Linehan, C., & Pantidi, N. (2019). Am I lazy, a drama queen or depressed? A journey through a pluralistic approach to analysing accounts of depression. *Qualitative Research in Psychology, 00(00)*, 1–21. https://doi.org/10.1080/14780887.2019.1677833

Department for Work and Pensions (DWP). (2018). *Personal Independence Payment How your disability affects you*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713118/pip2-how-your-disability-affects-you-form.pdf

Department for Work and Pensions (DWP). (2021). *Background information: ESA outcomes of Work Capability Assessments*. Retrieved from https://www.gov.uk/government/publications/esa-outcomes-of-work-capability-assessment-policies-and-statements/employment-and-support-allowance-outcomes-of-work-capability-assessments-great-britain-background-information

Department for Work and Pensions (DWP). (2021). *ESA50: Capability for Work questionnaire*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/631921/esa-50-capability-for-work-questionnaire.pdf

Department for Work and Pensions (DWP). (2022). *DWP benefits statistics: August 2022*. Retrieved from https://www.gov.uk/government/statistics/dwp-benefits-statistics-august-2022/dwp-benefits-statistics-august-2022

Department for Work and Pensions (DWP). (2023). *Completing the move to Universal Credit: Learning from the Discovery Phase*. Retrieved from https://www.gov.uk/government/publications/completing-the-move-to-universal-credit-learning-from-the-discovery-phase/completing-the-move-to-universal-credit-learning-from-the-discovery-phase#:~:text=the%2Ddiscovery%2Dphase-,Introduction,households%20in%20payment%20on%20UC%20

Dilthey, W. (1976). *Selected writings* (H.P. Rickman, Trans.) Cambridge: Cambridge University Press

Dolan, V. L. B. (2021). '…but if you tell anyone, I'll deny we ever met:' the experiences of academics with invisible disabilities in the neoliberal university. *International Journal of Qualitative Studies in Education,* 0(0), 1–18. https://doi.org/10.1080/09518398.2021.1885075

Donnelly, S., Wilson, A. G., Mannan, H., Dix, C., Whitehill, L., & Kroll, T. (2021). (In)Visible illness: A photovoice study of the lived experience of self-managing rheumatoid arthritis. *PLoS ONE, 16*(3) https://doi.org/10.1371/journal.pone.0248151

Duffy, S. (2018). Foreword in C. Hale (Ed.), *Reclaiming 'chronic illness'. An introduction to the chronic illness inclusion project* (pp. 3-4). Centre for Welfare Reform.

Dunleavy, P. (2012). The British general election of 2010 and the advent of coalition government. In G. Baldini & J. Hopkins (Eds.), *Coalition Britain: the UK election of 2010*. Manchester: Manchester University Press.

Durmaz, H. (1999). Film: a surface for writing social life. In Parker, I. & the Bolton Discourse Network (Eds.), *Critical textwork: an introduction to varieties of discourse and analysis* (pp. 103-115). Philadelphia, USA.

Dwyer, P. (2004). Creeping conditionality in the UK: from welfare rights to conditional entitlements? *The Canadian Journal of Sociology, 29*,265–287

Ellemers, N., Wilke, H., & Van Knippenberg, A. (1993). Effects of the legitimacy of low group or individual status on individual and collective status-enhancement strategies. *Journal of personality and social psychology, 64*(5), 766.

Ericsson, L. O. (1980). Charges against prostitution: An attempt at a philosophical assessment. *Ethics, 90*(3), 335–366.

Fancourt, D., Baxter, L., & Lorencatto, F. (2020). Barriers and enablers to engagement in participatory arts activities amongst individuals with depression and anxiety: quantitative analyses using a behaviour change framework. *BMC Public Health, 20*(1). https://doi.org/10.1186/s12889-020-8337-1

Farr, J., & Nizza, I. E. (2019). Longitudinal Interpretative Phenomenological Analysis (LIPA): A review of studies and methodological considerations. *Qualitative Research in Psychology, 16*(2), 199–217. https://doi.org/10.1080/14780887.2018.1540677

Ferber, M. (2000). Blake's 'Jerusalem' as a hymn. *Blake: An Illustrated Quarterly*, *34*(3), 82-94.

Fine, A. (1998) The viewpoint of no-one in particular, *Proceedings and Addresses of the American Philosophical Association, 72*(2): 7–20. doi: 10.2307/3130879

Finlay, L., & Gough, B. (Eds.). (2008). *Reflexivity: A practical guide for researchers in health and social sciences*. John Wiley & Sons.

Fisher, M. (2012). What Is Hauntology? *Film Quarterly, 66*(1), 16–24. https://doi.org/10.1525/fq.2012.66.1.16

Fisher, M. (2013). *Ghosts of my life: Writings on depression, hauntology and lost futures*. John Hunt Publishing.

Foster-Fishman, P., Nowell, B., Deacon, Z., Nievar, M. A., & McCann, P. (2005). Using methods that matter: The impact of reflection, dialogue, and voice. *American journal of community psychology, 36*, 275-291.

Foucault, M., & Gordon, C. (1980). *Power/knowledge: Selected interviews and other writings, 1972-1977*. New York: Pantheon Books.

Foucault, M. (1991). Nietzsche, Genealogy, History. In Rabinow, P. (Eds.), *The Foucault Reader: An Introduction to Foucault's Thought* (pp. 76 -100). London: Penguin.

Foucault, M. (1991). Questions of method. In G. Burchell, C. Gordon and P. Miller (Eds.), *The Foucault effect: Studies in governmentality*. Hertfordshire: Harvester Wheatsheaf.

Foucault, M. (1993). About the beginnings of the hermeneutics of the self. *Political Theory, 21*,198–227.

Friedli, L., & Stearn, R. (2015). Positive affect as coercive strategy: Conditionality, activation and the role of psychology in UK government workfare programmes. *Med Humanit, 4*1, 40–47. https://doi.org/10.1136/medhum-2014-010622

Frost, N. (2011). *Qualitative research methods in psychology: Combining core approaches*. McGraw-Hill Education (UK).

Hale, C. (2018). *Reclaiming 'Chronic Illness' An introduction to the Chronic Illness Inclusion Project.* Sheffield: Centre for Welfare Reform.

Hale, C., Benstead, S., Hardy, K., & Ingold, J. (2021). *"I already have a job getting through the day": Energy limiting chronic illness (ELCI), social inclusion, employment and social security*. Sheffield: Centre for Welfare Reform

Harrington, M. (2010). *An Independent Review of the Work Capability Assessment An Independent Review of the Work Capability Assessment*. London: The Stationery Office, for the Department of Work and Pensions (DWP).

Hendry, G., Wilson, C., Orr, M., & Scullion, R. (2022). "I Just Stay in the House So I Don't Need to Explain": A Qualitative Investigation of Persons with Invisible Disabilities. *Disabilities, 2*(1), 145-163.

Henriques, J., Hollway, W., Urwin, C., Venn, C., & Walkerdine, V. (1984). *Changing the Subject. Psychology, Social Regulation and Subjectivity*.

Holland, P., Burström, B., Whitehead, M., Diderichsen, F., Dahl, E., Barr, B., Uppal, S. (2016). How do macro-level contexts and policies affect the employment chances of chronically ill and disabled people?: The impact of recession and deindustrialization. *The Financial and Economic Crises and Their Impact on Health and Social Well-Being*, *41*(3), 256–276. https://doi.org/10.4324/9781315226927

Holmes, E. A., O'Connor, R. C., Perry, V. H., Tracey, I., Wessely, S., Arseneault, L., & Bullmore, E. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *The Lancet Psychiatry, 7*(6), 547-560.

Hood, R. (2016). Combining phenomenological and critical methodologies in qualitative research. *Qualitative Social Work, 15*(2), 160–174. https://doi.org/10.1177/1473325015586248

Gallagher, S. & Zahavi, D. (2008). *The phenomenological mind: an introduction to philosophy of mind and cognitive science*. New York: Routledge.

Galvin, K. T., & Todres, L. (2011). Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies on Health and Well-Being, 6*(4), 1–13. https://doi.org/10.3402/qhw.v6i4.10362

Galvin, R. (2002). Disturbing notions of chronic illness and individual responsibility: towards a genealogy of morals, 107–138.

Garnett, T. (2016). *The day the music died: a life lived behind the lens*. Hachette UK.

Garnett, T. (Producer) & Loach, K. (Director). (1966). *Cathy Come Home* [Motion Picture]. United Kingdom: BBC1.

Garthwaite, K. (2015). Becoming incapacitated? Long-term sickness benefit recipients and the construction of stigma and identity narratives. *Sociology of Health and Illness*, *37*(1), 1–13. https://doi.org/10.1111/1467-9566.12168

Garthwaite, K., Bambra, C., Warren, J., Kasim, A., & Greig, G. (2014). Shifting the Goalposts: A Longitudinal Mixed-Methods Study of the Health of Long-Term Incapacity Benefit Recipients during a Period of Substantial Change to the UK Social Security System. *Journal of Social Policy*, *43*(2), 311–330. https://doi.org/10.1017/s0047279413000974

Geiger, B. B. (2017). Benefits conditionality for disabled people: Stylised facts from a review of international evidence and practice. *Journal of Poverty and Social Justice, 25*(2), 107–128. https://doi.org/10.1332/175982717X14939739331010

Gendlin, E. T. (1968). The experiential response. *Use of interpretation in treatment*, 208-227.

Gerstenblatt, P. (2013). Collage portraits as a method of analysis in qualitative research. *International Journal of Qualitative Methods, 12*(1), 294-309.

Giles, D., & Shaw, R. L. (2009). The Psychology of News Influence and the Development of Media Framing Analysis. *Social and Personality Psychology Compass*, *3*, 375–393. https://doi.org/10.1111/j.1751-9004.2009.00180.

Giorgi, A., Giorgi, B., & Morley, J. (2017). The descriptive phenomenological psychological method. In Willig, C. & Rogers, W.S. (2017). *The SAGE handbook of qualitative research in psychology* (2nd edition) (pp. 176-192). London: SAGE.

Giroux, C. M., Corkett, J. K., & Carter, L. M. (2016). The Academic and Psychosocial Impacts of Ehlers-Danlos Syndrome on Postsecondary Students: An Integrative Review of the Literature. *Journal of Postsecondary Education and Disability, 29*(4), 407–418.

Gjersøe, H. M. (2015). Regulating Inflow or Outflow: A Comparison of the Work Capability Assessments in the UK and Norway. *Journal of Social Policy*. https://doi.org/10.1017/S0047279415000471

Godard, R., Hebl, M., & Nittrouer, C. (2022). Identity management in the workplace: Coworker perceptions of individuals with contested disabilities. *Journal of Vocational Rehabilitation, 57*(2), 177–186. https://doi.org/10.3233/JVR-221208

Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine, 8*(2), 134-138.

Golightley, M., & Holloway, M. (2016). Editorial. *British Journal of Social Work, 46*(1), 1–7. https://doi.org/10.1093/bjsw/bcw001

Goodman, S., & Carr, P. (2017). The just world hypothesis as an argumentative resource in debates about unemployment benefits. *Journal of Community & Applied Social Psychology, 27*(4), 312–323. https://doi.org/10.1002/casp.2314

Gov.uk. (2022). *New Style Jobseeker's Allowance*. Retrieved from https://www.gov.uk/guidance/new-style-jobseekers-allowance

Gov.uk. (2023). *Personal Independence Payment (PIP).* Retrieved from https://www.gov.uk/pip/eligibility

Gray, P. (2017). *The second independent review of the Personal Independence Payment*. Strategy, Policy and Analysis Group, Disability Benefits, PIP Policy Team.

Guillemin, M. (2004). Understanding illness: Using drawings as a research method. *Qualitative health research, 14*(2), 272-289.

Hajli, M. N. (2014). A study of the impact of social media on consumers. *International Journal of Market Research*, *56*(3), 387-404.

Hale, C. (2018). *Reclaiming 'chronic illness'. An introduction to the chronic illness inclusion project*. Centre for Welfare Reform.

Hansford, L., Thomas, F., & Wyatt, K. (2019). The impact of the Work Capability Assessment on mental health: claimants' lived experiences and GP perspectives in low-income communities. *Journal of Poverty and Social Justice, 27*(3), 351-368.

Harrington, M. (2010). *An Independent Review of the Work Capability Assessment An Independent Review of the Work Capability Assessment*. London: The Stationery Office.

Hills, J. (2014). *Good times, bad times: The welfare myth of them and us*. Policy Press.

Hodgetts, D., Radley, A., Chamberlain, K., & Hodgetts, A. (2007). Health inequalities and homelessness: Considering material, spatial and relational dimensions. *Journal of Health Psychology*, *12*(5), 709–725. https://doi.org/10.1177/1359105307080593

Höijer, B. (2004). The discourse of global compassion: The audience and media reporting of human suffering. *Media, Culture & Society, 26*(4), 513-531.

Hood, R. (2016). Combining phenomenological and critical methodologies in qualitative research. *Qualitative Social Work*, *15*(2), 160–174. https://doi.org/10.1177/1473325015586248

House of Commons Work and Pensions Committee (2023). *Health assessments for benefits. Fifth report of sessions 2022-23.* Retrieved from https://committees.parliament.uk/publications/34727/documents/191178/default/

Iacobucci, G. (2017). NHS in 2017: Keeping pace with society. *BMJ (Online)*, *356*, 1–3. https://doi.org/10.1136/bmj.i6738

Imison, C. (2021). Multiple long-term conditions (multimorbidity): making sense of the evidence. *National Institute for Health Research*. https://doi.org/10.3310/collection_45881

Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S., & Iverson, E. (2017). Living a secret: Disclosure among adolescents and young adults with chronic illnesses. *Chronic Illness, 13*(1), 49–61. https://doi.org/10.1177/1742395316655855

Kellett, S., Purdie, F., Bickerstaffe, D., Hopper, S., & Scott, S. (2013). Predicting return to work from health related welfare following low intensity cognitive behaviour therapy. *Behaviour research and therapy, 51*(3), 134-141.

Králová, J. (2015). What is social death? *Journal of the Academy of Social Sciences, 10*(3), 235-248. https://doi.org/10.1080/21582041.2015.1114407

King, N., Brooks, J., & Bravington, A. (2014). *The Pictor Technique: Exploring Collaborative Working in Nursing*. Sage Research Methods Cases. https://doi.org/10.4135/978144627305014537441

Kingston, A., Robinson, L., Booth, H., Knapp, M., Jagger, C., Adelaja, B., Wittenberg, R. (2018). Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation (PACSim) model. *Age and Ageing*, *47*(3), 374–380. https://doi.org/10.1093/ageing/afx201

Kirkham, J. A., Smith, J. A., & Havsteen-Franklin D. (2015). Painting pain: an interpretative phenomenological analysis of representations of living with chronic pain. *Health Psychology, 34*(4): 398–406.

Kitzinger, C. (1987). *The social construction of lesbianism*. Sage Publications, Inc.

Kitzinger, J. (2000). Media templates: patterns of association and the (re) construction of meaning over time. *Media, Culture & Society, 22*(1), 61-84.

Kress, G. (2011). Multimodal discourse analysis. In J. P. Gee & M. Handford (Eds.), *The Routledge handbook of discourse analysis* (pp. 35-50). Routledge.

Kruger, A. B. (2012). *The Rise and Consequences of Inequality in the United States.* Retrieved from https://obamawhitehouse.archives.gov/sites/default/files/krueger_cap_speech_final_remarks.pdf

Jenson, T., De Benedictis, S., Garthwaite, K., Patrick, P., & Allen, K. (2018). *Welfare Imaginaries: constructing rhetoric, realities and resistance over time*. Retrieved from https://welfareimaginaries.wordpress.com/about-the-series/

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243–248. https://doi.org/10.1046/j.1365-2648.2000.01466.x

Johnson, S., Burrows, A., & Williamson, I. (2004). "Does my bump look big in this?" The meaning of bodily changes for first-time mothers-to-be. *Journal of Health Psychology, 9*(3), 361–374. https://doi.org/10.1177/1359105304042346

Jowsey, T. (2016). Time and chronic illness: A narrative review. *Quality of Life Research, 25*(5), 1093–1102. https://doi.org/10.1007/s11136-015-1169-2

Langdridge, D. (2003). Hermeneutic phenomenology: Arguments for a new social psychology. *History and Philosophy of Psychology, 5*(1), 23–46.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Pearson Education.

Langdridge, D., Gabb, J., & Lawson, J. (2019). Art as a pathway to impact: Understanding the affective experience of public engagement with film. *The Sociological Review*, 003802611882282. https://doi.org/10.1177/0038026118822822

Larkin, M., Shaw, R., & Flowers, P. (2018). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology, 00(00)*, 1–17. https://doi.org/10.1080/14780887.2018.1540655

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology, 3*(2), 102-120.

Laverty, P. (2016). *I, Daniel Blake*. Route.

Lerner, M. (1965). Evaluation of performance as a function of performer's reward and attractiveness. Journal of Personality and Social Psychology, 1, 355–360. https://doi.org/10.1037/h0021806

Lian, O. S., & Lorem, G. F. (2017). "i Do Not Really Belong Out There Anymore": Sense of Being and Belonging among People with Medically Unexplained Long-Term Fatigue. *Qualitative Health Research, 27*(4), 474–486. https://doi.org/10.1177/1049732316629103

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P, Clarke, M., Devereaux, P.J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Annals of internal medicine, 151*(4), W-65.

Link, B. G., & Phelan, J. (2014). Stigma power. *Social science & medicine, 103*, 24-32.

Loopstra, R., McKee, M., Katikireddi, S. V., Taylor-Robinson, D., Barr, B., & Stuckler, D. (2016). Austerity and old-age mortality in England: a longitudinal cross-local area analysis, 2007–2013. *Journal of the Royal Society of Medicine, 109*(3), 109-116.

Lux, K. (2009). Work, Violence, or Both? Framing the Sex Trade and Setting an Agenda for Justice. *Advocates' forum*.

Machin, R. (2017). Made to measure? An analysis of the transition from Disability Living Allowance to Personal Independence Payment. *Journal of Social Welfare and Family Law*, *39*(4), 435–453. https://doi.org/10.1080/09649069.2017.1390291

Machin, R., & McCormack, F. (2021). The impact of the transition to Personal Independence Payment on claimants with mental health problems. *Disability and Society, 0*(0), 1–24. https://doi.org/10.1080/09687599.2021.1972409

Mair, F. S., & Jani, B. D. (2020). Emerging trends and future research on the role of socioeconomic status in chronic illness and multimorbidity. *The Lancet Public Health, 5*(3), e128–e129. https://doi.org/10.1016/s2468-2667(20)30001-3

Marx, K., & Engels, F. (1975). *Marx & Engels Collected Works Vol 01: Marx: 1835-1843*. Lawrence & Wishart.

McKee, M., & Stuckler, D. (2013). Older people in the UK: under attack from all directions. *Age and Ageing, 42*,11–13

McManus, S., Bebbington, P. P., Jenkins, R., & Brugha, T. T. (2016). Mental health and wellbeing in England: Adult psychiatric morbidity survey 2014. *Leeds: NHS Digital*, 405.

McNay, L. (2013). Foucault and feminism: Power, gender and the self. John Wiley & Sons.

Megari, K. (2013). Quality of life in chronic disease patients. *Health Psychology Research*, *1*(3), 27. https://doi.org/10.4081/hpr.2013.e27

Mehta, J., Taggart, D., Clifford, E., & Speed, E. (2020). "They say jump, we say how high?" conditionality, sanctioning and incentivising disabled people into the UK labour market. *Disability & Society, 0*(0), 1–21. https://doi.org/10.1080/09687599.2020.1766422

Milton, S., Buckner, S., Salway, S., Powell, K., Moffatt, S., & Green, J. (2015). Understanding welfare conditionality in the context of a generational habitus: A qualitative study of older citizens in England. *Journal of Aging Studies, 34*, 113–122. https://doi.org/10.1016/j.jaging.2015.06.002

Migliorini, L., & Rania, N. (2017). A qualitative method to "make visible" the world of intercultural relationships: The photovoice in social psychology. *Qualitative Research in Psychology, 14*(2), 131–145. https://doi.org/10.1080/14780887.2016.1263698

Monaco, J. (2009). *How to read a film: movies, media, and beyond. Art, Technology, Language.* History, Theory.

Moran, D. (2000). *Introduction to phenomenology*. Routledge.

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative research*, *6*(1), 45-59.

Moravcsik, A. (2019). *Transparency in Qualitative Research.* Sage Research Methods Foundation. Sage Publications.

Morris-Jones, W. H. (1949). *Socialism and Bureaucracy*. Fabian Publications; b Victor Gollancz Limited.

Morison, T., Lyons, A., & Chamberlain, K. (2019). Critical health psychology: Applications for social action. *The SAGE Handbook of Applied Social Psychology*, 215.

Morrison, V., & Williams, K. (2020). Gaining Longitudinal Accounts of Carers' Experiences Using IPA and Photograph Elicitation. *Frontiers in Psychology, 11*(December), 1–15. https://doi.org/10.3389/fpsyg.2020.521382

Murray, E. (2012). Web-based interventions for behavior change and self-management: potential, pitfalls, and progress. Medicine 2.0, 1(2), e3-e3.

Murray, L., & Nash, M. (2017). The challenges of participant photography: a critical reflection on methodology and ethics in two cultural contexts. *Qualitative Health Research, 27*(6), 923–937. https://doi.org/10.1177/1049732316668819.

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health: The cost of co-morbidities. *The King's Fund and Centre for Mental Health*, 1–32. https://doi.org/ISBN 9781857176339

Neale, B. (2021). *The craft of qualitative longitudinal research: the craft of researching lives through time*. Sage.

Newman, J., & Clarke, J. (2017). The instabilities of expertise: Remaking knowledge, power and politics in unsettled times. *Innovation, 1610*, 1–15. https://doi.org/10.1080/13511610.2017.1396887

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology, 00(00),* 1–18. https://doi.org/10.1080/14780887.2020.1854404

Nizza, I. E., Smith, J. A., & Kirkham, J. A. (2018). 'Put the illness in a box': a longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme. *British Journal of Pain, 12*(3), 163-170.

Norstedt, M. (2019). Work and invisible disabilities: Practices, experiences and understandings of (non)disclosure. *Scandinavian Journal of Disability Research, 21*(1), 14–24. https://doi.org/10.16993/sjdr.550

O'Brien, N. (2018). Administrative justice in the wake of I, Daniel Blake. *The Political Quarterly*, *89*(1), 82-91.

O'Brien, R. (Producer) & Loach, K. (Director). (2016). *I, Daniel Blake* [Motion Picture]. United Kingdom: Sixteen Films.

Ozamiz-Etxebarria, N., Dosil-Santamaria, M., Picaza-Gorrochategui, M., & Idoiaga-Mondragon, N. (2020). Stress, anxiety, and depression levels in the initial stage of the COVID-19 outbreak in a population sample in the northern Spain. *Public Health Reports, 36*.

Papaloukas, P., Quincey, K., & Williamson, I. R. (2017). Venturing into the visual voice: Combining photos and interviews in phenomenological inquiry around marginalisation and chronic illness. *Qualitative Research in Psychology, 14*(4), 415–441. https://doi.org/10.1080/14780887.2017.1329364

Parker, I. (1994). Reflexive social psychology: Discourse analysis and psychoanalysis. *Free Associations*.

Parker, I. (1999). the Bolton Discourse Network. *Critical textwork: an introduction to varieties of discourse and analysis*. Philadelphia, USA.

Patrick, R. (2014). Working on Welfare: Findings from a Qualitative Longitudinal Study Into the Lived Experiences of Welfare Reform in the UK. *Journal of Social Policy*, *43*(04), 705–725. https://doi.org/10.1017/S0047279414000294

Patrick, R. (2016). Living with and responding to the "scrounger" narrative in the UK: Exploring everyday strategies of acceptance, resistance and deflection. *Journal of Poverty and Social Justice*, *24*(3), 245–259. https://doi.org/10.1332/175982716X14721954314887

Patrick, R. (2017). Wither social citizenship? Lived experiences of citizenship in/exclusion for recipients of out-of-work benefits. *Social Policy and Society*, *16*(2), 293–304. https://doi.org/10.1017/S147474641600049X

Petticrew, M. (2007). 'More research needed': plugging gaps in the evidence base on health inequalities. *European journal of public health, 17*(5), 411-413.

Ponsford, D. (2022). How readers access news: Latest data on smartphones, podcasts and newsletters (Digital News Report). Retrieved from https://pressgazette.co.uk/news/how-readers-access-news/

Porter, T., Pearson, C., & Watson, N. (2021). Evidence, objectivity and welfare reform: A qualitative study of disability benefit assessments. Evidence & Policy: *A Journal of Research, Debate and Practice, 17*(2), 279–296. https://doi.org/10.1332/174426421X16146990181049

Pring, J. (2023a). *Half a million set to lose out when DWP scraps 'fit for work' test, figures show.* Retrieved from https://www.disabilitynewsservice.com/half-a-million-set-to-lose-out-when-dwp-scraps-fit-for-work-test-figures-show/

Pring, J. (2023b). Labour government will push for jobs for ‘not fit for work’ group, says Ashworth. Retrieved from https://www.disabilitynewsservice.com/labour-government-will-push-for-jobs-for-not-fit-for-work-group-says-ashworth/

Purdie, F., & Kellett, S. (2015). The influence of presenting health condition on eventual return to work for individuals receiving health-related welfare benefits. *New Perspectives on Health, Disability, Welfare and the Labour Market,* 107-125.

Pursglove, T. (2023). *Personal Independence Payment: Medical Examinations*. Retrieved from https://questions-statements.parliament.uk/written-questions/detail/2023-06-19/190229

Pybus, K., Pickett, K.E., Prady, S.L., Lloyd, C. & Wilkinson, R. (2019), Discrediting experiences: outcomes of eligibility assessments for claimants with psychiatric compared to non-psychiatric conditions transferring to personal independence payments in England. *British Journal of Psychiatry Open, 5*:2, e19.

Pybus, K., Pickett, K. E., Lloyd, C., Prady, S., & Wilkinson, E. R. (2020). Functional assessments in the UK social security system: The experiences of claimants with mental health conditions. *Journal of Social Policy*, 1–18. https://doi.org/10.1017/S0047279420000094

Raleigh, V. (2022). *What is happening to life expectancy in England?* The King’s Fund.

Ratcliffe, M. (2019). Emotional Intentionality. *Royal Institute of Philosophy Supplement, 85*, 251–269. https://doi.org/10.1017/s1358246118000784

Rich, R. (2013). *The Great Recession*. Retrieved from https://www.federalreservehistory.org/essays/great-recession-of-200709

Ritchie, H., Casebourne, J., & Rick, J. (2005). Understanding workless people and communities: a literature review. Department for Work and Pensions. Research Report 255. Department for work and pensions: Corporate Document Services. http://www.youthandpolicy.org/articles/generations-of-worklessness/

Ritchie, H., Casebourne, J., & Rick, J. (2005). *Understanding workless people and communities: a literature review*. Department for Work and Pensions. Research Report 255. Department for work and pensions: Corporate Document Services. http://www.youthandpolicy.org/articles/generations-of-worklessness/

Ritzer, G. (1993). *The McDonaldization of Society*. Thousand Oaks, CA: Pine Forge Press.

Robins, K. (2005). Tradition and translation: national culture in its global context. In *Enterprise and heritage* (pp. 29-52). Routledge.

Ronzi, S., Pope, D., Orton, L., & Bruce, N. (2016). Using photovoice methods to explore older people’s perceptions of respect and social inclusion in cities: Opportunities, challenges and solutions. *SSM - Population Health, 2*, 732–745. https://doi.org/10.1016/j.ssmph.2016.09.004

Rose, N. (1996a). Governing 'advanced' liberal democracies. In A. Barry, T. Osborne & N. Rose (Eds.), *Foucault and political reason: Liberalism, neoliberalism and rationalities of government*, (pp. 37–64). London: UCL Press

Roulstone, A. (2015). Personal Independence Payments, welfare reform and the shrinking disability category. *Disability and Society*, *30*(5), 673–688. https://doi.org/10.1080/09687599.2015.1021759

Sanders, T., Elliott, J., Norman, P., Johnson, B., & Heller, S. (2019). Disruptive illness contexts and liminality in the accounts of young people with type 1 diabetes. *Sociology of Health & Illness, 41*(7), 1289–1304. https://doi.org/10.1111/1467-9566.12906

Scott, S. (2020). The Unlived Life Is Worth Examining: Nothings and Nobodies behind the Scenes. *Symbolic Interaction, 43*(1), 156–180. https://doi.org/10.1002/symb.448

Shakespeare, T. (1999). 'Losing the plot'? Medical and activist discourses of contemporary genetics and disability. *Sociology of Health & Illness*, *21*(5), 669-688.

Shakespeare, T., Watson, N., & Alghaib, O. A. (2016). Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. *Critical Social Policy*, *37*, 22–41. https://doi.org/10.1177/0261018316649120

Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology, 7*(3), 233–243. https://doi.org/10.1080/14780880802699092

Shaw, R. L., Hiles, D. R., West, K., Holland, C., & Gwyther, H. (2018). From Mixing methods to the logic(s) of inquiry: taking a fresh look at developing mixed design studies. *Health Psychology and Behavioral Medicine*, *6*(1), 226–244. https://doi.org/10.1080/21642850.2018.1515016

Shaw, R. L., West, K., Hagger, B., & Holland, C. A. (2016). Living well to the end: A phenomenological analysis of life in extra care housing. *Int J Qual Stud Health Well-Being, 11*, 31100. https://doi.org/10.3402/qhw.v11.31100

Sherman, J. (2013). Surviving the Great Recession: Growing need and the stigmatized safety net. *Social Problems*, *60*(4), 409-432.

Shinebourne, P., & Smith, J., A. (2011) Images of addition and recovery: an interpretative phenomenological analysis of the experience of addiction and recovery as expressed in visual images. *Drugs: Education, Prevention and Policy, 18*(5): 313–322.

Sim, J., & Waterfield, J. (2019). Focus group methodology: some ethical challenges. *Quality & quantity, 53*(6), 3003-3022.

Skoy, E., & Werremeyer, A. (2019). Using photovoice to document living with mental illness on a college campus. *Clinical Medicine Insights: Psychiatry, 10*, 1179557318821095.

Sloan, M., Gordon, C., Lever, E., Harwood, R., Bosley, M. A., Pilling, M., & D'Cruz, D. (2021). COVID-19 and shielding: experiences of UK patients with lupus and related diseases. *Rheumatology advances in practice, 5*(1), rkab003.

Spiers, J., & Riley, R. (2018). Analysing one dataset with two qualitative methods: The distress of general practitioners, a thematic and interpretative phenomenological analysis. *Qualitative Research in Psychology, 00*(00), 1–15. https://doi.org/10.1080/14780887.2018.1543099

Smite, D., Moe, N. B., Hildrum, J., Gonzalez-Huerta, J., & Mendez, D. (2023). Work-from-home is here to stay: Call for flexibility in post-pandemic work policies. *Journal of Systems and Software, 195,* 111552.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*, *11*(2), 261–271. https://doi.org/10.1080/08870449608400256

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis. Theory, method & research*. London: SAGE.

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis. Theory, method & research* (2nd ed.). London: SAGE.

Smith, R. (2002). Spend (slightly) less on health and more on the arts. *BMJ (Clinical research ed.), 325*(7378), 1432–1433. https://doi.org/10.1136/bmj.325.7378.1432

Stafford, R. (2017, May 31). *I, Daniel Blake: social realism in a time of social media*. Retrieved from: http://ames.scot/resources/pdf/DanielBlakeNotes.pdf

Stanier, J. (2022). An Introduction to Engaged Phenomenology. *Journal of the British Society for Phenomenology, 53*(3), 226–242. https://doi.org/10.1080/00071773.2022.2081533

Stam, R. (1999). *Film theory: an introduction*. Malden, Mass: Blackwell.

Stewart, M. (2018). *Preventable Harm and the Work Capability Assessment*. Retrieved from https://www.centreforwelfarereform.org/

Stewart, M. (2019). *Psychological Tyranny Masquerading as Welfare Reform*. Retrieved from https://www.mostewartresearch.co.uk/wp-content/uploads/2019/03/Psychological-Tyranny-Masquerading-Welfare-Reform.pdf

Svenaeus, F. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care and Philosophy, 14*(3), 333–343. https://doi.org/10.1007/s11019-010-9301-0

Takata, Y. (2002). Supporting by a nurse teacher in a school infirmary using collage therapy. *Psychiatry and Clinical Neurosciences, 56*(4), 371–379. https://doi.org/10.1046/j.1440-1819.2002.01025.x

Tassinari, A., & Maccarrone, V. (2019). Riders on the Storm: Workplace Solidarity among Gig Economy Couriers in Italy and the UK. *Work, Employment and Society*. https://doi.org/10.1177/0950017019862954

The Academy of Medical Sciences. (2018). Multimorbidity: a priority for global health research. *The Academy of Medical Sciences*.

Thompson, G. (2010). *General election 2010*. Retrieved from http://www.parliament.uk/documents/commons/lib/research/key_issues/Key-Issues-General-election-2010.pdf

Thompson, L., Ford, H. L., Stroud, A., & Madill, A. (2019). Managing the (In)visibility of Chronic Illness at Work: Dialogism, Parody, and Reported Speech. *Qualitative Health Research*. https://doi.org/10.1177/1049732319825843

Thornton, I., & Iacoella, F. (2022). Conditionality and contentment: Universal Credit and UK welfare benefit recipients' life satisfaction. *Journal of Social Policy*, 1–29. https://doi.org/10.1017/S0047279422000241

Todres, L., Galvin, K., & Dahlberg, K. (2007). Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, *10*(1), 53–63. https://doi.org/10.1007/s11019-006-9012-8

Todres, L., Galvin, K. T., & Holloway, I. (2009). The humanization of healthcare: A value framework for qualitative research. *International Journal of Qualitative Studies on Health and Well-Being, 4*(2), 68–77. https://doi.org/10.1080/17482620802646204

Todres, L., Galvin, K. T., & Dahlberg, K. (2014). Caring for insiderness: Phenomenologically informed insights that can guide practice. *International Journal of Qualitative Studies on Health and Well-Being, 9*(1). https://doi.org/10.3402/qhw.v9.21421

Toombs, S. K. (1990). The temporality of illness: Four levels of experience. *Theoretical Medicine, 11*(3), 227–241. https://doi.org/10.1007/BF00489832

Toombs, S. K. (1993). The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient. *Annals of Internal Medicine, 119*(8), 864. https://doi.org/10.7326/0003-4819-119-8-199310150-00030

Trigg, D. (2020). The role of atmosphere in shared emotion. *Emotion, Space and Society, 35(January)*, 100658. https://doi.org/10.1016/j.emospa.2020.100658

Tseliou, E., & Benozzo, A. (2022). Inviting the Spectral in Photos: A Poststructuralist Engagement With Visual Data in Qualitative Inquiry. *Qualitative Inquiry, 28*(8–9), 906–916. https://doi.org/10.1177/10778004221093419

Tritter, J. Q., & Calnan, M. (2002). Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care*, *11*(3), 161–165. https://doi.org/10.1046/j.1365-2354.2002.00345

Tyler, I. (2008). “Chav mum chav scum” Class disgust in contemporary Britain. *Feminist media studies, 8*(1), 17-34.

Tyler, I. (2020). *Stigma: The machinery of inequality*. Bloomsbury Publishing.

United Nations. (2016). *Committee on the Rights of Persons with Disabilities: Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention*. Retrieved from http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc

van der Bom, I., Paterson, L. L., Peplow, D., & Grainger, K. (2018). ‘It’s not the fact they claim benefits but their useless, lazy, drug taking lifestyles we despise’: Analysing audience responses to Benefits Street using live tweets. *Discourse, Context and Media, 21*, 36–45. https://doi.org/10.1016/j.dcm.2017.11.003

Van Manen, M. (1990). *Researching lived experiences*. State University of New York Press, Albany.

Verschueren, J. (2001). Predicaments of criticism. *Critique of Anthropology*, *21*(1), 59–81. https://doi.org/10.1177/0308275X0102100104

Vessey, D. (2009). Gadamer and the Fusion of Horizons. *International Journal of Philosophical Studies, 17*(4), 531–542. https://doi.org/10.1080/09672550903164459

Vickers, M. H. (2001). Unseen chronic illness and work: Authentic stories from “women in-between.” Women in Management Review, 16(2), 62–74. https://doi.org/10.1108/09649420110386593

Vickers, M. H. (2003). Expectations of consistency in oraganizational life: Stories of inconsistency from people with unseen chronic illness. Employee Responsibilities and Rights Journal, 15(2), 85–98. https://doi.org/10.1023/A:1023524714053

Vickers, M. H. (2005). Illness, Work and Organization: Postmodern Perspectives, Antenarratives and Chaos Narratives for the Reinstatement of Voice. TAMARA: Journal of Critical Postmodern Organization Science, 3(2), 74–88.

Vogeli, C., Shields, A. E., Lee, T. A., Gibson, T. B., Marder, W. D., Weiss, K. B., & Blumenthal, D. (2007). Multiple chronic conditions: Prevalence, health consequences, and implications for quality, care management, and costs. *Journal of General Internal Medicine*, *22*(SUPPL. 3), 391–395. https://doi.org/10.1007/s11606-007-0322-1

Wainwright, E., Wainwright, D., Keogh, E., & Eccleston, C. (2015). The social negotiation of fitness for work: Tensions in doctor–patient relationships over medical certification of chronic pain. *Health (United Kingdom)*, *19*(1), 17–33. https://doi.org/10.1177/1363459314530738

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health education & behavior, 24*(3), 369-387.

Weinberg, A., & Doyle, N. (2017). *Psychology at work: Improving wellbeing and productivity in the workplace* (K. Scott & L. M. Coulthard, Eds.). The British Psychological Society.

Weiner, A. (1980). The function of the tragic Greek chorus. *Theatre Journal*, *32*(2), 205-212.

Wetherell, M. (2013). Affect and discourse – What's the problem? From affect as excess to affective/discursive practice. *Subjectivity, 6*(4), 349–368. https://doi.org/10.1057/sub.2013.13

White, R. (2014). Foucault on the Care of the Self as an Ethical Project and a Spiritual Goal. *Human Studies, 37*(4), 489–504. https://doi.org/10.1007/s10746-014-9331-3

Wilde, L., Quincey, K., & Williamson, I. (2020). "The real me shining through M.E.": Visualizing masculinity and identity threat in men with myalgic encephalomyelitis/chronic fatigue syndrome using photovoice and IPA. *Psychology of Men & Masculinities, 21*(2), 309–320. https://doi.org/10.1037/men0000220

Williams, A. M., Christopher, G., & Jenkinson, E. (2019). The psychological impact of dependency in adults with chronic fatigue syndrome/myalgic encephalomyelitis: A qualitative exploration. *Journal of Health Psychology*, 135910531664337. https://doi.org/10.1177/1359105316643376

Williams, C. (2006a), *Overcoming Anxiety: A Five Areas Approach*, London: Hodder Arnold.

Williamson, I. R., Quincey, K., Lond, B. J., & Papaloukas, P. (2021). Unanticipated voices? Reflections from our ongoing 'adventures' with participant-authored photography, interviewing and interpretative phenomenology. *Methods in Psychology, 5*, 100062. https://doi.org/10.1016/j.metip.2021.100062

Willig, C. (2016). Constructivism and 'The Real World': Can they co-exist? *QMiP Bulletin*, *21*. https://doi.org/10.1108/JCM-04-2015-1405

Willig, C. (2017). Interpretation in Qualitative Research. In C. Willig & W. S. Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 274–288). SAGE Publications Ltd. https://doi.org/10.4135/9781526405555.n16

Willig, C. (2021). *Introducing qualitative research in psychology* (4th ed.). McGraw-Hill Education (UK).

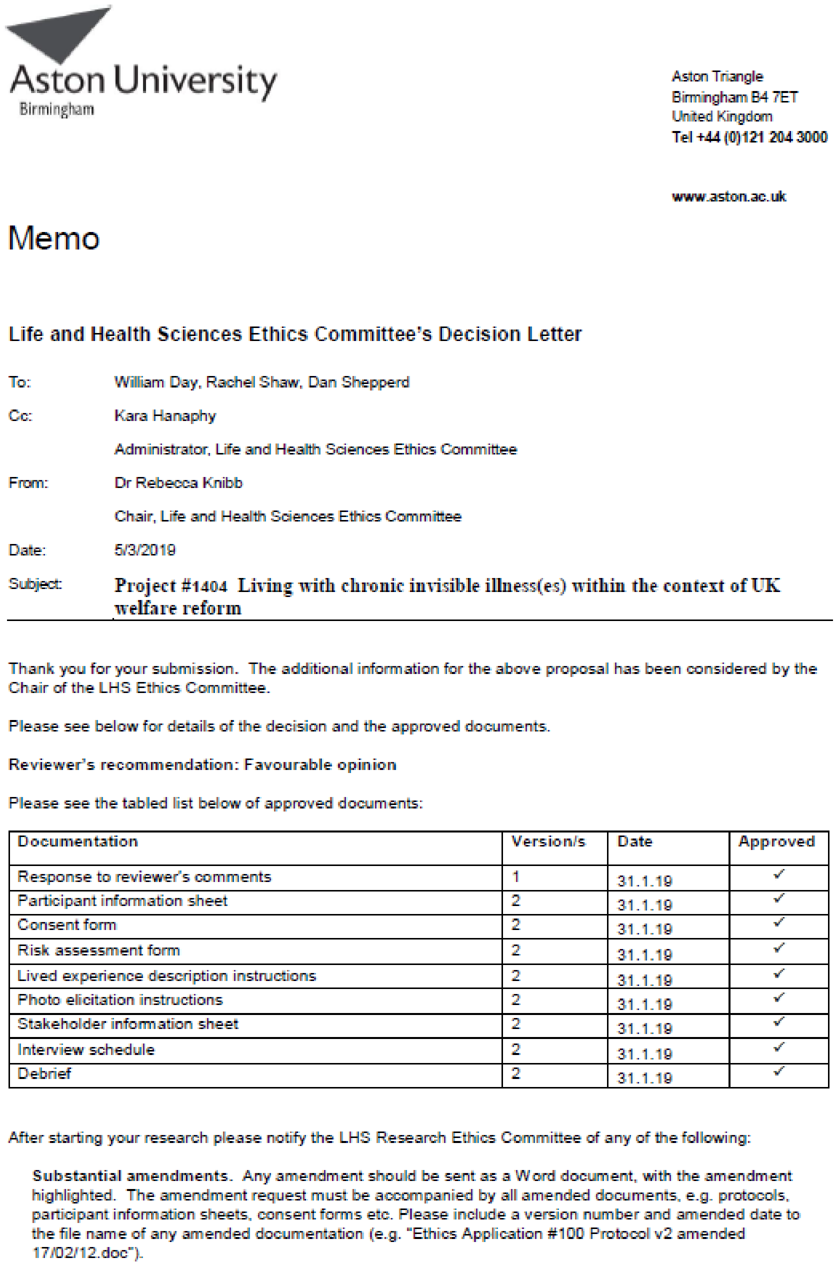
Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Yardley, L., & Bishop, F. L. (2017). Mixing qualitative and quantitative methods: A pragmatic approach. In C. Willig & W. S. Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 398-413). SAGE Publications Ltd. https://doi.org/10.4135/9781526405555

Yates, S., & Hiles, D. (2010). Towards a “Critical Ontology of Ourselves”?: Foucault, Subjectivity and Discourse Analysis. *Theory & Psychology, 20*(1), 52–75. https://doi.org/10.1177/0959354309345647

Appendices.

Appendix 1. Ethical approval.



Aston University
Birmingham

Aston Triangle
Birmingham B4 7ET
United Kingdom
Tel +44 (0)121 204 3000

www.aston.ac.uk

Memo

Life and Health Sciences Ethics Committee's Decision Letter

To: William Day, Rachel Shaw, Dan Shepperd
Cc: Kara Hanaphy
Administrator, Life and Health Sciences Ethics Committee
From: Dr Rebecca Knibb
Chair, Life and Health Sciences Ethics Committee
Date: 5/3/2019
Subject: **Project #1404 Living with chronic invisible illness(es) within the context of UK welfare reform**

Thank you for your submission. The additional information for the above proposal has been considered by the Chair of the LHS Ethics Committee.

Please see below for details of the decision and the approved documents.

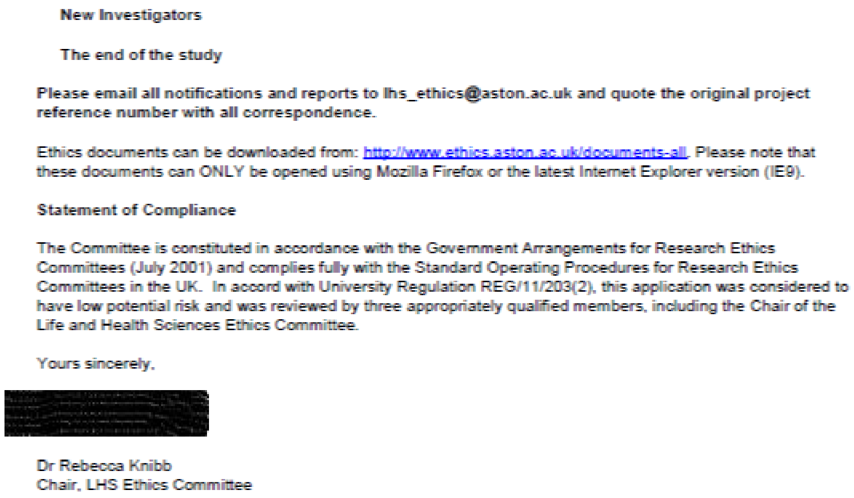
Reviewer's recommendation: Favourable opinion

Please see the tabled list below of approved documents:

Documentation	Version/s	Date	Approved
Response to reviewer's comments	1	31.1.19	✓
Participant information sheet	2	31.1.19	✓
Consent form	2	31.1.19	✓
Risk assessment form	2	31.1.19	✓
Lived experience description instructions	2	31.1.19	✓
Photo elicitation instructions	2	31.1.19	✓
Stakeholder information sheet	2	31.1.19	✓
Interview schedule	2	31.1.19	✓
Debrief	2	31.1.19	✓

After starting your research please notify the LHS Research Ethics Committee of any of the following:

Substantial amendments. Any amendment should be sent as a Word document, with the amendment highlighted. The amendment request must be accompanied by all amended documents, e.g. protocols, participant information sheets, consent forms etc. Please include a version number and amended date to the file name of any amended documentation (e.g. "Ethics Application #100 Protocol v2 amended 17/02/12.doc").



New Investigators

The end of the study

Please email all notifications and reports to lhs_ethics@aston.ac.uk and quote the original project reference number with all correspondence.

Ethics documents can be downloaded from: http://www.ethics.aston.ac.uk/documents-all. Please note that these documents can ONLY be opened using Mozilla Firefox or the latest Internet Explorer version (IE9).

Statement of Compliance

The Committee is constituted in accordance with the Government Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK. In accord with University Regulation REG/11/203(2), this application was considered to have low potential risk and was reviewed by three appropriately qualified members, including the Chair of the Life and Health Sciences Ethics Committee.

Yours sincerely,

[redacted]

Dr Rebecca Knibb
Chair, LHS Ethics Committee

Appendix 2. Interview schedule.

Can you tell me a bit about yourself?

Do you live locally?
Have you lived here long?
Do you live with family or are they close by?

You have been asked to participate in the interview today because you have a chronic and 'invisible' or 'unseen' health condition. Could you tell me more about your condition?

When were you first diagnosed?
How was your situation leading up to diagnosis?
What is your current treatment regime?
How would you describe the effect of your condition to someone who had no previous knowledge of the condition?

Could you describe the condition's effect on your day-to-day life?

Is there anything you now struggle with that you didn't previously?
How would those close to you (i.e. any family members/partners mentioned in previous responses) describe the effects of the condition?

Either pre or post diagnosis, has your condition affected your education or ability work?

Did you have to take any time off from school or work due to your condition?
Were your employer or friends supportive and understanding?
How did you colleagues react?
Did the 'invisible' aspect of your condition help or hinder people's understanding of your situation?

Could you tell me about your experience of going through the Work Capability Assessment or Personal Independence Payment (PIP) process?

Where did you have to go for your assessment?
Did you have a long or short wait for an appointment?
Which company did your assessment?
How did you feel about the person who did your assessment?
How did you feel during/following the assessment?
Was it a long or short process?

What was the outcome of your benefits assessment?

How did this decision make you feel?
Did having access to this benefit have an effect on your daily life?
Did you appeal the decision? (If so, was the appeal a success?)
Have you spoken to anyone else with your condition who has been through the WCA/PIP?

How do you feel about how the media *talks* about welfare claimants?

Have you seen any TV programmes about welfare claimants?
Seen any newspaper reports about welfare claimants?
What about online?

What do you think other people, friends/family or strangers, think about people who claim welfare?

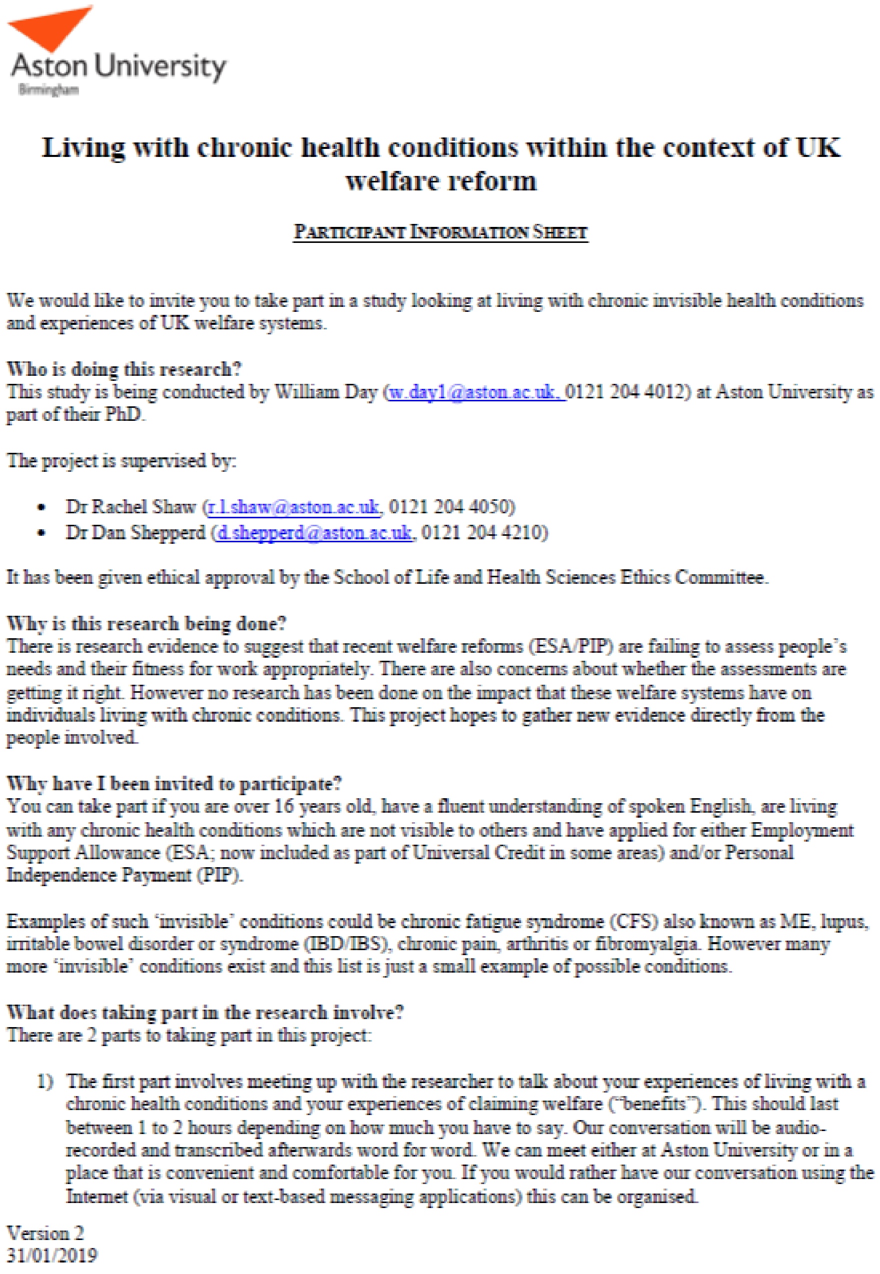
Have you ever experienced any discrimination, either because of your condition, or because you claim welfare?
Are your friends and family supportive?
How would you feel telling a stranger that you claim benefits?
As a welfare claimant, do you feel you have to 'act' in a certain way?

Based on your own experiences of the welfare system, are there any changes you would like to see made for future applicants?

how perhaps their experience could have been improved.
How do they see *themselves* in the future?

Is there anything you expected to be asked but weren't/anything further you'd like to discuss?

Appendix 3. Participant Information Sheet.



Aston University
Birmingham

Living with chronic health conditions within the context of UK welfare reform

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a study looking at living with chronic invisible health conditions and experiences of UK welfare systems.

Who is doing this research?
This study is being conducted by William Day (w.day1@aston.ac.uk, 0121 204 4012) at Aston University as part of their PhD.

The project is supervised by:

- Dr Rachel Shaw (r.l.shaw@aston.ac.uk, 0121 204 4050)
- Dr Dan Shepperd (d.shepperd@aston.ac.uk, 0121 204 4210)

It has been given ethical approval by the School of Life and Health Sciences Ethics Committee.

Why is this research being done?
There is research evidence to suggest that recent welfare reforms (ESA/PIP) are failing to assess people's needs and their fitness for work appropriately. There are also concerns about whether the assessments are getting it right. However no research has been done on the impact that these welfare systems have on individuals living with chronic conditions. This project hopes to gather new evidence directly from the people involved.

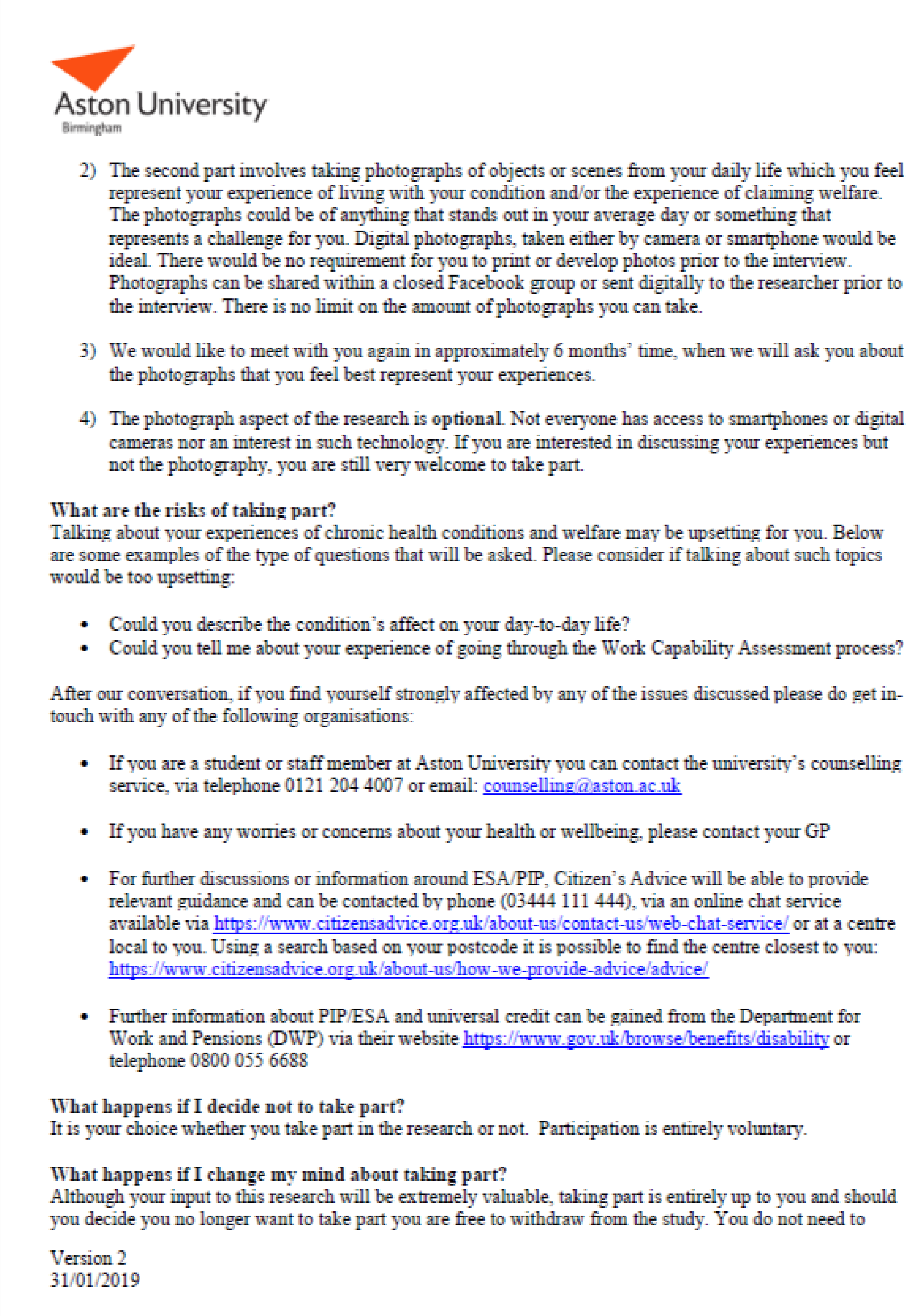
Why have I been invited to participate?
You can take part if you are over 16 years old, have a fluent understanding of spoken English, are living with any chronic health conditions which are not visible to others and have applied for either Employment Support Allowance (ESA; now included as part of Universal Credit in some areas) and/or Personal Independence Payment (PIP).

Examples of such 'invisible' conditions could be chronic fatigue syndrome (CFS) also known as ME, lupus, irritable bowel disorder or syndrome (IBD/IBS), chronic pain, arthritis or fibromyalgia. However many more 'invisible' conditions exist and this list is just a small example of possible conditions.

What does taking part in the research involve?
There are 2 parts to taking part in this project:

1) The first part involves meeting up with the researcher to talk about your experiences of living with a chronic health conditions and your experiences of claiming welfare ("benefits"). This should last between 1 to 2 hours depending on how much you have to say. Our conversation will be audio-recorded and transcribed afterwards word for word. We can meet either at Aston University or in a place that is convenient and comfortable for you. If you would rather have our conversation using the Internet (via visual or text-based messaging applications) this can be organised.

Version 2
31/01/2019



Aston University
Birmingham

2) The second part involves taking photographs of objects or scenes from your daily life which you feel represent your experience of living with your condition and/or the experience of claiming welfare. The photographs could be of anything that stands out in your average day or something that represents a challenge for you. Digital photographs, taken either by camera or smartphone would be ideal. There would be no requirement for you to print or develop photos prior to the interview. Photographs can be shared within a closed Facebook group or sent digitally to the researcher prior to the interview. There is no limit on the amount of photographs you can take.

3) We would like to meet with you again in approximately 6 months' time, when we will ask you about the photographs that you feel best represent your experiences.

4) The photograph aspect of the research is **optional**. Not everyone has access to smartphones or digital cameras nor an interest in such technology. If you are interested in discussing your experiences but not the photography, you are still very welcome to take part.

What are the risks of taking part?
Talking about your experiences of chronic health conditions and welfare may be upsetting for you. Below are some examples of the type of questions that will be asked. Please consider if talking about such topics would be too upsetting:

- Could you describe the condition's affect on your day-to-day life?
- Could you tell me about your experience of going through the Work Capability Assessment process?

After our conversation, if you find yourself strongly affected by any of the issues discussed please do get in-touch with any of the following organisations:

- If you are a student or staff member at Aston University you can contact the university's counselling service, via telephone 0121 204 4007 or email: counselling@aston.ac.uk

- If you have any worries or concerns about your health or wellbeing, please contact your GP

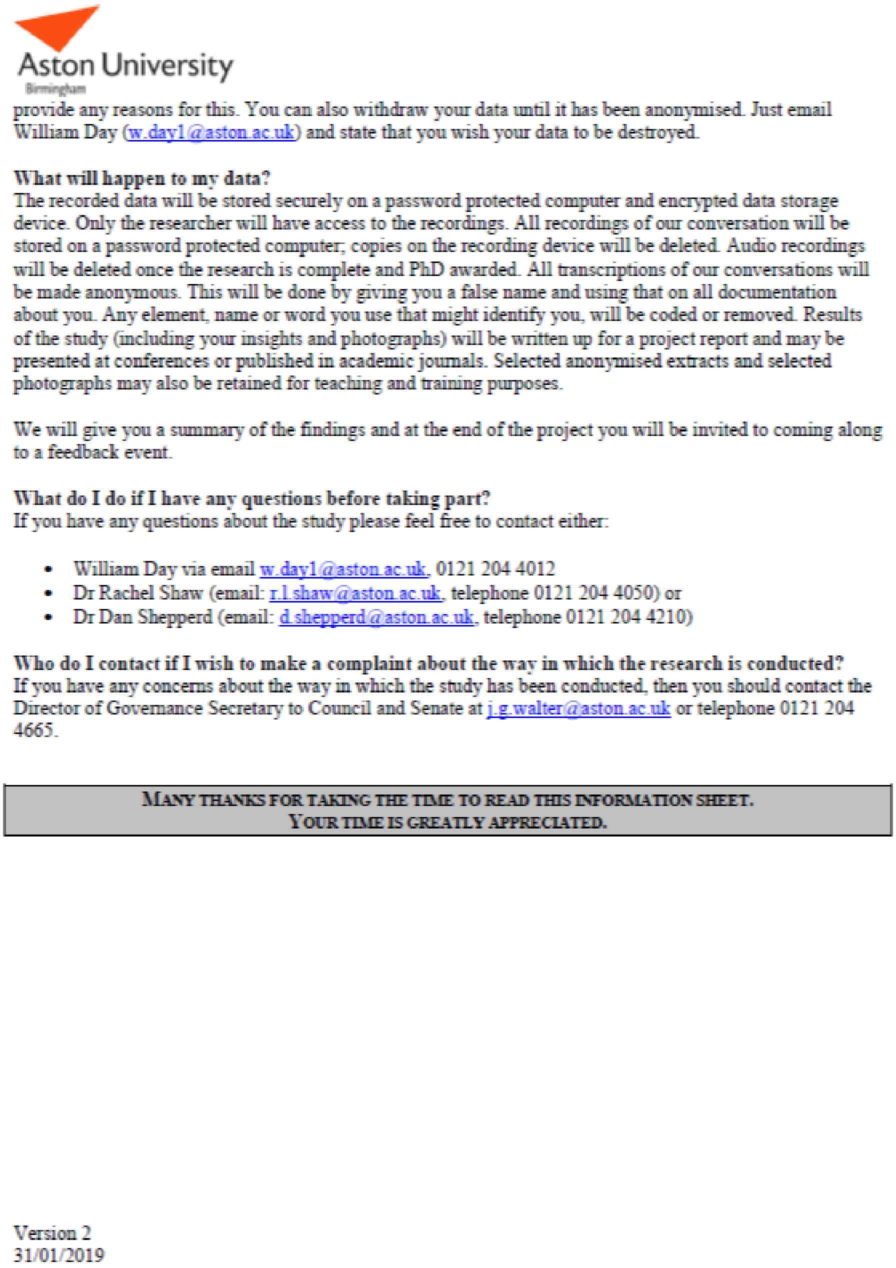
- For further discussions or information around ESA/PIP, Citizen's Advice will be able to provide relevant guidance and can be contacted by phone (03444 111 444), via an online chat service available via https://www.citizensadvice.org.uk/about-us/contact-us/web-chat-service/ or at a centre local to you. Using a search based on your postcode it is possible to find the centre closest to you: https://www.citizensadvice.org.uk/about-us/how-we-provide-advice/advice/

- Further information about PIP/ESA and universal credit can be gained from the Department for Work and Pensions (DWP) via their website https://www.gov.uk/browse/benefits/disability or telephone 0800 055 6688

What happens if I decide not to take part?
It is your choice whether you take part in the research or not. Participation is entirely voluntary.

What happens if I change my mind about taking part?
Although your input to this research will be extremely valuable, taking part is entirely up to you and should you decide you no longer want to take part you are free to withdraw from the study. You do not need to

Version 2
31/01/2019



Aston University
Birmingham

provide any reasons for this. You can also withdraw your data until it has been anonymised. Just email William Day (w.day1@aston.ac.uk) and state that you wish your data to be destroyed.

What will happen to my data?
The recorded data will be stored securely on a password protected computer and encrypted data storage device. Only the researcher will have access to the recordings. All recordings of our conversation will be stored on a password protected computer; copies on the recording device will be deleted. Audio recordings will be deleted once the research is complete and PhD awarded. All transcriptions of our conversations will be made anonymous. This will be done by giving you a false name and using that on all documentation about you. Any element, name or word you use that might identify you, will be coded or removed. Results of the study (including your insights and photographs) will be written up for a project report and may be presented at conferences or published in academic journals. Selected anonymised extracts and selected photographs may also be retained for teaching and training purposes.

We will give you a summary of the findings and at the end of the project you will be invited to coming along to a feedback event.

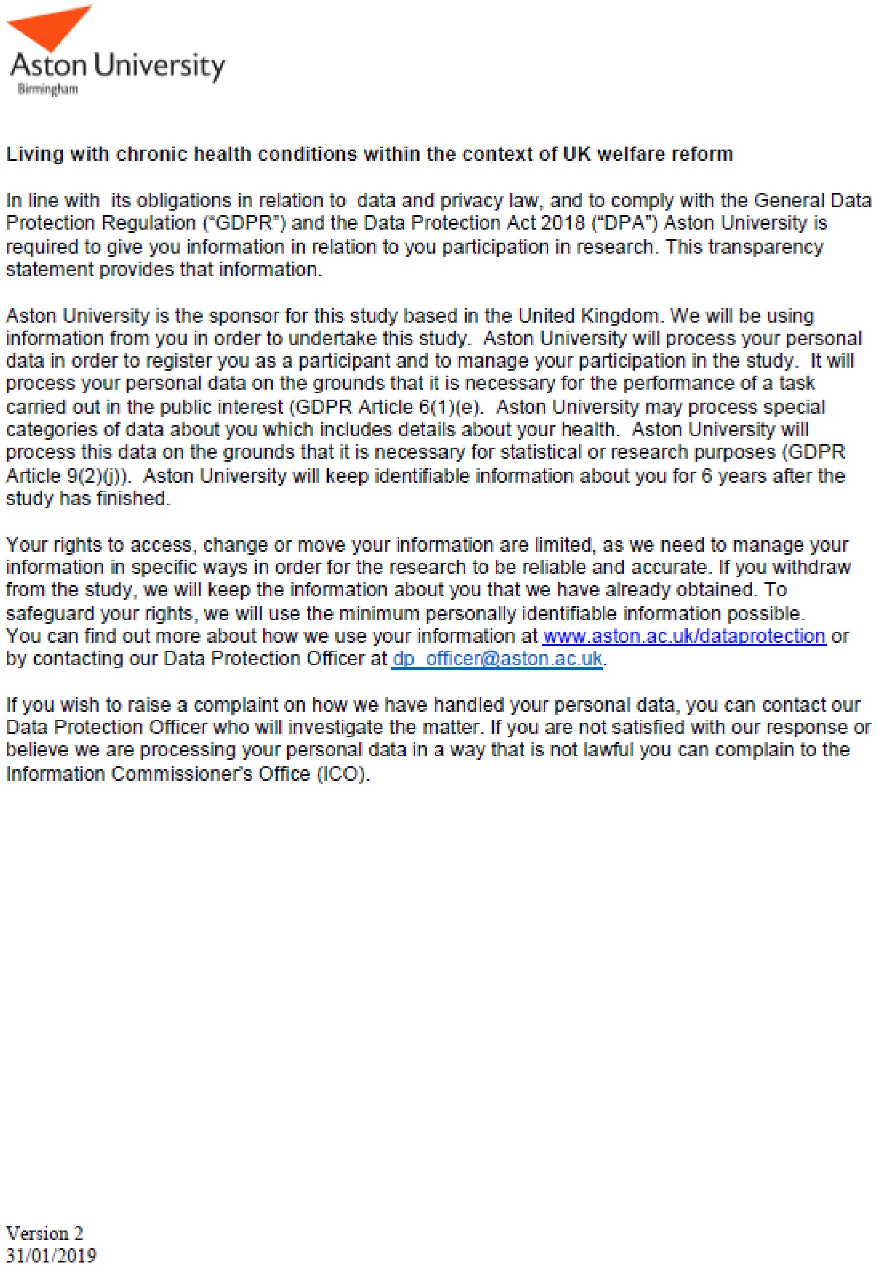
What do I do if I have any questions before taking part?
If you have any questions about the study please feel free to contact either:

- William Day via email w.day1@aston.ac.uk, 0121 204 4012
- Dr Rachel Shaw (email: r.l.shaw@aston.ac.uk, telephone 0121 204 4050) or
- Dr Dan Shepperd (email: d.shepperd@aston.ac.uk, telephone 0121 204 4210)

Who do I contact if I wish to make a complaint about the way in which the research is conducted?
If you have any concerns about the way in which the study has been conducted, then you should contact the Director of Governance Secretary to Council and Senate at j.g.walter@aston.ac.uk or telephone 0121 204 4665.

MANY THANKS FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.
YOUR TIME IS GREATLY APPRECIATED.

Version 2
31/01/2019



Aston University
Birmingham

Living with chronic health conditions within the context of UK welfare reform

In line with its obligations in relation to data and privacy law, and to comply with the General Data Protection Regulation ("GDPR") and the Data Protection Act 2018 ("DPA") Aston University is required to give you information in relation to you participation in research. This transparency statement provides that information.

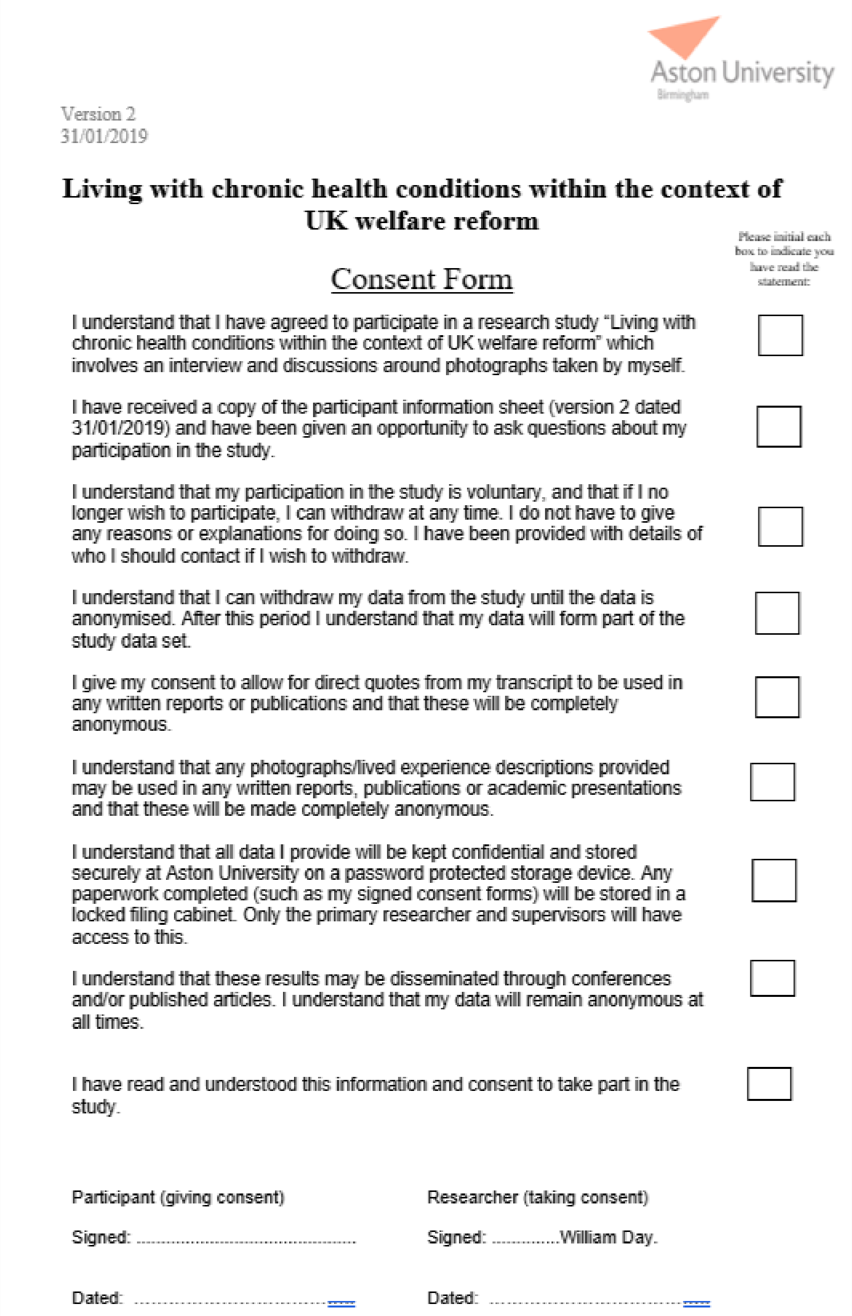
Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.
You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Version 2
31/01/2019

Appendix 4. Participant consent form.



Aston University
Birmingham

Version 2
31/01/2019

Living with chronic health conditions within the context of UK welfare reform

Please initial each box to indicate you have read the statement:

Consent Form

I understand that I have agreed to participate in a research study "Living with chronic health conditions within the context of UK welfare reform" which involves an interview and discussions around photographs taken by myself. ☐

I have received a copy of the participant information sheet (version 2 dated 31/01/2019) and have been given an opportunity to ask questions about my participation in the study. ☐

I understand that my participation in the study is voluntary, and that if I no longer wish to participate, I can withdraw at any time. I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw. ☐

I understand that I can withdraw my data from the study until the data is anonymised. After this period I understand that my data will form part of the study data set. ☐

I give my consent to allow for direct quotes from my transcript to be used in any written reports or publications and that these will be completely anonymous. ☐

I understand that any photographs/lived experience descriptions provided may be used in any written reports, publications or academic presentations and that these will be made completely anonymous. ☐

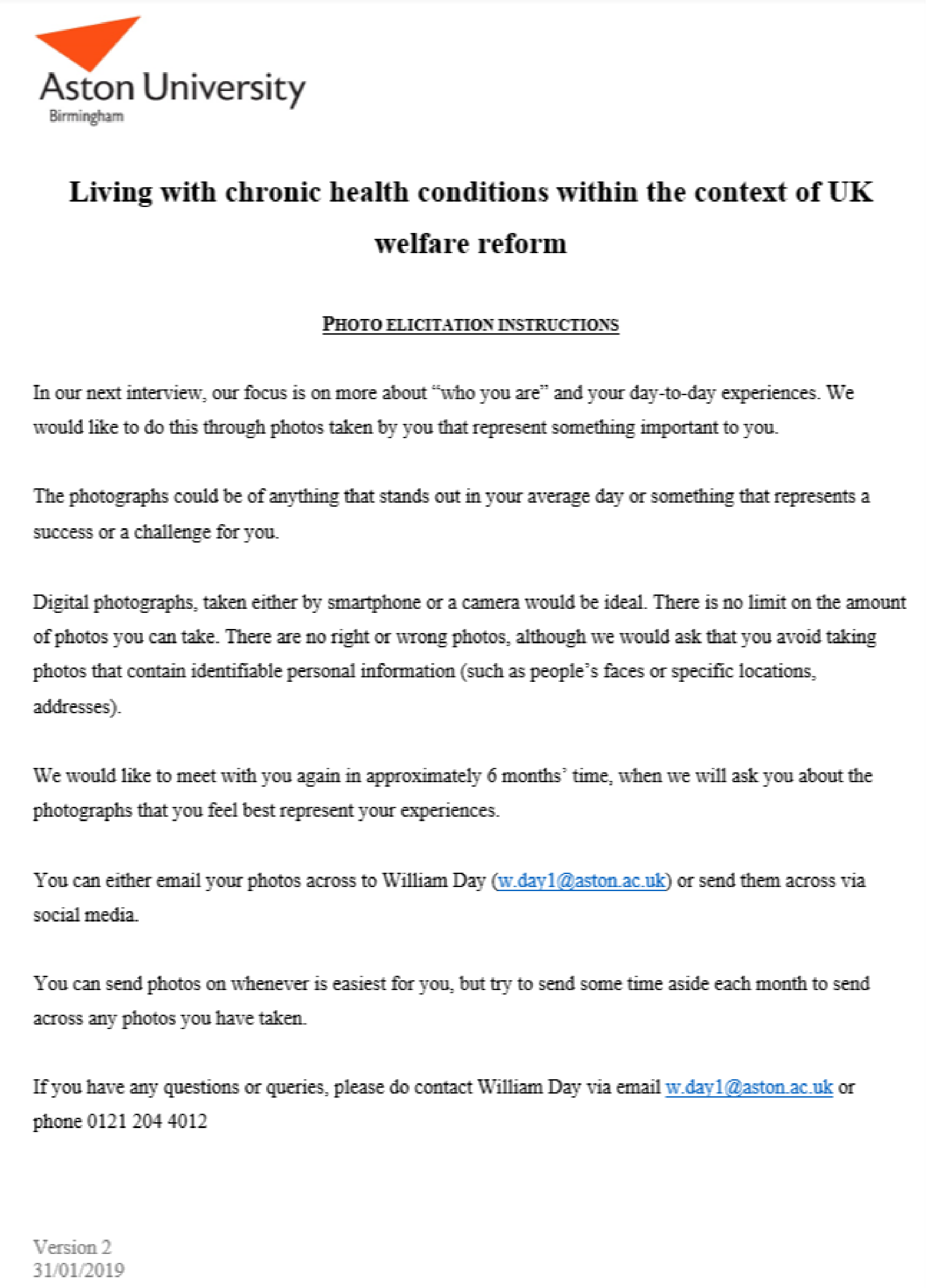
I understand that all data I provide will be kept confidential and stored securely at Aston University on a password protected storage device. Any paperwork completed (such as my signed consent forms) will be stored in a locked filing cabinet. Only the primary researcher and supervisors will have access to this. ☐

I understand that these results may be disseminated through conferences and/or published articles. I understand that my data will remain anonymous at all times. ☐

I have read and understood this information and consent to take part in the study. ☐

Participant (giving consent)	Researcher (taking consent)
Signed:	Signed: ....William Day.
Dated:	Dated: ....

Appendix 5. Participant photovoice information sheet.



Aston University
Birmingham

Living with chronic health conditions within the context of UK welfare reform

PHOTO ELICITATION INSTRUCTIONS

In our next interview, our focus is on more about "who you are" and your day-to-day experiences. We would like to do this through photos taken by you that represent something important to you.

The photographs could be of anything that stands out in your average day or something that represents a success or a challenge for you.

Digital photographs, taken either by smartphone or a camera would be ideal. There is no limit on the amount of photos you can take. There are no right or wrong photos, although we would ask that you avoid taking photos that contain identifiable personal information (such as people's faces or specific locations, addresses).

We would like to meet with you again in approximately 6 months' time, when we will ask you about the photographs that you feel best represent your experiences.

You can either email your photos across to William Day (w.day1@aston.ac.uk) or send them across via social media.

You can send photos on whenever is easiest for you, but try to send some time aside each month to send across any photos you have taken.

If you have any questions or queries, please do contact William Day via email w.day1@aston.ac.uk or phone 0121 204 4012

Version 2
31/01/2019