Getting Old and Forgetting Things

Design anthropology and the medicalisation of ageing

Guy Edward Parker Collier, MA

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Abstract

Mild Cognitive Impairment (MCI) is a relatively new diagnosis that describes the grey area between 'normal' age-related decline and dementia. Following increased interest in the developmental stages of Alzheimer's Disease in the 1980s, MCI was first proposed as a concept in 1988 before becoming an official diagnosis in 2004. While some clinicians and researchers argue that the MCI concept helps identify the earliest symptoms of dementia, others have pointed out that it does not guarantee further cognitive decline and arguably redefines 'normal' ageing. Although its definition, clinical use, assessment, treatment, and relationship to dementia remain topics of heated debate and controversy, MCI has recently become a topic of interest in the emerging field of 'design for health'.

This thesis is based on a four-year website design project called 'Living Well with MCI', in which I participated in as a researcher between 2015 and 2019. In this project, I worked on an interdisciplinary team alongside a User Experience (UX) designer to develop an online resource for people with MCI and their families. The purpose of this PhD was to embed 'design anthropology' into the co-design process to develop insights into the MCI category in real time. In doing so, the research aimed promote critical reflection on the ways in which design, as both a future-making activity and field of research, might shape and give form to new medical constructs in contemporary society.

Drawing inspiration from a 'new materialist' philosophy, science and technology studies (STS), and combining these with recent work in design anthropology, this research considers what happens when we conceptualise MCI as a socio-material 'assemblage'. An assemblage in this research refers to the interconnected web of practices, processes, materials, and systems that produce MCI as a 'matter of concern' for individuals and society. The thesis therefore explores how designing for people with MCI intersects with developments in neuroscience and pharmacology, dementia research, geriatric care, design, and broader cultural anxieties about ageing and cognitive decline. To do this embedded research, I carried out ethnographic fieldwork across a range different sites and contexts, including memory clinics and dementia research centres, while working on the design project.

The research found that older adults tend to internalise the ideas and thought-style of Western biomedicine as they attempt to negotiate what it means to age 'normally'. In the Living Well with MCI project, biomedical discourses shaped user 'wants' and 'needs' in specific ways, making it difficult to frame the experience associated with the MCI category in non-medical terms on the web resource. Therefore, in meeting these wants and needs, the website ultimately gave physical form to the beliefs and assumptions that underpin the Western biomedical model of ageing. The research also highlighted that conventional design tools and methods, which help designers 'empathise' with users and their experience, failed to support a critical orientation towards the deeper historical, social, cultural, and political processes that made MCI a 'thing' to design for in the first place.

The unique contribution of this PhD lies in demonstrating the complex ways in which designers participate in the formation of emerging (and contested) medical realities, highlighting the particular relevance of this to the field of design for health. Furthermore, it argues that design for health practitioners have a responsibility to contribute to debates about the use, validity, and ethics of new diagnostic constructs in society.

Table of Contents

Contents

Figures, tables & abbreviations

List of figures

List of tables

List of abbreviations

BRNZ
Brain Research New Zealand

DHW Lab
Design for Health and Wellbeing Lab

DSM
Diagnostic and Statistical Manual

HCI
Human-computer interaction

MCI
Mild Cognitive Impairment

PCR
Centre for Person Centred Research

SMC
Subjective Memory Complaints

STS
Science and Technology Studies

UX
User Experience

Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Guy Collier

September 2019

Co-authored works

Collier, G., Kayes, N., Reay, S., & Bill, A. (2017). Designing for mild cognitive impairment (MCI): a design anthropological perspective. *Studies in health technology and informatics, 242*, 445-448.

Reay, S., & **Collier, G**. (2017). Designing situated learning experiences: interdisciplinary collaboration for design education in healthcare. *Studies in health technology and informatics, 242*, 1030-1033.

Reay, S., **Collier, G.**, Kennedy-Good, J., Old, A., Douglas, R., & Bill, A. (2017). Designing the future of healthcare together: prototyping a hospital co-design space. *CoDesign, 13*(4), 227-244.

Reay, S., **Collier, G.**, Douglas, R., Hayes, N., Nakarada-Kordic, I., Nair, A., & Kennedy-Good, J. (2017). Prototyping collaborative relationships between design and healthcare experts: mapping the patient journey. *Design for Health, 1*(1), 65-79.

Acknowledgements

Undertaking this piece of work has stretched my thinking in surprising ways and sharpened my ability to explore and talk about complex ideas. On a personal level, writing this thesis has also allowed me to better understand myself, to uncover and articulate the ideas and values that motivate me not only as a researcher, but as a human being. Introspection is one of the things that makes PhD research notoriously isolating, but, having had the good fortune and pleasure of working with many supportive people over the past four years, I never really felt alone on this journey. Many thanks to everyone who supported me along the way.

Ethics approval

Ethical approval was obtained from the Auckland University of Technology Ethics Committee (AUTEC) (15/234) on 3 May 2016.

1.
Introduction

This thesis explores how design, as both a process and an inter-disciplinary field of research, intersects with the 'medicalisation' of ageing. Medicalisation, a key concept in the social sciences, refers to the processes by which ordinary human problems and experiences—such as depression, anxiety, addiction, and trauma—come to be defined and treated as distinct medical conditions (Conrad, 2008). The growing influence of biomedicine in everyday life has been described by some researchers as "one of the most potent transformations of the second half of the twentieth century" (Clarke et al., 2003, p. 161), in part because it has radically changed people's understanding of what it means to be 'normal', and perhaps even people's understanding of life itself (Rose, 2001; 2009).

Despite the rising number of new health products and services that extend the reach of medicine into previously non-medical realms (Fox, 2017), the concept of medicalisation has received surprisingly little attention in the design literature. This research investigates how design processes might be better informed about the construction of new medical concepts in contemporary society, highlighting the relevance of this for the emerging field of 'design for health' (Chamberlain & Craig, 2017; Reay et al., 2017; Tsekleves & Cooper, 2017).

In this thesis I draw on a single case study, a website design project called 'Living Well with Mild Cognitive Impairment (MCI)' in which I participated as a researcher between 2015 and 2019, to show how a critical perspective on medicalisation might be usefully integrated with design processes in real time. During this project I worked closely with Nathan,[1] a User Experience (UX) designer and colleague from the Design for Health and Wellbeing (DHW) Lab (Reay et al., 2017), alongside a wider interdisciplinary team, to develop and implement an online resource for people with MCI.

Currently a 'hot topic' in dementia research (Rossini et al., 2016), MCI is a new and controversial diagnosis that describes what many believe is a 'transitional' stage "between the expected cognitive decline of normal aging and the more serious decline of dementia" (Mayo Clinic website, accessed April 2019). People with MCI are those who experience problems with their memory and thinking that are beyond 'normal' age-related decline, but are not yet severe enough to justify a diagnosis of dementia. Neither here nor there, in many ways they find themselves 'betwixt and between' one culturally defined state and another (Turner, 1967).

The Mayo Clinic website explains that MCI is characterised by "any or all of the following" symptoms:

- You forget things more often.
- You forget important events such as appointments or social engagements.
- You lose your train of thought or the thread of conversations, books or movies.
- You feel increasingly overwhelmed by making decisions, planning steps to accomplish a task or understanding instructions.
- You start to have trouble finding your way around familiar environments.
- You become more impulsive or show increasingly poor judgment.
- Your family and friends notice any of these changes (Mayo Clinic website, accessed April 2019).

The MCI concept first appeared in the scientific literature in 1988 (Reisberg et al., 1988), reflecting a shift towards early diagnosis and intervention for Alzheimer's Disease, but only became an official diagnosis in 2004 (Peterson, 2004). However, in the absence of biological markers to distinguish so-called normal age-related decline from dementia, this shift has also lowered the threshold at which cognitive

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[1] All names in this thesis have been changed to preserve the anonymity of participants.

function is labelled pathological (Katz, 2012; Rose, 2009).

Although its definition, clinical use, assessment, treatment, and relationship to dementia remain topics of heated debate and controversy in both research and clinical settings (Klekociuk et al., 2016; Sardella, 2017; Schermer & Richard, 2019), the MCI category has become a focal point of healthcare innovation in recent years, intersecting with developments in neuroscience, pharmacology, geriatric care, and broader cultural anxieties about ageing and cognitive decline (Williams et al., 2012). Over the past decade, a number of products have been designed to specifically target people with MCI, including wearable technologies (Dibia et al., 2015), companion robots (Gross et al., 2011; Schroeter et al., 2013), monitoring devices (Hayes et al., 2008), cognitive training software (Li et al., 2011), virtual reality games (Eisapour et al., 2018), smartphone applications (Das et al., 2012; Solanas et al., 2013), and various assisted living technologies (Blasco et al., 2014).

Despite evidence that the clinical definition of 'normal' ageing has shifted (Katz, 2012), and that MCI does not guarantee progression to dementia (Gainotti, 2010; Hong et al., 2011; Lock, 2013), many design projects appear to assume that MCI is a discrete neurological condition that people 'have' and for which new products can be specifically developed. While research in the field of design for health has explored how to involve people with cognitive impairment as 'co-designers' in the design process (e.g., Rodgers, 2018; Hendriks et al., 2013; Astell et al., 2009; Barnett, 2000), few if any researchers have explicitly dealt with the role designers might play in constructing new medical concepts such as MCI, or the social and ethical implications of doing so. In fact, there has been no discernible debate about medicalisation as a broader social and cultural issue within the context of design—a gap in the literature that this PhD research begins to address.

This research draws on recent developments in design anthropology, an emerging field of research (Clarke, 2011; Gunn et al., 2013; Smith et al., 2016), to explore interactions between design, society, and culture, with a particular focus on the medicalisation of ageing. Recognising that design is a key site of future-making and the production of culture, anthropologists over the past decade have started working closely with designers. Their primary role in these partnerships has been to blend an understanding of human behaviour, material culture, and social values with a practical focus on addressing people's unmet needs and concerns (Murphy, 2016). Not only have these collaborations promoted a deeper understanding of the social and cultural contexts in which design processes take place, but they have also helped reformulate contemporary research practices in anthropology (Rabinow et al., 2008).

The inspiration for the title of this thesis comes from a participant I interviewed while working on the design project, a 79-year-old woman named Susan who had recently been diagnosed with MCI. Like many others I would meet over the course of the four-year project, Susan and her husband were sceptical that the changes she was experiencing represented anything beyond ordinary age-related decline. As she put it, "I was quite surprised when I heard that I had to go to the memory clinic. Why, I just accepted that I was normally getting old and forgetting things."

I was drawn to the phrase "getting old and forgetting things" for the simple way it captured the essence of what Susan felt she was experiencing. It contrasted starkly with jargon-filled clinical descriptions of MCI such as "the symptomatic predementia stage on the continuum of cognitive decline, characterized by objective impairment in cognition that is not severe enough to require help with usual activities of daily living" (Langa & Levine, 2014, p. 2551).

After I had chosen the title, it occurred to me that the title *Getting Old and Forgetting Things* carries at least two additional meanings that start to convey the central themes of this research. The first part of the title relates to the concept of medicalisation, which, having been a staple of social critique since at least the 1970s, is in some ways 'getting old'. Just over a decade ago, sociologist Nikolas Rose (2007) made the provocative claim that "medicalisation has become a cliché of critical social analysis" (p. 700), pointing out that many scholars use the term in disparaging ways, often without attempting to understand how or why it occurs,

the consequences it has for individuals and society, or what the potential benefits of medicalisation might be. Moreover, argued Rose, the term can often imply that people are passive recipients of medicalisation from the 'top down', overlooking the ways in which consumers participate in the process from the 'bottom up'. Following Rose, a series of recent articles have sparked renewed debate about the medicalisation concept, its analytic merit, and whether it ought to be reformulated in light of emerging technologies and practices (Busfield, 2017; Ryang, 2017; Williams, et al., 2017).

This last point relates to the second part of the title: are critics of medicalisation forgetting 'things'? In a seminal paper, anthropologist Bruno Latour (2004) argues that social researchers should not simply criticise discourse or the production of scientific knowledge (i.e., 'matters of fact'); they should also explore how social and material forces converge around particular problems (i.e., 'matters of concern')—that is, how problems are 'assembled' together in the first place. One of the primary aims of this research was to study how everyday things (project briefs, drawings, prototypes, models, users, clinics, designers, researchers, and so on) hold MCI together as a matter of concern for design, in spite of the controversy surrounding its status as a matter of fact.

'Things' also speaks to the political nature of design projects, where diverse ideas and perspectives come together in an attempt to resolve tensions and propose new solutions (Bjögvinsson et al., 2012). Indeed, as design theorist Pelle Ehn (2008) points out, the word *thing* was used in a technical sense by early Christian Nordic and Germanic societies to refer to "governing assemblies and places, where disputes were solved and political decisions made" (p. 1). In this sense, design projects can be seen as political arenas with the potential to create openings for new ways of thinking and being, and therefore new futures (Bjögvinsson et al., 2012). As such, design is a process of negotiating which realities we want to carry forward into the future, and which should be left behind (Moser, 2011).

This PhD aimed to integrate emerging social theory into Living Well with MCI to explore how the social and the material come together to participate in the development of a new health technology: an online resource for people with MCI. By making these things visible to myself, Nathan, and the wider project team, it was an opportunity to design in a more ethical and critically informed way, and to create space for alternative (i.e., non-medicalised) perspectives on ageing and MCI to be included in the process. Before discussing how I went about this, I will first provide some detail about my background and interests as a researcher.

Positioning statement

When I started this research four years ago, in 2015, I was almost completely unfamiliar with 'design' as a field of research and practice. As a former student of comparative religion, sociology, and medical anthropology, I had been introduced to the world of design research only a year earlier, when I was fortunate enough to get a research assistant role at the DHW Lab in Auckland City Hospital. The Lab's focus was on improving healthcare experiences through design in its many sub-specialties—graphic, product, spatial, digital, communication, and so on—and fostering collaboration between hospital staff, designers, and service users (i.e., patients and families).

With a social science background, my contribution to the Lab's activities was seen by others mostly in terms of the practical research methods that I could bring to various projects. I knew how to interview people, develop surveys, make detailed observations, and I had some understanding of ethical protocol when it came to conducting research with vulnerable groups and individuals. Some of the designers referred to me as the "people expert", and clinicians occasionally asked me to help them do "anthropology-type stuff" (which meant, as it turned out, qualitative research) for some service improvement projects.

Although I may have had some practical skills worth sharing with the team at the

DHW Lab, the interests that had been the driving force of my education and had ultimately led to this role were, compared to the pragmatic focus of design, quite obscure. As the only social scientist on the team at the time, I was happy to talk with designers about my interests and perspectives, but it wasn't at all obvious how these related to 'design for health'. This PhD is in many ways an exploration of how the questions and concerns of anthropology might be integrated with the practicalities of design research. As such, the following paragraphs will provide context to my background as a researcher and student, and how this has informed my approach to the question of designing for people with MCI.

Between 2008 and 2010, I completed a BA in religious studies and sociology. During my undergraduate training, I spent a lot of time thinking and writing about the changing religious landscape of (post-)modernity, where materialist science seemed to have explained away the need for religion. Modern secular life—unique within the context of the rest of the world's cultures—became an enduring obsession and formed the backdrop to much of my academic work. When I moved to Auckland in 2011, I completed a Postgraduate Diploma in social anthropology and developed an interest in the intersection between religion, spirituality, and 'alternative' health practices. My dissertation that year explored the eclectic mix of healing practices and philosophies that constitute the so-called New Age movement—a distinctly Western phenomenon in which many people, I argued, were seeking to reconcile the apparent divide between science and spirituality.

Then, in 2012, I began a Master's project that focused on Ayurveda, a 5000-year-old medical system based on Hindu cosmology, and its status as an alternative health modality in New Zealand. I wanted to explore what made it 'alternative' and 'complementary' as opposed to legitimate and mainstream, and how this shaped the ways it was thought about, studied, and practised. Was Ayurveda simply less effective than Western medicine? If so, why were some people still drawn to it and for what purposes? Who were its primary users? To what extent did practitioners seek legitimacy as 'experts' and position themselves in relation to the dominant medical system? Were they spiritual healers or serious medical doctors? Was this even a valid distinction?

Internally I was still a sort of rational materialist, but in speaking with practitioners, clients, and students of Ayurveda over the course of a year, I came to appreciate Ayurvedic philosophy and practice in a way I had not expected. Over time I developed a greater appreciation for holistic health modalities in general, many of which challenged the rational-materialist paradigm that I identified with. I even came to share many of my informant's critical perspectives of Western medicine and its limitations. I started to realise that although the concepts of Ayurveda could not be validated in Western scientific terms, they nevertheless offered deep insights into health and wellbeing that went unrecognised by Western medicine and its preoccupation with norms and functionality.

Through this study I encountered new topics and questions that I wanted to explore in more depth. I became interested in Western medicine (or 'biomedicine')—the only form of healing that I had grown up thinking was effective because it alone, I was taught to believe, produced 'real' knowledge about the body—as a powerful social force. Indeed, it appeared to be the standard by which all 'alternatives' were assessed and deemed ineffective. Paradoxically, it was the broken system that proponents of Ayurveda proudly defined themselves against, but also looked to for some kind of validation.

Drawing on insights from my background in medical anthropology, I started to think about biomedicine—often celebrated for its ability to gain unmediated access to *reality as such*—as a cultural system with its own unique history, philosophical foundations, assumptions, beliefs, values, and practices. (Indeed, it started to appear to me as itself a religious institution where disease was some form of sin, clinicians possessed sacred knowledge as priests, and people swallowed pills in holy communion with our modern god and saviour, Science.) I wanted to learn more about the way biomedicine operates in society, how it permeates the very ways in which people conceptualise and talk about their bodies in relation to 'illness',

'impairment', and 'disability'—and how these terms might be thought about and framed differently. It was a stroke of good luck that I ended up working in a context that allowed me to explore these questions further.

I should acknowledge here that my academic background, and in particular my interest in the relationship between science and secularisation, have influenced my approach to the topic of ageing and MCI. Decisions around data collection and analysis, for example, were informed by my perspective that MCI is culturally specific and underpinned by assumptions of scientific materialism, as discussed in Chapter Two.

Situating the study

Living Well with MCI was funded by Brain Research New Zealand (BRNZ) and carried out by AUT's Centre for Person Centred Research (PCR) in collaboration with the DHW Lab, an interdisciplinary design studio in Auckland Hospital. The project had two primary objectives. The first was to inform BRNZ, a Centre of Research Excellence, of the day-to-day experiences of people with MCI and their families. This aspect of the project had a particular focus on the strategies and supports that people found most helpful for managing MCI from day-to-day. The second objective was to design 'an interactive web resource'.

I was employed by PCR as the project's 'research officer' in 2015 and worked closely with Nathan, a UX Designer and colleague from the DHW Lab, to help develop the resource. Written by senior researchers at PCR, the original proposal to BRNZ suggested that the resource might be an online space where people with MCI could share homegrown strategies, supports, and resources with others. The proposal also stated that this would have the added benefit of generating new knowledge about the experiences of people with MCI over time, as people interacted with it (see Appendix A).

The Living Well with MCI project was supported by a steering group, who met on several occasions over the course of the project to help analyse interview transcripts and offer feedback and suggestions to support the ongoing development of the web resource. This wider group consisted of a combination of academics and clinicians, including a clinical psychologist, a health psychology researcher, two neurorehabilitation researchers, a design researcher, a sociologist, a nurse, and a psychiatrist. The psychiatrist directed a local memory clinic and played an important role in recruiting participants with a formal MCI diagnosis. He also helped us connect with other clinicians who would support recruitment in other memory clinics.

As a researcher on the project, my role was to help obtain ethical approval from the university and district health boards, support the recruitment process, interview participants, organise steering group meetings, contribute to the design process, help analyse data, and manage the day-to-day administration of the project.

The data for this PhD come partly from the interviews I conducted while working as a researcher on this project. However, data collection for this PhD moves beyond the scope of Living Well with MCI to enable more in-depth critical reflection on designing for people with MCI. To do this, I collected additional interview and observational data through my involvement with the funding body, BRNZ, which organised workshops and seminars for its cohort of researchers and encouraged a spirit of interdisciplinary collaboration. Through this I was able to hang out with and interview PhD students and Post-Doctoral researchers from 'hard' science backgrounds, many of whom were working on other BRNZ-funded projects and studying MCI alongside a range of other neurodegenerative conditions. This data would then help inform critical reflection on the MCI category. Ethics for this PhD was obtained as a nested component of the Living Well with MCI project (see Appendix B).

A number of these researchers were working in dementia prevention research

clinics (some of which I visited as part of this additional fieldwork) and trying to understand MCI from neurobiological, neuropsychological, and brain-imaging perspectives. I also spent some time with clinicians from the memory clinics from which our MCI participants were recruited. In addition, I presented at local, national, and international conferences and met experts from a range of fields, from neuroscience to design.

Through this deep immersion in the overlapping worlds of brain research, clinical practice, and design, combined with long-term contact with study participants, I was able to gain an appreciation for the multi-faceted complexity of the MCI category as an object of inquiry, a label, an experience, and, most importantly for this PhD, a design problem. In reaching beyond the scope of the design project and into these various spaces and contexts, I was able to explore the many different practices and processes that produced MCI as a matter of concern (Latour, 2004).

Unlike a traditional study in anthropology, therefore, this research was not an ethnographic description *of* the design project so much as an ethnographic reflection on the possibilities of anthropological research both *within* and *through* it (Gatt & Ingold, 2013). It shifted back and forth between design and anthropology, cutting across disciplinary boundaries, and opening up conversations between different fields and professional arenas.

This level of engagement in the design process meant that I had roles and responsibilities that overlapped with my PhD research. Sometimes it was difficult to separate my 'work' as a research officer from my 'fieldwork' as a PhD student. In later chapters I will explain how this played out ethnographically, and in particular how it involved some complex psychological manoeuvering between 'insider' and 'outsider' positions—between, for example, being seen as 'insider enough' among neuroscientists, clinicians, and other researchers to participate in conversations about MCI, and 'outsider enough' to get away with asking all sorts of naïve questions about what it is and what it means.

Later I will spend some time reflecting on how I built and managed relationships with my many informants and colleagues, and managed the tensions that surfaced when talking with people whose views on MCI, as it turned out, were different from my own. Below I will describe how I came to be involved in Living Well with MCI in the first place, and introduce the broader institutional relationships surrounding it. I want to start with this because it will help me explain how these opened up opportunities for 'design anthropological' research in this project.

Key relationships

This PhD research was made possible because I happened to find myself embedded in a network comprised of various institutions, organisations, and research centres. For example, through my involvement on Living Well with MCI, I became an 'early career researcher' for BRNZ, and as such became part of a large nation-wide network of clinicians, neuroscientists, and various other health researchers with a shared interest in ageing brain research. The DHW Lab was itself a hybrid organisation between AUT and the Auckland District Health Board (ADHB) and was located in the heart of Auckland City Hospital. These relations, which had long preceded my involvement on the project, helped me access memory clinics and dementia research laboratories as part of this research, and to investigate the MCI category from the perspective of design anthropology. It is important, therefore, to briefly sketch out these relations below.

The Design for Health and Wellbeing Lab

The DHW Lab was established in 2013 after a memorandum of understanding was signed between AUT's Faculty of Design and Creative Technologies and the ADHB. The aim of the partnership was to harness design capabilities to improve the experiences of patients, families, visitors, and staff at Auckland City Hospital.

I was employed as a research assistant at the DHW Lab in 2014. My first job was to gather ethnographic data on some early design projects in the hospital to be used as part of a sociological study on 'knowledge work and innovation ecosystems' (Bill et al., 2015). Later I helped write journal articles and conference papers that discussed the role of the DHW Lab in promoting co-design practices more broadly in the hospital (e.g., Reay et al., 2017).

While working at the DHW Lab, I helped design students think about the ethical implications of gathering data in the hospital for their projects (e.g., interviewing and observing staff and visitors), helped write website content and project proposals, and at one point worked with hospital staff as an interviewer for Patient Experience Week (see Figure 1).

Figure 1: Working as a researcher at the Design for Health and Wellbeing (DHW) Lab at Auckland City Hospital in 2015.

The Centre for Person Centred Research (PCR)

PCR is a multidisciplinary team at AUT's Akoranga campus on Auckland's North Shore. The centre conducts research in the areas of disability and rehabilitation as part of the Health and Rehabilitation Institute in AUT's School of Clinical Sciences. The core principle underpinning PCR's research is, as its name suggests, 'person centredness'.

Person-centred care has been conceptualised in many different ways, but shares many of the values of human-centred design, such as understanding a person's social and cultural context, and empowering healthcare users to make the system work in ways that suit their needs (Terry & Kayes, 2018). In clinical practice, person-centredness means treating the 'whole' person and what matters most to them, rather than thinking of them as a 'patient' with a collection of organs and symptoms to be fixed (Ghebrehiwet, 2011). Like human-centred design, this also means treating people as 'experts' in their condition and working with them to address what is most important (Ghebrehiwet, 2011).

PCR and the DHW Lab therefore had a number of overlapping values and approaches. The director of PCR approached the DHW Lab in 2015 looking for a researcher who could work across the boundaries of design and health as part of their newly funded project, Living Well with MCI. I had been looking for an

opportunity to do a PhD and was introduced to the PCR team as someone who could fill this role.

Brain Research New Zealand

Living Well with MCI was funded by a national partnership of clinicians and researchers called BRNZ. At the time I began my research, BRNZ had recently been formed as a government-funded partnership and Centre of Research Excellence (CoRE). It aimed to establish a network consisting of researchers and clinicians from different universities, research institutes, community organisations, and regional district health boards. The current version of the BRNZ website, which has changed since this research began in 2015, states the overall aims and objectives of BRNZ in the following way:

> Brain Research New Zealand – *Rangahau Roro Aotearoa* (BRNZ) is a national Centre of Research Excellence (CoRE) undertaking ground-breaking research on the ageing-brain and ageing-related disorders. We are a collection of leading neuroscientists and clinicians from across New Zealand who are working alongside community organisations to combat disorders of the ageing brain. Conditions such as stroke, Parkinson's, Alzheimer's disease and sensory loss pose the greatest medical and social challenge of our generation. Our interdisciplinary approach, founded on excellence and innovation, is the driver for undertaking research that will be translatable to the clinical setting, with the ultimate aim of improving brain health for all New Zealanders in the years to come (BRNZ website, accessed May, 2019).

Living Well with MCI was one of the few qualitative studies that BRNZ had funded, and certainly the only project with a 'design' component. Most of its funded projects fell into the 'basic science' category, exploring the biology of the ageing brain (genes, proteins, cells, and tissue), biological signatures ('biomarkers') of neurological disorders, and clinical treatments to prevent or delay the onset of disease. The important thing to emphasise here is that Living Well with MCI was a smaller component of this much larger science and innovation network, which included multiple systems of knowledge and many different, partially integrated communities of practice (Fischer, 2001) (see Figure 2).

Research questions and aims

One of the key premises of this research is that design projects are future-making events (Yelavich & Adams, 2014) and therefore ought to take seriously the social and cultural realities they inherit, reflect, and reproduce. For instance, because MCI is a new and contested medical reality (Whitehouse & Moody, 2006), and is associated with the expanding conceptual boundaries of dementia (Katz, 2012), Living Well with MCI was enmeshed in wider debates about medicalisation and overdiagnosis in contemporary society (Conrad, 2008)—debates that are not always visible to the members of a design team.

As such, I identified an opportunity to integrate a critical understanding of medicalisation into the design process through an in-depth investigation of the MCI category—the design problem around which the Living Well with MCI project was organised. Rather than taking MCI as a given, this PhD was an opportunity to question deeply held assumptions about the relationship between ageing and cognitive decline, to challenge 'common-sense' understandings of dementia, and to thereby explore other worlds, possibilities, and futures as part of the design process.

Using Living Well with MCI as a specific site of investigation, the overall focus of

Figure 2: A stakeholder map showing the wider 'ecosystem' in which this PhD research was nested.

this PhD project can be formulated in the following research question:

- How might embedding 'design anthropology' in a co-design process inform or develop critical insights into the MCI category, and shed light on the possible role of design in assembling new medical realities?

Two important focal points here are 'design anthropology' and 'MCI'. As discussed at length in Chapter Three, design anthropology is concerned with the relationship between objects and future-making (Smith et al., 2016), as well as with the wider social, cultural, political, economic, and historical contexts in which design processes unfold. Design anthropologists enable critical reflection on these processes and contexts while contributing to everyday design activities, including front-end research, planning, and prototyping (Otto & Charlotte Smith, 2013). As such, design anthropology departs from, and helps reformulate, traditional approaches to anthropological theory and practice (Rabinow et al., 2008; Murphy & Marcus, 2013). Drawing on these different aspects of design anthropology, this PhD is, in part, a reflection on the possibilities of this emerging field of research and practice (Otto & Charlotte Smith, 2013).

The other key focus of this research is the MCI category itself, which, as a new and contested diagnosis that expands the definition of 'pathological' memory for age (Katz, 2012), provides an entry point into debates about the medicalisation of ageing (Beard & Neary, 2013). As such, design anthropological inquiry was undertaken as part of Living Well with MCI so that the wider design team could be better informed about the possible ways in which design intersects with processes of medicalisation, and to critically reflect on the social and ethical dimensions of this.

Hence my involvement on the Living Well with MCI project was an opportunity to demonstrate the potential value of anthropological fieldwork within and alongside a design for health project, exploring how this might help design develop more

ethical solutions and futures (Smith et al., 2016).

Three main objectives were pursued in order to address the research question above. These were:

- to engage in a co-design process with people with MCI and their families
- to embed a design anthropological approach in the Living Well with MCI project
- to promote critical reflection on designing for people with MCI

Thesis structure

This introductory chapter has provided the necessary context and background to this research and its relation to a larger design project, Living Well with MCI. Building on some of the ideas introduced in the sections above, Chapter Two outlines my philosophical assumptions and presents a social constructionist perspective on MCI. It discusses how a constructionist perspective was adopted by Science and Technology Studies (STS) researchers who, in the 1980s, sought to understand the processes by which scientific knowledge or 'facts' come into being. It then describes the 'ontological turn' in the social sciences, in which objects and practices, rather than subjects, came to be a key focus in the production of social worlds. The chapter concludes with a reflection on how culturally specific attitudes towards ageing are 'acted out' and embedded in material realities, including those brought into the world by design.

Chapter Three situates my methodological approach within the context of anthropology's long history of ethnographic research. It describes a push towards innovative strategies in post-qualitative research that help depict the messiness of contemporary social research, and how design anthropology responds to the challenges of ethnographic representation in the contemporary world. Following this, Chapter Four describes the methods used in this research, and outlines how I sought to analyse data and integrate critical insights into the Living Well with MCI project in real time. Having established the rationale for experimenting with new forms of ethnographic representation in Chapter Three, Chapters Five to Eight are structured using a Double Diamond model (Design Council UK, 2007) (see Figure 3)—Discover (Chapter Five), Define (Chapter Six), Develop (Chapter Seven), and Deliver (Chapter Eight).

Figure 3: A typical Double-Diamond model showing four linear stages of 'divergence' and 'convergence'.

In design, the Double Diamond model begins with a general problem and proceeds through a four-part process of divergence and convergence to develop a design solution. The 'Discover' phase, which marks the beginning of a project, is characterised by divergence. In this phase the emphasis is on going broad to gain a wide range of insights and perspectives on the problem. The second quarter of the diamond, the 'Define' phase, is where those insights are boiled down (converge) into a clear brief for the design challenge. The 'Develop' phase is where

solutions and concepts are made, prototyped, and tested in an iterative process of modification and refinement. And finally, the 'Deliver' phase is where the final product or service is produced, delivered, and implemented.

However, in Chapters Five to Eight of this thesis, the Double Diamond model is not employed to show the activity in a design process as might normally be expected. Instead, the Double Diamond is used as a strategy of ethnographic representation and therefore only partially maps on to the process of designing the online resource. In this thesis, I use each phase of the Double Diamond model to explore various aspects of MCI as a new medical reality, while presenting observations from the main project and ethnographic data from my research.

The Discover phase (Chapter Five) is about the 'discovery' of MCI in the 1980s and looks at how many of the debates surrounding Alzheimer's Disease research manifest in present-day research on MCI.

The Define phase (Chapter Six) looks at what this new clinical definition 'does', how experts and technologies produce its parameters, and how people respond to the being labelled with MCI.

The Develop phase (Chapter Seven) considers how a social constructionist perspective might challenge conventional design methods used to 'develop' new products and services in healthcare.

The Deliver phase of this thesis (Chapter Eight) considers the extent to which Living Well with MCI, and my involvement in it, contributed to the construction of the MCI category and helped 'deliver' a set of discourses related to monitoring and managing the 'ageing brain'.

While there are a range of other possible design models that could have been used instead (Gericke & Blessing, 2012), I decided to use the Double Diamond because it is popular and widely recognised as 'design'. In addition, it also mapped on to the different aspects of MCI that I wanted to discuss, as outlined above.

In addition to this broader structural strategy, the presentation of content and data *within* Chapters Five to Eight is also experimental. The flow of these chapters is 'interrupted' at certain points with field notes, reflections, interview excerpts, footnotes, and images, capturing a sense of movement between the various sites and contexts that informed my ethnographic fieldwork. As such, they convey the 'messiness' of the research process within the Double Diamond structure, highlighting the fragmented (rather than linear) nature of both the design project and the additional fieldwork in which I was engaged (see Figure 4).

Figure 4: This PhD is structured using a linear Double Diamond model, but it also highlights the messy, non-linear nature of social science research within in a design context.

2.
Philosophical approach

This research was grounded in a philosophical approach that differs from the 'positivist' stance of modern biomedicine, which conceptualises illness, disability, and impairment in terms of physical pathology. As I highlight in later chapters, positivist research assumes that MCI is a brain disorder, and that 'normal brains' and 'MCI brains' are inherently different. Positivist research on MCI may seek to understand "biochemical and neuroanatomical alterations, synaptodegeneration, cell loss, neurotrophic failure, cellular genetics, neuronal selective vulnerability and other factors that occur in the MCI brain" (Mufson et al., 2012, p. 14). For example, researchers working from a positivist epistemology might study MCI in relation to cerebral hemodynamics (Beishon et al., 2017) or cerebrospinal fluid (Kern et al., 2019) in an effort to establish the biological substrate, or 'biomarkers', of the MCI concept (Minhas et al., 2018).

This PhD research, by contrast, begins with a 'social constructionist' approach to MCI. Starting from the assumption that MCI is an emergent rather than pre-existing category, a constructionist approach was suitable for exploring how MCI was produced across a range of sites and knowledge-making practices. Social constructionism, as I explain in this chapter, is a theoretical perspective that emphasises the historical, social, and cultural forces that shape human worlds (Hjelm, 2014).

A related idea in this thesis is that of ontological multiplicity. Put simply, this is a philosophical position that refers to the idea that there are many different ways or 'modes' of Being. This notion of Being is taken from Heidegger's (1962) formulation of the concept *Dasein*, or that which "determines entities as entities" (p. 25)—or, in the present example, that which turns certain features of ordinary ageing, such as forgetfulness, into a clinical entity (i.e., MCI). Within the context of this research, ontological multiplicity refers to the notion that the construction of MCI is multi-faceted, contingent, and embedded in an assemblage of social and material practices, and therefore does not signify a singular pre-existing condition 'out there' in nature, awaiting discovery in individual brains. MCI, as I will argue in this chapter, is distributed across social networks and practices. It is in this sense not one thing, but many.

This chapter will present the philosophical foundation for this PhD. In particular, I will attempt to bring these two approaches (social constructionism and ontological multiplicity) together before showing, in Chapter Three, how they relate to both design anthropology and the Living Well with MCI project. By locating the MCI category in social and material phenomena, a critical role of this research was to both explore and communicate how the design process, which *gives form to ideas* (Sanders & Stappers, 2008), was itself potentially (and problematically) involved in the construction of MCI as a new clinical reality.

Social constructionism

Social constructionism is a key theoretical orientation in the social sciences that has been influenced by a range of fields, disciplines, and intellectual traditions (Lock & Strong, 2010). It emerged during the 1960s and 1970s as a response to positivism and empiricism—epistemological stances that characterise the 'hard' sciences, such as chemistry and physics (Burr, 2015). Together, these philosophical positions hold that genuine knowledge can only be obtained through the logical interpretation of sensory experience, and therefore "that the nature of the world can be revealed by observation, and that what exists is what we perceive to exist" (Burr, 2015, p. 3). Social constructionism, by contrast, holds that reality is negotiated through interactions between and among individuals who are, in turn,

shaped by the social and cultural worlds they inhabit (Berger & Luckmann, 1966). As Vivien Burr (2015) explains,

> This means that the categories with which we as human beings apprehend the world do not necessarily refer to real divisions. For example, just because we think of some music as 'classical' and some as 'pop' does not mean that we should assume that there is anything in the nature of music itself that means it has to be divided up in that particular way. (p. 3)

Although this approach to the study of the human world encompasses a broad range of perspectives, social constructionism has a few distinct characteristics that can be identified as 'constructionist'. Sociologist Titus Hjelm (2014), for example, argues that a constructionist perspective has three main characteristics, all of which relate specifically to my approach to MCI.

First, it holds that the human world is historically and socially *contingent*. This refers to the idea that knowledge is the product of specific historical events and social forces rather than the result of direct and unbiased observation of the natural world.

Second, a constructionist view is *liberating*.[2] In other words, by pointing out the contingencies of the world, it shows that the categories and conceptual frameworks we use to describe it are not fixed, naturally occurring, or inevitable, but are continually open to debate and transformation.

Third, a social constructionist approach draws attention to the *social processes* by which particular understandings of the world come into being. In doing so it points out that knowledge about the world comes from interactions between people (i.e., human thought and action) rather than from God(s) or nature.

Hjelm (2014) notes that social constructionism also has four primary functions that follow on from the above characteristics. The first is what he terms the *ontological* function. This refers to the way constructionist perspectives offer a view of what the human world consists of by drawing attention to the relationships between things. From a constructionist perspective, facts about the world emerge through a complex set of relationships between human and non-human actors. As philosopher of science Ian Hacking (1999) suggests, "Ideas do not exist in a vacuum. They inhabit a social setting" (p. 10). Hacking calls this social setting a *matrix*. The matrix in which MCI is situated, for example, is comprised of complex relations between institutions, clinics, laboratories, instruments, discourses, and the practices of various experts such as clinicians, researchers, and designers.

The second is the *epistemological* function, which offers a view of how knowledge is produced. Because a constructionist perspective holds that knowledge is the product of historical and social processes, it is very different from positivism, as already mentioned. Positivism holds that reality is singular and external and that knowledge of that reality can only be gained through observation and measurement (Burr, 2015, p. 3). This implies that sensory data is the only valid basis for true knowledge. Constructionism, on the other hand, holds that reality is fundamentally social, since an understanding of it is arrived at by consensus and interpreted through people's subjective experiences, beliefs, values, attitudes, and so on. From this it follows that reality, from a constructionist point of view, is not singular but plural—a point I will elaborate on below.

The third is the *critical function* of a social constructionist approach, referring to the way it makes possible other ways of thinking about the world. It achieves this by challenging common-sense and taken-for-granted understandings about what is 'natural' or 'normal'. This often has wide-ranging political implications, as the constructionist distinction between sex (as a biological category) and gender (as a socio-cultural construct) has shown.

Its fourth function is the *methodological* function, which examines ways to study the processes by which the human world is constructed. Analyses of power and discourse have traditionally been key to understanding the processes of social

[2] Hacking (1999, p. 2) cautions that not all constructionist analyses are liberating. Although it may be clear from a constructionist perspective that, say, anorexia appears only within very specific historical and cultural conditions, this fact alone does not help those who are suffering. On the other hand, to see that, say, 'motherhood' is a social construct is to free mothers of the sense that how they are supposed to feel and act is governed exclusively by the biology of reproduction.

construction, but increasingly social scientists are drawn (as I am in this research) to studying how social realities are 'assembled' and 'produced' rather than 'known'. This has been referred to as the 'ontological turn' in the social sciences and will be explored in later sections of this chapter.

The social construction of what?

Hacking, in his book *The Social Construction of What?* (1999), notes that social constructionists who write about X (where X refers to some taken-for-granted or common-sense idea about the world) "tend to argue that

> (1) X need not have existed, or need not be at all as it is. X, or X as it is at present, is not determined by the nature of things; it is not inevitable.

> Very often they go further, and urge that:

> (2) X is quite bad as it is.

> (3) We would be much better off if X were done away with, or at least radically transformed." (p. 6)

Within the context of this thesis, X of course refers to the MCI category, the 'condition' that first served as a catalyst for the design project Living Well with MCI. A constructionist perspective was an appropriate philosophical starting point for this thesis (a) because the line between 'normal' and 'impaired' cognition cannot be determined at the level of individual biology, and (b) because definitions of 'normal' and 'impaired' are prone to change over time and differ from one context to another (Rose & Abi-Rached, 2013).

Given that a biological basis for MCI has not yet been established (Lock, 2013), and that recent changes to the diagnostic criteria for dementia have redefined what clinicians and researchers hold to be 'normal' age-related decline (Katz, 2012), the MCI category is therefore linked with the expanding conceptual boundaries of dementia and the medicalisation of otherwise cognitively healthy individuals (Rose, 2009). It follows that there must be identifiable historical and social forces (institutions, practices, processes, materials, structures, etc.) that give rise to and perpetuate the MCI category in clinical practice, research contexts, and, increasingly, in the world of design and innovation. Importantly, a constructionist approach also highlights the possibility that MCI, and modern society's response to ageing more broadly, might be different in the future.

However, note in Hacking's formulation above that social constructionists need not move beyond (1). Many do advance to (2) and (3), but this does not have to be the case. Indeed, as Hacking (1999) points out, there are "many grades of commitment" (p. 7) to a social constructionist approach. Hence it is important at this point to clearly specify what I mean by the claim that MCI is 'socially constructed', because this will have implications for how far I take the argument.

There are two main ways in which I am referring to MCI as a social construct. The first refers to MCI as *medical knowledge*. From a medical sociology perspective, the social construction of medical knowledge focuses on professional beliefs and the origins of diagnostic categories (Brown, 1995), and refers to the epistemological assumptions of various experts and the knowledge-making practices through which those epistemologies are enacted. In this thesis, I am interested in knowledge-making practices to the extent that these help perpetuate or 'stabilise' the MCI construct despite its ambiguous and contested nature.

The second sense in which I refer to MCI is inspired by the body of literature that looks at the social construction of *illness*. This literature is primarily concerned

with how individuals come to interpret and experience certain bodily phenomena in medical terms. Forgetfulness, for example, is a common age-related experience, but only in particular social and cultural contexts do people interpret and respond to this experience as a *medical problem* (i.e., as a 'cognitive impairment').

As a recent diagnostic construct, MCI is a clinical description that defines a particular set of cognitive changes (or 'symptoms'). However, as Hacking (1999) compellingly shows, diagnostic classifications and labels not only describe but may also *shape* the experiences and behaviours of those diagnosed. This is because people are not passive recipients of medical labels; they respond to them in conscious ways, and often act them out. In putting a name to certain human 'kinds', a dialectic is established between the classification and the person classified. As Hacking (2004) suggests, labels can generate a feedback loop between the clinical description and the person's interpretation of their experience, creating a dialectic process in which they come to 'fit' the label. Appropriating labels such as MCI for the purpose of 'design' therefore has all sorts of social and ethical implications that warrant critical examination.

Taking social constructionism as a guiding philosophical assumption, this research aimed to promote critical reflection on these two interrelated dimensions within the context of a design project. The purpose of critical reflection was not to deconstruct the foundations of the project (or, for that matter, the foundations of dementia research). Rather it was to separate the wheat from the chaff; that is, to point not only to what may be negative and harmful about the MCI category, but also to find what value there may be in keeping it and carrying forward into the future.

What I want to avoid in this thesis, however, is a realist-versus-constructionist dichotomy in which MCI must be *either* 'real' *or* 'constructed'. Instead I agree with Hacking (1983) when he writes: "We shall count as real what we can use to intervene in the world to affect something else, or what the world can use to affect us" (p. 146). Following Hacking's lead, my claim is that the measure of MCI's 'realness' depends on its *utility* as a conceptual tool—how useful it is, for whom, and under what circumstances—and that its utility, in turn, is tied to observable socio-material practices in the world: brain imaging, neuropsychological testing, diagnostic tools and, importantly in this research, design processes. This idea will be explored further in relation to new materialist inquiry in later sections of this chapter. Next, I will discuss the social construction of the 'pathological' in psychiatry to begin to highlight the important theoretical contributions that anthropology, as a discipline and style of thinking, can make within the context of designing for people with MCI.

The normal and the pathological

American anthropologist Clifford Geertz (1973) once wrote that "the Balinese definition of a madman [is] someone who, like an American, smiles when there is nothing to laugh at" (p. 27). This was clearly written with tongue in cheek, but his point about the relativity of 'madness' is an important one. Indeed, anthropologists have repeatedly shown that the categorical distinction between 'normal' and 'abnormal' behaviour is culturally defined: what we hold to be normal conduct in our culture may be considered abnormal in another, and what is thought to be normal elsewhere may be something we find strange or unusual (Benedict, 1934). In modern biomedical terms, abnormality is often described as 'pathological'. However, this category, too, is inseparable from the patterns of culture that define what is ordinary or socially accepted in everyday life.

In a classic essay titled *The Myth of Mental Illness*, psychiatrist Thomas Szasz (1960) argued that "the concept of illness, whether bodily or mental, implies *deviation from some clearly defined norm*" (p. 114). Szasz argued that there was insufficient evidence for the biological causes of mental illness, and that labelling someone with a mental illness was essentially a political act, one carried out

by those who had the power to define the 'norms' from which certain kinds of people were thought to 'deviate'. This was a radical position when Szasz first put it forward because it went against the basic philosophical assumptions of Western psychiatry, which were rooted in Western biomedicine and its commitment to scientific materialism (Adriaens & De Block, 2013). Like biomedicine, psychiatry had historically operated from a positivist epistemology in which illness was conceived in relation to its observable anatomical and physiological correlates, while norms were similarly thought to be determined at the level of the body's physical structure and biology (Good, 1993).

One consequence of this was that psychiatry, when it first arose in the nineteenth century, sought to identify and diagnose mental illnesses in ways that 'carved nature at its joints' (a metaphor taken from Plato's *Phaedrus*, where Socrates speaks of "dividing things again by classes, where the natural joints are" [Plato, 1925, p. 265e]). The boundaries and thresholds of various kinds of mental illness were assumed, in other words, to be naturally occurring, rather than socially constructed, divisions. Conceptualised as 'natural kinds', mental illnesses were thought to have fixed internal properties that could be identified, classified, and grouped in much the same way as plants and animals (Adriaens & De Block, 2013). But for Szasz, what we call mental 'illness' is situated within the context of a person's thoughts, feelings, behaviours, and relationships, and should therefore be characterised as a 'problem in living' rather than a disease of the mind or brain (Bracken & Thomas, 2010).

Another critic of psychiatry during the 1960s was the French philosopher Michel Foucault. Foucault conducted a series of historical investigations that explored how certain ideas, behaviours, and practices come to be socially accepted as 'normal' and others as 'abnormal' (Foucault, 1965; 1973). For example, in *Madness and Civilization*, Foucault (1965) describes how certain groups of 'undesirables' in the seventeenth century—criminals, prostitutes, the poor, and so on—were often physically confined in ways that made them conveniently visible to medical doctors, who saw their 'madness' first as an object of study and, later, as an illness that could be treated.

While their criticisms of psychiatry differed in a number of important ways (Bracken & Thomas, 2010), both Szasz and Foucault challenged the idea that madness was a strictly biological phenomenon. Both recognised the important role that society and culture played in shaping people's understanding of madness and normality. Their criticisms therefore challenged a deeply held belief within Western psychiatry, namely that its categories of illness and their expression would be reliably consistent through time and across cultures.

In the 1970s, Arthur Kleinman, an American psychiatrist and medical anthropologist, argued that epidemiological studies of mental illness in non-Western societies were often flawed because they did not take cultural context seriously enough. Such studies, he argued, often assumed that the line between normal and abnormal behaviour was natural rather than culturally defined, that Western illness categories were objective and universal descriptions of real illnesses *out there* in nature, and that their expression would therefore be the same everywhere. Kleinman (1977) called this a 'category fallacy', pointing out that Western psychiatric categories were not 'culture-free'. Rather, Kleinman (1977) suggested they were

> bound to the context of professional psychiatric theory and practice in the West. Psychiatry must learn from anthropology that culture does considerably more than shape illness as an experience; it shapes the very way we conceive of illness. (p. 4)

Cultural norms shape what a given society considers 'undesirable' and in need of diagnosis and medical intervention (Jutel, 2011). Consider the classic example of homosexuality in the Diagnostic and Statistical Manual of Mental Disorders (DSM), still the dominant classificatory system and manual for clinical practice in

psychiatry. Once given an honourable place in ancient Greek society (Benedict, 1934), homosexuality was originally listed in the DSM as a "sociopathic personality disturbance" (APA, 1952) and later promoted to "sexual deviation" (APA, 1968) before it was decided, not without a great deal of controversy and debate within the medical community (see, for example, Stoller et al., 1973), that homosexuality was in fact not a mental disorder at all and removed from the manual in 1973. It is also worth noting here that it was due to pressure from gay rights movements (rather than compelling new research findings in psychiatry or neuroscience) that this diagnostic category lost its credibility (Kirk, 1992).

While not an 'illness' per se, MCI is understood to be a category of impairment, which also implies norm deviation. The boundaries separating 'normal' and 'abnormal' memory are not formed beyond or outside the realm of history and society—even neuroscience, as I argue in this thesis, is a deeply social and cultural activity. A related point is that the giving and receiving of diagnostic categories is, as sociologist Annemarie Goldstein Jutel (2011) has written, "a cultural expression of what a given society is prepared to accept as normal and what it feels should be treated" (p. 3). As such, diagnostic concepts are often linked to broader ideas and discourses in society, which shape how people think about and treat, for example, older people.

In contemporary Western societies, 'normality' is defined in increasingly narrow terms, as the growing number of available diagnoses in the DSM clearly shows (Frances, 2013). When it was first published by the American Psychiatric Association in 1952, the DSM was 130 pages long and contained 106 diagnoses. The latest edition, the DSM-V, which was published in 2013, is 947 pages long and contains as many as 600 discrete diagnoses, of which one, mild neurocognitive disorder, is among the most recent additions to the manual and is derived from recent research on MCI (Sachs-Ericsson and Blazer, 2015).

Given that the previous one hundred years of intensive research has failed to find organic, biological foundations for the overwhelming majority of DSM disorders (Rapley et al., 2011),[3] it is appropriate to consider the social, cultural, political, and historical forces that have produced new medical realities such as MCI. It should be noted here, however, that these forces are not strictly 'discursive' or language-based. In this thesis, I contend that they are deeply embedded in the practices and materials that produce and sustain new diagnostic categories over time. To develop this idea further, the next two sections will outline the philosophical approach I used to study MCI. In this research, I conceptualise MCI as an 'assemblage' (Deleuze & Guattari, 1988) of different materials, objects, practices, processes, discourses. and technologies.

Science and Technology Studies (STS)

One of the more prominent fields to advance social constructionism in the 1980s was science and technology studies, which grounded a "cultural conception of knowledge" (Knorr-Cetina, 2007, p. 361) in ethnographic observations of scientific laboratories and other sites of knowledge production. Thomas Kuhn's classic (1962) study of 'paradigm shifts' in science, titled *The Structure of Scientific Revolutions*, in many ways laid the theoretical foundations for understanding the link between science, technology, and society.

Following the publication of Kuhn's book, anthropologists and sociologists increasingly carried out ethnographic research in natural science fields, such as physics and biotechnology, to show how the production of scientific knowledge was grounded in and supported by social practices and negotiated among key actors across a range of social settings. Truth claims about 'nature' were shaped by 'culture' and produced within the context of "ordinary social and cultural processes such as negotiation, competition, trust, symbolic activity or accommodation" (Beaulieu, 2010, p. 454). Two notable ethnographies from this period include Pickering's (1981) and Traweek's (1982) work on the world of high-

[3] Alzheimer's Disease, which falls under 'major neurocognitive disorder' in the DSM-V, is one of the few DSM disorders that actually do have an established biological basis. However, the relationship between the pathological mechnisms (i.e., neurofibrillary plaques and tangles in the neocortex) and their symptomatic expression in patients is still the subject of heated debate, as we will later see. MCI appears in the DSM-V under the name 'mild neurocognitive disorder' (mNCD) and has no biological signatures.

energy physicists, which highlight the everyday social practices at work in the production of scientific knowledge.

While these laboratory studies sought to account for the part that human beings played in constructing scientific realities, other approaches in science and technology studies reacted to this 'anthropocentric' inquiry, including its taken-for-granted binaries such as nature/culture, by focusing on how the 'objects' of science were themselves constituted. Actor Network Theory (ANT) (Latour, 2005) emerged in an STS context in an attempt to show how different social actors and entities (both human and non-human, material and immaterial) participated in the formation of scientific facts and realities.

ANT attempts to show how many relations exist between various socio-material-semiotic elements or 'actants' (i.e., objects and concepts *as well as* human agency) in order for a scientific theory or model or framework to be successful. As Bruno Latour (2004) explains, ANT is less a theory than "a multifarious inquiry [...] with the tools of anthropology, philosophy, metaphysics, history, sociology to detect how many participants are gathered in a thing to make it exist and to maintain its existence" (p. 246).

ANT's emphasis on how scientific realities are produced and sustained (rather than on whether or not they are 'true' or 'false') makes it a part of this shift in 1980s research from matters of epistemology to matters of *ontology*. Latour's work on the socio-material construction of scientific facts (Latour & Woolgar, 1979; Latour, 1987; Latour 1988), Michael Callon's studies of actor networks in science and technology (Callon, 1984; Callon, 1986; Callon, 1987; Callon, 1990), and John Law's work on socio-technical networks in science (Law, 1987; Law, 1990) are all notable examples of this 'turn to ontology' in the social sciences—i.e., the turn towards analysing the socio-material processes that give rise to and sustain certain 'ontologies', rather than focusing on how human subjects 'know' or 'perceive' those ontologies.

The anthropologist and STS researcher Marilyn Strathern, following work on 'situated knowledges' by technoscience writer Donna Haraway (1988), presented a case for ontological multiplicity in her book *Partial Connections* (1991), in which she grapples with the theoretical problems of literary ethnographic representation in anthropological research. Strathern was concerned with theorising the ways in which observed social realities in the field 'hang together'. Drawing inspiration from ANT, she argued that the 'whole' (e.g., the person; society) is composed of many overlapping and partially connected parts. Annemarie Mol advanced these claims in her book *The Body Multiple* (2002). *The Body Multiple* is an experimental ethnography of a *disease*—atherosclerosis—in which Mol chooses not to focus on how knowledge of atherosclerosis is 'made' or 'constructed' (verbs that tend to overemphasise human agency), but instead on how atherosclerosis is 'enacted' or 'practiced'—how it "hangs together" (Mol, 2002, p. 55)—across different social settings.

Mol argues that atherosclerosis is not one thing but many; there are many different, entangled versions of it being enacted throughout the hospital. Atherosclerosis, says Mol, is not the same thing in the lab, under a microscope, as it is in the clinic when it is being diagnosed in a patient, or in the surgical room when that same patient is 'under the knife'. Hence she shows how the 'reality' of atherosclerosis differs between sites and contexts. Following Strathern and Haraway, Mol's philosophical argument is that multiple realities of atherosclerosis emerge and connect through complex socio-material networks of medical practices, techniques, events, processes, and procedures. The aim of this approach, she says, is to study how these different ontologies hang together to form the 'object' of biomedical inquiry.

Picking up on these approaches, this research draws on 'new materialism', and in particular the notion of an 'assemblage' (Deleuze & Guattari, 1988), to explore how these proceses and practices come together to form a new diagnostic concept: MCI.

The New Materialism

The so-called ontological turn in the social sciences, emerging in reaction to anthropocentric or conventional 'humanist' social inquiry, has drawn together many different theoretical strands, including ANT, posthumanism, biophilosophy, and quantum physics (Fox & Alldred, 2015). Breaking with earlier reductionist accounts of materiality in the social sciences (in which, for example, researchers studied how manufactured objects *reflected* culture), new materialist approaches advance an alternative onto-epistemological stance that more fully accounts for the role of objects in the everyday production of social worlds and vice versa. From this stance, new materialists attempt to get beyond a 'realist'/'constructionist' dichotomy (and indeed many other oppositional binaries) in social research. New materialists do not accept that 'nature' and 'culture' inhabit separate realms; rather they are viewed as relational and emergent, mixed together on the surface (Fox & Alldred, 2015). As Alldred and Fox (2017) have written,

> By challenging any distinction between the materiality of the physical world and the social constructs of human thoughts and desires, [new materialism] opens up the possibility to explore how each affects the other, and how things other than humans (for instance, a tool, a technology or a building) can be social 'agents', making things happen. (p. 1163)

New materialist approaches have been inspired in large part by the philosophy of Gilles Deleuze and his collaborator Félix Guattari. Deleuze and Guattari's metaphysics was, in turn, largely influenced by the work of seventeenth-century philosopher Baruch Spinoza, with whom they shared an ambition to overcome the limitations of dualistic Cartesian thought (Gatens, 2000). Spinoza rejected all forms of transcendence (e.g., morality as originating from a Judeo-Christian god; thought or reason as a disembodied quality of the mind, etc.), and instead saw the world as one immanent substance: a lively, complex, univocal whole.

Adapted directly from Spinoza's non-dualist philosophy, Deleuze and Guattari's basic metaphysical concept is the "plane of immanence", which collapses or flattens out all presumed dualisms (mind and body, inside and outside, nature and culture, normal and abnormal) into a network of relations and processes. They refer to this network, a combination of the social and the material, the human and the non-human, as an 'assemblage' (Deleuze & Guattari, 1988).

Assemblages are made up of the relations between many different elements, which are ordered in such a way as to function in a machinelike fashion to produce a particular effect in the world (Fox & Alldred, 2015). Within Deleuzo-Guattarian metaphysics, agency is not exclusively a quality of human beings; rather it is distributed throughout an assemblage, and thus also refers to the capacity of non-human things to 'affect' (and be affected by) other elements (Deleuze & Guattari, 1988). These affective flows mean that assemblages are always in flux, or in a perpetual state of emergence or 'becoming'.

MCI can be conceptualised as a socio-material assemblage—an interconnected web of researchers, older adults, clinicians, medical technologies, equipment, academic infrastructures, funding processes, clinical practices, and so on—working in concert to produce and maintain the parameters in which some individuals become defined and labelled as cognitively 'impaired'. Put another way, the MCI assemblage produces impaired 'subjects' who are imagined to 'deviate' from a socially and culturally defined 'norm'. As I will explain in Chapter Three, this new materialist approach had a number of implications for data collection, analysis, and the presentation of findings in this research.

Before continuing, it should be noted here that I am not 'doing' new materialist inquiry per se, but attempting to implement new materialism in my research by drawing specifically on this notion of a socio-material assemblage. In this sense, I am not engaging with the original new materialist philosophers, but with

those who have tried to employ new materialist concepts in research related to healthcare and emerging health technologies (e.g., Fox, 2017; Mol, 2002). Engaging with the original thinkers would require a different form of thesis and possibly a less pragmatic approach than a design project permits. In this research, I am considering the extent to which new materialist concepts can be usefully integrated as part of a design process.

A note on new materialism and social constructionism

It is important to point out that there are ongoing debates about the compatibility between new materialism and social constructionism, and very few papers that articulate the points of correspondence between these two theoretical strands (Lemke, 2015). Since I am drawing on both in this thesis, it is important to highlight some key points in these debates and to position this research in relation to them.

New materialism does not represent a homogeneous theoretical approach, but encompasses many different perspectives from a range of fields (Fox & Alldred, 2015). As an emerging theoretical position, there is no single, agreed-upon way to employ new materialism in social research (Fox & Alldred, 2015). It is, in other words, an experimental enterprise in itself, even without attempting a synthesis with social constructionism, as I am in this research. The belief that they cannot work in parallel, however, is potentially based on a misconception of what each has to offer in terms of understanding the social (and material) world(s).

In emphasising the importance of materiality, relational ontologies, and the agency of non-human things, new materialism is commonly understood to be a *departure* from social constructionism, which has traditionally focused on language, knowledge, and culture. New materialists rightly point out that social constructionists do not adequately attend to the agency of everyday objects and materials, and as such reproduce a modernist, human-centric vision of the world. As Lemke (2015), suggests, new materialists generally argue that the emphasis on language and discourse "not only leads to impoverished theoretical accounts and conceptual flaws but also results in serious political problems and ethical quandaries, as it fails to address central challenges facing contemporary societies" (p. 4).

While these critiques of social constructionism are valid and important, my position in this thesis is that new materialism is not a 'departure' so much as an *extension* of more conventional social theory as represented by constructionist scholars such as Foucault. As such, the two should be able to work in harmony. In fact, a synthesis of new materialism and constructionist orientations (e.g., post-structuralism) in the present research offers a more comprehensive picture of the intersection between design and the emergence of MCI. In this view, constructionist concepts such as 'discourse' and 'governmentality' are perfectly compatible with, for example, the notion of a socio-material assemblage—indeed, assemblages include both material and discursive elements (Feely, 2016). This point deserves some further elucidation, as follows.

Lemke (2015) notes that Foucault's post-structuralist work helped destabilise 'fixed' categories and common sense understandings of 'human' subjectivities. One of the ways he did this was by focusing on technologies of power and discourse and how these shaped people's understanding of themselves and the world around them. It is seldom acknowledged, however, that Foucault also extended his analysis of power to include interactions between 'humans' and 'things'. For example, Lemke argues that Foucault's concept of the 'government of things', while it does not explicitly deal with the issue of human and non-human relations, nevertheless "critically engages with the ontological underpinnings of the new materialism" (p. 14). The concept, as Lemke points out, is suggestive of a relational new materialist ontology, in that it refers to "entanglements of [people] and things, the natural and the artificial, the physical and the moral" (p. 6).

The 'government of things' (i.e., the way in which power is distributed across

and embedded into materiality) therefore contains both material entities and discourses. In light of this view, MCI may be conceptualised not simply as a fixed or pre-existing object in nature, nor can it be reduced to language and discourse. Rather, MCI, in this view, comes into being through the interplay of both ontology and epistemology, and what Lemke (2015) calls the "dynamic ensemble of matter and meaning" (p. 14). In the present study, 'matter' refers to the materiality of design and its form-giving processes, but also to the brain, imaging technologies, blood samples, and robots for people with dementia—that is, the techno-scientific practices that produce MCI as a matter of concern. 'Meaning', on the other hand, refers to the process by which people come to understand and articulate their experiences of these things, as older people experiencing changes to their memory and thinking. This includes bioscientific discourses, which shape people's understanding of their embodied subjectivity and experience, and classify people as 'impaired' (Feely, 2016).

This thesis therefore includes an exploration of both discursive forces (e.g., language and culture) and the power of socio-technical practices (e.g., design and brain imaging). As such, I have chosen to draw on both new materialism and social constructionism, because neither should be excluded from an analysis of the processes by which MCI comes into being as a new medical reality.

Ageing and different ways of being

With its traditional focus on the politics of difference and otherness, anthropology has historically been well suited to the study of disability and impairment (Kasnitz & Shuttleworth, 2001). Some authors have even called for greater engagement with anthropology on dementia research and intervention strategies for age-related cognitive impairment (Whitehouse et al., 2005). I agree with Whitehouse et al. (2005) when they argue that the value of an anthropological perspective on such projects is that it can "illuminate implicit cultural, social, or institutional forces at work in the construction of medical realities" (p. 321).

An anthropological perspective recognises that new medical labels and diagnoses, such as MCI, are not fixed or universal but tied to specific social and historical contexts. It is clear, for example, that the meaning of the words 'impairment' and 'normal' vary through time and across cultures. Similarly, there are vast socio-cultural variations in the way people experience, adapt to, and make sense of ageing, most of which are ignored by the dominant biomedical perspective and its emphasis on managing physiological deterioration (Whitehouse et al., 2005). In short, anthropologists recognise the existence of 'alternative' cultural worlds.

These cultural worlds offer radically different ways of being, knowing, and doing (Escobar, 2018). To take one example, many older Māori[4] adults in New Zealand acquire a particularly high standing in their families and communities as *Kaumātua* or 'elders', at least in part because the concept of *poutama* is central to the traditional Māori understanding of ageing (Dyall et al., 2011). *Poutama*, which has religious and mythological significance for Māori, is also the name for the stepped patterns that are woven into mats and panels (*tukutuku*) in many Māori households (see Figure 5).

In these patterns, each level or step is linked to the next to create a continuous upward staircase pattern that symbolises the many levels of personal and spiritual growth through which one passes over the course of an individual lifetime and across generations (Dyall et al., 2011). Similarly, ageing from a traditional Māori perspective is sometimes equated with the act of climbing a mountain (*maunga*), a metaphor that evokes *poutama*—continual upward movement into the peaks of wisdom, experience, and sacred cultural knowledge (Edwards, 2010).

[4] Māori are the indigenous population of New Zealand.

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Figure 5: Tukutuku showing stepped Poutama patterns. The patterns symbolise various levels of growth, learning, and achievement. Poutama conveys ageing as a process of ascent rather than descent. Source: https://www.tpk.govt.nz/en/mo-te-puni-kokiri/our-stories-and-media/tukutuku-panels-journey-to-new-york

The disease-oriented paradigm of Western biomedicine, by contrast, tends to view the ageing process in terms of the various underlying pathologies and mechanisms that cause it to occur (Lock, 2013) (see Figure 6). This ontology tends to produce descriptions of ageing (and by extension the elderly) that go in the opposite direction from those provoked by a Māori worldview—that is, in the language and imagery of descent rather than ascent, and a corresponding emphasis on decline, deterioration, and dysfunction (Whitehouse et al., 2005). As I discuss in Chapter Five, ageing in the nineteenth century was studied and treated by European doctors as though it were a disease in need of a cure (Lock, 2013). This framing is traceable to a Cartesian philosophy, which produces the image of a machine-like material body that eventually yields to its imperfect design and breaks down.

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Figure 6: The Western biomedical model of ageing. Rooted in a materialist worldview, this model reinforces a cultural understanding of ageing as a process of physiological and cognitive deterioration (that is, descent rather than ascent). Source: http://sphweb.bumc.bu.edu/otlt/mph-modules/ph/aging/Aging_print.html

Following the philosophical framework outlined above, I am making this comparison not in order to suggest there are different world-*views* of the same reality, rather that there really are multiple worlds, multiple *ontologies of ageing*. As such, it is in fact more appropriate to speak of different realit*ies*, for reality is not singular and stable but configured and acted out locally (Mol, 2002). Social 'realities' (such as the various ways in which human beings make sense of and respond to age-related decline) are embedded, embodied, performed, and enacted (Mol, 2002; Moser, 2011). They are shaped and maintained through complex relations between humans and their material creations.

Design, in its various specialities (graphic, spatial, product, architecture, etc.), gives physical form to ideas by making things, such as prototypes, which bring concepts to life (Sanders & Stappers, 2008). In doing so, design practices, and the material artefacts that design brings about, have the potential to crystallise and perpetuate certain *ways of being* (see Figure 7). A design project, then, can be seen as a site of 'ontological politics' (Mol, 1999)—a collaborative, future-making event that gives form to, reflects, enacts, and disseminates particular realities, carving out new trajectories at the expense of a near-infinite number of other possibilities and ways of being (Yelavich & Adams, 2014). Ultimately—and this is where the onto-political significance of the Living Well with MCI project becomes clear—design projects are where designers, stakeholders, and users negotiate which realities they want to live with (Moser, 2011).

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Figure 7: Design gives physical form to cultural realities. Here, an advertisement frames ageing as an enemy to be fought against rather than embraced. Both the advertisement and the product give form to underlying assumptions about ageing. Source:https://culturedecanted.com/2015/05/10/the-semiotics-of-ageing-in-advertising-our-changing-discussion-on-ageing/

Summary

This chapter has presented the guiding philosophical framework for this PhD research. Beginning with a constructionist view of the distinction between 'normal' and 'abnormal' cognition, I argued that the MCI category is the product not of brain dysfunction, but of complex social, cultural, and historical processes. Drawing on new materialism, and exploring how it has been applied in STS, I suggested that MCI is not 'discovered' in the brain so much as produced and sustained through a complex 'assemblage' (Deleuze & Guattari, 1988) of relationships between concepts, processes, materials, practices, systems, structures, instruments, tools, and tests. The elements of this assemblage, I argued, work in concert to produce knowledge that frames the cognitive ability of some older people as distinct, in degree and in kind, from 'normal' age-related decline.

As noted in the above, it is not my intention in this thesis to extensively engage with the key theorists and concepts of new materialism. Rather, this research draws on literature that attempts to mobilise new materialist inquiry in particular fields of practice (e.g., Fox, 2017; Mol, 2002). Because my interest lies in exploring what new materialist inquiry might look like within the context of design anthropology, I am engaging with literature that has attempted to apply new materialism in practice. Thus, in the next chapter I will present a historical discussion of design and anthropology, how these fields link to new materialist philosophy, and how this link provides the basis for my research methodology.

3.
Methodology

In Chapter Two, I introduced new materialism as a key philosophical stance for this research. In this chapter, I will present the rationale for my methodological framework. Design anthropology is an important field of research and practice within the context of this research, and therefore requires considerable attention. This is an emerging field that combines insights from both design and anthropology to make theoretically informed contributions to various phases of the design process, and to develop conceptual frameworks and tools that can be integrated into interdisciplinary collaborations and interventions (Otto & Charlotte Smith, 2013).

In this chapter I will argue that developing anthropological inquiry *by means of* design (Gatt & Ingold, 2013) is one way for designers and other stakeholders to collaboratively engage in critical reflection on design processes as they unfold. The purpose of critical reflection in design contexts is to ensure that solutions are ethical (Tunstall, 2013). A secondary contribution of design anthropology in the present research is the way in which it offers strategies to reformulate and revitalise contemporary ethnographic fieldwork.

In order to contextualise this chosen mode of inquiry, I will start this chapter by discussing how both design and anthropology have transformed over time, and consider some of the ways in which the disciplines overlap and intersect. The sections that follow are not intended as a comprehensive historical overview of design and anthropology. Rather, I discuss the ways in which design and anthropology have developed and intersected over the past fifty years, emphasising the particular aspects of these histories that are relevant and formative to this PhD.

Changes within design

Until the second half of the twentieth century, design research was primarily concerned with the material, form, function, aesthetic appeal, and manufacturability of products. While these remain important considerations within the context of contemporary design education and practice, the subject matter and scope of design have expanded considerably. Below I will critically explore how experiments in design theory and practice have enabled this expansion and shaped the course of design research over the past fifty years.

The 1960s: Design Science

During the 1960s, there were a number of attempts to conceptualise design as a scientific process. The Design Methods Movement, as it became known, consisted of a number of prominent American thinkers who sought to establish a scientific basis for design. Perhaps the best-known example of such an attempt is economist Herbert A. Simon's book *The Sciences of the Artificial* (1969). In this influential work, Simon placed rational decision-making processes, rather than objects, at the heart of all design activities.

Like others associated with the Design Methods Movement, Simon argued that design was above all a problem-solving activity. His hope, along with a number of other theorists in the 1960s, was that the design process could be abstracted from the activities of individual designers and formalised into a transferrable scientific method. Indeed, if design was about solving problems, and if problems could be addressed through rational decision-making processes, then those processes, Simon argued, ought to be translated into teachable methods. In Simon's view, an efficient linear model of the process would help design become an analytically rigorous, and thus academically respectable, discipline.

Simon's ideas, which became influential in subsequent debates in design theory, uncoupled the design process from any particular subject matter or skillset.

Indeed, his definition of a 'designer' was broad enough to include "[anyone] who devises courses of action aimed at changing existing situations into preferred ones" (Simon, 1988, p. 67). As Buchanan (1992, p. 15) notes, critics quickly pointed out two main weaknesses in such an attempt to reduce design to a rational framework. One was that design processes in the real world are messy and non-linear. In any given design process there are multiple players, perhaps with their own distinct goals, values and agendas, who look at the problem in different ways. The problem itself is not always well formulated and attempts to solve it often fail. The second point of weakness was that designers were addressing increasingly complex problems that did not, in practice, yield to any single formulaic approach.

The 1970s: 'Wicked Problems'

In the 1970s an architecture teacher named Horst Rittel sought an alternative to linear models of design by emphasising the inherent messiness and complexity of design processes. Interested in the application of social science theories to design, Rittel argued that designers were primarily concerned with addressing 'wicked problems', which he defined as a "class of social system problems which are ill-formulated, where the information is confusing, where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing" (Buchanan, 1992, p. 15 n37). Rittel stressed that wicked problems were unique and often indeterminate, and therefore resisted 'systematic' treatment. In a seminal paper, Rittel (1972) argued that wicked problems require a far deeper understanding of human experience, pointing out that designers lacked theories for dealing with the complex social and cultural contexts in which people are embedded (pp. 67-69).

The 1980s: User-centred design

Following the birth of personal computing in the 1970s, new design methods and approaches were formulated in the 1980s to tackle the problem of designing user-friendly computer interfaces and systems. These methods were derived from many different disciplines. Human-computer interaction (HCI), for example, drew on several fields of study, ranging from computer science and engineering to a variety of behavioural and social sciences. User-centred design emerged out of HCI research as a methodology for improving interactive software systems (Norman and Draper, 1986).

Here the emphasis shifted towards understanding 'user experience', a term coined by human-centred design pioneer Don Norman in the late 1980s (Norman, 1988), over usability testing. Instead of simply designing software and then expecting users to adapt to a standardised layout, a user-centred approach allowed designers to tailor software design to the specific needs, capabilities, and experiences of end users. It did so by placing users at the front and centre of design processes. In user-centred design traditions, users are not simply studied or tested as design 'guinea-pigs' but are involved as active participants, or co-designers, in processes of making (Sanders and Stappers, 2008).

The 1990s to Present: Human-centred design

Since the 1990s, design research has become increasingly focused on the application of methods that seek to understand 'user experience'. Having grown out of a usability paradigm in software development, user experience or 'UX' design has become synonymous with web interface design. Another paradigm to have emerged in recent decades is human-centred design, which is semantically broader than UX, emphasising that design is for 'people' rather than simply 'users' of technological solutions. As Koskinen et al. (2011) point out,

> When computers became design material in the 1990s, humans became 'users,' which suggests that they are seen as parts of technical systems. Seen against the history of design, this was an extraordinary semantic reduction. At its narrowest, people came to be seen as barely more than biological information processing units in technical systems. (p. 34)

Human-centred design, by contrast, is an approach to user research that applies to the full spectrum of design disciplines. Global design firm IDEO is perhaps the most widely known champion of mainstream human-centred design methods, which are often derived from the social sciences. For example, IDEO's human-centred design 'toolkit' (IDEO, 2017), which can be found at www.designkit.org, includes a number of social science methods such as interviews, observations, and photo journaling. These methods are now commonly used in business and social enterprise contexts to uncover user needs (Fuge & Agogino, 2015). Their primary purpose, according to IDEO, is to help researchers develop 'empathy' for end-users and a "deep emotional understanding of people's needs" (Battarbee et al., 2014).

Limitations of Human-Centred Design

What this brief historical overview suggests is that design research has become increasingly 'anthropological' in its orientation. While form, material, aesthetics, and functionality remain important considerations within any design project, the emphasis in design research has shifted towards understanding *human experience* in order to create products and systems that are useful, useable, and desirable (Buchanan, 2001, p. 13). This emphasis on experience recognises that human beings make and use products in specific environments and contexts. Human-computer interaction researchers, for example, often draw on ethnographic methods to study how people use certain kinds of technology at home or in office environments, considering not only how products look and feel to the user but also what they *mean* within the context of their everyday life (Blomberg et al., 1996).

While these insights appear to offer a richer and more anthropological understanding of design, a human-centred design approach, I argue, still fails to take seriously the relationship between design and culture. Human-centred design methods may be useful tools for gaining deeper insights into the experiences and needs of individual end-users. However, this micro-level focus too often distracts designers from the broader historical, socio-cultural, and political contexts in which they are working. Put another way, understanding users and their needs in relation to 'wicked problems' fails to consider how those problems, and the groups who are perceived to embody them, are socially and materially constituted, limiting the degree to which designers can critically reflect on the futures and possibilities which their practice might open up or constrain.

A unique case study in this respect is Living Well with MCI, which, as I have already explained, set out to explore the day-to-day experiences and needs of people with MCI, and to design an online resource they would find 'useful, useable, and desirable'. However, in giving primacy to the experiences and needs of people with MCI, the project was methodologically unequipped to deal with broader societal debates relating to medicalisation in modern societies. As makers, problem-solvers, and form-givers, I argue that designers and design teams are key participants in debates of this kind.

In seeking to understand day-to-day experiences and identify unmet needs, the project was largely indifferent, in the beginning, to how participants' experiences came to be framed as medical problems in the first place, or whether medicalising changes to memory and thinking was seen as a help or hindrance. I was concerned when I started working on this project that questions of this kind—that is, questions of a more deeply anthropological nature—would be overlooked in favour of other, more pragmatic, design and usability considerations.

I also imagined that failing to ask such questions would limit critical reflection on the ways in which design as a socio-material practice intersects with the complex processes of medicalisation. Asking these questions, however, would require a level of analysis—a societal and cultural level—often obscured by an 'empathic' focus on individuals and their needs. This gap in the methodology of Living Well with MCI created the opportunity and scope for this PhD research.

Changes within anthropology

When I began this research, it was clear that the dynamic, approach, and scope of my fieldwork, which took place both within and alongside the Living Well with MCI project, would be radically different from what could be viewed as 'traditional' ethnographic research in anthropology. Anthropology has traditionally been defined by its emphasis on first-hand encounters with 'primitive' non-Western societies and tribal groups. The goal of anthropology, first articulated by pioneering ethnographer Bronislaw Malinowski in the early 1920s, was to "grasp the native's point of view, his relation to life, to realize his vision of his world" (Malinowski, 1922, p. 25). As Malinowski saw it, the anthropologist's job was to participate in the daily life of an exotic group in order to produce a scientifically 'objective' account of their culture.

Following his sudden death in 1942, Malinowski's personal diary was found on a shelf in his office at Yale University. In it were entries from two periods of fieldwork, covering his time in New Guinea (1914-1915) and in the Trobriand Islands (1917-1918). Written in Polish, it is almost certain that he never intended to have it published. Many of the darker passages suggested that Malinowski harbored secret contempt for his host communities. Amid the scandal that was caused in the wake of the diary's eventual publication in 1967, admirers of Malinowski's pioneering work were forced to make sense of troubling statements like: "I see the life of the natives as utterly devoid of interest or importance, something as remote from me as the life of a dog" (Malinowski, 1989, p. 167).

Until the 1970s, the anthropologist's personality or 'self' was entirely absent from their ethnographic writing. Orthodoxy maintained that the interior life of the researcher should be carefully hidden from the text so as not to tarnish what was then believed to be a more or less direct and unmediated 'account' of social life. As Clifford Geertz (1975) would later note, the squabble that unfolded after the publication of Malinowski's diary tended to revolve around the author's apparent lack of moral character when it should have generated a conversation about the nature of anthropological knowledge. Ironically, it was the unprecedented critical response to Geertz's own work that helped this conversation along.

Following a revival of 'grand theory' in anthropology, exemplified in works such as *Energy and the Evolution of Culture* (White, 1943) and *Theory of Culture Change* (Steward, 1963), Geertz had helped restore interpretivism to prominence in anthropology by promoting the metaphor of cultures as 'texts' (Geertz, 1973). Doing ethnography, he wrote, was "like trying to read (in the sense of 'construct a reading of') a manuscript – foreign, faded, full of ellipses, incoherencies, suspicious emendations, and tendentious commentaries, but written not in conventionalized graphs of sound but in transient examples of shaped behavior" (p. 10). For Geertz, ethnography was an intellectual effort defined by its emphasis on "thick description" (p. 6). He famously argued that the analysis of cultural forms was "not an experimental science in search of law but an interpretive one in search of meaning" (p. 5).

After the publication of Malinowski's diary, however, many social scientists argued that Geertz's metaphor, implying that one could simply interpret the cultural world of 'natives' as a dispassionate observer, over-privileged the ethnographer in the production of knowledge and ignored the cultural biases that might shape their observations in the field. In what is now broadly referred to as the Reflexive Turn, anthropologists were increasingly encouraged to expose rather than ignore or supress their biases, and to pay closer attention to the ways in which their subjects were represented in text (Marcus & Fischer, 1986).

While these changes in anthropology were at first intended to be both ethical and methodological, their epistemological implications soon became clear: there was no such thing as a neutral position from which anthropologists could observe and generate cultural insights, no chance of the sort of detached objectivity that Malinowski had promoted. Anthropology was less 'scientific' than it had previously been imagined. What the Reflexive Turn generated was a critical awareness that

the anthropologist's own cultural lens shaped what was observed and recorded in the field, and hence affected the final piece of work.

The ethnography, it turned out, was not an objective, scientific study of culture after all—it was merely an exercise in textual representation, a static, literary construction produced by people who were themselves very much *within* the realm of language and culture rather than beyond or outside it. Ethnographies were, in this sense, literary constructions rather than direct, unmediated accounts of the world (Marcus & Fischer, 1986). Thus, ethnographic research was partial and limited by the literary conventions, cultural frames of reference, and language of the ethnographer.

These criticisms, combined with a new attentiveness to ethnography as a form of *writing*, culminated in the publication of *Writing Culture: the poetics and politics of ethnography* (Clifford & Marcus, 1986), which opened up the possibility for new and experimental modes of inquiry to emerge. This new awareness of the ethnography as text led to the publication of a series of highly self-conscious (and quintessentially postmodern) accounts in which anthropologists reflected on the ways in which they were constructing and interpreting events so as to achieve *the effect* of objective accounts (Marcus & Cushman, 1982). An early example of this kind of work is Paul Rabinow's (1977) *Reflections of Fieldwork in Morocco*, in which the author focuses specifically on the process and validity of ethnographic fieldwork itself, rather than presenting a conventional anthropological 'account' of Moroccan life.

Representations of 'culture' were no longer seen as objective facts, but rather the product of an ongoing *collaboration* between the anthropologist and his or her research participants. Just as the idea of a solitary design 'genius' was replaced by the notion of partnership and co-production in the 1980s, discussions of ethnography in this same decade shifted from 'monologue' to 'dialogue', as this quote from Marcus and Fischer (1986) suggests:

> Dialogue has become the imagery for expressing the way anthropologists […] must engage in an active communicative process with another culture. It is a two-way and two-dimensional exchange, interpretive processes being necessary both for communication within a cultural system and externally between two systems of meaning. (p. 30).

Similarly, as anthropologist James Clifford (1983) wrote:

> neither the experience nor the interpretive activity of the scientific researcher can be considered innocent. It becomes necessary to conceive ethnography, not as the experience and interpretation of a circumscribed 'other' reality, but rather as a constructive negotiation involving at least two, and usually more, conscious, politically significant subjects. (p. 133)

Greater sensitivity to the politics of ethnographic representation of non-Western societies in the 1980s had also sparked calls for anthropologists to move away from the romanticised field spaces of the Exotic Encounter and to instead focus their attention on "studying up" (Nader, 1979)—that is, to study "the colonizers rather than the colonized, the culture of power rather than the culture of the powerless, the culture of affluence rather [than] the culture of poverty" (p. 5). To study sources of global power was to shift the ethnographic gaze away from the Exotic Other and towards the everyday practices of the West, its technologies, rationalities, and institutions—asylums, prisons, schools, hospitals, clinics, laboratories, and so on—and to study these in relation to the emerging concept of 'globalisation'.

The profound 'messiness' of this kind of social research (Law, 2004) has presented a number of challenges to anthropological concepts, representational strategies,

and ways of working. For instance, Marcus and Rabinow (2008) emphasise that "fieldwork [in anthropology] is no longer predominantly about people and hence 'society' or 'culture' but about temporal processes, e.g., the emergence of forms of rationalities, of institutions, of assemblages" (p. 93). The MCI concept, for example, is not produced within a single locale but extends across many different sites, institutions, timelines, and communities of practice.

The nature of this far 'messier' form of ethnographic research has been the focus of much theorising in anthropology (e.g., Marcus, 1995; Marcus & Fischer, 1999; Rabinow et al., 2008; Marcus, 2013). Now 'studying up' among experts in scientific disciplines such as nuclear physics and bioengineering, anthropologists have increasingly been forced to think of these experts as 'collaborators' or 'epistemic partners' rather than subjects or informants (Homes & Marcus, 2008). While these changes have brought about increased dialogue across disciplinary boundaries, and led to deeper anthropological engagement in policy, science, and industry (Marcus, 1999), they have also challenged a number of the discipline's core concepts (such as culture, identity, personhood, and so on) (Rabinow et al., 2008).

As such, the whole practice of contemporary anthropological research, including its conceptual frames and methods of inquiry, need to be reformulated in order to bridge connections between the discipline's past and present (Rabinow et al., 2008, p. 45). As I will argue in the following sections, doing anthropology with and through design can help 'rethink' conventional anthropological inquiry. First, I will contextualise the emergence of design anthropology and outline its relevance to this PhD research.

What is design anthropology?

The relationship between design and anthropology was prefigured by Scandinavian participatory design, a tradition that grew out of 1970s trade union projects, which sought to involve workers in the redesign of workplace technologies (for a more comprehensive overview of the relationship between design anthropology and participatory design, see Buur & Matthews, 2008; Kensing & Blomberg, 1998). Participatory design now refers broadly to a design approach that seeks to include end-users in the development and implementation of products, systems, and services. The approach began in the 1970s as a reaction to what were perceived to be the potentially dire consequences of introducing computer systems into modern workplaces (Kensing & Blomberg, 1998).

Amid widespread concerns that new computer technologies would deskill and potentially replace office workers, a number of social science researchers argued that the design and introduction of new workplace products and systems were only serving the interests of those on the upper rungs of the organisational hierarchy (Kensing & Blomberg, 1998). Building relations with work unions, these researchers sought to generate ways to help disempowered workers shape and control the conditions of their workplaces.

The implementation of participatory design approaches during the 1980s coincided with changes in ethnographic research in academic anthropology, which, as outlined above, was now often conducted in techno-scientific and institutional-type settings among various kinds of experts (such as scientists and engineers). For anthropologists, a growing number of these studies represented an exciting step towards interdisciplinary collaboration, an opportunity for anthropologists to work jointly with technologists and other scientists "to make science and technology tangibly useful to society at large" (Bauer, 1990, p. 116).

In the 1980s, anthropologists in America became increasingly sought after in corporate settings to conduct "theoretically informed, empirical investigations of everyday work practices and technologies in use, in relation to work and technology (re)design" (Blomberg et al., 1996, p. 238). Xerox Palo Alto Research Centre (PARC), an American research and development company located in Silicon Valley in California, is perhaps one of the most celebrated examples of

this integration of ethnographic research into the commercial sector in general, and technology development in particular. Founded in 1970, Xerox PARC has since been credited with developing many aspects of the modern office workplace—"the office of the future" (Suchman, 2011, p. 4)—with products that range from the laser printer to the computer mouse, digital information systems, and user interfaces.

As workplace technologies became more sophisticated and difficult to use during the 1980s, Xerox sought expertise in ethnographic research to understand the relationship between formal workplace procedures and people's actual (rather than reported) workplace habits. It was thought that on the basis of these observations, Xerox could customise technology designs to better meet the needs of office technology users, and to thereby have a competitive edge over other companies in the market. For example, Xerox employed anthropologist Lucy Suchman, whose ethnographic research in the 1980s became a foundational contribution to the field of human-computer interaction (HCI), and whose subsequent theoretical and methodological reflections on her 22-year career at Xerox PARC have more recently become influential in the field of design anthropology (Otto & Smith, 2013).

Today ethnographic research is widely used to support business strategy and innovation across commercial sectors. Many anthropologists work in commercial settings to deliver insights on people's everyday life so that business opportunities (such as new products and services) can be grounded in an understanding of end-users and their context. Commercial design anthropology is promoted by organisations such as the Ethnographic Praxis in Industry Community (EPIC), which helps businesses find ethnographic expertise from around the world, and holds annual conferences where academics and practitioners gather to share their expertise in the commercial sector (Otto & Smith, 2013).

One of the most common criticisms of the design-anthropology relationship is that it has been primarily one-sided, with anthropology (usually reduced to its central method, ethnography) for the most part subordinated to the service of commercial design. However, one of the most interesting features of this relationship is not simply that anthropology produces "implications for design" (Dourish, 2006), but also that there is an intellectual overlap—what Otto and Smith (2013) call a "genuine affinity," and Gatt and Ingold (2013) refer to as a "correspondence"—between the two disciplines. In academia, this overlap has been significant enough for practitioners from each discipline to recognise the mutual benefits of working, thinking, and learning together (Gunn & Donovan, 2016).

As anthropologists Keith Murphy and George Marcus (2013) have pointed out, design anthropology represents "a much needed rebalancing of the historically lopsided relationship between design and anthropology" (p. 253). Otto and Smith (2013) have gone so far as to suggest that the dialogue between design and anthropology constitutes a "distinct style of knowing" in itself, which, they argue, emerges through the proximity its practitioners enjoy to processes of designing and making, and through a unique incorporation of both analysis and action in the production of knowledge. Kilbourn (2013) argues that what distinguishes the field are the objects and materials (or 'tools of inquiry') that design anthropologists use to *think with*.

Some have suggested that thinking 'through design' can help reformulate anthropological inquiry and address some of the philosophical challenges mentioned in the section above, specifically those relating to the nature of knowledge production in the discipline (Rabinow et al., 2008; Murphy & Marcus, 2013; Marcus, 2014). As Murphy and Marcus (2013) suggest, the relationship between design and anthropology is one of the most productive sites for reworking contemporary ethnographic fieldwork and research.

As a collaborative enterprise, design anthropology departs from a long tradition of solo-authored 'accounts' (which still predominate in anthropology today) by encouraging researchers to take on roles in multidisciplinary design teams and work out novel ways of producing knowledge in real time (Gatt & Ingold, 2013).

Figure 8: Anthropology as the study of culture; design as the *making* of culture. This image was made by Nathan for a presentation on 'intersections of practice' in the design for health space. Disclaimer: the views and opinions expressed here do not necessarily reflect the position of the author.

By forcing anthropologists to rethink conventional ways of representing social complexity (i.e., by focusing on flows, relations, processes, and multi-sitedness rather than localised bounded cultural wholes [see Marcus, 1995]) this new mode of inquiry is suggestive of an "anthropology of the contemporary" (Rabinow et al., 2008).

One of the reasons design has become so interesting to anthropologists in recent years is that design projects can be conceptualised as the making and remaking of culture (Otto and Smith, 2013) (see Figure 8). Drawing on this idea, Elizabeth Dori Tunstall has usefully defined design anthropology as "an interdisciplinary field that seeks to understand the role of design artefacts and processes in defining what it means to be human" (2011, October 28).

In a similar way, although design projects unfold in the present, in the indeterminate here-and-now, they are in fact critical moments in the creation of possible futures (Yelavich & Adams, 2014). Because of this, anthropologists with an interest in the ethics and future implications of design must engage with and analyse projects in real time, rather than after the fact (Ingold & Gatt, 2013).

In addition, because design anthropologists work with a range of stakeholders and make contributions to various phases of the design process, one of their primary goals is to develop conceptual frameworks and tools that can be integrated into interdisciplinary collaborations and interventions, from which anthropology, in its more traditional forms, has shied away (Otto & Smith, 2013).

In her critical analysis of IDEO's *Design for Social Impact*, a *How-To Guide* that emphasises the power of design thinking in 'transforming' impoverished, non-Western communities, Tunstall (2013) argues that many of its values are couched within a "hegemonic paradigm of innovation" and tend to "draw from a progressive narrative of global salvation that ignores non-Western ways of thinking" (p. 236). Tunstall warns us that even the most well-intentioned innovation practices, of the kind anthropologists now find themselves involved in, have a tendency to reproduce an imperialistic and modernising agenda where Western design teams are represented as the agents of social transformation. By combining this critical perspective with a deep understanding of society and culture, anthropologists have the conceptual tools to promote critical reflection on 'innovative' design practices where such teams are addressing complex social problems.

Design projects are by their very nature future-oriented, and design anthropologists are forced to reorient their analytic gaze from past (how things have come to be) to future (what might be). This is not to say that design anthropology as a field

Figure 9: The intersection between anthropology and design.

ignores or denies the contingencies of history—to the contrary, it emphasises them. It simply means that design anthropology redirects the analysis of those contingencies *forwards* by looking at how possible futures and trajectories are igure 9).given form in the present (Ingold, 2011) (see Figure 9). Thus, while involved in rethinking anthropological inquiry (Murphy & Marcus, 2013), design anthropology maintains a strong commitment to a central idea in anthropology, namely that the world in which we live could be, and could have been, very different. By way of reference to a Deleuzo-Guattarian ontology, anthropologist Tim Ingold (2011) remarks: "our task is not to take stock of [the world's] contents but to f*ollow what is going on*, tracing the multiple ways of becoming, wherever they lead. To take these paths is to bring anthropology back to life" (p. 14).

In this doctoral work, I follow 'what is going on' within the context of MCI research and clinical practice, to see how and where design processes intersect with the emergence of a new medical reality. As I discuss in more detail below, however, I depart from Ingold by taking a more active approach and engaging fully in the Living Well with MCI design process from start to finish, not simply describing or 'tracing' that process to see where it leads.

Anthropology 'by means of' design

In my early reading of the literature I found a number of suggestions for how to frame anthropological inquiry in relation to design. Suchman (2011), for example, stresses that we need more of a critical anthropology *of* design, and less of an anthropology *for* design (as the relationship has historically been framed—see, for example, Dourish, 2006). She calls for, "among other things, ethnographic projects that articulate the cultural imaginaries and micropolitics that delineate design's promises and practices" (Suchman, 2011, p. 3).

Gatt and Ingold (2013) argue, however, that the sort of ethnography Suchman proposes would amount to a *critique* of these practices, captured in static text. The trouble with reducing anthropological inquiry to an anthropology-of-X model, they suggest, is that it reduces anthropology to a practice of ethnographic description of the Other, and complex social phenomena to an object on which the anthropologist delivers their "belated critical commentary" (Halse, 2013, p. 132).

Within the context of this PhD, my aim was not simply to provide a "thick description" (Geertz, 1973, p. 3) of the design process—this would be to ignore my role and contributions as a collaborator on the Living Well project. Thus framing this research as an 'anthropology *of* design' would constrain dialogue between design and anthropology by reducing Living Well with MCI to an object of study.

What Gatt and Ingold propose instead is anthropology *by means of* design. This is a practice of correspondence between the two disciplines in which the anthropologist, occupying a unique and deeply embedded position in the field, willingly participates in unfolding design practices. In doing so, the anthropologist takes their traditional 'participant observation' position one step further (as I do in this research) to *observant participation* (Gatt & Ingold, 2013, p. 154).

While the form and style of the design anthropologist's participation may vary—from facilitating co-design activities, to collecting data about end-users, to generating insights and even developing and testing design concepts— perhaps their most important contribution is to develop what Halse (2013) calls "technologies of the imagination" (p. 192) to enable and promote critical reflection *during* the design process. Embedding such technologies within the MCI resource, for example, would transcend text-based critical commentary.

I define anthropology *by means of* design as the application of design methods (which can be seen as a supplement to traditional ethnographic research methods such as interviews and observations) to probe deeper into the 'problem' at the centre of a design project. This is where I want to draw a distinction between a 'design problem' and a 'design anthropological problem' to clarify my focus in this research.

The term 'design problem' refers to the challenge of meeting specific user needs and requirements through the delivery of a given product or service. It is the problem as typically framed in a design brief. By contrast, I am introducing the term 'design anthropological problem' here to refer to the underpinning cultural logics and social practices that shape people's perceptions and understandings of a given design problem (e.g., MCI). A design anthropological problem refers both to the socio-cultural context in which a design problem is situated and to the many different and often competing conceptual worlds and practices that produce it.

In Living Well with MCI, for example, the design anthropological problem is not that people with MCI have nowhere suitable to share their stories and strategies for managing cognitive changes (this is the design problem); rather, it is that MCI is problematic in the first place. MCI is a relatively new, ambiguous, and contested diagnosis, and as such calls into question the supposed objectivity and solvability of the original design brief—to design a resource for people living with MCI.

In framing a design anthropological approach to this problem, there is also the question of how to conceptualise the relative importance given to each discipline. Gunn and Donovan (2016) invite us to consider three possible modes of design anthropological engagement outlined in Table 1 below:

design Anthropology (dA)	The theoretical contribution of the research is more for anthropology than it is for design.	E.g., The design project is itself the subject of anthropological inquiry.
Design anthropology (Da)	Research is conducted for and in the service of design.	E.g., Ethnographic fieldwork is carried out to generate insights and implications for design.
Design Anthropology (DA)	Research is balanced in such a way that each discipline feeds into and learns from the other.	E.g., The anthropologist and designer work together on a design project and inform each other's thinking.

Table 1: Three ways of 'doing' design anthropology. Adapted from Gunn and Donovan (2016, p. 8).

Because I am making use of and learning from 'designerly ways of knowing' (Cross, 1982) to explore and understand the onto-political problem of designing for MCI, the latter mode of inquiry, 'DA', best represents the methodological approach for this research. It also suitably reflects the nature of my involvement on the project,

in which Nathan and I worked closely together and built on each other's existing skillsets and knowledge. As I will show in subsequent chapters, I helped Nathan think more 'anthropologically' about MCI, while he taught me about UX methods and how to think like a designer. As such, there was an exchange of ideas, methods, and ways of thinking between our two respective disciplines.

Design anthropology and the new materialism

From a new materialist perspective, MCI is not the same thing in the memory clinic as it is in the lab or at home; it is distributed across an assemblage of objects, processes, and practices, and therefore expresses itself differently in different settings and contexts (Mol, 2002). Understanding how MCI hangs together across these spaces as though it *were* a perfectly coherent and natural 'design problem' is what I saw as my primary role as a design anthropologist. What makes MCI an interesting 'design *anthropological* problem' is that its current status as a hot topic in academic research is contingent on the socio-material assemblage that makes MCI a matter of concern (Latour, 2004).

There are a number of complex but identifiable forces at play in the production of MCI as a new medical reality—knowledge-making practices, experts, technologies, materials, institutional networks, complex power-relations, cultural logics, older people, public discourses—that can be brought to the surface and rendered visible for critical reflection. As a design anthropologist, what I wanted to convey to Nathan and the wider project steering group was that the MCI category is an assemblage of practices (of which design is itself a part) rather than a fixed or 'natural' entity in the brain—i.e., a 'condition' to design for.

This new materialist approach has a number of methodological implications for this research, which I have summarised in Table 2 on pages 41 and 42.. In particular, it implies that the MCI assemblage, rather than individual subjectivities, is the primary unit of analysis (Fox & Alldred, 2015). In Chapter Four I will explain my methods in more detail, but it is important to point out here that my participants are considered 'elements' within a socio-material assemblage (Fox & Alldred, 2015). Because I was interested in the relationships between different elements in the assemblage and how these produced MCI, interviews were focused not on perspectives so much as practices, processes, and the relationships between these.

This notion of an assemblage also extends to the research process itself, since the researcher, according to new materialism, is not a detached and impartial 'viewer'; rather, they are embedded in the very relationships they study. This means that the 'research assemblage' and the 'MCI assemblage' inevitably intersect and co-produce representations of the world (Fox & Alldred, 2015). As Table 2 shows, this also has implications for research *presentation*, which I will describe in more detail in the next section.

An ethnographic experiment

In this PhD, I am drawing on post-qualitative research in an effort to reflect on the possibilities of anthropological inquiry within and through design (Smith et al., 2016). As I have pointed out with reference to design anthropology, social science methodologies need to be reformulated in order to account for the fluid multiplicity and general messiness of social phenomena (Law, 2004). In conventional ethnographic accounts, complex social phenomena are always reduced to text (a linear narrative) even though the object of study is always prior to, transcends, and often outlives the written word. Descriptions of events and observations are always *too late* (Rabinow et al., 2008), and therefore unsuited for design projects, such as Living Well with MCI, in which there are time restrictions.

Following anthropologists such as Marcus and Rabinow, who have highlighted

design as a potential avenue for rethinking anthropology in the contemporary world (Rabinow et al., 2008), I suggest that anthropology *by means of* design is one way to revitalise anthropological inquiry and ethnographic representation, while producing insights for critical inquiry during the design process.

The (non-)representational strategies used in this thesis are an attempt to move, albeit incrementally, beyond static and text-bound ethnography. The inspiration for doing so has been taken directly from design; indeed, writing this PhD thesis can reasonably be conceived as a design process. As briefly mentioned in the Introduction, I have structured Chapters Five to Eight using the Double Diamond model. As such, these chapters suggest *linearity*, as ethnographies and other designed artefacts tend to, yet within them I have expressed what was in fact the very messy, non-linear process of my fieldwork and research process. I have done this by breaking up and interrupting the text with reflections, interludes, asides, creative non-fiction, interview excerpts, fieldnotes, artwork, and images. These interruptions juxtapose different realities and elements of the MCI assemblage while representing the multi-sited entanglements of this research.

Experimenting with these representational strategies is an attempt to capture not only the process of generating 'insights' into the MCI assemblage, but also the temporal, spatial, embodied, material, psychological, sensory, and performative qualities of the ethnographic journey as a whole (Vannini, 2015). The style presented in Chapters Five to Eight is an attempt to express the rhythm and texture of my journey, as well as the processes and challenges of aligning design anthropological fieldwork with the main project, Living Well with MCI. It reflects what Ken Gale (2018) calls 'madness as methodology', an attempt to break away from traditional modes of exploring, understanding, and representing the social world.

Interrupting the text with asides and reflections was one way of representing the fragmentary nature of multi-sited fieldwork in which I moved from one place to another, followed leads, returned to the project, performed my duties as a researcher, went away again, encountered new perspectives, gathered new insights, then returned and reflected through writing. As such, these reflections and asides capture the many 'lines of flight' (Deleuze & Guattari, 1988) I took during my fieldwork, in which I was both observer and participant.

Amid all this ethnographic movement, however, meeting with the designer, Nathan, formed a steady beat. We met at regular intervals to discuss emerging themes and ideas from my fieldwork to reflect on and imagine possible futures (Smith et al., 2016). To represent these moments of pause and reflection, the text is interspersed with extended interview excerpts (or 'critical reflections') with Nathan. These excerpts, being quite relaxed and conversational, have a different temporal feel from the rest of the text. They are often juxtaposed with more difficult and faster-paced conceptual discussions in the main body of text, showing how one-on-one conversations created space to slow down and reflect during the Living Well with MCI project. As such, they correspond to and reflect the necessity of creating time and space for critical dialogue within the project, in real time.

I am aware that these representational strategies are risky and perhaps, at times, difficult to follow. Perhaps they seem to 'jar', although I have done my best to ensure that each interlude corresponds to what is happening and being discussed in the main text. It should be noted, however, that these efforts are in keeping with a tradition of post-qualitative scholarship, which, as ethnographer Phillip Vannini (2015) writes, are "born out of a disorderly will to experiment and to fail—indeed to try and continue to fail better" (p. 324). He urges "readers and writers keen on transcending the limits of representationalism to break rules and to think, feel, and write differently. And to cultivate heterogeneity. And to never be afraid of being a little infuriating" (p. 324)

Summary

In this chapter I have presented a discussion of design and anthropology in order to show where the two disciplines have intersected in the past, how each has changed over time, and how they relate to the new materialist approach used in this research. I argued that design has become more 'anthropological' in its scope and application, while anthropology has turned to design in order to rethink some of the representational and conceptual challenges it has faced as a discipline. Emphasising the collaborative nature of knowledge production in both design and anthropology, I suggested that anthropology by means of design (Gatt & Ingold, 2013) is a way to both promote critical reflection on MCI and 'rethink' conventional anthropological inquiry (Rabinow et al., 2008). Hence, by drawing on a developing tradition of post-qualitative research, Chapters Five to Eight show my use of representational strategies to convey the 'messiness' (Law, 2004) of this embedded design anthropological process. I argued that these representational strategies are not only consistent with, but are necessitated by, a new materialist approach, which attempts to move beyond, and challenge, the limitations of traditional research practices (Gale, 2018). The next chapter will outline the methods used as part of this new materialist inquiry.

Table 2: Implications of a new materialist philosophy for data collection, analysis, and research presentation.

Social Constructionism	Science + Technology Studies	New Materialism	Design Anthropology

Key Ideas

'Reality' is socially negotiated.	Scientific and medical knowledge are socially produced.	Non-human things and objects have agency in the world.	Design is a future-making, culture-shaping practice.

Onto-epistemological implications

MCI does not exist 'out there' in nature—it is produced socially through particular knowledge-making practices, and culturally embedded in people's assumptions about what ageing is.	MCI is an assemblage of socio-material elements and practices (of which both Living Well with MCI and this PhD research are a part).

Methodological Implications

Primary unit of analysis is the assemblage (rather than people's perspectives or experiences 'of' MCI), with a focus is on relations between elements within the assemblage.

In addition, this PhD research is itself an assemblage of methods, ideas, assumptions, and relations between these. Therefore both MCI and the research assemblage are subject to analysis and interpretation.

Participants

People with MCI

'Experts' (i.e., clinicians and researchers whose work involves MCI category)

Designers and materials

Myself

Data Gathering

Data is collected through my involvement on Living Well with MCI project (e.g., interviews with people with MCI and families, and critical reflection sessions with Nathan). Data is also collected from ethnographic observations and interviews with experts in memory clinics and dementia prevention centres or 'labs'. Data collection methods are used to explore practices and relationships between elements within the MCI assemblage. Critical reflections are based on data gathered.

Analysis and presentation

Analysis is focused on relations and flows between elements (e.g., discursive forms and socio-material practices) within the MCI assemblage. Writing about this assemblage is itself a mode of analysis. Research is interrupted by interludes that aim to reflect (1) the 'messy' nature of new materialist social research; and (2) the interaction between the MCI assemblage and the research assemblage. Interludes focus on practices, processes, materials, and events observed during fieldwork.

4.
Methods

This research was undertaken using an iterative process that involved collecting and analysing data alongside the web design project to inspire real-time critical reflection on designing for people with MCI. Therefore, data sources for this PhD include both interview data from the Living Well with MCI project as well as additional data collected in parallel as part of this PhD. These data formed the basis for critical reflection throughout the design process. In this chapter I will outline these sources of data and detail my methods of data collection and analysis.

It should be noted from the outset that, because I collected and analysed data in ways that were appropriate to various stages of the design process, the methods described below were employed in a fluid rather than systematic fashion. Many of the key decisions that informed the direction of this PhD were shaped by my day-to-day experiences as a researcher on Living Well with MCI. As such, this research was not designed and then carried out according to any strict methodological procedure or 'recipe', but rather was more iterative and recursive as the design project, in which I was both a participant and an observer, unfolded.

As I will explain below, this more iterative approach is consistent with a new materialist methodology (Fox & Alldred, 2015). The methods outlined in this chapter are therefore not intended as a linear account of what I did so much as a description of the various processes I undertook as a 'design anthropologist' to arrive at the conclusions presented in later chapters.

Sources of data

This research combined both primary and secondary sources of data (see Figure 10). As I will describe in more detail below, secondary sources of data involved a review of both peer-reviewed and grey literature, a review of existing online resources, and a secondary analysis of the interviews with participants from Living Well with MCI, which I conducted as part of my role as a researcher on the project as described above. Primary data consisted of interviews with five 'expert' informants (i.e., MCI researchers and clinicians), four student designers, conversations with Nathan, and direct observations of various processes and practices within the MCI assemblage. I will begin with a description of my secondary data sources, since these helped inform my approach to primary data collection and analysis.

Secondary data

Secondary data for this PhD included existing literature and online resources, and interview transcripts from Living Well with MCI. I will discuss each of these in turn.

Reviewing literature and existing resources

My review of the literature served two main purposes. The first was to support my critical engagement with the MCI category to help shape my interpretation of the data and to put this data in context. The second purpose was to prepare for interviews and interactions with expert informants.

Before formally starting as a researcher on Living Well with MCI, I conducted an initial scoping of the literature, including a review of published peer-reviewed evidence as well as a grey literature search (e.g., existing web resources for people with MCI). To access this literature, I used keywords such as 'mild cognitive impairment', 'ageing', 'Alzheimer's disease', and 'co-design', in a range of databases including Google, Google Scholar, Anthrosource, and JSTOR. I did not have specific inclusion or exclusion criteria, as my goal was to read as widely and deeply

Primary

Secondary

Observational/
ethnographic
data

Academic
literature

**Data
Sources**

Expert
interviews

Existing
online
resources

Critical
reflection
sessions

Living well
with MCI
interviews

as possible, allowing for concepts and debates to be explored as they came up either during the design process or as part of my fieldwork.

Because one of my explicit aims from the outset was to integrate social science knowledge into the design process and to thereby promote critical reflection on designing for MCI, my reading of the literature was not intended as an exhaustive review of MCI. Rather, the intention was to set the direction of my research and to help make a critically informed stance when helping design a resource for the MCI category. I also read about the complexities of MCI from clinical and research perspectives in order to prepare myself for conversations with expert informants.

Because my review of the literature, as it appears in this thesis, was not intended to be exhaustive, it privileges certain aspects of MCI that had particular relevance to my research and focus. Following Foucault's (1977) concept of 'genealogy', for example, one of the primary aims of my literature search was to situate the MCI category within its socio-historical context by tracing its conceptual origins. To achieve this, I read about the history of Alzheimer's Disease, the technological developments that helped construct notions of pathological memory for age, as well as ethnographic research on MCI in clinical settings, some of which offered an entry point into some of the key debates and controversies surrounding the use and validity of the MCI concept. This was an iterative process in which I sought to deepen my understanding of these debates and concepts, with more targeted searching to explore key ideas further as the project developed.

In addition to reading historical and social scientific literature relating to MCI and medicalisation, I also delved into peer-reviewed neuroscience literature to familiarise myself with, and better understand, the relationship between neuropathology and dementia. I explored key innovations in neuropsychological research to understand how various scales and measures have helped shape present diagnostic and research inclusion criteria for MCI. I read this literature in preparation for interviews with various expert informants, with whom I wanted to have in-depth cross-disciplinary discussions about the category. Before interviewing an expert, I read about specific disciplinary practices depending on their expertise (such as brain imaging or neuropsychological testing) to familiarise myself with some of the language and concepts that constituted the different paradigms and perspectives within which these participants worked.

In addition to reviewing this literature, I also conducted a search of existing online resources. This included, but was not limited to, resources specifically for people with MCI, of which there were many available to draw inspiration for our design concept. Because the original design brief proposed that the website could be a platform of 'stories', I also searched for resources that presented user-generated stories of living with and managing dementia. In addition to this, I conducted a critical review of existing products, services, and experiences that had been designed for people with MCI. This helped situate MCI within the specific context of design.

Secondary analysis of interview transcripts

Additional secondary data for this PhD included interview transcripts from my interviews with participants with MCI and their families, undertaken as part of my role as a researcher on Living Well with MCI. The primary purpose of these interviews was to explore people's day-to-day 'strategies' for managing changes to their memory and thinking. As the original project proposal suggested, these strategies could then be incorporated into an interactive website where people could share and learn about different memory-aids and other strategies for managing MCI. These interviews were around one hour in length and were semi-structured to allow participants to discuss the issues and topics that were most important to them. While the vast majority of these interviews took place at participant's homes, two participants requested that the interview take place at the university, and one requested to meet in a café and to be interviewed there. Initial interview questions for people experiencing changes to their memory

and thinking (either formally diagnosed with MCI or without a formal diagnosis) included:

- How would you describe the changes you have experienced to your memory and thinking?
- How do these changes impact on your day-to-day living and experiences (your life/relationships/typical week)?
- What worries you most about these changes?
- Can you tell me about the things you do to manage your concerns/your health and wellbeing?
- What do you find most helpful?
- What is not so helpful?

Questions for significant others and family members included:

- Can you describe what it is like for you to live with someone who is experiencing changes to their memory and thinking?
- How do these changes impact on your/your loved one's day-to-day living and experiences?
- What worries you most about these changes?
- Can you tell me about the things you do to help manage your loved one's concerns/both your health and wellbeing?

There were (n=28) Living Well with MCI participants in total, consisting of (n=11) people who were formally diagnosed with MCI, (n=8) who identified as having subjective memory complaints (i.e., concerns about changes but no diagnosis), and (n=7) who identified as family members or significant others. Among those with a formal diagnosis of MCI, there were (n=6) males and (n=5) females. Among participants with subjective memory complaints, there were (n=4) males and (n=4) females. The average age of those diagnosed with MCI was 68.6 years. The average age of participants with subjective memory complaints was 73.6 years. The majority of Living Well with MCI participants (n=20) identified as Pakeha/ New Zealand European. Other ethnicities included Tongan (n=2), Samoan (n=1), Sri Lankan (n=3), Scottish (n=1), and Niuean (n=1).

I did not exclude any specific interviews from the Living Well with MCI dataset for this PhD, as I wanted to capture a wide range of perspectives on ageing, age-related decline, and MCI. Thus, I included in the analysis for this PhD not only people with a formal MCI diagnosis, but also significant others, family members, and people with subjective memory complaints who had not received, or sought, any diagnosis.

In this thesis, I use both pseudonyms and transcript codes in my presentation of Living Well with MCI data. I use pseudonyms when presenting more detailed information about participants, including their perspectives and circumstances, and transcript codes to make shorter, less detailed references to MCI participants (e.g., MCI_001), people with subjective memory complaints (e.g., SMC_001), individual family members (e.g. MCI_001_FM), and dyadic interviews (e.g., SMC_001_dyad).

Primary data

Primary data for this PhD consisted of four semi-structured interviews with five expert participants (i.e., working professionals and researchers with MCI expertise). This included three one-on-one interviews and one dyadic interview with a neuropsychologist and research nurse. I also spent time observing some

of the practices with which they were engaged, such as neuropsychological testing. Other observational data was obtained from conferences and symposia, where I met and spoke informally with a range of experts from design, health, and neuroscience disciplines. These were attended as part of my role as a researcher on Living Well with MCI. I also attended BRNZ meetings as an early career researcher and participated in a BRNZ brain-imaging workshop where neurodegenerative disorders, including MCI, were discussed. Another primary source of data for this PhD were the regular 'critical reflection' sessions with Nathan, in which we discussed emerging analytic themes from these interviews and observations. I also interviewed four design students who worked on Living Well with MCI for one semester to develop an animation for the website.

Sampling and Recruitment

Eligibility

Participants were eligible to take part in this PhD research if:

- They were working on the Living Well with MCI project and had indicated they would like to take part (e.g., Nathan and the student designers)
- Their professional work or research involved the MCI category (e.g., BRNZ researchers and clinicians).

Sampling strategy

I purposefully selected expert informants to capture a range of practices and disciplinary perspectives relating to the MCI category. Sampling aimed for diversity and variation in how MCI was conceptualised and 'enacted' across a range of social settings, such as labs and clinics.

Recruitment strategy and process

Expert informants were identified through professional connections made as a result of my involvement on Living Well with MCI. Participants included one psychiatrist, one brain imaging researcher, one research nurse, and two neuropsychologists (of whom one was a PhD candidate). Three participants were located in Auckland and two in Christchurch, New Zealand. All participants were connected with wider BRNZ research activities. I provided each potential participant with verbal and written information about this PhD research (see Appendix C), and followed up either via email or phone. After the research was discussed, written consent was sought and their participation was confirmed.

Data collection processes

In this research I drew on a range of tools and methods as part of my data collection process. In keeping with an anthropology-by-means-of-design approach, I used conventional social science methods (such as interviews and observations) in combination with more explicitly design-led research tools (such as card sorting and persona exercises). In the sections below, I present a detailed description of these methods and how they were used. Although I have separated them for the sake of clarity, these tools and techniques were used flexibly and in conjunction with one another rather than in isolation.

Observant participation

As an active contributor to the design process, I was not a 'participant observer' so much as an 'observant participant' (Gatt & Ingold, 2013). I was involved in all phases of the design process, from interviewing MCI participants and synthesising data,

to facilitating a co-design workshop and testing concepts with our users. Through this iterative process I wrote extensive fieldnotes to capture observations and reflect on my dual-role as both design researcher and design anthropologist (some of these fieldnotes will appear in both raw and edited forms during interludes in the following chapters).

Observant participation began as soon as I was offered a role on the project and continued through the design process. Key observation settings included meetings with the wider project steering group as well as weekly project meetings with Nathan. Through this deep immersion in the process I was able to learn about, and engage in, a wide range of UX design methods, while integrating my social science perspective on medicalisation with design processes.

Multi-sited fieldwork

In addition to observant participation within Living Well with MCI itself, I conducted additional multi-sited fieldwork to understand the broader social context of the project. Multi-sited ethnography is a method used for exploring complex systems and processes (Marcus, 1995), and therefore works well with a new materialist methodology and its emphasis on understanding socio-material 'assemblages'. It involves following a particular problem or topic (in this case MCI) for an extended period of time and exploring how it extends across multiple locations and contexts.

Part of this included observing and documenting the relationships between various practices and processes across different sites. Within the context of this research, this meant exploring a network of relationships between memory clinics, dementia research laboratories, academic institutions, and family homes. This was achieved through field visits in which I would meet, interview, and spend time with, expert informants in their work context. Through these encounters I would hear of and learn about other experts and practices that related to MCI, which I would then follow up.

In addition to these interactions, I attended a number of national and international conferences and symposia, the themes of which ranged from neuroscience and assistive technology, to designing for (and with) people with dementia. I was able to access these events as a researcher on Living Well with MCI, by virtue of which I was invited to attend events and present conference papers on the project. These events were important elements of the MCI assemblage, because they allowed me to meet aged care workers, caregivers, nurses, as well as other researchers and clinicians, and to talk with them informally about their work practices and how these related to identifying, diagnosing, studying, and treating MCI.

This immersion in the world of MCI research and clinical practice allowed me to gain insights into the scientific and clinical discourses surrounding the category, which in turn informed the direction and scope of my research. This data was captured in written field notes and reflections, which were between one and five pages in length, and analysed in the manner discussed later in this chapter.

When visiting clinics and laboratories, I gathered a range of additional materials. For example, I wanted to know what information, if any, clinicians gave to their patients following an MCI diagnosis. I collected these information resources and discussed them with Nathan. Similarly, I was interested in the tools used to evaluate and diagnose someone with MCI, because these both helped clinicians and researchers determine who had MCI and who did not, and, by extension, played an important role in lived experience. In cases where expert participants could not give me physical copies of tools or resources to take away, they directed me to online versions that I could download and print. Some of these will appear as images in later chapters.

Expert Interviews

Five in-depth semi-structured interviews with BRNZ experts (four one-on-one and

one dyadic interview with one nurse and one neuropsychologist) were carried out at different stages over the course of the Living Well with MCI project. Each interview was between 45 minutes to 1 hour in length and took place at participant workplaces (two research centres and one hospital). All interviews were audio-recorded and transcribed verbatim. In keeping with a new materialist approach, interview questions were focused around the participant's clinical or research practices relating to MCI. I asked a range of questions that were related to my particular topic and focus. While interviews were semi-structured to allow participants to raise and talk about topics of interest to them, I was particularly interested in how clinical and research processes connected to other practices and processes in other settings across the MCI assemblage (Fox & Alldred, 2015). Example interview questions included:

- How do you determine who has MCI and who doesn't?
- What tools or methods do you use to support this decision?
- Where did these tools come from?
- How do they differ from other tools used in MCI research/clinical practice?
- How are they similar?
- How do you inform someone that they have MCI?
- What information do you provide?
- Where does this information come from?

Critical reflection sessions

As part of this PhD research, I sat down regularly with my DHW Lab colleague Nathan, a New Zealand European UX designer in his late-twenties, for one-hour, audio-recorded 'critical reflection sessions' over a period of two years. These sessions had two main purposes. The first was to try and create a space where we could reflect on emerging insights from interviews with people with MCI, clinicians, and laboratory researchers, and discuss observations from my ongoing fieldwork. For example, I would tell Nathan about clinical practices (e.g., how MCI was evaluated and diagnosed) and the sorts of information that people with MCI were given when a diagnosis was made. We would talk about some of the issues around the diagnosis, different cultural interpretations of and responses to ageing and cognitive changes, and what this all meant in terms of defining our 'user group' (including the implications this would have for how the resource would meet their needs). I would also share insights from my conversations with neuroscientists about their 'cutting-edge' research on MCI. During these sessions we would draw and write on post-it notes as part of reflection exercises to 'visualise' problems relating to the category, exploring how these might play out within the context of Living Well with MCI (see Figure 11).

Figure 11: Example of a critical reflection activity with Nathan.

These sessions created opportunities to step back from the main project and to engage in higher-level reflections on key themes such as design, anthropology, MCI, and medicalisation more generally.

I would ask Nathan what he personally thought about the MCI category as a design problem, how he thought our work might be embroiled in the wider debates and practices that I had been investigating, and how some of these might be addressed within the context of our design process. How Nathan and I talked about MCI changed over time, and this is documented through interludes and extended interview excerpts in later chapters.

The second purpose of these sessions was to document Nathan's perspectives on MCI and how they changed over time. This was a way to gauge whether my PhD research and insights from fieldwork were having an impact on his thinking and approach to designing for people with MCI. As such, these sessions served as practical reflections within the project itself, and as a source of data for this PhD.

Most of these sessions took place at the DHW Lab, where Nathan worked, but others took place 'on the move' (for instance, when we went out to conduct user-testing sessions together in the later stages of the Living Well with MCI project). However, in these instances, because our conversations were often more opportunistic, some of these sessions were not formally audio-recorded. These less formal opportunities were naturally embedded as part of the design process (as, for example, when Nathan and I were drawing and developing concepts for the website prototype). While performing these activities, I brought up relevant observations and insights from my fieldwork and talked casually with Nathan about how they might relate to the development of our website .

Figure 12: A persona exercise to map assumptions about MCI.

Personas

In the early phases of the project, I conducted a persona exercise (Pruitt & Adlin, 2010) with a neuropsychologist and a research nurse who worked together at a dementia prevention research centre (see Figure 12). Personas are commonly used in design to imagine an 'archetypal' user constructed out of specific data about actual people (Pruitt & Adlin, 2010). Used in the context of this research,

the persona exercise was a useful way to explore how expert knowledge is used to construct an archetypal 'person with MCI'. After interviewing the neuropsychologist and nurse about dementia prevention research and how the MCI category related to their work, I asked them to develop an MCI persona using Post-It notes and a large piece of paper. I asked them to put themselves in the shoes of someone with MCI and then write down what they thought might be their concerns, goals, emotions, and feelings, as well as what they might think MCI means, who has it, and what lifestyle changes they might adopt. This allowed me to better understand their assumptions about the lived experience of MCI, which I was then able to compare and contrast with the interviews I had been carrying out among people with MCI and their families. As I collected their Post-It notes, the neuropsychologist and research nurse explained and elaborated on what they had written. This session was audio-recorded and transcribed.

Figure 13: A card sorting exercise

Card sorting

Another method I used with experts was card sorting (Righi et al., 2013). This was a conversational tool I used in conjunction with interviews with 'experts'. I carried out this activity with three of five participants (one brain imaging researcher, one psychiatrist, and one neuropsychology PhD candidate). I presented each participant with approximately fifty images that I collected from Google Images (see Figure 13). I chose a wide range of pictures that allowed for both metaphorical and literal interpretations. I spread these images out on a table and asked participants to choose five images that they felt best represented their understanding of MCI. These five images provided an entry point into a deeper discussion about their research or clinical practices and how these related to the images.

Reflective Journaling

While simultaneously working on Living Well with MCI and collecting data for this PhD, I kept a journal to record my interactions, observations, ideas, thoughts, and reflections. Most of these reflections related specifically to Living Well with MCI and the processes involved; however, some of them also captured broader reflections and observations relating to key analytic themes such as medicalisation. For example, I wrote extensive fieldnotes when attending BRNZ meetings, visiting labs and clinics, and going to conferences. While some of these journal entries appear in raw form

in this thesis, others formed the basis for more detailed reflections and narratives.

Analysing data

Forming the basis of real-time critical reflection on MCI, data collection and analysis were fluid and iterative processes, intersecting with Living Well with MCI at various points. Analysis continued both over the course of the design project and through the process of writing this PhD. I drew on a number of tools to support data analysis, including conventional approaches to coding data, which draw on a tradition of qualitative research (Denzin & Lincoln, 2005). In addition, I also incorporated post-qualitative techniques such as writing creative non-fiction (Richardson & St Pierre, 2005) as part of my analytic process, as outlined below.

Qualitative data analysis

Expert interview transcripts were each read once initially and then, in a second reading, coded for specific references to practices (e.g., diagnostic tools and procedures) and relationships between practices within the MCI assemblage (e.g., brain imaging or blood sampling). This orientation to the data is consistent with a new materialist methodology and its emphasis on how phenomena arise through such relations and practices (Fox & Alldred, 2015). I also coded for debates around the MCI category more generally in order to analyse how these debates potentially impacted on, or were resolved through, practices in research and clinical settings. This process was repeated in a secondary analysis of transcripts of interviews with Living Well with MCI participants. In this secondary analysis, instead of coding for 'debates' I coded for social and cultural factors influencing illness perceptions (Petrie & Weinman, 2006) and treatment seeking behaviour among participants to explore the ways in which these intersected with different elements within the broader MCI assemblage. For example, I coded for culturally specific attitudes towards 'ageing' and 'memory loss' to highlight other possible ontologies of ageing and how these related to, or problematised, diagnostic practices in clinics. I also coded transcripts for information about the processes by which MCI was diagnosed, what kinds of information were given, why participants sought diagnosis in the first place, what they hoped this would achieve, and how they understood MCI to be different from 'normal' ageing. I read all interview transcripts in an iterative way as both the design process and my PhD research unfolded. All transcript codes (e.g., 'memory complaint') were grouped into categories (e.g., 'determining what is normal versus abnormal'), forming broader analytic themes (e.g., 'problems in diagnosing MCI'), which, in turn, became the basis for critical discussion and reflection with Nathan during our regular sessions together.

Creative non-fiction as analytical practice

As part of my analytic process, I wrote creative non-fiction as a way to both capture and make sense of the data. Creative non-fiction is a form of 'creative analytical practice' in which the researcher writes as a way of both understanding and representing ethnographic data (Richardson & St Pierre, 2005). Following a tradition of experimental ethnographic writing (Clifford & Marcus, 1986), creative nonfiction is a method of inquiry in which writing is emphasised as an integral part of the analytic process.

As a method of data analysis, creative non-fiction attempts to move beyond conventional analytic processes in social research by showing how "[the written] product cannot be separated from the producer, the mode of production, or the method of knowing" (Richardson & St Pierre, 2005, p. 962). In other words, creative nonfiction as *method* acknowledges that the researcher is at all times present in the production of knowledge, and that ethnographic data is always filtered through the researcher's subjective lens. This method is therefore consistent with a new materialist approach and its implication that the researcher, data, methods, and analysis are all entangled as relational elements within a 'research assemblage' (as

I discussed in the previous chapter—see Table 2).

As part of the representational strategies used through Chapters Five to Eight, creative nonfiction appears in the form of interludes, asides, and reflections based on fieldwork carried out while working on Living Well with MCI. These were written immediately following, or shortly after, an interview, event, or observation in the field. As such, many of them appear in my own handwriting and, being raw, may include some mistakes. However, because these sections were written as part of my analytic process, these interludes are more than simply a 'representation' of what I observed during my fieldwork; they are also a record of the process by which I made sense of and interpreted the ethnographic data. Put another way, writing in this thesis is considered valid a way of thinking and knowing, as well as a method of representation (Richardson & St Pierre, 2005).

Summary

This chapter has presented the sources of data, data collection methods, and analytical processes used in this thesis to explore, and promote critical reflection on, the MCI assemblage. This PhD research draws on a range of conventional qualitative methods such as interviews and observations, but also attempts to move beyond these to incorporate design methods (e.g., personas and cart sorting) and creative writing practices (e.g., reflective journaling) in keeping with post-qualitative and new materialist modes of inquiry. Methods of data collection and analysis were used in a fluid rather than linear or systematic fashion, as the Living Well with MCI project unfolded. The primary purpose of the methods was not to uncover 'facts' about the MCI assemblage, but rather to generate insights on, and critical awareness about, the ways in which the MCI category is constructed as a matter of concern for individuals and society. These insights were generated from data used as part of the Living Well with MCI project itself, and from other sources of data collected in parallel with the project as part of this PhD (i.e., data collected from dementia research centres and memory clinics). They were then shared with UX designer Nathan and explored through regular critical reflection sessions during the design process (see Figure 14).

Figure 14: This research was an iterative process consisting of four main parts: collecting data, analysing data, critical reflections with Nathan, and design activity (also with Nathan) on the Living Well with MCI project.

5.
Discover

In the UK Design Council's (2007) Double Diamond model, 'Discover' is the first phase of the design process where the goal is to "look at the world in a fresh way, noticing new things and seeking inspiration" (Design Council, 2015, p. 7). It is open-ended and explorative, a period of 'divergence' in which the project broadens in scope before narrowing, in the 'Define' phase, into something concrete and manageable. The Discover phase is about identifying a problem, asking questions, and considering new perspectives and possibilities. It is when the designer, or design team, starts to generate a wide range of insights and ideas that might serve as the initial inspiration for a design concept.

In experimenting with the idea of doing anthropology by means of design (Gatt & Ingold, 2013), I began my embedded ethnographic project with a "phase of divergent thought" (Design Council, 2007) in which I departed from taken-for-granted ideas about MCI as a design problem. At the start of this project, Nathan and I were given a brief in which MCI was described as a "brain impairment", and a "condition" characterised by "deficits in functioning" (see Appendix A, p. 1).

Drawing on my background in medical antropology, I was interested to see whether there were other possible ways of thinking about MCI, and therefore other ways of approaching the problem. This involved learning and writing about the history of MCI in order to 'discover' its conceptual origins, and to thereby situate the design problem within this broader socio-cultural and historical frame of reference. In this way, I started to open up the possibility for critical reflection.

I therefore began this Discover phase by exploring the historical context that contributed to the production of MCI as both a concept and a diagnosis, drawing on the general principles of historical genealogy as described by Michel Foucault (1977). In doing so I extended my analysis (i.e., 'diverge') from individual subjects to broader historical flows, competing knowledges and discourses, with a view to better understanding the social practices through which these were enacted in the present.

This chapter explores some of the fundamental underlying assumptions of biomedicine and the biomedical understanding of the relationship between ageing and dementia. It traces conceptual developments and debates in Alzheimer's Disease research, showing how these debates manifest in contemporary MCI research. In keeping with post-qualitative, new materialist research, the chapter is punctuated by observational data on everyday social practices in labs and clinics, as well as reflections with Nathan showing how we attempted to make sense of MCI in the early phases of the project.

LIVING ALONE IN A SMALL STATE-OWNED PROPERTY IN ORAKEI, EAST OF CENTRAL AUCKLAND, MARGARET WAS EXPERIENCING SOME CHANGES TO HER MEMORY AND THINKING. HER SPELLING, WHICH HAD ALWAYS BEEN VERY GOOD, WAS BECOMING QUITE POOR. SHE WAS ALSO GETTING PEOPLE'S NAMES MIXED UP (WHICH, SHE ~~WAS~~ ADMITTED, WAS PERHAPS NOT ALL THAT SURPRISING FOR A 72-YEAR-OLD, BUT SHE WAS BEGINNING TO WONDER IF IT MIGHT BE BEYOND 'NORMAL' AGEING). ~~~~ SOMETIMES SHE WENT BLANK IN THE MIDDLE OF A TASK AND FORGOT ~~~~ WHATEVER IT WAS SHE WAS DOING. A FEW MONTHS AGO SHE WAS OUT DRIVING AND HAD ONE OF THESE MIND-BLANKS WHILE APPROACH-ING WHAT SHOULD HAVE BEEN, TO HER, A FAMILIAR CORNER NEAR HER HOUSE. SHE BECAME DISORIENTED. "I LOOKED AROUND AND REALISED I WASN'T SURE WHERE I WAS," SHE SAYS. "I GOT SUCH A SHOCK."

IT WAS AT THIS POINT, SENSING THAT SHE MIGHT BE ON A "DOWNHILL SLIDE", THAT MARGARET DECIDED TO GO AND SEE HER DOCTOR. HER FATHER AND GRANDMOTHER HAD BOTH DIED FROM ALZHEIMERS DISEASE, AND THIS DRIVING EPISODE LEFT HER ~~~~ WORRIED AND DESPERATE FOR SOME KIND OF CONCLUSIVE ASSESS-MENT OF HER SITUATION. ~~~~ SO SHE THEN ASKED THE DOCTOR WHETHER THERE WAS A BLOOD TEST FOR THE DISEASE:

MARGARET: "I DON'T KNOW WHETHER THERE'S A FAMILIAL THING THERE OR NOT BUT, GEE, ALL OF A SUDDEN, HECK, I NEED TO KNOW IF THIS COULD BE A **PRECURSOR**. AND SO [THE DOCTOR] LAUGHED AND SAID NO, THERE ISN'T A, YOU KNOW, A BLOOD TEST FOR IT OR ANYTHING LIKE THAT BUT ...YOU COULD BE EVALUATED. SO I WAS EVALU-ATED IN DECEMBER... AND, UM, THERE WAS MILD COGNITIVE IMPAIRMENT... BUT, YOU KNOW, I DON'T KNOW WHAT THAT MEANS... I WOULD LIKE TO KNOW, I SORT OF NEED TO KNOW."

Biomedicine and ageing

In this chapter, I draw inspiration from Foucault's concept of genealogy (1977) to begin to trace the historical development of MCI and to reflect on the knowledge practices and events that contributed to its recent emergence as a clinical entity. A historical genealogy is an examination of the "forces operating in history" (Foucault, 1977, p. 154) to discover how particular ideas, concepts, values, and knowledge are formed. The purpose of a genealogical examination, Foucault (1977) writes, is to "discover that truth or being do not lie at the root of what we know and what we are, but the exteriority of accidents" (p. 146). These accidents can be culturally specific, in the sense that certain ideas about human beings may arise only at particular times and places, and under particular social and historical circumstances. Within the context of this research, the aim of this genealogy of MCI is to point to the ways in which ageing, and the contemporary Western scientific understanding of it, are "totally imprinted by history" (Foucault, 1977, p. 148).

Modern biomedicine emerged as a branch of the biological sciences in Europe and America during the nineteenth century (Baronov, 2008). Rooted in a Western empirical scientific worldview, biomedicine shares with natural science the belief that reality consists of only that which can be observed and measured (Wilber, 1999). As such, illness is conceptualised in material terms, often as an entity that resides in the physical body, producing a discernible pattern of 'signs' and 'symptoms' in the patient. As medical anthropologist Byron Good (1993) has written,

> [The] "medical model" typically employed in clinical practice and research assumes that diseases are universal biological or psychophysiological entities, resulting from somatic lesions or dysfunctions. These produce "signs" or physiological abnormalities that can be measured by clinical and laboratory procedures, as well as "symptoms" or expressions of the experience of distress, communicated as an ordered set of complaints. The primary tasks of clinical medicine are thus diagnosis—that is, the interpretation of the patient's symptoms by relating them to their functional and structural sources in the body and to underlying disease entities—and rational treatment aimed at intervention in the disease mechanisms. (p. 8)

Anthropologist Margaret Lock (2013) notes that this biomedical conception of disease, stemming from a philosophy of scientific materialism, has given rise to definitions of biological and physiological 'normality'. Until the nineteenth century, she writes, "[using] the term 'normal' was virtually limited to the fields of mathematics and physics. It was not until an internalizing approach to the body based on anatomy took hold that arguments about the relationship between normal and abnormal biological states were seriously debated for the first time" (Lock, 2013, p. 42).

What Lock calls an 'internalising approach' is perhaps one of the defining characteristics of modern biomedicine. Separating the objective 'body' from the subjective 'person' (a process Foucault in his book *The Birth of the Clinic* [1973] called the 'medical gaze'), biomedicine is primarily concerned with categorising, detecting, and ultimately removing discrete pathological entities from the physical body.

This approach differs from 'traditional' non-Western medical systems, such as Ayurvedic medicine, in which illness is viewed as an imbalance of vital energies (or *doshas*) within the person, while health is understood to be a state of complete equilibrium between mind, body, spirit, and nature (Collier, 2013). Thus, in contrast to biomedicine, Ayurvedic interventions are not necessarily concerned with addressing specific entities in the body, but with restoring the body's subtle

energies to a state of harmonious balance (Leguizamon, 2005).

As new knowledge about the physical and material body was produced during the nineteenth century, scientists began to focus on the processes that underpinned bodily deterioration and death (Berrios, 1994). One consequence of their efforts was that the natural ageing process itself became conceptually linked with the progression of disease (Lock, 2013). In their descriptions of cellular and tissue degeneration in old age, for example, key figures in early geriatric medicine often suggested that ageing was itself a pathological process (Lock, 2013, p. 37). By the early twentieth century, the common signs and symptoms of 'senility', which the medical profession had previously regarded as natural age-related processes, were reframed as medical problems in need of a cure, and were thought about in terms of underlying causes and mechanisms.

As modern psychiatry was taking shape in Europe and America in the nineteenth century, many psychiatrists sought to show how the cognitive and behavioural peculiarities of so-called senile patients correlated to the presence of pathology in the brain (Davis, 2004). The hypothesis that these 'symptoms' had a material basis was often tested at autopsy when an analysis of a patient's brain tissue could be compared with clinical descriptions of the their behaviour.

German psychiatrist Alois Alzheimer was among the first to take advantage of an emerging staining technique to explore microscopic lesions in the brain, post-mortem. His explicit goal, as Lock argues, was to establish the notion that mental deterioration was not normal but pathological, and that it had an irrefutably material basis in the body (Lock, 2013, p. 29). Alzheimer's most famous case study, which has been recognised as the index case for Alzheimer's Disease since 1907, is that of a 51-year-old woman, known in the medical literature as Auguste D (see Figure 15).

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Figure 15: Auguste D. was Alois Alzheimer's first case study for the disease that was to bear his name. Source: https://www.mamamia.com.au/history-of-alzheimers-disease/

Alzheimer's fascination with Auguste D's condition began in 1901 at a psychiatric clinic in Frankfurt where he worked as a senior physician. Renowned for his scrupulous observations in the clinic, Alzheimer wrote extensively about the woman's declining condition, detailing her profound forgetfulness, paranoia, hallucinations, and unusual behaviour until she died in 1906, after which he requested her brain be sent to him for autopsy. In his public presentation of this case the following year, Alzheimer described how Auguste D's cerebral cortex was found to contain sticky amyloid plaques and neurofibrillary tangles, which were thereafter recognised as the pathological signatures of the disease that was to bear his name (see Figure 16). A few years later, in 1910, Alzheimer's Disease entered the pages of Emil Kraeplin's celebrated textbook *Psychiatrie*.

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Figure 16: Alzheimer's drawings of neurofibrillary tangles, based on Auguste D's material, are an early depiction of the progressive 'stages' of Alzheimer's Disease. Source: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0004-282X2015000200159

While this episode in some historical studies marks a medical triumph within a longer narrative of scientific progress, Jesse Ballenger (2006) points out that the remarkable thing from today's perspective was how insignificant it had all seemed at the time. Alzheimer's presentation hardly drew a reaction from the scientific community, and Kraeplin's description of the disease in his textbook was surprisingly casual, cautioning that "the clinical interpretation of this Alzheimer's disease is still confused" (Ballenger, 2006, p. 6). Much of this confusion stemmed from the fact that age-of-onset seemed to be a sufficient criterion to distinguish Alzheimer's Disease from ordinary 'senile dementia', which was already well documented as a degenerative (but 'normal') process that affected the elderly, but which shared the same clinical symptoms and pathological structure as this new disease (Ballenger, 2006, p. 7).

Alzheimer himself became involved in a number of debates about the aetiological significance of the plaques, which were relabelled 'senile plaques' in 1911—a situation that further confounded the issue of whether or not Alzheimer's Disease was a condition that exclusively affected the elderly (Lock, 2013). As debates advanced between those who saw similarities between senile dementia and Alzheimer's Disease, and those who saw them as categorically distinct (Lishman, 1994), Alzheimer's Disease eventually came to be seen as a kind of 'presenile dementia', a pathological condition whose material reality could be located in the brains of individuals as young as 40, and thus "suggested some process distinct from the mere passing of the years—something that could be viewed in terms of a disease" (Lishman, 1994, p. 46).

Debates about the relationship between ageing and dementia intensified following a landmark study carried out by a Swedish pathologist named Nils Gellerstedt in 1933. To test Alzheimer's hypothesis, Gellerstedt conducted a post-mortem analysis on the brains of 50 individuals who had not shown any symptoms of dementia while alive. Upon inspection, it turned out that Alzheimer's neurofibrillary plaques and tangles were present in a very large proportion (84%) of the brains of perfectly healthy (that is, non-demented) individuals over the age of 65 (Lishman, 1994). Gellerstedt also noted that the density and abundance of the neurofibrillary tangles did not closely correspond to their reported mental condition, and concluded that the correlation between clinical and pathological data was not as straightforward as earlier studies had suggested. Meanwhile, a number of other researchers in the 1930s showed that the brains of some individuals who appeared

to be severely demented at the time death were found to be relatively intact (Ballenger, 2006, p. 8).

This tenuous link between the clinical symptoms of dementia and its material presence in the brain was reconfirmed in David Snowden's famous "Nun Study", a longitudinal investigation that began in 1986 (Snowden, 1997). Snowden's team annually assessed the cognitive function of 678 Catholic nuns who agreed to donate their brains for post-mortem examination. The tests, evaluating cognitive skills such as language, concentration, memory and visuospatial ability, would later be compared with a post-mortem analysis of each participant's brain tissue.

By 1995, 161 nuns had died. A neuropathologist, blinded to the cognitive test scores, examined a sample of 102 brains. They reported that a number of nuns who had scored highly in the cognitive tests and had shown no signs of dementia were found at autopsy to have extensive neuropathologic damage in the neocortex—a finding that reflected Gellerstedt's study several decades earlier. Conversely, the autopsied brains of two nuns, who had shown all the symptoms of dementia in their final years of life, turned out to have "no significant neuropathologic findings" upon post-mortem examination (Snowden, 1997, p. 816).

What this brief history shows is that research on dementia has been driven in large part by an assumption that the symptoms associated with the condition (and indeed almost *any* behaviour that modern society deems either 'abnormal' or 'undesirable') must be correlated with material pathology in the brain. As the above studies show, however, establishing the relationship between cognitive impairment and the internal presence of brain-based pathology has proven to be very difficult.

Despite decades of research, the underlying neuropathogenic mechanisms of Alzheimer's Disease remain unclear (Mecocci et al., 2018a). The amyloid cascade hypothesis, which has been the predominant hypothesis of Alzheimer's pathology for the last twenty years, was recently challenged by a number of clinical studies (Herrup, 2015), once again raising questions about whether Alzheimer's Disease can and should be viewed as a distinct disease entity, separate from normal ageing (Mecocci et al., 2018b). As a result, some researchers are now moving away from the assumption that Alzheimer's Disease progresses according to the principle of linear causality (i.e., the idea that it progresses through a series of well-defined 'stages') (Xia et al., 2018)—a shift that has implications for the clinical use and value of MCI as a so-called transitional phase (Peterson et al., 2001).

The 'discovery' of MCI

In the absence of a definitive link between cognitive impairment and the plaques and tangles that Alzheimer had described, research on dementia entered a sort of Dark Age for nearly fifty years (Katzman & Bick, 2006). However, interest in Alzheimer's Disease was reignited in the 1970s following a series of technological developments and conceptual advances in a number of different fields (Ballenger, 2006; Katzman & Bick, 2006). The 'rediscovery' of Alzheimer's Disease during the 1970s led to increased public awareness and concern (Ballenger, 2006), and researchers began turning their attention to its earliest 'pre-clinical' phases.

Perhaps the earliest attempt to classify pre-clinical cognitive impairment was Kral's (1962) concept of 'benign senescent forgetfulness' (BSF), referring to subjective memory complaints associated with depression rather than dementia (or 'depressive pseudodementia', as Kral termed it). Such individuals were believed to be otherwise cognitively 'normal' and tended not to progress to dementia.

The idea of a pre-clinical stage *in between* 'normal' age-related cognitive impairment and dementia was not advanced until 1982, when two independent efforts were made to develop measures to identify what were believed to be the precise developmental phases (or 'precursors') of Alzheimer's Disease. One was a measurement known as the Clinical Dementia Rating (CDR) (Hughes et al.,

1982), and the other was called the Global Deterioration Scale (GDS) (Reisberg et al., 1982). Both scales attempted to define various stages along a scale of decline between healthy cognitive function and severe cognitive impairment (e.g., Alzheimer's Disease).

Furthermore, both scales attempted to isolate and name the deeply ambiguous intermediate stage in which the person was, categorically speaking, neither normal nor demented—a phase that, if it could be reliably identified in clinical contexts, would have enormous implications for early intervention and treatment. The 0.5 stage on the CDR scale was called "questionable dementia", while Stage 3 of the GDS was known as "mild cognitive decline".

In 1988, Reisberg and colleagues published a cross-sectional study that honed in on the psychometric characteristics of GDS Stage 3 (Reisberg, et al. 1988). In this paper they introduced the term "mild cognitive impairment" as a replacement for the previous terminology. The following decade saw numerous attempts from researchers and clinicians to refine the criteria for MCI in order to make it a clinically viable diagnosis for the early identification and treatment of Alzheimer's Disease.

In 1999, Ron Peterson and his colleagues at the Mayo Clinic in Rochester, Minnesota, succeeded in popularising MCI with a now-famous paper in *Neurology* in which they proposed formal diagnostic criteria. The authors defined MCI as simply: "(1) memory complaint, (2) normal activities of daily living, (3) normal general cognitive function, (4) abnormal memory for age, and (5) not demented" (Peterson et al., 1999).

In 2001, Peterson et al. published a seminal paper further promoting the "transitional" MCI category as "suitable for therapeutic intervention" (Peterson et al., 2001). Then, in 2004, Peterson wrote a solo-authored paper proposing guidelines to distinguish between *amnestic* MCI (which is primarily a memory impairment) and *non-amnestic* MCI (which includes 'deficits' in other cognitive domains: e.g., language, executive function, and visuospatial function) (Peterson, 2004). In this paper, Peterson proceeds to divide these subtypes into single-domain MCI (sd-MCI) and multi-domain MCI (md-MCI), which, as the names suggest, depend on the number of cognitive domains affected.

Figure 17: After exploring how the conceptual boundaries of dementia have expanded historically, I asked Nathan how we might 'visualise' this process. We worked together to produce this diagram, which shows the emergence of increasingly mild categories of impairment over time. This helped Nathan and I situate Living Well with MCI within the context of broader historical contingencies and processes, while reflecting on where this process of medicalisation might be going in the future (as indicated by the outer 'pre-MCI' and '?' layers).

KATE, A NEUROPSYCHOLOGY PHD STUDENT WHO WORKS AT A
DEMENTIA PREVENTION RESEARCH CENTRE IN THE SOUTH ISLAND,
WAS TAKING ME TO SEE THE ROOM WHERE SHE PERFORMS
"NEUROPSYCH" ASSESSMENTS. HER PHD WAS LOOKING AT HOW
THE ASSESSMENT PROCESS COULD BE REFINED IN WAYS THAT
BETTER PREDICT THE CONVERSION RATE FROM MCI TO DEMENTIA,
SPECIFICALLY AMONG PEOPLE WITH PARKINSON'S DISEASE. SHE LED
ME DOWN A ~~CORR~~ CORRIDOR AND THROUGH AN OFFICE
AREA WHERE HER COLLEAGUES WERE WORKING IN ROWS OF
NEATLY PARTITIONED CUBICLES, THEN INTO ~~AN~~ A PRIVATE
MEETING ROOM THAT OVERLOOKED A QUIET DOWNTOWN STREET.
SHE WENT IN AND SAT BEHIND THE DESK AND I SAT
OPPOSITE HER, IN THE SAME CHAIR THAT SUPPORTS HER
PARTICIPANTS WHILE THEY ARE BEING ASSESSED FOR MCI.
IT FELT LIKE I WAS SEEING A DOCTOR, OR A THERAPIST.
SHE REACHED INTO A DRAWER, PULLED OUT A HEAVY-
LOOKING FOLDER AND PLONKED IT ON THE DESK WITH A
THUD. IT WAS FULL OF INDIVIDUAL SHEETS OF PAPER
WITH PUZZLES AND BRAINTEASER-TYPE ACTIVITIES, OF
~~TH~~ THE KIND I IMAGINE ~~A~~ YOU'D HAVE TO DO DURING
AN IQ TEST. SHE SPLAYED A FEW OUT IN FRONT
~~OF~~ OF ME. THEY LOOKED A LITTLE ~~INTER~~ INTIMIDATING,
I HAD TO ADMIT. WERE THESE TESTS GOING TO REVEAL
HOW SMART, OR NOT, I WAS? I WASN'T ALLOWED TO
TAKE ANY PHOTOS — SOMETHING ABOUT COPYRIGHT,
INTELLECTUAL PROPERTY ETC. INSTEAD, SHE SAID, WE COULD
DO A FEW MOCK TESTS SO I COULD EXPERIENCE FIRST-
HAND WHAT IT FEELS LIKE TO BE ASSESSED — IN THE
HOT SEAT. SHE TOLD ME THEY HAD BEEN DESIGNED TO
EVALUATE A RANGE OF COGNITIVE DOMAINS. THE FIRST
ONE SHE SHOWED ME WAS A COMMON ONE FOR
ASSESSING AN INDIVIDUAL'S VISUO-SPATIAL PERCEPTION. IT
INVOLVED ASKING ME, THE "SUBJECT", TO IDENTIFY
PARTICULAR ICONS WITHIN A MAP OF ~~THE~~ PHILADELPHIA.
THE MAP WAS A4 IN SIZE AND FULL-COLOUR. IT WAS, TO
MY EYES, A PROFOUNDLY DISORIENTING BIRD'S NEST OF
LINES, LETTERS, NUMBERS, AND AMENITY SYMBOLS. KATE

THEN REVEALED A ~~second~~ SECOND PIECE OF A4
PAPER ~~which~~ WHICH HAD ON IT A LARGE KNIFE-AND-FORK
ICON. SHE ASKED ME TO POINT TO AS MANY CORRESP-
ONDING KNIFE-AND-FORK ICONS WITHIN THE PHILADELPHIA
MAP AS POSSIBLE — IN OTHER WORDS, TO FIND AS MANY
RESTAURANTS AS I COULD. I FELT A NERVOUS AND MY
PALMS ~~~~ BEGAN TO SWEAT. TO MY GREAT RELIEF, I
FOUND ONE AFTER A ~~few~~ FEW SECONDS. AND SOON I
FOUND ANOTHER, AND THEN ANOTHER.. ~~~~ CONFIDENCE
IN MY VISUO-SPATIAL PERCEPTION WAS RESTORED. BUT AT
THIS POINT IN THE TEST I NOTICED A POSSIBLE DESIGN
FLAW. THE PRINTOUT OF THE MAP WAS SO SMALL AND
SHRUNKEN ~~~~ DOWN THAT THE ICONS I HAD BEEN ASKED
TO LOOK FOR HAD ALMOST COMPLETELY LOST THEIR
RESEMBLANCE TO THE ORIGINAL KNIFE-AND-FORK ICON ON
THE ~~the~~ OTHER SHEET OF PAPER. THE SPACES BETWEEN
THE TINES OF THE FORK HAD ALL BUT DISAPPEARED,
~~~~ MAKING THE ~~~~ ICONS IN THE MAP LOOK
MORE LIKE A SHOVEL OR A PAINTBRUSH. EVEN THE
KNIFE HAD LOST ITS SHAPE ~~~~ SO THAT IT LOOKED
MORE LIKE A STRAIGHT ~~vertical~~ VERTICAL LINE.
~~~~ ~~~~ ~~~~ THIS WAS A MAJOR
OVERSIGHT, I THOUGHT, GIVEN THAT THE DIFFERENCE
BETWEEN "NORMAL" AND "ABNORMAL" COGNITIVE
FUNCTION WAS ON THE LINE HERE.

Some debates and controversies

As Stephen Katz (2012) points out, before MCI became an official diagnosis in 2004, cognitive impairment was defined by two standard deviations (SDs) below 'normal' on cognitive tests. Now, due in large part to an emphasis on identifying the earliest pre-clinical stages of dementia, that threshold has shifted to 1.5 SDs, meaning that "the definition of pathological memory has moved one step closer to normalcy" (Katz, 2012, p. 9). One consequence of these developments is that the conceptual boundaries of dementia have now expanded to the point where the subtle cognitive changes that were considered 'normal' and 'age-related' just thirty years ago are now considered to be pathological symptoms.

It would appear that this conceptual expansion is continuing (see Figure 17), with at least one paper proposing a model for *pre-symptomatic* MCI (Smith et al., 2008)[5]—a category that, if it ever became an official diagnosis, would lower the minimum threshold for potential medical intervention. Some researchers have argued that these new revisions to diagnostic criteria have expanded the market for pharmaceutical drugs that are currently being developed and sold to treat Alzheimer's Disease (Whitehouse & Moody, 2006). Similarly, the development of novel design interventions for MCI has been linked to the idea that there is growing market for them, which in turn is connected to the capitalisation of knowledge and the pursuit of intellectual property (Rose & Abi-Rached, 2013) (see Figure 18).

Figure 18: A brief Google search shows that there is ample evidence for the claim that there is an economic incentive behind the production of MCI. Unforgettable.org is a website that sells a wide range of consumer products for older people experiencing changes to their memory and thinking. The website has a whole product section devoted to MCI. Source: https://dementia.livebetterwith.com/collections/forgetfulness-mild-cognitive-impairment?rdrt=uf

[5] Aren't we *all,* in a sense, 'pre-symptomatically' impaired (Rose, 2009)?

Interview excerpt with Jill, 77, formal MCI diagnosis

Jill: When they first told me, <u>I hadn't a clue what [MCI] meant.</u> I was quite (upset) when they told me that one in so many would have dementia in <u>five years</u> or something [...]. They never told me that you could return to "normal" eventually. That never happened.

[handwritten: COMMUNICATION ISSUE ?]

[handwritten: BASELINE vs "NORMAL"]

Guy: That was never mentioned?

J: No.

G: Interesting.

J: It was just that there was a <u>fifty-fifty chance that you'll get dementia</u> and that was it [...]. The fact that I've been diagnosed with mild cognitive impairment, it's sort of like a brick wall. It seems to be a <u>very grey area</u> anyway, whether I am or I am not, because now they've <u>withdrawn the diagnosis.</u> So whether I ever had "it", who knows? Far better to just present what you can do about improving the situation rather than <u>putting a shutter down</u>, saying, 'You've got this, (tough,) you know? [...]

[handwritten: 50-50 ?]

[handwritten: SENSE OF UNCERTAINTY]

[handwritten: NO LONGER HAS MCI DIAGNOSIS]

[handwritten: MCI AS DISEASE ?]

[handwritten: METAPHOR - SHUTTING/CLOSING OFF]

[handwritten: NO SENSE OF HOPE ?]

G: When you said before that the MCI label to you was like a brick wall, can you elaborate on what you meant by that?

J: They've almost <u>written you off.</u>

[handwritten: LIKE A CAR ?]

G: Written you off?

[handwritten: MCI AS DISEASE]

J: 'Tough, you've (got) this'. Nobody came back with any suggestions for what you could do <u>to improve the situation.</u>

[handwritten: WANTS ADVICE/INFO FOR IMPROVING SITUATION]

G: Right. You just have a label and off you go.

J: That's it. 'Forget it. <u>You're just going to get worse.</u> You're just going to <u>get worse and worse</u>, you know, you might as well just.' you know.

[handwritten: ASSUMPTION OF LINEAR PROGRESSION/ DECLINE]

[handwritten: GIVE UP ?]

The relationship between MCI and dementia

While strong associative links have been made between MCI and Alzheimer's Disease, with some prominent researchers in the field defining MCI as a "symptomatic predementia phase of Alzheimer's Disease" (e.g., Albert et al., 2011), or a "transitional state" between normal ageing and dementia (Peterson et al., 2001), research has shown that the majority of people diagnosed with MCI do not progress to anything more serious. For example, in a longitudinal study of 263 older adults (aged 80 years and over) who were determined to have MCI at baseline, only 5% of the participants progressed to dementia two years after their assessment, while 2% progressed after four years, 3% after six years, and 4% after eight years (Hong et al., 2011).

On the other hand, many people diagnosed with MCI seem to improve over time. In one study, 130 older adults performed a battery of cognitive tests at baseline, and then again at 6 and 12 months. Of the participants whose scores indicated they had a cognitive impairment on one or more tests at baseline, as many as 48% 'normalised' after one year without any intervention (de Rotrou et al., 2005). The authors of this study point out that MCI can be 'accidentally' diagnosed, warning that "normal people can fail [standard cognitive assessments] just by chance or lack of motivation, be absentminded, be disturbed by external or internal stimuli – all of these things can lead to failure of concentration for a moment or two and thus, you fail the test" (de Rotrou et al., 2005, p. 879).

MCI lacks corresponding biomarkers in the brain because the difference between 'normal' ageing and MCI (and between MCI and other categories of impairment) cannot be determined at the level of individual biology (Lock, 2013). As a result, there are no objective biological tests to determine whether or not someone 'has' MCI. Instead, diagnosis relies on neuropsychological testing, which, as de Rotrou and colleagues (2014) point out, does not eliminate other possible reasons for poor performance and low test scores. As the authors suggest, cognitively healthy people can fail neuropsychological tests (and receive an MCI diagnosis) simply as a result of the stress and anxiety produced by test environments—an observation that challenges the notion that MCI can be identified as a discrete clinical entity independent of these other psychological states. This also raises ethical questions about diagnosing cognitively healthy individuals, particularly in light of the claim that MCI, even when identified 'properly', in the vast majority of cases does not progress to dementia (Hong et al., 2011). Despite this, many online resources suggest that MCI is a "transitional disease". (see Figure 19).

Figure 19: This online resource is one of many that seem to take MCI as a given. It describes MCI as a "transitional disease". Source: https://www.ucsfhealth.org/conditions/mild_cognitive_impairment/ .

A NEUROPSYCHOLOGIST AND A RESEARCH NURSE, WHO ARE INVOLVED IN LONGITUDINAL RESEARCH ON THE RELATION~ SHIP BETWEEN MCI AND DEMENTIA, ARE SHOWING ME THROUGH THEIR WORKPLACE: A NEW DEMENTIA RESEARCH CENTRE WITHIN A UNIVERSITY. "WE DON'T KNOW, WHEN PEOPLE HAVE MCI, IF THEY WILL GO ON TO DEVELOP DEMENTIA," SAYS THE NEUROPSYCHOLOGIST, A WOMAN IN HER ~~~~~ FORTIES. "SO IT'S (ABOUT) IDENTIFYING PEOPLE WHO COME TO THE CLINIC EXPRESSING CONCERNS ABOUT THEIR THINKING ABILITIES, BUT WE DON'T KNOW AT THAT POINT WHETHER THEY HAVE SUBJECTIVE COMPLAINTS, MCI, EARLY AD (ALZHEIMER'S DISEASE), OR SOMETHING ELSE." THE THREE OF US ARE STANDING IN A ~~~~~~ SMALL WINDOWLESS EXAMINATION ROOM. THERE ARE SEVERAL SUCH ROOMS AT THE CENTRE, OR "CLINIC", SOME OF WHICH ARE USED FOR COLLECTING ~~~~~ BLOOD SAMPLES. THE SAMPLES ARE TAKEN FROM PEOPLE WHO HAVE BEEN THROUGH A BATTERY OF NEUROPSYCHOLOGICAL TESTS AND ARE DETERMINED TO 'FIT' THE MCI DESCRIPTION. ~~~~~ THE NEUROPSYCHOLOGIST EXPLAINS THAT THEIR BLOOD SAMPLES ARE SENT TO AN ADJACENT BUILDING FOR ANALYSIS, PARTLY TO RULE OUT OTHER POSSIBLE SOURCES OF COGNITIVE IMPAIRMENT, BUT ALSO TO TRY AND IDENTIFY BIOMARKERS, OR, MORE ACCURATELY, "PATTERNS" OF BIOMARKERS, FOR MCI. THE ULTIMATE GOAL HERE, THEY SAY, IS TO FIND INDICATORS OR SIGNATURES THAT MIGHT PREDICT WHICH MCI PARTICIPANTS WILL GO ON TO DEVELOP DEMENTIA — THE 'HOLY GRAIL' OF DEMENTIA RESEARCH.

DETERMINING WHETHER OR NOT SOMEONE HAS MCI IN THE FIRST PLACE, HOWEVER, IS A MATTER OF SOME DEBATE WITHIN THE RESEARCH TEAM. THEY SHOW ME TO A MEETING ROOM WITH A LONG TABLE THAT LOOKS ABLE TO ACCOMMODATE MAYBE FIFTEEN PEOPLE. THEY TELL ME THAT THE CENTRE HOLDS WEEKLY MULTI- DISCIPLINARY MEETINGS HERE TO LOOK OVER THE PREVIOUS WEEK'S ASSESSMENTS, AND TO TRY AND REACH A ~~~ CONSENSUS ON WHICH POTENTIAL RESEARCH PARTICIPANTS 'HAVE' MCI.

"THERE'S A WHOLE GROUP THERE," SAYS THE NURSE. "HUGE AREAS OF EXPERTISE, A VAST NUMBER OF YEARS' EXPERIENCE IN THE ROOM."

REACHING A CONSENSUS ON WHO HAS MCI AND ~~WHO~~ WHO DOESN'T, HOWEVER, IS NOT EASY. SOMETIMES THERE ARE ~~~~ DISAGREEMENTS. THE NEUROPSYCHOLOGIST ~~~~ EXPLAINS: "SOMETIMES (A COLLEAGUE) WILL SAY 'I THINK IT'S MCI,' AND I'LL SAY 'NO, IT'S NOT!'" SHE LAUGHS. THIS MAKES ME WONDER ABOUT THE POWER DYNAMICS OPERATING BETWEEN DIFFERENT KINDS OF EXPERT KNOW- LEDGE WITHIN THE CLINIC, ABOUT WHOSE VOICE COUNTS ~~~~ THE MOST WHEN IT COMES TO MAKING A FINAL DECISION IN THIS CONTEXT, AND WHETHER THERE ARE SIMILAR CONTENTIONS IN OTHER MEMORY CLINICS. SHE TELLS ME, FOR INSTANCE, THAT HER FIELD, NEUROPSYCHOLOGY, IS THE "MOST RIGOROUS INVESTIGATION" OF MCI. THIS TABLE, IT SEEMS, IS A POLITICAL ARENA.

WHEN I ASK THEM WHETHER THEY HAVE ANY MĀORI PARTICIPANTS AT THE CENTRE, I GET THE DISTINCT FEELING THAT I'VE STUMBLED ~~~~ UPON A DELICATE ISSUE. THE NURSE TELLS ME THAT MĀORI ADULTS WITH MCI ARE A DIFFICULT GROUP TO "FIND." I PROBE A BIT FURTHER. THEY TELL ME MĀORI HAVE LOWER LEVELS OF EDUCATION ON AVERAGE, AND HIGHER RATES OF ADDICTION TO DRUGS AND ~~~~ ALCOHOL, MAKING OTHER POSSIBLE SOURCES OF COGNITIVE IMPAIRMENT MORE DIFFICULT TO ELIMINATE. I FIND MYSELF WONDERING WHETHER THIS PRESENTS A UNIQUE CHALLENGE TO THE WHOLE BUSINESS OF IDENTIFYING MCI AS IF IT WERE A DISTINCT BRAIN-BASED CONDITION; AFTER ALL, WHAT THIS CENTRE SEEMS TO BE LOOKING FOR IS A KIND OF 'PURE' MCI — A CLINICAL ENTITY THAT IS BIO- LOGICAL IN NATURE, UNIVERSALLY VALID, OBJECTIVE, MEASURE- ABLE, COMPLETELY INDEPENDENT OF MESSY SOCIO-ECONOMIC AND CULTURAL CONTEXTS. I ~~~~ INTERPRET THE SLIGHT AWKWARDNESS IN THE ROOM AT THIS POINT AS A QUIET ACKNOWLEDGEMENT THAT THIS MAY NOT, IN FACT, BE POSSIBLE.

Looking for MCI in the brain

In a Christchurch research centre I met Luke, a brain imaging researcher with a particular interest in the relationship between MCI and Parkinson's Disease. I brought my pile of assorted images and asked him to choose five to talk about in relation to his work. The first image he chose was the one with brain scans, and he explained that he had "a particular interest in cognitive impairments and mild cognitive impairment, so it seems quite straightforward that […] one would be interested in looking at brain images to see if they can tell you anything about the process of mild cognitive impairment." I was interested to hear him describe MCI as a process, which seemed to imply a kind of progressiveness or linearity, similar to the way dementia is often talked about. I wanted to probe deeper into his particular conceptualisation of MCI. However, being interested in his research practices, I stayed on the imaging theme:

Guy: Are there identifiable differences between a healthy brain and an MCI brain, if you like?

Luke: On average, at the group level, on average we can see an average difference between patients with mild cognitive impairment and, let's say, healthy individuals […] On the individual level, we're not there yet. Which means, so if you show me one individual with mild cognitive impairment and I looked at their brain, I'm probably not going to be able to tell you that person's mild cognitive impairment or that person has normal cognition. So at the group level definitely, at the individual level not quite there yet.

G: So that means that you can't do imaging to diagnose someone with MCI yet.

L: Not yet.

G: Can you use it to support a diagnosis?

L: Well you can absolutely use it to support a diagnosis of dementia, especially because if we think of dementia as being more end-stage, or more farther along in the process of the disease, larger changes have happened in the brain and a lot of them show up as being much more identifiable visually, as well as statistically. So what we do not use is imaging as a support for diagnosis of mild cognitive impairment. It's currently all—

G: —neuropsych.

L: Clinical neuropsych definition […] I mean we'd love to be able to, to take an image of an individual and have enough information from that image to tell us about the state of that person or the risk of that person for future decline. That's what we're working at, working towards, but we're not there yet.

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Figure 20: An example of a brain scan that shows apparent anatomical differences between a 'normal' brain and an 'MCI' brain. Source: https://www.stress.org/stress-alzheimers-and-memory-loss

While doing some preliminary research on MCI at the start of this project, I remember seeing an image of two brains, side-by-side. On the left was an 'MCI' brain; on the right, a 'normal' brain. There were clear, compelling differences between the them (see Figure 20). What I didn't understand at the time, but which my conversation with Luke helped me realise, was that the differences between the 'MCI' brain and the 'normal' brain were 'constructed' in a very literal, demonstrable sense. Both were composite images of dozens, perhaps hundreds of brains—they represented the "group level", as Luke put it.

Luke explained that there are no visible differences between 'MCI' and 'normal' at the individual level. Hence MCI could not be 'discovered' by looking at a single scan. But its anatomical characteristics, I learned, could be generated through a composite image that enhances similarities across multiple 'MCI' brains, and maximises apparent differences compared to a composite image of so-called normal brains—itself constructed at the group level. The more images, the more compelling the differences.[6] Another picture Luke selected from my pile of images was of a brain:

> **Luke:** And the brain I think probably speaks for itself because I obviously think that this is a brain disorder, something happening in the brain.
>
> **Guy:** Is MCI a brain disorder?
>
> **L:** That's a good question. I don't want to get into the semantics of what disorder means, but what I wanted to say with that is that I think MCI resides in the brain as opposed to… I don't know where else it would reside. I think it's a process of, I think it's a brain process, the function and structure of the brain.
>
> **G:** Different from normal ageing?
>
> **L:** Um, different from normal ageing. Yes, I think it—whether it's accelerated ageing or different entirely to ageing, I don't really know.

Clearly, Luke and I were speaking from very different ontological frames of reference. Luke saw MCI as a pathological process, distinct from 'normal' ageing; I saw MCI as historically contingent, inseparable from the social and cultural contexts in which 'normal' ageing is defined. He described MCI as "[residing] in the brain"; I, by contrast, believed that the distinction between 'normal' and 'pathological' memory was socially constituted and assembled, at least in part, through the imaging practices in which he was engaged.

[6] This made me wonder: couldn't you use this same composite imaging process to produce apparent anatomical differences between the brains of rich people and the brains of poor people?

Interview excerpt with Kate, neuropsychology PhD student

Guy: Do you think the Western emphasis on things like independence in old age and that kind of thing are playing into [MCI research]? I mean, in other cultural models of ageing, like in India, where you've got three generations under one roof, they're supporting the older person to live well. What are your comments on that?

Kate: I suppose it's not something I have any expertise on at all. But I mean that definitely seems plausible. I suppose the New Zealand culture is, you also have a lot of people living and working overseas and their parents are still back in New Zealand, and maybe they aren't as supported. Because New Zealand is so small as well but also really big when you've got memory issues, if you've say got your parents living in the South Island and you're living in the North Island, can't be there all the time to support them. That sort of thing.

[margin handwriting: SUPPORT.]

G: Whereas, when would it become a problem if you're living with your children and your grandchildren and they're helping you to live?

K: Exactly. Yes.

G: At what point does it become an issue?

[handwriting above: SCIENTISTS/ RESEARCHERS?]

K: Yeah. I mean, certainly for us the tipping point between MCI and dementia is when you're unable to perform your everyday activities.

[margin handwriting: THRESHOLD FOR DEMENTIA]

[handwriting: THIS DEPENDS ON THINGS 'OUTSIDE' OF THE BRAIN E.G. FAMILY SUPPORT.]

G: Right.

[margin handwriting: 'INDEPENDENCE' AS COMPONENT OF COGNITIVE HEALTH]

K: So I mean, you can have people who have really, really bad neuropsych scores but are still able to function in their everyday life. So we wouldn't call those people demented.

[margin handwriting: 'FUNCTIONALITY' AS INDICATOR OF COGNITIVE HEALTH]

G: Really? So they compensate, would you say?

K: Yeah, so they're still able to perform what they would always do, whether that's because they're well supported by a spouse or by children or by friends, but they definitely don't have dementia if they're able to live independently and are able to perform things and go on walks and do their shopping and all of that sort of thing.

[handwriting below: INDEPENDENCE]

[margin handwriting: DEMENTIA DIAGNOSIS DOES NOT DEPEND ON NEUROPSYCH SCORES NECESSARILY...]

G: Irrespective of the neuropsych scores.

K: Yeah.

G: That's really interesting.

K: Yeah, so in our area that's really well recognised as the distinction between dementia and those without. It's just trying to define this MCI which is the—

FUNCTIONALITY/ INDEPENDENCE

G: Because they're fine day to day, generally.

K: Yes, but they have a slowness in their thinking, they have issues with their memory and thinking, they're unable to do what they used to do, but they're still able to function. There's a difference between having issues and being able to function [...]. I mean, we have this one patient who, if you looked at his neuropsychological scores, he was, he just looked like he was completely demented, but yet he was running a Nordic walking group for the whole of [the city], and going out every week, picking new locations, gets dropped off by his wife.

SOUNDS LIKE AGEING.

DIFFERENCE BETWEEN ASSESSMENT SCORES AND REALITY.

G: How can you explain that?

NEUROPSYCH TEST AS KNOWLEDGE

K: You can't. I mean, you've got evidence of them having severe memory and thinking problems and yet in the world they're able to do something they enjoy and facilitate it for others, so. I mean this is when you have issues of education and that sort of thing. This is where the MCI debate gets nice and muddy [...]

FACTORS / CONTEXT BEYOND THE BRAIN.

G: So in the case of MCI, are you—how do I put this?—are you sceptical that there is such a thing as "pure MCI", that it can be separated from a person's social context and all that other stuff?

MCI AS A "THING".

K: I don't know. I think I went into my PhD thinking, yep, there's this thing and we're going to find it, we're going to nail it down, we're going to be able to clearly classify people and be like, yep, we've got a good group here, we can start doing stuff with this group. But the more I got into it, the more muddy it has become.

POSITIVISM — MCI AS ROOTED IN THE BRAIN

METAPHOR — UNCLEAR, MURKEY, NOT EASILY SEPARATED FROM 'NORMAL' AGEING.

Is MCI a 'Thing'?

The muddiness of MCI is inherent in the category—it describes the ambiguous space between 'normal' ageing and dementia. But there is also an assumption evident in Kate and Luke's thinking that further complicates matters; namely that MCI "resides in the brain", as Luke put it. Kate's use of the word 'thing' towards the end of the excerpt above, for example, highlights this idea that MCI has some sort of internal, material presence in the body or brain. (In fact, it was not uncommon for others I interviewed, including Nathan, to refer to MCI as a 'thing', particularly when discussing its clinical status and validity.)

Indeed, the word 'thing', having similar associations to the word 'object', implies the kind of materiality and empirical *realness* of something (some *thing)* you can observe, point to, and describe. From this perspective the use of the word 'thing' signifies that a distinction is being made between MCI as an immaterial concept (i.e., an abstraction) and MCI as a valid pathology (i.e., a discoverable entity). As Kate said, "there's this thing and we're going to find it, we're going to nail it down."

For Kate the window onto this pathology, this 'thing', was through neuropsychological assessments, which she thought would precisely determine who did, and who did not, 'have' it. But what she started to realise through her research was that the assessment scores were not in themselves sufficient indicators of impairment in the 'real world'. In the example she gave about the man who looked "completely demented" on paper, there was a discrepancy between what the test scores revealed about the various cognitive domains apparently affected, and how well the man appeared to function in his day-to-day life.

However, this discrepancy is surprising only if it is assumed that the neuropathology (in this case dementia) can be measured as a discrete entity that exists independent of an individual's unique circumstances and context—their environment and level of support, their existing skills and capabilities, and so on. As Kate recognised, this is what makes it difficult to "clearly classify people" using the tools of neuropsychology.

From a new materialist perspective, MCI is not located in the brain. There is no 'thing' independent of the socio-material assemblage that produces it as a matter of concern. MCI is the product of many different disciplinary practices working in harmony to produce its parameters and characteristics—its reality as a 'fact' of biomedicine. The neuropsychological parameters that define MCI as a diagnosis were not discovered 'in nature'—they were constructed through certain kinds of research practices and sustained by peer-reviewed publication and disciplinary consensus. Its characteristics—the way it manifests and presents in clinical and research settings—are not naturally inherent in the category. Rather, they are constructed from the bottom-up by a range of processes and practices in research and clinical settings.

Thus an 'MCI brain' looks a certain way because of the composite imaging practices that constructed apparent differences, at group level, between this and a 'normal brain'. At the level of individual anatomy, there is no identifiable distinction. Indeed, the changes associated with MCI (i.e., its 'symptoms') are not linked in any clear way to neuroanatomical changes (Lock, 2013). Instead, it is an assemblage of practices—from neurobiology and brain imaging, to neuropsychology and epidemiology—that produces a high-resolution picture of the clinical reality called 'MCI'.

The importance of social and cultural context

The assumption that MCI "resides in the brain" has its roots in a biomedical paradigm. This paradigm posits that categories of illness and impairment are "biological, universal, and ultimately transcend social and cultural context" (Good, 1993: 8). However, the belief that MCI is a diagnosable impairment 'out there' in nature can obscure the complex social and cultural milieus in which people live. Indeed, as I discovered during my research, cultural norms can influence how much (and how little) support an older person receives from their family, further blurring the line between 'normal' and 'pathological' cognitive function for age. Perhaps the most striking example of this from the Living Well with MCI project was the case of Ana, a Samoan woman in her 30s, and her 82-year-old mother-in-law, Malae.

Ana had been living with her mother-in-law for the past ten years, along with her husband and four children. Ana responded to recruitment material for the Living Well with MCI study because, in her words, "[Malae] was all good before, but we [can] see some changes, you know, and it's getting really hard." It became apparent early on in the interview that these "changes" were more severe than those described by other participants in the study. "She's forgetting things and, not only that, with her memory, she forgets to go to the bathroom and all that, so sometimes she does it, you know, in her bed and so it's very stressful for us." She continued: "She doesn't know my name. She used to know my name [...]. She only knows her son's name." When I asked if Ana had received a formal dementia diagnosis, she replied:

> **Ana:** No, not that, no.
>
> **Guy:** Has she seen—
>
> **A:** It's only diabetes and high blood pressure, yeah.
>
> **G:** Okay, so she hasn't seen anyone about her memory and thinking?
>
> **A:** No, because we haven't told the doctor, so we're dealing with it on our own.
>
> **G:** Right. Any reason why you haven't, or?
>
> **A:** We're too focussed on her health, like the sugar and, yeah, we're too focussed on that. We never take seriously, you know, her memory loss and although we see now it's getting worse, but after talking to [Pacific Trust], we're really like, 'Oh, okay, we can get help,' you know. We never thought of it. Yeah, we thought like, [...] we are just stuck with this and, you know, we never thought of sharing to anyone, to our doctor.

Malae's behaviour was not recognised as a problem until it had reached a point where Ana was finding it difficult to cope as a caregiver. Indeed, Ana did not seem to view cognitive changes, let alone the subtle changes associated with MCI, as a 'health' problem at all; the primary concern for Ana was managing Malae's *physical* wellbeing ("like the sugar"). Ana had been supporting Malae at home with showering, toileting, and preparing meals. Although she had recently found this level of personal care increasingly difficult and stressful, she told me that she had "learned to look at it as a privilege, as an honour, to look after her, and instead of looking at it as a chore or an obligation, I look at it as a privilege." I then asked her to elaborate on what she meant by "privilege":

> It's like, for my culture, if you look after your parents it's a good thing. That's how we've been raised, like, you'll get blessings from God for doing that to your parents and, well, think about it—they've been bringing you up [laughs], so I think it's time to give it back

to them. But with me it's hard […] because she's not my real Mum and sometimes I complain, 'Why am I doing this? I should be doing this to my Mum and Dad, my real Mum and Dad instead of [my husband's] Mum—she hasn't done anything to me.' But I think that was selfish of me. My parents are in Samoa. I can't do that to them but I think doing this to her is the same as doing it to my real parents, and I know God will bless me for that, yeah. And I'm looking at my children and I want God to bless them for what I'm doing to her. May that blessing go to my kids instead of me.

Living Well with MCI was, in general, lacking in cultural diversity. Interestingly, most of our participants identified as New Zealand European—they were mostly white and middle-class. One reason for this lack of diversity might be that different cultural groups have different perspectives on ageing, and culturally specific ways of relating to, thinking about, and treating older people (Cohen, 1994). In non-Western contexts, subtle cognitive changes may not register with the same concern expressed by those whose values are derived from a "hypercognitive" society (Post, 2000)—a particular context in which emphasis is placed on memory, rational thinking, and independent thought.

As medical anthropologists often point out, different cultures have specific ideas about what constitutes 'health' and 'illness' (as Ana's concern with Malae's 'physical' rather than 'cognitive' health also shows). Similarly, while independence, autonomy, and self-efficacy may be central to Western medicine's image of 'successful ageing' (Bowling & Dieppe, 2005), these notions may not be as relevant in cultural contexts where older people are well supported by an extended family.

None of this is to say that Ana and Malae did not need additional support at home, or that Ana's concerns were not valid. Rather, the point here is that the MCI concept is the product of a particular culture, which has a particular set of values that are not shared by everyone, everywhere. Perhaps this means that the category only 'works' for people who share the cultural values associated with 'successful ageing', and as a result happen to be more sensitive to the threat of cognitive change (assuming, of course, that an MCI diagnosis 'works' by helping people access services and treatment).

Given there are other cultural and familial practices that mitigate the impact of age-related changes, it is worth considering who might be excluded from the potential benefits of an MCI diagnosis—an important point to consider when designing a website for this 'condition'. It is for this reason that Nathan and I reflected on Ana's situation after I interviewed her, and on the extent to which MCI 'exists' independently of the social and cultural contexts in which older people live:

> **Nathan:** I mean it's interesting culturally because, you know, I think one of the challenges for us is like, well, how do we engage Māori and Pacific [people] with MCI when they don't relate to that [description]?
>
> **Guy:** Yeah, that's really interesting.
>
> **N:** And I would imagine it's similar in Asian cultures where, you know, it's the responsibility of the children to look after their parents […] And you probably just deal with it.
>
> **G:** Yeah, so in those cultures [MCI] is not a problem. Here, it is, but that's because of the way we think about ageing and older people.
>
> **N:** It would be fascinating if you could go into these homes of different cultural groups, family groups who had identified that someone in their family has changes to their memory and thinking, to the level that it's causing concern, if you could go into their houses and see if they have any interesting techniques or strategies

to deal with that.

G: But do you think that it would be a problem? Do you think they would interpret changes to their memory and thinking as a problem? When would it be a concern? [...]

N: I think the question would be, when does the change become a concern to the point where someone thinks it might be a thing,[7] as in, a medicalised condition. Because if it's like, 'Oh, they're getting old and they're forgetting things,' then you've basically got the cause and the effect. They're getting old, so their mind's deteriorating, and that's causing them to forget things. So when does that become—

G: —a medical issue.

N: They're getting old, forgetting things, why is that? Why might that be? Is this normal?

G: Yeah. But if they have a totally different system of thought where they don't subscribe to the biomedical view of ageing [...] they might not see it as a medical problem, ever, depending on the cultural context.

N: Yeah, exactly. So what you're alluding to is that, like, the medicalisation of this particular experience may be in itself closing off particular cultures to support [through this website]. It's kind of like, 'Oh, if you don't relate to this new terminology because you don't subscribe to the medicalised view that Westerners have, then we can't help you.'

Summary

MCI emerged in the 1980s as researchers attempted to describe and understand the progressive stages of Alzheimer's Disease (Reisberg et al., 1982; 1988). Underpinning this research was the assumption that Alzheimer's Disease progressed in a linear and predictable fashion. This assumption has generated strong associative links between MCI and Alzheimer's Disease, despite studies showing that most people diagnosed with MCI do not progress to Alzheimer's Disease (Hong et al., 2011). Indeed, the idea that Alzheimer's Disease is distinct from normal ageing, and that it proceeds linearly through a series of discrete stages, has recently been challenged in the neuroscience literature (Mecocci et al., 2018a; Mecocci et al., 2018b; Herrup, 2015). In a similar way, MCI is not linked in any straightforward manner to anatomical changes in the brain (Lock, 2013), which makes the ongoing search for MCI biological signatures particularly problematic (Moreiera, 2009).

In this chapter I have explored how these assumptions and debates manifest through contemporary research practices, and started highlighting the ways in which these practices construct and 'thingify' the notion that MCI "resides in the brain", as Luke put it. At the same time, I have attempted to put forward a more holistic understanding of MCI that more fully accounts for the historical, social, and cultural contexts in which the various meanings of cognitive changes are embedded. For example, I argued that a person's social context, which may influence how much or how little support they receive from day-to-day, plays an important role in determining whether or not they receive a diagnosis. Indeed, as I learned from Kate, the distinction between normal ageing, MCI, and dementia does not depend on neuropsychological scores; it depends on whether or not the person is still able to perform the activities of daily living, *irrespective* of their scores. Because MCI's 'symptoms' are enmeshed in this wider social context, it is very difficult, as neuropsychologist Kate pointed out, to "clearly classify people". Within the context of Living Well with MCI, this raised the question of who we were designing for and whether we could, in fact, design a website 'for people with MCI'.

[7] Here is another example of the word 'thing' being used to imply medical validity, objectivity, and realness.

In the next chapter, the 'Define' phase, I will pick up on this question by exploring how our users interpret and make sense of the diagnosis within the context of competing definitions of MCI. To return to the Double Diamond model, the Define phase is one of convergence, or, put another way, a narrowing of focus. Following this, I move away from these broader questions about MCI's conceptual origin (dealt with here in this 'Discover' phase), to its status as a clinical definition. In particular, I will explore how the production of MCI as a new clinical entity has simultaneously produced a new category of person—the 'Person with MCI'—who, from a clinical perspective, must be identified and diagnosed. The chapter will highlight the extent to which the apparent "hidden epidemic" (Braverman, 2011) of MCI emerges through a dialectic process in which individuals interact with various definitions and practices.

6.
Define

The symptoms associated with MCI are deeply intertwined with the ordinary processes of the ageing brain, making it difficult to draw a clear line between 'normal' age-related changes and more serious forms of cognitive impairment. In the previous chapter, I highlighted some of the debates and controversies that have characterised dementia research historically, and gave examples of how these debates and controversies manifest in contemporary research practices in New Zealand. I argued that the conceptual boundaries of dementia have expanded to the point where the cognitive changes that were once considered 'normal' have been redefined as pathological, suggesting that MCI does not simply "reside in the brain". Rather, I argue that MCI has a conceptual history and is constituted by the practices that produce and sustain the category over time.

In this chapter, I will show how the expansion of those boundaries has created a new 'type' of person—the Person with MCI—an 'end-user' towards whom various kinds of interventions, both pharmaceutical and non-pharmaceutical, are now targeted. In this chapter, 'Define' refers to both defining the design problem, and the problem of MCI as a definition. Having already discussed how MCI arose and some of the debates with which some experts are now engaged, this chapter will consider what the MCI definition 'does'—how it intersects with people's everyday realities, and how it is enacted across different social settings (Mol, 2002). I will also highlight some of the challenges this presents within the context of designing an online resource for people who supposedly 'have' MCI. To begin, however, I will present some theoretical literature I have used to explore the relational nature of clinical definitions, and to highlight what this potentially means in a design context.

Making up people

Ian Hacking (1998) advances a theory about "making up people", a phrase he uses to highlight the mutual construction of clinical descriptions and the people living under them. In a classic case study, Hacking discusses multiple personality disorder (MPD) (now called Dissociative Identity Disorder or DID)—whose essential feature is the presence in the individual of a number of distinct personalities where only one is dominant at any given moment—and argues that it was virtually non-existent in the first half of the twentieth century. In the 1970s there were thought to have been less than a dozen cases reported in the previous fifty years, and perhaps less than a hundred cases in the recorded history of Western medicine.

By the 1980s, however, the situation had changed. In 1982, MPD became an official diagnosis; by 1986, as many as six thousand people in America were thought to have been diagnosed with the disorder (Hacking, 1998). Hacking suggests that from about 1980 one can begin to see an exponential increase in rates of diagnosis. Public awareness was propagated by mainstream media who spoke of fighting the multiple personality epidemic. Existing clinics and wards filled up with new cases of MPD, new ones were established to keep up with the increasing demand of those seeking treatment.

There are, of course, a number of ways to account for what appears to be a sudden epidemic of MPD. One is that there really was a new form of mental illness sweeping across America, as if by contagion. Another is that the new classification simply gave a name to an existing condition that was perhaps already prevalent but for whatever reason had tended to go unrecognised. Perhaps it was diagnosed as something else, and clinicians had developed more accurate diagnostic criteria.

Hacking (1998) advances a more nuanced theory. He notes that multiple personality disorder, according to clinical psychiatric theory, is closely linked with childhood trauma, often resulting from child abuse. The historical and social

contexts are important here: Hacking argues that the meaning of child abuse, as we know it today, was not well understood in Western societies before the 1970s. The aspects to do with physical violence were perhaps better understood than the emotional trauma the individual carried forward into adult life, but 'child abuse', as an *idea*, was not widely recognised. One of the coping mechanisms for child abuse, so the psychiatric theory suggests, is not 'repression' but 'dissociation' (and hence the new category, Dissociative Identity Disorder)—the functional self needs to be separated from the dysfunctional, traumatised self in order to function. This is was what was thought to cause 'multiplicity' in individuals.

Hacking (1998) suggests that this link was not 'discovered' by psychiatrists so much as forged, and he explores the historical conditions that lifted memory to prominence in psychiatry. But the relevant point here is that before this kind of description became more widely available in society, people dealing with the confusing emotional trauma of abusive childhoods could not recognise themselves as belonging to this or that 'kind' of person or classification. The MPD category made this possible. It was an explanatory model that enabled people to better understand their experience.

Hacking (2004) is particularly interested in the interplay (or 'dialectic' [Hacking, 2004]) between individuals and the descriptions under which they come to live and act. He writes: "Naming has real effects on people, and changes in people have real effects on subsequent classifications" (Hacking, 2004, p. 280). He suggests that the ways in which people act depend in large part on the descriptions available to societies and individuals. These classifications, and the knowledge practices that underpin and support those classifications, can in turn profoundly shape how people come to understand their actions and sense of self.

Thus, the meaning that became formalised in the MPD diagnosis also became the label under which the diagnosed understood themselves. These meanings were also reinforced by the popular ideas about MPD that were in circulation in America at the time (such as the notion of a 'split personality'). Later reflecting on this specific piece of work, Hacking (2004) clarifies: "I do not say the epidemic caused the diagnosis or that the diagnosis caused the epidemic, but that they were mutually reinforcing, a case of positive feedback" (p. 279).

In the following next sections, I consider some of the ways in which this dialectic process may unfold in the context of MCI.

JULIE AND HER HUSBAND ALBERT ARE 79 YEARS OLD. THEY ~~ARE~~
HAVE BEEN MARRIED FOR MORE THAN FIFTY YEARS. JULIE
HAS RECENTLY BECOME CONCERNED ABOUT SOME CHANGES TO
ALBERT'S MEMORY AND THINKING. HOPING TO ~~REDU~~ REDUCE
UNCERTAINTY, SHE WANTS A STRAIGHT ANSWER FROM DOCTORS
ABOUT WHETHER THESE CHANGES ARE NORMAL FOR A 79-YEAR-OLD,
OR SYMPTOMATIC OF SOME UNDERLYING ISSUE. ALBERT RECENTLY
COMPLETED A NEUROPSYCHOLOGICAL ASSESSMENT AND WAS
ASSURED THAT HIS COGNITIVE FUNCTION WAS, AS HE ~~SUSPECT~~
HAD SUSPECTED, PERFECTLY 'NORMAL' FOR HIS AGE. JULIE, ON THE
OTHER HAND, WAS SCEPTICAL OF THE ASSESSMENT OUTCOME
AND IS STILL CONVINCED THAT ALBERT'S MEMORY HAS WORSENED
IN RECENT YEARS. ALBERT ADMITS THAT HE IS FORGETTING
NAMES MORE OFTEN THAN BEFORE, BUT HE'S NEVER BEEN
PARTICULARLY GOOD WITH NAMES ANYWAY. ~~HE WOULD~~ THERE WAS,
HOWEVER, AN ~~OCCASSION~~ OCCASION RECENTLY WHEN HE HAD
FORGOTTEN THAT HIS FRIEND'S DAUGHTER HAD DIED — "THAT
WAS PRETTY BAD" — BUT HE CAN **REMEMBER** HAVING FORGOTTEN
THAT, SO SURELY THAT MEANS IT ISN'T DEMENTIA, HE REASONS.
A PERSON GETTING DEMENTIA DOESN'T **KNOW** THEY'RE GETTING
DEMENTIA, DO THEY?

JULIE, HOWEVER, THINKS IT COULD BE DEMENTIA. THE DOCTORS
CAN'T SEEM TO TELL HER THOUGH, SO SHE HAS STARTED
PAYING CLOSER ATTENTION TO HOW WELL (OR NOT) ALBERT
~~RECALL~~ CAN RECALL CERTAIN EVENTS OR PIECES OF INFORMATION.
IF THEY HAD BEEN OUT FOR DINNER RECENTLY, FOR EXAMPLE,
JULIE WILL ASK ALBERT TO RECALL WHERE THEY WENT,
WHO THEY WENT WITH, AND WHAT THEY ATE. NOT ONLY
DOES THIS HELP HER KEEP TRACK OF ~~ANY~~ CHANGES TO
ALBERT'S MEMORY AND THINKING, SHE SAYS, BUT IT IS ALSO
A USEFUL EXERCISE FOR HIS BRAIN. FORCING ALBERT TO
REMEMBER THESE DETAILS CAN STRENGTHEN HIS NEURAL PATH-
WAYS, AS JULIE RECALLS FROM SOMETHING SHE READ ONLINE.

BUT ALBERT FEELS LIKE HE IS BEING UNFAIRLY SCRUTINISED BY
JULIE, CONTENDING THAT HER CLAIMS ABOUT THESE APPARENT
CHANGES ARE ALL BEING TWISTED AND BLOWN WAY OUT OF

PROPORTION. HE THINKS JULIE IS JUST HYPERSENSITIVE TO THE ISSUE OF COGNITIVE DECLINE, AND THAT'S FAIR ENOUGH, HE SAYS — IT WAS HER FATHER WHO'D DIED FROM ALZHEIMER'S DISEASE.

ALBERT DESCRIBES THE CHANGES HE HAS BEEN EXPERIENCING AS "ANNOYING" AND "INCONVENIENT" BUT THEY GENERALLY DON'T ~~WORRYING~~ BOTHER HIM BECAUSE THEY DON'T INTERFERE WITH HIS DAY-TO-DAY LIFE. ALBERT FIRMLY BELIEVES — ~~HE~~ HAS TO BELIEVE ~~THIS~~ — THAT HIS MEMORY AND THINKING ARE PERFECTLY NORMAL FOR ~~A~~ HIS AGE. HE FEARS THAT TO ADMIT OTHERWISE WOULD BE TO ADMIT THE POSSIBILITY OF RAPID COGNITIVE DECLINE — SOMETHING HE WOULD RATHER NOT THINK ABOUT. STILL, IT HAS BECOME DIFFICULT FOR HIM **NOT** TO WORRY RECENTLY, ESPECIALLY WITH ALL THE CONCERN JULIE HAS EXPRESSED ABOUT HIS FORGETFULNESS AT HOME.

JULIE AND ALBERT'S ~~TWO~~ TWO DAUGHTERS HAVE ALSO STARTED CLAIMING TO NOTICE HOW POOR HIS MEMORY IS, WHICH ALBERT SUSPECTS IS DUE TO SOMETHING JULIE HAS SAID TO THEM. HE FEELS AS THOUGH A CONSPIRACY IS GROWING AROUND HIM. HE FEELS THE MOUNTING PRESSURE TO CONVINCE HIS FAMILY, AS HE IS CONVINCED, THAT HIS MEMORY IS FINE, THAT HE ISN'T LOSING IT. BUT NOW HE ~~ACTUALLY~~ FINDS ~~HIMSELF~~ HIMSELF ~~INCREASINGLY~~ ~~UNABLE~~ QUESTIONING HIS ABILITY TO REMEMBER THINGS MORE THAN EVER ~~BECAUSE~~ ~~DUE TO~~ THIS NEW PRESSURE TO APPEAR 'NORMAL'. ~~BECAUSE~~ ~~THIS NEW PRESSURE~~

Identifying with MCI

The MCI definition creates an entirely new category of people: those who are experiencing changes to their memory and thinking that are greater than (what is now considered to be) 'normal' for older adults, but which are not severe enough to justify a diagnosis of dementia. Until MCI became an official diagnosis, there was no category 'in between' normal ageing and dementia, or any intermediate condition one could be diagnosed with or identify as 'having'.

Just as the emergence of an MPD label in Hacking's example above provided an explanatory model for people who had previously belonged to no accepted diagnostic category, MCI has also become a clinical definition with which older people with memory complaints may now identify.[8]

A small number of participants in the Living Well with MCI project did appear to identify with the MCI category, even to the point where they seemed to embrace the label as a new aspect of their identity. The best example of this was John. John was a 70-year-old man who had received a diagnosis of MCI from a gerontologist after experiencing what he felt were some "unusual" episodes.[9] This is how John described his pathway to diagnosis:

> I [...] decided perhaps I should seek some help initially through my GP, to see if what I was experiencing was unusual, because if you talk to anybody in my sort of age group, they all say, 'No, I don't remember names,' etcetera. But I just had some instances where I felt that was unusual, so that set me off on the train of going to my GP, who sent me to a geriatrician, where I did some tests, and basically I came out at the bottom end of normal. I was 90 on the, ACE test is it? The ACE test I think it is. I was about 90, 91, around there, and he said for a person of my background and abilities and so on, that's a bit unusual. So that was the start of realising that I did have some problems. I subsequently went to a gerontologist, I think, and yeah, did further tests, and at that stage it was sort of determined that, yes, I had MCI.

John was subsequently recruited into a longitudinal study on MCI at a research centre. Partly because of his involvement in the study, but also because Google was "pretty standard in [his] nature", John was a unique participant in our project because he had learned enough about the MCI category to be able to talk explicitly about MCI as his "condition". "I'd never heard of [MCI] before, so I immediately set out to find out more about it," he said. As a result, he had a far more thorough understanding of MCI than other participants. Demonstrating the extent of his knowledge, John explained to me that

> Because I have MCI, my chances of getting Alzheimer's or some other form of dementia is higher than for people who don't have MCI. The encouraging thing though is that some people with MCI can recover, and that's my goal now. Some will only stay at the initial level and not, in the short term anyway, develop much further, but there are others who will go on and develop dementia or Alzheimer's, so yeah, as I say, the more knowledge I get the better I feel about things. It's the unknown and that's what's affecting me a lot now.

Unlike other participants who did not understand the meaning of MCI, John had accepted his MCI identity and was mostly positive about having been diagnosed with it. In some ways, it was socially beneficial. The label provided a legitimate medical reason for his behaviour, relieving him, to some extent, of the embarrassment that came with forgetting names. Perhaps this is why John had no reservations about telling people about his 'condition'. As he put it:

[8] Whenever I mentioned my research in casual conversation with someone over, say, 50 years of age, and I would have to explain what MCI is, the person would often laugh and say, "Oh, yes, I think I have that," or, "I think I know someone who has that. Do you need any more research participants?"

[9] When asking participants about 'changes to their memory and thinking,' they often descibed very specific instances where they had either done something unusual or forgotten something important. These instances were usually the catalyst for seeking medical attention. In John's case, the "unusal" episode happened while doing his laundry. Instead of putting his dirty washing in the washing machine, John "neatly folded it and placed it in our yellow plastic rubbish bag, which is near the machine. And I still even to this day do not recall actually doing that."

I've now made a lot more people aware of the fact that I have MCI […] I want them to understand that I do have some problems but I, I wouldn't say I have it under control but I have, I'm aware of it and I am coping with it.

Through his involvement in the longitudinal study, and in collaboration with the network of clinicians and researchers that supported him as a research participant, John was able to learn strategies for managing cognitive changes. He explained:

I think also now when they see me, most people wouldn't realise I had a problem, because I've learnt how to overcome the fact that I've suddenly forgotten your name, I won't say, 'what's your name again?' I won't do that, I'll just go past it, or I might make a joke of it, and I think that's good because it doesn't make those people worried and concerned, and you know, hopefully they can realise that it's not the end of the world for me, so it's all about communication and in the right way.

The Person with MCI

In recognising himself as 'belonging' to the MCI category and identifying with the description, John was, through the dialectic process described in Hacking's (1998; 2004) theory, involved in the production of a specific 'type' of person. We might call this hypothetical individual the 'Person with MCI'—who is, in fact, the person I imagined we would be designing for when I first heard about the Living Well with MCI project. I imagined that the typical Person with MCI—our end user— would be like John. They would take the category more or less as a given, and describe it to others as something they 'have'. They would also have a reasonable understanding of what the diagnosis meant. Perhaps they would have learned a thing or two about their condition by looking it up online or reading about it in books and journals—a behavioural pre-requisite, I imagined, if they were ever going to find and access a web resource specifically for people 'with' MCI. Having done some reading online, they might even conceptualise MCI as a brain-based condition ("it's in the front of the brain," said John, "still got lots of stuff stacked at the back here"); that is, they may preserve the biomedical understanding of MCI as something that inhabits the body (Good, 1993). To follow Hacking's (1998; 2004) line of thought, the Person with MCI would 'interact' with the clinical description in ways that help to sustain it across time, making MCI a stable enough category to design for. In reality, however, designing for people with MCI was far more complex than we had anticipated.

Challenges of designing for MCI as a 'condition'

Only a few Living Well with MCI participants knew that they had been diagnosed with MCI, let alone identified with it or thought that it was a useful description or label. In fact most participants who had a formal diagnosis had either not been told about their diagnosis, or had possibly forgotten the verbal information they had received at their appointment. Because many Living Well with MCI participants had been referred to the study through memory clinics and had therefore been formally assessed and diagnosed, I would often turn up to an interview knowing that a participant had been diagnosed with MCI, but would have to refrain from using the term when it became clear that they, and their family, were not aware of this themselves. Consider the following segment from an interview with Mike and his wife, Susan, who, as I knew at the time, had just recently been diagnosed with MCI:

Mike: I would have thought they would have been a bit more

proactive in coming forward and explaining what it is. If someone had said, 'Hey, perfectly natural [for] your age [...] and so therefore expect it,' if they say, 'No, there's maybe something else we could look at, try to fix,' but nobody's mentioned nothing.

Guy: So what was the answer you got after all the tests?

Mike: No answer.

Susan: Nothing, no follow up, nothing.

According to Mike, Susan had not been provided with any information about her diagnosis after she had been assessed at the memory clinic, even though I knew at the time of this interview that she had come away from the assessment with a formal diagnosis. Because he was present at this appointment and did not recall any diagnosis being given, it would seem that the clinician that day had, for whatever reason, chosen not to disclose the diagnosis.

Mitchell et al. (2008) observed that it was common for clinicians not to inform patients and families of an MCI diagnosis after a formal assessment. From a clinician's perspective, there may be reasonable grounds for not confirming a diagnosis at the time of appointment. As I described in the previous chapter, there may be delays in receiving a diagnosis because the assessment is often discussed among clinicians before a consensus is reached. It is possible that Mike and Susan were still waiting on the final results at the time of this interview (though in any case it seems odd that I, a stranger to the family, was informed of Susan's MCI diagnosis before they were).

Nevertheless, while Mike had been concerned about changes to Susan's memory and thinking, and wanted some kind of objective measurement to assess the situation, Susan did not think she had a problem in the first place (a tension that was evident in a number of other dyadic interviews with family members and people with MCI in this research, and illustrated through Julie and Albert's story above): "I was quite surprised when I heard that I had to go to the memory clinic. Why, I just accepted that I was normally getting old and forgetting things."

Another participant, named Neil, was also diagnosed with MCI but seemed to be completely unaware of this. He was worried that he may have been experiencing the earliest stages of Alzheimer's Disease and was frustrated that he had not been given a straight answer one way or another:

> I don't know whether I've got Alzheimer's, neither does anybody else seem to know, which is very frustrating, extremely frustrating. There seems to be such a lot that is not known about the problem [...] to the extent where I've got no idea whether I'm suffering from it or not.

He was particularly irritated by this lack of certainty given the amount of modern research on Alzheimer's Disease:

> [There are] very few facts, which surprises me because I know there's such a hell of a lot of work going on behind the scenes in this field, and it surprises me that there's not more certainty, yet everybody keeps saying 'Oh, it will happen, it will happen,' and 'We're getting there,' but [it] seems to be taking an awful long time.

Although a doctor or memory specialist may have informed Neil about his diagnosis at some point, the ambiguous nature of the category may have made it difficult for him to conceptualise ("I've got no idea whether I'm suffering from it or not"). Indeed, other people I interviewed were aware of their diagnosis but did not know what it meant or how significant it was. Margaret stressed this point several times in an interview:

> I don't know how important [an MCI diagnosis] is, or not important.

Is it very important? Seriously important? Or not very important? I don't know.

I would like to know [what MCI means], I sort of need to know. I mean, so with other people who are my age, and my activity, I've always been a high-activity person, involved in a lot of stuff. So how does, how does that fit alongside people of similar circumstances? I don't know.

I'm not a medical person [...] I started out life as a radiographer, but, you know, that's paramedical, so I don't know what mild impairment means. Or cognitive impairment.

More alarmingly, at least one person I interviewed, a 65-year-old man named Simon, who had been formally diagnosed with MCI, had interpreted his diagnosis as early onset dementia, and was coming to terms with the frightening prospect of rapid cognitive decline, (even though MCI does not guarantee progression to dementia—see Chapter Five). Again, in this interview, I had to avoid using the term MCI, as Simon did not seem to be aware of his diagnosis.

Simon: They referred me to [hospital name], to a memory specialist there.

Guy: Right, and what did they tell you?

S: That I had early onset dementia.

G: And how did that make you feel?

S: A little gobsmacked I have to say.

It is worth pointing out that Simon also had leukemia and was going through chemotherapy at the time of his diagnosis. When he missed a couple of appointments at the hospital, Simon's oncologist suggested he go and see a memory specialist, who after assessing him determined that he had MCI. According to the neurological assessment, his memory problems were measurably worse than 'normal'. It is possible, however, that he was not adequately informed by his specialists about the negative effects of chemotherapy on cognitive functioning, which are well documented in the literature and commonly referred to as "chemo brain" (Staat & Segatore, 2005). Chemotherapy has been shown to cause short-term cognitive impairment and fatigue, which in most patients improve over time.

While I cannot know what went on at his consultation, the fact that Simon had interpreted his diagnosis as "early onset dementia" raises questions about both the nature of the information provided and the value of an MCI diagnosis. A contributing factor in Simon's interpretation may have been the recent death of his sister, who had dementia in later life. Nevertheless, making a link between his cognitive impairment and dementia, via the MCI diagnosis, seemed unnecessary given that an alternative explanation was potentially available in Simon's case.

People's understanding and interpretation of their assessment and diagnosis differed in many ways. While John had clearly taken the term 'MCI' away from his assessment and sought to understand what it meant 'clinically', other people appeared to be unaware that such a term existed at all. Susan and Neil, for example, had both been assessed and diagnosed with MCI but were unaware of this fact at the time I interviewed them. Simon, on the other hand, was aware that he had been diagnosed, but had conflated a diagnosis of MCI with a diagnosis of early onset dementia. This illustrates the idea that MCI, being an ambiguous diagnostic construct, was sometimes interpreted in ways that not only differed from the clinical definition, but also in ways that were potentially harmful.

Excerpt from Critical Reflection session with Nathan

Guy: So you're saying that our users' needs are slightly different because it's a blurry category.

Nathan: Yeah, well, I suppose what I mean is that <u>if they all had the same thing, and they all understood they had the same thing, then you could define parameters that they could all identify with</u>. Then it's easier to <u>design</u> something that may meet those needs, or help support that, versus, like, someone who, for example Rob, who doesn't identify with it, right?

G: With MCI? No.

N: But he has it. And then someone like Margaret, who doesn't.

G: She does.

N: She's been formally diagnosed?

G: Yeah.

N: And does she identify with [the category]?

G: No, she didn't know what it meant when she was diagnosed, and sort of expressed that she would like to know more about it, what it means for her, especially because she lives by herself.

N: Yeah, and to that point, like <u>her needs as someone who lives alone, she talked a lot about community</u> and 'what's happening around me?' Events and—

G: —she felt isolated.

N: Yeah, and, and <u>that's different</u> to what we would typically assume are the symptoms of MCI, around forgetfulness or loss of train of thought, or ability to, yeah, remember things, sequencing, all that kind of stuff. Like, that's not what she feels are <u>the issues of her life current</u>ly.

G: No. […] Which is why we sort of shifted away from the category but I'm kind of in two minds about it now […] So what would make things easier for us on this project?

[handwritten margin notes:]

MCI PARAMETERS IMPORTANT FOR DEFINING AUDIENCE/ PROBLEM

INDENFYING NEEDS BEYOND MCI PARA- METERS.

DIFFERENT NEEDS

N: Well we would either limit our scope to a particular set of features, or a particular field of information, or we might just say that, like, we're never going to meet the needs of everyone, whether they're formally diagnosed or not. Because it's one thing to be formally diagnosed, it's another to kind of accept it and identify with it to the point where you can say, 'I have this thing, there is a resource that supports people with this thing, I will use it because it is valuable to me.' It might be all of those things but you don't identify with it so you're not going to use it, even though it could actually be valuable.

DIVERSE NEEDS BEYOND MCI LABEL.

OLDER USER
↓
EXPERIENCING COGNITIVE CHANGES
↓
MCI DIAGNOSIS

YES ← │ → NO

YES → IS NOT INFORMED
YES → IS INFORMED

IS INFORMED → DOES NOT KNOW WHAT MCI 'MEANS'
IS INFORMED → KNOWS WHAT MCI 'MEANS'

KNOWS WHAT MCI 'MEANS' → DOES NOT IDENTIFY WITH DIAGNOSIS
KNOWS WHAT MCI 'MEANS' → IDENTIFIES WITH DIAGNOSIS

IDENTIFIES WITH DIAGNOSIS → DOES NOT USE INTERNET
IDENTIFIES WITH DIAGNOSIS → SEARCHES FOR ~~DIAGNOSIS~~ "MCI" ON INTERNET

SEARCHES FOR "MCI" ON INTERNET → ACCESSES WEBSITE FOR PEOPLE WITH MCI.

?

Defining MCI in the clinic

To get a better understanding of how MCI is diagnosed in memory clinics and the kind of information that is given to patients, I interviewed Robert, a geriatric psychiatrist at a memory clinic in Auckland. Robert was a member of the Living Well with MCI steering group and had helped us recruit participants for the project. Visiting him at the hospital one day, I asked him about the process he goes through when diagnosing someone with MCI. He told me that people often come to his memory clinic with "subjective memory complaints", which are either self-reported or, more commonly, noticed by a family member or spouse. As Robert explained:

> One of the key decisions that you need to make is whether this subjective memory complaint is due to, well you have to make a judgement about whether this cognitive complaint represents normal ageing, whether it represents the beginning of a dementia process [...], or whether it's somewhere in between, in that mild cognitive impairment zone, where there is evidence of change in cognitive function that's beyond what you would expect for normal ageing, but that is compensated for by strategies the person employs. And making a judgement call about when things are compensated for and when they're not is a bit of a line call and a clinical judgement. Everyone's a bit different [...] So one of the things about mild cognitive impairment is that it is prognostically uncertain, so you don't know for certain that mild cognitive impairment is going to progress to dementia, even though if you follow clinic samples up to a number of years, the majority of people with mild cognitive impairment do end up having dementia. There are a small subgroup who seem to stay stable and there are some people who improve. And we don't know exactly what's going on with all those people who stay stable or improve.

As I pointed out in the previous chapter, the progression rate from MCI to dementia is a highly contentious issue, with some studies disputing Robert's claim that the "majority of people" with MCI will go on to develop dementia (e.g., Hong et al., 2011). Robert rightly pointed out that MCI is "prognostically uncertain", but he also seemed to suggest that the "small subgroup" who did not progress to dementia were anomalous ("we don't know exactly what's going on with all those people who stay stable or improve"). I was particularly interested in the clinical tools and practices Robert used to 'navigate uncertainty' within the context of cognitive changes, recognising that "the realities of disease do not exist outside of the practices in which they are 'done'; rather they are constituted across socio-material practices and socio-technical arenas" (Swallow, 2016, pp. 125-126).

In clinical settings, the most common tools used to assess and review levels of cognitive impairment are the Addenbrooke's Cognitive Examination (ACE) and the Montreal Cognitive Examination (MoCA). Robert uses primarily the ACE in his clinical practice. As he explained:

We tend to use as our main assessment tool the Addenbrooke's Cognitive Examination which is a really widely used tool in this setting and you get, it's not, you know, an absolutely detailed and comprehensive test but you do get to the point where you usually get a sense of what's normal and what's abnormal. And there are norms for scores for those tests, which are helpful guides.

I asked Robert what a 'normal' score would be. He replied:

So it's often more useful to look at a subtest. So there are a couple of specifically memory subtests in the Addenbrooke's, there's a three object recall which you get the person to say three objects back to you, you get them to do an interim calculation task, and then you ask them about the three objects. So you know, someone with normal memory might drop one of them, but they don't usually come back with zero out of three. And there's a name and address recall task which is, the person's exposed to it three times towards the beginning of the test and at the end of the test they have to recall the name and address. And if someone's got no, absolutely no recall of the name and address, then that's raising alarm bells. If they mix up one or two elements of the name and address, maybe that's not so bad, yeah. And yeah there are other cognitive domains that get tested in that test so that might give you more of an overall score. But as I said before it's kind of putting all those things together, it's not, you don't tend to make the call just on the test score or just on collateral history.

I wanted to push Robert's definition of 'normal' because I was interested cultural and educational differences, and how these differences were managed within the context of diagnostic uncertainty:

Guy: So if, I'm just thinking of lower socio-economic communities where alcohol abuse is high and education levels are low—do you take that into account when you put them through this test?

Robert: Yeah, so. Yes you do.

G: How?

R: So it depends a little bit on the person's education level, what their primary language is, what their cultural background is, which test you'll use. So there are translations of the Addenbrooke's for a few cultures. There's a test called the MOCA test, which is a briefer test, which is translated into lots of different languages. It's, and there have been validation studies for it in many of those languages.

G: Is the baseline, the sort of threshold for normal ageing about the same throughout these culturally specific tests?

R: That's a really good question. I think for most of them, on the MOCA, I think, I'm not, I can't tell you actually, whether the norms are, the different versions, are different. And I think that the validation information is a kind of area that's building up as they add more information to it.

Excerpt from Critical Reflection session with Nathan

Guy: Just the other day, I went to do an interview, because this lady said 'Oh my husband has a formal diagnosis of MCI, will you come and talk to him?' I said 'Sure'. So I turn up and she gives me his—he was out, he'd forgotten that I was coming around. I saw his medical report and he'd done this ACE test, which is a standard assessment, and I had to exclude him in the end because there was 1 point in it, he was like 86, he was like 1 point over the threshold for MCI. And in the report it said 'I *think* he has early dementia.' Just that one point.

Nathan: That's literally what the report said?

G: Yeah.

N: So the person writing the report was like—

G: They concluded, 'I *think* he has early dementia.' And yeah, there was one point in it. Interesting, eh?

N: Hmm. So did you still do the interview or no?

G: No, I said we've got strict inclusion-exclusion criteria and he doesn't qualify. It didn't say mild cognitive impairment in the report. But there seemed to be so much speculation in it, you know, from the gerontologist. I guess there always is. So I didn't go ahead with the interview.

N: That's a shame [...]. What is the test criteria? Or is it a bunch of different things.

G: Have a look. Go to ACE version 3. [browsing] That one there. So this is what you do.

N: My God.

G: So there are instructions to the clinician doing the test as well. But that's it. You get a score for each section.

N: Hang on. So the clinician, so when it says 'ask', is that the clinician asking?

G: Yeah. They're instructions to you, the clinician. [To] ask the patient.

N: Oh, so the patient doesn't see this form.

G: No, that's right. So you assign points to each section and at the end you get something out of a hundred [...] So the interesting thing though is that although these people want some sort of objective measurement of their cognitive ability, their memory and thinking, it doesn't seem very objective when you have reports saying 'I think he's got early dementia' and there's one point in it between that and mild cognitive impairment [...] At the start it asks you to remember an address. And then at the end it asks you to recall that address, after going through all these other things. It's like—that's hard. I'd struggle. Imagine if you were nervous. Or tired, you know?

N: Do you have to remember an address?

G: It says something about that. And then at the end, 'Can you recall the address from the start?' [...] I think anyone would struggle with that [...] So this is an interview transcript from a guy with MCI, he says, 'I was 90 on the ACE test, about 90, 91, around there, and as he said for a person of my background and abilities and so on that's a bit unusual. So that was the start of realising I did have some problems and I subsequently went to a gerontologist I think and yeah did further tests and at that stage it was sort of determined that yes, I had MCI.'

N: So what score do you have to get? Do you have to get a hundred to not have MCI?

G: I don't know. I'm not sure. There is a bracket, I think 95 plus you're, I don't know [...]

N: *We* could have MCI, for all we know, based on this test.

G: That's the thing [...] It's like, is it helpful to be telling him that he's got MCI? And I asked him how he felt about it and he said yeah 'I'd never heard of it before so I immediately set out to find out more about it.' Googled it. So this guy's a good example of someone who's gone out of his way to learn about MCI.

Defining MCI in the lab

In clinical settings, MCI is defined according to psychiatric criteria derived from the DSM and 'diagnosed' using standardised assessment tools such as the MoCA or ACE tests (Swallow, 2016) (see Figure 21). In a research context, however, where MCI is not diagnosed per se but rigorously measured and assessed over time to predict rates of progression from MCI to dementia, there are many competing definitions. I learned through my fieldwork that this was particularly problematic in the field of neuropsychology. As Kate, a neuropsychology researcher and PhD student, explained to me:

> I think, for me, certainly as someone doing research in this area [...] it's very difficult to compare studies. So you've got this person over here saying one thing and this person over here saying another thing, and then you're really trying to look at, 'Okay, what's similar about these studies?' Because they've got different definitions of MCI, their findings are completely different. How do we then sort of compile that together and then come up with a view of MCI that is cohesive and can be applied across different countries and different people groups and that sort of thing? Because there's so much variation that really, when you look at the literature, it's almost impossible to just easily compare studies, and without being able to compare them, how can you look at results and know that they're something you can replicate, or something that, that there is something going on when people's definitions from the beginning are completely different, so how can the outcomes be comparable? That's certainly what I've found anyway.

I realised this may be partly why estimates of rates of progression from MCI to dementia varied so dramatically (Gainotti, 2010). Study findings were influenced by the different MCI definitions researchers used in their studies. Luke, a brain imaging researcher, shed more light on the situation for me. His analyses of brain scans were informed by neuropsych assessments that established sample groups of "normals", "MCIs", and "dementias". The research he carried out involved looking at differences across these groups, honing in on specific areas of the brain associated with memory function, executive function, or visuospatial function, and comparing MRI or PET scan images with the neuropsych scores. Reflecting on the use of the MCI category in this context, he said:

> I think it's nice to have a descriptor that we can kind of agree on, but by no means does everyone agree on [MCI] and there's ongoing fights about what it is, but the idea that there's this, there is this stage which is not normal but is not dementing is, is helpful. However, that said, the number of arguments we have about [...] the definition of MCI based on neuropsych, and it has to be a number of standard deviations below normal, and how many domains, and how many different tasks, and the number of—it's not fighting, it's academic thought, which I think is important and it's interesting, which it, but it almost seems artificial [...] I think that there is a kind of push to move beyond just the slot of normal, MCI, dementia, and moving into a realisation that it is completely continuous, which we've always had. We know that it's a continuum but for those reasons it can be quite helpful to have a label for the, for the middle bit.

If there is no guaranteed linear progression through 'stages', then what does MCI really mean for the person who is diagnosed with it? For Luke, who works in a research context, MCI is a "proxy" for identifying people who have a relative risk of developing dementia. But what is it relative to, I wondered, if the entire spectrum

of cognitive decline is, as Luke suggests, "completely continuous"? If this is true, then 'normal' cognitive decline must also be a diverse spectrum rather than a rigid category or state of being. Later in the interview, Luke reflected on the use of MCI in clinical practice:

> **Luke:** I mean, jeez, if someone has a diagnosis of MCI, what in the world does that mean given the fact there's […] 27 definitions of mild cognitive impairment.
>
> **Guy:** 27?
>
> **L:** Well I made that number up, just to emphasise that there's no hard-and-fast MCI diagnosis […] It's not a perfect description of the situation but it's an adequate one for the time being. So yeah, a diagnosis of MCI. What does it mean? I don't know.

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Figure 21: Montreal Cognitive Assessment (MOCA). Source: https://www.nzgp-webdirectory.co.nz/site/nzgp-webdirectory2/files/pdfs/MoCA-Test-English_7_1.pdf

Defining MCI for design

When Nathan and I first started thinking about the people we were designing for, I raised the point that not everyone diagnosed with MCI gets dementia. This was an attempt to challenge the assumption, often perpetuated in existing online resources for people with MCI, that dementia develops in a predictable succession of clearly defined stages from 'normal' ageing, through 'MCI', and then to 'dementia'. Nathan found this counterintuitive:

Nathan: I mean, why is it, okay—if it's such a massive problem, like dementia, what happens from the point of 'normality', quote-unquote, to dementia, if MCI doesn't sit in between those? Like, how are all these people getting dementia?

Guy: [...] When you define something as vague as MCI, which is an 'intermediate' stage—

N: —of dementia.

G: No, well, it could be defined as an intermediate stage of dementia, or it could be defined as a transitional stage of dementia, but really when you're dealing with just the psychiatric *symptoms*, then you are going to catch a lot of people who are just ageing, and that's the issue.

N: So if you were someone who had dementia—

G: —you would have definitely gone through an MCI phase.

N: So you definitely would have had MCI.

G: Sure, but not everyone with MCI gets dementia. Like maybe ten per cent do. Some studies say that.

N: But if we're talking about so many people with dementia, then surely those so many people would also have had MCI.

G: Yeah, but if you look at it the other way around and focus on all the people who have MCI, only a fraction of them are going to get Alzheimer's. A lot of them stay the same, a lot of them improve.

N: So this whole dementia thing, as in one of the big pressing issues in global health... is that being kind of blown out of proportion? That in fact there aren't many people who will get dementia, relative to the number of people who are ageing?

G: I don't know, no, I think it is a serious issue, because with the population ageing, you're more likely to get people with dementia.

N: It just doesn't seem to make sense that you would have all these ageing people who get dementia but not get MCI.

G: They do.

N: Or if they do, then why is it such a small percentage of the rest of the people who have MCI? It's basically like saying that everyone beyond a particular age range, even though that's not concretely defined, has MCI.

G: Yeah, or that the people past that age range who *don't* have MCI are exceptionally healthy... I mean the norm is decline, right?

N: So you're essentially just designing for old people.

G: That's what I think. It feels like it.

[...]

G: [Reading aloud from BRNZ website] 'One out of five people with MCI will go back to normal cognitive functioning within three or

four years.'

N: How do they define normal?

G: Exactly.

Some of the early debates within the wider research team, and between Nathan and myself, pertained to the use of language on the website. Specifically, we discussed whether or not it was appropriate to refer to or define 'MCI' when not every user of the online resource will relate to the MCI diagnosis (because many people who would meet the criteria for MCI, or even dementia, often manage to elude clinical services, but would perhaps still benefit from such a resource). However, from a design anthropological perspective, our efforts to de-medicalise the symptoms commonly ascribed to MCI and refer instead to 'changes to memory and thinking' presented another set of issues around defining the design problem, constraining the scope of the project, understanding our user group, and meeting their needs. Consider the following segment from a critical reflection session with Nathan, recorded in the early phases of the project:

> **Nathan:** The point of difference for this website really needs to be about changes to memory and thinking, but I don't think that definition really sells it. 'Changes to memory and thinking.co.nz.'
>
> **Guy:** So you think that as a website, in order for it to have credibility, we'll need to medicalise this and say up front that, 'This is MCI and this is what we're designing for'?
>
> **N:** A large part of me does. Because let's say you have a sore hip. If you're a proactive person, you will Google 'sore hip'. You'll find an overwhelming amount of information about what causes sore hips and what it refers to. You'll have all these terms. Or you might go to a physio who'll say it might be this, or this, or this, or that … But without having clear definitions to kind of tie to, it could be anything. Let's say you Googled 'hard time remembering things' or 'forgetting a lot' or whatever, and the Internet had decided not to use, 'we're not going to publish the term MCI', so you find nothing but dementia, Alzheimer's. Then you would just be like, 'Oh, shit, is this it? Do I have that?' And even though you may not, like, you may read about dementia and be like, 'Oh, well it's not that bad,' but you can't help associate one to the other.
>
> **G:** I agree actually. Maybe using the term is a good thing, in some ways.
>
> **N:** I just think it could be more helpful than detrimental. And that, that, my opinion of it is that the only place you get into trouble is when you get researchers and academics who are afraid of, like, putting people into boxes or putting labels on people. Because ethically maybe that's not correct. Or we're still not sure, or there's varying opinions on it. So that's kind of my thoughts on it.

As this segment suggests, Nathan was originally in favour of leveraging the MCI definition to constrain the scope of the project. This, he argued, would give the website a clearly defined audience and purpose, and allow us to hang it around something concrete and medically legitimate rather than something vague like 'changes to memory and thinking'. The steering group at this time was advocating for the latter (perhaps as a result of the above findings), but Nathan seemed to have interpreted this as a sign of academic 'political correctness'. He continued:

> **Nathan:** Although it has associations with dementia, which is likely

to, you know, frighten a lot of people, I think—you know, you've mentioned people that, once they've been diagnosed, they feel empowered by their diagnosis, because they *know*, okay, it's a thing, and they have it.

Guy: They can let their family and friends know that they have this thing called MCI and that legitimises their memory complaints, it's like 'okay, it's a medical issue.'

N: Yeah and you can be like, 'Oh, based on what I've read about it it's not that serious so don't worry about it.'

G: But one of the other issues is that some clinicians don't even disclose the diagnosis because they find that MCI is difficult for the patient to conceptualise. And some of them just say, 'Oh, you have early dementia' because that's easier for them to understand [...] What about the people who don't hear [about their MCI] diagnosis? They're diagnosed with it formally but the clinician decides not to give them that label, and then they're sent away. How are they going to access this website?

N: Yeah, I mean, that's a, that's an issue that would need to be addressed at a clinician level, like protocol. There needs to be some kind of channel directing people to this website who need it, or may benefit from it. I think it's better to come from a clinical, medical recommendation than an age-related, SeniorNet[10] kind of thing.

As this excerpt suggests, Nathan was initially concerned that if the website was not oriented around the MCI category, and instead focused on 'changes to memory and thinking', the user group would become too heterogeneous and vague for the resource to offer any value to anyone. He suggested that putting the diagnosis front-and-centre, by contrast, would tighten the scope of the project and make it easier to meet the needs of a specific audience. In another conversation he said:

I just think, how can you talk about what they're experiencing without defining it? Everything would just be so loose. 'Are you experiencing changes to your memory and thinking? Do you bla-bla-bla.' Which is basically describing the things that define MCI without saying it.

When I raised the point about access, noting that not everyone with MCI is aware that they have a diagnosis, he argued that this barrier would need to be addressed at the level of clinical practice.

10 SeniorNet is an Auckland-based service that provides older people with training and support in the areas of information technology and digital communication.

Excerpt from Critical Reflection session with Nathan

Nathan: Technically we're all ageing, every day. But there's a point at which, I'm assuming, but there's a point in someone's life where they acknowledge not so much 'I'm ageing,' but 'I'm getting old.' They cross that, I mean maybe it's just a socially constructed line that people think, 'Oh, shit, I'm 65, I've retired, I'm crossing the line, getting old,' and from there on it's a more and more exaggerated sense of that, you know? [...]

THRESHOLDS OF PASSAGE

Guy: Yeah, so MCI is [...] as far as cognitive decline goes, like, presumably we all deteriorate at different rates and to different degrees [...] and MCI is one, kind of, socially constructed category within all that. I don't know. It's not very helpful though. [...] It's almost like you have to assume that it's this real, concrete thing and then use the list of symptoms that define it, you know, and that becomes your user group. It would be easier that way.

N: Yeah, to a certain extent. But then you get all the people who may present those symptoms but not associate with [MCI] and feel, I don't know, pigeon-holed, with some sort of definition of themselves that they don't agree with or personally feel.

NOT IDENTIFYING WITH DESCRIPTION — HOW TO DESIGN?

G: Yeah, totally.

N: But then how on Earth do you, who's going to visit a website that's basically just a place to like share stuff about 'changes to your memory and thinking', without some kind of more concrete parameters around, 'what are these changes, who experiences these changes, who can help support you through these changes?'

DIFFICULTY DEFINING THE USER GROUP

Summary

Drawing on Hacking's (2004) notion of a 'dialectic' between the classification and the person classified, and then using John as an example, I began this chapter by arguing that people participate in the construction of new medical realities by 'identifying' with the descriptions available to them in society. While these descriptions are shaped in large part by knowledge-making practices in the realm of biomedicine, and perpetuated through clinical practice, the example of John in this chapter also suggests that new clinical definitions such as MCI are not simply imposed from the top-down—they also emerge from the bottom-up. I argued that the new MCI 'user group' is formed through a dialectic process.

I also noted that John, who embraced the category as a new aspect of his identity and was enthusiastic about its public promotion, was something of an exception. The vast majority of Living Well with MCI participants did not identify with the description, and only some knew they had been formally diagnosed. Exploring research and diagnostic practices in laboratories and memory clinics, I discovered that there were in fact many competing definitions of MCI, adding to the confusion of who our users were, how relevant the diagnosis was, what it really meant, and whether we could, in fact, build a website around it.

From a design perspective, these competing definitions made it difficult to explore 'experiences of MCI' as such, since there appeared to be many versions of it across clinical and research contexts (or, following Mol [2002], many different MCI 'worlds'). In an effort to resolve this, I proposed referring instead to 'changes to memory and thinking', but for Nathan this raised concerns about the scope of the website and who it was ultimately for. It also highlighted a tension between meeting the aims of the original brief—to implement an interactive online resource for 'people with MCI'—while simultaneously meeting user needs.

In the next chapter, I will describe in more detail the methods used to explore end-user experiences and needs, and how a social constructionist perspective challenged the notion that these could be explored and understood using conventional design tools.

Intermission

EMERGING TECH ..

+

THE IDEA THAT
DEPRESSION IS
"IN THE BRAIN"

=

BRAIN
STIMULATION
HELMET
FOR PPL w/
DEPRESSION

Some reflections at this halfway point.

#1: These words are crude impressions of things that have happened over the past few years, but they should not be mistaken for the things themselves.

#2: I am a participant in this research and not simply an impartial observer ~~(there is no such thing)~~. I am a kind of research instrument, but one with pre-existing interests.

#3: Interests present themselves as things of value. Value strongly influences what I see and write about, and what I decide to leave out of this thesis.

~~[Full disclosure: what I see in the 'data' is strongly influenced by my longstanding interest in science and religion. Reason and meaning. Scientific practices and religious practices. Scientific myths and religious myths. Religion as science, science as religion.~~

~~So bear in mind that these thoughts are present here, guiding the writing process.]~~

#4: The human brain is one of my interests. However, I am not interested in the human brain in the way that, say, a neuroscientist is interested in the human brain.

#5: I'm not interested in the brain 'as such'— more like how the brain has come to occupy such a central position in contemporary society. The idea that we are just our brains. The idea that depression is just a neurochemical imbalance; that empathy is just mirror neurons; ✳ that happiness is just endorphins; that love ✳ can be understood entirely in terms of neurophysiology. The brain not as organ but as culture.

#6: An observation from personal experience [where are the boundaries of this 'research'?]: younger people, when they've had an impressively big night and are

feeling a bit low, often say things like "I've used up all my serotonin". You don't need to understand a thing about how serotonin works to know what they mean. And neither do they. (The brain as culture.)

#7: [This is all discourse. Language. Mere words. What about things? Things matter.]

#8: Hypothesis: designed artefacts, whose production and consumption are supported by, and distributed across, complex systems and structures, reinforce "neurocentric" realities (and this could be problematic, at least metaphysically).

#9: Some data. Last week, at a design for health symposium in Melbourne, I listened to a university professor present a recent medical innovation—a brain stimulation helmet to treat people with depression at home. A beautiful artefact. Very sleek. Nicely

DEC 2018

NEW TECHNOLOGIES → BIOMEDICAL STYLE OF THOUGHT → NEW DIAGNOSES/ ILLNESS CATEGORIES

VR GOGGLES FOR ANXIETY.

photographed and talked about. The man behind the microphone was very articulate. The helmet seemed to miss the point though, in my opinion.

#10: My opinion. Depression is in part existential and cannot be reduced entirely to brain physiology. Currents of electricity, administered directly into the skull of the body-machine that's treating the material brain, not the whole person. And this all seems somehow typically modern Western. Or so it seems to me.]

#11: [That's discourse again. Words. Back to things. Objects.]

#12: Some possible elements in the brain-stimulation-helmet-assemblage (in no particular order): engineers, knowledge about the human brain, funding structures that privilege 'hard' rather than 'soft' science, health professionals, university departments, the medicalisation

of psychological and existential distress, the pressure to generate research 'impact', capitalism and the pursuit of intellectual property, deep collective existential conundra, electricity, plastic, the mind-body split. Drop one or more of these and the helmet will cease to be.

#13: Virtual Reality Goggles. Another design for health intervention. Another assemblage. More data. These goggles were presented at the conference as well, shown in one photo covering someone's entire face—not very person-centred.

#14: Apparently VR games can also be used to treat anxiety and depression. Maybe there are apps. I wonder how much they cost, and who buys them.

#15: I don't know how effective these products are—or for whom, when, and in what ways they are effective. But I can

personally report that they are highly affective, at least for me. A bit unsettling to look at, these shiny new health technologies, pulsating with intimations of the not-too-distant future. A future under construction, here and now. After a while, some of them start to conjure images of being plugged in at home and entertained practically to death. Fed through an intravenous drip.

#16: I start to wonder whether these interventions are addressing problems or creating more of them. Perhaps it is both. I'm pretty sure it is both.

#17: Lastly, a provocation: when biomedicine defines the problem [and then dictates how it should be addressed], designers will end up asking the wrong questions.

7.
Develop

During the Develop phase of a project, design concepts are transformed into specific products or 'prototypes'. In this chapter, Develop refers to the way in which this was achieved within the context of the Living Well with MCI project—that is, how Nathan and I developed the online resource prototype using methods and techniques derived from conventional design 'toolkits'. Design toolkits, such as those promoted and used by the global design company IDEO (e.g., IDEO, 2017), are widely used by design teams to gain knowledge about user experiences, behaviours, wants, and needs in order to design products that are useful, useable, and desirable (Buchanan, 2001). In presenting the 'tools' used as part of Living Well with MCI, this chapter addresses a broader issue relating to the potential limitations of such toolkits, highlighting the relevance of this to the specific field of design for health. It also considers the way in which design tools and methods are elements of the MCI assemblage.

Design 'toolkits' in health

Products and services must accurately respond to user needs if they are to be successful (Von Hippel, 2001; Von Hippel & Katz, 2002). However, acquiring a deep understanding of users and their needs is often complex and time-consuming. Methods of data collection, analysis, and ideation in design (i.e., design 'tools') are often simplified to suit the pace of industry and commerce. For example, while an anthropologist might spend a year or more in the field studying the behaviours and attributes of a particular social group, ethnographic user research in a design context is often "quick and dirty" (Hughes et al., 1995, p. 6). 'Rapid ethnography', as it is sometimes called, is a design tool that is commonly used to shed light on the wants, needs, and day-to-day experiences of end users (Millen, 2000), resulting in 'implications' for design solutions (Dourish, 2006).

Design toolkits can be thought about as a collection of methods and techniques for learning about a problem, stimulating ideas, and engaging users or stakeholders, who may not have any formal design training, in design-led innovation practices (Von Hippel & Katz, 2002). Other tools or methods might include expert interviews, card sorts, photo journals, persona exercises, journey maps, storyboards, and rapid prototyping (IDEO, 2017). In healthcare contexts, these are often used to engage patients, families, and healthcare professionals in design processes in order improve the efficiency and experience of healthcare products and services (Bessant & Maher, 2009; Tsianakas et al., 2011).

For example, journey maps and storyboards allow design teams to identify key 'touchpoints' within a health service (such as radiology or oncology) so that they can better understand where patients come into contact with service processes. These tools can help bring patient experience into focus and prioritise areas for service innovation (Bessant & Maher, 2009). Similarly, rapid prototyping methods allow service users to co-design, experience, develop, and test proposed solutions (Bessant & Maher, 2009, p. 563).

The broader field of 'design for health' (e.g., Tsekleves & Cooper, 2017; Chamberlain & Craig, 2017; Reay et al., 2016) has many examples of design tools being used to improve healthcare services and experiences both within and beyond the hospital environment. Many design for health projects focus on specific conditions and illness populations, such as cancer (Tsianakas et al., 2011), psychosis (Nakarada-Kordic et al., 2017), or late-stage dementia (Kenning, 2017), and draw on design tools to help shed light on the experiences and needs of such populations. The tools are often used to engage with user groups and enable them to contribute to the design process (Sanders & Stappers, 2008).

Living Well with MCI is an example of a condition-specific project in which certain tools were adopted to both engage participants and help the design team identify latent wants and needs through an iterative co-design process. Before describing these tools and how they were used, I will first explore the extent to which Living Well with MCI was, in fact, a co-design project.

Was Living Well with MCI a 'co-design' project?

Living Well with MCI was not formally articulated as a co-design project in the brief. However, because co-design was the favoured approach of the designers at the DHW Lab, and because Nathan had experience with co-design processes, it became the frame of reference for thinking about how to bring this particular project to fruition. Hence the language of co-design, and in particular co-designing with people with MCI, was adopted early on in the project.

Co-design in its purest sense means designing *with* rather than *for* end-users in order to develop solutions that respond to what matters most to them (Sanders & Stappers, 2008). Designing with users implies that the solutions are not predetermined; rather, the outcome should emerge through an iterative process in which the most appropriate solution to the problem is identified, developed, and tested with users who are positioned (by designers) as the 'experts' of their experience. The original design brief for Living Well with MCI, however, specified that the output (the 'solution') would be "an interactive web based resource" for people with MCI and their families. This meant that the project, while participatory and collaborative, would not be a genuine co-design process.

Indeed, the notion that a web resource was the most suitable medium for our participants was highly questionable. For example, it became clear during interviews with participants that a significant proportion of our end users did not have a computer or use the Internet. "The answer to your question, do I use the Internet, is no," (MCI_007) as one person bluntly put it. Others said things such as "[the computer] is just beyond me" (MCI_011), or "I can't operate a website [...] I don't want to [...] I'm just not interested" (MCI_007), or "never done computers really" (SMC_006_dyad).

Margaret said she "had an uneasy relationship with electronics" and found computers "a great source of frustration". Websites, she said, made her "eyes glaze over". Drawing a witty comparison, she said using the Internet was like "going out to get the mail and coming back half an hour later with [...] all these weeds in your hand"—in other words, full of distractions. Moreover, her understanding of the many uses and possibilities of the Internet was limited. Although she emphasised that she "need[ed] to know" what MCI means, it had not occurred to her that she could look it up online. This suggested that even if our participants did use the Internet, there was no guarantee that they would be able to find, or even search for, an informative resource for people with MCI on the Internet.

Even the most digitally literate participants struggled with basic tasks on the computer. One participant, Ellen, was 78 years old and had been putting considerable time and energy into learning how to use computers because she didn't want to "lose touch with everybody and every-*thing*". She had been attending computer lessons for several months when I first interviewed her in 2016. She could see the value in using computers for reminders and prompts, and kept many files on her computer—an old desktop PC—which she categorised according to her specific needs (e.g., health, recipes, church, and so on).

After the interview, I asked Ellen to show me how she used these files. I wanted to see whether we could use her home-grown computer-based strategy as inspiration for our design concept. As she was showing me her files, it became clear that she found it difficult to navigate through the computer. With multiple windows filling the screen, she became frustrated:

> **Ellen:** Now I don't know how to get back to where I was without

coming out of everything. Do you know?

Guy: Okay.

E: Do you click somewhere?

G: I think you can just [click] X there.

E: Yeah, well then that comes out of everything.

G: Does it?

E: Doesn't it? Oh no, it goes back to there. Yeah.

G: You can go back to the other files.

E: Oh that's right. That's right. Thank you.

G: That's it.

E: It's these things I don't know, you see?

G: Yeah.

E: I don't know how to retrieve things, how to go back simple steps.

Based on these insights, Nathan and I were sceptical that an Internet resource would be suitable for our participants. Nevertheless, we proceeded to create an "interactive web-based resource", partly because the original proposal to BRNZ promised that the project would "yield technological advance" (see Appendix A)—a promise we were contractually obliged to deliver, even though some of our users suggested they preferred more tangible information resources such as pamphlets.

However, this did not mean that a website was a completely inappropriate medium—John, for example, said Google was "pretty standard in [his] nature"—or that it could not be 'co-designed' with users (in a participatory sense). Even if the form of the solution had been predetermined, the users could still play an important role in shaping its content and features. With this in mind, Nathan and I set out to organise a co-design workshop (another common design tool) with our users.

Another short aside

If the world is complex and emergent rather than bounded and complete, wouldn't it make sense for depictions of that world to be complex and emergent themselves? If the world transcends the written word, then shouldn't that text somehow try to assimilate the stuff that lies beyond it, hidden from the reader? Shouldn't it somehow try and evoke the unsaid? Make the invisible visible? What about all the things that happen behind the page, that aren't words but immediate happenings? Aren't these just as important to include as whatever it is that ends up on the page, distilled into text?

Co-design workshop

In 2016, Nathan and I invited four study participants to take part in a co-design workshop (see Figure 22). We invited three participants with a formal MCI diagnosis and one significant other who had some concerns about his cognitive performance but no formal diagnosis. Because we wanted to capture a range of experience relating to the use of computers, we chose two participants who were relatively comfortable with computers and had been attending SeniorNet

classes, and two who reported being less comfortable with technology, but were nevertheless hopeful that their input might help others.

Nathan and I worked together to organise and prepare a set of activities for the workshop. These activities, which were conventional idea-generating co-creation tools, were designed to explore our participants' experiences and needs while actively engaging them in the early phases of the design process.

The workshop had two main objectives. First, we wanted to explore and unpack aspects of our participants' day-to-day experience that they felt were most important vis-à-vis changes to their memory and thinking. Second, we wanted our participants to help generate possible concepts for the web resource, reflecting on how it might help address some of their concerns.

Figure 22: Facilitating a co-design workshop with Nathan.

Each activity involved using Post-It notes and a large piece of cardboard. Each board had a number of different headings and sections designed to prompt reflection on what we thought would be some pertinent topics and themes, which had been informed by the interviews that I had conducted so far (see Figure 23). In the first exercise, for example, we wanted to explore how cognitive changes impacted on different areas of our participants' day-to-day experience, and which strategies they found most helpful in managing those particular areas. The two main sections we agreed to use for this activity, and which we imagined would allow us to explore issues most important to our participants, were 'Around the Home' (under which we included the subheadings Cooking, Cleaning, Relaxing, and Technology) and 'Out and About' (which included Appointments, Socialising, and Shopping). These were based on broad problem areas that had been described by interview participants. Participants in the workshop were invited to share their thoughts with the group if they wanted to, while Nathan and I walked around collecting their Post-Its and sticking them on the board.

'Around the Home' and 'Out and About' generated insights to do with some of the everyday challenges our participants faced and how they sought to minimise or overcome them. For example, one participant talked about the difficulty she had "recalling recipes" and how it was necessary to "get all ingredients first". importance of lists when shopping.

AROUND THE HOME

COOKING

MAKING TEA

Use of their essential

[illegible note about computer, display, avoid people interrupting, get all ingredients first]

[illegible note] knowing what to do

RELAXING

BETTER AT ALLOWING SELF NOW WORKING TIME

RELAXING TV AROUND

CLEANING

LESS THAN TIDY SELF

TECHNOLOGY

FORGOTTEN PASSWORDS

[illegible note]

EMBRACING (TRYING) TECHNOLOGY TRYING TO WRITE AND HOW TO SPELL

meaning for elderly eg Mitsubishi

OUT AND ABOUT

APPOINTMENTS

NOTES NOTES NOTES

APPOINTMENTS DIARY AND CELL PHONE

SHOPPING

SHOPPING OVER 3 ITEMS NEED A LIST

RESENT TIME SPENT SUPERMKT. NOT CARE TOO MUCH ABOUT CLOTH SHOPPING

[illegible note]

SOCIALISING

MUCH LESS INCLINED

SOCIALISING WITH FRIENDS A.SA [illegible]

[illegible note about names, remembering]

RECALLING NAMES NOW NOT NEXT WEEK

retrieval asking each other to really listen - lack same question and don't listen for answer

MOBILITY

DRIVING. TOO STIFF TO LOOK BEHIND.

Figure 23: The outcome of a workshop activity designed to collect data on our participants' everyday experience.

Figure 24: Another workshop activity exploring different aspects of our participants' day-to-day experience. Cognitive changes or 'MCI' were just one aspect of a much broader concern about ageing in contemporary society.
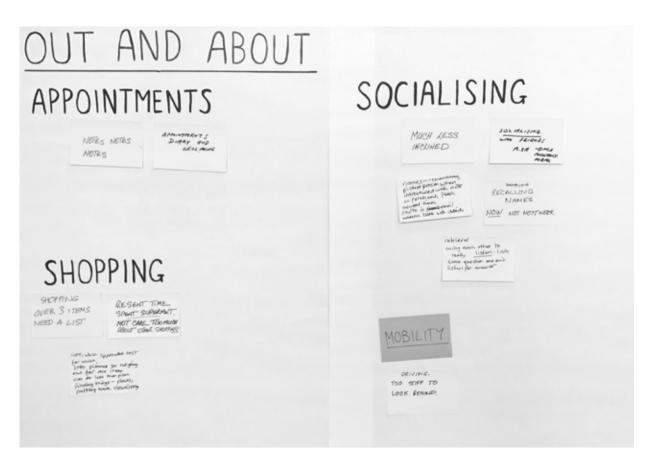
Another talked about how the "use of [a] timer [is] essential" to avoid the danger of forgetting about something cooking on the stove. Some participants had strategies for remembering important appointments. One wrote "notes, notes, notes", and another "diary and cell phone".

These concerns and strategies reflected what I had heard during interviews about how people managed changes to their memory and thinking. However, as Nathan and I delved deeper into their concerns and strategies around venturing 'Out and About', our participants' responses started to shift from having to do with cognitive changes, and towards other personal changes associated with ageing in general. Under 'Socialising', for example, one participant wrote that she was "much less inclined".

A discussion ensued about how our participants imagined they were perceived by others in social contexts. This became a major focus of the next exercise, derived from a conventional empathy mapping tool (Kelley & Kelley, 2013), in which we asked participants to reflect on the ways in which cognitive changes (still assuming this was the most important issue for people with MCI) related to 'Thinking', 'Feeling', 'Doing' and 'Belonging'—in other words, how MCI made them think, how it made them feel, how it affected what they did, and how it impacted on their social relationships.

Again, what was interesting about our participants' responses in this exercise was how few of them referred to cognitive changes at all. Although it had been made clear that the purpose of this workshop was to explore changes to memory and thinking, this was not necessarily the most important issue. Participants seemed much more concerned with the realities of ageing in a broader sense— social isolation, loneliness, feeling undervalued—and how the web resource might help address these. While responses to the 'Thinking' section included some of the expected difficulties associated with MCI ("forget words, train of thought", "categorising/sequencing"), the vast majority of comments did not directly relate to cognitive changes (see Figures 24 & 25).

Figure 25:. Post-It notes from the workshop.

For instance, one participant wrote "[I] want to still be part of what's happening" and indicated that she felt "no longer in mainstream". Similarly, under the 'Feeling' section, participants talked about "feeling out of the loop" and described a "loss of identity", "[feeling] like a ghost", "faceless w/out value", "decrepit" and "shut out – not relevant". One participant wrote "relinquishing dreams" under 'Doing', and another indicated under this section that they were "powerless, not able to make change." It is possible that participants were referring specifically to changes to their memory and thinking, but the narratives around these ideas seemed to bemore broadly linked to ageing rather than cognitive changes. To highlight some other examples, participants wrote under 'Belonging' that "people were no longer interested in [their] views" and that they were "being treated as a child". The word "faceless" appeared again in this section, and the same participant suggested that "people make assumptions about [her] and act accordingly".

These concerns about broader age-related changes (i.e., the social rather than cognitive aspects of ageing) were also evident during an idea-generating exercise in which participants made suggestions for website capabilities under the heading, "This website could be a place to…" One participant suggested that the web resource could be place for "emotional education about ageing". When we asked her to elaborate on this, she said that it could be a place for younger people to learn about the realities of old age, because most younger people, she said, don't have any idea what it is like to be old.

As a result of this, she continued, many people have unrealistic expectations for older people and sometimes treat them in ways that can be disrespectful or inappropriate. Other participants appeared to agree with this point, suggesting that the resource could be a place to "share stories/experiences [about] changing circumstances [of old age]". Another suggested that the website could be a place for "community support", while another, who lived alone, speculated that the website could be used to find out "what's going on locally and in [the] community".

Many of the issues to which these ideas were proposed as possible solutions related to staying connected with friends, family, and the wider community, suggesting that loneliness and isolation were just as important, if not more so, than memory problems.

Excerpt from Critical Reflection session with Nathan

Nathan: If you have MCI, sure, you have a mild impairment, as defined by a particular clinical definition, but that may be pretty insignificant in terms of how it impedes or impacts on your daily living, versus being lonely or social isolated. You could live a pretty 'normal' life with a mild cognitive impairment, but have tremendous benefits from staying socially connected and engaged.

Guy: It's so difficult to balance the funders expectations around designing a product for specific kind of neurological condition and then actually finding that the users have these much broader concerns around ageing. How is what we've designed so far being responsive to these bigger concerns? Is it?

N: No, I mean, I think you'd be better off making a website that's about supporting and assisting older people's engagement in the community or social activities [...] I think if you focus too much on the label then people can get quite down about it *NEGATIVE* and perhaps they identify with that label in a way that is *ASSOCIATIONS* detrimental to their daily living. *OF 'DECLINE'*

G: Is that a possible risk of the website [...], like, kind of emphasising MCI and focusing on the negative aspects of cognitive decline?

N: Yeah, potentially. I think if we reframed the site so that *NOW* *WANTING TO* it's more [about] ageing gracefully or something [...]. *MOVE AWAY* *FROM MCI* *LABEL.*

G: When you think about it, it's so narrow, focusing on MCI. Is that really what people are concerned about?

(MCI)
N: No. They don't even know it's a thing [...] Pretty misled to think that such a narrow, poorly defined, controversial diagnosis is something that can have a whole website resource created around it that people are actually going to engage with and understand.

TODAY I'M SITTING IN A LECTURE THEATRE AT THE UNIVERSITY OF SHEFFIELD ATTENDING THE 14TH ANNUAL "ASSOCIATION FOR THE ADVANCEMENT OF ASSISTIVE TECHNOLOGY IN EUROPE" (AAATE) CONFERENCE. HAVING BEEN TO ABOUT A DOZEN PRESENTATIONS SO FAR, I'M LEARNING THAT THE FIELD OF ASSISTIVE TECHNOLOGY CONSISTS LARGELY OF PILOT TESTING NEW MEDICAL PRODUCTS, MEASURING THEIR PSYCHOLOGICAL A PHYSIOLOGICAL IMPACT, THEN EVALUATING THE "FACILITATORS" AND "BARRIERS" TO THEIR "UPTAKE" AMONG VARIOUS CONDITION-BASED USER GROUPS. JUDGING BY THE HEAVY BRANDING OUT IN THE FOYER, WHERE PRODUCTS ARE DISPLAYED AND DEMONSTRATED DURING THE MORNING AND AFTERNOON-TEA BREAKS, COMMERCIAL VIABILITY APPEARS TO BE THE PRIMARY/DESIRED OUTCOME. PEOPLE WITH MCI ARE A PROMINENT USER GROUP IN THIS YEAR'S CONFERENCE PROGRAMME, WITH SEVERAL PRESENTA- TIONS MENTIONING 'MCI' IN THEIR TITLE. THE PRESENTATION I AM LISTENING TO RIGHT NOW IS ABOUT A ROBOT DESIGNED FOR PEOPLE WITH MCI. LOOKING AT THE PHOTOS ON SCREEN, I'D SAY THE ROBOT IS ABOUT FOUR OR FIVE FEET TALL. IT HAS WHEELS, A TOUCH SCREEN WITH MULTIPLE FUNCTIONS, AND A HUMANOID HEAD WITH LARGE, BLINKING EYES (WHICH SEEM TO HAVE NO APPARENT FUNCTION OTHER THAN TO MAKE IT APPEAR MORE HUMANLIKE AND HENCE [PERHAPS] FRIENDLIER. ONE OF ITS MANY PURPOSES, IS TO SERVE AS A SOCIAL COMPANION FOR PEOPLE WITH MCI. (AT NO POINT IN THIS PRESENTATION IS THE MCI CATEGORY DEFINED OR DISCUSSED IN ANY DETAIL, THOUGH WHAT IS MENTIONED HAS THE EFFECT OF MAKING IT SOUND LIKE A SERIOUS MEDICAL CONDITION THAT OLDER PEOPLE ARE "SUFFERING" FROM.) YESTERDAY IN A SESSION ON "INNOVATIVE METHODS" I PRESENTED A CRITICAL PERSP- ECTIVE ON MCI AND TALKED ABOUT HOW THE EXPANDING BOUND- ARIES OF DEMENTIA CREATE NEW CATEGORIES OF 'IMPAIRMENT' THAT REDEFINE 'NORMAL' AGEING, GENERATING NEW USER GROUPS WITH ASSUMED NEEDS. HERE IS A CASE IN POINT. THE PRESENTER MAKES NO DISTINCTION BETWEEN MCI AND MORE SERIOUS FORMS OF COGNITIVE IMPAIRMENT, AND SHE SEEMS TO REGARD THE NEEDS OF PEOPLE WITH MCI AS EQUIVALENT TO THOSE OF PEOPLE WITH MODERATE TO SEVERE DEMENTIA (EVEN THOUGH THE 'SYMPTOMS' OF MCI,

ACCORDING TO ITS CLINICAL DEFINITION, DO NOT INTERFERE WITH THE PERSON'S EVERYDAY ACTIVITIES — AN IMPORTANT DISTINCTION THAT SEEMS TO HAVE BEEN COMPLETELY OVER-LOOKED (PERHAPS INTENTIONALLY?) BY THIS PRESENTER AND HER ~~TEAM~~ TEAM). IN A VIDEO CLIP PLAYED DURING THIS PRESENTATION, AN OLDER WOMAN IS SHOWN STANDING IN FRONT OF THE ROBOT AS IT INSTRUCTS HER TO RAISE HER ARM, THEN LOWER IT, THEN RAISE HER OTHER ARM, AND LOWER IT. THE PRESENTER THEN COMMENTS ON THE ROBOT'S ABILITY TO ENGAGE OLDER 'USERS' IN THESE SORTS OF PHYSICAL EXERCISES, ~~CITING~~ CITING THIS AS EVIDENCE OF ITS VALUE AND EFFECTIVENESS AS A HEALTH INTERVENTION. THE PRESENTER TELLS THE AUDIENCE THAT PEOPLE WITH MCI AND THEIR "CAREGIVERS" (~~AND~~ AND NOW I'M WONDERING AT WHAT POINT ALONG THE SPECTRUM OF COGNITIVE DECLINE A PERSON'S ~~PARTNER~~ PARTNER BECOMES THEIR "CAREGIVER") FIND THE ROBOT BOTH ATTRACTIVE AND USEFUL. I PERSONALLY THINK THIS EVALUATION IS SELF-FULFILLING, OR MAYBE THE PARTICIPANTS SIMPLY DON'T WANT TO OFFEND THE RESEARCHERS. ~~ALSO~~ ALSO, ITS MULTIPLE FUNCTIONS ARE CLEARLY BIASED IN FAVOUR OF A ~~WESTERN~~ WESTERN BIOMEDICAL VIEW OF AGEING — MEDICATION ADHERENCE, PHYSICAL ACTIVITY, BRAIN TRAINING, ETC — AND DO NOT NECESSARILY RESPOND, AS FAR AS I CAN TELL, TO WHAT MATTERS MOST TO THE USERS (WHO SURELY HAVE A RANGE OF MORE IMMEDIATE CONCERNS THAT DO NOT RELATE TO MCI AT ALL). TO THE EXTENT THAT THIS COMPANION ROBOT RESPONDS TO SOCIAL ISOLATION, I WONDER WHETHER IT MIGHT ONLY MAKE THINGS WORSE BY LIMITING THE AMOUNT OF REAL **HUMAN** INTERACTION THE PERSON RECEIVES. THE WOMAN IN THE VIDEO CERTAINLY LOOKS LONELY, INTERACTING WITH A BOGGLE-EYED MACHINE AT THE FOOT OF HER BED, PRACTICALLY SHOUTING AT HER TO DO HER EXERCISES. IT'S CLEARLY AN IMPRESSIVE FEAT OF ENGINEERING, THIS ROBOT, BUT THE PROJECT AS A WHOLE SEEMS ~~TO~~ TO BE BASED ON SOME PRETTY QUESTIONABLE ASSUMPTIONS ABOUT MCI AND AGEING AND OLDER PEOPLE AND WHAT THEY ACTUALLY NEED. I HAVE HEARD THE TERM 'USER-ENGAGEMENT' MENTIONED SEVERAL TIMES AT THIS CONFERENCE SO FAR, BUT ONLY

IN REFERENCE TO USEABILITY TESTING AND ~~STRIKETHROUGH~~
PRODUCT VALIDATION, AND NOT IN THE CONTEXT OF
FRONT-END DESIGN RESEARCH. CO-DESIGN, GENERALLY
SPEAKING, APPEARS TO BE A PERIPHERAL SUB-INTEREST
OF THE ASSISTIVE TECHNOLOGY FIELD. I CANNOT IMAGINE
ANYONE I HAVE INTERVIEWED ~~STRIKETHROUGH~~ USING THIS MACHINE. FOR ME
THE WHOLE THING HIGHLIGHTS THAT ~~STRIKETHROUGH~~ CRITICAL REFLECTION
NEEDS TO BE EMBEDDED IN THESE SORTS OF PROJECTS, RATHER
THAN LEAVING IT UNTIL IT IS TOO
LATE, WHEN THE ~~STRIKETHROUGH~~ THING
ALREADY HAS ONE ~~STRIKETHROUGH~~
SWIVELLING FOOT IN
THE WORLD.

3D SENSORS!

CHEST-MOUNTED iPAD WITH ~~STRIKETHROUGH~~ **OPTIONS!**

BUILT-IN STORAGE!

EMERGENCY ALARM!

A ROBOT ~~STRIKETHROUGH~~ COMPANION FOR PEOPLE SUFFERING FROM **MCI**.

NAVIGATION LASER!

4WD!
(NOTE: ~~STRIKETHROUGH~~ MAY NOT ACTUALLY BE 4WD.)

AAATE
12 SEPTEMBER 2017
SHEFFIELD, UK

Figure 26: The workshop enabled participants to generate suggestions for what the website could be, do, and look like.

Based on the co-design workshop, Nathan and I identified six possible website functions following an analysis of the data generated (see Figure 26). These were (1) Information & Education; (2) Sharing Stories; (3) Sharing Strategies; (4) Peer-to-Peer Support; (5) Events; and (6) For Families. Below I will summarise each of these in turn.

Information and Education

Participants in the co-design workshop (and interviews) expressed that they wanted the web resource to provide information, particularly around brain health and the difference between 'normal' and 'abnormal' memory for age.

Sharing Stories

They also emphasised that they would like to learn from and connect with other people who are similarly experiencing changes to their memory and thinking. This supported the brief's original suggestion that the online resource would provide a platform of 'stories' that people could share and read.

Sharing Strategies

Similarly, participants said they wanted to know what other people were doing to manage their cognitive changes so that they could learn from others in a similar situation.

Peer-to-Peer Support

Others suggested that they wanted to connect and interact more directly with people who were experiencing changes to their cognitive function**.**

Events

Another suggestion was that the website could help users find out about what was happening in the wider community. This reflected the social concerns around loneliness and isolation and was not directly related to cognitive changes.

For Families

Participants also expressed the need for information specifically for family members and significant others. This information, participants suggested, would need to provide family members with knowledge about how to better support someone experiencing changes to their memory and thinking.

Sharing Strategies

Share everyday strategies for managing changes to your memory and thinking, and learn new strategies from others

Sharing Stories

Share your experiences and stories about how changes to your memory and thinking impact on your day-to-day life, and learn about the experiences of others

Peer-to-Peer Support

Connect and interact with people who are going through similar changes to memory and thinking

Information & Education

Find out more about cognitive changes, their relation to the ageing brain, and how to 'live well' with changes to your memory and thinking

Events

Find out about things that are happening in your local or wider community e.g. Senior Net classes.

For Families

Information for family members on how to better support those experiencing changes to their memory and thinking

Figure 27: Card sorting exercise. Nathan and I developed six cards to represent six possible website features.

Using these six categories, Nathan and I developed a card sorting exercise that I could carry with me as I continued interviewing study participants from Living Well with MCI (see Figure 27). Card sorting is a conventional UX research method commonly used to help organise and structure digital content according to user preferences (Righi et al., 2013). Each card corresponded to one of the six categories listed above. At interviews, I asked participants to arrange the cards in order of preference from most to least important (see Figure 28). This process helped determine where features should go within the hierarchy of content.

Card sorting narrows the range of possible design options down into something manageable (Righi et al., 2013). It also ensures that the design features will resonate with users. However, what it perhaps overlooks is the extent to which

individual users are themselves ensconced within dominant biomedical discourses and ways of thinking, and how these discourses might shape their apparent wants and needs. While card sorting theoretically gives users a certain degree of agency and control over what the design outcome should include and leave out, in our project I observed that the process also narrows down the possible ways in which 'cognitive changes' could be thought about and designed for, as I explain below.

As it turned out, *Information & Education* was the most preferred category and therefore seen as the most important component to include in the web resource. Unsurprisingly, people wanted knowledge about ageing in relation to cognitive impairment, since knowledge is seen to empower individuals to take control of and 'manage' their lives (Rose, 2001). That users chose 'information' and 'education' as the most desired feature was significant from a design anthropological perspective, since this invited into our website a dominant biomedical discourse that would ultimately frame both ageing and cognitive impairment as a medical problem—as I discuss in more detail in the next chapter.

As a pivotal moment in our design process, the card sorting exercise 'materialised' this particular discursive framing of ageing and cognitive impairment, making it difficult to think and talk about alternative (i.e., non-medical) frames of reference. Represented through our card sort exercise as an 'option' for the website—an option we presented based on what participants had talked about in interviews and at the workshop—information and education became a central feature. Naturally, they wanted reliable information about the ageing brain from trustworthy sources—which, as we shall see in the next chapter, meant 'scientific' information from biomedical sources.

Figure 28: A card sorting activity with participants. The purpose of this was to determine the heirarchy of content based on the six possible website features.

Prototyping an online resource

Prototyping was a process of solidifying and consolidating our ideas, based on our interactions with users. In addition to this, I observed that it was also a mechanism for solidifying biomedical discourses around ageing and age-related changes. After the initial co-design workshop, Nathan and I sat down together and started to create a low-fidelity paper prototype of the website that we could take back to our participants for their input. Paper prototyping is a UX method that is

commonly used in usability testing contexts, often to create website 'wireframes' (Still & Morris, 2010). Wireframes are a kind of blueprint that represents the basic structure of a website without any aesthetic detail (i.e., imagery or colour). Paper wireframes are used in UX design to relay the main elements—that is, its primary features and functions—back to the users so they can then cut out and rearrange them according to their preferences.

At a table in the DHW Lab, Nathan and I laid out a large piece of paper in front of us, representing the window that would contain the website. Along the top, Nathan drew a navigation bar and cheekily wrote a draft domain name: 'www.mymci.co.nz'. I started writing and drawing on some smaller pieces of paper, representing a few basic modules based on what we and our participants identified as the website's three most important features: information and education, sharing stories, and sharing strategies. Along a wall next to the table were the large pieces of cardboard we used in the workshop. We referred to the Post-It notes as we made decisions about which features to include, and which to leave out. As we moved the pieces of paper around on the table, trying out different layouts and imagining what the end result might look like, a website started to emerge (see Figure 29).

Although we had so far managed to avoid using the term MCI in the wireframes, I noticed how this emerging website was beginning to frame the experience associated with MCI in increasingly medical terms. Not recognising the extent to which I was myself embedded in biomedical discourses, I sketched a little box titled 'health tips and advice' and another titled 'understanding changes to your memory and thinking', and placed these on the large piece of paper. We were not yet sure what the actual content of these boxes would look like, but as we looked at what our participants had written in our workshop, we envisioned that they would be filled in with health information—perhaps with the help of the steering group psychiatrist. As we refined our thinking with the help of our steering group, Nathan and I developed some higher resolution wireframes (see Figures 30 & 31)..

Figure 29: An early paper prototype of the website wireframes. Nathan and I drew various features and modules based on workshop and interview data.

LIVING WELL WITH AGE RELATED CHANGES TO MEMORY & THINKING

Description of value proposition to end user

Understanding Changes to Your Memory and Thinking

Aging is a natural part of life but how we age is different for everyone. Some people start to experience changes to the way they think or whether they remember certain things....

DIAGRAM

● Some informative sentence about the effects of aging on the brain and associated changes to memory and thinking...

● Another informative sentence about the effects of aging on the brain and associated changes to memory and thinking...

● Yet another informative sentence about the effects of aging on the brain and associated changes to memory and thinking...

Health & Wellbeing

Aging Well

Tips about aging well and staying active physically and mentally

Healthy Hearts, Healthy Minds

Tips about aging well and staying active physically and mentally

Technology and the Mind

Tips about using technology to improve memory and thinking

Healthy Hearts, Healthy Minds

Tips about aging well and staying active physically and mentally

Website Name

Home

Stories

Strategies

About

Login to your account

yourname@email.com

your password

LOGIN

Figure 30: A more refined version of the website wireframes. These were developed from our earlier drawings (Figure 29). This page was designed in response to our user preferences for information and education about the 'ageing brain'. It shows some possible links and resources about staying well, reflecting our intention to keep t positive by emphasising wellness rather than 'decline'.

SHARE YOUR STORIES AND EXPERIENCES

A place to share stories and experiences with other likeminded senior citizens.

SHARE A STORY

Popular Stories

PLAY

Featured Story

The Key to Unlocking Your Mind is Clear
3:40 mins

By Brain Research Centre NZ

Description of story. Placeholder text goes here. More placeholder text follows with further information about the story.

Recent Stories

1:34 mins

2:56 mins

2:15 mins

Dealing with changes to your memory and thinking

How I embraced my condition and my identity

Who decides what 'normal' agining is anyway?

Website Name

Home

Stories

Login to your account

yourname@email.com

your password

Figure 31: Wireframes showing 'stories'. Some of the language in this page reflects some of the conversations that Nathan and I were having at the time about what 'normal' ageing is, and whether it is possible to embrace MCI as a label.

An interlude about designing for people 'with psychosis'

In 2016, while working at the DHW Lab, some colleagues began working with clinicians on a website for younger people experiencing psychosis. According to Medline Plus, a US website whose headline is 'Trusted Health Information for You', "psychotic disorders are severe mental disorders that cause abnormal thinking and perceptions. People with psychoses lose touch with reality. Two of the main symptoms are delusions and hallucinations" (Medline Plus, 2019).

The DHW Lab designers recognised that negative descriptions of this kind are unhelpful when it comes to understanding what people actually experience, so they engaged younger people with psychosis in the design process to learn from them directly, employing a range of design tools and techniques to do so. Not only did this approach allow the team to explore what mattered most to the users, it also allowed younger people experiencing psychosis to contribute to the project in a meaningful way. For example, medication adherence, which had been the original focus of the project, turned out to be less important for the users than it was for clinicians, so this was de-emphasised.

The design tools revealed that users wanted reliable information about psychosis, somewhere to share stories, and ways of connecting with and learning from other people in similar situations. The final web resource, Talking Minds (2019), provides educational and social support to people experiencing psychosis and is a good example of designing with, rather than for, end-users.

However, the well-intentioned focus on individual users and their needs meant that the project overlooked the deeper issue of how psychosis is currently conceptualised and framed by biomedicine, which could be problematic. Information about psychosis, for example, was clearly rooted in a reductive materialist paradigm, as the following segment from the Talking Minds website shows:

Psychosis has been linked to changes in neurotransmitter activity within specific areas of the brain. There are many different neurotransmitters in the brain including dopamine, serotonin and noradrenaline [...] For a person experiencing psychosis, there can be too much or too little activity of the neurotransmitter dopamine in certain parts of the brain. These changes in dopamine activity can affect our usual thought processes (Talking Minds website, accessed April 2019).

Here, psychosis is presented as a condition linked to biological processes in the brain and therefore amenable to pharmaceutical intervention. While this description may present a partial picture of psychosis, it also ignores other valid (and potentially more helpful) interpretations. To illustrate this, I will draw on some anthropological literature in the following paragraphs to offer an 'alternative' way in which to think about psychosis, including its cause and potential treatment—one that may have been important for the designers to consider, but which was unfortunately overlooked because the project was so entangled in discourses of biomedical truth.

A recent World Mental Health Survey showed that psychosis most commonly occurs in the transition between adolescence and adulthood (McGrath et al., 2016), a period during which younger people can experience tremendous psychological, emotional, and social stress. Sometimes the cumulative pressure of these various forms of stress can produce what psychiatrists Christina and Stanislav Grof (1989) have termed a 'spiritual emergency'—defined as "critical, experientially difficult stages of profound psychological transformation involving one's entire being" (Watson, 1994, p. 23)—which shares many of the same characteristics as psychosis and is commonly mistaken for mental disorder.[11]

Spiritual emergencies can be especially difficult in cases where the younger person has no mythological or symbolic frames of reference with which to make sense of the experience (Grof & Grof, 1989). As the anthropological literature suggests, myth and ritual have been central to the transition from adolescence to adulthood for most human cultures throughout

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[11] Christina and Stanislav Grof do not claim that *all* cases of psychosis are 'spiritual emergencies'— simply that the two are often conflated due to modern biomedicine's reluctance to acknowledge the psycho-spiritual dimensions of human health.

history. Initiation rituals, for example, appear to be universal. They involve a symbolic death and rebirth motif in which participants shed their old status as dependent adolescents in order to be 'reborn' as competent and self-responsible adult members of their society (Turner, 1967).

As psychologist Carl Jung has pointed out, myth and ritual are psychologically important because they symbolically reflect the archetypal stages through which the developing psyche passes on the way to fully individuated ego consciousness (see, for example, Neumann, 1954). The two go hand in hand: rituals are symbolic re-enactments of myths; myths are symbolic representations of deep archetypal and psychological realities (Neumann, 1954). The primary function of myth and ritual historically, in other words, has been to support and organise the developing human psyche (or in ancient terminology, 'soul').

In contemporary society, where myth and ritual play increasingly marginal roles in social life, and where adolescence extends indefinitely (perhaps even as a result of this) (Smith & Snell, 2009), many younger people are forced to make this psychological (or 'spiritual') transformation (or 'journey') alone—that is, without the psychological support of inner 'maps', such as well-established myths, rituals, or other symbolic forms and metaphors to guide younger people through these thresholds of passage.

From a Jungian perspective, the transition from adolescence to adulthood can involve (symbolically speaking) a descent into the Underworld, during which one may encounter archetypal imagery and projections arising from deep within the personal and collective unconscious (Neumann, 1954).[12] In premodern cultures, those individuals who grappled with this inner terrain most intensely were called shamans. Shamans were recognised as those who underwent a profound psycho-spiritual crisis in early adolescence and, with proper guidance from older members of the community, emerged from the experience with privileged insight and expanded consciousness (Campbell, 1972, p. 204).

It is conceivable, then, that individuals experiencing what modern people call 'psychosis' have plunged into "the same deep inward sea" as mystics and shamans, but, lacking the psychological support of myth and ritual, find they cannot swim (Campbell, 1972, p. 209).

What if the 'symptoms' of psychosis are the outward manifestation of these complex, inner, psycho-spiritual processes? What implications would this idea have for an online resource, if it were to be taken seriously by health providers? While acknowledging the 'spiritual' dimensions of human health and development might make many contemporary Western clinicians and researchers uncomfortable, there is growing evidence that 'spirituality' is associated with better health outcomes among adolescents (Cotton et al., 2006), and especially younger people experiencing psychosis (Ho et al., 2016).

The point is that the psychosis project, like Living Well with MCI, was shaped by knowledge that, in claiming to be 'objectively true', closed off other possible frames of reference that might have been valid and useful. Indeed, an alternative non-biomedical, non-materialist reading of psychosis may in fact be what people need in order to make sense of and cope with their immediate experience.

When viewed from the perspective that at least some forms of psychosis could be considered 'spiritual emergencies', it is not surprising that one of the participants in the Talking Minds project said that the website needed to be her "Salvation". Perhaps this comment speaks of a genuine need mythological language, or at least some alternative to the system that labels, medicates, and, in many cases, institutionalises those who deviate from an increasingly narrow   definition of 'normal'. Perhaps these mysterious psycho-spiritual phenomena can be deeply meaningful and transformative, if only people had the proper support and guidance to see the journey through.

My claim here is that important perspectives are overlooked when biomedicine is presented as the only 'true' way to think about variations in human experience. For me this highlights the importance of opening up space for to incorporate 'alternative' (i.e., non-biomedical) worlds in design for health research.

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[12]The ontological status of the 'collective unconscious' or 'archetypes', to the extent that they exist, cannot be validated from the perspective of biomedicine due to its commitment to scientific materialism. Hence these ideas are often regarded as unscientific. However, this conception may be changing with the new science of psychedelics, which is beginning to shed light on these mysterious inner dimensions of conscious experience (Pollan, 2018).

Summary

A presumption underpinning many design for health projects is that people who share the same health condition, or use the same system or service, have shared experiences and needs that can be identified using design tools. However, as this chapter has shown, Living Well with MCI provides a number of empirical examples where design tools, rather than helping us understand 'MCI' as such, instead seemed to undercut the legitimacy of MCI as a valid description of end-users and their experience. The tools did not help us understand what it is like to live with MCI (as if there were a 'typical' MCI experience that our participants had in common) so much as the changing circumstances of life as an older person, of which the memory problems associated with MCI, and the experience of its apparent 'symptoms', were only a part. Many of the experiences we explored and discussed in the co-design workshop were not related to the symptoms and experiences that health professionals commonly ascribe to MCI. Loneliness, exclusion, and negative social attitudes were all highlighted as equal, if not more important, problems for which the web resource was imagined to be a partial solution.

Because cognitive changes seemed to be only one (and often a relatively minor) aspect of our participants' day-to-day experience, Nathan and I identified a tension between meeting our user's needs and concerns while simultaneously meeting our funder's expectations—which was, as stated in the design brief, to design a website for people living with MCI (i.e., for individuals who are thought to fall somewhere between normal age-related cognitive decline and dementia). To ignore what appeared to be our participants' more pressing social concerns around ageing, and instead focus on those specific problems that characterise the MCI category, was to risk designing a website that did not meet our users needs and concerns. After all, the primary goal from a UX design perspective was to advocate for the wants and needs of users, and to thereby develop a website that our participants would find useful, useable, and desirable (Buchanan, 2001).

I have argued in this chapter that design tools tend to gloss over important social, cultural, and historical processes such as medicalisation, and therefore ignore the extent to which certain clinical realities are assembled 'by design'. Rather than recognising the complex ways in which public health problems and illness populations are socially constituted, design tools focus exclusively on individual experiences, behaviours, wants and needs. Put another way, design tools may help designers to 'empathise' with end users and their experience, but they are unable to interrogate and question the biomedical framing *of* that experience.

As I will argue in the next chapter, projects in the 'design for health' space often perpetuate medicalising discourses because these discourses conduct the conduct of designers.

Figure 32: The Grey Matters website in progress after a session with the wider steering group.

8.
Deliver

The final stage of the Double Diamond model is 'Deliver', where the product—in this case a website for people with MCI—is finalised, tested, validated, and put out into the world. In this thesis, 'Deliver' refers to the final stage of the Living Well with MCI project, but also to the ways in which the Grey Matters website helped give form to (i.e., 'delivered') certain ideas about ageing, risk, and self-care. For example, to what extent does the website reproduce the notion of 'successful ageing', and in what ways does it evoke anxieties around ageing 'badly'? And how do these ideas, when given material form, shape the ways in which people think about and respond to the changes associated with ageing?

The inspiration for this chapter arose while interviewing Living Well with MCI participants. During these interviews, I started to sense that there was a relationship between people's fears of cognitive decline, and the consumption of products such as brain training games, vitamins, board games, pharmaceutical drugs, and crossword puzzles. Participants often referred to these as strategies for slowing or preventing cognitive decline, and some suggested that the efficacy of these products was supported by modern science.

Whether or not these were effective did not really interest me. Rather, it seemed to me that these participants were thinking and talking about cognitive decline in ways that aligned with the expectations of modern capitalism, where products are presented as consumable solutions to life's problems. I began to wonder whether the discursive forces that had given rise to, for example, self-monitoring technologies and other consumable self-care products, might be operating in and around the Living Well with MCI project.

This chapter seeks to address the following questions: to what extent does Grey Matters help 'materialise' neoliberal health policies, which aim to transfer a 'burden of care' from governments to individuals? In what ways were the roles of 'researcher' and 'UX researcher' shaped by these discourses? And to what extent was I successful in challenging these discourses through my conduct as a 'design anthropologist'?

Governmentality, biopolitics, and neurocultural products

Foucault (2007) coined the term 'governmentality' to describe the ways in which individuals willingly participate in their own self-governance. He developed this concept (a combination of the words 'government' and 'rationality') after observing a tension at the heart of liberal democratic societies: namely that modern governments must find ways to effectively regulate the behaviour of individuals without restricting their freedoms (Foucault, 2007; Lemke, 2002).

A neoliberal model of governance, Foucault (2007) suggested, is characterised by a paradoxical use of freedom as a tool to organise, manage, and control individual subjects. As such, the concept of governmentality refers to a 'conduct of conduct' where the thoughts, attitudes, bodies, and behaviour of individuals, while apparently free, are in fact shaped and regulated (i.e., 'conducted') by a dominant discourse of self-responsibility (Rose, 1998). Within the context of public health, this indirect strategy of governance shifts attention away from certain state obligations by placing the burden of care on individuals (Lupton, 1995; Rose, 1998; Rose 2010).

Foucault was interested in how people internalised certain forms of knowledge and discourse, and how these, in turn, regulated behaviour on behalf of the state— that is, how it conducted their conduct. This process of internalisation is evident within the context of the MCI diagnosis and its interpretation, the construction of which can be seen as a form of 'biopolitics'—the political administration of the body for purposes of governance. For example, one of the consequences of MCI

is that the category redefines socially 'acceptable' levels of cognitive function for age (Katz, 2012) and, in lowering the threshold for diagnosable impairment, helps construct a new population of what Rose (1998) calls 'risky individuals'—i.e., people who are perceived to present a future risk to themselves and others as potential sufferers of dementia.

Within the context of a contemporary 'risk society' (Beck, 1992), where dementia is commonly framed as an economic burden on society (and therefore the state) (Rose & Abi-Rached, 2013), the MCI category helps clinicians and the wider public identify, and make visible, risky individuals who are seen to be 'ageing badly'. As such, governmentality in this context refers to the production of MCI as a form of 'risky' subjectivity that is intertwined with governmental aims and objectives—in this particular instance, to reduce the economic burden of an ageing population.

Supporting these governmental aims and objectives is the belief that bioscientific (and especially neurobiological) advances are key to understanding and identifying the distinction between 'normal' and 'abnormal' ageing (Rose, 2010). Despite the deep uncertainty surrounding MCI as a diagnostic construct, the category is supported by a biomedical understanding of the brain, which, in turn, is grounded in claims of objective scientific truth.

When viewed from the perspective of biopolitics, much of the scientific activity that surrounds the MCI construct produces what Rose (2003) calls the 'neurochemical self'—a kind of subjectivity that leads to a "recoding of everyday affects and conducts in terms of their neurochemistry" (p. 46). This, as Rose (2003) points out, is the most recent manifestation in a broader historical shift towards "understand[ing] our minds and selves in terms of brains and bodies" (p. 46). It is in the context of this dominant discourse that John, a Living Well with MCI participant, formulated his interpretation of MCI:

> I now know a lot about my situation. You know, it's in the front of the brain, still got lots of stuff stacked at the back here. Only, you know, one seventh or one ninth of my brain is affected, the other eight parts are going well.

Similarly, one MCI participant believed that her memory and thinking problems had to do with the presence of "something funny in my brain or blood" (MCI_013_dyad), and another supposed that there was "something wrong with my brain" (MCI_015_dyad). Another participant told me that, since being diagnosed with MCI, he had started learning about "what's missing in the brain" (MCI_021_dyad). Such statements were linked to the belief that 'abnormal' cognitive function can be objectively detected in the body with the same certainty as other conditions such as diabetes and cancer (which is, unfortunately, not the case [Lock, 2013; Rose & Abi-Rached, 2013]).

This bioscientific style of thought is related to other discourses that shape popular notions of ageing and what it means to be an older person in contemporary society. The image of the demented individual, for example, who in popular culture is often depicted as a bewildered zombie-like figure (Behuniak, 2011), sits in stark contrast to the image of one who embodies the modern paradigm of 'successful ageing' (Bowling & Dieppe, 2005)—one who is autonomous, productive, fit, and healthy.

Part of this successful ageing discourse is the idea that one's risk of developing dementia must be closely self-monitored (Williams et al., 2012). As Rose (2003) suggests, this idea is deeply connected with neoliberal strategies which

> oblige the individual to engage in constant risk management, and to act continually on him or herself to minimise risks by reshaping diet, lifestyle and now, by means of pharmaceuticals, the body itself. (pp. 58-59)

Hence successful or 'active' ageing implies that it is the individual's personal

responsibility—indeed, one's moral duty as a productive and responsible member of society—to engage in the self-monitoring and self-management of risk through various health-promoting behaviours.

As I engaged with participants on the Living Well with MCI project, I discovered that many had internalised bioscientific discourses of risk and self-care. Julie, for instance, a 79-year-old participant who was concerned mostly about her husband's memory and thinking rather than her own, was learning a second language to maintain cognitive health. Note the neurochemical language used in her rationale for this:

> Maybe [learning a second language] makes new connections in your brain. I think this is the thing. It's all the time maybe strengthening connections, every time the, neuron, you know, you have the word, neurons is it? Where they meet and there's the connection, and, you know, you get the chemicals across that gap and every time you're using [a second language], maybe that strengthens it and maybe it uses new connections [...] Time and time again I've read that they say if you use, learn and use a second language, it staves off Alzheimer's by three years four months. Well, to me that's worth it. If I can get another three years four months without going down the Alzheimer's track, I'm going to do it because I've seen my Dad and I don't want to go that way.

Her husband, Albert, added to this that he thought learning a second language might "keep one's brain cells going a bit longer"—something he and his wife had learned from "quite respectable sources". In a similar way, another participant wondered what he could do to "keep the memory cells going" (MCI_013_dyad).

This persuasive neurocentric style of thought, combined with contemporary attitudes towards the self-monitoring of risk, underpins an emerging market of 'neurocultural products' (Franzetto & Anker, 2009). Neurocultural products include brain-training games, brain health supplements, and other products that promise to optimise or enhance cognitive function (Williams et al., 2012). In a similar way, these same discourses have given rise to a burgeoning anti-ageing industry, in which ageing is framed as something to 'fight against' rather than embrace, and products (often cosmetics) are sold with an implicit promise that ageing can be slowed or reversed.

In keeping with neoliberal modes of governance, these products and technologies provide market-based solutions to complex social problems (e.g., health-related problems associated with an ageing population), allowing consumer-citizens to monitor their relative risk and care for themselves (Millington, 2012). Many of these artefacts, which often invoke and profit from age-related anxieties, hence reinforce the neoliberal idea that public and private health concerns are best managed through one's personal liberty to spend (Millington, 2012).

Grey Matters, of course, was not a particularly profitable neurocultural product— nor was it intended to be. However, to the extent that it drew on and reproduced some of the discourses that contribute to this situation, the website was entangled in a broader assemblage of neoliberal governance—of which I was inevitably a part. Having been trained in medical anthropology, I was interested, when I was first invited to work on this project, in non-biomedical ways of conceptualising the body in relation to health and illness. I set out to challenge the assumption that MCI was a biological 'condition' to design for—this being what I saw as one possible role of a design anthropologist working in such a context.

In the section below, I will reflect on the extent to which I was successful in this and on the degree to which my conduct as a researcher was governed by the bioscientific discourses and practices I had originally aimed to interrogate and expose.

One last short aside

Is complexity self-evident and pre-existing, or is it manufactured, like other social categories? If complexity is defined by the number and depth of relations between all parts that make up a whole, are those relations intrinsic or extrinsic to that whole? And who defines the 'parts'? And are 'relations' between 'parts' something that exist in nature, or does the anthropologist, a social creature, impose relations between things in order to make sense of them? Put another way, does the anthropologist study complexity or help produce it? Could it be both?

Design anthropology as counter-conduct

Knowledge-making practices, as I have been arguing throughout this thesis, help construct particular notions of ageing and what it means to be an older person in contemporary society. In a similar way, design practices draw on scientific knowledge and discourses to support it, and as such reproduces the mechanisms through which the conduct of individuals is governed. Tunstall (2007) has compellingly shown how design has become closely aligned with the strategies, practices, and technologies of neoliberal governance through the concept of 'trust', defined simply as "a feeling of certainty, often based on inconclusive evidence, that a person or object will not fail" (p. 2). Tunstall (2007) argues that design, as a discipline and a practice, should recognise that it "mediates the trust people hold in the practices of government by making them tangible (i.e., able to be seen, smelled, tasted, heard, felt, and experienced)" (p. 5).

This sense of trust comes, at least in part, from the confidence that modern people have in 'creativity'—and in particular, 'creative' design processes— which, as part of a neoliberal reformulation of the concept, has recently been framed as a key driver of economic success (Bill, 2017). Designers, often seen as the professional embodiment of creativity, are increasingly drawn into wider neoliberal assemblages to generate creative solutions to complex problems—in other words, to enable 'innovation' or, as the Living Well with MCI brief suggests, "novel approaches" to problem solving. Hence the everyday practice of designers, as form-givers and innovators of neoliberalised solutions, can be seen as an apparatus of governmentality.

Living Well with MCI was embedded in biopolitical discourses which it had the potential to make tangible by giving them form. As Nathan reflected towards the end of the project, "The more you get plugged into these things [as a designer], the more you start to believe [MCI]'s a thing." Part of my role as a design anthropologist, as I saw it, was to challenge the dominant scientific discourses surrounding the MCI category, and to advocate for 'alternative' ontologies and non-biomedical models of ageing—to challenge the notion that MCI was a 'real thing'. Foucault might refer to this as "counter-conduct", a form of political resistance that "involves an understanding of how one is conducted and how this conduct could be otherwise" (Demetriou, 2016, p. 218).

From the start of Living Well with MCI, I was 'conducted' as a researcher to support the design and delivery of a resource for people with MCI. As already discussed, there were a number of expectations associated with this role: I was to liaise with recruiters at memory clinics, interview people with MCI and their families, store and analyse data, and so on. Within this role, however, I also had the opportunity to conduct myself in ways that resisted dominant biomedical discourses around MCI and the ageing brain.

This was made possible through this associated PhD research in which 'critical reflection' on the MCI category was key to enabling conduct as a 'design anthropologist'. My research in design anthropology gave me permission to

question, challenge, and critique the category from inside a wider institutional assemblage—an assemblage that both enabled the design project and supported my involvement within it.

My conduct, which amounted to a kind of critical 'meddling' in the project, can be seen in the following example. As a researcher, it was my responsibility to write mock stories and strategies based on some of the interviews I had conducted. Nathan would find images to go with them and we used these as illustrative placeholders within the website prototype. These stories were written in the first person and designed to reflect the sort of home-grown content that might appear on the website in future. This task allowed me to embed 'personas' into the prototype in the hope that this would inspire critical reflection among those to whom the concept would later be presented. In the story below, I picked out what I identified as an alternative ontology of ageing from the data set, and wrote a narrative that problematises the MCI category and highlighted the cultural specificity of thinking about and managing age-related changes. The following was constructed as a composite narrative based on interviews with Pacific Island participants (see Figure 33).

A different perspective

By Talia Lotulelei

I live with my husband, two children, and mother-in-law. Recently we have noticed that my mother-in-law is forgetting things—her appointments, conversations, even the names of some of our family. We haven't mentioned anything to the doctor because she is in her 70s or 80s (we don't know exactly how old she is) and figure these changes are probably normal for her someone her age.

As a Samoan family, we believe it is a real privilege to care for and support our elders, just as they did for us when we were young. In our community, the elders are our leaders, the guardians and teachers of cultural knowledge. We understand that older people sometimes have problems with their memory and thinking, but we don't always see it as a 'medical' problem—we see it as the responsibility of everyone in the family, even the kids, to pitch in and support our elders as best we can. From a Samoan perspective, we believe that looking after my mother-in-law will attract fa'amanuiaga, or blessings from God, so we will continue to look after her as a family, even if it is sometimes difficult.

Figure 33: A screenshot taken of a fictional 'story' on the Grey Matters website.

The point of this story was to emphasise that not everyone thinks about changes to memory and thinking in 'medicalised' terms, however severe those changes may be. As I argued in Chapter Five, some people do not view the cognitive changes associated with MCI a medical problem. From a clinical perspective, changes to a person's memory and thinking may resemble the symptoms of 'MCI', but at home they may not be conceptualised as a problem in need of medical intervention. As discussed in reference to Ana in Chapter Five, this often depends on cultural context, which can shape how much or how little support an older adult receives, and therefore whether or not their forgetfulness becomes seen as a 'problem'. Including this story in our prototype was an attempt to make such alternative cultural ontologies visible, rather than embedding personas that supported the notion that MCI is always problematic.

As I will explain below, however, these efforts were severely constrained by the powerful biomedical discourses and structures in which the project was nested. These discourses and structures shaped my conduct as a researcher in ways that ultimately led to the construction of MCI as a matter of concern for individuals—something about which people ought to be informed in order to self-monitor and

manage the risk of ageing 'badly', relative to ageing 'normally'. Below, I will reflect on the extent to which I inevitably contributed to the construction of MCI in this context.

The inevitable construction of MCI

As discussed earlier in this chapter, it became clear during my interviews with participants that many of them had internalised the very discourses I was hoping to challenge, shaping their wants and needs in specific ways. For example, most participants in this project (with the exception of some significant others) had concerns about their memory and thinking and wanted information about what these changes may or may not signify. Specifically, many wanted to know whether the changes they were experiencing were 'normal' or 'abnormal' for their age, regardless of whether or not they had been diagnosed with MCI (which, as I have discussed in previous chapters, gives no certainty either way). The anxiety associated with their uncertain status was clear. As the significant other of one participant explained:

> The difficulty is, is it not, to know whether this is a normal ageing process or, obviously all our brains age at different rates and we all know that old people get forgetful [...] it is very difficult to know what is normal and what is not normal [...] We've got masses of friends in our age group and we all worry about this because we're all finding that we forget things and, well I'm lucky because I went for a test and apparently my memory is very good, so I don't have a worry and I didn't have a worry, but a lot of my friends, you know, their memory's not so good and they think, 'Help, am I on the way to Alzheimer's or am I not.' Because you read the statistics and it's quite frightening. It's one in five over 80 suffer from some form of Alzheimer's. It's actually quite frightening. Because I think of all the disabilities you could have, and there are some pretty horrid one's around, [...] it would be the worst.

When completing the card-sort exercise described in the previous chapter, most participants in the Living Well with MCI project selected 'information' as the top priority. From the perspectives of our 'users', this had to be a key component of the website. Many participants wanted access to medical or neurological "research" on the ageing brain and brain health. As one participant put it:

> **Participant:** The main thing is understanding, first of all. And keeping yourself well-educated, because all the time you're reading about more and more research into this and that's obviously very helpful [...] You can only deal with something if you really understand it, otherwise you're floundering.
>
> **Guy:** Is there any particular area that you want to know about, specifically?
>
> **P:** Well, I read the neurological magazine. And that's very good, because that nearly always has an article, an up-to-date article on research [...]. I suppose that's my main source of information.
>
> **G:** So it's to do with the brain? Neurology?
>
> **P:** Yeah.

Other participants were more interested in learning specifically about their MCI diagnosis—what it means, how it differs from 'normal' ageing and dementia, what can be done about it, and so on. As Margaret put it, "I don't know what [MCI] means [...] I want to know, I sort of need to know. I mean, with other people who are my age

and my activity [...] how does that fit alongside people of similar circumstances? I don't know." Some participants diagnosed with MCI seemed to believe they had been diagnosed with dementia, others that they were "just going to get worse and worse" (MCI_021_dyad).

One of my roles as the project researcher was to write copy for an information (or 'Learn') page on the website. This page consisted of two main sections: one for information on the "Ageing Brain", and the other on "Brain Health", both of which aimed to offer 'reliable' (i.e., medical and scientific) knowledge about changes to their memory and thinking. While conducting a review of existing MCI resources, Nathan and I noted that many websites talked about MCI in ways that suggested inevitable progression to dementia. An example of this is shown in the image below (Figure 34), a screenshot taken from mybraintest.com, which includes the following infographic related to MCI:

Figure 34: An existing resource with an image that implies linear progression.

From a communication design perspective, the arrow in this example suggests linear progression to Alzheimer's Disease, while the accompanying text refers to MCI as an "intermediate stage condition". As part of our information page, we aimed to provide greater reassurance that progression to dementia is neither linear nor inevitable.

Our starting point for this was a more accurate definition of MCI. In hoping to shed light on the meaning of MCI without instilling an unnecessary degree of fear and anxiety in the reader, I wrote the following description of the diagnosis:

> Sometimes clinicians will use the term 'mild cognitive impairment' to describe memory and thinking problems which are greater than they might normally expect to see in adults who are getting older, but which are not severe enough to justify a diagnosis of dementia.

Inevitably, however, in providing a more comprehensive overview of the diagnosis, I had to reproduce the notion of 'normal' ageing, thereby distinguishing this from both MCI and dementia. With the help of our steering group psychiatrist, I found myself writing the following copy for the website:

Some common changes associated with 'normal' age-related changes include:

- Slower recall and thinking
- Slower at solving complex or unfamiliar problems
- Difficulty learning new information
- Difficulty maintaining attention, particularly when there are distractions
- Difficulty multi-tasking (e.g., talking on the phone while cooking)
- Forgetting the finer details of conversations (but it is not usually normal to forget that the conversation occurred at all).

The section then went on to put boundaries around 'MCI' (see Figure 35):

Sometimes clinicians will use the term 'mild cognitive impairment' to describe memory and thinking problems which are greater than they might normally expect to see in adults who are getting older, but which are not severe enough to justify a diagnosis of dementia. People with MCI or those who know them will report one or more of the following:

Memory and Orientation

- Forgetting conversations more often than usual or asking repeated questions
- Forgetting important events such as appointments or social engagements
- Starting to have trouble navigating (e.g. when driving or finding your way out of a shopping centre)

Decision Making or Problem Solving

- Feeling increasingly overwhelmed by making decisions, planning steps to accomplish a task, or interpreting instructions.
- Becoming more impulsive or making decisions without thinking things through
- Being less tactful

Attention

- Losing your train of thought or the thread of conversations, books, or movies even when there are no major distractions

Language

- More significant word finding problems or slowed speech

Figure 35: Screenshot from the Grey Matters 'Information' page.

This, of course, contradicted my perspective that there is no clear ontological distinction between MCI and 'normal' age-related decline. However, this distinction seemed necessary to provide 'information' about the diagnosis, which is what our participants said they wanted. Without even realising it, I was drawing on the very discourses I had intended to make visible and critically examine. At the same time, an accompanying paragraph reveals my underlying effort to meddle in the project by challenging these discourses:

> Many people who experience these changes worry that they might be experiencing the early symptoms of dementia, even when they may not be. It can be very difficult, even for medical professionals, to know whether the changes we experience as we get older are 'normal' for our age, or the start of more significant changes to our memory or thinking. This is partly because every person is different. Our brains have varying levels of cognitive ability in the first place and, like other organs, age at varying speeds depending on multiple factors, such as our genetic makeup, diet and lifestyle.

The phrase "even for medical professionals" was intended to point out that medical knowledge is limited and cannot offer any degree of certainty regarding cognitive change. Similarly, "every person is different" was an attempt to suggest to the reader that 'normality' is more flexible than medical professionals might imply. I was also trying to situate 'the brain' within the wider context of "genetic makeup, diet and lifestyle" to highlight that cognitive changes depend on "multiple factors" outside of the brain, some of which may be socially and culturally shaped. This critique while providing accurate 'information' about MCI was difficult to maintain, as the following paragraph shows:

> It is common to worry that MCI will lead to dementia, where the person loses the ability to manage everyday tasks and needs assistance. However, not everyone diagnosed with MCI will develop a more serious form of cognitive impairment. In fact, research suggests that one in five people diagnosed with MCI will return to normal cognitive functioning within a few years. Many others will remain stable for several years or more without 'progressing' to dementia. Current research is trying to determine precisely who, of those diagnosed with MCI, will go on to progress to dementia, and identify the factors that contribute to the progression from MCI to dementia.

This section highlights a central paradox in designing a website for people with MCI: in responding to our users need for information about an inherently ambiguous diagnosis, I was forced to try and *explain* that ambiguity with reliable (i.e., statistical and hence 'scientific') data from BRNZ. This involved having to work within the constraints of biomedical terms and discourses such as "normal cognitive functioning". Hence in the effort to make an ambiguous diagnosis somehow *less* ambiguous, the information in many ways makes MCI a 'fact' of medicine, albeit an incomplete one. Similarly, in the effort to highlight the non-linear nature of MCI, the information links it to the linear "progression" of dementia, presenting those who "remain stable" as anomalous.

The assumption here was that MCI has predictive value and proceeds linearly to dementia, and that in the anomalous cases where it does not, it is not the category itself but "current research" that is insufficient—a claim that justifies and supports the MCI-research assemblage of which the project was part. In other words, if knowledge about the MCI category is insufficient, it is only because more research is required—something that contradicted my belief that such research does not shed light on MCI, as if it were 'out there' in nature, but rather produces it. This example helps show how my conduct as a researcher was shaped by these wider discourses related to ageing and dementia.

In a similar way, the "Brain Health" section draws heavily from biomedical discourses to provide information about maintaining healthy "cognitive function". This section was again developed in response to identified user wants and needs—in this case to provide practical advice on what can be done to slow or reverse cognitive changes. Again, this section was designed in response to identified user needs. For example, when talking about her experience of being diagnosed with MCI, one participant complained that: "Nobody came up with any suggestions about what I could do to slow it down or anything. You've got it and that's it [...] If you can put something in [the website] that gives [people] hope that they can improve the situation, you know?"

Here is an example of the kind of information I wrote (with the help of the steering group psychiatrist) for the "Brain Health" section:

> While it is difficult to predict whether our memory and thinking will worsen over time, there are things we can do to try and keep our brains healthy as we age. Experts often say that what is good for your heart is also good for your brain.[13] This is because your heart and brain are connected by arteries that supply blood, oxygen, and

13   "What's good for your heart is good for your brain" was a sort of mantra I heard repeated at BRNZ workshops and presentations. Its popularity among brain researchers was presumably due to the fact that it distils years of neuroscientific research into a single piece of practical advice for lay people.

nutrients. To put it simply, the brain needs a healthy heart in order to keep the brain cells functioning well. It follows that unhealthy habits which affect your heart, such as smoking, can also affect your brain. If your heart is unhealthy, your brain may not be getting the blood flow it needs, which means that your brain cells may be deprived of the food and oxygen that *they* need. The risk factors you can change are those which are likely to preserve the blood supply to your brain by maintaining the health of small and large blood vessels.

Further information about what people can do to "improve the situation" included the following section on diet:

- **Healthy Fats** – Much of the brain's cell structure is made up of "healthy fats". The brain requires an abundant supply of these fats from our diet to repair itself and grow new neurons. Salmon and tuna, for example, are particularly rich in omega-3 fatty acids, which can lower blood pressure and reduce blood clotting. Avocados are high in monounsaturated and polyunsaturated fats, B vitamins and folate, which have been shown to help prevent the tangled nerve fibres associated with Alzheimer's Disease.

- **Antioxidants** – As we get older, our brain cells can be broken down by "free radicals" in our bloodstream. Antioxidants merge with free radicals to make them harmless. Good sources of antioxidants include tea (especially green tea), blueberries, tomatoes, carrots, red grapes, broccoli, spinach, garlic, whole grains, soy, and dark chocolate.

- **High-Tyrosine products** – Tyrosine is a nonessential amino acid involved in the production of brain chemicals called neurotransmitters. High-Tyrosine foods include cheese, soybeans, beef, lamb, pork, fish, chicken, nuts, seeds, eggs, beans, and whole grains.

This was the best I could do to provide the sorts of 'scientifically credible' information that participants had asked for. I did not realise at the time how profoundly biomedical and uncritical this language was—how much my conduct as a researcher had been shaped by discourses of biomedical truth.

MCI Animation

Four students from a Visualising Information class at AUT designed an animation to be included as part of the Grey Matters information section. The Visualising Information lecturer approached the DHW Lab for specific problems for students to work on for an assignment. I suggested that the students could work on a problem I had identified while working on Living Well with MCI—namely that people diagnosed with MCI often did not understand what the diagnosis meant. Based on the observation that people were not provided with adequate information about the diagnosis, I wrote the following brief for the student designers:

> Mild Cognitive Impairment (MCI) is a relatively new clinical concept that describes "an intermediate stage between the expected cognitive decline of normal aging and the more serious decline of dementia" (Mayo Clinic). People diagnosed with MCI are typically over the age of 65 and are experiencing changes to their memory and thinking that are noticeable but not severe enough to justify a diagnosis of dementia. While MCI is sometimes described as a 'transitional phase', not everyone diagnosed with MCI will progress to a more severe form of cognitive impairment. Brain Research New Zealand (BRNZ) suggests that approximately one in ten people diagnosed with MCI will show a greater decline in cognitive abilities

within one year of their diagnosis. BRNZ also indicates that about out in five people diagnosed with MCI will go back to 'normal' cognitive functioning within three or four years of their MCI diagnosis. Others will remain stable over time. Because the category is so ambiguous, people find it very difficult to conceptualise. They are given little information once a diagnosis is made, and often have no idea what their diagnosis means or how significant it is. More alarmingly, some people interpret their MCI diagnosis as onset dementia (when what it really means is that the person may have a slightly greater risk of developing dementia in the future). A team of researchers are developing a web resource for people with MCI and their families. They are interested in exploring ways to effectively communicate the above points to those who may have recently been diagnosed with MCI, and who may be anxious, stressed, and uncertain about their future.

I also gave a presentation to the wider class about some of the complexities surrounding the diagnosis. To highlight the problem Nathan and I wanted the students to work on, I showed an existing image from Google that is commonly used in MCI research (see Figure 36):

Figure 36: A common image used to depict the clinical trajectory of Alzheimer's Disease (Sperling et al. 2011).

I pointed out that the image was misleading because the dotted line implies that the progression from MCI to dementia is linear and inevitable, despite longitudinal studies showing that not everyone with MCI will progress to more severe forms of cognitive impairment (Hong et al., 2011). The image also seemed to suggest that both MCI and dementia are altogether different from the 'ageing process'—an assumption I challenged in Chapter Five. I asked the class how we might design an illustration or animation that more accurately accounts for the complexities associated with an MCI diagnosis—what it potentially means, how significant it is, and to what extent it apparently differs from 'normal' ageing and more serious forms of impairment. As I discussed in Chapter Six, these were prevalent concerns among those who had recently received the diagnosis.

In small groups of 3 or 4, the class then started to generate ideas and concepts. One group went on to develop their concept in more depth as part of a class project. This group decided that the best way to visually communicate this

information to older people would be through a narrated animation. Nathan and I liased with these students via email, and occasionally met with them at the DHW Lab to see how they were progressing and whether we could help them in any way. The first time we all met together, about a week after my presentation to the class, the students showed us a storyboard of their animation concept. What Nathan and I liked about their idea was that instead of focusing on statistics and prognostic uncertainty, they centred their animation on people in order to tell a story. They developed two personas named Patsy and Joe, who had both been diagnosed with MCI but lived in different circumstances. After some revisions based on feedback from the project steering group and colleagues at PCR, the animation was refined and later tested with participants. Below is the final version of the animation script, including screenshots (Figures 37-45):

Figure 37: *This is Patsy. She is 71 years old, and lives with her cat Pebbles. Lately Patsy has been forgetting the little things. Like her washing, and important phone numbers. Patsy's family members are worried about her and are unsure what is going on.*

Figure 38: *This is Joe. He is 82 years old and enjoys gardening. Lately Joe has been misplacing things, such as his glasses and coffee cup. He has been experiencing mind blanks and forgetting conversations he has had. His wife has noticed these changes and together they agree that he should see a doctor.*

Figure 39: *Patsy and Joe have recently been diagnosed with Mild Cognitive Impairment. Mild cognitive impairment, or MCI, is a relatively new diagnosis that clinicians use to describe cognitive changes, or changes to your memory and thinking, that are greater than they would normally expect to see in a person of their age.*

Figure 40: *Some people find it scary when they start to notice these changes, or when they are told they have MCI.*

Figure 41: *However, most people with MCI are able to function from day and day, and enjoy all the things they would usually enjoy, by using strategies to manage those changes, such as using a diary, keeping lists, and getting support from their family and friends.*

Figure 42: *About two in ten people will eventually return to their previous cognitive ability.*

Figure 43: *Some people, about one in ten, may get worse and develop dementia. However, the majority will stay just the same.*

Figure 44: *This website is a place for anyone with concerns about changes to their memory and thinking, not just people with MCI.*

Figure 45: *This is where you can learn about how you can keep your brain healthy, share tips and tricks for managing changes from day to day, or share stories about your experiences so that others can learn from them.*

The animation provides a more positive take on the MCI concept by emphasising that not everyone diagnosed with MCI will go on to get dementia. From my perspective, having observed that the diagnosis can generate further anxiety about cognitive decline, this was the most important thing to try and communicate to our users. The animation highlights that some people will "return to their previous cognitive ability" (Figure 42), and that "the majority will stay just the same" (Figure 43). Furthermore, by showing how people (Patsy and Jo) can experience and respond to cognitive changes in different ways, it presents a more nuanced, person-centred perspective on MCI compared to other information resources that emphasise generic clinical symptoms and often overstate the likelihood of cognitive decline (e.g Figure 34).

However, as the animation and script also demonstrate, the students drew on biomedical discourses in order to present this information 'about' MCI as if it were simply a 'fact' of biomedicine. In taking the 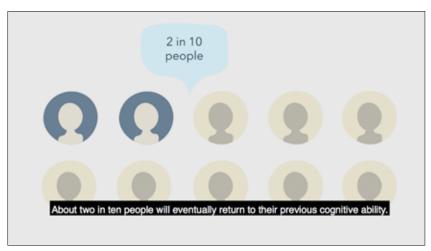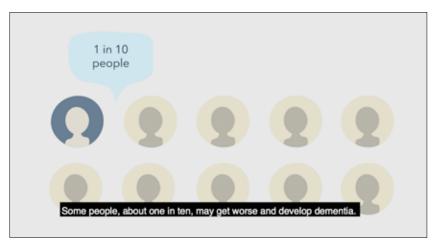category as a given in order to explain it, the animation reproduced some contentious ideas and imagery. A good example of this is shown in Figure 39, which depicts a male doctor in a white coat pointing to a screen as if to 'instruct' the viewer about MCI. The white coat is a symbol of his knowledge and status as an agent of biomedical truth, a messenger of facts about the body, and he points to a brain on the screen in order to show us where MCI is 'located'. The implication seems to be that MCI is associated with the physical brain, and is therefore 'real'.

Drawing on this 'common sense' imagery to talk about the MCI concept, the animation in many ways preserves this reductive, materialist underpinnings of biomedicine, despite alternative ways in which to think about ageing and age-related changes. Biomedical discourses are also supported by other phrases in the animation, such as "This is where you can learn about how you can keep your brain healthy". Thus, in providing information about MCI, the animation highlights the cognitive aspects of ageing and the general importance of 'brain health', overshadowing the social or 'immaterial' problems of ageing such as loneliness.

The students were, of course, simply making use of the discourses available to them in order to make sense of MCI, just as Nathan, myself, and our participants were also doing. It is therefore unsurprising that the animation, as an artefact, reflects and reproduces these by giving them form in the world.

Nathan and I were curious about how our participants would respond to the animation on the website, so we organised some user testing sessions—the topic discussed in the next part of this chapter.

Excerpt from Critical Reflection session with animation students

Guy: What did you first think when you heard about MCI?

Animation Student 1: When I first heard about it, I was like 'Oh yeah it's a precursor to dementia' and basically from then on I was like, okay, if you get MCI, they can maybe help you delay it a bit but you'll get dementia.

Animation Student 2: Yeah I thought it was something to do with like memory loss, things like that, just like sort of a, maybe Alzheimer's, I thought maybe it was connected to Alzheimer's, but before we had even like read anything about it, because we sort of got the [brief] and it was like Brain Research, and I was like, 'Oh yeah, cool, Alzheimer's, old people, same thing.'

G: So where did that understanding come from do you think?

A2: No idea [laughs]

DISCOURSE: MEMORY LOSS = DEMENTIA

A1: I think you just, whenever anyone talks about memory loss or cognitive changes, I automatically associate it with dementia to be honest.

A2: Or anything about, even about just the brain, it's just, and old people, it's always like, 'Oh, memory loss.'

AGEING BRAIN = MEMORY LOSS/ COGNITIVE DECLINE

A1: Dementia, Alzheimer's.

A2: Yeah, it's sort of like—

A1: You just jump straight there I guess.

'NATURAL' LINK/ ASSUMPTION

A2: Yeah, it's like 'Oh, yeah, they're like going to lose their memory.'

Delivering 'Grey Matters'

In this section I explore how participants responded to the full website prototype (which appears at the end of this chapter - see Figures , including the animation described above. In keeping with the theme of the website's entanglement in the construction of MCI, I will draw on data from a single user testing session in which two participants, Roy and Jill, spoke at length about the MCI category and its presence on the website (see Figure 46). We carried out four user testing sessions with a total of six participants (four formally diagnosed MCI participants, two of whom had significant others present), but it was Roy and Jill who had the most to say about MCI as a new diagnosis; other user testing participants either had little to say about it or did not mention it at all. Roy and Jill had had a particularly negative clinical experience and were sceptical of the term and its use in clinical practice. Their critical perspective provided the richest data about the interplay between design processes and the emergence of MCI as a new medical reality.

These user testing sessions involved presenting the website to participants and seeing how well, or not, they responded to the three main pages: Learn, Explore, and Share. During the sessions, I asked a series of questions while Nathan took notes and observed how participants interacted with the website prototype, looking for ways to improve the overall user experience. Questions included:

- What are your first impressions of this page/function?
- What do you think this page/function is for?
- How relevant is this information/function to you?
- What would you do next?

The Explore page—where users could explore people's strategies ('Tips & Tricks') for managing changes to their memory and thinking, and read other people's experiences ('Stories') about age-related changes—was relatively uncontroversial; users agreed that these sharing functions would be useful. For this reason, I will focus primarily on the 'Learn' page, where, in response to requests for information about ageing and the ageing brain, MCI is explicitly mentioned in both the text and in the animation.

Jill had been diagnosed with MCI more than a year previously, but by the time Nathan and I arrived at her and Roy's home for the user testing session, her diagnosis had been withdrawn. At the first interview, I learned that Jill had not been provided with adequate information about her diagnosis, at least according to her. As she put it then, "When they first told me, I hadn't a clue what [MCI] meant. I was quite upset when they told me that one in so many would have dementia in five years or something".

Figure 46: A user testing session with Roy and Jill.

Roy and Jill were ideal candidates for testing the information page and animation, which was supposed to provide more clarity (to the extent that any clarity is possible for an ambiguous construct) around the meaning and significance of an MCI diagnosis. I was interested to see whether they found it useful but became somewhat apprehensive as they engaged with the Learn page. Roy and Jill read through the "Ageing Brain" and "Brain Health" sections and watched the animation together. Although we had tried to provide a more accurate description of MCI, and to avoid framing it as a 'medical condition' (as other MCI resources often tend to do), Roy and Jill were quickly put off by the term. Simply mentioning MCI seemed to take them back to when Jill was first diagnosed and told she had "a 50-50 chance" of getting dementia in five years, conjuring up all the negative emotion associated with that experience:

> **Roy:** Cognitive impairment is a negative thing.

> **Jill:** It doesn't give you anything to aim for.

> **R:** If the doctor thinks you've got cognitive impairment then the doors come down, it closes off.

> **J:** That's the end of it, I'm getting worse. I'm just going to get worse and worse and there's nothing I can do about it. That's what it feels like.

Drawing on statistical data provided by BRNZ, the animation conveyed that one in five people diagnosed with MCI will go back to 'normal' cognition within three or four years, that many people remain stable over time, and that only one in ten will show a greater decline in cognitive abilities within a year. This information contradicted what Jill had been told when she was diagnosed:

> **Jill:** I thought it was a higher proportion of people who had mild cognitive impairment, I thought the ratio was higher of how many people [with MCI] get dementia.

> **Guy:** Yeah, so the numbers aren't very clear. There's a lot of contradictory research. The numbers you see in [the animation] come from Brain Research New Zealand.

> **J:** Right.

> **G:** So that's their take on it.

> **Roy:** So they're still provisional figures anyway.

> **G:** Yes, they could be different [...] Please feel free to be critical. What were your impressions?

> **J:** It gave me a different impression to what I felt I had been told initially.

Aside from the potential for conflicting information and further confusion about MCI, Roy had other concerns that came to mind as he was reading through the website:

> One thing that puzzles me with all this is, and this [website] sort of brings it up as well, looking at it, it says that 'It's common to worry that MCI will lead to dementia.' But one thing that bothers me with it is, saying this sort of thing means that MCI is much wider spread than you would've thought in the first place, because you don't always think of those sorts of things anyway—you just think you're absent-minded, you don't think you've had MCI. But looking at [this website] brings a lot more of it about, and also, it must be happening a lot quicker than anyone realises. Now, because you realise that, you start to worry about it, and will that again lead to more dementia?

Roy's concern is similar to that put forward by Nikolas Rose (2009), who wrote of the "apparent capacity of a diagnosis of MCI to shift an individual on to a social and experiential pathway to Alzheimer's" (p. 77). In giving the impression that MCI is a legitimate medical condition (one "much wider spread than you would've thought"), the website medicalises ordinary "absent-minded[ness]" and links this, albeit tangentially, to dementia. By invoking the fear and anxiety that accompanies the imagery of dementia, the MCI category has associations that, as Roy points out, might lead one "to worry about" one's situation in ways that potentially "lead to more dementia". This relates to Hacking's (2004) notion of a 'dialectic' process between individuals and clinical descriptions, which I described in Chapter Five. Hacking warns of the self-fulfilling tendencies of such diagnostic classifications, particularly when there are certain clinical expectations and ideas around them. Indeed, Roy was alluding to the potential harms of what Hacking (2004) calls a 'feedback loop' whereby people interact with the classifications under which they live, often in ways that are "mutually reinforcing" (p. 279).

This is particularly problematic in the case of MCI. As we saw in Chapter Five, MCI is underpinned by the biomedical notion of progressive linearity—a notion that Jill seemed, at least initially, to hold ("I'm just going to get worse and worse and there's nothing I can do about it"). Roy was concerned that the MCI diagnosis might instil this unhelpful idea in people like Jill—a potential harm in which the website, by giving the diagnosis greater credibility and status, would be implicated. The couple reflected on this as they continued through the website:

> **Roy:** You're just getting old really. It's not necessarily true.
>
> **Guy:** The label isn't necessarily helpful is it?
>
> **Jill:** No.
>
> **R:** It matters a lot, getting the right approach to [the website] so people will look at it.
>
> **J:** And they're labelling it without them even knowing whether or not it's a fact, because twelve months later they're having it taken off [my medical] records because they don't think it was [MCI]. Well, why tell somebody that's what they've got if they don't *know* that's what they've got?

While some users, for example Margaret, said that they "need[ed] to know" what MCI meant, our effort to meet this need by providing information about the category was viewed by Roy and Jill as unnecessary use of a "negative" term. For them, the information simply emphasised the possibility of further cognitive decline rather than offering advice about what can be done about it. Originally intended as a response to user needs for information, the website in this sense became a vehicle for negative biomedical discourses about the ageing brain, emphasising a linear sequence of decline, deterioration, and dysfunction (Whitehouse & Moody, 2006). Indeed, the overall effect of the information provided by this text was to further 'harden' the MCI category, despite (or perhaps even *because of*) our efforts to challenge the idea that MCI is distinct from normal ageing and necessarily leads to dementia.

ONE DAY, IN 2016, I WAS ~~INVITED~~ INTERVIEWED AS AN 'EXPERT' CONSULTANT FOR AN ENGINEERING PROJECT INVOLVING A SOCIAL COMPANION ROBOT FOR PEOPLE WITH MCI AND DEMENTIA. A MEMBER OF OUR LIVING WELL WITH MCI STEERING GROUP HAD ASKED WHETHER I WOULD ~~BE~~ BE INTERESTED IN TAKING PART, AND PASSED MY CONTACT DETAILS ON TO ONE OF THE RESEARCHERS.

I WAS INITIALLY INTERVIEWED FOR MY "EXPERT KNOWLEDGE" OF MCI AND WAS ASKED ABOUT WHAT SORTS OF FEATURES AND FUNCTIONALITIES I THOUGHT A ROBOT FOR PEOPLE WITH MCI SHOULD HAVE AND WHY. I MADE IT CLEAR AT THIS INITIAL INTERVIEW THAT, BASED ON MY EXPERIENCE ~~AND~~ AND UNDERSTANDING, I DID NOT THINK THAT A ROBOT WAS APPROPRIATE FOR THIS PARTICULAR USER GROUP.

NEVERTHELESS, I WAS CONTACTED AGAIN SEVERAL MONTHS LATER — THE RESEARCHERS HAD DEVELOPED A ROBOT FOR PEOPLE WITH MCI AND THEY WANTED MY FEEDBACK ON IT. THIS TIME THE INTERVIEW INVOLVED WATCHING A SERIES OF VIDEO CLIPS ~~THAT~~ SHOWING THE ROBOT INTERACTING WITH A 'USER' (PLAYED BY THE YOUNG POST-DOC ~~WHO~~ WHO WAS NOW INTERVIEWING ME) IN SIX DIFFERENT SCENARIOS.

THE ROBOT WAS VERY SIMILAR TO THE ONE PRESENTED AT THE AAATE CONFERENCE IN SHEFFIELD: ABOUT FOUR-FEET TALL, A RECTANGULAR TOUCHSCREEN HEAD DISPLAYING CARTOONISH EYES, A MOUTH, AND, WHEN TOUCHED, A MENU WITH ASSORTED OPTIONS. IT ALSO HAD LONG ARMS THAT GESTURED AWKWARDLY AS IT TALKED, FOR NO APPARENT REASON OTHER THAN, PRESUMABLY, TO MAKE IT APPEAR VAGUELY LIFELIKE, AND THEREFORE FRIENDLIER IT APPEARED TO ROLL ALONG ON WHEELS, BUT THE BOTTOM OF THE ROBOT WAS OUT OF THE FRAME.

DURING THE INTERVIEW I STRUGGLED TO ARTICULATE WHAT I THOUGHT WAS WRONG WITH THE ROBOT, WHEN CLEARLY IT HAD BEEN DESIGNED WITH GOOD INTENTIONS. IT HAD

BEEN DESIGNED TO MAKE LIVING AT HOME 'SAFER' ~~FOR~~ FOR PEOPLE WITH MCI (AND DEMENTIA). IT REMINDED THEM (AN INCREDIBLY DIVERSE GROUP, AS I HAD BY NOW DISCOVERED) TO TAKE THEIR MEDICATIONS, TO CLOSE WINDOWS AND LOCK DOORS WHEN GOING TO BED, TO DO THEIR EXERCISES, TO KEEP TRACK OF ~~APPOINTMENTS~~ APPOINTMENTS — ALL WORTHY OBJECTIVES.

AND YET, IN THE ~~VIDEOS~~ VIDEOS, THE ROBOT SIMPLY ~~SEEMED TO~~ APPEARED TO FOLLOW THE 'USER' AROUND THE HOUSE, DRONING ON TO DO THIS AND THAT — THE WHOLE THING TO ME LOOKED VERY PATRONISING AND INAPPROPRIATE. I COULD NOT IMAGINE ANYONE I HAD INTERVIEWED IN OUR PROJECT USING IT. HAD THEY GONE OUT AND TALKED TO PEOPLE TO UNDERSTAND THEIR EXPERIENCES OR IDENTIFY WHAT IS MOST IMPORTANT TO THEM, I ASKED? NO, THEY HADN'T — THEY WERE ONLY INTERESTED IN SPEAKING WITH 'EXPERTS'.

~~THE~~ AS WE WATCHED THE VIDEOS, THE POST-DOC ASKED ME QUESTIONS LIKE, "WHAT DID YOU LIKE ABOUT THE ROBOT'S PERFORMANCE IN THIS SCENARIO?" AND "WHAT DID YOU DISLIKE ABOUT THE ROBOT'S PERFORMANCE IN THIS SCENARIO?" AND "HOW COULD YOU IMPROVE THE ROBOT'S PERFORMANCE IN THIS SCENARIO?" ETC. THE ~~RESEARCH~~ POST-DOC DIDN'T REALLY RESPOND TO MY ANSWERS. THIS WAS NOT A CONVERSATION.

MY ANSWERS, I ~~FEEL~~ FELT, WERE VAGUE AND A BIT RAMBLING, BECAUSE I WASN'T INTERESTED IN THE ROBOT'S 'PERFORMANCE' AT ALL; I BELIEVED THE ~~~~ PROJECT AS A WHOLE WAS FLAWED IN DEEPER, MORE FUNDAMENTAL WAYS. I WAS SPEAKING FROM AN ALIEN WORLD, ANOTHER PARADIGM.

IT SEEMED TO ~~~~ ME, IN THIS PARADIGM, THAT THE ROBOT REPRODUCED A HIGHLY ~~~~ MEDICALISED, ALMOST DEHUMANISING, VISION OF OLDER PEOPLE — ~~~~

FRAIL, DEPENDENT, SICK, COSTLY. THE ROBOT WAS THE NEAR-PERFECT EMBODIMENT OF BIOMEDICAL DISCOURSES. THERE SEEMED TO BE A GREAT DISCONNECT BETWEEN WHAT THE (YOUNG) RESEARCHERS THOUGHT THEIR USER GROUP WERE LIKE AND WHAT THE USERS WERE ACTUALLY LIKE, IN ~~THEIR~~ REALITY. AS A RESULT, THE ROBOT WAS RESPONDING TO THE RESEARCHER'S ASSUMPTIONS ABOUT THE USERS AND THEIR NEEDS, INSTEAD OF WHAT MATTERED MOST TO THEM — WHICH WAS NOT ALWAYS, AS WE LEARNED IN OUR PROJECT, RELATED TO 'COGNITIVE ~~THAT~~ FUNCTION.'

AS SOME OF THE SCENARIOS INDICATED, THE RESEARCHERS HAD NOT REALLY CONSIDERED WHETHER OR NOT THEIR USERS HAD EXISTING SOLUTIONS TO SOME OF THE PROBLEMS THIS ROBOT WAS APPARENTLY ADDRESSING. IN ONE OF THE SHORTER SCENARIOS, THE 'USER' ASKED THE ROBOT, "WHAT IS THE TIME?" AND THE ROBOT, RATHER ~~UNHELPFUL~~ UNIMPRESSIVELY, RESPONDED WITH THE TIME. THE POST-DOC ~~TURNED~~ THEN TURNED TO ME AND ASKED WHAT I LIKED AND DISLIKED ABOUT THAT PARTICULAR SCENARIO. I COULD ONLY POINT OUT THAT, IN MY EXPERIENCE, ~~THAT AFTER~~ ~~WITH~~ HAVING TALKED TO ABOUT TWENTY PEOPLE WITH MCI, ALL OF THEM HAD CLOCKS AND CALENDARS — IN FACT, THEY HAD NO TROUBLE IN THIS DOMAIN AT ALL, IN MY 'EXPERT' OPINION.

FOR ME, PROJECTS OF THIS KIND HIGHLIGHT THE NEED FOR CRITICAL REFLECTION ON THE MCI CATEGORY IN DESIGN AND INNOVATION CONTEXTS. INDEED, THIS ROBOT SEEMED LIKE A STRANGE INTERVENTION FOR A 'CONDITION' WHOSE SYMPTOMS, ~~●~~ ACCORDING TO ITS OWN CLINICAL DEFINITION, DO NOT ~~INTERFERE~~ INTERFERE WITH A PERSON'S DAY-TO-DAY LIVING. ON THE ONE HAND IT SHOWS HOW THE EXPANSION OF 'DEMENTIA,' AND THE MEDICALISATION OF EVER-MILDER FORMS OF 'IMPAIRMENT,' CAN LEAD TO MISTAKEN ASSUMPTIONS AND NEGATIVE STEREOTYPES ABOUT OLDER PEOPLE'S CAPA-BILITIES, EXPERIENCES, NEEDS, AND CONCERNS. AT THE SAME

TIME, THE PROJECT SHOWS HOW MCI IS PRODUCED WITHIN AND THROUGH RESEARCH PRACTICES, WHICH OFTEN TARGET SPECIFIC 'FUNDABLE' CONDITIONS IN ORDER TO SECURE RESEARCH GRANTS.

ON A PHILOSOPHICAL LEVEL, THE ROBOT HIGHLIGHTS HOW DESIGNED ARTEFACTS CAN ENCAPSULATE ~~AND~~ AND CARRY FORWARD A CULTURALLY SPECIFIC ONTOLOGY (A 'STYLE OF THOUGHT'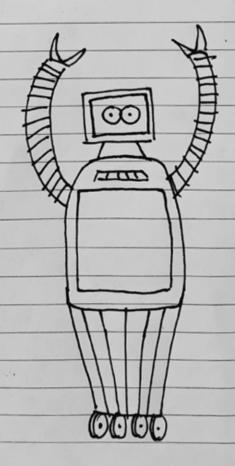) RELATED TO AGEING ITSELF. IN POTENT- IALLY 'HARDENING' THE MCI CATEGORY AS A VALID CONDITION TO 'DESIGN FOR', THE INCREASING SOPHISTICATION OF SUCH ARTEFACTS IN THE MCI MARKETPLACE SEEM TO CLOSE OFF THE POSSIBILITY FOR CRITICAL REFLECTION ON THE CATEGORY...

AFTER ALL, IF 'PEOPLE WITH MCI' ARE SEEN TO NEED ROBOTS ~~ORDER~~ TO TAKE CARE OF THEM, HOW THEN CAN YOU ARGUE THAT MCI IS NOT A 'THING'?

Making MCI a thing, together

My efforts to draw Nathan's attention to the complexities of knowledge and discourse, to show where and how design processes intersected with the production of the MCI category, were counterbalanced by Nathan's efforts to deliver a practical solution to the design brief—to design a website for people with MCI. This balancing act was often framed in our critical reflections as a tension between the analytical focus of anthropology and the more pragmatic considerations of design. We often talked about culture, systems, and processes, discussing how anthropology tends to focus on understanding people rather than making or intervening in their worlds. During our last session together, Nathan reflected on our work together in this way:

> I could jump to the pretty irrational conclusion that because you guys [anthropologists] don't look to create solutions that respond to your outcomes or findings, that it's a waste of time. And that's not my perspective. My perspective is that without having the collaboration alongside researchers, I think my practice would be much less informed, or well informed. I think it's just really useful to have a more critical perspective, provided it's balanced so that it doesn't become kind of, I suppose, paralysis of analysis, you know? Being able to say, 'Okay, that's interesting,' having this more zoomed-out academic perspective to say it's intertwined with all these other complexities, social, emotionally, biologically, whatever those things are, but being able to extract enough of that insight to be able to apply some practical ideas to it. So I think what's worked well here is that we've been able to maintain that balance of looking at [MCI] from that academic lens, but also translating that into the practical design-led lens. And that's where I've referred to, 'That's great, we've had a great conversation about that, but let's do something about it now, let's come up with an idea, or let's make something to go and explore that idea further, or test an assumption or hypothesis.' And ultimately, like I said earlier, with a view to actually bring some value and to try and make something better than it was before we started.

And yet, what Nathan and I didn't realise at the time was the extent to which we were ourselves trapped *inside* the discourses, practices, systems, and processes that had made MCI a matter of concern in the first place, and how these things constrained possibilities for resistance—that is, our ability to question or challenge the MCI construct. Although my design anthropological approach enabled some degree of critical reflection on MCI, Nathan and I were working from inside the machinery of biomedicine and, as such, were involved in the production of MCI ourselves. Reflecting on this too much, however, constituted a "paralysis of analysis" for Nathan. He understood the complexity surrounding Living Well with MCI and its constraints, and even the concept of medicalisation, but as a designer his response to this was to "do something about it", to "make something", even though whatever we did or made inevitably reinforced biomedical discourses and contributed to the production of the category. We had no other available discourses with which to talk about 'MCI'.

Admittedly, I was also excited about the possibility to create an online platform to perhaps shift the conversation around ageing, or challenge neoliberal and bioscientific discourses such as risk management, self-care, and 'successful' ageing. However, our first priority, as Nathan often said to me, was to advocate for the wants and needs of the end-user—to make something they would find useful, useable, and desirable (Buchanan, 2001). Yet most of our users seemed to have internalised these very modes of thought, making it difficult to deliver a solution that would both critique the system *and* meet our users needs. Our effort to "bring some value", as Nathan put it, was profoundly constrained (or, to borrow Foucault's term, 'conducted') by discourses related to ageing, the funding

structures that produced the project and predetermined its direction, and the wider brain research assemblage that was making MCI a 'thing'.

In meeting identified needs, Nathan and I helped make brain-health discourses around MCI more tangible and concrete by giving them form. Our users emphasised that they wanted scientifically reliable knowledge about the ageing brain and the relationship between normal ageing and dementia, as well as information about how to keep their 'brains' healthy and active—such was the strength and pervasiveness of this discursive 'style of thought' surrounding the project. The information section in the website localised MCI as a pathology of the brain, reinforcing a mechanistic and molecular vision of cognitive change. To this extent, our design processes and materials, by giving form and agency to a contested medical concept, contributed to a 'hardening' of the MCI category (Whitehouse & Moody, 2006).

Summary

This chapter has explored the extent to which the Grey Matters website gave form to a particular set of discourses related to ageing and the 'ageing brain'. In particular, I explored how MCI and dementia are positioned in relation to the contemporary Western ideal of 'successful ageing'; how cognitive impairment is seen as a form of 'unsuccessful ageing'; and how cognitive impairment is framed in terms of its potential future economic burden on the state. Using Foucault's concept of governmentality, I highlighted how this burden is placed on individual citizens who must self-monitor and self-manage their relative risk of ageing 'badly' on the state's behalf. Linked to this, I argued, is the common belief that ageing badly can be objectively detected using the tools and knowledge of modern science. Drawing on data from Living Well with MCI participants, I explored the various ways in which participants had internalised this belief, and how this, in turn, had shaped their wants and needs regarding the online resource. For example, many wanted reliable and scientific knowledge about 'brain health' and, by extension, about MCI and what could be done to prevent it. In seeking to provide reliable information through the online resource, however, I helped 'deliver' and reinforce the very forms of discourse and knowledge that made MCI a matter of concern for individuals and the state. As such, Grey Matters can be seen as an extension of a 'style of thought' that has its roots in scientific materialism, the implications of which I discuss in the next chapter.

Excerpt from Critical Reflection session with Nathan

Nathan: I suppose initially, like, when I was told 'Hey, you're working on this project with Guy,' my initial concerns were more around the context, like, 'What is MCI? Wait, are we designing a website for old people? How's that going to work?' And much less about 'I'm working with a researcher, an anthropologist'. Partly that's because I already knew you. I think what I found really useful and insightful talking to you in these reflections, both formally in recorded ones but also just travelling between different people's homes for interviews, was, you know, just trying to deconstruct what we've heard or witnessed or learned. I suppose it's being able to look at it from multiple perspectives, one being obviously quite strongly the social science, kind of lived experience, and your thoughts on how, like, what does [MCI] actually mean within the context of people's everyday lives versus this clinical perspective. So I think from that point of view it's been really useful in terms of working with a researcher, someone who looks at it largely through that lens, whereas if I was working with a much more biologically focused researcher who was studying MCI and biological patterns in the brain for example, I think potentially I might have been a bit more convinced of this category or this definition or this as a, essentially, clinical condition. And then maybe I'd kind of just be a bit more accepting of like, 'Oh yeah, it's important to design for people with MCI'.

GREY MATTERS

Minds grow, change and age. Let's talk about it.

Learn

About the ageing brain and
how to keep your brain healthy

Explore

Other people's Tips & Tricks
and Stories

Share

Your own Tips & Tricks or
Stories with others

What is Grey Matters?

It's normal to forget things. Your brain, like every other organ in your body, changes over time. Forgetfulness is a natural part of the ageing process, so it's not surprising that it happens most frequently among older people. It's common to experience other changes too: you might start to notice that you are finding it more difficult to come up with the right word, or losing the thread of conversations, books, and movies. You might walk into a room and forget what you were there for, or perhaps you have started to find it more difficult to follow recipes or to multi-task while cooking.

Some older people may experience only minor changes to their memory and thinking, while others may find that these changes are starting to interfere with their daily activities. How much these 'senior moments' interfere with your day-to-day life can depend on the kinds of strategies you have in place to minimise their impact. For example, you might use diaries, memory aids, bill payment systems, and be extra careful to avoid distractions while cooking. You might prepare simpler meals, write notes and To-Do lists, or use symbolic reminders, like tying string around your finger. These are all useful strategies (what we call "Tips and Tricks") that can help older people manage changes to their memory and thinking.

Grey Matters is a place where you can learn about the ageing brain, explore the many different strategies that people use to help them through the day, and share your own Tips, Tricks, and Experiences with others. You will find information about healthy ageing and be able to learn from others who may be experiencing the same changes as you. We hope that some of the stories and strategies you find here will help you in some way.

Click on one of the three buttons at the top 'Learn', 'Explore' or 'Share' to get started.

Figure 47: Grey Matters home page

Go Back

LEARN
All about the ageing brain

Ageing Brain | **Brain Health** | **Links & Resources**

The Ageing Brain

Your brain, like every other organ in your body, changes over time. Because of this, most of us are likely to experience some changes to our memory and thinking as we get older. We may start to notice that we are forgetting things more often than usual, or finding it more difficult to come up with just the right word, or losing the thread of conversations, books, and movies.

What are 'normal' changes for my age?

Some common changes associated with 'normal' age-related changes include:

- Slower recall and thinking
- Slower at solving complex or unfamiliar problems
- Difficulty learning new information
- Difficulty maintaining attention, particularly when there are distractions
- Difficulty multi-tasking (e.g. talking on the phone while cooking)
- Forgetting the finer details of conversations (but it is not usually normal to forget that the conversation occurred at all).

Many people who experience these changes worry that they might be experiencing the early symptoms of dementia. However, this is not necessarily the case. It can be very difficult, even for medical professionals, to know whether the changes we experience as we get older are 'normal' for our age, or the start of more significant changes to our memory or thinking. This is partly because every person is different. Our brains have varying levels of cognitive ability in the first place and, like other organs, age at varying speeds depending on multiple factors, such as our genetic makeup, diet, and lifestyle.

Diagnosing dementia or 'mild cognitive impairment' (MCI) involves putting together information gathered from the person's report of their memory changes, those observed by others who know them well, assessments of their memory and thinking, and other tests. Unfortunately no single test can reliably predict the development of dementia. Brain scans and blood tests are usually used only to rule out other, rarer causes of cognitive impairment, such as a vitamin B12deficiency, or to pick up an unexpected cause such as a stroke which has not presented the typical signs.

What is 'Mild Cognitive Impairment'?

Figure 48: Grey Matters Learn page
(Ageing Brain)

Go Back

LEARN
All about the ageing brain

Ageing Brain   **Brain Health**   **Links & Resources**
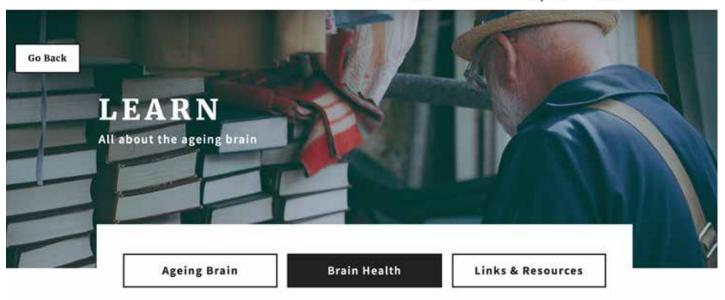
Keeping your brain healthy

While it is difficult to predict whether or not our memory and thinking will worsen over time, there are things we can do to try and keep our brains healthy as we age. Experts often say that what is good for your heart is also good for your brain. This is because your heart and brain are connected by arteries that supply blood, oxygen, and nutrients. To put it simply, the brain needs a healthy heart in order to keep the brain cells functioning well. It follows that unhealthy habits which affect your heart, such as smoking, can also affect your brain. If your heart is unhealthy, your brain may not be getting the blood flow it needs, which means that your brain cells may be deprived of the food and oxygen that *they* need. The risk factors you can change are those which are likely to preserve the blood supply to your brain by maintaining the health of small and large blood vessels.

Here are some good habits that can improve the health of both your heart and your brain:

Maintain a healthy diet

The food you eat may have some effect on your blood pressure, cholesterol, and blood sugar levels. The Mediterranean Diet probably has the greatest evidence to support benefits from a particular diet. This diet emphasises plant-based foods, vegetables and fruit, legumes and nuts, high fish intake and infrequent red meat (a couple of times per month).

Here are some food groups that experts recommend for keeping your heart and brain healthy:

- **Healthy Fats** - Much of the brain's cell structure is made up of "healthy fats". The brain requires an abundant supply of these fats from our diet to repair itself and grow new neurons. Salmon and tuna, for example, are particularly rich in omega-3 fatty acids, which can lower blood pressure and reduce blood clotting. Avocados are high in monounsaturated and polyunsaturated fats, B vitamins and folate, which has been shown to help prevent the tangled nerve fibres associated with Alzheimer's Disease.

- **Antioxidants** - As we get older, our brain cells can be broken down by "free radicals" in our bloodstream. Antioxidants merge with free radicals to make them harmless. Good sources of antioxidants include tea (especially green tea), blueberries, tomatoes, carrots, red grapes, broccoli, spinach, garlic, whole grains, soy, and dark chocolate.

- **High-Tyrosine products** - Tyrosine is a nonessential amino acid involved in the production of brain chemicals called neurotransmitters. High-Tyrosine foods include cheese, soybeans, beef, lamb, pork, fish, chicken, nuts, seeds, eggs, beans, and whole grains.

Stay socially connected

Experts also recommend staying socially connected because this is great for stimulating your brain

Figure 49: Grey Matters Learn page (Brain Health)

TIPS & TRICKS

Explore strategies other people find helpful

| Tips & Tricks | Experiences |

Select a category below to filter the list of experiences by other people

Show all | Cooking | Cleaning | Driving | Finance | Memory | Shopping | Socialising

The Importance of Shirt Pockets

By Bobby Parsons

If you were to inspect all the shirts in my wardrobe, you may notice that that each one has a pocket over the left breast...

Read more

Yellow flag for the car

By Harriet McBride

I can still drive, but sometimes when I go to the supermarket I'll forget where I've parked the car. It can be very frustrating and also quite fright...

Read more

Remembering the home phone number

By Anjali Sachdeva

I have noticed some changes to my mother's memory. It's obvious to me, because I live with her, but other people probably wouldn't notice...

Read more

Being more Mindful

By Pauline Walton

I was diagnosed with mild cognitive

Gas On/Gas Off

By Christopher Wilson

I'm 68 and have been worried about my

My digital clock projector

By Dennis Goodman

I'm 83 and was recently diagnosed with mild

Figure 50: Grey Matters Tips & Tricks page

EXPERIENCES

Read and learn from other peoples experiences

| Tips & Tricks | **Experiences** |

Select a category below to filter the list of experiences by other people

Show all | Ageing | Community | Exercise | Memory | Nutrition | Support Service | Transport

Getting a diagnosis

By Cory Matthews

My mother was behaving differently and I wasn't sure whether it was normal for her age. She was repeating herself more often, telling me things that she had already said earlier, adamant she was telling me for the first time. It was a bit worrying...

Read full story

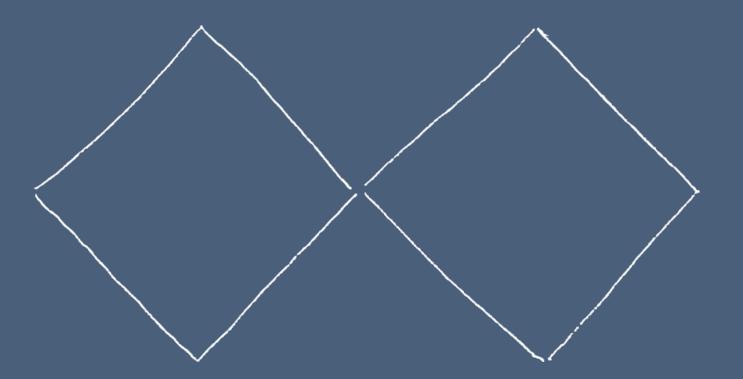## Tell me straight

By Jean Rhodes

I'm always forgetting appointments and have been getting lost quite a bit recently, which is very frightening. It's hard to say when it all started. I had a bad fall a few years back, while out hiking. I lost my footing and hit my head pretty hard...

Read full story

Figure 51: Grey Matters Experiences (previously called 'Stories') page

9.
Discussion

This final chapter aims to bring together the various strands that have emerged over the previous four chapters. Beginning with a summary of the findings and contributions to the field of design for health, I will elaborate on some of the key points before discussing these in relation to future work in design anthropology. In particular, I will highlight and expand upon three key points in the following sections. First, that design for health practices are underpinned by categories of biomedical thought, including its underlying assumptions about the nature of reality, which may be problematic. Second, that design arguably entrenches these assumptions more deeply in individuals and contemporary society by giving them validity and physical form in the world. And third, that design anthropology is in a unique position to not only enable 'critical reflection', which may be an insufficient response to the preceding points, but also to reimagine conventional design processes, tools, and methods with the help of emerging social theory (e.g., new materialism). These points are woven together in two sections following the summary of key findings and contributions below.

Key findings and contributions

This PhD research set out to explore how embedding a design anthropological approach into a co-design process might inform or develop insights into the MCI category, and shed light on the possible role of design in assembling new medical realities. The purpose of this was to enable critical reflection on 'designing for people with MCI' in an attempt to design in a more reflective, ethically aware, and critically engaged manner. To do this, I focused on exploring the wider MCI assemblage, tracing the many elements and relationships within it, to show how the MCI category was constructed through a network of research and knowledge-making practices, of which the Living Well with MCI project was a part. I hoped that exploring this assemblage and making it visible would prompt Nathan, myself, and the wider steering group to consider other possibilities and futures that challenged the disputed MCI concept.

The key findings and analysis presented over the last four chapters show that the Living Well with MCI project was entangled in, and ultimately reproduced, biomedical discourses, practices, and ways of thinking, despite efforts to challenge or resist these through a design anthropological approach. While I was deeply involved in everyday activities of the design team, and arguably had some influence on Nathan's thinking over the course of the project, our decisions and processes were nevertheless 'conducted' in ways that reproduced the MCI category.

From one point of view, this could be seen as a failure on my part to steer the project away from replicating dominant biomedical modes of thought, which tend to 'essentialise' diagnostic categories (Adriaens & De Block, 2013). However, documenting the ways in which this process unfolded was perhaps the most important contribution of this research. To the best of my knowledge, this PhD is among the first to explore and test a design anthropological approach as part of a design for health project, and certainly the first to investigate how design processes intersect with the construction of an emerging medical reality. It is therefore also the first to document some of the challenges of 'doing' design anthropology in a design for health context, and to identify opportunities for doing things differently in the future.

In many ways, employing design anthropology in this project was an attempt to bridge the gap between social theory and design practice. When I began working on this project, I had a limited understanding of design. Similarly, with a background in design, Nathan had little knowledge of anthropology. Yet as we worked together

towards our shared goal of designing a useful online resource for our user group, we tried to balance the theoretical orientation of anthropology (represented by my interest in the social production of MCI), with the pragmatic concerns of design (represented by Nathan's concern with understanding the users and meeting their needs). I helped Nathan become aware of MCI as a contested 'social construct' and the wider assemblage that produced it, and he taught me about his approach, methods, and ways of thinking.

Over the course of this interdisciplinary exchange, Nathan eventually recognised that there was a risk involved in prematurely 'hardening' the MCI category by giving it form through the web resource. And yet, from a design perspective, he was still attached to using the term MCI, since this provided a clear set of constraints around our target user group. For this reason, he was opposed to using the phrase 'people experiencing changes to memory and thinking'.

Despite integrating critical reflection as part of the Living Well with MCI project, Nathan was ultimately driven to design, build, and test a 'solution' to the 'problem'—or, as he put it, "to try and make something better than it was before we started." However, because MCI was formulated as a biomedical problem (a formulation supported by a broad assemblage of knowledge-making practices), this constrained possibilities for a solution that departed from a discursive framing in which MCI was a 'brain impairment'. As a result, the website arguably helped concretise the discourses that made MCI a matter of concern for individuals and society at large.

As I discussed in the Deliver chapter, I wrote content for the information section of the website. I pointed out that in the absence of alternative discourses with which to frame and talk about MCI, I was forced to replicate the biomedical understanding of MCI as categorically distinct from 'normal' ageing. There seemed to be no other way to talk about it. After all, this was what our participants wanted.

The content I wrote was an informed response to user needs and preferences. Living Well with MCI participants wanted 'reliable' and up-to-date scientific knowledge about the ageing brain and dementia. They had themselves internalised biomedical discourses in an effort to understand and articulate their experience. Although I had focused my attention on influencing Nathan's thinking, users themselves drew heavily on biomedical discourses, suggesting that simply being 'aware' of these discourses and making them 'visible' to designers is not sufficient. I was myself influenced by these dominant ways of thinking and found myself writing content that reproduced them, often without realising it. Indeed, the thought-style of biomedicine, with its emphasis on norms, averages, and materiality, provided a tangible sense of *knowing*, despite my new materialist position that MCI was not a 'thing' one could know anything 'about'.

This of course raises a number of questions regarding the extent to which design anthropology, at least as it has been employed in this PhD, can meaningfully influence design outcomes. My research suggests that although design anthropology can create much-needed space for critical reflection, this, as I explain below, is not sufficient if designers are to rise to "the challenges of realizing a paradigm shift in our health care" (Chamberlain & Craig, 2017, p. 6). As I argue later in this chapter, design anthropology needs to turn its attention towards rethinking human-centred design theory, methods, and pedagogy in light of emerging social theory (e.g., new materialist ontologies) to truly shift the existing healthcare paradigm.

Future-proofing a (Western biomedical) style of thought?

A key thread running through this research is the notion that design gives physical form to ideas. In a deep sense, to make something is to make something 'real'. The power of design is that it brings ideas out of the realm of abstraction and into the world, where, as sociologist Louis Neven (2010) suggests, they "may act in materialised form in society, while at the same time becoming nearly invisible and

seemingly part of the natural order of things" (p. 336).

One of the most potent, near-invisible ideas in contemporary society is scientific materialism. Scientific materialism is the belief that only physical reality, being objective and measureable, truly exists (Wilber, 1999). This philosophy underpins biomedical theory (Good, 1993) and is reflected in the research methods, structures, systems, and practices of Western medicine (Kirkengen et al., 2015). Often presented as the 'true' way to think about health and illness (Kirkengen et al., 2015), materialism supports and informs many projects in the design for health space. Scientific materialism is 'invisible' in the sense that it is commonly taken for granted in contemporary society. As a philosophy—or, more accurately, a metaphysical presupposition—it is quietly woven into modern people's everyday health-seeking practices, such as consuming vitamins or nutritional supplements (Rose, 2003). Its persuasiveness derives from the fact that it presents a compelling but partial truth—namely, that the human body is, in part, made of complex molecular structures and other 'matter'. As Kirkengen et al. (2015) explain,

> Within this [materialist] worldview, the human body is defined as matter, subject to natural law, and as such, *completely explorable* by means of fragmenting methods based on a presumption that the Truth about the essence of things resides in its smallest parts. (p. 497)

However, this metaphysical idea does not present a complete picture of human health, since it cannot account for many 'immaterial' but equally important aspects of wellbeing, including the historical, sociocultural, phenomenological, biographical, spiritual, and psychological dimensions of embodied human experience (Kirkengen et al., 2015). Indeed, these have largely been ignored by modern Western medicine for the simple reason that they do not really 'exist' from the materialist standpoint (Wilber, 1999). Pointing out that vast realms of subjective human experience have been reduced to corresponding biological and material processes, Wilber (1999) mockingly writes

> Instead of joy, let us examine levels of dopamine. Instead of depression, let us look to serotonin at the synapses. Instead of interior angst, let us look to empirical amounts of acetylcholine in the hippocalamus. These, after all, can be empirically seen and measured. (p. 82)

Despite growing awareness of biomedicine's theoretical inadequacies and their impact on global health (Kirkengen et al., 2015), and increasing recognition of the need for post-materialist frameworks in both science and medicine (Taylor, 2018), materialist ideas are nevertheless woven into the fabric of current design for health practice, as this research has shown. Through Chapters Five to Eight, I explored the ways in which MCI has been shaped by a long history of dementia research and its commitment to scientific materialism, a 'style of thought' that manifested in contemporary research and clinical settings as the idea that MCI "resides in the brain", despite evidence to the contrary. I highlighted that users shared with researchers and clinicians the belief that MCI was a condition of the brain, a discrete entity that could be readily detected and labelled, and for which drugs or other courses of treatment may one day be developed. This is problematic in light of recent discussions about the link between the medicalisation of ageing and health consumerism, and the ways in which this legitimises the Western understanding of ageing as physical deterioration (Salter & Salter, 2018).

In contrast, my 'constructionist' perspective from the outset was that the difference between 'normal' age-related changes and MCI (and between MCI and dementia, for that matter) are contested divisions that do not already exist 'out there' in nature, and therefore cannot be 'discovered' in the material brain. Instead, I argued, they emerged through complex interactions between phenomenological, social, cultural, political, and historical forces—in which the Living Well with MCI

project was entangled.

Regardless, our users, who often took these distinctions and categories as 'givens', wanted the online resource to include reliable information (that is, scientific knowledge) about what is 'normal' versus 'abnormal' ageing, about the difference between MCI and dementia, about what was good for the brain, and so on. By drawing on bioscientific ideas and discourses in order to meet these user needs and requirements, it was unavoidable (but perhaps not surprising) that the website reproduced these categories and the apparent distinctions between them as if they were matters of fact. In providing scientific and therefore reliable information about 'MCI' and 'the ageing brain', it made MCI seem less contentious and more factual—a 'condition' about which science *knows* something. Ultimately, the website gave form to biomedical assumptions and their underlying metaphysical claims about reality, which are problematic (Kirkengen et al, 2015; Taylor, 2018). Despite efforts to question the validity of the MCI concept, Nathan and I gave it more validity by designing a website around it, and making it *more* of a 'thing' for people to both learn and worry about.

My sense is that this is a common problem in the design for health space, where the categories of biomedical thought and practice, while questionable, are often taken for granted. For example, a European fashion designer recently developed a wearable, non-invasive 3D-printed headset for children with Attention-Deficit Hyperactivity Disorder (ADHD) (Lamontagne, 2017) (Figure 52). The purpose of the helmet was to enable researchers and families to monitor children's brain activity using electrodes and a camera. The project, called *Agent Unicorn*, is discussed in a conference paper in which the author seems to take the ADHD concept as 'fact', referring casually to "ADHD kids" and "affected children" (Lamontagne, 2017, p. 693).

However, the notion that the behaviours associated with the ADHD description are 'medical' in nature and reducible to brain activity—an assumption that *Agent Unicorn* makes tangible—is highly questionable (Timimi, 2018). Like MCI, ADHD has "no specific cognitive, metabolic or neurological markers and no medical tests" (Timimi & Taylor, 2004, p. 8). Indeed, the ADHD category is another contentious example where the therapeutic benefit of 'medicalisation' is disputed and alternative explanations are available. Nevertheless, the helmet is an example of 'hardening' the ADHD category and its implicit belief in the truth of scientific materialism.

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Figure 52: Agent Unicorn headset for ADHD. Source: https://www.fastcompany.com/90356112/this-magical-unicorn-horn-is-actually-a-wearable-device-for-kids-with-adhd

Similarly, while attending a design for health symposium in Melbourne in 2018, I listened to one researcher present on a brain stimulation helmet for treating depression at home (Figure 53). I referred to this in the 'Intermission' between the Define and Develop chapters (see pages 101-102). The helmet, which looks similar to an ordinary bicycle helmet, was clearly shaped by materialist assumptions, which it has inevitably reproduced and made more 'real'. Now 'acting' out there in the world, the helmet visually conveys the idea that depression—a complex form of psychological distress, which is fundamentally existential and, as such, tied to social, cultural, and historical conditions—is simply a physical disorder of the brain that can be reduced to neural activity and hence treated with electrical currents.

One can detect the influence of scientific materialism in a range of other recent design for health innovations, such as fitness trackers and other mobile or wearable 'mHealth' technologies (Lupton, 2013). These technologies are designed to measure or 'track' a range of bodily functions and indicators, including "blood glucose, body temperature, breathing rate, blood chemistry readings, body weight, heart rate, sleep patterns, cardiac output readings and even brain activity" (Lupton, 2013, p. 394).

A prominent critic of these products is sociologist Deborah Lupton, who recently applied a new materialist lens to what she calls 'the human-app health assemblage', showing how entanglements of "affective forces, [...] embodied experiences, social relationships, human and nonhuman affordances and cultural imaginaries" (Lupton, 2019, p. 13) produce particular identities and embodiments based on the persuasive thought-style of scientific materialism.

Many Living Well with MCI participants supposed that their experience could only be understood in terms of "what's missing in the brain" (MCI_021_dyad), or the presence of "something funny in my brain or blood" (MCI_013_dyad). These perspectives were of course entangled in an assemblage of various knowledge-making practices that supported and reinforced these beliefs. The practices were themselves driven in part by broader cultural anxieties around ageing and cognitive decline, and the belief that dementia could be explained, or perhaps even cured, by modern science (Lock, 2013). The stated objective of BRNZ, after all, was to "[unlock] the secrets of the ageing brain" (BRNZ website, accessed May, 2019).

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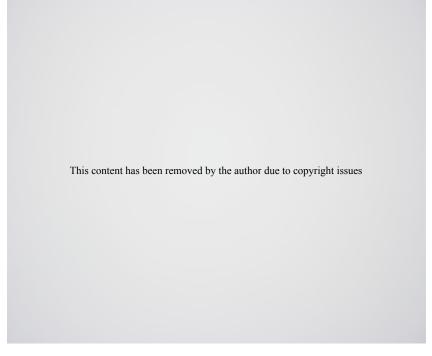
Figure 53: Brain Stimulation Helmet for depression. Source: https://www.monash.edu/mada/research/labs/health-collab/caloric-vestibular-stimulation-device

Given the many ways in which design for health projects become entangled in these vast assemblages of biomedical thought and practice, there is an ongoing risk that designers will inadvertently create the impression that a materialist ontology is simply part of "the natural order of things" (Neven, 2010, p. 336). As integral psychologist Jennifer Gidley (2006) observes, we hardly notice how "Western architecture [contains] a predominance of square boxes that reflect the structure of intellectual thinking" (p. 38). In other words, just as the online resource gave the MCI category and materialist assumptions 'form' in the (digital) world, the built environment as a whole (including robots, apps, buildings, and airplanes) is a physical manifestation of a culture's cosmology—it quietly reflects and reinforces a particular way of being, knowing, and doing (Escobar, 2018)..

Of course, scientific materialism has given rise to incredible new technologies in healthcare, including microscopes, magnetic resonance imaging, ultrasound, and hormonal therapy, and these achievements should be celebrated. At the same time, it is important to remember that a materialist worldview carries with it a number of contested ideas that other cultures do not share—which should at least give design for health practitioners pause for reflection. These ideas (or, rather, cultural biases) include, for example,

> that mental phenomena and consciousness itself are the product of neurological activity; that human beings and other living beings are biomedical machines who exist in ontological separation to one another, and who consist of genes whose purpose is to survive and replicate; that the origins and the evolution of life can be explained in terms of accidental factors; that consciousness or personal identity cannot continue following the death of the body and brain; that human behaviour and experience are determined by genetic and neurological factors; that the world and the universe are fundamentally mechanistic and inert; that paranormal phenomena cannot exist because they contravene the laws of nature, and so on. (Taylor, 2018, p. 150)

Materialist thinking, embedded in socio-technical systems and reproduced by design, is a facet of what physicist Fritjof Capra (1996) calls a 'crisis of perception' in contemporary society. Reflecting on the problems facing the modern world, and focusing in particular on environmental degradation, Capra (1996) argues that

> ultimately these problems must be seen as just different facets of one single crisis, which is largely a crisis of perception. It derives from the fact that most of us, and especially our large social institutions, subscribe to the concepts of an outdated worldview, a perception of reality inadequate for dealing with our overpopulated, globally interconnected world. (p. 4)

This worldview is rooted in the modernist philosophy that arose in Europe during the so-called Enlightenment era, as sociologist Max Weber has written (Weber, 2013). Observing the rise of scientific rationality in Europe during the nineteenth century, Weber was deeply concerned with what he called the 'disenchantment' of the modern world (Hewa & Hetherington, 1990). He argued that the increasing intellectualisation and rationalisation of society produced a mechanistic vision of the universe in which reality, consisting only of inert matter and mathematical laws, was reduced to only that which could be measured and quantified. Western medicine, which perpetuates a view of the body as a mechanical system, is one such social institution that subscribes to and upholds this outdated view (Hewa & Hetherington, 1990; Kirkengen et al., 2015).

The disenchanting 'rationalisation' of the world (or what Capra is calling a 'crisis of perception'), reduces life to empirically observable matter and processes (Wilber, 1999) and has thus had a profound impact on the way modern people conceptualise themselves, relate to others, and treat the environment. For example, from an

ecological point of view, this paradigm endorses a reckless attitude towards the environment, with its insistence that the world is made primarily of inert matter (Taylor, 2018). Indigenous cultures, by contrast, understand that their environment is inhabited by the spirit of their ancestors, and treat it accordingly (Davis, 2009). From a 'mental health' perspective, the modernist philosophy and its denial of the immaterial components of human experience is also arguably linked to rampant nihilism and consumerism in modern society, since if it is true that human beings are just genetic machines in an insentient and meaningless universe, as Taylor (2018) bluntly puts it, "they may as well just enjoy themselves as much as possible and take as much from the world as they can" (p. 150).

Design for health practitioners often reproduce the categories of biomedical thought in the context of their work, and in doing so they inadvertently give form to an outdated paradigm and its assumption that the world is mechanical and inert—an idea that has had a profound impact on people's health and wellbeing, broadly defined. This PhD research suggests that design for health, as it is currently conceptualised and practiced, is an unwitting defender of this dominant cultural narrative and its inherently limited and 'disenchanting' metaphysic, which devalues other (and perhaps more enchanting) possibilities.

Since both 'design' and 'health' are often ensconced within this worldview, it is important for designers to recognise the deep wisdom that 'alternative' ways of being may contain. The wisdom of indigenous worlds, in particular, as Borunda and Murray (2019) suggest, may "contain opportunities to heal trauma and sustain wellbeing" (p. 9), and for this reason should be taken seriously in the field of design for health. Historically, indigenous worlds have been dismissed as 'unscientific' or 'pre-rational' (Davis, 2009), but in fact they may offer unique solutions to some of the problems and crises facing the modern world (Davis, 2009; Borunda & Murray, 2019). Indigenous worlds have metaphysical assumptions that differ from non-Western ideas about the nature of reality, and therefore produce entirely different ways of being, thinking, and knowing that may positively inform contemporary design practices (Escobar, 2018).

This is a point I elaborate on in the sections below, where I suggest that design anthropology is well placed to start reconceptualising design tools, methods, and processes in ways that reach all the way down to this metaphysical level—the source, as I have argued, of many contemporary health and wellbeing challenges (Kirkengen et al., 2015; Taylor, 2018; Wilber, 1999).

Reimagining design/anthropology

As an emerging field of research, design anthropology represents an important shift in terms of the way design has historically been thought about and practiced (Otto & Smith, 2013). In taking the historical, social, cultural, institutional, and political contexts of design practice into account, it is an approach that recognises a multiplicity of worlds, possibilities, and futures (Kjaersgaard & Boer, 2016). By showing how knowledge and discourse give rise to new cultural forms (or indeed, sustain existing ones), it has the potential to make the politics of design practice visible to designers in order to inspire critical reflection on their work and its implications (Otto & Smith, 2013).

However, the present research suggests that having a single 'design anthropologist' on a project team may not be an adequate response to the powerful discursive (or, in the present case, 'medicalising') forces and assemblages in which design processes unfold. Although I was equipped with the conceptual tools to think about multiplicity and the power of discourse, and shared insights about these with Nathan whenever I could, the MCI project was permeated at every level by biomedical ways of thinking, seeing, and doing. It was a product of the very structure I wanted to question.

My original strategy was to make this assemblage and its ways of thinking, seeing, and doing visible to Nathan, hoping this would provide a solid foundation

to critically examine, question, and challenge the validity of designing for the MCI construct. From a design anthropological perspective, my inquiry led me to conclude that the MCI category did not really benefit those diagnosed and labelled. Overall, it did not provide people with any greater sense of certainty about their future. Nor did it put them in touch with support services. Often, it seemed to produce greater anxiety. I found that the MCI concept mainly served researchers, who could leverage the category to justify grant applications, secure funding, publish papers, present at conferences, and thereby maintain their positions within academic institutions where employment is both precarious and competitively sought. These structures, in creating new problems (and realities) to design for, are formed by, and reproduce, the dominant scientific discourses that in turn shape design responses. [14]

And yet, in spite of my efforts to make these points visible to Nathan and the wider design team, ultimately the website reproduced the MCI category. I was never able to steer the conversation away from this completely, with the exception of some minor, relatively inconsequential, shifts. These shifts were mainly language-based, such as avoiding the term 'MCI' and instead, where possible, using the phrase 'changes to memory and thinking'. Nevertheless, the materiality of the website and its entanglement in the socio-technical assemblage meant that reproducing the concept and its assumptions was inevitable. Critical reflection and making things visible, in other words, were not enough.

This raises the possibility of reframing the role of design anthropology itself, and I would like to offer some reflections on this in conclusion. I want to suggest that, rather than trying to shift thinking from within individual projects per se, future research in the field should focus its attention on rethinking design theory, methods, processes, and education as a whole.

Generally speaking, conventional design processes, tools, and methods do not in themselves allow designers to see or think about other cultural worlds or possibilities. Instead, they encourage designers to 'empathise' with users and their 'experiences', which amounts to little more than in-depth market research (Dourish, 2006). Of course, this is not at all surprising, since many design methods have their roots in modern capitalist aims and objectives (Forlano, 2017).[15]

Nor do these tools illuminate the deeper realities and contexts in which both designers and 'users' are embedded and problems framed. People with MCI, as I have already discussed, placed their trust in scientific knowledge and its experts, and had therefore internalised the dominant ways of thinking. Therefore, the tools we used (e.g., interviews and card-sorting) simply communicated this bioscientific mode of thinking back to us. Ultimately these discourses found their way into the web resource, which became a mirror in which the dominant cultural narrative was reflected.

Towards the end of this research, I began to grapple with the following question: how can design recognise other possibilities when design practice has itself been 'colonised' by the norms of dominant structures, systems, processes, and ways of thinking? Indeed, design as a discipline has historically been tied to the systems, structures, processes, and thought-style of the Western world. As authors from the *Decolonising Design Collective* (Abdulla et al., 2019) note,

> To date, mainstream design discourse has been dominated by a focus on Anglocentric/ Eurocentric ways of seeing, knowing, and acting in the world, with little attention being paid to alternative and marginalised discourses from the non Anglo-European sphere, or the nature and consequences of design-as-politics today. This narrowness of horizons and deficiency in criticality is a reflection of the limitations of the institutions within which design is studied and practiced, as well as of the larger socio-political systems that design is institutionally integrated into. (p. 130)

A design anthropological approach was used in the present research as an attempt

[14] The issue of power-knowledge, from a post-structuralist perspective, is worth considering in relation to research and funding, and the ways in which these construct realities and shape the future. Research teams in health often draw on biomedical understandings of the body, since 'science' has become the dominant discourse (over other possbile discourses) in the contemporary Western world. Indeed, these discourses are perpetuated through funding mechanisms that privilege a particular way of seeing the world. This way of seeing in turn produces new 'problems' to address, to keep researchers employed and their institutions in a position of relative power in society. For a more detailed exploration of scientific hegemony and control, see Malatzky et al. 2018; Rajan et al. 2013.

[15] I should acknowledge here that the preoccupation with 'empathy building' in design is relatively new and there are critics within the design community of this approach, and increasingly in the field of design for health (see, for example, Bennett & Rosner, 2019). It is important also to emphasise that there are myriad design tools and processes in design fields that do not perpetuate colonial structures or ways of thinking, particularly those that are oriented towards critical design, speculative design, generative design, participatory design, and co-design. The design tools used in Living Well with MCI were derived mostly from Nathan's UX background and perspective, which I did not challenge as much as I could have, perhaps because I did not feel like I had adequate 'design' expertise compared to him.

to think differently about MCI and the future of ageing, to expand horizons in terms of how these were conceptualised and enacted within these wider socio-political systems. Perhaps there is an opportunity for design anthropology to go a step further, to rethink human-centred design methods themselves, which currently reflect a market-driven concern for understanding individual 'user experiences' and 'needs'.

How might an appreciation for other ways of thinking and being (a primary concern of anthropology) help generate new processes, tools, and methods that begin to open up new worlds, rather than reflect back existing ones?

An important contribution of design anthropology could be to consider how these tools and methods might be reimagined in light of contemporary social theory. As design researcher Laura Forlano (2017) suggests,

> Human-centered design is founded on understandings of the human as a discrete, individual subject. Yet, our new relations to the natural world and to socio-technical systems are calling these previous understandings into question. The field of design is also commonly beholden to neoliberal, capitalist economic models that define the individual subject, primarily as a consumer with the power to make choices, but whose agency and participation in communal modes of resistance, and power to counter corporations and governments, has been weakened. As design expands into the social sector, and engages with problems within complex socio-technical systems, it is vital that we reflect on the basic assumptions that have underpinned earlier methods, models, and frameworks, and consider the relevance of emerging social theory. (pp. 17-18)

New materialism, for example, is beginning to highlight the emergent nature of these deeply interconnected systems (or 'assemblages'). Intriguingly, new materialist approaches hint at a potential solution to what Gidley (2006) calls the "dualistic, fragmenting, and conflict-producing instrumental rationality" of Western thought (p. 30). As such, emerging social theory is starting to align with indigenous models of the world, which tend to be 'holistic' and systems-focused rather than fragmented and compartmentalised. Consider, for example, the similarities between new materialist thinking and a Māori cosmology. As Garth Harmsworth and Shaun Awatere (2013) explain, the Māori world recognises

> a natural order to the universe, a balance or equilibrium, and that when part of this system shifts, the entire system is put out of balance. The diversity of life is embellished in this world view through the interrelationship of all living things as dependent on each other, and Māori seek to understand the total system and not just parts of it. (p. 274)

Given that designers are increasingly forced to think at the level of complex systems rather than focusing on isolated parts (Norman, 2009), what could they learn from indigenous ways of knowing, being, and acting in the world? How might design pedagogy be improved if, for example, it took seriously the implications of a relational Māori ontology? What influence would this have on design processes, tools, methods, and ways of working? And for the field of design for health in particular, what implications would such a model have for people's wellbeing (and, since they are inseparable, the planet as a whole)?

Design anthropology, with its sensitivity to the relationship between design and culture (or, to put it more emphatically, to the idea that design *is* culture) is in a unique position to start addressing some of these questions. Carl DiSalvo (2013) suggests that design anthropology may itself be "a kind of speculative intervention into the field of design research, a suggestion of what design might be" (p. 151). I would add, however, that this speculation requires designers and

design anthropologists to not only 'critique' or render 'visible' what is already the case, but to fundamentally shift their orientation towards what could be. This can only be achieved, I argue, by stepping outside the dominant paradigm in which design is currently practiced. Anthropologist Arturo Escobar (2018) puts it this way: "can design's modernist tradition be reoriented from its dependence on the life-stifling dualist ontology of patriarchal capitalist modernity towards relational modes of knowing, being and doing?" (p. xiii).

This is a very complex question, but the answer to this may turn out to be relatively simple. Because in the end, as Wade Davis (2003) provocatively suggests in his talk, *Dreams from endangered cultures*, it ultimately comes down to a choice:

> Do we want to live in a monochromatic world of monotony, or do we want to embrace a polychromatic world of diversity? Margaret Mead, the great anthropologist, said, before she died, that her greatest fear was that as we drifted towards this blandly amorphous generic worldview, not only would we see the entire range of the human imagination reduced to a more narrow modality of thought, but that we would wake from a dream one day having forgotten there were even other possibilities.

In light of Mead's haunting vision, designers have an urgent responsibility as form-givers and future-makers to rethink their usual modes of practice, move beyond prevailing narratives and structures, and use their skills to encourage the widespread acceptance of other ways. To do so, I argue, is to reawaken to the richness of the human imagination, to its depth and wisdom, and, most importantly, its infinite capacity to dream new worlds into being.

Limitations of this thesis

This thesis has some limitations that should be acknowledged here. The first limitation relates to its contextual nature. This PhD research was based on a particular design for health project with a particular focus on MCI in the New Zealand context. The conclusions I have reached in this research are the product of a specific line of inquiry, which has attempted to blend approaches from science and technology studies, new materialism, and design anthropology. Therefore, the key arguments outlined in this PhD and their implications do not necessarily apply to *all* design for health projects—rather, they are presented in this thesis as provocations for those working in the field to consider, engage with, discuss, and critique.

A second limitation is methodological. This has been my first attempt at new materialist inquiry. Being more familiar with conventional social science and critical theory (e.g., post-structuralism), I felt a strong tendency, while writing this thesis, to fall back into a critique of discourse and knowledge rather than exploring how reality is 'made' or 'assembled' from a new materialist standpoint. While I have attempted to show how discourse may be instantiated in the material world through design, I had to conduct my 'real-time' inquiry while learning about this methodology and how to apply it to the project as it unfolded. Because of this, I have been guilty of reproducing, at various points in this thesis, some of the dualisms (e.g., nature/culture, mind/matter) from which new materialists have attempted to move away. Having been trained to think sociologically, I also tended to focus heavily on the ways in which MCI was produced by complex systems, structures, and processes, often overlooking the role of non-human things and objects in this—a key focus of new materialism (Fox & Alldred, 2015).

Similarly, since it was my ambition to *apply* new materialist inquiry to a real-world context, I have drawn largely on applied new materialist research (e.g., Mol, 2002; Fox, 2017) rather than engaging with the original theorists (e.g., Deleuze & Guattari, 1988). Attempts to use new materialist inquiry in social research are

relatively new, and therefore there is still considerable debate about how to do it and what it should look like (Fox & Alldred, 2015). The same could be said about design anthropology, an emerging field with no standardised way of putting it into practice (Otto & Charlotte, 2013).

A third limitation of this thesis relates to the timing of this research in relation to Living Well with MCI. Because the PhD was in a sense 'built on to' Living Well with MCI, the project was already well underway before I had properly formulated, and was ready to start, my inquiry. This meant that I was unable to capture and document the project in its entirety. For example, I missed important details about where the idea came from and what materials and practices were involved before I was employed—all of which could have been included as data.

Similarly, this project is ongoing at the time of writing and so there is no record of its completion in this thesis. It should be noted here that the website is likely to change in response to user feedback as well as insights from this PhD, which I hope will continue to provide a basis for new directions going forward. In this sense, my research transcends the written thesis. To the extent that the website has been shaped by this research and will continue to evolve beyond the submission of this PhD, this research is not simply a textual and linear representation of the project as a bounded whole—instead it is a partial record of my ongoing involvement.

I should also point out that there is a lot of great work going on the design for health space that does not simply reproduce dominant biomedical discourses. Because it was my aim to promote critical reflection on MCI and its materialist underpinnings, I have not discussed some of the more holistic approaches to healthcare and healing in the context of design, of which there are many good examples that should be acknowledged (e.g. Adedoyin et al. 2014; Aldridge, 1994; Kossack, 2012; Lane, 2006).

Concluding summary

In this thesis, I have drawn inspiration from a new materialist philosophy, combined with theoretical insights from design anthropology and science and technology studies, to analyse MCI as a focus of 'designerly intervention' on the project Living Well with MCI. The purpose of this research was to explore the historical, social, cultural, and material processes by which the MCI diagnosis has been constructed as a matter of concern for individuals and society, and to embed critical reflection on the category within the project, in real time. Working as part of the wider design team, I aimed to open up space for reflecting on what we (the design team) were doing, why we were doing it, and how we might think differently about ageing and cognitive 'impairment'. By exploring the processes by which the MCI concept becomes a 'new medical reality', and how these processes relate to design as a social practice, I have made three key arguments which are intended to provoke critical examination within the emerging field of design for health. First, that design for health projects are often underpinned by philosophical assumptions that are historically contingent and culturally specific (e.g., reductive scientific materialism) and not necessarily shared by many of the world's cultures. Second, that design often gives those assumptions physical form in the world without due consideration for their possible consequences. And third, that future design anthropological work in the design for health space should move from critical reflection towards reimagining conventional design processes, tools, and methods, and how these are used. These arguments are not offered as 'findings' or 'conclusions' so much as provocations for future research and teaching in both design anthropology and the field of design for health. It is hoped that this research has promoted a deeper understanding of the complexities and challenges of these emerging fields, and how some of these might be addressed as they continue to evolve.

Postscript

In early 2018, the DHW Lab abruptly packed up and withdrew from Auckland City Hospital. The general atmosphere of the Lab in the months leading up to its closure was tense. It had become increasingly clear over the course of their five-year partnership that the two organisations, AUT and ADHB, had different expectations about what a hospital design studio was, how it should operate, and what it could become.

Towards the end of its relatively short life, the DHW Lab's projects had become mostly about 'fixing' problems within the hospital environment, rather than rethinking conventional approaches to healthcare in the way it had originally aspired to. It had become more of a handmaiden to internal 'innovation' agendas and performance improvement strategies, which ended up consuming most of its resources. Designers were often pulled into a project in its final stages to make things 'look nice'—they were not always valued for having their own unique ways of framing and solving problems. Their creative approaches often jarred with internal standards of rigour, which valued analysing 'hard' data over understanding people's experience. The hospital's strong aversion to risk meant that it was difficult to try anything new, and nearly impossible to implement any fresh solutions.

In the months following its closure, the remaining members of the DHW Lab reformed as a new entity, Good Health Design, where I now work, and moved to AUT's city campus. Drawing on a wealth of learning from their time in the hospital, the Good Health Design team is, at the time of writing, looking for opportunities beyond the confines of the hospital to explore how design can help promote 'wellbeing' in the community more broadly. This has opened exciting new avenues and possibilities from a design perspective, but some important questions about the future of design for health remain: how can design for health researchers resist dominant biomedical agendas *beyond* the hospital environment?

In the following section, I highlight some of the possible ways in which design anthropological approaches might help answer this question.

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Epilogue

[An Alternative Discussion Chapter in the Form of a Completely Made-Up Conversation with an Imaginary Brain Researcher]

Guy: Thanks for doing this.

Researcher: No problem.

G: I just thought that having a conversation with you might be a good way to conclude this thesis.

R: Happy to help.

G: I mean, not that this thesis really has a conclusion, because that would imply a definitive end-point when, in actual fact, everything I've been writing about is still unfolding. The website that I helped build lives on in cyberspace somewhere, and perhaps by now it is so popular that it has taken another form entirely, shaped from the bottom-up by thousands of users and millions of clicks. Or maybe no one uses it at all. I'm not sure. Anyway, it could be helpful to talk about what the website carries with it into the future, the ideas underneath the MCI category, if you like, and how these, too, continue to exist and unfold in the world. So, first of all, would you mind introducing yourself before we start?

R: Okay, sure. I'm a figment of your imagination, I suppose. A composite figure based on some of the brain researchers you have met over the course of your research.

G: Thanks. I thought I would start with a provocation. Because one of the things I've been thinking about recently is how dementia is often framed and talked about in very brain-centric terms, if that makes sense. And on the one hand this is obvious, because dementia is understood to be a disease of the brain. But it seems to me that much of the conversation about dementia in contemporary societies tends to overlook what happens outside of the brain. I'm talking specifically about society and culture, and how social and cultural forces shape people's perception of dementia and their response to it. So I guess my provocation is this: dementia is seen to be so awful and tragic and terrifying at least in part because the 'demented' individual violates modern cultural ideals of independence and rationality. And I would also add that other cultures respond to dementia in different ways because they have altogether different values and ideals, and that different ways of being

emerge from these.

R: Okay. That's an interesting point, and not something I have really thought about before. Most of the work I do has to do with measuring and quantifying cognitive impairment. I guess I'm not all that familiar with some of these ideas. So before we move on, I just want to clarify a couple of things. First of all, I noticed you said that dementia is 'understood' to be a disease of the brain, which implies that you don't really think it is. Is that right? Because my colleagues and I would say that dementia is without a doubt a disease of the brain. The empirical evidence for that is quite clear. I can take you to a microscope and show you amyloid plaques and tangles in the neocortex, which is what my research focuses on. I can explain to you the mechanisms behind the way it progresses in the brain and how it develops. This isn't really contestable. We know dementia is a disease. As for the social and cultural aspects—doesn't everything have a social and cultural dimension? We're human beings after all. Cancer has a social and cultural dimension. Does that mean it doesn't exist?

G: Oh, I'm not making claims about the 'existence' of dementia. I'm saying that it is talked about and framed as a biological phenomenon, primarily, and that the dominance of this view closes off other ways of thinking about and treating older people. We can go into that in more detail later. And second, with respect to your claim that everything has a social and cultural dimension, I could say the same thing in reverse. Dementia has a biological dimension and involves the human brain, like all human experiences. That doesn't mean that dementia is 'just' a phenomenon of the brain. It's both biological and cultural. Can we agree on that?

R: Sure, it's just that my area of expertise relates to the ageing brain, and I'm not as familiar with the study of social and cultural phenomena. So my understanding of dementia is firmly rooted in the biology of the brain.

G: That's why I thought it would be interesting to introduce a thought experiment to consider other cultural realities where dementia is not talked about as a disease, where the physical and objective aspects of reality are not—

R: But hang on a moment. I think I see where this is going. From my perspective, people who don't believe dementia is a disease simply don't have an accurate understanding of dementia. There is just one reality and we know about it through science. Science looks at the data and tells us that dementia is a disease, that it has a physical basis in the brain. How can there be other realities? Other cultures, sure, but other realities?

G: Well, to begin to understand what I mean by other realities, you need imagine yourself inhabiting a completely different way of being. I'm not talking about 'belief'. That's a very Judeo-Christian sort of idea. This is where the thought experiment comes in handy. Let's just look for a moment at a radically different cultural world. We'll take Tibetan Buddhism, simply because it is so radically different from modern Western culture. This is a reality in which what we call 'dementia' is inseparable from the natural ageing process. In fact, for Tibetan Buddhists, a person's 'true self', or atman, remains completely unaffected by the mental fog and disorientation of old age. The atman, the person's soul or spirit, is that subtle layer of consciousness which lies behind the 'impairment', observing the thinking mind

and—

R: Wait a minute. Spirits and souls? Atman? There is no proof for the existence of such things. Where is the evidence for any of this?

G: I guess there is no evidence, at least not the sort of evidence that a materialist worldview would expect. I'm trying to get you to think anthropologically, to step outside your cultural frame of reference and recognise the existence of different forms of rationality, other criteria for 'proof', and therefore other possibilities for being.

R: Can you explain what you mean by that?

G: If you look at it through an anthropological lens, you can see that the Tibetan Buddhist approach to ageing and death is based on the subjective experience of mind, not objective facts about the brain.

R: Okay. And what is the significance of that? What difference does it make?

G: Well, the inner experience of dementia doesn't feel like amyloid plaque and neurofibrillary tangles, does it?

R: Uh, I suppose not. But what's your point?

G: My point is that the Western way of thinking about and managing dementia is conditioned by a specific set of cultural assumptions—it starts from a materialist ontology and proceeds from that. From locating it in the brain, to developing drugs that target the brain, and so on. But when you think about it, this view doesn't offer anything to help people understand the inner experience of ageing and dementia—what it feels like on the inside, subjectively. Instead it reduces the experience to matter—to plaques and tangles in the brain. Whereas Tibetan Buddhism is concerned with mind. It is grounded in ancient concepts and practices that have to do with the subjective experience of ageing and death. For example, one text, The Tibetan Book of the Dead, provides instructions on how to navigate one's awareness through a series of well-defined states of consciousness, known as the bardo realms, which are those leading up to and following the death of the physical body. It outlines a set of practices whose specific purpose is to prepare the mind for the transition from life, through the difficult and mysterious dreamlike terrain preceding and after death, to rebirth. Much of Tibetan Buddhist practice is about preparing the mind for old age and death—things modern Western people would rather not think about; in fact, we seem to want a cure for ageing. Westerners see ageing and death as primarily a physical process, and therefore something modern science can control and perhaps, one day, defeat.

R: Okay. This is getting a bit weird, Guy. Bardo realms? Life after death? Again, where's the evidence for these claims?

G: These are just words, signifiers, but I'm talking about actual experience. And I'm not making claims about the existence of bardo realms, or atman, or life after death.

R: It sounds like you are.

G: We could argue about the 'existence' of these things, but we don't really need to. What I'm saying is that these ideas, regardless of their external validity from a scientific perspective, shape and support the culture's response to ageing and death,

and therefore how that culture collectively addresses what we in the modern world call dementia. The 'truth' is in some ways irrelevant—it's what these ideas *do* that matters. In the Western world, we think of personhood as tied to the brain whereas other cultures do not, and so when the brain is destroyed by dementia, we assume that no one's home anymore. They're no longer people. They're done, written off. And so we institutionalise them. Put them in homes. Medicate them. Etc. Tibetan Buddhists don't write older people off as demented because the material brain isn't as important to personhood in their context. Their reality is built on a sophisticated understanding of mind or consciousness, not knowledge about the objective physical reality, or the material brain. As a result, they continue to see older people as spiritual beings on the path to liberation, and treat them as such. They continue to help them grow spiritually. They don't see dementia as a separate entity from the ageing process—it's seen as part of the natural cycle of life, perhaps even experienced as a return to childlike wonder, to Oneness. Who knows? There's nothing intrinsically bad about this cycle, but in a hyper-cognitive Western culture that emphasises independence and rationality, where personhood is tied to brain function, where economic growth seems to be more important than spiritual growth, it's seen as the worst thing imaginable—it's thought about as a 'death before death'. And our responses to it reflect that understanding.

R: But thinking about it in terms of a disease allows us to focus our energy on intervening at the level of the brain, to develop medications that will help people suffer less. Isn't that a good thing?

G: The trouble is, these medications aren't available. These efforts to develop effective medications haven't worked. And who says medication is the best response to this anyway? My point is that there might be alternatives.

R: Look, we can show the effectiveness of some drugs in animal models. For example, we can effectively reduce the density of amyloid plaques in the brains of mice. So we're getting there.

G: We could be. However, humans are far more complex than mice. Do these studies translate into human contexts? In some ways, animal model studies make great snippets for the media, and the funding will keep pouring in so long as the public believes that it's a medical problem and that a cure is just around the corner, but I'm not convinced that this is necessarily a medical problem.

R: Why not, exactly?

G: Well, it's possible that the search for a cure for dementia has potentially been founded on some mistaken assumptions about the nature of consciousness. Science hasn't yet figured out the relationship between mind and brain—the 'hard problem' of consciousness. There hasn't been progress on that front for three hundred years. The assumption is that consciousness is a by-product of brain activity. Maybe that's false. I realise that this is a heretical suggestion to many scientists. But what if consciousness is more fundamental to reality than we think? That would explain why no one has figured out how 'matter' becomes 'mind'. It would also explain why the relationship between brain pathology and 'dementia' is so tenuous.

R: As a scientist I find it difficult to accept that consciousness

is not produced by anything other than the human brain. How can you prove that it's not?

G: Well, it's not a claim that can be validated using a materialist paradigm, obviously. The whole philosophical framework would need to change. Hence the need to step outside this narrow materialist frame of reference to explore other possibilities.

R: Okay, well, is there any evidence? And how does this relate to dementia?

G: Yesterday I was listening to an American podcast and heard about something called 'terminal lucidity'. It's widely reported. It's when people in advanced states of dementia unexpectedly become lucid in the moments shortly before death. They start addressing loved ones in the room. Saying their final goodbyes. It's as if the fog of their dementia lifts for a few minutes, and then they pass away. Apparently it happens with about 5 to 10 per cent of Alzheimer's patients. Anyway, from a materialist perspective, that shouldn't be possible. I mean, what are the amyloid plaques and tangles doing in there, exactly? And we already know from post-mortem studies that these plaques and tangles do not always correspond to clinical descriptions of dementia—sometimes people with no dementia have these plaques, and sometimes people with profound dementia turn out to have none. Consciousness is a deep mystery and perhaps it can't be explained in terms of matter. My personal view is that it can't.

R: Why not?

G: Well, something isn't working—even pharmaceutical companies are starting to disinvest from dementia research. In 2018, the largest pharmaceutical company in the world, Pfizer, pulled out of research into Alzheimer's. That's really saying something, given how profitable it would be for them to develop an effective treatment. But no one can seem to do it.

R: This is all interesting, highly speculative stuff, but where does MCI fit into all this? Wasn't this the focus of your research?

G: MCI is supposed to identify an at-risk population towards whom early interventions and treatments can be targeted, right?

R: Right.

G: The assumption being that dementia is progressive and linear and that MCI can predict who will go on to get dementia?

R: Correct.

G: Well, we know that neither of those things are necessarily true—dementia does not proceed through a series of clearly defined stages, because some people can improve or remain the same, and so MCI actually has very little predictive value. In fact, it seems to me that the MCI concept serves researchers more than people who receive the diagnosis. The diagnosis doesn't offer people any greater degree of certainty about their situation or future than they had before, because it has very little predictive value. It doesn't provide them with any information or advice other than to stay physically and mentally active, which everyone should do anyway. And it doesn't seem to help people access services. Plus, with ambiguous diagnoses like MCI, there's the potential for misunderstanding. I met someone who had interpreted his MCI diagnosis as onset dementia—that was

now his reality. It just doesn't seem very helpful to the people diagnosed, but researchers benefit from it immensely.

R: How do researchers benefit from the MCI concept?

G: Researchers can build their entire careers around MCI. It's as if a new disease has been discovered and researchers are trying to figure out what it is, who has it, and why—not realising that there is no 'it' to explore. They're studying MCI in hundreds of ways—causes, mechanisms, prevalence, experience, possible design interventions, relationship to other conditions—and building a portfolio of publications for a career in academia. You could say that I'm doing it right now. Through doing this PhD I've contributed to the growing body of literature on MCI. It's strange isn't it? How you can start to build a career around critiquing a diagnosis that most people haven't heard of?

R: Yes, or a career designing tools to help manage it—like the Grey Matters website. What's wrong with making things like that? Isn't it helping people?

G: It may help some people, but I think the focus on MCI, or even 'changes to memory and thinking', is too narrow. I hoped that maybe we could challenge this narrowness through critical reflection and create something other than a website for people with MCI—or at least a website that didn't medicalise age-related changes. But the project unfolded within these broader discourses of biomedical truth, which made it difficult to redirect the focus away from MCI. I mean, the whole thing was funded and developed on the premise that MCI was a medical condition, not a culturally specific and contested diagnosis. It was a fact of modern medicine! It was something concrete—a condition for which a web resource could be developed. Given the way the project was set up, I think it was inevitable that the website played into these medicalising discourses and reinforced them. And no, I'm not sure this is helpful.

R: So, what could you have built the website around, if not MCI? What would you have done differently?

G: First of all, it needn't have been a website. Co-design is about working with people to explore what they might need, not predetermining the outcome before you begin. We could have started from this point of open exploration, but unfortunately that isn't the way funding structures work—at least not in health research. The outcome had to be specified in order to secure the funding. But if we were to start again from scratch and open it right up to the possibility of open exploration, and not limit it to MCI, then perhaps the focus could have been on the experience of old age or ageing more generally. Of course, this is a broad topic represented by diverse groups with many different needs—and it's impossible to meet all of them. But I think design research is capable of looking for patterns of experience to identify design opportunities within those patterns. Sure, older people are often concerned about their memory and thinking—that's one pattern—but that's not all they're concerned about. I'll give you an example. One participant described how the world 'shrinks' as you get older. How you start to lose friends and family. How you aren't physically able to do the things you used to do. She talked about how isolating this is. Not just socially—which it most definitely is—but also existentially, because no one can fully appreciate the realities of old age until they experience it for themselves. And so younger people just don't understand, she said. They

aren't aware of these realities, the limitations, the loneliness. These patterns of experience. And so they can be insensitive and rude towards older people, she said. A bit disrespectful. She suggested that what we need to do is educate younger people. And I think maybe she's on to something—maybe designers have been looking at it the wrong way around.

R: Can you elaborate?

G: Most attempts to help older people have focused on older people. And don't get me wrong, I think it's important to design with older people, especially if they are going to be the 'users' of a given product or service. But I think from a design anthropological perspective, if you want to address some of the problems associated with 'ageing', maybe it's just as important to focus on younger generations.

R: Why?

G: It may seem a bit counterintuitive, but as I've been trying to say, I think many of the problems around ageing are culturally rooted. A lot of it has to do with the way ageing is conceptualised in modern Western societies, where scientific materialism has framed ageing as a disease to be cured, where youth culture is glamorised, and where the value of life is often measured in terms of one's ability to contribute to the economy. This all affects the way society thinks about and treats older people. But are younger people aware of this stuff? The way these cultural ideas help shape their perception of, and attitudes towards, older people? How they inform the ways in which they imagine their own journey through life? Their futures? How can design start a conversation about the realities of ageing in modern Western societies? And how could it make differences between cultures visible? I mean, what is it like to be an older person in India, or China, or Japan, or Papua New Guinea? What are the values that underpin practices of care within these cultures? Are there patterns? Or in the New Zealand context, what could younger Pakeha learn from a Māori worldview perspective? How could designers draw on these cultural values and modes of being in order to build connections and promote a deeper sense of understanding and compassion across generations? These are just questions, but they're starting points for design—and much better starting points than 'MCI', I would say. Because, ageing is not always seen as a medical problem. It is also a natural, whole-person experience, and this experience includes the way younger, more able-bodied people—i.e., those with a greater degree of power and influence in society—respond to older people. Ageing is something we all experience.

R: I see your point. But why can't we just continue to build websites and robots for people with MCI and dementia? Technology is extraordinarily helpful.

G: Maybe some people will benefit from these products. But it is worth pausing to reflect on the idea that designed artefacts are material expressions of underlying values. They act in the world, and the world is unfolding. So we want to be sure, going forward, that these artefacts don't close off other ways of knowing and being.

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Appendix A | Project proposal

Research Theme(s):   Theme 4 (data could relate to all themes)

Research Title: Living well with mild cognitive impairment

Project type: (Large)   **Project Duration:** (2 years)   **Start Date:** January 2015

Named Investigators (others to join as interested)

CoRE NI	Research Collaborators

Rationale: The intention of this programme of work is to embed the experience of those with brain impairment and their family/whānau in the CoRE. Whilst much is known about deficits in functioning caused by mild cognitive impairment (MCI),[1-3] less is known about how people live with the condition,[4] the strategies and supports people find most helpful, the language they use to describe their condition, and what they identify as being the best supports in regard to the issues that concern them. Rather than being hypothesis driven, our approach is hypotheses generating. When robust, qualitative approaches enhance understanding of complex topics where participants have key expertise and knowledge. Our design uses robust methods throughout and would make novel contributions in three ways:

a) develop new knowledge about 'living with MCI' (for people with MCI, whānau/family, health and social caregivers and indeed others concerned they might have MCI).

b) inform the CoRE on priorities for people with MCI, strategies where novel interventions could be developed and trialled, barriers to current therapies, and generate items for better outcome measures (ie focusing on what matters to people with MCI).

c) yield technical advance with regard to novel approaches that integrate findings in digital formats eg an interactive web based resource of 'stories' of people living with MCI, that provides site visitors with options to contribute data over time. We shall also investigate social media and mHealth tools to harness interactivity.

Research design and methods: We will use qualitative descriptive[5] and interpretative[6] approaches for the qualitative work. Whilst unfamiliar to some in neuroscience, qualitative work has an important place in advancing knowledge.[7] They are the best design to explore experiences of living with MCI; identify key issues of concern for those with the condition and their family/whānau; and investigate the strategies they find most helpful for health and wellbeing. Qualitative data in multiple forms (recorded and filmed interviews, participant journaling, drawing and photography) will be collected and analysed using methods our group has extensive experience in. Dissemination will occur in traditional research outputs (publications and conference presentations) but also via interactive digital media sources, which will in turn produce additional data over time. Partnership with Design and Creative Technologies researchers as well as health tech companies facilitates this novel component of the project. We will use rapid prototyping and agile development methods in laboratory

and field settings, with usability evaluation a key element of development and testing.

Methods: We will recruit 30 people with MCI (and consenting significant others) from existing memory clinics and from CoRE clinics when up and running, as well as referrals from partner agencies. We will recruit in Auckland and Dunedin where the PIs are based, and in Christchurch as appropriate. We will use purposeful sampling,[8] an approach ensuring wide variation in sampling according to key variables that may influence experience (types of MCI, including those with related or causative conditions such as stroke or Parkinson's disease, ethnicity, gender, severity of condition and time since diagnosis). Qualitative research does not use quantitative power analyses, rather decisions on sample size depend on the degree of heterogeneity in the population involved. Given the variability of MCI, and to ensure findings have relevance across the full spectrum of experience, a sample of 30 is likely to be necessary, but also sufficient for data saturation. We anticipate some dyadic interviews (with significant others: n=10), some participants wishing to be interviewed alone (n=15) and some significant others also being interviewed alone (n=5).

Data collection: consenting participants will be interviewed using semi-structured interviews, video or audio recorded according to preference. We will also utilise opportunities for participants to provide data in other formats (eg written text, photography), as this may convey important alternate representations of their experience. In addition, demographic data will be collected (including co-morbidities and cognitive assessment data – ideally incorporating a CoRE agreed minimum data).

Analysis: Audio visual material will be transcribed and analysed using thematic coding,[9] with key aspects of people's stories categorised during analysis to facilitate extraction into the digital media resources. Information will be synthesized in multiple formats to communicate findings to potential patients and their family/whānau, the general public, clinicians and researchers. We will develop an interactive website drawing on approaches such as http://healthtalkonlineaustralia.org/ or http://www.patientslikeme.com. These sites, and an increasing range of devices for lifeblogging (see http://getnarrative.com) provide valuable learning upon which we will build novel data acquisition and visualization techniques to enhance access to information for, and input from, New Zealanders concerned about, or interested in, MCI. Agile development methods will be used to evaluate multiple formats during the study (this being the key focus for the PhD position requested).

Research Impact: Primary data will enhance understanding of what it is to live with MCI. We will develop digital resources disseminating that widely, providing interactive capability for collecting further data from NZ'ers with MCI or concerned about it. Data could usefully inform a range of CoRE projects across themes for example: *intervention development* (regarding acceptability, preference, barriers and facilitators to engagement and treatment adherence), *hypothesis generation* (people with experience of the condition will undoubtedly contribute 'new' questions that warrant investigation), through to item *generation for better measures* of the impact of MCI. As such, the project will contribute across each of the objectives outlined for Theme 4. Whilst some of our goals are clearly known and achievable with the design outlined above, we are introducing exploratory aspects eg social media and lifeblogging technology for data acquisition and dissemination. These methodologies may prove to be highly valued by people with brain conditions and offer new opportunities for knowledge advance in the future and external grant submissions. Dissemination includes peer-reviewed publications, teaching, and digital media outputs.

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Appendix B | Ethics approval

AUTEC Secretariat

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3 May 2016

Faculty of Health and Environmental Sciences

Dear ▮▮▮

Re: Ethics Application: **15/234 Living well with Mild Cognitive Impairment (MCI).**

Thank you for your request for approval of an amendment to your ethics application.

The amendment to include Guy Colliers PhD project to be nested within this application is approved.

NOTE: The Consent Forms should provide statements with regard to release of photographs.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 7 December 2018;

- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 7 December 2018 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Guy Collier guy.collier@aut.ac.nz

Appendix C | Information sheet

Participant Information Sheet

Guy Collier's PhD Research:

Perspectives on Mild Cognitive Impairment

Researcher:	**Guy Collier** **Phone: 921 9999 ext. 9179** guy.collier@aut.ac.nz	

Date Information Sheet Produced:

Invitation

Tēnā koe, talofa lava and hello. My name is Guy Collier and I am a PhD student at AUT. As you may already know, our study 'Living Well with Mild Cognitive Impairment (MCI)' involves designing an online resource for people with MCI. My PhD, which is being carried out alongside this study, explores how different experts think about and address MCI. These experts include clinicians, neurobiologists, neuropharmacologists, designers, as well as people with MCI themselves (because they are the 'experts' of their lived experience with MCI).

This information sheet will explain the research in more detail. I appreciate you reading this material. Please consider:

- Your participation is voluntary and you may choose to withdraw any time prior to the completion of data collection.

What is the purpose of this research?

Design projects tend to involve a wide range of expertise. They are based on all kinds of external research and knowledge, but ultimately involve working with end-users as experts in order to better understand their needs. As part of the Living Well with MCI project, I want to find out where all these different kinds of knowledge and expertise intersect, how they feed into and inform one another, and how they work both in and around this project.

This research will allow us to see a much bigger picture of the ways in which MCI is being addressed in New Zealand, from various contributions to clinical research and practice, to

1

managing MCI at home and in the community. This will enable us to see the wider context into which healthcare strategies and design interventions like this one might fit. This PhD research might also inspire researchers and experts from diverse backgrounds to find better ways of working together to address issues around MCI.

How are people being chosen to be part of this study?

You are being chosen to take part in this research because you have been identified as someone with either personal or professional experience of MCI.

Who can take part?

You are able to take part in this research if

a) You are already a participant on the main project and have indicated that you would like to take part in this component; or
b) Your professional work or research involves the MCI category.

What will happen in this research?

Because I want to better understand what MCI is from your perspective, I might seek your permission to spend a short period of time with you as you go about your day, and to interview you for up to one hour.

You may also be invited to participate in these workshops at the Design for Health and Wellbeing (DHW) Lab at Auckland City Hospital to help us envision, develop, and test ideas. Please note that this component is entirely optional and you can withdraw at any time. These sessions will involve activities that aim to draw out your personal knowledge and experience of the condition, as well as those of other participants, including designers, clinicians, laboratory researchers, people with MCI and their family members. These activities may involve games, group drawing, mind mapping, and prototyping.

What are the costs of participating in this research?

There are no costs to you except your time. Please allow up to two hours for me to spend time and interview you (in the lab, in the clinic, or at home).

If you are invited to take part in the design workshops, we anticipate they will take between 2 – 3 hours each. We would like to host at least 4 workshops over a six-week period. Please note that you do not have to take part in all workshops—you may be invited to take part in just one.

We do not anticipate any discomfort or risks resulting from your involvement in this research. If during these workshops we see that you are experiencing distress or fatigue, you will be invited to take a short break or asked whether you would like to participate another time.

What are the benefits?

While there may be no direct benefit to you, this research will help us better understand how different contributions to MCI research and clinical practice reflect or impact on the personal