

**University College, London**

Division of Psychiatry

**PhD Thesis**

**Technologies of distinction**  
**Understanding social exclusion in later**  
**life and dementia**

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**Declaration**

I, Sébastien Libert, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



**Abstract:**

*Novel ideals of later life promoting active ageing have spread across the world influencing our perception of dementia as a condition that necessitates health prevention, self-management, and empowerment. Yet, little research has looked at the role that these new strategies play in maintaining a divide in the population between those who age ‘successfully’ by living an agentic and active later life, and those who ‘fail’ to do so due to irreversible impairments, dementia and frailty. Following four years of research, this thesis explores the presence of this divide in new technologies, interventions and policies for dementia using ethnography. 1) By exploring the motivations of healthy people ‘training their brain’ in the United Kingdom, it emphasizes how prevention reinforces the fear of dementia as an unwanted identity and leads to distinction from it by healthy individuals. 2) By looking at cognitive rehabilitation in memory clinics in Southern Europe, it presents how this therapeutic practice ascribes people with dementia in a trajectory of decline, separating them from ‘normal ageing’. 3) By studying an intervention to support independence in dementia in the United Kingdom, it reviews how this type of intervention prioritizes a dementia freed from its non-agentic aspects. 4) By looking at the perspective of experts and advocates with dementia, it presents the existence of different social positions among people with dementia. These case studies illustrating distinction, ascription and omission in interventions for dementia show how social positioning by agentic individuals represent a yet unconsidered source of exclusion for the most vulnerable and dependent people with dementia. This thesis therefore questions the capacity of current dementia strategies’ to address social exclusion and argues for the importance of tailoring solutions to reflect the different levels of agency and dependency that people in these positions have.*

*Keywords: dementia, social exclusion, technology, active cognitive ageing, distinction, ascription, omission, prevention, independence, empowerment, disability*



## **Impact statement**

The intractability of dementia and the shifts in scientific and political discourses evoking a growing epidemic have reinforced a collective fear of the condition, and its association with a ‘failed’ later life. In this context, having dementia has become an important factor of exclusion for large parts of the population and has recently led to multiple attempts to prevent dementia or to support inclusion through new strategies promoting a positive vision of dementia. These strategies are contradictory in their effects, and do not necessarily lead to more inclusion because they are limited in their understanding of the fear that decline and impairment in dementia provoke. This thesis positions itself as a critical appraisal of these novel strategies and their translation into technologies and interventions for dementia.

It primarily contributes to scholarship in ageing and dementia by indicating these neglected issues, emphasizing the contradictory effects of these novel strategies and proposing a more thorough assessment of social exclusion. It points out the important social role that the collective fear of dementia plays in these strategies. It therefore advocates for scholarship to more thoroughly assess the impact of this fear on exclusion.

Outside of academia, this thesis attempts to challenge the idea that dominant strategies based on prevention and changes to the narrative that surround dementia represent a best practice to address social exclusion. It wishes to engage a dialogue with both public health actors, researchers and experts in the field of ageing and dementia, people with dementia and citizens anxious about dementia on this matter. It hopes to enable them to better perceive the intrinsic contradictions contained in these dementia strategies and their potentially negative impact on people with dementia, while emphasizing their beneficial aspects. As a result, this thesis hopes to contribute to the development of strategies that are more tailored to support both the wishes of people with dementia who wish to stay active and engaged in the community, and address the needs for care and support for people with dementia who are more dependent.

Testimonies of this engagement include the publication of an article on technologies and social exclusion in dementia (Libert, Charlesworth, & Higgs, 2019) in the Cambridge University Press journal *Ageing and Society*, the co-

authorship of a report on disability and human rights for people with dementia supported by the EU's Health Programme and published by Alzheimer Europe (Gove et al., 2017), presentations at numerous international conferences in the USA, Canada, the UK, Italy, Spain and Denmark, including a keynote at Alzheimer Europe's 28th Annual conference (2018) and a public guest lecture at the Centre for Ageing and Dementia Research (UK). The researcher was also awarded a competitive UCL Doctoral School grant to study at Yale University (USA) as an exchange scholar in the Department of Anthropology from October to December 2019 to implement a programme of academic activities supporting this thesis.

On a longer time span, this thesis aims to detach our public discussion of dementia from fear and to propose nuance in our portrayal of the experience of living with dementia. It also wishes to support people with dementia engaged in advocacy by offering insights through research on the condition, social and political action. Overall, it wishes to make later life a more serene experience for everyone and to foster inclusion of people with various health conditions and impairments no matter what their healthcare and support needs are.



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## Introduction

Why is it relevant to look at social exclusion in dementia and later life today? Answering this question requires multiple levels of analysis, starting with the current context that surrounds dementia today. Amidst increasing concerns regarding the challenges of global ageing (United Nations Department of Economic and Social Affairs Population Division, 2015), dementia has become a widespread issue in the mainstream media and various national and international institutions (Department of Health, 2015; World Health Organization, 2016; World Health Organization and Alzheimer's Disease International, 2012). Often this is approached using a common register of fear regarding the condition (Lane et al., 2013; Latimer, 2018; Siddique, 2016). This is for instance the case in the press, no matter what the political orientation or format of the newspaper is. The Guardian<sup>1</sup> for instance, emphasizes that dementia has replaced ischaemic heart disease as the first cause of death in the population of England and Wales, and this article is one of many, often presenting the idea of a war against dementia (Lane et al., 2013). Another important instance of this cultural narrative can be found in public health policy. Dementia has been central to major public health campaigns aiming to guide the population in responding to this so-called epidemic of dementia. For instance, the *Prime Minister's challenge on dementia 2020* highlights the important fear that the condition generates and promotes individual prevention through a healthy lifestyle together with a call for diagnosing more and earlier as a solution (Department of Health, 2015, p. 10). This position is also reflected within much of the policy work of international organizations such as the World Health Organization and its *Global action plan on the public health response to dementia* (World Health Organisation, 2017, p. 15). All these manifestations of public anxiety and strategies are indirectly concerned with social exclusion. They ask how to handle the challenges that ageing societies imply and what to do with individuals whose conditions prevent them from participating, such as people with dementia. In such discourses, the emphasis is often put on care as a burden (Ballenger, 2008,

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<sup>1</sup> Siddique, H. (2016, November 14). Dementia and Alzheimer's leading cause of death in England and Wales. *The Guardian*. Retrieved from <https://www.theguardian.com/society/2016/nov/14/dementia-and-alzheimers-leading-cause-of-death-england-and-wales>

p. 503). They therefore carry an arguably exclusionary underpinning. Indeed, the question does not necessarily entail care for the vulnerable as an intrinsic part of existence. It often revolves around how to avoid having to provide this care in the first place, rather than about integrating individuals who require it. This approach carries the risk of relegating an important part of the population living in dependency as a burden to avoid. There appear to be important tensions at play in the priorities developed by these institutions and the policies that emerge from them as part of the solutions to the problem of social exclusion.

Beyond discourses and public health priorities representing care as a burden, strategies themselves can be sources of exclusion through the way in which they construct the identity of people with dementia as we will see throughout this thesis. Among these is the current turn toward prevention. Both the Prime Minister's challenge, the World Health Organisation and other policy reports provide many illustrations of this turn toward prevention in dementia. Anthropologist Margaret Lock (2013) lists this shift toward prevention as a central characteristic of our relationship with dementia in the 21<sup>st</sup> century, therefore representing a shift from the previous monopoly of the idea of cure that she attaches to the 20<sup>th</sup> Century.

Such turn toward prevention and risk-management has been contingent with, and most likely fostered by, the failure of curative research for dementia (George & Whitehouse, 2011, p. 590). Withdrawals of Research and Development agenda around dementia have been frequent activity by the pharmaceutical industry throughout the duration of my PhD research. Pfizer<sup>2</sup> announced its withdrawal from the pharmaceutical industry on dementia in January 2018, followed by the interruption of the research on the Aducanumab drug by Biogen and Eisai in March 2019<sup>3</sup>. These events marked another abrupt failure in regard to the promise that the amyloid hypothesis represented as the drug did not prove efficient in trial while it was specifically designed to clear the brain from amyloid plaques. These failures did not lead the way toward an increased focus on care. George and Whitehouse

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<sup>2</sup> Hawkes, N. (2018, January 9) Pfizer abandons research into Alzheimer's and Parkinson's diseases. *The British Medical Journal*. Retrieved from <https://www.bmj.com/content/360/bmj.k122>

<sup>3</sup> Kuchler, H. (2019, March 22). What next for Alzheimer's research after latest drug failure? *Financial Times*. Retrieved from <https://www.ft.com/content/9a9395d2-4c23-11e9-bbc9-6917dce3dc62>



(2011, p. 590) argue that it has paved the way to a new emphasis on prevention methods such as brain training.

Prevention strategies are bounded with narrative transformations about lifestyle in later life and about dementia. These gave rise to parts of the concerns of this thesis about social exclusion. For instance, the *Lancet international commission on dementia prevention and care* (Livingston et al., 2017) is a salient example of how research has been advocating a position that we can all do something to prevent dementia through responsible individual behaviour oriented toward more adequate lifestyle choices. Dementia is therefore no more of a condition that we can passively fear or ignore, desperately waiting for a cure, or simply not thinking about it. It is a threat that requires people to adopt strategies of active engagement. Hence, dementia remains a feared externality within the current rise of prevention as it has become a replacement to the previous curative approach. This idea of dementia as a threat to avoid is therefore shared between the biomedical approach looking for a cure and the preventative approach.

Nonetheless, a substantial part of the ageing population happens to live with symptoms of dementia (Niu et al., 2017; Reitz & Mayeux, 2014), and this proportion rises exponentially with age (Reitz & Mayeux, 2014). This observation poses important questions about the impact of these dominant discourses of cure and prevention on the significance of ageing and decline, and the ability of an ageing population to give meaning to the experience of dementia beyond the threat that it represents. Inevitably it leads us to considering the impact of this narrative on people with the condition, their identity, and status in society. As we will see, there is an intrinsic link between social exclusion in later life and social exclusion in dementia. Therefore, this thesis approaches this question of social exclusion in dementia by looking at Western society's current understanding of social exclusion in later life. It will look at current interventions and technologies developed for the condition as case studies to illustrate this link and understand this relation.

## **Current approaches to social exclusion in later life and dementia**

While this thesis traces the intricacies between the meaning of dementia, and the social significance of later life to explore the question of social exclusion, scholarship has approached this matter in various ways that do not necessarily consider this intricacy. Researchers in the field of dementia have had limited consideration for the influence of the social and cultural context of ageing on the social exclusion of people with dementia for instance. Meanwhile, scholars of ageing have considered social exclusion in ageing mainly by focusing on the idea of ageism and have remained relatively limited in their attempt to explain the mechanisms behind the social exclusion of people with dementia. This section proposes to review the principal theories behind social exclusion in ageing and dementia scholarship and proposes to regroup the perspectives of dementia and scholars of ageing according to their similarities.

As we will see, this variation in theories is both historical and epistemological. Some of these approaches are more recent than others, and their emergence at different periods in history correspond to important transformations in the cultural and social imaginaries defining Western society. They also emerge from the previous disciplinary concerns and conceptions of their research objects. Each of these definitions of social exclusion in later life are connected to varying understandings of the solutions needed to address this exclusion.

### ***Approach 1: Active ageing – a prevention approach to social exclusion in later life and dementia***

This approach to social exclusion in later life and dementia is arguably the most influential one. The dominant understanding of ageing in the West can be best characterized through the idea of *active ageing* or *successful ageing* (Lamb, 2014; Pack et al., 2019). This ideal informs most of the health policy around later life today, promoting a vision of later life emphasizing the importance of prevention for a wide array of conditions affecting health (Pack et al., 2019). The creation of this ideal is most connected to the work of Rowe and Kahn (1997). As they explain, ‘successful aging is multidimensional, encompassing the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained

engagement in social and productive activities' (Rowe & Kahn, 1997, p. 433). This ideal therefore sees decline as the principal source of exclusion in later life and has adopted an adversarial approach to it, grounded in avoidance and prevention with the idea that this decline can actually be prevented to a large extent.

Logically ensuing from the perspective of Rowe and Kahn (1997), dementia being conceived as a disease or disability is first seen through this lens of prevention and avoidance. As a result, the question of integrating people with dementia appears as an after-thought. The priority is placed on preventing dementia from happening in the first place, mainly through lifestyle adaptations and risk management. A similarity is evident between this approach of active ageing, and dominant understandings of dementia that this thesis has introduced above. In this framework, dementia is primarily a problem to treat as exemplified by the biomedical approach to dementia, or prevent through adequate lifestyle adaptations and the management of risk-increasing factors for dementia (Lock, 2013; Orgeta et al., 2019). Another approach drawing on this idea of active ageing and therapy expands the idea of treatment and prevention to people with dementia themselves, through the idea of cognitive rehabilitation (Clare, 2005; Clare & Woods, 2003). Here, the idea is to help people with dementia keep their capacity to function in daily life by applying a therapeutic regime directed toward the prevention of further decline in the general functioning of the person (Clare, 2005). The target of this type of intervention is therefore the individual with dementia who needs to be rehabilitated.

As a main weakness, this approach based on active ageing and a biomedical model of dementia presents a limited ability to articulate important questions relating to the meaning of decline, the finite nature of life and ageing generally (Cosco et al., 2013; Lamb, 2014). It also plays a role in the yet unconsidered processes of social exclusion that this thesis will review. Due to the dominant role that this ideal plays in defining ageing and dementia today both for researchers in the field of dementia and for an important part of the ageing population, we will further explore the significance of dementia in active ageing later in this introduction. The consequences of this approach in terms of social exclusion of people with dementia are specifically covered in the second, third and fourth chapter of this thesis, and its influence will be felt in the case studies presented in the other chapters as well.

## ***Approach 2: A citizenship and disability approach to social exclusion in dementia***

This second important approach to social exclusion in dementia originates from the idea of ‘malignant social psychology’ developed by Kitwood (1997b). This theory conceives the exclusion of people with dementia as a result of the oppressive relationship that can emerge between people with dementia and carers and institutions of professional care. They view the behaviour of the latter as either being oppressive or enabling for the person with dementia in relations of care (Kitwood, 1997b).

By extension, more recent theory expanded this idea of disabling relationship to society’s appraisal of dementia more generally, and its’ positioning of the person with dementia negatively as a result of stigma, discrimination, and disabling social and physical environment. Ideas of citizenship (Bartlett & O’Connor, 2007; Brannelly, 2011, 2016; Kontos et al., 2017) or the application of a social model of disability to dementia (Cahill, 2018; Dorenlot, 2005; Shakespeare et al., 2017) are important manifestations of this novel approach to dementia.

Through this idea, the origin of exclusion radically shifts from the cognitive impairment of the person with dementia to the social sphere – other individuals around the person with dementia, institutions, rules, infrastructures of society who become obstacles to the possibility of exercising agency. The emphasis is put on a struggle against discrimination, negative stereotypes and stigmatizing language, as well as the social and material environments that do not acknowledge the special needs of people with dementia. It is a struggle for the recognition of the rights of people with dementia (Cahill, 2018; Gilliard et al., 2005).

Following similar ideas of citizenship and social oppression, gerontologists and scholars of ageing Grenier, Lloyd and Philipson (2017) have proposed to approach social exclusion in later life and dementia through the idea of precarity. In this context, and in similar ways to the idea of citizenship developed by Kontos, Miller and Kontos (2017), the exclusion described by precarity is essentially ‘politically induced’, resulting from ‘failing social and economic networks of support’ leading to an ‘[exposure] to injury, violence, and death’ (Grenier et al., 2017, p. 322). As a solution, they propose to “shift the focus from constructs that reinforce the negative

valuations of age, to a recognised shared vulnerability, acceptance of the limitations of life and death, and shared political responsibility [which] can help to unhinge dementia and impairment from a ‘frail’ and ‘failed’ late life into a foundation from which to develop new types of care relationships” (Grenier et al., 2017, p. 327).

This approach to dementia and social exclusion in later life based on social oppression and its limitations will be specifically discussed in Chapter 5 and 6 of this thesis.

### ***Other conceptions of social exclusion in later life and their consideration for dementia***

Other approaches have attempted to explain social exclusion in later life, although with limited consideration for the role that dementia plays in this exclusion. Hence, we will review them briefly in this section due to this limitation.

Some researchers have argued for the presence of a structural process of discrimination against ageing individuals in Western society that they refer to as ‘ageism’ (Butler, 1969; Bytheway, 2005; Gullette, 2017). Proponents of this theory perceive ageing individuals as being a generic excluded category enacted through discriminatory practices and institutional processes similar to the ones creating sexism or racism (Butler, 1969; Bytheway, 2005; Gullette, 2017), and with contradicting views as to what exactly causes this ageism (Higgs & Gilleard, 2019).

Meanwhile, other researchers have attempted to explain social exclusion in later life as a result of social class inequalities (Lopes, 2015). They have attempted to do so in different ways, through ‘gradation theory’ – the idea that inequalities of class result from differentiated abilities to accumulate assets and capital earlier in life (Dannefer, 1987; O’Rand, 1996), or by looking at their access to power based upon a form of class identity defined by occupational groups in what is referred to as relational class theory (Bergman, Lambert, Prandy, & Joye, 2002; Lambert & Bihagen, 2014; Rose & Harrison, 2007).

These theories of social exclusion in later life have therefore structurally approached social division, seeing exclusion either as a cultural construct generated by Western society’s aversion for individuals in later life in the case of ageism, or

as a continuity of social divisions based on socio-economic differences appearing earlier in life and their accumulation in the case of social class divisions. While these approaches respectively take a post-modern, social constructionist approach to social exclusion in the case of ageism, and a materialist approach to it in the case of social class explanations, they have in common the absence of concerns for the role that impairments and health can play in generating exclusion. Considering the issues that this thesis will cover, they therefore have a limited ability to propose explanations for the negative social position and exclusion of people with dementia.

Throughout the different chapters of this thesis, we will consider the limitations of these theories. Firstly, we will see how theories of social exclusion produced by dementia scholars will appear limited in their ability to trace the causes of social exclusion due to their neglect of the contextual (social and cultural) factors influencing exclusion. Secondly, we will see how theories looking at social exclusion in later life will be limited in acknowledging the social significance of dementia for an ageing population and the role it plays in social exclusion. The role of health and impairment in exclusion is central to the issues that this thesis will highlight, both at an experiential/individual level and at a collective/contextual one. Accordingly, as an attempt to propose a preliminary explanatory framework considering both the individual experience of dementia and the social context of ageing, this thesis should now introduce the contextual factors defining this importance of health and corporeality in social divisions.

## **Linking fear of dementia and social exclusion – the cultural significance of dementia in later life**

Positioning dementia in current cultural understandings of ageing is essential to understand how the exclusion of people with dementia operates and how it relates to anxiety about decline.

The impact of culture on the experience of dementia is well recognized in the social sciences. For instance, Jones (2017, p. 304) states that ‘the experience of dementia is not a universal process and different sociocultural understandings and

conceptualisations have a profound influence over responses to the symptoms of dementia in different places and at different times.’ One can therefore see how socio-cultural understandings shape the social significance of dementia in the life of people. These cultural understandings of dementia are entangled with definitions of what it means to age today.

One of the most fundamental questions which comes up when approaching the entanglements of ageing and dementia is the following: is dementia a normal part of ageing? Or can it be separated from it? Attempts to answer this question have produced multiple positions informed by substantial cultural, economic and political variables.

Major health organizations and Alzheimer Associations tend to present a clear and definitive answer to this question. For instance, the 2017 World Health Organisation fact sheet<sup>4</sup> about dementia explains that ‘although dementia mainly affects older people, it is not a normal part of ageing’. Alzheimer’s Research UK, a leading dementia research charity; develops a similar narrative, visible in its “Share the orange” campaign<sup>5</sup>, in which dementia is described as a clearly defined pathology, neatly separated from the normal ageing process. Researchers have traced the existence of these positions to the needs of advocacy work, and fundraising. For instance, Ballanger (2008) explains how presenting this clear separation has been central to the capacity of biomedical research to convince the public opinion to fund Alzheimer’s disease research. Such process of separation has also been central to the development of geriatric medicine and its objective to define its object of research (Cohen, 1998, p. 60).

For other authors however, the aetiology of dementia is less clear than these statements present in term of its intricacy with the ageing process therefore asking what normality actually means with regard to ageing. Critical appraisals of the separation between normal and pathological have always been at the centre of explorations by philosophers and social scientists (Kleinman, 2012, p. 118), even

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<sup>4</sup>World Health Organization Website (2017), Dementia: key facts. Retrieved May 2018, from <http://www.who.int/mediacentre/factsheets/fs362/en/>

<sup>5</sup>Alzheimer’s Research UK Website (2018b). Share the orange. Retrieved May 2018, from <https://www.alzheimersresearchuk.org/orange/>

more so for categories such as Alzheimer's Disease whose physiology is unclear and whose entanglement with ageing is heavily marked (Gilleard & Higgs, 2010; Lock, 2013). As a critical standpoint on this question of normality in ageing and dementia, Cohen (1998, p. 60) writes that the normalization of ageing attached to the process of pathologization of Alzheimer's disease under the gaze of geriatric medicine has been consistently challenged by the absence of clear boundary between normal ageing and disease. Such process, as Cohen (1998, p. 60) argues, has participated to the paradoxical situation in which dementia has somehow freed ageing from decline and death by centrally attaching such process to Alzheimer's disease. What becomes apparent through these attempts to separate ageing and dementia is the apparent instability of the whole notion of normal ageing. These categories seem therefore arbitrarily defined and suggest the important social impact that notions of normality or abnormality can have on identity in later life.

These categories of normality and abnormality are important articulations of the social exclusion that this thesis will explore. As I will present below, current comprehensions of normality in ageing are part of a dominant narrative describing the most socially valued forms of ageing today, and as such have been attached to defining social exclusion in dementia.

### **Third age identities – how consumerism is shaping health in later life**

Scholars of ageing of various disciplines have referred to this novel desired identity idealistically freed from the decline of later life as the *third age* (Carr & Komp, 2011). As Neugarten (1974) explains, tracing the early sign of the emergence of the 'young old' in the second half of the 20<sup>th</sup> century in the United States of America, this group of older adults emerging in Western societies presents itself as 'relatively healthy, relatively affluent, relatively free from traditional responsibilities of work and family' and 'increasingly well-educated and politically active' (Neugarten, 1974, p. 187). However, there is still discussion about what the third age exactly is. Carr and Komp (2011, pp. 3–4) summarise the approach of different scholars to the third age by presenting how Bass (2006) sees it as a social



construct, Leibing (2005) as an ideology, Weiss and Bass (2002) as a life phase, James and Wink (2007) as an age period, and Katz and Marshall (2003) as a cultural sphere. As a generic approach, Carr and Komp (2011, p. 4) simply propose to describe the third age as ‘the period of healthy retirement in later life’. We will see that the particular approach of this thesis due to its concern for the social position of people with dementia will adopt a particular angle compatible with Gilleard and colleagues’ idea of the third age as a cultural field (2005; Gilleard & Higgs, 2007).

This group, or identity has progressively emerged in the twentieth century from a wide variety of social forces (Carr & Komp, 2011), to whom the definitional work of dementia research and geriatrics are only a part. The emergence of this identity belongs to broader social processes operating contingently, and whose main articulations can be traced in the cultural transformations that followed the end of the Second World War. The emergence of a third age identity, argue Gilleard and Higgs (2010), relates to demographic changes but also cultural ones, contingent on the former and mainly associated with the diversification of available lifestyle choices in later life.

With regard to the demographic changes, people from the West are living longer lives today than they used to in the first half of the twentieth century and before. As the *World Health Organisation World Report on Ageing and Health* (World Health Organization, 2015, p. 43) shows, the number of people aged 60 years or older has both increased in proportion, and in absolute number. Additionally, the ‘demographic boom’, or ‘baby boom’, taking place following the Second World War contributed to the increase of the general ageing population (Gilleard & Higgs, 2007, p. 20). This expansion led to an increase in the proportion of the population in later life able to matter in the cultural life of the general population.

Indeed, there is also a contingent cultural transformation operating in parallel to this demographic change. Following the emergence of pension and retirement systems, social scientists sustain the argument that *ageing has diversified*. By this, they mean that there has been a multiplication of lifestyle opportunities available to people as they reach retirement. For instance, Jones and Higgs (2010, p. 1515) explain that “normal ageing now takes on a multiplicity of forms; from an extended

working life to a retirement of leisure; from grand-parenting to late parenting; from sheltered housing to beach-front retirement communities”. What enabled this diversification, as Gilleard and Higgs (2002, p. 379) argue, is a result of complex post-war transformations of ‘rising income, increased personal freedom and increased material wealth, of changing patterns of work, expanding opportunities for consumption (...)’. According to these authors therefore, in today’s Western liberal societies, an important segment of the population in later life has more resources, more freedom of choice, and more accessible goods and services than it ever had in previous periods of history.

The generation of individuals ageing today therefore presents unique cultural characteristics. Among those, we should see that *idealised youthfulness* and the rejection of everything deemed ‘old’ is a central feature of this cohort. For Gilleard and Higgs (2002), there is a strong collective consciousness surrounding this diversification of lifestyle choices. Baby boomers have realized that they were sharing this novel experience of ageing together, in stark contrast with the previous cohort, generating a sense of generational belonging argue Gilleard and Higgs (2002). Youthfulness and the rejection of everything deemed old, a characteristic of the youth culture of the sixties have been elevated as ideals for this specific cohort (Marwick, 1998 cited in Gilleard & Higgs, 2002, p. 376). The cultural unity of this cohort and its celebration of the youthful body and mind exists beyond its mere demographic increase. This celebration of youthfulness constitutes an essential explanatory mechanism for this research exploring the origin of anxiety in later life and its connection to the social exclusion of dementia.

As these notions of lifestyle choice presented above suggest, *consumption* plays a central role in the diversification of experiences in later life. It constitutes the basis of this diversification (Gilleard et al., 2005; Gilleard & Higgs, 2010; Jones et al., 2008). Gilleard and Higgs (2010, p. 121) explain that ‘the commodification of the body, the development of anti-aging strategies, and the increasing differentiation of mass consumer society all illustrate how later life has been transformed as a field of agency and choice’. Consumer society therefore constitutes the soil in which these novel subjectivities grow, inserting themselves into the economic liberalization of Western society. ‘Third agers’ become the masters of their own

choices, and while inequalities remain between individuals in later life in their income and capacity to benefit from consumer society, Jones and colleagues (2008, p. 115) argue that ‘it is no longer possible to define later life as a period dominated by poverty and exclusion from society’. This increased agency through consumption is an indication of the factual limitation of the theory of precarity (e.g. Grenier et al., 2017) presented above as an explanatory framework for social exclusion in later life (Gilleard & Higgs, 2019).

In this context, consumer choice drives the quest for the most fulfilling and valued lifestyles, yet it also increases people’s *responsibility* to maintain their social status and identity (Rose & Novas, 2005, p. 441). Health, one of the most delicate equilibria to maintain for an ageing population, as we will see, plays a crucial role in the construction of current later life identity and does not escape the rational of individual consumer choice. Access to better healthcare fundamentally transformed the experience of later life in the West. At a historical level, it is in stark contrast with previous conditions of the aged. In their analysis of ageing in the Victorian era for instance, Gilleard and Higgs (2010, p. 124) recall that ageing used to be a tragic prospect where individuals in later life were often denied social status due to a lack of resources and the inability to participate to the requirements of an industrialized British society, often institutionalized in so called poor houses (Townsend, 1962).

Despite the recent demographic and cultural transformations leading to the emergence of a third age identity, later life has not been freed from the threat of institutionalization, and the aged remain vulnerable to irreversible life changing health issues, among those being impairment, frailty and dementia (Gilleard & Higgs, 2020, p. 96). Brayne (2007) has referred to these health issues as the ‘elephant in the room’ of later life. Indeed, although life has been prolonged, it has not been separated from the inevitable physical degradations of ageing despite having been relatively freed from the necessity of work and the risk of impoverishment through the establishment of social welfare systems and pension plans (Jones et al., 2008). Longer lives enabled by the numerous technological improvements of medicine, especially since the 1960s, have pushed back the time when the onset of serious health degradation and impairments become inevitable,

explains Kaufman (1994, p. 432). Yet, at a later point in the ageing process, she explains, the most disabling conditions become inevitable, and concentrated, resulting from the repercussions of survival through medical intervention for other health conditions (Kaufman, 1994, p. 432). The third age maintained through generalised consumer choice, responsibility, prevention and medical intervention becomes contingent when viewed against the alternative concentration of disabling conditions and more advanced impairments and illnesses associated with the last stages of life. Dementia, together with frailty as Kaufman (1994) or Gilleard and Higgs (2010) point out are the main conditions that represent the interruption of this novel active later life, hence the constant emphasis on their prevention today. Dementia therefore possesses a strong symbolic power that extends beyond the biological reality of the condition. It is an important source of fear for the third age as it represents a threshold marking the end of a successful later life (Breining et al., 2014; Gilleard & Higgs, 2015). The extent of this is so much the case that Gilleard and Higgs (2020, p. 96) argue that ‘most of the infirmities and impairments that ageing bodies acquire have a greater salience, in so far as they reflect ageing and at the same time act as one of its most critical points of difference’. As Gilleard and Higgs (2020, p. 96) emphasize, ‘these corporeal realities constitute some of the most salient divisions within ageing societies, particularly when they operate within later life itself’. When acknowledging the centrality that dementia occupies as a symbol of fear and difference in later life, it becomes difficult to think about studying social exclusion in dementia without considering the broader social and cultural contexts of ageing today and the central position that the fear of dementia occupies in them.

### **Shifting understandings of ageing successfully – the ideal of active ageing**

These cultural transformations and the representation of dementia as a threshold marking the end of a desired later life have had an impact on how individuals in later life behave and are advised to behave regarding their health. Health has taken central stage in lifestyle expectations in later life throughout the second half of the

twentieth century through the emergence of a concrete discursive and practical form defined by the ideal of *active ageing*. Active ageing, also called successful ageing, is a narrative and programme originally developed by Rowe and Kahn (1997) redefining later life through 3 main objectives that Pack and colleagues (2019, p. 2086) summarise as follow: ‘a) the avoidance of disease, decline and disease-related disability; b) the maintenance of high levels of physical and cognitive functioning; and c) sustained, active engagement in community and social life’. By relying upon a set of recommendations aligned with neoliberal governmentality and increased expectations of risk management and autonomy already attached to health in mid-life (Higgs, Leontowitsch, Stevenson, & Jones, 2009; Laliberte Rudman, 2015), this ideal rapidly became a reference guiding ageing today (Pack et al., 2019), and represents an important distinction from previous representations of ageing marked by decline, impairment and disengagement from society (Higgs et al., 2009; Katz, 2001). This ideal rapidly and efficiently spread across the world through Western institutions, public health campaigns, advertisement, news agencies, and other important actors in the global public sphere. Indeed, as Lamb (2014, p. 43 citing Rozanova, 2010, p. 215) explains, the ideal of *active ageing* is ‘an amalgam of textual and visual messages that appear and circulate in all kinds of public spaces, including, but not limited to, the media, policy documents, academic literature, and health care organizations’. Since it became part of the mainstream, the active ageing discourse further developed to integrate ‘notions of good health, functionality, independence, productivity, social connectedness and the capacity to engage in the activities of daily life’ as additional components (Pack et al., 2019, p. 2086 citing Asquith, 2009; Tulle-Winton, 1999). This ideal has recently become the dominant understanding of how to age successfully in Western society and has had an impact on our understanding of dementia thanks to its omnipresence, and constant promotion (Holstein & Minkler, 2003; Katz, 2000; Lamb, 2014).

Late capitalist society, its novel norms of individualism and the definition of identity through consumption (Bauman, 2000) have strongly influenced active ageing, so much so that it is now normalized and therefore unquestioned as a cultural assumption. To realize this normalization, it is pertinent to draw a cultural comparison. For instance, Lamb (2014, p. 50) presents variations in types of

governance directed toward the challenges of age, showing specific cultural dimensions in the priority given to individualized versus collectivist solutions regarding care. Collectivism can be found for example in the Maintenance and Welfare of Parents and Senior Citizens Bill legislated in India in 2007. This Bill legally requires individuals to take care of their parents, therefore establishing the family as a reference for the practice of care and the fulfilment of a desired later life. In contrast, the individualistic approach of active ageing presents a shift of values toward individual, rather than collective responsibility, as a key characteristic of its specific cultural understanding of the meaning of ageing. Lamb (2014, p. 44) explains that 4 cultural themes compose the ideal of active ageing: 1) ‘an emphasis on individual agency and control’; 2) ‘the value of independence and the importance of avoiding dependence’; 3) ‘the value of activity and productivity’; 4) ‘a vision of not aging at all, while pursuing the goals of agelessness and what could be termed a permanent personhood’. These four characteristics echo many aspects of the diversification of ageing presented earlier, namely the idea of self-determination, activity, the maintenance of productivity, and individual responsibility to stay healthy.

The discourse of active ageing is therefore normative in constituting new forms of *biological citizenship* in later life, consumer-citizens responsible for their own health within the context of late capitalist societies (Rose & Novas, 2005). Such transformation involves the transfer of collective responsibility for the ailments of ill health toward the individual (Jones & Higgs, 2010; Laliberte Rudman, 2006, 2015; Pack et al., 2019). Lifestyle modification becomes central to the management of health risk in this context. What emerges from this novel type of governmentality around health is the increased pressure on individuals to engage in health monitoring (Rose & Novas, 2005). Such transformation around health has even become consequential to the development of *healthism*, a lifestyle pursuit driven toward health as an ideal, a ‘super value, a metaphor for all that is good in life’ (Crawford, 1980, p. 365). Rose (2001, p. 147) in another exploration of the matter presents the important aspect of moral judgement associated with this turn toward individual responsibility in late capitalism. Health issues in ageing should therefore be avoided through rational choice and careful self-monitoring of behaviours presenting a risk for one’s health.

This ideal applied to later life in the form of active ageing however implies an inherent tension regarding the inevitability of bodily decline (Cardona, 2008; Lamb, 2014; Mendes, 2013). Elevating the continuous maintenance of a healthy self through monitoring becomes contradictory to the inevitable corporeal decline that ageing involves. Active ageing has a problematic tendency to omit decline in ageing – the fourth characteristic underlined by Lamb (2014, p. 44), also referred to as ‘ageless ageing’ by Andrews (2000). Although it is not a dismissal of the finite character of life, this ideal nonetheless obstructs discussions of decline and the implications of the ageing body.

### **Beyond healthy ageing – enhancement and the objective of fitness**

While the introduction of active ageing in the second half of the twentieth century led to new complexities in engaging with decline, this process did not limit itself to the idea of avoiding illness in ageing as an ideal. Most recent transformations engendered by late capitalism and its individualistic competitive conception of the subject further intensified this expectation of health, rendering decline even more problematic. These transformations to health involve the emergence of a novel *objective of fitness* influencing understandings of ageing in late capitalism, explain Jones and Higgs (2010, p. 1516). In a similar way to lifestyle diversification, this novel objective to reach in later life should be achieved through consumption as a process of identity-making. Consumption and the new ethos emerging from it has elevated ‘the attainment of a state of fitness which acts as a perpetually unattainable goal’ (Jones & Higgs, 2010, p. 1515 citing Bauman, 2001, 2005). As a result, and this is what Jones and Higgs (2010) underline based upon the theory of late capitalism of Bauman (2000), the most socially valued way to age is not a fixed goal that ageing individuals can attain anymore. It is a process, a constant state of transition toward an objective designed as unachievable. In some ways therefore, the objective of fitness erodes the possibility of satisfaction associated with a healthy body in ageing.

This shift in the transformation of our conception of a healthy body in later life has more recently started to encompass the brain. This is part of the argument that the

second and third chapter of this thesis will develop by presenting the emergence of new forms of *active cognitive ageing*. Active cognitive ageing has been enabled by a series of transformations in our understanding of the mechanisms of the brain and the often-distorted translation of these scientific findings into popular culture in the context of a consumer society. With regard to brain health more generally, the *neuro-turn* theorized by Rose and Abi-Rached (2013) associated with the emergence of molecular biology and its spread into observations and conceptualizations of the brain has further reinforced our comprehension of this organ as the physical object in which cognition finds its source, reconfiguring our understanding of the material origin of the mind. Frazzetto and Anker (2009, p. 816) refer to the concept of ‘brainhood’ to qualify this increased reference to the role of the brain in the constitution of identity and personhood. Such cultural understandings of the brain have played an important role as a basis for this idea of cognitive fitness and performance (Frazzetto & Anker, 2009, p. 818). For instance, the idea of brain plasticity and its recuperation within neoliberal modes of thought has intensified our description of the brain as a malleable object, amenable to change through the iteration of exercises (Pitts-Taylor, 2010; Rose & Abi-Rached, 2013). The brain as a plastic object, embedded inside a consumer society increasingly turned toward this objective of fitness, has straightforwardly enabled cognition to become a modality that can be acted upon by the responsible consumer-citizen inside the ideal of active ageing (Katz & Peters, 2008; Williams et al., 2011), suggesting that dementia itself can benefit from responsible action (Peel, 2014).

This expansion of enhancement into the brain, and the new unlimited norms of ageing that it brings is an important dimension of my approach to social exclusion in this thesis. Indeed, the constant pressure to reach new standards of health impacts people through the responsibility that they feel in fulfilling norms that are always beyond their reach. No matter how fit we are, we can always be fitter. This has a detrimental impact on society’s perception of people with dementia, leading to exclusion, as we should see in chapter two and three. Active cognitive ageing establishes a hierarchy of values around self and others in later life. This hierarchy places the active, independent and responsible consumer-citizen at the top, and



devalues others. How does devaluation in ageing operate as a result of these novel norms? This is what we should now introduce.

### **The fourth age – a feared imaginary of later life shaping our understanding of dementia**

The ideal of active ageing and its expansion into the realm of cognition through active cognitive ageing arguably affects our perception of those who develop health conditions in later life. It is particularly so for dementia and the individuals diagnosed with this condition.

However, we should first see that researchers have described the standing of people with dementia in society in different ways that do not necessarily consider the role of active ageing in affecting the position of people with dementia. Researchers such as Brannelly (2016) or Sweeting and Gilhooly (1997) have characterized their standing as a form of social death. In such a depiction, the person with dementia victim of a process of stigmatization and dehumanization is essentially perceived as passive, unable to engage in any form of meaningful social participation due to the cognitive impairment (Brannelly, 2011). Kitwood (1997a) describes how this negative positioning of the person with dementia is essentially due to the negation of its personhood – a concept that he describes as ‘a standing or a status that is bestowed on one human being, by another in the context of relationship and social being’ (Kitwood, 1997a, p. 8). By this Kitwood (1997a) explains how people with dementia are essentially described as unable to make decisions about their own care. This exclusion is what he refers to as an example of ‘malignant social psychology’ resulting from professional and informal carers’ lack of consideration for the remaining abilities of people with dementia to make decisions about their own care trajectories (Kitwood, 1997a). This transformation eventually led to the implementation of person-centred care as a guideline for the activities of care homes and healthcare facilities for people with dementia (Brooker, 2004).

Yet, some researchers have been critical of Kitwood’s theory by indicating that considering the social interaction alone is limiting, indicating that one should take

into account the role of the sociocultural context in the exclusion of people with dementia (Baldwin & Capstick, 2007; Bartlett & O'Connor, 2010; Innes, 2009). For instance, researchers have emphasized the need to take into account the impact of society's representations of dementia and social practices that constitute obstacles, sources of stigmatization and discrimination for people with dementia (e.g. Bartlett, 2016; Brannelly, 2016; Kontos et al., 2017; Tolhurst, Weicht, & Kingston, 2017). These researchers have approached dementia through a social model similar to the one of disability, emphasizing the need to counter these narratives and practices through empowerment, campaigns based on citizenship and human rights, and advocacy (Beard, 2016; Beard & Fox, 2008; Cahill, 2018; Shakespeare et al., 2017). They have essentially framed the exclusion of people with dementia as a matter of power, and the need to reinforce the citizenship status and standing of people with dementia while detaching ourselves from solely considering the exclusion of dementia as a matter of cognition and impairment located in the individual and the limitations of his body (Bartlett & O'Connor, 2007; Birt et al., 2017; Kontos et al., 2017).

These approaches have brought a valuable and important focus on disabling environments and issues relating to abuse and discrimination against people with dementia. However, both the approach of Kitwood and ensuing work about citizenship do not address the substantial mechanisms behind exclusion emerging from the the dominance of the active ageing ideal that surrounds dementia today, and existential and corporeal concerns linked to dementia. Active ageing participates in the constitution of a collective imaginary encompassing the most negative sides of ageing. Scholars of ageing Gilleard and Higgs (2010) have qualified this collective imaginary as the *fourth age*. By social imaginary of the fourth age, they understand 'a largely unstructured and inarticulate understanding of social situations' (Gilleard & Higgs, 2010b, p. 122 citing Taylor, 2004, p. 25). They describe it using the metaphor of a black hole, an ontological space for individuals that fall beyond the social, unable to exercise their agency as a fundamental condition to fulfil objectives of emancipation through consumption and lifestyle choice developed by active ageing (Gilleard & Higgs, 2010). A collective imaginary generated by society determines this space, which comes to encompass the most feared and unwanted aspects of ageing (Gilleard & Higgs,

2010). It is a collective fear of losing one's agency, and freedom of choosing one's own life in which dementia, frailty, and other irreversible conditions are understood as the central representations of this loss (Gilleard & Higgs, 2010).

Although it can sometimes be confused as such, this fourth age does not correspond to a specific period of life. The idea of the fourth age as a period of life encompassing the most unwanted dimension of ageing was originally found in the work of historian Peter Laslett (1989). However, Gilleard and Higgs (2010, p. 122) distinguish their theory from Laslett's (1989) definition of the fourth age who mainly describes a period of 'decrepitude' affecting people beyond their mid-eighties. Indeed, Gilleard and Higgs (2010, p. 122) explain that it is rather 'a cultural field shaped by the experiences of people who grew up and are now growing old within mass consumer society'. It is an imaginary space based on fear in which long term care and the nursing home represent terrifying prospects for 'third agers' (Gilleard & Higgs, 2010, p. 126). Knowing the determinant role that dementia plays in the referral to a nursing home, one can therefore understand how dementia is one of the main conditions feeding this imaginary. Those encompassed by the fourth age therefore become those whose presence stimulate this imaginary – dependent individuals with dementia in nursing homes for instance.

Through its determinant capacity to affect one's autonomy and agency, it is no surprise to see how dementia became elevated as a threat within the discourse of active ageing, an example of 'failed' ageing (Latimer, 2018). It is perceptible when looking at the first and second characteristics of active ageing presented by Lamb (2014, p. 44): 1) 'an emphasis on individual agency and control'; 2) 'the value of independence and the importance of avoiding dependence'. It therefore represents the interruption to possibilities of experiencing a later life ideally defined by the normative expectations of the third age. Hence, this can explain why dementia became the most feared condition in later life in the United Kingdom. If we look at various attempts to unpack this fear, they are articulated around specific aspects of dementia. For instance, Herskovits (1995, p. 148 citing Cohen & Eisdorfer, 1986) says the following:

*"The problem of debased personhood is implicit in the current Alzheimer's construct, due to its vividly disturbing metaphors and images of AD as 'the*

*funeral without end,’ ‘the loss of self,’ and ‘the death before death’. With the popularization of Alzheimer's disease, the subjective experiences of ageing and of ‘senility’ have become increasingly horrific and monstrous; we are all afraid of losing our minds as we grow old.”*

These many negative representations that Herskovits recalls, and the assumptions that they generate as part of this feared imaginary figure of later life and dementia articulate mainly around the idea of personhood. This idea sees personhood as the condition for the agentic self to exist.

This centrality given to agency and personhood is amplified by the current context of consumer society. Some researchers have referred to current consumer society as a ‘hypercognitive society’ (Katz & Peters, 2008; Post, 2000) emphasizing the priority given to an agentic self in an increasingly deindustrialized Western society relying upon a third sector economy highly reliant on cognitive abilities. These ‘hypercognitive norms’ play a role in our perception of dementia, yet it is also part of a broader system of exclusion and classification, one in which clinical practices play a fundamental role in creating the underlying ‘truth’ of the disease and its social signification. This is an argument that I will develop in chapter four by analysing the action of memory clinics for instance. These aspects of consumer society – although they are not explanatory for the existence of the fourth age alone – have reinforced the role of dementia as an important articulation of this imaginary.

Importantly, this interpretation should include the centrality given to lifestyle choice and responsibility in a consumer society as an important factor that reinforces the fear of dementia as it strengthens the social significance of agency. Indeed, to understand the increasing strength of this imaginary at the end of the twentieth century, one should come back to the transformations highlighted earlier in relation to late capitalism and the prolongation of active life. The third age, and its emergence as a continued space of experience in later life following the cultural transformations of the 1960s has enabled new ways of *being* into the world. As such, the whole ‘active ageing’ apparatus relies on an attempt to push back, prevent and hide conditions such as dementia and frailty. Therefore, it is no surprise that the development of an appeal to performance and limitlessness only strengthened

the original proposal of the ‘active ageing’ ideal. In such late capitalist version of this ideal, disability, and age-related pathology hang as numerous swords of Damocles over the head of individuals as they grow older. This culturally-strengthened anxiety of losing one’s mind and agency, of being excluded from this field of experiences so important to the construction of *identity* in a consumer society, is expressed through the social imaginary of the fourth age.

### **An imaginary blurring our representations of the ageing body**

In large part explaining the fear that people in the third age have of the fourth age, there is therefore what Gilleard and Higgs (2018) call the *corporeality* of ageing. Corporeality describes the non-social nature of the body and the inevitable bodily decline of ageing (Gilleard & Higgs, 2018). Such a corporeality of ageing is being given meaning in different ways by people reaching later life and therefore inevitably plays a social role in the community (Gilleard & Higgs, 2018). Regarding that subject matter, the desire to preserve youthfulness and hide the corporeality of decline is at the heart of the priority we give to successful ageing and corresponds to the way in which active ageing establishes certain meanings around ageing and decline. The idealization of a youthful body and mind is central to our perception of dementia as dreadful, opaque and all encompassing (Latimer, 2018), and represents one of the most important fears that people have as they age and when they work and live close to people with dementia (Behuniak, 2011; Cantegreil-Kallen & Pin, 2012; Kessler et al., 2014; Suhr & Kinkela, 2007). This fear of cognitive decline, when understood as part of a broader concern with ageing and decline hides inevitable existential concerns (Pickard, 2016). Pickard (2016), by studying the widespread imaginary character of the Hag, or witch in popular culture, explains how Western society’s age system constitutes later life as an inevitable source of anxiety for ageing individuals. Pickard (2016, p. 1) describes ‘[t]he sense of horror and tragedy, of dread and pity [that] we feel in [the] presence [of the Hag]’. This figure of the Hag, as Pickard (2016, p. 23) explains, ‘epitomizes our view of ageing as decline and loss of self and our horror at the loss of choice and control that finds its ultimate expression in death’. Although Pickard (2016, p.

4), like Gullette (2004, 2017), argues that this aversion of decline and existential anxiety results from a 'decline ideology'. Being critical of the excessive social constructionist nature of this idea of 'decline ideology', Gilleard and Higgs (2018) perceive the aversion for decline as a more intractable rejection of corporeal decline, the non-mediated feeling of 'otherness' and estrangement in front of one's own ageing body, fear in front of the lack of control of one's behaviour illustrated by aggression and incontinence, or one's impression of being betrayed by one's own body and its weaknesses. All these characteristics translate for them a fear of the 'relatively unmediated corporeal dimension of age and ageing' (Gilleard & Higgs, 2018, p. 9).

In its contribution to scholarship, this thesis analysing the impact of the fourth age on dementia and its role in social exclusion essentially attempts to fill a gap within the current literature on ageing and its polarisation between social constructionist perspectives on one side, and biomedical ones on the other. To this end, it aims at understanding the combined impact of corporeality and representations of later life in the social exclusion of people with dementia. Indeed, much of the work recently produced around ageing and dementia has been carried out by gerontologists with a focus on the novel cultures, or sub-cultures, of ageing, what Gilleard and Higgs (2019) qualify as an 'embodied ageing' rather than a corporeal one. Their approach therefore gives priority to a study of agency and lifestyle choice in later life. This approach is conducted at the expense of a more rigorous exploration of the implications of corporeality and decline in later life. It therefore risks presenting a sanitized vision of the ageing process lacking insight into the impact of consumer society in redefining dementia and the fear of its irreversible decline, a point also made with regard to health in later life more generally (Hazan, 2011a; Higgs & Gilleard, 2019). It therefore attempts to overcome a vision of exclusion limited to its understanding as an ideological construct linked to a Western emphasis on youthfulness as it is described by Gullette or Pickard for instance. It also wishes to overcome a biomedical understanding of exclusion which is solely concerned with mechanisms of prevention while having little consideration for social factors of exclusion or the exclusion of individuals in situations of dependency due to dementia.

By distancing itself from this gerontological approach, this thesis therefore attempts to describe how decline constitutes a fundamental fear in people's lives which is not properly considered within dominant discourses of active, healthy or successful ageing, therefore leaving this fear to generate stereotypical understandings of later life, or overlook people's perception of this corporeality of decline as abject or disturbing (Higgs & Gilleard, 2015). This description will help understand how the exclusion of these individuals who do not conform to the desired identity valued by the third age operates. Due to people's intrinsic fear of dementia, the fourth age is therefore an inevitable part of the ageing process and an important articulation of exclusion for people with dementia as we will see. However, as this thesis will argue, acknowledging the existence of this unwanted corporeality helps reduce the strength of this imaginary and should hopefully help to address parts of this exclusion. In the chapters that compose this thesis, I will spend time to explain how this exclusion operates by using the current expansion of technologies and social interventions for dementia as an ethnographic case study.

## **Rethinking exclusion in ageing and dementia**

This thesis also attempts to fill a gap in scholarship on social exclusion in dementia. As a corollary to the limited attention paid by gerontology to corporeality, the form of exclusion of individuals living with dementia and/or different forms of life-limiting impairment presented in this thesis has been neglected in ageing and dementia research. So far, much of the work on exclusion available in the scientific literature has been attached to theorize exclusion in later life as a result of socio-economic variables emerging earlier in life (Gilleard & Higgs, 2020), or through notions of ageism as an ideology that would pervade Western society, and set it against a general exclusion of the 'aged' (Higgs & Gilleard, 2019). For Higgs and Gilleard (2019), these positions appear inconclusive both because such socio-economic inequalities do not appear more substantial in later life as they are earlier in life, and because current evidence does not indicate that discrimination on the grounds of age alone presents a structural character similar to the one of racism or sexism for instance. It also appears incoherent as an explanatory system in

comparison with the kind of social exclusion that corporeality generates (Higgs & Gilleard, 2019), an argument sustained by this thesis presenting how exclusion in dementia can even appear as a result of the struggle against ageism – a paradoxical consequence resulting from a yet understudied process of exclusion that this thesis will refer to as *distinction*. This thesis will therefore attempt to fill this gap in our understanding of exclusion in later life by relying upon a study of technologies and interventions for dementia as a case study. As I should now present in detail technologies play a central role in producing and maintaining this division.

## **Understanding the role of technologies in social exclusion**

Why it is relevant to look at the role that technology plays in this exclusion today? Technologies are central to human activity. With regard to health, they have long been used and developed across history to facilitate the provision of cure and care, and improve the capacity of health services. It may therefore look like a necessary yet unsurprising exercise to research technologies in dementia. What makes this endeavour timely however is the current multiplication of digital technologies and its digitalization of social processes and relations (George, 2020), a process intensifying to the extent that authors such as Colin and Verdier (2012) speak of our time as a ‘digital age’. This digitalization of society is at the source of a major reconfiguration of human relations. Its generative power across all dimensions of life has affected health and healthcare in unique ways (Lupton, 2013), as well as ageing (Cutler, 2006; Peine & Neven, 2020; Taipale & Hänninen, 2018) and is currently developing for dementia (Astell et al., 2019; Ienca, Vayena, & Blasimme, 2018) as this section also presents below. This importance of technology within novel cultures of ageing explains why they play a central role within the processes of social exclusion in later life that I introduced above.

The most notable of these new trends has been the increasing digitalization of healthcare and its personalisation, breaking the boundary that traditionally existed between the institution of the clinic and daily life. As Lupton (2019, pp. 125–126) presents, ‘since their first release in 2008, millions of apps for smartphones, tablet computers and wearable devices such as smart watches and fitness bands have been



released onto the market’. Unsurprisingly when noticing the turn role that late capitalism played in fostering cultures of fitness, individualisation and responsibility, the vast majority of these ‘apps’ are designed for the sake of self-monitoring bodily functions (Lupton, 2019, p. 126). People play an increasing role as docile actors of their own health through careful planning and maintenance, improvement and self-diagnosis.

Such a process of self-monitoring translates intensifying processes of governmentality and their incursion into the domain of the intimate by shaping lifestyle, therefore qualifying these developments into the category of what Foucault (1988) termed *technologies of the self*. These technologies as ‘being the ones that, by their use, could enable individuals to develop a set of ‘operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality’ (Foucault, 1988, p. 18). Such novel trend is highly relevant to sociological and cultural inquiry therefore as the utilisation of technologies of the self is particularly sensitive to the kind of moral and normative order that society elevates around health. Beyond this aspect of governmentality, technologies are also productive of certain ways of being (Burkitt, 2002). As Burkitt (2002, p. 235) explains, ‘technologies of the self are forms of production as well as means of domination’. By this Burkitt (2002, p. 235) means that:

*They produce human selves with various dispositions and capacities that are formed in the matrixes of practical reason: that is, modes of activity that are supported and mediated by artifacts (as in the case of tool use for example) and social institutions, which aim to transform the world by the production of new works as much as they aim to reproduce the existing world.*

The technologies studied in this thesis are therefore approached with the understanding that they are integrally part of the social fabric of our society and our understanding of ageing and dementia. Beyond their mere functional aspect, they reproduce specific normative discourses and practices shaping a specific social order determining later life and the meaning of dementia. Reciprocally, this social order itself leads to the adoption of specific technologies and ways of being in later life and dementia, as described in this thesis. This interaction between

structure and individual, this dynamic of governance and production through the medium of technology use, habits and practices, presents how the self, the individual, becomes itself engaged in the reproduction of a specific social order (Bourdieu, 1977; Burkitt, 2002).

These novel trends around the digitalization of health have had a significant impact on population-wide approaches to dementia, both in shaping future biomedical research for the condition (Astell et al., 2019; Ienca et al., 2018), and to support the quality of life and social integration of people with dementia (Alzheimer Europe, 2010; Astell et al., 2019; Bennett et al., 2017). The scope of this thesis looking at social exclusion will specifically consider this second application. An interesting example explored in this thesis is self-monitoring in the current turn toward prevention in dementia. Indeed, technologies of the self have emerged as an essential interface fostering active engagement with dementia and cognitive ageing among the population in, or approaching later life. This thesis will present the expansion of the digital brain health market as a major commercial success, especially among people over fifty years old (Sharpbrains, 2013 cited in Simons et al., 2016). Meanwhile, several projects have emerged both in the United Kingdom and across the world to explore the potential of digital technologies for dementia to assist daily living through memory support (e.g. INDUCT, n.d.; Van der Roest, Wenborn, Pastink, Dröes, & Orrell, 2017), through cognitive training and rehabilitation (Galante, Venturini, & Fiaccadori, 2007; George & Whitehouse, 2011; Schreiber, Schweizer, Lutz, Kalveram, & Jäncke, 1999), but also through ‘information, company, reducing psychological distress, and engaging in daytime activities’ (Meiland et al., 2017, p. 2 citing Miranda-Castillo, Woods, & Orrell, 2013; Van Der Roest et al., 2009). The Interdisciplinary Network for Dementia Using Current Technology (INDUCT)<sup>6</sup>, research network of 15 researchers, to whom this PhD study belongs is also one of these projects. Parts of the studies developed in INDUCT relate to a more general strategy within the European Union’s Horizon 2020 research programme which aims to ‘keep older people active and independent for longer’<sup>7</sup>. The WHO presents a similar agenda within the

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<sup>6</sup> INDUCT (n.d.). Welcome. Retrieved June 2018, from <https://www.dementiainduct.eu/>

<sup>7</sup> European Commission Website (2018). Horizon 2020 on Health Demographic Change and Wellbeing, Retrieved May 2018, from <http://ec.europa.eu/programmes/horizon2020/en/h2020-section/health-demographic-change-and-wellbeing>

‘proposed actions for member states’ in term of research and innovation presented in the current WHO Global action plan on the public health response to dementia 2017-2025 (2017, p. 33). This plan lists the development of technological innovations to prevent cognitive decline or assist people with dementia as one of its recommendations. Researchers working on these projects envision them as being able to help people cope with the condition for as long as possible, by maintaining cognitive capacity, or autonomy as the condition progresses. This thesis explores the promise that surrounds some of these applications, attempting to understand how the fourth age articulates these developments. It will study a large-scale study exploring cognitive ageing and brain training (cf. chapter 3), a cognitive rehabilitation programme for people with dementia (cf. chapter 4), and an intervention promoting principles of empowerment and autonomy for dementia (cf. chapter 5) following these new trends.

Furthermore, the importance of considering the role of technology in dementia now is foregrounded given the context of the failure to find a cure for dementia. With this in mind and given the example of brain training, George and Whitehouse (2011, p. 590) speak about the way in which a ‘therapeutic void’ reinforced by the failure of over twenty drugs to cure dementia during the past decade has enabled the success of current brain training technologies for dementia. The success of brain training apps for instance is closely connected to the turn toward prevention that I presented earlier which is also an attempt to palliate the current failure of therapeutic research for dementia.

The attractiveness found in new technologies in times of incertitude regarding certain health conditions draws upon the work of DelVecchio Good (2010, p. 273) and her notion of the *biotechnical embrace*. This notion qualifies the power of attraction that cutting-edge treatment and therapeutic technologies in oncology can have over clinical staff, research policy, and the broader public (DelVecchio Good, 2010, p. 273). Such attraction constitutes what she calls a ‘political economy of hope’ around new therapeutic technologies and the promises that they contain. This political economy of hope seems to be therefore a convincing explanatory framework to explain the success of brain training and other technologies promising therapeutic virtues for dementia.

Besides this promise of brain training as an eventual substitute to cure, there may be a tendency for research and policy to see technologies as a response to the challenges of an ageing population following an overarchingly interventionist approach (Peine & Neven, 2019). In such a frame, technologies are therefore often presented as a support to daily life after the diagnosis in a context seeing the prolonged independence of the person with dementia as a means to reduce cost by ‘delaying entry into care and nursing homes’, an element of context that Meiland et al. (2017, p. 2) present in their article reviewing assistive technologies for dementia. The current climate of austerity around care and a perspective emphasizing the challenges of ageing populations also stimulates a market for technologies in later life as Moreira points out which includes dementia (Moreira, 2017). These politico-economic aspects partly influenced the development of policy frameworks such as the Prime Minister’s challenge on dementia 2020 (Department of Health, 2015), constituting the context influencing the development of some of the technologies presented in this thesis as we will see in chapter 5 for instance.

The role of social exclusion created by technology that this thesis proposes diverges substantially from the current scientific literature considering social exclusion and technologies for dementia. Firstly, this literature describes exclusion in technology as a problem of inclusive design presenting how the design of a technology can actually become an obstacle to utilization, an approach neglecting the fact that technology and ageing are co-constituted (Peine & Neven, 2020). For example, Jeremic and colleagues (2019) looked at the kind of barriers and facilitators that exist in the design of Xbox Kinect games developed for older adults. They present the way in which these games based on the recognition of movements may be problematic for older adults who have issues with their balance because the Kinect sensors would have difficulties to detect their movements with precision. A second frequent approach to exclusion in technology is often characterized by the term ‘digital divide’. This approach specifically points to exclusion as a result of inequalities of access to technology due to geographic or socio-economic factors (Neves et al., 2018). In these approaches, technology is applied to the life-world of older adults with limited consideration for their own representations of technology, its utility and meaning for them (Peine & Neven, 2020). Peine and Neven (2019)

characterise this approach as the ‘interventionist logic’ conceptualizing ageing as ‘a target for technological design’, a ‘set of problem to be solved’ making assumptions about the life-worlds and needs of older people (Peine & Neven, 2020, pp. 3–4).

Although these two approaches highlight important causes of exclusion, they neglect how technologies shape the meaning of ageing itself (Peine et al., 2015). Hence, they are limited in their ability to explore the intrinsic exclusionary characteristics of technologies and not able to characterise the widespread processes of exclusion that this thesis will describe, namely the ones generated by the social imaginary of the fourth age co-produced by the life-worlds of individuals in later life and technology. Primarily, this is because these studies overlook the cultural influences on the development of technologies and the impact of these technologies on the social configuration of later life. The question therefore is about detecting how technologies by their characteristics and social impact reflect certain strategies that are part of third age identity and lead to situations reinforcing the social imaginary of the fourth age. Understanding these situations would help to trace the exclusion of people with dementia as it is a consequence of the intensification of this imaginary. This thesis will shed light on this specific manifestation of third age identity and the fourth age in both technology use, development and design. Its argument will not be based on matters of the digital divide, issues of barriers and facilitators to use, or concerns of inclusive design because they do not play a central role in the social exclusion being described, although their indirect influence may be evoked from time to time.

## **Research question**

In relation to the current social context that surrounds ageing and dementia, and the increasing role that technologies play in ageing and dementia, this thesis will therefore propose to explore the following question: *how do technologies play a role in the social exclusion of people with dementia?* To do so, it will aim at understanding the exact nature of this process of social exclusion operating along

the parameters of the third/ fourth age divide, and explore its manifestation in four different sites across Europe.

As this thesis will argue, actors such as individuals approaching later life, developers and researchers implementing technological interventions for dementia, and people with dementia themselves play a role in yet unrecognized processes of social exclusion of people with dementia. These processes are highly variable, and localized. Hence this thesis will utilise ethnography as its chosen methodology. This approach looks at both the use, and development of technologies and how they insert themselves in localized social interactions and cultural narratives.

However, this thesis will not constrain itself to an account of technologies and their limitations in local settings. Using the different sites of this research as case studies, this thesis will attempt to explore how these local practices and discourses around specific technologies and interventions can enable us to theorize these processes of social exclusion. It will enable us to understand how Western norms and practices around ageing impact on people in later life living with dementia by implicitly or explicitly defining a part of these individuals as ‘abnormal’ – those individuals with dementia and other irreversible age-related impairments such as frailty. This thesis will therefore be holistic in its approach and therefore highly sensitive to the cultural and social context in which technologies are used and developed.

This thesis will apply theories of social positioning developed by Bourdieu (1979) to present how forms of exclusion enacted in its different research sites rely upon similar cultural assumptions about the nature of ageing and dementia and carry similar objectives of social positioning. His theories will therefore be used to analytically bridge these different sites and help to develop the theory of exclusion in dementia and later life constituting this thesis.

## **Outline of the chapters**

The research presented in this thesis is based on an ethnography across four different sites which are representative of the current trends around technologies and dementia – each site corresponding to one chapter. The first chapter will

discuss the methodology I used, mainly multisided ethnography, my choice for the different sites and participants, and important ethical considerations that emerged in the research. The second chapter will establish the theoretical foundations of the research, specifically regarding technologies of prevention and their capacity to create exclusion by valuing certain social positions in ageing and devaluing others. Using the marketing discourses and mechanisms of brain training apps as a case study, this chapter will theorize this particular social role of technologies of prevention to create differentiated social positions by introducing the concept of *technologies of distinction*. The third chapter of this thesis will use the four vectors of the fourth age – four key characteristics of the fourth age as described by Gilleard and Higgs (2015) – as analytical devices to understand the choices that individuals in or approaching later life make regarding brain training and how the social processes of distinction presented in the previous chapter influence these choices. It will therefore present how the fear that the social imaginary of the fourth age generates influences social positioning in this novel context emphasizing *active cognitive ageing* and prevention. The fourth chapter of this thesis will present how cognitive rehabilitation for people with dementia – a promissory strategy to respond to decline in dementia employed in memory clinics – represents a complementary process to *distinction* in separating people with dementia from the ‘normal’ ageing population. This chapter will help theorize technologies performing this social role of triaging and separation as *technologies of ascription*. The fifth chapter will describe a third attitude toward people with dementia present in society beyond distinction and ascription. It will look at the cultural representations of researchers engaged in an intervention promoting autonomy and empowerment in dementia – a novel and influential attempt to include people with dementia in society. By categorizing these interventions as *technologies of omission*, this chapter will present how they maintain the status quo around social exclusion by overlooking the impact of decline for a part of the people with dementia that cannot therefore benefit from these interventions. Finally, the sixth chapter of this thesis will present how people with mild to moderate dementia themselves maintain a *distinction* from people with more advanced dementia by looking at the action and representations of ‘experts by experience’ and advocates with dementia part of a dementia advisory group contributing to an emerging social movement of people with dementia. Here, ‘experts by experience’ refer to

individuals with dementia who play various advisory roles based on their own experience of the condition, a mode of engagement which has expanded in recent years, with advocates being people with dementia playing a more concrete political role as part of the movement (Preston-Shoot, 2007). This chapter will explain how such process of social positioning among people with dementia originally aims at resisting to social exclusion and diminishing the anxiety that the corporeality of advanced dementia provokes. As this chapter will present, this attempt can have indirect contradictory effects as it remains informed by the cultural norms of the third age. Highlighting this paradox will therefore enable us to critically assess the challenges associated with current approaches based on narrative change, citizenship and the social model of disability which are used as templates for an increasing number of interventions for dementia and strategies promoted by current dementia associations and advocacy groups.

Overall, and regarding the general argument of the thesis, this last chapter will enable us to better understand the contradictory nature of exclusion in later life and dementia, and to propose a more nuanced understanding of the technological solutions and interventions proposed to alleviate this social exclusion. Hopefully this analysis of social exclusion will help research and public health institutions to better understand the nature of social exclusion in dementia. It should enable them to better evaluate the social impact of novel technologies and interventions promoting approaches based on prevention and transformations of the narrative of dementia, and to more thoroughly evaluate the risk associated with neglecting care in the absence of a cure.



## Chapter 1: Methodology

*Illness is the night-side of life,  
a more onerous citizenship. Everyone who  
is born holds dual citizenship, in the  
kingdom of the well and in the kingdom of  
the sick. Although we all prefer to use only  
the good passport, sooner or later each of  
us is obliged, at least for a spell, to identify  
ourselves as citizens of that other place.*

(Sontag 1978 – Illness as metaphor)

This thesis, to achieve its analysis of social exclusion, connects macro-social analysis of the social imaginary of the fourth age and the tensions around ageing present within late-capitalist, consumer society to localized expressions of this exclusion within and around local use and development of technology. This thesis therefore relies upon a combination of social theory and empirical research supported by ethnography. It is at the crossing of anthropological knowledge in its capacity to connect localized practices and representations with macro-social phenomena, and broader social and sociological theories developed to understand social change in consumer society and its impact on ageing, health, and dementia. This connection between ethnography and social theory will be perceptible throughout the chapters. At a methodological level, the ethnographic dimension of this research occupies central stage. It relies upon the main principles and objectives of anthropology with regard to both ageing and dementia, and to technology, as well as a consideration regarding how to approach multiple research sites in parallel. In addition, it is also important to be aware of the rationale behind the selection of each site, and the need to understand the impact of the identity of the researcher on participants and research settings. These points will be discussed in this chapter, together with a discussion of important ethical matters involved in this research.

## **Developing an anthropology of ageing and dementia**

Following its theoretical and methodological affiliation with anthropology, this thesis looks at the interaction between 1) macro-phenomena and discourses linked to ageing, health and consumption in later life and dementia, and 2) the practices and cultural representations of older adults, people with dementia, healthcare professionals and researchers working on technological interventions in dementia. Such focus attempts to understand how ideas and discourses are generated and informed by the particular local moral worlds in which they are located, therefore looking at what Kleinman (1999, p. 77) calls ‘values in ordinary living’, and how ideas and discourses constitute a wider structure shaping localities and individuals (Bourdieu, 1977). Those localities are the temporally, spatially and socially located frames where social exclusion in ageing and dementia is naturalized, normalized or reified through the ‘mundane’ activities of daily life, and the mundane aspects of clinical and scientific activities (Kaufman, 2005, p. 332). This thesis therefore pays attention to ways in which individuals make sense of their experience of later life and dementia; how they envision this experience by paying attention to the analytical categories that they themselves construct – those ‘emic’ categories to which anthropology gives central stage. This thesis partly uses the inductive construction of knowledge enabled by ethnography to question some of the key concepts used by current sociological analyses of ageing. Such questioning will be present across the following chapters of the thesis each representing a different research site and ethnographic locality.

## **Approaching technologies and interventions as sites for the expression of social exclusion**

Technologies as I presented in my introduction occupy central stage as case studies to theorise social exclusion in later life and dementia. Technologies have been central to much theorizing in anthropology and even led to a specialized field of research and approach: Science and Technology Studies (STS). Therefore, this thesis should position its approach to technology regarding this field of research.

Following Peine and Neven's (2020) perspective, technologies as conceived in this thesis are always studied in relation to the social milieus in which they emerged. These milieus are used as ethnographic locations to study and illustrate the nature of social exclusion in the entanglements of structures and individuals defining dementia and later life. Hence, this thesis never detaches technologies from the context that surrounds their use and/or production. It sees technology as fundamentally the production of a certain culture at a specific time in history and locality in the world (whether it is a sporadic, virtual or interconnected one). Such a temporal and spatial localization resonates with Simmons' (1978) historical approach to technology: '[it] must I think be perfectly clear that to understand lives, the ordinary activities of human beings in ages other than our own, it is indispensable to consider the technologies that served them, for they formed in many respects the very frameworks of those lives themselves' (Simmons, 1978 cited in Bray, 1997, p. 1). A study of technologies and their impact on the world should overcome the divide that Latour (1993 cited in Peine & Neven, 2019) problematizes between the natural and the social sciences, acknowledging that technologies are co-constructed and never detached from the context in which they are embedded. Woolgar (2002, p. 14), another important theorist of STS also makes this point by explaining how 'the uptake and use of the new technologies depend crucially on local social context'. This thesis therefore follows the need to overcome this divide in order to fully account for the role that technologies play regarding social division in later life and dementia.

To an extent therefore, technologies shape people's perceptions of ageing and dementia in interactional manners as STS theories present. Yet this is only to an extent. As the chapters on brain training and cognitive rehabilitation will show, these two technologies which appear relatively similar may acquire a highly contrasted social meaning and impact depending on whether they are used by consumers attempting to sustain an active ageing or when they are implemented by therapists in a memory clinic. This bifurcation in the social effects of the same technology therefore indicates the role that the general context plays in situating the social significance of practices irrespective of what the actual relation between individual and material object may be. Knowing that, this chapter will propose to re-define certain commonly used technologies on the basis of the actual social

consequences of their implementation rather than on their material aspects or design.

Technologies are not neutral when they are considered within their particular social context. This thesis' position on technologies therefore resonates with one of the six laws of technology defined by Kranzberg (1995, p. 5) stating that 'technology is neither good nor bad; nor is it neutral'. Similarly, it draws upon Heidegger's (1977, p. xxviii) notion that technology is 'a mode of revealing'. Through this notion, Heidegger (1977, p. xxviii) explains how technologies reveal our way of being into the world, of 'ruling in all that is' (1977, p. xxviii). Accordingly, this thesis essentially presents how technologies illustrate a particular cultural conceptualization of the world at a particular time in history. Studying technologies helps us to understand how society defines particular social or natural problems and solutions to bring to them. Studying technologies also helps us to comprehend the cultural norms and assumptions involved in the definition of these problems. A pertinent example of this normative dimension of technologies can be found in the work of Wajcman (2010) on gender and technology. Wajcman (2010) explains how gender and technology are mutually constructed in fluid and situated manners and reading the meaning attached to them in particular contexts helps us to understand the norms that they reproduce or impose. Hence, Wajcman (2010, p. 144) argues to treat 'scientific and technological artifacts [...] as simultaneously semiotic and material'. Regarding cultures of ageing and dementia, technologies are profoundly inscribed within a field of power relations directed toward the categorization of ageing individuals (Aceros et al., 2015; Peine & Moors, 2015; Peine & Neven, 2020; Vermeer et al., 2019). They reflect with variable intensities the ideas and assumptions of their users and developers. Technologies enable them to construct or ascribe certain identities in later life, and potentially carry aspects helping or amplifying the social imaginary of the fourth age. Clive Baldwin (2005) approaches ethical considerations of technology developments in the field of dementia. In his deconstruction of the ideal aspects of these developments, Baldwin (2005) notes that technologies are shaped by our values and desires, and reciprocally, shape these values and desires as well. We have here a double-edged process – technologies shape the people within the life world in which they exist, and technologies are shaped by these same people within this life world.

Technologies *mediate* what remain fundamentally social interactions and power relations. In my research, technologies therefore constitute articulations or mediators of social interactions and power relations central to social exclusion. As Peine and Moors (2015) put it, ‘they redefine boundaries (between health and disease, between citizens and patients, between what is considered active and what is not), they limit or enable (sometimes in unexpected ways) agency in one way or the other, and they define new socio-technical arrangements in which responsibilities, actions and interactions are re-distributed among existing and new stakeholders involved with health and care’ (Peine & Moors, 2015). The study of each local site explored in this thesis embraces the meaning of this statement. This study explores the significance of a technology not according to its ontological characteristics alone but according to the social role that it plays in redefining identities and establishing their belonging along the line of the third/ fourth age divide.

### **Multi-sited ethnography bridging four different sites**

The nature of this thesis’ research question studying social exclusion in later life and dementia within the fragmented space of a highly stratified consumer society inevitably implies challenges in term of methodology. The phenomenon of social exclusion in later life studied in this thesis is neither limited to specific social classes or groups, nor to specific identities or localities. Meanwhile, anthropological approaches using ethnography are traditionally localized in single sites. How to develop a methodology reasonably combining the advantages of a localized ethnography, and the reality of a fragmented research object? The methodology I chose, multi-sited ethnography, appeared as most adequate to explore the existence of this divide across these fragmented sites and to bring different manifestations of the same exclusion.

This approach helps to compare different forms of exclusion by generating an analytically relevant contrast. Such methodology relies upon the seminal work of anthropologist George Marcus (1995), or sociologist Michael Burawoy (2000). Such method, by establishing short term ethnographies in multiple sites “moves out from the single sites and local situations of conventional ethnographic research

designs to examine the circulation of cultural meanings, objects, and identities in diffuse time-space” (Marcus, 1995, p. 96). In regard to ageing, such an approach is yet another means to demonstrate that global discourses around ageing are essentially locally produced in specific *lifeworlds* and that these local productions are constantly producing widely shared imaginaries of later life, a point that anthropologists like Cohen (1998) or Lamb (2014) previously demonstrated. To construct a research object, it therefore follows a specific imaginary of ageing, the one of the fourth age, and its creation of exclusion across multiple sites in a process that Marcus (1995) referred to as *following the plot, or narrative* in a fragmented world system. Although I should depart slightly from his proposal by pointing out that the point of connection that circulates across my research sites was to follow expressions of the social imaginary of the fourth age in these sites.

And how to find research site(s) which could support the nature of this research question? The thesis looks at diverse influential sites where the narrative that defines dementia today is being constructed – amidst places where influential psychosocial and technological interventions are being developed, implemented and used. These sites represent the novel approaches to the condition that attempt to distance themselves from previously dominant biomedical research. They therefore announce transformations to come in the domain of dementia and offer this thesis an opportunity to question change as it happens. These sites reflect the perspectives and practices of individuals engaged in prevention, clinical settings where dementia is being diagnosed and treated through novel principles of rehabilitation, interventions promoting novel ideas of ‘living well’ with dementia and sites where people with dementia themselves are engaged in shaping the narrative around their condition.

These sites involve technologies in various ways. They concern practices and discourses around technologies, the interventions and artefacts that people elaborate to solve different issues around social exclusion in dementia as they understand it. A focus on technologies and technological interventions enables the researcher to pragmatically identify discrete field sites with an internal coherence. Technologies and interventions can mobilize people around a single object, strategy or process.

The coherence of these units of social mobilization allows research to more easily establish connections between them. For instance, looking at brain training users approaching later life in the United Kingdom enabled this research to focus on the particular narratives that they constructed around this specific technology, to understand the effects of widely held public narratives encouraging prevention practices on behaviours, and to better understand the social exclusion that they may involve. Some other locations were even more discrete, such as the memory clinics implementing cognitive rehabilitation technologies, or interviews with a research team developing a psychosocial intervention to support independence in dementia, yet technology and/or intervention again was a central object around which the activities of these individuals were organized, and their construction of meaning about dementia converged. Each site presented a localized understanding translating aspects of the social imaginary of the fourth age and the complex relations that actors established with it.

The research site detailed in Chapter 6 of this thesis which examined advocacy in dementia seeks to understand social exclusion in particular localities, however it is somewhat different in scope by being centred on the activity of expertise and advocacy within dementia advocacy organisations, rather than considering a technology per se. As we will see, this institutionalised group can however be understood as a social assemblage performing a certain function. It therefore carries an element of technology in its broader sense (Matthewman, 2011, p. 58). It also helps to synthesize and shed additional light on the complexity of exclusion presented in the other chapters by presenting key tensions and paradoxes in social exclusion, therefore justifying its place as part of this thesis.

Beyond this general methodology, the research methods I used in each site were often defined by the kind of information I wanted to access, by the realities and constraints of the sites themselves, and by the necessity to ensure the comfort of the participants. My methodology was therefore constituted of a mix of interviews in two sites, and by participant observation in two other sites. Research in each of these sites focussed on the *emic* meaning-making processes that take place through practices and discourses relating to ageing and dementia, and the construction of

particular narratives around identity in dementia – an essential dimension of the anthropological approach presented above.

In parallel to these research sites, I also spent time exploring the marketing discourses of brain training and assistive technologies for dementia, as well as national and international strategies for dementia, policy reports, newspapers, blogs, and any other interesting material that could help inform this ethnography and answer my research question. This exploration of cultural artefacts constitutes the main source of data for the second chapter of this thesis establishing a theoretical framework around process of social exclusion in dementia realised prior to fieldwork.

Rapp (2000, p. 12) in her study of amniocentesis in America reminds us that the particular approach of multi-sited ethnography implies that there is ‘no obvious theoretical or situational limits’ to this type of study. This is a point I felt strongly in my own fieldwork as I was constantly accumulating new interviews, testimonies, both ‘grey literature’ and scientific literature from clinical disciplines. There is no concrete limit to fieldwork, and the constant unfolding of relevant events extended well before and after my formal period of fieldwork.

I will now present the four different sites constituting my fieldwork and details of my methodology for each site. The research sections presented in this thesis were reviewed and approved by the University College London’s Research Ethics Committee (reference ethics approval: 12275/001 and 12275/002) as they involved human research participants. The project was also reviewed and approved by the Southern European research ethics committee to conduct research within two memory clinics in a Southern European country (cf. Chapter 4)<sup>8</sup>.

### ***Brain training and the impact of prevention***

Prevention has become central to our approach to dementia in the 21<sup>st</sup> century, so much so that anthropologist Margaret Lock (2013) sees it as a paradigmatic shift. In her book *The Alzheimer’s Conundrum* (2013), she explains how novel forms of

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<sup>8</sup> Research ethics approval for the Southern European country available on request



genetic testing, and encouragements to operate lifestyle changes in order to prevent dementia, although currently limited or even considered useless in regard to Alzheimer's Disease, have the potential to become efficacious modes of treating dementia in the future. This section of my research sought to understand the consequences that the intensification and multiplication of these discourses of prevention could have upon social exclusion. In the frame of this research informed by current trends in consumption among individuals in later life, the current expansion of a market for brain training apps was an indicator of the relevance to study this paradigm and its consequences. To this end, I explored the narrative of these technologies in detail (the object of chapter 2), and the motivations of healthy adults living in the United Kingdom to use brain training for prevention purposes.

I chose to collaborate with a university research project based in the United Kingdom to recruit the participants of my research, one that I will call The Delta Project for anonymity purposes. The Delta Project wished to understand the influence of factors in middle-age on the risk of developing dementia later on. This project totalizes now over 20,000 participants and conducts assessments and interventions that they initially planned to follow for a period of 10 years. The interventions and lifestyle factors whose impact on the risk of developing dementia is being measured by the Delta Project include a brain training software tested on a period of one year. The game was still available throughout the rest of the study and therefore enabled participants to continue to use it beyond the formal period of the research. Thanks to the help I received in recruitment from the team of this project, I was able to explore the motivations and representations of 27 older adults using this brain training software to understand how they relate to technologies promoting messages of active ageing and prevention. I asked them questions through semi-structured interviews which lasted between thirty minutes and an hour on average to ask about their motivations to participate in a research project specifically exploring brain training's effect on the prevention of dementia. I also asked participants how they perceived ageing, dementia and cognitive decline. One of the key interests of interviewing these participants is that they had not been diagnosed with dementia – an initial criterion of inclusion to the Delta Project.

My research with the brain training users did not impose any specific limitation for participation beyond the requirement that people spontaneously engaged in the practice of brain training in relation to dementia (for instance outside of any prescriptive medical framework). It therefore helped to understand how third age culture influences the decision to engage in prevention. Other demographic characteristics were beyond my control as they were predetermined by the conditions initially set by the Delta Project. This set of initial criteria involved the requirement to be over 50 years old without having dementia.

The random recruitment of the 27 individuals interviewed based on voluntary participation did not lead to a representative sample of the population. White middle to upper-class highly educated women were disproportionately represented in the spontaneous sample of people who contacted me for the interview after having received my invitation to participate from the project team. Indeed, most of my participants completed a higher education degree, some to the level of a PhD, and a few of the participants were women or men from different Black or minority ethnic background. Beyond this demographic data apparent at the time of the encounter and within the responses provided by the participants, I did not aim at collecting demographic data and I have no awareness of the characteristics observed at the level of the entire study developed by the team of the Delta Project. The exploratory nature of my research however did not require a representative sample.

For pragmatic reasons, this research section only relied on interviews. It would not have been practical or even relevant to follow individuals daily in their houses and activities as to understand their engagement with prevention. Interviews appeared to be a more efficient mode of gaining insight into their engagement with brain training. As indicated above, interviews were semi-structured and gave an important space for reflection and the opportunity for respondents to raise topics of interest for them. I developed the first part of the interview guide using prompts exploring their motivations to participate in research on dementia and brain training, ways in which participants perceived the technology (motivation behind use, perception of efficacy, practicality and preferences in technology use). Following the second part of the interview guide, I explored characteristics of third

age identity. I developed my questions on third age identity following the four characteristics of active ageing that Lamb (2014, p. 44) defined: 1) ‘an emphasis on individual agency and control’; 2) ‘the value of independence and the importance of avoiding dependence’; 3) ‘the value of activity and productivity’; 4) ‘a vision of not aging at all, while pursuing the goals of agelessness and what could be termed a permanent personhood’. Finally, the third part of the interview guide aimed at exploring participants’ perspective on ageing and dementia. Namely, I asked how each participant understood and experienced ageing, and how it had evolved from what they thought about it earlier in life. This question usually led to rich and detailed answers about participants’ understanding of life, decline and death in which dementia was often spontaneously mentioned. I also asked how they perceived current narratives about dementia in the media and across society in order to understand the wider representations and moral beliefs that they constituted around dementia and ageing.

The interviews took place in settings that the participants felt most comfortable with – either at home around a cup of tea, or coffee, and biscuits, or in a meeting room of the UCL Division of Psychiatry. Many participants chose the latter, maybe because the department offered a space in which they could discuss these matters anonymously or without being interrupted, or they found it an opportunity to enjoy some time away from home. I recorded the interviews using an audio-recorder and transcribed them. I analysed these transcripts multiple times, the first round being a coding of the main themes that the participants mentioned using thematic analysis (LeCompte & Schensul, 1999), and some elements of inductive exploration borrowed from grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). I used the software NVivo to assist this coding and analysis process. Based on the answers of the participants, I created broad categories to guide the initial analysis. They concern motivations to use brain training technologies, and to participate in research on brain training for dementia, how people interact with brain training technologies, the lifestyle that they have beyond brain training, their general perspective on ageing, decline and dementia, and their representation of the mechanisms of the brain. Within each of these broad categories, I classified the answers of the participants inductively. Only after being familiar with the themes as I made sense of them, I engaged in a selection process through the prism of the

conceptual framework I present in chapter two, relating to social positioning in later life, and considering key characteristics that Gilleard and Higgs (2015) use to define the fourth age. The results of this process are the themes I present in the third chapter of this thesis.

### ***Memory clinics implementing cognitive rehabilitation in Southern Europe***

Novel clinical attempts to address decline in dementia have recently developed, in part inspired by principles of prevention. These novel therapeutic strategies for dementia follow the principles of rehabilitation – a long and iterative process of cognitive training and monitoring – in an attempt to slow down the progression of dementia. It appeared to be a pertinent case study for comparison with brain training due to its applications of the principle of neuroplasticity and active cognitive ageing within a medical institution, a very different context from the one of daily life. This similarity therefore suggested the relevance of this site for this thesis. To study this process, I chose to conduct a 3-months ethnography of cognitive rehabilitation in two memory clinics in a rural Southern European region, in collaboration with local research and clinical teams. To conduct this research section, I attended weekly classes and trained over a year and a half at the start of my PhD research to improve my basic knowledge of the language spoken in this southern European region. Thanks to this learning, I could conduct this research section using this language in a research site where many participants had little to no knowledge of English.

To understand my particular interest to look at memory clinics in this part of Southern Europe, I propose to take a step back and understand the position of this specific region in the broader European panorama of ageing. The population of this Southern European country is an ageing population, and among the first in Europe in terms of the proportion of its population over 65 being above 20 percent. Important parts of the young adults' population, and active middle-age had long left the city where my fieldwork in one of the memory clinics took place, which represents a haven for later life. Among the reasons behind this demographic feature, researchers (reference anonymized) note the important difference in the geographical distribution of industrialization and high-skilled employment across this Southern European country. This imbalance led to the depopulation of this

principally agricultural region by younger generations who migrated to important urban centres where job opportunities were more readily available inside and outside of the country. Furthermore, this emigration from the region has combined with an important decrease in birth rates in which the birth of new children during the late twentieth century was too small to replace the birth rate of the previous generation. For these reasons, this region is arguably an important epicentre of ageing populations in Europe and makes it a pertinent site to study interventions for dementia which are widespread in the region.

The first impression I had while walking along the streets of one of the two towns where the two memory clinics were located was to notice the high-concentration of pharmacies, and specialized shops selling hearing aids, glasses, various kinds of walk assistance devices and goods essentially catering for this ageing population. It showed how clearly adapted the consumer landscape was to this demography in this particular area. The implementation of cognitive rehabilitation technologies based on similar principles to the ones of brain training and the trial of cognitive rehabilitation systems for older adults in relation to dementia prevention were equally interesting.

During this section of my research, I was supported by a charity involved in the care and therapy of people with conditions affecting the brain, including acute brain injuries, as part of their general mission. Beyond the demographic factors of the region I describe above, the charity emerged as a great candidate to collaborate with as they are currently developing and implementing a cognitive rehabilitation programme for people with cognitive decline and dementia. The cognitive rehabilitation software that this charity developed is now used in several hundreds of centres across the world with an objective of rehabilitation, or maintenance of performance within people who are impacted by cognitive impairments, or neurodegenerative diseases. The software was used in the centres I researched in order to complement holistic strategies of cognitive rehabilitation for individuals affected by these conditions.

Across the three months of fieldwork I conducted in these two memory clinics, I observed clinicians, researchers and developers on these cognitive training and rehabilitation interventions, and discussed with them, exploring the multiple

concepts they used and the rationale for their clinical practice. The role and status of individuals I encountered within the memory clinics varied. Some were psychologists and neuropsychologists while being PhD and MSc students, others were senior psychologists and neuropsychologists, some had a managerial role in the clinic. I complemented these observations of clinicians' approaches with occasional observations of other activities relating to the memory clinics. These locations and activities included a hospital, a reminiscence workshop, physical activity sessions for individuals in later life, interactions between engineers, clinicians and individuals with dementia to test new technologies for the purpose of the memory clinics and different research and development projects collaborating with the charity, and observations of cognitive rehabilitation sessions part of a Randomised Control Trial assessing the use of cognitive rehabilitation to prevent dementia. Relocating the role of the cognitive rehabilitation technologies and the philosophical principles underlying them within the realm of daily life was essential to present some of the processes behind ascription that I describe in Chapter 4 of this thesis. Within the practice of participant observation, and the ethnography I produced out of it, I should echo again the words of anthropologist Sharon Kaufman (2005, p. 332) by saying that such work attached itself in observing and describing 'the mundane', 'what ordinarily happens' within the settings of memory clinics and around cognitive rehabilitation interventions.

In this specific section of my research, I describe the active role that researchers and clinicians play in defining the problem of dementia in certain ways and the impact that it has on the identity of people who reach the memory clinic for symptoms of cognitive decline. Accordingly, questions I attempted to ask in the field were the following: how did the researchers conceive potential challenges associated with the implementation of the cognitive rehabilitation intervention? How did they develop these technologies? How did researchers understand the problem that they were trying to address through the use of these technologies? How did researchers understand the needs of people reaching later life and people with dementia in the development of solutions such as cognitive rehabilitation and brain training? I also aimed at understanding how the clinicians and researchers implementing the cognitive rehabilitation program within the two memory clinics conceived the progressive nature of dementia. I took note of these interactions

through the daily keeping of fieldnotes, sometimes during the observations through ‘jot notes’, and/or following the observations through extended field notes. I then coded these fieldnotes inductively using thematic analysis (LeCompte & Schensul, 1999) and elements of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998) a method used to approach fieldnotes or interview transcripts inductively with the objective to understand the perspective of the participants themselves. What resulted from coding were therefore themes that represented the perspective of the participants I observed during their daily activities and that closely or loosely provided answers to the questions presented above. By analysing these themes along ‘a path of organization, abstraction, review, and frequently, further abstraction and organization’ (Bernard & Ryan, 2009; Saldaña, 2009; Strauss & Corbin, 1990, 1998 cited in DeWalt & DeWalt, 2011, p. 190), I produced the theories presented in Chapter 4 of this thesis. Due to fieldnotes being handwritten in a field journal, I proceeded by first scanning these fieldnotes to transform them into digital copies. Rather than using NVivo, I relied upon direct manual coding through Word which appeared more convenient to precisely code scanned copies of the field journal. I organized the answers presented above into a chronological process that describes the steps in the management and medicalization of patients by clinicians in the memory clinics. These different steps constitute the structure of the argument presented in Chapter 4 of this thesis.

### ***An intervention implementing empowerment and independence in dementia***

Beyond new attempts at prevention, and novel modes of medicalizing dementia, a recent shift in how we think about dementia has been initiated by dementia charities, public health institutions and researchers taking psychosocial approaches to dementia oriented toward a novel narrative of ‘living well’ with the condition. This shift has been oriented toward promoting empowerment and autonomy in dementia among others. These new modes of thinking about dementia have had an influence on current dementia strategies both at national and international levels, strategies that I describe in Chapter 5 of this thesis. Such a turn, finding some of its early principles within the work of Tom Kitwood (1997b), and more recent adaptations based upon ideas of social citizenship (Bartlett, 2016; Kontos et al., 2017; Shakespeare et al., 2017; Thomas & Milligan, 2018) represent a key terrain of

exploration for the cultural comprehension of ageing and dementia due to its intrinsic objective to address social exclusion through these means. Hence, a thesis exploring social exclusion gains much in understanding the impact that interventions based on these principles can have upon dementia, and the kind of assumptions that are built in these approaches.

As a case study, the Chapter 5 explores the development of an intervention oriented toward the empowerment of people with dementia to achieve more independence through coaching and education of carers and people with dementia in the period that follows a diagnosis. This exploration is the result of six interviews I had with researchers engaged in the development of an intervention aiming at supporting independence in dementia in the United Kingdom. The project started in 2015 and was funded by a national research body, with the aim of improving dementia care. More specifically, this project wished to develop an intervention activating networks of dementia advice workers, people with dementia and their relatives to support independence in daily life through decision making and an active lifestyle. This intervention relied upon a manual and an online platform providing guidelines as a material support.

The format of conducting semi-structured interviews with the researchers and developers was more suitable with the reality of their research and development activities spread across universities in the United Kingdom. It would have been difficult to conduct an actual participant observation with them as the work is done remotely and often computer based. I therefore chose to invite the researchers for this semi-structured interview lasting between thirty minutes and an hour on average in order to accommodate their planning and geographic location and obtain answers on specific topics in a brief amount of time.

The structure of the interview was relatively open and aimed at understanding how the researchers defined the problem that they identified and wished to address in dementia. This approach was similar in some ways to the one I used with the clinicians and researchers in memory clinics. It led to several sub-questions such as: what did they mean by independence? How did they envision who would benefit from the intervention? How did they take the progressive nature of dementia into account in the intervention? I also asked about their position on



different characteristics associated with active ageing and tried to understand how they considered the existence of decline and its impact on people with dementia. I asked about their perspective on notions of choice, activity and self-management that are built in their intervention. To deepen the topics during the interview, I also asked them to reflect upon different aspects of the handbook that they produced as a basis for the intervention. I was also referred to interesting material by the researchers during the development of the interview guide, such as presentations, theory or the handbook used as a basis for the intervention. This material informed the development of my interview guide. I also accessed publicly available online material regarding the project to support my analysis. So as for the other sites, I transcribed and analysed their interviews using thematic analysis and elements of grounded theory. The analysis of their interviews is at the basis of the argument developed in the fifth chapter of this thesis. I created broad themes in NVivo that categorize quotes answering closely or more broadly the questions described above, while I used more specific codes to inductively present the representations involved in the constitution of answers to these broader questions.

At first sight, this intervention could be conceived as a form of assistive technology. Indeed, promoting independence in the realm of daily life is one of the key objectives of assistive technologies for dementia (Astell, 2006). Assistive technologies assist people with dementia in various domains of their daily life. For instance, Meiland and colleagues (2017, p. 3) list the following domains: 1) ‘Devices intended to help persons living with dementia to manage their everyday life across the disease journey’, 2) ‘Technologies to help people engage in meaningful and pleasurable activities’, and 3) ‘Health care technologies that aim to support professional organizations and systems within dementia health and social care’. My comprehension that technology is more than the isolated material object of a handbook for instance in the case of this project, yet a complex assemblage of artefacts, individuals and standardized procedures applied to the fulfilment of a series of social objectives. As I presented above, a technology is never detached from the context in which it operates. These standardized assemblages are therefore key cultural expressions of our comprehension of specific problems linked to the human condition. Interestingly as we will see in Chapter 5, discussing the social context and objectives of the researchers

developing this intervention enables us to understand that this technology has more elements in common with the two previous technologies of brain training and cognitive rehabilitation based on neuroplasticity than it seems at first sight.

### *A collective of experts and advocates with dementia*

Finally, the last site I selected to participate in my multi-sited ethnography consists in a dementia advisory group composed of citizens and advocates diagnosed with dementia active across several countries. Again, one may be surprised by the apparent discontinuity between this site and the previous ones directly involving technologies and interventions. This is in some way intentional as it throws into relief some of the themes developed in earlier research sites. Uncovering an *emic* view of dementia advocacy allows for a fuller understanding of the complexities that are involved in aspects of negotiating the discourses associated with the condition. As I explained earlier, I view this sixth and last chapter of the thesis as a means to situate the complex zones of tensions that are inevitably part of the nature of social exclusion in later life today. I also regard its connection to institutional forms whereby research projects are encouraged to use this platform to receive advice on their practices as a sort of socio-technical arrangement, an advisory technology in its broadest sense. Looking at the specific example of advocacy and expertise in dementia, and how people with the condition deal with social exclusion offers a pertinent demonstration of the necessary nuances outlined by this research and the way that social exclusion can both be understood as universal and as particularised.

Advisory and advocacy groups by people with dementia have become more frequent in recent years (Bartlett, 2014). The reconstruction of an identity after a diagnosis is a corollary of the work of many of these collectives of individuals. They achieve this reconstruction through the central role that they play in proposing a novel narrative for dementia addressing power relations and discrimination. Engaging with this narrative appeared essential for this thesis in its attempt to understand social exclusion in dementia today as well as how society acts upon this condition.

Participant observation was a relevant methodology to approach this site as matters relating to identity and meaning-making practices and discourses are often performed in subtle yet iterative ways. Between the years 2017 and 2019, I conducted ethnographic research with a collective of these individuals with dementia hosted by a non-profit and non-governmental association active at an international level. This association involved people who actually live with the condition in their mission of making dementia a priority in governance and promote the use of an approach to dementia grounded in the discourses of human rights to support research on dementia, facilitate the engagement and citizen participation of people with dementia and their carers, and strengthen the [international] dementia movement. To support their mission, they hosted a platform of individuals diagnosed with dementia to review their own activity. This platform also engaged with the review of research projects across countries with the objective of reflecting the views of people with dementia. These modes of engagement were part of the many activities of consultancy that the individuals in the group performed.

I was engaged with this Dementia Advisory Group both as an observer in a process of familiarization, as a part time intern supporting some of their activities, as a researcher whose observations would be the basis of some of the vignettes and descriptions in Chapter 6, and finally as a presenter discussing early findings of my research with them. During this period, I followed their meetings lasting on average two to three full days and had friendly informal discussions across lunches and dinners in hotels across different countries.

The formal research period started in May 2018, when I already knew the group for approximately a year at the time through my other modes of engagement. I was therefore able to draw upon my previous experience with the group to direct my observations to interesting matters for the research. In December 2018, the final month of my research with the Dementia Group, I set up two recorded consultations lasting for an hour and half each, with 6 different members of the group and 3 supporters in one case, and 6 different members and 2 supporters in the other. Supporters were present in order to assist participants in case they needed help to understand the questions being asked during the consultations. This was due, either

to their impairment or because of the need to translate interactions into their mother tongue. Supporters also provided additional details to complement the responses of the participants with dementia they accompanied if they thought it could help to bring additional details to the opinion of the latter. It was also interesting to hear the supporters' perspective on these matters. One of the two consultations were supported by a project officer from the association who administered my interview in order to be able to hold the two consultations at the same time, a necessity when knowing the many items on the agenda of the advisory group during these meetings.

In the last chapter of the thesis, I will present an analysis of their perspective as individuals, therefore distinguishing their position from the objectives of the association itself. This is a deliberate choice that I made as the group interviews and observations tell more about the choices of their members than what their mandate for the association encompasses.

While my research did not include a demographic profile of the members I encountered, a substantial part of them correspond to the description that Bartlett (2014) makes of dementia advocacy in general as younger advocates with rarer forms of dementia, or with mild to moderate dementia. Their relatively good health facilitated their participation in the movement. Some of them also occupied positions associated with higher socio-economic status before they received the diagnosis of dementia or retired, such occupations included professors or executives and managers within corporations, or occupied roles requiring high skills and responsibility. Hence, the profile of several members was somewhat differentiated from the general membership of national organisations. National contexts to which members belonged also implied different regulations. Although some of these demographic aspects may have had an impact on shaping the narrative that this group has produced around dementia, the argument that Chapter 6 develops is not dependent on these variables.

This research section aimed at understanding the social position of the Dementia Advisory Group and how they conceived of their actions and identities in relation to the condition. It therefore asked the following questions: how does a condition so intensely marked by an imaginary of decline and dependency come to affect the

identity of those diagnosed with it, and how do they respond to this affect? To what extent do these members identify with active ageing and the identity of the third age? Are their actions oriented toward forms of social positioning regarding the fourth age? The participant observation already offered some answers to these questions, yet the two final consultations enabled the research to acquire additional depth on these matters by asking specific questions and gaining necessary clarifications. The two project officers in charge of organizing the meetings of the group offered support in the development of the interview guide for the consultation. The interview guides were developed, in part based upon the observations of the group meetings, and in part based on the questions described above. They broadly asked about the meaning that participants attached to their belonging to the group, and to living with dementia, their perspective on the link between ageing and dementia, and about their relation with activity, productivity and technology when having dementia.

I transcribed the consultations and coded them using a combination of principally thematic analysis and elements of grounded theory. In a similar fashion to the methodology that I had used for participant observation within the memory clinics, I took 'jot notes' during the meetings. This was accompanied with actual fieldnotes taken during the participant observation periods I had with the Dementia Advisory Group, and coded them through a process similar to the one I used for the transcripts of the interviews, while also relying on Word as a means to more precisely code the digital copies of my handwritten fieldnotes. I coded the focus group interviews using NVivo. Broad themes I first coded categorize the experience that these individuals have of dementia and how it affects their identity. They also categorize the nature of their collective identity: the dimensions of an identity with dementia that unite all people with dementia, and the ones that divide them. They categorize how they think their identity relates to the broader question of ageing, and how it is also different from it. Finally, they describe their objectives as a collective, how they see the future of dementia, and its inclusion in society. Further analysis and organization of these themes in relation to theories of social positioning in dementia constitute the basis of the argument presented in Chapter 6 of this thesis.

## **Reflexivity – age, corporeality and existential fear**

There are many factors, if not a virtually infinite number of factors, in which the embedded researcher comes to influence its research object, although some aspects of one's identity can be more salient than others in influencing the product of a research, be it an ethnography or a report of results. The anthropological approach therefore recognizes the need to engage in an exercise of reflection upon these influences, also called reflexivity. Anthropology has been a discipline particularly concerned with so-called matters of reflexivity or positionality. Here is how anthropologist Davies (2008, p. 4) describes reflexivity:

*'Reflexivity, broadly defined, means a turning back on oneself, a process of self-reference. In the context of social research, reflexivity at its most immediately obvious level refers to the ways in which the products of research are affected by the personnel and process of doing research. These effects are to be found in all phases of the research process from initial selection of topic to final reporting of results.'*

This importance attached to reflexivity in anthropology is due in part to the closeness that the researcher maintains to its research participants in the field, as Davies (2008, p. 4) points out. Overall, these relationships are heavily affected by matters of identity and power (Geertz, 1973a; Karnieli-Miller et al., 2009). In working in the field of dementia, a condition which can potentially make participants more vulnerable, and in being a participant observer during parts of my empirical research, I therefore spent much time reflecting upon these matters. Reflexivity in this thesis was essential, directly in the necessity to pay attention to these matters, but also indirectly in thinking about the question of social exclusion in dementia where relations of power are a source of exclusion. Reflexivity was therefore an important lens through which I analysed my data and the relations I established in the field.

More specifically, 'the turning back on oneself' that Davies (2008, p. 4) presents was directed toward understanding the aspects of my identity that had the most impact on my particular field of research exploring both the experience of people with dementia and the fear of individuals in later life. To this regard, my younger

age and my status as a healthy individual were the fundamental aspects of my identity constituting zones of tension within my research.

Regarding the influence of the variable of age on my interaction with participants, some interviews I had with individuals in later life, or approaching later life, were influenced by the recognition that people had of my visibly younger age and my belonging to a different generation. I anticipated this obvious difference and shaped some of my questions accordingly by recognizing its impact on my identity. For instance, a question I asked to my informants during my interview concerned what it meant for them to age, and how it was different from the impression they had about it earlier in life. By asking this question, I therefore adopted the stand of an attentive listener eager to learn about a whole new perspective on life. This question often led to some of the most generous testimonies I gathered during my interviews.

As another important dimension of my identity, my age influenced my anxiety with dementia, an anxiety intensely connected to the subjective perception of risk connected to chronological age. My anxiety therefore inevitably differed from the one of participants and required a strong exercise of empathy to understand their position. I was not as anxious about this condition as my participants were. I might have consequently missed some of the emotional effects of this anxiety on subjectivity with a possible influence on my analysis of the perception of decline. Meanwhile, one could also argue that this intrinsic experiential distance afforded by my identity gave me the opportunity to more serenely analyse my research object. There, I follow Anthropologist Sharon Kaufman (2005, p. 14) who points to the interest of emotional and experiential distance for the purpose of analysis in her own study of death in American hospitals. Following Kaufman, being detached from the fear of developing a dementia could equally be perceived as an analytical strength, a capacity to relieve this fear and think through problems without the challenge of self-identification with the potential risk of dementia.

Beyond age, my belonging to the 'kingdom of the healthy' as Sontag (1978, p. 3) would put it also generated a particular positionality regarding my understanding of dementia. Here is an anecdote from my fieldwork with citizens and activists with dementia that I believe is illustrative of this central aspect of my identity. Once, during a gathering of the Dementia Advisory Group I attended for my fieldwork,

the members with dementia gathered for a group picture. I came along to be on the picture with them as they usually ask me to do. However, this time the picture was specifically meant to include the people with dementia in the group alone, without the carers and project officers. The members of the group laughed when I mistakenly tried to join them, asking me whether I had dementia as well. This joke was telling in terms of highlighting belonging and identity differences around health and diagnosis. This barrier demarcates the ingroup from the outgroup in the operation of the activities of the Dementia Advisory Group, mainly relating to legitimacy (of public appearance, access to services, etc.). This identity centred on a health condition is what Rabinow (2005) theorized as *biosociality*. As such, Chapter 6 will present how this matter of identity and belonging plays in subtler ways among people with dementia and can even lead to experiences of discrimination.

Beyond discourses and representations, one should see how dementia in its corporeal dimension influences individual experience with an impact on identity. Dementia implies a variation of symptoms and experiences that one can fully understand only when one has the condition. I recall this time when I had a conversation with a member of the Dementia Advisory Group, sitting at the table for the dinner after one of their meetings. During a conversation, I asked how my neighbour at the table, a member of the group, found the meal. She replied she could not taste it unfortunately. I naively asked whether she had a cold, drawing on the most familiar cultural register I had in mind. She kindly addressed my naivety by explaining that her dementia had impacted her ability to taste. This is an example among many others in which the corporeality of a condition creates differences between self and other, creating differences in understanding. Empathy can help to take into account the differences in identity, in spite of not being actually able to live them. Empathy may be the main instrument to approach another's experience, yet it remains highly volatile and requires constant reminders. It has been my main concern during fieldwork to consistently maintain a sense of empathy. However, there always remains a gap in experience shaping identity. One can imagine but one does not live the virtually endless variations in another's experience of living with dementia – the complex interaction between one's mind, body, others, infrastructures and materials in the continuum of daily life. The invisibility of the



impairment associated with dementia renders people affected even more vulnerable to ruptures of empathy and even distrust as the sixth chapter will present.

Meanwhile, imagining the experience of ageing and decline can be challenging for the researcher him/herself, a challenge around identity and empathy often discussed in anthropology (Fainzang, 2007, p. 6). I recall the discomfort I experienced during one of the first interviews I had with people engaged in brain training when an informant outwardly mentioned her preference for euthanasia rather than to develop a dementia. She noticed my surprise with her forthright answer and added: *'That is not an easy subject to discuss, is it?'*. She therefore identified part of the discomfort I experienced when she introduced this topic. As my research progressed, I acquired more familiarity with complex matters relating to ageing and decline. I had to approach the sensitive character of some aspects of this research with care, and the anxiety that some participants could experience with dementia and manage this sensitivity for both my participants and to a certain extent myself. I will further discuss these matters in the ethical considerations below.

## **Ethical considerations**

As mentioned earlier, the research sections presented in this thesis were reviewed and approved by the University College London's Research Ethics Committee (reference ethics approval: 12275/001 and 12275/002) and by the Southern European research ethics committee to conduct research in the Southern European country where the memory clinics were located.

Research on dementia inevitably implies a series of ethical considerations that relate to this specific research domain. Here I discuss this matter regarding anthropology and its use of participant observation and look at the question of consent and the sensitivity of the topic of dementia specifically.

### ***Consent and the question of vulnerability***

The line that separates participants with and without capacity to consent to research autonomously is not always straightforward as I learned during the research for this

thesis. Issues of vulnerability and incapacity to consent were raised by the ethics committee because of the presence of people with dementia. The ethics committee indicated that my research required additional scrutiny and was regarded as ‘high risk’ research according to UCL criteria – the ‘high risk’ category encompasses research with vulnerable groups among other. This issue was raised due to a doubt about the capacity of people with dementia to understand the consent form and information sheet linked to the research due to their condition, and therefore to consent to research.

However, the part of my research that involved individuals with dementia – the one with the members of the Dementia Advisory Group – demonstrates how a diagnosis of dementia cannot be solely equated with incapacity. Indeed, a key argument of their advocacy challenges the fact that they are often systematically considered to be incompetent and vulnerable due to their dementia. The reply that we sent to the ethics committee mentioned this matter and pointed out that the individuals who I was interviewing were actively engaged in advocacy or advisory roles. This was often at an international level, with the group being involved in consultations with various international projects organised in conjunction with the organization in which my research was planned to take place. It also pointed out that they were leading public figures with only a mild to moderate dementia which did not impede their capacity to consent to research. We additionally proposed to contact the members and organization to testify of this capacity if required. These arguments satisfied the UCL Research Ethics Committee and represented an interesting example of the paradoxical tensions that the category of vulnerability can involve by potentially becoming exclusionary while it wanted to protect certain groups against abuse.

In these instances, it is important to take into account the viewpoint of people with dementia themselves. For instance, advocacy groups by people with dementia have produced guidelines on how to design dementia-inclusive research (e.g. Dementia Engagement and Empowerment Project, n.d.). Accordingly, I took precautions to facilitate communication around the information of the research following advice from people with dementia themselves following these guidelines. As sensorial capacity such as vision can be impaired by certain conditions linked to dementia, I took measures to adapt the information sheets and consent forms as much as

possible, by enlarging the size of the font used and reducing the length of sentences. I used a helpful guide *Writing dementia-friendly information* from the Dementia Engagement and Empowerment (DEEP) Project<sup>9</sup>, which lists the different points which can facilitate understanding by people with a diagnosis of dementia.

However, it is important to be aware of people's changing condition and to dynamically remember that consent is negotiated along the research process and is not acquired one's for all (DeWalt & DeWalt, 2011, p. 217). Although originally acquired during the first encounter in participant observation and ethnography, consent remains always negotiated in the day to day interactions that compose the field. This precaution is also important when it comes to working with people with dementia who may experience memory problems for instance (McKeown et al., 2010, p. 1938). Beyond the establishment of initial consent as a fundamental requirement, I therefore kept on negotiating this access, always being careful that informants agreed to, and were comfortable with my presence. Taking such precautions, none of my interactions with participants led to a situation of discomfort as far as I noticed.

Consent in research is a ramification of the more general development of a relation of trust between researcher and participant, a concern which especially applies to the encounter generated by participant observation (DeWalt & DeWalt, 2011, p. 48). An anecdote from my fieldwork is illustrative of the central role that trust takes in research. Anthropology remains a discipline which can appear esoteric. After having provided participants with lengthy explanations about my motives, and detailed information sheets and consent forms, some of them simply pointed out that they trusted my intentions while signing the consent forms, without being interested in all the details on the forms. Participants expect the results of research to be valuable and legitimate while also being respectful of the concerns and position of the informants in their social context. In the case of dementia research, the objective of improving the life of people with dementia is at the centre of the moral world of participants. They therefore expect the researcher to share this

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<sup>9</sup> Dementia Engagement and Empowerment Project Website (n.d.), *DEEP guides for organisations and communities*. Retrieved 6 August 2020, from <https://www.dementiavoices.org.uk/deep-guides/for-organisations-and-communities/>

objective of benefit for society. I kept this principle of trust and constructive critique toward this objective at the centre of my work. While disagreements on findings are always possible as a fundamental aspect of normal science (Kuhn, 1962), I hope that the argument I am making will lead to positive change to improve the integration and the quality of life of people with dementia and in later life. I also hope to inform the clinics and research networks I conducted my research with in constructive ways.

### *Care in discussing decline*

Another ethical matter I had to consider in my research concerns the sensitive nature of my topic. The section of my research with older adults engaged in brain training implied discussions around dementia that can be complex to discuss for some individuals, as it closely relates to issues around irreversible impairments, as well as matters linked to our understanding of the end of life, which can, as Arber and colleagues (2008, p. 374) explain, discourage participants to participate. Arber and colleagues (2008, p. 374) point out with regard to their own research that ‘the low recruitment rate may suggest that many older people view the subject of death and dying as too distressing to discuss, with our findings limited by our ability to only evaluate the attitudes of those who were willing to participate’. Such obstacles in discussions may not have substantially impacted my own research as the concern related to the use of the brain training technology in relation to dementia. The topic of discussion was therefore broader than solely being about dementia. Although it remained an aspect that required accrued attention from me. A series of participants discussed matter relating to dementia and the end of life spontaneously, offering meaningful reflections upon their own experience of decline and concerns which allowed comfortable exchange on these matters. I was also careful to let people lead the conversation regarding such topics and I always had a prompt ready to reorient the conversation toward a less sensitive topic if discomfort appeared. The format of a one-to-one interview and the guarantees of anonymity I provided through the informed consent and strict measures of data protection helped create a safe space for discussions. Such measures most likely helped participants to feel at ease with expressing their perspective on these topics within a research encounter. Additionally, the fact that the interviews took place in a familiar or

comfortable setting – either at home or in a separated room within the UCL Division of Psychiatry according to participants’ preference – facilitated these discussions and maintain anonymity.

The research section with the researchers working on autonomy and empowerment in dementia reported in Chapter 5 did not imply any major challenge and the interviews always remained centred on the general objectives of their interventions, only discussing researchers’ vision of their own project, and the objectives that they wanted to achieve with it. Perhaps my main challenge in this section was to convey an understanding of the objectives of my research and the interview in which the notions of social theory and cultural concerns around autonomy in dementia were sometimes elusive for researchers from other disciplines.

### *Anonymity*

Besides these ethical matters, I extensively anonymized all the research sections I present in this thesis by first changing the names of the individuals I researched and avoiding providing recognizable details. For the research sections within the memory clinics, I anonymized all the extracts presented in this chapter, and used either the term ‘therapist’ or ‘clinician’ rather than directly referring to their disciplinary background which could be recognizable. Secondly, I anonymized the name and recognizable features of the institutions where I conducted my research, for instance by changing the name of the Dementia Advisory Group, and the association hosting it. I used generic categories to describe geographic places, names, and recognizable features in people’s explanations. As DeWalt and DeWalt (2011, p. 219) recall however, it remains difficult to achieve perfect anonymity especially for individuals familiar with the settings and actors of a particular site – for instance when feeding back analyses to research teams participating in my study. Yet the extensive precautions I took and my awareness of the limits of anonymity should mitigate the risk of undesirable impacts on participants.

Participants’ preferences regarding anonymity were also an interesting consideration in this research, albeit limited as it only appeared once in its course. A participant from the Dementia Advisory Group asked why they had to be anonymized. This is a pertinent question to ask, especially when knowing that the

group is already publicly active and recognizable in the social field of dementia. I could have chosen not to anonymize the group – a decision implying additional moral responsibility from the researcher to protect the reputation or safety of their informant as Rössler and Röttger-Rössler (1991) explain. However, I decided to keep the group anonymous. This issue was only expressed by one of its members and making the identity of a single individual public would have inevitably exposed the rest of the group and therefore the identity of individuals who would have preferred not to. There is also an element of uncertainty involved around the potential outcomes of a research in its early stages. They may differ from the expectations of participants giving consent at that point in time, a concern also discussed by Rössler and Röttger-Rössler (1991, p. 206). These factors of consent and uncertainty combined led me to follow the safest route and keep anonymity as a precaution.

## Chapter 2: Technologies of distinction dividing later life

*'Everything we are is at risk'*

(Alzheimer's Research UK 2019b)

This chapter will present the theoretical framework I built to approach my research sites. It therefore precedes my empirical research and will constitute the foundation for my analysis across the rest of the thesis. The theoretical framework will outline what I will term technologies of distinction and show how they operate in later life. It will explore the theory and discourses behind brain training, a key case study of the shift toward prevention presented in the introduction. Brain training often refers in popular discourse to a series of cognitive games meant to be used on a regular basis by individuals in or approaching later life to maintain their cognitive capacity as they age. As we briefly saw in the introduction, these techniques represent key technologies constructing the manifestation of third age identity and its ideal of cognitive fitness. This first chapter results from a literature review conducted in the early stages of the research, before the actual fieldwork and interviews, which explore possible ways in which social exclusion might operate in later life in the context of technologies used to respond to dementia. Throughout the chapter, I will draw a parallel between the findings of this literature review and the public discourses used to advertise brain training technologies. As a result of this exploration, I will propose a theoretical model of the subtle ways in which social exclusion operates in technologies oriented toward prevention and impacts later life today. Regarding the thesis as a whole, this model will enable a comparative approach to other social contexts and technologies in dementia through multi-sited ethnography, and more efficiently trace this social exclusion across society.

This model will explain how technologies can play a yet unconsidered role in the exclusion of people with dementia, mainly by supporting processes of social positioning that I characterize as *distinction*. This chapter will present how technologies can be used as markers of social difference and ways to maintain socially valorised positions for the third age. This chapter will draw on the concept

of distinction developed by Bourdieu (1979) to describe the relationship between cultural practices and contemporary social hierarchies. I will explain how practices of distinction enacted in the third age play a key role in constructing the divisions in later life around dementia. In particular, this chapter will point to the often-overlooked role of prevention strategies in articulating practices of distinction which have much wider impacts.

I will show in this chapter how this field of ‘brain training’ has been rendered possible in contemporary cultures of ageing given the expansion of discoveries relating to the neurosciences (Rose & Abi-Rached, 2013). Specifically, I will argue that the concept of neuroplasticity has enabled the brain to become perceived as a malleable object on which people can act (Rose & Abi-Rached, 2013), and on which practices of health promotion can be transformed into ones of prevention through strategies of *active cognitive ageing* which in turn can become the basis for practices of distinction.

Finally, I will present how such technologies of distinction and their role in constituting a cognitive divide in later life can generate discourses leading to the ‘othering’ of people with dementia. Higgs and Gilleard (2014) use this term to describe how dementia is often portrayed as a state of being characterized by abjection and alienation and thus removed from the desires and aspirations of the third age. A consequence of this othering resulting from the practices of active cognitive ageing is the intensification of the exclusion of people with dementia from society both in discourse and practice – leading therefore to forms of social exclusion in later life.

### **Fear of dementia – how brain training relied on the divide between third and fourth age**

The market for brain training is thriving (George & Whitehouse, 2011), and new applications appear every year, carrying suggestive names such as Fitbrains, Lumosity, NeuroNation, or Peak. Many of these companies present brain training as a beneficial entertainment, offering the player the opportunity to enjoy the regular completion of games – puzzles, mathematical and logical enigma, language



quizzes, or games based on observational skills and reflexes among other activities – while stating that these games enhance the cognitive capacities of the player. These games therefore claim to support a training programme for individuals of any age looking at enhancing their cognitive capacities. They suggest the idea of being a gym for the brain, therefore equating the brain to a muscle that can be trained. Most of these companies offering brain training products work on a subscription model and provide access to a limited amount of free content, seemingly to attract new customers. Cognitive skills in brain training games are generally divided into different categories such as ‘adaptability’, ‘focus’, ‘memory’, ‘speed’ or ‘reasoning’ for instance in the game Cognito<sup>10</sup>. These applications therefore claim that the training they provide helps individuals to ‘stay sharp, build confidence, and boost productivity’ for instance (Elevate Website, n.d.), a discursive commonality across these companies. Accordingly, an important aspect of the marketing of these games is based on the idea of transferability of the skills developed in the games into daily life.

However, researchers have pointed out that engaging in a brain training game will most likely limit improvement to the capacity to perform the specific game being played (Bahar-Fuchs et al., 2013; Owen et al., 2010). Indeed, much doubt remains on the actual ability of in-game improvement to translate into improvement of cognitive capacities in daily life (Owen et al., 2010, p. 775). Such claims are even more controversial when it comes to looking at brain training games and their capacity to slow down age-related cognitive decline and dementia. As Corbet et al. (2015) point out, there may be some impact of brain training on cognition among healthy older adults, yet as Bahar-Fuchs and colleagues (2013, p. 12) remind us that there is currently no scientific consensus on brain training’s capacity to delay or prevent the onset of Alzheimer’s Disease and dementia. For instance, Lumosity<sup>11</sup> a brain training program developed by Lumo Labs company has been fined \$2 million dollars by the United States Federal Trade Commission for having ‘deceived consumers with unfounded claims that Lumosity games can help users perform better at work and in school, and reduce or delay cognitive impairment

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<sup>10</sup> Dredge, S. (2016). Five of the best brain-training apps. The Guardian. Retrieved from <https://www.theguardian.com/technology/2016/mar/23/brain-training-apps-five-of-the-best>

<sup>11</sup> Lumosity Webpage (n.d.). Discover what your mind can do. Retrieved August 6, 2020, from <https://www.lumosity.com/en/>

associated with age and other serious health conditions' (Federal Trade Commission Website). Jessica Rich, Director of the Federal Trade Commission Bureau at the time points out in the webpage attached to the report that 'Lumosity preyed on consumers' fears about age-related cognitive decline, suggesting their games could stave off memory loss, dementia, and even Alzheimer's disease' (Federal Trade Commission, 2016). This criticism also indicates the role that anxiety and the fear of decline can play both explicitly and implicitly in marketing strategies related to brain training. However, it seems to have had little effect on generating scrutiny amongst the broader public. Indeed, brain training games have had a substantial and growing success among people in later life starting in the first decade of the 21<sup>st</sup> century.

Besides the multiplication of commercial endeavours mobilizing principles of prevention and cognitive enhancement, there has been increasing engagement among the research community to explore the efficacy of these games with regard to cerebral ageing and dementia as the expression of a more general turn toward prevention in dementia and ageing (Lock, 2013). A noteworthy example of this trend is the European Union Horizon 2020 project 'Alzheimer's Disease (AD) Detect & Prevent – Presymptomatic AD detection and prevention' relying upon the testing of brain training as a mode of assessment and prevention for dementia<sup>12</sup>. Another example is the Platform for Research Online to investigate Genetics and Cognition in Ageing (PROTECT) Study exploring risk factors regarding brain ageing. This later major project researches, among other lifestyle influences, the effect of brain training on age-related cognitive decline and dementia in the United Kingdom. An indicator of the popularity of brain training research in ageing, the PROTECT study advertised a pilot of their research on the BBC show 'Bang goes the theory' and this led to 11,430 participants engaging in a six-week programme of study (Devlin, 2009). However, the PROTECT Study, in an article published in the scientific journal *Nature*, concluded that 'although improvements were observed in every one of the cognitive tasks that were trained, no evidence was found for transfer effects to untrained tasks, even when those tasks were cognitively

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<sup>12</sup> Alzheimer's Disease (AD) Detect & Prevent – Presymptomatic AD detection and prevention (n.d.). Factsheet. Retrieved August 11, 2020, from: <https://cordis.europa.eu/project/rcn/218312/factsheet/en>

closely related’ (Owen et al., 2010, p. 775). Despite this lack of scientific evidence around the actual efficacy of brain training regarding ageing and cognition, individuals in later life have become the main consumer group within an increasingly successful brain training market with an estimate of one half of all consumers being over 50 years old (Sharpbrains, 2013). Dementia therefore becomes one more arena in the global market of health ‘apps’ where techniques promoting *active cognitive ageing*, come into play as a response to the ‘therapeutic void’ existing around the absence of a cure for dementia (George & Whitehouse, 2011, p. 590). Brain training therefore exists as a consumer good and as a scientific endeavour within a system of exchange powered by hope in regard to both research and the market economy.

Discussing the *political economy of hope* – an economy in which hope plays a central role as a motor for investment, production and consumption (DeVecchio Good et al., 1990) – is central to understanding how the widespread success of a technology such as brain training can play a role in exclusion in later life. Worries and fear about dementia are instrumental when it comes to the brain training industry, be it implicitly or explicitly. Instances of previous abuse are an example of this explicit reference as the Lumosity trial testified. Other instances of the reliance upon widespread anxiety about dementia can be found in other brain training advertising messages. Company Dakim for instance lists the following: ‘As a result of unprecedented media coverage over the past few years, residents, prospects, and their families are acutely aware of both sides of the brain health issue – the threat of Alzheimer’s, and the evidence that *brain fitness activities can improve cognitive function and protect the brain from long-term decline*’ (Dakim, n.d.; emphasis by the company). Other companies while not directly mentioning dementia within their marketing messages however suggest this relation, therefore implicitly encouraging individuals in later life to associate brain training practice with dementia prevention. For instance, company NeuroNation in a category on their website called ‘scientifically proved, numerous studies support brain training [my translation from French]’<sup>13</sup>, lists various articles presenting the link between

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<sup>13</sup> NeuroNation Webpage (n.d.). Scientifiquement prouvé: De nombreuses études soutiennent l’entraînement cérébral. Retrieved August 6, 2020, from <https://www.neuronation.fr/science/scientifiquement-prouve-de-nombreuses-etudes-soutiennent-lentrainement-cerebral>

cognitive training and various conditions such as ADHD, and dementia. As these marketing techniques indicate, the success of brain training can be found in its capacity to propose an easy and readily available answer to the fear of dementia. It gives a sense of empowerment to people amid complex and unresolved existential worries about the intersection of ageing and cognitive decline.

Although fear may be an important factor leading to the success of brain training, the brain training industry is essentially opportunistic in suggesting this fear. Indeed, this fear is both structurally and existentially generated. Depictions of dementia, be it in the newspaper or research campaigns are often inclined to promote sensational or stereotypical narratives about the condition. These find their roots in more prolonged and pervasive transformations of understandings of ageing and pathology. For instance, Alzheimer's Research UK, an influential charity collecting funds for biomedical research in dementia, in its video 'Share the orange' relies upon the worrisome comparison between a human brain and an orange falling into pieces in order to stimulate fundraising. Various iterations of this campaign video have reached more than a million views on YouTube (Alzheimer's Research UK, 2018a), involving famous actors and public figures such as Samuel L. Jackson (Alzheimer's Research UK, 2019a). The fear of dementia and the hope for a cure is an important articulation of this current context that exists around dementia more generally. Another manifestation of this structural fear is often expressed through variations of the theme of the 'War on Alzheimer's' to which the 24/07/2017 *Newsweek* newspaper cover story is a pertinent example, using this title followed by the subtitle 'stopping the disease before it starts'. In such depictions, dementia is portrayed as a dangerous externality, an enemy who could be defeated if only we had the proper ammunition. The metaphor of curing illness as a war is not new and has been already criticised by writer Susan Sontag in *Illness as Metaphor* (1989). In her book drawing insights from her personal experience with cancer, she describes how this metaphor obscures or even obstructs our ability to approach the patient's experience – the experience of the one who is actually living with this 'enemy'. Such military metaphors in Alzheimer's disease are common practice and increasing in use both within the mainstream media and medical literature as Lane et al. (2013) present in their review on the topic. Although they judge this metaphor as helpful for fundraising, they also denounce its inappropriate character in

understanding patient experience and the priority it gives to the promotion of biomedical research and its cure-driven rationale. It seems likely that such metaphors play a role in reinforcing the opacity of the fourth age imaginary by proposing a Manichean view of dementia – a polarization between the sick and the healthy and a source of worries among individuals approaching later life. In the struggle of ageing societies with issues of mortality and decline, we therefore see that fear is an affect stimulated by the increasing importance of a divide between a third age looking to maintain a life without decline, and its fear of a fourth age encompassing the enemy of dementia. Brain training relies implicitly or explicitly, involuntarily or voluntarily, upon the existence of this divide.

What are the deeper historical conditions behind this recent shift from concerns about physical health in later life to concerns about brain health and the prevention of a feared dementia? To answer this question, a link can be drawn between the success of brain training and the increasing emphasis on cognitive capacities in post-industrial Western economies. Indeed, as Gilleard and Higgs (2018, p. 8) point out, citing Williams, Higgs and Katz (2012), ‘while third age cultures have supported a variety of embodied practices aimed at preventing or reducing the likelihood of overt corporeal betrayal, fear of the fourth age has become more cerebral — of losing one's place in society by losing one's mind. Embodied selves remain vulnerable. Alzheimer's and the brain form new sites of betrayal’. Brain health has become central to the third age's aspiration to maintain an agentic identity in later life, and brain training use is one expression of this growing concern about brain health. Progress in the neurosciences and their compatibility with increasingly influential market ideologies of late-capitalism are important characteristics of these deeper structural and ideological transformations generating these novel forms of ‘neuro-centrism’. For instance, recent progress in the neurosciences provide key elements for the possibility for brain training to exist, combined with the growing success of lifelong approaches to cognitive decline and ageing found in the rise of gerontological ideals. Indeed, the possibility for the idea of brain training to expand people's understanding of the ageing brain relies upon the emergence of a particular concept that Rose and Abi-Rached (2013) have traced in their analysis of a set of relatively recent scientific disciplines focusing on the brain that they call ‘*neuro-disciplines*’ (e.g. neuropsychiatry,

neuropsychology and the other neurosciences). This concept is the one of ‘neuroplasticity’ and has been central to the development of brain training (Millington, 2012, p. 434; Rose & Abi-Rached, 2013, p. 48; Simons et al., 2016, p. 105). Rose and Abi-Rached (2013, p. 48) explain this concept in the following terms: ‘by the close of the twentieth century, the brain had come to be envisaged as mutable across the whole of life, open to environmental influences, damaged by insults, and nourished and even reshaped by stimulation – in a word plastic’. Following this shift in science, the brain is therefore not seen as a static object anymore. It can therefore become the receiver of external influences able to alter its structure and the capacities it generates both negatively and positively. As Pitts-Taylor (2010, p. 636) explains, both synaptogenesis [the birth of new synapses] and neurogenesis [the birth of new neurones] are now presented as possibilities across the life course therefore enabling novel conceptualizations of the brain as mutable throughout the life course. In the context of later life now acutely influenced by the fear of dementia, neuroplasticity therefore offers the possibility for adequate lifestyle choices, the ones of the third age, to become generative for the brain and its capacity to act upon age-related cognitive decline, and by extension dementia.

Following this turn in the neurosciences, practices resembling brain training have most recently been promoted by recognized charities in the UK. For instance, Age UK wrote a section on its website in the form of a self-help guide explaining ‘how to stay sharp’ in later life. Although this guide reminds that evidence for brain training remains inconclusive, it lists a series of steps that people can follow in order to ‘stay sharp’ as they age. Besides encouragements to maintain physical activity or stop smoking to protect the cortex, this guide also lists learning a new language as an action that people can take as they age<sup>14</sup>. Although one could argue that this is not brain training *per se* and could simply be about the idea of learning new things as beneficial, it remains however that the suggestion which is made by the website through the idea of ‘staying sharp’ evokes aspects of brain training and

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<sup>14</sup> Age UK (n.d.). Look after your thinking skills. Retrieved August 11, 2020, from <https://www.ageuk.org.uk/information-advice/health-wellbeing/mind-body/staying-sharp/looking-after-your-thinking-skills/>

neuroplasticity implying that choosing not to engage with these regimes can lead to loss of this so-called ‘sharpness’.

Meanwhile, as Lock (2013), and Tiago and Palladino (2009) explain, dementia has increasingly been understood as a ‘diffuse clinical syndrome’ within the turn toward prevention in dementia. They describe how gerontologists, citing mainly Robert Butler and colleagues (Butler et al., 2008), have been important promoters of the idea that dementia and ageing are both conditions that need to be approached through life-long prevention strategies (Lock, 2013; Moreira & Palladino, 2009). The next chapter based on interviews of citizens engaged in brain training activities in later life, demonstrates this link between brain training games and a wide range of random intellectual activities. Indeed, these individuals often equate learning new languages or going to the University of the Third Age with brain training as various practices potentially able to sustain cognition. Mainstream ideas about brain training therefore tend to encompass a wide range of practices, and the popularization of various discoveries in the neurosciences has participated in the spread of this idea in later life.

These new imaginaries of the brain enabling structural ideas of *active cognitive ageing* have had a social impact in fostering the divide between third and fourth age. Indeed, they expand and intensify the reach of novel modes of governing the body and individuals, therefore generating new regimes of *biological citizenship*. The term *biological citizen*, developed by Rose and Novas (2005), and inspired by the Foucauldian notion of governmentality describes how individuals in later life are increasingly expected by society to individually manage their own health and the risk that they take through rational calculation and self-discipline. The influence of such calculus on lifestyle in later life has been made salient in various studies of physical and cognitive health (Jaye et al., 2018; Lawless & Augoustinos, 2017; Williams et al., 2012), as well as brain training more specifically (Millington, 2012, p. 438). Indeed, Williams and colleagues (2012, p. 73) note that ‘neuroculture (...) encompasses and expresses both ‘hopeful’ and ‘feared’ futures and as such mobilises people to think about themselves in terms of various risks, hopes and fears associated with cognitive health, mental capital and wellbeing’. Brain training is an integral part of this new neuroculture, and Williams et al. (2012) point out that the possibilities it opened to support this ethos of self-discipline in later

life have been central to blurring the boundary between third and fourth age. From these transformations and the novel gerontological discourses of lifelong prevention, what emerges regarding cognition is therefore a new field of responsibility and morality for ageing individuals.

### **Training the brain as a virtue – the ‘will to health’ in active cognitive ageing**

Self-discipline for the biological citizen of late capitalism is essentially a matter of consumer choice and training the brain today is increasingly presented as a desirable outcome of this consumer choice in (approaching) later life. Active cognitive ageing, this new regime of health in later life, provides a moral framework for the actions of individuals. The inclusion of brain training within the fabric of active cognitive ageing therefore renders it dependent upon the kind of moral virtue associated with the idea of prevention in cognitive decline and dementia. To this regard, Lawless, Augoustinos and Lecouteur (2018) conducted a review of the websites of eight non-profit dementia organizations promoted by Alzheimer Disease International. This review led them to argue that online information on dementia risk and prevention available to the public ‘works to construct participation in prevention as desirable, necessary, and obligatory, despite ongoing debate about the benefit of such practices’ (2018, p. 1548). Brain training is therefore, as I presented earlier in the introduction best understood as a ‘technology of the self’ as Foucault named it (1988). A technology whose use is most associated with the fulfilment of a quest for virtue by the individual in later life, a means to attain a higher order of morality by confronting decline and demonstrating that one is willing to contain its inevitability through risk management when ageing. Millington, in his study of brain training discourses already pointed out how brain training companies support a discourse of the ‘will to health’ (Millington, 2012, p. 438) promoting the social value of training the brain. Indeed, as he explains, brain training “exacerbates the pressure on older adults to demonstrate an obvious ‘*will to health*’ through ongoing consumerism” (2012, p. 429). This promotion encourages individuals to show to others that it is a ‘good thing’ to engage in strategies of brain training.



Indeed, there is an intrinsic element of comparison included within the design of brain training technologies. As I observed in my review of a brain training ‘app’ Fitbrains (x-www.fitbrains.com; application discontinued since 7<sup>th</sup> June 2018 and website unavailable<sup>15</sup>), these electronic platforms very often involve a social component within their use. The process is the following: first individuals engage in the exercises of brain training on their smartphone or other compatible devices. Each exercise is rated by the software and will then provide metrics that are broken down into arbitrarily defined categories of the kind that I presented earlier: memory, speed, logic, focus, language, etc. Each category is individually graded, and the software reviews all the scores of the participants who subscribe to the platform. The software will then generate comparisons by presenting for instance the ‘percentage of 80-89 year old females that [I] outperform in each brain game area’. The game is meant to create a constant situation in which one’s capacity will be assessed in comparison with the one of others. In this process, the *objective of fitness* (Bauman, 2000) as an attribute of the *ethos* of late capitalism is palpable; Millington (2012, p. 438) even argues that it is omnipresent in the mechanisms of brain training. Indeed, as Millington (2012) underlines, the use of metrics and index scores is part of the mechanisms of many of the available brain training packages available online, using notions of optimisation. Characteristics of the objective of fitness as described by Bauman (2000), a constant feeling of non-satisfaction, an impression that one ‘could do better’, seems to be therefore an important characteristic of how brain training creates novel norms in ageing today. These norms result from a constant tension between the capacities of one-self in comparison with the ones of others.

However, training the brain in later life is never detached from the threat being defined by the categories of the fourth age; a Damocles sword constantly hanging over the head of such individuals. Training the brain with the objective to prevent cognitive decline adds an additional pressure onto the continuous state of dissatisfaction that the norms of fitness bring. There is indeed always a risk of regression when one does not ‘sufficiently’ use one’s brain – the idea of ‘use it or

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<sup>15</sup> Rosetta Stone Website (n.d.). Discontinued Product Announcement - Fit Brains. Retrieved 6 August 2020 from <https://support.rosettastone.com/en/brain-fitness/articles/Discontinued-Product-Announcement-FitBrains>

lose it' is indeed a slogan of the brain training industry as Millington (2012) points out. At a social level, the virtuous imperative of the 'will to health' in active cognitive ageing combined with the fear of 'losing one's mind' create moral judgements of those who do not engage with brain training practices. Indeed, deciding not to conform to the recommendations of cognitive fitness, as Katz and Marshall (2018:66 citing Gilleard and Higgs 2010) argue, could therefore lead to the judgement of having given up on counteracting the progression of age and dementia. It triggers anxious feelings of unease associated with the fourth age within the surrounding social world and becomes directed toward the individual themselves. As Millington (2012, p. 442) emphasises, the will to health is 'both enabling and constraining'. Indeed, besides this negative social impact, fulfilling the imperatives of the active cognitive ageing regime can also create the pleasant feeling of gaining back control in one's own life and gives the impression that something can be done about dementia. To this regard, engaging in brain training can become a source of pleasure. Such feelings that brain training can generate refer to the notion brought by Wade (2018) of 'virtuous play'. His own study of the brain training industry points out that 'consumerist imperatives under late capitalism necessitate that achieving virtuosity need not be a chore, but rather enjoyable means of self-care' (Wade, 2018, p. 302). Most interestingly, the next chapter will show that this criterion of enjoyment plays a role among at least some of the individuals' decision to engage in brain training. And if these individuals identify alternatives that can fulfil similar objectives of distinction while avoiding the boredom that some experienced when using brain training devices for instance, they will turn to these other solutions. Yet, brain training is also constraining in the sense that it can generate feelings of failure. This tension with the existence of the fourth age has already been studied by Dionigi and colleagues (2013) among older athletes engaged in physical activity, in which their decision to train was very much informed by their fear of decline and the loss of capacity. The existence of active cognitive ageing has arguably enabled such tension with the fourth age to exist in brain training strategies. Furthermore, the existence of value judgment toward decisions to engage in prevention for dementia, and the constant element of comparison in brain training opens the door to situations in which attributions of 'unsuccessful ageing' could be applied upon those who do not engage with this ethos of the third age. This threat of negative attribution is reflected in a previously

unconsidered use of brain training that I define in this chapter, mainly through the idea that brain training can support strategies of *distinction*.

## **Distinction as a motivation to engage in prevention**

Previous sections of this chapter have established the importance of using concepts of the third and fourth age to understand the significance of brain training discourses in later life. Beyond the relevance of this divide to understand technologies of the self, my central argument in this chapter concerns how practices of *distinction* are central to the use of contemporary technologies of the self. In other words, adults in later life rely upon the consumption and use of brain training technologies to *position* themselves within the third age of active cognitive ageing and away from the intimation of cognitive decline and dementia; the latter being a central constituent of the feared social imaginary of the fourth age. In relation to the ‘will to health’ (Higgs et al., 2009), users could demonstrate to their peers that they seek to actively maintain their cognitive abilities as they age. Distinction in ageing is arguably an important form of social differentiation, and a novel way to present how later life itself is divided between those who are able to maintain a ‘successful ageing’ and those who are not able to do so, those who have ‘failed’ to age successfully. *Distinction* in later life is an adaptation of the idea of distinction brought by Pierre Bourdieu in his book *La Distinction. Critique sociale du jugement* (1979, French ed.) [*Distinction: A Social Critique of the Judgement of Taste*. (1984; English ed.)]. By distinction, Bourdieu (1979) explains how taste for certain consumer goods or art is used by social classes in France in order to distinguish themselves from each other and maintain an ascribed social order. As an elementary example for instance, one could connect the consumption of wine or abstract art by the bourgeoisie with a high cultural capital, instrumentalized by this social class to differentiate itself from a working class whose modes of consumption it defines as un-refined, or vulgar. There is therefore in the manifestation of distinction both an aspect of social positioning and the establishment of a hierarchy through taste and consumption. When it comes to the third age, distinction takes place through the establishment of a hierarchy between a desired later life seen as a renewed time of enjoyment and experience and the

attribution of a stigmatizing and externally applied identity associated with the fourth age. Bringing such an explanation for social exclusion in later life and dementia, the main argument of this thesis therefore complements the current scientific literature limiting itself to notions of ‘generational habitus’ to describe the practices of the third age (Gilleard & Higgs, 2005; Higgs & McGowan, 2013; Tulle, 2007) or that age is a source of habitus (Tulle, 2007). The concept of distinction and its application to the fear of decline in later life and exclusion of the fourth age has however remained unconsidered.

By applying the concept of distinction originally used to theorize social class to health and ageing, I therefore point to the body as a central form of expression of social worth. To this regard, Paulson (2005, p. 232) reminds us that “Bourdieu (1984) also offered a convincing argument for combining the social constructionist and phenomenological discourses. He defined the body in terms of ‘physical capital’, a commodification of the body, and described the social values given to the sizes, shapes and appearances of bodies. His concept of ‘habitus’ referred to socially instilled bodily dispositions. Thus, an individual’s bodily disposition is a direct reflection of their social class, and is portrayed by their embodied taste and style. Social stratification thus occurs through classification of the body; and cultural intermediaries are important in transmitting bodily dispositions.” (Paulson, 2005, p. 232). Bourdieu therefore already theorizes the body as an omnipresent instrument of social hierarchy. Hence, the translation of this theory into ageing and the important role that corporeality plays in defining the boundary between third and fourth age appears to be most convenient. As such multiple studies of the body as an individual and social enterprise have presented the existence of practices of distinction into physical health (Cockerham, Rütten, & Abel, 1997; Collyer, Willis, Franklin, Harley, & Short, 2015; Frew & McGillivray, 2005; Higgs & Gilleard, 2015; Korp, 2008; Williams, 1995), and in the active resistance to decline that individuals display to prove social worth as part of healthy ageing (Allain & Marshall, 2017; Palmer et al., 2018). What the emergence of active cognitive ageing following the neuroculture turn therefore brings to these practices of distinction is their translation into cognitive health and their application to cognitive decline and dementia.

## **The specificity of these technologies: creating positionality through quantification**

Standardized metrics in brain training are instrumental in supporting distinction. They enable individuals to attribute a numeric value to their capacities. I presented earlier how arbitrarily constructed capacities come to be numerically assessed. For instance, speed, memory, attention, etc. are rated separately and their combination offers a representation of cognitive function. We should now look at this process of quantification more closely in order to understand how it supports social positioning through distinction. Indeed, such quantifications attribute a dynamic social value to individuals' cognition. Their use and their characteristics as 'technologies of the self' differentiate these modes of self-evaluation as hallmarks of contemporary consumer societies different from previous attempts to evaluate cognitive capacity.

Indeed in previous disciplinary societies as Foucault (1975) or Deleuze (1992) describe them, forms of governmentality are primarily externally applied by an authority and linked to the management of populations within separate localities, for instance in the school, the hospital or the prison. Much energy is therefore given to administering population through different modes of categorization referring to specific roles (e.g. the prisoner, the sick or the healthy). These past systems of classification of cognitive capacity were therefore influenced by these cultural manifestations of power. For instance, IQ systems were an illustrative means to establish such classifications of individuals into fixed categories. Indeed, IQ scores as they were conceived were relatively fixed. Although there may remain some aspects of disciplinary society today, the kind of metrics that brain training brought up are characterised by their dynamism and flexibility, their agility, their constant ability to progress or diminish. Their existence in novel regimes of fitness as I presented earlier quoting Bauman (2000) and Higgs (2012) and following what Deleuze (1992, p. 5) calls the novel norms of *perpetual training* as a key component of post-modernity, or late capitalism, is also fostered by how such technologies generate age categories in order for people to compare themselves across the entire lifespan. For instance, the idea that I outperform X individuals in my age category, as I presented earlier, is a way to show how brain training

attempts to stay relevant into the entire developmental and ageing process. Metrics as they are designed in brain training software packages suggest that there is always a possibility to be better, no matter how good we already are. Deleuze (1992) locates this idea of perpetual training within the more general context of the *societies of control* in which we live today, novel regimes of power progressively replacing the predated disciplinary societies. There is therefore an important disciplinary power at play within the norms that these technologies and other technologies of the self establish. These norms of health, according to him, constitute “the new medicine ‘without doctor or patient’ that singles out potential sick people and subjects at risk” (Deleuze, 1992, p. 7). These transient metrics imply that individuals in later life are constantly in tension to become better than others. Metrics of the brain are therefore not externally applied like IQ for instance, rather they are constantly generated by individuals themselves. People become self-regulatory in their practices, leading distinction to exist in relation to the agency that people have gained upon their own metrics.

Furthermore, the omnipresence of comparison that these technologies enable connect to the point made by Lupton (2016b) about the comparative dimension she studied in monitoring technologies more generally. She refers to this dimension as ‘communal self-tracking’ (2016b, p. 108) in technologies like self-tracking watches and fitness ‘apps’. The social media platforms integrated within these ‘apps’ enable the spread of data about oneself and therefore reinforce this element of comparison among users. Such mechanisms are present in self-tracking technologies, whether they lead to actual practices of comparison within the population or not. No matter what its actual consequences are, brain training becomes part of a broader societal trend around ‘self-tracking’ and the intensification of data collection capturing more and more dimensions of individual existences for the purpose of data-mining. Together with scholars such as Nafus and Neff (2016), Lupton (2016b, 2019) has dedicated much effort in theorizing the impact of these novel modes of quantification of the self on individual subjectivities and social existence. As a subcategory of this novel research domain, research on self-tracking has been conducted in regard to health and ageing (Andersen & Whyte, 2014; Oxlund, 2012; Oxlund & Whyte, 2014). The kind of individualism promoted by brain training technologies as technologies of the self

is part of a more general context of comparison facilitated by the datafication of life. Users therefore are offered the possibility to engage in the creation and calibration of the hierarchy necessary for distinction in later life to operate. The ideas contained within neuroplasticity and the neurocultural turn (Williams et al., 2012) have offered the tangibility that was necessary for metrics to become dynamic, rather than reflect the previously static systems such that IQ measure used to offer. Engaging in these modes of distinction through self-monitoring and self-assessment is becoming increasingly valorised and desirable as part of the modes of consumption defined by a third age identity and its rejection of the fourth age.

### **How technologies of distinction shape the imaginary of ageing**

However, distinction in later life remains fundamentally different from other forms of distinction taking place earlier in life around the demonstration of a ‘will to health’ centred on ideas of enhancement, fitness and aesthetics in self tracking (Millington, 2012; Ziguras, 2004), or the kind of distinction that Bourdieu (1979) describes in term of social class. Indeed, all these forms of distinction essentially take place within an agentic society. The kind of distinction enacted by the third age is existential both in how individuals imagine a life with dementia, and as an attempt to create distance from the inevitable part of decline associated with ageing. Indeed, the fourth age explain Gilleard and Higgs (2010), remains ‘an inevitable end that could at best be marginalised to the edges of life’. This is a point that was already made by Peter Laslett in *A Fresh Map of Life* (1989) inspiring aspects of Gilleard and Higgs’s work (2010). Laslett (1989) describes the fourth age, representing a chronological stage of life, as a time predominantly marked by decrepitude and death. As I presented in the introduction already, Gilleard and Higgs (2010) depart from this chronological understanding of the fourth age by underlying its existence as a social imaginary, a more impalpable and feared social representation that impacts later life without being attached to a specific chronological threshold.

A recent and successful campaign from Alzheimer’s Research UK (2019c) is a relevant example for the way in which prevention in later life ultimately reflects the feeling of an imminent existential threat. One of the most recent examples of

this campaign called ‘share the orange’ using the metaphor of an orange to symbolize the human brain has had a substantial effect on British populations. Indeed, ‘the orange’ (understand ‘your concern about dementia, and link to our fundraising website’) had already been shared 2,194,552 times when writing this chapter in August 2020. The video starts with a man standing up with an orange in his hand, and a dramatic classical music piece playing in the background. With a serious tone, he announces: ‘like millions of you around the world, I have seen the life of a loved one devastated by dementia. But too many people still believe that dementia is just a natural part of ageing and that there is nothing to be done’. While promoting Alzheimer’s Research UK, the man delicately places the orange on a table while stating that everything starts and ends with the brain. Meanwhile, the camera makes a close-up on the surface of the orange which displays the stereotypical steps of a life, represented by small digitally animated characters walking on its surface. From childhood, adulthood, wedding and the birth of children, to childrearing, later adulthood and a well-deserved retirement, the small characters live happily on the surface of the orange. Suddenly comes the tragic turn in the plot. ‘Everything *we are* is at risk’<sup>16</sup> says the narrator. What appeared to be a happy couple of grandparents enjoying their life on the surface of the orange a second before then becomes the man alone, terrified and powerless, observing his wife vanishing. Slowly all the events of a lifetime symbolically inscribed on the peel of the orange vanish as well. Then the peel of the orange itself vanishes leaving the quarters apparent before they themselves fall into single vanishing pieces. In such a distressing narrative, the objective of treating dementia is presented as a war against not only a disease but the disappearance of a life into the abyss that only the funding of biomedical research can rescue. Dementia in this archetypical illustration of the social imaginary of the fourth age is therefore presented as an existential threat, and it is therefore with such an understanding in mind that one should consider the practice of brain training. Brain training is therefore not limited to a form of social positioning away from others who are deemed less fit. More significantly, it is also an attempt to distinguish oneself from intimations of decline and individuals who are perceived to be closer to the existential threat of dementia and brain death.

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<sup>16</sup> My emphasis in the quote.



Beyond the distinction from an inflated imaginary of the fourth age and its existential threat, I should also refer to Gilleard and Higgs' (2010) argument about the inevitability of decline associated with the fourth age. Distinction is therefore also a strategy of the third age living an 'ageless ageing' as described by Andrews (2000) to dissociate itself from an 'ageing without agency' that the fourth age typifies. Such fear of decline at the source of prevention has been theorized in various instances concerning physical health among master athletes as I mentioned earlier in reference to Dionigi and colleagues' study (2013). It is therefore an application of this fear to cognitive health. Also, Nosraty et al. (2015) show that this anxiety with decline does not apply to people in middle age only, so as their study of individuals over 90 years' old who are part of communities in Finland demonstrates. The idea of 'use it or lose it' as a common slogan for the brain training industry (cf. Millington 2012) also suggests that not solely fitness is at stake when it comes to training the brain in later life. Indeed, anxiety with ageing and health is the other side of the coin that 'virtuous play' and self-tracking can present. In their study of self-tracking among individuals with type 2 diabetes in Denmark, Andersen and Whyte (2014, p. 266) point out that changes in the metrics of individuals engaged in self-tracking can become a source of anxiety. As Andersen and Whyte (2014) explain, these metrics reify and quantify the functioning and capabilities of the body, giving a sense to individuals that they are able to grasp their improvement and decline. The fear of losing capacity therefore finds the possibility to become a daily struggle and obsession.

Brain training through its use of metrics as parameters defining the limits of the third age therefore constitutes a *technology of distinction*, a technology enabling individuals to demonstrate their commitment to the novel norms of 'ageless ageing' and to demonstrate to others that they take steps to maintain the fourth age and its existential threat of dementia away. This desirable ethos of the third age therefore relies upon processes of differentiation from the fourth age to justify the use of brain training, and at the same time reproduces or strengthens these processes of differentiation. We should now consider how this differentiation affects people with dementia by relegating them further in the fourth age.

## Considering the impact of distinction on people with dementia

This thesis fills a gap in the scientific literature on social exclusion in dementia and later life by theorizing the existence of distinction and its effect on people with dementia. Specifically, the social exclusion contained in distinction translates into a process of *othering* of people with dementia as a result of social positioning (Higgs & Gilleard, 2014). Higgs and Gilleard (2015, p. 264) define othering as ‘essentially a catch-all term to describe the attributions made by other people of persons who seem powerless to assert their own identity or realise their social agency’. This process affects people with dementia when they become encompassed within the fourth age imaginary of ‘failed ageing’. Othering therefore appears to be a side effect generated by the values of the third age and their rejection of the fourth age. Bourdieu’s theory already shows how practices of distinction around social class can become discriminatory and create othering. Indeed, when applied to taste and social class, Featherstone (1990) reminds us the following about Bourdieu’s theorization of distinction (1979), mentioning that his theory goes beyond the production of discriminatory judgements to include the transmission of these classifications to others. Indeed, he writes the following: ‘particular constellations of taste, consumption practices and lifestyle practices are associated with particular occupations and class fractions, making it possible to map out the universe of taste and lifestyles with its structured oppositions and finely graded distinctions which operate within a particular society at a particular point in history’ (Featherstone, 1990, p. 11). In the work of Bourdieu (1979) in regard to class fractions as Featherstone (1990) points out, consumption choices and tastes are discriminatory and aim at generating exclusion through the establishment of *insiders* and *outsiders* to certain social classes. In ageing, the constitution of insiders of the third age also defines who the outsiders are, namely people with dementia, and those who are substantially less able to maintain an agentic self in later life. Technologies of distinction such as brain training participate in the constitution of people with dementia as ‘others’ through external ascription. Distinction therefore works through the ascription of otherness on people with dementia in order to establish a positive difference for the third age.

The othering of people with dementia has been covered in the literature (Beard, 2004b, 2016; Beard & Fox, 2008; Tolhurst & Kingston, 2013). Yet these studies exploring social differentiation and the exclusion of people with dementia mainly base their approach on active ageing and leave concerns for the impact of the fourth age aside. Hence, they do not look at how cultural processes related to the anxiety created by the fourth age lead to social differentiation and exclusion. This understanding of differentiation omitting the fourth age mainly derives from the idea of ‘malignant social psychology’ brought by Tom Kitwood (1997b). His theory describes the othering of people with dementia as relational, and therefore heavily weights toward a social constructionist approach to dementia while leaving aside more corporeal and existential considerations in the fear of dementia. Kitwood (1997b) therefore argues that changing relations of care that are deemed as disabling because they negatively affect people’s capacities should therefore help restore their personhood. Attempts to overcome this ‘malignant social psychology’ have brought a series of reforms leading to the extensive implementation of principles of person-centred care in care homes and hospitals. It also led scholars to more recently consider the impact of the social and physical environment on the capacities of the person with dementia based on these novel principles of personhood (Bartlett & O’Connor, 2007; Brannelly, 2011; Fletcher, 2018; Kontos et al., 2017). Other influential research on how society’s relation to people with dementia can impact their agency and capacity to participate in society (Bartlett, 2016; Bartlett & O’Connor, 2010) have drawn their legacy from this approach. They have applied the concept of citizenship to dementia in order to ‘interpret inclusive and exclusive practices which potentially create opportunity for participation or reinforce the loss of citizenship for older people with dementia’ (Brannelly, 2011, p. 662). In other words, the source of the othering of people with dementia is interpreted as a result of society’s perception of people with the condition. Changing this perception can therefore help to alleviate othering. With this strategy in mind, organized groups of people with dementia have conducted much work across the world to act upon relational sources of exclusion. Language is an important articulation of this debate on the relational sources of exclusion.

Groups like Dementia Australia<sup>17</sup>, the Dementia Engagement and Empowerment Project<sup>18</sup> or researchers in dementia like Sabat et al. (2011) have advocated for the replacement of expressions such as ‘being demented’ by ‘having dementia’, ‘demented people’ by ‘people with dementia’, or for the avoidance of expressions such as ‘dementia sufferers’ in relation to the prejudices and stereotypes that these expressions imply. Although they have gained in importance and have arguably had an impact in shaping public discourse about dementia, it is difficult to assess their actual impact on exclusion. This thesis recognises the importance of these social movements in overcoming the many prejudices that affect people with dementia. Meanwhile, it also argues that these approaches have not considered other essential cultural processes leading to the othering and exclusion of people with dementia emerging from distinction.

Indeed, this account of the relational nature of exclusion of people with dementia through society’s perception does not engage with the intrinsic cultural phenomena that lead to the exclusion of people with dementia, namely the ones of the fourth age. Hence, despite these efforts an important process behind the exclusion of people with dementia remains unaddressed. This process is a result of the intrinsic existential fear involved in cultural perceptions of old age as a major source of stigma. The position of this thesis on stigma therefore reflects aspects of the critique brought by Scambler (2009) regarding the study of stigma more generally, which often does not consider the structural processes at the back of this social phenomenon. The fear of ageing and decline is not the hallmark of a single Western culture characterized by a ‘negative social psychology’ alone. It has a character which can be found across all cultures in some way or another, although its intensity is historically contingent and dependent upon cultural representations of later life. Distinction is a result of this intractable fear deeply rooted within existential and cultural perceptions of ageing, the one that I described by referring to the ‘share the orange’ narrative. Despite the best efforts from Alzheimer’s associations and dementia movements to engage in education and the struggle

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<sup>17</sup> Dementia Australia (n.d.). Dementia language guidelines. Retrieved 6 August 2020, from <https://www.dementia.org.au/resources/dementia-language-guidelines>

<sup>18</sup> Dementia Engagement and Empowerment Project (2014). Dementia words matter: Guidelines on language about dementia. Retrieved 6 August 2020, from <https://www.youngdementiauk.org/sites/default/files/DEEP-Guide-Language.pdf>

against stigma, this thesis argues that a part of this distinction is a consequence to the existence of a fourth age imaginary. The presence of this distinction is primarily existential rather than based on a systematic ageism or negative social representation of dementia. Acts of prevention and brain training are a result of this existential distinction, and therefore participate to this exclusion. Acknowledging this effect of the fourth age exposes paradoxical situations in which Alzheimer's associations engage in the struggle against stigma while also promoting prevention and the 'war against dementia' based on the idea of a clearly segregated disease entity, therefore involuntarily leading to distinction from the fourth age. Acknowledging the existence of the fourth age imaginary as the main reason behind distinction is a first step toward finding novel ways to address the social exclusion of people with dementia. There is therefore a need to understand that the struggle against the 'malignant social psychology', although being due to environmental factors and neglects of the personhood of the person with dementia, is also provoked by the intense effort that we put as a society in isolating dementia from ageing and establishing ever expanding regimes of self-monitoring and prevention.

## **Conclusion**

This second chapter has introduced the existence of distinction and social positioning away from dementia to explain the social exclusion that the rest of this thesis will develop. Centrally it aimed at showing how the current literature on dementia, technology and ageing research gives little attention to distinction from the fourth age as an essential form of social exclusion of people with dementia through technology. Indeed, previous research demonstrated how the exclusion of people with dementia in technology is the result of socioeconomic and geographic access to technology. As for the field of ageing research and gerontology, much effort has been given to demonstrate how the exclusion of dementia is the result of an ageist 'decline ideology' (Gullette, 2017) oriented against the old. Exclusion is essentially a result of perceptions and attitudes. Leading voices in this approach have therefore spent much effort in attempts at changing these perceptions as a perceived solution to alleviate this exclusion. In this chapter I have argued however

that exclusion as a result of access, the so-called digital divide, has remained relatively superficial in its understanding of the matter. As for ageism, this argument has been too deterministic, and therefore reductionist in explaining the exclusion of dementia (Higgs & Gilleard, 2019). Hence both arguments have each in their own way neglected the existence of a more pervasive cultural phenomenon explaining exclusion – the widespread need that people feel in positioning themselves away from the feared social imaginary of the fourth age. My exploration of brain training discourses started in the initial steps of this research has shown how brain training technologies intensely relied upon the need for people to position themselves within the coordinates of a desired third age, and away from an unwanted fourth age. The idea of ‘use it or lose it’ is pervasive in these technologies as Millington (2012) presented. The flourishing of the idea of neuroplasticity in the neurosciences has been a founding principle enabling the already existing discourse of active ageing and its idea of responsibility to spread into the domain of cognition, what I referred to as active cognitive ageing. Such expansion enabled the ‘will to health’ – the moral imperative associated with enacting prevention practices – to transfer into brain health. Meanwhile, dementia brought an existential dimension to this moral imperative. Based on Bourdieu’s work on distinction as a form of social positioning supporting class division, I therefore presented how people are increasingly pressured to display an ethos of self-care through consumer choice aiming at staying away from dementia. The point is that technologies such as brain training become obvious candidates to this choice in their capacity as ‘technologies of the self’ attached to demonstrating moral virtue (Foucault, 1988). Under the pressure of active cognitive ageing, they become technologies of distinction, these technologies able to demonstrate that people position themselves away from the existential threat of dementia. This chapter presented how this form of positioning based on an existential fear is also a discriminatory act whose result is the othering and exclusion of people with dementia.

With the spread of public health campaigns encouraging risk-management and prevention in dementia, the urge to enact distinction is enabled by a wide range of technological interventions in the field of ageing reinforcing the social division between third and fourth age. Brain training is a key example of these technologies

and interventions, yet they take multiple forms and are enacted by different actors across society as we should see in the next chapters. This multiplicity of forms enables this divide to be maintained through complementary processes to the one of distinction. The multi-sited nature of this research enables an understanding of the complementarity of these processes in the maintenance of exclusion. Sites as diverse as the ones of healthy users of brain training technologies in the United Kingdom, memory clinics in Southern Europe, an intervention implementing autonomy through empowerment in dementia in the United Kingdom; or the action of advocates and experts with dementia play a complex role in maintaining aspects of the status quo around social exclusion.

To study the local manifestation of this principle of distinction through its impact on practices and motivations, the next chapter will specifically present how distinction influences choice among a cohort of healthy individuals approaching later life who regularly ‘train their brain’ in relation to dementia. This next chapter will therefore display how distinction operates through subtle boundary making practices by the third age in a context of prevention and show the expansion of its logic in other domains of the life of these individuals. It will therefore continue the argument of this chapter by positioning brain training in the context of individual lives.





### **Chapter 3: Distinction in later life: exploring the motivations of brain training users**

*“To me it is very important; I want to be able to make my own choices and live my own way. Ideally, I’d like to stay like that until I fall off a cliff or not wake up one morning, rather than going through a decline.”*

(A brain training user – interview 19)

In a consumer society, distinction is fundamentally based on the divide between a ‘successful’ old age – a space of agency and lifestyle opportunities – and its ‘failed’ counterpart: the social imaginary of the fourth age. This dualism can be found in the discourses and mechanisms of brain training as we saw in chapter two and can generate forms of social positioning through distinction. We will see in this chapter based on interviews with 27 users of computer-based brain training ‘apps’ in the United Kingdom how distinction from the fourth age manifests itself concretely through the choices that individuals in the third age make. This chapter will add a sense of ‘ethnographic thickness’ (Geertz, 1973b) to distinction by grounding this practice in the daily life, worries and concerns, hopes and aspirations of individuals in or approaching later life. Amidst the fear of dementia, I will present how ‘training the brain’ has become an ‘act of faith’ in the promise of brain training, and part of a socially desirable active lifestyle and belonging to the third age. By ‘act of faith’, I understand a personal investment made following the hope that this practice could work to prevent dementia without certainty. I will also show how brain training as an ethics of life cannot be limited to the sole use of technologies I presented in the previous chapter. Brain training encompasses a various set of practices for healthy individuals in later life, or approaching later life specifically aimed at creating distinction, and a multiplicity of practices are perceived as means to fulfil this objective. Technologies of distinction such as brain training are therefore part of a wide range of practices and discourses supporting distinction as

a *boundary making process* for a third age identity to protect itself against the potentiality of a feared future with dementia, and to maintain dementia as external to ageing.

As we will see, the position of this boundary delimiting the third age is based on people's conceptualization of the fourth age – the threshold beyond which living becomes unworthy for them in their imaginary of dementia. Here I stress the notion of imaginary because dementia is feared only as an imagined experience. This imaginary of dementia and its intensity varies from one participant to another, yet it cannot be dismissed as a distant fantasy. Using the experiences of several participants as carers of people with dementia or witnesses of the condition, we can see that their imaginary is therefore a rich and complex one and cannot be reduced to simple stereotypes sometimes displayed in advertising campaigns, for instance the ones drawing on 'the war against dementia' (Lane et al., 2013).

This chapter will describe the richness of individuals' perceptions of dementia and their perception of the coordinates of the third age. It will present how distinction is an implicit component of this perception. It will use the *four vectors* defining the fourth age as theorized by Gilleard and Higgs (2015) as heuristic devices to explore these perceptions. These four vectors are namely *the social construction of frailty*, *the idea of abjection*, *the process of 'othering'* and *the moral imperative of care* – four key characteristics defining the fourth age. This chapter will spend time to define each of these four vectors separately and present how individuals in the third age enact their characteristics when they emphasise their status as insiders within the third age. This chapter will describe how brain training inserts itself into a broader 'ethics of life' based on distinction, and present how this ethics generates forms of othering.

As presented in the methodology outlined earlier, this chapter presents the result of in-depth semi-structured interviews in which individuals described their motivation to engage in brain training practices around dementia. It also presents their perception of dementia and ageing as well as their understanding of the idea of prevention. These individuals were recruited to the study thanks to a collaboration with the Delta Project, a longitudinal study exploring the ageing of the brain over a period of several years in the United Kingdom. As part of this programme of

research, they participated in a regime of computer-based brain training similar to the technologies I describe in the previous chapter. Overall, the candidates I interviewed were linked together by their decision to participate in this project on the ageing of the brain. Dementia and memory issues were therefore important characteristics present in one way or another in their motivations. Participants were therefore aware of the presence of this component of prevention through brain training before choosing to participate. They were also aware of the close monitoring that they would receive as part of their involvement in the study. Beyond these elements informing their original motivation to participate, each of these candidates developed a unique understanding showing how diversely the anxiety of dementia impacted their life, with varying intensity.

### **The fourth age and its impact on choice in later life**

How do individuals define their belonging to the third age and how do they live with the presence of the feared fourth age? How do questions of belonging and anxiety affect their choices and representations regarding later life and dementia? And what is the social impact of these choices? The concept of the social imaginary of the fourth age is useful as a heuristic device to further explore the nature of this anxiety and its impact on engagement in prevention among these participants. As we have noted, in their theorization Gillearn and Higgs (2015) propose that the social imaginary is constituted of four fundamental components or vectors: 1) the social construction of frailty, 2) the abjection brought by decline, 3) a process of ‘othering’ and 4) the moral imperative of care. The characteristics encompassed by these four vectors help us to understand how individuals in or approaching later life construct a cultural narrative of a desirable identity in ageing. These four vectors influence the choices that people make in preparation of their later life – a part of these choices being oriented toward brain training as a desirable practice.

#### ***First influence – the social construction of frailty***

The first vector which represents an influence on choice describes how mental and physical frailty are an important component of the feared fourth age, and an

important label from which individuals in the third age attempt to dissociate themselves. As Gilleard and Higgs (2015, p. 264) explain, “bio-medical scientists have been preoccupied with identifying a syndrome of ‘frailty’ distinct from both age and disease, one that serves as a biomarker of biological vulnerability.” (...). My ethnography indicates that this fear of being defined as physically or mentally frail is an important aspect explaining practices of distinction among the participants in brain training research I interviewed. A conversation I had with one of my participants is particularly illustrative of this distinction from frailty.

*Participant: I got an email the other day which really, it bothered me actually. It was for elderly. And one of the people in the office, she is much younger, she is in her fifties, sent the email to me, and said: ‘can you look after this’. It was to go and be filmed for a charity, and I actually objected to this email. They were looking for people over the age of sixty. And I said people over the age of sixty are not elderly anymore. How dare they send emails out for that!*

*Me: Specifically asking for...*

*Participant: ...elderly. You could ask for those who are over 60, and that’s fine. But to actually call ‘elderly’, I think that was wrong.*

*Me: Because it implies an identity....*

*Participant: ... I don’t have it.*

*Me: What is the elderly identity in general, in your opinion?*

*Participant: Hmm... someone older than me... [Laugh] Someone who can’t function in the same way. Somebody who has already got some impairment, some difficulties, physical or mental. I must tell you that my knees and shoulders are old. They are elderly... yes. My knees and shoulders are definitely older than the rest of me, but apart from that. (Interview 5)*

As we see in this discussion, the participant objected to being called elderly, an identification that she perceived as inappropriate. Despite the vagueness of this category, she saw it as rather offensive, and applied this category of the elderly toward other individuals, those with all-encompassing impairments. Her definition of elderly as a defining totality, a corporeal phenomenon that prevents one from

the ability to say that one has elderly knees and shoulders, shows how being elderly is essentially attached to frailty.

To link this statement with the structural context of ageing, the meaning of being old, being 'the elderly' has shifted within consumer society. Later life is not a 'residual social category' anymore within a consumer society as Gilleard and Higgs (2010) point out. This residual category has been filled by frailty, an unwanted identity marking what constitutes the 'real old age' at the basis of distinction. This example is a testimony of how the current cultural construction of ageing within the third age is primarily understood as a continuity of active life whose fulfilment of an identity through consumption can be maintained (Gilleard & Higgs, 2002). In this context, the invariable concerns that people have with the corporeal aspects of ageing and the risk that they become totalizing in defining identity in the fourth age remain. This is what the participant wishes to underline when she mentions that '[her] knees and shoulders are old'. By describing parts of her body as old, she externalizes decline. She detaches it from her 'ageless self', a ritual of self-definition which echoes aspects of the uncomfortable relationship that late modernity displays in regard to the ageing body (Hazan, 2011a; Kaufman, 1986). She then goes on to operate a distinction between herself and those whose decline become definitional as to who they are, 'those who can't function in the same way' as the 'real elderly' – therefore those whose frailty has expanded to an extent that it has become definitional. This distinction in the discourse around frailty therefore operates as a boundary-making process delimiting the identity of the third age, and the externality of the fourth age due to its unwanted and objectified corporeal decline. Being classified as vulnerable is an important concern for the third age, essentially defined by its norms of agency and productivity (Lamb, 2014). To this regard, Kaufman (1994, p. 56) specifies that frailty is 'a state of being that can be operationalized and measured instrumentally, as a parameter of risk for institutionalization, as a socially constructed problem, and as a quality and adaptation process, one that forces us to reconsider the meaning of independence and dependence in advanced old age'. Accordingly, frailty has the capacity to arbitrarily ascribe dependence as a defining characteristic for the ageing individual, hence the desire of participants to detach any sign that could suggest frailty, any

decline in parts of their body from their identity. Another way to maintain their sense of identity is also to establish their difference with others.

In this form of distinction from frailty, brain training plays an important role as a means of self-evaluation of one's own level of frailty. Indeed, another person I interviewed mentions how becoming mentally frail is a source of anxiety for her and how she uses brain training to assess her belonging to the desired third age.

*I was shocked at the beginning about how little I could remember one day. I was like, my god, I can't remember anything. I used to have an amazing memory when I was a child, I didn't study, I just listened in the lessons and that was it. And I had good marks. And then (...) I couldn't. And that's been, that's very scary to see how my memory had just disappeared. I couldn't remember, had no recollection of something that was just happening. So that is a bit scary, so. There was one exercise you had to remember, you had a list of words, and then you had to write them, and then afterwards, you had to write them down. I could only remember 3 out of 20... that was a shock. And then I managed to do it, and another time I did that exercise again, I was able to remember 8 or 9, but it still was not. I was not what I would have been able to remember a few years ago. It was a bit scary. (Interview 3)*

The shock that this person experiences seems to be a result of her fear that cognitive decline irreversibly sets in. What we can draw from her explanation of this fear is that it seems to signify the end of her desired self which was characterised by her capacity to have 'an amazing memory'. Being affected by *cognitive frailty* would mean entering a new stage of undesired ageing, an ageing which could be characterized as the fourth age. She is at first scared of the menacing potentiality of this undesired ageing setting in due to the low score that she obtains in the brain training memory game.

To operate distinction from this undesired fourth age, this person engages in the brain training memory game again later in time to re-assess her memory and confront the decline that she previously experienced. She confronts her previous fear with the hope that it did stabilize or did not worsen, signifying an irreversible decline. Thankfully, she then obtains a significantly higher score which could reassure her of her belonging to the third age. Brain training in this example

therefore plays the role of an ‘existential compass’ and supports her distinction from the fourth age. This particular cultural approach to decline gives an important space to metrics and reminds how arbitrary and objectifying measurements are at the centre of the social construction of frailty (Kaufman, 1994) and the definition of the fourth age (Gilleard & Higgs, 2015). In their role of distinction, metrics are used to reassure people of their belonging to the third age by invalidating the existence of decline, or the impression that one is going through a decline – a point also made in the previous chapter. These technologies of distinction therefore help to reassert the belonging of individuals to the third age and away from the fourth age. As mentioned by Libert and colleagues (2019) however, limited consideration has been given to the frustration that can emerge when technologies of distinction do not invalidate a previous experience of decline, but actually confirm it, for instance through decreasing scores. I will discuss this point at the end of the chapter.

Echoing these two examples presenting distinction from physical frailty and distinction from mental frailty among participants, this last example presents how training the brain not only establishes distinction from an undesired self but also from undesired others. This example illustrates how technology plays a social role beyond its mere therapeutic or self-evaluative status by constituting insiders and outsiders in relation to the third age. Here is what a participant says about the moral value of her engagement with brain training:

*And then there is also that reality, yes, I have got to work hard to keep my capacities of understanding, being able to be responsive. As well as being physically active, I’ve got to be able to use my brain. And it was seeing my mother-in-law who had not looked after herself, and had not challenged herself, how poorly she operated. And that’s why I am interested as to whether dementia can be kept at bay if you are actively using your brain. (Interview 8)*

In this example the participant establishes a direct comparison between her engagement with forms of brain training, her decision to ‘use [her] brain’ and her mother in law’s cognitive status defined by frailty. Through this comparison, she establishes a contrast between her lifestyle choices and the ones of her mother-in-

law which led to her mental frailty. Responsibility and risk-management through adequate consumer choices I should emphasise again are two essential dimensions characterising the ethos of the third age. The participant explains how she hopes to avoid reaching the same state as her ‘poorly operating’ relative by engaging in an ethic of self-care through brain training. She therefore uses brain training as a technology of distinction in order to position herself within the third age and dissociate herself from her mother-in-law’s closeness with the fourth age.

The three examples presented above therefore show how distinction from frailty is an intrinsic dimension of ageing today, and how ‘training the brain’ helps to establish a distinction through prevention and self-evaluation from frailty. Training one’s brain is a means to maintain difference from individuals identified as frail. Brain training, together with a range of lifestyle choices informed by active cognitive ageing are important means to establish difference for third agers and are enabled by participating in the construction of a boundary separating them from physical and mental frailty, the first vector of the fourth age. It indicates how the fear of becoming classified as dependent and vulnerable as well as concern with avoiding physical and mental decline drives or contextualizes practices of brain training, rather than it constituting a mere will to keep a healthy body and healthy mind.

### ***Second influence – the abjection of dementia***

At the source of the fear that people have of dementia, there is an intense concern with abjection. *Abjection* is the second vector defining the fourth age (Gilleard & Higgs, 2015, p. 264). Gilleard and Higgs (2015, p. 264) draw upon the work of Bataille (1999) and Kristeva (1982) to describe abjection as a social position of the fourth age constructed by society’s avoidance or concealment of people with dementia due to their perceived or actual inability to deal with their own failings and maintain coherent actions. For instance, they present how ‘the abjection of the fourth age might seem to be concerned with incontinence, a lack of self-care or the seemingly purposeless behaviour of older people with dementia’ (2015, p. 264). Such an apprehension with (cognitive) decline in later life is present in the testimonies of some of the participants.



This question of abjection is often linked to questions of dying in dignity in the concerns of participants in this interview. When looking at how they define dignity, it is interesting to note that they often make reference to the avoidance of abjection. Representations of the loss of self-control and the inability to perform self-care is central to several of these testimonies. They represent aspects of alienation from the third age for these participants. Ageing without dignifying care signifies the ascription of someone in the fourth age. This concern can also lead to forms of distancing from the institutions that embody the lack of concern for dignity.

Institutional responsibility for creating the possibility of abjection is an important factor generating practices of distinction among participants. A participant I interviewed constructed such a boundary by discussing the role that care homes play in the management of abjection, and how she draws a distance from people's inability to care for themselves in the fourth age.

*Participant: And I think there has been some positive stuff about how to deal with people with dementia. I mean I have done some training through my job. And I have learned things like, it's better not to ask 'what would you like to drink?' It's better to say: 'Would you like tea? Would you like coffee? Would you like water?' Just one thing at a time, and that gives the person some control over their life.*

*Me: It's an ability to choose what they want?*

*Participant: Yes, and that's important. ... Some of those homes are just dreadful, it smells.*

*Me: It is not very pleasant...*

*Participant: Not at all.*

*Me: Is there something we could do about it?*

*Participant: I know homes that are not, so yes. It is a question of how much one is prepared to put into them...*

*Me: Resources?*

*Participant: Yes. I visit these places regularly for my work, so I see it all the time.*

*Me: Because you go there to see people regarding...*

*Participant: Yes, I visit my members who are in these homes [Interviewee performs a religious role in the community]. So I see people all the time, and they are ones I wouldn't touch with a [inaudible], or that I wouldn't go near. It's horrible.*

*Me: So clearly research is one of the things that can help for you to...*

*Participant: That's why I'm happy to try and help the research. You know, I am aware that it may not be in time for me, but hopefully, you know. And hopefully there will be a time when the damage that is done to the brain can be stemmed. (Interview 5)*

Such testimony presents how this person perceives care homes as 'dreadful' due to 'the smell'. Those are key characteristics of abjection – abjection in the sense of proximity to 'dirt and disgust' that Bataille (1999) establishes in relation to certain social positions in society. Abjection is also present in how the respondent distances herself from some of 'her members' that 'she would not go near'. She stresses that those situations are the result of an absence of proper care. The social imaginary of the fourth age is nourished by the situations in which care leads to these consequences, therefore displaying people's inability for self-care as a source of their abjection. Higgs and Gilleard (2015, 2016b) point out to this role of undignified care in constructing the intensity of the fourth age.

This imaginary of the care home and the situations in which people become undignified are drivers for many of the participants I interviewed to engage in research on dementia and prevention. Avoiding abjection linked to the lack of care is therefore central to practices of distinction, as the situations and individuals that people identifying with the third age do not wish to experience or that they only approach with distance, as separate entities from their own identity. Although distinction may be in part directed toward abjection itself, the individuals I identify essentially point to the role that institutional neglect plays in reinforcing this fear. Distinction is therefore in part a product of the institutional treatment provided to people with dementia.

Beside a specific concern for abjection associated with undignified care, participants also distinguished themselves from another important dimension of abjection – the perceived incoherence of the actions taken by individuals with dementia, a point made earlier by Gilleard and Higgs (2015, p. 266). A participant engaging in brain training I interviewed describes her fear of dementia mainly because it would imply living a purposeless existence for her.

*Participant: Is it a good thing to find out if you actually have the beginnings of dementia, if you can't do anything about it? And when does the memory loss actually mean that its more than ageing memory loss? That's the biggest question.*

*Me: So this is something you would like to understand?*

*Participant: It's the big unknown. And if there is still nothing that can be done to stop it, is it a good idea to know?*

*Me: To know in advance... because you have the impression that we ask more and more about knowing in advance about dementia...*

*Participant: I think I probably would want to know... I am a believer in euthanasia. I probably would want to have control over ending my life if it looked as tho I had untreatable dementia and it had gone passed the stage.*

*Me: So it's having the knowledge in the time in which we still have control?*

*Participant: Yes, yes. I hope that won't happen. I absolutely don't want to be going to Dignitas or anything. But I would hope I could do that rather than end up a vegetable. That is not an easy subject to discuss is it? (Interview 2)*

This example is particularly significant as an intense expression of this other facet of abjection – the fear of living a purposeless life. It is an emotionally intense component of the fear of a dementia *in potentia* for several of my informants. In this testimony, the participant expresses her impression of a life with dementia 'passed the stage'. Her perception is driven by the imaginary of an existence without agency or purpose as her mention of 'ending being a vegetable' describes. Such statement echoes an important aspect of the fourth age in how people in the

third age often imagine 'the seemingly purposeless behaviour of older people with dementia' (Gilleard & Higgs, 2015, p. 264). To this regard, Hazan (1992, 2011b, p. 1131) recalls the use of similar imaginaries to describe residents with impairments in nursing homes. In the testimony I gathered, the respondent discursively enacts distinction when she mentions euthanasia in response to a life that she perceives as not being worth living. The participant therefore positions herself within the third age by referring to euthanasia as a possible means to reassert control toward a desired existence for her. Price et al. (2014) found similar concerns in their study, mentioning that although people were happy to discuss financial planning and disability in later life, they would avoid the issue of long-term care planning, or mentioning that they would prefer to die instead. The authors see it as a manifestation of the fourth age in this avoidance and statement (Price et al., 2014). Some participants mentioned other means of reasserting control against the perceived abjection and frailty of dementia, for instance through advanced decisions and completing a living will. In similar ways to euthanasia, they saw these practices as the last resort they had to be agentic in their life before the fourth age settles. The idea of 'living a meaningful life', a controlled life with a purpose is therefore significantly an ethic of life in which instances of distinction from the fourth age are discernible.

Brain training plays a role as an instrument to assert such control in the endeavour to maintain a meaningful existence. Hence, participants envision brain training as a technology that could help them in evaluating their cognition to make important decisions and enact distinction. Brain training and participating in research on dementia and the Delta Project providing the brain training were seen by most of the participants I interviewed as possibilities to monitor their cognition as we previously saw. Some also perceived their participation to the Delta Project as an opportunity to be externally monitored by professional researchers with the hope of being warned if there was any significant decline in their cognitive capacity. The idea of brain training as an 'existential compass' to position oneself in the third age against a fourth age defined by the loss of control and dignity can be found in this testimony for instance:

*Me: Was your choice to take part [in the Delta Project] kind of related to brain training in some ways? Or generally because it was a research [on dementia]?*

*Participant: I mean.. Both of those but also hoping that in taking part of it, I might spot if things are getting different, you know, so sort of self-monitoring for myself as well. Because I think for the moment it is quite hard to, you know, even get checked for it. If your GP doesn't think, you know, there is enough symptom, they are not gonna refer you because it costs money, doesn't it. So, taking part in something which is kind of self-monitoring. And my friend, who does the kind of one [inaudible], you know if he spots anything, I mean I don't totally trust him. That he would actually point out if he was noticing anything different. I might have a word with him actually, to try and encourage him to be trustful. (...) to be honest. Because it is really important to me that if he is spotting something that is changing, because I wanna know as soon as possible. I don't want...*

*Me: So what was the time when you started to think about self-monitoring, self-evaluation?*

*Participant: I think after because my mother died certainly with dementia, and then, both her siblings were with Alzheimer's for years, and died in a nursing home... so like three out of three in her family made me think: was that something they were exposed to when they were kids? Or is there a genetic element? You know. And then just that whole sense of powerlessness. I have actually completed a living will as well because I am really terrified of being without control over my life you know. And If I found that I was getting Alzheimer's. I might try and set something so that I might not fall in that bad state. So that's why I want to know first, you know, earlier. Because I don't want to end up in a nursing home, not knowing anything. (Interview*

*7)*

Here we find again this idea of brain training, and of the Delta Project as means for the participant to self-monitor in a context in which he is 'terrified of being without control over [his] life'. In this testimony, there is a strong suggestion of the fear about crossing what Gilleard and Higgs (2010, p. 125) call the 'event horizon' of

the fourth age, ‘a fear of passing beyond any possibility of agency, human intimacy, or social exchange, of becoming impacted within the death of the social, a hyper-reality from which there is no reality to return’ (Gilleard & Higgs, 2010, p. 125). Self-monitoring through brain training is therefore a means to establish the boundary delimiting the end of the third age to whom one belongs, and the start of the fourth age that one does not want to cross – a boundary dynamically constructed around the third age and maintaining the externality of the fourth age.

This testimony evokes again the importance of agency regarding one’s own decline until the last moment, the possibility of ‘doing something to not fall in that bad state’ and to avoid the nursing home as an archetypical space in which society relegates the abject. So as in the previous testimony, the notion of keeping control over one’s life is central to this one, as a comfort to know that one can assert one’s choice as a third ager no matter what future lays ahead. The final real worry within this testimony discussing the exercise of agency at the margin of the third age is for this choice to be made before it is too late, and self-monitoring is perceived as instrumental to address this last worry, to judge one’s proximity to this margin. This explains why this participant mentions his concern regarding his friend telling him the truth about his decline; hoping that he can still react before it is too late.

The choice to live the way they want as close as possible to the perceived edge of a dignified life is therefore a means for those in the third age to assert their distinction from abjection. In this context, brain training is instrumental as the measure of ‘a life worth living’ for some, a life away from dementia. Given that the imaginary sets the limits of a life worth living, it also inevitably constructs its antipode: the intense imagery of individuals ‘beyond the stage’ as abject or purposeless, an othering which is implicitly part of distinction. The presence of othering as a secondary consequence of distinction from frailty (vector 1) and abjection (vector 2) makes it a central articulation of the fourth age imaginary, and the practices surrounding prevention and self-monitoring technologies are illustrative and integrally part of this process of othering.

### ***Third influence – the ‘othering’ of people with dementia***

‘Othering’ is essential to the definition of the third vector of the fourth age for Gilleard and Higgs (2015, p. 264). It is intrinsically part of the process of distinction that this chapter describes. Indeed, as Gilleard and Higgs (2015, p. 264) point out, ‘othering’ is a “combination of ‘objectified frailty’ and ‘distanced abjection’”. This third vector is therefore bounded to the two previous ones and comes to characterize the many situations in which individuals in the third age establish a distance between themselves and dementia.

The fear of othering, the perception of people with dementia being without agency or stable individuality due to their condition remains, for at least some of the participants an important element of context for their participation in brain training and the Delta Project. One should note that this othering is not solely based on assumptions or prejudices. It inevitably emerges from the difficult experiences of carers themselves. Some participants’ perceptions of agency seem to have been impacted by their own experiences of caring for a relative, and drove their choice to engage in brain training as this testimony presents:

*That’s what really triggered it [participating in brain training research]. I so didn’t want to be like my mother-in-law. It was awful seeing what she went through. And with the lewy bodies, she hallucinated. She was convinced that there would be people in the room that shouldn’t be there: ‘why have you invited these men? Get them out! Why is there a child out in the garden?’ And right at the very end she was having hallucinations that were like something out of a Brueghel painting. That there were all these people and there was death... Or like the tsunami, that there were bodies on the beach. And she was so tormented by it, it was horrible. It’s pretty scary when you see that. I didn’t like to admit that, but yes I did find it scary, and it’s not easy to manage. My father-in-law was much better [at caring for her] than I would have been with her all day because It was just that from the beginning of waking up to going to bed some days.*  
(Interview 8)

Such a testimony describes the powerlessness experienced by the participant concerning her relative and the fear that witnessing intense symptoms of dementia provoked. It was an important motivation for her to participate in this brain training

research. Brain training again was an important means of maintaining oneself away from the perceived otherness that dementia can create; a means to maintain the boundary that separates oneself from the anxiety that the fourth age generates – in this particular example as a state of altered consciousness marked by dreadful visions of death.

Testimonies I presented earlier in relation to the two previous vectors – the objectification of frailty associated with the first vector, and the dissociation from abjection of the second vector – both lead to the existence of this third vector. They are unmistakably pointing out to othering as consequential to distinction. ‘Othering’ in these processes reflects some aspects of the definition of Gilleard and Higgs (2015, p. 264) as a ‘failure to acknowledge the subjective agency of an older person’. By citing the older person being denied subjective agency, they specifically refer to the person encompassed by the fourth age imaginary – for instance the so-called ‘elderly’ who is seen as not being able to function properly, the source of a distinction for a participant I cited above. A complex relation therefore becomes established with the person with dementia, a relation in which this person may not always be able to respond, and becomes objectified by imaginary representations of the abject, an imaginary of the third age toward the fourth age that Kristeva describes as ‘the contamination of life by death’ (Kristeva, 1982, p. 149). Indeed, the othering of old age and dementia that Higgs and Gilleard (2014, p. 15) describe, citing Foucault (1982) is ‘an othering of a totalising risk, which is equally severe and ill specified, leaves no fixed position from which to offer opposition or frame an agonistic response’. The way in which living with dementia was assimilated with ‘ending up like a vegetable’ in another response of a participant I presented above is yet another relevant example of this process of objectification and othering, of totalizing and irreversible risk leading to the agency of the person with dementia being denied within the imaginary of the fourth age.

#### ***Fourth influence – the moral imperative of care and the anxiety it brings***

Othering is not a practice applied to the distant ‘other’ only, yet an element of all relations of care, as Higgs and Gilleard (2015) point out, affected by the inability of the person being cared for to actually reciprocate. This relation of care in the absence of reciprocity is what Higgs and Gilleard (2015, 2016b) refer to as the



*moral imperative of care* – the reason which encourages care to take place as a moral obligation. As Higgs and Gilleard (2015, p. 101) explain, being *in need of* care makes you part of the fourth age, as a receiver of care who cannot reciprocate, or even recognize that s/he is being cared for. This moral imperative of care is the last element that constitutes the fear that people have of the social imaginary of the fourth age. Indeed, the fear of *needing* care – of being at the receiving end of this moral imperative – is prominent for several of my participants and constitutes the context in which distinction practices take place.

A participant I interviewed describes the distressing character of care without reciprocity in her relationship with her mother to whom she provides continuous care.

Participant: *How do I see dementia? So, I guess, it kind of robs you of... they use this word 'rob', and I use that word 'rob' because that's a phrase that's often used in the literature. That it kind of robs you of your sort of memories, maybe of your kind of cognitive abilities to kind of do daily tasks, and you need increasingly need more help from other people to help you, sort of day to day living. I am aware my mother is getting a little bit more passive-aggressive with me, and I am aware that some aspects of it... I don't know, it wouldn't be necessarily be personality change (...) but there is some moment and there seems to be... I kind of recognize when it might happen. That she would phone me and she is not being very nice to me. And I have to try not to rise to it. Like she phoned the other day, saying 'I just phoned just in case you want to know if I am alive or dead'. And I could kind of respond back [but tried to be nicer]. And I said: 'Ow that's good because I was going to see you tomorrow'. You try to be sort of light about it. I could almost hear her sort of like trying to... I don't know... not that I can kind of read her mind, but I didn't kind of come with a sort of an aggressive response, but it sort of helped to diffuse the situation, and I sort of said something else and she wasn't passive aggressive anymore. And we could move from that and have a sort of conversation (...) and then it was fine. So it is also about learning how to interact or be with people who have dementia and how to have conversations with them.*

(...)

Me: *What are your impressions of dementia, and how we should think about it?*

Participant: *My kind of personal experience is through vascular dementia, and Alzheimer's. The word that comes to mind is 'cruel', it is very cruel. For me, as a carer, it is a nightmare. (...). I think people should talk more about it. It is hidden. Naturally it is not visibly present in the person. Sometimes... And people are scared of it, or very scared of it because they don't understand it. And so, it is a scary... when you look after people, it is scary. (Interview 4)*

Fear and anxiety have been part of the experience of caring for the person interviewed, despite the description she gave of her dedication to caring for her mother. She describes it as a nightmare, therefore emphasizing the non-reciprocal dimension of this kind of relationship. Caring is therefore a potentially non-reciprocal relation which can be closely bounded to the abjection and othering of the fourth age as the ambivalent feeling of the participant describes. While being a dedicated carer, she presents the complex relationship that she sometimes has to establish with her mother: a relationship requiring certain strategies and forms of necessary emotional adaptation. This is what she means when describing how one needs to learn 'how to be with people with dementia'. We can feel in this type of response the necessity to employ mild forms of objectification – the strategic use of certain responses to avoid tensions and antagonism. Such strategies become a necessary element enabling the person I interviewed to support the absence of reciprocity and to maintain the caring relationship. In her testimony, we perceive how the moral imperative to care is the main motivation that helps her to attend to the 'nightmare' of caring. To this regard, Higgs and Gilleard (2015, p. 102) present how othering appears in the moral imperative of care enabling to support the non-reciprocity that may settle in the interaction. The question of personhood, emphasised as 'personality change' by the participant is part of this process of 'othering' in which it sometimes appears difficult for the surrounding to identify the nature of some behaviours, for instance some passive-aggressive behaviours in this case. This echoes a point made by Gilleards and Higgs (2015, p. 265) in relation to Canales (2000, 2010) who present how "accepting difference and otherness, even non-reciprocity (...) can still make care possible, whether from a sense of obligation or from feelings of pity, even though care is constrained by this sense of intractable 'otherness'".

Such othering of the fourth age in the relation of care may actually impact on the carer him/herself who becomes objectified as a carer, and partly denied its own agency when fulfilling the moral obligation of care. This is an argument that Kadri and colleagues (2018) made in regard to professionalized care in the United Kingdom for instance, where the actual agency and personhood of professional carers, often women from ethnic minority groups, is being denied through low status, poor working conditions and low wage. Among the participants I interviewed who had previously cared for a relative, some of them voiced this distressing experience of being objectified as a carer, as in the following quote I gathered:

*Me: Have you tried to maintain an activity throughout all your life? Is it something important to stay active as we get older? (...) Physically active but also engaging with people?*

*Participant: Yes, I mean... I was a carer for my husband for 6 years intensively, and for a few years to some extend before that, and it is a time in your life when you can become quite isolated and it is difficult to get exercise because you are caring for somebody all the time. So, for probably about 10 years I wasn't doing very much except for the things that we did together. We still listened to a lot of music together for instance, and I used to read to him and things like that. And I used to try and go out for a walk every morning. But your life is restricted in those circumstances. It is a time in your life when you can get isolated, except for the things we would do together. (...) Basically, you are a carer, not a human being. That sounds harsh, and don't misunderstand, I am very glad I did it. I simply had to do it. I would not have dreamt of not doing it but it is not easy. (...) Particularly as it happened, my husband had dementia, and he was physically disabled having broken his hip, so it wasn't easy at all. (Interview 13)*

This testimony presents the strength of the fourth age in encompassing even those who are not directly impacted by dementia, as a metaphorical 'black hole' (Gilleard & Higgs, 2010) absorbing the humanity of those cared for and those who care for. MacRae (1999) also explains this othering of the carer by referring to stigma. According to MacRae (1999), referring to the work of Goffman (1963), caring for someone with dementia can be a source of 'courtesy stigma' spilling from the

stigmatized person with dementia to the carer simply because they are associated through the relation of care. Essentially the difficult experience that several people I interviewed had with caring for their relatives was a part of the context in which they decided to engage in prevention research for dementia, as part of their wish to maintain this boundary between their independence from care in the third age, and their fear of becoming *in need of care*.

Some participants reflected upon this fear to impose a moral imperative of care to other relatives during the interview, as this testimony presents for instance:

*All four of our parents died relatively young, so we did not have any grandparents... so my parents were 74 which is quite young. Well, I think it's young, especially as I'm getting close to it, it's young. (...) So, we didn't actually have ageing parents to look after. It sounds a bit callous but we didn't have to go through the dementia bit, or the really difficult... because we got friends who have got parents who are well into their nineties, or going up to a hundred, and it is quite difficult, you know, with lots of problems. And they say, it feels almost as they have never... went through children, and now you have to look after your own parents. Sorry it sounds a bit callous and I am caring but it's... for us. So, I suppose we have invested more perhaps in our children. But I say we didn't have to... My parents, they didn't die of dementia, they didn't show signs, they were only in their seventies, but my husband's mother was definitely getting Alzheimer's, but she got cancer, so she died... So it was kind of... some things she did were very funny and sweet but I'm not sure it would have been so easy to manage if she hadn't certainly died anyway. It was kind of a quick short thing in lots of ways because you could only remember her in happy times. (...) a lot of people become quite difficult. So I don't know. I think you don't want to be a burden on your children, and dementia is often a burden on the generation below, yes.* (Interview 10)

As this quote presents, the third age therefore sees this need for care as an element located beyond the boundary of their idealized vision of ageing. This vision echoes aspects of an 'ageing without decline' that I presented earlier, in order to avoid the undesirability of becoming 'a burden on the generation below'. Escaping the moral imperative of caring for her parents was seen as a relief for the participant who

herself envisioned this eventuality as undesirable. In this narrative, the objectives of the third age are being maintained as far as the moral imperative of care remains absent, and brain training as well as other forms of prevention are part of this narrative, being perceived as means that could hopefully create an ageing without the need for care. Training the brain, and prevention more generally, therefore constitute the bulk of an ethic of life driven by the third age and delimits the boundaries of the fourth age based on the four vectors.

### **Training the brain as an ethic of life – the pervasiveness of active cognitive ageing**

What does brain training symbolize in this context? Can we conceive it only as a sporadic and dispensable technological means to achieve prevention, or is it more than that? One may eventually perceive these practices of brain training and the distinction from the four vectors associated with them to be isolated acts, although I argue that distinction through prevention is more totalizing in its social significance. Indeed, studying brain training cannot simply be reduced to the practice and the technology itself. The idea of training the brain is part of a broader set of symbols and narratives defining our experience of life, ageing and dementia within the consumer society in which we live today. Training the brain together with other preventative practices is more totalizing because it is bounded to a complex web of moral concerns – a moral framework – defining ideal norms of being in ageing today. Prevention and its corollary of distinction from the four vectors of frailty, abjection, otherness and the moral imperative of care are characteristics of a valued identity in later life associated with a normativity able to dynamically maintain the boundary beyond which individuality becomes objectified by the fourth age. The moral dimension of identity at the source of this normativity is perceptible in the testimonies that several of the individuals I interviewed provided. Prevention, or the lack of it, is often associated with a moral judgement by those engaged in active cognitive ageing. For instance, avoiding dependence is perceived as a moral choice as one of the participants explain:

Me: *Does it resonate to you the idea that brain training would be a sort of physical training but for the brain?*

Participant: *Yes, it's a muscle that needs exercising. Yeah. (...)*

Me: *So then in a way, if you don't train it you would lose your abilities?*

Participant: *Yeah, yeah... I think laziness is a big factor. And I think as you get older, you are more likely to opt for something that's easy. Like for example if there is something on television that I want to see, or reading my challenging book, and I have the choice to do both. Then I would watch the television because it's easier.*

Me: *Yes, and is it something that plays against yourself?*

Participant: *I feel slightly guilty, I do feel guilty. I have always got my mother sitting on my shoulder, saying to me: 'do this, do this, you should be doing that', you know.*

Me: *So what makes you feel a bit guilty about it?*

Participant: *If I neglect something, if I know that I am neglecting using my brain, or challenging it, I will eventually get around into doing it, because the level of guilt or anxiety about it will kick in. (...) I need to be more disciplined. (Interview 17)*

As presented in this testimony, morally significant notions of laziness and guilt influence decisions to follow a cognitive prevention regime. Self-discipline in terms of brain health becomes an adequate response to the moral judgement associated with laziness in later life. We therefore find back in this idea of self-discipline in later life Foucault's notion that technologies of the self are very much defined by the governmentality that they imply in postmodern societies (Foucault, 1988), their capacity to drive individual behaviour from within individuals themselves, without the application of forms of authority. This moral principle in the use of brain training is also the one that Millington (2012) talks about when describing the 'will to health' that this technology implies in regulating individual behaviour. When it comes to distinction, this moral dimension assorted to prevention has the capacity to further strengthen the boundary between third and

fourth age, therefore reinforcing exclusion. Positioning oneself in the cultural identity of the third age is therefore not only determined by the anxiety that the fourth age generates, but also emerges from the pressure imposed by the judgemental gaze of others and of society more generally. In the quote above, the participant inputs a moral judgement toward people lacking engagement in cultures of prevention. Not training the brain therefore positions the individual a step away from the identity of the third age and leads the individual to be a step closer to crossing the boundary that separates her/him from the fourth age. The moral significance of prevention therefore shows how brain training cannot be considered alone and is a ramification of moral values that run deeper within the fabric of society and its conception of health and later life. It is also important to note that while this pressure to engage in prevention practices can be resisted by individuals, its dominance renders it unavoidable and inevitably exposes those who resist to the judgement of others. The quote above is a pertinent example of this exposure.

This moral imaginary can be found as well in how a substantial part of the participants I interviewed were actually sceptical about the efficacy of training the brain to prevent cognitive decline. Despite this doubt, some were still dedicated to brain training regimes. Some of this dedication is arguably related to their interest to support research. But it may also be due to the fact that these technologies have acquired a symbolic rank as a practice enabling to display the ethos of a desired third age. A participant explains how brain training was one of the means for her of ‘taking control over her destiny’. She also integrated brain training within a wide range of practices such as being careful with what you eat, drinking more water, keeping a fit and healthy body. This participant even considered doing her PhD and learning a new language as brain training as well.

This integration of the brain into a wide range of self-care practices is also particularly relevant. Another participant considered brain training in the same way as part of a broader range of practices at the basis of a morally desirable ethos of the third age, establishing a distinction from the deviant ethos of her relative.

*Me: So it is important to be productive as we get older?*

*Participant: Definitely, It is up to you. I think it is entirely up to you whether you sink... I am quite a lazy person, and I'm going on holiday with a friend at the*

*end of September, very unwillingly, because I've got other things to do, and they are interfering with them. I have my busy day. I usually start at least 6, maybe before, and I don't want to go out in the evening. That's when I seat there [inaudible] without realising it. But I will be busy during the day, and I think if you can do that then... (...). And I have a cousin who is very inward, and she lives in a retirement home, and doesn't mix with anybody, moans to me a lot about how lonely she is And I say: why don't you go in the house with everybody else? 'I won't like them; I know I won't' [her friend says]. So you are never going to get that sort of person to live their life to the full. (Interview 16)*

The contrast that this person presents between her decision to live her life to the full, and the destiny of those who do not – those who 'sink' – demonstrates the virtue that she sees in cultivating a third age identity, in staying productive. The imperative to engage with cultures of the third age to keep one's status and belonging is as much externally defined as it is internal. It is a matter of social position, and the ethic of life to whom brain training belongs is the support of this positionality implying the discriminatory judgement of others. Previous observations of 'courtesy stigma' in the quotes above and the work of MacRae (1999) also suggest that practices of distinction can have a discriminatory effect on carers as well due to their proximity to the existential threat that the social imaginary of the fourth generates.

There remains a paradox that I introduced earlier, however. What if brain training happens to record the existence of an actual decline thereby marking a step toward the fourth age? Some of the participants have spontaneously discussed this point and came up with their own perspective on the matter by mentioning their anxiety about diminishing scores on the digital brain training application and the actions that they may take to this regard, be it advanced decisions, evocations of euthanasia, preparing their family, or intensifying their prevention regime. As I said earlier, some saw this self-monitoring as desirable to keep control over one's life in the face of an inevitable decline. Distinction remains present in brain training asserting the power of its social role beyond a purely technical efficacy often attributed by the so-called neutrality of technology. It has become part of a more complete ethic of later life based on prevention and self-monitoring, an ethic which has expanded to add new regimes of brain health to existing regimes of physical



health. With this expansion to ‘matters’ of the mind, anxiety with the fourth age and distinction seem to become even more totalizing in their capacity to define identity and exclusion in later life.

## **Conclusion**

Based on the results from interviews with participants engaged in a brain training regime in relation to dementia conducted with The Delta Project, this chapter presented how the choice to engage in brain training among individuals in the third age is largely informed by a distinction from dementia. This chapter showed that the identity of the third age itself is socially negotiated through the reproduction of this distinction and presented how individuals in the third age dynamically and continuously maintain the boundary that separate them from the fourth age through these discourses and practices marking a difference. These discourses and practices are performed across the various domains that compose the social imaginary of the fourth age – what Gilleard and Higgs (2015) refer to as the four vectors of the fourth age. This chapter used the theory of the four vectors as a heuristic device to explore and emphasize these domains around which distinction operates. These 4 modes of response showed how pervasive and substantial the fear of dementia can be and how it manifests itself through anxieties of being categorized as mentally frail, of being defined by abjection, of being objectified and denied one’s agency as a process of othering, and of becoming someone in need of care while not being able to reciprocate the support that one receives. Making oneself vulnerable to the ailments of the fourth age implies the risk of being cast as an outsider to the culture of the third age by others. As this chapter explained, the threats that constitute this imaginary play a role of causality in the choice that people make to use technologies of distinction.

Finally, this chapter argued that distinction through prevention is more totalizing in its social significance than a simple set of sporadic choices that people can adopt. It presented how training the brain together with other preventative practices have become central to the generation of a moral framework determining ideal ways to age today. Such ability of active cognitive ageing technologies to constitute a morally virtuous self has inevitably correlated with the condition of an undesired

other. We see therefore how the manifestations of late capitalism and the flourishing of consumer society in later life have had the consequence to reshape the way in which individuals perceive later life and people with dementia altogether and to further reinforce the othering of the latter.

Being aware of the specificities of this fear of the fourth age and its origin in active cognitive ageing is a first step in addressing this fear and its influence on people's choice of distinction. In that way we can similarly hope to improve the standing of people with dementia in society.

Drawing upon technologies similar to some extent to brain training technologies, the next chapter will present a complementary process to distinction able to maintain or intensify the current divide in later life. It will explore how the application of cognitive rehabilitation technologies used within the realm of the clinic to control cognitive decline for individuals who developed a dementia become integrally part of the constitution of a fourth age identity through medicalization.

## **Chapter 4: Medicalizing dementia: considering the ascription of an abnormal identity in later life**

This chapter will extend the analysis of distinction by presenting the existence of a complementary process in society generating an identity separated from later life. While the first half of this dualism was achieved by individuals through prevention and self-monitoring as I describe in the previous chapter, the topic of this chapter will consider its other half, showing how society ascribes an identity of dementia upon individuals. This complementary process is principally enacted through different modes of medicalization around dementia.

Medicalization, a concept originally developed by Zola (1972) and systematized by Conrad (2007) characterizes the process transforming a human condition into a medical problem in society through the action of medical expertise. In the case of dementia, medicalization is understood here in its generic sense as the transformation of cognitive problems, including memory problems, usually happening in later life into medical issues characterized as dementia, or Alzheimer's disease. This process of medicalization for dementia has been previously characterized as part of the 'alzheimerization of aging' (Adelman, 1995). The diagnosis and the application of different types of therapy including pharmaceutical ones are relevant examples of this medicalization of dementia. This chapter is particularly interested in how this medicalization participates in the creation of a differentiated identity in later life within the social context defining ageing today – an identity-making process and form of social differentiation that I characterise as *ascription*.

This differentiation may be roughly described as a dualism between a normal ageing without dementia and an abnormal ageing with dementia. Although the ethnography presented in this chapter will show that this difference involves gradations of identity in between, defined by the effect of therapy on individuals. Ascription acts as a complement to distinction in its reproduction of the binary between third and fourth ages and its maintenance of an exclusionary boundary, an overarching system of difference whose presence can be felt in numerous sites across society. However, this chapter will present how the nature of ascription differs from the one of distinction by negatively inscribing people with memory

and cognitive issues to a declining identity, rather than allowing them to build a positive identity in later life distinct from decline as it was the case with brain training.

This chapter will widen our understanding of the processes generating the social exclusion of people with dementia and the role of technology in this process. To demonstrate the existence of this gradual process of differentiation, this chapter will present how technologies of distinction become *technologies of ascription* in the realm of the clinic. In this regard, it will present how brain training – a technology instrumentalized by the third age to become a symbolic means of distinction from the fourth age – can have an opposite effect of *ascribing* people in a trajectory of decline when it is used in a clinical context. This chapter will be based on an ethnography describing the implementation of a cognitive training and rehabilitation software for people with dementia, acute brain injury and other neurodegenerative conditions in two memory clinics in Southern Europe. It will describe relevant events, practices and discourses pertaining to the daily life of developers, researchers and clinicians while they implement these cognitive rehabilitation programmes for people with dementia specifically. This chapter will demonstrate how the context of implementation, the status and role of the people who implement it, as well as their aim and understanding of decline lead to distinction becoming ascription for a technology similar in many aspects to brain training. Hence, this chapter will argue that such technology of ascription assorted with the objectives of the memory clinic recasts people with dementia as outsiders from the third age by reifying their decline.

To support this argument, this chapter will review different aspects of the process of rehabilitation and their impact on identity through ascription. As this chapter will show, this ascription operates at two different but parallel levels: a social one, and a more individual one affecting subjectivity. These levels of ascription emerge through the trajectory that people who are referred to the memory clinic follow, and the processes implemented by the clinical staff. Accordingly, this chapter will present the definitional role of the first encounter with the clinic and the baseline cognitive assessment as a first step into the establishment of an identity with dementia. It will then look at the implementation of the technology as part of the prescription of a cognitive training regime and its imposition of norms around

cognition through the construction of a ‘hypercognitive space’ for the consultation. It will describe how these norms render cognitive decline more salient to enable intervention and therapy. It will also show how the process establishes a relationship for the person with dementia with their own decline. It will present how this oppositional approach to decline constructs the experience of rehabilitation as a form of boundary crossing exercise contrasting the capacities and agency of an identity in the third age with the diminishing agency and decline of the fourth age. This chapter will conclude by arguing that this process can lead to an effective separation of people with dementia as those who cannot benefit from the rehabilitation anymore. In so doing it creates a correspondence of personal identity with the images prevalent in the social imaginary of the fourth age.

Before starting, we should ask ‘what is the role of cognitive rehabilitation in a study into the social impact of technologies on people with dementia?’ First, cognitive rehabilitation – a technology originally designed to treat brain injury – has recently gained traction as an emerging treatment for dementia. There are multiple examples of large scale research studies on the potential of this therapy and technology for dementia. One example is the GREAT Study (University of Exeter, n.d.) funded by the Alzheimer’s Society. There has also been a boom in already existing products using such technologies such as the software I describe in this chapter, or products like RehaCom advertising their relevance for dementia<sup>19</sup>. Cognitive rehabilitation also fits within the current objectives of policy for dementia and later life around autonomous living and agency (cf. Chapter 2).

Brain training and cognitive rehabilitation for dementia have many links and the two technologies are similar in many ways, to the extent that memory clinics sometimes use both terms interchangeably. Cognitive rehabilitation mechanisms are based on the regular practice of cognitive exercises aiming at training various functions of the brain. These functions are classified according to criteria that echo the ones of brain training, such as ‘memory’, ‘associative memory’, ‘executive function’, ‘attention’, or ‘reasoning’. Training these functions is envisioned as a means to improve autonomy and functioning in daily life, based on the idea of an

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<sup>19</sup> RehaCom Website (n.d.), Dementia and RehaCom: People with dementia and their caregivers are often advised that some form of ‘mental exercise’ may be helpful. RehaCom fits the bill. Retrieved 11<sup>th</sup> November 2020 from <https://www.rehacom.co.uk/dementia>.

optimum ability – an objective of ‘enabl[ing] people who are disabled by injury or disease to achieve their optimum physical, psychological, social and vocational well-being’” (Clare, 2005, p. 328 citing MacLennan, Nicholas, Morley, & Brookshire, 1991). So as for brain training, there seems to be an expectation that the skills trained on specific exercises will lead to improvement in the abilities of people to function in daily life. Similarities between these different practices seem to be frequent, and it may be that the absence of unified definitions for the cognitive rehabilitation practice as observed by Wilson (2002) most likely produced these similarities. Indeed, she explains that approaches to cognitive rehabilitation vary depending on the approach of each practitioner (Wilson, 2002). The main difference between practitioners seems to be balance of the optimum capacities that can result from training on one hand – a matter pertaining to the ideal of fitness – and the capacity for rehabilitation on the other, which aims at ‘optimal functioning’ for the individual. However, this notion of optimal functioning is also difficult to define. These variations probably explain the current lack of consensus around efficacy and further strengthens the value of a cultural understanding of their success as proposed by this chapter. One could ask what optimal functioning actually means, or point out that there is a difference between training and rehabilitation based on the idea of optimal functioning versus fitness. This is, however, besides the point given that figuring out this distinction is not the key issue for understanding the ascription processes I describe in this chapter as these are essentially contextual, emerging from the normativity of the clinical settings in which cognitive rehabilitation is administered.

What about the therapeutic benefits of brain training and cognitive rehabilitation? Have these matters been left aside in this theorization? In this regard I should point out that this chapter is not concerned with whether cognitive rehabilitation has an actual impact on cognition or not. Such current concern for efficacy does not influence the processes of ascription described, nor does it have an impact on the process of distinction theorized in the previous chapter. It might have mattered if dementia could be alleviated through rehabilitation or prevention. If this was the case, it may have suppressed the symbolic ability of dementia to feed the existential fear of the fourth age. Unfortunately, dementia remains an incurable condition that

none of these approaches have managed to address. It remains therefore a strong signifier of this fear associated with the social imaginary of the fourth age.

As outlined in the methodology chapter, this chapter mainly examines the daily practices of researchers and therapists alongside their cultural representations of decline in dementia in two memory clinics combining therapeutic and research activities in a rural region of Southern Europe. Through instances of thick description (Geertz, 1973a), and the use of thematic analysis (DeWalt & DeWalt, 2011, p. 190; LeCompte & Schensul, 1999) and aspects of grounded theory (Charmaz, 2006; Glaser & Strauss, 1967) this chapter places such practices of rehabilitation in their cultural and social context. This chapter uses an ethnographic sensibility and observational skills to grasp their approaches and emic understandings of the challenges of dementia and later life. This participant observation was guided by the following questions: how did researchers develop and implement these technologies? How did they understand the problem that these technologies should solve regarding dementia and the people who could benefit from them? This research also aimed at understanding how the clinicians and researchers implementing the cognitive rehabilitation programme within the two memory clinics conceived the progressive nature of dementia – a means to understand how the social imaginary of the fourth age manifests itself in this clinical context.

### **First level of ascription: ascribing a declining identity in society**

The first level of ascription in the fourth age within cognitive rehabilitation is social, and principally takes place through certain practices characterizing memory problems as medical problems as part of the medicalization of later life. These practices are the referral of individuals to the memory clinic, the assessment of their condition and the establishment of a prescribed routine of cognitive rehabilitation. The entry into rehabilitation marks the beginning of a trajectory of decline. This trajectory of decline starts through the referral process by a family member or clinician following the informal observation of alterations in identity and cognition. During my period studying the memory clinics, I had the opportunity to observe important milestones of this trajectory.

When I mention ‘trajectory of decline’ however, I do not mean that the rehabilitation creates decline per se. I rather state that this institutionalization of decline establishes its social role in the life of people through the legitimacy that this institution possesses within society in providing a diagnosis of dementia. Indeed, my argument follows the point made by Gilleard and Higgs (2010) that ‘the fourth age emerges from the institutionalization of the infirmities of old age’.

### ***The referral – defining abnormality***

Such trajectory starts outside of the clinic with the informal referral process. It then becomes more significant through the first encounter between the patient and the memory clinic. This first vignette describes the nature of the first encounter between the potential patient and the memory clinic and the normativity around ageing and dementia established during this first encounter.

*12<sup>th</sup> December 2018, inside the memory clinic: We sit together with the therapist and a couple who attended a first appointment with the memory clinic in order to consider a cognitive rehabilitation therapy. We are in a small room of the memory clinic, arranged like a comfortable and minimalist living room. The couple comfortably sits on one side of the room while I am introduced by the therapist. She asks them if there is a problem with my presence. They agree to my presence and the encounter starts. She carefully explains the process involved in starting a cognitive rehabilitation programme with the memory clinic. Meanwhile, she looks at the references from the neurologist who has referred the couple to the memory clinic. She introduces herself to them and explains her role as a (neuro-)psychologist in the centre, as well as what the centre does for whom in term of therapy. She tries to reassure the person potentially concerned by the therapy that there are many different types of memory problems affecting different aspects of memory. She also points out that there can be multiple causes behind memory problems. For instance, she describes traffic accidents or seizures. She also explains that memory problems can be diagnosed if the kind of memory issues encountered differ from the trajectory of ‘normal ageing’ [literal quote]. She presents the rehabilitation process, and the voluntary nature of participation. This process*



*starts with a cognitive assessment to understand the specificities of the memory problems encountered, the results of which could be shared with the partner if the person being evaluated consents. Then a programme is tailored to the person's needs, she explains. She provides an example by stating that two to three sessions of one to two hours could be prescribed every week. She then discusses the price and the possibility of eventually being eligible for reimbursement by the city council.*

A series of interesting points come out of this first vignette. Overall, this first encounter can be understood as a revelation of the various conditions implied by the therapeutic contract between the potential patient and the memory clinic. This process illustrates what Strong (1979) developing the work of Goffman (1967) theorizes as the 'ceremonial order of the clinic' – a blend of formal and informal rules generating meaning around illness and identity in a clinical encounter. One can perceive how the therapist defines the nature of the problem before presenting the actual therapy that the memory clinic can propose. One can also perceive in this definition a first attempt by the institution to establish a certain narrative about dementia, as a memory problem clearly distinct from 'normal ageing'. This distinction may seem straightforward in this encounter. It however brings insights about a boundary between normal ageing and pathology which remains an essential field of tension within geriatrics and gerontology, based on 'decisions depend[ing] in large part on expectations about aging that are profoundly influenced by culture and politics' (Lock, 2013, p. 233). This is a fundamental step in the constitution of ascription, as a socially and culturally determined boundary making process establishing the start of the fourth age as abnormal ageing and delimiting the third age as the normal way to age. As Jones and Higgs (2010, p. 1515) point out however, the idea of 'normal ageing', and the definition of pathological ageing processes are themselves culturally and socially determined. The referral of the neurologist is the first step in establishing the legitimacy of the medicalization and the process of ascription of abnormality. We therefore perceive the cultural and social determinacy influencing the referral and its definition of 'abnormal ageing'. As Cohen (1998, p. 70) points out, any ageing process could equally be described as pathological, suppressing the idea of normal ageing altogether. These positions exemplify a long-held debate around the activity of geriatrics (Pickard, 2011,

2013), and which correspond to political transformations around society's and medicine's comprehension of the ageing body (Pickard, 2013). As Pickard (2013, p. 965) says: 'to understand changing medical paradigms around older bodies is to understand the changing place of old age in society.' As Pickard (2013) explains, the definition of the normal body in later life today is not based simply on chronological age as it was the case in earlier geriatric medicine. Rather it is more attached to separating the less healthy fourth agers from the healthy third agers based on a standardized definition of normality, Pickard (2013) specifies. Through this first encounter, we perceive therefore how the psychologist institutionalizes the need for therapy for the potential future patient, ascribing the abnormality of his memory problems ensuing from the psychologist's idea of what constitutes a normal ageing process. This act in itself does not escape this debate in geriatrics on the separation between a normal and a pathological ageing. It is only an expression of this debate in the domain of cognition, which Adelman (1995) or Fox (1989) have described, Adelman (1995) characterizing it as the 'alzheimerization of ageing'. This process, Fox (1989) explains, has led to the transformation of normal cognitive ageing previously described as senile dementia, into its categorization as Alzheimer's disease, an abnormal process in later life. This transformation had important consequences in modifying our understanding of cognitive decline in old age as a condition that we were powerless to confront, into a medical entity which could receive therapeutic intervention (Fox, 1989, p. 97). What this separation actually does at a social level is to create a divide between those who cognitively age in a 'normal' way, and those whose condition is qualified as abnormal, therefore requiring medical intervention. Memory clinics play a central role in establishing and crystalizing this divide.

### ***From agency to dependency in dementia***

As the therapist in the vignette above describes, cognitive rehabilitation starts with a cognitive assessment in order to establish the person's *needs*, and the way in which the program of activity will be tailored accordingly. This is also an important definitional element of the fourth age and a key difference from brain training. In such a situation, the participant becomes *in need of* rather than *choosing for* an engagement with cognitive exercises. This is crucial to determining the fourth age

as it establishes the patient as a passive receiver of care, rather than an active third ager engaged in cultures of fitness linked to active cognitive ageing. As such, passivity established within a non-reciprocal relation of care is also part of the fear that people engaged in prevention practices have of dementia. A mention of the potential eligibility of the patient for reimbursement of the therapy by the city council at the end of the encounter further establishes this passivity and its ascription at the level of the community. The patient is therefore not an entrepreneurial self, idealized by market ideology anymore, rather a receiver of therapy and beneficiary of the welfare state, a status that pro-market discourses even associate with moral flaw (Bauman, 2005b; Scourfield, 2007). This is yet another difference that signifies the imminent ascription of the potential patient into a different identity marked by the passive reception of care, the one that the fourth age implies in its moral imperative of care directed toward individuals in situations of dependency (Gilleard & Higgs, 2015, p. 268).

***The assessment – exposing capacities and deficiencies in a controlled environment***

After this first encounter, the assessment is the next logical step. During my stay, I observed three baseline assessments. They are less common occurrences than the regime of weekly meetings part of the actual cognitive rehabilitation programmes. Hence, most of my observations concerned cognitive rehabilitation sessions. The vignette below describes one of these baseline assessments:

*December 2018, consultation room: A therapist invites me to observe how she conducts a cognitive assessment. I meet her in the consultation room, and I am granted authorization to stay by the patient in order to observe her work. The assessment will last for over an hour and a half, one cognitive test after the other. She strictly controls the conditions of the assessment and carries a stopwatch with her to keep track of time during the assessment with precision. She starts the assessment with the two usual questions, part of the procedure of cognitive rehabilitation consultations, namely on temporal and spatial orientation. ‘what is the date?’ and ‘where are we?’ she asks the person being assessed. Naively forgetting that it was part of the test, I try to help the person. She interrupts me immediately with a fast and discreet gesture before I start*

*intervening, while listening to the participant. I stay quiet and the test goes on. I find the questions she asks to the patient challenging to answer, and I am unable to answer some of them. The atmosphere is tense, and the participant focused. He probably realizes that test results are meant to inform various medical parties, exposing the capacities and deficiencies of brain function to the medical gaze. The test is composed of various standardized scales of measurement based on questions displaying unique answers, either right or wrong. While the patient replies, the therapist does not provide any clues of answer's correctness, and only the time she spends scribbling on the paper with her pencil can eventually give a hint about the accuracy of the answers provided. The therapist asks if it is the first time that the patient does such a test. I feel a slight apprehension in the idea that such a test aims at establishing an interpretation of the capacities of a person in such details. Parts of this apprehension may be due to the capacity that these technologies – be it digital cognitive rehabilitation, or batteries of standardized tests – have of constructing the reality of a diagnosis and exposing cognitive deficiencies. Trust in the medical profession seems to be an essential condition in the process of assessing and reifying cognition.*

*The assessment ends and we spend time together with the therapist to discuss my observations. I tell her about my thoughts, and she shares her impressions of the test, and her first thoughts on the dysfunctions it probably indicated. She then explains me how each singular test works while drawing a parallel between the objectives of these tests and a complex cartography of the brain, the functions associated with each of its areas and how the tests aim to indicate issues in them. A test result therefore becomes the indicator of 'neuro-localized' zones of cognitive success and failure, a numerical coordinate enabling to draw a map of the (dys)functional brain.*

The assessment presented in this vignette is a meaningful event both for patients and therapists, as it drives many of the measures taken subsequently to orient the trajectory of care. It is a node in which the new social reality of brain function is being defined, a symbolism with potentially life-changing consequences. Firstly, for the patient, one could say that it reifies decline into a diagnosis of dementia.

What was previously an unnamed phenomenon becomes labelled and is rendered actionable for the procedures of rehabilitation. The assessment of the person plays a fundamental role in the ascription process of the fourth age.

The first assessment also marks the start of a new power relation between clinician and patient. Rose and Abi-Rached (2013) aptly describe the nature of this kind of encounter within the novel means that the neurosciences have established to assess the operation of the mind.

*“When it comes to seeing the brain, seeking to discover within its fleshy volume the traces of the pathological or normal mental processes that the brain might embody, it involves the designation of those who have the authority to see: doctors, neurologists, researchers, psychopharmacologists, geneticists, and now, of course, the imagers. It also involves the subjectification of those who are spoken about— subjectification in the sense that living creatures become subjects of these visualizing technologies only as a consequence of certain technical interventions, and subjectification in another sense, in the case of humans, whose sense of themselves may well be transformed as a result of the images of their brains with which they are presented.”* (Rose & Abi-Rached, 2013, p. 55)

There are therefore two roles within the therapeutic encounter of the cognitive assessment that I observed within the memory clinic; the therapist as the one ‘who [has] the authority to see’, the careful assessor strictly controlling the conditions of the assessment with its stopwatch and standardized scales, and the patient as *subjectified* under the operation of this clinical gaze. This explanation also translates the intense meaning which a therapeutic encounter in the domain of the neurosciences involves as an experience deeply influencing the sense of self. In the parallel that I draw between my own fieldwork and the definition of Rose and Abi-Rached, one may see the similarity that there is between the cognitive assessment and the medical imagery. They are both technical means to represent the mechanisms behind the operation of the brain, and they both require, as Rose and Abi-Rached (2013) point out, a form of interpretation that will lead to the establishment of a pathological entity, or the construction of a certain concept of ‘abnormality’. This imagery is the one I point to when I mention the ‘numerical

coordinate enabling to draw a map of the (dys)functional brain'. And this is where the idea of cognitive rehabilitation as a technology of ascription finds one of its first key resonances. Rose and Abi-Rached explain how an important aspect of the medical gaze 'is technical or perhaps technological. It consists in the means, the apparatus and devices, that render that which is observed into marks, lines, colors, spaces and edges, patterns and patterning' (Rose & Abi-Rached, 2013, p. 55).

### ***Diagnosis as the ascription of a differentiated social status***

A result of this process of subjectification, this medicalization process, is the reconfiguration of 'the sense of themselves' (Rose and Abi-Rached 2013: 55) that participants may experience as the outcome of the interaction. When drawing a link with the social significance of a diagnosis of dementia (cf. Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Clare et al., 2014; Vernooij-Dassen et al., 2005), one could easily perceive how this reconfiguration of the sense of self also happens in the perspectives of others – relatives, and society – on the person recently diagnosed. Hence, one can understand why the therapist I described earlier in the first encounter indicated the choice that the patient has to disclose, or not, the results of the cognitive assessment to the partner (or relatives a fortiori). This possibility offered to choose disclosure or not further indicates the symbolic intensity and stigma attached to such a totalizing diagnosis. A large part of the anxiety that these tests generate for the patient arguably results from the capacity of the cognitive assessment to mark the passage toward another status. Again, we are far removed from the symbolism attached to the experience of the agentic self in brain training, and this reconfiguration of the self may well be a key element leading to the ascription of a novel identity, the one of a person with dementia at the centre of the social imaginary of the fourth age.

When attempting to define ascription in the fourth age, I should inevitably discuss aspects of the long history of social research on labels and stigma, and the difference that Scambler (2009) denotes between the 'normal' and the 'abnormal' according to social norms. I should note however that the therapeutic practices that I studied during my participant observation in Southern Europe are not meant to stigmatize people and keep the integration of individuals in the community as a primary objective. My approach mainly points out that this type of approach to the

challenges of dementia establishes differences by defining who fits in the norms of decline associated with ageing, and who does not, by marking their need for rehabilitation. Whether stigma emerges or not depends on the way in which a diagnosis and practice establishing difference is perceived within the cultural and social norms of a particular society. Technologies of ascription are therefore technologies ascribing a difference in the social nature of the self and the negotiation of identity, a *label* according to the seminal work of sociologist Howard Becker (1963). As I presented above, and in the introduction to this thesis, the perception of a diagnosis of dementia remains driven by the way in which the third age has relegated dementia as part of the most negative sides of ageing defined by the social imaginary of the fourth age. Despite the best intentions motivating the attribution of a diagnosis of dementia, as it is the case for instance in the memory clinics presented in this chapter, there is unfortunately a likeliness for stigma and forms of othering to emerge in our current society when a label is given (Aminzadeh et al., 2007; Birt et al., 2017; Vernooij-Dassen et al., 2005). I provided an illustration of this existence of the exclusion and othering of dementia in chapter 2 in how brain training and prevention support processes of distinction from dementia and the people diagnosed. The ascription of a diagnosis therefore is the complementary *antithesis* to distinction, a negative classificatory social process.

### ***Micro-surveillance enabling the sustainability of ascription***

The assessment in a memory clinic is however not a singular event, yet an iterative practice marking the continuous application of the medical gaze upon the patient through time. There may be an initial assessment to determine the original and core needs of the person, but the practice of assessment in a memory clinic is recurrent and omnipresent, possessing the attributes of a form of surveillance medicine (Armstrong, 1995) applied to cognition in term of its continuous monitoring of risk factors and the necessity to activate specific areas of the brain following the idea of ‘use it or lose it’ (Millington, 2012). Due to the progressive nature of dementia, cognitive rehabilitation exercises need to be constantly tailored to the perceived needs of the person in term of rehabilitation, and forms of ‘micro-surveillance’ become routinized, and enhanced through technologies. In this context, therapists in the memory clinics are recursively confronted by the following questions: how

is someone doing? Has the functioning of the person in daily life been improved? How is decline progressing? Is this exercise too challenging and does it induce frustration in the patient? Or is it too easy, therefore impeding the fulfilment of therapeutic objectives? Detailed files corresponding to each patient and their progress through time are kept by the clinicians I encountered. Ascription is invariably a result of these forms of micro-surveillance necessary to any practice of rehabilitation, and they translate the existence of the person as being under the monitoring of the clinic.

The increasing use of computerised technologies is an important aspect of this ascription through micro-assessment. For instance, discussions with a (neuro-) psychologist led me to understand that an important aspect of the decision to digitalize the cognitive rehabilitation, an ongoing process in the clinics where this fieldwork took place, was meant to enable enhanced tracking of the capacities of the participants by the psychologists. Elements of the interaction between the individual and the computer that could possibly be measured were perceived as a potential way to generate metrics for the memory clinic. This transformation seems to be connected to a more general trend toward ‘datafication’ (van Dijck, 2014) and ‘metricization’ as means to ‘us[e] numbers to monitor, measure, normalize and manage elements of human life that may previously have been regarded as unquantifiable (Amoore & Piotukh, 2015; Day et al., 2014; Pugliese, 2010)’ so as Lupton (2016a, p. 115) explains. For instance, the therapist mentioned to me that the computer-based cognitive rehabilitation software now allows to record the speed at which the participant hits the touch screen following the moment when the script of the exercise is being displayed. These metrics can then be aggregated to provide clues about the participants’ speed and progression of capacities, expanding the medical gaze and its ability to define identities in a trajectory of decline.<sup>20</sup>

Metrics also play a symbolic role of ascribing monitored identities within the community. In a Randomized Control Trial testing the adaptation of cognitive rehabilitation exercises for prevention among healthy older adults that I observed

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<sup>20</sup> Although it may sometimes simply record technical issues or lack of familiarity with the device among the users as I observed several times during the sessions, watching users desperately hitting the right answer in face of a tactile screen helplessly ignoring their action.



while in fieldwork, a research activity set up by the association managing the two memory clinics, dozens of individuals from the region engaged in brain training sessions spread over an extended period of time. Everyone received a digital profile tracing the evolution of its cognition across time exemplifying this communal metricization (Lupton, 2016a) of later life in the region. Hence, ascription leads to individuals in a given community being divided between those who require cognitive surveillance and those who do not. This is yet another intimation of the existence of a divide between the identity of the third age and those individuals being monitored therefore facilitating the social imaginary of the fourth age taking hold on them. Such a statement is similar to the one already made by Kaufman (1994) regarding frailty. She describes it as ‘a state of being that can be operationalized and measured instrumentally, as a parameter of risk for institutionalization, as a socially constructed problem, and as a quality and adaptation process, one that forces us to reconsider the meaning of independence and dependence in advanced old age’ (1994, p. 56). Knowing that both frailty and dementia are conditions feeding into the social imaginary of the fourth age, we therefore see how this surveillance helps cognitive rehabilitation to further become a key articulation of the divide in later life and its expansion in the community. Micro-surveillance is also part of a more general trend within the policy agenda directed toward the optimisation of independent living in dementia. For instance, the *Prime Minister’s challenge on dementia 2020* (Department of Health 2015, p. 6) lists the inclusion of ‘a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check’ as a future healthcare policy to support people in later life to manage their risk behaviour for dementia. It is arguable therefore that we may see the intensification of technologies of ascription through ‘communal metricization’ in the future, as means to ‘rationally’ separate those in later life who can be acted upon through rehabilitation from those in need of institutionalization.

Such ascription of monitored identities takes place as well through their attendance to the cognitive rehabilitation sessions. As I described in the first referral by the clinician, the cognitive rehabilitation itself consists in the attendance of regularly scheduled sessions, twice a week for some individuals. The clinics I studied aimed at embedding their services close to communities as an important objective. The

regular intervention of clinics closely related to communities is yet another means for medical interventions to become integrated in the routine of individuals, socially inscribing some of them as regular receivers of medical services. Such regularity is different from the autonomous decision of many users of brain training engaged in regimes of prevention I interviewed in the previous chapter. Brain training use in the third age, no matter its regularity, is often the result of agency. Cognitive rehabilitation is the result of prescription. It may be based on the conscious adherence to a therapeutic contract, yet it symbolizes to a large extent the integration into a regime of care, rather than a form of consumer choice.

### **Second level of ascription: ascribing decline in the self**

Beyond its social role, cognitive rehabilitation plays a symbolic role in generating a new social identity in later life, closer to that of the fourth age. The activities that rehabilitation involves lead to what I suggest is a form of ascription of decline. This decline is ascribed into the subjectivities of the patients through the norms set up by the rehabilitation sessions for the purpose of therapy. This process of ascription involves the integration of the norms of the clinic into the body and the mind. This ascription therefore shapes the perception that patients have of their own identity. This second level of ascription is essentially based on a differential between the norms imposed by the clinic and the capacities of the individual. It has the capacity to invoke ascription in the fourth age by relegating the person with dementia as an outsider to these norms through its oppositional relation to decline. This is a process that operates alongside the cognitive rehabilitation, from the time of the assessment to the cognitive rehabilitation per se.

### ***Assessment and the anxiety of classification***

The assessment, beyond its ability to medicalize decline, is a first instance suggesting a process of exclusion of people in the fourth age constructed by the norms of the third age. I presented in a previous vignette how the baseline cognitive assessment at the beginning of the rehabilitation process is marked

by a tense atmosphere probably due to the anxiety of failure and the experience of having one's abilities scrutinized by the clinical gaze. An extract from the interview of an individual going through an assessment as part of a promotional video circulated by the Oxford Health NHS Foundation Trust confirms that such experience can generate feelings of unease. The man being interviewed in this video expresses the following about his experience of the assessment: “[w]ell it’s a bit threatening in a way to feel that you are going to be under examination, psychologically as it were, but when we did arrive, we met warmth, pleasant people, and we were treated as decent, normal human beings”<sup>21</sup>. This testimony points out to the confrontational aspect that an assessment intrinsically carries, as it is a first encounter with a normative template against which one will be evaluated – a confrontation with one's own decline. This normative template is invariably the expression of the ‘normal ageing’ that the clinician describes earlier in the first encounter with the patient. The indication of an abnormal decline is a first step in the process of ascribing difference for someone referred to a memory clinic. As this testimony also points out, the ascription can be welcomed by the patient and her relatives, seeking solutions to the issues that they encounter in relation to the experience of cognitive decline. Again, asking whether cognitive rehabilitation is relevant or not is beyond the scope of this chapter. It however points out that cognitive rehabilitation is a technology that plays the role of ascribing the individual further along a trajectory representing important anxieties relating to the social imaginary of the fourth age.

### ***The cognitive rehabilitation – individuals confronting cognitive norms***

The cognitive rehabilitation session is the second relevant instance in which norms are being confronted by the patient, rendering the presence of an impairment encompassed by the fourth age more salient. The reference point for these norms is different however, fluidly established for therapeutic purposes according to the capacities of the patient, rather than based upon a concept of normal ageing as it

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<sup>21</sup> Oxford Health (2016), Welcome to the memory clinic. Retrieved 5<sup>th</sup> August 2020 from <https://www.youtube.com/watch?v=gRxM7LuCaYY>

was the case for the cognitive assessment. In the following vignette, I describe a discussion I had with a therapist within one of the two memory clinics.

*December 2018, memory clinic: We start the discussion sitting at her desk in front of her computer while she is presenting several of the functionalities that the new cognitive rehabilitation software enables. Interested to know more about the actual ideas behind the technology, and principally cognitive rehabilitation, I ask her how the progression of dementia, the notion that dementia possesses a trajectory of decline, is taken into consideration through the design of the software. She tells me that there are different levels of difficulty for each exercise. She specifies that each cognitive rehabilitation session starts with an exercise of 'orientation'. By 'orientation' she describes the prompt that clinicians in the two centres systematically ask when encountering their patients: they ask about the date. What day is it? The simplicity of this scripted prompt is also what constitutes the strength of its power of ascription. Many times, I observed patients ruminating with great concentration or displaying doubt to provide this clear-cut answer to the psychologist. In some instances, this prompt also involves asking the patient to locate himself spatially, to indicate where the room of the consultation is inside the building for instance. Coming back to the software and how it accommodates cognitive rehabilitation, she then goes on to explain that the difficulty of exercises will also be greater for patients with schizophrenia for example. (...) If she notices that the patient cannot do the exercises anymore, there will be a discussion with the family and the person may have to be referred to a day centre. Then she moves on to show me exercises so I can try them, and we develop an exercise together from the start. She also explains me the importance to properly assess the patient at the start of the cognitive rehabilitation in order to avoid frustration if the patient cannot do the exercises. The experience that patients have of their own decline seems to be a matter of concern for the staff as they attempt to solve the tension that inevitably occurs between the reality of dementia as a progressive condition on one hand and the restoration of function associated with the objective of cognitive rehabilitation on the other.*

The main point to extract from this conversation with the clinician is that the cognitive rehabilitation is *normative* in mediating the patient's relation to her/his own decline, sometimes in confrontational ways. Indeed, cognitive rehabilitation is normative in creating expectations around the capacity of the person. It mediates the relation that the patient has with her decline because it signifies to this patient that decline is a condition to confront rather than accept. Cognitive norms are essentially part of the therapy as exercises need to be challenging enough to stimulate the necessary areas of the brain to support the improvement of people's functions in daily life. The mechanisms involved in cognitive rehabilitation, as a clinician explained to me on another occasion at the memory clinic, need to be difficult enough for the patient in order to provoke the bodily sensation of having to challenge oneself while solving a problem. Probably in an attempt to simplify the physiological mechanism behind the therapeutic process to facilitate my lay understanding, the clinician explained to me how such sensation intensifies the transmission of glucose to the specific areas of the brain being trained, supporting the restoration of capacity. Possible frustrations in confronting difficult tasks for the person experiencing a cognitive deficit and the careful tailoring of exercises by therapists to avoid this frustration is especially complex.

Part of this complexity is due to the therapeutic philosophy behind cognitive rehabilitation. Cognitive rehabilitation as a philosophical approach to symptoms of illness is peculiar because of the confrontational nature of its attempt to restore cognition in a degenerative condition. One could contrast this therapeutic philosophy to modes of approaching symptoms in healthcare that are oriented toward the alleviation of experiences of distress. For instance, we may give painkillers to alleviate a headache, or a medication to avoid a symptom, to forget about it and support quality of life. On the contrary, the philosophy of rehabilitation in approaching decline means that if decline needs to be alleviated, it should be confronted rather than ignored. One should expose the symptoms of decline by creating an artificially challenging situation for the patient in the form of a cognitive rehabilitation exercise to fulfil or a prompt to answer to such as 'what day are we today?' Hence, there is a substantial difference of therapeutic orientation between regularly exposing the symptoms of dementia in a controlled environment on one hand, and hiding them from the person by providing care and

support on the other with seemingly important differences on the perception of one's identity and declining capacities.

The main point, that makes this confrontation with decline a form of ascription, is how decline becomes ascribed into one's identity as something that matters for the sake of therapy. While medicalization is generally associated with a fourth age imaginary, the rehabilitation itself is a normative space based upon ideals of the third age linked to agency and capacity. These ideals are transcribed in softened versions within artificial situations and exercises (calculation, enumeration of objects and animals, re-ordering of sequences of action of daily life, recognition of faces and expressions, etc.). As such these ideals and their translation into norms of therapy follow a "deeply felt cultural conviction that individualized will can influence bodily processes" (DelVecchio Good et al., 1990, p. 75; Hay, 2010). This normative space oriented by the rationality and desire of third age identity in term of cognitive capacity can further incorporate the socially perceived abnormality of decline into one's self-perception and identity. Confronting decline, experiencing it as an obstacle to overcome within one's life implies that one needs to recognize one's own decline as an obstacle in the first place, a problem to overcome. The repetitive act of confronting this decline several times a week, through cognitive rehabilitation sessions, but also through cognitive rehabilitation exercises to practice at home further strengthens a sense that one's decline should be understood essentially as a problem to address in a disciplinarily fashion. Furthermore, this integration of the problematic nature of one's own decline is further reinforced if the rehabilitation is unsuccessful. From being a problem that may be solved through individual will, decline becomes increasingly understood as problematic while being experienced as unsurmountable. Both this problematization of decline and the impossibility to alleviate it can potentially participate in the integration of a failing cognition into one's identity.

### ***Expanding norms – the rehabilitation as a 'hypercognitive space'***

I should now propose to look more closely into the space of a cognitive rehabilitation consultation per se in order to further expand upon the idea that the cognitive rehabilitation plays a transformative role on the self-perception of the patient orientated toward ascription. This transformation of identity and self-

perception results from the norms and expectations created by the cognitive rehabilitation consultation. These norms and expectations characterize the consultation as a ‘hypercognitive space’ set up for the purpose of therapy – a specific configuration of infrastructure, activities and human actions oriented toward challenging cognition. This is what the following vignette describes:

*12<sup>th</sup> December 2018, Memory clinic: I met with two clinicians to attend the cognitive rehabilitation session. The room is a casual classroom setting, with two round tables, and a series of computers on the side. We enter the room and spend around an hour and half there. The length of the consultation and the level of the challenges set are important. The session for one of the patients starts with thirty minutes of cognitive exercises through the traditional ‘paper and pencil’ rehabilitation – a contrast with the novel use of computers – followed by another thirty minutes of computer-based rehabilitation. The computer-based session requires the patient to sit in front of the computer, and carefully answer the prompts and exercises that the cognitive rehabilitation software automatically generates. Then the person comes back for thirty minutes of the same ‘paper and pencil’ cognitive rehabilitation exercises. We sit together at the table, two patients, the clinician, and me, and start the exercises. The clinician alternatively spends time with each patient, quickly shifting from one patient to the other in order to set up the exercises and monitor the patient. Each ‘paper and pencil’ exercise follows the same pattern: the clinician lays square-shaped cards down on the table with images of objects of different kinds printed on them: a shirt, a bowl of soup, a train, keys and so forth. The patient then tries to remember this sequence of objects represented on the cardboards by creating a narrative based on these objects. Here could be an example, I put my shirt on, drank some soup and left the house while closing the door with the key, and took the train. Cards would then be put face down and the patient would attempt to recall the shirt, the soup, the house, the keys, and the train printed on the cards in a sequential order by remembering the story. What I notice during my observation is the variation in the amount of time that the clinician spends with each patient depending on the stage of cognitive impairment. After an*

*hour and a half there, we finish with a mundane discussion about Christmas plans in our respective countries. Everyone participates enthusiastically in the conversation, be it the patients or the clinicians, while we wait for the shuttle to pick up the patients and take them back home. What fascinates me with this conversation we have together is how the apparent challenges that the patients previously experienced in executing specific memory tasks during the cognitive rehabilitation session suddenly seem to vanish, only leaving a mundane talk to remain.*

The main point of this vignette is the following: the consultation of the cognitive rehabilitation establishes a cognitively challenging space in which decline becomes apparent by revealing the cognitive difficulties that patients experience. Each patient is confronted by memory prompts as part of the rehabilitation. Each task requires different abilities, which imposes different challenges according to each individual's level of cognitive abilities. Rates of success and failure more neatly expose the presence of the impairment than mundane interactions actually do – for instance when we start discussing about Christmas plans. Individual capacities impacted by dementia are seemingly less exposed and noticeable by others in these latter mundane interactions. Even more significantly, cognitive impairments are probably less perceptible by the patients themselves in term of the consciousness they have of their own decline in non-challenging situations. Hence, this contrast leads me to describe the space of the consultation as a 'hypercognitive space', requiring a heightened level of cognition to 'move' through it easily. Such a space is fundamentally defined by the norms that it establishes around cognitive performance. I draw this idea of hypercognitive space from the concept of 'hypercognitive society' that Post (2000 cited in Katz & Peters, 2008) uses to describe how cultural ideals of modern society are based on norms of optimal memory. As Post (2000, p. 249) says: "[w]ere ours not a hypercognitive culture, would we fear dementia enough to label it AD [Alzheimer's Disease] at a certain threshold?" Although cognitive rehabilitation is for therapeutic purposes and patient's return to their routines at the end of the consultation, what I wish to point out is how such a space of rehabilitation implies a significantly higher level of cognitive challenge from the one of mundane situations of care and support for people with dementia. The specific referral of people with dementia to this space



is yet another way to ascribe difference and a fourth age identity. It is another way for the third age to establish the abnormal nature of dementia and its exclusion from normal ageing.

### ***Realising one's own decline***

At a subjective level, the consultation may be a way through which the person with dementia realizes her own decline and entry in the fourth age. This could be therefore the experience of a boundary crossing exercise that emerges from this confrontation with decline, an ascription of decline upon the individual. Again, it exemplifies the idea introduced by Gilleard and Higgs that people enter the fourth age by 'a combination of a public failure of self-management and the securing of this failure by institutional forms of care' (Gilleard & Higgs, 2010, p. 122). Indeed, each experience of failure, each moment marked by the inability to succeed in specific tasks implies a confrontation with one's failing memory.

The presence of anxiety in the confrontation with one's own decline in dementia has been observed in other situations. Some physicians have called 'Alzism' specific forms of distress experienced by healthy individuals in later life systematically avoiding situations that would require them to challenge their memory and therefore expose an imagined, or actual, decline in cognition (Cohen, 1998, p. 126). As a result of this anxiety individuals become increasingly isolated, sometimes staying at home for prolonged periods of time in order to avoid any social contact that could expose this subjective deficit (Cohen, 1998, p. 126). Another example of this hypercognitive space in my fieldwork could be seen in the prompt I presented earlier around the date of the day and spatial localization. Several times during my observation of the consultations, participants required assistance to answer these questions or failed to answer. I should point out however that these failures are carefully managed by psychologists so that they are not distressing, yet they represent forms of micro-interaction that signify the entry in a trajectory of decline, and its validation by health and care institutions. The memory clinic also performs this validation of cognitive decline as we have seen during the first significant cognitive assessment, and the regular micro-assessments that follow. This validation as Gilleard and Higgs (2010) explain, represents a boundary crossing through which an individual becomes ascribed in the fourth age.

In regard to this validation, the memory clinic has a capacity to determine who can benefit from the rehabilitation and who does not meet the criteria of rehabilitation – in this latter case, the terminal destination is a relegation within the day centre or the nursing home when the level of impairment renders the rehabilitation too difficult to implement. The fact that this ascription takes place despite the therapeutic objectives of cognitive rehabilitation may be the result of this therapy being applied to a progressive condition, as opposed to a stable one. Such a move to increase institutionalization also represents a step further into the moral imperative of care, the duty of relatives and eventually society to provide care for a person with dementia when its remaining abilities for self-care become impaired (Gilleard & Higgs, 2015, p. 268). Becoming a passive receiver of care – a key characteristic of the anxiety generated by the fourth age –symbolizes the completion of this ascription process. Cognitive rehabilitation in dementia therefore stands in this ambiguous space between its therapeutic objectives and the reality of its accompaniment and subsequent ascription of people on the path leading to the fourth age, a location that Hazan (2011b, p. 1129) describes as ‘deep old age, which lies beyond the corrective power of therapy.’

## **Technologies of ascription as instruments of social classification**

The historical origin of cognitive rehabilitation therapy is also important in explaining these tensions between decline and rehabilitation as well as their impact on identity. Indeed, the cause of this oppositional approach to decline could be that cognitive rehabilitation was originally developed as a therapeutic approach for stable conditions rather than progressive ones such as dementia. Indeed, cognitive rehabilitation was originally tailored to treat traumatic brain injury. To this regard, Prigatano (2005, p. 5) traces the emergence of modern forms of cognitive rehabilitation in the aftermath of the First and Second World War, mainly ‘propelled by the social responsibility of rehabilitating brain-injured soldiers given their significant personal sacrifices’. Only later appeared the idea that cognitive rehabilitation could be applied to dementia. These later developments appeared as a result of the work of Clare and Woods (2003) among others. As Clare (2005) explains, this development required adaptations to meet the needs associated with

a progressive condition such as dementia. A psychologist during my period of fieldwork in the memory clinics indicated that several of the patients were visiting the memory clinics due to brain injuries relating to traffic accidents, and that some of them would follow a course of rehabilitation spread across many years, often for longer periods than individuals requiring rehabilitation for dementia. Cognitive rehabilitation seems to have a different significance for dementia as the idea of rehabilitating a degenerative condition can appear rather antithetical.

This confrontational nature of cognitive rehabilitation to decline is recognized at a clinical level in the work of Prigatano (2005, p. 6) although its significance at a social level in term of ascribing identity has not been considered. He indicates that the 'careful observation of patients' response to failures and their natural preferences for using one form of compensation or substitution over another' (2005, p. 6) is an important principle for the implementation of cognitive rehabilitation. Hence, Prigatano (2005, p. 6) warns us that the level of difficulty of exercises should be progressively adapted in order to avoid feelings of failure and frustration. Hence, researchers are aware that exposing decline in a progressive condition can potentially create frustration if not adequately managed.

However, there seems to be a limit to this adaptation. As the clinician indicates in a vignette I present above, the non-fulfilment of a minimum threshold of capacity necessary for the rehabilitation to operate can lead to the person with dementia being referred to a day centre. At a social level, this confrontation is due to the inability of the patient to conform to the norms of cognition established by the therapist during the cognitive rehabilitation. As the capacity of the patient to meet these norms reaches its limits, institutionalization is required. It therefore marks a step further toward the ascription of the individual into the feared fourth age. Institutionalization represents an important factor marking exclusion from society (Gilleard & Higgs, 2010). As the explanation of the clinician illustrates, this decision is not the one of an agentic third age, yet primarily a discussion between the memory clinic and the relatives of the person with dementia. The loss of control over one's own future marks the completion of this trajectory of ascription within the fourth age, a transformation of one's social identity.

Cognitive rehabilitation is fundamentally the ascription of someone to a trajectory of irreversible decline, a trajectory which is archetypical for the fourth age. Indeed, Gilleard and Higgs (2010) describe the fourth age as ‘a terminal destination’. We can identify the symbolic power that a diagnosis of dementia possesses when it becomes distinguished from normal ageing in the Western imaginary of later life. As a psychologist pointed out during an interview part of the fieldwork presented in this chapter, a rehabilitation will not lead to the improvement of a lost capacity. The psychologist gave the example of aphasia, the loss of speech associated with a brain deterioration in the Broca’s area. She explained how such deterioration would not be overcome by rehabilitation per se. When it comes to dementia therefore, rehabilitation as this person explained would not lead to an improvement of the condition, yet it would be an attempt to maintain the remaining capacities of the person for as long as possible before the degenerative process affecting brain functions continues. The role of rehabilitation is ultimately to maintain the functions that are not lost yet in order to maintain a certain quality of life for the patient. The cognitive assessment and subsequent establishment of a diagnosis is therefore instrumental in ascribing the negative social imaginary of the fourth age. Beyond that, it is a classificatory process separating those who can be rehabilitated from those who cannot be rehabilitated due to the progression of their condition.

In the definition of this social role of cognitive rehabilitation, we progressively unveil how ascription is a different yet complementary process to distinction. To understand this difference, we should look more closely at the transformations operating around identity in distinction. This idea of ascription in the fourth age closely relates to the distinction made by Linton (1936) and Kemper (1974) between *achieved* and *ascribed* identity, a long-theorized concept in sociology. Achieved identity describes instances in which individuals are able to realize a status and role within society which aligns with their desired self-definition (Kemper, 1974). Meanwhile, Kemper (1974) explains, an ascribed identity is an identity which is socially attributed to a person or physiologically determined. It is therefore not the result of individual choices and/or does not result from self-definition. The fourth age is not the result of a particular habitus or choice and therefore represents an identity which is externally ascribed.

For instance, the social role that brain training and cognitive rehabilitation play is central to determining their diametrically opposed impact on later life despite their reliance on relatively similar mechanisms. The main characteristic that determines the role of cognitive rehabilitation technologies as technologies of ascription relate to their integration in processes of medicalization. Conrad (2007) describes how the process of medicalization transforms a human condition into a medical problem involving a medical solution. For instance, Conrad (2007) explains how certain life processes such as ageing or individual characteristics such as attention have become categorized as attention deficit hyperactivity disorder (ADHD) or chronic fatigue syndrome (CFS) due to their perceived divergence from normative expectations. For instance, Conrad (2007) explains, citing Fox (1989), how Alzheimer's Disease in its original definition was once an 'obscure disorder' – meaning a rare occurrence – and when age was removed as a criterion of exclusion from this category, came to include the previously defined senile dementia leading AD to become one of the five leading causes of death in the USA. In the case of rehabilitation, this medicalization aspect attributes a label of dementia to individuals in later life affected by memory problems outside the normal expectations of the third age and is visible at different levels in the process of rehabilitation, therefore leading to their ascription in the fourth age.

The contrast is stark with the brain training 'apps' used by the active third age. In the hands of someone engaged with third age culture, they represent yet another engagement with the 'healthy body, healthy mind' described by active cognitive ageing (cf. chapter 2 and 3). A person using brain training can therefore ideally be perceived as an agentic and entrepreneurial individual engaged in valued forms of self-care (Millington, 2012). These 'apps' also symbolize a distinction – a social position that the individual takes regarding the non-agentic fourth age. Therefore, being the receiver of a cognitive rehabilitation regime as part of a medical process, and being prescribed regular consultations, often as a result of the request of a relative comes to challenge the agentic and entrepreneurial self of the third age. The context of the memory clinic itself is consequential in shifting the role of cognitive rehabilitation as a technology of ascription rather than a technology of distinction. It represents the dedication of a space to the medicalization of

cognitive problems. It is therefore an institution whose role is to establish a distinction between ‘normal’ and ‘abnormal’ ageing.

Is ascription also present in other types of clinics beyond memory clinics? In this regard, other studies in the social sciences explore the impact of clinical encounters on identity (e.g. Armstrong, Michie, & Marteau, 1998; Strong, 1979) but they do not demonstrate that the identity being construed following the transformative action of the clinic leads to similar existential fears around the loss of agency and abjection. Processes of ascription in the fourth age are specific to memory clinics due to the profound *existential* consequences of the classification they operate along the third/fourth age divide. It does not mean that other types of clinics are not transformative for identity, yet this identity does not possess as intense a capacity of exclusion as a diagnosis of dementia.

Technologies of ascription are not limited to cognitive rehabilitation and can categorize other technologies that play a similar social role in dementia. Indeed, a parallel can be made between the forms of medicalization involved in cognitive rehabilitation and the ones involved in the consumption of psychopharmaceuticals for memory decline in later life as presented by Lopes et al. (2017). In their research, Lopes and colleagues (2017) present how psychopharmaceuticals can either play the role of managing disease and risk, what they refer to as a ‘logic of medicalization’, or be used for the sake of anti-ageing when it is promoted by the anti-ageing industry – a logic of prevention and enhancement. This recently emerging logic relates to an understanding of medicine ‘concerned less with disease than with building better bodies’ as Gilleard and Higgs (2011, p. 145) point out, characterising it as ‘aspirational medicine’. Here the former can be characterized as a technology of ascription in the fourth age through its role in medicalization, while the latter can be characterized as a technology of distinction from the fourth age in its objective to maintain the cognitive abilities of the third age. Brain training and cognitive rehabilitation, just like psychopharmaceuticals, could be described as technologies of ascription in some instances, and technologies of distinction in some other instances depending on the context and purpose of use. Such attempt at classification between the aspirational technology, the technology of distinction and the technology of ascription requires a localized analysis embedding technologies in their social context. These processes are also

complementary and can act in parallel, being ascriptive for some while generating distinction for others. For instance, when cognitive rehabilitation ascribes individuals who cannot be rehabilitated, it also enables those who can be to demonstrate their distinction from the fourth age. Similarly, cognitive testing can ascribe those whose cognition is deemed abnormal by the memory clinics while enabling the distinction of those reassured about the normality of their cognition based on their test result. Ascription and distinction also depend on the individuals being considered in the analysis and their position along the third/fourth age divide. Overall, understanding and researching this yet unconsidered classificatory role of technologies in dementia through distinction or ascription, and the essential role that the context plays in determining the social function of these technologies is therefore central to understanding social exclusion in later life today.

## **Conclusion**

This chapter presented how distinction is not the sole process in which technologies are involved to generate social exclusion in later life. Another important role played by technologies in social exclusion is the one of *ascription*. Technologies of ascriptions are the ones which externally ascribe individuals with dementia in an identity marked by decline and dependency. This chapter presented how novel therapeutic approaches of cognitive rehabilitation used for dementia in memory clinics are a relevant case study to illustrate the presence of these processes of ascription in society. It showed through a set of vignettes representing key scenes of the routine that composes the activities of two memory clinics in Southern Europe how cognitive rehabilitation specifically operates as a technology ascribing people experiencing cognitive decline into a state increasingly marked by the fourth age.

This chapter showed how medicalization as a process transforming the experience of decline into a medical problem determines the social role of cognitive rehabilitation. More specifically, this chapter demonstrated how cognitive rehabilitation operates through a definition of the problem of dementia as a distinct entity from a so-called normal ageing within the memory

clinic. It presented how the assessment itself represents a first step into the formal ascription and legitimation of a trajectory marked by the fear of an irreversible decline. It explained how this ascription in the fourth age is maintained through the establishment of forms of monitoring and micro-surveillance around cognitive abilities both within traditional rehabilitation techniques and the establishment of novel forms of ‘datafication’ and ‘metricization’ of cognition further enabled by the current digitalization of this therapy. It then presented how cognitive rehabilitation sessions themselves could be conceived as hypercognitive spaces. By this, it meant that they lead to the exposure of individual deficit through the utilization of norms of capacity being purposefully challenging for the person with dementia in order to activate the therapeutic mechanisms behind the rehabilitation. It explained how this hypercognitive space is a blueprint for the ideal that the third age deploys, based on values of agency and cognitive capacity. It argued that this exposition of difference from normal ageing is yet another way in which the identity of the fourth age is ascribed upon the person with dementia, by exposing decline through challenging tasks. Finally, it presented how technologies of ascription are classificatory by leading to a differentiation between those who can, and those who cannot benefit from rehabilitation, the latter being relegated into institutions most representative of the fourth age, such as the day centre or the nursing home. I suggested therefore that cognitive rehabilitation can be conceptualized as a gradual transition from an ideal identity of the third age defined by active cognitive ageing to a location overshadowed by the social imaginary of the fourth age and marked by dependency and decline. Along with other technologies playing a role in the medicalization of dementia, cognitive rehabilitation represents an important illustration of how technologies of ascription maintain the boundary between third and fourth age as a widespread form of exclusion in later life, through complementary processes to the ones of distinction.

Overall, this chapter presented how addressing the discomfort that dementia can create through medicalization is a unique cultural characteristic of how late modernity approaches the problem of dementia and the end of life. Understanding the cultural nature of medicalization processes and their social



roles could help opening discussions of their benefits while also understanding their social consequences in term of ascription. Technologies of ascription may become more frequent in the future as the current expansion of other forms of medicalization of decline testify. Categories of pre-dementia, and Mild Cognitive Impairment (Katz & Peters, 2008; Lopes et al., 2017), or the scaling up of ‘metricization’ in brain health using digital technology across Western society and beyond are examples of these other expanding forms of medicalization.

This chapter demonstrated the importance to study the impact of these new developments linked to medicalization if one wishes to address the potential intensification of social exclusion in later life. Meanwhile, the next chapter will present how the divide in later life is not only maintained by technologies identifying dementia as a medical problem to treat or prevent, but is also present in technologies that wish to detach themselves from this narrative based on the definition of abnormality in later life. It will show how social exclusion in later life is even more complex and pervasive than distinction and ascription illustrated.



## **Chapter 5: Technologies of omission: Has decline been left aside in the implementation of independence for dementia?**

In parallel to long lasting discourses depicting dementia as a threat that needs to be either cured or more recently prevented, attempts to reframe dementia in a positive narrative of ‘living well’ have multiplied in the last two decades across Western countries (McParland et al., 2017). They therefore mark an important rupture with previous and still dominant biomedical discourses portraying dementia essentially as a tragedy (McParland et al., 2017). In this novel narrative, dementia is envisioned not as a time of loss of personhood, functional and cognitive capacities, and decay, but as a time marked by the continuity of agency, previous life choices and lifestyle opportunities enabled by adequate support and assistive technologies. In rethinking dementia positively, this approach hopes to alleviate parts of the stigma it identifies as resulting from the tragedy narrative. Ideas of independence, self-management and empowerment in dementia have been important dimensions of this novel approach, hoping to restore confidence in the person with dementia and foster their engagement in daily life, therefore encouraging social inclusion, decision-making and an active and healthy lifestyle through self-management.

The emergence of this approach results from a long process of social change involving national and international organizations and policy makers, dementia advocacy groups and researchers whose inception McParland et al. (2017) trace back to the innovative work of Kitwood (1997b). The objective of maintaining independence for people with dementia amidst the progression of their condition is increasingly presented as best practice within the policy agenda of important national and international institutions to address the challenges associated with ageing societies and the rising prevalence of dementia around the world (e.g. Department of Health, 2015; World Health Organisation, 2017). For instance, the WHO Global action plan on the public response to dementia 2017-2025 lists ‘[e]mpowerment and engagement of people with dementia and their carers’ as the second most important of its seven ‘cross-cutting principles’, explaining that ‘[p]eople with dementia, their carers and organizations that represent them should

be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia.’ (World Health Organisation, 2017, p. 5). This description by the WHO presents how the ‘living well’ discourse and agenda wishes to establish a novel standing of the person with dementia in society through mechanisms of empowerment, a focus on ‘remaining strengths and recognizing enduring personhood’ (McParland et al., 2017, p. 259) to counter the social exclusion of people with dementia. To this aim, this approach often draws on the idea of citizenship applied to dementia, which has become an important concept in the work of several scholars aiming at this objective of empowerment (e.g. Bartlett & O’Connor, 2010; Kontos et al., 2017).

Interventions based on this narrative have multiplied in recent years. Indeed, a wide range of social interventions and research projects aiming at supporting autonomy and independent living for people with dementia has developed following the inclusion of citizenship and empowerment in the conceptualization of this condition. Such projects support failing memory, activity planning, mobility and communication among other with the idea to maintain people with dementia away from institutionalization (e.g. Alzheimer’s Society, n.d.-a; Moreira, O’donovan, & Howlett, 2014; UK Dementia Research Institute, n.d.). They attempt to interpret these principles, through community-based, non-pharmacological interventions for dementia, for instance in the US (e.g. Kaldy, 2013), and the UK (e.g. The GREAT study<sup>22</sup>; Alzheimer’s Society, n.d.-b).

Although its objectives appear positive, the practical application of this narrative and associated interventions to dementia is not without challenge. As McParland et al. (2017) or Gilleard and Higgs (2020, p. 120) explain, this reframing of dementia involves important tensions around the actual experience of people further along the trajectory of decline, as well as those most affected by the disabling effects of ageing. It risks overlooking the circumstances of people whose condition is intensely marked by the effects of infirmity, complex life-limiting impairments and comorbidities that prevent them achieving these objectives. As these authors note, while this narrative may have a positive effect for some people with dementia who are more functional and able, there is a risk that it might further

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<sup>22</sup> GREAT Cognitive Rehabilitation (n.d.). GREAT Cognitive Rehabilitation for people with dementia. Retrieved August 10, 2020, from <https://sites.google.com/exeter.ac.uk/great-cr/home>

exclude those individuals who cannot meet these rising expectations around cognitive capacity and autonomy.

However, the reach of this critical standpoint problematizing the discourse of 'living well' in dementia has remained limited in the field of dementia research. More specifically, little empirical research has been conducted on the practical challenges resulting from the application of this discourse in novel psychosocial interventions for dementia. This chapter therefore departs from the identification of this gap in the literature to further explore and document the paradoxical consequences of this current societal attempt to address social exclusion in dementia.

To this end, it will explore challenges and tensions in the development of a large research project whose objective is to support people to maintain well-being and an independent life after a diagnosis of dementia. This project which mobilized over twenty researchers across several universities and countries over a five-year period and received an important national research grant intends to develop an intervention to support the independence of people with dementia in daily life by activating networks of dementia advice workers, relatives, and people with dementia themselves through the means of a handbook and an online platform providing guidelines to support decision making, social inclusion and an active lifestyle.

This chapter presents the analysis of semi-structured interviews with six researchers and a Patient and Public Involvement (PPI) participant participating in the development of this larger project. During these interviews, I discussed the meaning that researchers attribute to independence in dementia and their understanding of the benefit of empowerment, agency and choice for people with the condition. By questioning researchers about their experience of the development of the project and its piloting phase with participants, I also explored tensions involved in the application of these principles supporting learning and progress in a neurodegenerative condition and how they reflect a particular understanding of decline in dementia and later life. Finally, I explored how the researchers conceived the individuals that could potentially benefit from this intervention and the criteria that they used in selecting them.

As a result of the analysis of these interviews, the tensions discussed show the difficulty of defining independence in dementia, as well as the impact of this priority given to independence on our understanding of dependency in ageing and dementia. This chapter will also show how maintaining an objective of independence in dementia implicitly mobilizes principles of prevention. Finally, it will problematize how decline is conceived in the project and how people with advanced dementia are considered as a result.

The results of this analysis will hopefully enable us to better understand the tensions involved in current ideas of ‘living well’ with dementia by grounding them in the practical implementation of actual interventions. As a result, it will enable us to more generally assess the capacity of this dominant narrative to respond to social exclusion through current policies and interventions across Western societies.

This chapter will contribute to the argument of the thesis by demonstrating how causal mechanisms behind social exclusion in dementia and their enactment through technologies and interventions can be more subtle and pervasive than the previous chapters presented. It should therefore present how social exclusion is challenging to identify and address adequately even through these attempts in policy, advocacy and research.

## **Researchers’ interpretations of the idea of independence in dementia**

How do researchers working on the intervention understand independence and its application to dementia? The question seems straightforward; however, we should see that the definition of this idea in the project remains a complex process involving interpretations relying upon disciplinary pre-notions and contextual elements which are inherently cultural. This process explains how a practical intervention with an objective to support independence in dementia emerges as a result of the narrative of ‘living well’.

### *Defining independence in dementia*

It appeared that the project had no unified definition of independence at the start. Answers indicated that researchers on the project had different understandings of the concept of independence. Some of the researchers were sceptical of the application of this concept to dementia specifically due to the excessive individualism that it implicitly translates. Some of the researchers highlighted for instance that notions of ‘interindependence’ or ‘assisted autonomy’ are probably more meaningful for people with dementia. There is therefore an initial recognition by the researchers that using independence as a principle to drive the intervention in dementia is not without tensions.

Meanwhile, it is also interesting to note that the project did not formally analyse or problematize this concept for dementia in its early development. As a researcher pointed out during the interview:

*(...) that wasn't part of the work program, so in the original protocol, the original proposal, there was no work package around defining how the word independence was going to be used in people with dementia.*

*(Interview 1)*

This absence of definition however did not prevent them from developing the intervention. It seems to indicate that findings from previous research enabled them to elaborate a research proposal which only used independence subsequently as a concept that could encompass the main ideas of the project. Such an observation also explains why the researchers who mentioned the inherently individualistic nature of independence as problematic were not limited by this critique in developing their intervention. It shows how independence was most likely embraced by the researchers for its symbolic appeal, while the content of the project was defined through other means. It does not mean that independence is irrelevant to the project, but that the project brought its own interpretation of this term based on other principles.

Indeed, the research project like many other interventions in dementia combined previous discoveries and scientific literature as to propose a novel set of interventional mechanisms that could be regrouped together into a single coherent

research agenda. The different work packages of the project were developed according to existing literature on different aspects of psychosocial interventions in dementia that previously showed positive or encouraging results, leading to further research conducted throughout the lifetime of the project.

However, this mobilization of the scientific literature deemed relevant for the researchers and its recombination into a new project did not operate in a vacuum. It was culturally informed by the context that surrounds dementia today, the one of ‘living well’ with dementia described in the introduction of this chapter. A researcher on the project explained how the project relied on interpretation of the national policies around dementia that prevailed at the time of the development of its research proposal, the one that McParland et al. (2017) have identified as promoting this particular narrative of ‘living well’. Imperatives of the political economy of research funding therefore accounted for part of these theoretical choices and mechanisms.

Definition of the nature of this project therefore appears to be a product of disciplinary tradition and the interpretation of the current policy ‘mood’ around dementia. This interpretive and co-constitutive process led to a set of principles that therefore both represented a continuity of previous intellectual tradition and an extension of current policy, representing a key example of the practical application of the principles of ‘living well’ in dementia. We should now review the main principles that resulted from this intellectual process.

### ***Maintaining an agentic self***

In this regard, one of the key principles behind the interpretation of independence by researchers is to ‘[enable] people to make decisions and choices, [enable] agentic choices’ as a researcher pointed out in the interview. Accordingly, researchers perceive the ability to make choices and decisions for oneself as a key objective to achieve for people with dementia, and they envision the intervention as instrumental in supporting this process.

For researchers on the project, the existence of agency principally results from a combination of *individual will* on the part of the person with dementia, and *support* from their relatives and social network. Researchers describe how agency can



potentially be compromised and require an external intervention to be reactivated. A researcher describes how the project intends to re-activate this agency:

*Decision-making is everyday, if you want to do something, if you want to make up your mind, how you want to do it, decision making. So from there, they say 'oow yes, I decided to go to a park', but they are still making decisions. Yes that's right, so we help them to understand decision-making is not a big decision of doing something, but is everyday routine, so they feel good. I still have made a decision. (Interview 5)*

As this extract describes the project's plans to support people in regaining confidence in their own agency by making them understand that they can still be actors in their own lives even after a diagnosis of dementia. 'Coaching', 'education' and 'empowerment' is central to this process as researchers on the intervention pointed out. For instance, another researcher explained how the intervention is about individual goal setting and coaching so that people with dementia can achieve their objectives [notes from interview 5]. Researchers therefore represent agency as a dormant capacity that needs to be 'enabled' both at an individual level and through social transformations.

Following this logic of coaching, empowerment and education, during one of the interviews a researcher pointed out regarding her perception of the project that taking a self-management approach should have a very empowering effect on people [fieldnotes from interview 1]. Future participants in the intervention will be invited by the researchers to develop a plan of activities to implement in their daily life. This represents for the researchers a means to maintain this ethos of agency and enterprise in the person with dementia. Indeed, the researcher explains that people take the plan that they have developed as part of the intervention with them and might be able to follow this plan and actually make changes into their lives [fieldnotes from interview 1]. This approach to agency in dementia based on self-management therefore principally relies upon the will of individuals to implement lifestyle transformations, and the intervention is designed as a support to achieve this objective. In this approach to independence achieved through self-management and monitoring, we find important characteristics of the governmentality described by Lupton (2016b) regarding self-tracking technologies. There seems to be a

disciplinary element directed toward the responsabilization of individuals to manage their own dementia and achieve independence, beyond the neutral conception of empowerment proposed by the researcher.

However, and as briefly introduced above, the intervention's objectives are not limited to solely coaching the individual with dementia. It also aims at educating her/his social network to reconfigure how it supports and cares for this person. As a researcher explained during the interview, it specifically aims at preventing situations in which the agency of the person with dementia is being dismissed or neglected by the relatives. By this the project identifies the importance of the social network in influencing impairment in dementia and the negative impact that it can have on the agency of the person. It therefore recognizes the impact of *power relations* in influencing the symptoms of dementia. Hence, researchers on the intervention regularly use the notion of *empowerment* to describe their action.

Empowerment as a concept used in the health domain is not without critique, and some of these critiques are relevant to understand the implication that the use of this concept can have in dementia. For instance, Grace (1991), Aujoulat and colleagues (2008) propose a critical analysis of the notion of empowerment as it is used within the logic of medical interventions for patients. Empowering in health promotion can also mean controlling, as Grace (1991) points out. Empowering follows the logic of the health consumer in late capitalism, in creating responsible and careful consumers of health services dedicated to the management of their condition. On a similar note, Aujoulat and colleagues (2008) explain that interventions relying on the principle of empowerment are essentially turned toward the objective to encourage patients to control their own condition in order to maintain the separation between their identity and their illness. Such process, Aujoulat and colleagues (2008) emphasize, overlooks the need to 'let go' 'by accepting to relinquish control, so as to integrate illness and illness-driven boundaries as being part of a reconciled self' (2008, p. 1228). Aujoulat and colleagues (2008) argue that the approaches of 'controlling' and 'letting go' are both necessary when attempting to improve the well-being of patients and that one shouldn't be privileged at the expense of the other.

According to the description of the researchers regarding empowerment in dementia presented in this chapter, the re-construction of agency following a diagnosis of dementia is essentially the result of the person with dementia's will to overcome decline, and the will of others to provide adequate support toward this end. This approach tends to follow an approach drawing on the principle of control presented by Grace (1991) or Aujoulat and colleagues (2008). Meanwhile, the idea of integrating decline following this logic of 'letting go' introduced by Aujoulat and colleagues (2008) remains peripheral in the project and its strategy based on empowerment toward independence. To sum up, maintaining an agentic self is the first objective defined by researchers on the project as part of the practical application of a positive reframing of 'living well' with dementia. This approach and its idea of controlling one's condition can lead to tensions as we will see later in the chapter.

### ***Maintaining an active self***

In the perspective of the researchers I encountered, mechanisms of empowerment, coaching, and education are not solely implemented for the sake of supporting agency. They also aim at encouraging an *active lifestyle in dementia*. This second important objective constitutes another dimension of the attempt of the project to reframe dementia in a positive light, as an active version of oneself opposed to passivity and inactivity.

This priority given to activity in its physical, cognitive and social dimensions is an important component of the guidelines and topics contained in the handbook and digital app' that the project team developed as the main material support for the intervention. The handbook offers a framework providing structured guidelines for the person with dementia and her relatives helping them to select activities of a physical, cognitive and social nature that they can implement in their lives. It also offers advices and tips to manage the challenges that dementia brings. Researchers expect that this handbook and app', together with the help of relatives and a dementia advice worker will help people with dementia to develop and implement an activity plan thereby creating a schedule of the physical, cognitive and social activities that they will undertake in their daily lives. The researchers I interviewed hope that such activity plan will help the person with dementia to maintain their

health, autonomy and well-being as a result. This objective of activity therefore combines the previous objective of agency to create an integrated whole, a vision of life with dementia where decision-making is both maintained through the continuous undertaking of initiatives, and the implementation of a regime of health relying on principles of self-management.

This approach can be categorised as an example of reablement, a strategy consisting in ‘supporting older people’s specific goals and needs; with an emphasis on involving older people themselves in the process of goal-setting’ (Clotworthy et al., 2020, p. 11) that emerged under the shape of a set of formalized programmes in 1994. Generally speaking, Clotworthy and colleagues (2020) explain that this type of strategy eventually became more focused on people’s ability to function at home, resembling more the traditional programs of physical rehabilitation in use until 2011, rather than fostering social integration and consensual goal setting with the older person. As a result, evidence of the efficacy of this strategy eventually appeared limited regarding its capacity to improve the condition of people in later life (Clotworthy et al., 2020, p. 12). While the idea of social integration and consensual goal-setting is present in the project reviewed in this chapter, it however carries some of the aspects of more recent iterations of the idea of maintaining function through self-management.

Hence, the project’s objective of empowerment specifically oriented toward the maintenance of an active and healthy lifestyle is inherently *normative*. Outside the field of dementia, the normativity attached to empowerment has been previously documented (e.g. Aujoulat et al., 2008; Cruikshank, 1999; Grace, 1991). This normativity is present in the application of the strategy of empowerment to later life, carrying a dimension of control as we saw above in the work of Grace (1991), and Aujoulat and colleagues (2008). When it comes to dementia, empowerment is constitutive of an ethic of life with specific standards to maintain in ageing and dementia. The regular review of the activity plan through meetings with the dementia advice worker, the person with dementia and their relatives constitutes an occasion for this norm to be monitored and stabilized through time.

The translation of a narrative of ‘living well’ into practice can therefore be characterized by this objective of *stabilization* of the condition. This is where

tensions emerge, in the apparent paradoxical relationship existing between this objective of *stabilization* emerging from the contextual and scientific development process of the intervention, and the neurodegenerative nature of dementia which often leads to a substantial progressive decline in cognitive functions and capacities necessary to support an autonomous and active life. As we will see in more detail in the next section, through this idea of stabilization of the condition, the project carries a dimension of controlling which can override the other approach of ‘letting go’ (Aujoulat et al., 2008) and integrating the decline of dementia into one’s identity.

### **Tensions implied by a narrative of stabilization in dementia**

Indeed, when considering the decline present in most of the cases of dementia, this objective of stabilization can appear antithetical at first sight. Experiences of the researchers with the implementation of the pilot phase of the project based on this approach indicate the presence of practical tensions.

#### ***First tension: autonomy as a norm and the implicit devaluation of dependency***

A first tension in the project concerns the risk of conflating *autonomy as a possibility* which should be supported in dementia if the person expresses a preference for it, or welcomes interventions toward this end, with *autonomy as a normative expectation* maintained by the objective of stabilization in dementia and systematically applied to individuals with the condition. Indeed, the former principle does not expect people to act autonomously while the latter actually implies a value judgement when autonomy is not achieved. This value judgement is not necessarily explicit and direct, but it can be implicit and indirect.

This normative expectation of autonomy in the project is perceptible in one of the interviews. A researcher on the project told me how choice can be a burden for some individuals based on her experience during the exploratory phase of the project.

*Yeah, yeah, I talked to people and they didn’t wanna make a decision. It was too hard. They were happy to be told what to do because actually it was too*

*physically tiring to have all of those thoughts going round in their head. 'Do I want my blue jumper or my red jumper? Etc.' And the wife said [her spouse] was getting so agitated, even when she offered two choices that in the end she just laid his cloths out. And he said I am much better now, I was getting so stressed about whether I made the right choice. So we assume people want to make decisions and choices.* (Interview 6)

In this extract, we see how the experience of the individual ends up contradicting the hierarchy of values established by the project placing autonomy at the top. Individuals living with dementia may not always prefer autonomy over assistance and may find well-being within decisions made by proxy. Dependency can be a means to avoid distress, maintain quality of life and identity as this testimony indicates.

The experience described by the researcher in the interview is relevant to nuance the position taken regarding independence in the project. The researcher him/herself points out that the expectation that people with dementia wish to make decisions and exercise their agency can be an assumption which is made about them.

### ***Second tension: the risk of portraying dependency as agency***

In assuming that dementia is a stable condition, decline risks being misinterpreted as a choice. Agency therefore risks becoming *a performance* maintained by individuals surrounding the person with dementia, a projection of the expectations of the carer or the administrator of the intervention on the person with dementia. A pertinent example illustrating this risk is perceptible in the use of narratives that can potentially lead to misinterpreting care and dependency, and mistakenly defining it as autonomy within the project.

A pertinent example of this possible confusion can be found in the mechanisms used by carers to facilitate decision-making by the person with dementia. *Option-listing* is one of these mechanisms. This term is used to describe a specific technique of person-centred care where for instance a carer/supporter asks a person with dementia whether she prefers to drink tea, coffee, or orange juice. The technique consists in enumerating the possibilities available to choose from for the

person with dementia, for instance by enumerating three different drinks. This manner of asking a question can appear less distressing and easier to understand for some individuals with dementia than actually asking the open-ended question ‘what would you like to drink?’ which could lead to confusion due to the large variety of mental pathways that the individual would have to go through (e.g. understanding that we are speaking about drinks, that this is a preference that one should express, recalling previous life events on which this preference is based, etc.). This option-listing technique is a common practice in situations informed by theories of person-centred care.

Let us now consider the response of a researcher on the project to understand the tensions involved in this technique:

*From my interviews, for different people they describe different choices. For example, one carer said: ‘with my mom, if you give her four choices, none of the choices it’s going to be. So for them 3 maybe maximum, or 2. But for some people they want to give more choices. It is helping them to pick the right choices. That is something you have to understand what their situation is.* (Interview 5)

In this extract, the researcher presents the necessity to narrow down choices based on the cognitive capacities of the person following this technique of option-listing to facilitate the understanding of the person with dementia. Although one could argue that this technique is a key means to support agency and autonomy in dementia, the level of interventionism required from the carer in this process should also be emphasized. From the vast array of choices that the person would have made in a life prior to dementia, there only remains two options available in this example, transferring a substantial part of the agency of the person with dementia to the carer and his/her own biases in selecting possible choices based on assumptions of the person with dementia’s preferences. These preferences may be deduced from previous habits if the person applying the technique knows the person with dementia well and is well meaning, but the technique may also be applied within the framework of a professionalized care therefore substantially reducing the chances that the professional carer will know about the preferences of the person. This idea of knowing the preferences of the person from experience

prior to the progression of dementia also implies that preferences used as a basis for the constitution of the list are stable attributes. It therefore implies that taste does not evolve across the life course. Overall, and beyond considering whether this strategy of reducing choices by the carer is done by necessity or not, it already represents a process in which decision-making is substituted. We can therefore already question the categorization of this strategy as an example of actual independence or autonomy.

Furthermore, this researcher mentions the idea of a ‘right choice’ as defined by the carer, supporter, or clinician. This idea of a ‘right choice’ also interferes with independence due to its interpretative dimension based on the understanding of the carer, supporter, or clinician about the possibilities that should be available to choose from for the person with dementia – the ones that are ‘right’ (and implicitly the ones that should be prohibited because they would be ‘wrong’). There may therefore be an inevitable drive for the carer/supporter to propose only the possibilities to choose from that they deem appropriate.

To this regard, Toerien and colleagues (2018) explain how ‘option-listing’ can generate the illusion of choice while implicitly directing the person toward the preference of the carer or the healthcare professional – healthy food or activity for instance – even if they contradict prior preferences of the person with dementia. Independence risks becoming an illusion rather than actually being based on the exercise of agency. This illusion potentially hides the challenges that dementia imposes on autonomy in public narratives and discussions. Hence, qualifying this practice as an example of autonomy could therefore overlook a discussion of how dementia itself can impair independence and the ideal of person-centred care.

The argument here is not about rejecting the practice of ‘option-listing’ altogether, as it can be an adequate means to enable a certain level of choice in advanced dementia for instance. However, there can be an illusory nature to choice which is obscured by ideal representations of autonomy.

Other examples of this reframing of the impairment of dementia as an expression of agency and autonomy can be traced in the project. For instance, an advice for people with dementia written in the handbook supporting the intervention states the following:



*‘[d]oing less of something because you are having trouble with it, or need more support with it? Doing less, or stopping doing something is okay as long as it’s a positive choice for you’.*

In this extract, interrupting an activity is presented as an outcome of choice, of the person with dementia exercising agency. Through this approach the experience of decline in dementia can potentially be reframed as a choice rather than a loss of the ability to continue doing what one previously enjoyed. It therefore risks not recognizing loss and impairment or impeding discussions of decline when it is part of a broader strategy reframing dementia in a positive light.

The use of the idea of compensation by one of the researchers interviewed implies similar concerns in potentially impeding discussions of decline. Following my question ‘[h]ow does the manual respond to the decline that comes with dementia?’ the researcher responded the following:

*The manual gives some foundation through the information. It encourages them to search for new activity. So as the dementia is progressing, it is to the person to adapt some of the activities that they can still do. To come back to my theory, they compensate. (...) we have to encourage them to look at their strength.*

*(Interview 5)*

Just like the reframing of loss as choice, the promotion of compensation for the person with dementia to address their own decline similarly tends to hide the presence of decline behind a reference to decision-making. Compensation, and by extension self-management as referred to earlier by a researcher appear compatible with values of autonomy and self-definition yet become less applicable to individuals in the later stages of dementia and risk generating pressures on the person to maintain autonomy which may obstruct possibilities to discuss experiences of decline for the person with dementia. One may ask therefore to what extent this expectation of compensation can prevent people with dementia from voicing their struggle with decline.

We can draw a parallel between the tensions between agency and decline, and the important questions Basting (2001) posed in her previous work on storytelling in dementia. Basting (2001) set up a play based on storytelling workshops she conducted with people with dementia. While the play was a success overall in

displaying a positive image of dementia to the public, Basting (2001) pointed out her understanding that it may be hard for people directly engaged with dementia to find meaning in this positive vision of the disease, while enduring the daily challenges of a caregiving role and the decline of a loved one. Such difficulty inevitably transpires in the intervention studied in this chapter, and the more general context emphasising the idea of ‘living well’ with dementia. It risks neglecting the issue of suffering and loss in dementia. While the image of a positive dementia may work for the time of a play, it can be more challenging to conceive as a long-lasting objective to implement for a whole intervention as it is exemplified in this section mentioning the risk that independence becomes performative and illusory as the dementia progresses.

### ***Third tension: prevention as a necessary condition for independence***

To overcome the paradox generated by a stabilization narrative seeing dementia as a sustainable social position defined by agency and activity, researchers inevitably had to mobilize elements of *prevention*. Indeed, to some extent, the project sees the ‘behaviour change’ programme it plans to implement as a means to slow down the decline engendered by dementia.

A first intimation of this preventative nature of the project can be found in the following answer from a researcher presenting her perception of the benefits to teach and coach people with dementia to make decisions:

*(...) when you involve in the activity. You make a decision to do it. Yeah, so that is what we want the participant to understand they are still very active, they still can make decisions, because decision is not a big decision I have to go on holiday, which is a lot of discussion. Decision is an everyday activity. When you engage in the activity, that means you are more active and you can make more decisions. For example, if I decided to do some walking. Because of that it makes me feel better; I feel good, so I might decide the next day, I go to a day centre. One thing leads to the other. So, when they understand that, they feel like, ‘ow I still can make a decision’.* (Interview 5)

This testimony suggests the idea of positive progress linked to decision making. This strategy could be beneficial to individuals in the early stages of dementia as it

might help to restore self-confidence for instance. It seems to be therefore more concerned with well-being than with prevention. However, such a benefit seems to be more difficult to sustain as the dementia progresses. Again, the conception of dementia as a stable condition is perceptible in this example.

While this example is limited in suggesting prevention as it can also evoke the idea that being active helps to support confidence and well-being, other replies of the researchers in the study more substantially mobilize this principle. For instance, a researcher [interview 1] refers to the idea of ‘use it or lose it’ within the interview to evoke some of the processes behind the intervention. In the same way, another researcher on the project uses an interesting metaphor to present how inactivity can harm cognition:

*Me: So being involved helps people retain capabilities of decision making?*

*A researcher: Yes, for example if you leave a bike in the rain it gets rusty. And then at some point you can't ride your bike anymore because the rust is too much. So you know, if you keep things going as much as you can and just make those little adjustments, put a bit of oil... you know that's gonna actually help people in the long run. (Interview 4)*

By using this metaphor of the rusty bike, this quote also illustrates the idea of ‘use it or lose it’. What could be described as ‘cognitive immobility’ in the researcher’s explanation is seen as deleterious. Like a bike in the rain, the brain accumulates a form of metaphorical ‘rust’. This example presents how the project ensures part of the stability implied by the narrative of independence in dementia by encouraging individuals to sustain autonomous living as much as they possibly can through adequate lifestyle adaptations and regimes of health. These regimes of health rely upon physical and cognitive activity resembling instances of brain training presented in the second and third chapter of this thesis which also mobilize this idea of ‘use it, or lose it’.

Another factor indicating the presence of prevention is reflected in the priority that the project gave to people with mild dementia as the main beneficiaries of the intervention, when the loss of capacities is limited. As a researcher explains:

*I can't remember what the inclusion criteria... I mean my understanding is sort of people with mild dementia or possibly mild to moderate dementia who is still at that stage when they can potentially maintain some level of independence. So, I don't think it would be used for people with severe dementia for example. But, ... I will have to check the inclusion criteria again... But I think a level of independence... independence can be conceptualized at all stages. So, if somebody is living in a care home and highly dependent, it may still be that they can independently feed themselves or choose what they want to wear that day. Or, they can make decisions about various things, often that gets done for them, and they are not encouraged or allowed to remain independent on these slightly more limited things. But I think at all stages of the dementia journey, we can still be thinking about independence to some degree. (Interview 2)*

This choice from the project team for individuals with mild to moderate dementia shows how ideas of 'maintenance' and prevention are inevitably connected to prioritizing certain groups of individuals with dementia, with the idea being to slow down the decline in their capacity to live autonomously. Although the researcher mentions how independence can also be relevant for more advanced dementia, we see that the way in which the intervention was designed, and how it specifically targeted individuals in the early-to-moderate stages of the condition, it inevitably omitted individuals with advanced dementia.

## **Technologies of omission naturalizing social exclusion**

These previous sections showed the presence of tensions in practical applications based on the abstract narrative of 'living well' in dementia, and how they gave priority to individuals in early-to-moderate stages of the condition. We should now use these tensions to more critically assess the principal ideas composing this narrative and the nature of social exclusion associated with it.

### *Tensions challenging the narrative of ‘living well’ in dementia*

This intervention indicates how practical applications of the narrative of ‘living well’ in dementia give central stage to encouraging agency and decision making. An important ramification of the ‘living well’ discourse has generated important claims for the virtue of a *citizenship approach* in dementia (Bartlett, 2016; Kontos et al., 2017; Yates et al., 2019, p. 1616). Ideas of empowerment described in the interviews above closely follow novel citizenship approaches to dementia (Bartlett & O’Connor, 2007, 2010). Indeed, these approaches give similar importance to notions of empowerment and the centrality of individual agency in implementing changes in daily life, only impaired by negative power relations imposed by people’s social environment. As Kontos and colleagues (2017, p. 183) explain regarding what they call ‘relational citizenship’, this is ‘a model that stands to advance the discourse on citizenship by offering an important rethinking of notions of selfhood, entitlement, and reciprocity, which are central to a sociology of dementia’. By introducing ‘relational citizenship’, these authors expanded the approach beyond the realm of relations of care previously advocated by Kitwood (1997b) in order to frame the inclusion of persons with dementia as a matter of citizenship and highlight the oppression of people with dementia by society and their existence as a marginalized group (Bartlett & O’Connor, 2007).

However, the first tension presented in this chapter described how researchers had to deal with the fact that independence may not always be desired by the person with dementia because it is simply distressing. By extension, living independently may not always be feasible for the person with dementia due to the extent of her impairment. Hence, if we look at citizenship in dementia through a lens acknowledging this tension, we should question whether individuals always wish to engage with their dementia through this lens of independence and citizenship. Is this dimension of citizenship not creating novel norms around dementia which may not always be attainable, and could therefore become exclusionary for some?

By reviewing the strategy of option-listing, the second tension presented in this chapter explored how there is a risk for the promotion of agency to not recognize the implicit directiveness of these strategies and subsequently overlook the existence of decline and impairment. Hence, we should ask whether a citizenship

approach does not carry a similar risk of unconscious directiveness and non-recognition of decline for a part of the people with dementia? Just as there is a risk of bias in the idea of the ‘right choice’ for people with dementia, there is also a risk of bias toward the ‘right citizenship’ for individuals with the condition. Gilleard and Higgs (2010) previously characterized the agency of individuals encompassed by the social imaginary of the fourth age in relations of care as a ‘hyper-reality’, making choice a projection of the preferences of the carers and staff. Similarly, this risk of projection should be raised in applying citizenship in dementia as it can misrepresent the needs of those beyond the mild stages of the condition who may not have expressed these claims toward citizenship themselves.

As we have also seen through the third tension in the project, independence in dementia is inevitably connected to stabilization, and stabilization requires prevention to remain sustainable. This promotion of activity, stability and prevention is an important aspect of the approach of community-based social interventions for dementia more generally (Burgener et al., 2009). When placing dementia into the broader context of ageing, one can see how approaches based on stability and prevention of cognitive and physical decline relate to the objectives of *active (cognitive) ageing*. The narrative of ‘living well’ in dementia strongly echoes the principles developed by this ideal dominating current ideological approaches to ageing and health across Western countries and beyond (Gilleard & Higgs, 2010; Lamb, 2017).

This similarity of the ‘living well’ discourse to active ageing probably accounts for its positive reception among policy makers, advocates and researchers. Yet, in sharing a similar approach to decline in relation to active ageing, this narrative of ‘living well’ in dementia also shares its limitations. Burgener and colleagues (2009) whose theory inspired the intervention presented above note that community-based, non-pharmacological interventions often rely upon theories of neural regeneration and plasticity. We can see more clearly how the intervention presented in this chapter with its mobilization of principles drawing on neuroplasticity – the idea of ‘use it or lose’ in the project – and other similar community-based interventions connect to the practice of brain training I presented in chapter two and three. There may be differences in term of the intensity between the mobilization of neuroplasticity in brain training and in these psychosocial

interventions. However, the allusion to prevention in ‘living well’ discourses remains a fundamental issue due to its antagonistic relationship with decline in the absence of evidence supporting prevention strategies for dementia. This discomfort with decline is shared with active ageing more generally.

### ***Technologies of omission naturalizing social exclusion***

Accordingly, the most important shortcoming of current strategies relying on the discourse of ‘living well’ in dementia, including those based on the novel idea of citizenship in dementia, is their inherent *omission* of decline, and the individuals which are most affected by it, those with more advanced dementia. This chapter therefore proposes to categorize strategies and interventions of ‘living well’ in dementia, those who attempt to stabilize dementia through the promotion of agency, activity and prevention, as *technologies of omission*. As this chapter illustrated, technologies of omission are limited in their ability to support individuals as they progress along the trajectory of decline.

Unlike technologies of distinction and ascription which socially positioned people with dementia in a trajectory of decline encompassed by the social imaginary of the fourth age, technologies of omission play a more passive role in this process by simply overlooking the condition of those individuals with advanced dementia who are only secondary beneficiaries of this type of intervention. While it may have limited effects when being promoted in a single intervention like the one in this chapter specifically targeting individuals with mild to moderate dementia, the sheer dominance of this narrative in current dementia strategies becomes more concerning because it accepts, or even naturalizes the social exclusion of the most vulnerable and dependent individuals with dementia as unavoidable.

Something that technologies of omission have in common with distinction and ascription is their ability to generate *othering*. They prevent us from adequately assessing the needs of those whose conditions prevent them from benefiting from these interventions. Kaufman (1994), Agich (1990) or Kittay (2011) already considered this issue with regard to impairment in care for instance. As Kaufman (1994, p. 47) emphasizes, citing the position of Agich (1990), “[i]n a recent assessment of autonomy in long-term care, George Agich notes how abstract ideals

of autonomy are counterproductive and that an adversarial approach to independence/dependence prevents us, as a society, from developing adequate models of care and choice”. Kittay (2011, p. 55) also problematized the use of autonomy as a norm in care in the negative impact that it has by disregarding any dependency as problematic. Independence becomes a pressure due to its normative nature. It can hinder our ability to assess and address decline, and obscure our ability to make it an object of reflection that can be manipulated as part of societal discussions. To this regard, Hazan (2011a, pp. 13–14) points out that ‘seductively obscure terms such as empowerment, resistance, resilience, gerotranscendence, and spirituality have been amply employed in recent gerontological discourse to serve as a vocabulary in the moral economy of aging (Minkler & Estes, 1991), thus absolving society from practical accountability and responsibility for the unsettling category of the socially disenfranchised’. Technologies of omission are inevitably preventing us from considering the more complex questions posed by the corporeality of decline.

## **Conclusion**

As a means to trace another important process of social exclusion present in current technologies and interventions for dementia, this chapter explored the underlying tensions behind the novel narrative of ‘living well’ in dementia which presents itself as a means to address the stigma linked to previous biomedical narratives emphasizing loss, infirmity and dependency. A few researchers such as McParland et al. (2017) or Gilleard and Higgs (2020, p. 120)) emphasized the inherent exclusion that this narrative generated toward those who are most affected by dementia due to its normative expectations.

This chapter proposed to further explore this critique by looking at the actual application of this narrative in an intervention. It proposed an analysis of the responses of 6 researchers and a PPI participant involved in the development of an intervention supporting people with dementia to remain independent after a diagnosis. It highlighted that such intervention, through its promotion of agency, activity and empowerment implicitly conceived dementia as a stable condition. It presented how this conception was a source of tension at three different levels: 1)



in how it elevated independence as a norm, therefore involuntarily devaluing dependency; 2) in how an emphasis on agency in a progressive condition affecting decision-making could overlook issues linked to dependency; and 3) in how it implicitly relied upon prevention to stabilize dementia, therefore prioritizing individuals in the early stages of the condition with the hope that they could stay independent for longer, therefore leaving those in the later stages aside.

This chapter then proposed to depart from the tensions highlighted in this practical application of ‘living well’ to further assess the consequences of this narrative in term of social exclusion and generalize this specific case study. It specifically questioned the idea of citizenship contained in this narrative based on the tensions highlighted in the intervention. As a result, it proposed to characterise technologies and interventions relying upon this narrative as *technologies of omission* characterized by their limited ability to respond to the exclusion of individuals who are most dependent and impacted by dementia, especially when this type of intervention is prioritized across society as it is increasingly the case today. This chapter therefore presented how the multiplication of this type of intervention can result in the naturalization of the social exclusion of these individuals, portraying their condition as inevitable, and preventing us from asking more complex questions around care and life in the most advanced stages of the condition that should be addressed to palliate this exclusion.

While this chapter was concerned with large scale interventions and strategies prioritizing a certain narrative of dementia which appears more valuable to address the social exclusion of individuals in the early stages of the condition, the next chapter will more thoroughly consider the manifestation of this narrative of citizenship as it is advocated by people with dementia themselves. It will pay attention to the tensions that can emerge around identity beyond this issue of omission, and to the new divide that it could create among people with dementia themselves beyond the already existing divide in later life between third and fourth age.



## **Chapter 6: Tensions in identity: distinction among advocates and experts with dementia**

The previous chapters of this thesis explored the existence of distinction, ascription and omission as important components of a process of social positioning generating social exclusion in dementia. These chapters presented the role of collective representations informed by the social imaginary of the fourth age within these processes. They also pointed out their capacity to position people with dementia negatively, or to overlook the existence of those who are less able to engage with the expectations of active cognitive ageing. Accordingly, the work presented thus far, indicated the presence of an important yet neglected cause of social exclusion in later life today. In the previous chapter on technologies of omission, we reviewed how tensions emerged around the abstract principles of independence contained in the ‘living well’ discourse when researchers translate these principles into practical interventions for people with dementia. We saw how this process led to assumptions about the needs and preferences of people with dementia, especially the ones who are more dependent as a result of impairment. These tensions pointed to the existence of a social division in later life which has not been acknowledged properly in research and policy for dementia. They also indicated how social processes either enacted by individuals in later life, or researchers and policy-makers maintain or foster this divide by negatively positioning people with dementia, or positively positioning them while omitting those who are most dependent. One interesting question that remains is how does social positioning operate among people with dementia themselves?

The diversification of the condition due to the expansion of diagnostic categories further indicates the important role that social positioning could play among people with dementia. In recent years, we have observed important transformations in the diagnosis of dementia with a push toward earlier diagnosis and the identification of forms of ‘predementia’ in the population (e.g. prodromal dementia, Mild Cognitive Impairment (MCI), or subjective cognitive decline) (Beard & Neary, 2013; Swallow, 2016; van der Laan, 2016). This transformation has had an important impact on the identity of people with dementia with the diversification of their experience of living with the condition. Indeed, individuals are now

diagnosed earlier with forms of mild dementia, or conditions often assimilated with predementia phases such as MCI. Has this diversification of identities related to dementia led to different social positions, some of them being more excluded than others? And how has this diversification of identities influenced the existence of actions by people with dementia to claim more rights and recognition of their position in society? What effect did it have on the social inclusion of people with dementia across society?

These important transformations in diagnosis and policy in dementia and previous social changes around disability rights and identity have influenced the emergence of a social movement of people living with dementia. Following examples from other social movements orientated around a health condition and the involvement of patients in decisions around health, advocates with various neurodegenerative conditions have regrouped under a common umbrella of dementia and have increasingly been included as ‘experts by experience’ in research and policy for instance in the United Kingdom (Parveen et al., 2018; Preston-Shoot, 2007). In society’s attempt to address social exclusion in dementia, the social movement of people with dementia is gaining importance in defining the meaning of dementia according to people with the condition in research and policy (Bartlett, 2014; Bryden, 2015; Weetch et al., 2020). We therefore see that this social movement is an important site to study this diversification of identities in dementia and the different degrees of inclusion of the individuals who compose it, as well as their influence on the social configuration of later life. It is therefore relevant to ask how this social movement is itself concerned by possible issues of social positioning in dementia who play an important role in social exclusion. It is also relevant to ask to what extent can dementia become the basis of a social movement based on identity, and whether these possible issues of social positioning play a role in this unity.

At the centre of this matter lays an important question about the possibility for health and dementia to join the ranks of other important dimensions of identity such as gender, sexual orientation, ethnicity, or disability in constituting New Social Movements (NSMs) during the second half of the twentieth century (Kelleher, 2001; Scambler & Kelleher, 2006). NSMs refer to the new ways in which forms of

collective mobilization of citizens around shared social claims have been concerned with matters of social and personal identity, lifestyle and environmental choices in late capitalist society, rather than about the organization of relations of production and the distribution of benefits as it was previously the case in pre-war industrial society (Scambler & Kelleher, 2006). Hence, claims have shifted from class interests, to identity, and the recognition of difference. Some of these movements have based their collective identity on illness experience, and the normalization of personal identity affected by ill-health as a difference that should be recognized by society (Brown et al., 2004). As this chapter will present however, the reliance on illness as a dimension at the centre of a social movement is not without tension. This chapter will therefore ask: can dementia be celebrated as a valuable difference, rather than an unwanted part of one's identity?

This question appears especially relevant given the importance that is now attached to involving people with dementia in both research and policy around their condition, as well as the increasing promotion of a disability approach to dementia (Mental Health Foundation, 2015; Thomas & Milligan, 2018; Williamson, 2015). Relatively little attention has been given to the issue of the social positioning of people with dementia themselves in constructing their identity and standing in society after a diagnosis of dementia. Due to the diversification of conditions and abilities encompassed by the label of dementia, a small section of the population of people diagnosed with dementia has increasingly engaged in identity reconstruction through self-help, support groups and collective mobilization (Beard, 2004a; Beard & Fox, 2008). It seems therefore relevant to also ask the following questions as part of this thesis: How is the social division around dementia and later life along the line of the third/ fourth age divide recognized by people with dementia themselves? How does such a divide manifest itself among people with dementia and how does it impact their life and sense of identity? Can we trace the existence of processes of social positioning such as *distinction* and *ascription* in the attempts of people with dementia to reconstruct an identity after a diagnosis? And how does it influence the normalization of dementia, and the constitution of a unified social movement based on dementia as presented in the previous question above? Hence, this chapter will explore how collective identity is being constructed among people with dementia after a diagnosis and how social

positioning manifests itself among people with dementia by looking at identity reconstruction among experts by experience with dementia and advocates with the condition who contribute to different degrees to the social movement of dementia.

As a case study to ground the argument of this chapter, I will consider the particular action of these experts and advocates with dementia who are part of a dementia expert group. This is an institutionalized group of people with mild-to-moderate dementia active in reviewing research and policy for different projects and organizations, hosted by an association promoting the rights and well-being of people with the condition across these domains. This case study is based on ethnographic research conducted over eight months looking at the activities of this dementia expert group, and their actions contributing to the integration of people with dementia in shaping policy and research, and to the social movement of dementia. This research relied on participant observation, an important method in anthropology and the social sciences ‘in which a researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one of the means of learning the explicit and tacit aspects of their life routines and their culture’ (DeWalt & DeWalt, 2011, p. 1). My active engagement with this group of people with dementia occurred as part of their meetings throughout the research period, for instance through support in the moderation of the meetings of the group, and the review of the topics discussed, through formal presentations and informal discussions during meetings, meals and breaks. Access to the meetings was granted thanks to the support of the organization hosting them, and keen support of the members of the group. The participant observation during the meetings of the group led to the organization of two focus groups with parts of its members at the end of this observation period (cf. *chapter 1: methodology* for details).

Using data from this research as an articulation, this chapter will explore the social position of experts and advocates in society and their experience of discrimination and exclusion, as well as their modes of resistance to this exclusion. It will then explore the challenges they face in their attempt to reconstruct an identity with dementia, and the implication that these tensions linked to identity can have in the creation of a new social movement of dementia. More specifically, it will explore this matter in the recent approach of members of this social movement to advocate

for the recognition of dementia as a disability in order to address social exclusion. It will present how *distinction*, the process of social positioning presented in Chapter 2 and 3, constitutes an important challenge for the social movement in its objective to address social exclusion.

### **Characterising the action of the dementia expert group**

Before starting this exploration, we should first attempt to define the action of the dementia expert group which constitutes the basis of this exploration to present how findings inform us about modes of involvement and mobilization of people with dementia in society. The group is primarily constituted by *experts by experience* who have been diagnosed with a condition (or combination of conditions) causing dementia (e.g. Alzheimer's disease, Lewy body dementia, vascular or frontotemporal dementia) and whose membership results from their nomination by their local dementia associations gathered under the umbrella of a larger dementia organization which hosts the group. In this role, they support the association by reviewing its policies and research projects, and the ones of partnering scientific consortiums and associations, therefore making sure that all these stakeholders consider the opinion and experience of people with the condition in their action. The action of experts by experience is therefore not characterized by a bottom-up collective mobilization, yet by an advisory role within a series of organizations involving many other actors without dementia such as professionals from the field of dementia, researchers and project officers among other. Their existence into an existing entanglement of various stakeholders echoes Beard's description of the Alzheimer's Disease movement generally, its 'more macro national approach easily converted into an interest group aimed at making policy changes from within existing social structures' that she sees as contrasting with the AIDS movement which kept its 'local grassroots focus' (Beard, 2016, pp. 171–172). The action of these experts by experience follows a more general trend within the health domain which has been characterised by the increasing, yet limited and insecurely established, involvement of users' movements in shaping welfare and

research policy during the past fifty years, with different degrees of influence depending on sectors (Barnes, 2009; Preston-Shoot, 2007).

While it is difficult to define the position of this dementia expert group in terms of advocacy given its advisory role and entanglement with other stakeholders, several of its members more readily qualify as advocates following their will to transform the public opinion and institutional structures and policies impacting dementia. This is a key characteristic of social movements more generally (Melucci, 1980; Sorensen & Siemsen, 2006; Whittier, 2017), and reflects the experience of other health movements based on illness experience (Brown et al., 2004; Kelleher, 2001; Scambler & Kelleher, 2006). Brown and colleagues (2004) previously studied the role of new social movements in putting embodied illness experience at the centre of their actions as well as providing the basis of a social critique of policy, the availability of services and of patient rights. Some of these members belong to a wider network of advocacy groups spanning across different countries that embody this grassroots mobilization by people with the condition. They are also public figures engaged in a cultural and political struggle to change the standing of people with dementia in society for instance by advocating for rights and recognition of the citizenship of people with dementia. Making a distinction between experts and advocates may not even be relevant with regard to their contribution to the social movement of dementia if we follow the characterization proposed by Klawiter (1999). Indeed, Klawiter (1999) argues that both experts, advocates, and other actors such as scientists and politicians allied to the movement contribute to a culture of action oriented toward the transformation of the standing of people with particular conditions in society, in this case being dementia.

Overall, by acknowledging the variety of perspectives on dementia within the group and its constitution through nomination by local dementia associations, this chapter does not consider it as a homogeneous entity with a unified agenda beyond the role set by the association that hosts them and structures their mission. The chapter recognises their role as part of a broader ‘embodied health movement’ (Brown et al., 2004) oriented toward the recognition of their experience, rights and needs in regard to policy and research. Departing from Brown and colleagues (2004) however, this chapter will more specifically look at how a health condition



such as dementia can become part of a strategy which has extended the claims of ‘embodied health movements’ toward the recognition of a unique identity and the normalization of this identity. Indeed, the dementia movement’s advocacy for an approach to dementia based on the social model of disability, a key exemplar of this normalizing process, echoes a view made by several members of the group during the ethnographic fieldwork presented in this chapter.

Besides this concrete claim for the recognition of dementia as a disability, other perspectives and actions of members of the group also translate the importance that they attach to shaping the narrative that characterizes the experience of dementia, and the identity attached to it. Hence, as part of this movement, this chapter focuses on the personal experience of its members in reconstructing an identity with dementia, their motivation to participate in this dementia expert group, and the actions they take within and beyond the group. It relies on the notion of ‘tertiary deviance’ (Kitsuse, 1980; Sorensen & Siemsen, 2006) to understand how individuals with dementia recuperate a previously stigmatized and excluded condition and transform it into a dimension of individual identity that should be normalized. It therefore allows us to understand how they give meaning to their lives with dementia, to the integration of this diagnosis as part of their identity, to their relationship with other people with the condition, and indirectly considers the nature of their contribution to the social movement of dementia more generally. This chapter also explores how this attempt unfolds in practice, and how tensions can emerge in the construction of this collective identity through the concept of *distinction* presented above.

### **Social position of members and their experience of social exclusion**

Many, if not all, the experts and advocates who participated in this research describe instances where they were socially excluded based on their condition. This experience of social exclusion is an important factor influencing the decision of many members to join the dementia expert group. A frequent form of discrimination leading to this exclusion experienced by these members concerns other people’s *doubt about the validity of their diagnosis*. During one of the group

consultations part of this research, we discussed the manifestation of this doubt and its possible origin with members. To this regard, a member interviewed as part of the two focus groups in this research described the link that people enacting this kind of discrimination establish between understandings of ageing and dementia. Here is a relevant extract of this discussion:

*Interviewer: “But does [ageing] affect yourself in the kind of stereotypes that people can make, or assumptions that they can make about you in everyday settings?”*

*A member: “Of course, because they say it is only an older person’s illness, and how did you get it? Ow you couldn’t have it? It is just for older people.”*

As we read in this quote, this person’s experience of dementia is unvalidated by the interlocutor because of the understanding that her appearance does not correspond to the one of a person who has dementia, being usually in later life. This kind of discrimination was common among some members of the group I encountered during my fieldwork. They developed dementia earlier in life following a rarer type of dementia such as Lewy-body, frontotemporal or vascular dementia. They therefore often appeared younger than those who are affected by the more commonly diagnosed Alzheimer’s disease which usually develops in later life. Some were also diagnosed at an early stage of Alzheimer’s disease.

The appearance of several advocates which diverges from this common association between dementia and later life therefore played an important role in causing this discriminatory judgement. Hence, this testimony illustrates how the fact that dementia is primarily a condition affecting people in later life can lead to assumptions that discredit younger people with dementia in the group.

This discrediting of the diagnosis is widespread. It may relate to one’s younger appearance linked to an earlier diagnosis, but also to the intensity of the impairment as people with rarer forms of dementia or diagnosed earlier can happen to conserve more cognitive capacities or autonomy than people diagnosed at an advanced stage of Alzheimer’s disease, or people in later life affected by various comorbidities and other age-related impairments. For instance, in 2017, the advocacy organization

Dementia Alliance International organized a webinar called the “But you don’t look like you have dementia” Master Class<sup>23</sup> in which members diagnosed with dementia gave testimonies about their experiences of this kind of discrimination based on doubt. Most of the participants described their continuous experience of this doubt that other people expressed toward the validity of their diagnosis, how it made them feel they were impostors and added to the distress that they already experienced as a result of their impairment. This experience of discrimination seems to primarily happen after the person with dementia publicly discloses her diagnosis and appears either younger or more competent than the imaginary of decline associated with dementia suggests. Interestingly, this process reverses the convention that usually sees felt stigma – the subjective awareness of one’s socially discredited condition – preceding the existence of enacted stigma – the actual stigmatizing behaviour of others, a point described by Scambler (2009, p. 446). This reversal can be explained by the process of coming out as a person with dementia as a form of ‘visibility politics’ – an act affirming one’s desire to publicly normalize difference in the frame of a social movement (Whittier, 2017). We will discuss this aspect of visibility more thoroughly later in this chapter.

This discrimination through enacted stigma can also take a different shape by assuming that the person is incompetent and profoundly dependent, as this member of the group explained during one of the two consultations:

*I think stigma is certainly one thing that brings us all together. Because in every country there is an element of stigma. But I think that the lack of understanding about our illness, like for [this other member with dementia], how we are able to live in our home, what is that supposed to mean? it doesn't look good. It is ridiculous people are in their understanding of what your illness is. They just don't understand that you can still function. I think this is one of the things that certainly my four years here, in the group is that [this] thing is there, stigma, and lack of understanding that we are still able to carry on, and have a life, do whatever we were doing in being involved in our community or carrying on*

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<sup>23</sup> Dementia Alliance International (2017). DAI Master Class: “But you don’t look like you have dementia”. Retrieved from <https://www.youtube.com/watch?v=Hj9elmWa1Zg>

*taking care of our home, our families. Not the same as we were doing in the past you know we have a deficit.*

In this response, the person described how she was *impacted by the systematic doubt that people had about her ability to participate in society*. In her description, this assumption of incapacity, and its related doubt about the diagnosis of dementia relates to a widespread perception that the condition is inevitably causing incapacity and the end of an autonomous life. This person describes this assumption as a stigma, a negative label which often affects her relationship to others and results from a lack of understanding of the condition. It is inevitably mediating her inclusion in society. While this member recognises that the deficit is present, she points out that it does not prevent her from being able to sustain an autonomous life and her engagement with others.

As she explains, this assumption of incapacity plays an important role in the motivation of individuals to join the dementia advisory group, and for some of them to actively take part in the social movement of dementia.

Beyond mediating relationships, this stigma of being either seen as an impostor or marked as incapable seems to have a more concrete impact on the life of people with dementia. It influences care trajectories and the availability of support for individuals with mild-to-moderate dementia as a caregiver interviewed during one of the two consultations explains:

*For me as a caregiver, I went to ask help just to talk with somebody, The nurse who works in the church, she has asked me do I still want to be married and what kind of care home do I want to put my husband in ? That was the support that I get. I said I don't wanna talk with you anymore. And that was somebody who is from our church who I trusted.*

In this quote, the carer describes the assumption made by the nurse about her husband, a man who otherwise maintains a relatively autonomous life at home despite his condition and is an engaged member of the dementia expert group. As it appears in this question by the nurse, the assumption of incapacity directly affects the solution proposed to this carer and the way in which it is proposed. It takes the shape of a third person talk about the person with dementia to the carer, assuming that the nursing home is the most adequate solution for her husband. This third

person narrative represents an important form of othering excluding the person with dementia through an alienating and unfounded attribution of incapacity and vulnerability (Higgs & Gilleard, 2014). This manner of asking the question therefore denies the husband's capacity to decide his trajectory of care – he is not involved in the discussion by the nurse – and his capacity to remain at home and live autonomously with the support of his wife.

These different quotes therefore present how this form of discrimination works in two different ways among participants in the dementia expert group: either by 1) denying the validity of the diagnosis of the person with dementia, or by 2) denying the cognitive capacity and personhood of the person with dementia. This doubt about the diagnosis or assumption of incapacity are forms of prejudice which have been regularly described by the members of the group from the start of my fieldwork. In other instances, some members mentioned how staff in airports and other forms of public transport for instance would not believe that they required assistance. Most discriminations and their resulting social exclusion emerge from these situations denying the validity of one's diagnosis, or misrepresenting one's abilities, challenges and difficulties related to dementia for the members of the group who described them.

### **Norms of ascription defining resistance**

Members of the group have found in their involvement in the group, and in advocacy for several of them, a means to challenge these discriminations based on assumptions about their capacity or the truth of their diagnosis. They mainly resist these assumptions of incapacity by constituting an antithetical narrative of living with dementia. Their strategy of communication therefore relies upon affirmations of capacity, agency, independence and the validity of their diagnosis and experience of the condition. For instance, a substantial public intervention of the dementia expert group in 2018 during the annual international conference of the organization hosting them illustrates this strategy:

*They have been carefully rehearsing this moment throughout preceding meetings of the group. They stand up in front of a large audience, seemingly*

*around 200 professionals from the field of dementia research, care and healthcare policy. Ten members of the group are present. They sometimes travelled thousands of kilometres by plane, taxi and train from their respective countries with their supporters to present despite the challenges brought about by their health conditions. I take a seat in the middle of the audience. They seem to look at the crowd with calm and confidence. Several of them have presented at conferences relating to dementia before and some are actively taking part in public events relating to dementia in their own countries, meeting with researchers, local and national authorities to share their experience of dementia.*

*Under the diffuse lights of the conference room, members of the group are sitting in a single row in front of the audience. They each take turn to stand up and share their experience of dementia, explaining how they find the strength to live with its challenges. The rationale of their intervention follows a statement that some of them repeated on multiple occasions during my fieldwork: it is about sharing their experience, and not representing others. 'I'm an expert in my own experience' they would say.*

*A member stands up, she does not speak English yet spent time with her relative to translate her message prior to the day. While she reads in her mother tongue, a slideshow in her back displays the translated text to the gaze of the public, as well as a picture of her and her relative. Here is what she says:*

*"My name is Sarah, and I have Alzheimer's and I believe I can use my experience to increase our society's awareness of what it's like to live with Alzheimer's. I show people what it's like to live with dementia and how I fight stigma and stereotypes about the condition.*

*If you ask me if I am happy, I say yes, no doubt. I had to accept this disease and learn how to live with it, but I'm happy.*

*Don't look at me as a person with dementia. We all have different abilities and not all abilities are different with Alzheimer's disease. I still feel able to do many things and take pleasure in life."*

*A few more experiences are provided and they often convey a similar message. The round of presentations finishes with a speech by a member of the group from another country, also translated. This discourse illustrates his life in his country, his struggle with the condition, and the many ways in which he finds support, thanks to assistive technologies for instance. This is a joyful yet engaging talk. The presentation comes to an end. The members raise their voices, addressing the audience in a carefully planned intervention:*

*“Many voices together make our voice stronger”*

*Following their presentation, many attendees stand up and applaud with enthusiasm. The presentation is then followed by questions from the audience. During this question session, one of the members of the group will remind the audience that beyond the humoristic tone of the presentation, we should not forget that ‘dementia is a terrible disease, and if you don’t joke about it, you have nothing else’.*

*Following a question from the audience, a member speaks about early onset dementia and her keenness to keep a professional activity despite the condition. Proactivity and acceptance are also part of the answer given by a member’s supporter when she mentions accepting the diagnosis and moving forward. She warns of the risk attached to ‘sitting at home and doing nothing’ while having dementia. Others also present this interest of keeping active, exercising and doing sport, training one’s memory, keeping oneself busy. Another member points out that this strategy of keeping active always co-exists with the difficulties, the stigma and third person talk experienced by people diagnosed with dementia.*

This vignette essentially describes how the group constitutes a narrative and identity with dementia through its engagement with the public. Indeed, the principal purpose of this presentation is to narrate the life of people with the condition, the challenges and positive experiences that this experience involves. Such a presentation aims at articulating a different narrative of dementia to a public composed in this case of professionals in the field of dementia who already have their own narrative of the condition driven by their discipline or professional

affiliation, for instance to biomedical research, psychology or medicine. The objective of this presentation is therefore to constitute an alternative understanding of dementia and the identity of individuals who are affected by it, to challenge aspects of these other narratives which affect their lives negatively.

The identity of dementia that this public performance wishes to constitute is characterised by a display of agency and decision-making capacity, a desire of self-determination based on the ‘voice’ of people with dementia, and the continuity of an active and productive lifestyle reminding people that a diagnosis of dementia does not signify the end of one’s engagement with society. It is therefore in direct opposition to the stigma presented in the previous section which assumes incompetence and dependency.

Members of the group construct this narrative through many other platforms allowing for a wide reach and continuous engagement with the public. Some members have been writing books and blogs about their life with dementia<sup>24</sup>. Outside of the group, examples of such publications by individuals with dementia include successful books such as *Somebody I used to know* by Wendy Mitchell, *Dancing with Dementia: My Story of Living Positively with Dementia* by Christine Bryden (2005) or *What the hell happened to my brain? Living Beyond Dementia* by Kate Swaffer (2016). They all participate in the constitution and circulation of a different narrative of dementia, told by people with dementia themselves. Some members I spent time with also have an important social media presence, address politicians and regularly collaborate in research on dementia.

Disclosing one’s diagnosis of dementia is instrumental to this public engagement and the reconstruction of the narrative that surrounds dementia to the extent that some members describe ‘coming out’ with dementia as a duty or responsibility. As an advocate and member of the group pointed out during one of the interviews:

*It is part of your own responsibility that you tell other people that are close to you, probably the ones who are very close to you know this already but the ones around you must know that you have this disease.*

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<sup>24</sup> References to these books by some of the advocates part of this research will be kept anonymous due to ethical considerations.



Disclosure plays an important role in this notion of *visibility*, these public performances aiming at transforming the meaning attached to this condition. It seems particularly compatible with the strategy of advocates to build a new narrative of dementia, as it helps the public understand that their lifestyle and engagement is also part of a life with dementia. To make dementia a positive label through public performance, advocates need to recognize and integrate this label to their identity first. This strategy aligns with the practice of identity politics which is part of the action of NSMs described by Whittier (2017), and that she qualifies as ‘visibility politics’. This strategy of visibility seemingly connects with the notion presented above that presents how felt stigma is not necessarily present, or insufficient to affect strategies of advocacy and prevent many people from the group to disclose their condition. Iterative practices and discourses, small objects like the disability card always carried by a member of the group in his wallet, or a bracelet indicating that one has dementia that another member always wears around her wrist, exemplify this practice of being visible, enabled by the belonging of members of the group to a social movement. These symbols create a visible identity with dementia and signify the affirmation of their rights as disabled citizens. This affirmation of an identity with dementia through public performance, diagnostic disclosure, and material expressions and symbols is constitutive of this novel narrative of agency, autonomy, and capacity.

### **Distinction as a resistance to ascription in advocacy**

As a result of this novel narrative of dementia emphasizing agency, self-determination, activity and engagement, the identity with dementia translating loss and dependency becomes an identity to keep at a distance, as this quote presents:

*And you know people assume we cannot do things, and they only assume by hearing a word of Alzheimer's that they think is for 80 year old, or 90 year old, not for somebody that was 57 you know, so I think it is education, and education is the key. Do you know what else I have discovered over the years, it is by being visible in that community. Of course, by being out I forget my phone, I forget my keys in the supermarket, I do all the things we all do, but you know I think at the end of the day I am*

*still doing them. I am still taking my driving test every year and drive my car. I think by being visible, we are slowly trying to break that down. But we are a long way from it.*

In explaining how the meaning of dementia is often associated with a certain conceptualization of advanced old age marked by incapacity, this member perceives her condition as standing out from the usual dementia. She emphasizes that dementia in advanced old age implies a diminished participation, a perspective often circulated in popular understandings of later life and dementia (Higgs & Gilleard, 2014). She does not recognize herself in this identity. In order to redress this inadequate identity, she explains how her objective is to construct a narrative of the condition which operates as a *distinction* from incapacity. Hence, she does not necessarily question the norms which associate advanced old age, dementia and withdrawal from the community but points out that it is inaccurate to describe her, that her identity is different from this portrayal of the condition.

To dissociate herself from this negative identity, she explains how she engages in a series of visible public actions aiming at demonstrating to others that dementia does not necessarily signify incapacity and dependency. By engaging with her community, by continuing the activities she used to do before the diagnosis such as driving the car or going to the supermarket despite her impairment, she hopes to change the narrative of dementia from dependency to capacity. This strategy of distinction adopted by several members of the group plays an important role in their resistance to negative ascriptions.

The existence of this distinction can be subtle and implicit, for instance within this earlier reference to age. However, it can also be more straightforward and directed toward dependency in dementia. A discussion with a member involved in advocacy during one of the two focus groups provides a clear example of this distinction at play. This member explains to the carer of another member with dementia who is among the youngest of the group with a diagnosis to be patient while waiting for him to be willing to disclose his diagnosis to people around him and in public settings. This member then explains the interest of this disclosure:

*Give him the time, he will say it [that he has dementia] because, (...), one point (...). The media, the mass media have a very important part*

*to play, they have to show positive stories, they have to bring to people: 'look how life is possible, look how it changes life, look at him how he is active and not always persons who are in the final stage and almost dying.' So media has an important part [to play] and my view for the future is like we have an ambassador for disability on the highest level in a ministry of health, we need an ambassador for people with dementia.*

This member sees an interest in the other member publicly disclosing his diagnosis because of the example he could set in advocacy: in this case an active individual with early-onset dementia who presents a valuable contrast with the one of individuals with advanced dementia.

This example further presents the issue of visibility and disclosure while also explaining its purpose in strategies of distinction. This strategy more directly emphasizes a perceived difference between the dementia of active and engaged individuals which should be represented in advocacy and the one of individuals in advanced stages of the condition, those marked by dependency, incapacity and proximity to death – those who are ‘almost dying’. As this member points out, a distinction *from* the person with advanced dementia is directly mentioned as instrumental to construct a positive narrative of dementia and influencing policy at the highest level. The constitution of an active identity with dementia and the distinction from this identity of advanced dementia is integrally part of the advocacy process for this advocate.

## **Distinction to cope with decline**

Beyond its use as a form of resistance to the image of advanced dementia in later life and a strategy for advocacy, distinction is also a means to maintain a sense of hope for both experts with dementia and advocates in the group.

Being part of the group, surrounded by similar people who keep active and engaged with society despite their condition is important for many members. It helps them cope with their diagnosis and maintain the most worrying sides of dementia at a distance, therefore preserving them from a part of the anxiety that the condition

generates. For instance, when I asked members of the group how their participation influenced their life positively, they responded the following:

A member: *“Yes, of course, it influenced. Gave me so much power and confidence. And yes, as [another member] says: valued. But valued you get if you have a job to do. And here we have a job. And now even if we are seating here, we are talking, it is our job. And they say great, you did something great. And the tone, nobody cares. So, it is also a part of inclusion.”*

Another member: *“It is nice to know that you can still do something. And it gives you a lot of value.”*

A supporter translating for a member also explained a similar motivation to belonging to the group:

*I think it is more or less what my [relative with dementia] has written about feeling valued in society. And in a way, since she has got the diagnosis, it was very different when she became a member of the [group], because she felt her life was stopped, was finished.*

As these testimonies present, there is an intrinsic benefit perceived by advocates and experts by experience in keeping a continuous engagement with society. It helps them to cope with their condition, to maintain a sense of hope. In these examples, members equate feeling valued and participating amidst the challenges brought by the condition. Being diagnosed with dementia as a member points out made her feel that ‘her life was stopped, was finished’. The group and its collective dynamic, its projects and engagements, helped this member to feel valued and find meaning in her life again, to feel that life was worth living. As it appears from these quotes, the absence of participation represents a threat for members, the anxiety of being depreciated and of falling into a purposeless life. Participating in the group and maintaining an engagement with society is therefore not only about challenging assumptions and stigma, it is also more intimately linked to one’s own sense of self-worth.

As a feared negative to this intrinsic well-being found in participation, the existential threat of an identity marked by decline defines the parameters of an

unwanted life for members of the group. For instance, three members described this feared identity simultaneously when I asked them if there were things that divided people's experience of dementia during one of the focus group discussions. Here is their answer:

Member 1: *"Can I just say that there is a lot of things that unite us all. But one thing that does divide people's experience of dementia is the stage that they might be in. If you are at a very early stage, you don't want to join a club where they are in late stages. So it is not about age, it is about stage."*

Interviewer: *"It is about stage. That is for you the key point?"*

Member 1: *"Yes, yes. You wanna be with people in a similar stage."*

(...)

*"Yeah, you see your future. You don't wanna see your future."*

Carer of member 2: *"Because you need to live now and enjoy."*

Carer of member 3: *"That's why we are here [in the group]."*

In the joint assertion by this member and two supporters of other members of the group, we can see how the fear of decline is an essential concern and factor of differentiation regarding identity for at least a part of the individuals I interviewed. The identity of advanced dementia is an intrinsic source of anxiety, of existential distress. It takes place through the recognition of one's feared anticipation of a potential future in the identity of another with more advanced dementia.

This existential fear leads to a process which implicitly defines the social position of otherness, the one of individuals with advanced dementia. Hence, it is an intrinsic source of *division* among people with dementia. The following quote by the carer of a member with dementia gathered during one of the focus groups describes how this existential fear translates into a division. This person recalls how she discovered the existence of the group and its adequacy for her partner with dementia:

*And [my partner] cannot just join the group with people around 80 years old. He wouldn't have much to relate, the same topics or he would not feel motivated, so it is good that.. Here I was so shocked in [this*

*international conference] how active those people [with dementia] are, because we struggle with this as well. [My partner] simply lost his motivation to do anything. I need to be the driver. Just go and do this, just go running, ...*

This carer presents how she struggled to find a group that her partner diagnosed with dementia could join to build a network of support. She explains how it was a relief for her to discover the existence of the group, to finally see that there were active people with dementia who could support her partner with early-onset dementia to remain motivated and engaged in his life. In this regard, she described the positive role model that members of the group could represent for her partner:

*Yeah, different speed, different pace, different motivation, and it is good to see that people can be so active here, because the positive example is the best.*

She describes the group as a positive example. Her statement is comparative and establishes a hierarchy of value between groups of people with dementia: it is the 'best' example. As her first quote presents, the group contrasts with the passivity of other groups of people with dementia she encountered. She initially described this inadequacy of other groups as a result of 'old age'. Interestingly, she eventually corrects her initial identification of 'old age' as an issue:

*This is what, I didn't express myself properly [about joining groups of older people]. I meant that [my partner] cannot meet people who are much further in the disease because he would just see where it goes to.*

This division and hierarchy between groups is therefore not a matter of age, it is a matter of stage of dementia. In direct relation with the statement of the three members of the group cited above, the decision they made for her partner to take part in the dementia expert group is in part based upon a desire to protect him from the distress that he could experience if he confronted individuals who are more impaired by dementia than he is. This idea that he 'cannot meet people who are much further in the disease because he would just see where it goes to' exemplifies how the constitution of 'otherness' and division among people with dementia takes place in the attempt of individuals to reconstruct an identity with the condition. It is an *internal process* resulting from the existential distress that dementia provokes

yet it is *socially expressed* through the othering of advanced dementia. In these quotes we see how his fear of this unwanted corporeality of advanced dementia is an important cause of distinction which complements the one used in strategies of resistance to stigma presented in the previous section.

## **Distinction as a tension around identity in dementia and its implication for the social movement**

This case study constitutes a key illustration of the presence of processes of distinction among people with dementia both for the purpose of advocacy and as a result of existential distress. We should now explore the cause of this distinction among people with dementia and how it can inform the attempt of the social movement to address social exclusion. To this end, we should first widen our gaze to look at the *social norms* that generate exclusion in the first place. We should then look more closely at the role of *corporeality* as a source of distinction and a tension to address for this novel approach to dementia through the constitution of a social movement of individuals with the condition.

### ***Understanding the structural origin of distinction from advanced dementia***

The *norms* that a society elevates around dementia play an important role in generating this distinction in advocacy. These norms primarily produce the stigma experienced by advocates and experts with dementia described in the first section of this chapter. This assumption about the incapacity of people with dementia to participate in society circulates widely in society through popular discourses and imaginaries around this condition (Bartlett & O'Connor, 2010; Van Gorp & Vercruysse, 2012). Booth and Booth (1999 cited in Beard, 2004a) described such forms of discrimination as the expression of the *presumption of incompetence* that surrounds dementia. Beard (2004a, p. 798) sees this presumption of incompetence as a result of the glamorization of a 'youthful, fit body and mind' which negatively impacts the standing of people with dementia whose condition transgresses this ideal of fitness and youth.

Here we find again some of the central themes presented in the previous chapters of this thesis – the role of active ageing and cultures of the third age in creating distinction through their rejection of decline (Gilleard & Higgs, 2010; Higgs & Gilleard, 2016a; Latimer, 2018). For instance, Gilleard and Higgs (2010; 2016a) explain that the dominant ideal of active ageing that pervades current understandings of later life and unrealistically emphasizes youthfulness, fitness and productivity. It therefore plays a central role in generating this negative appraisal of dementia. The stigma toward people with dementia can indeed be understood at first sight as a result of the stark contrast that exists between decline in dementia and this unrealistic ideal defining later life. This ideal strengthens the position of dementia as a symbol of intractable decline and incapacity, and younger advocates with the condition or those with mild dementia are systematically encompassed by this imaginary of dementia predominantly associated with later life as the quotes above presented. Their diagnosis acts as a label, or stigma stimulating this imaginary. As it is described in the quotes above, this stigmatization directly affects the life of experts and advocates part of this research as it limits their opportunity to enact their citizenship and participate in society as well as receive adequate support for this participation.

Yet, distinction mainly emerges as a result of the strategies that advocates, (as well as some experts by experience) use to respond to the stigma generated by these norms defining dementia and later life. These strategies project a novel approach to dementia based on principles of citizenship and the social model of disability which is gaining increasing traction both as a field of scholarship and as a policy guideline (Bartlett, 2016; Cahill, 2018; Dorenlot, 2005; Marshall, 2005). This approach based on disability has now found resonance in the action of influential dementia associations and mental health organisations across the world (Gove et al., 2017; Hare, 2016; Mental Health Foundation, 2015; Shakespeare et al., 2017; Thomas & Milligan, 2015), and is also supported by an increasing number of scholars in the field of dementia (Cahill, 2018; Shakespeare et al., 2017; Williamson, 2015) despite the fact that this transformation took time to emerge (Cahill, 2018, p. 27; Shakespeare et al., 2017). This approach challenges the most common narrative of dementia which assumes dependency and loss of agency – the one affecting advocates and experts in this research – a narrative based on a



biomedical model of the condition which is dominant in public health and dementia policy (Thomas & Milligan, 2015, p. 14). Essentially this discourse refuses to locate the limitations of the person in her impairment alone by pointing out that limitations that people with dementia experience in participation are also imposed by society through discriminatory practices – ‘social oppression, cultural discourse, and environmental barriers’ (Shakespeare, 2016, p. 214). It therefore refuses part of the ascription of individuals experiencing cognitive difficulties into ‘diseased identities’ associated with social disenfranchisement following a diagnosis (Beard & Fox, 2008, p. 1509). Asserting a visible and proactive identity in dementia, a social position defined by agency, active engagement and autonomy, distanced from an externally ascribed identity implying dependency and the lack of capacity, is a key means to challenge these limitations imposed by society by demonstrating that the impairment is not the main issue that prevents people with dementia to live an active and engaged life in society. It therefore recuperates the diagnosis as a resource to generate novel forms of citizenship (Beard & Fox, 2008, p. 1509) through processes falling into a category merging embodied health movements’ characteristics (Brown et al., 2004), and identity claims found in NSMs (Whittier, 2017). Following embodied health movements (Brown et al., 2004), the contribution of members of the dementia advisory group to the dementia movement is enacted through a ‘politicized collective identity’ and a mode of action constructed around the specific biological condition of dementia. Yet, by embracing principles of the social model of disability, the dementia movement goes beyond the mode of action of ‘embodied health movements’. It organizes its action around the idea of recognizing dementia as a difference rather than an impairment, a point emphasized in NSMs (Whittier, 2017) and in the social model of disability (Shakespeare, 2016, p. 214). Hence, the goal of sections of the movement is to normalize the condition as a disability, a difference which should be recognized rather than arbitrarily excluded, an objective both described by some members of the group and researchers contributing to the social movement (Cahill, 2018; Thomas & Milligan, 2018). This mode of action embodies part of this novel idea of citizenship in dementia and its enactment through practices of everyday life representing modes of resistance outside of the political sphere (Bartlett, 2016, p. 455), within ‘mundane spaces of daily sociability’ (Neveu, 2015, p. 147). In this action drawing on the social model of disability, dementia inherently becomes a

form of ‘tertiary deviance’, enacted through the recuperation of the condition by advocates and its normalization as a difference requiring adaptations from society. This normalizing process operates for instance through the public demonstration that one can still be active and engaged while having dementia.

However, this approach to dementia overlooks tensions emerging as a result of this normalizing process. These tensions can be perceived in the actions of the movement operating through a distinction from dependency and incapacity. Indeed, as we saw in the quotes above, this narrative transformation operated by advocates and experts with dementia does not necessarily challenge the normative structure which stigmatizes people with dementia in the first place. Rather than deconstructing the othering of those who are dependent as a detrimental consequence of the discourse of active ageing, this strategy operates a distinction from individuals in situation of dependency. This distinction is here understood in a similar sense to the one depicted in chapter 3 of this thesis, as a means to demonstrate difference from negative aspects of an identity and attain a positive standing in society, often following the lines of active ageing. Arguably, this conformism to active ageing can be caused by the structural constraints linked to the dominance of this ideal in Western society; the difficulty for advocates and experts to find a safe space outside of the norms of active ageing. Bourdieu (2001) and Steinberg (1999) have reported similar challenges around dominant norms for other social movements. As Bourdieu (2001) explains for instance, the impact of social norms on victims of sexually based discrimination creates a resistance which ‘is inevitably trapped in one of the most tragic antinomies of symbolic domination: how can people revolt against a socially imposed categorization except by organizing themselves as a category constructed according to that categorization, and so implementing the classifications and restrictions that it seeks to resist’ (Bourdieu, 2001, p. 120). The oppression of certain cultural narratives can be such that they blur the boundaries between the practices that lead to emancipation, and those that further reproduce oppression.

Previous critiques have also pointed to similar normative constraints in the discourses produced by current dementia organisations and a series of national strategies in Canada, Ireland and the United Kingdom for instance (McParland et al., 2017, p. 259) despite the fact that they wish to support emancipatory practices

for people with dementia. As McParland and colleagues (2017, p. 265) explain with regard to the discourse of ‘living well’ in dementia generally, ‘[w]e risk a discourse that urges those living with dementia to fight to continue to meet society’s definition of a life that is normal and has value, rather than challenging the very definitions of normality and value’. While this observation was cautionary in its critique of the discourses that society elevates around dementia, this case study shows that this pressure ultimately influences modes of advocacy by people with dementia themselves. The presence of distinction showed how difficult it is for individuals with dementia to detach themselves from the norms that exclude them in the first place, and to challenge these norms.

Beyond the question of norms and their reproduction, this chapter presents how a reliance on the normalization of difference in dementia calqued on the approach of contemporary social movements also implies divisions due to the existence of distinction processes creating a fracture in dementia. It challenges the constitution of a unified identity and agenda for people with dementia and the social movement which includes both those individuals who can sustain norms of active ageing and its narrative, and those individuals whose dependency prevents them from doing so, and whose standing in society is ultimately devalued by this ideal. However, this is not the whole story.

### *Understanding the origin of distinction in corporeality*

Indeed, it would be reductionist to think about distinction from dependency and decline only as a normative practice constrained by the dominance of the discourse of active ageing, and paradoxically reinforcing some of its exclusionary norms. The desire to stay active and engaged as some of the quotes above presented is integrally part of the reconstruction of a sense of stability and a means to give meaning to life after a diagnosis of dementia.

The importance of engagement as a source of meaning has been documented for other health conditions. For instance, Hay (2010) presents the value derived from engagement and activity among those living with chronic health conditions. She points out that ‘[people with a chronic illness] remain active because it is meaningful for them and because they are physically able to do so. They do not act

because of a cultural model' (Hay, 2010, p. 269). This obvious desire to stay away from decline is also a point made by various researchers regarding health and ageing more generally (Gilleard & Higgs, 2015; Lamb, 2017). This desire is present among the experts and advocates with dementia I encountered, for whom living an active and engaged life in dementia is also a source of hope and relief despite their dementia – a means among others to maintain a meaningful life.

To understand the meaning found in distinction, we should look more closely at the role of *corporeality* in the life of advocates and experts. Corporeality is a concept representing the materiality of the body (and the conditions which affect this materiality such as dementia) and its impact on the life of people with dementia (Gilleard & Higgs, 2018, p. 9). Corporeality, as Gilleard and Higgs (2018, p. 9) explain, 'represents the body as something that is reacted to – the objectivity of the person rather than his or her subjectivity'. Corporeality therefore represents the material nature of the body of a person and the direct impact it has on her life. In a similar way, the corporeality of dementia, its bodily impairment, or the prospect of developing this bodily impairment has a direct impact on the life of a person with dementia. This corporeality of dementia can also have a social impact in influencing the decisions of others (Libert et al., 2019). For instance, the corporeality of dementia, the irreversible decline that it involves, can stimulate an intrinsic fear of the condition at the basis of the social imaginary of the fourth age (Gilleard & Higgs, 2010). This fear of a future corporeal decline can affect people with dementia themselves as this case study presented. This imaginary remains the source of a fundamental anxiety in the attempt to reconstruct an identity with dementia. Unlike part of the stigma based on discourses of active ageing that advocates attempt to resist, this fear of decline finds its origin in corporeality, not in discourse (Higgs & Gilleard, 2016b, p. 89). It does not only derive from the attitude of others. It is ultimately an intrinsic production of the existence of advocates as it derives from their own fear of a possible future decline – an anticipated corporeality. It inevitably drives the choices of advocates and their wish to stay engaged in society.

In its social dimension, this fear of irreversible decline also drives the desire of parts of the members of the group to stay away from those with more advanced dementia. Indeed, the capacity of this fear to constitute social divisions is

perceptible in some of the advocates' and experts' relation with others embodying this decline, hence for instance the desire of some of them not to join groups of individuals with more advanced dementia – they 'don't wanna see [their] future'. Avoiding the presence of advanced dementia represents a key element of the fear of the fourth age and its abjection described by Gilleard and Higgs (2015). It explains the will of these advocates to distinguish themselves from it and join more active groups of people with dementia who do not stimulate the imaginary of this feared destination. This rejection of abjection is therefore a matter of identification – it comes from an unwanted identification with a future in potentia. Paradoxically it may be that the closeness to advanced dementia that the diagnosis creates among people with early dementia actually reinforces the strength of their distinction.

### ***Implications of distinction for the social movement of dementia***

The presence of this divide between a dementia constructed through the politics of visibility, advocacy and a distinction from the common perception of dementia as a condition marked by loss and decay suggests yet unconsidered challenges around the construction of a collective identity capable of unifying the social movement against social exclusion. For instance, distinction represents an important conceptual challenge for the social movement of dementia in its recent adoption of principles of the social model of disability and the normalization of the condition.

An important dimension of the social model of disability has been to advocate for the recognition of disability as a difference (Shakespeare, 2016; Shakespeare et al., 2017). In this model, an impairment becomes perceived as a unique and accepted dimension of one's identity being normalized through the idea that the definition of the impairment as a problem to address is essentially the result of exclusionary social norms. It therefore opposes the idea that disability should be 'fixed' by medical technologies for instance as medicalization of the impairment implies the abnormality of this identity. Although the intensity of this position varies within the social movement of disability and can be divisive, it is generally accepted that the emphasis should be put on ways in which society and the public opinion need to adapt to address social obstacles to participation (Shakespeare, 2016, p. 217).

While dementia advocates find an interest in this approach, distinction from advanced dementia remains an intrinsic source of tension in the adoption of this model. The ethnography I presented above shows how difficult it is to recognize dementia as a celebrated difference, an example of human diversity that only disablist social norms exclude, especially as the dementia progresses, an important dimension of the NSMs. While several advocates and experts presented in this ethnography advocate for ‘coming out’ with the condition, that people should know about it, they sustain this sense of being proud and living well with dementia to a certain extent only. Beyond a certain ‘stage’ defined by the parameters of the social imaginary of the fourth age, this approach to dementia becomes increasingly problematic for the citizens with dementia I encountered, leading to the exercising of the practices of distinction. One can remember the example of this advocate stating that we should mediatize active and engaged people with dementia and not only the ones in the final stage of the condition. Such statement shows the limits of the politics of visibility in dementia. Some images of dementia are more disturbing than others, and an active person with dementia is more desirable for the sake of advocacy as a member of the dementia advisory group explained. Distinction operates as a zone of tension and obstacle limiting the rejection of the negative connotations attached to dementia. This rejection is a necessary condition to the constitution of a new social movement – the transformative process of ‘tertiary deviance’ mentioned above (Kitsuse, 1980; Sorensen & Siemsen, 2006). Distinction therefore represents a limit to the constitution of a unified social movement around dementia.

This intrinsic concern with corporeal and cognitive decline in dementia explains why a majority of the individuals I interviewed are motivated by the idea of finding a cure for their condition, therefore to some extent going against this ideal of the disability movement that disability should not be ‘fixed’ or ‘cured’. We should note however that Shakespeare (2013, p. 172) already pointed out the difficulties of the disability movement itself in engaging with decline. As he explained, ‘[t]he power of social model approaches may have made it harder for the disability rights community to engage with debates about illness, impairment and end of life’. This is even more so for dementia due to the increasing intensity and irreversibility of its impairment. Distinction therefore simultaneously points to the limitations of the

social model of disability itself and the capacity for illness-related conditions to become envisioned through the framework of the NSMs generally. Regarding dementia, this tension represents an important challenge for the social movement to use this approach as a best practice to address social exclusion. It demonstrates the presence of differences between different groups of people with dementia in term of the most adequate solutions to propose to social exclusion and the contradictory effects that active and visible identity politics can have through distinction, inducing further problematization of the dependency and disengagement of parts of the people with dementia.

Presenting this tension around distinction does not mean that seeing dementia as a disability or reframing and embracing dementia as a resourceful identity for the purpose of advocacy is not valuable; yet such an approach may not be adequate to solve the issue of social exclusion for all people with dementia. Distinction and the social division that it generates point to the *fragmented nature of identity in dementia*. Different social positions compose the population of people diagnosed with the condition, between an experience of dementia informed by the third age drawn toward the pursuit of a life to a certain extent guided by the objectives of active ageing, and an experience of dementia encompassed by the fourth age as a worrying prospect.

These positions are assorted with different processes through which social exclusion operates, and therefore require different strategies. As we have seen earlier in the quotes and vignettes, a citizenship and disability approach to dementia plays an important role for members of the dementia advisory group in fostering their standing in society and well-being. They find in it a unique opportunity to elevate themselves as a collective better able to challenge some of the obstacles that society currently creates – prejudices, denial of services, presumption of incompetence, etc. The social model is most likely to benefit these individuals whose capacities allow them to more readily sustain the aspirations of the third age and benefit from the empowerment that the social movement offers. Yet, it remains more limited in its capacity to respond to the needs of those further along the disease trajectory. The intensity of the impairment and the presence of distinction challenge the capacity of a social model based on empowerment, citizenship and narrative transformations to address the exclusion contingent with the corporeality

of advanced dementia. It also more generally questions the possibility for health-related conditions to become constitutive of unified social movements that are similar to the ones deployed as a response to racism, sexism or other socially constructed forms of exclusion and discrimination. At the start of this chapter, we asked: can dementia, or other health conditions be treated as mere socially constructed differences, or will they remain unwanted dimensions of the human condition? As this ethnography illustrated, the presence of distinction in dementia, and the intrinsic fear that the fourth age generates even for experts and advocates themselves seems to indicate the latter rather than the former. Other solutions that are not solely the result of the social movement acting on the narrative that surrounds dementia remain required.

Hence, although distinction reminds us about the influence of the fourth age on exclusion, the responsibility to address this exclusion remains one for society. Solutions are required for people with advanced dementia to enable them to live a more dignified life in the community. Their condition and the continuous need for care and support that it often implies also indicates the necessity to develop available, adequate and well-resourced care systems. Addressing social exclusion in dementia therefore also implies directing support toward people in situations of dependency and revalorizing the role of care in maintaining the dignity of the most vulnerable – a solution already advocated by scholars regarding care more generally (Higgs & Gilleard, 2016b; Kittay, 2011). Perhaps, being conscious of the presence of distinction and diversifying attempts to address social exclusion on both sides of this divide will be beneficial.

## **Conclusion**

This chapter further explored the nature of social exclusion in dementia by considering its manifestation among people with dementia. To this end, it relied on an ethnography of a group of experts and advocates with dementia active in advising policy and research around the condition at an international level. This ethnography was based on participant observation and focus group interviews as part of this group.



This chapter considered the nature and complexity of exclusion among its members by looking at practices and discourses. It first proposed to explore their experience of social exclusion and ways in which they resist to it. It then presented how advocates and experts found in their active participation and engagement in society a means to challenge current negative perceptions of the condition portraying individuals with dementia as lacking capacity and agency. It reviewed how this strategy involved a degree of social positioning – a distinction from the most negative aspects of dementia involving dependency and passivity for the purpose of resistance to stereotypes and advocacy.

Beyond its use as a counter narrative to stigma, this chapter presented how distinction was also a means to keep at a distance a corporeality of advanced dementia representing a source of fear for experts and advocates. This chapter presented how this fear is inevitably bounded to the manifestation of a fourth age imaginary.

This chapter then proposed an analysis of these two instances of distinction and their interrelation. It presented how the advocates and experts' experience of discrimination derived from dominant norms of society informed by active ageing and the identity of the third age. It showed the existence of a paradox where norms discriminating against individuals with dementia determined their practices of resistance, therefore leaving these norms ultimately unchallenged. Visibility and the need to display an active and engaged identity with dementia were important aspects of advocacy for some members of the dementia movement. It also showed how difficult it may be for experts and advocates to proceed differently because of an intrinsic fear of decline inevitably leaving the dependency and decline of dementia irremediably unwanted.

This chapter presented how this paradox and intractable division represents a challenge for the social movement around dementia in applying principles of citizenship and the social model of disability to address social exclusion in dementia. While it does not deny the worth of this approach, this chapter points out that it remains difficult for individuals of the movement to simply embrace the whole spectrum of conditions that dementia involves as part of their identity and the public display of this identity as part of advocacy. This difficulty indicates the

different social positions existing among people with dementia themselves; between those most able to identify with the ideals of active ageing and the third age, and those overshadowed by the fourth age whose representation of loss and decay in dementia becomes an intrinsic source of fear and othering.

This chapter therefore challenged the idea that there is a unique solution available to address social exclusion in dementia found in principles of advocacy, visibility and empowerment through a unified social movement. It also more generally showed how illness remains problematic as a characteristic able to become an identity trait equating concepts of gender, race, disability or sexual orientation at the centre of a social movement.

In place, I support this approach of the social movement based on identity to respond to socially constructed aspects of exclusion in dementia (prejudices, denial of support, absence of adequate infrastructure, etc.) while also pointing out that solutions to advanced dementia need to be thought of differently, emphasizing the need for adequate, available and well-resourced care in order to support a dignified life and maintain social *inclusion*, even in situations of advanced dependency.

## **Conclusion: Is there a best practice to address social exclusion in dementia and later life?**

This research aimed to understand how technologies play a role in the social exclusion of people with dementia. By answering this initial question through specific examples and case studies of technologies and interventions for dementia, it proposed a more extensive understanding of the processes involved in the social exclusion of people with dementia and in later life across society. It aimed at clarifying and redefining current understandings of social exclusion relating to ageing and dementia. It indicated that these processes of social exclusion are more complex than currently conceived, with the consequence that solutions proposed in current policy and interventions can appear inadequate, even contradictory. These contradictions relate to the presence of an unacknowledged divide in later life between the third age, a particular societal understanding of ageing successfully, and the fourth age, a negative social imaginary representing the ideas of failed ageing in the population. What this thesis specifically showed is how people are encouraged to socially position themselves along the line of this divide, by either demonstrating their capacity to fulfil the expectations of ‘successful’ ageing, or by being relegated into the category of ‘failed’ ageing. Hence, this thesis presented how interventions and technologies developed to address social exclusion today often involuntarily and implicitly classify individuals reaching later life along this divide through processes of social positioning. These processes effectively determine the social worth of part of the population in later life according to their capacity to meet the expectations of successful ageing. This thesis used pertinent case studies which describe key technologies, interventions and practices for dementia across Europe to illustrate these processes. Case studies included the increasing popularity of brain training technologies for later life, the expansion of the activities of memory clinics using cognitive rehabilitation for dementia, the development of psychosocial interventions aiming at empowering people with dementia to become more independent, and platforms involving people with dementia as advisors and ‘experts by experience’ for research and policy. Utilising these case studies, this thesis theorised these processes of social positioning by categorizing such interventions as *technologies of distinction, ascription*, and

*omission*. Each intervention having a different, yet complementary, role in positioning people with dementia; either positively or negatively according to the norms of successful ageing, thereby creating a divide in later life between those who succeed and fail to do so.

To argue for the existence of this important triad of exclusion, this thesis sequentially operated as follows. It first introduced sociological and anthropological analyses of ageing by presenting key social and cultural conditions that give meaning to later life today, and the significance of dementia in this context. It presented how an ideal vision of ageing called active ageing, or successful ageing, emerged following important social and cultural transformations in the post-World War II period and offered novel opportunities to free individuals in later life from previous social structures defining later life. It described how this later life freed from its status as a residual social position following the improvement of health and longevity through technology and the development of social security and retirement plans became a space in which ‘consumer-citizens’ could enjoy a novel existence, involving new modes of defining their identity through consumption and the development of different lifestyles and sub-cultures valorising autonomy and youthfulness.

This thesis also presented the ‘cost’ of this newly acquired freedom and idealized later life by describing how novel norms of individualism and responsibility imposed by these developments led individuals in later life to experience heightened pressures to maintain their health and status as they age. People increasingly gained a sense of their responsibility to maintain their own health and to sustain new norms around health and well-being. These norms were defined by a virtually unreachable ideal of fitness that operated in a state of heightened competition against others. This resulted in unfulfilled desires on the part of individuals to achieve greater health, independence and happiness, against the inevitability of ageing and decline. These novel understandings of health and responsibility led Western society to see later life as a continuity of active mid-life, with raised expectations about what it means to live a ‘successful’ later life. Scholars of ageing defined this novel cultural field composing later life as the third age (e.g. Carr & Komp, 2011; Gilleard & Higgs, 2007, 2010, 2005). As the introduction to this thesis presented, cultures of the third age are constitutive in

defining what constitutes a ‘failed’ later life. This is a departure from previous theories which problematically identified chronological age as a factor of exclusion, referring to categories of the ‘oldest old’ (Baltes, 1998), or ideas of a ‘period of individual decline and decrepitude that particularly affected those who lived beyond their mid-80s’ (Laslett, 1989, p. 41). In this cultural approach to exclusion in later life, the experience of an irreversible decline connected to ageing became an essential factor of exclusion from these novel lifestyles and expectations. Diagnosed conditions such as dementia and frailty constitute ruptures to the opportunities offered by the third age. Dementia therefore acquired symbolic power in contemporary consumer society as a source of existential fear, a symbol of ‘failed’ ageing – a fear that some like Pickard (2016) or Gullette (2017) identified as a result of a decline ideology, while others such as Gilleard and Higgs (2010) defined as an element belonging to the fourth age, a negative yet inevitable social imaginary encompassing decline and abjection in later life. This thesis proposed to explore the role that current interventions and technologies for dementia play in maintaining this social division between those whose life represents a successful ageing and those who are perceived as failing to meet the criteria set by the third age, and become socially excluded as a result.

The *first chapter* of this thesis proposed a methodology to explore this matter through multi-sited ethnography. This choice of methodology resulted from a reflection on how to best study the existence of exclusion in society, in individual meaning-making practices and experiences of discrimination in ‘real life’ settings (outside of the laboratory). It attempted to trace the presence of this social exclusion across different sites and establish connections between these sites through interpretation and contextualization of these specific localities. These sites were selected due to their key-contribution to applying novel theories proposed to address social exclusion in dementia today. These sites included interviews with the users of these technologies in the United Kingdom, two memory clinics implementing cognitive rehabilitation therapy in dementia in Southern Europe, a research project implementing principles of empowerment and independence in dementia in the United Kingdom, and a group of experts and advocates with dementia active internationally in reviewing research and policy relating to dementia. It used a critical and interpretive approach analysing these local realities

in relation to the broader social context of contemporary consumer society characterised by the divide between successful and failed ageing. This chapter presented how participant observation and in-depth, semi-structured interviews were relevant methods to access the meaning-making practices and representations of the researchers, developers of technology, clinical staff, and people with dementia participating in this research. It then presented how these practices and representations were analysed, mainly through thematic analysis and using some inductive methods borrowed from grounded theory.

Entering the depth of the topic, the *second chapter* explored the discourses and mechanisms behind brain training technologies and their influence on perceptions of later life. It argued that brain training emerged as a successful and influential technology for later life because it efficiently managed to utilize the fracture between third and fourth age, and the fear that the social imaginary of the fourth age generates. This chapter proposed that the context marked by the expansion of active ageing to encompass the ageing brain, what it called active cognitive ageing, played a key role in this success. In this context, the fear of dementia represented an influential argument for people in later life to engage in prevention through brain training. Furthermore, as a novel contribution to the scientific literature on exclusion, this chapter argued that the mechanisms and discourses of brain training and prevention encouraged people approaching later life to engage in processes of social positioning that it referred to as *distinction*. Indeed, brain training and its reliance on the fear of dementia encouraged healthy people in later life to distinguish themselves from those who embody the idea of a failed ageing represented by the fourth age – people whose dementia signifies the end of agency, autonomy and social participation in the imaginary developed by the third age. Through this theorization of distinction in later life, this chapter aimed at developing a template to approach the other case studies of this thesis and how they represent important modes of social positioning.

Departing from this theorization, *chapter 3* explored how individuals approaching or in later life perceived the discourses of brain training, and their own engagement in practices of distinction from the fourth age. To this end, this chapter relied on semi-structured interviews of brain training users identified and recruited thanks to their participation in an important research project looking at the ageing brain in

the United Kingdom. As a theoretical framework to understand their engagement with distinction, this chapter used the four principal constituents or vectors constituting the social imaginary of the fourth age identified by Higgs and Gilleard (2014) as a heuristic device to trace the existence of distinction from this imaginary among the participants. It showed how their motivations closely reflected aspects of the four vectors and were linked to attempts to position themselves at a distance from dementia. Namely, it presented how modes of distinction were influenced by 1) an imaginary of frailty in later life; 2) a fear of the abjection that participants often attached to dementia; 3) an imaginary of dementia as a source of substantial and unwanted difference; and 4) the undesired position of becoming in need of care that the participants sometimes identified as a burden. These factors were found at different rates among the participants as motivations behind their widespread engagement with modes of prevention for dementia. This chapter also expanded the notion of training the brain by showing how it reached beyond the mere use of brain training technologies alone. Hence it presented how the idea of brain training beyond the technology shapes a more pervasive ethic of life encompassing other dimensions of later life. It showed how mundane practices of daily life were often reframed as opportunities to train the brain, and how they often involved an attempt to maintain a difference between ageing well and failing to age successfully for individuals. In adding to the previous chapter exploring positionality in brain training discourses, this chapter therefore further illustrated how brain training and prevention constitute practices of distinction excluding dementia from representations of a successful later life.

Drawing upon the presence of this distinction as a positive mode of defining one's identity in later life and belonging to the third age, *chapter 4* proposed to explore the existence of parallel processes to distinction negatively inscribing people with dementia. Taking the development of cognitive rehabilitation technologies for people with dementia as a case study, it presented how memory clinics and the medicalization of dementia – the reinforcement of its definition as a medical category – play a role in separating people with cognitive decline from the so-called 'normal' population in later life. Through an ethnography of two memory clinics implementing this therapy, it studied in detail how this separation from 'normal ageing' operates in the clinic, sequentially, through 1) the definitional moment of

the first encounter between the potential patient and the therapist, followed by 2) the diagnosis of dementia, and the prescription of a cognitive rehabilitation regime as a first step in the definition of an abnormal cognitive state and social position. This process, as this chapter presented, was then continued by 3) a long period of sessions of active monitoring and cognitive rehabilitation playing a role in the definition of a novel identity with dementia through the confrontation of the individual with his own decline, offering therapeutic attention while also influencing the identity of the person with dementia by rendering decline more salient through monitoring and cognitive challenges. Overall, this chapter presented how medicalization *ascribed* a novel social position for people experiencing cognitive decline away from normal ageing. As this chapter presented, cognitive rehabilitation described as a *technology of ascription* constitutes a means for society to separate individuals reaching later life from the normal population. Cognitively impaired individuals who cannot benefit from cognitive rehabilitation anymore are prepared for potential institutionalization – a final step marking the ascription of the person in the social imaginary of the fourth age and their relegation from society.

After having theorized distinction and its negative process of ascription in the previous chapters, *chapter 5* of this thesis proposed to continue this exploration of social positioning as a source of social exclusion in dementia by considering specific attempts to positively position people with dementia through novel ideas of ‘living well’ with the condition. This chapter explored strategies drawing on this principle of positive social positioning by looking at the implementation of interventions to empower people with dementia toward more independence and autonomy, an important dimension of national and international dementia strategies developed today. By drawing upon interviews of researchers working on such an intervention as a case study, it highlighted a series of tensions which are intrinsic to this kind of project. Notably it presented how the emphasis put on independence and choice in these strategies led to the constitution of norms and expectations around agency and autonomy that could eventually: 1) neglect the status of individuals who are more dependent due to their condition; 2) portray dependency as agency therefore avoiding some of the important conversations to have about decline; and 3) implicitly rely on prevention as a necessary condition



for the sustainability of such interventions as the dementia progresses. This chapter presented how these tensions limited the applicability of the narrative of ‘living well’ with dementia, while neglecting the exclusion of those with more disabling symptoms and impairments affecting autonomy. It therefore argued that these novel strategies and the discourse of ‘living well’ could be conceived as *technologies of omission* circumventing the most challenging aspects of dementia in their attempt to positively position people with the condition.

Finally, the sixth and last chapter of this thesis further explored the complexity of the fracture between third and fourth age by presenting the presence of processes of distinction among people with dementia themselves as exemplars of different social positions and their varied aspirations with regard to the solutions to propose to social exclusion. This chapter relied upon participant observation over a period of 8 months and on focus group interviews with experts and advocates with dementia active at an international level as part of a dementia advisory group reviewing research projects and policies for dementia. By examining the representations and actions of members of the group, this chapter studied the stigma and discrimination that these individuals experienced, mainly through assumptions that equated their diagnosis of dementia with incompetence. It presented how their principal mode of resistance to this excluded identity was by distinguishing themselves from it through active participation, advocacy, and the maintenance of an active and agentic life in the public sphere through public engagement and participation in their community and advocacy to improve their rights and standing in society, and in private settings by maintaining an active life through leisure, self-care and social participation. This chapter therefore argued that this resistance to ascription was a means to maintain a desired social position in the third age through a process of distinction comparable to the one enacted by individuals through brain training in preceding chapters. Ensuing from the existence of distinction among advocates and experts with dementia, the chapter presented how their action did not necessarily challenge the norms generating the divide between third and fourth age in the first place, and evoked an identity most informed by the aspirations of the third age. This chapter then drew a parallel between this tension and the current choice of the social movement of dementia to adopt a disability model for the condition. As a result of this tension, this chapter argued for the importance to

detach ourselves from the idea that there would be a single, best practice to address social exclusion in dementia. This chapter presented how the solutions that we develop to alleviate social exclusion should be sensitive to the different social positions that exist between an identity with dementia embracing the third age, and one which is most encompassed by the social imaginary of the fourth age. Hence, this chapter did not necessarily identify this positionality as an issue, rather it identified it as an inevitable difference in positions to acknowledge linked to the intrinsic fear that dementia generates as an unwanted identity, and the pressure that society's normative expectations generate for people with dementia. Practically, the chapter discussed for instance how the strategy based on a social model of disability presents intrinsic contradictions around identity and may not benefit all people with dementia equally due to the presence of distinction practices. In this regard, distinction showed the contraction that there is for experts and advocates in embracing dementia as a valuable difference, an approach generally adopted by members of the disability movement (Shakespeare, 2016), while also rejecting its most negative aspects – the abjection and loss of agency. Such distinction indicates the challenge for individuals, whose agency and autonomy are most affected by dementia, to benefit from the potential achievements of this strategy as they embody this fear that experts and advocates have. Such difficulty questions the possibility to create a unified social movement across the entire population of those affected by dementia. This limitation indicates the need for complementary solutions to social exclusion beyond the adoption of a disability approach – a point that will be further discussed below.

Overall, theorizing technologies of distinction, ascription, and omission helped better understand how the social exclusion of people with dementia operates in society, not necessarily as a result of direct discrimination alone, yet as a complex cultural and social process constituted across multiple sites both by people with and without dementia, and resulting from the collective anxieties that we share about later life as a society. This thesis showed how this exclusion was influenced by culture in terms of both its intensity and in terms of the existential threat that it represented. This related to our fear of decline and the finite nature of life, as well as our difficulty to constitute a symbolic system able to give meaning to decline. Observations of this existential fear challenge the idea that exclusion would solely

be a social construct deriving from a ‘decline ideology’ (Gullette, 2017; Pickard, 2016) – it is more complex than that. The complexity to give meaning to this process and its role in the social exclusion of people with dementia led us to build incomplete and sometimes contradictory solutions, practices and discourses to foster inclusion, reinforcing existing identities connected with particular social positions along the fracture between third and fourth age. The constitution of these identities and their position indeed is essentially a result of these processes of distinction, ascription, and omission. Some of these identities attached to later life may gain in recognition within our particular system of value defined by active cognitive ageing. For example, the distinguished identity of the healthy individual engaged in an ethic of life defined by self-management and the careful prevention of dementia; or, the individual with dementia able to sustain his agency and engagement in his community after a diagnosis, or to engage in advocacy and public participation. Meanwhile these positive positions contrast with the increased devaluation of those whose condition is marked by decline, the loss of agency and institutionalization, who could not benefit from the new programs of empowerment supposed to sustain their status in society, falling through the cracks of interventions supposed to maintain their inclusion, while their condition is increasingly seen as a moral failure and lack of responsibility. The exclusionary triad of distinction, ascription and omission points to this polarization and the reinforcement of the existing divide between third and fourth age.

### **How did this thesis bring a new insight into our understanding of social exclusion in later life and dementia?**

How did this thesis contribute to our understanding of social exclusion in later life and dementia? How did it depart from previous theories of social exclusion in dementia? This thesis contributed to addressing a gap in the scientific literature described in the introduction. This gap was found in the absence of concern for the corporeality of dementia, its social role and its significance in defining the cultural and social meaning of ageing today. It was arguably the result of the strongly anchored positions found in the history of knowledge about later life and dementia, the difficulty to find a balance between previously held 1) positions linked to the hegemony of the biomedical model and its expansion through novel ideas of

prevention, rehabilitation and the expansion of diagnostic categories, and 2) attempts to free dementia from only viewing it as a disease through forms of post-modern theories and social models emphasizing the power struggle in society, caring networks and dyads (e.g. Bartlett & O'Connor, 2007; Kitwood, 1997; Kontos, Miller, & Kontos, 2017). This thesis attempted to strike a balance between these two poles.

This thesis first challenged this purely medical approach and the active ageing discourse, and its recent expansion into active cognitive ageing. It showed how this ideal is limited in its ability to include people with dementia due to its neglect of the social consequences of a diagnosis and its hostile appraisal of dementia most exemplified by the war against Alzheimer's disease. By assessing the impact of discourses of prevention through the case study of brain training, it showed how this ideal has fostered the necessity for a population entering later life to dissociate itself from dementia as a symbol of 'failed ageing'. This thesis inevitably led to demonstrating how this distinction can be a source of othering for people with dementia, constructing them as part of an unwanted social position. It also showed the contradictory nature of the action of dementia associations, both promoting inclusion through 'destigmatization' while also encouraging prevention without understanding the consequences it can have in othering people with the condition.

The second approach to social exclusion in dementia that this thesis challenged, namely the one of citizenship and a disability model, represents in itself a source of tension between the aspirations of those in the early stages of the conditions, and those who are further along the trajectory of decline. These tensions have been principally considered in chapter 5 and 6. These tensions showed that while it is important to recognize the need to address disabling relations of care, and forms of discrimination based on society's appraisal of dementia, the corporeality of dementia, and the fear that it generate remain important factors generating exclusion. These factors composing the social imaginary of the fourth age fall beyond the reach of these theories, limiting their ability to offer satisfying answers to the social exclusion lived by people with dementia whose agency is most affected.

As to other theories of social exclusion in later life, namely those considering the impact of ageism, or socio-economic factors on exclusion, this thesis presented how they similarly risk overlooking the role that impairments linked to dementia play in provoking division in later life and the intensity of the exclusion lived by people with dementia. This limitation was theorized at a sociological level, emphasizing how studies on socio-economic causes of exclusion in later life neglect the impact that impairments can have in generating economic and social exclusion (Gilleard & Higgs, 2020; Higgs & Gilleard, 2019). Adding an ethnographic depth to previous research presenting the intrinsic role of impairments and corporeality in exclusion, this thesis showed the symbolic intensity of exclusion, the fear associated with a condition which is one of the most undesired for people reaching later life. Discussion of euthanasia and the preference to avoid dementia at any cost among participants in brain training, the fear of being a burden for the family as a result of dementia that they evoked are indicative of this symbolic strength of dementia as a source of profound division among people in later life. One can also perceive this division in the fear that advanced dementia can generate in people with early dementia, and distance that people with early dementia wish to establish with people with advanced dementia through distinction, as chapter 6 presented. The definition of abnormality linked to medicalization, a factor indicating the need for cognitive rehabilitation inside memory clinics, is also an important indication showing the depth of this divide in later life as chapter 4 presented – a condition leading to being separated from a so-called normal ageing, and which can eventually lead to institutionalization. Finally, we also saw that attempts to address social exclusion in dementia through ideas of independence, empowerment or citizenship, ideas composing a more general approach of ‘living well’ with dementia, can neglect the experience and position of individuals in the most advanced stages of the condition, therefore maintaining the *status quo* of their existence as a residual social category.

## **How can we move forward with this matter practically? Is there a best practice to address social exclusion in dementia and later life?**

What should we practically do about the presence of distinction, ascriptions and omission? How should interventional research and policy, and the action of the dementia movement move forward when acknowledging the existence of these processes? Beyond the essentially analytical nature of this thesis, we should note that suggestions may vary and depend upon the context in which researchers, policy-makers, or people with dementia and members of the social movement of dementia evolve. This thesis is essentially therefore a means to encourage a reflection on the question of social exclusion for this audience, who should then decide for herself how to best foster inclusive practices. As a suggestion, this thesis wishes to question the idea that there would be a best practice to address social exclusion in dementia and later life. As we have seen throughout the chapters of this thesis, a third age bias tends to propose a unitary understanding of social exclusion that can be alleviated through a combination of prevention, rehabilitation, empowerment and political transformations based on disability rights and principles of citizenship. As we saw throughout the thesis, this approach most remarkably translated into comprehensive dementia plans and strategies, be it the one of national governments and international institutions such as the WHO, sometimes with the supervision of important international and national dementia associations. The issue is that this third age bias, in its difficulty to properly consider the existence of decline, does not fully recognise the contradictions present in this unitary strategy or ‘best practice’.

Tensions around distinction, ascription and omission point to the fragmentation of social positions, and arising from this, of identities and claims for improvement in dementia and later life. Contradictions become apparent in strategies when the presence of these different social positions is acknowledged, as we have seen for instance regarding prevention and ‘destigmatization’; regarding forms of medicalization which ascribe individuals in later life to a stigmatized identity while attempting to help them through different forms of therapy; utilising empowerment strategies more relevant to those in the early stages of dementia, while neglecting those whose agency is most affected; and regarding modes of public engagement

and political changes strengthening norms of the third age, while creating distinction from those positioned in the fourth age. These current solutions are essentially detached from the broader social context constituted by representations of ageing and later life and need more consideration for the challenges imposed by the fourth age, and the stigma which inherently results from the existential fear that the condition creates.

A novel approach to dementia should therefore attempt to recognize these contradictions in term of benefit for the population. While society should find ways to support the desire of people with dementia who wish to keep their agency, independence and participation in society and benefit from eventual progresses of therapy, we need to more willingly name and face the challenges that dementia provokes for agency and the difficulty we face in reaching the experience and desires of those most encompassed by the fourth age. We should adopt a more straightforward and active objective of improvement of the care system for people living with dementia who will benefit those most affected by the condition while also addressing part of the anxiety affecting those reaching later life. Despite current recognition of the importance of care, support for the care of people with dementia and care provision remain of poor quality around the world (OECD, 2018), a challenge to the dignity of people with dementia, and a factor increasing the intensity of the negative social imaginary of the fourth age, invoking the moral imperative to care for individuals encompassed by this social imaginary (Higgs & Gilleard, 2015).

Finally, beyond these considerations regarding the unavoidable corporeality of dementia, this approach needs to understand that the anxiety that dementia provokes is in part a symptom of more structural factors and collective imaginaries of ageing. It needs to recognize the taboos that society elevates around later life preventing a clear understanding of ageing and decline and thorough discussions around matters of care in later life. At a conceptual level, we will have to reinforce the lexicon that we use to articulate our discussion of the fourth age and understand its complexity: the cultural system that constructs it, and the corporeality of decline that it encompasses – to this regard, some have called for gerontology to more thoroughly study the fourth age (Hazan, 2011a, 2011b). The existence of distinction, ascription and omission suggests that there is currently no single

solution, or 'best practice', to social exclusion in dementia, yet a variety of approaches with differentiated benefits and inherent contradictions defined by the different social positions composing later life today, between the active third age, and the frailty and dependency of those encompassed by the social imaginary of the fourth age, between people with dementia who remain relatively autonomous and will benefit from measures aiming at changing the attitude of society following a disability model, support and empowerment, and those whose dependency implies a higher level of routinized care and institutionalization. The development of these solutions adequately serving all people with dementia will have to understand the social (rather than solely interpersonal or individual) nature of social exclusion in order to alleviate processes of distinction, ascription and omission. Only then we will be better able to understand how to improve the moral worth and social position of people with dementia and their carers, and address as much as possible the anxiety that later life generates in a late-capitalist society.

### **What are the new research questions that this thesis generates?**

The recognition of distinction, ascription and omission generates the following questions for future research. The existence of distinction points to the interest to more thoroughly study the consequences of prevention narratives in dementia on the life and anxiety of individuals entering later life. Knowing that exclusion is partly a result of the fear that people have of dementia, how do prevention discourses impact well-being and the anxiety that people have about dementia? Are the eventual benefits of prevention outweighing this impact? How does the emphasis on new risk behaviour and lifestyle factors (e.g. level of education, physical activity, diet, etc.) affect collective perceptions about people with dementia? Can we document other sites in which distinction from people with dementia (or people whose agency is more intensely affected by dementia) operates within society?

Regarding ascription, this thesis generates an important set of questions to more critically assess the consequences of medicalization. Hence, knowing that a diagnosis of dementia has the capacity to separate individuals from current ideas of 'successful' or 'normal' ageing, how can we more critically weigh the benefits



of these strategies against their exclusionary capacity? In other words, how do we weigh the therapeutic benefits of medicalization against their social consequences and associated ascription? This questioning is applicable to a wide variety of practices. For instance, how do we evaluate the interest of an early or predementia diagnosis and risk categories such as MCI or prodromal dementia against its social consequences in term of ascription? How do we evaluate the impact of intensified cognitive monitoring on an increasing part of the population by memory clinics? Regarding the therapy itself, one may also ask: do we prioritize well-being in ageing and dementia, or norms of capacity associated with the third age? How is the balance between these two competing priorities established in different therapeutic systems for dementia? These two last questions also directly concern the study of ascription because they ask to what extent our ideals for later life reinforce the categorization of cognitive decline as an abnormal condition.

Regarding omission, one may ask: do the strategies we develop to prevent social exclusion in dementia address enough the concerns of the fourth age? Or do we risk overlooking these concerns, therefore leaving the position of individuals who experience them unaddressed? To what extent are imperatives of a socio-economic nature prioritized in strategies centred on the maintenance of independence at the expense of the interests of people with dementia and their needs for assistance?

Other questions around omission also apply to current technological developments in the domain of care. In recent years, there has been a craze around the possibilities offered by promising technological developments such as artificial intelligence (Bharucha et al., 2009; Ienca et al., 2017) and robotics (Pfadenhauer & Dukat, 2015). To what extent are we attributing excessive problem-solving capacity to these technologies? To what extent are we neglecting the importance of a well-resourced care workforce most necessary to people encompassed by the fourth age by overemphasizing the relevance of these technologies? These are important questions to ask. It does not mean that these technologies cannot be useful in supporting care but we should keep a critical gaze on distinguishing between the abstract promise of technological development influenced by politico-economic objectives on one hand and its actual benefit in real world settings on the other.

## **Limitations of the research**

Other aspects could have been explored in this research with the potential to generate interesting analysis. Principally, I did not collect demographic data on participants beyond the inclusion criteria used to recruit them and there is no analysis of gender difference. Collecting and analysing these demographic aspects would have certainly brought up interesting research questions. Indeed, Gilleard and Higgs (2019) have discussed the gendered nature of the social imaginary of the fourth age and other demographic characteristics and identity traits could have had an influence on the fourth age as well. However, this decision not to collect these demographic variables was consciously made because I essentially focused on exploring processes of exclusion through in-depth qualitative analysis. I did not aim at generating representative samples of specific identity groups. Neither a systematic collection of demographic variables, nor a discussion of gender difference would have been necessary to theorize the processes of exclusion I present in this thesis. As such, existential concerns around decline are not exclusive to a specific identity group in society, a point also made by Gilleard and Higgs (2014, p. 6). Overall, this thesis remains exploratory and proposes a first insight into the relatively uncharted territory of social exclusion and active cognitive ageing. Future research in this domain could complement this research by focusing on these demographic aspects to offer additional insights and nuances.

## **Concluding remarks**

As a critical contribution to our understanding of dementia, this thesis proposed a theory of social exclusion emerging from common practices and discourses that are often taken for granted, unquestioned, and accepted as best practice (Eriksen, 2001, p. 85). As the anthropologist Eriksen puts it, ‘we must look into what people actually do, and why they do it, in order to understand what these phenomena mean and why they are maintained or transformed through time’ (2001, p. 85). This questioning of one’s own practices and the ones of others is an important pillar of the social sciences (Davies, 2008). It proposed to rethinking our understanding of social exclusion in later life using theories of social positioning, therefore enabling a novel and more compelling insight into the nature of the processes involved. By

doing so, it also enabled us to understand the contradictory nature of the solutions that we propose to the exclusion of people experiencing cognitive decline in later life. This thesis showed that the dementia strategies being developed and the creation of a social movement around dementia can lead to benefits on one side, while having drawbacks on another, and are inevitably serving the interest of particular positions in later life defined by the aspirations of the third age.

Yet, the critique offered by this thesis to other disciplines and practices should not be interpreted as outright criticism. It rather attempts to signpost the origin of exclusion by tracing its origin into the complex ideas that society develops about the nature of decline and the meaning of later life. The reach of this conclusion goes beyond the action of individual stakeholders and point to the necessity of a concerted effort to recognize the space that we give to decline in our conceptualization of later life. This critique does not question the different stakeholders' ideal to improve the life of people with dementia, it only points to the contradictions and limitations of their actions for the sake of improvement, and hopes to contribute to this shared ideal.

Overall, this thesis shows the mundane forms that exclusionary processes can take in dementia, and how they only become significant through their multiplicity when being combined at a larger scale, forming historically specific discursive points in society. Many practices and discourses come together to compose these exclusionary processes. As this thesis has presented, they can include the relatively innocuous act of training one's brain. They can be found in new medical practices delineating what constitutes abnormal ageing today. These exclusionary processes can also be found in therapeutic narratives putting more emphasis on certain aspects of dementia (e.g. the ones desired by an active third age) rather than others. Taken in isolation from each other, these multiple acts can appear to be without any substantially negative impact on the standing of people with dementia. It is only when these many micro-practices, discourses, and their significance are combined and become part of the collective imaginary of a society that they constitute a social process capable of creating social division through their valuation of certain social positions in later life. This is particularly the case with the ones characterized by the desirability of the third age which occur at the expense of others; the more frightening realities of physical and cognitive decline,

abjection, frailty and dependency. This thesis, by researching and establishing connections between multiple sites that may appear relatively unrelated at first sight beyond the fact that they attempt to address the challenges posed by dementia, has attempted to bring the existence of this collective imaginary and its exclusionary capacity into plain sight. Through the holistic approach and reflexivity that the social sciences can offer, it therefore attempts to present the bigger picture, detaching itself from other approaches more focused on resolving specific practical problems without attending to their broader social significance. Hence, while some scientific disciplines have asked how to prevent dementia, or rehabilitate people with the condition, this thesis reviewed the social significance of prevention or rehabilitation itself. While some disciplines have asked how to empower people with dementia and strengthen their social participation, this thesis took a step back by considering who would actually benefit from this type of intervention, and how empowerment itself can be constrained by the norms of society and their implicit emphasis on agency and autonomy as a necessary condition to participation. Through its theorization, this thesis hopes to transform these isolated practices into tangible objects of reflection and debate enabling us to understand the tensions and exclusion inhabiting the meaning that we attribute to cognitive decline and later life in contemporary Western society. Importantly, this thesis showed that describing the existence of decline as a matter of concern in later life should not be interpreted as an insulting and inaccurate representation of later life as it is increasingly stated by proponents of the cultural turn in gerontology fighting against any representation that associates ageing with decline. It should instead be recognised as an intrinsic, and yet unwanted, dimension of the human condition confronted by those who age today and those who will age tomorrow. Overlooking this issue of cognitive decline, for instance by reformulating dementia as a mere difference which can be well lived also neglects the discomfort and distress of an important part of the population who experiences it, both people living with dementia and their caregivers.

Yet, even when being recognized by society, this social division between those deemed to age ‘successfully’ and those understood as ‘failing’ to do so can appear acceptable or unactionable, naturalized as inevitable. If we break the taboo that surrounds ageing and decline, if we accept that not all people with dementia can be

empowered to live an independent life or 'live well' with dementia, and that dependency remains an intrinsic dimension of the experience of many individuals reaching later life, then we should be abler to realistically identify the challenges they face and respond to their exclusion. Addressing frailty, abjection and the exclusion of the most vulnerable members of our societies through adequate care and support should be a priority, not an afterthought or a peripheral program.



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## Annexes

### 1. Interview guide users of brain training (cf. chapter 3)

#### Introduction questions and questions on brain training

- Tell me about what you are doing with the [Delta Project].
- How did you come to participate to the [Delta Project].
  - How important is this research for you?
  - Did you speak about your participation with your family? With your friends?
    - What do they think about it?
- Is it the first time you do brain training?
  - If yes, is it something that you would have done spontaneously?
  - If no, how did you come to brain train in the first place?
- Did you hear about brain training before the [Delta Project]?
- What is brain training doing to you? How do you feel about doing brain training?
- What were your impressions when using the brain training device?
- What do you think brain training does to you?
- What did you expect from BT when you first tried it? (in case the person has already stopped using it, because not convinced about it)

#### Perspectives on ageing

- How do we see life, and ageing from your perspective? Did your perspective on life as you aged change since you were in your mid-twenties? Where does the practice of brain training appear in these changes?

#### Questions about active/successful ageing (partly informed by criteria defined by Lamb, 2014)

- Do you have the impression that ageing is a topic that circulates a lot in the media, be it newspaper, internet or television?
  - What is your impression of the messages that circulate about ageing in the media nowadays?
- 1) 'An emphasis on individual agency and control' (Lamb, 2014);
    - Do you think it is important to remain in control of our lives as we age?
  - 2) 'The value of independence and the importance of avoiding dependence' (Lamb, 2014);
    - Is it important to remain independent for you? Or is it fine to get some help from your relatives as you get older?

- 3) 'The value of activity and productivity' (Lamb, 2014);
  - Are you part of a sport club, or any intellectual activity group?
  - Would you encourage other people to do the same?
- 4) 'A vision of *not* aging at all, while pursuing the goals of agelessness and what could be termed a permanent personhood' (Lamb, 2014).
  - Is there a better way to age for you?
  - How would ageing 'better' look like for you?
  - Is there anything that worries you about ageing?
  - Is this a moral responsibility to stay active as we age?

#### Perspectives on cognitive ageing

- Do you engage in any activity that aims at staying intellectually/mentally/cognitively fit?
- What are these activities? And how did you come to engage in these activities?
- What do you think these activities do to you?
- Would you encourage other people of your age to engage in such activities as brain training as well?

#### Questions relating to dementia and distinction from the 4<sup>th</sup> Age

- Do you have the impression that dementia is a topic that circulates a lot in the media, be it newspaper, internet or television?
- What is your impression of the messages that circulate about dementia in the media nowadays?
- At what point did you think about joining research on dementia? How did you come to make the choice to participate in research on dementia?
- Is dementia something that worries you?
- How do you feel about the information that circulates today about preventing dementia?

#### Question on their participation to future research

- Explore whether the participant has planned to participate to future research on dementia, and ask what the future research will be.

## **2. Interview guide researchers on independence (cf. chapter 5)**

### Questions relating to the emergence of [the project you developed] and problematic addressed

- How did [the project you developed] emerge? What kind of problematic does it aim to address?
- Tell me a bit more about your role in [the project you developed]?
- Were there precedents to [the project you developed]?
- What is the novelty brought by [the project you developed]?
- What has been your impression of with [the project you developed] so far in regard to the original plan to promote independence? Have there been interesting findings, surprising findings, or unexpected challenges?
- How do you expect these findings to influence the development of [the project you developed]?

### Questions relating to the concept of independence in the intervention

- What does the intervention aim to achieve?
- How important was the notion of independence in the development of the intervention?
- What does this notion of independence uncover for you?
- Why is it important to stay independent, and to participate in society while having a diagnosis of dementia?
- Were there different understandings of this concept [among members of the team] when you developed the intervention?

### Question relating to the notion of choice

- Is independence about being able to choose for oneself?
- How does the intervention help people with dementia to choose for themselves?
- How is the dementia advice worker or the carer involved in the choices made by the person diagnosed with dementia?
- Are there more appropriate choices than others? Do carers and dementia advice workers evaluate the choice of activity made by the person with the diagnosis? On what basis?
- In a way, independence and choice involve having more control over one's life for a person with dementia. Why is it important to have more control over one's life?

#### Questions relating to users and the progressive nature of dementia

- Who were the users for whom [the project] was originally developed?
- How does the intervention adapt to the progressive nature of dementia?
- How does the intervention aim to accommodate the progressive dependence of people with dementia?
- Are there mechanisms in the intervention that help users to cope with the progressive nature of dementia, and how? Is it something that falls into the scope of the intervention?
- Is there a correlation between cognition and choice?

#### Questions relating to the technologies developed

- What kind of technology is being developed in the intervention?
- How did you start thinking about such technology?
- Was [the project you developed] originally meant to be a technological intervention?
- What can technology offer to the intervention?
- What kind of problematic does this technology aim to address?

### 3. Consultation guide Dementia Advisory Group (cf. chapter 6)

#### Discussion 1: Belonging to the [Dementia Advisory Group] and living with dementia

*This discussion is relevant to my research because I wish to understand what motivates you to be part of the [Dementia Advisory Group], and what it means for you.*

*I also wish to understand more about your experience of dementia, and how it relates to your participation in the group.*

Q1: What motivated you to be part of the [Dementia Advisory Group]?

Q2: Has being a member of the [Dementia Advisory Group] changed your experience of living with dementia?

Q3: How did the diagnosis of dementia become part of your life?

*...for example, how did you experience the first symptoms, and diagnosis?  
How did you first find support following your experience of the changes associated with your condition and your diagnosis for instance?*

Q4: Is it important for you to speak out/inform the public/raise awareness about your condition? If so, why?

Q5: Has dementia influenced how you think about life in general?

Q6: In your opinion, are there experiences that unite all people with dementia?

Q7: In your opinion, are there issues that divide people experiencing dementia?

*...for example, how might the experience of a person with younger onset dementia be different from the experience of someone having the condition later in life?*

Q8: In your opinion, does the type of diagnosis influence the experience that we have of dementia?

*...for example, what connects and what differentiates the kind of support to offer to someone diagnosed with frontotemporal dementia from someone diagnosed with Alzheimer's disease?*

Q9: What would you like to see improved in the inclusion of people with dementia in society?

Q10: What do you hope for your future, and for the future of people with dementia?

#### Discussion 2: Considering ageing and dementia

*This discussion is relevant to my research because I wish to understand how the meaning of ageing has changed throughout history and across cultures.*

*Today, society often draws a link between ageing and dementia, and I wish to understand how this link has eventually impacted you. I also wish to understand what your own perspective on ageing and dementia is.*

Q1: Do you have the impression that dementia is associated with old age in society? If so, in what way?

Q1.1. Do you think about any example for this association between dementia and ageing?

Q2: If yes, have you experienced the link that society makes between dementia and ageing yourself? If so, how? Could you give me any examples of situations in which this has happened?

Q3: Did you, yourself, see a link between dementia and old age before your diagnosis?

Q4: Do you think age influences people's experience of having dementia?

Q4.1. Do you think age influences the kind of support to offer to people with dementia? If so, how?

Q4.2. Do you think there is such a thing as 'being old', and do you think it can influence how people live with dementia? If yes, how?

### Discussion 3: Considering the importance of activity, productivity and technology in dementia

*Such discussion is relevant to my research because I wish to understand the position of members of the [Dementia Advisory Group] on the importance to stay active and engaged in the society after a diagnosis.*

*My question is informed by current scientific literature on chronic illness which questions the impact of high cultural expectations of productivity - meaning 'doing something of personal or social value' (Hay 2010) - and activity in Western culture on people's life.*

*I wish to understand how members position themselves concerning this ideal of productivity and activity and how they experience it.*

Q1: Do people around you assume that having a diagnosis means that you cannot participate in society anymore? What do you think about this assumption?

Q1.1. Has being part of the [Dementia Advisory Group] helped you to counter this assumption?

Q1.2. If applicable, has being part of a national association or doing advocacy work helped you to counter this assumption?

Q2: Have you changed your daily life since the time of diagnosis?

Q3: What does being active and contributing to society mean to you, and has this meaning changed since the time of your diagnosis?

Q3.1. Are their activities/occupations of your daily life that you felt you had to change/adapt, or ask for support since you experienced the first symptoms of dementia? And how did you experience this adaptation?

Q4: Was it important for you to continue a professional activity after having been diagnosed? If so, why?

Q.4.1. Were you able to do so? If not, was this your own choice or due to circumstances beyond your control (e.g. your employer asking you to leave)?

Q5: Have you started new activities and/or learned new skills after your diagnosis? If so, what were your motivations, and what did it bring you?

Q6: What do you think about the advice to stay active, and start new activities and/or learn new things after being diagnosed with dementia?

Q6.1. What do you think about assistive technologies/interventions that aim to support the planning of meaningful activities for dementia? Do you think they adequately support people with dementia?

Q7: Do you think experiencing a progression of the symptoms of dementia affects the use of assistive technologies, and technologies for people with dementia generally?

Q7.1: Do you think the progression of the condition is something which is considered in the technologies proposed for people with dementia on the market?

*General impression? Examples?*

Q8: How important should be the proportion of resources given to developing technologies for people with dementia in current and future national/international dementia strategies?

Q8.1. In your opinion, are there other matters within dementia strategies that should require more/less attention?

### Closing discussion

Are there any comments that you would like to add to the topics discussed today?

*...for example something that has not yet been mentioned and that you think is important with regard to belonging to the [Dementia Advisory Group], or how current understandings of ageing and dementia, or in connection to our discussion about activity and technology?*



#### 4. List of participants in the research

<b>Users of brain training recruited with the Delta Project in the United Kingdom (Chapter 3)</b>
<ul style="list-style-type: none"> <li>• 27 older adults (above 50 years old), and without dementia engaging in the practice of brain training as part of the research of the Delta Project. Participants volunteered for the research (note on representativity: majority of white middle to upper-class highly educated women volunteered).</li> </ul>
<b>Participants in ethnography of memory clinics implementing cognitive rehabilitation in Southern Europe (Chapter 4)</b>
<ul style="list-style-type: none"> <li>• 8 clinicians (neuropsychologists, and psychologists) at different career levels (MSc, PhD students, others playing a more senior role), some of them playing simultaneously the role of researchers and developers working on cognitive training and rehabilitation interventions in two different memory clinics.</li> </ul>
<b>Participants in interviews exploring an intervention implementing empowerment and independence in dementia in the United Kingdom (Chapter 5)</b>
<ul style="list-style-type: none"> <li>• 6 researchers engaged in the development of an intervention aiming at supporting independence in dementia in the United Kingdom.</li> </ul>
<b>Participants in the ethnography with a collective of experts and advocates with dementia</b>
<ul style="list-style-type: none"> <li>• 12 individuals diagnosed with dementia belonging to the collective of experts and advocates with dementia, from different nationalities</li> <li>• 5 supporters/caregivers of these individuals from different nationalities</li> </ul>

## 5. Research ethics applications sent to the UCL Research Ethics Committee for review

### 5.1. Research ethics application for section on dementia advocacy and memory clinics (anonymized) [UCL Ethics reference: 12275/001]



#### UCL Research Ethics Committee

**Note to Applicants:** It is important for you to include all relevant information about your research in this application form as your ethical approval will be based on this form. Therefore anything not included will not be part of any ethical approval.

You are advised to read the *Guidance for Applicants* when completing this form.

#### Application For Ethical Review: Low Risk

Are you applying for an urgent accelerated review? Yes ☐ No ☒

If yes, please state your reasons below. Note: Accelerated reviews are for exceptional circumstances only and need to be justified in detail.

Is this application for a continuation of a research project that already has ethical approval? For example, a preliminary/pilot study has been completed and is this an application for a follow-up project?

Yes ☐

No ☒

If yes, provide brief details (see guidelines) including the title and ethics id number for the previous study:

#### Section A: Application details

1	Title of Project	Brain training as an exclusionary process in people with dementia
2	Proposed data collection start date	15/01/2018
3	Proposed data collection end date	30/12/2018
4	Project Ethics Identification Number	12275/001
5	Principal Investigator	Prof Paul Higgs
6	Position held (Staff/Student)	Professor
7	Faculty/Department	Division of Psychiatry
8	Course Title (if student)	
9	Contact Details	
	Email: [REDACTED]	
	Telephone: [REDACTED]	
10	Provide details of other Co-Investigators/Partners/Collaborators who will work on the project.	
	<b>Note:</b> This includes those with access to the data such as transcribers.	
	Name: Mr Sébastien Libert	Name:

Position held: PhD/MPhil Student Faculty/Department: Division of Psychiatry Location (UCL/overseas/other UK institution): UCL Email: <input type="text"/>	Position held: Faculty/Department: Location (UCL/overseas/other UK institution): Email:
If you <b>do not know</b> the names of all collaborators, please write their roles in the research.	

<b>11</b>	<b>If the project is funded (this includes non-monetary awards such as laboratory facilities)</b>
Name of Funder	Horizon 2020 European Union Framework Programme for Research and Innovation Marie Skłodowska-Curie Action, Innovative Training Network (ITN) Code: H2020-MSCA-ITN-2015 676265 INDUCT
Is the funding confirmed?	Yes

<b>12</b>	<b>Name of Sponsor</b>
The Sponsor is the organisation taking responsibility for the project, which will usually be UCL. If the Sponsor is not UCL, please state the name of the sponsor. Horizon 2020 European Union Framework Programme for Research and Innovation Marie Skłodowska-Curie Action, Innovative Training Network (ITN) Code: H2020-MSCA-ITN-2015 676265 INDUCT	

<b>13</b>	<b>If this is a student project</b>
Supervisor Name	Prof Paul Higgs
Position held	Professor of the Sociology of Ageing
Faculty/Department	UCL Division of Psychiatry
Contact details	Email: <input type="text"/> Telephone: <input type="text"/>

### Section B: Project details

The following questions relate to the objectives, methods, methodology and location of the study. Please ensure that you answer each question in lay language.

<b>14</b>	<b>Provide a brief (300 words max) background to the project, including its intended aims.</b>
<p>The proposed research intends to explore attitudes and practices of adults approaching later life who use computer-based brain training along with other technologies as ways of promoting 'active ageing'. It also wishes to study how particular technologies are implemented.</p> <p>This proposed research draws on a research literature that identifies the widespread active ageing ideal as promoting a dominant cultural understanding of what ageing means today and comes with a set of tensions and challenges for individuals growing older (Lamb 2014<sup>1</sup>). This research aims at exploring these tensions and challenges by looking at people's</p>	

<sup>1</sup>Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies*, 29, 41-52.

experiences of new technologies and how these relate to people's attitudes toward ageing, the prospect of cognitive decline and dementia.

This research is comparative, and has been divided into 2 sections.

- One section (presented in another ethics application) will look at the motivations that lead adults reaching later life to use computer-based brain training.
- In this section, I will conduct research with researchers who have worked or are currently working on the brain training intervention by [REDACTED]. The purpose of this study is to understand how researchers understand the needs of people reaching later life and people with dementia in the development of solutions such as brain training.

Additionally I intend to apply for an engagement with [REDACTED] to observe their committee meetings in order to understand how active ageing discourses influence the use of technologies by this group as well as how their participation and public engagement in the development of new technologies influences how we currently understand dementia.

Through comparison between these two sections, I will be able to develop an analysis of the current trends in technology development relating to dementia, and how they connect with the ideal of active ageing.

<b>15</b>	<b>Methodology &amp; Methods</b> (tick all that apply)	
	<input checked="" type="checkbox"/> Interviews* <input checked="" type="checkbox"/> Focus groups* <input type="checkbox"/> Questionnaires (including oral questions)* <input type="checkbox"/> Action Research <input checked="" type="checkbox"/> Observation <input type="checkbox"/> Documentary analysis (including use of personal records) <input type="checkbox"/> Audio/visual recordings (including photographs)	<input type="checkbox"/> Collection/use of sensor or locational data <input type="checkbox"/> Controlled Trial <input type="checkbox"/> Intervention study (including changing environments) <input type="checkbox"/> Systematic review <input type="checkbox"/> Secondary data analysis – (See Section D) <input type="checkbox"/> Advisory/consultation groups <input type="checkbox"/> Other, give details:
	*Attach copies to application (see below).	
<b>16a</b>	<p><b>Provide – in lay person's language - an overview of the project;</b> focusing on your methodology and including information on what data/samples will be taken (including a description of the topics/questions to be asked), how data collection will occur and what (if relevant) participants will be asked to do. This should include a justification for the methods chosen. (500 words max)</p> <p>Please <b>do not</b> attach or copy and paste a research proposal or case for support.</p> <p>Participants will be:</p> <ol style="list-style-type: none"> <li>1) Developers of the intervention and researchers part of the activities of [REDACTED]</li> <li>2) Experts with dementia, members of the [REDACTED] their supporters, and [REDACTED] (International).</li> </ol> <p>There are no additional criteria in the selection.</p> <p>Participants will be recruited through the associations [REDACTED] and [REDACTED]. [REDACTED] will contact the participants first.</p>	

	<p>For [REDACTED], the process will be different. This [REDACTED] regularly meets to be consulted by many researchers across Europe. I will contact [REDACTED], Project Officer in charge, and [REDACTED] will book a timeslot for my consultation day with the [REDACTED]. I will also conduct observations during a couple of these planned consultations to understand what it means to be an expert with dementia.</p> <p>The research methodology will be the following:</p> <ol style="list-style-type: none"> <li>1) Semi-structured interviews and observations looking at researchers' work [REDACTED]</li> <li>2) A group consultation with [REDACTED] + observations during their committee meetings.</li> </ol> <p>Interviews, and observations with [REDACTED] will aim at exploring the representations and practices of researchers and developers of [REDACTED] implementing these technologies, and how their activity may, or may not carry the values of active ageing.</p> <p>During the group consultation with [REDACTED], I will ask questions relating to the ideal of active ageing and to technology for people with dementia. I will also ask questions their role as dementia experts.</p> <p>My observation of the [REDACTED] committee meetings will also help to answer the same questions. Observations will help to produce data in a more inductive way, enabling me to discover important themes that I didn't think about yet.</p>
16b	<p><b>Attachments</b></p> <p>If applicable, please attach a copy of any interview questions/workshop topic guides/questionnaires/test (such as psychometric), etc and state whether they are in final or draft form.</p> <p>I have attached the interview guides to this application form. Though, as said earlier in the methodology, the guides will evolve throughout the research to explore emerging themes relevant to the research question.</p>
17	<p><b>Please state which code of ethics (see Guidelines) will be adhered to for this research (for example, BERA, BPS, etc).</b></p> <p>Following my background (MSc in Anthropology), and approach to the current research, I will adhere to the American Anthropological Association's code of ethics.</p>
<p><b>Location of Research</b></p>	
18	<p><b>Please indicate where this research is taking place.</b></p> <p><input type="checkbox"/> UK only (Skip to 'location of fieldwork')</p> <p><input checked="" type="checkbox"/> Overseas only</p> <p><input type="checkbox"/> UK &amp; overseas</p>
19	<p><b>If the research includes work outside the UK, is ethical approval in the host country (local ethical approval) required? (See Guidelines.)</b></p> <p style="text-align: right;">Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>If no</b>, please explain why local ethical approval is not necessary.</p> <p><b>If yes</b>, provide details below including whether the ethical approval has been received.</p>

	<p><b>Note:</b> Full UCL ethical approval will not be granted until local ethical approval (if required) has been evidenced.</p> <p>For [REDACTED] I am currently in contact with [REDACTED] from [REDACTED]</p> <p>[REDACTED] is international in its scope, members of [REDACTED] are from more than 9 different nations, and the [REDACTED] have dedicated a component of their activity to support researchers. Hence, consultations, including the one for this project, are led by the Projects officers [REDACTED] who closely monitor the consultations according to the standards of the association. They will be continuously present during the observations and consultations, involved in discussions of the research design to ensure that my consultation and observations respect the standards of ethics of the association.</p>
20	<p>If you (or any members of your research team) are travelling overseas in person are there any concerns based on governmental travel advice (<a href="http://www.fco.gov.uk">www.fco.gov.uk</a>) for the region of travel? Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p><b>Note:</b> Check <a href="http://www.fco.gov.uk">www.fco.gov.uk</a> and submit a travel insurance form to UCL Finance (see application guidelines for more details). This can be accessed here: <a href="https://www.ucl.ac.uk/finance/secure/fin_acc/insurance.htm">https://www.ucl.ac.uk/finance/secure/fin_acc/insurance.htm</a> (You will need your UCL login details.)</p>
21	<p>State the location(s) where the research will be conducted and data collected. For example public spaces, schools, private company, using online methods, postal mail or telephone communications.</p> <p>With [REDACTED] research institutes, offices or departments where [REDACTED] works</p> <p>With [REDACTED] during the committee meetings for the consultations of the [REDACTED] organized by [REDACTED]</p>
22	<p>Does the research location require any additional permissions (e.g. obtaining access to schools, hospitals, private property, non-disclosure agreements, access to biodiversity permits (CBD), etc.)?</p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>If yes, please state the permissions required.</p>
23	<p>Have the above approvals been obtained? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, please attach a copy of the approval correspondence.</p> <p>If not, confirm they will be obtained prior to data collection. Yes <input type="checkbox"/> No <input type="checkbox"/></p>

### Section C: Details of Participants

In this form 'participants' means human participants and their data (including sensor/location data, observational notes/images, tissue and blood samples, as well as DNA).

24	Does the project involve the recruitment of participants?
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Yes ☒ Complete all parts of this Section.

No ☐ Move to Section D.

#### Participant Details

- 25 Approximate maximum number of participants required: 25  
Approximate upper age limit: None Lower age limit: 18  
Justification for the age range and sample size:
- With [REDACTED] I wish to do a group consultation and observation with the 20 members of the groups (9 experts with dementia, 9 supporters, 2 project officers). There are no other criteria of selection besides being part of the [REDACTED] or being a project officer or supporter, hence all the persons that are present altogether during the committee meetings.)
- With [REDACTED] There is no criteria of age for the developers and researchers, and I will conduct fieldwork with 5 researchers and developers part of [REDACTED]

#### Recruitment/Sampling

- 26 Describe how potential participants will be recruited into the study.
- Note:** This should include reference to how you will identify and approach participants. For example, will participants self-identify themselves by responding to an advert for the study or will you approach them directly (such as in person or via email)?
- Participants from [REDACTED]  
I will contact [REDACTED] Project officer [REDACTED] to organize the consultation and observations during the committee meetings of the [REDACTED]  
[REDACTED] The association will initiate the procedure with the group.
- Researchers and developers from [REDACTED]  
I will identify the potential researchers and developers willing to participate by contacting first the manager of the project [REDACTED] The manager will identify the researchers and developers that could be interested and ask them if they wish to transmit their contact to me. I will then contact the potentially interested researchers to ask them if they wish to meet me and discuss the project.

#### Informed Consent

- 27a Describe the process you will use when seeking to obtain consent.
- Note:** This should include reference to what participants are being asked to consent to, such as whether their contribution will be identifiable/anonymous, limits to confidentiality and whether their data can be withdrawn at a later date.
- (An annotated template information sheet and consent form have been provided for your use.)*
- For [REDACTED] when participants have accepted to be contacted, I will meet them and seek to obtain consent.
- I will talk them through the information sheet and consent form step by step to be sure that every point of the information sheet and consent form have been properly understood. In all cases, I will emphasize their right to withdrawal at any time, and their right to ask for data on them to be securely destroyed if they request it, and this without

	<p>any need to justify their decision. I will therefore underline that I ask their signature to signify their understanding of the project and their wish to participate.</p> <p>As for [REDACTED] members of the [REDACTED] have a capacity to consent and regularly participate in research consultations. There is a structured process to ask consent which is included in the planning of the consultation meetings. The consent process is well organized by the 2 project officers, who will monitor the consent process, and support me while I ask consent. They will ensure that experts with dementia have understood the consent form and information sheet properly.</p> <p>Therefore, and with the help of the projects officers, I will take experts with dementia through the information sheet and consent form step by step to be sure that every point of the information sheet and consent form have been properly understood. In all cases, I will emphasize their right to withdraw at any time, and their right to ask for data on them to be securely destroyed if they request it, and this without any need to justify their decision. I will therefore underline that I ask their signature to signify their understanding of the project and their wish to participate.</p>
27b	<p><b>Attachments</b> Please list them below:</p> <p><i>Ensure that a copy of all recruitment documentation (recruitment emails/posters, information sheet/s, consent form/s) have been attached to the application.</i></p>
27c	<p>If you are <b>not</b> intending to seek consent from participants, clarify why below: NA</p>

28	<p>How will the results be disseminated (including communication of results with participants)?</p> <p>I will ask to the participants what their preferred means of communication is (Written form, phone call, etc.). I will transmit the results at the end of the study through a summary of the research to the participants.</p> <p>Regarding public dissemination, I will analyse the data for the thesis, presentations (poster, conference, seminar), and scientific publications in journals on ageing, health, technology, social sciences, and public policy.</p>
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#### Section D: Accessing/Using Pre-collected Data

<b>Access to data</b>	
29	<p>If you are using data or information held by third party, please explain how you will obtain this. You should confirm that the information has been obtained in accordance with the UK Data Protection Act 1998.</p> <p>Because both [REDACTED] and [REDACTED] are not British projects and associations, I will be careful to respect the standards of the UK Data Protection Act 1998, as well as the respects the standards relevant for these projects.</p>



<b>Accessing pre-collected data</b>	
<b>30</b>	<p><b>Does your study involve the use of previously collected data?</b></p> <p><b>No</b> <input checked="" type="checkbox"/> Move to Section E.</p> <p><b>Yes</b> <input type="checkbox"/> Complete all parts of this Section. <b>Note:</b> If you ticked any boxes with an asterisk (*), ensure further details are provided in Section E: Ethical Issues.</p>
<b>31</b>	<b>Name of dataset/s:</b>
<b>32</b>	<b>Owner of dataset/s (if applicable):</b>
<b>33</b>	<p><b>Is the data in the public domain?</b> Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p><b>If not, do you have the owner's permission/license?</b> Yes <input type="checkbox"/> No* <input type="checkbox"/></p>
<b>33</b>	<p><b>Is the data anonymised?</b> Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p><b>If not:</b></p> <p>i. Do you plan to anonymise the data? Yes <input type="checkbox"/> No* <input type="checkbox"/></p> <p>ii. Do you plan to use individual level data? Yes* <input type="checkbox"/> No <input type="checkbox"/></p> <p>iii. Will you be linking data to individuals? Yes* <input type="checkbox"/> No <input type="checkbox"/></p>
<b>34</b>	<p><b>Is the data sensitive (<a href="#">DPA 1998 definition</a>)?</b></p> <p>Yes* <input type="checkbox"/> No <input type="checkbox"/></p>
<b>35</b>	<p><b>Will you be conducting analysis within the remit it was originally collected for?</b></p> <p>Yes <input type="checkbox"/> No* <input type="checkbox"/></p>
<b>36</b>	<p><b>If not, was consent gained from participants for subsequent/future analysis?</b></p> <p>Yes <input type="checkbox"/> No* <input type="checkbox"/></p>

## Section E: Ethical Issues

<b>Ethical Issues</b>	
<b>37</b>	<p>Please address clearly any ethical issues that may arise in the course of this research and how they will be addressed. Further information and advice can be found in the guidelines.</p> <p><b>Note:</b> All ethical issues should be addressed - <b>do not leave this section blank</b>. All projects give rise to ethical issues. If you think there are no ethical issues, you need to provide an explanation as to why.</p> <p>Observation periods:</p> <p>I will thoroughly discuss activities considered during the observation periods with the participants of [REDACTED] beforehand. Hence, I will closely follow the most relevant period to conduct observations so that they remain convenient for the participants. I will take great care of respecting the wishes of the participant at any time in regard to the exact conditions of the observation.</p>

	<p>For [REDACTED] I will only stick to the meeting periods of the [REDACTED] [REDACTED] hence, my presence in observations will be clearly defined, following the duration of these meetings in which my presence will be planned with the project officers and announced at the start of the meeting. Hence there shouldn't be any issue with planning the most adequate time.</p> <p>Confidentiality:</p> <p>I will take great care of securely storing all the personal information falling under the data protection act 1998. During the research phase with [REDACTED] and [REDACTED] and following interviews, I will transfer the data from recording devices (Audio-recorder; and laptop field notes) to the UCL network on a password protected file or encrypted hard drive as soon as possible. I will store the physical supports (encrypted hard drives, or field notes) as soon as possible after the observation period in a locked container in a locked room at the UCL Division of Psychiatry.</p> <ul style="list-style-type: none"> <li>• In the case of an interview, I will listen to the recording and write it down in a transcript. Anything said in the interview that might identify the person will be removed. The researcher will then look in the interview transcript for common themes.</li> <li>• As for the observation, I will anonymize the notes by replacing names with a pseudonym. I will also remove extracts that might identify the person. I will then use extracts from these field notes to illustrate themes and analyses.</li> </ul> <p>Additional notice: I will remove information that can identify participants from interviews and field notes with great care. In rare cases, due to the limited sample size in each project, I will not be able to always guarantee that the developers and researchers participating could not be recognized by people who are familiar with the associations. Being aware of these limitations, I wish to involve researchers and developers more fully throughout the progress of the study, as to offer them the opportunity to discuss topics, transcripts and field notes that solely concern them if they wish to. Furthermore, I will remind the participants that they have the right to withdraw from the study at any time, and ask for the destruction of data that concerns them (see below).</p>
<b>Risks &amp; Benefits</b>	
38	<p>Please state any <i>benefits</i> to participants in taking part in the study (this includes feedback, access to services or incentives),</p> <p>I hope that the research will be an opportunity for the participants to voice their views, perspectives, and opinions regarding how they feel about current social norms connected to cognition and ageing in a safe space that allows them to have their voice heard. Ultimately, I hope that the participants will appreciate that their input could help to create solutions and perspectives that can improve their daily lives, and the daily lives of other families, and people experiencing cognitive decline. Hence, the benefits for the participant are both individual, and collective, through altruistic feelings of participating to the improvement of knowledge about ageing, cognitive decline, and dementia at the level of the society.</p>
39	<p>Do you intend to offer incentives or compensation, including access to free services)?</p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>If yes, specify the amount to be paid and/or service to be offered as well as a justification for this.</p>
40	<p>Please state any <i>risks</i> to participants and how these risks will be managed.</p>

	The study is observational, and involves discussions in the context of daily life. The researcher does not envision any risks for the participants. Observations with [REDACTED] are only looking at the development of computer based technologies (on personal computer or laptop), there is no risk involved either.
41	<p>Please state any <i>risks</i> to you or your research team and how these risks will be managed.</p> <p>There is no risk envisioned by the researcher, that go beyond what is already experienced in daily life. Furthermore, participants are all well known, and observations only take place in groups with many people of trust already known by the researcher, both at [REDACTED] and [REDACTED].</p>

## Section F: Data Storage & Security

Please ensure that you answer each question and include all hard and electronic data.

42	<p><b>Will the research involve the collection and/or use of personal data?</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>Personal data</b> is data which relates to a living individual who can be identified from that data OR from the data and other information that is either currently held, or will be held by the data controller (the researcher).</p> <p><i>This includes:</i></p> <ul style="list-style-type: none"> <li>– any expression of opinion about the individual and any intentions of the data controller or any other person toward the individual.</li> <li>– sensor, location or visual data which may reveal information that enables the identification of a face, address, etc (some postcodes cover only one property).</li> <li>– combinations of data which may reveal identifiable data, such as names, email/postal addresses, date of birth, ethnicity, descriptions of health diagnosis or conditions, computer IP address (if relating to a device with a single user).</li> </ul> <p>If you do not have a registration number from Legal Services, please clarify why not:</p>
43	<p><b>Is the research collecting or using</b></p> <ul style="list-style-type: none"> <li>– sensitive personal data as defined by the UK Data Protection Act (racial or ethnic origin / political opinions / religious beliefs / trade union membership / physical or mental health / sexual life / commission of offences or alleged offences), and/or</li> <li>– data which might be considered sensitive in some countries, cultures or contexts.</li> </ul> <p><b>If yes</b>, state whether explicit consent will be sought for its use and what data management measures are in place to adequately manage and protect the data.</p> <p>NA</p>
44	<p><b>All research projects using personal data must be registered with Legal Services before the data is collected, please provide the Data Protection Registration Number: Z6364106/2017/10/117</b></p> <p>If you do not have a registration number from Legal Services, please clarify why not:</p>


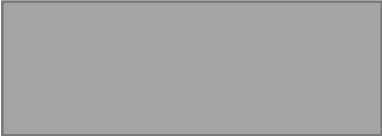
**During the project (including the write up and dissemination period)**

45	<p><b>State what types of data will be generated from this project</b> (i.e. transcripts, videos, photos, audio tapes, field notes, etc).</p> <p>The data generated will be: audio recordings, transcripts, and field notes.</p> <p><b>How will data be stored, including where and for how long?</b> This includes all hard copy and electronic data on laptops, share drives, usb/mobile devices.</p> <p>During the research phase across the different projects and association listed above, and following interviews, the data will be transferred from recording devices (Audio-recorder; and laptop field notes) to the UCL network on a password protected file, or encrypted hard drive as soon as possible. For the physical supports (encrypted hard drives, or field notes), they will be stored as soon as possible after the observation period in a locked container in a locked room at the UCL Division of Psychiatry, and will be kept there until the end of the PhD research.</p> <p><b>Who will have access to the data, including advisory groups and during transcription?</b></p> <p>The researcher, and his supervisor will be the only ones accessing to the data.</p>
46	<p><b>Do you confirm that all personal data will be stored and processed in compliance with the Data Protection Act 1998 (DPA 1998).</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>If not, please clarify why.</b></p>
47	<p><b>Will personal data be processed or be sent outside of the European Economic Area (EEA)?*</b></p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p><b>If yes, please confirm that there are adequate levels of protection in compliance with the DPA 1998 and state what the arrangements are below.</b></p> <p><b>*Please note</b> that if you store your research data containing identifiable data on UCL systems or equipment (including by using your UCL email account to transfer data), or otherwise carry out work on your research in the UK, the processing will take place within the EEA and will be captured by Data Protection legislation.</p>


#### After the project

48	<p><b>What data will be stored and how will you keep it secure?</b></p> <p>Audio recordings, field notes, and transcripts will be archived securely at the UCL Records Office.</p> <p><b>Where will the data be stored and who will have access?</b></p> <p>The field notes, transcripts, and encrypted hard drives containing the data will remain at UCL Records Office for secure archival. Only my supervisor and I will have access to it.</p> <p><b>Will the data be securely deleted?</b> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p><b>If yes, please state when this will occur:</b></p>
49	<p><b>Will the data be archived for use by other researchers?</b> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p>

	If <b>yes</b> , please provide further details including whether researchers outside the European Economic Area will be given access.
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<b>Section G: Declaration</b>	
I confirm that the information in this form is accurate to the best of my knowledge.	
Signature	
Date	5 <sup>th</sup> March 2018
<b><u>If student:</u></b>	
I have met with and advised the student on the ethical aspects of this project design.	
Supervisor Name:	Paul Higgs
Supervisor Signature:	
Date:	5th March 2018

<b>Signature of Head of Department (or Chair of the Departmental Ethics Committee)</b>
<p><b>Part A</b></p> <p>I have read the 'criteria of minimal risk' as defined on page 3 of the Guidelines (<a href="http://ethics.grad.ucl.ac.uk/forms/guidelines.pdf">http://ethics.grad.ucl.ac.uk/forms/guidelines.pdf</a>) and I recommend that this application be considered by the Chair of the UCL REC.</p> <p>Yes <input type="checkbox"/>      No <input checked="" type="checkbox"/></p>
<p><b>Part B</b></p> <p>I have discussed this project with the principal researcher who is suitably qualified to carry out this research and I approve it. I am satisfied that** (highlight as appropriate):</p> <p><b>1. Data Protection registration:</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> has been satisfactorily completed</li> <li><input type="checkbox"/> has been initiated</li> <li><input type="checkbox"/> is not required</li> </ul> <p><b>2. A risk assessment:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> has been satisfactorily completed</li> </ul>

<ul style="list-style-type: none"> <li>▪ has been initiated</li> </ul> <p><b>3. Appropriate insurance arrangements are in place and appropriate sponsorship [funding] has been approved and is in place to complete the study.</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>4. A Disclosure and Barring Service check(s):</b></p> <ul style="list-style-type: none"> <li>▪ has been satisfactorily completed</li> <li>▪ has been initiated</li> <li>▪ is not required</li> </ul> <p><b>Note:</b> Links to details of UCL's policies on the above can be found at: <a href="http://ethics.grad.ucl.ac.uk/procedures.php">http://ethics.grad.ucl.ac.uk/procedures.php</a></p> <p><b>**If any of the above checks are not required please clarify why below.</b></p>	
Name:	Glyn Lewis
Signature:	
Date:	8/3/2018

Updated 19.10.2017

**5.2. Research ethics application for section on brain training users and researchers on independence in dementia (anonymized) [UCL Ethics reference: 12275/002]**



**UCL Research Ethics Committee**

**Note to Applicants:** It is important for you to include all relevant information about your research in this application form as your ethical approval will be based on this form. Therefore anything not included will not be part of any ethical approval.

*You are advised to read the Guidance for Applicants when completing this form.*

**Application For Ethical Review: Low Risk**

Are you applying for an urgent accelerated review?		Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
If yes, please state your reasons below. Note: Accelerated reviews are for exceptional circumstances only and need to be justified in detail.			
Is this application for a continuation of a research project that already has ethical approval? For example, a preliminary/pilot study has been completed and is this an application for a follow-up project?		Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
If yes, provide brief details (see guidelines) including the title and ethics id number for the previous study:			

**Section A: Application details**

1	Title of Project	Brain training as an exclusionary process in people with dementia – section with adults without dementia, researchers and developers
2	Proposed data collection start date	15/01/2018
3	Proposed data collection end date	30/12/2018
4	Project Ethics Identification Number	12275/002
5	Principal Investigator	Prof Paul Higgs
6	Position held (Staff/Student)	Professor
7	Faculty/Department	Division of Psychiatry
8	Course Title (if student)	
9	Contact Details	
	Email: [REDACTED]	
	Telephone: [REDACTED]	
10	Provide details of other Co-Investigators/Partners/Collaborators who will work on the project. <b>Note:</b> This includes those with access to the data such as transcribers.	
	Name: Mr Sébastien Libert	Name:

1



Position held: PhD/MPhil Student Faculty/Department: Division of Psychiatry Location (UCL/overseas/other UK institution): UCL Email: <input type="text"/>	Position held: Faculty/Department: Location (UCL/overseas/other UK institution): Email:
If you <b>do not know</b> the names of all collaborators, please write their roles in the research.	

<b>11</b>	<b>If the project is funded (this includes non-monetary awards such as laboratory facilities)</b>
Name of Funder	Horizon 2020 European Union Framework Programme for Research and Innovation Marie Skłodowska-Curie Action, Innovative Training Network (ITN) Code: H2020-MSCA-ITN-2015 676265 INDUCT
Is the funding confirmed?	Yes

<b>12</b>	<b>Name of Sponsor</b>
The Sponsor is the organisation taking responsibility for the project, which will usually be UCL. If the Sponsor is not UCL, please state the name of the sponsor. Horizon 2020 European Union Framework Programme for Research and Innovation Marie Skłodowska-Curie Action, Innovative Training Network (ITN) Code: H2020-MSCA-ITN-2015 676265 INDUCT	

<b>13</b>	<b>If this is a student project</b>
Supervisor Name	Prof Paul Higgs
Position held	Professor of the Sociology of Ageing
Faculty/Department	UCL Division of Psychiatry
Contact details	Email: <input type="text"/> Telephone: <input type="text"/>

## Section B: Project details

The following questions relate to the objectives, methods, methodology and location of the study. Please ensure that you answer each question in lay language.

<b>14</b>	<b>Provide a <i>brief</i> (300 words max) background to the project, including its intended aims.</b>
The research presented here wishes to explore attitudes and practices of adults approaching later life who use computer-based brain training, and other technologies materializing aspects of the cultural ideal of 'active cognitive ageing', including their implementation process. Previous research says that attempting to fulfil the standards of normality as they are defined in the widespread active ageing ideal comes with a set of tensions and challenges (e.g. Lamb 2014 <sup>1</sup> ). This research aims at exploring these tensions and challenges by looking at people's experiences with new technologies, and the relation of these experiences with people's attitudes toward ageing, the prospect of cognitive decline and dementia. The	

<sup>1</sup>Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies*, 29, 41-52.



researcher will approach the subject-matter by looking at the daily life of users around brain training and other technologies relating to the ideal of active ageing inside the [REDACTED]. The researcher will also explore the representations of researchers who worked or are currently working on ongoing interventions such as the [REDACTED].

15	<b>Methodology &amp; Methods</b> (tick all that apply)
	<div style="display: flex; flex-wrap: wrap;"> <div style="flex: 50%;"> <input checked="" type="checkbox"/> Interviews*  <input type="checkbox"/> Focus groups*  <input type="checkbox"/> Questionnaires (including oral questions)*  <input type="checkbox"/> Action Research  <input checked="" type="checkbox"/> Observation  <input type="checkbox"/> Documentary analysis (including use of personal records)  <input type="checkbox"/> Audio/visual recordings (including photographs)         </div> <div style="flex: 50%;"> <input type="checkbox"/> Collection/use of sensor or locational data  <input type="checkbox"/> Controlled Trial  <input type="checkbox"/> Intervention study (including changing environments)  <input type="checkbox"/> Systematic review  <input type="checkbox"/> Secondary data analysis – (See Section D)  <input type="checkbox"/> Advisory/consultation groups  <input type="checkbox"/> Other, give details:         </div> </div> <p><i>*Attach copies to application (see below).</i></p>
16a	<p><b>Provide – in lay person's language - an overview of the project;</b> focusing on your methodology and including information on what data/samples will be taken (including a description of the topics/questions to be asked), how data collection will occur and what (if relevant) participants will be asked to do. This should include a justification for the methods chosen. <b>(500 words max)</b></p> <p>Please <b>do not</b> attach or copy and paste a research proposal or case for support.</p> <p>Participants will be: healthy participants between 50 and 65 years old, without a diagnosis of dementia; developers of the intervention and researchers. These participants have been, or are part of the activities of the following projects: [REDACTED]</p> <p>There is no additional criteria in the selection.</p> <p>Participants will be recruited through the associations listed above, and first contacted by these associations, or in collaboration with these associations.</p> <p>The research methodology will be the following: semi-structured interviews, observations.</p> <p>Content of the interviews will aim at exploring the representations and practices of participants between 50 and 65 years old towards the technologies they are using as part of the [REDACTED] and of the researchers and developers implementing these technologies, and how their use, or implementation relates to:</p> <ol style="list-style-type: none"> <li>1) The cultural ideal of <i>active ageing</i>, and what they find empowering, and challenging about it, as well as how it has expanded from the domain of bodily fitness to the domain of cognition. Active ageing is a cultural ideal that values agency and control, independence, productivity, and a vision of not ageing at all (Lamb 2014, see above for reference) throughout the ageing process.</li> <li>2) The 4<sup>th</sup> Age, which is a social imaginary that defines the most negative parts of ageing, and how people might attempt to stay away from it. By trying to fit in the social norms of cognitive health, people might attempt to distance themselves from the individuals who do not fulfil these norms following the ageing process.</li> </ol> <p>Interviews are iterative, and will be semi-structured interviews. They aim at the production of inductive knowledge about the research matter. Hence, the first</p>

	<p>interviews are mainly defined around the themes of successful ageing. After a first interview, the researcher will ask to the participants if they wish to be interviewed again later on. The themes of the first interview will be reconsidered, and deepened with the participants, as to reach deeper layers of understanding of people's representations, and allow them to reflect upon the evolution of their understanding throughout the project.</p> <p>Observations of the activity of developers and researchers around the development of these technologies, will look at how they develop (for both studies), and implement (only in the case of the [REDACTED]) these technologies. This section of the research aims at analysing interactions among researchers, between developers and researchers, and among developers, around the themes listed above.</p>
<b>16b</b>	<p><b>Attachments</b></p> <p>If applicable, please attach a copy of any interview questions/workshop topic guides/questionnaires/test (such as psychometric), etc and state whether they are in final or draft form.</p> <p>I have attached the interview guides to this application form. Though, as said earlier in the methodology, the guides will evolve throughout the research through an iterative process of interviewing, and as to most adequately produce inductive data.</p>

<b>17</b>	<p><b>Please state which code of ethics (see Guidelines) will be adhered to for this research (for example, BERA, BPS, etc).</b></p>
<p>Following my background (MSc in Anthropology), and approach to the current research, I will adhere to the American Anthropological Association's code of ethics (qualitative interviews + observations).</p>	

<b>Location of Research</b>	
<b>18</b>	<p><b>Please indicate where this research is taking place.</b></p> <p><input checked="" type="checkbox"/> UK only (Skip to 'location of fieldwork')</p> <p><input type="checkbox"/> Overseas only</p> <p><input type="checkbox"/> UK &amp; overseas</p>
<b>19</b>	<p><b>If the research includes work outside the UK, is ethical approval in the host country (local ethical approval) required? (See Guidelines.)</b></p> <p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p><b>If no</b>, please explain why local ethical approval is not necessary.</p> <p><b>If yes</b>, provide details below including whether the ethical approval has been received.</p> <p><b>Note:</b> Full UCL ethical approval will not be granted until local ethical approval (if required) has been evidenced.</p>
<b>20</b>	<p><b>If you (or any members of your research team) are travelling overseas in person are there any concerns based on governmental travel advice (<a href="http://www.fco.gov.uk">www.fco.gov.uk</a>) for the region of travel?</b></p> <p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p><b>Note:</b> Check <a href="http://www.fco.gov.uk">www.fco.gov.uk</a> and submit a travel insurance form to UCL Finance (see application guidelines for more details). This can be accessed here: <a href="https://www.ucl.ac.uk/finance/secure/fin_acc/insurance.htm">https://www.ucl.ac.uk/finance/secure/fin_acc/insurance.htm</a> (You will need your UCL login details.)</p>

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21	<p><b>State the location(s) where the research will be conducted and data collected. For example public spaces, schools, private company, using online methods, postal mail or telephone communications.</b></p> <p>Research institutes or departments where the [REDACTED] and [REDACTED] are taking place. Interviews with the participants of the [REDACTED] will take place both in the houses of participants and public spaces, or in any other place that is convenient for the participants and researcher.</p>
22	<p><b>Does the research location require any additional permissions (e.g. obtaining access to schools, hospitals, private property, non-disclosure agreements, access to biodiversity permits (CBD), etc.)?</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>If yes, please state the permissions required.</b></p> <p>I discussed the research with both managers of [REDACTED] and [REDACTED] projects already, and both have been welcoming to a potential collaboration. [REDACTED] gave me a series of documents to fill in to formally ask for their collaboration in my research. As for [REDACTED] I had a meeting with them. Both told me I should seek UCL ethics approval before we formally start the collaborations.</p>
23	<p><b>Have the above approvals been obtained?</b> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p><b>If yes, please attach a copy of the approval correspondence.</b></p> <p><b>If not, confirm they will be obtained prior to data collection.</b> Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p>

### Section C: Details of Participants

In this form 'participants' means human participants and their data (including sensor/location data, observational notes/images, tissue and blood samples, as well as DNA).

24	<p><b>Does the project involve the recruitment of participants?</b></p> <p>Yes <input checked="" type="checkbox"/> Complete all parts of this Section.</p> <p>No <input type="checkbox"/> Move to Section D.</p>
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Participant Details	
25	<p>Approximate maximum number of participants required: 30</p> <p>Approximate upper age limit: 65 Lower age limit: 18</p> <p><b>Justification for the age range and sample size:</b> I will conduct research with researchers and developers of digital technologies, and participants between 50 and 65 years old without a diagnosis of dementia. 50 years old is the minimum age to participate in the [REDACTED] and logically determines the minimum age of my participants recruited through them. It is also an age in which the ageing process becomes something people start to experience, imagine or envision, also due to their approaching retirement. As for the maximum age, it corresponds to the maximum age limit before which participants are most likely to still be in their active life, while anticipating their retirement, and being concerned about the ageing process. There is no criteria of age for the developers and researchers. I will look for data saturation, hence, the number 30 is an approximation of the maximum number of participants that I would have the time to interview during the project. The number of participants might be lower, also depending on the length of the observations with researchers and developers.</p>

	Additionally, this project wishes to explore social processes rather than demographic variables, which does not require to create samples.
<b>Recruitment/Sampling</b>	
26	<p>Describe how potential participants will be recruited into the study.</p> <p><b>Note:</b> This should include reference to how you will identify and approach participants. For example, will participants self-identify themselves by responding to an advert for the study or will you approach them directly (such as in person or via email)?</p> <p><b>Participants between 50 and 65 years old</b></p> <p>The researcher will contact them through the [REDACTED] who will identify potential participants fitting the requirements. The process will be the same as the one listed above, hence, the association will always initiate the first contact. Following this first contact, the person will authorize the researcher to contact him/her, and eventually after, the researcher will present the information sheets, and consent forms to the participant.</p> <p><b>Researchers and developers</b></p> <p>The researcher will identify the potential researchers and developers willing to participate by contacting first the manager of the projects [REDACTED]. By after, the management team will send information to the researchers and developers, and ask them if they wish to be contacted again.</p>
<b>Informed Consent</b>	
27a	<p>Describe the process you will use when seeking to obtain consent.</p> <p><b>Note:</b> This should include reference to what participants are being asked to consent to, such as whether their contribution will be identifiable/anonymous, limits to confidentiality and whether their data can be withdrawn at a later date.</p> <p><i>(An annotated template information sheet and consent form have been provided for your use.)</i></p> <p>When participants have accepted to be contacted, the researcher will meet them and seek to obtain consent, by talking them through the information sheet and consent form step by step in order to be sure that every point of the information sheet and consent form have been properly understood. In all cases, the researcher will emphasize their right to withdrawal at any time, and their right to ask for data on them to be securely destroyed if they request it, and this without any need to justify their decision. The researcher will therefore underline that he asks their signature to signify their understanding of the project and their wish to participate.</p>
27b	<p><b>Attachments</b> Please list them below:</p> <p><i>Ensure that a copy of all recruitment documentation (recruitment emails/posters, information sheet/s, consent form/s) have been attached to the application.</i></p>
27c	<p>If you are <b>not</b> intending to seek consent from participants, clarify why below:      NA</p>

28	<p>How will the results be disseminated (including communication of results with participants)?</p> <p>The researcher will ask to the participants what their preferred means of communication is (Written form, phone call, etc.). The researcher will transmit the results at the end of the study through a summary of the research to the participants.</p> <p>Regarding public dissemination, the researcher will analyse the data for the thesis, presentations (poster, conference, seminar), and scientific publications in journals on ageing, health, technology, social sciences, and public policy.</p>
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#### Section D: Accessing/Using Pre-collected Data

##### Access to data

- 29 If you are using data or information held by third party, please explain how you will obtain this. You should confirm that the information has been obtained in accordance with the UK Data Protection Act 1998.
- The [REDACTED] is a [REDACTED] respecting the UK Data Protection Act 1998. As for the [REDACTED] it is a project which is based at [REDACTED] and which respects the standards of the UK Data Protection Act 1998.

##### Accessing pre-collected data

- 30 Does your study involve the use of previously collected data?
- No ☒ Move to Section E.
- Yes ☐ Complete all parts of this Section. **Note:** If you ticked any boxes with an asterisk (\*), ensure further details are provided in Section E: Ethical Issues.

31	Name of dataset/s:		
32	Owner of dataset/s (if applicable):		
33	Is the data in the public domain?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	If not, do you have the owner's permission/license?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>
33	Is the data anonymised?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	If not:		
	i. Do you plan to anonymise the data?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>
	ii. Do you plan to use individual level data?	Yes* <input type="checkbox"/>	No <input type="checkbox"/>
	iii. Will you be linking data to individuals?	Yes* <input type="checkbox"/>	No <input type="checkbox"/>
34	Is the data sensitive ( <a href="#">DPA 1998 definition</a> )?	Yes* <input type="checkbox"/> No <input type="checkbox"/>	



35	Will you be conducting analysis within the remit it was originally collected for?	Yes <input type="checkbox"/> No* <input type="checkbox"/>
36	If not, was consent gained from participants for subsequent/future analysis?	Yes <input type="checkbox"/> No* <input type="checkbox"/>

## Section E: Ethical Issues

### Ethical Issues

- 37 Please address clearly any ethical issues that may arise in the course of this research and how they will be addressed. Further information and advice can be found in the guidelines.
- Note:** All ethical issues should be addressed - **do not leave this section blank**. All projects give rise to ethical issues. If you think there are no ethical issues, you need to provide an explanation as to why.
- Observation periods:
- The researcher will thoroughly discuss activities considered during the observation periods with the participants beforehand. Hence, the researcher will closely follow the most adapted period to conduct observations so that they remain convenient for the participants. The researcher will take great care of respecting the wishes of the participant at any time in regard to the exact conditions of the observation.
- Confidentiality:
- The researcher will take great care of securely storing all the personal information falling under the data protection act 1998. During the research phase across the different projects and associations listed above, and following interviews, the researcher will transfer the data from recording devices (Audio-recorder; and laptop field notes) to the UCL network on a password protected file, or encrypted hard drive as soon as possible. The researcher will store the physical supports (encrypted hard drives, or field notes) as soon as possible after the observation period in a locked container in a locked room at the UCL Division of Psychiatry.
- In the case of an interview, the researcher will listen to the recording and write it down in a transcript. Anything said in the interview that might identify the person will be removed. The researcher will then look in the interview transcript for common themes.
  - As for the observation, the researcher will anonymize the notes by replacing names with a pseudonym. The researcher will also remove extracts that might identify the person. He will then use extracts from these field notes to illustrate themes and analyses.
- Additional notice for the section with researchers and developers of the [REDACTED] and the [REDACTED] the researcher will remove information that can identify participants from interviews and field notes with great care. In rare cases, due to the limited sample size, the researcher will not be able to always guarantee that the developers and researchers participating could not be recognized by people who are familiar with the research projects. Being aware of these limitations, the researcher wishes to involve researchers and developers more fully throughout the progress of the study, as to offer them the opportunity to discuss topics, transcripts and field notes that solely concern them if they wish to. Furthermore, the researcher will remind the participants that they have the right to withdraw from the study at any time, and ask for the destruction of data that concerns them (see below).

Risks & Benefits	
38	<p>Please state any <i>benefits</i> to participants in taking part in the study (this includes feedback, access to services or incentives),</p> <p>The researcher hopes that the research will be an opportunity for the participants to voice their views, perspectives, and opinions regarding how they feel about current social norms connected to cognition and ageing in a safe space that allows them to have their voice heard. Ultimately, the researcher hopes that the participants will appreciate that their input could help to create solutions and perspectives that can improve their daily life, and the daily life of other families, and people experiencing cognitive decline. Hence, the benefits for the participant are both individual, and collective, through altruistic feelings of participating to the improvement of knowledge about ageing, cognitive decline, and dementia at the level of the society.</p>
39	<p>Do you intend to offer incentives or compensation, including access to free services)?</p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p><b>If yes, specify the amount to be paid and/or service to be offered as well as a justification for this.</b></p>
40	<p>Please state any <i>risks</i> to participants and how these risks will be managed.</p> <p>The study is observational, and involves discussions in the context of daily life. The researcher does not envision any risks for the participants.</p>
41	<p>Please state any <i>risks</i> to you or your research team and how these risks will be managed.</p> <p>The researcher will be careful when conducting interviews and observations in the houses of strangers. However, any risk of aggression appears very unlikely for the researcher, as participants are identified by the research teams and staff of [REDACTED] and the [REDACTED] already. Hence, they are recorded in existing documents. Additionally, the researcher will keep a phone at his disposal, and warn his colleagues or friends and relatives about the localisation of his encounters, prior to, and after the interviews in the house of the participants.</p>

## Section F: Data Storage & Security

Please ensure that you answer each question and include all hard and electronic data.

42	<p><b>Will the research involve the collection and/or use of personal data?</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>Personal data</b> is data which relates to a living individual who can be identified from that data OR from the data and other information that is either currently held, or will be held by the data controller (the researcher).</p> <p><i>This includes:</i></p> <ul style="list-style-type: none"> <li>any expression of opinion about the individual and any intentions of the data controller or any other person toward the individual.</li> <li>sensor, location or visual data which may reveal information that enables the identification of a face, address, etc (some postcodes cover only one property).</li> </ul>
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	<ul style="list-style-type: none"> <li>– combinations of data which may reveal identifiable data, such as names, email/postal addresses, date of birth, ethnicity, descriptions of health diagnosis or conditions, computer IP address (if relating to a device with a single user).</li> </ul> <p>If you do not have a registration number from Legal Services, please clarify why not:</p>
43	<p><b>Is the research collecting or using</b></p> <ul style="list-style-type: none"> <li>– sensitive personal data as defined by the UK Data Protection Act (racial or ethnic origin / political opinions / religious beliefs / trade union membership / physical or mental health / sexual life / commission of offences or alleged offences), and/or</li> <li>– data which might be considered sensitive in some countries, cultures or contexts.</li> </ul> <p><b>If yes</b>, state whether explicit consent will be sought for its use and what data management measures are in place to adequately manage and protect the data.</p> <p>NA</p>



44	<p><b>All research projects using personal data must be registered with Legal Services before the data is collected, please provide the Data Protection Registration Number: No Z6364106/2017/11/84</b></p> <p>If you do not have a registration number from Legal Services, please clarify why not:</p>
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<b>During the project (including the write up and dissemination period)</b>	
45	<p><b>State what types of data will be generated from this project</b> (i.e. transcripts, videos, photos, audio tapes, field notes, etc).</p> <p>The data generated will be: audio recordings, transcripts, and field notes.</p> <p><b>How will data be stored, including where and for how long?</b> This includes all hard copy and electronic data on laptops, share drives, usb/mobile devices.</p> <p>During the research phase across the different projects and association listed above, and following interviews, the data will be transferred from recording devices (Audio-recorder; and laptop field notes) to the UCL network on a password protected file, or encrypted hard drive as soon as possible. For the physical supports (encrypted hard drives, or field notes), they will be stored as soon as possible after the observation period in a locked container in a locked room at the UCL Division of Psychiatry, and will be kept there until the end of the PhD research.</p> <p><b>Who will have access to the data, including advisory groups and during transcription?</b></p> <p>The researcher, and his supervisor will be the only ones accessing to the data.</p>
46	<p><b>Do you confirm that all personal data will be stored and processed in compliance with the Data Protection Act 1998 (DPA 1998).</b></p> <p>Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><b>If not</b>, please clarify why.</p>
47	<p><b>Will personal data be processed or be sent outside of the European Economic Area (EEA)?*</b></p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p>



	<p>If <b>yes</b>, please confirm that there are adequate levels of protection in compliance with the DPA 1998 and state what the arrangements are below.</p> <p><b>*Please note</b> that if you store your research data containing identifiable data on UCL systems or equipment (including by using your UCL email account to transfer data), or otherwise carry out work on your research in the UK, the processing will take place within the EEA and will be captured by Data Protection legislation.</p>
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<b>After the project</b>	
<b>48</b>	<p><b>What data will be stored and how will you keep it secure?</b></p> <p>Audio recordings, field notes, and transcripts will be archived securely at the UCL Records Office.</p> <p><b>Where will the data be stored and who will have access?</b></p> <p>The field notes, transcripts, and encrypted hard drives containing the data will remain at UCL Records Office for secure archival. Only my supervisor and I will have access to it.</p> <p><b>Will the data be securely deleted?</b> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>If <b>yes</b>, please state when this will occur:</p>
<b>49</b>	<p><b>Will the data be archived for use by other researchers?</b> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>If <b>yes</b>, please provide further details including whether researchers outside the European Economic Area will be given access.</p>

Section G: Declaration	
I confirm that the information in this form is accurate to the best of my knowledge.	
Signature	
Date	29 Nov 2017
<p><b><u>If student:</u></b></p> <p>I have met with and advised the student on the ethical aspects of this project design.</p> <p>Supervisor Name: Paul Higgs</p>	
Supervisor Signature:	
Date:	28 Nov 2017

**Signature of Head of Department (or Chair of the Departmental Ethics Committee)**

**Part A**

I have read the 'criteria of minimal risk' as defined on page 3 of the Guidelines (<http://ethics.grad.ucl.ac.uk/forms/guidelines.pdf>) and I recommend that this application be considered by the Chair of the UCL REC.

Yes ☒ No ☐

**Part B**

I have discussed this project with the principal researcher who is suitably qualified to carry out this research and I approve it. I am satisfied that\*\* (highlight as appropriate):

**1. Data Protection registration:**

- has been satisfactorily completed
- has been initiated
- is not required

**2. A risk assessment:**

- has been satisfactorily completed
- has been initiated

**3. Appropriate insurance arrangements are in place and appropriate sponsorship [funding] has been approved and is in place to complete the study.**


Yes ☐ No ☐

**4. A Disclosure and Barring Service check(s):**

- has been satisfactorily completed
- has been initiated
- is not required

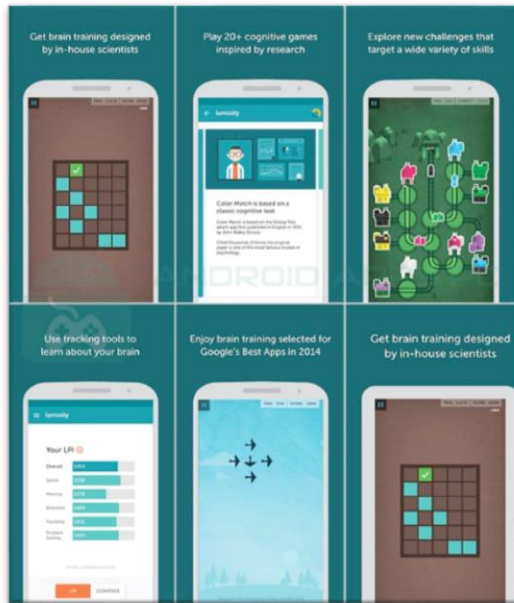
**Note:** Links to details of UCL's policies on the above can be found at: <http://ethics.grad.ucl.ac.uk/procedures.php>

**\*\*If any of the above checks are not required please clarify why below.**

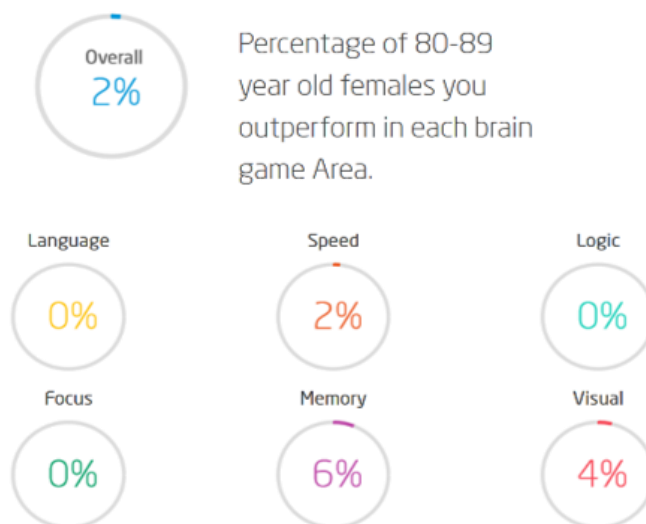
Name:	Glyn Lewis
Signature:	
Date:	6/12/2017

## 6. Some examples used in discourse analysis (introduction and chapter 2)

### 6.1. Brain training game – Lumosity (n.d.)



### 6.2. Example of brain training scores – Fit brains (n.d.)



6.3. Example of active cognitive ageing and prevention – extract from the AgeUK (n.d.) action plan to ‘stay sharp’ in later life

Your action plan: what can you do to stay sharp?

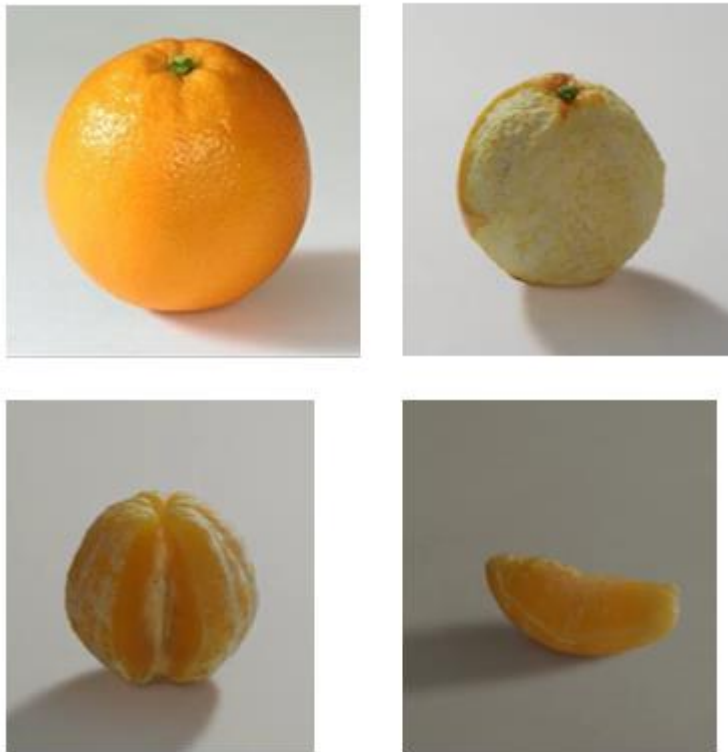


6.4. Example of the ‘war against Alzheimer’s’ in the media – Newsweek newspaper (2017)



### 6.5. Extract from the Alzheimer's Research UK (2016) and (2019b) 'share the orange' campaign video

2016 campaign



2019 campaign and blogpost



Alzheimer's Research UK has joined forces with Samuel L. Jackson to battle the serious misconception that dementia is an inevitability of old age. The '#ShareTheOrange' campaign highlights that *physical* diseases cause dementia, most commonly Alzheimer's using an orange to symbolise the weight of matter lost in the brain as the condition develops.

