A Participatory Action Research Study: Dementia & Human Rights

Scott Andrew Stephen Bartle

A thesis submitted in partial fulfilment of the requirements of the University of East London for the degree of Professional Doctorate in Clinical Psychology

September 2022

Aswonvos / Acknowledgements *(Kernewek / Sowsnek: Cornish / English)*

Y komendyav an hwithrans ma, yw rann finel an dismyk a as vy dhe braktisya avel brysonydh medhegvael, dhe'n re a vettiv, avel rann system a wodhvo yn fenowgh gallos warnedha. Yth afiav gul devnydh a’m offis gwella gylliv ha sevel yn-bann, hag offendya, nag avel keffrysias hepken, saw avel keskal rag defendya gwiryow denel.

Wostalleth, yth aswonav gras dhe’n aluseneth leel ha dhe’m keshwithroryon drefen bos hemma aga hwithrans.
Er kov Yiayia Iroula.

My a vynsa godhvos gras a’ga skoodhyans dhe’m kowetha, teylu, gorwolysi, kowethysi, ha dhe dhew gevosen a’m gorras omma. Gras arbennik a skoodhyans gorwolyades ow hwithransow, Dr M. Castro Romero, ha gorwolyades ow desedhans pennskol, Dr L. Farquharson. Meur ras dhe Navya Anand ynwedh rag daswel a'm kynsskrif finek. Keffrys ha dhe’m kowethes hweg, Julie Bradford-Aaberg, a’y dewlagas dha.

Profys dhe’m gwreg, Lenia, ha dhe’m fleghes, Ioannis hag Evangelos. Er kov ow Ewnter Steve ha Papa (John) neb a’m erghis, ha my ow kasa skol orth 15 bloodh heb kwalifiansow vyth, a omdhyghtya. Gras dhe’m mamm dres an termyn na. Yn trubyt dhe’m hendasow – onen hag oll.

I pledge this thesis that forms the final part of the puzzle that enables me to practise as a clinical psychologist to all people of whom I’ll meet, as part of a system that may often hold power over them. I affirm to use my position to the best of my ability and to stand alongside, and resist, not merely as an ally, but as an accomplice in the defence of human rights.

My first thanks are to the local charity and co-researchers as this research is theirs.
In memory of Yiayia Iroula.

I wish to thank the support of friends, family, supervisors, colleagues, and two cohorts. Particular thanks for the support of my research supervisor Dr M. Castro Romero, and university placement supervisor Dr L. Farquharson. Thanks as well to Dr N. Anand for review of a final draft. As well as my dear friend, Julie Bradford-Aaberg for her good eyes.

Dedicated to my wife Lenia, and my children, Ioannis and Evangelos.

In memory of my Uncle Steve and Papa (John) who told me upon leaving school at 15 without qualifications to get it together. Thanks to mum at that time. In tribute to my ancestors - onen hag oll.

Abstract

Dementia is considered by the World Health Organisation to *be 'a physical, psychological and economic burden'*, in part due to stigmatisation maintained by barriers to participation for people given labels of dementia (PGLAD) in daily life. It is increasingly recognised visibility can be key to challenging stigma by enabling PGLAD to reclaim identities masked by power inequalities arising from negative stereotypes. This research answered a challenge from government and a call by the United Nations and the British Psychological Society for a redistribution of power in clinical, research and policy settings by sharing Participatory Action Research (PAR) with people affected by dementia labels as a tool to claim their human rights.

Knowledge was generated with action taken through a collective letter disseminated to assumed power-holders in health, government and the third sector. Awareness was raised of issues related to stigma and the lived experience of PGLAD at the individual, social and structural levels. Responses from people in authority, either appointed or elected were considered, with non-responses also seen as a response. Co-researchers were commended for their insights and pledges to act were made. Pledges included change as an individual and as part of wider systems, including motivation to ensure PGLAD's voices are heard developing policy across the region.

Consequently, PAR enabled authentic participation of people with diverse abilities in research which delivered a community level intervention that achieved social and political change at a structural level, despite a pandemic as a barrier to participation. It showed the utility of anarchism as a conceptual approach that can complement a human rights-based approach to psychological research involving power dynamics. This highlights the continued importance of participation of PGLAD in research and the potential of human rights-based approaches as stigma intervention strategies.

Contents

This remainder of this page is intentionally left blank

a. Self-Reflexive Statement

It needn't be said that "human development is a product of interaction between the growing human organism and its environment", but Bronfenbrenner (1979, p. 16) felt he had to since equal emphasis by psychology was not given to the environment. An issue still relevant, as we saw with Read et al., (2009), who critiqued reductionist approaches to human development as offering merely the "bio-bio-bio model". Recognising that environmental events and conditions outside any immediate setting can profoundly influence a person and play a critical role in defining the meaning of an immediate situation to a person (Bronfenbrenner, 1979, p. 18).

The immediate situation is this research project, and it was advised I put into context what influenced my approach towards clinical psychology, that I am grateful to have had an opportunity to enact in research at the University of East London. If I was really to start at the beginning, it might be said I wouldn't be alive if it wasn't for University of East London, or North East London Polytechnic as it was known then as this is where my parents met. An institute known for a large number of working class and mature students (Woodward, 2002), my mother and father, respectively, that was called the "people's university" (e.g. UEL, 2022) in its opening speech by Cornishman John Passmore Edwards, who is revisited in Section 4.5.

Bronfenbrenner (1995, p. 641) thought development was "powerfully shaped by conditions and events occurring during the historical period", recognising that historical events such as economic and social changes (p. 643) can affect the developmental course of families within and across generations (p. 642). Bronfenbrenner and Morris (2006, p. 822) underlined Elder and Shanahan (2006, p. 692) 's view that "individuals construct their life course through choices and actions they take within the opportunities and constraints of history and social circumstances", and I believe like Passmore Edwards, the social circumstances of Cornwall is what led me to here. Therefore, I start from the "macro-time" (Bronfenbrenner & Morris, 2006, p. 796) before funnelling back to now.

Cornwall is described by Deacon (2013) as "England's first (and last?) colony", and a curious child can't avoid a cultural history distinct from the discourse imposed by

England's parliament upon it. Remnants of a violently suppressed language (Mills, 2010) survive in ordinary conversations and offer insight into the origins of people and places that carry the words (Mackinnon, 2021, p. 123 & p. 206). It shaped a questioning orientation towards established authority as the community knowledge differs from the teachings of government. For example, a 'Norman Invasion' taught from the position of Saxons by the 'national' curriculum, in contrast to what is referred to as an 'Armorican Return' for the Cornish (Mills, 2010, p. 193). A time when the Cornish fled the Saxons in Britain between 300-700AD and settled Armorica, to become Bretons, then allied with Normans to return and overthrow the Saxons in Cornwall[1]. The relevance of this was to seed autonomy for Cornwall to the degree it retained a different sovereign to England (Kirkhope, n.d.) and was primarily self-governing with its own courts and parliament (still on statute) until the 19th century (Williams, 2003). The Magna Carta 1215, Europe's first written constitution (LII, 2020), outlines this distinction as it states it applies to "Anglia et Cornubia". We also see clues in the name Cornwall derived from 'Corn walas', with 'walas', the root of 'Welsh' from the Saxon for 'strange' people or 'foreigners' (Earle, 1865, p. 65).

This outcome is that Cornwall, as a territory de jure to England, was treated as such, leading to conflict and the destruction of the colleges at Glasney and Crantock central to Cornish identity (Lyon, 2012) and the double taxation as 'foreigners'. Judge (2007, p. 182) reported a calculation from 1974 that between 1337 and 1837, £20 billion[2] was taken out of the Cornish economy due to this taxation. A redistribution of wealth away from Cornwall that contributed to poverty and the breakup of families throughout the 17th to 20th centuries by emigration to find work[3]. Williams (2003) described how this led to the loss of native capital and skilled workers who became a

---

[1] Weatherhill (2016) reported that William of Worcester said Cadoc, the last of the Cornish Royal Line, was still alive and referred to as Eorl (meaning chief) in 1066. However, he may have died before William I was appointed an Earl of Cornwall, so the Breton's Brient and Alan were then chosen to mark the affinity between Cornwall and Brittany, as the Cornish/Breton language remained similar.

[2] Adjusted for inflation by the Bank of England calculator this figure in 2022 is £173,910,579,393.89.

[3] "Wherever there is a hole in the earth, you would find a Cornishman at the bottom", it was once said, and this was a hard life with untimely death through accident (e.g. In 1924, my Great Grandfather Leslie Carlyon aged 17 survived a dynamite explosion in South Crofty mine that killed his colleague William Harris, who was aged just 31 with two young children) or illness (such as TB or Phthisis).

political class and labour aristocracy elsewhere[4]. This, alongside the fragility of the mining industry, is what Williams (2003) thought contributed to Cornwall at the time being the most economically deprived area in Britain or, more recently, the second most deprived area in Northern Europe (Smallcombe, 2018).

With this context of poverty in the community I grew up in came social degradation with a frequency of mental health issues (e.g. Elliot, 2016) that led to an understanding of the four horsemen of statutory services (Council, NHS, Social Services, and Police). In the late 90s and early 00's their power appeared to be exercised with an iron fist, and I became familiar as a young teenager observing abuses in a mental health system which had let me onto its hospital wards as a guest to visit friends. I witnessed violence inflicted on those detained by staff, underscoring why these institutions have long-held bad reputations[5] (e.g. Becquart, 2017). At the time, I challenged a member of staff who warned me that I wouldn't be allowed back if I spoke of it again. This led me to critical psychology/psychiatry literature and an interest developed in legal checks and balances to excesses of state power. Then, as an undergrad, a focus on human rights and mental health set me up for jobs where I learnt the skills and psychological models to challenge threats to rights in services. Lived experience of a family member labelled with dementia and intersecting services then raised my awareness of rights implications in this area.

Hunt (1881, p. 26) spoke of how the Cornish, completely cut off from England were informed of the world beyond them by travelling historians called 'droll-tellers'. They would constantly wander from house to house, finding a "hearty welcome" and accommodation in exchange for a song or a droll (story)—an ancient practice where knowledge was held away from centralised power that disappeared upon the arrival of the newspapers. My experiences have led me to join a profession cut off from the world beyond it, intentionally, as we see with paywalls guarding knowledge contained in the journals. I believe clinical psychologists need to step away from protectionism to become the droll-tellers, as it is from communities that 'our'

---

[4] Williams gave South Australia as an example of how Cornwall may have developed politically and socially, given Cornish cultural and political influence there. It was founded on Cornish Parliamentary Law introduced by John Bentham Neales in 1865 (Bonython cited in Wright, 1890, p. 194).

[5] A culture of abuse exposed in the wider trust services (CSCI & Healthcare Commission, 2006).

knowledge is ultimately derived, and away from us, in people's homes, this knowledge given away needs to be applied.

1. Introduction

Dementia[6] is an umbrella term and label applied to people who may be experiencing a range of issues; biomedical, psychological, social and, as we shall see, political, that are associated with a progressive decline in cognitive abilities, adaptive functioning and power to claim their human rights. The different perspectives held as to the nature of dementia will be explored in Section 1.2.

As we begin, we can see above the concept of power has been introduced and, in this context, we are talking about power in the ordinary sense with regard to the extent a variable or phenomena has to influence something. This is known as the 'capacity' definition of power and termed as 'power-to' by Gordon (2010, p. 41-46) in a three-fold analysis[7] of power which will be explained now. The other elements present in terms of opposing forces with 'power-over'; as a type of domination, and 'power-with'; as a non-coercive influence. Power-over is influence in the absence of choice by force, coercion, manipulation or authority. Power-with is defined as a voluntary, cooperative type of power that occurs in the absence of conflicts, wills or interest. It is anarchism (2.4.1) in exposing these dialectics that "instituted itself as the ideology and political thought of the critique of power" (Ilbanez, 2019, p. 55).

---

[6] As the dementia label is stigmatising (Batsch & Mittelman, 2012; Werner, 2014) it's use could be seen as counterproductive to the intentions of this research. Yet, the cultural context and place in time in which this research is written contains dominant discourses with which one must engage before any paradigm shift occurs. Use of this word is, therefore, intended to engage with dominant paradigms out of recognition that labels are a source of power which mediate citizenship rights and access to resources in our society. Use of this term is not intended to diminish personhood as such when discussing people affected by this label, People Affected by Dementia Labels (PABDL) will serve as the favoured and inclusive descriptor. This is out of a recognition developed later in the chapter that this label is relational affecting not only people given labels of dementia (PGLAD), but family and loved ones, who have faced stigmatisation by association.

[7] Gordon (2010, p.41) reported this definition arose from the American feminist, anarchist and author Starkhawk (Born Miriam Simos; 1951-) before being taken up in wider feminist literature.

The first documented use of the word ‘Dementia’ was by Saint Isidore (560-636 A.D.) and in Latin (Yang et al., 2016). The prefix *‘de’* means privation or loss, *‘ment’* as a stem means mind, with a suffix *‘ia’* indicating a state of being is translated to *‘a state of losing one’s mind’.* The concept is thought to stem from antiquity as historical evidence has linked age to a decline in memory (Boller & Forbes, 1998), judgement (Yang et al., 2016) and mental health (Harding & Palfrey, 1998).

This label has remained associated with increasing age (Van der Flier & Scheltens, 2005), but can affect various ages to a lesser degree (5.2% of people; Prince, et al., 2014) and are applied more often at a younger age for people labelled with an intellectual disability, Down’s Syndrome (BPS & RCP, 2015) and Parkinson’s (Aarsland, et al., 2005). Cicero (106-43 B.C.E) was credited as one of the first to challenge any inevitable association with age (Boller & Forbes, 1998; Yang et al., 2016). Cicero (ca. 44 B.C.E/1884) saw complaints of old age as more correlated with wealth, resources, social status or ability to find meaning in life. These are factors confirmed by modernity, as increased likelihood of receiving dementia labels (DL) can be related to stressful live events (Zuelsdorff, et al., 2020), poverty (Cadar, et al., 2018) and race (Mayeda, et al., 2017); more so for people occupying intersections of each (Zuelsdorff, et al., 2020; Alzheimer’s Association, 2022). Furthermore, these intersectionalities are determinants of psychosocial conditions (WHO, 2014), which increase the risk of non-consensual psychiatric ‘treatment’ and receipt of medications (Mendez, 2013) that, in addition to what they are ‘treating’*,* are risks factors for dementia in themselves (Zilkins et al., 2014; Cai & Huang, 2018).

850,000 people are estimated to have DL in Britain, and this figure is projected to double by 2040 (Prince, et al., 2014) with Lewis (2015) anticipating one-in-three born in 2015 may receive this label. Despite 700,000 people providing informal care for PGLAD in Britain (Lewis et al., 2014), 60-70% provided by women (Alzheimer’s Research UK, 2015) and carers of minority ethnic backgrounds less likely to access services (Greenwood et al., 2015), the economic cost of dementia worldwide is estimated to reach two trillion USD by 2030 (Wimo et al., 2017).

Alzheimer’s Disease International and World Health Organisation (2012) have described the impact of dementia upon caregivers, families as a “physical, psychological, social and economic… burden” perpetuated, in part, due to a lack of awareness and understanding of the construct which led to stigmatisation, so they declared it a public health priority. Successive UK Government policies on dementia (DOH, 2009; DOH, 2015) and papers from the third sector (Warner et al., 2010; Alzheimer’s Disease International, 2019) confirm stigma has posed a barrier and serious detriment to the quality of life for PGLAD. Indeed, Milne (2010) reported stigma was pivotal in the experience of dementia as it undermined PGLAD’s psychosocial wellbeing and quality of life.

The UN Department of Economic and Social Affairs (UNDESA) programme on ageing (2016) saw stigma as the main factor behind the large gap between estimated prevalence and diagnosis rates. They claimed less than 50% of people perceived to be affected by dementia received a diagnosis. A challenge of circularity, as stigma in part, can arise from the use of diagnostic labels for treatment and research purposes, which can serve as cues that activate stereotypes and stigma (Garand et al., 2009). The negative beliefs reduce help-seeking behaviour due to fears about how their family might be treated after receiving a diagnostic label (Parker et al., 2020). The label became what Rioux (2003) might describe as the Faustian bargain made to access citizenship rights such as services or financial resources, in exchange for stigma that could lead to denial of citizenship rights, social exclusion and being hidden away from public life (UN DESA, 2016).

The challenge we have is systematic reviews on dementia and stigma (Herrmann et al., 2018; Nguyen & Li, 2020) found limited literature, with no consensus on how to evaluate stigma best or develop stigma reduction approaches. Both called for research to consider ways to reduce dementia stigma as there were no existing approaches. Whilst both found public stigma to be pervasive, including among healthcare professionals, they found personal exposure to PGLAD directly (Herrmann et al., 2018) or in awareness campaigns (Nguyen & Li, 2020) offered hope for stigma reduction. However, stigma is associated with negative emotions like fear and behavioural responses that included social distance (Nguyen & Li, 2020), which reduced likelihood of personal exposure. It might be asked if this dearth in literature, coupled with findings of Mann and Hung (2019) who reported few studies actively involved PGLAD and instead using proxies, which they outline as dehumanisation, exemplifies avoidance.

To proceed from this conundrum, this research took inspiration from (Freire, 1970) to develop awareness as to the circumstances in which power operates between stigma and a label of dementia to lay the groundwork for acting in Chapter 3. Critical consciousness will be enacted mindful to three components (Watts et al., 2011):

a. *Critical Reflection;* on our understandings of dementia and stigma.
b. *Political Efficacy;* as we consider means an individual or group may have to effect political or social change. A Human Rights Based Approach (HRBA) introduced in Section 2.3 will provide a conceptual framework for *Critical Action* influenced by anarchism in Chapter 3.
c. *Critical Action* refers to the steps taken to attempt to change aspects of society, such as institutional policies or practices perceived as unjust.

1.1. Search Strategy

An initial scoping exercise found research around Dementia and Stigma was limited (Herrmann et al., 2018; Nguyen & Li, 2020) so a narrative review was undertaken as the first step of critical consciousness. The idea was to explore key concepts or definitions of stigma, and dementia labels to ascertain how they might converge.

A literature search cycle (Deacon University Library, 2017) was adopted as a framework to identify the main concepts, select the library resources to search, then review and refine the results. Vocabulary identified considered synonyms and keywords of papers identified during scoping. This included dementia and variants (‘Alzheimer’s’, ‘Vascular’, ‘Lewy-Body’, ‘Parkinson’s’, ‘Fontotemporal’, ‘Creuztfeldt-Jakob’, ‘Wernicke-Korsakoff’, ‘neurocognitive disorder’), descriptors (‘forgetting’, ‘memory loss’, ‘cognitive difficulties’, ‘cognitive dysfunction’) lay or outdated (‘brain-fog’, ‘senility’, ‘demented’), stigma types (‘self-stigma’, ‘structural-stigma’, ‘public-stigma’) and related descriptors (‘discrimination’, ‘attitude’, ‘perception’,’ belief’). Resources searched included the university library, google books, databases of PUBSCO, PSYCINFO, PSYCHARTICLES, PROQUEST, Google Scholar, and Google for grey literature. Bolean operators, wildcards or truncation were used which led to results that were refined with a view to find theories, concepts or models as per the aim. References and bibliographies that arose from the literature were checked and reviewed as part of this cyclical process.

Data emerged that appeared as if dementia and stigma could be theorised on three levels: individual, social and structural. The results are presented in 1.2 and 1.3 with this as a framework to aid readability and later comparison.

1.2. Understandings of Dementia

Values and political ideology that underpin ideas can often be unspoken yet retain the power to clarify, confuse, reveal or obscure insight (Alderson, 1998). The section will now present understandings of this label at the individual, social and structural levels to elucidate the background, values and ideological implications of each.

1.2.1. Individual

This section will describe the Classical (medical) Model of dementia (Harding & Palfray, 1997) which considers dementia to be an umbrella term for more than 100 specific medical labels, each with distinct bio-medical presentations (Rahman, 2017).

The view there are specific medical conditions that can be delineated into special presentations is derived from The Age of Enlightenment (Bristow, 2017). From this, an approach to understanding the world, or epistemology, known as positivism and credited to the philosopher Auguste Comte (1798-1867; Acton, 1951) developed. Positivism has an assumption there are universally constant, replicable facts and general laws about relationships between phenomena to be discovered (Alderson, 1998). Inspiration from botanists’ classification of plants led to aphorisms (concise statements of principle) being developed for medical practice. Aphorisms were first used to track causes, effect, or cures for disease, then moved from body to mind (French, 2003; Munsche & Whitaker, 2012).

The evolution of which was the Diagnostic and Statistical Manual of Mental Disorders from the American Psychiatric Association and the International Classification of Diseases by the World Health Organisation. A brief history of diagnostic labels in Appendix A demonstrates a lack of clarity around these constructs, which is problematic as inherent to positivism are notions of objectivity with subjective experiences or values deemed unimportant (Park et al., 2020). Nonetheless, disregard of values does not render this approach devoid of values, as how a disability is perceived, diagnosed and treated reflects assumptions about societal responsibility towards disability (Rioux, 2004).

Lyman (1989) surmised the Classical Model to have three facets:

- First, dementia is pathological, individual, and an abnormal condition of cognitive impairment.
- Second, it is bodily or organic aetiology caused by progressive deterioration of brain areas that control memory.
- Finally, although no cure, it is to be assessed, treated and managed by medical authorities.

This understanding of disability rests in individual pathology and positions dementia with relation to a norm so is called a comparative incapacity (Rioux, 2004). Disability and associated costs are seen as an abnormality and social burden, with medical authority positioned as gatekeeper of ‘legitimate’ disability. Consequently, diagnosis is overseen by state institutions to control access to social entitlements (ibid). This approach has a focus on primary prevention to eliminate or cure the condition and ameliorate or provide comfort (ibid) hence, emphasis on early detection, diagnosis and support (NICE, 2018). The individual is the focus of analysis for research and policy so depicted as the primary point of intervention, yet this has not gone without challenge, so next, we will consider alternative perspectives.

1.2.2. Social

The social approach asserted dementia labels were problematic on conceptual and scientific grounds (e.g. Kitwood, 1988; Lyman, 1998; Bender, 2003). This section will share these critiques and a proposed progression to the focus on the context of a person in relation to values of broader society (Chester & Bender, 2004).

Kitwood (1989) argued the medical aetiology of dementia he equated as*:* “X -> Neuropathic change -> Dementia (where X = mysterious agents)” was so simple, that its charm obscured a need to consider psychosocial factors. He emphasised a circularity where mood or behaviour changes were perceived to be a result of cognitive damage so structural changes in the brain post-mortem attributed to Alzheimer’s were considered self-evident. Chester and Bender (2004) also believed the medical aetiology was unfounded and led to validity issues around diagnosis. With all problems in living attributed to brain damage, they stated the effects of the social world was too easily discounted. Thus, brain as an organ cloaked the complexity of mind or experience and was reductionism (e.g. Martin, 2004; Bickle, 2012). Chester and Bender (2004) thought this served to distance medics from discomfort relating to PGLAD, as ‘brain problems’ did not need emotional contact with their suffering. They asserted this disregard of subjective experience created “non-people” who could not have relationships by virtue of this status, so relatives became depersonalised as “carers”. Detachment allowed medics to maintain a focus on the brain in the present, and avoid any emotions elicited from relational ties.

Kitwood (1988) rejected pathologisation fundamental to the classical model and contended most difficulties of later life were socially constructed and not a consequence of ageing as a process, but norms society held towards old age. Kitwood (1990) offered an alternative view centred on relationships between elders and neurological impairment (NI) with malignant social psychology (MSP). First, he contended dementia was compounded by the effects of NI and MSP. Second, NI in an elder attracted MSP and, lastly, the effect of MSP on elders, who may be physiologically vulnerable, created NI.

Kitwood (1998) said he chose “malignant” to convey a powerful, insidious and destructive effect analogous to “a cancer of the interpersonal environment”. He stated this need not imply malice, as MSP can come from ignorance, preoccupation or lack of resources due to embedded cultural practices. Breadth of MSP is beyond the scope of this paper to report, however, can be reviewed in Kitwood (1990, 1993, 1996, 1997, 1998; Kitwood & Brooker, 2019). Essentially, MSP eroded personhood; defined as “the individuality and uniqueness we hold with relation to our sense of self, and capacity to relate to others" (Kitwood 1994, 1998). MSP (Kitwood & Brooker, 2019) of particular relevance may include:

- Stigmatisation: treating someone as a "diseased object, alien or outcast"
- Labelling: Using a category as the main basis for interacting with someone or describing their behaviour
- Objectification: treating a person without due regard as sentient beings

Another definition of personhood was given as "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being" (Kitwood, 1997; Kitwood & Brooker, 2019). This faced criticism (Baldwin et al., 2007) almost as a form of MSP in itself, as unidirectional and individualistic, for it was perceived to focus on PGLAD to the exclusion of relationships. Further, 'bestowal' suggested a lack of mutuality, which positioned PGLAD as potentially vulnerable to the unjust whims of others. The concern was it portrayed PGLAD as passive and dependent upon others for affirmation (Bartlett & O'Connor, 2010). Dewing (2019) believed Kitwood, if alive, might have revised this definition as, for him relating was noncontingent upon roles, power or organisational status. She argued the South African word ubuntu, meaning "humanity towards others", better reflected his intention of personhood as derived from society rather than individuality.

Societal influences on PGLAD were also the focus of Chester and Bender (2004), who considered the economic and social consequences of stigmatising valuations. They emphasised negative stereotypes around "chronic illness" or being seen as "too old, ugly, economically useless and resource wasting" as a threat to identity. MSP led to internalisation of negative attitudes towards the self and contributed to low mood causal of a decline in functioning but misattributed to brain changes. Further compounded by age, class, gender, ethnicity or occupation inequalities, that led to denigration and systematic denial of access to resources or opportunities. As such, they advocated moving away from the "diseased brain" to focusing on PGLAD's emotions and understandings in the context of relationships with society.

To surmise, the social approach said dementia was not inherent to the individual, but to the social, environmental and economic structures around them (Rioux, 2003).

Thus, intervention necessitates focusing on social change, rather than the individual. Disabilities like dementia are recognised as differences, rather than anomalies, so the inclusion of PGLAD becomes a public responsibility. Social structure is the focus of research and policy analysis with emphasis on how structures pose barriers to disability which can be changed to enable equal participation within society (ibid.). Whilst there is overlap with the structural approach, the social model has faced criticism for a limited and partial explanation of the experience of people with disabilities (Oliver, 2013), which will be considered next.

1.2.3. Structural

Structural perspectives positions dementia as a human rights issue and a disability (Cahill, 2018) adversely affected by political choices that shape social inequalities. Sources of power within society interact to undermine citizenship entitlements (Behuniak, 2010) like access to resources so erode personhood (Kitwood, 1997). Here, social responsibility is to recognise dementia as a disability inherent to society, provide social and political entitlements and reform political policies (Rioux, 2003).

From this stance, Kitwood's concept of personhood was criticised for being apolitical (Baldwin et al., 2007; Bartlett & O'Connor, 2010), "neither new or revolutionary" (Mitchell & Agnelli, 2015), with a focus on the individual to the disregard of politics, systems, institutions or government failures (Cahill, 2018). Yet Kitwood started from a place where PGLAD were treated as "non-human"[8] so if human rights are possessed by "virtue of being human" (Fasel, 2018) claiming personhood is an immensely political act, as it is from being human all of our most fundamental rights

---

[8] It is possible that Kitwood, like Wolfensberger (2002), recognised that those perceived as non-humans were at greater risk of abuse and of being killed, individually and collectively. Often a consequence of instrumental actions termed death-hastening (Brogden, 2001) or death-making (Wolfensberger, 2002) that occurred as a result of dehumanisation from MSP. Death became not only permissible if perceived to result in social good, like relieving society of a "burden" (Wolfensberger, 2002), but an implicit social obligation, legitimised and hastened by regulation or inspection agencies with a policy that perpetuated statuses of as non-humans (Brogden, 2001). Bureaucratisation enabled emotional distancing from collective actions by causing death (Wolfersberger, 2002) through a routine and mundane methodology (Brogden, 2001).

are derived. It is possible Cahill (2018) overlooked Kitwood's wider cannon such as his (1990) assertation people rarely acted purely as individuals so it was a mistake not to reflect on the psychological effects of hierarchies from states to world systems. This theme continued in Kitwood (1994) where he outlined a crisis where social forms like nation-states, centralised government, global-trade, industrialisation, capital accumulation, subordination of others and associations of professional elites demonstrated to us the failures of modernity. None solved scarcity, he said, but created social and environmental issues with an economic-political lens detrimental to the care of PGLAD. With crisis, he stated, came opportunity as undoing old structures held potential for a radical and benign distribution of power. This had an air of revolution he was critiqued for lacking, yet Kitwood (1990 p. 276) knew "insight over and against" oppressive contexts were "a slow process, hard won".

Kitwood (1998) focused on power inequalities in social structures as he saw these cultures and hierarchies held great relevance for PGLAD. As Kitwood (1990 in Baldwin & Capstick, 2007 p. 294) maintained, only prejudice or tradition continued the idea formal hierarchy was the optimum form of societal organisation. He (Kitwood, 1998) called for domination within society and care regimes to be reduced by a move to an egalitarian social order he saw as legitimised by human rights. Inherent to which were conditions of equality and respect, he believed, enabled people to fulfil the utmost potential of their mental capabilities. With this opportunity he asserted recovery of individuality and self-assertion arose and left care providers in "fear of chaos" with two options: "re-establish a repressive regime and use chemicals to numb dissidents into silence or allow the situation to develop" (Kitwood, 1998 in Baldwin & Capstick, 2007, p. 167). From this, he reported practitioners discovered chaos did not arise, but a new social order came and stabilised "as if a natural or instinctive" way of being.

As this thesis progresses, we shall notice how this shares the anarchist insight (Section 2.3.1) and reflects a philosophy of structural change where flexibility and creativity enable the pursuance of objectives gradually from the bottom-up (Quinn, 1982). Top-down (or rationalist) choices can be made by organisations to establish a different culture mechanically and were not disregarded as a method by Kitwood and

Bredin (1992), as they thought the transition to a rights-based culture could be a symbiosis of both bottom-up and top-down processes.

1.2.4. Utopia

“A learned brahmin was travelling through the forest when he was waylaid by a ghastly-looking ogre, gaunt and pale. ‘I shall eat you presently,’ said the terrible creature, ‘but if you can tell me why I am so pale and thin, I shall let you go’...[9]
…with a tranquil mind, he gazed into the ogre’s eyes, as one creature gazing at another, and he read there the whole history of the monster’s pain…[10]
…The ogre was nourished by this answer. The brahmin, by giving words to his condition, had made it more bearable. He praised the brahmin and let him go.”
(Satyamurti, 2015, p. 761-762)

The above quote is from the Mahabharata, an epic of ancient India said to originate from 2000 BCE (Doniger, 2015, p. 21) and a philosophy of social and ethical relations intended to highlight an interdependent relationship between the individual and society (Venugopalan, 2018). The quote might be one of the oldest, if not the oldest, recorded examples of what psychologists call a 'formulation[11]' in history. Here a brahmin saw beyond the images evoked by an ogre to provide an understanding of a sentient being within a social and structural context. Knowledge from the ogre

---

[9] Continued: “*The brahmin kept calm and considered his options. He could try to escape, but he knew the monster could run faster than he could. He could try to bargain for his life, but he had no possessions that he could offer.”*

[10] Continued: *“You are living alone in this forest, without the company of your family and friends; that is why you are pale and thin. You treat your friends well, but still they are hostile to you, because they are mean-spirited. Although you try your best, you see others effortlessly rising in the world, while you are stuck here. Others look down on you and show you no respect. That is why you are so pale and thin. You have tried to steer others away from wrongdoing, but they simply despise you for it. You have worked hard, only to see others profit from your efforts. You cannot always find the right words, and that makes you ashamed and angry. You know how you would like to live, but cannot see how to achieve it. That is why you are so pale and thin, O rakshasa.”*

[11] Although there is no universally agreed definition of a formulation (BPS, 2011, p. 3), BPS (2011) reported that a formulation describes how "difficulties may relate to one another" (p. 6) and "surmises and integrates a broad range of biopsychosocial causal factors" (p. 1).

allegory that words given to a condition can nourish and make things more bearable has of course, been established by the art (or science) of psychological formulation.

Like the idea of an ogre, the concept of dementia is a 'spook[12]' that has served to obscure rather than elucidate hence the unpacking of perspectives detailed above. Stirner (1845/1907) emphasised all spooks are 'transitory', and Parker et al., (2021) outlined that dementia, too, is a representation that will ultimately be replaced. The question then arises as to what the alternative vision of dementia might look like, and "the highest aspirations of the imagination are called utopia" (Clark, 2009, p. 9). According to Goodway (2012, p. 99), Stirner rejected spooks in favour of an "intuitive recognition of the existential uniqueness of each individual", in which case progress, as per Clark (2009, p. 11), can only be achieved by multiplicity and difference, where "beings are mutually determined by and even contain within themselves the other". From this he argued knowledge would develop into sympathetic understanding and participatory consciousness rather than typical origins of conquest and subjugation.

Down (2000) warned that an individual approach to dementia has subjugated awareness of inadequate social or structural responses to PGLAD. Parker et al., (2021) argued that it was intentional and enabled neoliberal globalism to maintain power within the politico-economic world of health. They reported that this allowed profits to be generated from a social problem and ensured the continuance of business interests within dementia industries until a further profitable social problem was established[13]. This emphasises the need to democratise knowledge as if utopia comes from multiplicity, participatory means for PGLAD to put words to[14] their own

---

[12] Coined by Max Stirner (1806-1856), who was a philosopher influential to anarchism with a focus on oppressive social institutions (Leopold, 2019) from a psychological perspective. He was reported by Goodway (2012, p. 99) as a precursor to 20th-century existentialism in his rejection of nations, religion, class and ideologies to abstractions like 'morality, justice, obligation, reason, or duty'. He (1845/1907) called these concepts 'spooks' as he recognised they were social constructions that necessitated "endless Danaid-labour" (e.g. an eternity of carrying water with sieves) in reification.

[13] A problem Tucker (1899) suggested is maintained by the state creation of a patent/copyright monopoly to enforce the “exclusive ownership of an idea”.

[14] Or formulate.

experience is paramount. Academia must not subjugate this, as there is a hazard of not recognising disability as something to be valued in its own right (Szivos, 1992).

1.3. Understandings of Stigma

This section will focus on stigma at the individual, social and structural levels with a view to aiding comparison to our understandings of dementia. The models are complex and beyond the scope of this paper to review in their entirety so may have been truncated to maintain focus. However, the intention is to expose factors that may affect wellbeing or limit access to resources for PGLAD, to explore a knowledge-based approach to stigma reduction of utility to research.

1.3.1. Individual

I will now present an individualistic perspective commencing with Goffman (1963) who is credited with popularising the concept of stigma (Young et al., 2019), a word derived from Greek, denoting a bodily sign that signified something unusual or bad about the moral status of the holder. Stigma arose from the assumptions we hold of people with an attribute or social category that differed from our normative reference group[15]. Beliefs anticipated personal or structural characteristics to create a "virtual social identity" (VSI), or a stereotype of a person that influenced their treatment. Goffman suggested these cognitions were beyond our immediate awareness until expectations from the stereotype were disconfirmed. An idea difference might be situated at different stages of awareness was expanded by Burnham et al., (2008). They stated differences could be "invisible and unvoiced" like the VSI, and also "invisible and voiced", "visible and unvoiced", or "visible and voiced". Visible and voiced differences, if stigmatised to Goffman (1963) led to people being discredited.

---

[15] This research recognises reification of discrete, concrete boundaries and their causalities are problematic (Brubaker, 2004) but does not wish to dispute the reality, power or significance of, culturally bound differences on peoples lived experience. For this reason, groups will be situated within a framework of social difference devised by Burnham et al., (2008). They created a mnemonic *'Social GRACES'*, to remind us of differences (such as Gender, Race, Ability, Culture, Education, Sex), that are interrelated and constitutive of a person's experience in aspects of their life. These are differences perceived to affect levels of power afforded to us within society (Partridge, 2019).

Whereas those with invisible and unvoiced differences were discreditable, so held anxiety of exposure. From this, we see how perceptions of difference can shape hierarchy and power relations (e.g. Burnham et al., 2008) on a path to discrimination (Goffman, 1963). As if differences[16] were viewed negatively like "bad, dangerous or weak", the VSI shifted from being typical to tainted (ibid). Stigma arose from the relationship between the attribute and the stereotype (Link & Phelan, 2013).

Figure 1 (below) shows a model (Taylor & Field, 1993) that drew upon Goffman's work to propose stereotypes and negative social views perpetuated a cycle of stigmatisation that led to increased isolation and social withdrawal, in a similar way to the impairment or disability. Within this cycle, we see a relationship described by Corrigan et al., (2006) between public stigma, the negative attitudes held towards others that underpin discrimination and self-stigma, a process whereby stigmatising attitudes are internalised to the detriment of self-esteem and, in turn self-efficacy. They stated self-stigma occurred through agreement with stereotypes, and negative effects are solidified through self-concurrence, a perception these internalised beliefs applied to themselves. Subsequent sections will expand upon the influence of social views and stereotypes, including transmission by media, to provide a social context.

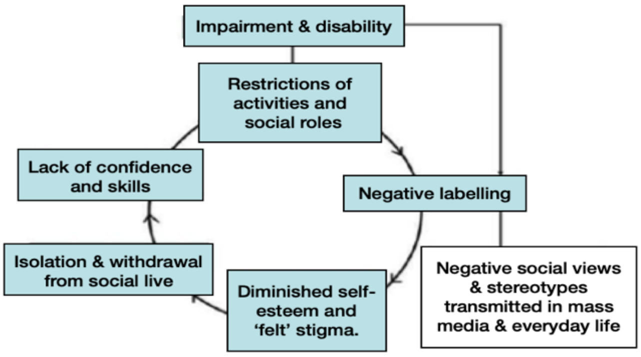


Figure 1: Feedback Loop (Taylor & Field, 1993, p. 128)

---

[16] Goffman (1963) identified three sources of stigma; that *of the body;* physical differences or impairment, *tribal stigma;* which might be inherited by race, nation or religion, and from *blemishes of character;* by one's traits, attitudes or beliefs. Blemishes of character could also be inferred from "mental disorder, alcoholism, sexuality, unemployment, suicide attempts and radical political behaviour". He did not define 'mental disorder', but contemporaneous psychiatric nomenclature situated dementia in the category of a "mental or behavioural disorder" (Weir, 2017). Later research found dementia to also be a form of tribal stigma as Chinese and Vietnamese PGLAD reported it was seen as a sign of a family's moral failure, and failure to meet familial obligations (Liu et al., 2009).

1.3.2. Social

Link and Phelan (2013) critique Goffman for disregard of social processes, as the emphasis on an attribute linked to a person downplays the process of selecting and applying labels. They felt too much attention on cognitive processes distracted us from the effects of discrimination. They (Link & Phelan, 2001) expanded Goffman's theory with a focus on how stigma arose from the relationship between the attribute and the stereotype at the intersection of five interrelated components (Figure 2). Thus 'stigma' is applied when "elements of labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation" (p. 367) that lets stigma unfold.

The Stereotype Content Model (SCM; Fiske et al., 2002) can add to this by elucidating social mechanisms that mediate stigma. From an euro-centric philosophical basis, SCM assumes what distinguishes humans from other creatures is the capability to express intent and exercise autonomy (Fiske, 2018). This necessitated an evolutionary "want" to understand individual or collective intent towards others or our associated groups to mitigate potential danger.

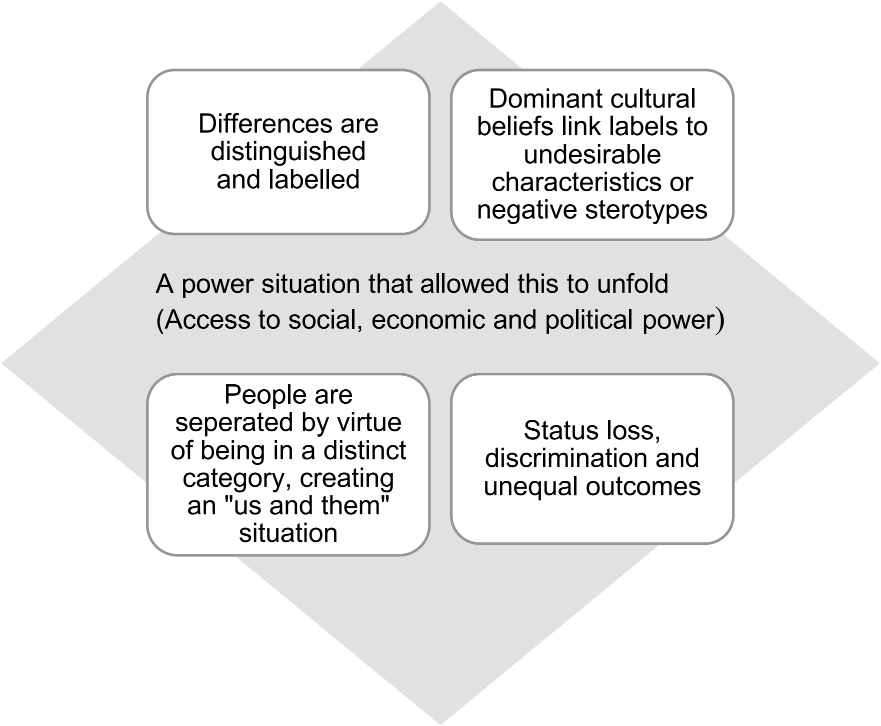


Figure 2: Stigma (Link & Phelan, 2001)

SCM (Fiske et al., 2002; Fiske, 2018) proposed that intent was assessed based on a calculation between an individual or group's perceived warmth, i.e. their trustworthiness or sociability and their capability or competence to act upon intent. The placement on these dimensions were determined by stereotypes arising from a history of interpersonal or intergroup relations.

According to SCM (Cuddy & Fiske et al., 2009) stereotypes became a universal human phenomenon as a survival need to identify friend or foe, due to social hierarchies and competition for resources. SCM was found to predict how groups were likely to be stereotyped based on their structural relationships with other groups in their society (ibid). Common stereotypes of socioeconomic status or age were shared internationally, but other stereotypes varied nationally (Fisk, 2018). Notably, a positive stereotype of a group on dimensions of warmth or competence did not contradict prejudice but could be consistent with unfavourable stereotypes on the other dimension (ibid). For example, older adults attributed a positive stereotype of warmth alongside a negative stereotype of low competence. She proposed mixed stereotypes like these were paternalistic and portrayed outgroups as neither inclined nor capable of harming harm the ingroup as a means to maintain the advantage of more privileged groups.

SCM established emotions evoked by groups were more predictive of discriminatory behaviour than stereotypes (Cuddy et al., 2007). For example, they found admired groups (warm, competent) elicited facilitation tendencies (aiming to benefit a group), whereas hated groups (cold or incompetent) aroused harm tendencies (acting against either individually or institutionally through discriminatory policies). For PGLAD whose ability evoked negative stereotypes of low competence*,* other differences like age or immigration status may affect perceptions of warmth, leading to discriminatory treatment due to the emotions evoked. However, this raises a possibility the opposite is true as if perceptions of low competence for PGLAD can be shifted by platforming other skills, like participation in research, it might affect emotions evoked and reduce discriminatory behaviours.

We have seen SCM is complimentary to Burnham et al., (2008) explaining how difference, projected through stereotypes, can shape hierarchy and power relations. Structural privilege maintained as socially desirable traits placated nonthreatening or disadvantaged groups; warmth ensured compliance, whilst stereotypes of low competence justified their subordination (Fiske et al., 2002). Within the next section, critical reflection will be given to these structural privileges to further a knowledge base that informs the second tenet of critical consciousness; political efficacy (Watts et al., 2011), namely the means we have to effect change.

1.3.3. Structural

The Framework Intergrading Normative Influences on Stigma (FINIS; Pescosolido et al., 2008) will now be introduced as it too drew upon Goffman (1963) and has the structural lens. Pescosolido et al., (2008) offered FINIS as a general framework to be applied to any stigmatised condition but advised it to be tailored in substance and hypotheses for utility. With this in mind as FINIS is a complex model beyond the scope of this paper to address entirely, a brief overview will be provided. This is followed by tailored consideration of the media and national context with a mind to critical consciousness, as this is where a foundation for critical action may reside.

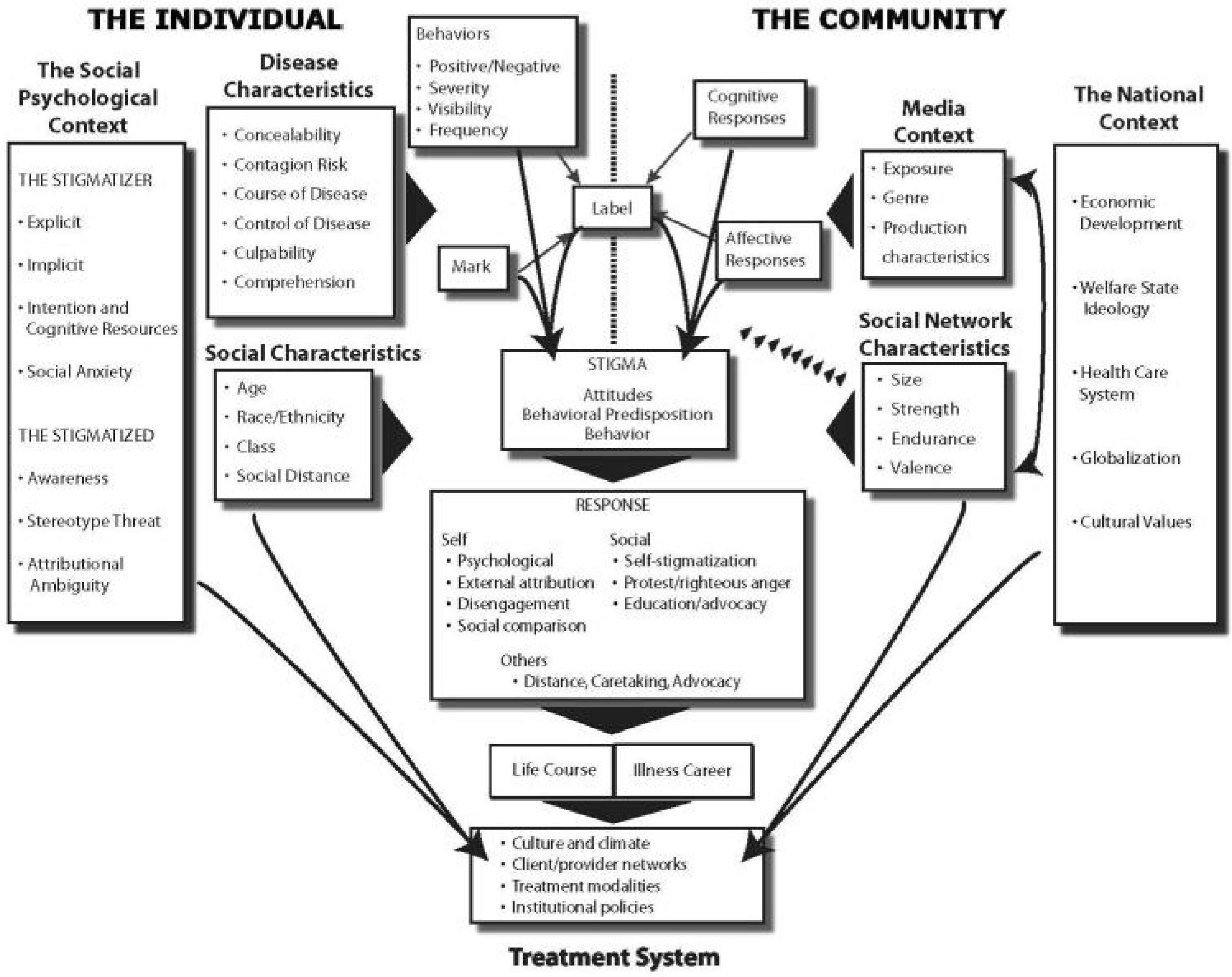


Figure 3: FINIS (Pescosolido et al., 2008)

To the left of Figure 3 Pescosolido et al., (2008) report Goffman's influence as FINIS delineates the psychosocial context and illness features that affect belief systems. Whilst FINIS accepts on an individual level internal processes shape interaction, they consider it unextractable from the influence of external structures of reference that provide normative expectations which perpetuate stigma. Like Burnham et al., (2008) in Section 1.3.1 and touched upon in Section 1.3.2, FINIS highlighted social differentiation between observed and observer, coupled with the number of devalued statuses the observed holds, increases the likelihood of their evaluation as problematic in some way and lead to negative responses towards them. The right of Figure 3 advances how these beliefs, which constitute VSI in 1.3.1 or stereotypes in SCM of 1.3.2 form stigma and are situated in the wider macro context. The authors report that these variables mediate the degree of stereotyping, beliefs that define others and how groups accept, modify or reject dominant cultural beliefs. If these factors constitute the power situation Link and Phelan (2001) said enabled stigma to develop, we now have a knowledgebase relevant for critical action. The next subsections result from FINIS being tailored to the focus of this project as it will assert media and national context are pertinent for political efficacy.

1.3.3.1. *Media Representations*

Representation in the media relates to how aspects of society, such as the differences contextualised by Burnham et al., (2008), are presented to, and received by audiences. Media representations of PGLAD consisting of negative stereotypes about age or ability were, for Latimer (2018), created as "spectacles of othering" (p. 834) that reaffirmed the values of established social hierarchy. She contended this reinforced a political economy where people were objectified based upon their perceived cost to society, legitimising individualist ideas of dementia partly as a notional and neoliberal depiction of dementia as poor self-care and not living well.

FINIS (Pescosolido et al., 2008) proposed media shaped our beliefs through a two-step model of learning, and then construction. From media viewing, learning occurred that subconsciously[17] informed our understanding of the world. Over a lifetime, this generated a source of stereotypes that affected attributions of others. This notion of data drawn from the subconscious aligns with Burnham et al., (2008) idea of difference being situated at different stages of our awareness.

Historically, people were perceived as defenceless to the influence of an all-powerful media (Curran et al., 1982; Bineham, 1988), but research came to a recognition people manipulated media based on dispositional factors, group characteristics or cultural influences (Katz & Lazarsfeld, 1955; Klapper, 1960). Subsequently, Two Step Flow Theory (TSFT; Katz, 2015) arose and proposed ordinary people labelled “opinion leaders” (OpL) interpreted and modified media messages to influence others (Opinion Followers, OpF) two steps from the source (Ognyanova, 2017). OpL were widely dispersed in society and shared characteristics with their OpF (Klapper, 1960), moreover, OpL and OpF influenced each other (Troldahl & Van Dam, 1965). Thus, ability to shape public opinion was not necessarily reliant on wealth, power or status but was a-hierarchical (Katz & Lazarsfeld, 1955; Bineham, 1988; Katz, 2015). This offers an avenue where established sources of power or influence over societal discourse can be challenged by people who are marginalised.

1.3.3.2. *National and Political Context*

The state is ubiquitous yet has been diminished in our political consciousness (Lindsey, 2013) and we see this by FINIS foregrounding the political constitution, which might be considered software, at the expense of the state, which we might view as the hardware. For this reason, before we touch upon the political constitution as a variable of FINIS, a classical understanding of the state.

---

[17] An idea we are but passive receptacles for information delivered by media into our subconscious is in accordance with the Hypodermic Needle Model (HNM). A brief history of which is in Appendix B.

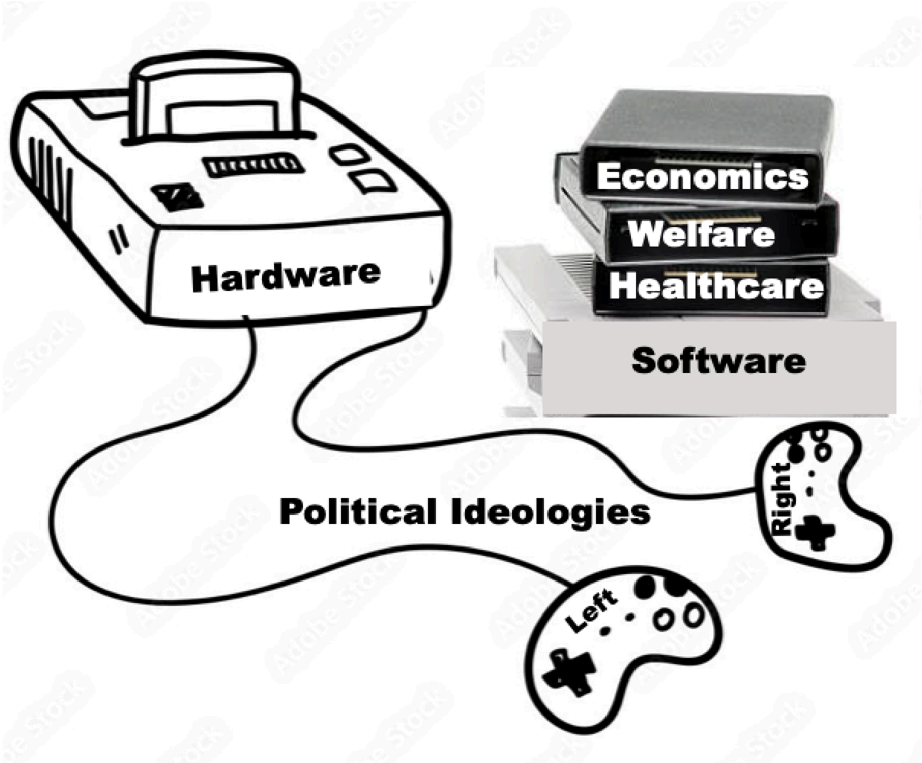


Figure 4: National and Political Context Analogy

1.3.3.2.1. *The Hardware*

Like hardware, the state is durable, generally static over time and provides mechanisms that enable the software to run which is why we may forget it is there. Aristotle (et al., 1991) proposed the state was a natural progression from pairing for reproduction to creating a household to forming a village, multiple of which became the state. He observed, “every state was an association, and every association was formed with a view to some good purpose” (p. 54) like acquiring resource or meeting life’s necessities. He compared the state to a body (p. 60) with limbs (people) subordinate to the whole as a natural and universal pattern, akin he suggested to slavery and maintained out of expediency and mutual dependency. On the surface, these relationships were portrayed by Aristotle, whose context was of a time, like voluntary cooperation. Yet he knew they rest on an authority backed by force, for he asked, how else is a leader “to impose will on those who seek to resist”? (p. 234)[18].

---

[18] This might bring the analogy of the state to slavery closer to contemporary understanding as whilst slavery as a practice is ongoing (Global Slavery Index, 2018), the inevitability of it has been challenged in the same way human rights discourse has challenged the inevitability of state violence.

For Hobbes (1651/2017), force was the purpose of the state, an "artificial man" created of greater strength and stature than "natural man" to prioritise safety that was given life through sovereignty. Weber (1946, p. 77) echoed this with a definition of the state as a "human community that (successfully) claimed the monopoly of the legitimate use of physical force within a given territory". Although Aristotle (et al., 1991) did think the state needed to be about more than just a military alliance or promoting trade, he felt the purpose should be virtue, with the ultimate aims to enable a good life; for people to live well, happily and nobly (p. 198).

1.3.3.2.2. *The Software*

This section considers the national context and will reflect upon politics which like software is interchangeable, dependent upon whim or will, and necessitates power derived from hardware and exercised through its components to operate. For Yang et al., (2007), it was state agencies and agents that enacted stigmatisation of groups. FINIS (Pescosolido et al., 2008) outlined this was because the national context provided an overarching ideology for a community through categorisation of groups and the provision of indicators of how to act with each other.

Structural stigma manifested through policy, laws, and institutional practices has a cumulative impact and enables political distance from a need to acknowledge whose interests are served at the macro-level (Link & Phelan, 2014). A defence of utility, as Pinker (1970/2017) reasoned stigma did not negate a need to meet basic needs so social policies were negotiated through coercion of the privileged by the deprived and resistance of the privileged to such coercion. He saw stigma as the most common form of violence used in democratic societies, covert (e.g. Link & Phelan, 2014) and rarely associated with physical aggression, so resisters could be tarnished as the first to use force. Hence Tyler (2020)'s premise stigma developed as a deliberate government policy. FINIS (Pescosolido & Martin, 2015) identified five areas where stigma has been cultivated:

- Economic development
- Welfare state ideology
- Healthcare system
- Globalisation
- Culture

Economics and globalisation are beyond the scope of this paper as the relationship between socioeconomic variables and stigma is too complex for firm conclusions (Koschorke et al., 2017). Welfare and culture will now be briefly considered, holding in mind the presence of economics lurking in the background.

1.3.3.2.2.1. *Welfare*

In states with universal healthcare, FINIS reported norms of entitlement to access healthcare might reduce levels of stigma around health (Pescosolido et al., 2008). Conversely, as expectations for social welfare rose in industrial societies, Pinker (1970/2017) suggested governments mitigated this through weaponisation of stigma to encourage disgust in the public towards welfare usage. Instrumental use of media representations to stigmatise welfare claimants remains a deterrent strategy (Fletcher & Wright, 2018) and as per SCM, emotions like revulsion are a predictor of discriminatory behaviour. Exacerbation of stigma has a knock on where discrimination can lead to precarious employment and threaten families' survival, particularly in low-and-middle-income countries (Koschorke et al., 2017). From this, we see the relationship of government towards factors that inhibit or elicit stigma is bidirectional and a technique for resource management (Pinker, 1970/2017).

1.3.3.2.2.2. *Culture*

Like Aristotle and Hobbes (Section 1.3.3.2.1), Durkheim (1925/1961) used a body politic metaphor[19] to describe society as a being, with a 'collective consciousness'; namely shared beliefs, cultural values and norms to enable it to survive and thrive. For Pinker (1970/2017), this collective consciousness included an economic ethos that valued money as a means to protect autonomy and saw its exchange as a relationship between equals. Cultural values of self-help, independence or resilience today (Joseph, 2013) were amplified by the state to generate dissonance towards those reliant on welfare. Reminiscent of the "strivers vs shirkers" discourse (Patrick, 2014), this led to a culture where society was divided into givers, portrayed with moral superiority, and welfare takers who were diminished (Pinker, 1970/2017). This

---

[19] Body politic is reported by Rollo-Koster (2017) to be an ancient metaphor in which institutions (state, society or church) are compared to a human body.

stigmatisation led to cultural values permissive to coercion embedded into the welfare system through the software of government where agents or professionals served a dual therapeutic and stigmatising function. The use of stigma to perpetuate exploitation, management or control Link and Phelan (2014) labelled “stigma power”. Motivations for which included: keeping people down; maintenance of wealth, power or social status, keeping people in check; regulation of social norms and keeping people away; avoidance of disease.

1.4. Human Rights (HR)

It has been identified how the experience of both dementia and stigma are shaped by social and structural factors, including statehood itself. These can feel distant and perhaps difficult to influence, yet for both dementia (e.g. Kitwood, 1998; Cahill, 2018) and stigma (e.g. Pescosolido & Martin, 2015), the solution posited to oppressive contexts was to change the structures that shape our relationships. Less clear might be the how, despite HR in section 1.2.3. being positioned as the means to effect political or social change for PGLAD. Opining on HR risks straying into what Freire[20] (1970, p. 87) called the unauthentic word. This he said, is when words become deprived of their dimension of action, lack possibility to change reality and manifest a “alienated and alienating blah”. With the hope to not offer “idle chatter” (also Freire, 1970, p. 87), this section will introduce HR as a mechanism for social change by sharing a brief history, explaining compliance and the application of this for PGLAD.

.

1.4.1. Background

HR were surmised as a moral, political and legal framework that embodies our greatest societal aspirations and guides us to a just world (Butler & Critelli, 2019). They arose as Hobbes (1651/2017)[21] artificial man faced sickness and death, which led to conflict and a need for agreement on civilised conduct between each other. The first recognised agreement, The Peace of Westphalia 1648, ended a period of

---

[20] Paolo Freire (1921-1997) is seen as the most important educationalist of the 20th Century and seminal for the philosophical development of critical pedagogy (Schugurensky, 2014).

[21] In Hobbes (1651/2017) conceptualisation of the artificial man, he saw equity and laws as artificial reason and will, concord; health, sedition; sickness and civil war; death.

European history that left approximately eight million people dead (Wilson, 2008). These treaties enshrined tolerance as a guiding principle and mediated the state's relationship with marginalised people (Gross, 1948). Further, it set a precedent that influenced The Little Treaty of Versailles 1919, which guaranteed international protection for minorities when Poland became a state (Fink, 2004). This bound states to comply with principles of governance and evolved into the UN[22] (Gross, 1949) and the Universal Declaration of Human Rights (UDHR), which is the foundation of international law (UN, u.d). International law provides a final safeguard against HR violations by the government (Soussan, 2015). Alongside the UDHR, there are nine core HR instruments detailed in Figure 5 below.

Acronym	**Instrument**	**Date**	**Monitoring Body**
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination	21 Dec 1965	CERD
ICCPR	International Covenant on Civil and Political Rights	16 Dec 1966	CCPR
ICESCR	International Covenant on Economic, Social and Cultural Rights	16 Dec 1966	CESCR
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women	18 Dec 1979	CEDAW
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	10 Dec 1984	CAT
CRC	Convention on the Rights of the Child	20 Nov 1989	CRC
ICMW	International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families	18 Dec 1990	CMW
CPED	International Convention for the Protection of All Persons from Enforced Disappearance	20 Dec 2006	CED
CRPD	Convention on the Rights of Persons with Disabilities	13 Dec 2006	CRPD

Figure 5: Core Human Rights Instruments *(OHCHR, u.d)*

---

[22] The UN Charter was ratified on 24 October 1945 and set its purpose: "To achieve international cooperation in solving international problems of an economic, social, cultural, or humanitarian character, and in promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion". Tertiary to its first purpose: "To maintain international peace and security, and to that end: to take effective collective measures for the prevention and removal of threats to the peace, and for suppression of acts of aggression or other breaches of the peace". Aristotle might have seen a supranational organisation as a natural evolution of associations and Hobbes another bigger, stronger man.

HR are implemented through social policy, which are: “any action proposed or adopted by government or intergovernmental body at a local, state, federal or international level” (Bowen et al., 2019). Action could be explicit; within laws, legislation, regulations, public programmes, non-binding articles, strategy papers, documents and declarations. Or implicit with appreciation, an action taken under one policy might impact other groups.

UDHR was brought into European Law by the European Convention on Human Rights (ECHR), and ratified into UK law through the Human Rights Act (HRA) 1998. HRA made it illegal for the conduct of public authorities or organisations of public function to be incompatible with the act. HR underpin the NHS constitution (DOHSC, 2021) and form the regulatory framework for health and social care (CQC, 2019). Staff are legally bound to defend HR, and proactive measures taken are called a Human Rights Based Approach (HRBA). Principles of a HRBA are captured by the acronym PANEL (Figure 6) and are endorsed as a tool to defend rights of PGLAD (WHO, 2015; ENNHRI, 2017; MHF, 2015).

Principles	**Definitions**
Participation	Enabling meaningful **participation** of all key people and stakeholders.
Accountability	Ensuring clear **accountability**, identifying who has legal duties and practical responsibility for a human rights approach.
Non-discrimination & equality.	**Non-discrimination:** discrimination avoided, attention paid to groups made vulnerable.
Empowerment	**Empowerment** of staff and service users with knowledge, skills and commitment to realising human rights.
Legality of rights	Expressly apply human rights **laws**, particularly the Human Rights Act.

Figure 6: PANEL Principles (BIHR, 2014)

Nonetheless, practitioners, policymakers and PGLAD are reported to have low awareness of the implications of HR, particularly concerning dementia labels (Cahill, 2018). Yet HR offers citizens positive control of their government and provide a means to prohibit interference in their personal, social and political lives as individuals, or in relation to group identity (Donnelly, 2013). I will discuss the relevance of a HRBA to clinical psychology in Section 1.5.

1.4.2. Compliance

“Almost all nations observe almost all principles of international law and almost all of their obligations, almost all of the time” observed Henkin (1979, p. 470) yet reasons for this are contested (Guzman, 2002) nor properly understood (D'Amato, 2010). Hobbes (1661/2017, 17.2) stated, “covenants without the sword are but words and of no strength to man” indicating a view a treaty needed to be backed by force. This is known as the Enforcement Model (EM) and is commonly seen by citizens, media and parts of academia as crucial to international law (Chayes & Chayes, 1995).

EM was challenged by (Burgstaller, 2005), who highlighted that no coercive power in the international system is equivalent to that enforced by law in a state. He believed this was because social orders maintained by force were counterproductive and risked collapse as repression bred resentment and resistance to regimes. Chayes and Chayes (1995, p. 2) thought coercion in treaties was a “waste of time” as compliance was better achieved from a cooperative problem-solving approach as this was in a state’s interest for reasons of efficiency, self-interest and social norms. It made economic sense to conserve expensive government resources for urgent priorities rather than unnecessary deviation of rules. Particularly as compliance was incentivised from a long treaty negotiation process that accommodated the interests of negotiating parties. Moreover, obedience to law is expected in society, and treaty compliance is a norm of international law.

The Management Model (MM) posits noncompliance is not necessarily deliberate but a result of limitations in resources or capacity of government or ambiguity of rules (Burgstaller, 2005). In this way, MM aligns with Kitwood (Section 1.1.3) and indicates conscious-raising as to HR lapses could serve as a point of structural intervention. Indeed, each HR instrument has a committee of experts to monitor states’ implementation of treaty provisions (OHCHR, n.d.). Concurrently, HRBA is a bottom-up approach for employees of public authorities, as compliance is the duty of everyone, without any need for technical knowledge (Curtice & Exworthy, 2010).

1.4.3. Application

FINIS authors Pescosolido and Martin (2015) asserted the clear conclusion of stigma research was a focus on knowledge had limited value compared to change. As action is needed to defend the rights of PGLAD (Dixon et al., 2020), CRPD has been put forward as a tool to support this (Cahill, 2018; Dixon et al., 2020). The social model influenced CRPD in response to individualism of the medical model yet it is considered a paradigm shift as it codified a HR model of disability (Degener, 2017). Central Degener (ibid.) argued was the universality of rights as it affirmed neither identity or impairment could deny HR. Further, she reported CRPD drafters purposely did not comment on how ability may affect quality of life, to avoid negative judgements on impairment. This she stated, was so people with disabilities would never again be regarded as a life not worth living or perhaps even a “burden”.

Challenging stigma was a key priority of CRPD (Baranger, 2017), as observed in the Article 8 measures (Figure 7). In addition, participation and inclusion are fundamental to the CRPD (Della Fina, 2017) and this included full involvement in processes of research (UN CRPD, 2009, E/A3/13).

Article 8 – Awareness Raising
1. States Parties undertake to adopt immediate, effective and appropriate measures: (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; (c) To promote awareness of the capabilities and contributions of persons with disabilities.
2. Measures to this end include: (a) Initiating and maintaining effective public awareness campaigns designed: (i) To nurture receptiveness to the rights of persons with disabilities;

(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention.

Figure 7: Article 8 CRPD measures to reduce stigma

Although not directly enforceable in the UK (Mr A Britliff V Birmingham City Council, 2019), Dixon et al., (2020) reported CRPD holds persuasive influence, but implementation depends on political will. Hence, they argued that challenging stigma at a structural level necessitated awareness and advocacy campaigns, using case examples to advocate how HR can be defended at an individual level. This is supported by a review of stigma-reduction strategies (Heijnders & Van Der Meij, 2006) that identified HRBA at the structural level, as well as education, contact, advocacy and protest at the community level as appropriate means (Figure 8).

Level	**Strategies**
Intrapersonal level	Treatment Counselling Cognitive-Behavioural Therapy Empowerment Group Counselling Self-help, advocacy and support groups
Interpersonal level	Care and support Home care teams Community-based rehabilitation
Organisational/Institutional level	Training Programmes (New) policies, like patient-centred and integrated approaches
Community level	Education

	Contact Advocacy Protest
Governmental/structural level	Legal and policy interventions Rights-based approaches.

Figure 8: Stigma-Reduction Strategies (Heijnders & Van Der Meij, 2006).

We saw in Article 8, empowering people to claim rights and hold organisations to account is intrinsic to HRBA (Greenhill & Golding, 2018). As “No one knows the needs of (PGLAD) better than (PGLAD)” (Seetharaman & Chaudhury, 2020, p. 5), only through elevation of PGLAD’s political voice might we know how to act (Bartlett & O’Connor, 2010). WHO (2015) called for “empowering and engaging the full and active participation of PGLAD and their caregivers, and families, as well as overcoming stigma and discrimination” (p. 42) as a direct action against dementia. Notions of empowerment risk a critique reported by Bartlett & O'Connor (2010) reported in Section 1.2.2 of Kitwood denying PGLAD’s autonomy. Yet Heijnders and Van Der Meij (2006) emphasised people affected by stigma were not passive in the stigma-reduction process. They found several studies where an active role was taken as people aware of barriers to HR were best placed to set priorities for change.

Herrmann et al., (2018)’s systemic review found broad personal exposure to PGLAD was a key strategy to reduce stigma. Means may include involvement in committees on strategies, policies and research, and academic collaboration as co-researchers (Seetharaman & Chaudhury, 2020). Understandable, as barriers to PGLAD’s involvement in knowledge creation is a recognised epistemic injustice intrinsic to rights to speak, be heard and believed (Young et al., 2019). Further collaborations tap into what Harper (2005, p. 56) described as an “appeal to expert discourse” which might legitimise PGLADs views in the eyes of policymakers. PGLAD valued purpose, personal growth and solidarity with wider communities of PGLAD from such involvement (Seetharaman & Chaudhury, 2020). Indeed, Seetharaman and Chaudhury (2020) reported participation explicitly and implicitly challenged stigma as nonconformity to stereotypes of PGLAD dispelled discriminatory attitudes. SCM in 1.2.2 might see this as a change to intergroup relations through interpersonal dynamics to obtain a shift in perceptions of competence. The idea contact “typically reduces prejudice" is known as the contact hypothesis, which Paluck et al., (2019) reaffirmed evidence for from a meta-analysis. They found contact worked particularly well to reduce prejudice towards people with mental or physical disabilities, which might encompass PGLAD. When these groups were removed from their data-set, the contact effect weakened, which they suggested meant prejudice at the intersection of other differences, might be less amenable to change by contact alone. PGLAD did report discrimination to Seetharman and Chaudhury (2020), and Carr (2007) reported conflict like this might be inevitable due to power differentials between professionals and people with lived experience of issues accompanied by "contested notions of truth, reality, method and language" (p. 269). This indicates personal insights that necessitate a degree of vulnerability to share (Carr, 2007) may have emotional implications (Faulkner & Thompson, 2021) exacerbated by responses from professionals who might feel threatened by their ideas (Carr, 2007). The PGLAD in Seetharman and Chaudhury (2020) were resolute in that these attitudes confirmed a stronger need for inclusion, involvement and representation.

Bartlett and O'Connor (2010) advocated citizenship, which they defined as the relationship we have with the state across our lifespan, as a social practice. They claimed dementia research focused on social relationship to the detriment of identities PGLAD held to the state, and this oversight missed how the experience of dementia was shaped by national context. To countermand this, they highlighted ways PGLAD have engaged in citizenship through charity fundraisers, letter-writing to MPs, consumer choices, care complaints, protest or demonstrations. This was similar to a HRBA outlined by Patel (2003) of writing letters, demanding explanations or change, and providing support, consultation and guidance for services to defend HR. Bartlett and O'Connor (2010) reported whilst PGLAD involved in public campaigns used their voices explicitly in a political way, political narratives were harder to discern in healthcare settings. This, they said emphasised action to listen to what PGLAD had to say about their wishes and human rights as citizens, and community members, rather than a welfare 'burden'. Through narrative citizenship practices, Baldwin (2008) reported the stories told could subvert the status quo and open the door "to new ways of telling, and new ways of being" (p. 223). Yet this he stated, necessitated agency, opportunity and resources PGLAD are often denied.

As health is a HR issue, O’Sullivan and Hocking (2013) saw knowledge production action in itself as data gathered aided challenge of inequities in provision. Littlechild et al., (2015) reported statutory organisations welcomed this as an effective way to learn about the experiences of their service users. They believed the passion, conviction and clarity with which service users could deliver their messages increased the authenticity and persuasiveness of the findings. However, one manager reported this experience uncomfortable as they were left with “nowhere to hide” (p. 26) so had to acknowledge and address the issues raised. In this way, the action became what O’Sullivan and Hocking (2013, p. 23) called a communicative space to explore “the way things are” and point the direction towards social change.

1.4.4. Voices of PGLAD

Ensuring the voices of PGLAD are heard was indicated in the previous section as an HRBA to stigma intervention, so it would be apt to report PGLAD views on stigma or human rights. Unfortunately, as detailed earlier the literature on the lived experience of PGLAD, let alone on specific topics like stigma or human rights is sparse due to epistemic injustice detailed in Section 1.4.3. This is despite it being recognised PLGAD have insight into their own experiences (Johnson, 2016, Bryden, 2022) irrespective of the typical stereotypes associated with the label. Within this section, we shall first consider some perspectives PGLAD have on stigma, then consider possibilities for academia to enrich its understanding of the lives of PGLAD.

As part of a stigma intervention study, Harris and Caporella (2014)[23] documented the view of PGLAD and families towards stigma through a focus group. All participants accepted stigma around dementia labels was present, however, it was found that their responses to it differed, as although some felt it, others actively rejected it. One PGLAD suggested stigma arose from the negative connotations “associated with the later stages and death” (p. 277) which supports Link and Phelan (2013)’s view of stigma as relationally derived between attributes and the stereotype. We see PGLAD report similar negative beliefs associated with the dementia label in Johnson (2016, pp. 706-707) who describes it as analogous to “stupid” or “foolishness” and

---

[23] This study was described as “promising” for the future of research in this area by Hermann et al., (2018)’s systematic review reported as we commenced this paper.

“something to be feared” (p. 703) so they avoided being defined by this term. To avoid stigma PGLAD in Harris and Caporella (2014) reported they withdrew socially. Younger PGLAD (Hunt, 2011) also reported social withdrawal out of frustration from being treated differently as soon as other people know about their label. PGLAD in Harris and Caporella (2014) also described this, with a feeling they were put under surveillance for cognitive decline, whilst another person reported reluctance to tell anyone including friends to avoid being a “subject of pity” (p. 277). Conversely, a PGLAD did report the diagnosis lifted “a great burden” (p. 277) as they found once people knew, they were accepting, concerned, and willing to help. Interestingly, those funded to help such as health staff and a PGLAD charity were reported to be sources of frustration or feelings of devaluation (Hunt, 2011, p. 30).

Education was perceived by the Harris and Caproella (2014) focus group as a tool to tackle stigma, as they reported with awareness came knowledge of how to help. Whilst they recognised public education was enhanced by publicity arising from head injuries in sports or disclosures from famous figures, it was stated they all had a role. Indeed, younger PGLAD (Hunt, 2011, p. 28) emphasised the way to help PGLAD was by “insisting people listen to them and acknowledge their capabilities”. Thus, we have examples of knowledge disseminated by social structures and drawn on by people irrespective of the interest, or lack of, from academia.

Writing online and in books was reported by PGLAD in Hunt (2011, p. 29) as a positive and therapeutic approach to getting their voices heard. Personal publishing has been extended to academia itself, for example, Sterin (2002)’s essay about their lived experience of Alzheimer’s. Bryden (2022) who also published autobiographical work emphasised that analysis of an issue from experience as a member of a group offers member-researcher status and provides a valuable insider perspective. Further, Clark-McGhee and Castro (2015) demonstrated through a narrative analysis of poetry that meaningful experiences of PGLAD were captured by written arts and offered the potential for academia to reach out and interpret other narratives to know more about PGLAD from their voices within contexts of their creation. These examples of knowledge shared by PGLAD via structures extrinsic to science to widen societal understandings of their experiences suggest that academia, which has seen this as its role, risks marginalising itself, as it has done PGLAD.

Summary and Relevance

1.4.5. Summary

To surmise this introduction has aimed to lay the groundwork for this project by enacting critical consciousness mindful to three components (Watts et al., 2011). *Critical reflection* was provided on understandings of dementia and stigma at the individual, social and structural levels to raise our understanding of belief systems that might influence particular courses of actions. It was outlined how both dementia and stigma are shaped by social and structural factors, including statehood itself. To consider more about the mechanisms of how the state facilitated this and to lay the ground for *political efficacy*, a two-part analogy of our nations structure was provided. To analogise the state as hardware is to emphasise the mechanism which gives power to the software that arises from political decisions. This anticipated the introduction of human rights as a framework for *critical action*. A tool PGLAD could draw upon through research to challenge the drivers of malignant social psychology and unjust institutional policies or practices that might be emboldened by the state.

1.4.6. Relevance to Clinical Psychology

"Science… will become more fruitful, useful and expansive when a sage is no longer a stranger to manual labour. For work's sake as much as for the sake of science, there must no longer be division into workers and scholars" (Bakunin, 1869/2021).

With echoes of Bakunin[24] (quoted), Pedro Casaldaliga[25] (1981, as cited in Oropeza, 2020) called on psychologists to be "workers of science, alongside the workers of the hoe, or the oven, or the panela" and not to end up "well-paid officials, psychologists of the privileged world, useful allies of exploitation and, maybe, of repression" (p. 58). As Martín-Baró[26] (1994) foresaw, if psychology attended to knowledge people had of themselves, as individuals and as a group, this knowledge of everyday praxis might

---

[24] Mikhail Bakunin (1814-1876) had a profound influence on anarchist philosophy and highlighted "the importance of anger and protest to be linked with others and directed upward" (Leier, 2006).

[25] Pedro Casaldaliga (1928-2020) was a founder of Liberation Theology (Oropeza et al., 2020).

[26] Ignacio Martín-Baró (1942-1989) was a renowned liberation psychologist dedicated to human rights in El Salvador who was assassinated by the government (Critical Therapy Institute, 2014).

assist humanisation and the taking command of their own existence. Resonance occurs in Clements and Rapley (1996), who argued for clinical psychology to free itself from pretension or desires of elitist status or power and, like Martín-Baró (1994, p. 46), cease emulation of professional classes. Martín-Baró (1994, p. 46) thought applying psychological knowledge to new problems might “dispel some inertia”. Clements and Rapley (1996) proposed plumbing as the aspirational career model for psychologists, as they are useful, with skills in demand and imperatively able to turn their hand to real-life problems. There is a role for clinical psychology to do just this and direct its skills to deliver a pipeline between the voices of people we hope to serve and the academia that informs practice - for the sake of science itself.

Literature indicated PGLAD’s well-being was under pressure from state actions and obstructed by the weaponisation of stigma. We saw how cooperation between people over time inbuilt a safety valve of human rights that state agents, such as clinical psychologists, have legal and ethical duties to defend. This is observed in the NHS Constitution (DHSC, 2021) and the profession’s code of ethics (BPS, 2018) which shares HR values. HR were described by Ulrich and Wainwright (2020, p. 90) as “resonating strongly” with guiding ethics of psychology and providing an agreed moral compass to clinical psychology. For Patel (2020), this direction of travel was explicitly towards structural change as she outlined the shared aspirations of clinical psychology and human rights to improve lives. Limited research with PGLAD (Milne, 2010; Alzheimer’s Society, 2010) including evidence-based stigma reduction approaches (Hermann et al., 2018) indicate academia Is a structure that needs change. If, due to stigma, barriers to participation in research arose that rendered PGLAD invisible (Bryden, 2016) then psychology may have been in dereliction of ethical and legal obligations, so too requires change.

Patel (2003) set a challenge for psychologists to critically reflect how they may have applied psychology in a way that ignored relationships between the individual and historical, social or political contexts which shape lives and give rise to their distress, then seek more just alternatives. A contrast made by Nelson and Prilleltensky (2010a, p. 175) between social aid, treating symptoms of social problems, versus social change, action on causes. They too, argued for a focus shift from the individual to societal levels, which this research has applied through critical consciousness (Watts et al., 2011) that will also serve as a meta-action.

1.5. Research Aims and Questions

1.5.1. Aims

Bryden (2016) stated visibility was critical in challenging stigma, and like the HRBA, this meant opportunities for PGLAD to participate as equal partners in research to improve support and services. Likewise, Alzheimer’s Society (2010) called for the perspectives of PGLAD to be heard through participatory approaches in research. An aim will be to do this and also meet a challenge set by government (DOH, 2015) towards the NHS to provide opportunities for PGLAD to participate in research.

Participation constitutes part of an ideological change called for by the United Nations (Pūras, 2017) and endorsed by the British Psychological Society (and Mental Health Europe et al., 2017, August 8) towards a redistribution of power in clinical, research and public policy. Therefore, this research aims to embrace Bryden (2016, p. 62) stance of “Nothing about us, without us” to collaborate with people affected by dementia as equal partners, as an action in defence of HR in itself.

1.5.2. Research Questions

Participatory Action Research (PAR) differs from traditional research because questions do not emerge directly from literature as this bias favours academia’s interests (Levin, 2008) and is problematic as PGLAD are neglected from research. Levin (2008) explained how PAR has an alternative approach as knowledge is co-created with the intention of using everyday experience to resolve local problems. This he recognised posed a challenge to academic practice and was experienced when applying for ethical consent in this research as questions were necessitated. Consequently, Levin (2008)’s recommendation of formulating questions of such breadth to enable the co-researchers to direct inquiry was adopted below:

i. To explore dementia with a person-focus in the context of *how* society is organised, and the relationships people may have with it?

ii. Consider issues that may have emerged from dementia and *how* society may impinge upon the attainment of economic, social and wellbeing standards?
iii. Consider *how* to act upon these issues with a view towards promoting and protecting human rights to enhance or maintain psychological wellbeing?

2. Methodology

The previous chapter critically reflected on how dementia labels and stigma might shape a person's experience, and then HRBA was presented as a tool for change. This chapter will justify why PAR has been chosen as a methodology in keeping with HRBA and outline why the anarchist insight is complementary to research aspiring to the highest axiological principles and influences the conceptual framework for action.

2.1. Research Paradigm

As Psychology the discipline transitioned from philosophy to science, how it viewed the world (Ontology) and defined knowledge (Epistemology) changed. This affected how Psychology acted in the world and how it was applied (Teo, 2009). Accordingly, consequences arose from often-unspoken beliefs or assumptions of science that affect how phenomena like dementia labels are understood. To illuminate this, as per this chapter, is an aspect of critical consciousness as epistemic systems are struggles of power, each with histories of conflict and resistance (Moore, 2012).

2.1.1. Approach

This project recognises voices of PGLAD are unheard and accepts epistemes of co-researchers might differ due to the multiplicity of societal beliefs (Kock, 1993) so it aspires to reduce the risk of conflict reported in Section 1.4.3 (e.g. Carr, 2007). Consequently, epistemological anarchism (EA; Feyerabend, 2010) was adopted as an embrace of theoretical pluralism may avoid subjugation of co-researcher knowledge (Midgley, 2000). Thus, it does not matter if co-researchers are realists or relativists, objectivists or subjectivists as to paraphrase Marx (1845/2002, pp. 13-15), philosophers only interpret the world in various ways, the point is to change it.

The approach of the ontological anarchist for Moore (2012) was to be certain of nothing except the nothing over which they hover and from which they sprung. He asserted an anarchist affirmation of nothingness was a refusal to be categorised, a revolt against everything, totality and social relations typified by control. Yet from nothingness, he said, came existential freedom and a source of immense creativity that could be channelled according to values, will or desire. To surmise, EA is pluralist; it is an acceptance of competing knowledge and the accommodation of divergent interests. In doing so, EA is critical and poses a challenge to power, which in turn is an indication of the orientation towards action.

2.2. Axiology

In addition to ontology, epistemology and methodology, Heron and Reason (1997) argued values were a fundamental, yet often forgotten feature of a research design. Values affect how research projects are selected (Hill, 1984), approached and their outcomes (Hogue, 2015). For Hill (1984), responsible researchers must embody the highest axiological principles, yet he highlighted not all projects met this standard, which has HR implications. Hill (1984) stressed values are entwined with decisions we make towards realisation of the future, so HR values adopted for this research is an act of prefiguration[27]. Yet, Feyerabend (1987, pp. 11-12) warned us to be wary of ‘values’ as universalistic constructs can impede rational thought from undue deference to experts or the beliefs and actions elicited. I chose HR in this specific context as a shared moral language with structural power beyond the state and red lines co-created by humanity for governments not to cross. I recognise perspectives on HR can differ by culture (i.e. the Asian Values Debate, outlined by Jenco, 2013), judicially or between each other, which is how EA (Section 2.1.1) comes in and why transparency of the ideology that influences their use here follows in Section 2.3.

2.3. Ideology

Political ideology was defined by Beresford (2021) as an ethical set of ideals, principles, doctrines, myths or symbols of a social movement, institution, class or

---

[27] Prefiguration is defined in Appendix C..

large group that explain how society should work. He outlined how ideologies permeate each aspect of life, thought, ideas and behaviour yet are rarely constructed in a participatory way. This section will suggest anarchist ideology embedded in the methodology of this project can counterpoise this.

2.3.1. Anarchism

"A New Declaration of Independence… We hold these truths to be self-evident: that all human beings, irrespective of race, colour, or sex, are born with the equal right to share at the table of life; that to secure this right, there must be established… economic, social and political freedom" (Goldman, 1909, p. 1).

The above quote from Emma Goldman[28] was chosen as it conflicts with how anarchism is commonly employed as a synonym for chaos, with an anarchist portrayed as a nihilist and devoid of principles (Woodcock, 1977, p. 11). However, from this quote, we can see truths considered radical for their time, later established in HR discourse. Misrepresentation occurred to protect the established social order as anarchism sought to replace forms of hierarchy and domination with other means of organisation practised today (Heckert, 2013). This of course, included the anarchist's infamous foe the state, but we can notice an anarchist insight within HR. Central to the UNDHR (Section 1.4.1) is the principle rights are inalienable, or ours, by virtue of being human so by definition, are noncontingent on state approval. Bray (2019) reported turn of the century anarchists drew upon rights discourse as a logical outcome of the scientific investigation of nature that applied equally across humanity. Yet HR are critiqued by modern anarchists on efficacy grounds e.g. whether rights enforced by government ever run contrary to their own interests (Black, 2019).

Although anarchists remain disparaged through media representations of an individualistic notion of freedom incompatible with equality (Heckert, 2013), anarchists recognise freedom is only achieved through cooperation (Woodcock, 1977, p. 12). In this regard, Kropotkin (1902/2019) first deconstructed the Darwinian notion of "survival of the fittest" and emphasised cooperation (or mutual-aid)

---

[28] Emma Goldman (1869-1940) was considered essential to the rise of political anarchism in the early twentieth century and opened it up to diversified interpretations and practices (Hsu, 2021).

contributed to success over force in the struggle of existence. Kropotkin's theory became known as "survival of the friendliest", and studies of prosocial behaviour in the animal kingdom (Brucks & Von Bayern, 2020; Brauer, Stenglein & Amici, 2020) are still confirmatory of his view of mutual-aid as a factor for successful evolution. "Survival of the friendliest" was co-opted as a book title by Hare and Woods (2020), who presented research that supported the evolutionary advantage of prosocial traits over aggression. They outlined humans went through a self-domestication process that contributed to further changes adaptive for prosocial behaviour. As part of their theory, they proposed dehumanisation was a universal tendency but predicted it to was more likely to occur in extremist ideologies, of which they situated anarchism. This is erroneous as the opening quote reflects an anarchist push for equality when the middle was a barrier to its attainment. Freedom and equality are complementary because as Water (1969, p. 163) stated "freedom without equality means the poor and weak are less free than the rich and strong, and equality without freedom means we are all slaves together". Like the HRBA, anarchists aspire to strengthen social bonds by reinforcing community relationships at the grassroots (Woodcock, 1977).

Anarchism was delineated by Franks et al., (2018) into three areas; core (C), adjacent (A), and peripheral (P) concepts. Core concepts set anarchism apart from other ideologies, adjacent concepts provide nuance and anchoring, whilst peripheral concepts are on the margin of anarchism but enable it to apply ideas to reality. A detailed discussion of this is beyond the scope of this paper, however, concepts with relevance to the research will be touched upon as we progress through this chapter. These definitions of anarchist concepts can be found detailed in Appendix C.

2.3.2. Application

Three elements of anarchism (Woodcock, 1977, p. 16) are enacted by this project: a criticism of society as it is, a vision of a desirable alternative and a plan to fulfil this. Martín-Baró (1994) stated psychology needed to serve social justice, and research is recognised praxis (Lather, 1986), so a form of direct action (Ordonez, 2018). Anarchism has shown other ways of being are possible, and beneficial to ecological, social and psychological wellbeing (Heckert, 2013). Thus Jourard (1968 p. 42)'s call for clinical psychologists[29] to be "responsible anarchists" and "loyal opposition committed to a search for endless ways to foster growth, wellbeing, idiosyncrasy, freedom and authenticity" fits this context. Moreover, anarchists have been at the fore of HR activism throughout history (Bray, 2019) and have always sought various approaches to challenge power structures (Bowen & Purkis, 2012). Accordingly, methodology becomes apt for prefiguration (Franks, 2018) due to a shared tradition between science and anarchism of exploring and testing ideas (Heckert, 2013).

2.4. Method

Epistemological anarchism (EA) has favoured methodological pluralism (MP) (Feyerabend, 2010), the principle of picking the aptest method to explore a problem, even if it differs from a researcher's personal preference (Payne, 2006). This echoes Maslow's (1958b, p. 2) view that psychology should be "less absorbed with means and methods" to be more problem-centred. Albeit MP as a "reasonable compromise that may solve a problem but satisfy no one at the same time" (Chevalier & Buckles (2019, p. 54) might be closer to the truth. Niaz (2020:p. x-preface) termed EA "how science really works" as a scientist can employ numerous methodologies with an appreciation the majority of attempts to generate scientific knowledge may not succeed (Quale, 2007). MP and creativity are interrelated and a sign of community psychology praxis[30] (Kagan & Burton, 2001). With MP, methodological strategies are not necessarily decided a-priori (Niaz, 2020), so it is cognate with anarchist ideas of agency, horizontalism and DIY described in Appendix C as a framework for action.

2.4.1. Participation Action Research (PAR)

MP is characteristic of PAR (Chevalier & Buckles, 2019); a process Barroso (2002) credited to Paulo Freire of coming together to articulate concerns and take collective action to negotiate new relationships with those who hold power over them, "including the state" (p. 4). PAR aims to address power imbalances and oppressive

---

[29] Jourard (1968, p. 42) wrote "psychotherapists" of which clinical psychologists share a role, and in Jourard (1971, p. 14) he defined his audience broadly as "psychiatrist, clinical psychologist, social worker, pastoral counsellor, or (any) who seek to help people", to ask "help them do or be what".

[30] The co-dependent activity of action/reflection or theory/practice is described by Freire (1970).

structures through knowledge generation, action and consciousness-raising (Vikstrom, et al., 2015). Although a collaborative process PAR is not a power-free form of research (Kesby et al., 2007), its values are influenced by social movements that sought to challenge dominant power structures (Cahill, 2007; Cahill et al., 2010). PAR encourages a critical stance on knowledge production to resituate power away from the hierarchies typical to research (Rowan, 2001). However, Kesby et al., (2007, p.21) highlighted a risk of power abuses from PAR governance:

- Domination: If facilitators use ‘ground rules’ to impose conduct on co-researchers or impose a particular form of representation on local knowledge.
- Coercion: participation only from fear of poverty or a promise of resources.
- Manipulation: If co-researchers are used to circumvent communities or if distrust of academics or self-critique is urged under cover of innocuous topics.
- Authority: If co-researchers concede expert status and control to a facilitator.

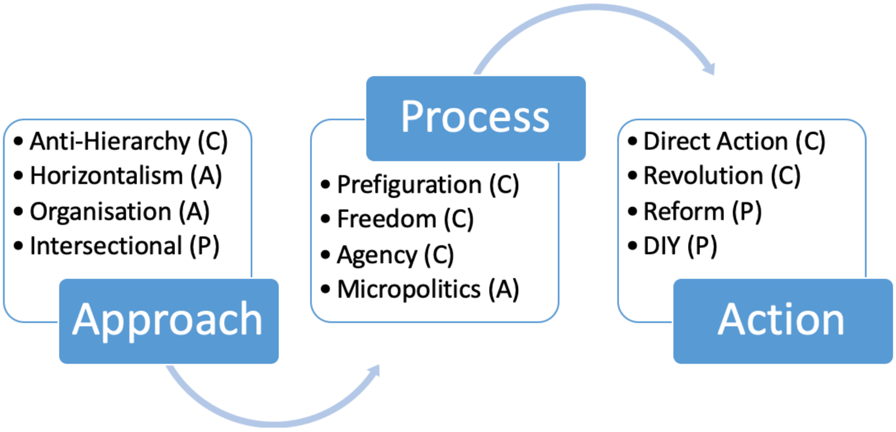


Figure 9: PAR as anarchist praxis

Figure 9 shows how an anarchist insight in PAR might mitigate governance risks. An intention to elevate the voices of PGLAD over the institutionalised authority of academia is an anti-hierarchical stance complemented by horizontalism as a means to alleviate domination through collective democracy. Organisation, as per the procedure in Section 2.5, describes steps taken to defend against coercion and manipulation whilst encouraging intersectional participation, such as through the use of the Processual Consent Model (Hughes & Castro Romero, 2015). Further, evaluation in 2.4.1.4 aims to provide a final safeguard against risks of authority in governance. PAR process is an act of prefiguration as it enacts research in a way we might wish research to be, with MP facilitating freedom and respect of PGLAD’s agency enabling unbounded actions, which is a form of micro-politics. Whilst choice in the action facet reflects EA in manifesting Feryerabend's (1987, p.27-28) assertion that research should not be a privilege of special groups as knowledge must be a "local commodity designed to satisfy local needs and solve local problems".

2.4.1.1. *Participation*

A PAR study by O'Connor et al. (2018) saw stigma as critical to the lived experience of dementia but linked to the diagnostic label, not changes in their skills. Yet ability is presented as why PGLAD are excluded from research as cognitive and communication differences necessitate adaptation of methods which, alongside finding expertise to support inclusion, posed a barrier (Smith & Phillipson, 2021).

Exclusion has reinforced stigma and negative stereotyping (Mann & Hung, 2019) hence why PAR with PGLAD is currently a meta-action. Suppose stigma is the barrier to taking part (Mann & Hung, 2019), shrouded under the cloak of ability. In that case, methodological pluralism of PAR (Chevalier & Buckles, 2013) should encourage creativity to adapt, where traditional research paradigms have struggled. Despite this, PGLAD, particularly those viewed as having later stages of dementia, were primarily excluded from PAR (Smith & Phillipson, 2021) hence the necessity to consider how to ensure the process is inclusive in the following sections.

2.4.1.2. *Process*

Littlechild et al., (2015) warned of the danger that moral argument for participation could obscure the practical implications and realities of involvement. Some truths might include the discomfort felt using frameworks that challenge power when the powerful resist (Kara, 2015). Others are procedural and arise from an observation 'research' as a term used by PAR does not refer to any standardised method, procedure, type of data collection or analytic approach (Smith et al., 2017, p.413). Indeed, there is no consensus on PAR approaches in psychology (Pain et al., 2012; Levac et al., 2019), so the integrity and authenticity of the process is questioned by those aligned to traditional and positivist research paradigms (Littlechild et al., 2015). This challenge emerges from PAR as an iterative process of reflection, planning, action and observing (Smith et al., 2015). This 'action-reflection' is conceptualised as a process of 'observe - reflect – act – evaluate - modify - move in new directions'

(Figure 10) by McNiff and Whitehead (2006, p.9). However, as noted by Pain et al., (2012), evaluation can be saved until actions are complete.

Kidd and Kral (2005, p. 187) found this reflexive approach necessitated vagueness and ambiguity in method, as each PAR project was in effect a “custom job”. They saw PAR as more than a method but the creation of a context in which knowledge production and change might occur. For Smith et al., (2017, p. 413), possibilities were entwined with the co-researcher’s agency and action, so they were “essentially limitless”. Smith and Phillipson (2002) considered data collection through creative means to be emancipatory, as it freed them from old ways of thinking and provided new ways to engage with and meaningfully include PGLAD.

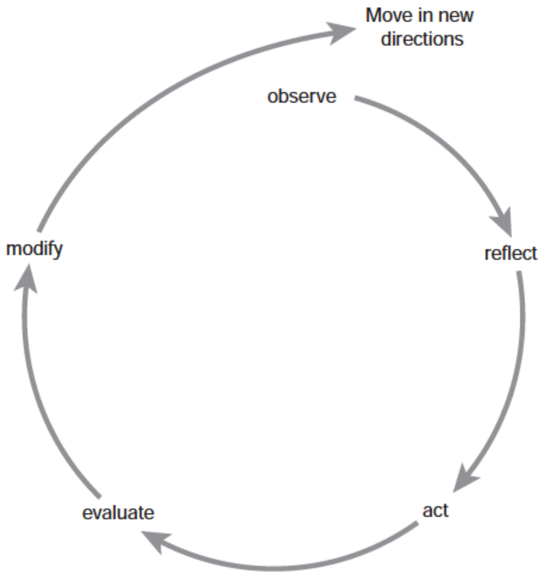


Figure 10: PAR Cycle (McNiff & Whitehead, 2006, p.9)

2.4.1.3. *Action*

Kidd and Kral (2005, p. 189) defined action as “any concerted effort to remove some impediment that hampers the growth of a group of people, be it structural or ideological”. They saw action as intrinsically linked to knowledge production and, in terms of scope or focus, “essentially limitless” but stressed the importance of being open to change as the incorporation of co-researcher’s knowledge is negotiated. Typically, action, according to Trentham and Neysmith (2018), included raising public awareness on issues, to lobby for social change that is emancipatory and relevant to marginalised people or group. For example, within their PAR, co-researchers who were elders claimed their citizenship through political actions, like letter-writing campaigns, political dispositions and producing information on discrimination. This consciousness-raising over power relations and social injustice is the crux of action at a structural level (O'Sullivan et al., 2014) and congruent with a HRBA to stigma reduction detailed in Section 1.4.3.

2.4.1.4. *Evaluation*

Evaluation in PAR differs from traditional research by the emphasis on participation as a means to contribute to science and social change (Froggatt & Hockley, 2011). This contrasts with dementia research, where academics have often established the research outcomes and how to measure them based on their values and research agenda rather than the PGLAD (Di Lorito, et al., 2017). Whilst Di Lorito et al., (2017) acknowledge peer research by PGLAD is novel with limited literature available, they recommended counterbalancing this by considering if involvement is meaningful with PGLAD, rather than tokenistic. However, Kidd and Kral (2005) remind us evaluation must be used with caution, as it can obscure efforts (conscious or not) to devalue local modes of knowledge, action and evaluation, as well as restore established roles within power hierarchies, such as academia. Thus, this project is evaluated in three ways:

a. Co-created by co-researchers

The success of PAR is considered by Kidd and Kral (2005) to be best measured by the changes in the participant's lives and the larger group represented by the people in the project. They emphasised local methods for consensus of what is of value must be considered valid, and so evaluation considerations devised by co-researchers are in Section 2.5.5.

b. Authenticity of participation

Froggatt and Hockley (2011) highlighted the need for rigour, and methods used for evaluation in PAR does not differ to other research, but the distinction occurs as to the point of evaluation. They report the nature of action-reflection cycles means more attention is paid to formative processes throughout PAR rather than just the summative evaluation employed in other research designs. Consequently, they recommended using specific frameworks like the Aldrevast Sjuharad (AVS) model to enhance the rigour of PAR.

AVS (Magnusson et al., 2001) was designed to assess the authenticity of participation in constructivist and action research, and is based upon the authenticity criteria by (Guba & Lincoln, 1989). As we can see in Figure 11, Nolan et al., (2003) revised concepts using the letters E.A. for each label as they were considered unnecessarily complex and contrary to the framework ethos. We can also observe Ontological Authenticity and Educative Authenticity reflect Freire's (1970) conscientization (critical consciousness). This will be supported by guidance for using the AVS model with elders from Brown, Wilson and Clissett (2011).

Concept	**Definition**	**Renamed**
Fairness	Are the voices of all the major interest groups heard? (That is, are all their opinions listened to and valued?)	Equal Access
Ontological Authenticity	Does the study provide participants with new insights into their own situation?	Enhanced Awareness of the position or views of self/own group
Educative Authenticity	Does the study help participants to better understand the position of other interest groups?	Enhanced Awareness of the position or views of others
Catalytic Authenticity	Does the study stimulate or identity areas for change?	Encouraging Action by providing a rationale or impetus for change
Tactical Authenticity	Does the study facilitate, enable or empower change?	Enabling Action by providing the means to achieve or at least begin to achieve change.

Figure 11: Authenticity Criteria (Nolan et al., 2003).

c. Application of Human Rights

Evaluation through PANEL (Figure 4), which are principles considered to be good practice to use when evaluating a human rights-based project (Donald, 2012) and endorsed by Alzheimer Europe for research involving PGLAD (Gove, et al., 2018).

2.5. Procedure

2.5.1. Consultation Stage

In discussion with my supervisor, a tentative approach with organisers of community groups for PGLAD was made about the idea of PAR and expressions of general interest received. Upon receiving ethical approval (Appendix D), an expression of interest was followed up, and a meeting with the charity CEO accepted. Infographics were prepared as an adaptation to provide visual information about PAR (Appendix E and F). This meeting went positively, and the CEO disseminated the information to the community group organiser, who in turn shared with the PGLAD.

2.5.2. Recruitment

Co-researchers were from a self-organised community group for PABDL in a borough of a large city. Locality was important to complement the axiology of this project, so the author could be a resource for a community they shared. Close proximity was intended as an anti-hierarchical action to reduce the traditional distance between researcher and participants. Furthermore, as someone with lived experience of a family member affected by dementia labels within the borough, the project was inspired by this person and our experiences with them. A move away from social relations based on power over as a ‘researcher’ to power with, together, in common or amongst (Amster, 2018) is enacting prefiguration and micropolitics.

2.5.3. Inclusion Criteria

The only criteria for co-researchers were that they attended the community group. As previously stated PABDL was intentionally a broad term to include people directly affected, their family, loved ones or those who identify as carers. This openness was to avoid the risk raised by Hughes and Castro Romero (2015) of cherry-picking only people able to communicate in forums designed by professionals.

2.5.4. Co-researchers

As per The Processural Consent Model (Hughes & Castro Romero, 2015) each person was entrusted with the agency to determine their involvement with this research at different times and at various stages of the project. At the initial stages there was a large group of 21 people, then a smaller group of five and, finally three who continued by telephone due to the pandemic restrictions (see Figure 11). The co-researchers lived within the locality, and the large community group appeared reflective of the diversity within the borough. Of those who gave written consent four were White British, one White Greek, and one Asian/Other. Ages ranged from 60 to 85 years old, and they were mixed in terms of gender, and physical and cognitive abilities. Phases transitioned from a large group discussion (LGD), to large group workshop (LGW) to small group discussion (SG), and finally, one-to-one telephone discussion (TD). Figure 11 details the phases of participation for the co-researchers in this project who are identified in the table by initial and number code in the extract reporting. There was a gap in contacts due to the pandemic. M suffered a deterioration in health and could no longer continue in the action stage. D took a break due to the loss of his wife B, during the research. N was not always contactable by telephone, R and DM did not provide contact details.

Meeting Type	LGD	LGW	SG	SG	LG	T	T	T	T	T	T
PAR Phases	Preparatory	Observe			Reflect			Act	Act	Act	Act
PNI Phases	Collection				Sensemaking			Return			
	Jan	Jan	Feb	Feb	Feb	June	July	Aug	Aug	Sept	Sept
M - (5)	✓	✓	✓	-	-	✓	✓	✓	-	-	-
D - (1)	✓	✓	✓	-	-	✓	✓	-	✓	✓	✓
B - (2)	✓	✓	✓	-	-	-	-	-	-	-	-
N - (3)	✓	✓	✓	✓	-	✓	-	-	✓	-	-
R - (4)	✓	✓	✓	-	-	-	-	-	-	-	-
DM - (6)	✓	✓	-	-	-	-	-	-	-	-	-

Figure 11: Table of participation

2.5.5. Phases of Research

Phase 1 - Preparatory

An invitation was received for a preliminary meeting with the community group to share information about the research process and answer any questions. Research infographics provided visual information about PAR (Appendix E & F). Stories were shared around issues related to health and wellbeing and how we might capture this information, so awareness of these needs could become known. Information was presented about methods from creative approaches, such as art or music, to more traditional forms of data capture, like surveys or talking groups. The following week the group discussed the research on their own, which led to an invitation to return with a view to engage in creative research methodologies.

Phase 2 – Observe and Reflect

With acknowledgement of the differences of ability within the group, The Tree of Life (Ncube, 2006) was chosen as an option to bridge both forms of data capture and share stories about living well, be that challenges or sources of strength. This was facilitated with the group facilitator, group assistant and the author using Goggans (2013) Tree of Life activity, following which six co-researchers signed consent forms that they wished to continue with the research. Whilst knowledge was produced by this activity, co-researchers felt they would prefer to continue by group discussion. This was because some co-researchers had motor skill differences that affected their ability to engage with some of the creative approaches. I facilitated this through Narrative Sensemaking[31] (Kurtz, 2014) which involved four elements:

- Contact: discussion and story exchange, enabling co-researchers to read, hear or experience each other's observations.
- Churning: repeated and varied contact with the stories, putting together and taking apart the observation multiple times. A context where speaking, listening and negotiating reasons for what they are doing can shift.
- Convergence: where co-researchers negotiate compromises and linkages between their stories, which leads to ideas for
- Change: the actions arising from the project.

As this project proceeded, the declaration of a global pandemic led to contact between people being seen as dangerous and something to fear; people who attended the community group, as well as co-researchers, were at risk on grounds of their age and physical health. There was a pause of the project during what was an understandable period of upheaval until contact recommenced by telephone with three co-researchers. Not all co-researchers were contactable outside of the physical environment of the community setting. Sadly, one co-researcher passed away, and their husband, also a co-researcher, understandably, took time out but wished to continue after a break. The processes were supplemented with notes taken during telephone calls, then sent out to co-researchers in the post or read verbally to enable further reflections in accommodation of memory differences.

---

[31] Narrative Sensemaking is technique within Participatory Narrative Inquiry (Kurtz, 2014) which is discussed in the results overview in Section 3.1.

Phase 4 - Act

During this phase, convergence shifted to ideas for change, which were restricted due to the pandemic. An open letter was created and sent to those in positions of power with regard to the issues identified. This included representatives of health, social care, tiers of government and charities, the media and the UN. To aid evaluation of the project questions for recipients were devised by the co-researchers:

a) What are your thoughts on our letter?
b) How did it make you feel?
c) What could you now do differently?
d) Are there changes that could be made to your policy or practice?
e) Who could you sit down with or approach about these issues?

Responses were collated, with no response also considered a response, and detailed in the results section. During this stage co-researcher M suffered a serious deterioration in health, and my thoughts are with them.

2.6. Ethical Considerations

2.6.1. Informed Consent

Mann and Hung (2019) emphasise the label of dementia does not mean a person automatically lacks the capacity to make decisions to participate in research and contribute their knowledge. Instead, capacity relates to the ability to make or communicate decisions and is fluid and dependent upon the situation (Mental Capacity Act, 2005 [MCA]). An important principle of MCA law is that we must assume hold capacity, unless proven otherwise. To accommodate differences associated with dementia labels that could lead to a flux in capacity, this project used a processural approach to consent (Hughes & Castro Romero, 2015). Consequently, whilst written informed consent was obtained from co-researchers (Appendix G) more reflexive assessment of consent was undertaken using verbal and behavioural cues to ascertain their choice to continue participation (Appendix H). Adjustments made to enhance capacity included pace, use of visual aids, and thought to different ways of supporting people as the project iterated (Department of Health, 2015).

2.6.2. Confidentiality and anonymity

In PAR co-researchers sometimes wish to be named and contribute to their accounts within the cycle of research (McNiff & Whitehead, 2006). The intention was for this to be revisited at the end of the project, but unfortunately due to deterioration in health of some co-researchers and loss of contact with others due to the pandemic, this conversation was not possible. In discussion with remaining co-researchers, the decision was made to be identified as an initial as per McNiff and Whitehead (2006) guidance. Identifiable information such as group name and location are anonymised. Consent forms, recordings and transcripts, are kept in a locked environment, and physical data will be safely destroyed after three years.

2.6.3. Right to Withdraw

Co-researchers were advised of their right to withdraw from the research at any time without the need to provide a reason. This was reiterated on information sheets and consent forms and formed part of Processural Consent Model (Hughes & Castro Romero, 2015). If a co-researcher withdrew from the study, they were aware there would be no prejudice and that there was an option for their contribution to be destroyed on request. However, they understood this would not be possible after a three-week window from the end of the study due to analysis.

2.6.4. Risk

There was potential for co-researchers to become distressed during the project given the impact dementia labels can have upon people. A reflexive approach to this was taken in the moment as per the Processural Model (Hughes & Castro Romero, 2015) drawing upon my clinical skills. Details of organisations relevant for PGLAD were provided as part of the debrief. This research was affected by the pandemic, but PAR enabled adaptation to methods in line with BPS (2020a, 2020b) and COVID-19 guidance (UK Health Security Agency, 2020) and advice from my supervisor.

3. RESULTS

3.1. Overview

In Section 2, it was described how PAR provides a context for knowledge generation to happen and so mixed-methods may be adopted in response to dynamic changes. As such, the results are presented using one method drawn upon in response to local changes, which is a framework for working with people's stories[32] by Kurtz (2014) called Participatory Narrative Inquiry (PNI). As a meta-result that occurred through iteration of PAR, a brief introduction is provided here, whereas if planned, it would be documented previously.

PNI as a method combines Narrative Inquiry or "the raw stories of personal experience" (Kurtz, 2014, p.86) with PAR to invite co-researchers to work with their own stories. PNI is not a "dogmatic set of fixed prescriptions", but a "changing, idiosyncratic, connected, diverse, complex, of its-time-and-lace, living body of work" Kurtz (2014, p.91). Figure 12 represents three elements of this:

a. *Collection:* Community members tell stories around a topic of concern, and these stories are collected in some way (that can vary widely).
b. *Sensemaking:* Some or all community members make use of gathered stories to better some situations or issues better.
c. *Return:* What has been gathered and produced in the first two phases is returned to the community and enters into collective discourse.

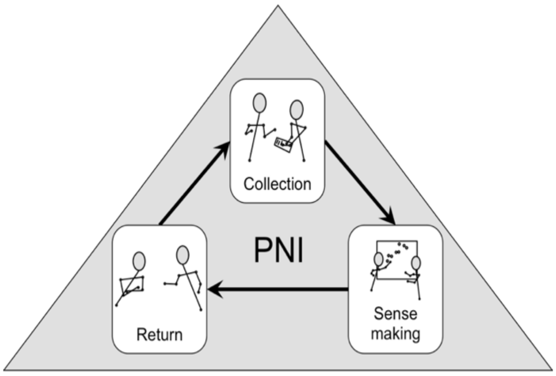


Figure 12: Elements of PNI (Kurtz, 2014).

---

[32] A story was defined by Kurtz (2014) to consist of three facets:

a. *Form:* The communicative structure and meaning, such as the setting, characters, plot, value, conflict, themes, audience or purpose.
b. *Function:* It's value to thought, decision and action. Function is related to connections between peoples plans, goals and actions, as well as cause and effect.
c. *Phenomenon:* How a story survives and spreads through conversation and memory of people. This deals with context.

As accommodations were made to the manner of data collection, PNI enabled the essence of initial stories to be held through each iteration and made sense of by the co-researchers, then returned to the community as a form of collective action.

Within PNI, a project facilitator does not interpret or change stories as only the community can decide what the stories mean. The facilitator’s role is to help the stories get to where they need to go in order to help achieve the communities’ goal. Within this in mind, secondary analysis is not undertaken here as the analysis or sensemaking was carried out by the co-researchers during the PAR process

Presentation of the results necessitates a distinction to be made between each part of PNI, but it should be noted the boundaries were porous and interconnected. Therefore, the results section intends to enable the reader to be a ‘fly on the wall’ through the process and convey what happened at the particular phase. In addition, mindful of risks to PAR Governance (Section 2.4.1) reflections will be shared in the discussion to ensure that they do not detract from co-researcher voices.

3.2. Collection

The collection encompassed a range of formats. Large group discussion (LGD) transitioned to a large group workshop (LGW), which led to a small group discussion (SG) and a one-to-one telephone discussion (TD) which are surmised here.

3.2.1. LGD

LGD felt two types of research were important; first, the cure for dementia, and the second “living well with dementia”. Some thought national charities were completely focused on the cure but forgot the needs of PGLAD living with the experience now. A discussion on living well with dementia led to stories shared of how vital the dementia café was to their wellbeing. They stated the cafe was run by a national charity that suddenly withdrew from the provision. Conversations were had about if this charity or the council knew how important the cafe was to them. Stories were shared on how they might feel lost if the cafe closed, with one co-researcher describing it as the “highlight of their week”. They valued the café’s social context and other social groups due to the attendees shared experiences.

Stories unfolded to dementia-friendly communities with ideas shared about practices in place around the UK they would like locally. This included dementia friendly supermarkets and special tables in public cafes where PGLAD could feel safe to go and have a conversation with others if they felt lonely. They contemplated if action from the research might include advocation to power-brokers as to their wishes for dementia-friendly communities locally.

3.2.2. LGW

The Tree of Life workshop provided a context for co-researchers to connect and exchange stories, with the initial focus being storms: the challenges or difficulties they experienced in everyday life. The impact of memory difficulties on recreation was discussed with a sense of loss at no longer being able to follow plots in novels, compensated for by the discovery of shorter art forms like poetry. This led to stories shared around the challenges of timely assessment, diagnosis and appropriate treatment. Articles from the workshop are in Appendix I.

3.2.3. SG

SG facilitated sharing stories with more personal context as co-researchers negotiated issues arising. Selected extracts that represent the flow of discussion placed in Appendix J are surmised and highlight the churning and convergence.

As contact commenced, we can see from Extract 1 that conversations reflective of the LGW continued concerning the relationship co-researchers had to services. Frustrations around assessment were shared and the process involved was perceived to lack timeliness and experienced as a “fight”, which did not leave researchers with the certainty they hoped for. Extract 2 followed this as a co-researcher reported that despite multiple diagnostic labels (Parkinson’s, Alzheimer’s and short-term memory loss) medical treatment was insufficient and their expectations for help not forthcoming. Post-diagnostic support was also experienced as a “fight” as co-researchers reported they were left to “do it all” when they would have preferred a direct approach and “knock” on the door.

Issues around the diagnosis and post-diagnostic support resonated with a co-researcher in Extract 3 who was also upset about the length of time to diagnosis and felt disappointment at unmet hopes for help. An assertion society “doesn’t want to know” was somewhat alleviated by family support. This led to stories of coping on their own instead of services in Extract 4, but this left doubts for co-researchers if they were doing the right thing to maintain independence. A co-researcher expressed fear if something should happen to them as they live on their own. Convergence occurred around being alone and feeling “thrown in the dustbin and forgotten”. Discussions shifted to consideration of where help might reside with a co-researcher asserting it was the GP. In Extract 5, we see stories of informal caregiving arrangements with adult children and a question was raised as to the role of a national charity in providing help.

In Extract 6, stories were shared of the effect of involuntary migration on the support network of co-researchers when displaced from families in their new country. Neighbours were identified as a positive source of support, but situationally specific.

Further churning can be seen In Extract 7 as co-researchers revisited concerns around timeliness of diagnosis and medical treatment, with an analogy of retirement and being “put on a scrapheap”. Parity with physical health was raised by co-researchers in Extract 8, highlighting societal stigma around dementia labels. Convergence around negative perceptions of others continue in Extract 9. Co-researchers connected with indignation about jokes made about Alzheimer’s that left them feeling insulted and shamed. They saw this as another sign society did not take their conditions seriously.

Conflicting relationships with healthcare providers are discussed in Extract 10 with the GP loved and respected for the time given to explain things, contrasted with the healthcare provider who offered abrupt diagnosis but no additional support. Dementia’s impact upon mental health is considered in Extract 11, with co-researchers sharing strategies they used to cope. Dementia was reported as “bloody depressing” by a co-researcher who felt they had no choice but to get on with it, which led to reflections on what did help. The dementia café was again highlighted as a valuable resource for people on their own, or with no family to make social links. Ideas for change arose as co-researchers asserted it should be open for longer and on more days. Devices like TV and ipad were considered beneficial but this was mediated by interest or technological competence.

3.2.4. TD (Sensemaking)

TD as a phase consisted of sensemaking. Co-researchers reported life to have changed considerably due to the pandemic. Co-researcher M reported a move to a care home felt like being placed in a cocoon as they were less aware of what was happening in the outside world. As a sense emerged of where responsibility was held for issues they raised, modes of action were limited by the pandemic. For example, co-researcher D stated he “would like to see every man, woman and child demonstrate in front of 10 Downing Street and demand action”, but this was not possible due to government restrictions. A letter was agreed as the most appropriate type of action given the circumstances, as co-researcher M shared they had written articles for magazines in the past. A collective letter (Appendix K) was co-created that made sense of the issues of concern, identified changes they would like to see, and disseminated where power was perceived to reside.

3.3. Return

Dissemination targets for the letter were identified in Lower Tier Local Government, Upper Tier Local Government, National Government. The NHS, Charities (local and national), international bodies, and the media.

3.3.1. Dissemination

In this section, the target’s for dissemination will be described, followed by their response, or lack thereof, if that is the case. An overview is in Figure 13.

Dissemination	**Response**
Lower Tier Local Government	
Councillor with portfolio on Adult Wellbeing	X
Councillor with portfolio on Equalities	X
Elected Leader	X
Chief Executive (Paid Official)	✓
Upper Tier Local Government	
Local Elected Member	X
Chair of Healthcare Committee, cc Deputy & two committee members	✓
Leader	✓
National Government	
Local MP 1	X
Local MP 2	X
Minister for Care	X

Prime Minister	X
All Party Parliamentary Group on Dementia	X
NHS	
Local Dementia Service	✓ then X
Local Region NHS Trust Governors	X
Local Clinical Commissioning Group	X
Department of Health Funded Local Healthwatch Group	X
Charities	
Local Charity 1 (Research Host)	✓
Local Charity 2 (Dementia and other activities)	✓
Local Charity 3 (Carers Dementia Project)	✓
National	
Alzheimer's Society	✓
Dementia UK	X
Alzheimer's Research UK	✓
DEEP: The UK Network of Dementia Voices.	✓
International	
Dementia Alliance International	X
UN Special Rapporteur on the rights of persons with disabilities	X
Media	
Local newspaper	X

Figure 13: Dissemination Responses

3.3.2. Lower Tier Local Government (LTLG)

LTLG provide the majority of day-to-day services within a particular geographic area (Gov.uk, n.d.-a). Dissemination included elected political representatives with remit relevant to the letter, their political leader and Chief Executive whose professional responsibilities include public engagement.

Although no response from elected representatives, the Operational Director of Social Care (ODSC) responded due to contact with the Chief Executive (Appendix L). They expressed thanks for bringing to their attention the experience of local residents as "information that indicates that our services, that of our partners or the availability and access to support in the community could be improved, is a driver for us to do more".

The response from the ODSC, albeit not directly engaging with questions asked by the co-researchers, indicated receptivity to the issues raised within the letter.

They claimed a “commitment to and record of working in co-production”, citing unspecified design projects, partnership boards that brought “challenge and input from those in receipt of services”, and a PGLAD group who “provide direction and steer to the development of dementia services” within the area. Consequently, ODSC reported their dementia strategy and plan was not led by LTLG but was “owned and directed” by the aforementioned PGLAD group, with support of the voluntary sector, LTLG, CCG and “wider health service landscape”. This included GPs, local business and other facets of LTLG that included Children and Young People’s departments, Regeneration and Environment and Public Health.

On resource allocation, ODSC stated that whilst their “information, advice and guidance are available to all”, “only a very small percentage” of PGLAD needed LTLG assessment and an “even smaller proportion” received LTLG support. They called this their “strength-based service”, where a focus on getting PGLAD to identify what they could do for themselves, or with aid of social networks or wider community enabled LTLG to distribute their “limited resources” to those “who truly need it most”. They stated this kept “others independent and well outside of a statutory service”.

They outlined LTLG as a partner to achieve ‘‘Dementia Friendly Status’ in the area and highlighted they have a ‘Living Well with Dementia Strategy 2018-2023’. ODSC claimed the strategy had an agreed action plan which targeted many issues raised in the letter. An example given by ODSC was a specific focus on improving access to diagnosis, so services could be clarified for PGLAD and they did not feel forgotten. This included a commitment by their partners to be “dementia aware” and help “direct and signpost (PGLAD) and their carers to the right service”, have features on dementia in local media and train senior LTFG staff as “dementia friends”. With acknowledgement there is “always more” they can do, they committed to reviewing the information adult social care held on their website around dementia, linking to a voluntary organisation website as their agreed point for collating public information.

Acceptance for the critique of delays to adaptations was less explicit as they claimed a simplified referral route had led to a smaller period to assessment, as well as removal of means testing which they claimed helped more people. However, this was caveated by a statement that applications were “routinely screened” to determine urgency of applications and allocate work in accordance with priority.

ODSC responded to the point “cafes or clubs should be funded to be open for more days and longer” with positive recognition these were valued local resources. However. they claimed being independently run by the voluntary sector meant the cafes were “more sustainable and not dependent on local funding”, so could “be more responsive to local needs, and alter their times or activities based on demand”. ODSC recognised LTLG’s role in communicating support or services available to PGLAD and stated they would adopt the idea of using the LTFG magazine for this.

3.3.3. Upper Tier Local Government (UTLG)

UTLG includes an oversight committee focused on health and wellbeing issues. Dissemination included the elected leader, local political representative, the chair and deputy of the health committee and two committee members. Responses were received (Appendix N) from the chair of the health committee (CHC) and a previously unknown dementia lead (DL) as a result of dissemination to UTLG leader.

The leader was reported by DL as unable to respond due to a high volume of correspondence but was said to be a ‘Dementia Friend’ and committed to action at UTLG as they had a ‘Dementia Friendly’ region campaign in partnership with the Alzheimer’s Society. They reported the letter was “very power and thought-provoking” and “being written from the perspective of (PGLAD) added further weight”. They said it made them feel “sad to know (PGLAD) feel like this” and “frustrated, sad, and angry that attitudes towards dementia are still so negative that so many people – often unthinkingly – reinforce negative stereotypes”. However, they were “determined to build on what we’re doing and do more for everyone affected and to raise awareness across” the region. On what they would do differently, they stated over 50% of UTLG had attended ‘dementia friend’ sessions, which occurred at the transport provider, police and regional fire brigade. Also, an audit led by PGLAD at UTLG that led to environmental changes. DL reported they were working with policy teams across UTLG, including culture, planning and housing to build in dementia-friendly policy, and would disseminate this research.

CHC reported the letter was “an important reminder about the real, lived experiences of (PGLAD)” as “so often we hear about research or statistics, but rarely do we understand just how it affects people, and those around them, until unfortunately a friend or relative is affected”. They felt the letter was “very moving” and “powerful to hear collected voices that can so often be marginalised or spoken on behalf of”. They reported it made them “feel resolved to continue to advocate for those affected however (they) can…”, “…to amplify their voices and make sure they are heard”. They found it “upsetting to hear the delays waiting for assessment and support” and stated it was “something we must address”.

On what CHC might now do differently, they pledged to continue to advocate for PGLAD at UTLG health committee. Further, the letter reminded them to ensure “the voices of people with lived experience of the condition are heard, not just the voices of policy and health professionals” when reviewing this topic, as they did in 2018 when investigating “young-onset dementia”. CHC asserted they must ensure the policies put in place to make the region dementia-friendly are “founded on the experiences and needs of” PGLAD. When considering changes to policies or practice CHC reported they do not make policy but represent people in the region to hold the leader to account. They would do this by “ensuring the voices of (PGLAD) are at the forefront of all future work in this area”. Further, they asserted the health committee “in advance of any future work in this area should approach PGLAD through… patient groups or researchers working directly with these people”.

3.3.4. National Government

Dissemination included the Prime Minister as leader of government and responsible for all policies and decisions (Gov, n.d.-b), The Minister of State for Care and Mental Health, who leads om dementia (alongside other areas), the All-Party Parliamentary Group on Dementia (APPPG) who are cross-party peers and MPs with interest in dementia, and the two local MPs. No responses were received.

3.3.5. NHS

This was sent to the local Dementia Service, NHS Trust Governors, CCG and Healthwatch Group, which is funded by the Department of Health. There were no responses from the governors the CCG or the Healthwatch group.

There was a well-considered response from a senior healthcare professional at the local Dementia Service who answered all questions, which was later retracted, as they had to send “an official response from the service”. The retraction occurred during communications with the Service Manager (SM) who contacted the author and raised some concerns about the letter. They perceived it as a specific criticism of their service, so it was clarified co-researchers recognised there was a broader context hence the distribution list for letter. SM stated “Feedback from PGLAD and their carers is always welcome as a way to acknowledge where we are doing well and to identify how we can improve”. They claimed they would speak to the Clinical and Borough director and clarify that they were “able to respond to the questions”. They later communicated they intended to respond and apologised for the delay but stated the pandemic was taking up a lot of their focus. A later message indicated they would respond, yet no response was received.

3.3.6. Local Charities

CL was disseminated to three local charities; the research host (LC1), a broad charity with a dementia project (LC2), and PGLAD carers group (LC3).

There were two responses from LC1, from the charity lead (CL) and the project lead (PL). CL stated that they looked at the letter with Peer Designers and received “some very strong and positive feedback”. The group queried if this was being publicised, and one member asked if they could share it with housing associations. PL thought the letter was “very moving and straight to the point, and easy to read”, “it bears no punches and tells it how it is”, and made them feel “angry and sad”. On what they might do differently PL stated they would try “to never forget the lived experience and how important being human and people have the right to information *[sic]*”. They felt “maybe more advocacy is needed on behalf of people we work with”, and they could approach funders, commissioners and communities about the issues.

LC2 reported they found the open letter “really interesting”, and the findings would fit “very nicely” with their work on a “manifesto for change” developed with PGLAD.
LC3 requested to use the letter as a focus for their next group for carers of PGLAD. Responses are in Appendix N.

3.3.7. National Charities

Alzheimer’s Society (AS), Dementia UK (DUK) and Alzheimer’s Research UK (ARUK) were contacted alongside the Dementia Engagement and Empowerment Project (DEEP), a network of 80 dementia groups. Responses were received from AS and DEEP, but not DUK or ARUK (Appendix O). AS stated the letter was of “real interest” and offered thanks for sharing it. Without directly responding to the questions, AS shared information regarding the breadth of their research programme which provided answers as to their focus. They reported three research centres each focusing on areas identified by PGLAD, including living well with dementia, post-diagnostic support and living at home independently. They provided a link to their website and summaries of research they fund, and stated 47% of this is into care for living with dementia. They described a research network of volunteers who are PABDL who review funding applications alongside scientific experts and have funded preventative research that has found 12 modifiable risk factors for dementia.

DUK stated they would respond if relevant and gave no other response. DEEP said it was an interesting piece of work and requested to share it on their website.

3.3.8. International

The remit of Dementia Alliance International and the UN Special Rapporteur on the Rights of Persons with Disabilities includes the monitoring of the Human Rights of PGLAD internationally. Neither office responded to the letter.

3.3.9. Media

The local newspaper was contacted, and no response received.

4. Discussion

This chapter will first consider the results by evaluating how it met the research aims. The limitations of this research will then be attended to, followed by the implications for future research finishing with my reflections on the PAR process.

4.1. Revisiting the Research Aims

The questions that provided the scope for this research were:

i. To explore dementia with a person-focus in the context of *how* society is organised and the relationships people may have with it?
ii. Consider issues that may have emerged from dementia and *how* society may impinge upon the attainment of economic, social and wellbeing standards?
iii. Consider *how* to act upon these issues to promote and protect human rights to enhance or maintain psychological wellbeing?

The aim from a HRBA was to invite PGLAD to participate authentically as equal partners in research that led to action on issues that were important to them.
To consider how this project met these aims, the results including co-researcher defined evaluation will be considered from the framework of the research questions, considering what it tells us about the individual, relational and structural levels.

4.1.1. Dementia with a person focus in the context of how society is organised, and the relationships people may have with it.

"We question if a focus on the cure meant living well with dementia is forgotten" (Collective Letter; Appendix J, p.1)

The above quote from the collective letter arose as a discussion point when the research commenced, and if there was an overall theme of this research, it might be suggested this is a good contender. From this, we can see the value of research to explore dementia with a person-focus reified, as the implications are that a cure for dementia, although valuable, may have done a detriment to PGLAD in the now. This supported the critique of the medical model outlined in Section 1.2.2, that a focus on the brain obscured co-researchers' relationships to their social world. PAR enabled a context for co-researchers to provide what was described by one letter response, as a rare glimpse into lived experience of PGLAD. The intention now is to convey this appreciation, with the aid of a map in Figure 14 (below, p. 73) based on the FINIS model of Section 1.3.3. This section will now consider what has emerged, then in Section 4.1.2 the impact on PGLAD's wellbeing will be discussed.

Whilst it was emphasised how experience[33] differed at an individual level, we saw convergence over issues related to a society (i7) perceived not to care, which of course, is an example of the continued relevance of Kitwood (1998)'s Malignant Social Psychology (MSP). At the structural level this is typified by an experience of the withdrawal by a national charity from running the dementia café. Co-researchers felt this as a shock, so this generates questions of how those who organise society, such as commissioners or decision-makers relate to and communicate with PGLAD. Particularly, as co-researchers reported the dementia café as the "highlight" of their week due to opportunities for social connection with other PABDL. They questioned if the charity or council knew the importance of this resource to them, indicating they felt neither visible nor acknowledged, so were deprived of their personhood.

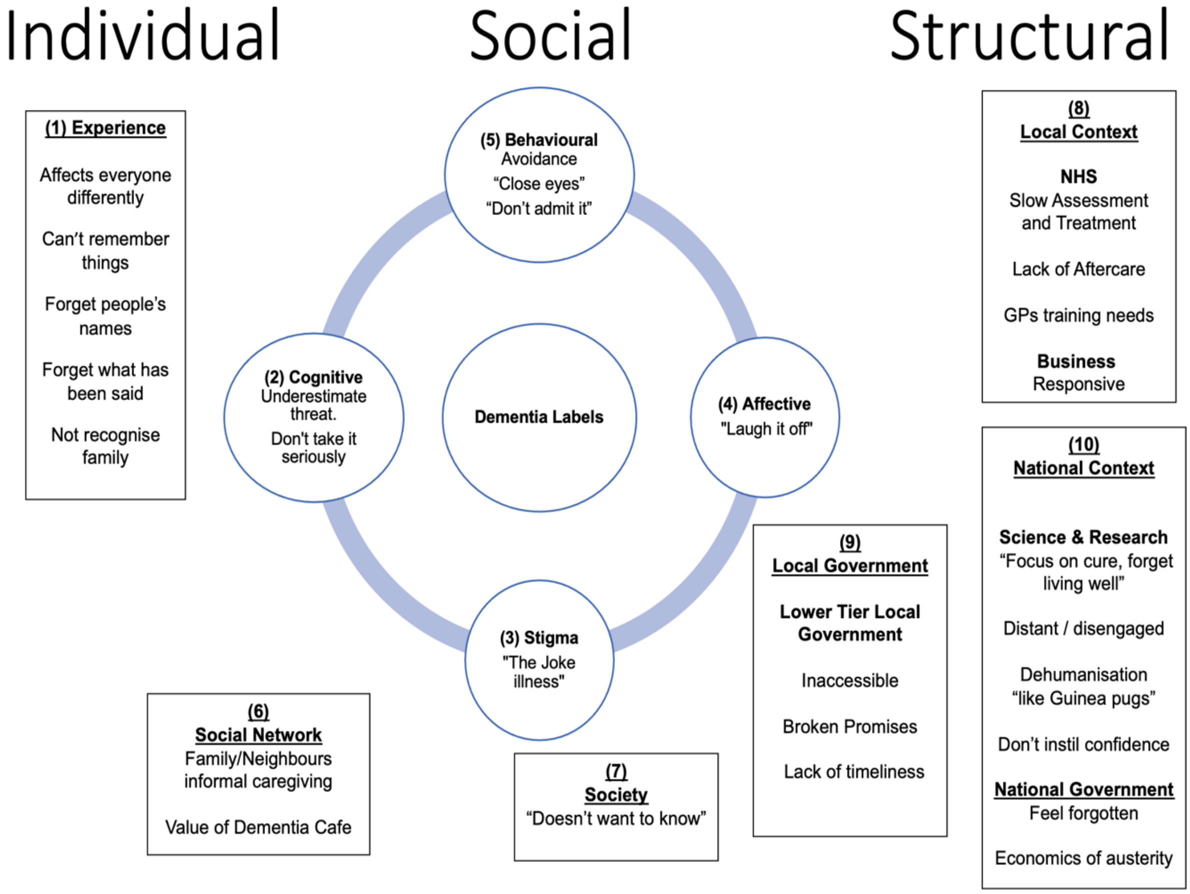


Figure 14: Mapping the experience of dementia labels

---

[33] Item 1 of Figure 14, which is reflected upon in the following Section 4.1.2. Further items referred to in Figure 14 will be represented in brackets within the text with a prefix 'i' followed by a number.

Co-researchers did feel visible to the broader community and saw changes to social organisation facilitated by business (i8) as positive examples of differences that could be made to enhance connections with others. This highlighted an interplay where withdrawal of state and charitable sector services led to PGLAD finding alternative ways to connect and feel safe within the community. We might view this through the lens of counterhegemonic cultural practices as PGLAD appear to have drawn upon their economic power ala the "grey pound" (Cook, 2011) to encourage businesses to change to meet some of their needs. However, the unsaid context behind this is a negative relationship between PGLAD and national policy (i10) due to the economic approach of austerity[34], which has been detrimental to vulnerable groups (UN Committee on the Rights of Persons with Disabilities, 2017; Macdonald & Morgan, 2020). Government might claim this response by PGLAD is a positive example of their "Big Society" initiative (Bamford & Berry, 2012). Big Society was a programme of health and social care reform that correlated in timing with austerity with an objective of "unleashing the creativity and enthusiasm of local communities to maintain independence and prevent dependency" (Department of Health, 2010, p.10). We did observe the tenacity of PGLAD filling a gap relational to the structural and stigmatising discourse of economic burden, but "unleash" was a curious word choice from DOH (2010, p.10) as it is defined as "to suddenly release a violent force that cannot be controlled" (Cambridge University Press, 2022a). Co-researchers reported a "fight" in the context of barriers to accessing support from services that left them feeling "thrown in the dustbin and forgotten". Further analogies of being "put on the scrapheap" or "retirement" pointed to discrimination at intersections of age and ability. Thus, co-researchers outlined a violent force they expended physical energy to resist, but this originated from state agencies.

Interestingly, we saw in Extract 3 of small group discussions barriers to accessing support were connected to the belief society did not want to know (i7), indicating a belief a power beyond the state might hold influence. Co-researchers were familiar

---

[34] Defined as "a difficult economic situation caused by a government reducing the amount of money it spends" (Cambridge University Press, 2022c).

with non-state organisation, as in lieu of services informal caregiving arrangements with families and neighbours were reported as a means to maintain independence. However, this was problematic for people on their own or diaspora with family in multiple countries who reported fear should something happen to them. Neighbours looking out for each might be considered an example of mutual aid, but not all had such relations. Co-researchers highlighted public stigma around dementia labels through disparaging jokes and revealed negative attitudes that left them feeling as if society did not take their experience seriously (i3). On this note, the collective letter asked, “does anybody care?” and made explicit that they felt “forgotten and pushed aside” with a perception neither society nor government did.

Feeling forgotten may have been reinforced once requests for state resources were made such as home adaptations organised by Lower Tier Local Government. This is a physical barrier to maintaining confidence and skills, as the vast majority of PGLAD wish to stay at home as long as possible (Alzheimer’s Society, 2016) and relatively small and inexpensive adaptations can achieve this (Evans et al., 2019). Understandably so, PGLAD consider home as a centre for meaning, a place for retreat, solitude and rejuvenation and centre for socialisation and meaningful activity (Forsund, et al., 2018). This is compounded by ‘broken promises’ (i9), as a promise is a form of social contract meant to sustain cooperation (Gneezy & Epley, 2014). Gneezy and Epley (2014) outlined how broken promises lead to negative evaluations that diminish relationships as they link to notions of fairness and trustworthiness.

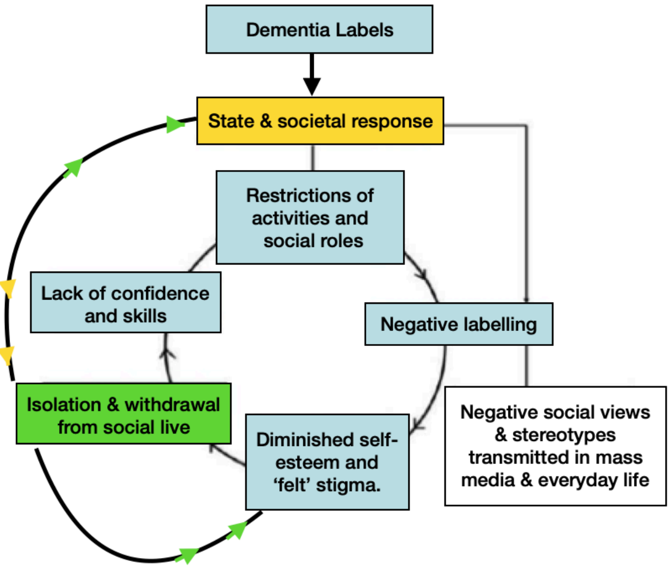


Figure 15: An Expanded Feedback Loop

The pattern that occurs as a consequence is reminiscent of the Feedback Loop (Taylor & Field, 1993) of Section 1.3.1. which I have now updated in Figure 15. As broken promises coupled with physical barriers to leaving home and limiting community presence may understandably ebb the confidence and skills of PGLAD and mediate the ability to carry out meaningful activities. Co-researchers identified state and society as a critical mediator to their ability to fulfil valued social roles and not be “placed on the scrapheap”, which underlines how their action was directed. As this form of enforced withdrawal, characteristic of objectification in terms of MSP (e.g. Kitwood & Brooker, 2019), may understandably affect self-esteem or ‘felt’ stigma and thus ability to influence state or society responses to dementia labels.

4.1.2. Issues that may have emerged from dementia and how society may impinge upon attainment of wellbeing standards

“You might close your eyes to it and pretend that nothing’s wrong, as you’re not taking it seriously. We may all laugh it off, but we shouldn’t” (Collective Letter; Appendix K, p.1)

Issues arising from individual and social levels will now be considered starting with the use of humour, given it features in the i2, i3, i4 of Figure 14. The opening quote from the collective letter invites this as it outlines humour as type of avoidance detrimental to the wellbeing of PGLAD. Humour, as reported by Papousek et al., (2017), can serve several functions; some of which are positive such as bonding or achieving social connection with others. Some are considered negative like status enhancement or maintenance, ostracism of out-group members and enforcement of conformity. In the quote, co-researchers imply an appreciation of invisible and unvoiced differences (e.g. Burnham et al., 2008), so a question might arise if humour obscures anxiety of exposure and being discredited (e.g. Goffman, 1963). Since if this was a physical illness, co-researchers asserted, “you’d be to the doctor straight away, but when it’s something like this”, there was reluctance to seek help. This is a severe barrier to the attainment of wellbeing standards as delays in help-seeking are compounded by interruptions related to inequalities in service provision. From this, we observe a dilemma from FINIS in Section 1.3.3.2.2, as the welfare state ideology necessitates differences to be distinguished and labelled within the healthcare system for economic and health entitlements to be conferred. This evidences stigma, both public and self (Corrigan et al., 2006), as a mediator of delay and thus access to resources, particularly as co-researchers reported waiting up to 8 years when finally reconciled to seeking help.

Inefficient processes could confirm Pinker (1970/2017)'s view of stigma as an intentional structural barrier for the state to manage resources. However, government might challenge this as the national strategy for dementia (NHS England, 2016) which directs the distribution of state resources outlines timely, accurate diagnosis, a care plan and review as part of 'Diagnosing Well'. This sits alongside four other strategy items, which NHS England (2016) detail as:

- Preventing Well: providing people with the information to reduce their risk of developing dementia.
- Supporting Well: Access to safe, high-quality health and social care for PGLAD and carers.
- Living Well: PGLAD to live normally in safe and accepting communities.
- Dying Well: PGLAD to be able to die in dignity in a place of their choosing.

In this case we may have touched upon the implementation gap between knowledge and clinical practice. For example, Patient Safety Learning (2022) reports delays to diagnosis, as reported in the collective letter, are an example of avoidable harm, in part, perhaps, due to a knock on to areas covered by 'Supporting Well'. They stated there was no panacea as systemwide change requires everyone from politicians, policymakers, patients, families and communities, clinicians, managers, regulators, researchers and academics, and health and social care leaders involved. This was an appreciation of co-researchers who identified nearly everyone above as dissemination targets for their collective action.

As NHS England (2016)'s transformation framework was established many years ago, the local context raises questions as to the overall success of the strategy. Suppose we consider 'Preventing Well' and 'Living Well', co-researchers asked how to "live well" and "live now" in the collective letter (p. 2), which by definition is a knowledge barrier that may affect wellbeing standards. Co-researchers reported they were not told enough about preventative strategies and described having their confidence in doctors diminished by tentative recommendations for medications that made them feel as if they were “guinea pigs”. This was typified in CL (p. 2) with a question for the NHS “if time lost was spent on treatments, memories may have been saved”. A stark reminder of the collective letter (p. 1) where co-researchers relayed the hurt experienced as memory declines, leaving them to feel as if they are but a “shell” of their former selves. This may be exacerbated by the lack of follow-up raised by co-researchers, as aftercare was found to be vital in enabling PGLAD to live as well as possible (Bamford et al., 2021). It also touches upon dignity issues and parity of esteem (e.g. Millard & Wessely, 2014) which co-researchers raised in their assertion dementia was not taken as seriously as physical health conditions.

This knowledge gap appeared to be bridged by the charity-run dementia café which gave an opportunity for peer learning about citizenship rights or entitlements. As, whilst technology like the internet was a resource co-researchers were aware of, not all saw this as in their interest or ability. This increases the significance of the concerns in the collective letter (p. 2) the council did not know who PGLAD were nor actively make it known what help or support was available. In this regard it is notable demands to this level of government focused on enhanced access to information. Thus, increased funding for community groups and a request for dissemination of information in an established physical format such as the local council magazine were logical alternatives. The findings here resonate with Allen et al., (2020), who found PGLAD preferred relational sources of information such as healthcare professionals who could provide individualised information as opposed to non-relational sources like the internet that left them feeling overwhelmed. Further, PGLAD reported to Allen et al., (2020), support groups and charities provided the most understandable information, perhaps as health or social care professionals were the least accessible sources. This indicates the digital transformation agenda in services (i.e. LGA, 2014) may pose a risk to wellbeing standards for PGLAD due to information not necessarily being as accessible as assumed.

4.2. Evaluation

The final question was how to act upon this to promote and protect human rights to enhance or maintain psychological wellbeing. This necessitates evaluation of the actions taken to explore whether the ‘how’ taken was appropriate. The outcomes of this project will now be considered, first, as created by co-researchers, then the rigour of method, and finally from a human rights-based approach.

4.2.1. Co-researcher devised

“Does anyone care” was the question posed by co-researchers in the Collective Letter (Appendix J, p.3) to solicit a response as they questioned if anyone did. From this direct action, 9 responses were received from 26 possible dissemination targets. Few responded directly to the questions co-researchers devised to elicit their thoughts and feelings, and consider actions as an individual and as part of a system. Direct co-researcher involvement in evaluating these responses would have been desirable, but it was impossible due to the pandemic and academic constraints. Nonetheless, this section will consider the co-researcher’s questions through critical reflection of the responses, including evaluation of those non-responders.

4.2.1.1. Lower Tier Local Government (LTLG)

No response from any councillors was curious[35], but It might be they were aware the Chief Executive asked ODSC[36] to respond. Yet without acknowledgement, political disengagement may appear wilful ignoring and suggest politicians did not care. ODSC’s response revealed power was perceived to operate not within the LTLG, but within a PGLAD group who were reported to lead and steer the local services. On paper, this cooperation sounds very positive but in the context of the concerns raised in by co-researchers there is a possibility this diffusion of responsibility could serve to obscure accountability. Menzies (1960)[37] might suggest this is an organisational defence against anxiety, as reducing the burden of responsibility through the distribution of decision-making leaves no-one personally liable. This of course, is

---

[35] The primary role of a councillor is to represent the views and issues of people in their locality and respond to queries and investigate concerns (LGA, 2022a). In an audit of political engagement (Hansard Society, 2019) only a small minority of people (only 8 to 12% over the course of 9 years) reported they had contacted an elected representative at least once in the past year. This suggests they are not necessarily overloaded with demands from constituents so should have flex to respond.

[36] Operational Director of Social Care, as defined in Section 3.3.2.

[37] In what Lawlor (2009, p. 523) called an “almost iconic” paper that stood the test of time (p. 529).

helpful for politician’s in maintaining power come election time when their records are scrutinised, as it is harder to be held to account for distant group decisions.

Direct action was successful at conscious-raising within this level of government as ODSC stated knowing PGLAD’s experience was a driver to do more. However, we have obfuscation through ‘doublespeak’, defined by Herman (1992) as the misuse of words by implicit redefinition for political purposes. For example, limited support offered by LTLG following the assessment of PGLAD was described as part of a “strength-based service” and presented here as innovation. ODSC stated resources were for those who “truly” needed it; providing evidence of a moralising discourse in LTLG around a worthy/unworthy PGLAD. This is called ‘dichotomisation’, a systematic practice employed to divide groups in the service of political agendas (Herman & Chomsky, 2008). Romano (2017) spoke of these binaries as an attempt to aid those in need whilst limiting regard only to those who met social expectations of deservedness or merit. Thus, we have found evidence of stigma power (Link & Phelan, 2014) as values of resilience and self-help are presented as a virtue to help PGLAD keep “independent and well outside” statutory services. ‘Well’ was a notable emphasis as it presents ‘outside’ as a desirable state of being. Yet we know from Section 4.1.1 it is a big step for PGLAD to reconcile stigma to seek help, thus are unlikely to see the provision of help as aversive. Further evidence of doublespeak was seen in reframing cuts as opportunities by the claim not funding dementia cafés helped the dementia cafés to be more responsive to local needs.

Actions that arose from the ODSC included a commitment to upgrade their digital information and in light of the knowledge gap (Section 4.1.2) was a positive as it would enhance accessibility for people less familiar with technology. This is helpful if supplemented by ODSC’s commitment to adopt the co-researcher’s suggestion of using the LTLG magazine to communicate support and services for PGLAD.

There did appear to be acceptance of issues raised by co-researchers as the ODSC reported their Living Well with Dementia Strategy 2018-2023 had an agreed action plan with actions that targeted concerns raised in the letter. As the issues were known, and it is near 2023, it raises a question as to how success is evaluated.

4.2.1.2. Upper Tier Local Government (UTLG)

Despite no response from the directly elected member, the dementia lead (DL) and chair of the healthcare committee (CHC) demonstrated co-researchers were heard and the value of participatory approaches to research. This was seen in DL's view of the letter as powerful and thought-provoking with extra weight as written from the perspectives of PGLAD, and is in support of Littlechild et al., (2015) in Section 1.4.3. Further, the report from CHC this was a reminder of the "real, lived experiences" of PGLAD undelivered by research or statistics, offers a critique of traditional science. As if objectification (e.g. Kitwood & Brooker, 2019) in methodology affects the ability of policymakers to hold PGLAD in mind about issues that directly affect them, then it might cause reflection for the research community on their axiology.

From the UTLG results, we found evidence to compliment Cuddy et al., (2007) of the Stereotype Content Model (SCM; Fiske et al, 2002) in Section 1.3.2, on how emotional responses to groups shape behaviour tendencies. We have a varied range of emotions, with CHC reporting to be moved and upset from the power of hearing voices that are often marginalised or spoken on behalf of. This evoked what Cuddy et al., (2007) called active facilitation tendencies, or actions in the form of personal resolve to advocate for PGLAD, and to amplify their voices. For DL, feelings of frustration, sadness and anger from negative attitudes towards PGLAD raised in the collective letter led to active facilitation actions. This included a determination to build on their work for PGLAD, awareness raising (including a pledge to disseminate this research), training and policy initiatives across UTLG.

Enhanced motivation from hearing PGLAD may be positive in a setting with a struggling workforce (LGA, 2022b), as intrinsic motivation is negatively correlated to strain outcomes from work-stressors that can cause burnout (Rubino et al., 2009). Further, motivation guides the direction, intensity and persistence of performance (Fischer et al., 2019), which as DL and CHC are opinion leaders due to positions of structural power, might suggest some support for a-hierarchical influence in 1.3.3.1. Yet co-researchers were aligned to a university with a position of societal influence, so a question arises if self-organising groups might be received to the same degree?

The direct action achieved organisational change (e.g. Figure 8; Heijnders & Van Der Meij, 2006) such as CHC recognition assessment and support was something they “must address” and continued advocacy for PGLAD at the health committee, which means the voices of co-researchers will continue to influence others at UTLG. Other structural level change included a commitment to ensure PGLAD are involved in policy development. Consultation with PGLAD on regional infrastructure changes and “ensuring voices of PGLAD were at the forefront” of future dementia policies, with a pledge to approach PGLAD in advance of future work offers hope for change. Whilst it is not possible to know if this will be realised, an inclusive host is considered a first step in the creation and actualisation of partnerships for change (Nelson & Prilleltensky, 2010b, p. 218). This highlights a snowball effect, whereby participation of PGLAD in research has encouraged power-holders to ensure more opportunities.

4.2.1.3. Charities

As the letter was returned to the community through local charities, we observed the cascade model of dissemination in action (e.g. McDevitt, 1998) as it was requested to be shared with housing associations, serve as a focus for a PABDL group and influence work on a “manifesto for change” being developed with PGLAD. Likelihood of dissemination may have benefited from the positive feedback given to the charity lead that as well as moving, the letter was “straight to the point and easy to read”

In Section 4.2.1.2 we saw how emotional responses to groups shaped behaviour and, in this case, intra-interpersonal actions, and organisational level responses. Feelings of anger and sadness influenced facilitative tendencies such as personal resolutions to “never forget lived experience”, the importance of “being human”, a “right to information”, and professional actions. This included advocacy and actions to approach funders, commissioners and communities about issues raised.

Of the national charities contacted, there were responses, although none responded directly to the questions raised in the CL. However, information provided by AS on their research programme did include issues identified in the CL which may provide evidence of communication barriers between this charity and the people they serve. This disconnect has been said to occur due to the concentration of resources large charities command which may be to the detriment of the responsivity and quality of support offered by small charities (Mohan & Breeze, 2016). DEEP however, acted to disseminate the collective letter further through their own network.

4.2.1.4. Non-responders

Whilst no response from government, media or international organisations, who might be considered too big/busy to make contact, the NHS response was curious. The management forced retraction in the local dementia service raised questions about how power is situated and their relationship with service-users. Since the NHS is inherently medically orientated, it is possible we touched upon a manner of engaging with PGLAD as reported at the individual level in Section 1.2.1. On an institutional level, Menzies (1960) might lead us to ask if this was a type of depersonalisation and detachment from anxiety-provoking situations that may be evoked from the relationship of the staff to people who access their service. As if we recall Littlechild et al., (2015), it might be leadership felt discomfort from otherwise having “nowhere to hide” (p.26) from the issues raised. As per Kara (2015), I found some discomfort was reciprocal in liaising with power-holders who may have perceived a challenge to their authority so did not wish to engage authentically.

Lack of response from trust governors is problematic for the NHS as they are direct representatives of local communities (Monitor, 2013). As we can see from Figure 16, their role is to listen to the public and act to review services by challenging and questioning the directors to ensure the trust is running effectively (Governwell, 2013). In both instances, we have epistemic injustice as PGLAD were not heard by active choices locally and potentially by omission in higher governance. This is a barrier to accountability for issues faced by PGLAD and a Human Rights issue (Young et al., 2019) as co-researchers have found the NHS not acting compatibly with legal duties.

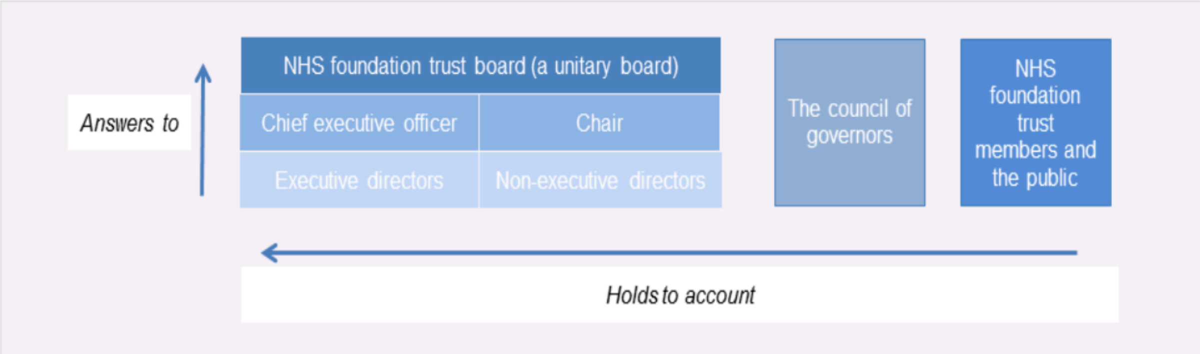


Figure 16: Accountability in NHS Foundation Trusts (Monitor, 2013, p.10).

4.2.2. Authenticity of Participation (AVS)

Authenticity of participation (Magnusson et al., 2001) is considered in Figure 18 on the next page. The results indicate strong authenticity of participation in each domain up to the product, which was the collective letter.

Concept	**Planning**	**Process**	**Product**
Equal Access	Written information for recruitment was provided in different formats (talk and graphic posters). Use of Processural Consent Model (Hughes & Castro Romero, 2015) helped include people with a range of abilities, including co-researchers who may have been excluded from other research due to 'late stage dementia'. Anti-hierarchical research stance to move away from social relationships of power over in the context of researcher-participant but to power together, or amongst as co-researchers.	Methodology a "custom job" (Kidd & Kral, 2005, p. 187) which enabled adaptation according to individual needs and ethos of agency (Bates, 2018). E.g. Flexibility of research design enabled change from creative format to discussion groups to accommodate motor differences. Telephone as a change from face-to-face, accommodated the risk to health from contact in the pandemic.	CL format was co-created from a horizontalist stance (Bray, 2018) that enabled multiple viewpoints to be present. The knowledge and sense made of it was co-created. Transcripts were gone through in telephone calls and supplemented with written information to share with co-researchers who requested it to ensure stories were accessible for reflection.

Enhanced Awareness of Self	Aims and research questions offered space to develop an understanding of selves and guide action.	Range of methodological tools such as Tree of Life, Discussion Groups and use of PNI facilitated awareness of selves and PGLAD as a group through discussions.	Critical awareness of issues that affect self is evidenced through the PAR process that led to direct action and new insights into the situation of PGLAD.
Enhanced Awareness of Others	Ethical considerations around confidentiality and anonymity.	Co-researchers shared stories around topics of concern for PGLAD. This gave space for a range of awareness of various perspectives to be developed.	Co-researchers made sense of the gathered stories, which were then returned to the community in a collective letter.
Encouraging Action	Project set up with a research methodology with an explicit orientation of action. Human Rights underpin project intrinsic to which was an aim to empower co-researchers to claim rights and hold organisations to account (Greenhill & Golding, 2018).	Project enacted critical consciousness (e.g. Watts et al., 2011) as the process first facilitated space to reflect on issues that affected self and others. Next, co-researchers made sense of this and considered they means they had as a group to effect political or social change.	Co-researchers took direct action and elevated the voices of PGLAD to direct those who held systemic power how to act to resolve issues that arose that impacted on wellbeing (e.g. Bartlett & O’Connor, 2010).

Enabling Action	Research methodology, co-researchers lived experience and author's knowledge of research, support of a research supervisor, academic institution and NHS as resources and means.	Knowledge production as an action in itself (O'Sullivan & Hocking, 2013) for PGLAD whose voices are marginalized from research and academia.	Co-researchers direct action took the form of a collective letter as a tool to effect political and social change. As a result, steps were pledged by recipients to changes things within their power, including policies or practices that were seen as unjust.

Figure 17: AVS Model matrix evaluation (as per Brown Wilson and Clisse, 2011).

4.2.3. Human Rights

In Figure 18 (below) is an evaluation of the research from a Human Rights Based Approach with evidence of good concordance with PANEL principles.

Principles	**Evidence**
Participation	Project involved seldom heard group, marginalised on the grounds of intersections of disability and age, which are protected characteristics. Meaningful consideration was given to issues of accessibility, including access to information as part of project planning to ensure PGLAD were free to make an informed choice around participation. Rights to participation were protected as part of the ethical considerations of the research with the Processural Consent Model (Hughes & Castro Romero, 2015). Authenticity of participation was assessed in Section 4.2.2., which demonstrates equality of access was considered through the planning, process and products of the research. Participation was encouraged through collaboration with PGLAD as co-researchers.
Accountability	Information was provided to highlight accountability procedures for completing the research and how to raise concerns through my research supervisor or the institution. Research involved developing

	awareness of raised of issues that influence rights, with action taken to hold those with legal duties or practical responsibilities accountable.
Non-discrimination & equality.	Needs of co-researchers with protected characteristics due to age and disability were considered in the planning and process of research. Epistemological Anarchism meant differences of epistemology could be held in the framework as were working towards a shared goal. Research aims included the identification of issues that emerged from dementia as a protected characteristic and affected wellbeing. An outcome of the study included awareness raising around issues that may constitute discrimination and a demand they be remedied.
Empowerment	Research Methodology involved building the capacity of rights holders to claim their rights through reflecting on issues that affected rights, then action taken to claim them. The means for this was a letter that involved awareness raising and advocating for policy changes.
Legality of rights	Within Section 1.4 of this report, relevant human rights standards are identified that underpin the foundations of this research. Moreover, the application of this is specified with mechanisms for claiming rights.

Figure 18: HRBA Evaluation through PANEL Principles (BIHR, 2014)

4.3. Critical Review

This section will critically review this project through each research stage to identify considerations for future PAR projects.

4.3.1. Planning

PAR differs from traditional research in emphasising meaningful participation (Froggatt & Hockley, 2011), yet Frideres (1992) challenged the authenticity of this if the ability of lay people to carry out 'scientific research' was not addressed. Part of this relates to the complexity of academic language, which Lather (1996, p. 526) highlighted as a barrier to both praxis and the dissemination of ideas. She thought this served to reinforce authority and legitimise the exclusion of those who did not understand and risked being "masturbatory activity aimed at a privileged few" (p. 528). This is not to reject all authority as Bakunin (1871) observed, "In the matter of boots, I refer to the authority of the bootmaker…"[38], but he would not let them impose their authority upon him. Instead, he said to listen freely, with the respect the person merited, whilst reserving a right to criticism, censure and consult multiple others. Increasing the accessibility of research and providing a context where co-researchers could listen freely with a right to dissent intact were key considerations in planning. For example, the infographics in Appendix E and F, and a presentation about different types of research. Consequently, this project sought to evaluate participation in Section 4.2.2 and showed good evidence for authentic involvement.

Yet, there might be barriers to participation arising from the recruitment process. For example, a gate-keeper mediated access to people affected by dementia labels (PABDL) meaning inclusion or exclusion, was determined by an individual's choice to attend a particular charity-run group. If stigma contributes to social exclusion, then insights of PABDL who do not access community resources would benefit from participation. There may also be a self-selection bias (Olsen, 2008), as those who chose to participate may have beliefs that aligned with research aims, yet were not representative of the broader communities of PABDL. This project aspired to flatten hierarchy through PAR rooted in a community that I belonged to and as someone with lived experience of a family member affected by dementia labels, a 'shared struggle' (Kidd & Kral, 2005). However, these risked issues being identified only specific to a small geographic area, and broader knowledge might be obtained with co-researchers across a larger region. This locality has high levels of ethnic diversity, and this was reflected in the initial large group, but diversity could have been enhanced from small group discussions. Whilst not possible due to the academic constraints, it might be as someone white, Cornish and male, being joined by a co-facilitator of different contexts may have encouraged wider participation, and enhanced project capacity. Inclusion could also be enhanced with funding for interpreters so PGLAD without English as first language are included, as reversion to primary languages can occur in the context of dementia (Alzheimer's Society, 2019).

---

[38] Continued: "…concerning houses, canals, or railroads, I consult that of the architect or the engineer. For such or such special knowledge, I apply to such or such a savant". Bakunin (1871) was conscious that no universal person was capable of grasping "all that wealth of detail, without which the application of science to life is impossible, all the sciences, all the branches of social life".

A planning concern was if marginalised voices might be undermined by non-adherence to standardised approaches, despite methods formed to the problem, as per the intentionality of PAR. For example, Frideres (1992) argued the basis is of scientific knowledge is the establishment of laws which can be subject to scrutiny and tested. Whereas PAR, PNI and theoretical underpinnings employed by this study[39] could be said to resist prescription and as such pose evaluative risks. Indeed, action research has been critiqued on methodical and theoretical grounds since 1957 (McTaggart, 1994, p. 322) yet is 'yma o dyd[40]'. Frideres (1992, p. 9) argued that the process of acquiring knowledge required "synthesis, systemisation and accumulation", and an anti-theoretical stance was "doomed to failure" if it was unable to generalise knowledge away from the uniqueness of individual contexts. The planning drew upon the longstanding history of action research to remedy this through incorporation of a transparent evaluation criteria that is open to scrutiny. Further a literature review laid the groundwork for developing theory as per Frideres (1992)'s "goal of science" with implications of this project considered in Section 4.4.

4.3.2. Process

PAR enabled adaptation to issues as they arose because rather than a methodology per se, it is a macro context that facilitated responsivity to dynamic changes (Kidd & Kral, 2005). Yet a project with this level of uncertainty is limited by resources of time and knowledge available to the facilitator. Adaption touches upon issues related to research paradigm that emphasise a non-hierarchical structure. Yet, power imbalances are unavoidable given a role distinct to other co-researchers as the facilitator. For example, my clinical skills helped me to adopt a 'one-down position' (Jankowski, 1998) to try and remove myself from a position of expertise, but acts of managing time or balancing opportunities for different speakers, particularly those with communication difficulties placed this at risk.

Although the notion of a 'Tree of Life' (TOL) used as a method is not culture-bound as it is an ontological device that transcends historical frameworks, there is a question, given its origins as a community psychology intervention within Africa,

---

[39] Epistemological Anarchism and Methodological Pluralism.

[40] 'Still here' as they say in Cymru[40]

whether it should form part of the cannon of a professionalised industry in Europe. Particularly given a history within clinical psychology of appropriation and commodification of knowledge from communities, including the East, such as mindfulness derived from Buddhist traditions (Mehta & Talwar, 2022). This touches upon a societal discourse around cultural appropriation vs cultural appreciation, which questions power relations and ethics of sharing ideas between cultures. Cattien and Stopford (2022) argue that this is a false dichotomy as appreciation and appropriation co-occur and what is ultimately important is a critical attitude to ourselves and our socio-historical and cultural relations to phenomena or products. One anarchist view[41] would reject this proposition entirely as Tucker (1899) highlighted that unlike property, with state protections that arose due to scarcity, ideas are not subject to the same rules as they can be used by an "unlimited number of individuals… to an unlimited extent and in an unlimited number of places"[42]. Caution should be applied around premises of appropriation as it may paradoxically serve to perpetuate socio-historical power relations between Europe and Africa, in that paternalism[43] may undermine the dignity and autonomy of African practitioners In the case of TOL, it was successfully propagated by Ncazelo Ncube, through facilitating training and conferences worldwide without barriers such as copyright.

---

[41] Touched upon in the footnotes of Section 1.2.4

[42] We can see this dispersal of ideas from the history of TOL intervention itself. Ncazelo Ncube (2006), a child psychologist from Zimbabwe who is the author that popularised this approach, reported that she was introduced to TOL by a "colleague and friend called Jonathan Brakarsh" (p. 6), who is also a psychologist from Zimbabwe. Ncube (2006, p. 8) reported that in 2003 she introduced this to children affected by HIV/AIDS in Eastern and Southern Africa and in 2005. a team from the Dulwich Centre (Michael White, Cheryl White, Shona Russell and David Denborough) witnessed and appreciated the work, which led to a collaboration to develop this further. Denborough (2008, p. 72) reported this originated from Sally Timmel and Anne Hope (1984) as the 'Tree of Hope' who, in turn, had derived inspiration from Paulo Freire.

[43] Koot (2020, p. 3) offered a definition of 'paternalism' as "thinking or behaviour by people in authority that results in them making decisions for other people… that prevent them taking control of their own lives". They saw this as typical of colonial relations and an unequal power balance that perpetuated dependency and reinforced a belief in white supremacy. Koot (2020, p. 12) reported that paternalism posed a barrier to development and empowerment as it perpetuated a form of top-down thinking that displayed notions of 'participation', 'community-based' intervention and 'bottom-up' thinking as nothing but a type of rhetoric.

The critique above relates in part to a limited and unidirectional notion of power which we might also consider in the context of TOL as my academic status may have meant that I held inaccessible research knowledge. However, power is multi-faceted, and age differentials and experience are areas co-researchers held status. As Bakunin (1871) said “there is no fixed and constant authority, but a continual exchange of mutual, temporary, and, above all, voluntary authority and subordination”. Thus, a de-centred approach, checking in and listening when motor ability was raised as an issue was an example of an activity that could ameliorate this to enable research progression. Nonetheless, Kidd and Kral (2005) saw differences in role as a strength, as they believed it was a facilitator’s knowledge combined with the co-researchers that helped understand and change systems.

Constraints from my academic context meant it was not possible for the involvement of co-researchers in further analysis, discussion or write-up. This lack of participation was a key weakness that would benefit from being rectified if this research is disseminated to journals and mitigated in future PAR projects.

4.3.3. Product

Political instability from the pandemic impacted upon the planning schedules, and choices available for action. One co-researcher wanted to “march upon Downing Street” but was restricted by government rules that limited movement. Another co-researcher wished to write articles for a magazine but was unfortunately affected by a sudden deterioration of health which made this no longer possible. A letter as a tool of direct action is an established stigma reduction strategy (Section 1.4.3); however, as a form of communication typified by distance it may have provided an opportunity for recipients to avoid a response. It might be letters supplemented by personal visits increase the likelihood of response so there is truly “nowhere to hide”.

Lack of physical contact previously possible within the community group also posed a barrier for the large group to step in and out as co-researchers as per the Processual Consent Model (Castro Romeo, 2015). Further, the telephone negatively affected participation as it was a barrier to participation for co-researchers who did not wish to be communicated by this method or struggled in their ability to do so.

4.4. Concluding reflections and implications

Now concluding thoughts and the implications at individual, social and structural levels that were adopted as a framework earlier in this project.

4.4.1. Individual

The context of the individual and their ability is claimed as a reason why PGLAD are excluded from research, but this left silent the role of other individuals; researchers, who may have struggled to adapt research methods. Yet, an outcome of this project is that PAR has been shown to accommodate individual differences and enable adaptation to societal changes experienced in a pandemic, which has implications for the veracity of reasons given for non-participation of PGLAD in future research.

Anarchism was shown as complimentary to PAR thanks to an epistemology that supported the most apt method to solve a problem, even if not facilitator preference. For example, co-researchers were offered a choice of quantitative or qualitative methods, and we would have run with either irrespective of my individual strengths. What was not anticipated is the preparation that went into being able to facilitate the initial method affected how I felt when requested by co-researchers to change tact. I noticed disappointment in not being able to see it through, which left me curious if this might relate to internalisation of conflicting cultural beliefs in clinical psychology. For example, values of perfectionism, which are at unhealthy levels in Trainee Clinical Psychologists compared to the general population (Patel, 2020). Thus, I may have happened upon possible insight into a potential motivator for PAR governance breaches (Kesby et al., 2007, p.21) detailed in Section 2.3.1. Particularly as a sense of security does come from research rules, so deviation can elicit discomfort from academic guilt and emotional effects of PAR with a desire to help (Klocker, 2015). Klocker (2015) stated this is because there is no pretence in PAR of being objective or neutral so there will be emotional connection surfacing from shared endeavour. After all, with science comes an appreciation most attempts to generate knowledge will not succeed (Section 2.4), and as a Trainee Clinical Psychologist not only is career progression at risk, but a personal connection built with co-researchers who were candid sharing stories with emotional implications (Carr, 2007; Faulkner & Thomson 2021) so there is a need for it to succeed (Klocker, 2015). Where security was reduced by methodology, it was, however, to be found within axiology. Here the anarchist insights of anti-hierarchy, agency and freedom with a desire for this project to reflect future aspirations for how research should be (prefiguration) underpinning human rights values were protective factors to maintain high academic standards.

To surmise, this study found perceived barriers to participation in research for PGLAD could be overcome by a flexible methodological approach to research like PAR. In doing so, it demonstrated the utility of anarchism as a conceptual approach that compliments a Human Rights Based Approach to research of power dynamics.

4.4.2. Social

From direct action, responses included a view voices of PGLAD carried additional “weight” and authenticity rare in research, which have implications at the social level. ‘Weight’ is defined as “respect, influence, trust or importance” (Cambridge University Press, 2022b), and contrary to beliefs of stigmatised groups as “bad, dangerous or weak” (Goffman, 1963), and negative stereotypes of age and disability as low competence (reported by SCM[44] in Section 1.3.2). Indeed, this perception of competence occurred with warm emotions stemming from compassion, and as previously discussed elicited active facilitation behaviours, as per the SCM. Curious were facilitation tendencies arising from sadness, which might be considered a way to alleviate personal discomfort from a situation, perhaps where they have influence. Sadness occurred with anger, so given an urge to act, it could be righteous anger/protest as detailed in FINIS (Figure 3; Pescosolido et al., 2008) and a social response to structural stigma. Emotions are known to be central to PAR as they motivate a researcher to act in response to injustices (Klocker, 2015), so it is noteworthy from this project we have examples of emotions elicited in response to PAR which has motivated powerholders to act. Consequently, this research has shown not only the potential of PAR as a tool to challenge stigma by foregrounding PGLAD away from negative stereotypes that defined them but also the power of critical consciousness (Watts et al., 2011) to influence others to act alongside them.

---

[44] The Stereotype Content Model (SCM; Fiske et al., 2002)

4.4.3. Structural

This project applied a policy initiative from the United Nations and endorsed by the British Psychological Society (2017) to redistribute power in clinical and research settings to effect change in public policy settings as an act to defend human rights. PAR enabled the authentic participation of PGLAD with a range of abilities in research which delivered a community-level intervention that achieved social and political change at a structural level, despite a pandemic as a barrier to participation.

Part of the aim, if we recall in Section 1.2, was to expose the values or political ideology that can often be unspoken, but retain power (Alderson, 1998). From this regard, it was revealing to see how embedded cultural beliefs and political ideology are into the structural of our society. For example, neoliberal ideas of self-sufficiency and discourse of worthy/unworthy PGLAD implicit to the local government approach. The reframe of the effects of austerity which cut service provision across the country into an aspirational state of being, showed the seep into collective consciousness. This touched upon the revulsion towards welfare usage described by Pinker (1970/2017), and as these views came from a welfare provider, points to cognitive dissonance when using stigma as an administrative tool to manage resources. Nonetheless, they were receptive to acting where they perceived it to be within their ability to change, which provided support to an insight from the Managerial Model of compliance described in 1.4.2. This model suggested human rights breaches were not necessarily deliberate and could be remedied through conscious raising on gaps. This evidences Kitwood and Bredin (1992) point in 1.2.3 that transition to a rights-based culture can be a symbiosis of bottom-up and top-down processes, as it took PABDL as a community, to encourage those in power to make top down change. If we consider this research in the context of Heijnders and Van Der Meij (2006)'s stigma intervention strategies (Figure 19) we have witnessed more of a synergism[45].

---

[45] "The combined power of a group of things when they are working together, that is greater than the total power achieved by each working separately" (Cambridge University Press, 2022d).

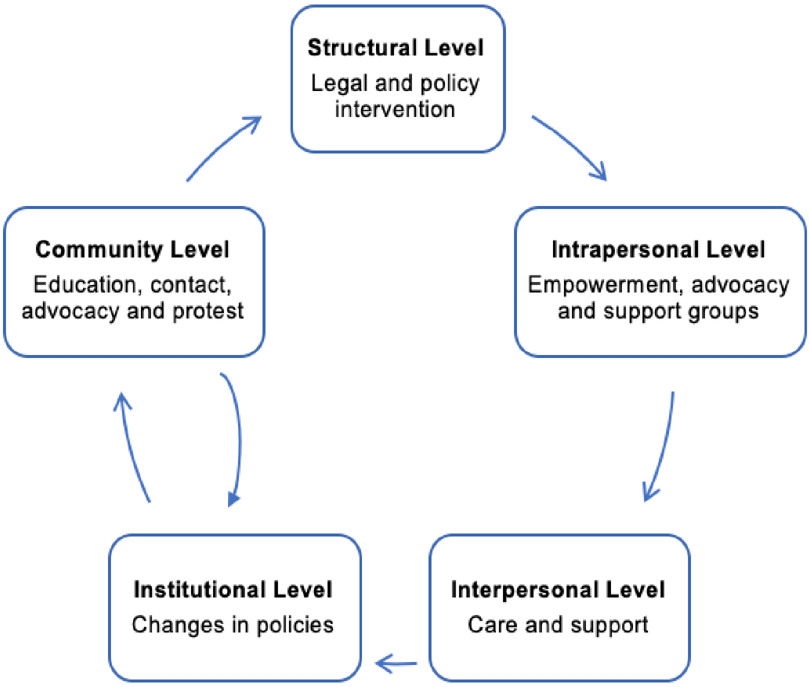


Figure 19: Synergism of Stigma Reduction Strategies (Heijnders & Van Der Meij, 2006)

If we recall research aims in 1.6.1, one was to answer challenge set by government (DOH, 2015) for the NHS to provide chances for PGLAD to participate in research. This was a policy intervention at the structural level that led to an intrapersonal intervention related to empowerment and advocacy within a local community group. At this point, there was a cycle between community and institutional level change occurring as direct action took the form of education, contact, advocacy and protest and this led to pledges of actions around policy. However, a question does arise whether or not these changes will be implemented without further organised scrutiny. The rarity of the insight into experiences of PGLAD was recognised by those in power who reported it motivated them to ensure PGLAD's voices are heard when developing policy that affects the lives of PGLAD across a large region. Yet, the nature of something 'rare' is that it is scarce, so where will motivations be derived? This highlights the ongoing utility of enacting critical consciousness (Freire, 1970; Watts et al., 2011) in research, and its potential as a synergistic stigma intervention.

4.5. Concluding Remarks and Recommendations

"No barriers whatever to human progression, to thought or investigation are placed by anarchism; nothing is considered so true or so certain, that future societies may not prove it false… other schools of thought are composed of crystallized ideas… too sacred to be disturbed by close investigation… lest some pet idea melt into myth… But anarchism is the usher of science, the master of ceremonies to all forms of truth" (Parsons[46], 1905/2010).

Figure 20: Physical Barriers of the University of East London, Stratford Campus.

The University of East London (UEL), from which this research is based, occupies a campus with a building given to the people by John Passmore-Edwards (1823-1911). Passmore-Edwards was a Cornishman of working-class origin and poverty who came to wealth through newspaper ownership which he gave away in the service of removing barriers to education for the working-classes (Baynes, 1995). As I passed physical barriers to education at UEL (Figure 20), I wondered what Passmore-Edwards would say about clinical psychology; a profession with barriers to access for working-classes (Goddard et al., 2021), racialised minorities (Newnes, 2020, p.10) and men (Himmerich, 2019). Newnes (2021, p. 10) suggested that clinical psychology might be just "for white middle-class professionals to be delivered by white middle-class professionals". Yet as a Cornishman of working-class origin from a community rendered underclass by a national context that led to the conditions which placed us under greater surveillance from the psy-industry (e.g.

---

[46] Lucy Parsons (1853-1942): one of the most influential anarchist leaders in USA, of working-class origin and a racialised minority commended for her work on gender and racial unity (Williams, 2007).

Newnes, 2016) than in prosperous areas, I am conscious of these biases. Since, as outlined by Newnes (2016, p. 144), surveillance from middle classes to those ‘othered’ is often “in absence of this gaze having positive results for the population observed”. Newnes (2021, p. 11) stated this was because clinical psychology sunk “under the weight of modern scientism, a culture grounded in culturally specific dinosaurs”, which perhaps led us to this situation where little is known about the experiences of marginalised people like PGLAD, who we hope to serve. Indeed, Patel (2003, p. 26) contended psychology in the west is “unquestionably culture-bound” and its assumptions of universality obscure individual differences. Worse, sometimes individual differences are positioned as antithetical to equality, yet this denies how difference has contributed towards ideas of equality (Rioux, 2003, p. 309). This is why I believe the anarchist insight as reflected in the opening quote does, as argued by Ramnath (2011, p. 16), enable us to prefigurate the conditions of emancipation, whilst embracing pluralism, with clinical psychology as our praxis.

My co-researchers were clear in their demands of scientists and researchers that they wanted more of a focus on living well; should it need academia to validate this? For Maslow (1958a, p. 3), this was the mission of the psychologist; to be “an arm of the human race, a help to them...” not playing “games in the corner of a laboratory”. An idea that has perhaps come around again as BPS (2021) proposed a new job of a neighbourhood psychologist to build on communities’ assets and strengths, whilst ensuring their practice is firmly rooted in local experiences and needs. As we know to ‘live well’ is idiosyncratic, Maslow (1958b, p. 5) identified this and criticised a preoccupation with the “generalised man”, asserting the special task of psychology was to do what no other science has, set about studying uniqueness. This is why future research might also benefit from anarchism for axiology; as Ramnath (2011, p. 16) pointed out, what distinguishes it from other ideologies is that “limitless variation is possible amongst divergent visions of an idealised future”. She saw “even in the midst of a struggle, the visions can’t be postponed, since the route we choose determines where we end up”, as highlighted by the effect of the different values that underpinned understandings of dementia labels in Section 1.2.

To further this research, clinical psychology needs to continue to offer opportunities for marginalised people to generate knowledge that is meaningful to their lived experiences, platforming their voices in academia and laying a foundation for evidence required to take practical steps towards social change. To ensure the integrity of this, we would benefit from greater study on authenticity of participation, but alongside the authenticity of action. As whilst we had a tool to measure participation (Magnusson et al., 2001), we are lacking that for action, as although pledges of action were received how can we be sure they are delivered? This might necessitate funding being allocated for longitudinal PAR studies, or trainee clinical psychologists being given the opportunity to step into established PAR groups to further the objectives of co-researchers, as a thesis project. BPS (2021) argued PAR could be core to the role of their proposed neighbourhood psychologists, and perhaps this might provide the appropriate opportunities for this work to be done.

Additional issues are that we need further analysis of power to better understand ableist power relations maintained by state and the economy, and to explore more about centres of resistance by marginalised people. Research could undoubtedly be enhanced by knowing more about the politics of everyday life for PGLAD and to consider how these issues interact in an intersectional framework. Finally, axiology should receive more study as to its history, uses or influences in clinical psychology, as we seek out how to push academia towards the challenges of everyday life.

“Anarchism was born among the people; in the struggles of real life, and not in the philosopher’s studio… it will continue to be full of life and creative power only as long as it remains a thing of the people” – (Kropotkin[47], 1903/2012).

---

[47] Peter Kropotkin (1842-1921) was considered a lead theorist of anarchism, and a founder of anarchist movements in England, Russia and a lesser extent France (Avrich & Miller, 2022).

REFERENCES

Aarsland, D., Zaccai, J., & Brayne, C. (2005). A systemic review of prevalence studies of dementia in Parkinson's disease. *Movement Disorders: Official Journal of the Movement Disorder Society, 10*(20), 1255-1263.

Abrams, D., & Levine, J. M. (2012). Norm formation: Revisiting Sherif's autokinetic illusion study. In J. R. Smith, & S. A. Haslam, *Social psychology: Revisiting the classic studies* (pp. 57-75). Thousand Oaks: Sage Publications Ltd.

Acton, H. B. (1951). Comte's Positivism and the Science of Society. *Philosophy, 26*(99), 291-310.

Alderson, P. (1998). The importance of theories in health care. *British Medical Journal (Clinical research ed), 317*(7164), 1007-1010.

Allen, F., Cain, R., & Meyer, C. (2020). Seeking relational information sources in the digital age: A study into information source preferences amongst family and friends of those with dementia. *Dementia, 19*(3), 766-785.

Alzheimer's Association. (2022). *Alzheimer's disease facts and figures: Special Report More than Normal Aging: Understanding Mild Cognitive Impairment.* Chicago: Alzheimer's Association.

Alzheimer's Research UK. (2015). *Women and Dementia: A Marginalised Majority.* Alzheimer's Research UK.

Alzheimer's Disease International. (2019). *World Alzheimer Report 2019: Attitudes to dementia.* London: Alzheimer's Disease International.

Alzheimer's Society. (2010). *My name is not dementia: literature review.* London: Alzheimer's Society.

Alzheimer's Society. (2016). *Fix Dementia Care Homecare.* Retrieved 2022 May, from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_homecare_report.pdf

Alzheimer's Society. (2019, June/July). Losing your English: 'Reverting' to your mother tongue as dementia progresses. *Dementia Together Magazine*.

Amster, R. (2018). Anti-Hierarchy. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 15-27). Abingdon: Routledge.

Aristotle, Sinclair, T. A., & Saunders, T. J. (1991). *The Politics.* London: Penguin Books.

Asch, S. E. (1951). Effects of group pressure upon the modification and distortion of judgements. In H. Guetzkow, *Groups, Leadership and men; research in human relations* (pp. 177-190). Oxford: Carnegie Press.

Avrich, P., & Miller, M. A. (2022, July 24). *Peter Alekseyevich Kropotkin*. Retrieved from Encyclopedia Britannica: https://www.britannica.com/biography/Peter-Alekseyevich-Kropotkin

Alzheimer's Disease International and World Health Organisation. (2012). *Dementia: A Public Health Priority.* Geneva: World Health Organisation.

Bakunin, M. (1869/2021). *Integral Education II.* Retrieved January 2022, from Revolt Library: http://www.revoltlib.com/anarchism/integral-education-ii-men-of-genius-race-bakunin-mikhail-1869/

Bakunin, M. (1871). *What is Authority? from Dieu et l'etat.* Retrieved 2022 December, from Panarchy: https://www.panarchy.org/bakunin/authority.1871.html

Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies, 22*, 222-228.

Baldwin, C., & Capstick, A. (2007). *Tom Kitwood on Dementia: A Reader and Critical Commnetary.* Maidenhead: Open University Press.

Baldwin, C., Capstick, A., Phinney, A., O'Connor, D., & Chaudhury, H. (2007). Conceptualising personhood in dementia. In C. Baldwin, & A. Capstick, *Tom Kitwood on dementia: a reader and critical commentary.* Maidenhead: Open University Press.

Bamford, C., Wheatley, A., Brunskill, G., Booi, L., Banerjee, S., Harrison Dening, K., & Robinson, L. (2021). Key components of post-diagnostic support for people with dementia and their carers: A qualitative study. *PLOS, 16*(12).

Bamford, S.-M., & Berry, C. (2012). *Long term care for older people, social productivity and the 'big society': the case of dementia.* London: The RSA.

Baranger, A. (2017). Article 8 [Awareness-Raising]. In V. Della-Fina, R. Cera, & G. Palmisano, *The United Nations Convention on the Rights of Persons with Disabilities* (pp. 213-223). Cham: Springer.

Barroso, M. (2002). *Reading Freire's Words: Are Freire's Ideas Applicable to Southern NGOs?* CCS International Working Paper.

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship.* Bristol: Bristol University Press.

Bates, D. (2018). Agency. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 60-73). Abingdon: Routledge.

Batsch, N., & Mittelman, M. S. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia.* London: Alzheimer's Disease International.

Baynes, P. (1995). John Passmore Edwards: a Neglected Victorian. *Library History, 11*(1), 37-40.

Becquart, C. (2017, Sept 17). The history of St Lawrence's hospital in Bodmin: From the 'lunatic asylum' to the urbex hotspot. *Cornwall Live*.

Behuniak, S. M. (2010). Toward a political model of dementia: Power as compassionate care. *Journal of Ageing Studies, 24*(4), 231-240.

Beresford, P. (2021). *Participatory ideology: From exclusion to involvement.* Bristol: Policy Press.

Bineham, J. L. (1988). A historical account of the hypodermic model in mass communication. *Communication Monographs, 55*(3), 230-246.

Black, B. (2019). *Anarchism and Human Rights.* Retrieved August 2022, from Academia.Edu: https://www.academia.edu/38151519/ANARCHISM_AND_HUMAN_RIGHTS_docx

Boller, F., & Forbes, M. M. (1998). History of dementia and dementia in history: an overview. *Journal of the neurological sciences, 2*(158), 125-133.

Bowen, E. A., Murshid, N. S., Brylinski-Jackson, A., & Gabel, S. G. (2019). Moving Towards Trauma-Informed and Human Rights-Based Social Policy: The Role of the Helping Professions. In L. D. Butler, F. M. Critelli, & J. Carello, *Trauma and Human Rights: Integrating Approaches to Address Human Suffering* (pp. 55-74). Cham: Palgrave Macmillan.

Bowen, J., & Purkis, J. (2012). Introduction: why anarchism still matters. In J. Purkis, & J. Bowen, *Changing anarchism: Anarchist theory and practice in a global age* (pp. 1-20). Manchester: Manchester University Press.

Brauer, J., Stenglein, K., & Amici, F. (2020). Dogs (Canis Familiaris) and wolves (Canis Lupus) coordinate with conspecifics in a social dilemma. *Journal of Comparative Psychology, 134*(2), 211-221.

Bray, M. (2018). Horizontalism. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 101-114). Abingdon: Routledge.

Bray, M. (2019). Beyond and Against the State: Anarchist Contributions to Human Rights History and Theory. *Humanity: An International Journal of Human Rights, Humanitarianism, and Development, 10*(3), 323-338.

Bryden, C. (2020). Challenging the discourses of loss: A continuing sense of self within the lived experience of dementia. *Dementia, 19*(1), 74-82.

Bristow, W. (2017, August 29). *Enlightenment*. (E. Zalta, Producer) Retrieved June 2020, from The Stanford Encyclopedia of Philosophy: https://plato.stanford.edu/archives/fall2017/entries/enlightenment/

British Institute of Human Rights. (2014). *The Difference It Makes: Putting Human Rights at the Heart of Health and Social Care.* Retrieved March 2022, from https://www.bihr.org.uk/Handlers/Download.ashx?IDMF=6a2726a4-a220-418f-9f4a-1fc03ca93cdc

British Psychological Society. (2018). *Code of Ethics and Conduct.* Leicester: The British Psychological Society.

British Psychological Society. (2020a). *Guidance: DClinPsych Training and Covid-19.* Retrieved from British Psychological Society: https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCP/DClinPsych%20training%20and%20Covid-19.pdf

British Psychological Society. (2020b). *Guidance: Adaptations to psychological practice: Continuing guidance during Covid-19 pandemic.* Retrieved from https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Adaptations%20to%20psychological%20practice%20-%20interim%20guidance%20during%20Covid-19.pdf

British Psychological Society. (2021). *A Neighbourhood Community Psychologist: Potential and possibilities.* Leicester: British Psychological Society.

British Psychological Society and Mental Health Europe et al. (2017, August 2018). *Open letter endorsing the Report of the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.* Retrieved October 2018, from https://www.ohchr.org/sites/default/files/Documents/Issues/Health/RightToMentalHealth/UNOpenLetter-HCZeid_MentalHealthEurope.pdf

British Psychological Society and Royal College of Psychiatrists. (2015). *Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.* Leicester: The British Psychological Society.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design.* Cambridge Massachusetts: Harvard University Press.

Bronfenbrenner, U. (1995). Developmental ecology through space and time: A future perspective. In. P. Moen, G. H. Elder, & K. Luscher (Eds), *Examining lives in context: Perspectives on the ecology of human development* (pp. 619-647). American Psychological Association.

Bronfenbrenner, U., & Morris, P. A. (2006). The Bioecological Model of Human Development. In R. M. Lerner, *Handbook of Child Psychology: Volume 1: Theoretical Models of Human Development.* Hoboken, New Jersey: John Wiley & Sons, Inc.

Brogden, M. (2001). *Geronticide: Killing the Elderly.* London: Jessica Kingsley.

Brown Wilson, C., & Clissett, P. (2011). Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry. *Journal of Advanced Nursing, 67*(3), 677-686.

Brubaker, R. (2004). *Ethnicity without groups.* Cambridge, Massachusetts and London: Havard University Press.

Brucks, D., & Von Bayern, A. M. (2020). Parrots Voluntarily Help Each Other to Obtain Food Rewards. *Current Biology, 30*(2), 292-297.

Bryden, C. (2016). *Nothing about us, without us! 20 years of dementia advocacy.* London: Jessica Kingsley Publishers Ltd.

Burgstaller, M. (2005). *Theories of Compliance with International Law.* Leiden, The Netherlands: Koninklijke Brill NV.

Burnham, J., Palma, D., & Whitehouse, L. (2008). Learning as a context for differences and differences as a context for learning. *Journal of Family Therapy, 30*, 529-542.

Butler, L. D., & Critelli, F. M. (2019). Traumatic Experience, Human Rights Violations, and Their Intersection. In L. D. Butler, F. M. Critelli, & J. Carello, *Trauma and Human Rights: Integrating Approaches to Address Human Suffering* (pp. 11-53). Cham: Palgrave Macmillan.

Cadar, D., Lassale, C., Davies, H., Llewellyn, J., Batty, D., & Steptoe, A. (2018). Individual and Area-Based Socioeconomic Factors Associated With Dementia Incidence in England: Evidence From a 12-Year Follow-up in the English Longitudinal Study of Ageing. *JAMA Psychiatry, 7*(75), 723-732.

Cahill, C. (2007). Repositioning Ethical Commitments: Participatory Action Research as a Relational Praxis of Social Change. *ACME: An International Journal for Critical Geographies, 6*(3), 360-373.

Cahill, C., Quijada-Cerecer, D. A., & Bradley, M. (2010). '"Dreaming of . . . "': Reflections on Participatory Action Research as a Feminist Praxis of Critical Hope. *Affilia, 25*(4), 406-416.

Cahill, S. (2018). *Dementia and Human Rights.* Bristol: Policy Press.

Cai, L., & Huang, J. (2018). Schizophrenia and risk of dementia: a meta-analysis study. *Neuropsychiatric disease and treatment,* (14), 2047-2055.

Cattien, J., & Stopford, R. J. (2022, March 2). The appropriating subject: Cultural appreciation, property and entitlement. *Philosophy & Social Criticism*.

Cambridge University Press. (2022a). *Meaning of unleash in English*. Retrieved May 2022, from Cambridge Dictionary: https://dictionary.cambridge.org/dictionary/english/unleash

Cambridge University Press. (2022b). *Meaning of weight in English*. Retrieved from Cambridge Dictionary: https://dictionary.cambridge.org/dictionary/english/weight

Cambridge University Press. (2022c). *Meaning of austerity in English*. Retrieved August 2022, from Cambridge Dictionary: https://dictionary.cambridge.org/dictionary/english/austerity

Cambridge University Press. (2022d). *Meaning of synergy in English.* Retrieved August 2022, from Cambridge Dictionary: https://dictionary.cambridge.org/dictionary/english/synergy

Carr, S. (2007). Participation, power, conflict and change: Theorizing dynamics of service user participation in the social care system of England and Wales. *Critical Social Policy, 27*(6), 266-276.

Chayes, A., & Chayes, A. H. (1995). *The New Sovereignty: Compliance with International Regulatory Agreements.* Cambridge, Massachusetts and London, England: Harvard University Press.

Chertkovskaya, E., & Stoborod, K. (2018). Work. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 188-202). Abingdon: Routledge.

Cheston, R., & Bender, M. (2004). *Understanding Dementia: The Man with the Worried Eyes.* London: Jessica Kingsley Publishers.

Chevalier, J. M., & Buckles, D. J. (2019). *Participatory Action Research: Theory and Methods for Engaged Inquiry.* Abingdon: Routledge.

Clark, J. P. (2009). Anarchy and the dialetic of utopia. In L. Davis, & R. Kinna, *Anarchism and utopianism* (pp. 9-32). Manchester and New York: Manchester University Press.

Clark-McGhee, K., & Castro, M. (2015). A narrative analysis of poetry written from the words of people given a diagnosis of dementia. *Dementia, 14*(1), 9-26.

Clements, J., & Rapley, M. (1996, February). Go to the mirror! *Clinical Psychology Forum*, pp. 4-7.

Cook, J. (2011). The socio-economic contribution of older people in the UK. *Working with Older People, 15*(4), 141-146.

Cordon, A., & Sainsbury, R. (2006). Exploring 'Quality': Research Participants' Perspectives on Verbatim Quotations. *International Journal of Social Research Methodology, 9*(2), 97-100.

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*(9), 875-884.

CQC. (2019). *Our human rights approach for how we regulate health and social care services.* Retrieved February 2022, from https://www.cqc.org.uk/sites/default/files/20200922_Our_human_rights_approach_post_consultation_document_FINAL_WEB_accessible.pdf

Critical Therapy Institute. (2014, November 23). *In Memory of Ignacio Martin-Baró*. Retrieved 2020 March, from Critical Therapy Institute: https://criticaltherapy.org/2014/11/23/in-memory-of-ignacio-martin-baro/

CSCI and Healthcare Commission. (2006). *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust.* London: Commission for Healthcare Audit and Inspection.

Cuddy, A. J., Fiske, S. T., & Glick, P. (2007). The BIAS map: Behaviors from intergroup affect and stereotypes. *Journal of Personality and Social Psychology, 92*(4), 631-648.

Cuddy, A. J., Fiske, S. T., Kwan, V. S., Glick, P., et al., (2009). Stereotype content model across cultures: Towards universal similarities and some differences. *British Journal of Social Psychology, 48*(1), 1-33.

Curran, J., Gurevitch, M., & Woolacott, J. (1982). The study of the media: Theoretical Approaches. In M. Gurevitch, T. Bennett, J. Curran, & J. Woollacott, *Culture, society and the media* (pp. 11-29). New York: Methuen and Co.

Curtice, M. J., & Exworthy, T. (2010). FREDA: A human rights-based approach to healthcare. *The Psychiatrist, 34*(4), 150-156.

D'Amato, A. (2010). A Few Steps Toward an Explanatory Theory of International Law. *Santa Clara Journal of International Law, 7*(2), 1-24.

Deacon, B. (2013, April 6). *English Identity in Cornwall*. Retrieved from Cornish studies resources Cornwall: history, surnames and society, from Bernard Deacon: https://bernarddeacon.com/identities/english-identity/

Deacon University Library. (2017). *Search tips and planning.* Retrieved Sept 2018, from Deacon University Library: https://www.deakin.edu.au/__data/assets/word_doc/0006/2054247/Search-planner.docx

Degener, T. (2017). 10 years of Convention on the Rights of Persons with Disabilities. *Netherlands Quarterly of Human Rights, 35*(3), 152-157.

Della Fina, V. (2017). Article 3 [General Principles]. In V. Della Fina, R. Cera, & G. Palmisano, *The United Nations Convention on the Rights of Persons with Disabilities* (pp. 119-136). Cham: Springer.

Denborough, D. (2008). *Collective Narrative Practice: Responding to individuals, groups, and communities who have experienced trauma.* Adelaide: Dulwich Centre Publications.

Department of Health. (2015). *Dementia 2020 Citizens' Engagement Programme.* London: Crown Copyright.

Department of Health & Social Care. (2021, January 1). *Guidance: The NHS Constitution.* Retrieved February 2022, from https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

Department of Health. (2009). *Living Well with Dementia.* London: Crown Copyright.

Department of Health. (2010). *A Vision for Adult Social Care: Capable Communities and Active Citizens.* Retrieved May 2022, from http://www.cpa.org.uk/cpa_documents/vision_for_social_care2010.pdf

Department of Health. (2015). *Dementia 2020 Citizens' Engagement Programme.* London: Crown Copyright.

Dewing, J. (2019). On being a person: Commentary by Jan Dewing. In T. Kitwood, & D. Brooker, *Dementia Reconsidered, Revisited: The person still comes first* (pp. 17-23). London: Open University Press.

Di Lorito, C., Birt, L., Poland, F., Csipke, E., Gove, D., Diaz-Ponce, A., & Orrell, M. (2017). A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia. *International Journal of Geriatric Psychiatry, 32*(1), 58-67.

Dixon, J., Laing, J., & Valentine, C. (2020). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia, 19*(2), 221-236.

Donald, A. (2012). *A Guide to Evaluating Human Rights-Based Interventions in Health and Social Care.* London Metropolitan University, Human Rights and Social Justice Research Institute.

Doniger, W. (2015). Foreward: The Mahabharata, a Text for All Seasons. In C. Satamurti, *Mahabharata: A Modern Retelling* (pp. 21-33). New York and London: W. W. Norton & Company.

Donnelly, J. (2013). *Universal Human Rights in Theory and Practice.* Ithaca, New York: Cornell University Press.

Downs, M. (2000). Dementia in a socio-cultural context: An idea whose time has come. *Ageing & Society, 20*, 369-375.

Durkheim, E. (1925/1961). *Moral education: A study in the theory and application of the sociology of education.* New York and London: The Free Press of Glencoe.

Earle, J. (1865). *Two of the Saxon Chronicles: Parallel.* London: Macmillan and Co.

Elder, G. H., & Shanahan, M. J. (2006). The Life Course and Human Development. In R. M. Lerner, *Handbook of Child Psychology: Volume 1: Theoretical Models of Human Development.* Hoboken, New Jersey: John Wiley & Sons, Inc.

Elliot, I. (2016). *Poverty and Mental Health: A review to inform the Joseph Rowntree Foundation's Anti-Poverty Strategy.* London: Mental Health Foundation.

European Network of National Human Rights Institutions ENNHRI. (2017). *Respect My Rights: An ENNHRI Toolkit on Applying a Human Rights-Based Approach to Long-term Care for Older Persons.* Retrieved 2021 August, from http://ennhri.org/wp-content/uploads/2019/10/ennhri_17_005_toolkit_for_care_providers-03a-page.pdf

Evans, S., Waller, S., Bray, J., & Atkinson, T. (2019). Making Homes More Dementia-Friendly through the Use of Aids and Adaptations. *Healthcare, 7*(43), 1-11.

Fasel, R. (2018). 'Simply in virtue of being human'? A critical appraisal of a human rights commonplace. *Jurisprudence, 9*(3), 461-485.

Feyerabend, P. (2011). *The Tyranny of Science.* Cambridge: Polity Press.

Feyerabend, P. (1987). *Farewell to Reason.* London & New York: Verso.

Feyerabend, P. (2010). *Against Method: Outline of an Anarchistic Theory of Knowledge.* London: Verso.

Fink, C. (2004). *Defending the Rights of Others: The Great Powers, the Jews and International Minority Protection, 1878-1938.* Cambridge: Cambridge University Press.

Fischer, C., Malycha, C. P., & Schafmann, E. (2019, February 4). The Influence of Intrinsic Motivation and Synergistic Extrinsic Motivators on Creativity and Innovation. *Frontiers in Psychology, 10*.

Fiske, S. T. (2018). Stereotype Content: Warmth and Competence Endure. *Current Directions in Psychological Science, 27*(2), 67-73.

Fiske, S. T., Cuddy, A. J., Glick, P., & Xu, J. (2002). A model of (often mixed) stereotype content: Competence and warmth respectively follow from perceived status and competition. *Journal of Personality and Social Psychology, 82*(6), 878-902.

Fletcher, D. R., & Wright, S. (2018). A hand up or a slap down? Criminalising benefit claimants in Britain via strategies of surveillance, sanctions and deterrence. *Critical Social Policy, 38*(2), 323-344.

Forsund, L. H., Grov, E. K., Helvik, A.-S., Juvey, L. K., Skovdahl, K., & Eriksen, S. (2018). he experience of lived space in persons with dementia: a systematic meta-synthesis. *BMC Geriatrics, 18*(33).

Franks, B. (2018). Prefiguration. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 28-43). Abingdon: Routledge.

Franks, B., Jun, N., & Williams, L. (2018). *Anarchism: A Conceptual Approach.* Abingdon: Routledge.

Freire, P. (1970). *Pedagogy of the oppressed.* Harmondsworth: Penguin.

French, R. (2003). *Medicine Before Science: The Rational and Learned Doctor from the Middle Ages to the Enlightenment.* Cambridge: Cambridge University Press.

Frideres , J. S. (1992). Participatory Research: An Illusionary Perspective . In J. S. Frideres, *A World of Communities: Participatory Research Perspectives* (pp. 1-13). North York, Ontario: Captus University Publications.

Froggatt, K., & Hockley, J. (2011). Action research in palliative care: defining an evaluation methodology. *Palliat Med, 25*(8), 782-7.

Garand, L., Lingler, J. H., Conner, K. O., & Dew, M. A. (2009). Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in gerontological nursing, 2*(2), 112-121.

Gneezy, A., & Epley, N. (2014). Worth Keeping but Not Exceeding: Asymmetric Consequences of Breaking Versus Exceeding Promises. *Social Psychological and Personality Science, 5*(7), 796-804.

Goddard, A., Brookes-Smith, C., Henshaw, E., Place, K., St Ledger, S., Curvis, W., & Campbell, B. (2021, April). *Position Statement: The Impact of Class in Clinical Psychology.* Retrieved August 2022, from #ClassClinPsych: ttps://www.researchgate.net/publication/350837301

Goffman, E. (1963). *Stigma: Notes on the management of spoiled Identity.* New Jersey: Prentice Hall.

Goggans, N. (2013, March 25). *Narrative Therapy: "Tree of Life" Activity:* Retrieved January 2020, from Prezi: https://prezi.com/nf7d-k0k4zn3/narrative-therapy-tree-of-life-activity/

Goldman, E. (1909, July). A New Declaration of Independence. *Mother Earth, 4*(5).

Goodway, D. (2012). *Anarchist Seeds beneath the Snow: Left-Libertarian Thought and British Writers from William Morris to Colin Ward.* Oakland: PM Press.

Gordon, U. (2010). Power and Anarchy: In/equality + In/visibility in Autonomous Politics. In N. J. Jun, & S. Wahl, *New Perspectives on Anarchism* (pp. 39-66). Plymouth: Lexington Books.

Gordon, U. (2018). Revolution. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 86-98). Abingdon: Routledge.

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., . . . The European Working Group of People with Dementia. (2018). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health, 22*(6), 723-729.

Governwell. (2013). *NHS Providers.* Retrieved August 2022, from So you are thinking about becoming a governor…: https://nhsproviders.org/media/1093/1pre-induction-text-version.pdf

Greenhill, B., & Golding, L. (2018). Human rights and critical psychology. In C. Newnes, & L. Golding, *Teaching Critical Psychology: International Perspectives.* London: Routledge Taylor & Francis Group.

Greenwood, N., Habibi, R., Smith, R., & Manthrope, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health and Social Care in the community, 23*(1), 64-67.

Gross, L. (1948). The Peace of Westphalia, 1648-1948. *The American Journal of International Law, 42*(1), 20.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth Generation Evaluation.* Newbury Park: SAGE Publications.

Guzman, A. T. (2002). A Compliance-Based Theory of International Law. *California Law Review, 90*(6), 1823-1887.

Hansard Society. (2019). *Audit of Political Engagement 16: The 2019 Report.* London: Hansard Society.

Harding, N., & Palfrey, C. (1997). *The Social Construction of Dementia.* London: Jessica Kingsley Publishers.

Harding, N., & Palfrey, C. (1998). *The Social Construction of Dementia: Confused Professionals?* London: Jessica Kingsley.

Hare, B., & Woods, V. (2021). *Survival of the Friendliest: Understanding Our Origins and Rediscovering Our Common Humanity.* New York: Random House.

Harper, D. (2005). The critical professional and social policy: negotiating dilemmas in the UK Mental Health Act campaign. *International Journal of Critical Psychology, 13*, 55-75.

Harris, P. B., & Caporella, C. A. (2014). An Intergenerational Choir Formed to Lessen Alzheimer's Disease Stigma in College Students and Decrease the Social Isolation of People With Alzheimer's Disease and Their Family Members: A Pilot Study. *American Journal of Alzheimer's Disease and Other Dementias, 29*(3), 270-281.

Heckert, J. (2013). An Other State of Mind is Possible: Anarchism and Psychology. *Social and Personality Psychology Compass, 7*(8), 513-525.

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3), 353-363.

Henkin, L. (1979). *How Nations Behave: Law and Foreign Policy.* New York: Columbia University Press.

Herman, E. S. (1992). *Beyond Hypocrisy: Decoding the News in an Age of Propaganda.* Boston: South End Press.

Herman, E. S., & Chomsky, N. (2008). *Manufacturing Consent: The Political Economy of the Mass Media.* London: The Bodley Head, Random House.

Heron, J., & Reason, P. (1997). A Participatory Inquiry Paradigm. *Qualitative Inquiry, 3*(3), 274-294.

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can we move the Stigma Dial? *The American Journal of Geriatric Psychiatry, 26*(3), 316-331.

Hill, M. (1984). Epistemology, Axiology, and Ideology in Sociology. *Mid-America Review of Sociology, 9*(2), 59-77.

Himmerich, J. (2019). *Male clinical psychologists: role of the male gender in therapy and on the route to qualification.* PhD Thesis, Canterbury Christ Church University, Salomons Centre for Applied Psychology.

Hobbes, T. (1651/2017). *Leviathan.* London: Penguin Classics.

Hogue, R. J. (2015). *Developing an Appreciative Understanding of Epistemologies in Educational Research - One Bloggers Journey.* Retrieved 2021 December, from https://www.researchgate.net/publication/275834166_Developing_an_Appreciative_Understanding_of_Epistemologies_in_Educational_Research_-_One_Blogger's_Journey/link/554853b10cf26a7bf4dabd0f/download

Hsu, R. H.-C. (2021). *Emma Goldman, Mother Earth, and the Anarchist Awakening.* Notre Dame, Indiana: University of Notre Dame Press.

Hughes, T., & Castro Romero, M. (2015). A processural consent methodology with people diagnosed with dementia. *Quality in Ageing and Older Adults, 16*(4), 222-234.

Hunt, D. A. (2011). *The Lived Experience Of Young-onset Dementia.* Retrieved December 2022, from Electronic Theses and Dissertations, 2004-2019: https://stars.library.ucf.edu/etd/2053

Hunt, R. (1881). *Popular Romances of the West of England or The Drolls, Traditions, and Superstitions of Old Cornwall.* London: Chatto and Windus.

Ilbanez, T. (2019). *Anarchism is Movement.* London: Freedom Press.

Jankowski, P. J. (1998). Columbo therapy as one-down positioning with families. In T. S. Nelson, & T. S. Trepper, *101 More Interventions in Family Therapy* (pp. 73-76). New York: Routledge.

Jenco, L. (2013). Revisiting Asian Values. *Journal of the History of Ideas, 74*(2), 237-258.

Jeppesen, S. (2018). DIY. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 203-218). Abingdon: Routledge.

Jewell, A. (2019). Dementia: Are we all on the spectrum? *Journal of Religion, Spirituality & Aging, 31*(3), 255-268.

Johnson, H. F. (2016). Exploring the Lived Experience of People with Dementia Through Interpretative Phenomenological Analysis. *The Qualitative Report, 21*(4), 695-711.

Joseph, J. (2013). Resilience as embedded neoliberalism: a governmentality approach. *Resilience, 1*(1), 38-52.

Jourard, S. M. (1968). *Disclosing Man to Himself.* New York, Chicago, San Francisco: Van Nostrand Company.

Jourard, S. M. (1971). *The Transparent Self.* New York, Cincinnati, Millbrae: D. Van Nostrand Company.

Judge, A. (2007). *Linguistic Policies and Survival of Regional Languages in France and Britain.* Basingstoke, Hampshire: Palgrave Macmillan.

Jun, N. (2018). Freedom. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 44-59). Abingdon: Routledge.

Kagan, C., & Burton, M. (2001). *Critical community psychological praxis for the 21st century: Working Paper.* Manchester Metropolitan University, IOD Research Group.

Kara, H. (2015). *Creative Research Methods in the Social Sciences: A Practical Guide.* Bristol: Policy Press.

Katz, E. (2015). Where Are Opinion Leaders Leading Us? *International Journal of Communication, 9*, 1023-1028.

Katz, E., & Lazarsfeld, P. F. (1955). *Personal influence: the part played by people in the flow of mass communications.* New York: Free Press.

Kesby, M., Kindon, S., & Pain, R. (2007). Participation as a form of power: Retheorising empowerment and spatialising participatory research. In S. Kindon, R. Pain, & M. Kesby, *Participatory Action Reseach approaches and methods: Connecting people, participation and place.* London: Routledge.

Kidd, S., & Kral, M. (2005). Practicing particpatory action research. *Journal of Counseling Psychology*, 187-195.

Kirkhope, J. (n.d.). *The Cornwall Foreshore Case.* Retrieved from Academia.Edu: https://www.academia.edu/36183726/THE_CORNWALL_FORESHORE_CASE

Kitwood, T. (1988). The contribution of psychology to the understanding of senile dementia. In B. Gearing, M. Johnson, & T. Heller, *Mental Health Problems in Old Age: A reader.* Chichester: John Wiley & Sons.

Kitwood, T. (1989). Brain, mind and dementia: with particular reference to Alzheimer's disease. *Aging and Society, 9*(1), 1-15.

Kitwood, T. (1990). On Organsations: their imperatives and constraints. In *Concern for Others: A new psychology of conscience and morality.* London: Routledge.

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing and Society, 10*(2), 177-196.

Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatic Psychiatry, 8*(7), 541-545.

Kitwood, T. (1994). The concept of personhood and its relevance for a new culture of dementia care. In G. Jones, & B. Miesen, *Caregiving in Dementia.* London: Routledge.

Kitwood, T. (1996). A dialectical framework for dementia. In R. T. Woods, *Handbook of the Clinical Psychology of Ageing.* London: John Wiley & Sons.

Kitwood, T. (1997). On being a person. In *Dementia Reconsidered: The person comes first.* Buckingham: Open University Press.

Kitwood, T. (1998). Towards a theory of dementia care: ethics and interaction. *Journal of Clinical Ethics, 9*(1), 23-34.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society, 12*(3), 269-287.

Kitwood, T., & Brooker, D. (2019). *Dementia Reconsidered, Revisited: The Person Still Comes First.* London: Open University Press.

Klapper, J. T. (1960). *The effects of mass communication.* New York: Free Press.

Klocker, N. (2015). Participatory action research: The distress of (not) making a difference. *Emotion, Space and Society, 17*, 37-44.

Kock, A. M. (1993). Poststructuralism and Epistemological Basis of Anarchism. *The Philosophy of the Social Sciences, 23*(3), 327-351.

Koot, S. (2020, Oct 9). Articulations of inferiority: From pre-colonial to post-colonial paternalism in tourism and development among the indigenous Bushmen of Southern Africa. *History and Anthropology*.

Koschorke, M., Evans-Lacko, S., Sartorius, N., & Thornicroft, G. (2017). Stigma in Different Cultures. In W. Gaebel, W. Rossler, & N. Sartorius, *The Stigma of Mental Illness - End of the Story?* Cham: Springer.

Kropotkin, P. (1902/2019). *Mutual Aid: A Factor of Evolution.* Retrieved 2021 December, from The Anarchist Library: https://theanarchistlibrary.org/library/petr-kropotkin-mutual-aid-a-factor-of-evolution

Kropotkin, P. (1903/2012). *Modern Science and Anarchism*. Retrieved 2022 August, from The Anarchist Library: https://theanarchistlibrary.org/library/petr-kropotkin-modern-science-and-anarchism

Kurtz, C. F. (2014). *Working with Stories in Your Community or Organization: Participatory Narrative Inquiry.* Mountain View, California: Creative Commons.

Lalancette, M. F., & Standing, L. G. (1990). Asch fails again. *Social Behaviour and Personality: An International Journal, 18*(1), 7-12.

Lather, P. (1986). Research as Praxis. *Harvard Educational Review, 53*(3), 257-278.

Lather, P. (1996). Troubling Clarity: The Politics of Accessible Language. *Harvard Educational Review, 66*(3), 525-546.

Latimer, J. (2018). Repelling neoliberal world-making? How the ageing–dementia relation is reassembling the social. *The Sociological Review, 66*(4), 832-856.

Lawlor, D. (2009). Test of Time: A Case Study in the functioning of Social Systems as a Defence Against Anxiety: Rereading 50 Years On. *Clinical Child Psychology and Psychiatry, 14*(4), 523-530.

Lazar, H. (2018). Intersectionality. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 157-174). Abingdon: Routledge.

Leier, M. (2006). *Bakunin: The Creative Passion.* New York: St. Martin's Press.

Leopold, D. (2019). *Max Stirner*. Retrieved December 2022, from The Stanford Encyclopedia of Philosophy: https://plato.stanford.edu/archives/win2019/entries/max-stirner

Levac, L., Ronis, S., Cowper-Smith, Y., & Vaccarino, O. (2019). A scoping review: The utility of participatory research approaches in psychology. *Journal of Community Psychology, 47*(8), 1865-1892.

Levin, M. (2008). The Praxis of Educating Action Researchers. In P. Reason, & H. Bradbury, *The SAGE Handbook of Action Research: Participative Inquiry and Practice. Second Edition* (pp. 669-682). London: SAGE Publications Ltd.

Lewis, F. (2015). *Estimation of future cases of dementia from those born in 2015.* Office of Health Economics.

Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft , L. (2014). *The Trajectory of Dementia in the UK - Making a Difference.* Office of Health Economics and Alzheimer’s Research UK.

LGA. (2014). *Transforming local public services using technology and digital tools and approaches.* Retrieved May 2022, from Local Government Association: https://www.local.gov.uk/digital-transformation-programme

LGA. (2022a). *The role of a councillor*. Retrieved May 2022, from Local Government Association: https://www.local.gov.uk/our-support/councillor-development/new-councillor-hub/role-councillor

LGA. (2022b, March 23). *Public health staff shortage and exhaustion warning as COVID-19 infection rates rise*. Retrieved from Local Government Association: https://www.local.gov.uk/about/news/public-health-staff-shortage-and-exhaustion-warning-covid-19-infection-rates-rise

LII. (2020). *Magna Carta*. Retrieved November 2022, from WEX Library: https://www.law.cornell.edu/wex/magna_carta

Lindsey, J. R. (2013). *The Concealment of the State.* London: Bloomsbury Academic.

Link, B. G., & Phelan, J. (2014). Stigma power. *Social science & medicine (1982), 103*, 24-32.

Link, B. G., & Phelan, J. C. (2001). Conceptualising Stigma. *Annual Review of Sociology, 27*, 363-385.

Link, B. G., & Phelan, J. C. (2010). Labelling and Stigma. In T. L. Scheid, & T. N. Brown, *A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems* (pp. 571-587). Cambridge: Cambridge University Press.

Link, B. G., & Phelan, J. C. (2013). Labelling and stigma. In C. S. Aneshensel, J. C. Phelan, & A. Bierman, *Handbook of the sociology of mental health* (pp. 525-541). Berlin: Springer Science + Business Media.

Littlechild, R., Tanner, D., & Hall, K. (2015). Co-research with older people: Perspectives on impact. *Qualitative Social Work, 14*(1), 18-35.

Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (n.d.). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology, 23*(3), 283-99.

Lyman, K. A. (1989). Bringing the Social Back in: A Critique of the Biomedicalization of Dementia. *The Gerontologist, 29*(5), 597-605.

Macdonald, K., & Morgan, H. M. (2020). The impact of austerity on disabled, elderly and immigrants in the United Kingdom: a literature review. *Disability & Society, 36*(7), 1-23.

MacKinnon, K. (2021). *Papers on Cornwall and the Cornish Language: 2nd Edition.* (M. Davies-Deacon, Ed.) Merryn Davies-Deacon.

Magnusson, L., Nolan, M. R., Hanson, E., Berthold, H., & Bengt-Arne, A. (2001). Developing partnerships with older people and their family carers: The Äldre Väst Sjuhärad model. *Quality in Ageing, 2*(2), 32-38.

Mallinson, D. J., & Hatemi, P. K. (2018). The effects of information and social conformity on opinion change. *PloS OnE, 13*(5), Article 20196600.

Mann, J., & Hung, L. (2019). Co-research with people living with dementia for change. *Action Research, 17*(4), 573-590.

Mark, K. (1845/2002). *Thesis on Feuerbach.* Retrieved December 2021, from Marx/Engles Internet Archive: https://www.marxists.org/archive/marx/works/1845/theses/theses.pdf

Martín-Baró, I. (1994). The Role of the Psychologist. In *Writings for a liberation psychology (Aron, A. & Corne, A. Eds.).* Cambridge, MA: Harvard University Press.

Maslow, A. H. (1858b). The Mission Of The Psychologist: Part 2. *MANAS Journal, XI*(18), 1-6.

Maslow, A. H. (1958a). The Mission Of The Psychologist: Part 1. *MANAS Journal, XI*(17), 1-5.

Mayeda, E. R., Glymour, M., Quesenberry, C. P., Johnson, J. K., Perez-Stable, E. J., & Whitmer, R. A. (2017). Survival after dementia diagnosis in five racial/ethnic groups. *Journal of Alzheimer's & Dementia:* (13), 761-769.

McDevitt, D. (1998). How effective is the cascade as a method for disseminating ideas? A case study in Botswana. *International Journal of Educational Development, 18*(5), 425-428.

McKay, I. (2018). Organisation. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 115-128). Abingdon: Routledge.

McNiiff, J., & Whitehead, J. (2006). *All You Need to Know About Action Research.* London: SAGE.

McTaggart, R. (1994). Participatory Action Research: issues in theory and practice. *Eduational Action Research, 2*(3), 313-337.

Mehta, N., & Talwar, G. (2022). Recognizing Roots and Not Just Leaves: The Use of Integrative Mindfulness in Education, Research, and Practice. *Psychology from the Margins, 4*(6).

Mendez, J. E. (2013). *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.* United Nations.

Mental Health Foundation. (2015, August). *Dementia, rights, and the social model of disability: A new direction for policy and practice?* Retrieved March 2022, from https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-policy-discussion.pdf

Menzies, I. (1960). A case-study in the functioning of social systems as a defence against anxiety. A report on a study of the nursing service of a general hospital. *Human Relations, 12*(2), 95-121.

Midgley, G. (2000). Methodological Pluralism. In *Systemic Intervention. Contemporary Systems Thinking* (pp. 171-216). Boston: Springer.

Millard, C., & Wessely, S. (2014). Parity of esteem between mental and physical health. *BMJ, 349*.

Mills, J. (2010). Genocide and Ethnocide: The Suppression of the Cornish Language. In J. Partridge, *Interfaces in Language* (pp. 189-206). Cambridge Scholars.

Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health, 19*(3), 227-233.

Minker, M., & Wallerstein, N. (2003). *Community based participatory research for health.* New York City: Jossey-Bass/Wiley.

Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard, 30*(7), 46-50.

Mohan, J., & Breeze, B. (2016). *The Logic of Charity: Great Expectations in Hard Times.* Basingstoke: Palgrave Macmillan.

Monitor. (2013, August). *Your statutory duties A reference guide for NHS foundation trust governors.* Retrieved from In association with: Care Quality Commission, Department of Health, Foundation Trust Governors Association and Foundation Trust Network: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/284473/Governors_guide_August_2013_UPDATED_NOV_13.pdf

Moore, J. (2012). Lived poetry: Stirner, anarchy, subjectivity and the art of living. In J. Purkis, & J. Bowen. Manchester: Manchester University Press.

Mr A Britliff V Birmingham City Council, UKEAT/0291/18/BA (Employment Appeal Tribunal judgment of Judge Auerbach August 16, 2019).

Munsche, H., & Whitaker, H. A. (2012). Eighteenth century classification of mental illness: Linnaeus, de Sauvages, Vogel, and Cullen. *Cognitive and behavioral neurology: official journal of the Society for Behavioral and Cognitive Neurology, 25*(4), 224-239.

Ncube, N. (2006). The Tree of Life Project: Using Narrative ideas in work with vulnerable children in Southern Africa. *The International Journal of Narrative Therapy and Community Work*, 3-16.

Nelson, G., & Prilleltensky, I. (2010a). Social Interventions. In *Community Psychology: In Pursuit of Liberation and Well-Being* (pp. 173-200). Basingstoke: Palgrave Macmillan.

Nelson, G., & Prilleltensky, I. (2010b). Organisational and Community Interventions. In *Community Psychology: In Pursuit of Liberation and Wellbeing* (pp. 201-226). Basingstoke: Palgrave Macmillan.

Newnes, C. (2016). *Inscription, Diagnosis, Deception and the Mental Health Industry: How Psy Governs Us All.* Basingstoke: Palgrave Macmillan.

Newnes, C. (2021). *Racism in Psychology: Challenging Theory, Practice and Institutions.* Oxford: Routledge.

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia, 19*(2), 148-181.

NHS England. (2016). *NHS England Transformation Framework: The Well Pathway for Dementia.* Retrieved 2022 May, from England.nhs.uk: https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf

Niaz, M. (2020). *Feyerabend's Epistemological Anarchism: How Science Works and its Importance for Science Education.* Cham: Springer Nature Switzerland AG.

NICE. (2018). *Dementia: assessment, management and support for people living with dementia and their carers.* National Institute of Clinical Excellence.

Nolan, M. R., Hanson, E., Magnusson, L., & Andersson, B. (2003). Guaging quality in constructivist research: the Aldre Vast Sjuharad model revisited. *Quality in Ageing, 4*(2), 22-27.

O'Connor, D., Mann, J., & Wiersma, E. (2018). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping socail citizenship. *Journal of aging studies, 44*, 45-51.

Ognyanova, K. (2017). Multistep Flow of Communication: Network Effects. In P. Roessler, C. Hoffner, & L. Van Zoonen, *The International Encyclopedia of Media Effects* (pp. 1-10). New York: Wiley-Blackwell.

OHCHR. (u.d). T*he Core International Human Rights Instruments and their monitoring bodies*. Retrieved June 2021, from United Nations Office of the High Commissioner: https://www.ohchr.org/en/core-international-human-rights-instruments-and-their-monitoring-bodies

Oliver, M. (2013). The social model of disability: thirty years on. *Disability & Society, 28*(7), 1024-1026.

Olsen, R. (2008). Self-selection bias. In P. J. Lavrakas, *Encyclopedia of survey research methods* (pp. 809-809). Newbury Park: Sage Publications, Inc.

Ordonez, V. (2018). Direct Action. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 74-85). Abingdon: Routledge.

Oropeza, I. D., Pereira, M. F., Pineda, L. M., & Prada, P. V. (2020). *Psychology and Pathologies of capitalism, 7*.

O'Sullivan, G., & Hocking, C. (2013). Translating Action Research into Practice: Seeking Occupational Justice for People with Dementia. *Occupational, Participation and Health, 33*(3), 168-176.

Ottosson, S. (2003). Participation action research: A key to improved knowledge of management. *Technovation, 23*, 87-94.

Pūras, D. (2017). *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.* A Report to the United Nations Human Rights Office of the High Commissioner, United Nations.

Pain, R., Whitman, G., & Milledge, D. (2012). *Participatory Action Research Toolkit: An introduction to using PAR as an approach to learning, research and action.* Durham: Durham University.

Paluk, E. L., Green, S. A., & Green, D. P. (2019). The contact hypothesis re-evaluated. *Behaviour Public Policy, 3*(2), 129-158.

Papousek, I., Ruch, W., Rominger, C., Kindermann, E., Scheidl, K., Schulter, G., . . . Weiss, E. M. (2017). The Use of Bright and Dark Types of Humour is Rooted in the Brain. *Scientific reports, 7*.

Park, Y. S., Konge, L., & Artino, A. R. (2020). The Positivism Paradigm of REsearch. *Academic medicine: journal of the Association of American Medical Colleges, 95*(5), 690-694.

Parker, J., Cutler, C., & Heaslip, V. (2021). Dementia as Zeitgeist: Social Problem, Construction and the Role of a Contemporary Distraction. *Sociological Research Online, 26*(2), 309-325.

Parker, M., Barlow, S., Hoe, J., & Aitken, L. (n.d.). Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International psychgeriatrics*, 1-24. Advanced online publication.

Parson, S. (2018). Ecocentrism. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 219-233). Abingdon: Routledge.

Parsons, L. E. (1905/2010, April 29). *The Principles of Anarchism.* Retrieved August 2022, from The Anarchist Library: https://theanarchistlibrary.org/library/lucy-e-parsons-the-principles-of-anarchism

Partridge, K., Dugmore, P., Mahaffey, H., & Chidgey, M. (2019). 'Step by step, side by side': the quest to create relational artistry through systemic practice within children's social care. *Journal of Family Therapy, 41*(3), 321-342.

Patel, N. (2003). Clinical Psychology: Reinforcing Inequalities or Facilitating Empowerment. *The International Journal of Human Rights, 7*(1), 16-39.

Patel, N. (2020). Criitcal human rights-based approach to applied psychology: context and power. In P. Hagenaars, M. Plavsic, N. Sveaass, U. Wagner, & T. Wainwright, *Human Rights Education for Psychologist* (pp. 61-77). Abingdon: Routledge.

Patel, S. (2020). *An examination of maladaptive perfectionism, perfectionistic self-presentation, wellbeing and the disclosure of mental health difficulties.* UCL.

Patient Safety Learning. (2022, April 7). *Mind the implementation gap: The persistence of avoidable harm in the NHS.* Retrieved from Patient Safety Learning: https://s3-eu-west-1.amazonaws.com/ddme-psl/Mindtheimplementationgap_ThepersistenceofavoidableharmintheNHS_2022-04-07-121554_vhao.pdf

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*(4), 705-725.

Payne, G. (2006). Methodological Pluralism. In V. Jupp, *The SAGE Dictionary of Social Research Methods* (pp. 174-175). London: SAGE Publications.

Pescosolido, B. A., & Martin, J. K. (2015). The Stigma Complex. *Annual review of sociology, 41*, 87-116.

Pescosolido, B. A., Martin, J. K., Lang, A., & Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). *Social Science & Medicine, 67*(3), 431-440.

Pinker, R. (1970/2017). Stigma and Social Welfare. In J. Offer, & R. Pinker, *Social policy and Welfare Pluralism. Selected writings of Robert Pinker.* Bristol: Policy Press.

Portwood-Stacer, L. (2018). Micropolitics. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 129-141). Abingdon: Routledge.

Prince, M., Knapp, M., & Guerchet, M., et al., (2014). *Dementia UK: Update.* Alzheimer's Society.

Quale, A. (2007). Radical Constructivism, and the Sin of Relativism. *Science & Education, 16*, 231-266.

Quinn, J. B. (1982). Managing strategies incrementally. *Omega, 10*(6), 613-627.

Rahman, S. (2017). *Enhancing Health and Wellbeing in Dementia: A Person-Centred Integrated Care Approach.* London: Jessica Kingsley Publishers.

Ramnath, M. (2011). *Decolonising Anarchism.* Oakland: AK Press.

Rioux, M. H. (2003). On Second Thought: Constructing Knowledge, Law, Disability and Inequality. In S. S. Herr, L. O. Gostin, & H. H. Koh, *The Human Rights of Persons with Intellectual Disabilities. Different But Equal* (pp. 287-317). New York: Oxford University Press.

Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiologia e psichiatria sociale,* 18(4), 299-310.

Rollo-Koster, J. (2017, October 2). *body politic: political science*. Retrieved Aug 2022, from Encyclopedia Britannia: https://www.britannica.com/topic/body-politic

Romano, S. (2018). *Moralising Poverty The 'Undeserving' Poor in the Public Gaze.* London and New York: Routledge.

Rowan, J. (2001). The humanistic approach to action research. In P. Reason, & H. Bradbury, *Handbook of action research: Participative inquiry and practice* (pp. 114-123). London: Sage Publications.

Rubino, C., Luksyte, A., Perry, S. K., & Volpone, S. D. (2009). How do stressors lead to burnout? The mediating role of motivation. *Journal of Occupational Health Psychology, 14*(3), 289-304.

Satyamurti, C. (2015). *Mahabharata: A Modern Retelling.* New York and London: W.W. Norton & Company.

Schugurensky, D. (1998). The Legacy of Paulo Freire: A Critical Review of His Contributions. *Convergence, 31*(1/2), 17-29.

Schugurensky, D. (2014). *Paulo Freire.* London: Bloomsbury Publishing.

Seetharaman, K., & Chaudhury, H. (2020). 'I am making a difference': Understanding advocacy as a citizenship practice amongst persons living with dementia. *Journal of aging studies, 52*.

Shannon, D. (2018). Economy. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 142-154). Abingdon: Routledge.

Sherif, M. (1935). A study of some social factors in perception. *Archives of Psychology, 187*.

Simpson, J. R. (2014). DSM-5 and neurocognitive disorders. *The journal of the American Academy of Psychiatry and the Law, 42*(2), 159-164.

Smallcombe, M. (2018, Sept 7). Cornwall is the Second Poorest Region in all of Northern Europe. *Cornwall Live*.

Smith, L., & Phillipson, L. (2021). Thinking through participatory action research with people with late-stage dementia: research note on mistakes, creative methods and partnerships. *International Journal of Social Research Methodology, 24*(6), 775-780.

Smith, L., Shenk, M. K., Tran, C., Poon, D. C., Wabba, R., & Voegtli, K. (2017). "There's Not a Rug Big Enough to Hide Us Under": Participatory Action Research As Anti-Ageist Psychological Practice. *Professional Psychology: Research and Practice, 48*(6), 412-420.

Soussan, A. (2015). From Law as a Means to Law as an End: About the Influence of International Human Rights Law on the Structure of International Law Rules. In N. Weiss, & J. Thouvenin, *The Influence of Human Rights on International Law* (pp. 3-12). Cham: Springer International Publishing.

Sterin, G. J. (2002). Essay on a word: a lived experience of AD. *Dementia, 1*(1), 7-10.

Stirner, M. (1845/1907). *The Ego and His Own.* (T. f. Byington, Ed.) New York: Benj. R. Tucker.

Stroud, N. J., & Choi, S. (2017). Selective Perception and Retention. In P. Rossler, C. A. Hoffner, & L. Zoonen, *The International Encyclopedia of Media Effects.*

Szivos, S. (1992). The Limits to Integration? In H. Brown, & H. Smith, *Normalisation: A Reader for the Nineties* (pp. 112-134). London: Routledge.

Taylor, S., & Field, D. (1993). *Sociology of Health and Health Care.* Oxford: Blackwell Scientific Publications.

Teo, T. (2009). Philosophical concerns in critical psychology. In D. Fox, D. Prilleltensky, & S. Austin, *Critical Psychology: An Introduction.* (pp. 36-53). Thousand Oaks, CA: Sage.

Timmel, S., & Hope, A. (1984). *Training for transformation: A handbook for community workers.* Gweru, Zimbabwe: Mambo Press.

Trentham, B. L., & Neysmith, S. M. (2018). Exercising senior citizenship in an ageist society through participatory action research: A critical occupational perspective. *Journal of occupational science, 25*(2), 174-190.

Troldahl, V., & Van Dam, R. (1965). Face-to-face communication about major topics in the news. *Opinion Quarterly, 29*, 626-634.

Tucker, B. R. (1899). *The Attitude of Anarchism Toward Industrial Combinations.* Retrieved December 2022, from Molinari Institute: https://praxeology.net/BT-AIC.htm

Tyson, S. L. (1932). The Caduceus. *The Scientific Monthly, 34*(6), 492-498.

Ulrich, G., & Wainwright, T. (2020). Human rights and professional identity. In P. Hagenaars, M. Plavsic, N. Sveaass, U. Wagnar, & T. Wainwright, *Human Rights Education for Psychologist* (pp. 79-93). Abingdon: Routledge.

UN Committee on the Rights of Persons with Disabilities (CRPD). (2009, November 18). *Guidelines on treaty-specific document to be submitted by state parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities*. Retrieved April 2021, from https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/2/3&Lang=en

UN Committee on the Rights of Persons with Disabilities. (2017, October 24). *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: Report of the Committee. Retrieved 2022 March, from United Nations Human Rights Treaties Bodies: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f15%2f4&Lang=en

UN Department of Economic and Social Affairs. (2016). *Health and Well-Being in Older Age.* New York.

UN. (u.d). *The Foundation of International Human Rights Law*. Retrieved June 2021, from United Nations: Peace, dignity and equality on a healthy planet: https://www.un.org/en/about-us/udhr/foundation-of-international-human-rights-law

United Nations. (2006, December 13). *Convention on the Rights of Persons with Disabilities*. Retrieved from https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

University of East London. (2022). *UEL Celebrates 125 years of Pioneering Futures*. Retrieved November 2022, from https://uel.ac.uk/about/125-years

Ušto, M., Drače, S., & Hadžiahmetović, N. (2019). Replication of the "Asch Effect" in Bosnia and Herzegovina: Evidence for the Moderating Role of Group Similarity in Conformity. *Psihologijske teme, 28*(3), 589-599.

Van der Flier, W. M., & Scheltens, P. (2005). Epidemiology and risk factors of dementia. *Journal of neurology, neuropsychology, and psychiatry., 5*(76), v2-v7.

Venugopalan, K. V. (2018, December 31). *Mahabharata - An Introduction*. Retrieved from TemplePurohit: https://www.templepurohit.com/mahabharata-an-introduction/

Vikstrom, S., Sandman, P. O., & Stenwall, E., et al., (2015). A model for implementing guidelines for person-centred care in a nursing home setting. *International Psychogeriatrics, 27*(1), 49-59.

Walter, N. (1969, June). About Anarchism. *Anarchy, 9*(6), pp. 161-192.

Warner, J., Milne, A., & Peet, J. (2010). *My name is not dementia: literature review.* London: Alzheimer's Society.

Watts, R. J., Diemer, M. A., & Voight, A. M. (2011). Critical consciousness: current status and future directions. *New directions for child and adolescent development, 134*, 43-57.

Weatherhill, C. (2018, October 24). *County, Duchy, Nation or Country? The Case For Cornwall!* Retrieved November 2022, from Worldwide Cornish e-Magazine: https://www.cornwall24.net/2016/10/county-duchy-nation-or-country-the-case-for-cornwall/

Weber, M. (1946). Politics as a Vocation. In H. H. Gerth, & C. Wright-Mills, *From Max Weber: Essays in Sociology* (pp. 77-128,). Oxford: Oxford University Press.

Weir, K. (2017). Dementia is a psychological disorder. *Monitor on Psychology, 48*(7), 52.

Werner, P. (2014). Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In P. W. Corrigan, *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 223-244). American Psychological Association.

Williams, C. (2007, Summer). Whose Lucy Parsons? The mythologizing and re-appropriation of a radical hero. *Anarcho-Syndicalist Review, 47*.

Williams, L. (2018). Reform. In B. Franks, N. Jun, & L. Williams, *Anarchism: A Conceptual Approach* (pp. 175-187). Abingdon: Routledge.

Williams, M. (2003). Why is Cornwall Poor? Poverty and In-Migration since the 1960s. *Contemporary British History, 17*(3), 55-70.

Wilson, P. H. (2008). The Causes of the Thirty Years War 1618-48. *The Englsh Historical Review, CXXIII*(502), 554-586.

Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., Prina, A. M., Winblad, B., & Prince, M. (2017). The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & dementia: the journal of the Alzheimer's Association, 13*(1), 1-7.

Wolfensberger, W. (2002). *The new genocide of handicapped and afflicted people (3rd ed.).* New York: Syracuse.

Woodcock, G. (1977). *The Anarchist Reader.* Glasgow: William Collins Sons & Co Ltd.

Woodward, W. (2002, May 21). Survival of the fattest as class divide widens. *The Guardian*.

World Health Organisation and Alzheimer's Disease International. (2012). *Dementia: a public health priority.* Geneva: World Health Organisation.

World Health Organisation. (2014). *Social determinants of mental health.* Geneva: World Health Organisation.

World Health Organisation. (2015). *Ensuring a human rights-based approach for people living with dementia.* Retrieved March 2021, from https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf

World Health Organisation. (2015). FIRST WHO MINISTERIAL CONFERENCE ON GLOBAL ACTION AGAINST DEMENTIA. Geneva.

Wright, H. K. (1890). *The Western Antiquary or, Devon and Cornwall Note-book.* Plymouth: W. H. Luke.

Yang, H. D., Kim, D. H., & Young, L. D. (2016). History of Alzheimer's Disease. *Dementia and neurocognitive disorders, 4*(15), 115-121.

Young, J. A., Lind, C., Orange, J. B., & Savundranayagam, M. Y. (2019). Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory. *Journal of Aging Studies, 48*, 76-84.

Zlkens, R. R., Bruce, D. G., Duke, J., Spilsbury, K., & Semmens, J. B. (2014). Severe psychiatric disorders in mid-life and risk of dementia in late- life (age 65-84 years): a population-based case-control study. *Current Alzheimer Research, 7*(11), 681-693.

Zuelsdorff, M., Okonkwo, O. C., & Norton, D., et al., (2020). Stressful Life Events and Racial Disparities in Cognition Among Middle-Aged and Older Adults. *Journal of Alzheimer's diseases: JAD, 2*(73), 671-682.

APPENDICES

Appendix A: Evolution of Dementia Labels

Brands of diagnostic manual have had multiple editions which allow us to notice changes in the medical perception of dementia over time. If we take DSM as an example, we can see how an Organic Brain Syndrome (OBS) characterised by a chronicity and irreversibility was revised into dementia as a concept in DSM-II by the 1980s following a dispute OBS as a construct (Boller and Forbes, 1998). By DSM-IV dementia was listed as a memory impairment accompanied by an aphasia (language), apraxia (coordination), agnosia (sensory processing) or executive functioning (like memory, attention or behaviour) condition that led to a significant decline in occupational or social functioning from previous ability. We reach DSM-V to note a label change to *"Neurocognitive Disorder (NCD)"* with criteria for a *'major NCD'* evidence of significant cognitive decline from a previous level of ability in one or more cognitive domains. DSM-V now drew upon neuropsychology in their construct, rather than diagnoses in their own right (such as aphasia in DSM-IV) and focused on domains of learning and memory, language, executive function, attention, perceptual-motor and social cognition. A diagnosis of Major NCD is given if decline has led to interference in everyday activity. Incidences that do not meet threshold meeting the new criteria for a new diagnosis of mild NCD, indicating introduction of dementia as a spectrum. This change led to concerns raised around the application of NCD to specific medical labels that have come under the dementia umbrella such as Alzheimer's, Parkinson's, or Huntingdon's that might have features which vary on the continuum of mild to major (Simpson, 2014). On the other hand, (Jewell, 2019)) reported evidence too much of a distinction may have been made between elders labelled, and those undiagnosed.

Appendix B: Models of Media

The Hypodermic Needle Model (HNM) of media evolved in the 1920s/1930s from the observation industrialisation had left people detached from a network of stable social relations and, so it was believed, removed from the inherited cultural values reflective of their rural communities. As a result, people were perceived as *‘susceptible and defenceless’* to *‘manipulation and brainwashing’* from an *‘all-powerful’* media (Bineham 1988, Curran, et al., 1982). It was thought the media fired *‘word bullets’* into *‘inert and passive victims’* (Curran et al., 1982), indicating a strong belief in the power of the media over the unconscious.

The paradigm shifted in the 1960’s with a reversal in power relations to a view media was manipulated by people, so it held limited influence (Curran, et al., 1982). This shift called a Limited Effect Model (LEM), was attributed by Bineham (1988) to Katz and Lazarsfeld (1955)’s contention that individual differences in character, values, or subculture affected the media’s power to influence us. Katz and Lazarsfeld (1955) proposed these differences might modify or distort the reception of media messages. Klapper (1960) advanced this by identifying three mechanisms that enable us to manipulate the media; selective exposure, selective perception, and selective retention. The first, selective exposure is an appreciation people choose media based upon their interests, attitudes and social norms, leading to conscious or unconscious avoidance of content, not in keeping with idiosyncrasies. On selective perception, Klapper (1960) reported that even if media was incongruent with our beliefs, classic psychological studies of conformity (Sherif, 1935; Asch, 1951) are considered to hold today (Abrams & Levine, 2012; Mallinson & Hatemi, 2018) indicated habits and social or physical reward mediated perception.
Interestingly, an Asch (1951) replication study by Lalancette and Standing (1990), which failed to reproduce the ‘Asch Effect’; where expression of beliefs was found to be influenced by social responses, is also supportive of Klapper (1960) and Katz and Lazarsfeld (1955). Due to an awareness of other successful replication studies, they declined to reject the Asch Effect but proposed their failure was evidence conformity (as an effect of influence) was not a universal phenomenon. They, too, suggested that the extent of influence was dependent upon dispositional factors, group characteristics or cultural influences. This finding was supported by Ušto, et al., (2019), who found that influence could be enhanced where the in-group was of the majority. The final means Klapper (1960) identified was selective retention, a tendency to recall information consistent with our beliefs. He recognised that this was difficult to distinguish from selective perception, but they add to our understanding as both are individual-level variables that mediate the media’s influence (Stroud & Choi, 2017).

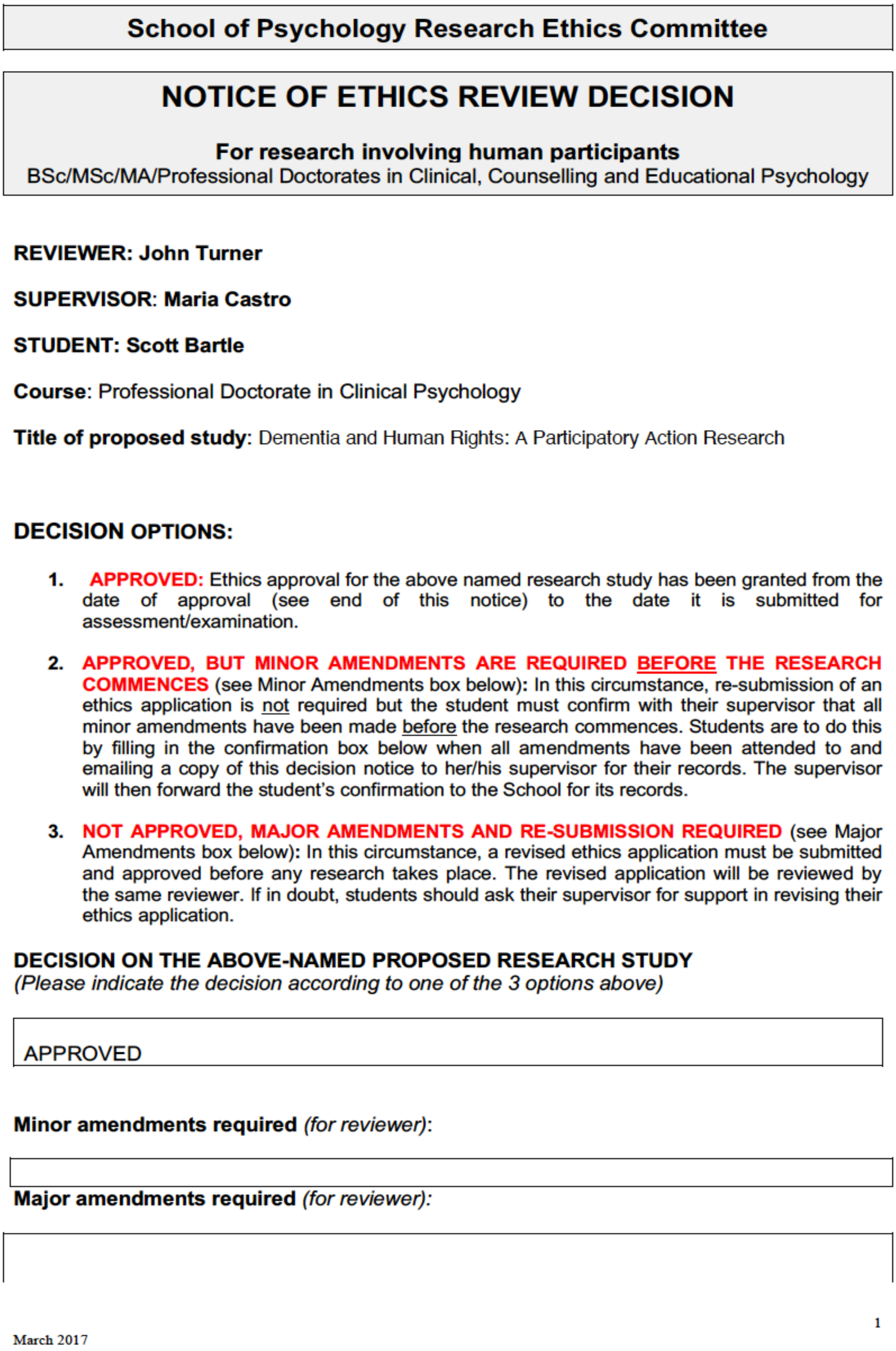
Appendix C: Anarchism Deconstructed (Franks et al., 2018)

Please see following page for table.

	Concept	**Definition**
C	Anti-Hierarchy (Amster, 2018)	A critical analysis of hegemonies surrounding governance, economics, social relations, knowledge production. Movement from power over social relations to ones based on power with, together, in common, or amongst.
	Prefiguration (Franks, 2018)	Knowledge is created by practical activities, where objectives are identified and realized through social practices which unify norms, organization and method to generate internal goods and shared external goods.
	Freedom (Jun, 2018)	A condition marked by achievement of maximal human development or flourishing. Creation of the possible.
	Agency (Bates, 2018)	The extent we are not subject to external forms of coercion, and the extent we can exercise our capacities.
	Direct Action (Ordonez, 2018)	Multiform and unbounded. It encompasses different actors and situations, where oppressed try to overturn power relations. Ends and means are indistinguishable given the correspondence between goals and praxis.
	Revolution (Gordon, 2018)	Rapid social change, abolition of systemic inequalities, and transformation of social structures. To bring lived experience of free association and mutual aid into conflict with logics of command at every feasible opportunity.
A	Horizontalism (Bray, 2018)	Directly democratic, popular mobilization. Culture of openness, rejection of dogma, normalisation of multiplicity.
	Organisation (Mckay, 2018)	The product of an interaction between people, and it is how we associate that determines if we are free.
	Micropolitics (Portwood-Stacer, 2018)	Beliefs about how power should be distributed at the macro level, translated to action at a micro level. Violence of power directed at and felt by the individual, so the individual is key originary point of resistance to power.
	Economy (Shannon, 2018)	A hierarchical arrangement of property, by organized state violence, that reproduces unequal power dynamics.
P	Intersectional (Lazar, 2018)	Universal emancipation. Liberty dependent on freedom for all, from all forms of interlocking domination.
	Reform (Williams, 2018).	To work with a range of opportunities, including political that includes persuading others change is necessary.
	Work	How work defines our status as humans and shapes power relations (Chertkovskaya and Stoborod, 2018).
	DIY (Jeppesen, 2018)	DIY rather than expecting the state or corporations to serve us. Counterhegemonic cultural practices.
	Eco (Parsons, 2018)	Ecocentrism contends civilization is responsible for environmental degradation and human subjugation.

Table to show Core (C), Adjacent (A) and Peripheral (P) concepts to anarchism (Franks et. al., 2018)

Appendix D: Ethical Approval



School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: John Turner

SUPERVISOR: Maria Castro

STUDENT: Scott Bartle

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Dementia and Human Rights: A Participatory Action Research

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer)*:

1

March 2017

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data. Student's name *(Typed name to act as signature):* Student number: Date: *(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: John Turner

Date: 24.09.2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix E: PAR Visual Infographic 1

Dementia

Participation – Action – Research

1

Switching up Research

Traditionally, if Government, NHS or Universities want to know something they do research, but the agenda is generally theirs.
Participants are 'subjects' without a say.

2

It doesn't have to be like this

Nothing should be about you, without you.
Your knowledge.
Your experiences.
Your priorities.
The issues you may be facing, deserve to be heard.
Let me help, by working with you.

3

Participation

You will set the research agenda.
I will share my knowledge of research methods.
Together, we can plan how to generate knowledge.
You will be co-researchers.

4

Take Action

We will carry out the research activities.
We'll think together on what we've found.
Our results will become "scientific evidence".
A knowledge base for what needs to change.
We'll take action upon what we've found.

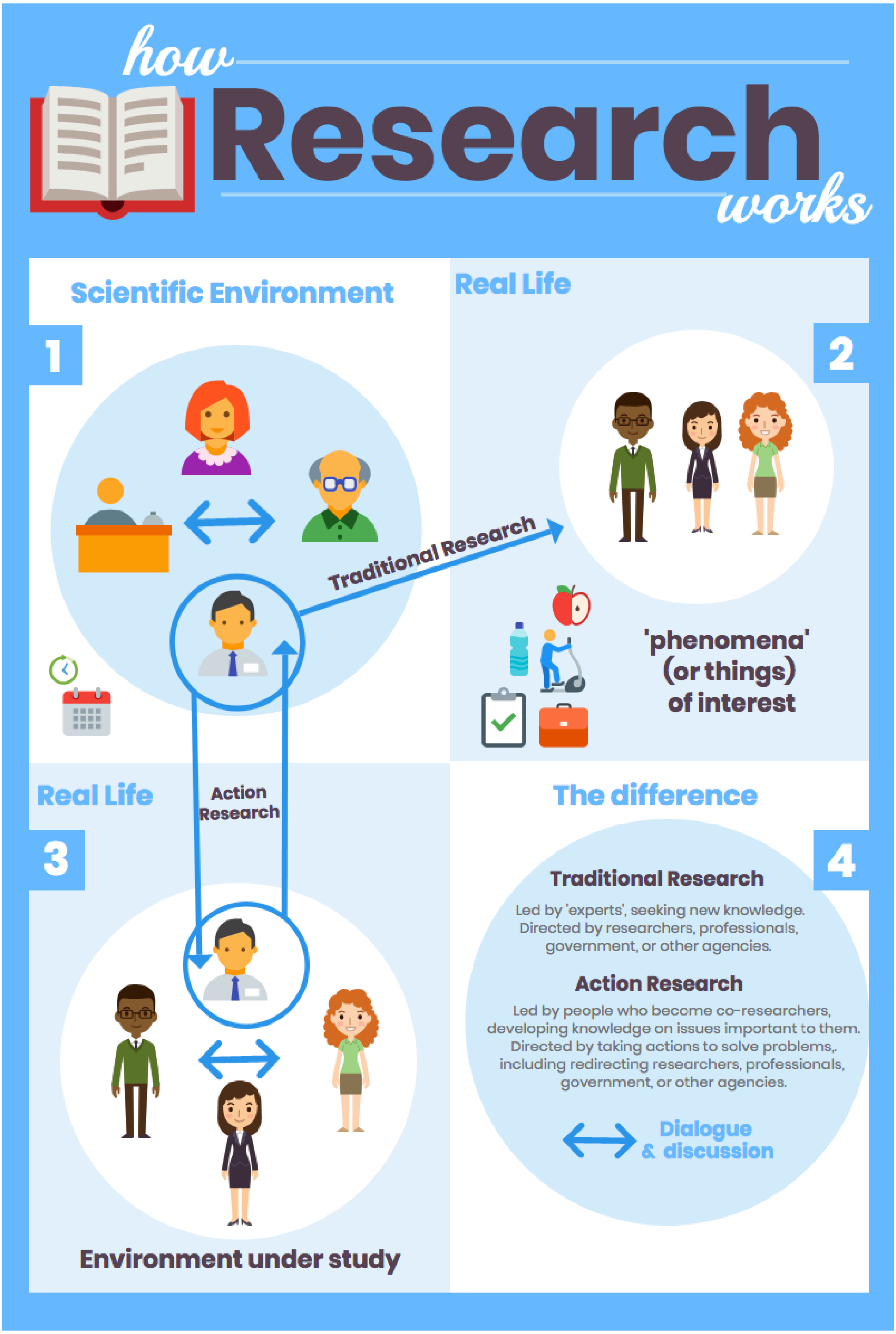
5

Read all about it!

We can share the research we created:
To government, the NHS, commissioners.
Your voices will be heard.

For more information contact: Scott Bartle, Trainee Clinical Psychologist, University of East London. Email: U1622763@uel.ac.uk

Appendix F: PAR Visual Infographic 2



how Research works

Scientific Environment

1

Traditional Research

Real Life

2

'phenomena' (or things) of interest

Real Life

3

Action Research

Environment under study

The difference

4

Traditional Research

Led by 'experts', seeking new knowledge. Directed by researchers, professionals, government, or other agencies.

Action Research

Led by people who become co-researchers, developing knowledge on issues important to them. Directed by taking actions to solve problems,. including redirecting researchers, professionals, government, or other agencies.

↔ Dialogue & discussion

The information in this infographic is derived from a graphic in Ottosson (2003).

Appendix G: Information Sheet and Consent Forms

PARTICIPANT INVITATION LETTER

Dementia and Human Rights: A Participatory Action Research

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

My name is Scott and I am co-ordinating the research in which you are being invited to participate. I have been a carer and, since 2017, I am studying for a Professional Doctorate in Clinical Psychology. As part of my studies we are given an opportunity to contribute to knowledge in an area we are interested in and I would like to promote and protect human rights of people affected by dementia labels, whether they are accepting or rejecting of them.

What is the research?

Traditionally, research is done according to the agenda of organisations (top down) and not to the agenda of people affected by dementia labels, their friends, supporters or family (bottom up). I have chosen bottom up style of research, to work with people affected by dementia labels to generate knowledge and seek to make changes according to their priorities.

All participants would be considered 'co-researchers' and would have an equal say on the entire project developed together. This is known as Participatory Action Research and has a broad remit of Dementia and Human Rights, meaning we can explore the issues that are most important to you. We will decide together what actions can be taken to address what we have found.

The School of Psychology Research Ethics Committee has approved my research. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as someone who is a member of a local community organisation and may be affected by dementia in some way.

What will your participation involve?

If you agree to participate, you will be asked to become a co-researcher and be involved in the planning and design of research with the aim to form a basis for social action.

I will bring my knowledge of research methods to share with co-researchers, and together we can generate knowledge to ensure your issues and challenges are heard.

I will not be able to pay you for participating in the research but your participation would be very valuable in helping to develop knowledge and understanding of this area. However, you can be co-author of any publications following on from this research.

Your taking part will be safe and confidential
Your privacy and safety will be respected at all times. Information will be stored securely for the period of time necessary for transcription and destroyed thereafter.

Co-researchers will not be identified by the data collected, on any written material resulting from the data collected, or in any write up of the research, unless they decide that they want to be.

You can choose to take a break or end your participation at any time.
Consent to participate will be continuously sought through the process.

What will happen to the information that you provide?
All the information you provide for the purposes of the study will be anonymised and stored securely on password protected devices.

The results obtained from the research will be incorporated into a doctoral thesis that will be submitted to the University of East London. The thesis may be published in an academic journal in the future, however, any identifiable data about you will not be included in any report or publication, unless you choose otherwise.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. However, if you withdraw I would reserve the right to use (anonymised) data once analysis has begun.

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Email: [Personal Email Redacted]   Telephone: [Personal Number Redacted]

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Maria Castro Romero,
m.castro@uel.ac.uk
or
the Chair of the School of Psychology Research Ethics Sub-committee: Dr Mary Spiller, m.j.spiller@uel.ac.uk

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Dementia and Human Rights: A Participatory Action Research

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the process in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study that has been fully explained to me. Having given this consent I understand that I have the right to take a break or withdraw from the study at any time without disadvantage to myself and without giving any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………………..

Researcher's Signature

…………………………………………………………………………………………

Date: ……………………..……

Appendix H: Processural Consent Model

1. Establishing basis for consent: staff at the recruitment sites identify people who meet the inclusion criteria. For those who usually involve a carer, friend or relative in their decision making, provide the carer with an information sheet and ask for written or verbal indication as to whether they know of any reason why their relative would object to, or be distressed by, being approached to discuss or participate in research. Where no carer is usually involved in decision making with the PABDL, researchers work with staff to understand the usual ways in which the person would communicate consent or non-consent, and record evidence of such. Staff approach potential participant and seek verbal consent for researchers to introduce themselves and the research. If the above processes indicate that it is acceptable, researchers meet each potential participant and invite them into initial conversation about the research.

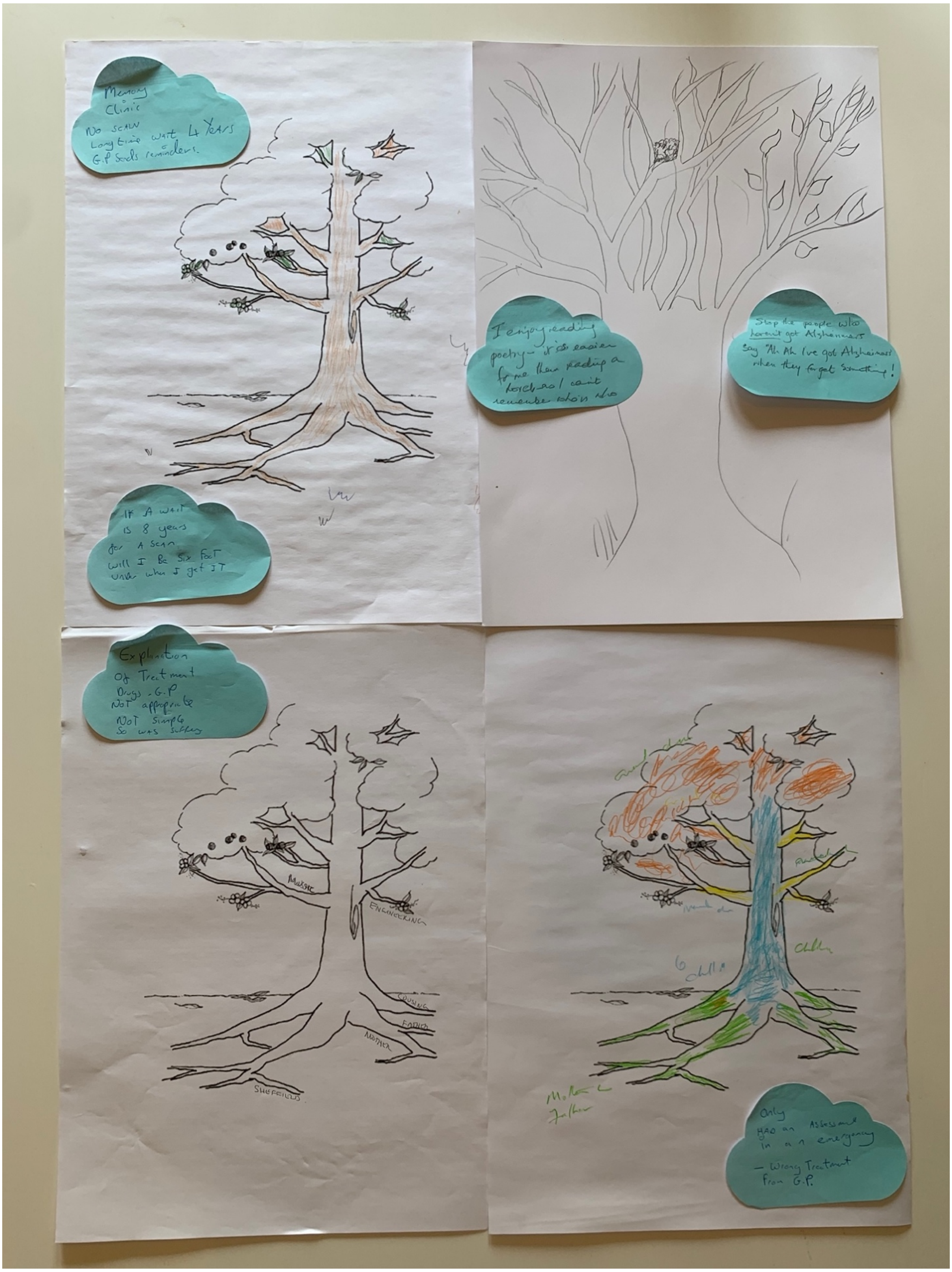
2. Initial consent conversation: an unhurried consent meeting between researchers and potential participants. Share with each potential participant an accessible illustrative information sheet (piloted with consultants). Explain information verbally, and elicit consent to participation verbally and behaviourally, reflexively checking understanding and consent. Researchers maintain field notes and discuss observations with staff and carers to contribute to the information available to aid the informed-consent process. (Note: this is an alternative to seeking written consent, which in the context of dementia may create anxiety as when people may remember signing an official form, but not recall why).

3. Ongoing consent monitoring: assessment of the individual's choice to continue participation. Includes the researchers' monitoring of behaviour and verbal utterances to assess frustration, tiredness, anxiety, etc., and asking both when these cues indicate distress and, at regular intervals in the research encounter, whether the individual continues to assent to participation and/or would like to reschedule. Request consent to use the data collected for analysis and write-up on completion of the interview. Participants, carers and staff provided with contact details for the researchers for discussion or queries regarding participation.

4. Support: the process-consent method requires researchers' critical reflection and skills in their interactions with the person with dementia. In this research, this was supported by the researchers' clinical experience in a dementia context and supervision.

Source: Hughes and Castro Romero (2015) adapted from Dewing (2007).

Appendix I: Articles from Tree of Life Workshop



Memory
Clinic
No scan
Long time wait 4 Years
G.P sends reminders.

I enjoy reading
poetry – it's easier
for me than reading a
novel – as I can't
remember who's who

Stop the people who
haven't got Alzheimers
say "Ah Ah I've got Alzheimers
when they forget something!

If A wait
is 8 years
for A scan
will I Be six foot
under when I get IT

Explination
Of Treatment
Drugs . G.P
NOT appropriate
NOT simple
So was suffering

Only
HAD an Assessment
In a n emergency
– Wrong Treatment
From G.P.

Appendix J: Extracts from SG

Within these extracts of verbatim quotations readability was enhanced by the use of ellipses where quotes have been shortened, and information is provided in [square brackets] to aid context as per Corden and Sainsbury (2006).

Extract 1

> 1: My wife has been suffering from Alzheimer's for just over four years. She had a bad turn last Monday, I took her to the GP (…) he sent a memo to the hospital and I have to wait until June [Almost six months from time of SG] for her to have that memory scan. Why does it take so long? I phoned my GP up this morning and he said no it's wrong. It should be a couple of days and he is looking into it. I have had to fight since I, my wife was diagnosed. Well she hasn't been completely diagnosed 'cause there has been two verdicts. Our first GP said: "You haven't got Parkinson's". The second one done a lot of tests, she went to the hospital, they done tests, they said: "yeah, she's got Parkinson's".

Extract 2

> 2: Has she got Parkinson's as well has she?
> 1: Yeah and Alzheimer's
> 2: They often go together don't they
> 1: Yeah, plus short-term memory loss and nothing. The only thing that has been and gone is she has got to take the tablets and a patch on her back. But any time I want support I've got to fight for it. They're not knocking on my door saying: "Oh we know about your wife's condition and what can we do to help you?"
> I'm getting none of that, I have to, me and my son have to, like come and listen to you [directed at the author] and find out things. I've got to do it all on my own, it's really wrong. I didn't even know (…) that my wife could claim money (…).

Extract 3

> 2: It takes ages [for support]
> 1: It's just over 4 years since she got diagnosed, and every time I've had to take my wife to the GP, [and] he (…) referred to the hospital, I have had to wait months for the appointment.

2: I was 8 years. If I had been straight away, it wouldn’t have been so bad.

1: It’s like hitting your head against a brick wall. I have to keep fighting. Me and my son have to keep fighting and going to tell them what’s wrong and I’m getting no response.

2: I don’t think there is any point in going once you’ve been diagnosed. I don’t think there is any point. You’ve been diagnosed, you have Alzheimer’s. bye-bye.

1: Yeah that’s the way I look at it. Society just doesn’t want to know.

2: I’m lucky that my family are very good and try to help me, my children.

1: Yeah, same as mine. My son and his wife and everybody. Luckily enough he just lives down the road, so we’re in contact.

Extract 4

1: (…) I help my wife in a lot of ways where I help her with her memory. We play music, think about things she likes to talk about, the past and everyone else and what we did in the past.

2: Yeah, but your long-term memory stays with you, (…) it’s what you did this morning… or yesterday.

1: Yeah, I do that in the mornings. I might be too strict on her, as I let her do some of the housework, but I watch her as she is bad on her feet, so I have to be there.

2: Is she a bit shaky on her feet?

1: Yes, she is unfortunately, but then I’m not getting no response. The hospital knows she can’t walk properly, but I’m having no referral. I’m waiting for that (…)

2: It affects your balance (…)

4: Yes… actually I live on my own for a few years and when they said… I am scared. Woe is me. What if something happened to me like that? What is happening? If there is any care, anywhere can I get any help from?

2: You’re diagnosed and that’s it, get on with it. You don’t see anybody.

1: Since coming here, that’s what seems to be happening. We have all the same story where we [are] left on our own. Thrown in the dustbin and forgotten like.

4: We have to get help from our GP.

Extract 5

3: I’m not that bad, (…) my daughter she looks after me. If my daughter wants to go out for a few hours, I’m okay. But she never leaves me for a couple of days or goes away. She looks after me, she is very good. My son is near you know as well, so sometimes my son takes me to weekends with them (…).
2: I think we are all in the same boat where we rely on our children quite a lot for help and support. I think we are all in the same boat in that respect as you don’t get any…
1: We are. You don’t… no-one coming to see you and knocking on your door to come and say I am here to help you. What can I do to help you?
2: I mean Alzheimer’s Society haven’t done a thing. I don’t quite know what their role is. Alzheimer’s Society, what is their role?

Extract 6

4: I have one son, my son he is living [in a different country (DC)]
3: You’ve got one son? I thought you had nobody?
2: Would you think of going to live [DC]
4: I can’t. My son keeps asking me… come here.
2: Why can’t you?
4: [DC] people is not very friendly (…). it’s very extreme.
2: Do you think English people are friendlier?
1: Yes, they do keep themselves to themselves [DC], I’ve been there a few times.
4: If I go there I get depression.
3: (…) I’m from [second DC] it was a colony for many years (…). That’s why we came here, and I came the [third DC] invasion we lost everything. I lost my parents as well, in six months. My father in December and my mother in July, so we can’t go back as [third DC] took us. My children have grown up, gone to university and so everything changed. I miss my family you know. When I came here I. was 18 years old and it was terrible for me. But I have good neighbours.
4: I see my neighbours. Hello, how are you? Nice weather and that’s it. They’re very busy.
1: [where] I live is all bungalows and all senior citizens and we all look out for each other. If they don’t see you, they knock on the door to see if you are alright. Everyone looks after everyone else.

Extract 7

2: It was ridiculous, it was 8 years. I was going to the GP for 4 years before they actually sent me to the memory clinic [...].so it was 8 years delay of getting onto medication. What can you do?

1: It’s wrong.

2: But it was very, very bad.

4: But I heard it has changed?

6: I don’t know.

4: They said now it is much better?

2: They send you more quickly to the… yes?

1: It’s like when you retire. They just throw you on the scrap heap…

2: Laughs.

1: Nobody tells you what you are entitled to but it’s the same as that… they should be knocking on the door.

4: Yes, you’re tired.

1: You’ve worked all your life, then at the end of it, it seems like you’re just put on a scrapheap.

Extract 8

2: (…) Then they diagnose you. Yes, you’ve got Alzheimer’s… BANG you never see anybody or hear from anybody, or have anything to do with anybody… NOBODY does anything for you. Nobody. If you had cancer you’d have a nurse there every day.

1: Yes, yes

3: Yes.

2: Alzheimer’s... it’s the… It’s the joke illness. It’s the joke illness.

1: Yes, yes.

3: Very, very.

(…)

2: People will forget something silly and say “ha-ha-ha I’ve got Alzheimer’s”. It’s the joke illness. If they have a pain in their leg they wouldn’t say “ha-ha-ha I’ve got cancer”.

1: No, no.

4: I heard it yes, they don’t take it seriously… society.
2: It’s the joke illness. It’s a JOKE.

Extract 9

2: (…) [When they say they’ve got Alzheimer’s] I say have you? When were you diagnosed?
1: Exactly, exactly.
2: It makes me angry. It makes me angry.
1: Yes, it’s an insult. It’s an insult. You know it’s nothing to be ashamed of.
2: and it’s nothing to be laughed at.
1: No, no that’s right.
4: Yes.
2: It’s the most depressing illness you can have.
4: The people in society they do not take it seriously.
2: No, they don’t.
4: I had this once some people said exactly the same.
5: I try to keep happy
1: Yeah you do don’t you.
2: Oh yes, yes.
5: It doesn’t always work out that way
2: No, it doesn’t, but at least you’re trying.
5: Yes, but at least you’re trying.

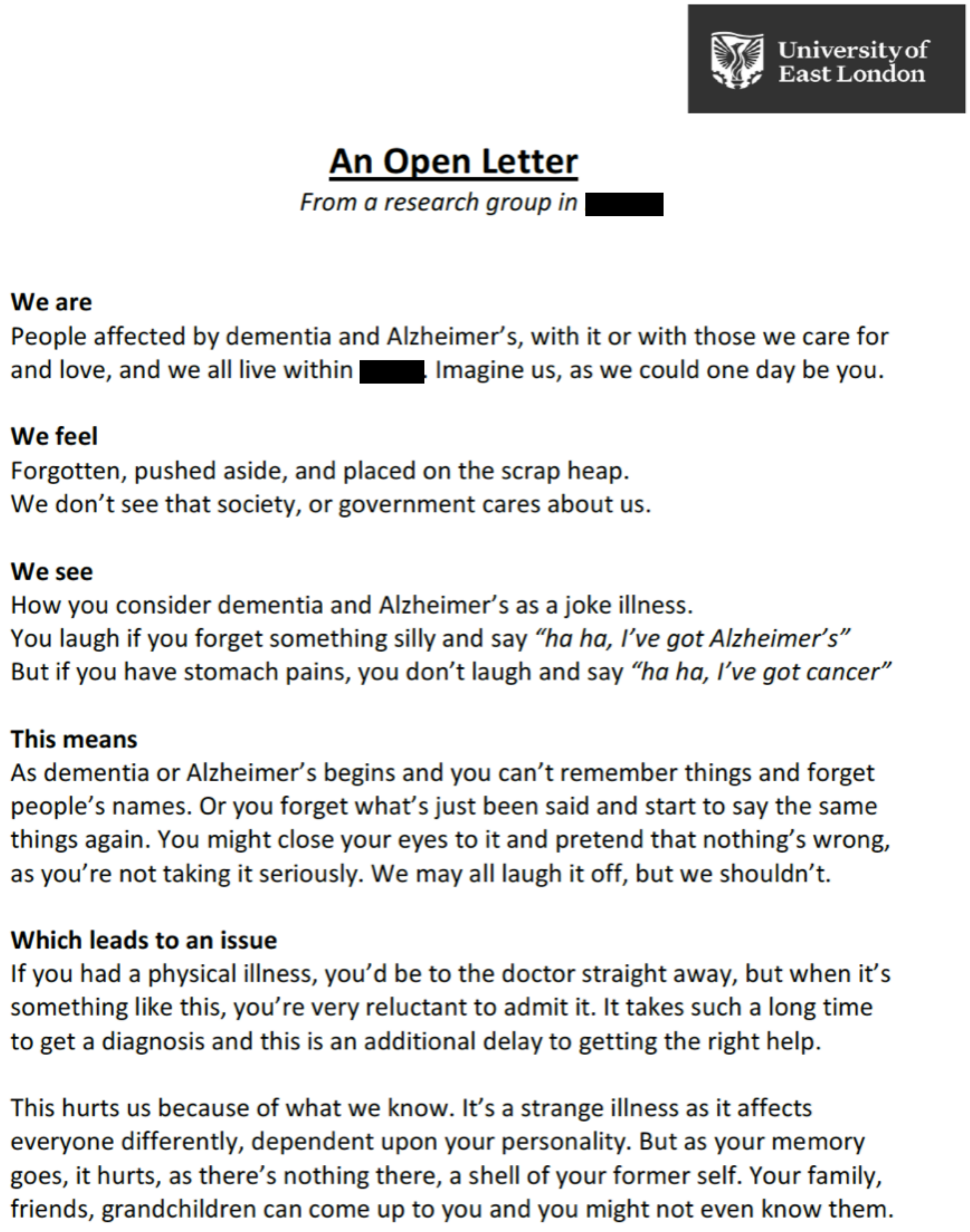
Extract 10

5: I love the doctors, I couldn’t go to a hospital.
1: Our GP, what we love about him, not only does he help, he shows us different things about different tests. If there is a drug that he is going to give you, they have all these long words, he’ll break them down so you understand it and tell you what symptoms to look for (…). He won’t just say here’s your tablets take them 3 time a day and say bye-bye.
1: That’s very good.
5: I want to see if I can remember this, as [they] have a job of giving you information, but it doesn’t always work out like this (…) Then they diagnose you. Yes you’ve got Alzheimer’s… BANG you never see anybody or hear from

anybody, or have anything to do with anybody… NOBODY does anything for you. Nobody. If you had cancer you'd have a nurse there every day.

Extract 11.
2: I can tell you what it's like living with dementia. It's bloody depressing. It's really depressing. I just get on with it. I don't have any choice.
1: This is another thing… these [dementia] cafes should be open for more days, instead of just two a week, they should be open longer.
5: I love coming here […]
1: If a woman is on her own with no family around and knows about this place she can go every other days. It's like a senior's place, it's the same thing. The council should be opening these places longer. I know they have to look at money and it's getting tight nowadays, but it's all about helping the poor guy sitting in a room, just staring at the four walls every day.
3: This place is very good, it's friendly. We all know each other, it's very good. Sometimes we go out together. It's very good.
2: We've all made friends through here.
5: (…) They should have more places like that because it keeps you active and your mind active. If you want to learn some new whatever you can do that.
1: It's like sitting in a room at home staring at four walls having no one to talk to and exercise your brain. All you have is the television and watching that 7 days a week would do your head in
2: I don't know what I'd do without my TV, I love TV.
1: If I had my way I'd never have one in my place. I love my ipad, I'm always on my ipad.
2: your what? Ipad?
1: I google a lot of things I want to know. Questions you know?
2: Unfortunately, I left it too late the computer thing. It doesn't do anything for me at all.

Appendix K: Collective Letter



University of
East London

An Open Letter

From a research group in [redacted]

We are
People affected by dementia and Alzheimer's, with it or with those we care for and love, and we all live within [redacted]. Imagine us, as we could one day be you.

We feel
Forgotten, pushed aside, and placed on the scrap heap.
We don't see that society, or government cares about us.

We see
How you consider dementia and Alzheimer's as a joke illness.
You laugh if you forget something silly and say *"ha ha, I've got Alzheimer's"*
But if you have stomach pains, you don't laugh and say *"ha ha, I've got cancer"*

This means
As dementia or Alzheimer's begins and you can't remember things and forget people's names. Or you forget what's just been said and start to say the same things again. You might close your eyes to it and pretend that nothing's wrong, as you're not taking it seriously. We may all laugh it off, but we shouldn't.

Which leads to an issue
If you had a physical illness, you'd be to the doctor straight away, but when it's something like this, you're very reluctant to admit it. It takes such a long time to get a diagnosis and this is an additional delay to getting the right help.

This hurts us because of what we know. It's a strange illness as it affects everyone differently, dependent upon your personality. But as your memory goes, it hurts, as there's nothing there, a shell of your former self. Your family, friends, grandchildren can come up to you and you might not even know them.

What we need you to know

The NHS
Some of us have waited up to 8 years for assessment and support: visiting the GP for four years and the memory clinic for another four before diagnosis. We wonder if time lost was spent on treatments, memories may have been saved.

- *We want quicker access to assessment and treatment.*

Once you've been diagnosed, it is like *'you have Alzheimer's goodbye'.*
They seem to think, *'oh well, you have it bye bye'.*

- *Where is the follow up or aftercare?*

We are left wondering how do we live now, and how do we live well?
Some of us might not have internet, and some of us might be alone.

- *We think there should be a register.*
- *For the GP to tell the council so social care already know about us.*
- *For the GP to let other services know who might help us with support.*

Our GPs have told us that they need more training on dementia & Alzheimer's.
- *We ask if this can be provided, so our GPs have up to date information.*

The Council
It takes so much time for us, to find out what help to get, and from where.
We don't know about you, and you certainly don't know about us.

- Find out about us, telephone us, or knock on our door.
- Say *"Hello we're social care, how can we help"* and ask what we need.
- Make it easier for us to find out about home care and equipment.

You make promises, like adaptations to homes, which you cannot keep.
If someone can't get in or out of their home, and you've said you'll provide a ramp, it's not right that we're waiting over a year for that to happen, everyone seems to be dragging their feet, when time is not what we've always got.

- *Recognise who is a priority and get the surveyor down there quick to see what needs to be done, then bring the builders down to do the job.*

Dementia is a depressing illness, and we worry about those left home alone. We're interested in things to stimulate us and keep our minds active. We've made friends at the dementia clubs and cafes, and enjoy activities and events.

- *Cafés or clubs should be funded to be open for more days and longer.*
- *We want you to let everyone know, what's available across Brent.*
- *Why can't you put this information for us in your Brent magazine?*

Scientists and Research

We don't hear anything from the large dementia or Alzheimer's charities. We question if a focus on the cure, meant living well with dementia is forgotten.

- *We want more of a focus on living well with dementia.*
- *We want to hear from more from you, about what you're doing.*

We're told how to look after our bodies, to exercise and eat well. We're never told how to look after our most important organ, the brain.

- *We'd like more research on how we feed or nourish our brains.*

We value the help of our doctors, but sometimes they say: *'let's try this medication'* or *'that medication'* and seem to be working from best guess.

- *We're not Guinea pigs, we want more confidence in medications.*

Politicians and Government

If it wasn't for coronavirus, we would want to see every man, woman and child protesting at 10 Downing Street. You should be doing more to help us.

- *We do not accept being forgotten.*
- *We want more resources or funding for our health and research science.*

Does anybody care?

These are actually our demands.

University of East London

What we want to know

What are your thoughts on our letter?

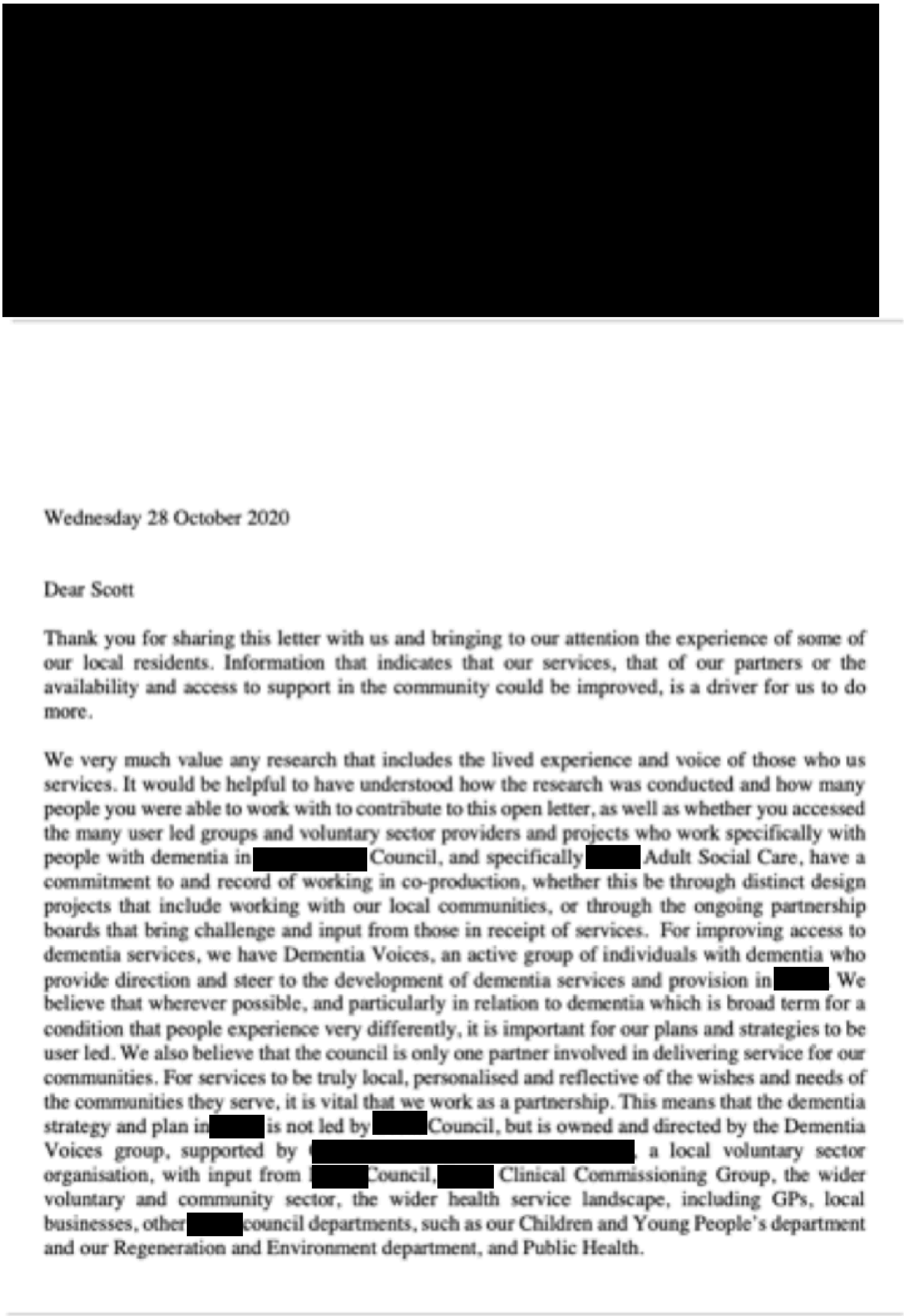
How did it make you feel?

What could you now do differently?

Are there changes that could be made to your policies or practice?

Who could you sit down with or approach about these issues?

Appendix L: LTLG Response to Letter



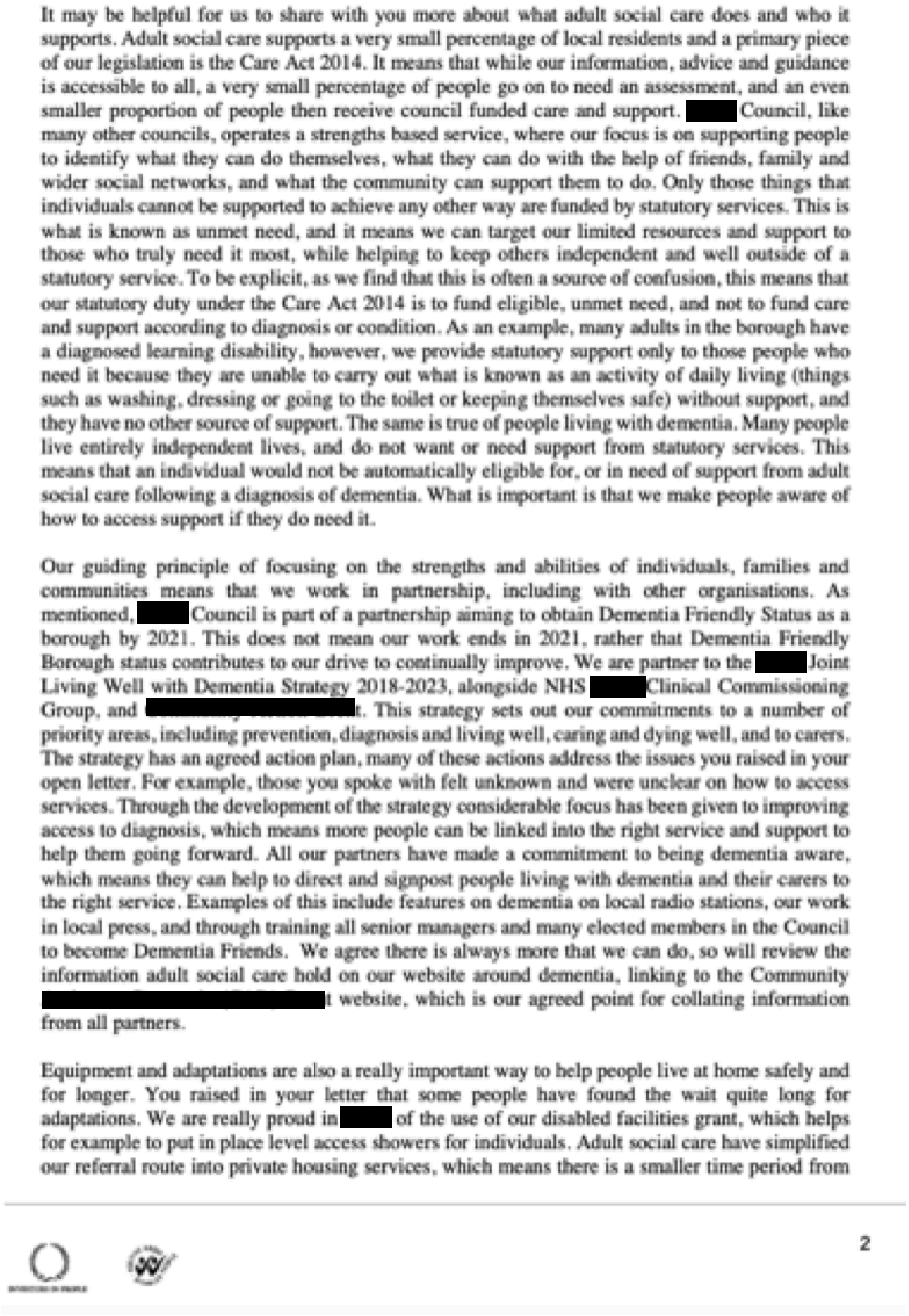
[redacted]

Wednesday 28 October 2020

Dear Scott

Thank you for sharing this letter with us and bringing to our attention the experience of some of our local residents. Information that indicates that our services, that of our partners or the availability and access to support in the community could be improved, is a driver for us to do more.

We very much value any research that includes the lived experience and voice of those who us services. It would be helpful to have understood how the research was conducted and how many people you were able to work with to contribute to this open letter, as well as whether you accessed the many user led groups and voluntary sector providers and projects who work specifically with people with dementia in [redacted] Council, and specifically [redacted] Adult Social Care, have a commitment to and record of working in co-production, whether this be through distinct design projects that include working with our local communities, or through the ongoing partnership boards that bring challenge and input from those in receipt of services. For improving access to dementia services, we have Dementia Voices, an active group of individuals with dementia who provide direction and steer to the development of dementia services and provision in [redacted] We believe that wherever possible, and particularly in relation to dementia which is broad term for a condition that people experience very differently, it is important for our plans and strategies to be user led. We also believe that the council is only one partner involved in delivering service for our communities. For services to be truly local, personalised and reflective of the wishes and needs of the communities they serve, it is vital that we work as a partnership. This means that the dementia strategy and plan in [redacted] is not led by [redacted] Council, but is owned and directed by the Dementia Voices group, supported by [redacted], a local voluntary sector organisation, with input from [redacted] Council, [redacted] Clinical Commissioning Group, the wider voluntary and community sector, the wider health service landscape, including GPs, local businesses, other [redacted] council departments, such as our Children and Young People's department and our Regeneration and Environment department, and Public Health.



It may be helpful for us to share with you more about what adult social care does and who it supports. Adult social care supports a very small percentage of local residents and a primary piece of our legislation is the Care Act 2014. It means that while our information, advice and guidance is accessible to all, a very small percentage of people go on to need an assessment, and an even smaller proportion of people then receive council funded care and support. [redacted] Council, like many other councils, operates a strengths based service, where our focus is on supporting people to identify what they can do themselves, what they can do with the help of friends, family and wider social networks, and what the community can support them to do. Only those things that individuals cannot be supported to achieve any other way are funded by statutory services. This is what is known as unmet need, and it means we can target our limited resources and support to those who truly need it most, while helping to keep others independent and well outside of a statutory service. To be explicit, as we find that this is often a source of confusion, this means that our statutory duty under the Care Act 2014 is to fund eligible, unmet need, and not to fund care and support according to diagnosis or condition. As an example, many adults in the borough have a diagnosed learning disability, however, we provide statutory support only to those people who need it because they are unable to carry out what is known as an activity of daily living (things such as washing, dressing or going to the toilet or keeping themselves safe) without support, and they have no other source of support. The same is true of people living with dementia. Many people live entirely independent lives, and do not want or need support from statutory services. This means that an individual would not be automatically eligible for, or in need of support from adult social care following a diagnosis of dementia. What is important is that we make people aware of how to access support if they do need it.

Our guiding principle of focusing on the strengths and abilities of individuals, families and communities means that we work in partnership, including with other organisations. As mentioned, [redacted] Council is part of a partnership aiming to obtain Dementia Friendly Status as a borough by 2021. This does not mean our work ends in 2021, rather that Dementia Friendly Borough status contributes to our drive to continually improve. We are partner to the [redacted] Joint Living Well with Dementia Strategy 2018-2023, alongside NHS [redacted] Clinical Commissioning Group, and [redacted]t. This strategy sets out our commitments to a number of priority areas, including prevention, diagnosis and living well, caring and dying well, and to carers. The strategy has an agreed action plan, many of these actions address the issues you raised in your open letter. For example, those you spoke with felt unknown and were unclear on how to access services. Through the development of the strategy considerable focus has been given to improving access to diagnosis, which means more people can be linked into the right service and support to help them going forward. All our partners have made a commitment to being dementia aware, which means they can help to direct and signpost people living with dementia and their carers to the right service. Examples of this include features on dementia on local radio stations, our work in local press, and through training all senior managers and many elected members in the Council to become Dementia Friends. We agree there is always more that we can do, so will review the information adult social care hold on our website around dementia, linking to the Community [redacted]t website, which is our agreed point for collating information from all partners.

Equipment and adaptations are also a really important way to help people live at home safely and for longer. You raised in your letter that some people have found the wait quite long for adaptations. We are really proud in [redacted] of the use of our disabled facilities grant, which helps for example to put in place level access showers for individuals. Adult social care have simplified our referral route into private housing services, which means there is a smaller time period from

when people ring requesting support, to the referral being sent direct to the team to assess for this adaptation to be made. We have also used our discretion to remove the means testing element normally applied to the disabled facilities grant, allowing us to offer adaptations and support to a wider range of people who can benefit. All applications we received for support, whether for equipment and adaptations or for assessment and social care support, are routinely screened so that we understand the urgency of the application, and work is undertaken in order of priority. We also have a recent Technology Enabled Care Strategy, focusing on sensors and innovations in technology that help people remain at home, while also providing assurance and confidence to those who provide care.

It was really positive to see in your open letter that people are making connections at the dementia clubs and cafes, and that these are a valued part of the resources in [redacted] These are all independently run by the voluntary and community sector, which means they are more sustainable and not dependent on local funding. It also means individual cafés can be responsive to local needs, and alter their times or activities based on demand. We acknowledge that the Council and adult social care can play a large role in promoting the services and support available for people with dementia, and thank you to those who took part in your research for suggesting information in the [redacted] magazine. This will be taken forward, along with a review of the information available on the [redacted] Council website directing people to the [redacted] site which is our agreed local source of information on dementia services.

What I have set out here is only a fraction of the dementia provision and services in [redacted], because we recognise that this is a collective task and one that will be ongoing to continually improve the experience for those living with dementia and their carers. However, I do hope it provides a glimpse into some of the services we provide and ways that we will act on feedback from those with lived experience.

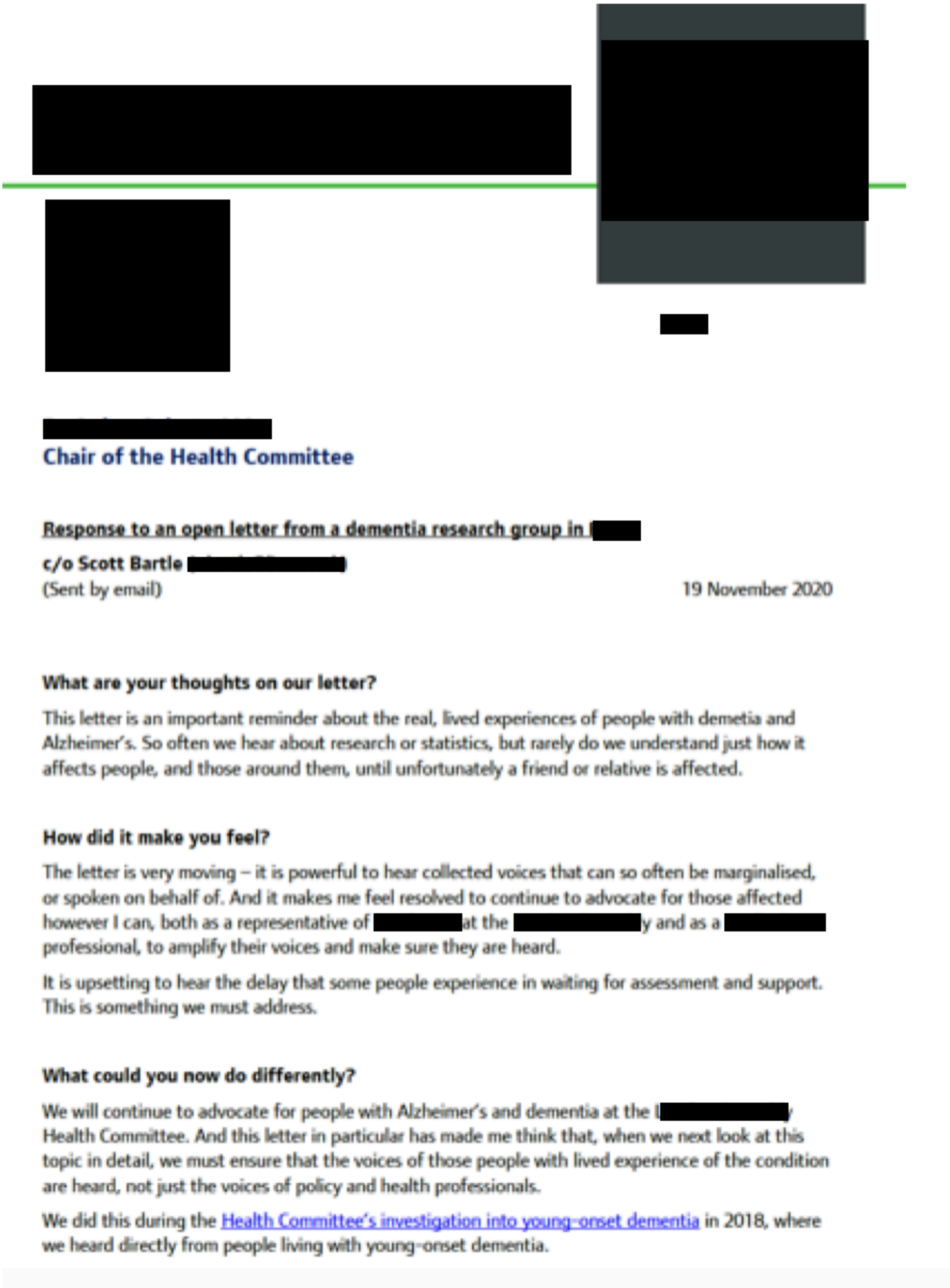
Best wishes

[redacted]

[redacted]

Operational Director Social Care, [redacted]

Appendix M: UTLG Response to Letter



[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Chair of the Health Committee

Response to an open letter from a dementia research group in [redacted]

c/o Scott Bartle [redacted]

(Sent by email) 19 November 2020

What are your thoughts on our letter?

This letter is an important reminder about the real, lived experiences of people with demetia and Alzheimer's. So often we hear about research or statistics, but rarely do we understand just how it affects people, and those around them, until unfortunately a friend or relative is affected.

How did it make you feel?

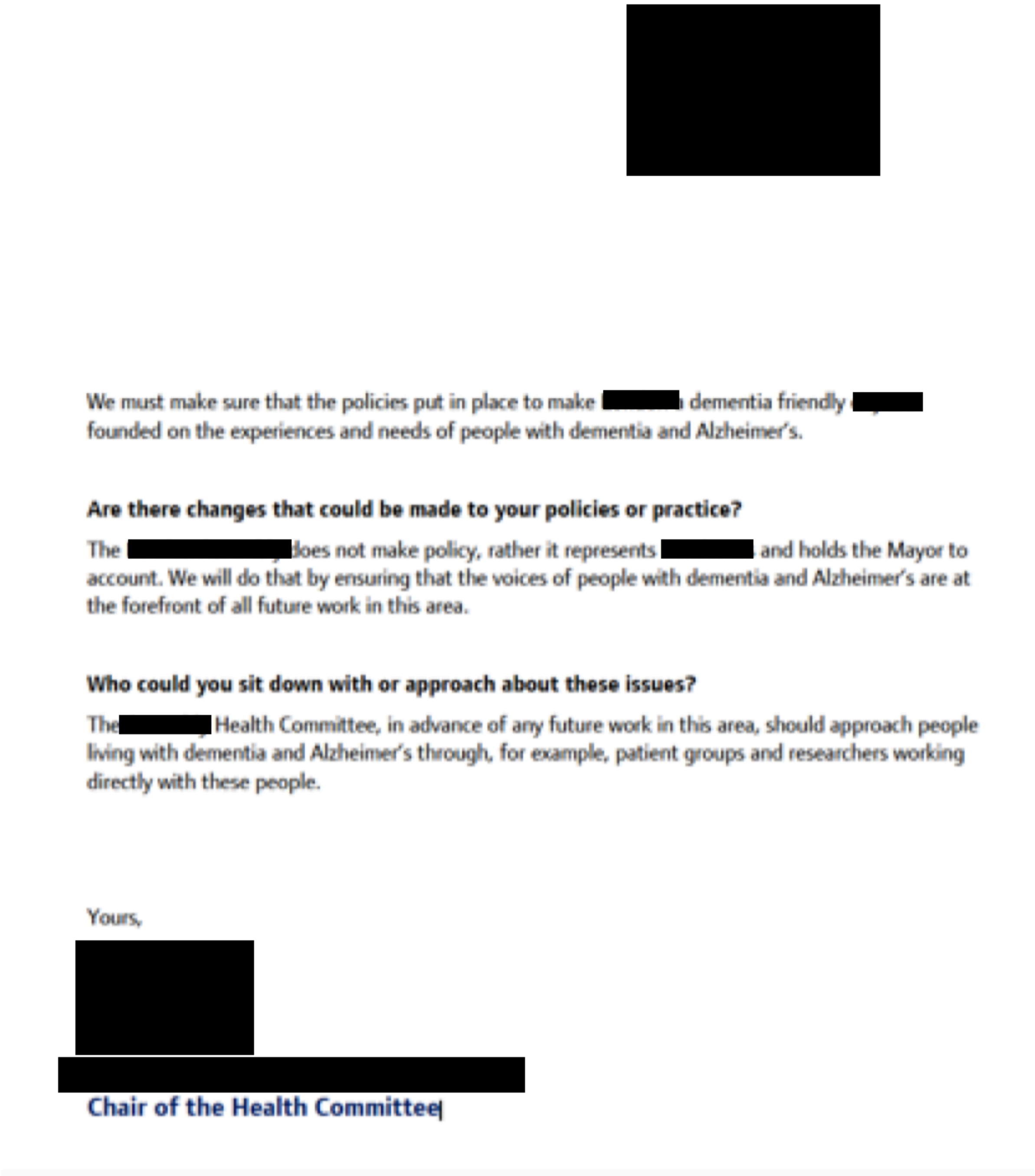
The letter is very moving – it is powerful to hear collected voices that can so often be marginalised, or spoken on behalf of. And it makes me feel resolved to continue to advocate for those affected however I can, both as a representative of [redacted] at the [redacted] and as a [redacted] professional, to amplify their voices and make sure they are heard.

It is upsetting to hear the delay that some people experience in waiting for assessment and support. This is something we must address.

What could you now do differently?

We will continue to advocate for people with Alzheimer's and dementia at the [redacted] Health Committee. And this letter in particular has made me think that, when we next look at this topic in detail, we must ensure that the voices of those people with lived experience of the condition are heard, not just the voices of policy and health professionals.

We did this during the Health Committee's investigation into young-onset dementia in 2018, where we heard directly from people living with young-onset dementia.



[redacted]

We must make sure that the policies put in place to make [redacted] dementia friendly [redacted] founded on the experiences and needs of people with dementia and Alzheimer's.

Are there changes that could be made to your policies or practice?

The [redacted] does not make policy, rather it represents [redacted] and holds the Mayor to account. We will do that by ensuring that the voices of people with dementia and Alzheimer's are at the forefront of all future work in this area.

Who could you sit down with or approach about these issues?

The [redacted] Health Committee, in advance of any future work in this area, should approach people living with dementia and Alzheimer's through, for example, patient groups and researchers working directly with these people.

Yours,

[redacted]

[redacted]

Chair of the Health Committee

From: Mayor [redacted]
Sent: 27 October 2020 14:07
To: s.[redacted]
Subject: MGLA131020-6989 From Dementia Research Group in [redacted]

Dear Mr Bartle
Thank you for your letter to the Mayor of London of 12 October. The Mayor is a Dementia Friend and it's an issue he is passionate about and is committed to taking action at [redacted] launched Dementia Friendly [redacted] in partnership with Alzheimer's Society.
Unfortunately, due to the very high volume of correspondence, it is not always possible for the Mayor to reply to every letter personally. I lead the work on dementia at the [redacted] I've completed the questions below.

What are your thoughts on our letter?
- I think the letter is very powerful and thought-provoking. Being written from the perspective of people living with dementia adds further weight.

How did it make you feel?
- it makes me sad to know that people with dementia feel like this. It makes me frustrated, sad and angry that attitudes towards dementia are still so negative and that so many people - often unthinkingly - reinforce negative stereotypes. It makes me determined to build on what we're doing and do more for everyone affected and to raise awareness across [redacted]

What could you now do differently?
- we are already running Dementia Friends sessions for [redacted] staff and over 50% are now Friends. This is also happening at [redacted] Police and [redacted] Fire Brigade. We're completed an initial audit of [redacted] by people with dementia and have put in place new signage in response. there's still more to do. We are working with policy teams across the building including culture, planning and housing to build in dementia-friendly policy.

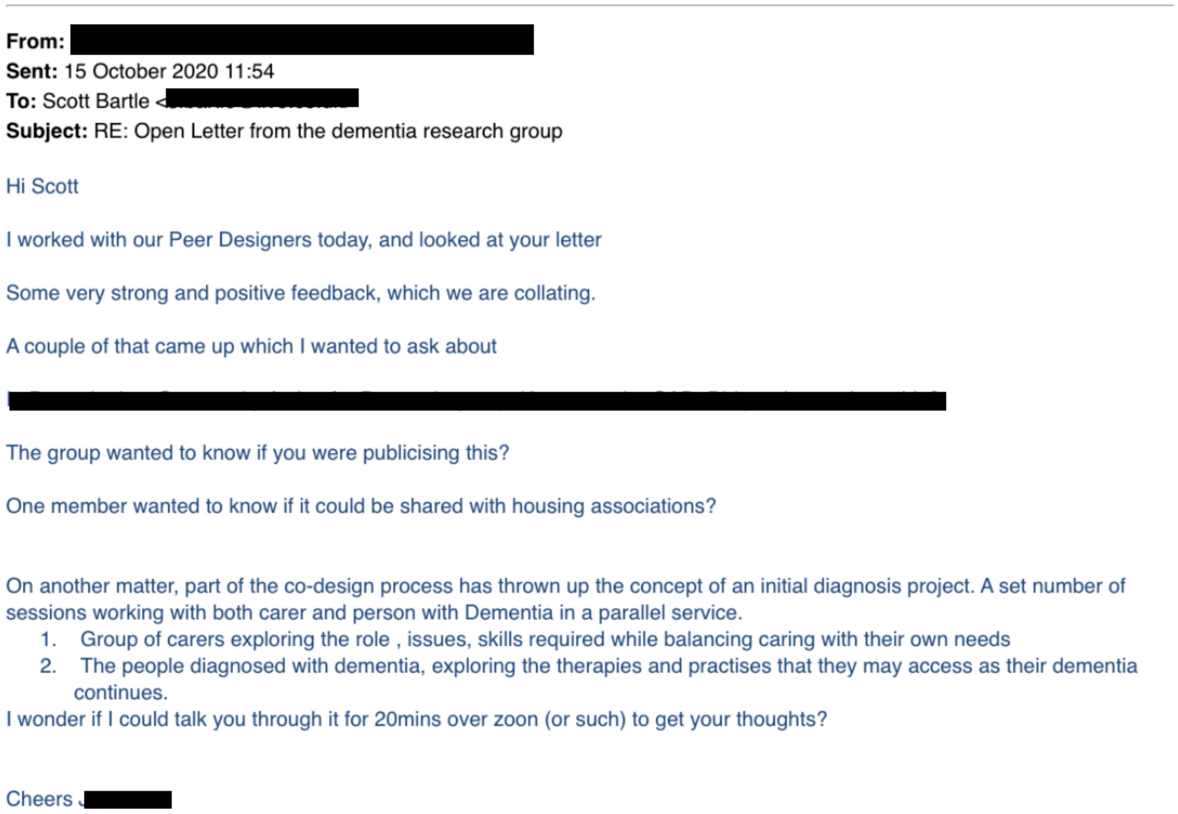
I'd be interested to see the final research and would be happy to share it with colleagues and partners. You can contact me directly [redacted]

Yours sincerely

[redacted]
Communities and Skills Directorate

NHS health information and advice about coronavirus can be found at nhs.uk/coronavirus

Appendix N: Local Charities Response to Letter



From: [redacted]
Sent: 15 October 2020 11:54
To: Scott Bartle <[redacted]
Subject: RE: Open Letter from the dementia research group

Hi Scott

I worked with our Peer Designers today, and looked at your letter

Some very strong and positive feedback, which we are collating.

A couple of that came up which I wanted to ask about

[redacted]

The group wanted to know if you were publicising this?

One member wanted to know if it could be shared with housing associations?

On another matter, part of the co-design process has thrown up the concept of an initial diagnosis project. A set number of sessions working with both carer and person with Dementia in a parallel service.

1. Group of carers exploring the role , issues, skills required while balancing caring with their own needs
2. The people diagnosed with dementia, exploring the therapies and practises that they may access as their dementia continues.

I wonder if I could talk you through it for 20mins over zoon (or such) to get your thoughts?

Cheers [redacted]

From: [redacted]
Sent: 16 October 2020 15:01
To: Scott Bartle [redacted]
Subject: Re: Open Letter from the dementia research group

Dear Scott,

I hope this email finds you well.
Thanks so much, for this very moving lived account of an individual's lived experience of living with dementia.

Here is my response to the questions;

What are your thoughts on our letter?

It's very moving and straight to the point and easy to read. It bears no punches and tells it how it is.

How did it make you feel?

Angry and sad

What could you now do differently?

Trying to never forget the lived experience and how important being human and people having the right to information

Are there changes that could be made to your policies or practice?

I feel maybe more advocacy is needed on behalf of people we work with

Who could you sit down with or approach about these issues?

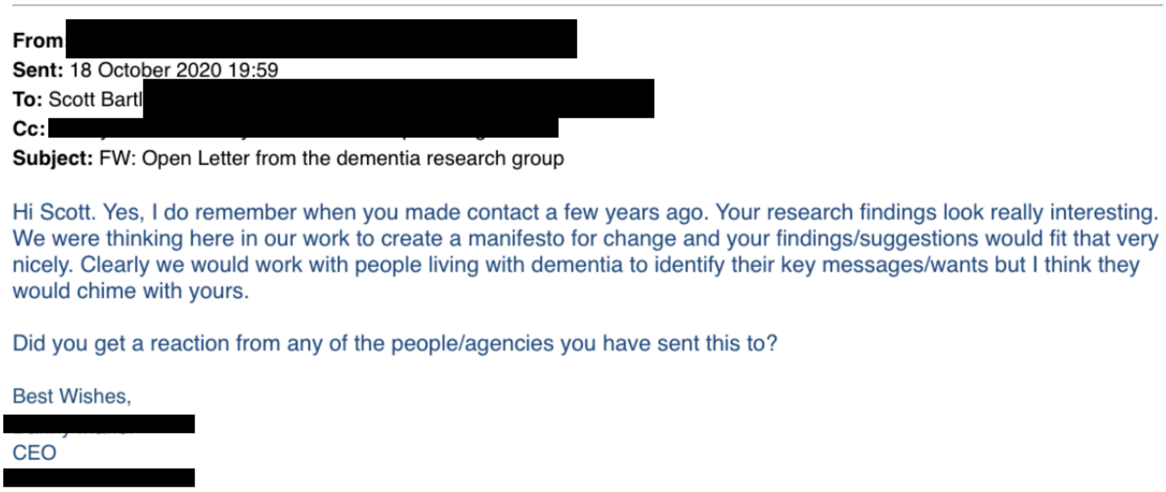
I think reminding our funders and commissioners and generally our coummunties around us

Have a lovely weekend

Kind regards

[redacted]

Wellbeing Manager



From [redacted]
Sent: 18 October 2020 19:59
To: Scott Bartl [redacted]
Cc: [redacted]
Subject: FW: Open Letter from the dementia research group

Hi Scott. Yes, I do remember when you made contact a few years ago. Your research findings look really interesting. We were thinking here in our work to create a manifesto for change and your findings/suggestions would fit that very nicely. Clearly we would work with people living with dementia to identify their key messages/wants but I think they would chime with yours.

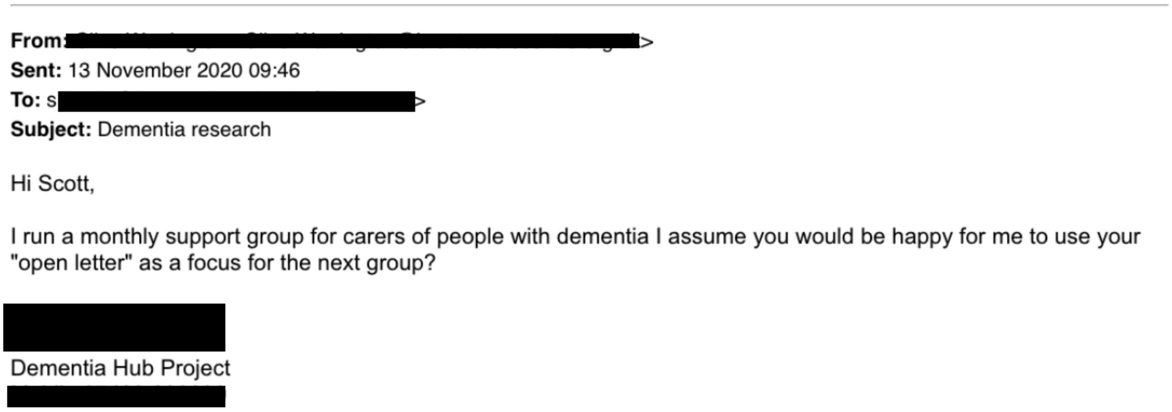
Did you get a reaction from any of the people/agencies you have sent this to?

Best Wishes,

[redacted]

CEO

[redacted]



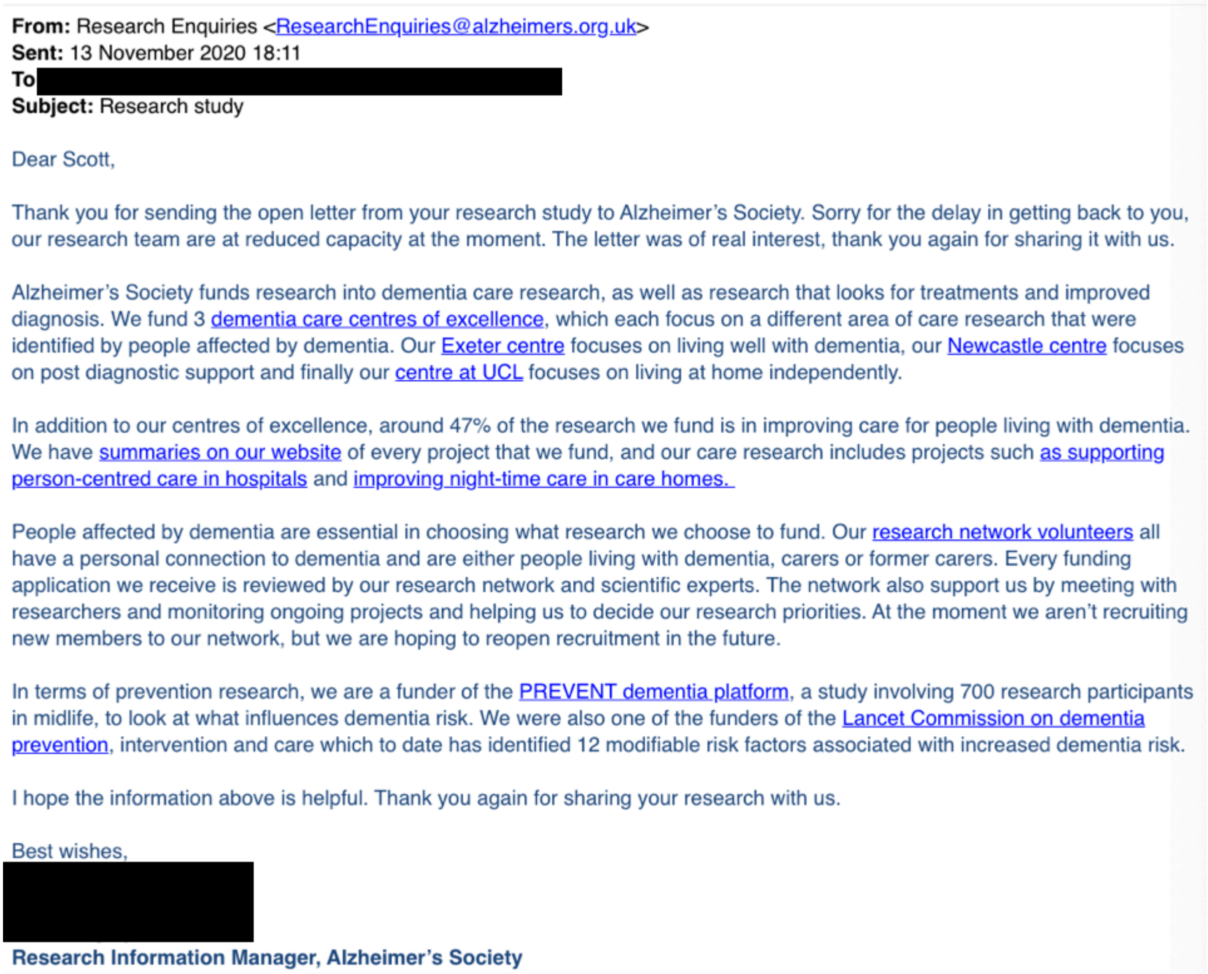
From:[redacted]>
Sent: 13 November 2020 09:46
To: s[redacted]>
Subject: Dementia research

Hi Scott,

I run a monthly support group for carers of people with dementia I assume you would be happy for me to use your "open letter" as a focus for the next group?

[redacted]
Dementia Hub Project
[redacted]

Appendix O: National Charities Response to Letter



From: Research Enquiries <ResearchEnquiries@alzheimers.org.uk>
Sent: 13 November 2020 18:11
To[redacted]
Subject: Research study

Dear Scott,

Thank you for sending the open letter from your research study to Alzheimer's Society. Sorry for the delay in getting back to you, our research team are at reduced capacity at the moment. The letter was of real interest, thank you again for sharing it with us.

Alzheimer's Society funds research into dementia care research, as well as research that looks for treatments and improved diagnosis. We fund 3 dementia care centres of excellence, which each focus on a different area of care research that were identified by people affected by dementia. Our Exeter centre focuses on living well with dementia, our Newcastle centre focuses on post diagnostic support and finally our centre at UCL focuses on living at home independently.

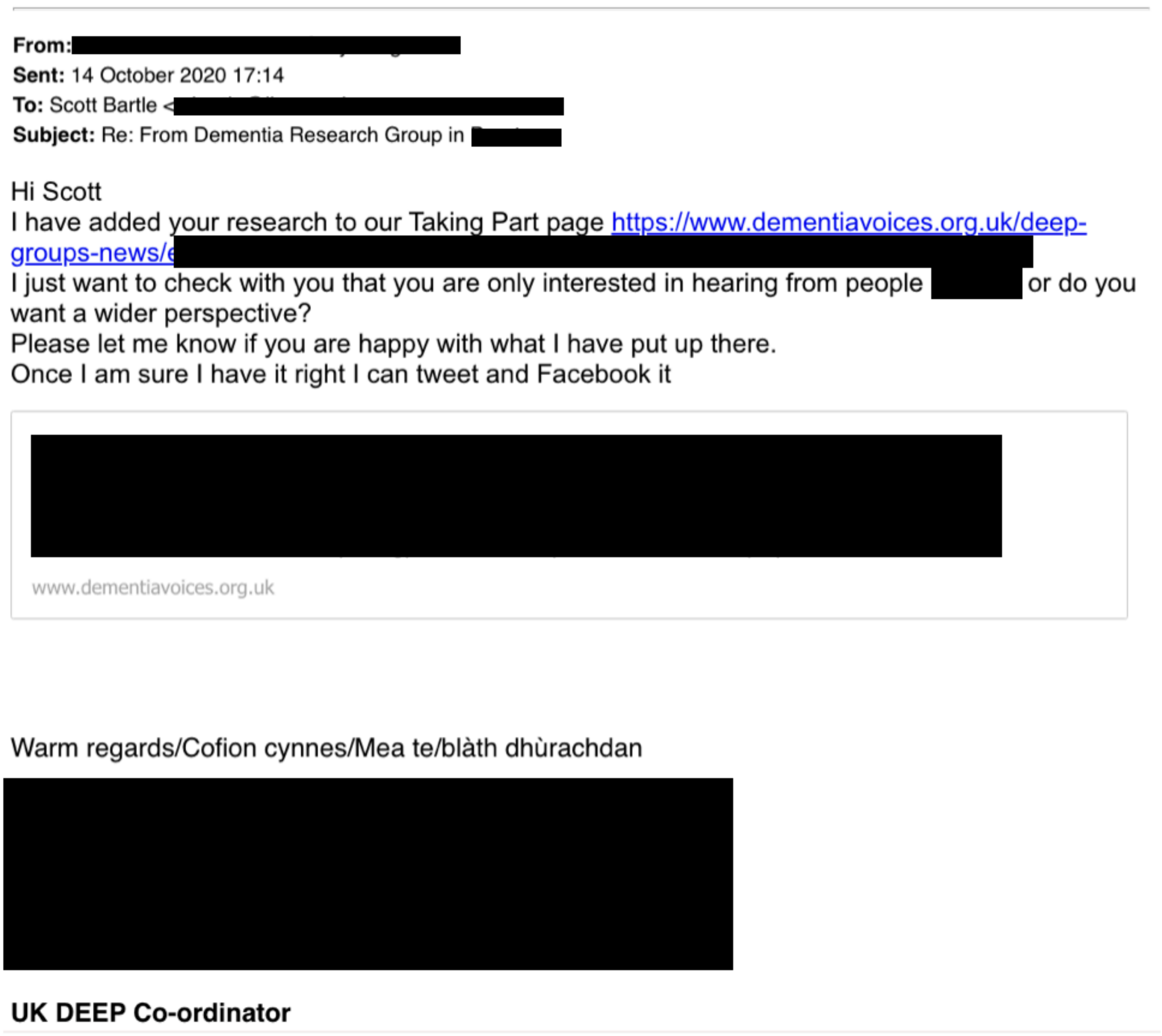
In addition to our centres of excellence, around 47% of the research we fund is in improving care for people living with dementia. We have summaries on our website of every project that we fund, and our care research includes projects such as supporting person-centred care in hospitals and improving night-time care in care homes.

People affected by dementia are essential in choosing what research we choose to fund. Our research network volunteers all have a personal connection to dementia and are either people living with dementia, carers or former carers. Every funding application we receive is reviewed by our research network and scientific experts. The network also support us by meeting with researchers and monitoring ongoing projects and helping us to decide our research priorities. At the moment we aren't recruiting new members to our network, but we are hoping to reopen recruitment in the future.

In terms of prevention research, we are a funder of the PREVENT dementia platform, a study involving 700 research participants in midlife, to look at what influences dementia risk. We were also one of the funders of the Lancet Commission on dementia prevention, intervention and care which to date has identified 12 modifiable risk factors associated with increased dementia risk.

I hope the information above is helpful. Thank you again for sharing your research with us.

Best wishes,
[redacted]
Research Information Manager, Alzheimer's Society



From: [redacted]
Sent: 14 October 2020 17:14
To: Scott Bartle <[redacted]
Subject: Re: From Dementia Research Group in [redacted]

Hi Scott
I have added your research to our Taking Part page https://www.dementiavoices.org.uk/deep-groups-news/[redacted]
I just want to check with you that you are only interested in hearing from people [redacted] or do you want a wider perspective?
Please let me know if you are happy with what I have put up there.
Once I am sure I have it right I can tweet and Facebook it

[redacted]

www.dementiavoices.org.uk

Warm regards/Cofion cynnes/Mea te/blàth dhùrachdan

[redacted]

UK DEEP Co-ordinator