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**CONDITIONS OF EVERYDAY
TECHNOLOGY USE AND ITS INTERPLAY
IN THE LIVES OF OLDER ADULTS
WITH AND WITHOUT DEMENTIA**

Sarah Wallcook



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CONDITIONS OF EVERYDAY TECHNOLOGY USE AND ITS INTERPLAY IN THE LIVES OF OLDER ADULTS WITH AND WITHOUT DEMENTIA

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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To a more inclusive everyday life for people living with dementia

POPULAR SCIENCE SUMMARY OF THE THESIS

Technology is an inevitable and increasing part of everyday life at home and in society so that people of all ages are expected to use it, including older adults living with and without dementia. Everyday Technologies include all those common to everyday life in society, for example: alarm clock, microwave, computer, payment card, and chip and PIN device. Many of these technologies are found or used outside home, in a range of places that are essential to everyday life (shops, banks, transportation centres). Others are designed to duplicate or replace the need to go to such places (internet banking, online shopping). These technologies may be making everyday life more convenient for some people. But for others, perhaps especially people with dementia, they may present a challenge so that places are avoided, or tasks go uncompleted. This thesis aimed to find out more about how technology interplays with everyday life and suggests practical solutions for a more dementia-, age, and human-friendly society.

Data was collected in the US, UK, and Sweden. In total 315 older adults took part in these studies, 99 of whom had dementia. One investigation involved everyone, whereas the others focussed on particular groups (i.e. 64 people with dementia and 64 people without dementia in England). Participants were interviewed in their own homes by an occupational therapist. These structured interviews were designed to find out more about participants' everyday technology use and participation outside home.

The findings are presented as a rhyme, created to give a personalised insight into the findings of this thesis and to stimulate conversation among people directly affected by dementia. It is being produced as a song with video courtesy of a commission with Ronald Amanze and Jilly Jarman funded by Svensk Förening för Kognitiv Medicin Stipendium 2020.

I think I know my own mind

Lyrics: Ronald Amanze and Sarah Wallcook

Music: Ronald Amanze and Jilly Jarman



Ronald Amanze by Jilly Jarman

Ronald Amanze, is a trustee with Arts4dementia, a Dementia Champion with the Alzheimer's Society, a Dementia Diarist with DEEP and an Ambassador for The Stroke Association, working to ensure there is better dementia service provision and research involvement for BAME communities. A musician and music producer by background he is passionate about the role of creativity in improving quality of life experience for people living with dementia.

Jilly Jarman is a music director, composer, jazz musician, multi-instrumentalist and visual artist. She is the creative director and founder of the transformative social enterprise, BlueJam Arts.

Self-portrait by Jilly Jarman



I think I know my own mind and what I can do
I need technology to be easier to use.
You can design tech better,
With my needs in mind -
And if I am able, and permitted to try
then perhaps I will learn and even buy

a new shiny thing -
That signifies I'm just like you
I'm a part of society with the same jobs to do
We all feel the pressure of playing our part,
But for me, it's an extra squeeze and a band on my heart.
I don't want to let you down when you think that I can
But I'm not so sure and that burden weighs me to the ground.

If I give in to your suggestion and take a new tech -
Will you still love me if I fail to connect?
Have you considered the problems I might have?
How I feel when I fail?
And when I've given all that I can give
Sometimes I feel like a guinea pig.
Smooth and mellow,
That's what I need

I know you're pushing with the best intent,
but this feels like an intellectual argument.
As I've done best that I can do,
Have you not considered alternative points of view?

The relief I feel when I get to choose
It means my tech choices fit like a good pair of shoes.
They're comfortable to use
and there's much less strife,
because they fit
inside my life

It's starting to occur to me
Ain't you heard
There's so much joy inside of me
Ready to learn

Together, the studies of this thesis showed that there is not always a big divide between older adults who do and do not have dementia, since technological abilities and preferences often overlapped. Negative perceptions of dementia may mean that older adults without dementia and their significant others resist empathising to this rhyme. However, the situations raised may indeed feel familiar and discussing these situations and possible solutions may help smooth aspects of everyday life among older adults more widely.

Readers are encouraged to explore their own ideas about how to respond as relevant in their own unique, but similar situations as my reflections and interpretations below may not be suitable.

“I think I know my own mind...”

People with dementia may have uncertainty but can speak for themselves regarding their technology use. And they can and do use technologies, even as abilities to use them might decline. Also, there is no good reason to assume that one technology (i.e. a flip phone with buttons) is easier to use than another (i.e. a smartphone) – in fact the opposite could be the case. While staying with the most familiar technologies is advised, the best thing to do when choosing a new technology is to try before you buy exploring the functions that are most interesting and relevant.

“We all feel the pressure of playing our part...”

People close to a person with dementia have a vital and complicated role to play when it comes to technology use in and outside home. Especially when it comes to a belief that someone with dementia can use an expensive technology, like a computer, perhaps when it has not been in their life before. It is important to really listen to someone’s hesitations, especially if the person lives alone. Think through all aspects of using a computer to feel confident that it will make life easier and not just add a support need that was not there before. It is not only about the person and the device itself. Consider: is the internet connection of good enough quality (especially in rural locations and from inside the house)? Is the system that the internet service provider uses for customer support easy enough for the person to use? Is the service provider good at, and willing to solve problems? Are the bills easy to understand and pay? Is help on hand?

“Have you considered the problems I might have?...”

It might seem nothing to get upset about, but tricky technological situations can be worrying in terms of letting people down and damaging relationships. For some people with dementia, they sacrificed their own will and put aside their fears for the other person. Being ready to reassure, taking things gently and acknowledging these small, but big things that someone with dementia may do to show their love could help support confidence in relationships.

“I know you’re pushing with the best intent...”

Knowing when to step in and how much is a tricky balance. This can be about sharing the

technology use between the person with and without dementia. A common example was the person with dementia using the petrol pump, while the person without used the payment technology. But also, for people who found shops and banks stressful, technology used with the sensitive help of another person (who manages the passwords for example) provided a suitable solution via internet shopping and banking. Technology is only used to get a job done, so the question may be, what is the optimal way to get that job done? For example, when maintaining contact with people outside home, the easiest solution may be the landline telephone, with the call made by the person who does not have dementia. In some cases, it may be relevant to consider whether new difficulties with technology are indicating wider problems in everyday life. In this case, there may be a need to discuss support.

“The relief I feel when I get to choose...”

The easiest to use technologies may be those that are most familiar and well-rehearsed, so it may be wise to listen if a person does not wish to change or update technologies. Ultimately, some technologies may fall out of use over time, and being ready to accept this can lead to a feeling of relief since those technologies that remain may fit better with everyday life...

“It’s starting to occur to me...”

...However, it is an ongoing process, since an overall pattern of letting go of some technologies does not mean that new ones are not interesting or desirable. People with dementia may still want to learn and benefit from the new technologies that are constantly being developed. Wider efforts are being made to make technological designs more inclusive of people with dementia’s cognitive abilities. This may mean that new technologies are found to be less challenging and easier to use.

In summary, the conditions that shape older adults with and without dementia’s technology use are complex and changing. It is hoped that the wider patterns that have been used to create the discussion points above can give insight into different situations of technology use in and outside home.

As each person’s situation is unique and evolving, some people will feel that these points are relevant and applicable, and others will not. It may also be that the rhyme feels familiar, but you would interpret it differently and do different things faced with the same situation. That is very much to be encouraged. Being dementia-friendly, or just human-friendly in real life is not an exact science and takes being open to trying things in different ways.

Lastly, the ways in which technology interplays with life inside and outside home means that there are other people in society who have a role to play. Suggestions for these other people have not formed part of this summary, but are available here:

<https://www.dementiainduct.eu/news/new-lay-report-published/>

https://www.dementiainduct.eu/?s=ESR4&post_type=recommendation.

ABSTRACT

Background: Increased reliance on technology in society incurs a risk that older adults with and without dementia could become excluded from participating in aspects of everyday life in and outside home. This thesis responds to a gap in present understanding about the conditions for Everyday Technology (ET) use (i.e. ticket machines, smartphones) in different international and geographical contexts. By generating new knowledge about the interplay of these conditions on participation, practical information and guidance follow to support both dementia- and age-friendliness as well as general inclusivity in society.

Aim: To illuminate the conditions, particularly different country and geographical contexts, of ET use and the interplay of these conditions with participation and inclusion in everyday life both in and outside the home for older adults living with and without mild stage dementia.

Methods: Participants with dementia ($n = 99$) and with no known cognitive impairment ($n = 216$) were recruited in the US (sub-study **i**, $n = 114$), Sweden (sub-study **i**, $n = 73$, **ii**, $n = 69$), and England (sub-studies **i**, **iv**, $n = 128$, rural sub-study **iii**, $n = 10$). These four cross-sectional studies used multiple predominantly quantitative methods (**i**, **ii**, **iv**) and a case study approach also involved qualitative data (**iii**). Structured home-based interviews used the Everyday Technology Use Questionnaire to map respondents' use of technologies, and the Participation in Activities and Places Outside Home Questionnaire to investigate the amount and pattern of participation outside home. Qualitative data included fieldnotes, observations, annotated maps and more. The findings of the four studies were synthesised using an approach to triangulation.

Findings: The triangulation approach yielded three themes: 1) *Dementia as a condition of ET use*, 2) *National, geographical, public and home context as a condition of ET use*, 3) *Interplay of conditions with participation*. 1) Dementia was generally not found to be a condition that impacted the challenge of ETs, however groups with dementia typically regarded less ETs to be relevant. There were notable exceptions in both instances. 2) The varying social, infrastructural, and service conditions surrounding national and geographic contexts were seen to shape the constitution and use of ETs outside home. 3) There was a complex interplay between the conditions of ET use and participation outside home. Close and distant human relationships, structural inequalities and transportation options were implicated as stabilising and de-stabilising everyday life.

Conclusions: Insights are provided into the interplay between the conditions of ET use and participation in everyday life outside home among older adults with and without dementia. These insights provide opportunities for many different people in societies, communities, neighbourhoods and household to take action. Reducing any friction that people encounter when using ETs in public places and allowing opportunities for manualised participation in occupations outside home could lead to a more inclusive everyday life.

LIST OF SCIENTIFIC PAPERS

- I. Wallcook S, Malinowsky C, Nygård L, Charlesworth G, Lee J. ... Kottorp A. (2020) The perceived challenge of everyday technologies in Sweden, the United States, and England: exploring differential item functioning in the Everyday Technology Use Questionnaire, *Scandinavian Journal of Occupational Therapy*. doi.10.1080/11038128.2020.1723685.
- II. Wallcook S, Malinowsky C, Kottorp A & Nygård L (2019) The use of Everyday Information Communication Technologies in the lives of older adults living with and without dementia in Sweden. *Assistive Technology*. doi.10.1080/10400435.2019.1644685
- III. Wallcook, S., Malinowsky, C, Ryd, C., Charlesworth, G., Nygård, L. Illuminating the everyday technological lives of rurally dwelling older adults with dementia in the North of England: A multiple case study. Manuscript.
- IV. Wallcook, S., Nygård, L., Kottorp, A., Gaber, S. N., Charlesworth, G. & Malinowsky, C. (2020) Kaleidoscopic associations between life outside home and the technological environment that shape occupational injustice – revealed with cross-sectional statistical modelling, *Journal of Occupational Science*. doi.10.1080/14427591.2020.1818610

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LIST OF ABBREVIATIONS

ACT-OUT	Participation in ACTivities and Places OUTside Home Questionnaire
BAME	Black, Asian, and Minority Ethnic
CI	Confidence Interval (95%)
COVID-19	Global pandemic of Novel Coronavirus
DEEP	Dementia Engagement and Empowerment Project
DIF	Differential Items Functioning
DTF	Differential Test Functioning
EICT	Everyday Information and Communication Technology
ET	Everyday Technology
ETUQ	Everyday Technology Use Questionnaire
EWGPWD	European Working Group of People with Dementia
FODNC	Focus on Dementia Network group Cumbria
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
IMD	Index of Multiple Deprivation
INDUCT	Interdisciplinary Network for Dementia Using Current Technology
MoCA	Montreal Cognitive Assessment
MOHO	Model of Human Occupation
PPI	Citizen involvement in research
SST	Self-Service Technology
UK	United Kingdom
US	United States of America
WHO	World Health Organization

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1 INTRODUCTION

1.1 PERSONAL INTRODUCTION

Understanding what is happening in the circumstances and structures behind my work as a music facilitator and occupational therapist has always been a focus for me. Ever since I asked one of my very first singing students why she had been attending singing lessons. And the answer I heard was completely unexpected. “Because I have five brothers, and now I can speak up at the dinner table, where before I used to sit silent”.

My natural assumption at that time, was that participation in singing lessons would be motivated by some aspect singing itself. Instead, my eyes and ears were opened to the complexity of interactions between people and their voice, the consequences and divergent experiential outcomes that were possible to unleash by the power of doing. Since then, I have facilitated singing and music with many different groups, including older adults and people with dementia at different stages. It was this work especially that ultimately inspired me to want to become an occupational therapist so that I could use different types of doing – occupation – as my medium since music was of course not for everyone. Learning how to tap into people’s motivations and facilitate how they could best access what they wanted, and needed to do, and how best do it have been one part of my exploration as a practitioner. And learning how to overcome the barriers that stand in the way of a person participating, which often lay extrinsically, in a complex web of circumstance well beyond the reaches of our short time spent together, became another entwined part.

My exploration has deepened over time and led me to this PhD: seeking to understand what lies in the conditions and interplay surrounding everyday technology use that may thwart older adults with and without dementia from optimal participation in their daily lives. With this thesis I contribute knowledge that can be used to practically facilitate the occupation that lies behind the technology use.

1.2 SETTING THE SCENE

Ageing societies and an increasing prevalence of dementia form the backbone of dementia-friendly and age-friendly initiatives that have gathered pace and prominence in international policy since the mid-00s (World Health Organization, 2007, 2017). These policies respond to an urgency to ameliorate the environmental friction that older adults encounter in their everyday lives. These challenges have been identified in interactions within the built, social, and technological environments where discrimination and exclusion have been designed in and conditioned at every turn (Biggs, Carr, & Haapala, 2019; Brorsson, Öhman, Lundberg, Cutchin, & Nygård, 2020; Brorsson, Öhman, Lundberg, & Nygård, 2011; Kottorp et al., 2016; Rosenberg & Nygård, 2014). Age-related discrimination intersects with the stigma of dementia and means that the challenges of poorly designed and conditioned environmental interactions create friction for older adults in general (Mannheim et al., 2019; Marston & van Hoof, 2019; Van Hoof, Kazak, Perek-Białas, & Peek, 2018; Wethington E., 2016).

It is only since the mid-1990s that people with dementia have begun to be directly and more regularly listened to in research (Gillies, 2000). Prior to this, there was an assumption, that often still prevails, that people with dementia cannot speak for themselves regarding even mundane aspects of their everyday lives, nor assert their wishes (Gillies, 2000; Nygård, 2006; O’ Shea, O’ Shea, Timmons, & Irving, 2020). The rights of people with dementia to consent, express their wishes and control what happens to them have since been asserted in conventions and policy in a delicate balance with safeguarding increased vulnerability (Cahill, 2020; Shakespeare, Zeilig, & Mittler, 2019; Thorogood et al., 2018).

Consequently, directly involving people with dementia in age-friendly and dementia-friendly initiatives and research is regarded as potentially generating more relevant knowledge and asserting the rights of people with dementia (Rahman & Swaffer, 2018). These initiatives of friendliness have in common the aim to optimise participation in everyday life by addressing accessibility and usability at various levels. The levels include cities, rural settings, communities, neighbourhoods, institutions, groups and single buildings where objects have also been attended to, such as seating at bus stops and in parks (Jeste et al., 2016). However, despite early calls to do so, technological objects (i.e. travel ticket and cash machines), that have high and ever-increasing prevalence in society, have been poorly considered (Baltes, Smith, & Staudinger, 1992; Coleman, 1998; Lindqvist et al., 2018; Marston & van Hoof, 2019).

Technology’s interplay can therefore be little noticed, or lauded and exploited for its convenience and fit within everyday life. This thesis forms part of the Interdisciplinary Network for Dementia Using Current Technology (INDUCT) which was developed, in part to identify the practical, social, and cognitive factors that would improve the usability of technology in everyday life. As technology becomes more embedded so too do idealisms that problems with technology may fall into history as the older adults of the future are expected to be more technologically comfortable and capable (Brown et al., 2019; Esteban-Navarro, García-Madurga, Morte-Nadal, & Nogales-Bocio, 2020). However, given the right conditions and intersections, such as the global COVID-19 pandemic, a sudden increased reliance on technology has thrown dimensions of digital exclusion and social inequality into sharper relief. Exclusion which is impacting the older adults of the future right now and thwarting their participation in occupation when using current technologies, whose future form is unknown but ever-changing (Beaunoyer, Dupéré, & Guitton, 2020). This thesis holds its focus on the older adults of today, particularly those with dementia whose risk of digital exclusion is higher with consequences to participation likely to have been exacerbated during the pandemic (Seifert, 2020; Seifert, Cotten, & Xie, 2021).

2 LITERATURE REVIEW

2.1 AGEING AND DEMENTIA

In some societies today, older people are under pressure to cope with the process of ageing by causing the minimum of fuss and expense to others. This has been argued as reframing ageing as a social problem and creating divisions between people in later life who age with relatively good health, capability, and independence, and those who do not (Gilleard & Higgs, 2011; Higgs & Gilleard, 2017). However, growing older incurs increased risk of disability and co-morbidities so that the age-related disease burden makes up just under 50% (46.7%, CI 43.3–50.3), of the overall disease burden in the super region of high-income countries that include the United States of America (US), the United Kingdom (UK), and Sweden (Chang, Skirbekk, Tyrovolas, Kassebaum, & Dieleman, 2019). Dementia is recognised as a significant contributor to this burden and its prevalence was estimated at 5.9% of Europe's population of 176.61 million in 2015. The affected population is anticipated to undergo a 78% proportional increase by 2050 which underscores the priority of planning for dementia in society (Cahill, 2020; Prince et al., 2015).

Social planning for inclusivity and meeting support needs is especially warranted as there is currently no cure for dementia, which presents with complex chronic or progressive problems in many domains (El-Hayek et al., 2019; Livingston et al., 2020). While Alzheimer's disease is most common and widely known, there are over 100 subtypes of dementia syndrome with different disease progressions and outcomes. As such, the presentation of difficulties can vary widely and include, among others, possible visuospatial, language, memory, information processing and decision-making deficits; and alterations to impulsivity, inhibition, apathy, mood and personality (Robinson, Tang, & Taylor, 2015). People with dementia themselves report that these difficulties can lead to changes and losses in many areas of everyday life. For example; social activities and relationships with friends and family (Biggs et al., 2019; Graff et al., 2006; Thoft & Ward, 2020), domestic arrangements and going out (Clarke et al., 2010), the range of places participated in outside home (Chaudhury, Mahal, Seetharaman, & Nygaard, 2020; Gaber, Nygård, Brorsson, Kottorp, & Malinowsky, 2019; Margot-Cattin et al., 2021) managing personal administration choices and attending appointments (Samsi & Manthorpe, 2013), driving and travelling (Liddle et al., 2016; Sinclair, Larkin, Vaughan, Murray, & Nabizadeh, 2019), and use of everyday technology (Hedman, Nygård, Almkvist, & Kottorp, 2013; Rosenberg, Kottorp, Winblad, & Nygård, 2009).

Negative social perceptions that are often combined with age discrimination, have led to stigma that impacts upon people with dementia and persists in many countries, including the US, UK and Sweden (Herrmann et al., 2018; Moore & Cahill, 2013). Stigma can be both internal and external and applies when a person's identity is seen to have been spoiled by the presentation of disability so that a person is devalued, discredited and discounted from participating in society (Goffman, 2009). Given that there is currently no cure or effective treatment to halt progression, psychosocial research and community efforts focus in part on

approaches to break the stigma of dementia, improve inclusivity and facilitate participation in society (Cahill, 2020).

2.2 PARTICIPATION IN EVERYDAY LIFE AMONG OLDER ADULTS WITH AND WITHOUT DEMENTIA

Internationally, planning for ageing societies and dementia has developed from more biomedical approaches, to public health prevention with some countries now incorporating a rights based approach that emphasises participation and choice (Buffel, 2018; Buffel et al., 2016; Cahill, 2020). Participation is defined within the *International classification of functioning, disability and health* as “involvement in a life situation” (World Health Organization, 2001). It has been pointed out this definition has shortcomings with respect to encompassing the subjective experience of participation and dichotomises the environment into barriers or facilitators rather than noting it can be both. This thesis concurs with an occupational perspective of participation, which is a way of regarding the doing in everyday life and therefore the implied purpose with which people relate to and within their multiple environments (technological, physical, social, etc.) (Njelesani, Tang, Jonsson, & Polatajko, 2014). Using this perspective, it has been noted that meaning and autonomy are absent from consideration within the ICF definition. Further evident, is a lack of appreciation for the continuity of everyday life situations and simultaneous experiences of environmentally situated, multi-layered participation (Hemmingsson & Jonsson, 2005). Participation can also be viewed as a neutral prerequisite for doing, where the quality of experience is implied so that the consequences of participating can be located on a continuum of repulsion to absorption (Morris & Cox, 2017). Equally if a person is not interacting with certain elements (i.e. internet banking) then this could be viewed as a form of non-participation, which similarly has consequences in everyday life (Morris & Cox, 2017). Whether participation or non-participation occurs, noting the potential for unjust consequences are essential for supporting the enactment of a rights-based perspective (Shakespeare et al., 2019). Issues of occupational justice arise when people are deprived of, or marginalised in their doing, as a consequence of how external human and non-human elements interact in an individual’s everyday life (Durocher, Gibson, & Rappolt, 2014).

The emphasis on participation has followed a growing body of research that investigates the impact of dementia upon everyday life. Particularly influential has been the concept of a shrinking world whereby outdoor activities were seen in a qualitative study to reduce in frequency and become restricted to more familiar places (Duggan, Blackman, Martyr, & Van Schaik, 2008). In response, attention turned toward understanding the environmental conditions that promoted or hindered continuing participation in places. For example, discovering the role of public art in navigation, problematic situations when grocery shopping, being a pedestrian, being outdoors in nature, or socially active in the neighbourhood (Brorsson et al., 2020; Brorsson, Öhman, Lundberg, & Nygård, 2016; Clark et al., 2020; Kelson, Phinney, & Lowry, 2017; Odzakovic, Hellström, Ward, & Kullberg, 2018).

Recent quantitative studies appear to support the shrinking world concept as participation in a possible range totalling 24 places outside home was found to be statistically significantly lower among a group with dementia compared to a matched group with no known cognitive impairment in Sweden (Gaber et al., 2019). A subsequent cross-sectional study in Canada indicated a shrinking trend from past, to present, to future ultimately concluding total place abandonment for the group with dementia. However, the same study also highlighted lower participation over time in places for recreational and physical activities also for the group of older adults without known cognitive impairment (Chaudhury et al., 2020). This indicates that a shrinking world may not be unique to people with dementia and may be a process reflected more widely among older adults. The findings of the two studies in Sweden and Canada were subsequently confirmed in a mostly rurally dwelling Swiss sample where a significantly lower amount of total places and greater abandonment over time points were found among the group with dementia compared to the group without (Margot-Cattin et al., 2021). However, a longitudinal study among people living with dementia in Stockholm found continued, albeit decreased participation in places generally alongside an increase in going to nature places over time (Gaber et al., 2021). Consequently, it makes sense to caution against considering the shrinking world as uniform across places and instead consider complexity and nuance in how abandonment occurs, e.g. through the role of driving cessation (Margot-Cattin et al., 2021).

People with dementia in rural contexts have been seen to delay driving cessation which can especially be an issue rurally as public transport is more often inadequate (Rapoport, Hyde, & Naglie, 2020). People age in rural places, as they do in urban, however the unique challenges of living in remote locations may not become clear until such time as the distance from health services or support networks become tangible (Stockdale & MacLeod, 2013). The natural environment and informal networks of the rural idyll have been seen to bring benefits to social participation. However, this same landscape has been referred to as a beautiful prison and men with dementia have described how the terrain can become challenging to negotiate (Evans, Jones, & Smithson, 2014; Hicks, Innes, & Nyman, 2019). It may therefore be useful to consider the rural context for participation and whether this is reflected in the places frequented by older adults with and without dementia.

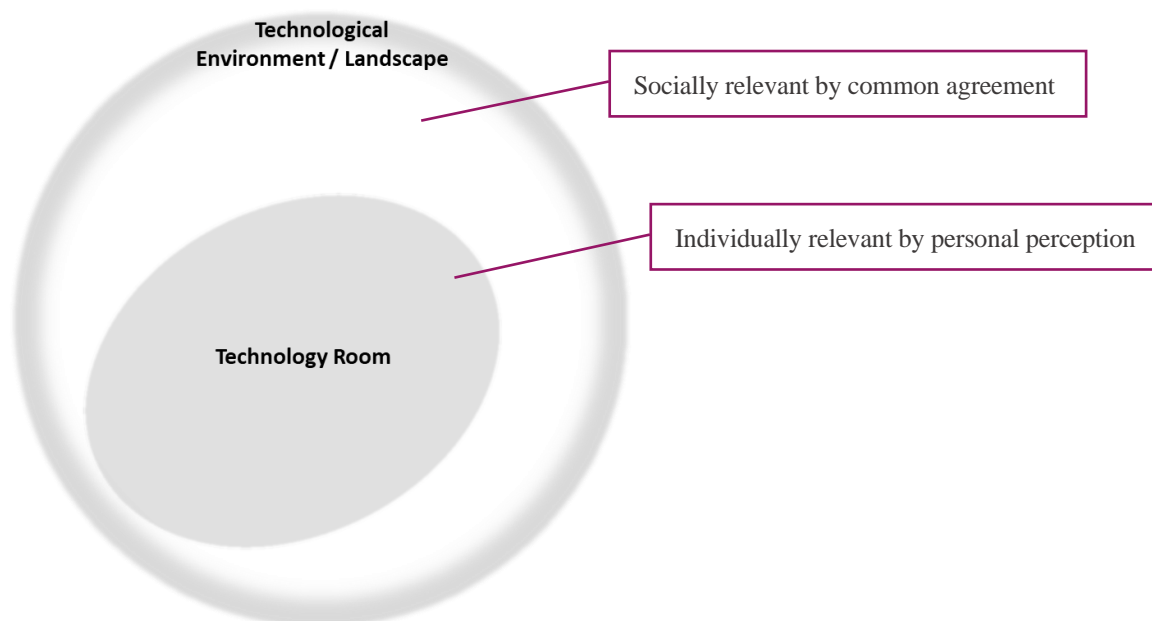
Despite a growing disparity in internet speeds between rural and urban locations in the UK, technologies are typically regarded as a route to overcoming issues of rural isolation (Bosworth, Price, Collison, & Fox, 2020; Gerli & Whalley, 2018; Philip, Cottrill, Farrington, Williams, & Ashmore, 2017; Salemink, Strijker, & Bosworth, 2017). Smart countryside initiatives are emerging in parallel to those of smart cities, yet their inclusivity with respect to older adults and people with dementia remains unclear (Bosworth et al., 2020; Marston & van Hoof, 2019; Zerrer & Sept, 2020). Technologies have been seen to interact with participation outside home to create problematic situations for people living with dementia. For example, self-service systems in libraries and shops, payment technologies at check-outs and access to health care mediated by automated phone services. These technologies replaced familiar person-to-person contact and incurred new, additional, and cognitively challenging steps for

participation in activities (Brorsson et al., 2020; Brorsson et al., 2011). A focus group study involving people with mild cognitive deficits found that everyday technologies (ET) had a contrasting role as both stress-provoking and hindering to everyday life outside home, but also offered enabling solutions (Lindqvist et al., 2018). These findings echo those of an earlier focus group study involving predominantly people with dementia, which similarly found that everyday technologies could support or hinder access to places connected to a feeling of being in, or out, of place (Brittain, Corner, Robinson, & Bond, 2010).

2.3 EVERYDAY TECHNOLOGY (ET) USE AMONG OLDER ADULTS WITH AND WITHOUT DEMENTIA

Everyday technologies (ETs) form a crucial aspect of inclusive participation in society today and include items such as; microwaves, hairdryers, ticket machines, smartphones and their functions i.e. internet banking, making a call. The term *technological landscape* is used often in this thesis (synonymous with *technological environment*) and refers to a commonplace set of ETs that would commonly be agreed to circulate widely in people’s homes and society (refer to fig. 1a) (Hagberg, 2008). Within fig. 1a, the boundaries of the technological landscape are depicted as blurred to indicate that it is culturally and socially amorphous and can flexibly expand and contract according to contextual and temporal differences regarding commonplace agreement. People compose from this landscape ‘technology rooms’ comprising ETs of personal relevance that circulate within a specific person’s everyday life and surroundings (Hagberg, 2008) (refer to fig. 1a). *Relevance*; in addition to accounting for the availability of an ET (i.e. whether a person owns or encounters the ET) also considers the intention to use, current use or recent historic use of that ET (Rosenberg, Nygård, & Kottorp, 2009).

Fig. 1a: Depicting the relation between the technological landscape/environment and technology room



Information and Communication Technologies (ICTs) refer to those technologies that capture, process, store, and exchange information (Gagnon et al., 2009). Everyday Information and Communication Technologies (EICTs) in this thesis are a subset of ICTs circulating in the everyday technological landscape i.e. telephones (landline, mobile, smart-), computers (touchscreen, or desktop) and their functions e.g. messaging, internet banking, games (Wallcook, Nygård, Kottorp, & Malinowsky, 2019). ETs found in public space include lifts (elevators), entry keypads and self-service technologies (SSTs); defined as technologies whose design intent is for the customer to produce their own service without direct employee involvement (Meuter, Ostrom, Roundtree, & Bitner, 2000). For example; cash machines (ATMs), automated supermarket check-outs, check-ins at health care centres and airports, and travel passes.

While many ETs remain stable in challenge, some SSTs and EICTs have been perceived to become disproportionately more challenging to use over time even when controlling for reducing abilities. While this may relate to changing routines with reduced frequency of ET use, it may also be a consequence of new or updated design features, where added layers of security and multifunctional demands may impel increased challenge (Hedman, Kottorp, Almkvist, & Nygård, 2018; Malinowsky, Kottorp, Patomella, Rosenberg, & Nygård, 2015). A study exploring variation in ET challenge according to diagnosis found that ETs presented mostly stable challenge to people with cognitive impairment. However, those ETs that presented disproportionately greater challenge to groups with a range of cognitive impairments, including dementia, were mostly EICTs (Kottorp, Malinowsky, Larsson-Lund, & Nygård, 2019). This is particularly concerning in relation to repeated calls to consider and improve the ease of use of internet connected EICTs and SSTs over recent decades (Baltes et al., 1992; Coleman, 1998; Lindqvist et al., 2018; Marston & van Hoof, 2019).

While EICTs may have relatively stable design features globally, international comparisons could highlight variation in societal demands that could impact upon the level of challenge when using such technologies. For example, Sweden is considered a highly technologised society compared to others internationally as the nation has more rapidly taken up *e*-governance and *e*-services that necessitate EICT and SST use (OECD, 2016). This may impact the level of international ET challenge, perhaps increasing it due to added complexity, or decreasing it due to increased frequency of familiarity of use (Patomella, Kottorp, & Nygård, 2013). Exploring this impact could provide actionable information about what to expect regarding societal demands and the potential for inclusionary or exclusionary consequences in countries heading or planning to head along similar digitalisation tracks.

The everyday technological landscape/environment is an important underpinning concept to the *Everyday Technology Use Questionnaire (ETUQ)*. This tool was designed to investigate the ability of older people living with dementia and cognitive impairments when using technology, as a growing facet of everyday life at home and in society (Rosenberg, Nygård, et al., 2009). The ETUQ originated within Sweden in 2002 and at its inception, the scope of technological items aimed to reflect the contexts (i.e. the environment) and personal

characteristics (i.e. volition, habituation and performance capacity) of older adults in Western societies (Kielhofner, 2008; Rosenberg, Nygård, et al., 2009). The ETUQ has been shown to produce valid measures of ability to use ET with acceptable rating scale function, internal scale validity and person response validity in Japan (Malinowsky, Kottorp, Tanemura, et al., 2015), Sweden (Nygård, Pantzar, Uppgard, & Kottorp, 2012; Patomella et al., 2017), and Portugal (Patomella et al., 2017). As the ETs contained in the tool are designed to be flexible in order to reflect international and cultural variations in the technological landscape, it is relevant to investigate possible measurement bias when using the tool with groups in new contexts, e.g. anglophonic countries such as the US and UK. Additionally most studies using the ETUQ have been undertaken in an urban context, which suggests that it is important to generate knowledge about ET use in rural areas, where variation in infrastructure and services may shape use differently. Furthermore, as the technological landscape changes over time, so too are ETUQ items updated in response necessitating renewed confirmation of the tool's psychometric properties. The most recent update followed an extensive process undertaken in 2014-2015 to reflect rapid changes to the landscape regarding information communication technologies (EICTs) and ETs found in public spaces (Malinowsky, Kottorp, Patomella, et al., 2015; Nygård, Rosenberg, & Kottorp, 2016). This warrants investigation into the challenge levels of these updated ETUQ items as the results may practically inform improvements to the cognitive inclusivity of ETs.

Investigations of data collected using the ETUQ have repeatedly shown that on a group level, people with dementia have typically lower abilities to use technology and consider lower amounts of technology to be relevant in everyday life in comparison to similarly aged older adults with mild cognitive impairment or no known cognitive impairment (Kottorp et al., 2019; Nygård et al., 2012; Ryd, Nygård, Malinowsky, Öhman, & Kottorp, 2015). However, there are overlaps between groups and qualitatively, the downsizing of a technology room has also been witnessed among the oldest old with no known cognitive impairment (Å. Larsson, 2009). Additionally, people with dementia and cognitive impairments have still reported learning to use and incorporating new technologies in their lives even as ability to use ET declines (Hedman et al., 2018; Malinowsky, Kottorp, Patomella, et al., 2015). The possibility of an overall goal of downsized doing has instead been raised as reasoning contradictions between the downsizing of a technology room, or the retaining and incorporating of ETs (Hedman, Lindqvist, & Nygård, 2016)

Comparing groups with and without dementia in terms of their ET use is therefore useful for highlighting divisions among older adults that may lead to inequalities of participation in everyday life. Highlighting divisions leads to options for societal action to improve inclusivity and the potential for all older adults to optimally participate in society. For example, ETs and most especially EICTs, are commonly considered as offering solutions in daily activities and people living with dementia have themselves repurposed their own technologies to better support their everyday life (Gibson, Dickinson, Brittain, & Robinson, 2015, 2019; Hwang et al., 2020; Schulz et al., 2015). However, studies in Sweden and the US have indicated that fewer relevant ETs can predict lower activity engagement and increased

need of support in everyday life among older adults with and without cognitive impairment (Ryd, Nygård, Malinowsky, Öhman, & Kottorp, 2017; Walsh et al., 2018; Walsh et al., 2020). Interestingly, ability to use ET has only been found to associate with minimal or no support needs in a smaller pilot study in Sweden involving 76 participants with mild cognitive impairment or mild Alzheimer's disease (Ryd et al., 2017). This association was tentative in a larger analysis of 108 urban dwelling older adults in the US (Walsh et al., 2020) and further, ET ability was not seen to associate with activity engagement (Walsh et al., 2018). Additionally, another study exploring the association between ETs perceived relevant outside home (including EICTs and SSTs) and the amount of places the people visited found statistically non-significant and small positive correlations among a group with and a group without dementia. The same study, however, found that ET ability shared a positive relationship only to the amount of places frequented by the group with dementia and not among the group with no known cognitive impairment (Gaber et al., 2019). Taken together, these studies point towards the possibility of new insights into inter-relationships between amounts of relevant technologies (i.e. the scope the current technological environment that is relevant to groups of older adults) and the abilities of older adults with and without dementia to use ET. Furthermore, what is known both qualitatively and quantitatively about how technology interplays with life outside home remains at an early stage of development. However, the state of the knowledge suggests that the conditions of ET use interplay with one another and with participation in everyday life in contextually variable ways (Gaber, Nygård, Brorsson, et al., 2020; Gaber et al., 2021). In some circumstances perhaps higher ET ability may occur with a larger technology room and greater independence in everyday life. Conversely, other conditions may conspire to engender a smaller technology room that associates with more restricted participation in everyday life. Additionally, participation may be more desirable and more impacted by ET in particular places over others. This interplay of different conditions of ET use is, as yet little explored, particularly in its relation also to everyday life in other contextual circumstances, e.g. between rural and urban contexts.

2.4 THEORETICAL PERSPECTIVES

The theoretical perspectives used in this thesis have evolved over the course of the author's doctoral education. This evolution was part of an effort to more deeply embrace the complexity of the interplay that was being observed between technology use and everyday life and in order to advocate for social change. This section relays that journey from the first underpinning perspectives through to a holistic perspective where the ideas are more unsettled and require further development.

The ecological model of ageing is highly influential to the field of gerontology, particularly the environmental press hypothesis, which asserts that the optimum zone of performance occurs in a balanced juxtaposition between the person's abilities and environmental demands (Lawton & Nahemow, 1973; Lawton, 1986). From the perspective of this thesis that would mean paying attention primarily to the abilities of older adults as they meet the demands of the ETs they encounter. An implication from which would be an assertion to reduce these

demands so that the ETs are optimised to fit a person's declining abilities (due to dementia for example), or to improve the abilities of the individual to meet the demand of the ET.

This fundamental assertion of the ecological of ageing is grounded with the Model of Human Occupation (MoHO) (Kielhofner, 2008). However, this model goes further to integrate the purpose for this interaction between people's characteristics (i.e. their volition to use a particular ET for a particular purpose, their habituation to that ET and their facility and capability when using it) and their environment (i.e. the design features of the ET, its siting and position in the wider physical and socio-cultural environment), the outcome of which is described a person's occupational performance (i.e. the extent to which the purpose motivating the technological interaction is fulfilled) (Kielhofner, 2008). Further, the model integrates systems theory so that each performance becomes part of an open system with an ongoing impact to both the constitution of the technological environment (i.e. the person acquires or rejects ETs) and to the person's characteristics (i.e. the person becomes less or more motivated, habituated and competent in their use of ET) that informs future interactions. This perspective from the MoHO as development from the environment press hypothesis underpins the ETUQ construction. The measures that come from this instrument express occupational performance as a relation between a person's perceived ability to use ET and the challenge presented by the technological environment as it is normal and valid to the respondent (Nygård et al., 2016). Issues of a mismatch between people whose abilities are systemically hampered (not only due to cognitive impairment) and societal demands to use technology have been argued as an issue of injustice (Kottorp et al., 2016). However, to address this issue requires use of a theoretical perspective that centralises the wider aspects of the environment that comprise the systems that hamper people's technological abilities.

Both the ecological model of ageing and the MoHO have been criticised for composing a dualistic view of the environment where these systemic aspects of wider context are disconnected from the interaction involving ETs, people, and occupation. This leads to further issues that occupation has been focussed too deeply upon the individual and requires a transcendent move to regard the people as inseparable from the world. Such a move focusses upon the functional coordination of the relations concerning technologically mediated occupations, which as seen as complex and inseparably situated among other elements (Cutchin, Aldrich, Bailliard, & Coppola, 2008; Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006). This movement towards a transactional perspective in occupational science has gained ground over the last 15 years. Notably the perspective is argued as facilitating a community orientation which may be useful to support the enactment of older adults with and without dementia's rights to participate in their communities and wider society (Cutchin, Dickie, & Humphry, 2017). However, it has also been asserted that the transactional occupational perspective remains tied to the primacy of the human through the strong social contextual underpinnings, leaving non-human elements less developed (Lee Bunting, 2016). Given the strong foregrounding of technology in this thesis, a complementary perspective was sought which would facilitate greater focus upon technologies' (as opposed to people's) interactions and relations with other non-human and human elements. By de-centring the

person, it was hoped that the potential to functionally coordinate technologically mediated occupation would be located beyond person and ET.

In 2017, Barlott and colleagues introduced the work of Deleuze and Guattari as a critical perspective to occupational science that could support an active research process of becoming minor to illuminate marginalisation and decentre the individual. This work takes a flat (non-hierarchical) ontological perspective focused upon the assemblage of interconnected human and non-human elements, which all have equal status (Barlott, Shevellar, & Turpin, 2017; Deleuze & Guattari, 1987). While Deleuze and Guattari's work provides a dense and complex perspective of reality, it has been considered challenging to pragmatically apply. Consequently, DeLanda's developments towards assemblage theory have been influential in supporting a practical view everyday life as an assemblage of interrelating component parts. Parts which include, but are not limited to, ETs and older adults, housing, infrastructures, occupation, shops (DeLanda, 2006). The flat ontology of assemblage theory provides a perspective at multiple scales, since as DeLanda asserts 'entities operating at different scales can directly interact with one another...a possibility that does not exist in a hierarchical ontology' (DeLanda, 2016; p19–20).

In assemblage theory, it is the *capacities* of the interactions between the parts that are in focus: so how ETs, places, people etc. have the capacity to shape everyday life as a product of their internal and external relations with one another. Furthermore, each part can be viewed as an assemblage in its own right whose ontological status is equal; i.e. the landline phone is comprised of interrelating wires, chips that externally relate to people, an electricity supply, connected to a telecommunications network, all of which can also be viewed as an assemblage at different scales. Through the capacities of the internal and external relations of parts, the assemblage takes its form via ongoing processes that can be seen as stabilising and/or destabilising. In the case of the landline phone these processes have led to changes in the assemblage; from analogue to digital, corded to wireless. People gained increased convenience and portability, moving from a fixed position at the telephone table at the home entrance, to having a chat from the comfort of the sofa. While the service provider profited from short perfunctory calls becoming longer and more intimate communications. Simultaneously, the landline now externally relates to other assemblages like the smartphone with its external relations to mobile data and the internet. This device has put people in a more permanent latent or actual state of participation in an increasing array of activities. Ultimately the processes expressed by the relation between these two devices could be to stabilise each device as a territorialised assemblage where the borders between are clearly delineated and impermeable. That is to say that there is a clear distinction between these two heterogeneous phones as there is today with heterogeneous groups of people who relate to one or both phones. Alternatively, these processes as they are continuing, may be destabilising and de-territorialising the assemblage of one or both devices. Interconnected patterns of human use may be releasing capacities that blur the boundaries between these phones so that perhaps only one homogeneous device emerges from these processes as recognisable. In this scenario the process of stabilising and destabilising, territorialising and

de-territorialising can be seen as simultaneous. While the boundaries of the landline become completely open to territorialisation from the smartphone, the smartphone emerges from the processes as a more homogeneous and consolidated entity. Concurrently, the interrelating infrastructures (satellite, cable), services, policy, economies are all undergoing this process of emergence. The assemblages of people who use the landline, or use the smartphone, or use both, or use neither are implicated by their relations so that each assemblage is simultaneously being de-/stabilised and de-/territorialised. Processes which have further consequential impacts to participation within the everyday life assemblage of individuals. This example gives insight into how assemblage theory and thinking is evolving in this thesis and providing practical support for the author in moving her attention across the different scales in the assemblage of everyday life.

By having a view on the interacting parts of everyday life as equal and interconnected, the author's focus can be shifted from the immediacy of the assemblage formed by the internal relations between ET, person, place, purpose and so on; to view its external relations i.e. with infrastructure, policy, governance, geography, transport, societal values and norms. By moving across these scales, the de-/stabilising processes that are underway to de-/territorialise the assemblages contributing to social in-/justice as relating to older adults' participation can be highlighted. In highlighting injustice, opportunities for action can be identified as located beyond the person-ET interaction.

The forthcoming section introduces the wider scale of the current societal situation with a view to critically identifying interrelating parts that may be impacting the conditions of older adults' technology use and participation in everyday life.

2.5 A CRITICAL PERSPECTIVE ON DEMENTIA-FRIENDLINESS AND TECHNOLOGICAL (OR DIGITAL) INCLUSION/EXCLUSION

The influence of the ecological model of ageing also underpins aspirations of becoming 'age-friendly' and 'dementia-friendly', the latter of which originated in the 1990s as a specific term. Initially, efforts to relieve environmental stress treated people with dementia as passive and were focussed upon the physical environmental aspects of homes, health and care facilities (Cox & Keady, 1990; Marshall, 1999; Parke et al., 2017). Up to the present day, the term has become more extensively used and broadened to encompass social aspects of communities where people with dementia actively participate in initiatives (Gan, Chaudhury, Mann, & Wister, 2021; Shannon, Bail, & Neville, 2019). However, with respect to both age- and dementia- friendliness, aspects of technology have been largely unaccounted for despite its ubiquity in the environment (Lindqvist et al., 2018; Marston & van Hoof, 2019).

Although use of the term 'dementia-friendly' has increased, it attracts criticism for being wishy-washy and weak in terms of its potential to redress the inequalities, exclusion, and oppression that people living with dementia continue to experience in society (Shakespeare et al., 2019). Furthermore, while the ambition of dementia-friendly initiatives is to optimise participation in everyday life, some consequences have been exclusionary and marked people

out as ‘other’ in ways that reinforce stigma (Swaffer, 2014; Rahman & Swaffer, 2018). Although dementia-friendliness and age-friendliness have sprung from a place of empowering older people in society, they are also connected to managing “the burden of ageing” and dementia. As such, both terms remain underpinned by economic agendas that are served by capitalising upon fomenting a personal responsibility to ‘age healthily, successfully, actively’ or ‘live well with dementia’ (Ramsay-Jones, 2016; Rudman, 2006).

Regardless, the term ‘dementia-friendly’ is well-used and understood positively by people with dementia themselves as efforts that are made to ensure that they “are understood, respected and supported...so that people with dementia can continue to live life the way they want to and in the community they choose” (Alzheimer's Society, 2021). This leads to moral assumptions about equal capacities to *be* and *act* dementia-friendly in societies, when in reality people’s potential to understand, respect and support one another is highly diverse. It also leads to assumptions that choice, and choice-making are straight-forward and self-directed, driven by defined end goals, which can be identified as comparably preferable and desirable (DeLanda, 2006). For example, the choice to identify an available ET as relevant or not relevant i.e. a train ticket machine in the context of what the machine is for; i.e. as part of a choice to travel somewhere to do something. However, much choice-making begins within the contextualised *means* of reaching the ends, a process of imagination that first shapes the possible forms of the choices, followed by a process that evaluates the optimal consequences of the identified choices to determine which, if any, is best. To extend the given example, this means imagining using the ticket machine, undertaking the journey and possible connections, coping with delays and disruptions, whether the transport timetable can allow for such disruption, fulfilling the purpose at the destination. It may also entail imagining available alternatives of going to a ticket booth, getting a lift, and the cost-benefit (personal, social, financial) analysis that accompanies this imagining – i.e. stress and getting lost, or embarrassed, missing the last train, versus time spent with another juxtaposed with possibly inconveniencing others and whether the purpose for the journey is sufficiently urgent and worth any trouble or potential disruption incurred. In this example, choice may not be straight-forward at all, but highly constrained within a chain reaction of consequences that people may need to account for.

Understanding the tensions and drawbacks of this term, ‘dementia-friendliness’ is used in this thesis in connection with contributing to the enactment of people with dementia’s rights in society (Shakespeare et al., 2019). However, it is also used with compassion considering the complexity of achieving these ambitions in an imperfect society and with the knowledge that people and communities have different strengths and assets to contribute (Rahman & Swaffer, 2018; Shakespeare et al., 2019). Ultimately, in arguing for the increased friendliness of technological interplay specifically towards people with dementia, it is anticipated that this interplay will become friendlier for everyone (Marshall, 1999). Ideals which form the underpinnings of socially responsible, inclusive design; whereby technological environments, products and services are democratised to include the most users possible (Clarkson, Dong, & Keates, 2003).

Older adults have been living within a rapid phase of post-world war II technological change, which accelerated further still with the advent of the internet. This was the innovation that spurred concerns about an age-related digital divide, which focussed on the disparity of older adults becoming left in the wake of an upcoming generation of digital natives. The notion of a divide has always belied the nuance behind the concept, which has from the outset acknowledged the intersectional conditions that impact technology use; where generation (perhaps rather than age), meets disability, meets education and income, meets rural, meets loneliness for example (Cullen, 2001; Gilleard & Higgs, 2008; Johansson, Gulliksen, & Gustavsson, 2021; Liu, 2020; Olsson & Viscovi, 2020; Shrewsbury, 2002; Walker, 2019). As time has progressed, the language has broadened towards a more spectral and relative view of multi-levelled digital -exclusion, -inclusion, -inequalities. Such a view better relays the complexity of corresponding online and offline conditions that culminate in injustices relating to an individual's participation in everyday life (Helsper, 2012; Van Dijk, 2020). Consequently, definitions surrounding the digital exclusion have moved on from straightforward internet 'haves' and 'have nots', to incorporating skills and useage, and finally to focus on exclusionary outcomes with respect to social, cultural, economic and individual participation in society (Compaine, 2001; Van Dijk, 2020).

Justice and equal rights have, in part, always motivated research and practices focussed on closing the digital gap (Cullen, 2001; Larsson-Lund & Nyman, 2020). However the parallel irony is that technologies are argued as economically oriented and located within capitalist structures that exacerbate inequalities (Zuboff, 2019). The persistent ideal of autonomous technology use by archetypal responsible older individuals has pervaded research (Beimborn, Kadi, Köberer, Mühleck, & Spindler, 2016). Consequently, people who represent the alternative have been referred to as disengaged, disconnected, an underclass and on the wrong side of the divide (Esteban-Navarro et al., 2020; Fischl, Lindelöf, Lindgren, & Nilsson, 2020; Helsper & Reisdorf, 2017; Olphert & Damodaran, 2013). However, it is not a minority of older adults who get positioned in this way. A recent study in Sweden revealed that of 1,264 respondents to a postal survey, 81% could be considered at risk of some form of digital exclusion. While internet non-use accounted for almost 36% of excluded respondents, the remaining 45% were online. However, this 45% were online less often, had no smartphone in addition to another device, had no internet bank, were not able to pay bills online and had never used an online public service (Olsson & Viscovi, 2020).

An occupational perspective on everyday technological exclusion takes a broader view to appreciate a perpetual situation of relative disparity where everyone is differently positioned at the frontier of new successive waves of technologies in all areas of everyday life (Malinowsky, Kottorp, Patomella, et al., 2015). Rather than viewing non-use as an aberrance, it becomes an inevitability, since taken in its entirety, the technological landscape is not intended for everyone. Instead, each of the technologies that comprise the landscape are designed to corner market shares. Whether an older adult with or without dementia is expected to envision themselves as a user of a particular ET, just as others in society, is shaped by societal discourses. Discourses of ageing can be particularly influential when

harnessed to sell technologies, as they simultaneously sell ideals and expectations about everyday life to the individual and/or significant others. Pertinent in this regard are discourses of ageing (-well, -in place, -positively, -successfully) which are used to sell e.g. wearable surveillance and fitness technologies, thereby externally motivating and selling personal responsibility alongside particular lifestyles and occupations (Laliberte Rudman, 2006; Rudman, 2006; Vermeer, Higgs, & Charlesworth, 2020). Furthermore, these discourses of ageing have driven an interventionist logic to technological development, where technologies have largely been commodified and framed as a biomedical solution to ageing seen as a social problem (Peine & Neven, 2019; Wanka & Gallistl, 2018). Discourses, which are internalised by older adults themselves to inform the technologies they perceive as aligning to their identity and sense of self (Astell, McGrath, & Dove, 2020).

As stressed by issues of the digital divide and ageing discourses, the relevance of a technology is not a free choice but a product of interactions with societal expectations and free market principles. There are dimensions of the landscape, not only EICTs, that hold stronger expectations of universal conformity to use which include older adults, where personal relevance is disregarded and non-use is socially problematised e.g. SSTs. An occupational perspective of injustices stemming from everyday technological exclusion focuses upon the implicated aspects of everyday life; travelling and transport, finance and purchasing, communication and personal administration in any area of life – social, health care and so on (Kottorp et al., 2016). This means that the individual older adult's perspective on their interactions with their technology room, although crucial, cannot alone be used to establish, unpick and tackle issues of injustice. Focussing too much at the scale of the individual can lead to a failure to see the structures and systemic roots of inequality that are served, reproducing hegemonies of social order (Angell, 2014). The social order perpetuated by facilitating technologically mediated occupation, is not only to serve prevailing discourses of ageing but is also to serve and commute power to the architects of surveillance capitalism (Zuboff, 2019). As Zuboff theorises, surveillance capitalism is not a technology, but a logic, a new imposition of economic and behavioural order that threatens human nature and seeks dominance over society. As such, facilitation of technology use is guarded in this thesis by a consciousness that to seek justice for older adults' equal participation in the everyday technological landscape could be to serve the architects of digital enforcement (Díaz Andrade & Techatassanasoontorn, 2021). From this position comes an ethical imperative to maintain a critical eye on the appearance of choice and free will in technology use and to uphold the autonomy of those in society who seek a manualised everyday life.

2.6 CITIZEN INVOLVEMENT IN RESEARCH (PPI)

PPI stands for Patient and Public Involvement in research and refers to research that has been carried out *with* members of the public, in this case mostly people with dementia, rather than *for* them or *about* them (INVOLVE, 2012). However, from a research perspective focussed upon social action and rights, both the term patient and public are inadequate for this thesis. Other terms, e.g. 'expert by experience' also have drawbacks, i.e. edges of elitism which are

unhelpful for encouraging a broad base of involvement. Consequently, the term citizen has been adopted for this thesis, which is also more commonly used in a Swedish context [medborgarmedverkan i forskning]. The original acronym is retained purely to facilitate parity across international contexts.

PPI is entirely different from taking part in research as a participant and distinct from Participatory Action Research. This is because PPI occurs outside of the participant context and across the whole research cycle, from identifying and prioritising the research foci through to evaluation and reporting its impact (INVOLVE, 2012). As such, PPI can be considered a form of citizen science [medborgarforskning] (where the general public are involved in data gathering (Bonney et al., 2009)), that is applied within health and social care (Borda, Gray, & Downie, 2019; Burns, Korzec, & Dorris, 2019).

Involving citizens has been shown to benefit research quality and relevance, improve the efficacy of recruitment strategies, and enhance the potential for the social uptake of findings (Brett et al., 2014a). These outcomes in turn have led to motivations in favour of PPI as a moral duty that democratises research by centring the citizen's rights, and increasing the accountability and transparency of research by constructing it beyond only institutions (Greenhalgh et al., 2019). Within the UK, PPI is an essential component of research funding and ethical approval, which is not the same in Sweden or the US, despite also acknowledged weaknesses in how it is undertaken. PPI faces accusations of being tokenistic and exclusionary in its failure to include a diversity of individuals and to facilitate genuine influence on the research process as equally valued partners (Ocloo & Matthews, 2016). People with dementia have tended to be under-involved in research and their involvement can be attended by specific challenges. These challenges include curtailed engagement over time due to dementia progression, capacity concerns, poorly tailored engagement opportunities, and societally informed lack of self-belief due to prevailing stigma (Bethell et al., 2018). Not-involving people with dementia in research can therefore perpetuate stigma as other groups, by contrast, are involved, and this could reasonably hinder validity if expertise by experience of the social phenomena under investigation is ignored (Swaffer, 2014). By involving people with dementia in previous studies, research output was found to be enriched, new perspectives were incorporated and the relevance of the research to people with dementia was enhanced (Brett et al., 2014a; Di Lorito et al., 2017; Poland, Charlesworth, Leung, & Birt, 2019).

2.7 RATIONALE

In summary, the rationale for this thesis is grounded within a perspective that asserts the rights of older adults, particularly those with dementia to be involved in research, and to participate outside their homes in society and in the technological landscape. The increased technologising of society incurs a risk that older adults with and without dementia could become excluded from aspects of everyday life. Understanding how to achieve societies that are inclusive and facilitate participation in everyday life outside home becomes an urgent task as the prevalence of dementia is increasing globally. This thesis responds to an established

gap in present understanding about the conditions for technology use among older adults with and without dementia in different international and geographical contexts. Alongside, is a need to examine the performance and suitability of instruments in each new context that is investigated. Empirical knowledge is lacking with respect to how different types of context impact technology use. The consequences of these impacts may reasonably facilitate or impede the use of technology in various contextually specific ways that once understood, could inform design, planning, and policy. Furthermore, everyday life is expected to be shaped in a complex interplay with these conditions which are currently under-explored. By generating new knowledge about this interplay, practical information and guidance will follow that can support both dementia-friendliness and age-friendliness as well as general inclusivity in society.

3 RESEARCH AIMS

The overall aim of this thesis is to illuminate the conditions, particularly different country and geographical contexts, of ET use and their interplay with participation and inclusion in everyday life, both in and outside the home, for older adults living with and without mild stage dementia.

1. To explore whether the country context (Sweden, U.S. and England), where public space ETs and EICTs are used by older adults, or having a diagnosis of dementia, impacts upon the level of challenge of those ETs. For any ETs that vary in challenge level, to identify the comparative proportional relevance of that ET between each subgroup. To investigate whether any country or diagnosis-specific differences impact upon the measures of person ability to use ET between countries.
2. To identify the relevance of, use of, and ability to use EICTs among a group of older adults living in Sweden with mild stage dementia in comparison to a matched group with no known cognitive impairment. To identify the level of challenge perceived by both groups of older adults in using EICTs.
3. To illuminate how people living with dementia in a rural area of the North of England react and respond to the interplay between everyday technologies and everyday life situations.
4. To explore the association between (particularly out of home) ET use (amount relevant and ability to use ET), and the number of places a group of people go to, with and without dementia, in a rural versus urban environment.

4 MATERIALS AND METHODS

This section begins with an overview of the citizen involvement foundations that informed the design of this thesis and built throughout the research process, before continuing with a more familiar presentation of the methods.

4.1 CITIZEN INVOLVEMENT (PPI) AS A FOUNDATION TO THESE STUDIES

The foundation of this thesis began before the author, in INDUCT's partnership with Alzheimer Europe and the European Working Group of People with Dementia (EWGPWD). The EWGPWD members have each been nominated by their national Alzheimer organisations and the group steers the work of Alzheimer Europe including PPI for the European projects that Alzheimer Europe partners. As such the EWGPWD was involved in setting the INDUCT's research priorities and objectives, was engaged in the Ethics Oversight Committee for the network and took active involvement in every phase of the research that was conducted (see fig. 2).

To support development and implementation of research design and management (i.e. ethics, recruitment) and dissemination strategies, a number of other community stakeholders in the UK were engaged (dementia strategy groups, faith groups, community groups, local charities and networks) (see fig. 2).

As the studies of this thesis are contextually driven between international and rural contexts, a second group, the Focus on Dementia Network Group Cumbria (FODNC), were engaged at the close of the recruitment as consultants in the UK. Inviting the FODNC to consult was motivated by a number of perceived reciprocal benefits aligned to areas of shared purpose and interest between the group and author. These included: a) That the research could remain grounded in a rural context from which the studies in part arose (**i, iii, iv**) and provide a route to sharing findings directly back into that context (**i-iv**) (Brett et al., 2014b). b) A research involvement opportunity could lead to social action, demonstrating to the wider community and dementia-friendly initiatives that people with dementia can contribute to decisions that directly affect their lives (Bartlett, 2014). c) By collaborating in partnership with an existing group, issues of professionalised PPI could be mitigated and a diverse ability range included (Ocloo & Matthews, 2016; Staniszewska, Denegri, Matthews, & Minogue, 2018).

Furthermore, the policies and procedures of the organisation behind the group and their regular facilitator offered support, familiarity and trust, and provided an option for dealing with ethical concerns of difficulties or distress that may have arisen (Di Lorito et al., 2017). This collaboration also minimised the risk of leaving a void at the end of the consulting period and meant that activities could be sensitive and non-threatening to the viability of the fragile wider offering of social activities and events in the area. These wider contextual considerations of collaborative working in a rural social activity context added to the acknowledged inter-personal complexity of managing expectations when undertaking PPI activities (Poland et al., 2019).

Fig. 2 Indicating the phases of the research cycle with citizen involvement.

Research Cycle (INVOLVE 2012)	Identifying and prioritising	Commissioning	ϕ Design and management	Undertaking	Disseminating	* Implementation	* Evaluation and impact
EWGPWD	x	x	X	X	X	X	X
FODNGC				X	X	X	X
Wider stakeholders			X		X		

x Only applied across the ITN rather than specifically to these studies

X Applied to the specific studies of this thesis

ϕ Applied to UK-based studies (i, iii, iv)

* These parts of the cycle remain ongoing

The FODNC supported particularly the *Undertaking* and *Dissemination* phases; interpreting analysed data (ii, iii), prioritising and contextualising findings (i-iv), developing implications and guidance (i-iv), and identifying target audiences for dissemination (i-iv) (see fig. 2).

Further details of how all three of these PPI contributors were involved in the research process are contained in the relevant following sections of the methods (section 4.3.1, section 4.5.3).

4.2 STUDY DESIGNS

The studies of this thesis used cross-sectional designs to provide a view on older adults' interactions with everyday technology and the interplay of these interactions with participation at a particular point in time (refer to table 1). Three studies followed various quantitative designs to explore the different factors that shape the challenge and use of everyday technology (i, ii) and participation (iv). Study iii adopted a case study design to highlight the role of context in technological interactions utilising both qualitative and quantitative data.

4.3 PARTICIPANTS

Each sub-study involved between one and three different country samples that a total of 315 participants had been recruited to; the United States of America (US) (i), Sweden (i,ii), and England (i, iii, iv). Figure 3 depicts the sample and sub-groups, their sizes and relationships with respect to each study.

4.3.1 Sampling and recruitment

Inclusion criteria common to all three groups was that participants lived in ordinary housing in the community with varying levels of (or no) support. People living in purpose built retirement housing, including warden supported housing were included, while care or nursing homes were excluded. Additionally, participants needed to be able to consent to participate in

Table 1: An overview of the sub-study designs

	i	ii	iii	iv
Focus	To explore country/ diagnosis specific differences in relative ET challenge	To compare ET use and challenge between diagnostic groups	To illuminate the rural context of ET interactions among people with dementia	To explore associations between ET use and participation among older adults
Design	Cross-sectional			
	Quantitative		Multiple case study	Quantitative
Data collection	Structured interview at the participant's home or another place of their choosing:			
	ETUQ, ACT-OUT, DQ, MoCA		ETUQ, ACT-OUT, DQ, MoCA Observations, fieldnotes, memos, annotated maps, secondary situational data (i.e. bus timetables)	ETUQ, ACT-OUT, DQ, MoCA
Instrument~	ETUQ, DQ, MoCA [#]		ETUQ, ACT-OUT, DQ (including IMD), MoCA [#]	
Participants*	<i>n</i> =315 (Swe, US, Eng)	<i>n</i> =69 (Swe)	<i>n</i> =10 (Eng)	<i>n</i> =128 (Eng)
Everyday Technologies[^]	EICTs (<i>n</i> =41) and public space ETs (<i>n</i> =16)	Subset of EICTs (<i>n</i> =31)	All ETs including plus items	Subset of EICTs (<i>n</i> =31) and public space ETs (<i>n</i> =16)
Primary Analyses	Differential Items Functioning and Differential Test Functioning	Comparative medians testing and correlations	Within and cross-case analysis	Logistic regression

* Refer to figure 1 for further participant sampling and sub-sampling details.

~ ETUQ: Everyday Technology Use Questionnaire, DQ: Non-standardised demographic questionnaire, MoCA: Montreal Cognitive Assessment, ACT-OUT: Participation in ACTIVities and Places OUTside Home Questionnaire, IMD: Index of Multiple Deprivation

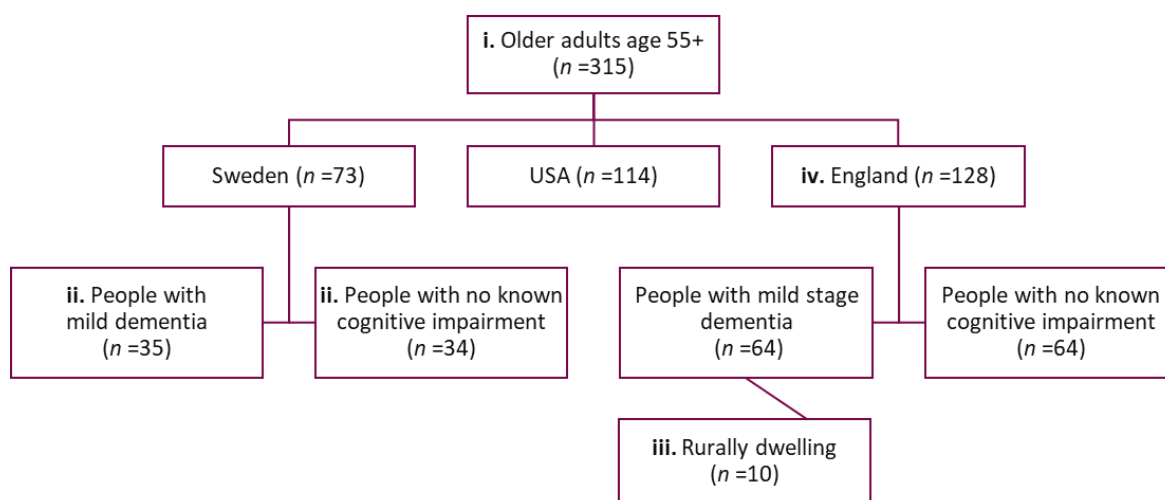
MoCA used only descriptively and to support matching of sub-groups - not for analytical purposes

[^] Refer to figure 2 for further details regarding the ETs in focus from the ETUQ

the research themselves (i.e. not via a proxy) according to the relevant legal and policy frameworks in each country (refer to 4.3 Ethics). To have the possibility of including people with young onset dementia (i.e. younger than age 65 and generally pre-retirement) (Rossor, Fox, Mummery, Schott, & Warren, 2010), participants were included in the groups from England and Sweden if they were aged 55 and over, whereas the criteria for the group from the US was age 65 and over. Participants in England and Sweden shared further inclusion criteria that prospective participants continued to go to at least some places and use at least

some ETs whether independently or with others. Participants in England and Sweden were excluded if they experienced any sensory or communication impairment (non-compensable by aids) that could inhibit the interview. Participants in England were required to be able to participate in English and participants in Sweden, Swedish. It is not known how many people declined to participate due to the varied and open recruitment processes between each country (see below) and the multiple points at which a person could decline.

Figure 3. A depiction of the relationships between the sample and sub-samples of participants in each sub-study (i-iv) together with the number of participants (n).



The groups of participants in Sweden and England were purposefully sampled to comprise approximately equal subgroups of people who either had received a diagnosis of mild (England) or mild to moderate (Sweden) stage *dementia* (American Psychiatric Association, 2000), or major neurocognitive disorder (American Psychiatric Association, 2013), or had *no known cognitive impairment*. As cognitive impairment due to dementia was in focus, participants were excluded if they had received diagnoses with similar consequences to cognition, such as: stroke, AIDS, multiple sclerosis, Parkinson's.

Participants with *dementia* in Sweden were recruited from three memory investigation units in the Stockholm region and municipality run activity groups specifically for people with dementia (i.e. memory café). Participants with *no known cognitive impairment* (based upon self-report) were recruited following presentations about the research given at activities provided by Stockholm area municipalities for people in retirement, community, leisure and social activity groups. To mitigate probable confounders to the analysis of sub-study **ii**, the two sub-samples (*people with dementia* and *people with no known cognitive impairment*) were frequency matched for age, gender, years of education and living situation. These matching criteria together with cognitive assessment scores (refer to section 4.4.4.4) led to the exclusion of four participants.

Participants with *dementia* in England were recruited through five National Health Service sites; two in predominantly rural Cumbria and three in urban London and Greater Manchester. Additionally, participants with dementia could participate in the research having heard about it through the same recruitment channels as those with *no known cognitive impairment*. Namely, through information circulated via mailing lists and newsletters (i.e. belonging to stakeholder and other charity and community groups) and posters on display in public places (i.e. libraries), small businesses, meeting, activity, and worship venues in Cumbria and London. A sub-group of rurally dwelling participants were drawn from the main sample for sub-study **iii** on the basis that they contributed substantial information to the topic and found the topic important to discuss.

The group from the US was formed of a convenience sample drawn from a community centre for older adults based in a Chicago suburb. This group was not purposefully sampled for a diagnosis of dementia, nor for having no known cognitive impairment. As such, this group was anticipated to vary widely in terms of cognition due to the prevalence of cognitive impairment in society, whether *with* dementia (US 8.2%-9.4% age 65 and over in 2012 (Langa et al., 2017)) or *without* dementia (US est. 22% age 71 and over in 2002 (Plassman et al., 2008)). Similarly, due to increasing co-morbidities with age, diversity was expected in all three country groups with respect to health conditions (chronic or acute) and physical functioning.

Recruitment materials were designed to conform to guidelines laid out by the Dementia Engagement and Empowerment Project (DEEP, 2013). The EWGPWD and stakeholder PPI groups reviewed the recruitment materials for clarity and offered guidance to tailor recruitment strategies to the specific UK contexts (i.e. London, Greater Manchester, Cumbria) in order to overcome recruitment barriers and improve effectiveness and reach. Subsequently, stakeholder groups supported circulation of the recruitment materials and introduced prospective participants to the research either directly, or by inviting one of the two researchers to give presentations. In all three countries, the internet was deliberately avoided as a recruitment channel due to the potential for the sample to become biased in favour of more able users of everyday technology (Patomella, Kottorp, Malinowsky, & Nygård, 2011).

4.3.2 Participant characteristics and representation

Overcoming barriers to participation in research was a recruitment priority to improve the applicability of the findings to groups of people that are often under-represented (Bartlett, Milne, & Croucher, 2018). Research with older adults has identified an under-representation of people with mobility and health impairments, people aged over 85, people from socio-economically disadvantaged backgrounds, and Black, Brown, and some White minoritised people (Condon et al., 2019; Kammerer, Falk, Herzog, & Fuchs, 2019; Liljas et al., 2019). Within the country context of Sweden ethnicity was not monitored. It is considered more relevant to look at representation between Swedish background/birth versus foreign

Table 2. Characteristics of the participants overall (n =315) and within each sub-study (i-iv)

	Total (n =315)	i US (n =114)	ii Sweden (n =69)	iii Rural (n =10)	iv England (n =128)
Diagnosis	(N =201)				
Dementia n (%)	99 (49.3)	-	35 (50.7)	10	64 (50.0)
NKCI ^a n (%)	102 (50.7)	-	34 (49.3)	-	64 (50.0)
MoCA score adj.^b	(N =309)	(N =108)			
Median (IQR)	24 (20-26)	24 (12-26)	23 (18-27)	-	24 (21-26)
Range	4-31	13-31	4-30	14-21	12-30
Gender	(N =314)	(N =113)			
Men n (%)	161 (51.3)	69 (60.5)	26 (37.7)	6	65 (51.2)
Women n (%)	153 (48.8)	44 (38.6)	43 (62.3)	4	63 (49.2)
Age					
Median (IQR)	75 (68-81)	73 (68-79)	76 (71-81.5)	-	76 (68-82)
Range	55-96	65-92	59-96	72-84	55-96
Over 85 n (%)	37 (11.7)	12 (10.5)	6 (8.7)	0	16 (12.5)
Race and ethnicity*	(N =242)				
Black and Brown people n (%)	64 (26.4)	43 (37.7)	-	0	21 (16.4)
White people n (%)	178 (73.6)	71 (62.3)	-	10	107 (83.6)
Living situation					
Alone n (%)	163 (51.7)	70 (61.4)	40 (58.0)	5	49 (38.3)
Co-habiting n (%)	152 (48.3)	44 (38.6)	29 (42.0)	5	79 (61.7)
Geography	(N =310)		(N =68)		
Rural/countryside [‡] n (%)	36 (11.6)	0	6 (8.8)	10	30 (23.4)
Urban n (%)	274 (88.4)	114 (100)	62 (91.2)	0	98 (76.6)
Education					
< 12 years	127 (40.3)	24 (21.1)	33 (47.8)	8	67 (52.3)
12 or more years	188 (59.7)	90 (78.9)	36 (52.2)	2	61 (47.7)
Diagnoses^ϕ					
None n (%)	107 (34.0)	28 (24.6)	34 (49.3)	6	43 (33.6)
1 or more n (%)	208 (66.0)	86 (75.4)	35 (50.7)	4	85 (66.4)
Overall ability[‡]					
Independent n (%)	132 (41.9)	47 (41.2)	29 (42.0)	1	56 (43.8)
Requires assistance n (%)	183 (58.1)	67 (58.8)	40 (58.0)	9	72 (56.2)
Date range of data collection	Aug 2015- Nov 2017	Nov 2016- May 2017	Aug 2015- Oct 2017	May-Nov 2017	May-Nov 2017

^a NKCI: No known cognitive impairment ^b Scores adjusted: one additional point given for <12 years of education (Nasreddine et al., 2005). ^{*} No further information available for the US group. England sub-group: *Black and Brown people*: Asian/Asian British - 9 (7.0%); Black/African/Caribbean/Black British - 8 (6.3%); Mixed/multiple ethnic groups - 2 (1.6%); Other ethnic group – 2 (1.6%). *White people*: British - 93 (72.7%), Irish - 4 (3.1%), Gypsy or Irish Traveller - 1 (0.8%), Any other white background (including 7 who self-identified as Jewish) - 9 (7.0%). Black and Brown recognises historic and current growing use in both the US and the UK and rejects the controversial and diminishing term ‘minority’ within the acronym BAME (Dar & Ibrahim, 2019). [‡] Rural according to definitions in England (Bibby & Brindley, 2013) and Sweden (Jordbruksverket, 2015). ^ϕ Category *one of more* may include a diagnosis related to cognitive impairment for the US sub-group, but not in the Sweden and England sub-groups. [‡] Given according to guidelines within in the ETUQ, refer to section 4.4.3.1

background/birth. However this stance is criticised for its colour-blindness and for overlooking multi-ethnic groups' experiences of racialisation in society (Osanami Törngren, 2020). Through an intersectional lens, these socially constructed dimensions of race, ethnicity, gender, disability, and social class form the foundations of societal differences which shape participation (Angell, 2014; Melbøe, 2018). Collecting and presenting this information is part of ensuring that recruitment, involvement, and findings can be appraised with respect to the diversity of society in the three countries. Although appraisal is hampered by a non-uniformity of collected demographic information, there are indications that recruitment aims have broadly been achieved for two sub-studies. The characteristics of participants in table 2 show that the voices of Black, Brown and White ethnically minoritised adults, aged over 85, and with a range of functional abilities and health situations have been included in this research.

4.4 ETHICAL CONSIDERATIONS AND DATA COLLECTION PROCEDURES

4.4.1 Consent procedures

Ensuring that participants had the opportunity to give fully informed consent was a prominent consideration due to potential vulnerability and difficulty safeguarding integrity which can be experienced by people with cognitive impairments (Grady, 2015). Safeguarding was however balanced with the person's right to self-determination and promoting the common good (Thorogood et al., 2018). Within the UK, the legal construct of mental capacity guides assessment of a person's ability to make an informed decision and consent, in this case, to participation in research (Mental Capacity Act, 2005). Mental capacity is presumed, unless a prospective participant established otherwise by seeming to not understand, retain, or weigh up information as part of the decision-making process (Mental Capacity Act, 2005).

Participants were supported to exercise their right to make independent decisions and give informed consent, in part through the information giving process. In the UK, Dementia Engagement and Empowerment Project guidelines were again followed to optimise the clarity of the participant information sheets and consent forms, which were reviewed and revised following feedback from a member of the EWGPWD (DEEP, 2013). In all three countries, information sheets contained details of the a) study procedures, b) purpose and intentions, c) benefits and burdens, d) audio recording, e) the voluntary nature of participation, f) freedom to withdraw without reason, g) confidentiality and anonymity, h) data analysis, transfer and storage, i) indemnity, j) ethical approval, k) researcher details. Participants consented to each of the information points d)-h) individually via check boxes in the consent form.

In accordance with recommendations, consenting to participate was viewed as a process (Nygård, 2006; Thorogood et al., 2018), which was similar between countries and involved participants; a) receiving verbal information, b) requesting or agreeing to receive written information, c) receiving contact from the interviewer to follow-up on information received;

decline, take more time, or book an interview, and d) confirm the decision face-to-face and proceed with consent procedures. The minimum time between steps b) and c) was 24 hours. This process ensured that on no less than three occasions, each participant received repeated information, had the opportunity to ask questions, and consistently communicated a will to consent to participate. Before the face-to-face interview commenced, participants completed and signed a written consent form. As capacity may fluctuate, it was re-assessed at every interview occasion and informed consent was verbally re-confirmed. No one volunteering to take part in the research was subsequently declined on the basis of capacity. One participant did withdraw after giving consent but before completing the interview.

4.4.2 Ethical permits

Approval for all four sub-studies were granted by the Stockholm regional ethics board against permit 2015/77–31/5 (i, ii) and permit 2017/4:3 (i, iii, iv) in Sweden. The University of Illinois at Chicago’s institutional review board in the U.S. granted permission for sub-study i against permit 2016-0797. The United Kingdom’s Health Research Authority¹: South West – Frenchay Research Ethics Committee granted permission for sub-studies i, iii, iv relating to IRAS project ID: 215654, REC reference: 17/SW/0091.

4.4.3 Instruments

To explore conditions and interplay with the technological environment, the predominant instrument of this thesis is the *Everyday Technology Use Questionnaire*, data from which underpins all four sub-studies (Nygård et al., 2016). Additionally, to explore technology’s interplay with participation, data from the *Participation in ACTivities and Places OUTside Home* questionnaire was used in studies iii and iv (Margot-Cattin et al., 2019). Conditions of technology use and participation were also explored from the perspective of demographic and relative neighbourhood deprivation data collected in a non-standardised questionnaire. Scores from the *Montreal Cognitive Assessment* were used to support matching in sub-study ii, and otherwise were used only to describe the ranges in cognitive function between and within groups and sub-groups (Nasreddine et al., 2005).

4.4.3.1 Everyday Technology Use Questionnaire (ETUQ)

The ETUQ can be used to measure the perceived abilities of respondents to use 90+ ETs at home and in society. Although primarily designed for use with older adults with or without cognitive impairment (Rosenberg, Nygård, et al., 2009), the tool has also facilitated investigation of the relevance of ETs and ability to use ET among people of different age groups and with a variety of disorders and health conditions (Fallahpour, Kottorp, Nygård, &

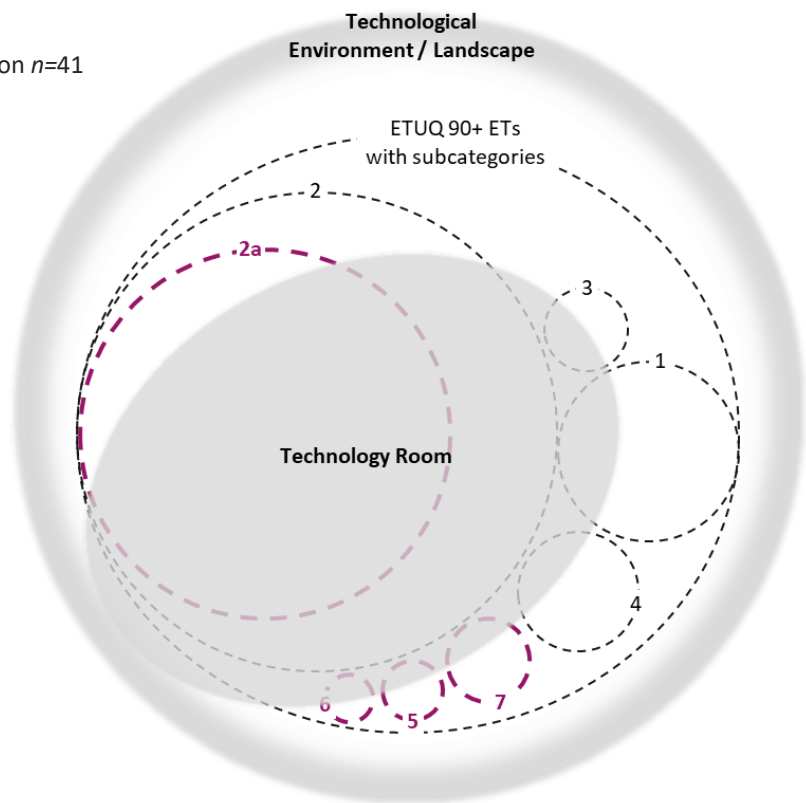
¹ At the time of ethical approval, there were separate application systems between the four nations of the UK so that approval applied to England only. This context is reflected so that the three sub-studies are described with reference to England rather than as UK-wide.

Lund, 2014; Hällgren, Nygård, & Kottorp, 2011; Kaptain, Kottorp, Patomella, & Helle, 2017).

The ETUQ can currently be administered in Swedish or English after a training course. The questionnaire is undertaken in a face-to-face interview with the respondent, typically in the person's own home, and ratings are given based upon the person's own responses describing their use of ETs. The relation of the ETUQ as an inventory of items that comprise the technological landscape is approximated within the earlier figure 1a (refer to figure 1b). The 90+ items are divided into seven sub-categories within the questionnaire, which are shown proportionally with respect to one another in figure 1b. Additionally, a bold, coloured outline indicates both the predefined categories and the specially comprised categorisations of ETs that are central to this thesis (All together referred to as *Out of home ETs*; comprising *EICTs*, and *Public space ETs* which include: *Accessibility, Economy & Purchasing, and Travel*).

Figure 1b: Depicting the ETUQ inventory of items in relation to the everyday technological landscape/environment and the technology room.

1. Home $n=16$
2. Information and communication $n=41$
 - a. EICTs $n=31$
3. Self-care $n=7$
4. Maintenance and repair $n=10$
5. Accessibility $n=5$
6. Economy and purchasing $n=4$
7. Travel $n=7$



Relevance is a key concept of the ETUQ and is defined by the respondent not only reporting that they have access to the ET item, but also reporting their use of the item, i.e., that they have used the ET in the past, use it now, or intend to use it in the future. Once a technology is established as relevant, the respondent's reported use of that item is rated according to the response alternatives shown in table 3. An often-important sub-category of relevance in this

thesis are those ETs that are currently *used*. Against each item is a space to optionally record comments and the questionnaire closes with two open-ended questions that gather additional information about the person’s history and future as a technology user and what about technology they value.

Table 3: Description of the ETUQ rating scale steps (Nygård et al., 2016).

Not Relevant	Rating scale steps				
	Relevant			Not used	
	Used				
Technology - is not present in the person’s environment/life. - has never been used and is not intended to be used.	Technology is used with no difficulties or hesitation.	Technology used with limited difficulties or hesitation.	ET item is used with extensive difficulties that arise often.	ET item is used only together with another person.	ET item is not used anymore, or has not yet come into use, even if it is relevant.

Lastly, the respondent’s need for overall assistance is evaluated and recorded based upon the following four alternatives: a) the person can live independently in the community, b) the person needs minimal assistance or supervision to live in the community, c) the person should have moderate assistance to live in the community, d) the person should have maximum assistance to live in the community. The definitions for these alternatives originate within the Assessment of Motor and Process Skills and the assessment is made based upon all the information available, both formal and informal following the interview (Fisher, 2010; Nygård et al., 2016). These assessments are used in this thesis only to describe and indicate variations in functional ability between and within groups.

4.4.3.2 Participation in ACTivities and Places OUTside Home questionnaire (ACT-OUT)

This instrument was developed by research teams in three countries (Sweden, Switzerland, and the US) using a transactional perspective to capture how people with dementia participate in places and activities in combination (Margot-Cattin et al., 2019). The fourth version was made available for use in 2016, and with British English terminology in 2017, following a multiphase process that involved expert collaboration and successive rounds of cognitive interviews (Margot-Cattin et al., 2019).

The questionnaire is comprised of three parts, data from all of which are used in sub-study **iii**, whereas data from only part one is used in sub-study **iv**. Part one enquires about 24 places allocated to four domains (see table 4) and asks whether participants a) go there now, b) went

there in the past, c) intend to go there in the future. If the respondent answers ‘no’ to all three options, then that place is determined *not applicable* to the individual. If the response is ‘yes’ to all three options, then that place is identified as a place which is *stable* and if the respondent provides a mix of ‘yes’ and ‘no’ answers, then that place is identified as a place where *change has occurred* (i.e. the person went there in the past, goes there now, but does not anticipate going in future). Part one therefore maps a footprint of participation at a particular point in time and over time. Additionally, respondents can choose to add another place of importance to them that has not already been mentioned (e.g. a school for adult education or picking up grandchildren, an office for volunteering or work). This additional place is included in the counts of places in sub-study **iii**, but not in sub-study **iv**.

Table 4: Place domains A-D listed in part one of the ACT-OUT.

A. Purchasing, administration, and self-care places (n =6)	B. Places for medical care (n =5)	C. Social, spiritual, and cultural places (n =6)	D. Places for recreation and physical activity (n =7)
<ul style="list-style-type: none"> • Small grocery shop • Supermarket, mall, big shop • Small shop • Hairdresser, salon, barbershop • Bank or post office 	<ul style="list-style-type: none"> • Doctor’s office • Hospital or health centre • Dentist’s office • Therapy • Day care 	<ul style="list-style-type: none"> • Friend or family member’s house, • Restaurant, café, bar • Senior centre, social club • Building for worship • Cemetery or memorial place • Entertainment or cultural places 	<ul style="list-style-type: none"> • Garden, backyard • Park, green area, community garden, allotment • Forest, lake, mountains, seaside • Cottage, summer house, chalet • Sports facility • Transportation centre

In part two of the ACT-OUT, respondents are asked to select one place in each of the four domains which is *stable*, and a second where *a change has occurred*. They are then asked a further nine open and four closed (with response alternatives) questions about each place. For example: “what kind of activity do you do there?”, “why do you choose that particular place?”, “how often do you go there; multiple times daily, daily, weekly, monthly, yearly, more seldom?”. Lastly, part three gathers information on a four-point Likert scale about the person’s attitude to risk-taking, life satisfaction, and concern about: getting lost, falling, being stressed when going out, and getting into an embarrassing situation.

4.4.3.3 Demographic questionnaire and Index of Multiple Deprivation (IMD)

The demographic questionnaire was designed to collect information that has been theorised or evidenced as influencing either technology use, or participation outside home, or both. As such, information was collected regarding e.g., a person’s age, self-identified gender,

ethnicity, driving status, education, occupation, health issues/functional impairments, living situation (alone or with another), geographical context (rural or urban), availability of support.

Postcode data was also collected from the group in England which provides access to geographical classification data; urban or rural (Bibby & Brindley, 2013) and IMD data for the small area geography that respondents lived in (Department for Communities and Local Government, 2015). The purpose of the IMD is to rank every small area in England (total 32,482), which each have approximately equal population size, from most deprived to least deprived across seven dimensions of deprivation. These dimensions can each be considered separately (income, employment, health, education, crime, access to services and living environment) and are also weighted and calculated into one composite measure of multiple deprivation. The dimensions push beyond personal poverty to consider the circumstances of all the people living in that small area and support identification of wider, external factors that impact opportunities and resources (Department for Communities and Local Government, 2015).

4.4.3.4 *Montreal Cognitive Assessment (MoCA)*

The MoCA is a ten minute cognitive screening tool administered with participants to describe their cognition at the time of interview (Nasreddine et al., 2005). This tool was chosen for its sensitivity in detecting early cognitive deficits and for its facility in distinguishing differences in cognitive abilities between groups (*people with dementia* and *people with no known cognitive impairment*). The MoCA has repeatedly demonstrated superiority at detecting mild cognitive impairments (in comparison to the Mini-Mental State Exam) and has also been used for investigations of subjective cognitive impairment (Pinto et al., 2019; Yue et al., 2021). Additionally, for sub-study **ii**, the individuals' MoCA scores were used for matching purposes to ensure the cognitive abilities of the comparison group. Based upon investigations of false-positive rates of cognitive impairment using the MoCA, participants were accepted into the comparison group with a minimum score of 23 (Carson, Leach, & Murphy, 2018) together with the clinical judgement of the interviewer. Two participants with scores of 22 and 21 respectively were regarded as fit in conjunction with the clinical judgement of the interviewing occupational therapist.

4.4.4 Interview procedures

Participants in each country were given the option to have the interview in their own home or at another place of their choosing. Interviews were given by registered occupational therapists who were also research professionals, and attention was paid to the flow and focus of the interview and to building trust by optimising the order of the instruments. Instruments are presented in section 4.4.3 according to their importance in the thesis, since to meet requirements for further planned research, instruments varied between each country.

Interviewers were careful to allow respondents to set the pace of interviews and schedule sufficient time to avoid any feeling of pressure or stress. As guided by participants, time was

given to social niceties and cultural aspects of making new acquaintances (i.e. having coffee or tea), appreciating family photos and taking walks to see close-by places that had been discussed.

Altogether, interview tools took a minimum of 90 minutes and a maximum of 3 hours to complete. Timings were flexible, with respondents able to choose to stage the interview over three occasions within a four-week period. The main interview tools had been designed to be completed by people with cognitive impairments, who had also been involved in the development (Margot-Cattin et al., 2019; Nygård et al., 2016). To support participants with feelings of comfort and normalcy a trusted other was also welcome to be present, although not to act as a proxy.

Interviewers maintained an awareness of respondents' potential to become tired and were prepared to support participants to bring sessions to a close. Although the potential was low, there remained a possibility that participants could become distressed by losses highlighted in their responses and so could benefit from interviewers feeding back in a positive light. In the case of more serious issues or support needs coming to the fore, researchers were prepared to signpost the participant to appropriate health, social care or voluntary services (Rosenberg & Nygård, 2014).

4.5 DATA ANALYSIS

4.5.1 Preparatory analysis

An initial step that applied to all studies was to logarithmically transform the ordinal ETUQ raw scores into linear measures (logits) using a Rasch model in WINSTEPS[®] (Linacre, 2016, 2018). Expressed in 0-100 logits, the model simultaneously produces two sets of estimated measures: *challenge measures* for each of the ET items, and measures of *ability to use ET* for each person (Bond & Fox, 2007). The calibrated level of challenge for each ET item, from low to high, was located on a logit scale in relation to the other ETs in the sample. Similarly, each person's ability to use ET, from low to high, had been calibrated and located in relation to the other people in the sample. Furthermore, the logit scales for these two independent measures are common, meaning that the location of each ET item's challenge can be seen relative to each person's ability (Bond & Fox, 2007).

Each respondent's summed total of *relevant* and *used* ETs was collated from their raw ETUQ data to form variables according to the technological groupings of interest for each sub-study (i.e. amount of relevant EICTs; refer to table 5 for more details). These groupings were designed to highlight the conditions surrounding particular types of technology use and their interplay with participation and inclusion. The *total amount of relevant ETs* for each respondent is considered in this thesis as comprising their *Technology Room*. This concept provides insight into those ETs from the landscape that are more permanently at the disposal of each individual (Hagberg, 2008; Hedman, 2015), an example of which is depicted in figure 1b in relation to both the ETUQ and the *Technological Landscape/Environment*. A technology room can also be mapped based upon specific categories (i.e. to comprise an

EICT room), upon the proportion of the room that is *used* and on a group level to compare rooms (i.e. between a group of people with dementia, and a group with no known cognitive impairment).

Variables were drawn from the ACT-OUT data based upon the sum amount of places each participant reported going to - in the past (**iii**), present (**iii, iv**) and future (**iii**) - overall (**iv**) and within the different domains (**iii**) (refer to table 4). In sub-study **iii** the concept of participation could therefore be reflected by all parts of each case's ACT-OUT responses, whereas the concept was constrained by the overall amount of places participants currently went to in sub-study **iv**.

The distribution of all continuous variables was checked for normality using visual inspections (e.g. of boxplots, histograms) and Shapiro Wilks tests ($p < .05$). Although there were instances where the variables appeared to be approximately normally distributed, there were others that appeared skewed. Consequently, distribution free (non-parametric) testing was selected in all instances to prevent any violation of test assumptions related to parametric testing procedures.

4.5.2 Primary analysis

Detailed descriptions of the analytical methods used are given in each sub-study and summarised in table 5.

4.5.3 PPI consultations as part of the process of data analysis

Via their regular meetings, the FODNC consulted on the analytical process for the studies by considering processed data (graphical displays, short vignettes based on examples within the case reports, and written and verbal summaries). This processed data was sent in advance of meetings and had been tailored to suit the abilities and routines of the group (Gove et al., 2018; Tanner, 2012; Waite, Poland, & Charlesworth, 2019). In discussions facilitated by their regular group facilitator, the FODNC contributed their perspectives on the material leading to new theoretical links and insights which enhanced interpretation. Through a back-and-forth process, the group contributed to the positioning of the findings leading to societal implications and recommendations for the *discussion* sections of each paper.

4.5.4 Integration and synthesis

Having used three differently focussed statistical analyses and a case study approach to achieve the overall aim of thesis, it was hoped that integrating the findings would facilitate examination of the completeness and uniqueness of these different facets of topic exploration. The integration of findings for sub-studies **i-iv** was supported by a clear approach to triangulation inspired by given guidelines (Bazeley, 2018; Farmer, Robinson, Elliott, & Eyles, 2006). Even across multiple quantitative (in addition to qualitative) methods, such an approach has been shown to have utility in identifying how the findings agree or extend from one another (convergence and complementarity), while also identifying points of dissonance and disagreement (contradiction) (O'Cathain, Murphy, & Nicholl, 2010). Engaging in this

Table 5: Summary of the variables/data used, the analytical methods and their purpose, evaluation criteria and software used in each of the sub-studies (i-iv)

Sub-study	Variables/data	Method/test	Purpose	Evaluation criteria	Software
i	Rasch generated ET challenge hierarchy ($n=88$ ET items). Rasch generated measures of Ability to use ET ($n=315$). Proportion of each sub-group who reported an item relevant.	Differential Items Functioning (DIF) (Bond & Fox, 2007) Differential Test Functioning (DTF) Pearson χ^2	To identify DIF in the challenge of public space ETs ($n=16$) and EICTs ($n=41$) between countries and diagnoses. To identify the impact of DIF on the person ability measures. To compare the relevance of DIF displaying items by country/diagnosis.	Adjusted significance level of $p < .01$ for Welch t -test and Mantel χ^2 statistics. No more than 5% of items to display evidence of DIF. No more than 5% of ability measures to exceed $z > \pm 1.96$. Significance level $p < .05$.	WINSTEPS® (Linacre, 2017) Microsoft Excel. SPSS Statistics for Windows, version 26 (IBM Corporation, 2019)
ii	Ability to use ET ($n=69$) EICT challenge hierarchy ($n=31$) Median amount of EICTs relevant Median amount of EICTs used	Mann-Whitney comparison Test with effect size (Cohen's d) Spearman's rank correlation analyses (r_s) and 95% confidence interval (CI). Fisher's r -to- Z transformation and Steiger's Z (Silver & Dunlap, 1987; Steiger, 1980)	To compare the median amounts of relevant and used EICT, and ability to ET between the groups (with and without dementia) To investigate the associations between relevant and used EICT, and ability to ET. To compare significance of the magnitude of the differences in these relationships between groups.	Significance level $p < .05$. (< 0.2), Cohen's d : effect size small ($\geq 0.2 < 0.5$), medium ($\geq 0.5 < 0.8$), or large (≥ 0.8) (Cohen, 1988). Cohen's (r) for the magnitude of the association ($0.1-0.3 =$ small, $0.3-0.5 =$ medium, and $0.5-1.0 =$ large). 95% confidence intervals. Significance level $p < .05$. q -effect sizes, evaluated using the same criteria as d (Cohen, 1988)	WINSTEPS® (Linacre, 2017) BM SPSS Statistics for Windows, version 25 (IBM Corporation, 2019) Non parametric effect sizes and CIs (Lenhard & Lenhard, 2014, 2016) Fisher's r -to- Z transformation and Steiger's Z calculators (B. Weiss, 2010)
iii	All available data from instruments including comments observations, fieldnotes, memos, annotated maps, secondary situational data (i.e. bus timetables)	Multiple case study. Within and cross-case analysis (Stake, 2006; Yin, 2003) Assemblage theory (DeLanda, 2006)	To illuminate the rural context and consider the particularity and analytical generalisability of the interplay between everyday technologies and everyday life situations.	Compiling 26 within-case technological interactions. Preliminary PPI analysis. Evaluated for utility against the research question. Cross-case analysis identified five themes. Interrogated with other researchers. Merged in two sections.	NVIVO12 and by hand (QSR International, 2018)
iv	25th, 50th, and 75th percentile of total places respondents were going to ($n=128$). Amount of relevant out of home ETs. Amount of relevant total ETs. Ability to use ET. Demographic.	Unconditional binary logistic regression model (DeCoster, Gallucci, & Iselin, 2011; Hosmer & Lemeshow, 2004; Kuo, Duan, & Grady, 2018)	To explore the association between ETs and participation outside home among people with and without dementia in rural and urban contexts.	Significance threshold of $p < 0.25$ for β coefficient in the univariate analysis. Backwards block procedure $p < 0.25$ for inclusion in the model, and $p > 0.05$ for exclusion.	WINSTEPS® (Linacre, 2017) IBM SPSS Statistics for Windows, version 26 (IBM Corporation, 2019)

approach may potentially enhance the validity of the four sub-studies by bringing forward a more comprehensive view. Consequently, the aim of the triangulation was to illuminate the conditions, particularly different country and geographical contexts, of ET use and ET challenge and their interplay with participation and inclusion in everyday life, both in and outside the home, for older adults living with and without mild stage dementia. A fifth research question was formulated to support this integration of the thesis findings: What conditions of ET use were found to interplay with participation and inclusion in everyday life across the four studies, and in what ways?

The approach to triangulation treated the individual sub-study *findings* sections as equally weighted source data which were sorted and coded in NVivo 12 according to the integrated RQ (QSR International, 2018). The codes supported identification of a set of themes that applied to each individual sub-study. Each individual theme was then compared and contrasted pairwise (i.e. i:ii, i:iii, i:iv etc) for its a) *prominence* and b) *exemplifications* across all four sub-studies in a convergence matrix. The purpose of the comparisons was to consider levels of pairwise agreement, silence, or dissonance for each theme. To fully agree, both studies must equally weight the theme for both a) *prominence* **and** b) *exemplifications*, whereas partial agreement only requires equal weighting on a) **or** b). Silence indicated that the theme was present in one sub-study, but not another. Dissonance could only be allocated where there was a legitimate and direct contradiction that was not a consequence of differences in the nature and focus of the sub-studies (Bazeley, 2018). Lastly, themes that were present in only one sub-study were not considered any less significant for their contributions to the RQ, although they were not comparable in the convergence matrix. Comparisons included an assessment of completeness which involved considering the scope and coverage of each theme and becoming more aware of limitations (Farmer et al., 2006). Finally, descriptions of each theme were produced to merge the findings in a unified rather than additive figure (Bazeley, 2018).

5 RESULTS

The results of each paper in turn are briefly presented before focussing on the triangulation of the findings across papers which includes further details of the statistical and case study evidence.

5.1 VARIATION IN ET CHALLENGE BY COUNTRY (BETWEEN SWEDEN, USA AND ENGLAND) AND BY DIAGNOSIS (WITH OR WITHOUT DEMENTIA) (I)

In sub-study **i**, nine of 88 total ETs (10.2%) were shown to be statistically more or less challenging (displayed evidence of DIF) according to the country participants lived in, which exceeded the allowable 5%. Five of these ETs were concentrated within the 16 public space ETs (31.3%): ATM, automatic ticket barriers, self-check-in, baggage drop-off, petrol/gas pump. The direction of the DIF varied to indicate there was no difference in the challenge of these public space ETs to expressly favour of one country group over another. No DIF displaying ETs were among the 41 EICTs (0%). Refer to table 8 in section 5.6.

Three of the 88 total ETs (3.4%) showed significant DIF by diagnosis, which was within the allowable 5%. All were within the 41 EICTs (7.3%) located at the upper end of the challenge hierarchy with a consistent direction of DIF. This DIF indicated these three EICTs on the computer were significantly more challenging for the group with dementia: searching the internet, word processing, internet banking. Refer to fig. 5 in section 5.5.

There was no evident impact to the person measures of ability to use ET attributable by item DIF due to country or diagnosis in the DTF analysis since the z -scores of the standard errors did not exceed ± 1.96 . This indicates a) that the measures of ability to use ET are stable, b) the suitability of the ETUQ for use in these three countries and c) reconfirms suitability for use among older adults with and without dementia.

5.2 EICT RELEVANCE, USE AND ABILITY TO USE ET IN SWEDEN (II)

Findings for sub-study **ii** showed statistically significant lower amounts of relevant (median = 7) and used (median = 5) EICTs (maximum 31), and lower ability to use ET (median = 53.24 logits) among the group with dementia compared to the group with no known cognitive impairment (median relevant EICTs = 11, $p < .05$, $d = 0.64$, median used EICTs = 10.5, $p < .001$, $d = 0.93$, median ability to use ET = 60.71 logits, $p < .001$, $d = 1.85$). Refer to table 7 in section 5.5.

Additionally, a statistically significant medium-large relationship between relevant amounts of EICT and ability to use ET was evident for the group with dementia ($r_s = 0.587$, 95% CI [.315, .770], $q < .01$) while no such relationship was evident for the group with no known cognitive impairment ($r_s = .026$, 95%CI [-.315, .361], $p > .05$). These relationships were compared between the two groups and found to be statistically significantly different (Fisher $Z = 2.568$, $q = .647$, $p < .05$).

The Rasch analysis of the raw ETUQ scores generated challenge measures for the 21 EICTs (max. 31) that had responses from at least 10 participants. The ten missing scores related to smartphone and tablet functions which indicated low relevance of these devices to both groups of older adults. A floor effect invalidated the challenge measure for messaging/ emailing on a smartphone as all participants reported no difficulties in using this function. The landline telephone was perceived by the whole sample as having the lowest level of challenge (39.90 logits) and searching for information on a tablet received the highest (56.30 logits). Refer to fig. 5 in section 5.5.

5.3 ILLUMINATING RURALLY CONTEXTUALISED INTERACTIONS WITH ET IN ENGLAND (III)

Findings of sub-study **iii** highlighted cases' reactions and responses to rurally contextualised interactions that involved EICTs, driving and parking technologies, shopping, banking and payment technologies.

Illuminated in these technological interactions was the interplay with wider aspects of rural everyday life. These aspects implicated staff and customers in shops, nearby neighbours and isolated dwellings, significant others both co-habiting and at a distance, telecommunications and transportation infrastructures and options, policies and local service providers.

These interacting factors, including technologies, could be seen to have variously stabilising and destabilising consequences to everyday life. Cases' reactions and responses to their everyday situations were seen to involve processes of technologising and manualising in order to stabilise their everyday lives and mitigate destabilising threats.

5.4 ASSOCIATIONS BETWEEN PLACES AND TECHNOLOGIES OUTSIDE HOME IN ENGLAND (IV)

Within the six regression models of sub-study **iv**, the amount of relevant out of home ETs (max. 49) and relative level of neighbourhood deprivation were most persistently associated with the amount of places people went to (refer to table 6). Reporting fewer relevant out of home ETs increased the odds of going to least places (less than 13) by a factor of 1.802 for every five ETs. These odds decreased to 1.560 when the outcome of places was split at the median (16.5). For each decrease in deprivation decile (indicating a higher relative level of deprivation) the odds of going to least places increased by a factor of 1.283, a ratio which also decreased at the median split to 1.195.

Associations were found with ability to use ET only when investigating the upper quartile, where the odds of going to most places (more than 18) increased by a factor of 2.154 for a 4.41 logit higher ability measure (the median difference between the four groups). Refer to table 6.

Associations with diagnosis and education were more tentative as these were only evident when the overall amount of relevant ETs (max. 90) was entered into the model and not found to associate with the amount of places. This indicated that domestic ETs appeared to have no

influence or relationship to the amount of places. No association was apparent with rurality in any model. All models had low potential to explain the proportion of variation in the outcome variable (< 24%) according to evaluation of the Nagelkerke R^2 . The model made at the 25th percentile of least places had the greatest classification accuracy with the specificity high being high (98.1%), but sensitivity was low (18.2%) (refer to table 6).

Table 6: Binary logistic regression results for the models including the amount of Relevant Out of Home ETs (maximum 45). Outcome split at going to least places (<13, 25th percentile), median places (16.5, 50th percentile) and most places (\geq 18, 75th percentile), identified using the ACT-OUT.

	Least places (<13, 25%ile)		Median places (16.5, 50%ile)		Most places (\geq 18, 75%ile)	
	OR, <i>p</i>	95% CI	OR, <i>p</i>	95% CI	OR, <i>p</i>	95% CI
Decile of deprivation	1.283, .023	1.035-1.590	1.195, .025	1.022-1.396		
Amount of relevant out of home ETs*	1.125, .002	1.042-1.213	1.093, <.001	1.040 1.148	NS	-
Perceived ability to use ET [#]	NS	-	NS	-	1.190, .005	1.054-1.344
<i>Omnibus test</i>	$\chi^2 = 19.213, df = 2, p < .001$		$\chi^2 = 20.313, df = 2, p < .001$		$\chi^2 = 9.840, df = 1, p < .01$	
<i>Nagelkerke R²</i>	0.232		0.196		0.113	
<i>Hosmer & Lemeshow Test</i>	$\chi^2 = 4.666, df = 8, p = .793$		$\chi^2 = 4.295, df = 8, p = .830$		$\chi^2 = 9.659, df = 8, p = .290$	
<i>Classification Accuracy</i>	84.4%		69.5%		76.6%	

NS. Non-significant

* OR/CI is shown for a difference of 5 relevant ETs as indicating a more meaningful contrast in amounts between participants.

OR/CI is shown for the median difference in ET ability of 4.41 logits between participants in the lowest and highest quartile of places (refer to table 9 in section 5.7.1 and table 10 in section 5.7.2).

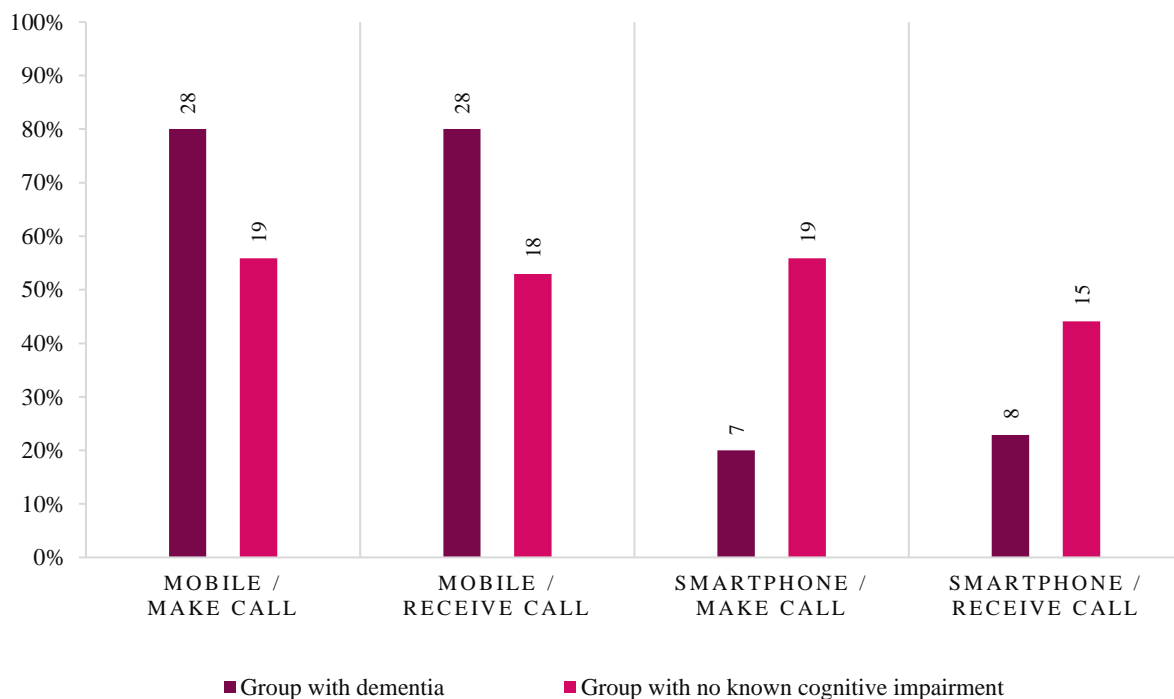
5.5 DEMENTIA AS A CONDITION OF ET USE

Three sub-studies contributed to this theme highlighting dementia as a condition of ET use in varying ways (**i-iii**). In the pairwise comparisons for the convergence assessment, these three studies were deemed to partially agree since they were imbalanced regarding the prominence and meaning of this theme. Dementia was much more clearly in focus in sub-studies **i** and **ii**, while more part of the contextual fabric of sub-study **iii**. Similarly, the exemplifications partially agreed and revealed varying and complementary facets of dementia as a condition of ET use, adding to the completeness of this theme. Instances of silence occurred in pairwise comparisons with sub-study **iv**, where sub-study **iv** was not designed to investigate this theme.

In general, the DIF analysis by diagnosis in sub-study **i** found that the challenge of ETs was perceived as largely consistent among older adults, since the proportion of technologies

displaying evidence of DIF (three of $n = 88$, 3.4%) were within the allowable 5%. This provides no evidence that having a diagnosis of mild stage dementia is a condition which impacts the relative challenge level of ETs (i). This indicates that the 90+ ETs of the ETUQ are not systematically biased so as to measure the perceived abilities to use ET of people with and without dementia differently resulting in a reordering of the ET challenge hierarchy. Furthermore, the DTF analysis indicated no impact to the ability measures as a consequence of the three DIF displaying EICTs, since no z -score of each person measure's standard error exceeded ± 1.96 (i). This finding complemented the stability of the EICT challenge hierarchy presented in sub-study ii, which also showed a discrepancy in the group comparison between the pushbutton mobile phone and smartphone. The mobile was relevant and used by a higher proportion of participants with dementia, whereas the smartphone was relevant and used by a higher proportion of the comparison group (refer to figure 4) (ii).

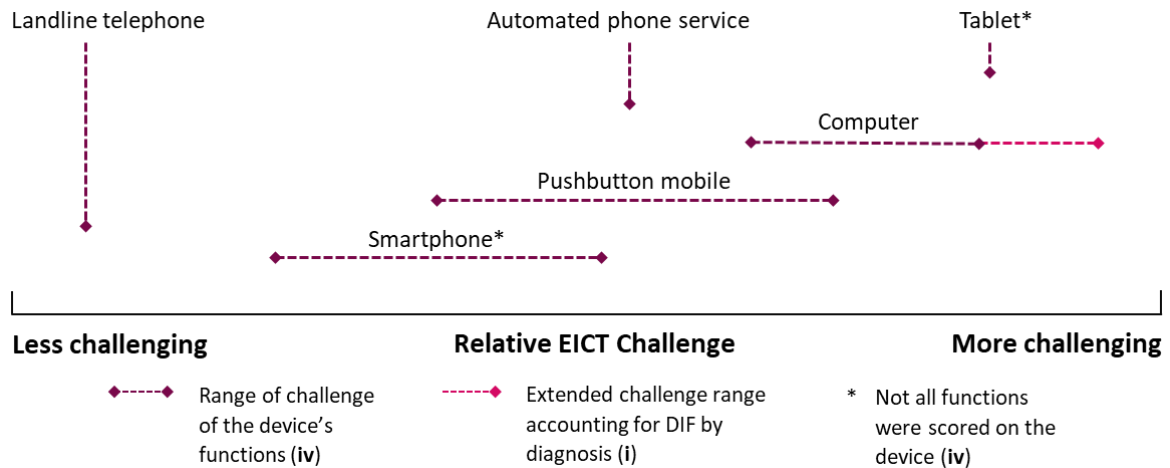
Figure 4: Proportional bar chart showing the relevance of the smartphone and pushbutton mobile phone for making and receiving a call to the sub-groups of participants with and without dementia in Sweden (ii).



Despite the variation in relevance and use of smartphones and pushbutton mobiles in the nested sub-sample of people with and without dementia (ii) (refer to fig. 4), the ET challenge hierarchy was shown to be stable with respect to these devices in the larger sample (i) (refer to fig. 5). This combined result of ET challenge from sub-studies i and ii indicates that the findings enhance and strengthen one another. It also therefore enhances the indication that a diagnosis of dementia alone is an insufficient condition for promoting use of a pushbutton

mobile phone over a smartphone. This is because the challenge is shown to be at least comparable between the two devices, with some functions posing less challenge when housed on a smartphone (i.e. alarm and camera) **(ii)** (refer to fig. 5).

Fig. 5: Illustration approximating the relative challenge, and the spread of the challenge of EICT functions on each device from less to more challenging investigated in sub-studies **i** and **ii**.



The minimal bias that was found in the DIF analysis to impact the challenge of three EICTs (computer; word processing, information searching and internet banking), indicated no disordering of the hierarchy of ET challenge. Instead, these EICTs that were already in the upper reaches of challenge, were perceived to be disproportionately, even more challenging by the group with dementia than those without **(i)**. This was despite the median ability to use ET of the group with dementia being statistically significantly lower (median difference = 5.38 logits, $U=1536.5$, $p<0.001$), refer to table 7 **(i)**. It can be considered therefore, that dementia provides a condition for the scale of ET challenge to be stretched at the upper extremity where these DIF displaying computer functions are contained **(i)**. Equally, however, no substantiation is provided to suggest that any other ETs are disproportionately more challenging to use on the condition of having a diagnosis of dementia **(i)**.

Table 7 collects together the differences that were identified in the nested samples, identifying significantly lower median ability to use ET **(i, ii)**, amount of relevant and used EICTs **(i, ii)** and public space ETs **(i)** between people with dementia in comparison to those with no known cognitive impairment. The same table 7 shows that the median findings in relation to ET ability, EICT and public space ET relevance and use among people with dementia were broadly matched by those of the nested case study sample **(iii)** where participants highlighted specific cognitive deficits attributable to dementia (i.e. memory problems, executive functioning, orientation) in relation to technology use (i.e. remembering

Table 7: Median and interquartile ranges for the measures of 'Ability to use ET', perceived amount of 'EICTs relevant', and sub-amount of relevant 'EICTs used' of people with dementia in the three sub-studies.

	i (n=99)	ii (n=35)	iii (n=10)
Ability to use ET (logits) M (IQR, MD with CG)	50.83 (5.23, -5.38 ^{***})	53.27 (7.14, -7.47 ^{***})	49.01 (1.75)
	(N=41)	(N=31)	(N=40)
EICTs relevant[#] M (IQR, MD with CG)	13 (7, -5 [^])	7 (7, -4 [*])	13.5 (8.5)
EICTs used[#] M (IQR, MD with CG)	8 (7, -9 [^])	5 (7, -5.5 ^{***})	6 (4.25)
Computer word processing n (% , PD with CG)	40 (41.4%, -27.2% ^{***})	9 (25.7%, -36.1% [^])	4
Computer web searching n (% , PD with CG)	48 (48.5%, -26.0% ^{***})	17 (48.6%, -22.0% [^])	5
Computer internet banking n (% , PD with CG)	28 (28.3%, -25.6% ^{***})	15 (42.9%, -13.0% [^])	2
Public space ETs relevant M (IQR, MD with CG)	8 (4, -2 [^])	-	6 (2.5)
Public space ETs used M (IQR, MD with CG)	6 (5, -3 [^])	-	3.5 (3.25)

[#]The maximum amounts of ET designated as EICTs are unequal between sub-studies.

M = median, IQR = interquartile range, MD = median difference, CG = comparison group, PD = Proportional difference.

^{***} = significant at $p < .001$, ^{*} = significant at $p < .05$, [^] = difference not tested for significance.

a PIN, navigating web search functions, remaining within timed parking restrictions) (**iii**). Additionally, study **ii** found a significantly large, positive relationship between perceived ability to use ET and the amount of EICTs relevant in the group with dementia ($r_s = 0.587$, 95% CI [0.315, 0.770], $p < .01$), but no relationship between these variables in the group with no known cognitive impairment ($r_s = 0.026$, 95%CI [-0.315, 0.361], $p > .05$) (**ii**). The case study enhances a view on this relationship between the size of the technology room and the perceived abilities of people with dementia. Cases highlighted that the acquisition and use of EICT often needed to be imaginable with respect to their ability along with a number of other considerations (i.e. value for money, or the desires of others) (**iii**). Additionally, among cases who considered themselves to be engaged in a pattern of manualising (i.e. moving from technological to non-technological options e.g. banking), ETs were deemed irrelevant and ejected from the technology room (**iii**). However, low relevance seems to not only occur among groups of people with dementia, since challenge measures could not be produced for all EICTs in sub-study **ii** due to low relevance of particularly smartphone and tablet functions among both groups.

Taken together, albeit with caution relating to the sample nesting, these findings complement one another to indicate that while dementia does not unduly impact the perceived relative challenge of ET, it may lead to conditions that result in lower relevance and use of particularly EICTs and public space ETs, and an overall pattern of manualising (**i**, **ii**, **iii**). This is in addition to an expectation that the cognitive impairments attendant with dementia have an impact that results in lower average abilities to use ET when comparing groups (**i**, **ii**, **iii**).

5.6 NATIONAL OR GEOGRAPHICAL, PUBLIC, AND HOME CONTEXT AS A CONDITION OF ET USE

Two sub-studies explicitly aimed to give equally high prominence to the context of ET use and challenge and also provided agreement in the high prevalence of this theme (i, iii). Each sub-study, however, was designed to address different aspects of context: national (i) and geographic (iii) so the exemplifications of this theme are silent between the studies. While sub-studies ii and iv were undertaken specifically in Sweden and England, the analyses were not designed to investigate these national contexts for their specific influence on the findings. Consequently, although relevant aspects of each national context are discussed with respect to their possible influence on the respective findings, the findings of these two sub-studies per se are regarded as silent on this theme.

The results of the DIF analysis by country exceeded the allowable 5% (10.2%, 5 of $n=88$) to illuminate that variation in the level of challenge was concentrated solely within the category of public space ETs (31.3% of 16 public space ETs) (i). However, these DIF-displaying ETs were shown to have no impact on the person ability measures between countries in the DTF analysis and given that 89.8% of ETs showed no evidence of DIF, this indicates that the challenge of ETs generally is mostly stable between countries (i).

In addition to the variation in challenge of five public space ETs, there were differences and similarities in how relevant each of these ETs were to participants within the country sub-groups. While there was more evidence of bias in the sub-group country comparisons with Sweden, rather than between the US and England, the direction of this bias was not always consistent (see table 8).

Table 8: Comparisons of contrasts in DIF and proportional relevance according to each country sub-group (i) juxtaposed with the differences between the national and nested rural sample, who all have dementia (iii). (For a graphical display of the proportional difference, refer to figure 6 below.)

Item	DIF contrast		DIF (logits)*	Relevance contrast		Proportional difference^	
	Easier	Harder		Less	More		
Automatic ticket gate	Swe	Eng	5.86	US	Swe	25%	
				Eng		27%	
Self-check-in kiosk	US	Swe	6.14			NS	
	Eng		5.59				
Baggage drop-off	US	Swe	9.26			NS	
Cash machine/ATM	Swe	US	6.39	US	Swe	26%	
		Eng	5.87		Eng	28%	
Petrol/gas pump	US	Swe	5.56	Swe	US	36%	
						Eng	32%
					Eng	Eng rural	40%~

* Differences tested using Welch t -statistic, Mantel Chi Square, with adjusted significance set to $p < .01$.

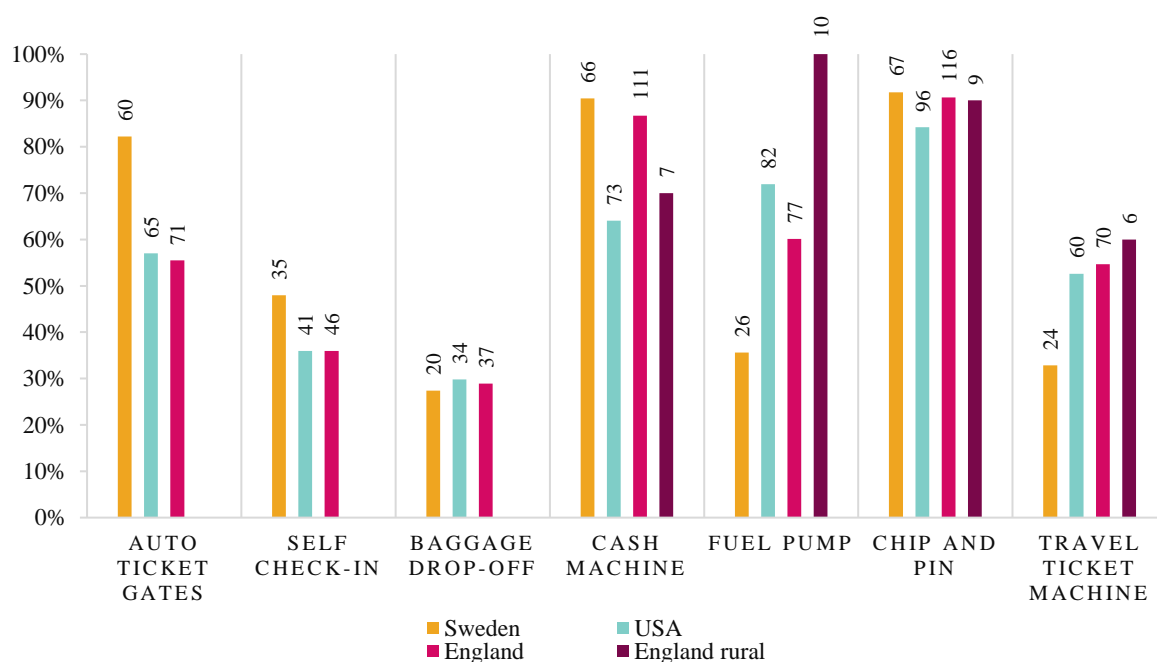
^ Pearson Chi Square, significant at $p < .001$. Sweden ($n=73$), US ($n=114$), England ($n=128$).

~ Differences tested using Fisher's Exact Test after removing the nesting (England $n=118$, England rural $n=10$), significant at $p < .01$.

NS No statistically significant difference found between the groups.

The final row of table 8 provides a comparison between the England sample ($n = 118$, nested case study sample removed) and the rural sample of people with dementia from the case study ($n = 10$). Recalling that lower relevance of ET is typical among people with dementia, the stark additional relevance of the petrol pump (+48%) in the rural context is brought to the fore (refer to table 8 and figure 6). Within the case study, a dearth of suitable public transport was a consequence of living in a rural context culminating in the need to drive or be driven, which led all 10 cases to describe their interactions with driving-related technologies (i.e. petrol pumps and parking ticket machines). Even after some cases had stopped driving, they continued to use the petrol pump (albeit often manualised) as part of a shared responsibility for transportation which reasoned this technology’s ongoing relevance rurally (iii).

Figure 6: Proportional bar chart showing the relevance of public space technologies according to each country sub-group (i) juxtaposed with the nested rural sample, who all have dementia (iii). (For statistical significance of the differences refer to table 8 above.)



The sparsity of rural contexts was also highlighted as shaping policy and service decisions that altered access to financial services (i.e. closure of banks and post offices) and to reliable and efficient telecommunications services and maintenance (iii). Such rural shaping altered cases’ access to and use of payment technologies leading cases to use chip and PIN devices ostensibly as replacement cash machines and banks (iii). Additionally, the use of communication devices (i.e. mobile or smartphones, and even home computers) could be demotivated among cases where rural sparsity and isolation created conditions that meant connection could not be guaranteed either within or outside home (iii). Rural barriers of

distances and transportation to shops and services could facilitate internet-based ICT use (i.e. for gathering information, shopping and banking) provided telecommunications services were unimpeded and free from maintenance demands (iii). Finally, the stereotype of an intimate rural life where everyone knows everyone else's business was seen to motivate opposite responses in two cases. One case, Elsie, welcomed this aspect of community so that use of ICT was both facilitated and negated by neighbours who would help her if she needed (i.e. they could hear her calling for help, or use her mobile phone on her behalf). John however, spoke of internalised stigma, relaying that he did not want people he knew to see him struggling in public, which motivated him to move his out of home activities indoors and onto ICTs (iii).

Together the results lead a to more complete perspective of how stability and variations in ET use and challenge are motivated in different national and geographic contexts. While the challenge of ET may be broadly stable between the three national contexts (i), the cases describe infrastructural conditions, particularly around ICT use, that could reasonably impact and increase the challenge level in sparse rural contexts (iii). So, a lack of within-country variability in challenge is not assured. While the stability and variation in cross-national challenge and relevance of ETs can be identified in the analysis of sub-study i it cannot be explained by sub-study i's results. The case study offers possible pragmatic explanations, since the geographic context of rurality was shown to be shaped by policy and infrastructure, which are driven not only locally, but nationally (iii). At the national level then, contexts are created that lead to localised differences in how spaces are technologically constituted, designed and interacted with, both within and outside home so as to impact the relevance, and more rarely impact the challenge of ETs (i, iii).

5.7 INTERPLAY OF CONDITIONS WITH PARTICIPATION

Sub-study iii dominantly contributes to this theme with sub-study iv in partial agreement both with respect to the prominence of the theme and examples provided. In sub-study iv, participation is indicated by the quartile amount of overall places that respondents reported currently going to in the ACT-OUT. The direction of influence was pre-assumed to explore the influence of factors, including technology use, upon participation. Sub-study iii takes a broader, more contextualised view of how the components of each case's everyday life assemblage interacted with participation in different directions to produce de/-stabilising effects. While sub-studies i and ii centralise discussion of the how findings regarding technological conditions may interplay with participation and inclusion, the methods preclude the findings themselves from directly contributing to this theme. The presentation of this theme is given according to the quartiles of participation identified in sub-study iv juxtaposed with findings from the case studies whose footprint of places corresponded with each quartile.

5.7.1 Indicators and interplay motivating least participation in places

The regression model that explained the highest proportion of variance ($R^2=23.2\%$) with highest classification accuracy (84.4%) was based upon exploration of participants going to the 25th percentile of least amount of places (<13 places, $n =22$) (iv). Within this model, two factors were associated with significantly increased odds of going to least places. These factors were; reporting a lower amount of relevant out of home ETs, which increased the odds by a factor of between 1.228-2.626 (95% CI) for every five ETs; and a higher relative decile of deprivation, which increased the odds by a factor between 1.035-1.590 for each decile (iv).

Through the cases, sub-study iii illuminates how technological and non-technological factors/components interacted in different directions to produce de-/stabilising effects on participation. Furthermore, this study utilised the cases' changing footprint of places over time to provide an indication of the overall current and future stability of their life space (refer to fig. 7).

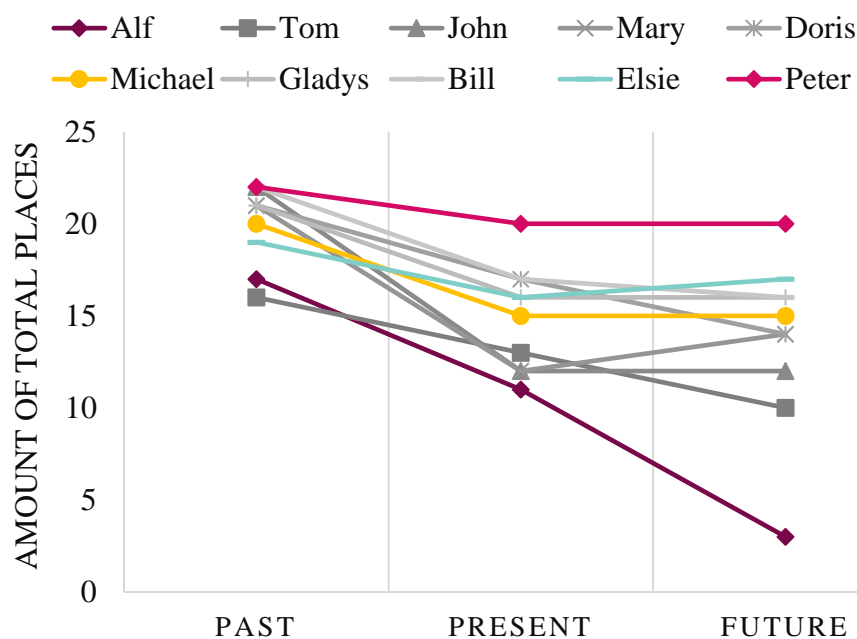
Table 9: Joint display of the characteristics of participants from sub-studies iii and iv whose level of participation fell within the lowest quartile of places frequented ($n <13$).

Factors/ components	Findings from sub-study iv England ($n = 22$) Median (IQR) or Total (%)	Cases from sub-study iii		
		Alf	John	Mary
Amount of places	11 (3)	11	12	12
Out of home ET relevant	15 (7.5)	4	28	12
In home ET relevant	22 (5)	18	21	20
Ability to use ET (logits)	49.47 (4.57)	49.4	49.07	44.81
MoCA score	22 (5.5)	14	16	15
Sparse rural setting	1 (4.6)	Yes	No	No
Driving	8 (36.4)	Yes	No	No
IMD decile	4.5 (3)	5	4	10
Environment decile	4.5 (4)	1	4	8
Barriers to services decile	3 (4.75)	1	9	5
Living alone	10 (45.5)	Yes	No	Yes

Within the case study (iii), the reciprocal nature of these interactions between participation in places, relevant out of home ETs, facets of relative deprivation and other components became clearer. The main case, Alf, (refer to table 9) illustrated how barriers to services (in the form of restricted access and long distances) combined with looming driving cessation to threaten the stability of his pattern of places (anticipated to reduce from the current 11, to only 3, refer

to figure 7) (iii). Restricted access to telecommunications services combined with environmental deprivation (poor insulation, open fire, unmanageable and unavoidable maintenance) to hamper his technology room keeping it small and low tech. These conditions were, in part, a product of housing policy and service decisions i.e. not upgrading to central heating and keeping adjacent properties untenanted. The interplay of these conditions impacted Alf's participation, compounding his sense of growing social isolation, and threatening the tenability of his living situation. His vision of participation was becoming more restricted and homebound, which in turn increased his reliance on EICTs, where problems were ongoing despite receipt of service assistance. Alf was motivated by wanting to cause as little trouble to loved ones as possible and to show recognition of, and reciprocate, the care and attention shown to him. Consequently, Alf was considering accepting a loved one's suggestion to get a computer, despite having no desire for one and no vision of himself being able to use one. Furthermore, in addition to suspecting it would not solve his communication issues, he worried it may even create friction in their newly re-established relationship.

Figure 7: Chart showing the footprint of places across all clusters from past, to present, to future for each case.



This short summary of Alf's participation (iii) illuminates the complexity of the interplay between a relatively more deprived neighbourhood, a smaller technology room and smaller footprint of places seen in the regression model (iv). The summary points to multiple interacting factors and highlights how the impact of such interactions can motivate enough precarity in everyday life to impel Alf to ultimately relocate. Such complexity also provides

potential reasons for the low sensitivity (18.2%) of the regression model (iv), as Alf's everyday life and relatively small pattern of places is revealed as particular to his participatory circumstances (iii). These circumstances go far beyond the composite of out of home technologies and neighbourhood deprivation (iii-iv).

5.7.2 Indicators and interplay motivating most participation in places

At the opposite end of the participation indicator, going to most (≥ 18) places was explained only by having a higher ability to use ET in a regression model which explained 11.3% of variance with 76.6% classification accuracy (iv). In this instance, having a significantly higher ability to use ET increased the odds of going to most places by a factor of between 1.261-3.683 (95% CI) (iv).

The cross-case analysis involving particularly Peter, additionally illuminates how high abilities to use technology can be connected to an almost full footprint of participation (refer to figure 7), with his reduction in places only connected to the medical care cluster (iii). Peter was also among other cases whose technology rooms were dominated by ETs connected to previous working identity on a continuum with current interests (in his case, maintenance and repair ETs). These technologically connected interests were shared with others and motivated Peter to participate in a wide range of places in his everyday life, many of which were within an easy walking distance. This more comprehensive picture revealed a tight and comfortable interplay between not only his higher ability to use ET and his more extensive participation in places but wider technological and non-technological aspects of participation (see table 10).

Table 10: Joint display of the characteristics of participants from sub-studies iii and iv whose level of participation fell within the highest quartile of places frequented ($n \geq 18$).

Factors/ components	Findings from sub-study iv England ($n = 22$) Median (IQR) or Total (%)	Cases from sub-study iii Peter
Amount of places	20 (1.5)	20
Out of home ET relevant	23 (15.5)	14
In home ET relevant	25 (6.5)	18
Ability to use ET (logits)	53.88 (4.32)	52.52
MoCA score	25 (7)	20
Rural setting (not sparse)	4 (13.8)	No
Not Driving	7 (24.1)	Yes
IMD decile	7 (5)	8
Environment decile	4 (5)	6
Barriers to services decile	6 (5)	8
Co-habiting	19 (65.5)	Yes

Peter highlighted how technological participation in places and activities could also be facilitated by a co-habitant. Someone to whom technology use could be delegated or struggled through together (inputting bowling scores on the computer). But also, someone willing to divide and share a task (his wife drives while he pumps fuel and pays with cash at the staffed kiosk) and to reciprocally appreciate and value the successful co-fulfilment of these aspects of everyday life (iii). Peter's case highlights how collaboration in technology provides an additional resource that enhances both his ability to use ET and his wider participation. Other cases similarly illuminated how the willingness and role of others in society could motivate their use of chip and PIN devices to access cash. Here, the layout of the till area and the often-tacit security and assistance that staff offered were not only implicated in the technological interaction, but also in facilitating financial services participation against a backdrop of bank closures (iii).

The wider conditions that Peter's case (iii) highlights as interplaying with his participation illuminates the complexity of the interplay between ability to use ET and the range of places a person frequents (iv). Peter adds interacting factors of previous working life, an environment that facilitates localised participation in his interests, enjoying wide interests that he shares with others, and having a supportive collaborator in ET use. These interacting factors are particular to Peter's everyday life assemblage while providing reasonable motivations for higher participation that others may also share (iii). The low sensitivity and explanation of variance of this regression model similarly point towards a widely varying picture of conditions that motivate higher participation in places beyond a person's ability to use ET (iv).

5.7.3 Indicators and interplay motivating the middle ground of participation

At the median amount of places (16.5), the odds associated with the amount of relevant out of home ETs was significant (1.217-1.994 CI) in a model that explained 19.6% of the variance with 69.5% classification accuracy. If the overall amount of relevant ETs was put into the model instead, then ET was not significant, but a diagnosis of dementia emerged as increasing the odds of going to less places by a factor of between 1.211 and 5.666 (iv). This indicates that dementia itself can become a condition motivating below average participation in places particularly when the amount of relevant out of home ETs, which was found in these models to have a more influential interplay, is not considered. Explanation for this somewhat contradictory picture of participation may be offered by two contrasting cases of the four whose level of participation fell within the second quartile (iii) (refer to table 11).

Within this lower middle ground of participation investigated in the regression models (iv) is Elsie (iii), who highlighted how ETs were of little consequence to her everyday life outside home (refer to table 11). Instead, Elsie highlighted that her ways of participating in place were motivated by human connection and doing for others (e.g. supporting local shopkeepers, choosing medical appointment times, and keeping tidy grounds). This inconsequentiality of ET was further heightened by her close-knit village location meaning there was never a need to telephone for help since a neighbour would always be able to hear her calling. As a

Table 11: Joint display of the characteristics of participants from sub-studies **iii** and **iv** whose level of participation was distributed below the median places frequented ($n < 16.5$).

Factors/ components	Findings from sub-study iv England ($n = 42$) Median (IQR) or Total (%)	Cases from sub-study iii			
		Michael	Gladys	Elsie	Tom
Going to <16.5 places	15 (3)	15	16	16	13
Out of home ET relevant	20 (11)	28	16	4	8
In home ET relevant	22 (1.25)	21	23	19	16
Ability to use ET (logits)	51.63 (2.43)	50.83	45.83	48.49	45.51
MoCA score	23 (6.25)	21	15	12	18
Sparse rural setting	3 (7.2)	No	Yes	Yes	Yes
Driving	21 (50)	Yes	Yes	No	No
IMD decile	5.5 (4)	7	5	9	5
Environment decile	4 (3)	2	3	3	1
Barriers to services decile	3.5 (5.5)	1	3	3	1
Living alone	18 (42.9)	Yes	Yes	Yes	No

counterpoint, technology was highly consequential to Michael's (**iii**) choice of places and interactions within the same lower middle ground of participation investigated in the regression model (**iv**) (refer to table 11). He generally chose places that offered his preference to interact with the visual display afforded by technologies, as this design feature offered him greater control and feedback to see what he was buying and spending. However, Michael's regular shopping was contingent upon interaction with a surveillance parking technology, which set time limits but offered no feedback about when to depart. This interaction was consequential in a disruptive way that led to uncompleted shopping and repeated trips to avoid becoming unaware of time and risking a penalty fee.

These apparent contradictions in the relations between technological and non-technological participation in the case study (**iii**) serve to complement the tentative nature of the statistical models (**iv**) with respect to their low sensitivity and propensity to explain quantities of place with variable factors. Together the sub-studies illuminate that in some instances there is an intimate technological interplay with place and participation, and in other instances the interplay is more distant. Furthermore, whether the interplay is loose or tightly woven, the properties of the interactions have the potential to motivate seemingly contradictory consequences, either stabilising or de-stabilising everyday life to impel a continuous interplay of responses and actions. A descending pattern of places (**iii**), or a cross-sectionally lower amount of current places that a person frequents (**iv**) may suggest instability to participation in everyday life. However, these outcomes alone seem insufficient to indicate the threat of negative consequences, as individuals appear to implicate a number of other resources into the interaction to stabilise and mitigate threats to everyday life.

6 DISCUSSION

This section will open by discussing each of the synthesised results separately before entering into methodological discussion and implications.

6.1 DIAGNOSIS AS A CONDITION OF ET USE?

In general, it can be concluded that no evidence was found to indicate that ETs varied in challenge according to diagnostic group (dementia or no known cognitive impairment), with only three exceptions relating to computer functions (searching for information, word processing, internet banking) (i). These three exceptions suggest that a disproportionate challenge was presented to the group of people with dementia when using these functions. This indicates that these three functions may be more sensitive to discriminating the declining abilities of the group with dementia (i). Such sensitivity aligns to a separate study with older adults in a memory clinic, which suggested that falling behind in the use of computers and touchscreen devices as manifested by reduced, non-daily usage, may reflect underlying cognitive difficulties (Wu, Lewis, & Rigaud, 2019). The evidence further confirms the position of computer functions at the upper reaches of the ET challenge hierarchy where they have been since their inclusion in the ETUQ (Malinowsky, Kottorp, Patomella, et al., 2015; Patomella et al., 2011). Given the ubiquity of computers in everyday life, it might be considered surprising that the level of ET challenge, although constantly changing, has not yet come down over time for all older adults. This may be especially the case when comparing the apparent relative ease of use of similar functions on a smartphone and the wider and ever-evolving variety of computers and (touchscreen) laptops now available (i, ii). This variety in design is both a strength and weakness of the ETUQ as people respond based upon their own ET devices which means that no insights can be offered regarding the features of specific interfaces that facilitate ease of use. The findings about ET challenge will therefore reflect participants' perceptions of a range of brands, simplified and standard mobiles, interfaces that have been variously customised and personalised to suit.

Among older adults, it has previously been found that touchscreen EICT devices may be easier to use in comparison to keypad devices (Page, 2014). The findings of this thesis seem in agreement, as the overall challenge of smartphones was perceived by participants both with and without dementia to be generally lower than that of pushbutton mobile phones (i, ii). However, acting upon this information when choosing between mobile and smartphones is suggested with caution as the findings do not provide an absolute measure of difference in challenge between ETs. Older adults' experiences of using touchscreens can vary according to their abilities, their history and situations for use, and their preferences regarding ever-improving design features, e.g. use of a pen (Elboim-Gabyzon, Weiss, & Danial-Saad, 2021; Gorce, Nadine, & Motti, 2017; Motti, Vigouroux, & Gorce, 2014). For this reason, in concert with others, a *try before you buy* approach to EICT acquisition is suggested, particularly for people who suspect they may have difficulties using a device (Damodaran, Olphert, & Sandhu, 2018; Ferguson & Damodaran, 2018; Marston & Samuels, 2019; Ramondt, Sandhu, & Damodaran, 2013).

The challenge of EICT can be unfeasibly high in some situations so that sensitivity and compassion is warranted when people with dementia are dealing with more challenging computer/laptop use (**i-iii**). It can be that at this more challenging end of the scale, sharing and delegating responsibilities for use (whether at home or in adult-education settings) becomes an appropriate strategy, possibly as part of a longer-term manualising process (**i-iii**) (Damodaran et al., 2018; Hwang et al., 2020; Jakobsson, Nygård, Kottorp, & Malinowsky, 2019; Ramondt et al., 2013). For example, one person manages logging in and passwords, or entering transaction details, while the other checks the bank account, or loads the shopping cart. However, other people with dementia may benefit from a more rehabilitative approach to ET use and occupational therapy interventions that optimise, tailor and adapt existing EICTs for prolonged use (**i-iii**) (Fischl, Blusi, Lindgren, & Nilsson, 2020; Laver et al., 2020; Swaffer, 2021).

The greater proportional relevance of the more challenging to use device (pushbutton mobile) among people with dementia (despite having lower overall abilities to use ET) could be indicative of prevailing habits and familiarity in using a longer-standing EICT (Jakobsson et al., 2019). Where people are habituated to a particular device, then this interaction should be left alone or if necessary, tailored to facilitate continued use (Fischl, Blusi, et al., 2020). However, it could also indicate that society holds assumptions about EICTs (i.e. older technologies are also easier to use technologies) and who those EICTs are for (**ii, iii**). This could be a consequence of marketing messages and beliefs and attitudes about the capabilities of people with dementia whereby their opportunities to become owners and users of updated devices (i.e. smartphone) are oppressed. Being dementia-friendly in this context means noticing and challenging these assumptions and the age-related stigma built into ideals of EICT ownership (Köttl & Mannheim, 2021; Mannheim et al., 2019; McDonough, 2016). This stigma may be hindering older adults with and without dementia from accessing easier to use devices and thereby compromising their potential to engage in EICT-facilitated occupations (**iii**). In the case of acquiring new EICTs, an individual may benefit from the opportunity to explore whether a smartphone is suitable, even if they ultimately find a push-button mobile more fitting. Reluctance to acquire ETs in instances of high challenge may also not be attributable to stigma, but to an accurate, and assets-based appraisal of personal abilities in relation to other interacting circumstances. These interacting circumstances may entail consideration of essential prerequisite conditions for use of the device, e.g. appropriate infrastructure for internet connection and service and the ability to manage such services (**iii**) (Damodaran et al., 2018; Hwang et al., 2020; Marston & Samuels, 2019). Added to these circumstances, appropriating new EICTs can also be a complex process that brings with it new needs for ongoing technological support in relation to setting up, teaching, software, updating, passwords (Hwang et al., 2020). Prerequisite conditions are likely to be contextually variable i.e. between rural and urban locations due to the increasing rural-urban digital divide (Esteban-Navarro et al., 2020; Philip et al., 2017). Building awareness in society of the high challenge of computer/laptop functions and the prerequisite contextual

conditions of usability could promote more realistic expectations of use and the need for improvements and adaptations.

Engendering dementia-friendly approaches to the EICT environment gains layers of complexity and nuance as the interplay with a person's everyday life assemblage is unpicked. While choice and optimised participation may be intended in each act of respect, support and understanding, the consequences may not always achieve dementia-friendliness as an outcome. Instead, arriving at a technological end destination that is dementia-friendly may need to be viewed as a process of trial and error that recognises reciprocal efforts and accounts for shifting impacts to the in-/stability of everyday life over time.

6.2 NATIONAL AND GEOGRAPHICAL, PUBLIC AND HOME CONTEXT AS A CONDITION OF ET USE?

In general, the findings indicate there is no evidence that DIF had any impact on the person measures of ability to ET. Consequently, it can be concluded that the ETUQ is suitable for use in the US, Sweden and UK since the findings infer there is no systematic measurement bias indicating that the ETUQ favours the abilities of one country group over another. However, the presence of DIF concentrated within the realm of public space ETs warrants further consideration and suggests high variability between country groups' participation in interactions with these specific types of devices (i). Furthermore, the case study illuminates conditions that motivate the use of these types of devices in ways that may also support an understanding of within-country variation in ET challenge (iii). Driving both the variance in ET challenge and relevance between country contexts may be international and within-country variations in; a) societal shifts and differences that impact wider routines and habits, and b) constitution of the space where the technology is sited together with design features.

a) Societal differences and shifts that impact wider routines and habits

Evidence of DIF to suggest variation in the perceived challenge of technologies used for travelling (i.e. automated ticket barriers, airline check-in, bag drop and petrol pumps) highlight possible international variation in conditions of access to the various modes of travelling (i). Such conditions may include the geospatial aspects of each country, prevailing weather conditions and temperatures, provision of accessible, affordable, and efficient public transport together with climate policy initiatives in favour of reducing aviation and use of private transport (Larsson, Elofsson, Sterner, & Åkerman, 2019; Prakash, Teksoz, Espey, Sachs, & Shank, 2017). International variation in these conditions would reasonably lead to variation in the types of transport that are habitually used and therefore the relevance and challenge of necessary technologies incorporated with the use of that transport. However, the stark increased relevance of the petrol pump to the sub-group of cases living with dementia highlights how variations may occur due to unequal *within*-country provision of transport services (iii). Rural provision of public transport in England is acknowledged to be at best limited and often completely unavailable which motivates increased reliance on private transport (DEFRA, 2019). A qualitative study of three different rural locations in south,

central and northern Sweden highlighted the private car as playing a central role for engagement in everyday activities against a backdrop of poor public transport (Berg & Ihlström, 2019). Consequently, it cannot be assumed that the finding of lower relevance and increased challenge of the fuel pump to a predominantly urban-dwelling group from Sweden would be applicable among a rurally dwelling sample. This indicates a potential commonality between rural international contexts that warrants attention to geographical representation in sampling and continued investigations into the geographical conditions of everyday technology use.

Evidence of DIF for the cash machine (ATM) indicated that this ET was relatively easier to use in Sweden and relevant to a greater proportion of participants. This could be indicative of each country being located in different phases of a shift towards cashless societies with varying availability of face-to-face, in-bank services (i). Sweden is at the forefront of this shift where perhaps only two branches of one major bank continue to offer a face-to-face teller service. Additionally, only 9% of people in Sweden reported that their last transactions took place with cash. Although this figure was higher at 13% among older adults (aged 65-84), over half of whom were not in favour of declining use of cash (Sveriges Riksbank, 2020). A lack of face-to-face service, and continued preference for cash would motivate the relative ease of use and higher relevance of the ATM to the group from Sweden (i) as higher frequency of use can facilitate improved performance (Kielhofner, 2008; Patomella et al., 2011). However, as use of cash is decreasing so too are ATMs in decline and Sweden's central bank is now taking measures to slow the cashless progression having noted that older adults and people living in rural areas are at risk of exclusion (Sveriges Riksbank, 2020).

The UK received expert advice from Sweden to ensure inclusivity on the route to cashless societies (Access to Cash Review, 2019) and the Bank of England envisions that cash will remain essential for supporting financial inclusion (John, 2019). However, disparities are once again noted regarding the disproportional impact of ATM and bank branch closures to older, less well-off and rurally-dwelling individuals, arguing that cashlessness could even undermine the viability of rural communities (Access to Cash Review, 2019; Langford, Higgs, & Jones, 2020). The cashless progression was a prominent issue among the rural cases in England (iii) who described using workarounds that highlighted the face-to-face role of shop staff combined with chip and PIN devices as an essential route for accessing cash.

The US faces similar situations where low banking provision has been shown to relate to low population density, but also with poverty, where African Americans are most affected in urban areas and Native Americans are most affected rurally (Kashian Russell, Tao, & Drago, 2018). The trend towards reduced bank branches has also been established in Chicago, the results of which highlight that the convenience sample for sub-study i was drawn from a suburb of uncommonly high branch density (Hegerty, 2020). The lower relevance of the ATM for this sample may indicate a preference for face-to-face services which are under threat in all three countries. It may also explain the greater difficulty of the ATM to this group, since a sample that has less cause to use a technology may be less familiar with it

leading to higher perceived difficulty in its use (Patomella et al., 2011). This convenience sampling bias, which led to over-representation of people with higher banking access, calls into question the strength of conclusions around inter-country challenge variation. However, the same bias inadvertently illuminates pockets of unequal access to different services as a condition that could motivate within-country variation in ET challenge.

b) Constitution of the space where the technology is sited together with design features

The above discussion has highlighted the importance of available and accessible face-to-face services for mitigating occupational injustice and facilitating continued participation in everyday life. Furthermore, the discussion highlighted the need to mitigate digital exclusion pointing towards the possibility that provision of face-to-face services impacts the relevance and challenge of the technology. Connected to becoming cashless are SSTs, and all five ETs displaying DIF by country fall within this definition: petrol pump, automatic ticketing barriers, airline self-check-in, and bag drop-off (i). The internationally variable ways in which progression has been made towards the use of SSTs perhaps impacts their challenge level through variation in the SST's design features, how it is sited in the space and how it is constituted in relation to other public space features (Malinowsky, Almkvist, Nygård, & Kottorp, 2012; Patomella et al., 2013; Petrie & Darzentas, 2018). For example, public transport ticketing barriers were often described by the sub-sample from England in relation to Transport for London (TFL). In TFL contexts at the time of data collection, there was typically an onus on passengers to remember to seek out the SST exit touch points. Users must then touch-out with access passes or contactless payment cards and failure to comply incurs the maximum daily charge. However, in Stockholm's public transport service (SL), single journeys are fixed price with no requirement to touch out and any exits are funnelled so that all passengers will pass the barrier. This variation between design features and siting of the technologies may explain why the automatic travel barrier is perceived to be more challenging for the group from England compared to Sweden (i).

Such variations in design features and siting also occur in relation to fuel pumps, particularly the siting of the self-service payment technology and its location adjacent to a non-technologised alternative (iii). Such SSTs might be embedded within a single pump, or standing alone and operable for a number of pumps, and may or may not be sited together with a kiosk, where a face-to-face service with an employee can be accessed. Two experimental studies, among 312 older adults, found that using face-to-face services in preference to food ordering SSTs related to older age, even among a sample aged between 18-60 (Kardes, Wu, & Liu, 2020). This preference was only expressed in situations where a choice was presented, and while the situation for customer service is fuel rather than food, it may be that co-siting technologised and manualised options are a key feature of reduced challenge. The rural cases illuminated how such a choice motivated variety in service-participation, i.e., participating with or without others and using or not using the technology. This variety ultimately supported inclusion by mitigating social exclusion from services (i.e. purchasing and transport). This had a wider effect of preventing occupational injustice since

cases were then not deprived of aspects of everyday life (i.e. co-fulfilling a shared responsibility for travelling) (iii).

That no DIF was found between countries regarding EICTs is perhaps unsurprising, since these types of technologies are highly globalised and therefore more uniform in design (i). The home-based nature of the ETUQ interview may encourage respondents to recall the home as the context for the use of EICTs. It should therefore not be assumed that equal challenge is presented when participating outside of home, where perhaps the spatial constitution incurs greater risks, distractions, security and privacy concerns that create problematic situations increasing the difficulty of using EICTs (Gaber, Nygård, Brorsson, et al., 2020; Malinowsky et al., 2012; Patomella et al., 2013). Furthermore, as indicated by the case study (Elsie), the relevance of the device and function may be similarly impacted so that a mobile phone only becomes relevant outside home, where others could use it on the owner's behalf if needed (iii). This indicates that the purpose for the use of the device and its functions alters according to context and may impact its relevance. Such an indication has been previously evidenced in a comparative study in Sweden where EICT functions for general use were found to be of unanimously greater relevance than the same function used for eHealth (Jakobsson, Nygård, Kottorp, Bråkenhielm Olsson, & Malinowsky, 2020a).

Although EICTs are internationally pervasive, the rural cases pointed to inadequacies in the constitution of infrastructural prerequisites for the use of these devices (iii) (Olsson & Viscovi, 2020). Inequalities of the rural-urban digital divide often create conditions of unreliable and slower mobile and internet connections that suggest a possibility that EICTs may be systematically less useable in rural contexts internationally (Esteban-Navarro et al., 2020; Lai & Widmar, 2021; Philip et al., 2017; Salemink et al., 2017). Such conditions could therefore engender a hindered interaction between the older person and their EICT device that manifests in a greater degree of perceived challenge.

6.3 INTERPLAY WITH PARTICIPATION IN EVERYDAY LIFE

The findings from the regression models indicated that lower out of home technology use and a higher relative level of neighbourhood deprivation may independently associate with a lower amount of places outside home (iv). However, the facet of technology use was not consistent; as participation in the highest quartile of places associated with higher *ability to use ET*, whereas the lowest and median quartile of places associated with a smaller *relevant technology room*. These findings concern a particular subset of ETs, which include EICT devices and their functions and SSTs, but exclude domestic technologies (iv). The case study further illuminated instances where the interplay with SSTs impacted upon freedoms to socially participate (iii). Together, the associations and illuminations found in these sub-studies suggest that it is appropriate to widen consideration of the digital divide beyond EICTs and the internet to include SSTs and other ETs found outside home (iii, iv). Sub-studies iii and iv also provide empirical evidence that inequalities of technological participation (relevance of EICTs and SSTs, ability to use ET, telecommunications infrastructures and services) can correspond to inequalities in wider social participation (i.e.

smaller or descending footprint of places, proximity and possibility to travel to places) to present an issue of occupational injustice (Durocher et al., 2014; Helsper, 2012; Kottorp et al., 2016; Wilcock & Townsend, 2000).

The outcome used in sub-study **i**, total places that a person currently goes to, provides only a limited view of participation. Consequently, the perspective generated via cross-sectional statistical modelling alludes to, but cannot clearly indicate, instability in everyday life. However, a longitudinal study based upon data from the same sub-sample of participants with dementia in sub-study **ii**, complemented the cross-sectional view of the association found in sub-study **iv** to find that decreasing use of ET outside home associated with a reducing footprint of places over time (Gaber et al., 2021). Such a descending pattern of places may be indicative of instability in people's lives but could also indicate adaptive measures that people take to stabilise and optimise participation. In-/stability in this thesis is considered not only with respect to a person's footprint of places over time or the size of that footprint, but also wider descriptions regarding routines, transport options, relationships etc. The case study (**iii**) helps to illuminate and offers explanations for the complexity of the dynamic interplay between places and associated everyday technology use in a rural context.

The interplay between conditions of ET use and participation will be discussed with respect to; 1) relationships with significant others, 2) in public and customer services relations, and 3) with inequalities and transportation.

6.3.1 Technological interplay in relationships with significant others

By comparing and contrasting the regression models and their sensitivity (**iv**) together with the case study findings, the role of others in stabilising participation comes to the fore. Shared use of ET was seen to correspond with co-fulfilling wider occupations in everyday life in sub-study **iii**; i.e. fuelling the car to travel for shopping, leisure, socialising and so on. While this in part provides a well-worn care perspective on people with dementia receiving help or support to participate, it also points towards stability as gained through reciprocal co-fulfilment in everyday life (Fischl, Asaba, & Nilsson, 2017; Graham & Bassett, 2006; Hwang et al., 2020; Ryd, 2017).

The findings of sub-study **iii** highlighted how from the perspective of the person living with dementia, recognition and acknowledgement of delegated or shared ET-implicated tasks needed to be proportionate and flexible to the situation. This could mean tacitly downsizing doing, by sharing and delegating tasks in ways that naturally adapted the way that things had long been done, i.e. one pumps the fuel and the other goes in to pay (i.e. Peter) (Hedman et al., 2016). It could also mean being able to share fears about the impact of failed ET use and being listened to as part of affirming and building the relationship, giving reassurance and showing appreciation of wanting to put each other first (i.e. Alf). This indicates a complex and dynamic state of flux where everyday interactions with technology are co-constituted and entwined in an ongoing process of give-and-take in relationships (Graham & Bassett, 2006; Hwang et al., 2020; Jakobsson et al., 2019; Ryd, 2017). As Alf highlighted; *doing for others*

can be the sole motivating factor for ET acquisition so that the locus of control can shift towards oppressing the person with dementia if this gift of doing goes unnoticed (iii). The consequences of failed, or sub-optimal use of a device are weighed not only financially and practically, but emotionally with ramifications to closeness and reciprocal care in relationships. Such ramifications can create both friction in relationships and new technological support needs that threaten to destabilise participation (iii) (Hedman et al., 2016; Hwang et al., 2020).

6.3.2 Technological interplay in customer services relations

Reciprocity was also seen to extend to customer services relations as frequenting local shops and selecting face-to-face services over SSTs was often regarded as contributing to the stability of a fragile rural economy (iii). Research into SST use among older adults frequently acknowledges that non-use can be motivated by not wanting to do people out of jobs or by a preference for human contact (Dean, 2008; Kardes et al., 2020). However, it is seldom considered that in some instances taking the manualised choice is about exercising personal responsibility to participate in society in tangible, noticeable ways. For example, making a deliberate choice to use cash in the village and supporting the local shop (iii). These choices can be reciprocally appreciated and acknowledged as contributing towards stabilising everyday life for others in the community as well as for the choice-maker. To continue the example; the custom given by the person supports the viability of the shop, secures the service for others, and contributes to making cash transactions worthwhile and sustainable. Taking the manualised choice may therefore produce socially connective interactions that are part of co-constituting and reproducing a stable sense of neighbourhood and familiarity enacted beyond the scale of the individual older adults (Clark et al., 2020). At wider scales these SST interactions implicate the local workforce and their work tasks so that employment opportunities and how businesses deliver services are stabilised in co-constitution with older adults.

Stabilising and co-constituting access to financial services could also be seen in how shop and post office staff were implicated as supporters in the use of SSTs and facilitators of acquiring cash (iii). The willingness of staff to be implicated in this wider service provision was attested to by several cases and indicates that local community amenities and services can and do act in dementia-friendly ways. This willingness to take inclusive and flexible action to support more vulnerable inhabitants has been explored from the perspective of more than 173 workers in a community outside Milan (i.e. pharmacists, postal workers, public transport drivers, shopkeepers etc.). A spectrum of actions and attitudes were displayed among these workers, with many highly attuned to variation in customer needs who described how they adapted accordingly. However, others were reluctant and perceived that meeting extra-ordinary needs was not their responsibility (Zappella, 2019). This poor potential of some staff to adapt and respond may partly explain why other cases (i.e. Michael and John) chose SSTs and EICTs to stabilise their participation in services and everyday life occupations thereby avoiding unwanted social encounters (iii). However, in John's case, it

was just as much other customers that presented a challenge creating obstacles with their bodies and trolleys as they stopped to chat in the supermarket. This challenging type of situation has been equally seen in other studies which added issues of crowds, intoxicated people, and clutter from e.g. baby gear (Gaber, Nygård, Brorsson, et al., 2020). While this indicates a need for better awareness among staff in the places people go to, it also indicates a need for better awareness throughout the whole community. Perhaps this awareness could be achieved by “information going out to the households” as one participant in this interview study describes (Smith, Gee, Sharrock, & Croucher, 2016; p190). The intricacies of situations mean that not everyone in society can alter how they are in places to ameliorate problems for people with dementia (i.e. the baby needs its gear). Furthermore, ensuring that other people in the community could go about their daily lives unhindered and causing little trouble to others was a point of focus for some cases. However, this study which interviewed people with dementia and their care givers about dementia-friendliness in their African American churches revealed that being dementia-friendly can be subtle and does not have to be troublesome. A friendly and welcoming way of being could help put people at ease and reduce anxiety, and knowledge was perceived as helping the congregation to be more understanding and accepting when worship situations went outside the norm (Epps et al., 2020). Improved awareness of dementia within communities may therefore support community members to identify their own possibilities for action which need not be onerous or complicated. This may lead to more inclusive opportunities for the likes of John and Michael to continue participating in everyday life outside home.

6.3.3 Technological interplay connected with inequalities and transportation

Taken together, sub-studies **iii** and **iv** enhance a perspective on the structural and societal intersections that combine with technology use to impact participation. Sub-study **iv** found that these intersections were highlighted by indicators of relative deprivation, which include barriers to housing and services, indoor and outdoor living environment, crime and safety, economic, education and health status (Department for Communities and Local Government, 2015).

The rural case study connected barriers to services with the threat of imminent driving cessation together with malfunctioning and unreliable telecommunications infrastructures and services, as well as the EICT devices themselves (i.e. landline telephone, TV, computer). Through their interactions in Alf’s case, these components could be seen to destabilise everyday life (**iii**). These findings add to those of a focus group study with 18 rurally-dwelling older adults from the North of Sweden which also pointed towards the importance of well-functioning ICT devices to engender a sense of security (Fischl, Lindelöf, et al., 2020). High speed internet access is considered a feature of higher living environment quality and housing standards, which together have been asserted as essential prerequisites for digital inclusion (Olsson & Viscovi, 2020). These assertions were supported by sub-study **iii** which highlighted how a more deprived living environment could limit the availability and quality of services to hamper the size of a person’s technology room (**iii**).

Sub-study **iv** did not highlight driving status as influential on the overall amount of places, however, sub-study **iii** pointed towards driving as having critical interplay in sustaining rural participation. Taken together, the sub-studies suggest possible protective factors, such as proximity to services (**iii, iv**), having access to and being willing to accept car rides provided by others (**iii**). Driving, particularly in more remote rural contexts with inadequate or no public transport provision, is considered largely essential for facilitating participation outside home and avoiding loneliness (Fischl, Lindelöf, et al., 2020; Hansen, Newbold, Scott, Vrkljan, & Grenier, 2020; Neville, Adams, Napier, Shannon, & Jackson, 2018). The case study also highlighted that the interplay with driving-related parking technologies could impact routines and habits regarding where to go, how often and how long to be there. Ultimately, these changes could thwart the purpose for the trip so that the occupation remained partially or totally unfulfilled, i.e. supermarket shopping (**iii**).

The importance of being able to park easily surfaces in wider empirical research with respect to most aspects of everyday life outside home; in particular for community engagement, leisure and healthcare. However, it has typically been only the physical aspects of parking that have been identified as influential; i.e. sufficient availability of spaces, manoeuvrability within the parking space, proximity to the place (Innes, Page, & Cutler, 2016; Neville et al., 2018; Parke et al., 2017). From 2019 in the UK, people with dementia could apply for disability parking permits on the grounds of severe psychological distress, being at risk of harm or experiencing difficulty or inability to walk (Hare, 2019). These grounds make some allowances for cognitive aspects albeit more indirectly, so that steps have not yet been taken to be inclusive of issues such as difficulty with using parking technologies and staying within time limits. This may be because of internal and external stigma, fuelling assumptions that a person with dementia who experiences this issue must also be unfit to drive (Byszewski et al., 2013; Goffman, 2009). However, such conflation could be inaccurate due to the highly various ways in which dementia presents and progresses, combined with a lifetime familiarity with driving but unfamiliarity with new parking technologies. As opposed to direct concerns of driving fitness, this kind of inaccuracy could lead to peripheral issues of ET use pre-emptively and unjustly impacting a person's transition to driving cessation and wider participation. The consequences of this impact to everyday life are exacerbated when alternative means of public transportation are unavailable, as is more often the case in rural areas (Rapoport et al., 2020; Sanford et al., 2018). Free or concessionary public transport provision has been seen to associate with going to a greater number of places, reduced depressive symptoms and loneliness, and increased contact with friends and children (Gaber, Nygård, Kottorp, et al., 2020; Reinhard, Courtin, van Lenthe, & Avendano, 2018). Thus, it stands to reason that in contexts without transport provision, the threat of driving cessation can be highly destabilising to the tenability of everyday life (Fischl, Lindelöf, et al., 2020; Hansen et al., 2020). What sub-studies **iii** and **iv** add, is that ET use and infrastructures can also interact to produce a destabilising interplay that interferes with participation and can ultimately impel relocation.

6.4 METHODOLOGICAL AND ETHICAL CONSIDERATIONS

The cross-sectional sub-studies of this thesis have used multiple methodological approaches to illuminate the conditions of ET use, and the interplay of these conditions with participation in everyday life among older adults living with and without mild stage dementia. The following sections reflect upon the main methodological considerations of the thesis interwoven with ethical considerations.

6.4.1 Statistical methods

Central to all studies was the use of Rasch analysis to generate linear person measures of ability to use ET. The power calculation was based upon an earlier estimation with the conclusion that $n = 33$ is a sufficient sub-sample size to generate a clinically and statistically significant difference of 4.0 logits between groups of people with dementia and without known cognitive impairment ($p < .05$ power 0.90) (Nygård et al. 2012). For the purposes of comparing abilities between sub-groups, the sample sizes were shown to be adequate (**i**, **ii**, **iv**). Non-parametric statistics were in general preferred, even when data was shown to be normally distributed, for two main reasons among other advantages. Firstly, small sample sizes do not unduly influence the results of nonparametric analyses. Secondly, they are more efficient under conditions of non-normality and when dealing with outliers and only lose marginal efficiency in comparison to parametric statistics under normal conditions (Leech & Onwuegbuzie, 2002). However, it is less straightforward to evaluate the confidence intervals of nonparametric statistics, and the specific non-parametric effect sizes of the results require transformation procedures back to Cohen's d (Whitley & Ball, 2002). Obtaining Cohen's d and confidence intervals was done using a range of calculation, conversion, and evaluation tools at psychometrica.de (Lenhard & Lenhard, 2014, 2016).

A sample size that is too small carries a risk of a type I error, leading to conclusions that falsely; identify DIF (**i**), find no difference between groups (**ii**), or find a variable has no influence on the outcome (**iv**) when in fact the opposite is the case. Conversely, a too large sample size carries the risk of a type II error so that conclusions are made in favour of a significant statistically significant result when in fact there is none.

In the case of sub-study **i**, the sample sizes were regarded as small with respect to DIF analyses as $n < 200$ for each sub-group (Scott et al., 2009). To reduce the risk of identifying DIF by chance, a conservative approach was taken whereby the significance threshold was increased to $p < .01$, and agreement between two statistical procedures was required (Fidalgo, Ferreres, & Muñiz, 2004).

The samples of $n = 35$ (group with dementia) and $n = 34$ (group with no known cognitive impairment) were found to be adequate for investigating the differences in relationships between variables in sub-study **ii**. However, the combined group size of $n = 69$ was insufficient for generating challenge measures for all ET items (**ii**), a problem which was remedied when combined with the larger sample $n = 315$ (**i**). Increasing the sample size is recommended where the Rasch generated ET challenge measures are central to the

investigation in order to ensure insights into e.g. every EICT function. However, this needs to be pragmatically weighed with respect to the resource intensity of data collection and the potential for burdening an unnecessarily large number of people. Furthermore, rapid changes in the technological landscape make calculating an adequate sample size difficult. For example, in 2021, it may be that 69 older adults from Stockholm recruited to a new study would be sufficient to generate measures for every ET item as older adults' technology rooms may have substantially changed in the last 5-6 years. Arguably for sub-study **ii**, discovering the lack of relevance of particular EICT functions in 2015-2016 (i.e. internet banking on the tablet) among both groups offered more relevant insights into the study context than knowing the relative challenge of that function.

The ACT-OUT is a newly developed instrument and as such no power calculation informed the sample size for sub-study **iv**, however, the findings can be used to support future calculations. The overall sample size of $n = 128$ was considered to be underpowered for the logistic regression approach based upon the number of variables (between 9-13) that indicated possible influence on the outcome in the univariate analysis (**iv**). The criterion of ensuring more than 10 Events Per Variable (EPV) is a commonly cited, although controversial and likely too low, criterion to ensure out of sample performance (Bujang, Sa'at, Sidik, & Joo, 2018; van Smeden, Moons, de Groot et al. 2019). For sub-study **iv**, the criterion would need to apply to the outcome at the 25th percentile of places where $n = 22$ meaning only two variables could be included in the model. Only the associations within the sample were intended to be explored, however due to this power issue, the findings were still interpreted with caution. Particularly around whether e.g. diagnosis of dementia and rural/urban context do, or do not have an effect on participation as an amount of places. Furthermore, the choice of a conditional, rather than unconditional regression method may have been more appropriate (Kuo et al., 2018). This is because there were equal numbers of people with dementia or no known cognitive impairment intended to be matched as two groups for a variety of demographic characteristics. It may have been that individuals in the sample also matched at the pairs level, which would have affected the results. However, choosing a conditional model could have led to similar concerns in the opposite direction that the model was unsuitable due to insufficient matching between individual cases and controls. As the outcome was explored at the quartiles, a nonparametric quantile regression model may have provided a more efficient analytical tool for exploring the associations. Quantile regression modelling also has utility for discovering weaker relationships and relationships that are not simply linear (Huang & Nguyen, 2018). Lastly, the direction of the models in sub-study **iv** were assumed with no clear indication that the association may not be present in the opposite direction (i.e. participation influences ET use, rather than ET use influences participation). An alternative approach that would have allowed for bi-directional investigation of the associations would have been a reciprocal causation testing model (Finkel, 1995). In summary, alternative statistical methods of exploration were possible for sub-study **iv**. However, taking an explorative binary logistic approach at different quartiles of participation was regarded as aligning with an assemblage perspective that embraced the temporal

impermanence of the context in which this data was collected. Furthermore, this approach allowed the associations found to be explored as conditions and relations that motivate variation in participation rather than more rigidly predicting or causing it (DeLanda, 2006).

By using the entirety of the data from the ACT-OUT and ETUQ with other more open data forms, the multiple case study approach was found to yield rich insights into the study context. A broader exploration was facilitated by involving a greater number of cases (10) than the more typical number of three to four (iii) (Yin, 2003). This higher number was made possible by the data that been collected. While this data was adequately rich, it was not gathered from a basis of open questioning as cases had already been clearly steered into the topic by the tools. This means that the technologies that were observed had been prompted during the ETUQ interview as relevant to each case and so observations were inconsistent between cases (i.e. one case had four observations of technological interactions, two others had none). By interviewing in relation to 90 ETs, ET interactions of especial interest, importance or tension stood out to both the case and the author. Selecting ETs that stood out in these ways became the observational focus which provided a rich insight into the interaction (i.e. the emotionally and cognitively taxing use of matching flip phone's bought by one case's non co-habiting partner for tandem remote contact). Richer insights may therefore have been gained by observations beyond the home-based setting, e.g. interactions with ATMs, chip and PINs and shop staff, which were not observed. A more typical way to apply the methodology would have been to have fewer cases and use consistently richer methods i.e. in depth or walk-along interviews. Collecting data from others relevant to each case's everyday life is another common component of the case study method (Stake, 2006; Yin, 2003). Viewing this topic from different perspectives may have led to more holistic view on technological interactions leading to more applicable and realistic implications for e.g. customer services, transportation and public places. Focussing only upon each person with dementia, however, perhaps offered an open opportunity to voice their views, free from concerns about others' perspectives potentially being given more attention.

6.4.2 Triangulation

The triangulation approach used to integrate findings of the four sub-studies highlighted how the findings largely complemented one another as a function of their design to address different facets of enquiry (Farmer et al., 2006). By combining the findings from the different methodological approaches, a more complete and merged, rather than additive, perspective of the topic has been elucidated (Bazeley, 2018). For example, by comparing across studies, conditions that motivated ET use at different scales (national, geographic, public, home) were combined to attain a more complete picture of the interplay with contextual overlaps and distinctions.

Equal weight was given to the findings of the four sub-studies in the triangulation process with an intention to balance the level of detail with which the findings were presented (Farmer et al., 2006). This intention was most challenging to achieve with regard to the interplay with participation, where the relative lack of detail in the regression models (iv) was

subsumed by the richer, more complex and nuanced detail contributed by the case study (iii). In these cases, however, the balance was strived for by centring focus upon the specific statistical finding (i.e. the association between higher ET ability and higher participation) and enhancing how the association could be understood in relation to other implicated conditions that were provided by the case study (iii-iv). The original discussion of instability relating to the statistical models given in the publication of sub-study iv was largely theory driven, which yielded more speculative interpretations regarding the outcome of participation as an overall amount of places. When triangulated with sub-study iii, the interpretation of sub-study iv's findings was empirically enhanced with case descriptions of the interplay that explored possible explanations for that statistical instability.

The main challenge in this approach was that the variation in methods and research questions meant variation in the presence or absence of themes and furthermore, dealing with complexity in the levels of agreement and silence. However, this was perceived as an advantage, since using a clear approach to comparing and combining data afresh provided a more consolidated perspective of the findings. Consequently, it became clearer where the findings enhanced and overlapped to deepen understanding, or where they complemented and formed alliances with one another to extend the view. For example, being able to see how rural and international policies and infrastructures may contribute to the conditions of ET use. This combined finding sharpened the picture more broadly to provide a view on how these conditions may apply at different scales. As such, the triangulation approach in this thesis has been rigorously used in a way that is considered to have enhanced the validity of the interpretations of each sub-studies' findings (Farmer et al., 2006).

6.4.3 Data collection

Regardless of the variety in methodological approaches that formed the basis of the triangulation approach, the findings of this thesis are largely grounded within data from two dominant tools; the ETUQ and the ACT-OUT. As such the perspective on the topic is influenced and limited by the theoretical viewpoints, constructs and concepts that underpin these tools. The case study goes some way towards broadening the topic perspective via additional and more open data gathering procedures. These procedures brought into focus elements such as the threat of driving cessation, interplay with driving technologies and the role of others. These elements are otherwise backgrounded or obscured altogether by each tool individually, but when used together and with an open approach these elements come through more clearly. Multiple methods in this thesis therefore contribute useful findings about the performance of the ACT-OUT and ETUQ, particularly in relation to nuances of transport with respect to ET and its significant interplay with participation in a rural setting.

Both the ETUQ and ACT-OUT are self-report instruments that have been constructed with the considerably varied abilities of respondents with dementia in mind. The instruments provide a supportive framework for a focussed interview on self-perceived ET use and participation in places and activities outside home. Such a structure, carried out in a person's own familiar surroundings and promoting shorter interactions, may guard against recall

difficulties that are more common in interviews with older adults with dementia (Nygård, 2006). Equally, more open interview processes of the type undertaken in sub-study **iii**, have also been shown to yield rich data about people with dementia's own everyday lives when undertaken in familiar surroundings (i.e. home) (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016; Novek & Wilkinson, 2017). However, traditional interview methods may not have suited all potential participants to this study and as such, more naturalistic modes of enquiry such as walking interviews, or videography may have promoted more inclusive recruitment practices (Keady, Hydén, Johnson, & Swarbrick, 2017; Phillipson & Hammond, 2018). The focus of this thesis on interview as a method of enquiry may have biased the recruited sample in favour of people who were willing to participate in this way, perhaps due to higher retained communicative abilities (Phillipson & Hammond, 2018). This should be considered when weighing the analytic generalisability and representativity of the thesis findings.

In this thesis, a flexible approach to the interview was encouraged where participants could have someone present only for reassurance and normalcy and not as a criterion for participation or to act as a proxy. It was a common experience of the author that the significant other stepped out of the room once comfort was assured. This may have been a further source of influence for the interviews as the presence of a significant other alters the interview dynamic and may have inhibited responses. Another person can bring with them wider influences to introduce imbalances of power so that the interviewee may censor themselves or defer to the other person for responses (Digby, Lee, & Williams, 2016; Nygård, 2006). Despite these possible negative impacts to reporting, people with dementia can face exclusion from participating in research if they have no one willing to take on, or do not wish to burden someone with the role of study partner (Bartlett et al., 2018). This requirement for additional perspectives is tied to doubts regarding the veracity of the information provided by people with dementia and instead the views of significant others or care professionals are preferred or at least used as confirmation (Bartlett et al., 2018; Digby et al., 2016). Such doubts are common also among people with dementia, who themselves may question whether they retain the abilities and insights to make accurate contributions (Di Lorito et al., 2017; Waite et al., 2019). High regard for veracity and obtaining a common perception of reality have led to studies that compare self-reports of people with dementia with proxy reports. Concerning ET use, a study comparing ETUQ responses of people with cognitive impairment to those of a proxy well-known to them found high levels of agreement in the reporting of relevant ETs, and 81% agreement in ability to use ET. The authors concluded that the perspectives of people with dementia should therefore be prioritised (Jakobsson, Nygård, Kottorp, Bråkenhielm Olsson, & Malinowsky, 2020b). Additionally, a clinical observation assessment of the management of ET has been seen to correlate with ETUQ reports among participants with dementia, but not participants with mild cognitive impairment (Bartels, Assander, Patomella, Jamnadas-Khoda, & Malinowsky, 2020). Both the lack and the presence of variation point towards the importance of people speaking for themselves and providing valuable perspectives into their subjective realities of everyday life

lived with dementia (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Within this thesis, subjective perception is in focus and each respondent is relaying information only about their own use of ET and participation in places and activities. Focussing on the participants' experience in interview has repeatedly been shown to deliver authentic if not always objectively verifiable contributions to research (Digby et al., 2016). As such, the findings of this thesis are located solely within the respondents' self-reported perceptions of the conditions of ET use and its interplay with participation in everyday life. This one-sided view on issues that emerge e.g. the use of payment technologies to access finance in rural shops highlights the potential for gaining a broader range of perspectives from community stakeholders on the potential for action on these issues.

The MoCA's small role in this thesis warrants justifying in relation to the regular and yet often distressing cognitive testing that can occur for people with dementia, which has led to recommendations to exclude such tests from research unless strictly necessary (Hellström, Nolan, Nordenfelt, & Lundh, 2007). Additionally, this more invasive element of the interview may have been off-putting to older adults from both groups, impacting recruitment of people who did not wish to thrust their cognitive performance into focus (Provencher, Mortenson, Tanguay-Garneau, Bélanger, & Dagenais, 2014). While the MoCA was used in these studies to describe differences in cognition between the groups of participants with and without dementia, it is prudent to reflect not only on the recruitment and sampling impact, but also upon the ethical benefit to this research with respect to the burden to the participant. Quantifying the group level cognitive difference and overlap in this thesis was arguably superfluous to the investigations since impaired cognition is central to receiving a diagnosis of dementia (American Psychiatric Association, 2000, 2013) and ultimately, only the diagnostic status was statistically investigated. However, what the descriptive data for the MoCA helps to highlight is the lack of a clear diagnostic dividing line in cognitive performance among recruited older adults, since the range of the scores overlapped between those with confirmed dementia and those without. The variation of scores may better represent society and the blurring between age-related cognitive decline and the trajectory of cognitive impairment due to dementia (Watson et al., 2019).

Raising the topic of dementia directly in the interviews was treated with caution considering the known issue of causing distress to someone who was unaware of, did not relate to, or had forgotten, their diagnosis (Novek & Wilkinson, 2017). As such, dementia itself was only discussed if the person explicitly brought it up and relayed the relevance of their dementia to their ET use and participation in everyday life. This ethical sensitivity may have meant that participants with dementia who found out about the research via the general recruitment channels were wrongly allocated to the comparison group if they did not explicitly disclose their diagnosis. Furthermore, the author experienced that on at least one occasion participation in the group with no known cognitive impairment seemed to have been motivated by personal concerns about cognition and wanting to access a professional opinion on interview performance. Experiences such as this, point towards the importance of carefully assessing risks of harm to so-called healthy controls where in this instance the

participant was signposted towards appropriate services as per the ethical plan. The small sample size meant that every MoCA assessment and score could be inspected, individually considered, and controlled for, with respect to its possible impact on the analyses of sub-studies **i**, **ii**, **iv**. For example, a lower score that indicates cognitive decline among the control group participants may have been sufficient to create or inflate associations between relevant ETs and ability to use ET (**i**) or participation outside home (**iv**). Being able to empirically account for such an impact contributes to the robustness of the thesis findings and without the cognitive measures there would be no other statistical control mechanism.

6.4.4 Sampling and representation

A range of non-probability sampling methods (convenience and purposive) were used which are consistent with the exploratory aims of this thesis and a social realist ontological position and epistemology that seeks contextual complexity to understand the conditions that motivate the occurrence of a statistical outcome (DeLanda, 2006; Harman, 2015; Price-Robertson & Duff, 2016). Replicability of these findings is considered unlikely as the context for the thesis is a rapidly changing technological environment and complex social context that has already changed since data collection, tangibly so due to COVID-19. Instead, the concept of analytic generalisability, which encourages contextual replication logic and reasoning, is deemed more appropriate for judging the theoretical applicability of these findings beyond the participating groups (Hays & McKibben, 2021; Onwuegbuzie & Collins, 2007; Polit & Beck, 2010). Aspects of design and recruitment that may have restricted study participation have already been considered to a degree, and within this section, the recruited sample itself will be reflected upon with respect to external validity.

In sub-study **i** the intention was to compare the international parity of the ETUQ as part of ensuring cultural equivalence and identifying possible bias in the measurement of ability to use ET (van de Vijver & Tanzer, 2004). However, the samples themselves, although drawn from the respective countries have not been claimed in this thesis as representative of these countries or their populations. A group from urban Chicago or Stockholm cannot represent the whole of the US or Sweden. Neither can groups drawn from London and the North of England represent the whole of England much less begin to represent Northern Ireland, Scotland or Wales – devolved nations of the UK that have legislative autonomy (UK Government, 2013). This is not to say that there will not be commonalities shared between all three contexts as homogeneity will transcend national borders and urban/rural delineations. However, recognising these commonalities should not come at the expense of understanding variation, or the interplay that arises where national/geographical delineations are impacting upon technological interactions and everyday life.

Purposive sampling endeavours to recruit groups based upon gaining insights into the phenomena of interest with a purposeful selection designed to maximise understanding (Onwuegbuzie & Collins, 2007). Both convenience and purposive sampling approaches have advantages with respect to pragmatic concerns of time and capacity which were pertinent to undertaking the research in this thesis. A key issue that can result from these sampling

approaches is that sociodemographic subgroups can be underpowered for full investigation in the analysis but can introduce variation that is difficult to control for (Bornstein, Jager, & Putnick, 2013), which was suspected in sub-study **iv**. While there was no intention to expressly examine socio-demographic differences in the regression analysis (**iv**), there was no expectation that these variables would not influence participation as an amount of places. For example, the UK has a complex colonial and imperial history where Black, Brown and some White older adult participants may have faced discrimination, minoritisation and segregation throughout their lives. Even after the Race Relations Act was signed in 1968, people continued to be barred entry from places, and community participation opportunities and health (including dementia) services have long been identified as often not representing the needs and interests of many people who experience discrimination on the grounds of race and/or ethnicity (Campbell & McLean, 2002; Roche, Higgs, Aworinde, & Cooper, 2020; Shubin, 2011; Solanke, 2018). Furthermore, the introduction of hostile environment policies has led to people who legally immigrated to Britain over 50 years ago being treated as illegal immigrants (Taylor, 2020). This treatment has disproportionately impacted Black British, African and Caribbean people and has led to denied access to personal bank accounts and health care provision, and emotional and financial hardship (Hewitt, 2020; Hiam, Steele, & McKee, 2018). Logically then, the consequences of systemic and institutional racism in governance and policy are wider inequalities in participation regarding the range of places that people have available to go to freely and without fear of discrimination (Hiam et al., 2018; Iacobucci, 2021). It is important that policy contexts like the hostile environment are weighed for their impact when considering the analytic generalisability of this thesis' findings. While cautioning against racialisation, alternative, contextually relevant explanations should be considered regarding older adults' interactions with e.g. health services, banks, and associated technologies, including in rural areas. For some older adults, progression towards cashless societies may interplay in different ways due to the impact of the hostile environment having a greater influence over their technology use and participation.

Although policies have been explored when discussing the findings, to fully reveal policy impacts would require non-probability sampling methods beyond the scope of these small-scale explorations. However, non-probability methods are not always suited to complex contexts and population-based studies that claim representativeness can also have shortcomings hampering their generalisability (Bornstein et al., 2013). This can be particularly the case when demographic characteristics are treated singularly rather than at an intersectional social location (Jaehn et al., 2020). Consequently, this thesis asserts the need for reflection upon the value and limitations of the restricted view offered by all sampling approaches with respect to the social complexity of the context in which technology and participation studies take place.

6.4.5 Reflection on the contribution of PPI to the research process

A total of 11 Focus on Dementia Network group Cumbria (FODNC) research consultation meetings were attended by two to four experts by experience of living with dementia with the group membership changing over time. Meetings were facilitated by the regular group facilitator with the author variously attending face-to-face, remotely from Sweden, or not in attendance and instead receiving the minutes of the discussion. Consultations progressed most intensively during the ‘undertaking’ phase of the research, in particular with respect to analysing and interpreting findings (INVOLVE, 2012). So, reflecting upon aspects of the PPI process with the FODNC becomes a significant methodological consideration due to their involvement in shaping the findings. This reflection is given solely from the perspective of the author due to the impact of the COVID-19 pandemic causing the collaboration to be suspended.

Undertaking consultation activities was perceived to bring confirmatory as well as dissenting perspectives to the data analysis and interpretation phases of each study. In line with recent calls questioning the desirability of consensus, alternative perspectives were regarded as particularly valuable for highlighting practical and moral controversies that could arise from suggested implications (Charlesworth, 2018). For example, suggesting that face-to-face services were offered in parallel with digital services was considered by the FODNC to be potentially unjust since ensuring inclusivity of technologised services should be prioritised. Dealing with such controversies were experienced as supporting the author to engage in continual reflection during the research to process; revealing and challenging the author’s world views, biases and assumptions (Russell, Fudge, & Greenhalgh, 2020). By opening up the research process in dialogue between people with lived experience (FODNC) and training (author), rigour in the methodological approach was perceived to be enhanced (Cowley, Kerr, Darby, & Logan, 2019; Di Lorito et al., 2017). FODNC group members occasionally acted upon the findings, i.e. purchased and transitioned to a smartphone and fed back to the group and author about their experiences. Occurrences such as this provided the author opportunity for further reflection and refinement to the studies’ practical implications. For example; encouraging open-mindedness to trial options while upholding current technological habits and bearing in mind that the findings are not an absolute indication of ease of use. Taking action was also perceived by the author as an indication that group members related to the data and studies adding credence to the trustworthiness and applicability of the findings and interpretation (Poland et al., 2019). Such active engagement also indicated that the PPI activities had been undertaken meaningfully, ethically, and had been empowering (Di Lorito et al., 2017). Lastly, these instances with the FODNC contribute towards demonstrating the capability of people with dementia more broadly to contribute to the analytical process of the research, despite their own as well as others misgivings (Waite et al., 2019).

Achieving these outcomes demanded flexibility in co-designing the activities and was not without challenges, particularly around balancing expectations with regard to taking social action following research discussions (Bartlett, 2014; Greenhalgh et al., 2019; Poland et al., 2019). Ultimately the impact of the pandemic thwarted these social action ambitions, so that

we were unable to co-create our poster for national conference and local co-presentation, and the conference was cancelled. Furthermore, the group's own concerns about the fragility and sustainability of their rural group came to pass as their activities were suspended and we lost contact. For one group member who did his shopping with the facilitator after each session, this impact will have been substantial as he often exclaimed in discussions that "these are the only people I see!". It was not just the group they lost, as local staff were furloughed and regular face-to-face contact with proactive, familiar support staff was replaced by telephone contacts. Such impacts have been felt by people with dementia and their significant others across the UK, where worsened quality of life and anxiety have been linked to experiencing loss of supportive social activities and services under the pandemic (Giebel et al., 2020; Giebel et al., 2021).

6.4.6 Use of the 'd' word

The word dementia (and its Greek equivalent) can be traced to the first century BC and its meaning has evolved over time so that it is commonly understood in society albeit with contextual variation in how the syndrome is socially perceived (Pujol Domenech & Azpiazu Artigas, 2015; Rabins & Lyketsos, 2011). The stigma of living with dementia has often meant, and continues to mean, that it can be difficult to use the 'd'-word, as was relayed in section 6.4.2 (Milne, 2010; Moore & Cahill, 2013). Ultimately the most recent version of the diagnostic and statistical manual of mental disorders has replaced the term dementia with major neurocognitive disorder (American Psychiatric Association, 2000a, 2013a; Remington, 2012). While this may help clinicians in their discomfort using the word dementia, it may also create misunderstanding and confusion for the person receiving the diagnosis and does little to break the stigma of living with the disorder in society (Milne, 2010; Rabins & Lyketsos, 2011; Sachdev et al., 2014). Understanding that language evolves and changes, this thesis uses the word dementia throughout and unabashedly in conjunction with person first terminology which is currently considered respectful and recommended by a number of countries (Swaffer, 2014). This use of language helps to clearly position this thesis in a social context while ensuring clarity and consistency of communication between research, clinical and public contexts at the present time.

6.4.7 Reflection on the findings with respect to the COVID-19 pandemic

The issue of being able to compensate for lost out of home participation via technological means has come further to the fore internationally due to the ongoing pandemic (Seifert, 2020; Seifert et al., 2021). The findings of this thesis point to exacerbated digital and social exclusion among those older adults who are most vulnerable, whether with or without dementia. While those who previously went to more places potentially had more to lose in their everyday lives, the findings would suggest that this likely depended on the extent to which they could compensate for these losses with their higher ability to use ET and larger ICT room. In sympathy with other studies, the findings also indicate that the people most resilient to out of home losses wrought by the pandemic are also likely to be co-habiting or in close contact with someone who can sensitively support them in their ET use (Hwang et al.,

2020; Jakobsson et al., 2019; Ryd, 2017). COVID-19 related restrictions have been linked to increased hospital admissions and changes to routines that have exacerbated dementia symptoms (i.e. memory, concentration, mood) and led to increased difficulties at home (Nazarko, 2021). Greater abilities, resources and living with a significant other form conditions that are likely to better support rehabilitation from functional decline experienced under restrictions back into a more social post-pandemic out of home life.

Arguably then, those who may have lost the most may be those who had less to begin with. Those living alone, whose footprint of frequented places was already reducing, with no use of the internet, increasingly problematic use of the telephone, and a more distant network of supporters who may have become largely inaccessible. This argument is echoed by the results of a telephone survey in Spain which noted the relevance of TV-based support services, particularly for respondents with cognitive impairment living alone, who were found to have lower wellbeing and reduced sleep compared to co-habiting respondents (Goodman-Casanova, Dura-Perez, Guzman-Parra, Cuesta-Vargas, & Mayoral-Cleries, 2020). The precarity of everyday life for this population group has been found to require urgent attention as the pandemic had led to isolation and distress, fear, misinformation, and support needs that require essential services (Portacolone et al., 2021). While people with dementia have been enduring losses to out of home life and the exacerbation of a shrinking world (Talbot & Briggs, 2021), the pandemic has similarly been impacting the support infrastructures. Not only have face-to-face activities been suspended, but revenue streams have throttled with the economy, and human resource capacity has become stretched (Giebel et al., 2021; Johnson, Rauhaus, & Webb-Farley, 2020; Mahase, 2020). This has impelled extensive changes to how non-profit support services are offered to older adults as they have largely moved to telephone or online (Alzheimer's Society, 2020; Brooke & Jackson, 2020). And therein lies the injustice. That at a time of increased need, those who need familiar, localised support the most, however temporarily, may be facing the most restricted access to it (Giebel et al., 2020; Nazarko, 2021).

This desperate situation points to the precarity of contextual conditions that surround technology use and its interplay with participation. They highlight acutely how irreplicable and temporary findings in this area of research can be and yet simultaneously how such knowledge can provide analytically generalisable and pragmatic contemporary insights. Insights that in this instance suggest a widening injustice that must be dealt with and learned from to prevent such impacts as part of future pandemic and other disaster preparedness.

7 POINTS OF PERSPECTIVE

7.1 IMPLICATIONS

The implications that follow are strongly connected to the findings of this thesis and to the broader research context taking into account recent evidence. Suggestions are made with respect to a) households, families and neighbours, b) occupational therapists, c) public places and services, d) social and infrastructural policy makers, e) designers of ET.

7.1.1 Inclusive participation for households, families, and neighbours

Inclusive participation in society for older adults with and without dementia means paying attention to the technologies that are most comfortable and familiar (**i-iv**). Comfort may extend beyond the device to how it is used, i.e. some people may prefer to receive a call, whereas others may be wary about who is ringing and prefer to make the call. Knowing a person's preferences when using technology could smooth and contribute to a stable, reassuring everyday life.

The way in which older adults use technologies may also change over time; i.e. a preference to continue pumping fuel, but not make the payment (**iii**). Being ready to support and adapt through these changes may be a process of trial and error. The reciprocal efforts of both parties need to be recognised and a willing maintained to revisit previous choices (Hwang et al., 2020; Ryd, 2017). If technology becomes very problematic, then considering an alternative way to participate and achieve the goal may be more suitable but may also entail adjustment to new routines (**ii-iii**).

Being aware of people's potential challenges in using technology could be a lifeline for those whose struggles are attended by other restrictions in everyday life. Even a landline phone can be unsuitable for contacting someone, so that the only means of offering useful support and reassurance may be through a physical welfare check. (**ii-iv**)

7.1.2 Occupational therapy for optimising participation

The prevalence of everyday technology and its significant interplay with participation means that the scope of occupational therapy practice should extend beyond people's homes and include the possibility to design and deliver interventions that address barriers in this interplay. Rapid societal changes are a threat to older adults' participation (i.e. the move towards cashlessness) and occupational therapy may be able smooth this transition. (**i-iv**)

Occupational therapists could play a significant role in enabling older adults with and without dementia to continue using personally relevant technologies that support participation in important aspects of everyday life outside home. Equally, occupational therapists may be able to support older adults in finding solutions that enable them to continue participating outside home without the use of technologies. (**i-iv**)

A person's perceptions of their technological environment may provide a view into their wider socioeconomic and health situation (iv). Paying close attention to which aspects of contexts, including those in public space, can be modified could better optimise older adults' everyday lives (iii-iv). Occupational therapists can balance these wider contextual considerations to make clear recommendations that match older adults to new technologies that best fit their circumstances and abilities (i-iv). To best benefit people with and without dementia, occupational therapists therefore need to be free to make such recommendations (i-ii). At the other end of the scale, occupational therapists can investigate changing support or housing needs among people with or without dementia who present with new difficulties in using technology. Technological difficulties may for some people be indicating a pattern of manualising and instability in wider participation that requires therapeutic intervention (iii).

7.1.3 Ensuring inclusivity of public places and services in society

Health, social, financial, and other services that are mediated by EICT present a high challenge to many older adults through the demand to use internet-connected devices and automated phone systems. Services must remain available through simpler and more familiar means; i.e. direct telephone contact and face-to-face provision. These are the most viable ways of preventing a significant portion of older adults and people with dementia from being excluded from service provision. (i-iv)

More complex technologies are often thought of tools that may potentially reduce social inequalities. These technologies tend to involve EICTs together with e.g. codes, identification, authentication which continue to arise in new places (see e.g. adjacent photo of a SMS-lift/elevator operating device used for gaining access to a level in the hospital that is relevant for people with cognitive impairment). This set of technological tools are currently thought of as solving problems rather than thinking of the problems that the technology may cause. Where people fail in the expectation to use these devices, rather than considering technology as the problem, the person is problematised as a non-conformist who requires to be digitally included. Instead, using technological tools to mediate service delivery should be regarded as creating unacceptable sites of potential social injustice that contribute to social inequality (Weiss & Eikemo, 2017, 2020). The most accessible means of delivery (i.e. no, or low-technology) should be prioritised for the benefit of those most at risk of exclusion from needed services. (i-iv)



Photo: Charlotta Ryd, April 2021
Lift technology in a Stockholm public hospital operated by a code received via text message

To achieve accessibility, a technology should not be procured for use in public places or for services if exclusionary technological features can be identified. Such features may mean that

a technology has been advertently or inadvertently designed to expose a person's weaknesses. Perhaps causing inconvenience, embarrassment, pain, late attendance (i.e. the lift technology shown); or extorting penalties for the benefit of the procurer/contractor (i.e. surveillance parking technologies). **(i, iii)**

It is necessary to adequately consider inclusive design that attends to people's diverse cognitive abilities as part of the procurement of technologies. Involving people with dementia would offer unique and potentially more accurate insight into the inclusivity of the options available. Such consideration and involvement could facilitate participation by removing unnecessary technological barriers to driving (parking) and therefore shopping, healthcare etc. As part of these decision-making processes, the siting of the technology in its wider context should also be considered balancing i.e. security, distractions, noise, privacy, proximity to help and a non-technologised alternative. For example, locating a cash machine on a busy street, or quiet ally, or behind a secured vestibule to a bank branch. **(i, iii)**

Furthermore, an overall goal of human-friendliness would acknowledge and uphold as equal those people in society who seek to be manualised, or who have always been manualised. Such a universal move could be part of reimagining an alternative and more ethical future where the choice to be offline becomes realistic and redresses the emerging global power imbalance of digital enforcement (Díaz Andrade & Techatassanasoontorn, 2021). **(i-iv)**

7.1.4 Policy to address social and infrastructural inequalities of ET use

As well as technology creating conditions that exclude some people from participating; social inequalities can interplay in ways that exclude older adults from accessing and using technology **(ii-iii)**. Socioeconomic inequalities should continue to be addressed as part of improving access to places and ETs outside home across the lifespan. This may mean addressing inequalities in infrastructure between and within rural and urban areas i.e. transport, internet connectivity, banking. Where inequalities persist, older adults should be able to easily access realistic information from about how to meet their needs e.g. which internet or mobile service providers best fit the context. Service providers could provide this information, or it could be cascaded via sources that are tailored to local contexts (i.e. community groups, libraries, newsletters/noticeboards). Supporting people to make sometimes difficult and contractually committing decisions about service providers weighed against infrastructural limitations could remove any unnecessary barriers and difficulties in using ETs **(iii)**.

The preference that some people with dementia showed for cash and face-to-face banking following rural branch closures present an opportunity to create resilient and sustainable banking processes. These processes should not demand high abilities to use complex cash and banking technologies, but could include increasing awareness in society of inclusive options; i.e. cards used with signature, or rubber stamp (Gor & Aspinall, 2015). Inclusive options that support people to make payments and retain control over and insight into their finances may need to be developed in contexts where no options currently exist. **(i, iii)**

7.1.5 Ensuring inclusive design of ETs

While this thesis asserts the importance of non-technologised options for participation, the rights of older people with and without dementia as active citizens of a technological society are also upheld. To this end, the cognitive usability of ETs must be considered and ideally ensured within the design of new ETs so that the level of challenge is reduced, particularly in relation to more complex EICTs (i-ii). This will generate conditions that support more people with cognitive impairments and neurodegenerative conditions to be able to continue using ETs that are relevant to their everyday lives for as long as possible. Such reductions in challenge could be achieved by reducing navigation demands, maximising simplicity and minimising steps (Harvey, 2020). Auto-/personalisation approaches that increase the possibility for users to control how their own ETs, the ETs they encounter and the information that they receive via these ETs match their own preferences hold inclusive potential (Vanderheiden & Jordan, 2019). Properly tested and ethical implementation of ambient and intelligent assistive technologies in public places may also support optimisation of people with dementia's participation in society (Meiland et al., 2017).

Continuing to develop and implement forthcoming cognitive accessibility standards supported by appropriate legal enforcement may contribute to ensuring the inclusivity in the design of ETs (Lewis & Seeman, 2019). People with cognitive disabilities including due to dementia should be involved in developing these standards and supporting their implementation as part of the design and procurement of new technologies. (i-iv)

7.2 SUGGESTIONS FOR FUTURE RESEARCH

While this thesis forms part of early investigations into the interplay between ET use and participation, this area remains rich in terms of its potential to generate knowledge in support of dementia- and age-friendliness. Further studies using the ETUQ and ACT-OUT in different contexts are suggested together with new ideas for data collection that could build knowledge in this area.

7.2.1 Generating new insights into unstable participation

The thesis overall indicates a tight and potentially bi-directional interplay between participation outside home and technology use where reciprocal association testing these two variables could yield new insights. An unstable and descending pattern of participation indicated by the ACT-OUT may also prove useful to probe, since the combination of sub-studies iii and iv revealed that instability resulting in a low footprint of participation seems to hold the highest consequences. The thesis findings suggest instability may be indicated by a person's existing everyday technological resources, current unmet care or support needs, recent changes to household/family constellation, and perceptions of *future* access to public or private transport. The frequency with which a person goes to places may also hint towards this instability, even if change in frequency (i.e. going less/more often) cannot be captured with the ACT-OUT. The consequences of instability may hold high economic personal and societal costs in potential care and rehousing needs, so it is important to identify who in

society, and with which progressive health conditions, are most at risk. Deeper knowledge of the conditions of unstable participation could be used to guide policy and funding priorities focussed on mitigating and preventing negative participatory consequences to the individual and society. Such mitigation and prevention may also include further occupational therapy research into the strategies that older adults who are most at risk use to stabilise their participation. This knowledge could be cascaded via third sector organisations and groups that older adults frequent and used as a basis from which to devise interventions targeted to those most in need of occupational therapy support.

7.2.2 Gaining community perspectives on (technological) participation

The problematic and varied use of finance and travel technologies were found in this thesis to create conditions that threatened aspects of participation for people with dementia. This interplay involved a variety of places, implicating the people who work there and highlighting arenas for potential social action. However, these arenas are so far only illuminated from the perspective of people with dementia. For the purposes of building dementia-friendliness in society, it could be useful to undertake research with a variety of community stakeholders. Stakeholders' perspectives could highlight the potential for feasible action and gather existing effective actions that have eased technological friction in places and activities central to occupational justice. For example, shop staff may already be aware of their extended role as offering a financial service via cash back payments and may already be adapting how they act to facilitate the situation as needed. However, across different service sectors (i.e. banking, postal, retail, public transport) the extent to which, and how, people respond and adapt is unknown.

Generating such knowledge could produce practical guidance that could be implemented more widely, facilitating participation for a wider section of society. All everyday life situations are complex and making changes and adaptations to how everyday life is lived in interaction with others constitutes a kind of complex intervention. Consequently, it is important that changes to the interactions are made flexibly and reflectively with the potential for continual responsive evaluation and action. This aligns with a co-produced living lab and/or participatory action research approach (Brandsen, Steen, & Verschuere, 2018; Brankaert, 2016; Greenhop & Smith, 2018; Kemmis, McTaggart, & Nixon, 2013). The views of people with dementia would need to be central to such an endeavour, particularly those who are living alone and are most at risk of being unable to compensate for difficulties in technological interactions via the support of a significant other. A rural context would be an ideal setting for this kind of methodology as the economic viability of services in rural areas depends greatly on appealing to the whole community, rather than targeting a particular demographic. This interdependence may increase the motivation for shops and services to sustain custom from more vulnerable members of the community increasing engagement in research with the aim of enhancing dementia-friendliness and inclusion. In this instance, the knowledge flow could be reversed, with rural areas unusually generating best practices and approaches that could be cascaded into urban areas.

7.2.3 Developing knowledge about ET use in wider contexts

Ongoing research regarding digital inclusion/exclusion combined with the findings in this thesis justify further investigations into possible differences in the challenge of technology between more remote rural and urban contexts. Variation in challenge may be anticipated due to rural conditions of technological infrastructures (poorer speeds, coverage and connectivity), the composition of technologies available as well as the frequency with which ETs is encountered. The stability of the measure of ability to use ET generated using the ETUQ should be assured across a range of contextual conditions. Furthermore, the information generated could build upon the case study to provide broader insight into the potential for older adults more widely to be included or excluded from e.g. smart countryside collective transport initiatives.

The relative lack of DIF internationally between three similar countries similarly justifies wider international investigation of the validity and applicability of the ETUQ. The ETUQ collects data that is highly relevant for identifying support needs with respect to both using and modifying the technological landscape and individual technology rooms. In today's globally technologising context, this information can be used to tackle and ameliorate injustices at and beyond the level of the individual. Global research priorities and funding are overwhelming focussed and allocated to wealthier contexts which drives an ethical imperative to move the research context into lower income economies. This is particularly the case for dementia research where 60% of the world population of people with dementia (currently estimated at 50,000,000) live in low and middle income countries (Prince et al., 2015).

At the same time, however, decolonisation demands redistribution of power with non-paternalist approaches to research and knowledge generation. While undertaking this research and education, the author has been and continues to reflect upon and learn about how Western paradigms have dominated knowledge building, including at the intersection between older adults, dementia, technology and participation. Particularly since the subject matter requires theories of the environment and occupation where the quest to overcome dualism is ongoing within occupational science. Opening up to non-Western and Indigenous ontological perspectives and epistemologies on participation and the environment could motivate a new theoretical basis to instruments that investigate, with greater inclusivity, technology use and participation. For example, Sami animism has been argued as a route to melting boundaries between humans, animals, culture and nature to better understand how humans and non-humans interrelate (Helander-Renvall, 2010). However, diverse perspectives are typically delegitimised in research and have not formed the developmental basis of most tools that are then used with people who may face discrimination in society (Kovach, 2005; Kuokkanen, 2000; Martin, 2017). Within the heterogeneity of diverse societies, as those in Sweden, the UK and USA, it may be beneficial to this field that people with inside knowledge of Indigenous and diasporic perspectives investigate the construct validity of instruments such as the ACT-OUT and ETUQ. While again cautioning against racialisation and cultural stereotyping, construction within dominant Western paradigms may mean that

some respondents experience instruments designed to investigate their participation and use of technology as alienating and ill-suited to their world views on everyday life. Additionally, the data and knowledge generated would then not accurately reflect the lived realities of these respondents. This would be especially problematic if the data were then used to generate knowledge about participation that denied the lived experience of people who face racism or ethnic discrimination and further, obscured societal issues such as structural racism.

Conducting research that examines the applicability of the ACT-OUT and ETUQ in relevant languages to communities whose views tend to be marginalised is therefore suggested as a prior first step. This step may or may not highlight a need for revision or even reconstruction. Subsequently, research could then be focussed upon illuminating conditions of participation and technology use within these communities, as these communities deem such investigations to be valuable and relevant.

7.2.4 Pursuing updated knowledge for a post-pandemic society

Lastly, these studies shed light upon the continually changing technological relations which were seen to profoundly shape participation in everyday life as of four years ago. As the image in section 6.5.3 show, the technologies that older adults encounter and are expected to use can suddenly become unfamiliar and challenging due to new innovation. The pandemic has revealed how a sudden shift in social situation can completely change the conditions that surround technology use and people's possibilities and desires to participate in places so that the need for up-to-date knowledge continues. The new reliance on technology that was suddenly precipitated by the pandemic may have led to changes in the challenge of ET in relation to the perceived abilities of older adults with a variety of cognitive abilities. The ETUQ could be used to understand how technology rooms have altered and whether new items, such as virtual assistant technologies i.e. Alexa have become more integrated to participation in everyday life.

Whether there is a bigger role for technology in rebuilding post-pandemic participation and re-forming everyday life should not be assumed. Some people who technologically expanded under the pandemic may be keen to revert to more manualised ways and may be looking forward to returning to bigger footprint of places. These people's perceptions of whether a reversion is possible, how they would achieve it, and at what cost could yield new insights into the processes and conditions of digital enforcement. Additionally, much could be learned from understanding how older adults who were less, or un-technologically connected during the pandemic continued to participate and where. In light of the conditions in focus, this information would clearly need to be collected manually, with face-to-face contact and possibly via creative methods and/or collaborative co-research. Participating could also perhaps provide a welcomed chance to get out of the house, a social opportunity, and a confidence booster. It may also provide a route to both express and process what for many has been a torrid time: "A chance to get the badness out", as a member of the FODNC consulting group said of his involvement. This kind of research would provide valuable

information, particularly for voluntary and charity organisations about how to provide more effective support in future situations.

Likely variation in people's needs means that research could be undertaken to investigate the future balance required between technologised and non-technologised community participation opportunities across a range of sectors (i.e. health, social, leisure, culture). Generating this knowledge could provide practical information to aid appropriate allocation of resources to meet the post-pandemic societal needs of older adults with and without dementia. Ultimately, a lot has happened in the last 12+ months and the priorities of older adults, especially those with dementia may have shifted. Next steps for research into technology use and participation may be better informed by involving citizens in the identification of priorities.

8 SUMMARY CONCLUSION

This thesis provides insight into the conditions of ET use outside home among older adults with and without dementia in three different countries and between rural and urban contexts. Investigating across these contexts using multiple methods has highlighted the complex ways in which a diagnosis of dementia acts as a condition of ET use. Variations between these international and geographic conditions were also seen to shape older adults' ET use and this was viewed in relation to policy and service delivery differences across different sectors.

The impacts of these conditions were manifested in the challenge of the ET and older adults' possibilities to encounter and perceive those ETs as relevant. Furthermore, these conditions were seen to have a complex interplay that could both stabilise and destabilise older adults' participation in society. This interplay was illuminated with respect to close relations and family members, customer services relations, wider inequalities and transportation options.

In response to discussion of the findings, practical implications are suggested at different scales to engage people from a broad section of society in taking action. This engagement may also continue via a number of options for future research that would build both further knowledge and the case for social action. People are encouraged to reduce the technological friction that older adults may encounter in a wide range of places by considering technology as the problem that needs to be fixed rather than the solution to the problem. Reducing this friction may mean providing non-technologised options that uphold as equal those people in society those who seek a manualised everyday life. These provisions could contribute to a more inclusive society that facilitates the participation of everyone in everyday life.

9 PUBLIC DISSEMINATION ACTIVITIES

Forthcoming presentation: Wallcook, S. & Amanze, R. “‘I think I know my own mind’”: People with cognitive disorders as consultants and co-producers of research’, *Nionde nationella konferensen I kognitiv medicin – att leva med kognitiv nedsättning [The ninth national conference in cognitive medicine – Living with cognitive impairment]*, 25 November 2021.

Forthcoming presentation: Wallcook, S., Malinowsky, C., Nygård, L., Charlesworth, G., Lee, J., Walsh, R., Gaber, S.N., Kottorp, A. ‘The resilience of an occupational therapy tool to the changing technological environment’, *2nd COTEC-ENOTHE CONGRESS 2020*, online, 15-18 September 2021.

Ryd, C. & Wallcook, S. ‘Äldre personers samspel med andra när de använder teknik i dagligt liv - en kritisk granskning av individualism och fokus på självständighet’ [Older people’s collaboration in the use of everyday technology – a critical perspective on individualism and the focus on independence], *Arbetsterapi Forum 2021*, 16-17 March 2021.

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10 THE LOST VIGNETTES

This section is a record of some of the most poignant accounts given by a number of participants with dementia about their ET use. These stories have stayed with me, and inspired rhyme and music which can be found via Jilly Jarman's web presence. Jeff Wallcook has co-written two of them with me.

Stocks and Shares, or Solitaire?

After breakfast – each and every day
I visit my home office – just along the passageway
It's set up just as I like it
With a desktop computer,
landline phone and books on the shelf
It's my calibration space – a place to find myself

I power up the computer – a familiar whirring sound
And I wait to see what version of myself will be found

How will I function today?

'Stocks and shares' or 'Solitaire'?
'Investment banking' or an 'incomprehensible stare'

Like a boss to their secretary
I phone along the passageway to my wife
Requesting the morning papers and a cup of tea
Familiar comforts in an ever-unknowing life

I will join her when I am fully informed of myself

The Brick

I loved my iphone with its vibrant display
It was filled with messages and photos
Of loved one who had passed before their day

I'd sit in my room all alone
And yet with that phone
I was never on my own

Swiping the memories from left to right
Zooming in on eyes still bright
Their smiles filled with joy and light
Bringing both sadness and comfort
Through day and night

I'd keep it on silent to avoid its shrill
Just for someone to say
"do you need owt?" or "have you remembered to take your pill?"

I didn't want it to invade my space
To tear me from my sacred place
Of memories and people and of times gone by
Of things we'd done together - side by side

"It's very inconsiderate not to pick up the phone"
"We worry about you, now you're all alone"
"Perhaps she doesn't know how to answer or make a call"
"She has got dementia after all"

They bought me a new phone
With a big red button on the side
They inserted my sim-card
And for the second time my loved ones died

Gone was my connection to that heavenly cloud
Where my memories were stored
Where loved ones could be heard
Talking and laughing out loud

No longer swiping from left to right
Zooming in on eyes still bright
No longer was I never alone
But always in my room – on my own

That brick of a phone with its button bright red
To press rather than dial 999 instead
The brick that brought me isolation and gloom
Oh, to throw that brick across the room!

But every once in a little while
I look at the brick with a cheeky smile
How tempting to press that button red
In the dark of the night when all are in bed

To hear the sirens and the banging on the door
Their expectation to find me lying on the floor
But then to see me with a grin on my face

But I won't
For that will not bring back my sacred place.

--

I watch the flames
They tell me the names
Of the people within
Whose lives begin
In the twists and turn
Of the snapping burn
I interpret those motions
Depict their devotions
While eyes all a shimmer
My family whisper:
That I am anointed...
The storyteller appointed

In several decades
I've not sat and regaled
From the flames of the fire
But I've still the desire
To let you know

That my only foe,

The one to prevent
- But I'll have this lament –
“It's the end of the line
for my tales!”, I twine

Appointed my defeater:
My underfloor heater

At the end of a game of golf at the club,
they have to put their scores in
at the Ninth Hole computer.

He is supposed to do his own.

He leans forward and smiles as he confides:
“I pretend I left my glasses in my locker.”

Someone will always offer to do it for him.

‘Cry from the heart from a Grandma’

Granma Vi Goodhand responded to the poem that Ronald and Jilly are producing and I was delighted that she was willing to share it in my book. The next step is to test it out on strangers.

‘I think I know my own mind’.

I’m not too sure about that - my mind keeps wandering in different directions. Yes, I’m still ME, the same person, but life is confusing, breaking up around me.

Things once so familiar are difficult to use, even my phone must change and shops don’t want cash any more.

Why must I learn this new technology...to make things easier..to do what? Buy stuff I don’t need just to be like you and all the others out there following the latest trends?

Oh, yes, I do want to be part of the wider world ...if I can cope. I just need a patient tutor with lots of patience and understanding to gently lead the way, to reassure me that this way is the right one for me. Be prepared, I might fail, I might give up.

This makes me anxious...don’t abandon me, ‘the stress burdens me’...

I still need to be loved whatever the outcome.

I know you are trying to lead me into the now confusing world out there. I am waiting, I am ready, I WILL try. Yes!

Take me shopping, show me how to use chip and pin, pay at the self-service counter, shop online, deal with passwords, use a mobile phone, flip phone, smartphone (what is that?) etc.

Understand my memory fades out, concentration is limited, eyesight failing, I may not hear or understand your words. I need to be told over and over (never say I’ve already told you that!) Be patient I just may not want to go where you think I should go. But I will try.

Like you, I enjoy the life I have, even if it lacks the things you have. Include me ‘in’, even while my mind is fading. I can still live and love and share the sheer joy of living!

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