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**THE PARTICIPATION OF OLDER PEOPLE  
WITH AND WITHOUT DEMENTIA IN  
PUBLIC SPACE, THROUGH THE LENS OF  
EVERYDAY TECHNOLOGY USE**

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# The participation of older people with and without dementia in public space, through the lens of Everyday Technology use

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

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The thesis will be defended in public in room H3, Zanderska Huset, Karolinska Institutet, Alfred Nobels Allé 23, Huddinge.

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*To Hosna & Martha*



## POPULAR SCIENCE SUMMARY OF THE THESIS

This thesis sits at a critical juncture for an ageing and increasingly technological society. On the one hand, in countries like Sweden and the UK, people are ageing and living for longer in their communities. Living in one's community involves participating not only at home but also in one's chosen activities and places within public space. And as a greater number of older people live and participate in their communities, they may do so with age-related diagnoses such as dementia. On the other hand, the ability to access and use Everyday Technologies whilst participating in activities and places within public space, for instance a smartphone using a navigational app, a ticket machine for public transportation or a self-service checkout at a supermarket, is taken for granted. Assumptions about the neutrality of technology have contributed to a knowledge gap about the relationship between the technologies that we encounter and use in our everyday lives and our participation in society.

Participation has been explored through four unfolding studies, using different methods, data visualisations, and two questionnaires developed by the CACTUS (Cognitive Accessibility and Technology Use when aging in home and Society) research group at Karolinska Institutet, Sweden. This thesis contributes findings from the perspective of older people with and without dementia themselves. The findings provide insights into participation in activities and places within public space, among older people with and without dementia in two European countries (Sweden and UK), and how different aspects, such as the relevance and perceived ability to use Everyday Technologies, interact with and influence participation, over time.

Contributions of the research include an emphasis on the complexity of participation within an ageing and increasingly technological society and an inquiry of the way that we view and think about dementia. By viewing the participation of older people with and without dementia through the lens of Everyday Technology, it becomes apparent that dementia is not simply the static status of disease, disability, or mere difference. Rather, Everyday Technologies play an active role in the older person with and without dementia's ability to enact their citizenship, through a nuanced and dynamic process of participation in activities and places within public space. This may affect the older person with and without dementia, as well as on other levels of policymaking, clinical practice, and the ways in which we plan and design places, technologies, and services.

## ABSTRACT

Participation in activities and places within public space has been linked to numerous health benefits and yet, little is known about participation among older people with and without dementia. Insights about participation in activities and places within public space can contribute to the somewhat ambiguous definition of participation, as “involvement in a life situation”, by acknowledging the complexity and interrelatedness of subjective, social, contextual, temporal, and technological aspects of participation. Thus, the overarching aim of the four studies was to explore participation in activities and places within public space, among older people with and without dementia in two European countries (Sweden and UK), and to evaluate how different aspects, such as the relevance and perceived ability to use Everyday Technologies (ETs), interact with and influence participation, over time.

Across all studies, interviews used the Participation in Activities and Places Outside Home Questionnaire (ACT-OUT) and the Everyday Technology Use Questionnaire (ETUQ), in order to focus on the perspectives of older people with and without dementia themselves. **Study one** explored stability and changes in participation in places visited within public space in relation to the relevance of ETs used in public space, among a baseline Swedish sample. **Study two** utilised ordinal regression to investigate the ways in which perceived risks and ET use were associated with out-of-home participation, among a UK sample of older people. Using a mixed methods design and data visualisations, **study three** delved into aspects of social participation in more depth, including ET use and social deprivation of the living environment, among two UK sub-samples of older people with and without dementia. **Study four**'s longitudinal design and multilevel modelling deepened the knowledge about how use of ET outside home, relates to participation in places visited within public space among a Swedish sample of older people with dementia over time.

**Study one**'s findings demonstrated a statistically significant positive association between a higher person measure of ability to use ETs and higher participation in places visited within public space, among the Swedish sub-sample of older people with dementia but not those without dementia. According to the ordinal regression model in **study two**, a higher probability of ET use was associated with a higher level of out-of-home participation, among the UK sample of older people. By elucidating motivators, considerations that require extra attention, and management strategies among UK sub-samples of older people with and without dementia, **study three** provided insights into the nuances of social participation. Finally, **study four**'s findings revealed that decreasing use of ET outside home was associated with decreasing participation in places visited within public space, in a statistically significant way when accounting for age.

In summary, this thesis contributes empirical insights about the participation of older people with and without dementia in activities and places within public space, through the lens of ET use. Such knowledge can be used to develop targeted health and social care planning and the design of more inclusive places, technologies, and services.

**Keywords:** Alzheimer's disease, citizenship, data visualisations, dementia, longitudinal, mixed methods, occupational therapy, older adults, risk, social participation, technologies.



## LIST OF SCIENTIFIC PAPERS

- I. Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., & Malinowsky, C. (2019). Everyday technologies and public space participation among people with and without dementia. *Canadian Journal of Occupation Therapy*, 86(5), 400-411. <https://doi.org/10.1177/0008417419837764>
- II. Gaber, S. N., Nygård, L., Kottorp, A., Charlesworth, G., Wallcook, S., & Malinowsky, C. (2020). Perceived risks, concession travel pass access and everyday technology use for out-of-home participation: Cross-sectional interviews among older people in the UK. *BMC Geriatrics*, 20(1), 1-12. <https://doi.org/10.1186/s12877-020-01565-0>
- III. Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., Charlesworth, G., Wallcook, S., & Malinowsky, C. (2020). Social participation in relation to technology use and social deprivation: A mixed methods study among older people with and without dementia. *International Journal of Environmental Research and Public Health*, 17(11), 4022. <https://doi.org/10.3390/ijerph17114022>
- IV. Gaber, S. N., Nygård, L., Malinowsky, C., Brorsson, A., Kottorp, A., & Hedman, A. (2020). *Enacting citizenship through participation in a technological society: A longitudinal three-year study among people with dementia in Sweden* [Manuscript submitted for publication]. Department of Neurobiology, Care Sciences and Society, Karolinska Institutet.



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## **LIST OF ABBREVIATIONS**

ACT-OUT	The Participation in ACTivities and Places OUTside Home Questionnaire
AD	Alzheimer's Disease
ADL	Activities of Daily Living
ET	Everyday Technology
ETUQ	Everyday Technology Use Questionnaire
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
IMD	Index of Multiple Deprivation
MCI	Mild Cognitive Impairment
MoCA	Montreal Cognitive Assessment
MOHO	Model of Human Occupation

# INTRODUCTION

## Personal introduction

The remnants of universal design, and its associated terms (i.e. inclusive design, design for all) are evident in the places we visit, the technologies we use and the services we access. Through mainly physical adaptations, universal design has influenced the creation of places, technologies and services which are intended to be accessible to the greatest number of people, irrespective of their abilities or disabilities. However, opportunities to participate in society cannot yet be assumed to be universal, particularly due to a lack of consideration for aspects of cognitive accessibility.

During my training in art and architecture in London and Edinburgh, I worked as a carer for older people living in the community, many of whom were diagnosed with dementia. Whilst in the studio and at university, I immersed myself in the utopic visions of innovative and inclusive cities based on universal design. This counterposed my experiences, as a carer, witnessing various challenges that restricted the opportunities for older people with and without dementia to participate beyond the boundaries of their homes. My critical reflection on universal design informed my subsequent training in occupational therapy as I witnessed a range of universal design “solutions”, including assistive technologies and policies promoting age- and dementia-friendly communities. There seemed to be a lack of consultation with users or empirical evidence to substantiate these “solutions”. This ignited a curiosity about the way in which older people with and without dementia participate in activities and places that they perceive as necessary or meaningful, beyond their homes and within public space. Based on my interdisciplinary training and practice, I realised that if I were to pursue a doctoral education, the impetus should come from the older people with and without dementia themselves, as *occupational beings*. Thus, the initiative for developing more inclusive places, technologies, services and indeed, communities, can arise from an occupational therapy perspective, according to the person’s patterns of participation and experiences of everyday life, and not merely based on architecture or technology design.

In recent years, there has been an emphasis on inclusive research, design, and development processes. Involving a broader range of users to inform and inflect all stages of the design and development of places, technologies and services can produce more inclusive, accessible, welcoming public space but also a public space which is more intuitive and targeted to the needs of different users. Such approaches rely on interdisciplinary expertise and perspectives, combining the scientific and the social, quantitative data and more qualitative aspects of perception and experience. This thesis harnesses interdisciplinary perspectives of participation in public space and explores an alternative perceptual mode based on the reports of older people with and without dementia themselves. I propose that the perceptions of people and communities who may traditionally have been viewed as vulnerable or marginalised, both in society and research, can yield novel insights into the everyday context of participation in activities and places within public space and in relation to technology use.

## Introduction

The introduction provides an overview of this thesis, including a statement of the purpose and problem under investigation, as well as its significance. The scope of this thesis is delineated according to relevant assumptions, and through an outline of the methodology and structure of this thesis.

### Purpose and problem statement

The purpose of the research project and thesis was to develop empirical insights into the participation of older people with and without dementia in public space, through the lens of Everyday Technology (ET) use. The purpose is motivated by a disjuncture between the plethora of national and international policies that advocate for older people with and without dementia to age in their communities, without due consideration for the ways in which they live in their communities. Living in one's community typically necessitates participation outside the home, in activities and places within public space, and involving some type of ET use, independently or with support from others. For instance, a person regardless of their diagnostic status, may need to use ETs to access public transportation, for purchasing food at the supermarket, or to maintain social contact with family and friends (Brorsson, 2013; Lindqvist et al., 2016). However, the ubiquity of ET and the ability to use ET proficiently are taken for granted. In the few instances that it is mentioned in policies for age- and dementia-friendly communities, technology is presented in a subsidiary or neutral role without critical inquiry about how it may impact the way in which older people with and without dementia participate in society (Peine & Neven, 2020; Marston & van Hoof, 2019).

### Rationale and significance

This thesis is the outcome of a doctoral education at Karolinska Institutet and it also formed part of the *Interdisciplinary Network for Dementia Using Current Technology* (INDUCT, 2020). INDUCT is an international and interdisciplinary research framework for Europe, funded through the Horizon 2020 Marie Skłodowska Curie Actions - Innovative Training Networks (INDUCT, 2020). The goal of INDUCT is to improve technology and care for people with dementia, and to develop an evidence base to show how technology can support the lives of people with dementia. This thesis contributed knowledge to the INDUCT project about how older people with dementia relate to technology in everyday life, in order to provide insights about the practical, cognitive, and social factors to improve the usability of technology.

This thesis harnesses the international INDUCT collaboration and it utilises Swedish and UK data. The rationale for collecting data in both Sweden and the UK was inspired by earlier research which indicates that activities of daily living (ADLs) (Kielhofner, 2008) as well as access to and use of ETs may be influenced by cultural factors (Kottorp et al., 2016). Sweden and the UK are both high income, west European societies with a similar proportion of older people in the population (Eurostat, 2019). Both Sweden and the UK have been described as

information societies due to their reliance on Information Communication Technologies (ICTs) (Reisdorf, 2011). Moreover, the countries share overlapping approaches to dementia health and social care, including the Swedish National Guidelines on Dementia launched in 2010 (Swedish National Board of Health and Welfare, 2010) and the National Dementia Strategy introduced in the UK in 2009 (Department of Health, 2009). Of particular interest is the Swedish Government's national strategy for dementia (Swedish National Board of Health and Welfare, 2017), the vision to be a world-leader in e-Health by 2025 (The Ministry of Health and Social Affairs & The Swedish Association of Local Authorities and Regions, 2016), and plans for Stockholm to be a smart city (Stockholms Stad, 2014). Furthermore, in the UK the Mayor of London has called for London to be the first dementia-friendly capital city in the world by 2022 (Alzheimer's Society, 2018). An exploration of these seemingly similar countries enables a "fine-grain" analysis.

Positioning the research through the conceptual lens of ET use, facilitates an inquiry of the ways that older people with and without dementia participate in society to enact their citizenship. This may include navigating occupational injustices that infringe upon the human right to participate in activities and places, within public space. The relevance and perceived ability to use ETs is potentially a matter of occupational injustice, as a determinant of participation in a technological society. There is a need to explore ET use in relation to participation as research suggests that participation, especially in cognitive and social activities, may have health benefits, such as reducing isolation and preventing cognitive decline among older people at risk of developing dementia (Evans et al., 2019; Mangialasche et al., 2012; Marioni et al., 2015; Zhou et al., 2018). Such knowledge is potentially significant for gaining insight into how older people with and without dementia participate in activities and places within public space, in relation to ET use, as a way of enacting their citizenship, and to enhance or maintain their health.

## **Researcher assumptions**

The exploration of participation in relation to occupational injustices pertains to an underlying assumption which delineated the scope of the research and this thesis. Throughout this thesis, the participants, older people with and without dementia, were viewed as *occupational beings*. Whilst the theoretical considerations evolved across the unfolding exploration of participation in activities and places within public space in the four studies, the view of older people with and without dementia as *occupational beings* remained consistent. In occupational therapy and occupational science, the term *occupational beings* refers to the human need and desire to engage in occupations (Drolet, 2014; Wilcock, 1993). Occupation has been described in various ways. For instance, what a person does in work, play or self-care (Kielhofner, 2008). In this thesis, occupation concerns participation in activities and places which are perceived as meaningful or purposeful to the person participating in them (Hitch et al., 2014; Wilcock, 1993).

The view of older people with and without dementia as *occupational beings* warranted a review of the values of occupational therapy and the philosophical assumptions that guide such values. The review showed that like other disciplines, occupational therapy has inherent

core values (axiological normativity) (Drolet, 2014). The axiological normativity of a profession can help to guide its identity, attitudes, beliefs and values (Drolet, 2014). The assumption that people are *occupational beings* is evident in the value statements of occupational therapy professional organisations, such as the World Federation of Occupational Therapists (WFOT), the Canadian Association of Occupational Therapists (CAOT), the American Occupational Therapy Association (AOTA), the Royal College of Occupational Therapists (RCOT) in the UK, and the Swedish Association of Occupational Therapists (Sveriges Arbetsterapeuter), and yet, the interrelationship of concepts such as the person, the environment, and occupation, are prioritised to varying degrees (Drolet, 2014; RCOT, 2015). The interrelationship of the concepts of the person, the environment, and occupation are discussed across the different chapters of this thesis, including the view of ETs as a dimension of the environment.

The axiological assumptions of this thesis are linked to a definition adopted by the RCOT: “As occupational beings, people are intrinsically active and creative, needing to engage in a balanced range of activities in their daily lives in order to sustain health and wellbeing. People shape, and are shaped by, their experiences and interactions with their environments” (RCOT, 2015, p.1). Based on the RCOT’s definition and others, there is an assumed need and desire for older people with and without dementia to participate in meaningful activities and places, including those within public space. Whilst there is an implicit assumption of active, healthy ageing in such definitions (Nilsson & Townsend, 2010), the frequency, combination, motivations, and other modalities of participation among older people with and without dementia may vary and therefore cannot be assumed (Aw et al., 2017). Throughout the unfolding exploration of participation in activities and places within public space, this thesis presents a more nuanced and complex understanding of participation, acknowledging not only the potential health benefits of being active but also other issues related to perceived risks and social deprivation of the living environment. For the purposes of this thesis, occupation was not understood as an outcome of human function but rather as integrated into the older person with or without dementia’s interactions with their environment, as they participate in activities and places within public space.

## **Overview of the methodology**

The research was investigated in two different countries, in Sweden and the UK. The data is based on a sub-sample of older people with dementia and a sub-sample of older people without dementia as a comparison group, for each country. Hereafter, the participants are referred to as older people with and without dementia. The Swedish sample included 35 older people with dementia, in the mild to moderate stage, and 34 older people without dementia (i.e. no known cognitive impairment). The UK sample was comprised of 64 older people with dementia, in the mild stage, and 64 older people without dementia. Across all of the studies, data was collected through face to face, semi-structured interviews using four tools: (i) the Participation in ACTivities and Places OUTside the Home Questionnaire (ACT-OUT); (ii) the Montreal Cognitive Assessment (MoCA); (iii) a demographic questionnaire; (iv) the Everyday Technology Use Questionnaire (ETUQ). The data was analysed using different



approaches, including descriptive and inferential statistics, multilevel modelling, and content analysis. Data visualisations were used to analyse the data and to present the findings.

## **Structure of this thesis**

This thesis follows a compilation structure with four manuscripts compiled at the end of this thesis. The four manuscripts are introduced and contextualised according to seven preceding chapters, including this introduction in **chapter one**. In **chapter two** the literature is reviewed, and the research aims are specified. In **chapter three**, the theoretical and methodological resources are outlined, in preparation for an explanation of the methods and analyses in **chapter four**. In **chapter five** the findings for each study are presented and then, synthesised. **Chapter six** comprises a critical discussion of the synthesis of the findings, in addition to methodological and ethical considerations. **Chapter seven** provides a conclusion with contributions and suggestions for future research and finally, a reflection on the social impact of the research.

## BACKGROUND

This chapter presents a critical review of the state of the art of the research field that this thesis is situated in, including the identification of knowledge gaps that this thesis seeks to contribute to.

### Older people with and without dementia

Older people with and without dementia are *occupational beings*, just like the rest of society (Drolet, 2014; Strandenaes et al., 2018; Wilcock, 1993). According to an occupational perspective, there is an inherent need and desire for *occupational beings* to participate in meaningful activities and places, however, this need and desire may be compromised by the vast fiscal and societal costs of dementia (Alzheimer's Disease International [ADI], 2018; Livingston et al., 2020). The World Health Organisation (WHO, 2012) has declared that dementia is a global health priority and there are currently 50 million people with dementia worldwide (ADI, 2018). The number of people with dementia in Europe is growing and it is projected to almost double by 2050 (Alzheimer Europe, 2020). In Sweden alone, official reports indicate that there are currently between 150,000 (Svenska Demensregistret [SveDem], 2020) to almost 170,000 people with dementia and the National Quality Registry for Dementia (SveDem, 2020) estimates an increase of 24,000 people diagnosed with dementia each year (Alzheimer Europe, 2020). In the UK, there are approximately 885,000 older people with dementia, and the majority of these people live in England (Wittenberg et al., 2019). Research shows that age is a leading risk factor for dementia (Livingston et al., 2020) and reports suggest that the increase in the number of people with dementia in both Sweden and the UK may in part be attributable to an increase in the number of people aged over 65 years old, with a specific increase in those over 85 years old (Alzheimer Europe, 2020).

As an umbrella term, dementia includes over 100 different diseases and symptoms and the most common type of dementia is Alzheimer's disease (AD) (Houston et al., 2018). Dementia is a chronic condition, characterised by the progressive deterioration in previously attained cognitive levels (Livingston et al., 2017). Research shows that dementia can impact participation in various ways, including changes in cognition, executive functioning, memory, planning, attention, processing, orientation, functional ability, mobility, motivation and other skills required to perform ADLs (Classon et al., 2016; Giebel & Challis, 2015; Jekel et al., 2015; Wahl et al., 2013). However, the presentation of dementia can vary across people, time, and contexts (ADI, 2019) and it is pertinent to consider how such variability relates to participation. This highlights a need to gain insights into how dementia impacts participation, as a precursor to the facilitation of participation in activities and places within public space for this population.

## Participation, dementia, and ageing

The majority of older people with and without dementia reside in their homes, within their local communities (Fæø et al., 2019; WHO, 2012). As a greater number of older people with and without dementia live and age in place, this involves not only participating in their homes but also within public space. And yet, much of the research targeting older people with dementia focuses on long-term care settings or solely within the confines of the older person's home (ADI, 2015; 2018). The frequency of participation outside the home has been linked to a person's cognition and their ability to perform ADLs (Mlinac & Feng, 2016). Research shows that older people with mild cognitive impairment (MCI) and mild-stage dementia may experience changes in their cognition, which can change or disrupt activity patterns and prove burdensome (Johansson et al., 2015). Longitudinal research among older people with MCI has revealed profiles of decreased engagement in activities, in particular activities within public space, such as shopping, socialising, recreation and driving (Hedman et al., 2017). Similarly, profiles of decreased engagement in activities have been associated with the degree of cognitive severity in older people with MCI (Hedman et al., 2017) and AD (Nygård & Kottorp, 2014). Whilst longitudinal studies among older people with MCI suggest that there is may be a descending pattern in participation over time, there is a lack of comparative studies among older people with dementia. Thus, there is a knowledge gap about the patterns of participation among older people with dementia over time.

Few studies have investigated the patterns of participation in ADLs over time for older people with dementia and especially, regarding participation in activities and places outside the home, within public space. This knowledge gap is potentially problematic for at least two reasons. Firstly, studies suggest that older people, including those with dementia perceive value in participating within public space, for various reasons (Brorsson, 2013). This includes an appreciation of opportunities for social interactions (Kearney, 2006), physical activity (Sugiyama et al., 2009), and an enjoyment of one's natural environment (Ward Thompson & Travlou, 2007). Secondly, research has revealed that participation in cognitive and socially-stimulating activities, which may occur within public space, is a potential protective factor to prevent cognitive impairment or decline among older people at risk of developing dementia (ADI, 2018; Winblad et al., 2016; Mangialasche et al., 2012). Thus, perceived value, a sense of enjoyment, and potential health benefits have been associated with participation in activities and places within public space, among older people with and without dementia.

The Lancet Commission on dementia prevention, intervention, and care has identified twelve modifiable risk factors for dementia which account for approximately 40% of the cases of dementia globally which may be preventable (Livingston et al., 2017, 2020). The risk factors include depression, diabetes, hearing impairment, hypertension, lower educational levels, obesity, physical inactivity, smoking, excessive alcohol consumption, traumatic brain injury (TBI), air pollution, and lower social contact (Livingston et al., 2017, 2020). Social contact in particular, has been revealed to be a more important protective factor for cognitive health and wellbeing (Evans et al., 2019; Marioni et al., 2015; Sommerlad et al., 2019; Zhou et al., 2018) than previously assumed, based on a life-course model of dementia (Desai et al., 2020; Livingston et al., 2020). Whilst the identification of modifiable risk factors is relevant for a prophylactic approach to dementia care and research, the focus on lifestyle factors has also

been criticised as it may locate the burden of responsibility solely on the individual (Cahill, 2020). Social contact, however, involves participation in activities and places, typically with other people and within public space (Clarke & Bailey, 2016). This suggests that social contact and participation are not necessarily individualistic endeavours. There is a potential role for healthcare professionals as well as other community stakeholders to help facilitate opportunities for social contact and participation in activities and places within public space (Haak et al., 2008). Arguably, occupational therapists are well positioned to contribute to dementia prevention, intervention, and care (The National Institute for Health and Care Excellence [NICE], 2018) based on their in-depth training in activity analysis and their experience working with varied groups of people to facilitate participation, through adaptive and compensatory approaches (American Occupational Therapy Association [AOTA], 2017).

## **Participation in activities and places within public space**

### *Participation and social participation*

The International Classification of Functioning, Disability and Health (ICF) defines participation as “involvement in a life situation” (WHO, 2001). Despite this formal classification and its widespread use across various disciplines, it is limited due to its ambiguity and emphasis on rehabilitation, or the rehabilitative potential of the individual (Piškur et al., 2014; van de Velde, 2018), which may not be applicable for older people with a progressive diagnosis such as dementia. The ICF definition has also been criticised due to its neglect of subjective (Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003) and social aspects of participation (Piškur et al., 2014; van de Velde, 2018). Increasingly, dementia research has focused on social aspects of participation, referred to as social participation (Turcotte et al., 2018). Piškur et al. (2014) contend that social participation is not a distinct concept from participation but rather it is a type of participation. Based on a systematic review, Levasseur et al. (2010) developed a taxonomy of participation in activities and defined social participation as: “a person’s involvement in activities that provide interaction with others in society or the community”. However, there is still a lack of clarity about what types of activities and places social participation encompasses. The ICF definition of participation may be improved by gaining insight into social aspects of participation, through research targeting social participation. Such an approach embraces the complexity of social participation and conceptualises it as a continuum, from relatively passive to increasingly more active involvement (Levasseur et al., 2010).

Whilst the conception of a continuum of participation is useful in dispelling the notion of participation as static or fixed, other scholars such as Aw et al. (2017) underline the complexity and variability of the concept of social participation depending on multiple contextual factors. These may include the type of environment for the activity, the time of day, the involvement of ET, as well as person-related factors, including whether a person has a functional impairment or mobility issues. There is research to suggest that interventions promoting social participation among older people should consider the variability of their needs and preferences (Dawson-Townsend, 2019). And yet, there is a dearth of knowledge targeting the self-perceived (subjective) needs and preferences of older people with dementia,

or comparative studies investigating social participation among both older people with and without dementia.

There is an absence of literature regarding participation within public space among older people with and without dementia. Public space refers to a geographical location and built environment, which may include activities, places and people as well as other contextual factors (Agnew & Livingstone, 2011). In this sense, the activities and places that people participate in are embedded within public space. Like public space, places have physical and geographical properties, however in addition to this, places also encompass the dynamic and evolving physical, social, cultural, economic and temporal relations that are formed as people and communities live and age in places (Lawrence-Zuniga, 2017). Whilst other scholars have explored how people form relations through the creation of a sense of place (i.e. place-making) (Johansson et al., 2013; Li et al., 2019; Rowles & Bernard, 2013), this thesis utilises the concepts of public space and place to investigate the ways in which older people with and without dementia enact their citizenship, through participation in activities and places within public space over time.

#### *Citizenship: whose right is it to participate?*

Scholars underline the importance of gaining knowledge about the public sphere of citizenship as older people with dementia, particularly those with mild to moderate stage dementia have been shown to value participation outside the home and within public space (Clarke & Bailey, 2016; Li et al., 2019; Phinney et al., 2016; Ward et al., 2016). Research suggests that citizenship operates on various levels. Baldwin and Greason (2016) propose that there are four different levels of citizenship that are relevant to the dementia discourse. Meta-citizenship and macro-citizenship occur at an abstracted level through national policies, such as national dementia strategies. Midi-citizenship concerns actions taken at an organisational level such as the initiatives of local Alzheimer's Associations or advocacy groups. Whereas, micro-citizenship addresses the concrete, ADLs that people and communities participate in. According to the level of micro-citizenship, Bartlett (2016) emphasises the everydayness of participation in everyday, concrete activities and places, and Neveu describes the everydayness of citizenship, as enacted through participation in "mundane spaces of daily sociability" (Neveu, 2015, p. 147).

Micro-citizenship is defined as "those actions and practices of individuals, in immediate relationship, which uphold the liberties and freedoms of those involved while generating or supporting a sense of identity and belonging" (Baldwin & Greason, 2016, p. 293). Studies exploring micro-citizenship include, Phinney et al.'s (2016) ethnographic study about a social activity group among younger people with dementia, who engaged in walking and socialising in their neighbourhoods. This simple activity was perceived as a way of constructing a sense of citizenship through shared interactions with their neighbourhood and other people (Phinney et al., 2016). Similarly, Ward et al. (2016) explored the routine occupation of visiting a beauty salon among older people with dementia as a way of creatively and communally enacting their citizenship, including the accompanying sense of agency and interaction with other people such as the hairdresser. In the literature, there are fewer studies

specifically among older people with dementia and there is little mention of the role of ET use (Nedlund et al., 2019; Phinney et al., 2016). However, there is a consistent view that participation in one's neighbourhood is not merely valued as a matter of functional or physical activity (Phinney et al., 2016). Rather, participation in places, such as the neighbourhood, is valued as way for the older person with and without dementia to enact their citizenship and to create a sense of belonging to a place or to a community over time (Calvert et al., 2020; Phinney et al., 2016; Rowles & Bernard, 2013).

### *The neighbourhood*

The neighbourhood refers to a lived place and historically it has been defined as a place where residents live and interact with each other and their environment, within geographic boundaries (Li et al., 2019). The importance of the neighbourhood as a core component of communities and cities is evident in ageing and dementia research (Clark et al., 2020; Li et al., 2019) and policies (Keady et al., 2012). Notably, studies from the international *Neighbourhoods: our people, our places* project emphasised the active role that neighbourhoods can perform in the lives of people with dementia, by setting opportunities but also constraints (Ward et al., 2018). Research exploring what matters to older people when discussing social connectedness found that the older people prioritised getting out of the house into their neighbourhoods and that the neighbourhood was integral to their sense of social connectedness and interpersonal relationships (Morgan et al., 2019). Studies emphasise a sense of familiarity associated with the connections that older people form with their social and physical neighbourhood environment (Duggan et al., 2008; Margot-Cattin et al., 2020).

A perceived sense of familiarity in the neighbourhood is potentially significant for this population, based on the presentation in literature of older people with dementia as particularly susceptible to spatial disorientation and the risk of getting lost (Wiener & Pazzaglia, 2020). Whilst there is a specific focus on spatial disorientation among older people with dementia, research indicates that navigational performance is influenced not only by cognitive impairment but more broadly speaking, it is an early indicator of the pathological ageing process (van der Ham et al., 2020). One of the reasons that older people with dementia in the mild stage, such as those included in this thesis, are considered susceptible to spatial disorientation challenges is because they may still be capable of mobilising outside home independently but once they are in public space they can encounter spatial disorientation (Brorsson, 2013; Wiener & Pazzaglia, 2020). Due to the challenges with spatial orientation, participation even in activities and places that were once familiar for the person with dementia may be compromised (Burton & Mitchell, 2006), contributing to a reduction in participation outside home and an associated decline in a person's cognitive and social health (Teipel et al., 2016).

### *Social deprivation of the living environment*

An unfamiliar neighbourhood environment may constrain a person's participation in social or outdoors activities (Li et al., 2019), however, research suggests that there may be other

factors which also impact the older person with and without dementia's perceived value and participation in the neighbourhood. There is an emerging knowledge base which posits that the older person's participation is not only determined by their choices, but also in negotiation with other contextual factors, described as the social determinants of health (Northwood et al., 2018; Theorell, 2020). The social determinants of health refer to a social gradient of health based on a broader concept of health which recognises the influence of various socio-economic, cultural and environmental conditions which may influence a person's health over their life course (Marmot, 2010, 2020). This is particularly relevant as population-based reports indicate that older people in the EU are at increased risk of poverty and social exclusion (Eurostat, 2019; Pensionsmyndigheten, 2018). In the context of the neighbourhood, social determinants of health have been linked to the social deprivation of the living environment. Research indicates that health benefits associated with participation in the older person's neighbourhood are accentuated by increasing the density and access of resources for participating in cognitively, socially and physically stimulating activities (Cassarino & Setti, 2015; Clarke et al., 2015; Katayama et al., 2020; Russ et al., 2012; Wu et al., 2020). According to the WHO (2008), policies may not be able to create participation, however, there is an opportunity to develop spaces to foster participation, particularly among potentially marginalised or vulnerable communities, such as older people with dementia. Research using population indices of the social deprivation of the living environment, such as the Index of Multiple Deprivation, have linked loneliness, lower life satisfaction (Longley & Singleton, 2009) and reduced digital engagement (Demakakos et al., 2006) with deprivation of the living environment among older people, however, there is a lack of research specifically addressing older people with dementia. Thus, there is an apparent consensus of the importance of the neighbourhood in the literature, although questions persist about the degree to which older people with dementia perceive that they are able to participate in their neighbourhoods over time, how this compares to their participation in other types of places, and whether there are similarities or differences to older people without dementia.

### *Perceived risks and public space*

The planning and design of many European cities owes to the influences of the International Congresses of Modern Architects (CIAM), an organisation of prominent modernist architects whose principles took little consideration for the diversity of society, such as the needs of older people with and without dementia (Boys, 2017). Since the emergence of modern cities, works such as Georg Simmel's *The Metropolis and Mental Life* (1903) have presented public space as hazardous for people (Whitworth, 2007), particularly for older people with cognitive impairments or dementia, due to the ever-increasing exposure of external stimuli, such as traffic, crowding, noise and pollution (The Centre for Urban Design and Mental Health [UD/MS], 2018). This is epitomised by the Mayor of London's Transport Strategy that aims to ensure that public transportation in the city of London is safer and easier for people with some type of cognitive impairment (Wilson & Howard, 2018). However, the strategy assumes that people with impaired cognition, including those with dementia, are especially unsafe and incapable of using public transportation. However, this is unknown due to insufficient research exploring how risks within public space are perceived by older people with dementia (Manthorpe & Iliffe, 2018; Sandberg et al., 2017). Thus, it is somewhat

contradictory that policies promote older people to age in place in their communities (ADI, 2019; Ang, 2020; Sturge et al., 2020), participating in health-promoting and active lifestyles and yet, the environment in which these activities and places are situated, including public transportation, is portrayed as increasingly hostile, unfamiliar and risky for this population in policies, such as the Mayor of London's Transport Strategy (Wilson & Howard, 2018).

A fundamental question in research about risk and dementia is who should be afforded primacy to decide the type and severity of risk (Iliffe & Manthorpe, 2016). One of the obstacles to addressing this question is the conflation between the concepts of risk and safety across gerontological and dementia research, policies, and the media. Conflation of these concepts can be stigmatising and limits opportunities for risk-taking that may enable beneficial health outcomes, among older people with dementia (Manthorpe & Iliffe, 2018; Morgan & Williamson, 2014) and without dementia (Grenier et al., 2019). Safety is commonly used in conjunction with other terms, such as security, surveillance and trust, as opposed to descriptions about the person's actual experience or enjoyment whilst participating in activities and places within public space (Hillman & Latimer, 2017). Stevenson et al.'s (2018) review of the concept of risk in dementia care, found that quantifying observed risks for people with dementia is challenging because some risk outcomes, such as getting lost, may be difficult to document, whereas other types of psychological risks may not be easily recognised. Instead, this thesis builds on Brorsson's (2013) research into how people with dementia perceive risks whilst participating within public space. Problematic situations may arise when a person perceives different types of risks, such as the risk of falling, of getting lost, of feeling stressed or embarrassed (Bartlett & Brannelly, 2019). The problematic situations may necessitate self-initiated management or adaptive strategies to respond to problematic situations (Sturge et al., 2020). These may involve remembering to bring items such as keys and one's phone when leaving home, or finding the way to, and from, a grocery shop without getting lost (Brorsson, 2013).

### *Transportation, mobility, and functional impairments*

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that, people with and without disabilities, including dementia, have the right to live independently and participate fully in all aspects of life (United Nations [UN], 2006). Older people with dementia have a human right to be able to participate in their chosen activities and places within society and yet in practice, people still experience participatory barriers (WHO, 2015). The literature indicates that transportation (Carlsson, 2004), in particular issues pertaining to the accessibility and usability of public transportation, may inhibit a person's ability to participate in activities and places within public space (Shrestha et al., 2017). Hammel (2017) names inequitable access to transportation as one of the constraints on a person's right to occupational engagement. Issues with access to public transportation are particularly relevant for this population as research attests to the high prevalence of voluntary, or involuntary, driving cessation following a diagnosis of dementia (Holden & Pusey, 2020). This may be catalyst to increased dependency on public transportation (Graham et al., 2020; Sanford et al., 2020). In spite of the calls for increased accessibility of public transportation, the focus has been limited to mainly physical adaptations, such as ramps, seating, enlarged



texts for information and signage (ADI, 2020), with only a few studies exploring cognitive aspects and these concern cognitive impairment based on other aetiologies than dementia, such as stroke (Ståhl & Månsson Lexell, 2018). This is problematic as older people with dementia report increased challenges in using public transportation, as well as accessing support due to the perceived invisibility of their condition compared to more visible physical impairments or disabilities (Flynn et al., 2018).

Research exploring transportation and participation within public space among older people with and without dementia assumes that the older person is free from mobility restrictions (Phinney et al., 2016; Spinney et al., 2015). This contradicts other studies which demonstrate that the majority of older people live with some form of comorbidity, such as diabetes, arthritis, mobility issues, or a visual impairment (Divo et al., 2014; Livingston et al., 2017; Singer et al., 2019). Various medical diagnoses, functional and sensory impairments may be in addition to the older person's diagnosis of dementia (Bunn et al., 2014; Griffith et al., 2016). These may intensify the challenges that older people with and without dementia encounter when attempting to access and use public transportation.

Studies indicate that older people with dementia are at increased risk of falling (Peek et al., 2020), as well as getting lost (Bartlett & Brannelly, 2019; Schaat et al., 2020). However, research suggests that older people with dementia can also experience challenges related to limited information on how to plan multi-modal door-to-door journeys or how to access basic facilities, such as sheltered seating and waiting areas, toilets or supportive staff (Carlsson, 2004; Harvey et al., 2019). Other studies corroborate the increased difficulties that older people with dementia can face due to the need to manage unexpected changes (Brorsson, 2013). For instance, the need to plan alternative routes using an application (app) on one's own smartphone or global positioning system (GPS) technologies, can potentially exclude older people with and without dementia due to limited access (Astell et al., 2019; Kottorp et al., 2016) or ability to use ETs (Hedman et al., 2018; Malinowsky et al., 2010). Thus, the research indicates a need to consider that other factors, such as comorbidity, perceived risk of falling or getting lost, and the need to manage unexpected changes, in addition to a person's dementia, may shape their ability to participate in their chosen activities and places within public space.

### *Inclusive communities*

On the one hand, the branding of places, technologies, services and communities as dementia-friendly has been credited with raising awareness about dementia and challenging stigma due to a lack of understanding about the behaviours, abilities and needs of people with dementia. This is especially important due to the conspicuousness of problematic situations within public space (ADI, 2019). On the other hand, the concept of dementia-friendly communities has been criticised for not actively involving people with dementia in the conceptualisation or realisation of dementia-friendly communities (Heward et al., 2017; Swaffer et al., 2014). A recent publication co-authored by people with dementia, including Agnes Houston, Wendy Mitchell, Kathy Ryan, Nigel Hullah, Paul Hitchmough and Tommy Dunne, contests that the concept of dementia-friendly communities is not sufficiently based

on empirical evidence or the lived experiences of people with dementia (Houston et al., 2020). In particular, it is not known whether proponents of dementia-friendly communities have taken into account the activities and places that people with dementia actually value or need to participate in their everyday lives. Houston et al. (2020) underlined the importance of involving people with dementia across all stages of the design and development of communities. Hence, in the literature there is a trend towards using the term inclusive communities which emphasises the involvement of people with dementia, in the design and development of their communities (Hung et al., 2020; van Hoof et al., 2018).

The initial drive towards dementia-friendly communities emerged from the WHO's (2007) age-friendly cities agenda. Age-friendly cities endeavour to bring together different stakeholders to promote active and healthy ageing, through inclusive environments (Herbert & Scales, 2019). Given that age is the leading risk factor for dementia, there are similarities in the approach and target audiences of both the age-friendly and dementia-friendly communities' initiatives. However, there is a specific focus on people with dementia in dementia-friendly communities and recommendations include cities but also other types of communities and settings (ADI, 2020). There are various broad definitions for dementia-friendly communities which seek to encompass a range of different groups, organisations and interests (Buckner et al., 2019). For instance, the Alzheimer's Society (2013, viii) defines dementia-friendly communities as, "... one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them". Both the age- and dementia-friendly communities' agendas have been accused of neglecting the role of technology access and use, in order to realise the goals for increased opportunities to participate in society (Marston & van Hoof, 2019). The lack of consideration for technology in the policies and research on age- and dementia-friendly communities is in opposition to policies and research advocating increasingly smart cities and communities, for older people (Suopajarvi, 2018) as well as the mainstream population (Lee et al., 2020; Green, 2019; Kempin Reuter et al., 2019). This may risk creating diagnostic specific communities which are segregated from an increasingly technological mainstream society.

#### *Access to a concession travel pass (CTP)*

Research shows that reduced use of public transportation is associated with reduced participation outside the home, which may result in social isolation, immobility and thus, adverse effects on the older person's health and wellbeing (Mackett, 2014, 2015; Shrestha et al., 2017; Webb et al., 2016). Important questions emerge from the inclusive communities' concept, including the lack of consideration for the relation between spaces that people participate in, as they travel from one increasingly inclusive, age- or dementia-friendly place, to another, within public space (Chaudhury et al., 2020; Clark et al., 2020; Mitchell et al., 2003). Transportation and mobility technologies such as, GPS, ticket machines and smart travel passes, provide the literal and theoretical vehicle for people to move around their communities, and to engage in their chosen ADLs. A prominent example in policy but not necessarily research, is the introduction of smart ticketing technology, including concession travel passes (CTP), across European countries (Musselwhite, 2019). Smart ticketing

technology has provided older people in the UK with concessionary bus travel since 2008 (Harvey et al., 2019). Access to a CTP is an automated solution which may help to ameliorate the older person's need to be a skilled user of ET. Many public transportation CTPs are eligible to older people and people with a disability, particularly mobility restrictions but people with dementia may also apply if they can demonstrate a need (Department for Transport, 2010). Due to the automated renewal process of the CTP, the person is able to use public transportation without the need to access online payments or ticket machines. However, there is also research to show that it is the actual concession and subsidisation which increases opportunities for participation (Coronini-Cronberg et al., 2012; Mackett, 2014). Similar subsidisations exist in areas of Sweden, to a lesser degree. Subsidised travel is influenced by national and local policymaking and access to subsidised public transportation is currently under debate in the UK (Age UK, 2020).

## **Digital inclusion**

### *The relevance and perceived ability to use Everyday Technologies (ETs)*

A number of studies suggest that ET use is an increasingly important determinant of engagement in occupations and of participation within society (Marston & van Hoof, 2019; Patomella et al., 2018; Peine & Neven, 2020). ETs are ubiquitous across all areas of our lives, including domestic ETs that are used within the home environment, such as a kettle, or an oven. Or ETs found within public space, such as automated teller machines (ATMs) and public transportation ticket machines (Emiliani, 2006). An additional category of ET that cannot be confined to a single type of environment, are portable ETs. Portable ETs may be transported or used by a person both inside and outside the home, for instance smartphones, tablets, hearing aids, and pedometers. The portability of the ET may in turn influence patterns of participation within public space and in one's community (Köttl et al., 2020). In an increasingly technological society, the relevance and perceived ability to use ETs in order to participate in activities, such as public transportation (Risser et al., 2015), grocery shopping (Brorsson et al., 2018) and managing finances (Giebel et al., 2019) is increasingly taken for granted. Nevertheless, questions persist about the interrelationship between people, ADLs, and ETs as a dimension of the environment. Further research is required to appreciate which types of ET are used, in regard to the person's motivation, the context, and leading to what experiences and consequences.

### *Everyday Technology use, dementia, and ageing*

There is limited research about how participation in activities and places relates to the relevance and use of ETs among older people. There are even fewer studies among older people with dementia. Older people, especially those with dementia are not portrayed, or understood, as active users of technology. Typically, based on the diffusion of innovations, older people are presented as late adopters of technology in comparison to their younger, early adopter counterparts (Rogers, 1983). Across policy and research, there is a drive towards digital inclusion which is based on the premise that the late adopter, older population

are at risk of becoming a ‘digital underclass’, excluded from various activities and places dependent on ET use (Helsper & Reisdorf, 2017). Research indicates that there are at least two components of the so-called digital divide which position older people with and without dementia as passive recipients of digital technology (Rosales & Fernández-Ardèvol, 2020). The first division concerns whether a person is able to access digital technologies, or not, and the second division pertains to differences in skill acquisition opportunities, purpose of use and motivation (Rosales & Fernández-Ardèvol, 2020). In spite of the research and policy about the digital divide, studies have shown that older people with and without dementia can be active users of ET. This has spawned an emerging field of gerontechnology comprised of technologies designed for older people (Chen & Chan, 2013). Many of these include assistive technologies intended for use by older people with and without dementia, as well as other groups of people with various impairments. Gerontechnologies are typified by passive surveillance or monitoring devices, such as pendant fall alarms and GPS trackers (Bergschöld, 2018; Piau et al., 2014; Peine & Neven, 2019). However, the bias towards specialist, assistive and medicalised technologies may actually disable the older person as it segregates the older technology user from other technology users of everyday, mainstream technology (Emiliani, 2006).

Scholars such as Peine and Neven (2020) argue that an interventionalist logic limits the understanding of technology as an instrument. According to the interventionalist logic ageing, or dementia, is the target for an intervention, or the source of the problem for the technology to solve (Gallucci et al., 2020; Green, 2019; Peine & Neven, 2020). This reinforces the assumption that mainstream technology use performs a subsidiary or neutral role in the lives of older people, including those with dementia unless it is used as an assistive device or part of a health intervention (Peine & Neven, 2020). Due to the interventionalist logic, earlier studies have focused on the acceptance and usability of technology, for the purpose of proficient technology adoption, with a particular bias towards ICTs at the expense of other types of ETs (Astell et al., 2019; Pinto-Bruno et al., 2017). However, research shows that increased availability of relevant ET, and not only ICTs, is associated with both higher activity engagement among older people with and without dementia (Walsh et al., 2018), as well as life satisfaction among older people with dementia or MCI (Köttl et al., 2020). Such research contributes to a growing evidence base which destabilises the interventionalist assumption that technology use performs a subsidiary or neutral role in the lives of older people with and without dementia.

Due to the lack of research about the everyday lives of older people with and without dementia in the context of public space, including a lack of knowledge about the specific activities and places they participate in, any association between their participation in activities and places and relevance or perceived ability to use ETs remains unclear. This ambiguity is compounded by the absence of theory development about the relationship between ageing and technology, or dementia, ageing and technology. Peine and Neven (2019) propose that ageing and technology co-constitute each other. On the one hand, technologies for older people are influenced by perceptions about ageing. For instance, perceptions of frailty versus active ageing, or digital literacy versus illiteracy may impact the way that technologies are designed for older people. On the other hand, ageing is shaped by

technology. Technology use can impact patterns of behaviour, habits and relationships as people age. A study by Fischl et al. (2017) showed that use of digital technologies was linked with the way that older people conceive of their identities, and how they pursue and experience meaning in their everyday lives. The relationship between a person's use of technology and participation in society is nuanced and dynamic, especially for older people with dementia who have been shown to experience increased difficulty using ETs (Nygård & Kottorp, 2014; Patomella et al., 2018). A longitudinal study of challenge levels of ETs, as perceived over five years by older people with MCI or mild AD found that changes in perceived challenge of ETs was associated with functional change in people with cognitive decline (Hedman et al., 2018). However, identification of common characteristics among ETs that became more challenging remained inconclusive (Hedman et al., 2018). Further research, particularly longitudinal research is recommended to investigate the co-constitution of ageing and technology, as technology changes over time.

### *The role of Everyday Technology (ET) use in navigation and wayfinding*

There are a plethora of studies exploring the feasibility of novel technologies to support navigation and wayfinding in clinical settings, among older people and particularly those with dementia, however, there is a lack of critical discussion about the use of technology in the older person's everyday lives for these purposes (Astell et al., 2019). A number of studies indicate that ICTs may be suitable for supporting older people with dementia, particularly those in the mild stages, to navigate their way around public space (Pulido Herrera, 2017; Kwan et al., 2020; Schaaf et al., 2020). In theory, studies suggest that assistive technology devices such as wearable technologies containing hardware and software with sensors or GPS may help to prevent falls (Haux et al., 2016), and to promote the older person with dementia's safety and independence, enabling them to live and age in their communities for longer (Malmgren Fänge et al., 2020). Such technological interventions also seek to promote the older person with dementia's autonomy and spatial self-efficacy whilst participating within public space (Malmgren Fänge et al., 2020). However, technologies have been criticised in practice, due to potential issues related to the subsidiary role of technologies passively tracking and surveilling the older person with dementia, whether the person is consciously aware, or not (Vermeer et al., 2019; Zwijsen et al., 2011). Furthermore, the majority of studies investigating these types of technologies have been performed in clinical settings based on pre-determined navigational tasks (Wiener & Pazzaglia, 2020), using novel technologies without consideration of the ETs that the older person actually uses, or that they are familiar with (Thordardottir et al., 2019). This underlines a lack of consideration about the contextual factors underlying the use of ETs for navigation and wayfinding, mirroring the knowledge gaps for ET use in general, among older people with and without dementia. Thus, this review of the literature and identification of knowledge gaps motivated the rationale and research aims which follow.

## Rationale and research aims

The studies are presented in a sequential order, as an unfolding exploration of participation in activities and places within public space among older people with and without dementia, through the lens of ET use. The overarching aim of this thesis was: *to explore participation in activities and places within public space, among older people with and without dementia in two European countries (Sweden and UK), and to evaluate how different aspects, such as the relevance and perceived ability to use Everyday Technologies (ETs), interact with and influence participation, over time.*

- **Study one** introduced the overarching aim of this thesis and served as a baseline. The specific aim for study one was: *to explore stability and changes in participation in places visited within public space in relation to the relevance of ETs used in public space. Stability and change are identified among a Swedish sample of older people with and without mild- to moderate-stage dementia.*
- Building on the findings of study one, in addition to consultations with the European Working Group of People with Dementia (EWGPWD) and outreach activities in the London region, older people with and without dementia reported a need for more research to understand how issues related to public transportation and mobility relate to out-of-home participation. In part, this informed the aim of **study two**: *to investigate the ways in which perceived risks and ET use are associated with out-of-home participation, among older people in the UK.* Further research questions built on this aim to ask, how are perceived risk and other factors e.g. having a functional impairment or access to a concession travel pass (CTP), associated with out-of-home participation among the sample?
- The rationale for focusing on social participation was based on the findings from studies one and two which demonstrated that among the Swedish and UK samples, places associated with social participation seemed to be abandoned to a higher degree than other types of places and therefore, these places required a more in-depth inquiry. The aim of **study three** was: *to investigate social participation, in relation to total ET use outside home and social deprivation of the living environment, among participants with and without dementia in the UK sample.*
- Having discovered that participation in places visited within public space is a nuanced and dynamic construct, study four sought to build on the prior studies through a longitudinal investigation. The aim of **study four** was: *to deepen the knowledge about how use of ET outside home, relates to participation in places visited within public space among people with dementia, over time.*

## THEORETICAL AND METHODOLOGICAL RESOURCES

This chapter contextualises this thesis according to the predominant discourses in dementia research and provides the rationale for situating this thesis within an occupational perspective. This thesis is situated within an occupational perspective, specifically in relation to conceptualising older people with and without dementia as *occupational beings*, and how issues of occupational injustice may pertain to this. This thesis also embraces other relevant theoretical and methodological resources, with a view to enhancing the occupational perspective of participation in activities and places within public space, among older people with and without dementia.

### **Framing the dementia discourse: disease, disability, or mere difference?**

In order to understand the impetus to facilitate older people with dementia to participate in activities and places in public space, including dementia-friendly communities, it is important to explore the way in which dementia is perceived and framed in the current discourses and relevant to this thesis. At least three perspectives are evident in the literature on dementia: (i) dementia as a disease (i.e. biomedical model, positivist epistemology), (ii) dementia as a disability (i.e. social model of disability), or (iii) dementia as mere difference (i.e. advocacy and philosophical discourse from a critical realist perspective).

Firstly, a biomedical perspective of dementia relies on standardised diagnostic criteria such as the International Statistical Classification of Diseases and Related Health Problems (ICD) (WHO, 2014, 2018) and Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association [APA], 2013). At the time that the data collection began, the ICD-10 was in use and it categorises dementia (ICD code: F00-F03) as “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” (WHO, 2014). In 2018, the ICD-11 publication shifted the categorisation of dementia in closer alignment with the DSM-V (WHO, 2018). The DSM-V defines dementia as a major neurocognitive disorder, which specifies that a substantial impairment is present in one or more cognitive domains, to such a degree that it restricts the person’s independence in ADLs (APA, 2013). Thus, the biomedical model has been associated with a positivist epistemology (Broom & Willis, 2007) whereby quantifiable and observational assessments are used to diagnose and classify the disease and severity of the person with dementia (George et al., 2011; Pujol Domenech & Azpiazu Artigas, 2015). In the case of the DSM-V, a severity criterion was used to indicate the number of standard deviations in relation to psychometric normality. Based on standardised criteria of the disease, the biomedical approach utilises a combination of pharmacological and non-pharmacological (i.e. psychosocial) interventions to care for, or manage, the person who is exhibiting symptoms of the dementia disease (Dyer et al., 2018). Whilst not rigidly positioned in the biomedical model, the studies in this thesis acknowledge its important contributions, and standardised diagnostic criteria were utilised in the

recruitment of older people with a diagnosis of dementia, as given by a physician. This is described in the methods chapter.

Secondly, there is an emerging discourse presented by authors such as Thomas and Milligan (2018) which situates dementia as a disability. Traditionally, disability advocacy and legislation have focused on physical and so-called “visible” disabilities, such as mobility restrictions. The social model of disability has been used to advocate for adaptations and changes in one’s environment as it was believed to be the social structures and environmental barriers that reinforced a person’s disability, as opposed to their medical diagnoses. In recent years international organisations such as Dementia Alliance International (DAI) and Alzheimer’s Disease International (ADI) have campaigned for dementia to be supported and protected under disability legislation such as the CRPD (UN, 2006). Article 9 of the CRPD is integral to this thesis as it seeks “to enable persons with disabilities to live independently and participate in all aspects of life”. The ability to exercise one’s autonomy and to make choices about one’s life is also a central tenet of an occupational perspective, according to the concepts of occupational justice and injustice, which will be explored in the latter part of the chapter in relation to citizenship.

Thirdly, in juxtaposition to the biomedical model, there is a philosophical discourse that proposes dementia is mere difference. Disability rights activists and philosophers, notably Barnes (2014), state that disability is not inherently bad for you, but rather it is a manifestation of human diversity which is analogous to other differences in society such as ethnicity, sexual orientation or gender. This may be considered as a type of critical realist interpretation which is concerned with the underlying patterns of causation, agency and identity (Baldwin & Greason, 2016). Just as the aforementioned differences are associated with stigmatisation and marginalisation, Barnes argues that disability may fall victim to an ableist agenda. Proponents of disability as mere difference typically use physical or sensory paradigmatic cases (i.e. physical, visual or auditory impairments) to substantiate their argument (Barnes, 2014; Kahane & Savulescu, 2016). According to this view, people with a specific disability (i.e. auditory impairment) are not simply a collective of people with common characteristics but also members of a unique community (i.e. the deaf community). The community may share interests, experiences, services and supports. Furthermore, there may be intersectionality where an older person with dementia may live with multiple mere differences, in addition to their dementia (Nedlund et al., 2019). If older people with dementia are considered a specific community or group, then dementia advocates have called for members of the community to have rights and to have the opportunity to voice their own needs (Swaffer, 2016; Taylor, 2007). This is applicable to the development of age- or dementia-friendly communities, to provide tailored environments, services and supports for communities of people with specific needs (ADI, 2020).

There are, however, counterarguments to each of these discourses on dementia. For instance, the traditional biomedical view of dementia has been criticised for its reliance on pharmacological interventions to care for, or manage, older people with dementia in a standardised rather than personalised, or holistic way (Bartlett & O’Connor, 2010). Alternatively, confining dementia to a perspective of mere difference, or of disability, may risk overlooking the specific issues that older people with a disease, such as dementia, face (i.e. distinct from young-onset dementia). Specific issues that older people with dementia



encounter include a burden of disease for themselves, their carers, family and friends, as well as the impact on their health, quality of life and ability to make choices about their participation in ADLs. In summary, this thesis recognises all three discourses as a starting point as they all contribute valuable knowledge to how we perceive and frame dementia.

## **An occupational perspective of older people with and without dementia as citizens**

Building on the aforementioned discourses on dementia, this thesis aligns itself most closely with a fourth discourse concerning citizenship – an occupational perspective of citizenship (Nedlund et al., 2019). Whilst the previous discourses refer to dementia in a somewhat abstracted way, this thesis refers directly to *older people with and without dementia*.

According to an occupational perspective, when any people, including those with or without dementia, are unable to enact their rights and responsibilities as a citizen, occupational injustices may arise. Townsend and Polatajko (2007) describe occupational injustice as occurring when specific social groups face greater restrictions in their choices or decision-making in their participation in everyday occupations, arising from invisible expectations, norms, and standards. This differs from a predominant theory of a shrinking world in dementia research, whereby the size of the older person with dementia's outdoor activity decreases, or shrinks over time, until they only participate in the places they are most familiar with (Duggan et al., 2008). In juxtaposition, an occupational perspective postulates that participation is a more complex process, dependent on not only changes in the person's capabilities but also in relation to occupational injustices that may occur in their environment (Njelesani et al., 2014; Townsend & Polatajko, 2007). For instance, when an older person with dementia is unable to participate in their chosen activities and places within public space due to inaccessible ETs or social deprivation of the living environment. The occupational injustice may occur by inhibiting the older person with or without dementia's participation in an activity or place within public space (Morgan-Brown et al., 2019) but also by inhibiting the ability to enact their citizenship through participation in society. It is not yet known whether the occupational injustices that older people with dementia perceive whilst participating in activities and places within public space are similar or different to those perceived by older people without dementia and hence, more research is needed among both older people with and without dementia.

This thesis seeks to contribute to the citizenship discourse by adopting an occupational perspective, in order to explore the ways in which older people with and without dementia participate in activities and places within public space, in relation to ET use, as a way of them enacting their citizenship. According to Whiteford and Townsend (2011, p.67) an occupational perspective involves, "examining what individuals do every day on their own and collectively; how people live and seek identity; how people organize their habits, routines, and choices to promote health; and how systems support (or do not support) the occupations people want or need to do to be healthy". An occupational perspective facilitates an exploration of enacting citizenship through the individual and collective process of participation in activities and places, within public space and their communities, and on

different levels. Baldwin and Greason (2016) explore the concept of micro-citizenship as one level where people with dementia may enact their citizenship, through participation and relationships, as opposed to an individualistic status bestowed upon them (Bartlett & O'Connor, 2007, 2010; Seetharaman & Chaudhury, 2020). Other levels of citizenship include meta-, macro- and midi-citizenship. The other levels of citizenship are concerned with national, organisational and collective action (Baldwin & Greason, 2016). This thesis focuses on micro-citizenship which is concerned with a person's social relationships and their participation in activities and places in the context of their everyday lives (Baldwin & Greason, 2016).

### *How can micro-citizenship be enacted?*

A critical reflection of the methodological resources involves asking not only what a theoretical resource *is*, but also *how it can be used* and *how it can be presented* (Chinn & Kramer, 2004). Whilst the MoCA and demographic questionnaire were used in data collection, this thesis focuses on two main questionnaires: the ACT-OUT questionnaire and the ETUQ. The ACT-OUT questionnaire builds on a transactionalist perspective and the ETUQ was inspired by the Model of Human Occupation (MOHO).

A transactional perspective on occupation, draws upon the theories of John Dewey and proposes that participation in occupations is a transactional relationship that connects the person and their environment (Cutchin et al., 2008; Cutchin & Dickie, 2013; Dewey & Bentley, 1946). For the purposes of the ACT-OUT, participation in occupations refers to the person's perceived participation in activities and places within public space (Margot-Cattin et al., 2019). Participation in activities is embedded in places within public space and the transactional relationship between the person, the occupation, and the environment is situated according to the unique physical, social, cultural, economic and temporal context that the person inhabits (Margot-Cattin et al., 2019). Participation in activities is therefore embedded *within* places visited in public space, as conceptualised in the sub-studies of this thesis using part one of the ACT-OUT. The emphasis is on participation in places *within* public space, as opposed to participation in places *in* public space. This subtle distinction is important to the transactionalist perspective underlying the ACT-OUT. The former emphasises the person's embedded and integrated participation *within* their environment, this includes technological dimensions of the environment. Whilst the latter implies that the environment is an inanimate container that the person enlivens through their participation *in* it (Cutchin & Dickie, 2013). This distinguishes the transactionalist perspective from alternative frames of reference, such as the Person Environment Occupation model (PEO) (Law et al., 1996) in occupational therapy and the theory of Environmental Press (Lawton et al., 1978; Wahl & Gerstorf, 2020) from gerontology. The transactionalist perspective differs from frames of references such as the PEO and the theory of Environmental Press, for at least two reasons. Firstly, by emphasising the embedded relationship between the person and their environment, it challenges the false dichotomy of the person and the environment. Secondly, it reconfigures the unit of analysis away from the individual, towards their participation in a given situation, which in the context of public space may also be communal and social.

The MOHO's influence on the ETUQ is evident through the questionnaire's exploration of how a person's occupational performance is related to their motivation, interests, habits, roles, and functional state (Kielhofner, 2008; Nygård et al., 2016). Drawing upon the MOHO, the ETUQ foregrounds the occupational performance involving the relevance and perceived ability to use ETs. According to the MOHO, a person's occupational performance is shaped by the characteristics of the technological item, such as the design features of the smartphone, in addition to the person's ability to use the technological item (Nygård et al., 2016). In the MOHO, the environment or situation, referred to as the *occupational setting*, where the activity involving the technological item takes place is generally in the background to this occupational performance. This differs from a transactionalist perspective which is more closely aligned to the architectural concept of the *architectural programme* than the MOHO's *occupational setting*. In both occupational therapy and architecture, the environment is a core concept (Blomqvist, 2016). However, the *architectural programme* provides a more holistic concept encompassing the spaces, objects and forms that orchestrate the everyday public activities and relations between varied groups of people (Blomqvist, 2016; Pallasmaa, 2012; Pallasmaa et al., 2013). Whilst it is interesting to gain knowledge about a person's relevance and perceived ability to use ETs, this thesis argues that it is more insightful to foreground the contextualisation of the relevance and perceived ability to use ETs, in relation to the person's participation in activities and places within public space. This motivates the use of the ETUQ in conjunction with the ACT-OUT to acknowledge the complexity of ET use, as situated in a particular situation and context.

The transactionalist perspective provides a valuable starting point to capture "the messiness of human life" (Rosenberg & Johansson, 2013, p.151) which acknowledges the complexity of contextual factors underpinning participation in a technological society. However, the acknowledgement of the complexity of everyday life is also one of the limitations and challenges of applying a research method to compliment the transactionalist perspective (Lee Bunting, 2016). Whilst no single perspective covers the multidimensionality of participation, Cutchin and Dickie (2013) propose using a combination of different methods to understand a transactional perspective of occupation, including mixed methods (Lee Bunting, 2016). Moreover, it has been suggested that different types of visualisations (i.e. data visualisations) and visual methods (i.e. photovoice or photo elicitation) are congruent to capturing the complexity of participation, particularly in relation to the context for participation (Lee Bunting, 2016; Hartman et al., 2011).

#### *How can micro-citizenship be presented?*

As this thesis has a focus on ET use, it was salient to also consider the use of ETs in the production and communication of the research. Living within a technological society means that we increasingly interact with data visualisations through ET. For instance, through the graphical interfaces on smartphone apps, the news reports we read via social media on our tablets, or the announcements we observe on public transportation (Cairo, 2020). Data visualisation has been defined as the presentation of data in a graphical or visual way (Cairo, 2020). Whilst people encounter more and more ETs and data visualisations in society, analysts, designers, and technology developers increasingly advocate for more humanising

ways to interact with ETs and data (Yuan, 2019). Data humanism is a theory put forth by the architect and data visualisation designer, Giorgia Lupi. According to Lupi (2017), humanising data combines the conventional analysis of general patterns and trends in quantitative data with the additional recognition of the people, the behaviours, and context behind the numbers, including what may be perceived as imperfect or missing data. This approach questions the conventions of knowledge production and communication (D'Ignazio and Klein, 2016), which may marginalise different perspectives, such as those of older people with and without dementia. A data humanist approach to the analysis and visualisations of the data emphasises that knowledge is situated. This has influenced the embrace of local data, utilising smaller samples to consider the social, cultural, and environmental provenance of the data. The data visualisation procedures used in this thesis are described in more details in the methods chapter.

## METHODS

This chapter provides a summary of the methods, including a description of the data analyses used for each study. A detailed reflection on the rationale for the methods and potential limitations is provided in the discussion chapter.

### Study designs

**Studies one** and **four** focused on a Swedish sample whilst **studies two** and **three** drew upon a UK sample. **Studies one, two** and **three** used a cross-sectional, observational design, whereas **study four** used a longitudinal design. In this way, **studies one** and **four** may be regarded as bookends to this thesis, as the baseline data from **study one** was followed over the course of three years, culminating in **study four's** longitudinal findings. An overview of the studies is presented in Table 1.

**Table 1.** Overview of the studies.

	<b>Study one</b>	<b>Study two</b>	<b>Study three</b>	<b>Study four</b>
<b>Focus</b>	Exploring stability and change in participation, in relation to the relevance and perceived ability to use portable ETs and public space ETs	Investigating perceived risk, concession travel pass access and ET use as factors for out-of-home participation	Visualising social participation in relation to ET use and social deprivation	Investigating the use of ET outside home in relation to participation in places within public space over time
<b>Design</b>	Cross-sectional			Longitudinal
<b>Data Collection</b>	Structured interview using four questionnaires, within the participant's home or another preferred location of their choice.			
<b>Participants</b>	Swedish sample. 35 older people with mild to moderate dementia and 34 older people without dementia.	UK sample. 128 older people with and without mild dementia.	UK sample. 64 older people with mild dementia and 64 older people without dementia.	Swedish sample. 35 older people with mild to moderate dementia at baseline. Year 1 (n=26) Year 2 (n=16) Year 3 (n=9)
<b>Instruments*</b>	ACT-OUT; ETUQ; MoCA; Demographic Questionnaire.			
<b>Data Analyses</b>	Descriptive and comparative statistics, including Modern test statistics.	Descriptive and comparative statistics, including logistic regression.	Mixed methods including exploratory data analysis and content analysis.	Descriptive statistics and random intercept modelling.

\*ACT-OUT (Participation in ACTivities and Places OUTside Home Questionnaire); ETUQ (Everyday Technology Use Questionnaire); MoCA (Montreal Cognitive Assessment).

## Participants

Through the unfolding exploration of participation in activities and places within public space, the *older people with and without dementia* were viewed as *occupational beings*. However, for the purposes of analyses, the older people were divided into a sub-sample of older people with dementia and another sub-sample of older people without dementia. Across both the Swedish and the UK samples, the inclusion criteria specified that all participants were (i) able to give informed consent to participate themselves, (ii) aged 55 years or over, (iii) living in ordinary housing in the community, (iv) participating in activities outside home independently or with support, (v) using at least one ET independently or with support, (vi) without vision or hearing impairments which could not be compensated via technical aids and, (vii) without any other condition that may impact the person's participation and use of ETs, such as multiple sclerosis or a stroke. Examples of functional impairments included fine motor impairments, limited walking ability, limited arm function, vision or hearing difficulties which were not compensable through technical aids, or a medical diagnosis such as diabetes. Furthermore, an ability to communicate in Swedish language was required for the Swedish sample and an ability to communicate in English was required for the UK sample. For the Swedish sub-sample of older people with dementia (**studies one and four**), a diagnosis of dementia in the *mild to moderate stage*, or with a major neurocognitive disorder in the mild stage, was required by a physician (DSM-IV and DSM-V, APA, 2000, 2013). For the UK sub-sample of older people with dementia (**studies two and three**), a diagnosis of dementia in the *mild stage*, or with a major neurocognitive disorder in the mild stage, was given by a physician (DSM-IV and DSM-V, APA, 2000, 2013).

## *Recruitment*

The Swedish sub-sample of older people with dementia (n=35) were recruited through three memory investigation units in the Stockholm region, in addition to open, voluntary community-based activities for older people with dementia organised by local Stockholm municipalities, such as memory cafes and day care services. Once approximately one third of the sub-sample of older people with dementia were recruited, recruitment progressed for a sub-sample of older people without dementia. This approach was used to ensure that a sub-sample of older people without dementia (i.e. no known cognitive impairment, n=34) were matched to the sub-sample of older people with dementia. Participants were matched on a group-level according to certain aspects which have been shown to be significant based on earlier research in this field, namely age, gender, years of education and living arrangements (cohabitation or living alone) (Kottorp et al., 2016). The UK sub-sample of older people with dementia were recruited across five National Health Service (NHS) research sites (London, Cumbria, Greater Manchester regions). The UK sample of older people with dementia (n=64) were recruited through the NHS (e.g. memory clinics) and local, community-based groups (e.g. memory cafes, and local Alzheimer Associations). The UK sample of older people without dementia (n=64) were recruited via local networks such as, community-based activity, faith, cultural or social groups. A description of the characteristics of the older people in the Swedish sample (at baseline) and the UK sample is provided in Table 2.

**Table 2.** Characteristics of the participants in the Swedish sample (study one and the dementia sub-sample for study four at baseline) and the UK sample (studies two and three).

	Sweden		UK	
	Participants with dementia (n=35)	Participants without dementia (n=34)	Participants with dementia (n=64)	Participants without dementia (n=64)
<b>Gender</b>				
Female	22.00 (62.86%)	21.00 (61.76%)	29.00 (45.31%)	34.00 (53.13%)
Male	13.00 (37.14%)	13.00 (38.24%)	35.00 (54.69%)	30.00 (46.87%)
<b>Age * †</b>				
Median [Min, Max]	75.00 [59.00, 90.00]	77.50 [62.00, 96.00]	79.0 [62.00, 96.00]	71.00 [55.00, 89.00]
IQR	68.00, 79.00	71.00, 82.30	74.00, 83.00	64.00, 80.80
<b>Education</b>				
Median [Min, Max]	11.00 [6.00, 18.00]	12.50 [6.00, 19.00]	11.00 [7.00, 21.00]	13.00 [9.00, 19.00]
IQR	9.00, 13.00	10.00, 15.00	10.30, 13.00	11.00, 16.00
<b>Living arrangement †</b>				
Cohabits	16.00 (45.71%)	13.00 (38.24%)	39.00 (60.94%)	40.00 (62.50%)
Lives alone	19.00 (54.29%)	21.00 (61.76%)	25.00 (39.06%)	24.00 (37.50%)
<b>Geography<sup>a</sup> ** †</b>				
Urban/ suburban	14.00 (41.18%)	16.00 (47.06%)	51.00 (79.69%)	47.00 (73.44%)
Rural/ semi-rural	20.00 (58.82%)	18.00 (52.94%)	13.00 (20.31%)	17.00 (26.56%)
<b>Years of residence</b>				
Median [Min, Max]	20.00 [0.00, 57.00]	17.00 [1.00, 60.00]	20.00 [1.00, 60.00]	20.00 [1.00, 56.00]
IQR	7.00, 40.00	10.80, 29.30	10.00, 40.00	8.50, 31.00
<b>Driving **</b>				
Driver	4.00 (11.43%)	19.00 (55.88%)	26.00 (40.63%)	46.00 (71.88%)
Non driver	31.00 (88.57%)	15.00 (44.12%)	38.00 (59.37%)	18.00 (28.12%)
<b>Home help</b>				
Home help	14.00 (40.00%)	8.00 (23.53%)	21.00 (32.81%)	10.00 (15.63%)
No home help	21.00 (60.00%)	26.00 (76.47%)	43.00 (67.19%)	54.00 (84.37%)
<b>Support from others<sup>b</sup> ‡</b>				
Support	31.00 (96.88%)	7.00 (21.21%)	61.00 (95.31%)	56.00 (87.50%)
No support	1.00 (3.12%)	26.00 (78.79%)	3.00 (4.69%)	8.00 (12.50%)
<b>Functional impairment<sup>c</sup></b>				
Functional impairment	31.00 (96.88%)	33.00 (97.06%)	54.00 (84.38%)	56.00 (87.50%)
No functional impairment	1.00 (3.12%)	1.00 (2.94%)	10.00 (15.62%)	8.00 (12.50%)

→

**Table 2** continues on the next page



**Table 2.** Continued from the previous page.

	Sweden		UK	
	Participants with dementia (n=35)	Participants without dementia (n=34)	Participants with dementia (n=64)	Participants without dementia (n=64)
<b>MoCA<sup>d</sup></b>				
Median [Min, Max]	19.00 [4.00, 30.00]	27.00 [21.00, 29.00]	21.00 [12.00, 28.00]	26.00 [21.00, 30.00]
IQR	13.00, 22.00	24.80, 28.00	18.00, 23.00	25.00, 28.50

Note. All information was gathered through self-report. IQR = Interquartile range; MoCA = Montreal Cognitive Assessment (potential score range 0–30; higher scores indicate higher cognitive status). <sup>a</sup>One Swedish participant with dementia missing. <sup>b</sup>One Swedish participant without dementia and three Swedish participants with dementia missing. <sup>c</sup>Three Swedish participants with dementia missing. <sup>d</sup>One Swedish participant with dementia is an outlier according to MoCA score of four.

\* $p < .05$  and \*\* $p < .01$  statistically significant differences for participants with dementia, between countries.

† $p < .05$  and ‡ $p < .01$  statistically significant differences for participants without dementia, between countries.

The Pearson chi-squared test was used as a comparison test for the categorical data (or Fisher's exact test where counts were  $< 5$ ) and the Mann Whitney U-test was used for continuous data. A more detailed discussion of the statistically significant differences between the sub-samples, within countries, is described in the study publications.

## Ethical considerations

Ensuring informed consent was an ethical priority for the research. Capacity to make one's own decisions is crucial to maintaining individual autonomy, across many areas of one's life, including reasons related to finances, driving, voting, research, and medical treatment (Hegde & Ellajosyula, 2016). A condition affecting cognition, such as dementia, may impact capacity (Darby & Dickerson, 2017). However, to avoid stigmatisation and undue prejudice, an older person with dementia cannot be assumed to have impaired capacity based on their diagnosis alone (Pennington et al., 2018). International procedures may vary, for instance in the Swedish data collection, the rapport-building stage before each interview was used as an opportunity for the interviewer and interviewee to get to know each other. This also involved the interviewer's subjective assessment that the older person had the capacity to take part in the interviews. In the UK sample, capacity to participate in the research was ascertained in accordance with the Mental Capacity Act (2005). Despite these differences, there are four common determinants involved in capacity evaluations: *understanding* (i.e. does the potential participant understand what the research is about and what their participation entails, for example when the researcher met potential participants they provided information about the scope of the study and discussed with the participant about any questions they may have), *communication* (i.e. is the potential participant able to communicate about their choice to take part or not), *appreciation* (i.e. is the potential participant able to appreciate the consequences of their participation or their non-participation, including any risks or benefits, for example, participants were notified of their right to withdraw from the research at any time, without giving a reason, or facing any consequences for doing so) and finally, *reasoning* (i.e. is the potential participant able to weigh up the situation and give a rational reason for their choice)

(Appelbaum, 2007). These four determinants formed the basis of capacity-testing throughout this research.

In addition to the evaluation of capacity, verbal consent was taken, and all participants independently gave written informed consent to participate in the research. Prior to their participation, the participants with and without dementia were provided with written information about the research and were provided with time to consider the research, including multiple opportunities to ask questions and to discuss the research with the data collectors. Participants were provided with a Personal Introduction Card which featured photographs and contact information about the data collectors, in order to familiarise potential participants with the people who would be visiting their homes and interviewing them. Careful consideration was given to all verbal, visual and written communication about the research. Clear and simple language using concrete examples and repetition, was used throughout the consent-taking and research process. This approach is based on the best practice guidelines of the Dementia Engagement and Empowerment Project (DEEP, 2020). DEEP is a UK network of people with dementia and their guidance was sought throughout different stages of the research. Feedback about the information was also provided by the INDUCT Ethics Oversight Committee (EOC), which included a person with dementia, a family carer, and an ethicist. The Regional Board of Research Ethics at the Karolinska Institutet (2015/77-31-5) granted ethical approval for the Swedish studies. Ethical approval for the UK studies was gained from the Health Research Authority, South-West Frenchay Research Ethics Committee (IRAS project ID: 215654, REC reference: 17/SW/0091). The UK studies were also included on the National Institute of Health Research Clinical Research Network Portfolio (NIHR, ID: 33163). Eligibility for the NIHR portfolio is determined based on the research being considered of value to the NHS and its feasibility within the NHS.

## **Data collection**

Collection of the Swedish data commenced in May 2015 and the final wave of data collection was completed in February 2020. The Swedish data was collected by Swedish-speaking occupational therapists who are members of the CACTUS research group. This sample was investigated in **study one** and the sub-sample of older people with dementia was followed for three years, culminating in **study four's** four-wave longitudinal study. Data for the UK **studies two** and **three** were collected between May and December 2017, by two occupational therapist who are members of the CACTUS research group, the author of this thesis and another doctoral student.

### *Procedures*

All data collection was administered by registered occupational therapists. The data collectors had clinical and research experience with older people, including those with dementia. Prior to data collection, the data collectors engaged in training in the use of the standardised tools, in the case of the ETUQ this entailed a two-day training workshop. To

facilitate inter-rater reliability, the data collectors participated in critical discussions about the use of the tools with the tool creators and members of the data collection team, this included discussing any uncertainties about the scoring. The data collectors gathered the self-reports of the participants using the data collection tools, this also involved writing the participants' comments to the free-text questions verbatim (and making audio recordings), for subsequent data analysis. The interviews were most frequently undertaken in the participant's home. However, participants were given the option to choose another location if they preferred and without having to give a reason. For example, a significantly higher number of the Swedish participants without dementia favoured having the interview in an alternative location (i.e. day centre or community centre) (Table 3). This may have increased a sense of ecological validity which is discussed in more detail in the subsequent discussion chapter.

Table 3 shows that in both Sweden and the UK, a significantly higher number of the participants with dementia chose to have a significant other present during their interviews compared to the participants without dementia. Participants could choose to have a significant other (i.e. family member, friend, carer, faith leader) present, this was intended as a support but *not for proxy reporting*. Interviews were divided into a maximum of three sessions over four weeks, lasting a maximum of 90 minutes per session. Most participants favoured completing the interviews in one to two sessions with a mean duration of 1 hour and 45 minutes in total. Approximations were possible for the time it took to administer the tools (ACT-OUT questionnaire: 40 minutes; Demographic questionnaire: 10 minutes; MoCA: 10 minutes; and ETUQ: 30-45 minutes).

**Table 3.** Description of the interview location and presence of a significant other in the Swedish sample (studies one and four at baseline) and UK sample (studies two and three).

	Sweden		UK	
	Participants with dementia (n=35)	Participants without dementia (n=34)	Participants with dementia (n=64)	Participants without dementia (n=64)
<b>Interview location</b> ** ‡				
Home	25.00 (71.43%)	8.00 (23.53%)	63.00 (98.44%)	47.00 (73.44%)
Alternative location	10.00 (28.57%)	26.00 (76.47%)	1.00 (1.56%)	17.00 (26.56%)
<b>Significant other present</b> <sup>a</sup> **				
Significant person present	12.00 (34.29%)	0.00 (0.00%)	43.00 (67.19%)	6.00 (9.38%)
Interviewed alone	23.00 (65.71%)	33.00 (97.06%)	21.00 (32.81%)	58.00 (90.62%)

Note. <sup>a</sup> One Swedish participant without dementia missing data.

\*p < .05 and \*\*p < .01 statistically significant differences for participants with dementia, between countries.

†p < .05 and ‡p < .01 statistically significant differences for participants without dementia, between countries.

The Pearson chi-squared test was used as a comparison test for the categorical data (or Fisher's exact test where counts were < 5). A more detailed discussion of the statistically significant differences between the sub-samples, within countries, is described in the study publications.

## *Data collection tools*

All four studies shared the same approach to data collection through one-to-one, semi-structured interviews. The semi-structured interviews were comprised of four instruments, administered in the following order: the Participation in ACTivities and Places OUTside the Home Questionnaire (ACT-OUT) (Margot-Cattin et al., 2019); the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005); a demographic questionnaire; and the Everyday Technology Use Questionnaire (ETUQ) (Nygård et al., 2016).

### *The Participation in ACTivities and Places OUTside the Home Questionnaire (ACT-OUT)*

Based on a transactionalist perspective, the purpose of the ACT-OUT questionnaire is “to capture detailed information on activities and places in combination, specifically identifying participation restrictions and pointing out barriers and facilitators in different contexts” (Margot-Cattin et al., 2019, p.2). The ACT-OUT questionnaire is a standardised questionnaire that was developed due to a growing awareness of older people with and without dementia who are ageing-in-place. Ageing-in-place involves not only living and ageing in one’s home but also participation in activities and places within public space (Binette & Vasold, 2018). As part of a cross-cultural project, the ACT-OUT questionnaire was developed concurrently in three different countries (Sweden, Switzerland, and the UK) and it is available in three languages (Swedish, French, and English). The development process is described in detail in an earlier publication (Margot-Cattin et al., 2019). The translation and harmonisation process of the ACT-OUT questionnaire and the other data collection tools is described in the discussion chapter.

Throughout the three parts of the ACT-OUT questionnaire, the interviewer elicits responses from the participant describing their perceived participation in activities and places within public space. In part one, the participant is asked to report a yes or no answer to whether they participate in each of the 24 places in the present, the past and the future (including one additional “other” place where a participant can describe an alternative place which is not included in the current version of the ACT-OUT questionnaire). The 24 places are divided into four domains: (i) consumer, administration, and self-care places (n=6 places); (ii) places for medical care (n=5 places); (iii) social, spiritual and cultural places (n=6 places); (iv) places for recreation and physical activities (n=7 places). Table 4 describes the places included in each of the ACT-OUT questionnaire domains.

Part two is comprised of two sections, the same questions are used for each section, however, the first section concerns a place where the participant has reported *no change* (i.e. currently participating in the place, previously, or in the future), and the second section explores a place where there has been a reported *change* or where there is an *anticipated change* in the future. In each of the sets of questions, nine open-ended questions are used to enquire about the type of activity performed at the place, how the person goes to the place and back to their home, and whether there is anything that they have to be careful about or pay extra attention to at the place or during their journey. A further four Likert-scale questions are used to prompt a positive or negative valence response about perceived

frequency, distance and familiarity of the place and the journey. Finally, part three includes general questions about the participant's attitude towards risk-taking, perceived life satisfaction and perceived concern about getting lost, falling, being stressed when going out, or getting into an embarrassing situation whilst participating in activities and places in public space. For instance, when you go out/are outside, how concerned are you about getting lost?

**Table 4.** Overview of the Participation in ACTivities and Places OUTside Home (ACT-OUT) Questionnaire.

Part one		Part two		Part three
Mapping participation in 24 places (+ one other place)		Describe a place: (i) where there was no change; (ii) where there was a change		General questions
Domain	Place Type Present, past and future participation in ...	Questions about activity and place	Questions about going there and back	Questions about perceived risks whilst participating in activities and places within public space
A	Small grocery shop	What kind of activity do you do there?	How do you get there? And back?	Attitude to risk-taking  Perceived life satisfaction  Perceived concern about getting lost  Perceived concern about falling  Perceived concern about being stressed when going out  Perceived concern about getting into an embarrassing situation
	Mall, supermarket, big shop		Does somebody go with you?	
	Small shop		If yes, why does somebody go with you?	
	Pharmacy		How long does it take you to get there? And back?	
	Hairdresser, salon or barbershop		According to you, is it close by or far away? (Likert-scale response)	
	Bank or Post office		How well do you know the place? (Likert-scale response)	
B	Doctor's surgery	Why do you go to that particular place?	How well do you know the way to get to that place? (Likert-scale response)	
	Hospital or health centre		Imagine getting there. What do you have to be careful about or pay extra attention to?	
	Dentist's surgery			
	Therapy			
	Day care			
C	Friend or family member's place	When during the day (year) do you go there?  How often do you go there? (Likert-scale response)		
	Restaurant, café or bar			
	Senior centre or social club's premises			
	Building for worship			
	Cemetery or memorial place			
	Entertainment or cultural places			
D	A garden in your backyard	How well do you know the place? (Likert-scale response)  Picture yourself in that place. What do you have to be careful about or pay extra attention to?		
	Park, green areas, or community garden/ allotment			
	Forest, mountain, lake, or sea			
	Cottage, summer house, or chalet			
	Neighbourhood			
	Sports facility			
	Transportation centre			

### *The Everyday Technology Use Questionnaire (ETUQ)*

The ETUQ evaluates relevant and self-perceived ability to use ETs. Through the investigation of the relevance and perceived ability to use ETs, the ETUQ contributes to the inquiry of three broad questions about interactions between people and their technological environments: which ET does a person perceive as being relevant in their life situation? To what extent does a person perceive difficulties when using ET artefacts and services? To what extent does a person not use ET that are relevant to them? An ET is considered relevant if it is available to a person, either through use in the past, present, or through the intention to use it in the future (Nygård et al., 2016).

The Swedish and British English language versions of the ETUQ were used in this thesis. These versions of the ETUQ are comprised of 90+ mechanical, electrical, and digital technological artefacts and services, commonly used at home or in society. The choice of technological items included in these versions of the ETUQ is based on clinical experience from the research group, in addition to earlier research which suggests that older people may encounter difficulties when using both well-known ETs, such as the telephone or television, as well as newer technologies, such as self check-in kiosks at airports (Nygård & Starkhammar, 2007). Due to the rapid pace of technological development and the evolution of perceptions about ETs, the ETUQ includes additional checkboxes for “other” options, where new or alternative types of ET can be recorded for future development of the questionnaire (Nygård et al., 2016).

In the ETUQ, ETs are categorised according to seven types of ADLs that the ETs can be used for (i) Home maintenance (e.g. microwave or washing machine), (ii) Information and communication (e.g. smartphone), (iii) Self-care (e.g. hairdryer or hearing aid), (iv) Maintenance and repair (e.g. lawnmower), (v) Accessibility (e.g. lift or public toilet), (vi) Economy and purchasing (e.g. ATM) and, (vii) Travel (e.g. GPS or public transportation ticket machine). The ETs in the ETUQ may be viewed as encompassing the broad spectrum of technologies that people use to perform their ADLs, but they can also be conceptualised according to spatial relationships between people and their environments. The ETUQ includes domestic ETs (e.g. an oven or television) used solely in the home environment (Emiliani, 2006). Due to this research project’s focus on ET used within public space, particular attention is given to the 16 public space ETs that can be used outside home (e.g. ticket machine for public transportation), as well as the 33 portable ETs which can be used across multiple locations, inside or outside home (e.g. smartphones) (Gaber et al., 2019).

Once an ET has been determined as relevant, the ETUQ provides a systematic method for evaluating the person’s perceived ability to use ETs. The interviewer records the responses by marking one of the optional response alternatives for each question, based on the person’s answer. Table 5 shows the rating scale that the interviewer utilises to evaluate that the ET is used. Alternatively, the ET is rated as not used, if it is not in use anymore or has not come into use, even if it is relevant (i.e. it is available to the person, has previously been used, or may be used in the future). The ETUQ was developed for use with older people and it has been validated for use among older people with no known cognitive impairment, as well as older people with cognitive impairments for various reasons, including dementia,

stroke and acquired brain injury (Malinowsky et al., 2017; Nygård et al., 2012; Patomella et al., 2017).

**Table 5.** ETUQ response ratings and their aggregation into 3 categories.

Aggregated Rating	Not relevant	Used				Relevant but not used
		Used with no uncertainty/difficulties at all	Used with uncertainty, limited difficulty, with “crib”	Used with extensive difficulties that arise frequently or regularly	Used only together with another person	
<b>ETUQ rating for perceived ability to use ETs</b>	Not present in the person’s environment / life, or never used and/or no intention of use	Used with no uncertainty/difficulties at all	Used with uncertainty, limited difficulty, with “crib”	Used with extensive difficulties that arise frequently or regularly	Used only together with another person	Not used anymore or has not come into use even if it is relevant
<b>Dichotomised count for ET use</b>	0 (non-use)	1 (use)				0 (non-use)
<b>Dichotomised count for ET relevance</b>	0 (not relevant)	1 (relevant)				

### *The Montreal Cognitive Assessment (MoCA)*

The purpose of using the MoCA (version 3) in this research was to assess current levels of cognitive function among all participants. It is a standardised and comprehensive screening tool that was designed to detect early cognitive deficits, or MCI (Lischka et al., 2012; Zadikoff et al., 2008). The MoCA assesses multiple cognitive domains including (short-term and working) memory, visuospatial abilities, executive functions, attention, concentration, language and orientation (to time and place) (Nasreddine et al., 2005). The tool has been validated for the target population used in this research (Borland et al., 2017; Abd Razak et al., 2019). Research indicates that the MoCA has good sensitivity and specificity for cognitive impairment and dementia in older people, relative to other cognitive screening tools, such as the Mini Mental State Examination (MMSE) (Breton et al., 2019; Julayanont et al., 2017; Nasreddine et al., 2005). A minimum cut-off score of 23/30 was adopted for the participants without dementia, as a means of eligibility for the comparison group and to differentiate them from the participants with dementia (Carson et al., 2018). Based on research, a minimum cut-off of 18 was used for participants with dementia in the mild to moderate stage, however, this was reviewed for individual cases as described in the **study one** publication.

### *Demographic questionnaire*

A non-standardised demographic questionnaire was used to gather information about a range of socio-demographic characteristics including age, gender, years of education, living arrangements, geographic location, driving, and occupation. The socio-demographic characteristics were collected in order to investigate their effects or to control for their effects, in relation to ET use and participation in activities and places within public space. Earlier research suggests that socio-demographic factors in addition to a dementia diagnosis, may influence the relevance and perceived ability to use ETs (Kottorp et al., 2016). However, there are relatively fewer studies regarding socio-demographic characteristics and participation in activities and places within public space among older people with and without dementia, particularly in relation to social participation, and this compelled further investigation.



# Data Analyses

## Preparatory analyses

A range of analytical approaches were utilised across the four studies, in order to explore the structure of the data, to identify patterns, and to describe stability and change over time. For all analyses, the alpha level was set at  $p < .05$ . Cohen's (1988) recommendations were used for interpretation of effect size, including Cohen's  $d$  (.2 = small, .5 = medium, .8 = large), the correlational effect of  $r$  (.1 = small, .3 = medium, .5 = large, .7 = very large), and for interpretation of associations (.1 - .3 = small association, .3 - .5 = medium association and .5 - 1.0 = large association). Across all the studies, the preliminary analyses involved developing graphical displays of the data (i.e. boxplot, histogram, scatterplot) and descriptive numerical summaries (i.e. the five number summary: minimum, maximum, median, upper and lower quartiles) to understand the structure and distribution of the data (Tukey, 1977). The distribution of the residuals was evaluated using normality probability plots as well as the Kolmogorov-Smirnov (KS-test) and Shapiro-Wilk (SW-test) tests in the Statistical Package for Social Sciences (SPSS) computer software, version 24 and 26 (IBM Corp, 2016, 2019). The tests revealed that the residuals of the continuous variables were not normally distributed (apart from the number of relevant public space ETs which was normally distributed in **study one**), and this motivated the use of non-parametric tests to make more conservative inferences based on the findings.

Across all studies, the response variable (participation in total number of places visited within public space) was calculated based on the sum of the total number of places that the participant reported visiting in the present tense, this was out of a maximum score of 24 places in the ACT-OUT questionnaire. To investigate technologies used in public space in **study one**, three variables were generated from the ETUQ data. The ETUQ ratings for public space ETs ( $n = 16$ ) and portable ETs ( $n = 33$ ) were each dichotomised and each summed together to produce the following two explanatory variables: (i) the number of relevant public space ETs, and (ii) the number of relevant portable ETs. To gain deeper insight, the ability to use ETs was explored using: (iii) the person measure of ability to use ETs variable. For continuity, in **study two, three and four**, an outside home ET use variable comprising 49 ET items was developed by combining the 16 public space ETs and 33 portable ETs from **study one**. The choice of ETUQ variable was based on the logic that it is more likely for those ETs that can be used outside home, such as an ATM, ticket machine, or smartphone, to influence participation outside home compared to domestic ETs used at home, such as a kettle or stove. Moreover, earlier research revealed an association between decreasing ET use and reducing involvement in activities, particularly in those activities performed outside home and activities related to social participation (Hedman et al., 2017).

## Descriptive and inferential statistics

**Studies one and three**, used descriptive statistics, including Pearson's chi-squared test, Fisher's exact test, and Mann-Whitney U test (for continuous variables), to check whether the sub-sample of older people with dementia and the sub-sample of older people without

dementia were sufficiently matched regarding socio-demographic characteristics (age, gender, years of education and living arrangements), as well as to account for potential confounding factors. The findings were based on analyses between each country based on the matched samples. The findings were only compared on this group-level between countries to make meta-inferences. Within countries, where there was a difference in sample size (i.e. Swedish sub-sample of 34 older people with dementia and a sub-sample of 35 older people without dementia) statistical tests, such as the Mann-Whitney U test, were used to compare the sub-samples as this type of test can be used for data with unequal variance based on its use of rank values (Pett, 2016). To determine a hierarchy of which types of places were retained or abandoned to a higher degree over time, counts from past participation in places were subtracted from present participation for each place and compared between the sub-samples in **study one** or as a single sample in **studies two** and **four**. Furthermore, Spearman's rank correlation coefficient (two-tailed) was used to explore associations between participation in total number of places visited within public space, and the explanatory variables for **studies one, two** and **three**.

Descriptive statistics and data visualisations were used to complement the statistical modelling by exploring participation in the different types of places visited within public space and the types of ET used outside home. In **study four**, the descriptive statistics were performed on a sub-sample of participants that completed the study to year two, to minimise the attrition bias identified for year three in the sensitivity analysis. To further elucidate the influence of time on participation in places visited within public space, a profile line plot (spaghetti plot) visualised each participant's trajectory of participation in places visited within public space over time.

## **Data visualisations**

The data visualisations in this thesis were generated using coding in computer programmes such as R (R Core Team, 2020). Research indicates that there are benefits in developing data visualisations in this way, which are tailored for specific datasets and audiences (O'Donoghue et al., 2018). This differs from the standard approach of using generic visualisations or templates, such as Microsoft Excel, SPSS, or stock images downloaded from websites (Cochrane UK, 2020), which may risk concealing patterns within the data, or introduce generic visual artefacts (O'Donoghue et al., 2018). For this reason, the studies in this thesis have incorporated tailored visualisations based on best practices in data visualisation to harness the efficacy of using specific data visualisation elements for specific purposes (Cleveland & McGill, 1985; O'Donoghue et al., 2018). The data visualisations included choropleth maps which are a type of map that uses colours or patterns to relate a geographical area to a numerical value (Schiewe, 2019). Radar visualisations were also used as a succinct way to visualise comparisons between the data in a radial graph, resembling a "spider web" (Saary, 2008). The data visualisations were developed with reference to best practice guidance for dementia-friendly (DEEP, 2020) and accessible visuals, as well as feedback from older people with and without cognitive impairment. Tools such as ColorBrewer were used to produce colour-blind friendly palettes, with consideration given to

the accessibility of a broader audience of people with varying sensory and perceptual needs (Brewer et al., 2020).

## **Rasch analysis**

In **study one** the person measure of ability to use ETs variable was determined using a Rasch model. According to Modern test theory (Rasch measurement model), the person measure of ability to use ETs variable was developed by transforming the ordinal raw scores across all of the ETUQ technology items into linear-like measures in logits (Bond & Fox, 2007). This log transformation provided an advantage to the Rasch model because it is possible to calibrate each person's measure of ability to use ETs and each of the ET item's difficulty on a common scale, in this case a common scale for perceived ability to use ETs (Bond & Fox, 2007; Malinowsky, 2011). For the person measure of ability to use ETs, this is preferable to an ordinal scale where the distance between scoring alternatives is unknown. Building on earlier research (Malinowsky, 2011), the Rasch model also provides more targeted information about the ETs that the older person with or without dementia perceives as relevant rather than assessing all participants on the same ETs. Thus, the measures may be described as test-free (Wright & Linacre, 1987). Using a computer application of the Rasch model (WINSTEPS® version 3.69.1), the person measure of perceived ability to use ETs is based on the response patterns for all of the ETUQ items and all of the participants in the sample. A higher person measure of perceived ability to use ETs corresponds to a higher ability to use ETs (Linacre, 2020). Using the Rasch measurement model, goodness-of-fit testing was used to check the person response validity in the generated person measure of perceived ability to use ETs measure (i.e. infit mean square (MnSq) value  $\leq 1.4$  and an associated z-value  $\leq 2.0$ , Bond & Fox, 2007; Linacre, 2002).

## **Ordinal regression**

In **study two**, ordinal regression was chosen in order to investigate how outside home ET use, perceived risk of falling outside home and other factors, such as having a functional impairment or access to a CTP were associated with ordinal levels of the response variable (out-of-home participation), among a sample of older people in the UK. Ordinal regression acknowledges the order and the effect of each explanatory variable and unlike other approaches such as linear regression, it does not assume normal distribution of the residuals of the response variable, which suited the response variable which was ordinal, ordered and its residuals were not normally distributed. Ordinal regression is applied in a similar way to standard logistic regression with the exception of using ordinal levels of participation rather than a dichotomous response variable (Koletsi & Pandis, 2018). Using ordinal regression is considered to preserve and utilise more information from the data which may be lost through a dichotomisation of the data (Abreu et al., 2008). The ordinal levels of the response variable (out-of-home participation) were based on quartiles. A series of preliminary tests were performed which satisfied the assumptions required to perform an ordinal regression. Testing indicated the absence of collinearity among the explanatory variables except for collinearity

found between dementia diagnosis and ET use. Upon consultation with a statistician, a decision was made to analyse the sample as a single group of older people with and without dementia. This decision was motivated by the overall aim of **study two** which was to investigate the ways in which perceived risks and ET use are associated with out-of-home participation. The focus of **study two** was on ET use and thus, diagnosis of dementia was not included as an explanatory variable. This approach is also aligned with a more nuanced view of older people which involved other aspects such as their citizenship and not only relies on a biomedical perspective of their dementia diagnosis.

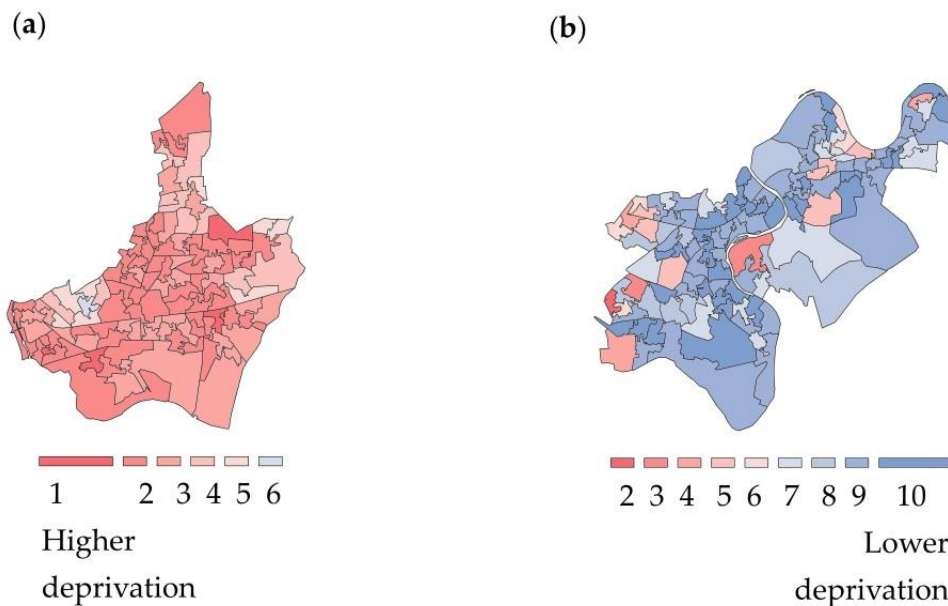
Using ordinal regression, associations were reported using log-adjusted regression coefficients (odds ratio), the estimate of the effect with confidence intervals, and statistical significance was also highlighted. According to the odds ratios, for a one unit increase in the explanatory variable, the response variable of out-of-home participation is expected to change by its respective regression coefficient in the ordered log-odds scale, whilst the other variables in the regression model are held constant (Koletsis & Pandis, 2018). Interpretation of the probability of a person having a higher level of out-of-home participation is based on five technology items for the ET use variable because a difference of one technology item was not considered clinically significant. Goodness-of-fit of the ordinal regression model was verified by the parallel regression test (Hosmer & Lemeshow, 2000) which showed that homogeneity of the effects across categories of the response variable was satisfied (McCullagh, 1980).

## **Convergent mixed methods**

Building on **studies one** and **two**, **study three** utilised a convergent mixed methods approach. According to a convergent mixed methods approach, the researcher collects and analyses quantitative and qualitative data regarding the same phenomenon (social participation) and then, converges the findings during the interpretation stage of analysis (Burke Johnson & Onwuegbuzie, 2004; Guetterman et al., 2015). To validate earlier research from Swedish (Gaber et al., 2019) and Swiss (Margot-Cattin et al., 2019) samples, data visualisations were used to determine whether data from the UK sample followed a similar pattern, with places for social participation abandoned to a greater degree than other types of places. The social participation construct was conceptualised according to two variables in part one of the ACT-OUT questionnaire: (i) social participation in Domain C (total count of participation in places for social, spiritual and cultural activities, out of a maximum of 6 places) and, (ii) social participation in Domain D (total count of participation in places for recreation and physical activity, out of a maximum of 7 places).

Additionally, an Index of Multiple Deprivation (IMD) score was used to contextualise the social deprivation of the living environment of participants into 10 equal groups (deciles), with 1 corresponding to the most deprived 10% of neighbourhoods in England and 10 representing the least deprived 10% of neighbourhoods in England (Ministry of Housing, Community & Local Government, 2015). This involved coding choropleth maps in R computer programming for each of the neighbourhoods where data was collected (Figure 1). The IMD score was calculated based on a weighted sum of seven sub-domains of deprivation: (1) income, (2) employment, (3) education, skills and training, (4) health and

disability, (5) crime, (6) access to housing and services, and (7) living environment (Smith et al., 2015).



**Figure 1.** Choropleth maps showing social deprivation of the living environment. Choropleth maps were created for each of the living environments (neighbourhoods) where data was collected in the UK, according to the deciles of the Index of Multiple Deprivation (IMD). Figure 1 shows two examples: (a) Barking and Dagenham, London; (b) Richmond upon Thames, London. Based on the scale, 1 (red) corresponds to the most deprived 10% of neighbourhoods, and 10 (blue) indicates the least deprived 10% of neighbourhoods, in England. *Contains Ordnance OS data © Crown copyright and database right (2020).* Originally published in Gaber et al. (2020b).

The convergent mixed methods approach was used to compare and contrast the findings and to help to validate quantitative findings with qualitative findings (Creswell & Creswell, 2018). The convergent mixed methods approach was applied in three sequential steps: (i) statistical analysis of the data from the ACT-OUT questionnaire and ETUQ; (ii) content analysis of the free text responses from the ACT-OUT questionnaire through coding the data, using Atlas.ti (version 8) software programme, and collapsing the codes into categories, and; (iii) integration of the findings from these two types of analyses in the discussion section, according to a side-by-side comparison and graphical joint display (Creswell & Creswell, 2018; Guetterman et al., 2015). A graphical joint display is a way of simultaneously presenting different types of data in the form of a table, figure, or visualisation, in this case a table. Graphical joint displays are used in mixed methods studies in order to integrate quantitative and qualitative data and to elicit meta-inferences, which may not be possible by analysing the data in isolation (Guetterman et al., 2015). The three steps of the convergent mixed methods approach were described in detail in the **study three** publication (Gaber et al., 2020b).

## Multilevel modelling

**Study four** utilised a longitudinal study design and analytical framework. Gerontological scholars suggest that whilst longitudinal research is not a panacea for gerontological research, it can provide an enhanced and dynamic understanding of ageing as a temporal process, as opposed to more static conceptions of the older person (Alwin & Campbell, 2001). A longitudinal study seeks to acknowledge age- and temporal-related issues such as a person's biography, history, as well as their relationship to the cohort (Wang et al., 2017). This compelled the rationale for incorporating a longitudinal study into this thesis, with the objective of capturing the *process* of participation in places visited within public space in relation to the use of ET outside home over time. By analysing the effect of time, it was possible to elaborate on **study one's** exploration of the concepts of stability and change in participation in places visited within public space. In **study four**, the concepts of stability and change in participation in places visited within public space were viewed as processes and the effects of time were emphasised.

A random intercept model with maximum likelihood parameter estimation was used to test the hypothesis that the decreasing use of ET outside home is associated with decreasing participation in places visited within public space over time in older people with dementia. A maximum likelihood estimation was used to maximise the likelihood that the process described in the model matches the observed data (Fitzmaurice et al., 2011). A rationale for using a random intercept model which is a type of multilevel modelling, is that it includes both random and fixed effects. It does this by adjusting for the variation among participants through the inclusion of an intercept for each participant (Hedeker & Gibbons, 2006). Therefore, the participants were set as random effects in the model. Use of ET outside home and time were added as fixed effects and in particular, use of ET outside home was added as a time-dependent variable (i.e. enabling it to change over time). To control for the effect of age on the response variable, the age group variable was also included as a fixed effect. The age group variable was developed according to two groups, above and below the median baseline age cut-point (DeCoster et al., 2011).

This type of statistical modelling can accommodate incomplete data which is assumed to be missing at random (Fitzmaurice & Ravichandran, 2008). Dropout analysis was used to determine that there were no statistically significant differences between the participants that completed the study and those that left the different waves of the study. This is a way to investigate whether the data is missing at random or not. The Mann–Whitney U test was used to investigate continuous variables and Pearson's chi-square test, or Fisher's exact test was used for categorical variables. No statistically significant differences were found except for the baseline MoCA score which differed significantly between the participants who left the study and those that completed the study to year three ( $U= 42,500$ ,  $Z= -2.83$ ,  $p<.01$ ,  $r= -.48$ ). The statistically significant difference in the MoCA score suggests that those who had more cognitive challenges at baseline were more likely to drop out and thus, they may not be missing at random.

## **Integration and synthesis of the findings**

The process of integrating and synthesising the findings involved an initial mapping of the findings of the four studies, according to three categories: (i) Participation in activities and places visited within public space; (ii) The relevance and perceived ability to use Everyday Technologies (ETs) and; (iii) Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space. The findings were mapped onto three graphical joint displays (Tables 6-8). The rationale for choosing to visualise and combine the findings in this way was to build on the use of a graphical joint display in **study three**. The process was similar to the process described in **study three** but this time the findings from all of the studies were incorporated into the side-by-side convergent joint displays. In order to array findings from statistical data and the free text comments together according to an overarching category (Creswell & Creswell, 2018). This facilitated a process of cross-comparison and synthesis of the findings across all the studies between the author of this thesis and two of her supervisors. Following ongoing critical discussions and different iterations of the graphical joint displays, no new categories emerged and summaries of the key findings, including convergent and divergent inferences, were formulated as meta-inferences (Guetterman et al., 2015; Younas et al., 2020). The graphical joint displays and resultant meta-inferences are presented to facilitate transparency regarding the process of synthesising the findings (Tables 6-8).

## 5

### **FINDINGS**

This chapter presents a mapping of the findings of the four studies according to graphical joint displays, for the following three categories: (i) Participation in activities and places visited within public space; (ii) The relevance and perceived ability to use Everyday Technologies (ETs) and; (iii) Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space (Tables 6-8). Next, the synthesis of the findings is summarised. The meta-inferences shape the discussion on the synthesis of the findings, in order to elucidate converging and diverging trends, also to discern conclusions and contributions in the subsequent chapters.



**Table 6.** Synthesising the findings through graphical joint displays and meta-inferences (Participation in activities and places visited within public space).

Category	Swedish sample				UK sample		Meta-inferences of participation in places visited within public space
	Sub-study one Participants with dementia (n=35)	Participants without dementia (n=34)	Sub-study four Participants with dementia (sub-sample, n=16)	Sub-study two Participants with & without dementia (n=128)	Participants with dementia (n=64)	Sub-study three Participants without dementia (n=64)	
Participation in activities and places visited within public space	<ul style="list-style-type: none"> <li>Hospital, health centre</li> <li>Dentist's surgery</li> <li>Restaurant, café, bar</li> <li>Neighbourhood</li> <li>Friend, family member's place</li> </ul>	<ul style="list-style-type: none"> <li>Mall, supermarket</li> <li>Hospital, health centre</li> <li>Neighbourhood</li> <li>Pharmacy</li> <li>Dentist's surgery</li> </ul>	<ul style="list-style-type: none"> <li>Neighbourhood</li> <li>Friend, family member's place</li> <li>Dentist's surgery</li> <li>Cemetery, memorial place</li> <li>Restaurant café, bar</li> </ul>	<ul style="list-style-type: none"> <li>Doctor's surgery</li> <li>Mall, supermarket</li> <li>Garden</li> <li>Neighbourhood</li> <li>Restaurant café, bar</li> </ul>	<p><i>Motivators for (social) participation</i></p> <p>For Domain C, 36.51% reported visiting a friend or family member's place, to participate in activities such as socialising and to provide support.</p> <p>For Domain D, 28.33% reported visiting their garden to participate in activities such as taking care of the garden, sitting, enjoying the garden.</p>	<p>For Domain C, 23.43% reported visiting an entertainment, cultural place to participate in activities such as watching a film at the cinema or visiting the library.</p> <p>For Domain D, 24.14% reported visiting the forest, mountain, lake, sea to participate in activities such as going on a trip, walking, and relaxing, alone or with other people.</p>	<p>The neighbourhood was one of the most frequently visited places within public space, among both older people with and without dementia (M1).</p> <p>The older people with dementia frequently participated in a friend or family member's place (M2).</p> <p>The most frequently visited places did not directly correspond with those activities and places that older people with and without dementia chose to discuss in more detail (M3).</p>
		<p><i>Types of places least frequently participated in</i></p> <ul style="list-style-type: none"> <li>Sports facility</li> <li>Doctor's surgery</li> <li>Forest, mountain, lake, sea</li> <li>Cottage, summer house</li> <li>Therapy</li> </ul>				<p><i>Considerations for (social) participation that require extra attention</i></p> <ul style="list-style-type: none"> <li>ETs including alarms regularly going off</li> <li>Uneven walking surfaces and trip hazards</li> <li>Physical context exacerbated by weather conditions, poor lighting, and darkness</li> <li>Urban dwellers reported concerns about the traffic, fumes, and parking</li> <li>Rural dwellers reported concerns about flooding, tides, and wildlife</li> </ul>	



**Table 6.** Continued from the previous page.

Category	Swedish sample				UK sample			Meta-inferences of participation in places visited within public space
	Sub-study one Participants with dementia (n=35)	Participants without dementia (n=34)	Sub-study four Participants with dementia (sub-sample, n=16)	Sub-study two Participants with & without dementia (n=128)	Participants with dementia (n=64)	Sub-study three Participants without dementia (n=64)		
Participation in activities and places visited within public space	18.00	19.00	<ul style="list-style-type: none"> <li>• Baseline= 18.00</li> <li>• Year 1= 16.50</li> <li>• Year 2= 16.00</li> </ul>	<i>Median participation in places visited within public space</i> <ul style="list-style-type: none"> <li>• Domain C= 3.00</li> <li>• Domain D= 5.00</li> </ul>			<ul style="list-style-type: none"> <li>• Domain C= 5.00</li> <li>• Domain D= 5.00</li> </ul>	<p>The statistical findings showed an overall tendency for older people with dementia to participate in places within public space, to a lesser degree than older people without dementia (M6).</p> <p>A number of the places abandoned to a higher degree such as forest, mountain, lake, sea; sports facility; and cottage, summer, house, corroborate with the types of places where there was a lower degree of participation in the present and these tended to be places for recreation and physical activity (Domain D of the ACT-OUT) (M7).</p> <p>The transportation centre was abandoned by older people with and without dementia, but particularly in a Swedish context (M8).</p> <p>The bank, post office was abandoned by the Swedish sample of older people with dementia in the longitudinal study and this was evident for the sample at baseline in study one's cross-sectional analysis (M9).</p>
	<ul style="list-style-type: none"> <li>• Forest, mountain, lake, sea (-25)</li> <li>• Sports facility (-20)</li> <li>• Cottage, summer house (-14)</li> <li>• Bank, post office (-10)</li> <li>• Transportation centre (-9)</li> </ul>	<ul style="list-style-type: none"> <li>• Sports facility (-15)</li> <li>• Forest, mountain, lake, sea (-13)</li> <li>• Transportation centre (-13)</li> <li>• Cottage, summer house (-11)</li> <li>• Therapy (-6)</li> </ul>	<ul style="list-style-type: none"> <li>• Transportation centre</li> <li>• Bank, post office</li> <li>• Hospital, health centre</li> </ul>	<i>Types of places abandoned over time</i> <ul style="list-style-type: none"> <li>• Therapy (-46)</li> <li>• Sports facility (-42)</li> <li>• Cottage, summer house (-41)</li> <li>• Forest, mountain, lake, sea (-38)</li> <li>• Park, green area (-34)</li> </ul>			<ul style="list-style-type: none"> <li>• Sports facility (-30)</li> <li>• Entertainment, cultural place (-24)</li> <li>• Cottage, summer house (-23)</li> <li>• Senior centre, social club (-23)</li> <li>• Forest, mountain, lake, sea (-22)</li> </ul>	



**Table 6** continues on the next page

**Table 6.** Continued from the previous page.

Category	Swedish sample				UK sample			Meta-inferences of participation in places visited within public space
	Sub-study one Participants with dementia (n=35)	Sub-study one Participants without dementia (n=34)	Sub-study four Participants with dementia (sub-sample, n=16)	Sub-study two Participants with & without dementia (n=128)	Participants with dementia (n=64)	Sub-study three Participants without dementia (n=64)		
Participation in activities and places visited within public	<ul style="list-style-type: none"> <li>Day care (3)</li> <li>Building for worship (0)</li> <li>Neighbourhood (-1)</li> <li>Restaurant, café, bar (-1)</li> <li>Hospital, health centre (-1)</li> </ul>	<ul style="list-style-type: none"> <li>Hairdresser (4)</li> <li>Mall, supermarket (2)</li> <li>Neighbourhood (0)</li> <li>Day care (0)</li> <li>Dentist's surgery (0)</li> </ul>	<ul style="list-style-type: none"> <li>Neighbourhood</li> <li>An increase in participation was associated with the doctor's surgery and the forest, mountain, lake, sea.</li> </ul>	<ul style="list-style-type: none"> <li>Doctor's surgery (-1)</li> <li>Mall, supermarket (-5)</li> <li>Restaurant, café, bar (-7)</li> <li>Day care (-9)</li> <li>Small store (-9)</li> </ul>	<ul style="list-style-type: none"> <li>Restaurant, café, bar (-3)</li> <li>Garden (-4)</li> <li>Neighbourhood (-5)</li> <li>Cemetery, memorial place (-7)</li> <li>Friend, family member's place (-10)</li> </ul>	<ul style="list-style-type: none"> <li>Restaurant, café, bar (-4)</li> <li>Friend, family member's place (-4)</li> <li>Entertainment, cultural place (-5)</li> <li>Neighbourhood (-6)</li> <li>Garden (-6)</li> </ul>	<p>The neighbourhood was one of the places that older people with and without dementia continued to participate in over time (M10).</p> <p>The building for worship was one of the places retained by the Swedish sub-sample of older people with dementia; however, it was also one of the places abandoned by the UK sub-sample of older people without dementia (M11).</p>	
	<p><i>Types of places retained over time</i></p>							

**Table 7.** Synthesising the findings through graphical joint displays and meta-inferences (The relevance and meta-inferences ability to use Everyday Technologies (ETs)).

Category	Swedish sample		UK sample		Meta-inferences of the relevance and perceived ability to use Everyday Technologies (ETs)
	Sub-study one	Sub-study four	Sub-study two	Sub-study three	
The relevance and perceived ability to use Everyday Technologies (ETs)	Participants with dementia (n=35)	Participants with dementia (sub-sample, n=16)	Participants with & without dementia (n=128)	Participants with dementia (n=64)	<p>The older people with dementia were able to use ETs and did use ETs, although to a lesser degree than older people without dementia (M12).</p> <p>In both the Swedish and UK samples, the types of ETs that were used to a higher degree than other types of ETs, tended to be public space ETs (M13).</p> <p>In both the Swedish and UK samples, the types of ETs that were used to a lower degree than other types of ETs tended to be portable ET, in particular Information Communication Technologies (ICTs) (M14).</p> <p>Older people with and without dementia reported using ETs for preparation and wayfinding activities within the home, as part of their strategies for managing their subsequent (social) participation outside the home (M15).</p>
	Participants without dementia (n=34)			Participants without dementia (n=64)	
	Person measure of ability to use ETs (logits)	53.24	60.71	60.71	
		<p><i>Types of ETs used most frequently</i></p> <ul style="list-style-type: none"> <li>• Lift/ elevator (100.00%)</li> <li>• ATM (87.50%)</li> <li>• Automatic ticket gate (for travel) (81.25%)</li> <li>• Credit/ debit card and PIN (68.75%)</li> <li>• Door lock on public toilet (68.75%)</li> </ul>	<p><i>Types of ETs used least frequently</i></p> <ul style="list-style-type: none"> <li>• Credit/ debit card and PIN (90.63%)</li> <li>• Lift/ elevator (85.16%)</li> <li>• ATM (74.22%)</li> <li>• Door lock on public toilet (64.84%)</li> <li>• Fuel pump (60.16%)</li> </ul>	<p><i>Number of outside home ETs used (max. 49)</i></p> <p>10.00</p>	
					<p><i>Management strategies for (social) participation involving ET</i></p> <ul style="list-style-type: none"> <li>• Preparation and wayfinding involving ET</li> <li>• Searching online for information</li> </ul>
		<ul style="list-style-type: none"> <li>• Tablet (internet banking) (0.00%)</li> <li>• Tablet (games) (0.00%)</li> <li>• Tablet (transaction) (0.00%)</li> <li>• Smartphone (internet banking) (0.00%)</li> <li>• Smartphone (transaction) (0.00%)</li> </ul>	<ul style="list-style-type: none"> <li>• Mobile phone (alarm) (4.69%)</li> <li>• Mobile phone (camera) (8.59%)</li> <li>• Smartphone (games) (9.38%)</li> <li>• Tablet (internet banking) (9.38%)</li> <li>• Pedometer (9.38%)</li> </ul>		

**Table 8.** Synthesising the findings through graphical joint displays and meta-inferences (Associations between ET use, person-related, contextual factors, and participation in places visited within public space).

Category	Swedish sample		UK sample		Meta-inferences of associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space	
	Sub-study one	Sub-study four	Sub-study two	Sub-study three		
Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space	Participants with dementia (n=35)	Participants with dementia (sub-sample, n=16)	Participants with & without dementia (n=128)	Participants with dementia (n=64)	For the Swedish sample, a statistically significant association was identified between ET use and participation in places visited without public space among older people with and without dementia. However, this statistically significant association was not found between the relevance of public space ETs, or portable ETs, in relation to participation in places within public space (M16).  The Swedish sample of older people with dementia continued to use ETs over time but the number of ETs used decreased over time (M17).  For the UK sample, higher ET use was associated with a higher probability of higher out-of-home participation. Furthermore, a statistically significant association was found between ET use and participation in places for places of recreation and physical activity (Domain D) for older people with and without dementia but not between ET use and participation in places for social, spiritual, and cultural activities (Domain C) (M18).	
	Participants without dementia (n=34)			Participants without dementia (n=64)		
	<i>Association between ET use &amp; out-of-home participation</i>					
	<i>Association between number of relevant public space ET &amp; participation in places visited within public space</i>					
	$r = .22$ $p = .20$	A one-unit decrease in the number of ETs used was significantly related to a decrease in the number of places visited by .18.	ET use was associated with a 1.49 higher probability ( $p < .001$ , 95% CI= 1.04 to 1.13) of a person having a higher level of out-of-home participation, given that the other variables were controlled for	Domain C: No significant association ( $r_s = .18$ ; $p = .15$ ) Domain D: Small-medium significant association ( $r_s = .34$ ; $p < 0.01$ )		
	$r = .31$ $p = .08$			Domain C: No significant association ( $r_s = .18$ ; $p = .16$ ) Domain D: Small significant association ( $r_s = .25$ ; $p = .05$ )		
	<i>Association between number of relevant portable ET &amp; participation in places visited within public space</i>					
	$r = .33$ $p = .05$					
	$r = .15$ $p = .41$					

→ **Table 8** continues on the next page

Table 8. Continued from the previous page.

Category	Swedish sample		UK sample		Meta-inferences of associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space
	Sub-study one	Sub-study four	Sub-study two	Sub-study three	
Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space	Participants with dementia (n=35)	Participants without dementia (n=34)	Participants with & without dementia (n=128)	Participants with dementia (n=64)	Participants without dementia (n=64)
	Association between person measure of ability to use ETs & participation in places visited within public space	Association between age & participation in places visited within public space	Association between perceived risk, access to a concession travel pass, having a functional impairment & out-of-home participation	Association between social deprivation of the living environment & social participation	Association between social deprivation of the living environment & social participation
	$r = .55$ $p < .01$	With increased age, participation in places visited within public space decreased by .42, however the association was not statistically significant.	A higher probability of perceived risk of falling outside home (OR= 2.50; $p < .05$ ; CI= 1.24 to 5.05) and, access to a concession travel pass (OR= 3.94; $p < .001$ ; CI= 1.97 to 7.89) were associated with a higher level of out-of-home participation. Having a functional impairment was associated with a low probability of a higher level of out-of-home participation (OR= .47; $p = .12$ ; CI= .18 to 1.22).	Domain C: No significant association ( $r_s = .04$ , $p = .79$ ) Domain D: Small significant association ( $r_s = .27$ , $p = .03$ )	Domain C: No significant association ( $r_s = .16$ , $p = .21$ ) Domain D: No significant association ( $r_s = .01$ , $p = .91$ )
					Whilst ET use may be a determinant of participation in places within public space, there are a variety of other issues to consider including perceived risk of falling, access to a concession travel pass, having a functional impairment, and social deprivation of the living environment (M19).  Age did not have a statistically significant effect on participation in places visited within public space over time for the Swedish sub-sample of older people with dementia (M20).

## Summary of the synthesis of the findings

### (i) Participation in activities and places visited within public space

#### *The frequency of participation in places within public space*

Overall, there was a pattern of statistically significant lower participation in places visited within public space, among older people with and without dementia in both Sweden and the UK. In **study one**, the Swedish sub-sample of older people with dementia reported statistically significantly lower total participation in places visited within public space ( $Md= 18.00$ ), relative to the sub-sample of older people without dementia ( $Md= 19.00$ ,  $U= 425.00$ ,  $Z= -2.06$ ,  $p= .04$ ), although the effect size was small ( $r= -.25$ ). Similarly, in the UK sample in **study three**, there was statistically significantly lower social participation in Domain C among the sub-sample of older people with dementia ( $Md= 3.00$ ), as opposed to the sub-sample of older people without dementia ( $Md= 5.00$ ,  $U= 1434.00$ ,  $Z= -3.00$ ,  $p< .01$ ). The effect size was also small ( $r= -.18$ ). However, the median social participation in Domain D was equal for the sub-sample of older people with dementia and those without dementia ( $Md= 5.00$ ,  $U=1900.00$ ,  $Z= -.72$ ,  $p= .47$ ,  $r= -.04$ ).

Whilst the older people with dementia participated in a lower total number of places visited within public space compared to the older people without dementia, **study two** indicated that both older people with and without dementia participated in at least some places within public space. Based on the ordinal levels of out-of-home participation in the UK sample of 128 older people in **study two**, the lowest proportion of the sample, 22 older people (17.19%), reported participation in 1-12 places. Thus, indicating that the majority of the UK sample of older people with and without dementia participated in 13 or more of the 24 places included in the ACT-OUT questionnaire. The highest proportion of the sample, 42 older people (32.81%), reported participation in 13-16 places and 35 older people (27.34%) reported participation in 17-18 places. 29 older people (22.66%) reported participation in 19-24 places. Furthermore, in the longitudinal **study four**, the Swedish sample of older people with dementia did participate in a number of places within public space, although this decreased over time. For each increased year (one unit in the time variable), participation in places visited within public space decreased by .61. This is indicative of the statistically significant time effect for participation in places visited within public space ( $F= 5.34$ ,  $p= .02$ , 95% CI= -1.14 to -.08).

#### *Participation in different types of places within public space*

Despite the overarching patterns in the *number* of places participated in, there was a degree of variability in the *types* of places that the older people with and without dementia participated in. In **study one**, a frequency hierarchy comparing counts of changes in past and present participation in places visited within public space showed that both the Swedish sub-samples of older people with and without dementia reported relatively high participation in the neighbourhood, which remained stable from the past to the present

(Figures 2 and 3). However, the neighbourhood was an exception among the types of places for recreation and physical activity (Domain D), which were abandoned to a higher degree (lowest count) between past and present participation for both sub-samples, especially the sports facility, and forest, mountain, lake, sea. The type of places retained (highest count) over time among the Swedish sub-sample of older people with dementia, included day care and a building for worship, which differed from those types of places retained over time by the sub-sample of older people without dementia, which included a hairdresser and mall, supermarket.

Similarly, for the UK sample in **study two**, a frequency hierarchy showed that there was no clear trend in the types of places which were most frequently retained. However, participants reported continuing to participate in places for medical care (Domain B e.g. doctor's surgery; day care), consumer, administration and self-care places (Domain A e.g. mall, supermarket; small store), and to a lesser degree social, spiritual and cultural places (Domain C e.g. restaurant, cafe, bar). However, there was a discernable pattern of abandonment among the types of places used for recreation and physical activities (Domain D, e.g. sports facility; cottage, summer house; forest, mountain, lake, sea; park, green area), and to a lesser degree social, spiritual and cultural places (Domain C, e.g. senior centre, social club; building for workshop; entertainment, cultural places).

The findings in **study three** elucidate emerging trends in the types of places retained or abandoned in the findings from **studies one** and **two**. **Study three's** radar visualisations showed that once again the neighbourhood was one of the places retained to a higher degree, relative to other types of places, among the UK sub-samples of older people with and without dementia. However, other places used for recreation and physical activities (Domain D, e.g. sports facility; cottage, summer house; and forest, mountain, lake, sea) were abandoned to a higher degree than the different types of places by both the UK sub-samples of older people with and without dementia. Social, spiritual and cultural places (Domain C) were also abandoned to a higher degree than other types of places by the sub-sample of older people with dementia (e.g. entertainment, cultural place) and by the sub-sample of older people without dementia (e.g. building for worship). The overall frequency of abandonment between past and present participation was higher for the sub-sample of older people with dementia, as opposed to the sub-sample of older people without dementia, especially in those places in Domains C and D. This motivated the focus on Domain C and D in **study three** and thus, social participation was operationalised as encompassing social, spiritual and cultural places (Domain C) as well as places for recreation and physical activity (Domain D) (Figures 2 and 3).

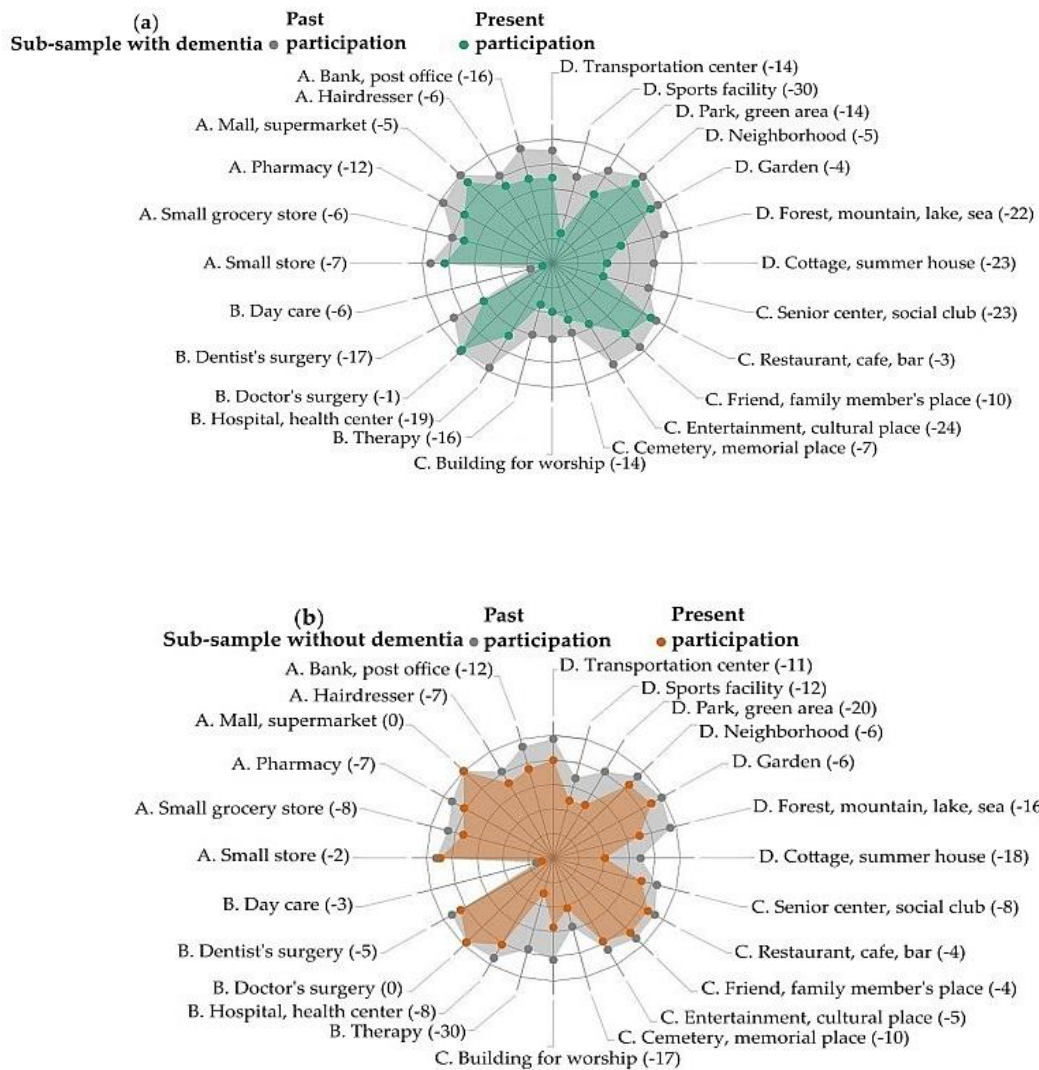
Based on the Swedish, longitudinal data in **study four**, the frequency hierarchy revealed an overall trend for the participation between the years to remain stable in the majority of places, whilst controlling for the attrition bias using the sub-sample of 16 older people with dementia. Across 20 of the 24 different types of places, there was a change of no more than three counts. Corroborating the findings in the earlier studies, the neighbourhood (Domain D) was associated with relatively high participation over time. A stable pattern of relatively high participation over time was linked to the friend, family member's place (Domain C); dentist's surgery (Domain B); cemetery, memorial place (Domain C); restaurant, café, bar



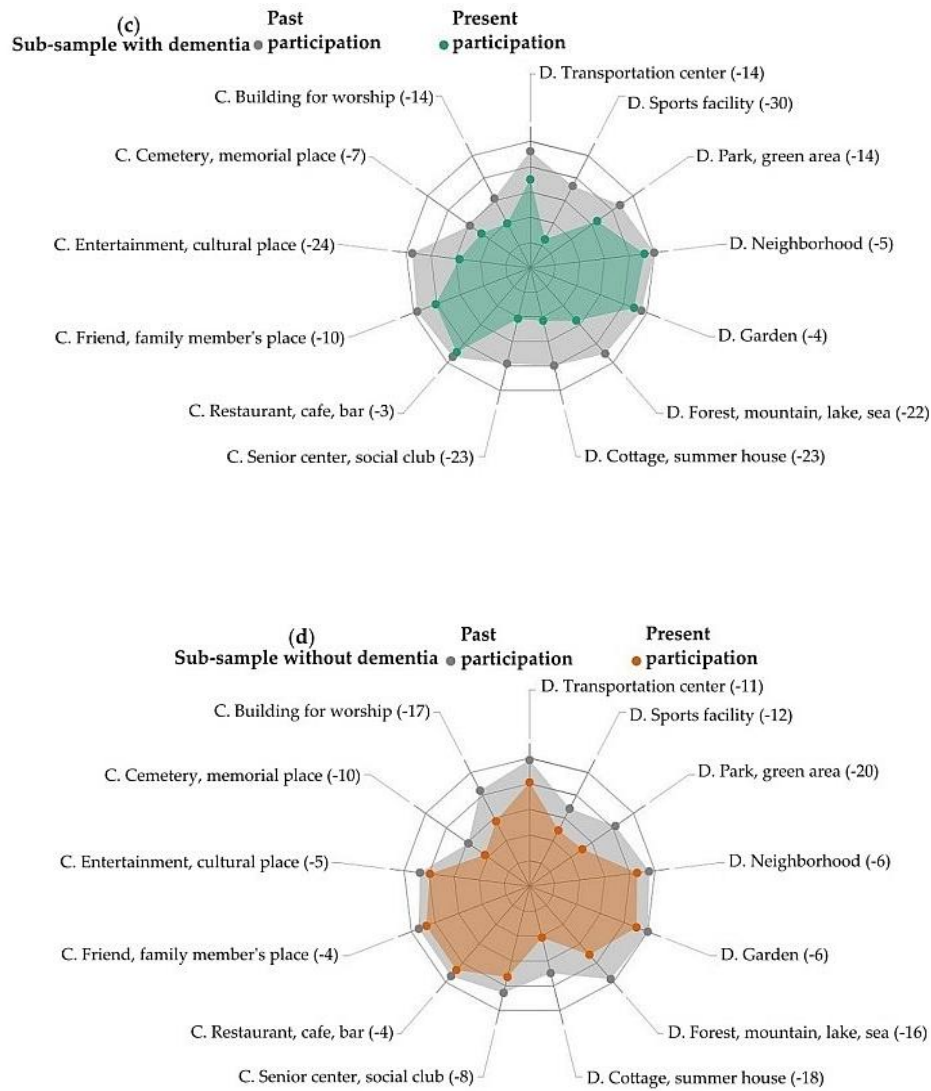
(Domain C); and pharmacy (Domain A). There were, however, examples of places where participation increased over time, including the doctor's surgery (Domain B); and forest, mountain, lake, sea (Domain D). It was somewhat surprising that in **study four** the Swedish sub-sample of older people with dementia reported an increase in participation in the forest, mountain, lake, sea, given that the Swedish sub-sample of older people with dementia in **study one** reported a decrease from past to present participation in this place. However, the finding of an increase in participation in the forest, mountain, lake, sea, in the longitudinal **study four** was not based on the full sub-sample of 35 older people with dementia as in **study one**. Instead, **study four's** finding was based on the Swedish sub-sample of 16 older people with dementia, after controlling for the attrition bias. Participation was consistently low in places, such as the sports facility (Domain D); and day care (Domain B). Furthermore, there was a descending trend in participation over time for the transportation centre (Domain D); the bank, post office (Domain A); as well as the hospital, health centre (Domain B) to a lesser degree.

#### *Participation in different types of activities and places within public space*

The finer grain analysis in **study three** also offered insights into the patterns of participation in activities performed in the different types of places. In Domain C, the sub-sample of older people with dementia (36.51%) most frequently reported participation at a friend or family member's place, for activities, such as visiting family to socialise and provide support. The sub-sample of older people without dementia (23.43%) most frequently reported participation in entertainment or cultural places, for activities, such as watching a film at the cinema or visiting the library. Whereas in Domain D, the sub-sample of older people with dementia (28.33%) most frequently reported participating in their garden, for activities, such as taking care of the garden, sitting out and enjoying it. The sub-sample of older people without dementia (24.14%) most frequently reported participation in the forest, mountain, lake, sea, for activities, such as going on a trip, walking, relaxing, alone or with others.



**Figure 2.** Radar visualisations to present stability and change between past and present participation, among all of the activities and places in the Participation in ACTivities and Places OUTside Home Questionnaire (ACT-OUT). The green coloured radar visualisation (a) refers to the UK sub-sample of older people with dementia. The orange coloured radar visualisation (b) corresponds to the UK sub-sample of older people without dementia. The bracketed numbers represent the decrease between past and present participation, according to Domains: (A) places for purchasing, administration, and self-care; (B) places for medical care; (C) places for social, spiritual, and cultural activities; (D) places for recreation and physical activity. Originally published in Gaber et al. (2020b).



**Figure 3.** Radar visualisations to indicate stability and change between past and present social participation, across Domains C and D in the Participation in ACTivities and Places OUTside Home Questionnaire (ACT-OUT). The green coloured radar visualisation (c) refers to the UK sub-sample of older people with dementia. The orange coloured radar visualisation (d) corresponds to the UK sub-sample of older people without dementia. The bracketed numbers represent the decrease between past and present social participation. Originally published in Gaber et al. (2020b).

## (ii) The relevance and perceived ability to use Everyday Technologies (ETs)

### *The frequency of ETs used*

The relevance and perceived ability to use ETs (i.e. person measure of ability to use ETs) was significantly different in a statistical way, between the Swedish sub-sample of older people with dementia and the sub-sample of older people without dementia. In **study one**, the number of relevant public space ETs was significantly lower among the Swedish sub-sample of older people with dementia ( $Md= 8.00$ ) than the sub-sample of older people without dementia ( $Md= 9.00$ ,  $U= 392.50$ ,  $Z= -2.44$ ,  $p= .02$ ), although the effect size was small ( $r= -.29$ ). Similarly, the number of relevant portable ETs was significantly lower for the sub-sample of older people with dementia ( $Md= 7.00$ ) relative to the sub-sample of older people without dementia ( $Md= 10.00$ ,  $U= 394.50$ ,  $Z= -2.42$ ,  $p= .02$ ), and the effect size was small ( $r= -.29$ ). The person measure of ability to use ETs was also significantly lower for the sub-sample of older people with dementia ( $Md= 53.24$ ) compared to the sub-sample of older people without dementia ( $Md= 60.71$ ,  $U= 125.00$ ,  $Z= -5.64$ ,  $p\leq .001$ ), however, the effect size was large ( $r= -.68$ ). Corresponding to the Swedish findings, the UK findings in **study three** showed that total ET use outside home which was significantly lower for the sub-sample of older people with dementia ( $Md= 10.00$ ), compared to the sub-sample of older people without dementia ( $Md= 21.00$ ,  $U= 556.50$ ,  $Z= -7.11$ ,  $p<.001$ ), and the effect size was large ( $r= -.63$ ).

In addition to the observed between-group trends in the relevance and perceived ability to use ETs, **study four's** findings also highlighted within-group trends over time. Among the Swedish sample of 35 older people with dementia, the median use of ET outside home at baseline was 10.00, and this continued to decrease at year one ( $Md= 9.50$ ), and year two ( $Md= 7.50$ ). When controlling for attrition bias in the sub-sample of 16 older people with dementia, the median use of ET outside home was slightly higher but it still showed a similar decreasing pattern, from baseline ( $Md=14.00$ ) to year one ( $Md=11.50$ ), and year two ( $Md= 7.50$ ). In year three, the median use of ET outside home for the remaining sample of 9 older people with dementia was 11.00. This was slightly higher than the baseline value for the sample of 35 older people with dementia but it was lower than the baseline when the attrition bias was accounted for in the sub-sample of 16 older people with dementia.

### *The different types of ETs used*

The findings on the types of ETs used are based on statistical analyses from **studies two** and **four**, in addition to the content analysis of free text comments in **study three**. Across the Swedish and UK samples, public space ETs tended to be used to a higher degree, and this was evident for older people with and without dementia. According to the UK sample in **study two**, the percentages of counts of ET use showed a trend for the sample of older people with and without dementia to use portable ETs, which can be used both inside and outside the home, such as a mobile phone using the alarm and camera functions; a smartphone using the games function; a tablet for internet banking; and a pedometer, to a

lesser degree. Conversely, the type of ETs used to a higher degree tended to be ETs typically used outside home and within public space, such as credit or debit card and PIN; a lift or elevator; an ATM; a door lock on public toilet; and a fuel pump.

In **study four**, the Swedish sub-sample of 16 older people with dementia tended to use public space ETs to a higher degree than portable ETs over time. More specifically, a lift or elevator, an ATM, an automatic ticket gate for travel, a credit or debit card and PIN, and a door lock on public toilet, were among the public space ETs which were used to a higher degree by the sub-sample of 16 older people with dementia, at baseline as well as over time. However, the automatic passport control, GPS or satellite navigation, and fuel pump were public space ETs that were used to a lesser degree by the sub-sample of 16 older people with dementia, at baseline as well as over time. In terms of portable ETs, the mobile phone was used to a higher degree by the sub-sample of 16 older people with dementia at baseline and over time. The sub-sample of 16 older people with dementia reported using the mobile phone for the functions of making a call and receiving a call but the range of functions performed on a smartphone or tablet, were used to a lesser degree, at baseline and over time. Whilst there was a trend for ET use to either remain stable, or decrease, over time for each ET, there were exceptions where some ET use increased. A slight increase in use over time was evident for the tablet (for transactions i.e. online purchases), the smartphone (for internet banking), the smartphone (for transactions), and the hearing aid. There were also fluctuations in use over time, for ETs, such as an ebook reader and a mobile phone (for camera functions).

In **study three**, ET use was described as being a key part of preparation and wayfinding management strategies. Preparation and wayfinding management strategies were viewed as integral to whether an older person with or without dementia was able to engage in social participation, or not. Such management strategies commonly involved ET use at home as a preparatory activity, for subsequent participation in activities and places within public space, exemplified by a compass or GPS used on a smartphone or online booking services operated on a computer. Attitudes towards the need to plan and prepare for social participation, with a particular reliance on the use of ET, conveyed complex and nuanced meanings. Such nuances were shown in the ways that the UK sub-sample of older people with and without dementia reported embedding ET use into their planning and preparatory routines. These routines were described as assistive to social participation in places within public space but also problematic because the need to plan and prepare for social participation in advance was linked to anxiety and at times, even conflicts between people. Perceived issues, including tensions between spouses or family members, intensified when a person encountered difficulties with ET use.

### (iii) Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space

#### *Associations between ET use and (social) participation*

Positive associations were identified between ET use and participation, among the Swedish and UK samples of older people with and without dementia. In the Swedish sub-samples in **study one**, a positive but not statistically significant association was found between participation in total number of places visited within public space, and (i) the number of relevant public space ETs (sub-sample of older people with dementia,  $r_s = .22$ ,  $p = .20$ ; sub-sample of older people without dementia,  $r_s = .31$ ,  $p = .08$ ). The association between participation in total number of places visited within public space and (ii) the number of relevant portable ETs was slightly above the threshold ( $p < .05$ ) therefore it was not considered statistically significant for the sub-sample of older people with dementia,  $r_s = .33$ ,  $p = .05$ , or the sub-sample of older people without dementia,  $r_s = .15$ ,  $p = .41$ . A large, statistically significant and positive association was discerned between participation in total number of places visited within public space and the person measure of ability to use ETs among the sub-sample of older people with dementia ( $r_s = .55$ ,  $p < .01$ ) but not among the sub-sample of older people without dementia ( $r_s = .22$ ,  $p = .21$ ). Similarly, for the UK sample in **study two**, the ordinal regression model demonstrated that ET use was significantly associated with a 1.49 higher probability ( $p < .001$ , 95% CI= 1.04 to 1.13) of a person having a higher level of out-of-home participation, when controlling for the other variables. The statistical modelling in **study four** revealed that decreasing use of ET outside home was associated with decreasing participation in places visited within public space over time, in a statistically significant way among the Swedish sample of 35 older people with dementia. The effect of use of ET outside home on participation in places visited within public space was statistically significant ( $F = 7.59$ ,  $p = .01$ , 95% CI= .05 to .31). Thus, a one-unit decrease in the number of ETs used was significantly related to a decrease in the number of places visited by .18.

Regarding social participation, **study three's** findings showed a small, statistically significant and positive association between social participation in Domain D and ET use outside home for the UK sub-sample of older people with dementia ( $r_s = .25$ ,  $p = .05$ ), and a small to medium, statistically significant, positive association was identified for the sub-sample of older people without dementia ( $r_s = .34$ ,  $p < .01$ ). However, a non-significant association was identified between social participation in Domain C and ET use outside home, for the UK sub-samples of older people with dementia ( $r_s = .18$ ,  $p = .16$ ) and without dementia ( $r_s = .18$ ,  $p = .15$ ).

#### *Associations between person-related, contextual factors, and participation in activities and places visited within public space*

According to the UK sample of 128 older people with and without dementia in **study two**, univariate analysis revealed non-significant associations between three of the four types of perceived risk and the ordinal levels of out-of-home participation: (i) getting lost (OR: .62,  $p =$

.26, 95% CI= .28 to 1.41), (ii) feeling stressed (OR: 1.20,  $p = .60$ , 95% CI= .61 to 2.33), and (iii) feeling embarrassed (OR: .86,  $p = .66$ , 95% CI= .42 to 1.72). However, the univariate analysis demonstrated a significant association was identified for perceived risk of falling, indicating a higher probability of perceived risk of falling outside home was associated with a higher level of out-of-home participation (OR: 3.58,  $p < .001$ , 95% CI= 1.84 to 6.97). Based on the ordinal regression model, a perceived risk of falling outside home was associated with a higher probability of a person having a higher level of out-of-home participation (OR: 2.50,  $p < .05$ , 95% CI= 1.24 to 5.05).

Access to a CTP was associated with a higher probability of a person having a higher level of out-of-home participation (OR: 3.94,  $p < .001$ , 95% CI= 1.97 to 7.89) among the UK sample of 128 older people with and without dementia in **study two**. However, having a functional impairment was associated with a low probability of a higher level of out-of-home participation (OR: .47,  $p = .12$ , 95% CI= .18 to 1.22.). This association was not statistically significant, although it did indicate that having a functional impairment, which may be in addition to dementia for those with a dementia diagnosis, may be associated with a lower probability of a person having a higher level of out-of-home participation.

Due to the mixed methods design of **study three**, findings from the free text responses supplemented the aforementioned statistical findings. The free text responses from the two UK sub-samples revealed underlying associations between motivators, considerations that require extra attention and management strategies, and social participation in Domain C and D. Four key findings were identified from the free text responses among the sub-samples of older people with and without dementia: (i) purposeful activities as a motivator for social participation; (ii) the journey as a natural continuation of the activity; (iii) the need to pay extra attention to the social context, and; (iv) the need to pay extra attention to the physical context.

The first key finding was that both the UK sub-samples of older people with and without dementia emphasised the value of purposeful activities as a motivator for social participation. Although the degree of complexity associated with the purpose of social participation varied. The degree of complexity ranged from participation in a place to perform a single, specific activity, such as walking in the park or eating in a restaurant. To increasingly complex repertoires of activities, such as participation in a place in order to perform multimodal activities, including going to a community centre to meet people, see friends, pray, pass time, and for enjoyment.

The second key finding was that the journey was conceived of as a natural continuation of the activity, rather than as two distinct parts. Participation in the journey as a continuation of activity provided opportunities to socialise with other people including their spouse, family, and friends, or as a group member. Motivators for participation in the journey or activity with other people included a shared interest in the activity, the pleasure of companionship, or to support each other with travel arrangements which became increasingly important due to changing life circumstances, such as driving cessation.

The third key finding was that both of the sub-samples of older people with and without dementia spoke about concrete, contextual factors in relation to considerations that require extra attention for social participation. In terms of the social context, familiarity with people

in one's neighbourhood was presented as an additional layer of support and security for social participation. A familiar and supportive social context was described as a buffer against problematic situations associated with ET use, for instance misplacing ETs, or forgetting to charge ETs.

The fourth key finding involved the need to pay extra attention to the physical context, including technological aspects. Considerations related to the physical context included the disorientating sound of alarms, uneven walking surfaces, and trip hazards. These considerations were exacerbated by wet weather conditions, poor lighting or temporal factors, leading to perceived risks and the avoidance of participation in places within public space, for example during darkness at night-time. Whilst there was a consensus among urban- and rural-dwellers that extra attention needed to be afforded to contextual factors, these differed based on the local environment. Similarly, contextual factors in the local environment were explored with regard to social deprivation of the living environment (IMD). In **study three**, a non-significant association was discovered between the social deprivation of the living environment and social participation in Domain C for the UK sub-samples of older people with dementia ( $r_s = .04, p = .79$ ) and without dementia ( $r_s = .16, p = .21$ ). A small, statistically significant association was determined between social deprivation of the living environment and social participation in Domain D for the UK sub-sample of older people with dementia ( $r_s = .27, p = .03$ ) but not for the older people without dementia ( $r_s = .01, p = .91$ ).

In general, the sub-samples of older people with and without dementia in **study three** reported commonalities in the motivators, considerations that require extra attention and management strategies underlying their social participation. This suggests that a number of the issues perceived by the older people with and without dementia whilst participating in activities and places within public space pertain to not only a diagnosis of dementia but are also applicable to older people in general. However, based on the Swedish sample of older people with dementia in **study four**, age group at baseline had a non-significant effect on participation in places visited within public space over time ( $F = .15, p = .71, 95\% \text{ CI} = -2.67$  to  $1.83$ ). An increase in age was associated with a decrease in participation in places visited within public space by  $.42$ .



## DISCUSSION

The first part of this chapter discusses the synthesis of the findings. The findings are discussed in relation to the literature delineated in the introductory chapter of this thesis. The second part of this chapter provides a reflection on the rationale for the methods described in chapter four, including potential strengths and limitations as well as ethical considerations.

### (i) Participation in activities and places visited within public space

On a general level, the synthesis of the findings attest to the declining participation over time among older people with dementia, and to their significantly lower total participation in places visited within public space, in comparison to the older people without dementia. However, a finer grain analysis indicates that participation in activities and places within public space, among older people with and without dementia, is more nuanced and dynamic than assumed by a theory of a uniformly or passively shrinking world, based solely on familiarity and proximity (Duggan et al., 2008; Margot-Cattin et al., accepted for publication). There is also a tendency to focus on those places lost or abandoned within the theory of a shrinking world, which may amplify the older person with dementia's deficits and an assumed inability to participate, rather than a more holistic view of their participation in activities and places within public space. To challenge this disabling trend in the literature, the chapter begins by discussing a type of place that both the older people with and without dementia participated in over time – the neighbourhood.

#### *The centrality of the neighbourhood*

According to Mitchell and Burton (2010), an accessible and usable neighbourhood is a prerequisite for older people with dementia to participate outside the home, which in turn may enhance their health and wellbeing (Evans et al., 2019). The perceived value of the neighbourhood is echoed across the constituent studies of this thesis. Across the contextual parameters of Sweden and the UK, the neighbourhood was one of the most frequently visited places within public space compared to other types of places. This corroborates earlier, albeit primarily qualitative studies, which emphasised the centrality of the neighbourhood in the everyday lives of older people with dementia (Blackman, 2006; Duggan et al., 2008; Oswald et al., 2010). However, this thesis not only confirms earlier research on the significance of the neighbourhood for older people with dementia, it underlines that this perceived value may also be shared by older people without dementia. The exploration of comparative patterns of participation between sub-samples of older people with and without dementia in **studies one** and **three** indicated that a pattern of higher participation in the neighbourhood was evident for both older people with and without dementia. Thus, the synthesis of the findings suggests that the perceived value of participation in the neighbourhood is not a peculiarity to older people with dementia (van

Dijk et al., 2015) and that the perceived value of participating in the neighbourhood, for various reasons, including to foster a sense of social connectedness and interpersonal relationships (Morgan et al., 2019) is not solely dependent on diagnosis.

### *Visualising the neighbourhood as an anchoring point*

By visualising participation in the neighbourhood in relation to other types of places, **study three** provided insights into the hypothesised shrinking world for older people with dementia (Figures 2 and 3). The radar visualisations showed that the neighbourhood was one of the places that both older people with and without dementia continued to participate in, to a higher degree than other types of places, between the past and the present. The neighbourhood was visualised as a type of anchoring datapoint, for both older people with and without dementia. There was little change between past and present participation in the neighbourhood compared to greater changes in past and present participation in other types of places. Similarly, prior research has conceptualised the neighbourhood as the loci of an *activity radius* among older people with and without cognitive impairment (Brorsson, 2013; Oswald et al., 2010). The *activity radius* refers to the area where the older person performs their activities in relation to their home (Brorsson, 2013; Oswald et al., 2010). Based on the findings, there is an overlap in the types of places explored in the ACT-OUT questionnaire and the common view of what constitutes the neighbourhood. Together these form the *activity radius*. The findings enhance existing conceptions of the neighbourhood by looking more closely at a variety of different types of places which may overlap, or even constitute the neighbourhood. The continued participation in the neighbourhood according to the radar visualisations is confirmed in the other studies of this thesis, in particular through the longitudinal investigation of participation in **study four** where the Swedish sample of older people with dementia continued to participate in the neighbourhood to a higher degree than other types of places, over the course of three years. The synthesis of the findings concerning patterns of participation in the neighbourhood appears to support Duggan et al.'s (2008) theory of a shrinking world. Whereby the life world, or *activity radius*, that the older person with dementia participates in, decreases in size and those places that the older person with dementia is most familiar with or that are within the vicinity of the home, namely the neighbourhood, are retained over time (Duggan et al., 2008; Li et al., 2019; Shoval et al., 2011).

### *A critical discussion of the neighbourhood*

The centrality of the neighbourhood to the everyday lives of older people with and without dementia should, however, be interpreted with a degree of humility. This is due to a lack of clarity regarding the definition or description of the construct of the neighbourhood and indeed, whether the definitions proposed in the literature are emblematic of the varied perspectives and experiences of its participants. In the literature, the neighbourhood has been defined in different ways. Some definitions emphasise the walkability of area constituting the neighbourhood (Odzakovic, 2020) which may have exclusionary consequences for people with mobility limitations. Other broader definitions describe the

neighbourhood as a place where people live and interact with each other and their surrounding environment (Li et al., 2019). There is a challenge in drawing conclusions about research on the neighbourhood because the construct of the neighbourhood is inherently localised and imbued with personal and social meaning. This may vary according to scale, such as a street or part of a city, or according to social cues and historical attachments (Brorsson, 2013). Moreover, the neighborhood may be viewed as part of the larger ecosystem of the environment and it is subject to stability and change based on a mutualistic relationship between how people interact with their neighbourhood and how in turn, the neighbourhood shapes the everyday habits and routines of the people that participate in it (Jacobs, 1961). For these reasons, the neighbourhood was a place self-defined by the older people with and without dementia across the four studies in this thesis. Thus, the findings embrace a degree of variability in what constitutes a neighbourhood, including diverse interpretations of familiarity and proximity. Notwithstanding this diversity, the older people with and without dementia consistently emphasised a need or a desire, to participate in a place that they perceived as their neighbourhood.

*Perceived quality or quantity of participation: purposeful activities as a motivator for social participation*

Whilst the older people with dementia participated in the neighbourhood to a higher degree than other types of places over time, there was an overall trend for the older people with dementia to participate in fewer places within public space over time. From a biomedical perspective, this finding may be interpreted as confirming that participation is dependent on the older person's diagnostic affiliation as either a person with or without dementia. The finding corroborates prior research which found that the frequency of participation outside the home is associated with a person's levels of cognition as well as ability to perform ADLs (Chiu et al., 2013; Mlinac & Feng, 2016). Similarly, other studies have shown that older people with MCI and mild-stage dementia experience vicissitudes in their cognition which may disrupt their participation in activities (Johansson et al., 2015). The overall tendency for older people to participate to a lower degree than older people without dementia was also evident between their reports of both past and present participation. Reinforcing earlier research which demonstrated that profiles of decreased engagement in activities may be related to cognitive severity in older people with MCI (Hedman et al., 2017) and AD (Nygård & Kottorp, 2014).

Intriguingly, the types of places which were most frequently visited did not match the types of activities and places that the older people with and without dementia chose to speak about, in more detail, through their free text comments in **study three**. The free text comments showed that the older people with and without dementia reported multiple reasons for why they were motivated to visit places in public space to participate in activities. The motivators were not limited to proximity and familiarity but rather they included varied and personal motivators, such as a desire to participate in activities that were perceived as meaningful. In particular, the older people with dementia frequently participated in a friend or family member's place, to socialise but also to engage in a

mutualistic exchange of giving and receiving support. The older people with and without dementia reported actively participating in specific types of places, for the purpose of individual activities or for a more complex repertoire of multiple meaningful activities. Whilst the modalities of their reported participation may have been adapted for pragmatic reasons, such as a preference to participate outside the home in daylight or to travel by car with a significant other, this was not described as a passive decline in their participation, akin to the theory of a shrinking world (Duggan et al., 2008). The older people with and without dementia did not describe themselves as victims of an inaccessible public space as may be inferred from the theory of a shrinking world. Instead, the synthesis of the findings points to a more balanced view whereby the older person with and without dementia negotiates not only accessibility issues in the environment but also in relation to their sense of agency and citizenship (Baldwin & Greason, 2016; Nedlund et al., 2019; Phinney et al., 2016). This negotiation may reinforce the older person with and without dementia's sense of agency, being, and belonging by enacting their citizenship through participation in activities and places within public space (Hitch et al., 2014). Thus, it is possible to infer that the size of the life world, or *activity radius*, may be less important than the perceived quality and the meaning of the experience to the older person, with and without dementia, themselves. The frequency of participation provides empirical insights, however, the exploration of a two-dimensional effect of a shrinking life world is enhanced by the free text comments from **study three**. **Study three's** mixed methods findings in relations to the findings from the other studies suggests that a more nuanced three-dimensional contemplation of the underlying motivators for participation is required.

### *Participation and citizenship*

On the one hand, participation in the community and one's neighbourhood is a reoccurring topic in research. On the other hand, reviews of policy (Keady et al., 2012) and the current national dementia plans (ADI, 2020) have revealed a tendency to focus on generic aspects of the environment or legal frameworks of dementia care, on a meta- or macro-citizenship level. This has eclipsed an investigation of more granular insights or guidance about the environment or contextual factors, pertaining to micro-citizenship through participation in the older person with and without dementia's everyday lives. To pursue a more granular exploration, the studies of this thesis not only explored total participation but also participation according to the different types of places, incorporating data visualisations. The synthesis of the findings demonstrated that older people with dementia did still participate in a variety of different types of places within public space but that they did also abandon specific types of places. The findings of each study draw upon tools to measure a unit of analysis on the micro-citizenship level, based on participation in activities and places within public space. However, due to the complexity of participation, these findings are still interconnected with other levels of citizenship, such as meta- and macro-citizenship due to broader issues affecting each older person's patterns of participation, such as policymaking as well as the design of communities that older people live in.

In accordance with the Swedish dementia-friendly policy, which prioritises a need to make banking more dementia-friendly, the bank, post office was abandoned by the Swedish

sample of older people with dementia in the longitudinal **study four** and this was evident for the sample at baseline in **study one**. In **study one**, the tendency to abandon the bank, post office was evident for the Swedish sub-sample of older people with dementia but not for those without dementia. There may be various reasons for this difference, including the abundance of ETs involved in banking or other administrative tasks. Other reasons include a shift towards a cashless economy (Eaton et al., 2018), which may increase the complexity of the activity but also decrease the need to physically visit a bank or a place to collect post, frequently found in supermarkets or kiosks in Sweden. It is also possible to contextualise this finding according to earlier research which indicates that older people with dementia can experience challenges with instrumental activities of daily living (IADLs), such as managing their finances or administrative tasks (Giebel et al., 2019) and thus, may require additional support with these activities.

### *Social participation, citizenship and health*

It is salient to consider the trend of older people, particularly those with dementia, in both the Swedish and the UK samples, to abandon places for social, spiritual, and cultural activities (Domain C) such as the senior centre, social club, as well as places for recreation and physical activity (Domain D), such as the sports facility; forest, mountain, lake, sea; and cottage, summer house. Whilst the trend may reflect the older person's choices and preferences, there may also be other factors inhibiting the older person's participation (Rantakokko et al., 2017). More research is required to understand why specific types of places may be abandoned. Specifically, the tendency to abandon places for social, spiritual, and cultural activities (Domain C) and places for recreation and physical activity (Domain D) may echo a tendency to focus on the cognitive health of the older person with dementia rather than a more holistic view of their health, inclusive of their social health (Dröes et al., 2017) and their physical health (Livingston et al., 2020). In terms of places for recreation and physical activity, it is possible to infer that the assumed ability to use various ETs to enter a gym, to access a locker and to operate an exercise machine, may inhibit an older person with and without dementia's participation in a sports facility. Another factor to consider in relation to the abandonment of places such as the sports facility is this population's increased risk of comorbidity. **Study two** found that having a functional impairment was associated with a low probability of a higher level of out-of-home participation. Thus, when an older person with or without dementia is unable to participate in activities or places of their choice, particularly those that may benefit their health such as sports facilities, this may be considered an occupational injustice.

Social health is an additional concern related to the pattern of abandoned places revealed in the synthesis of the findings. Social health reflects a person's ability to participate in social interactions and the influence of the social environment to balance their opportunities and limitations (Huber et al., 2011). Research suggests that social participation in one's environment, specifically their neighbourhood, is related to a person's social health status (Li et al., 2019). Paradoxically, the types of places for social participation, including social, spiritual, and cultural activities as well as recreation and physical activity, are not afforded consideration in the official age- and dementia-friendly policies in Sweden and the UK.

And yet, older people with and without dementia did report feeling motivated to attend places for social participation in groups as in the case of social clubs and senior centres, and the older people with dementia frequently participated in a friend or family member's place in **study three**.

The seeming mismatch between policy and the reports of older people with and without dementia themselves is problematic, particularly in light of the CRPD which states that all people have the right to participate in cultural life, recreation, leisure and sport (UN, 2006). Moreover, the Sustainable Development Goals (SDGs) reinforce the human right to participate in an inclusive society, particularly when this can promote health and well-being. SDG 3 advocates for the need to “ensure healthy lives and promote well-being for all at all ages”, whilst SDG 11 calls for the need to “make cities and human settlements inclusive, safe, resilient and sustainable” (UN, 2015). It is possible to infer that current policies may benefit from considering the specific types of activities and places that older people with and without dementia retain or abandon over time as this may be conducive to a more holistic understanding of health maintenance and promotion. This is not to imply that it would be possible or advisable to develop guidelines for participation in activities and places within public space based on dosages of recommended frequency of participation, akin to guidelines prescribing recommended physical activity levels (WHO, 2020). Rather, it points to an opportunity for healthcare professionals, especially occupational therapists to facilitate and promote participation among older people with and without dementia, drawing on their in-depth training and practice around activity analysis (AOTA, 2017).

#### *Enacting one's citizenship through participation in activities and places within public space*

The changing configuration as well as size of the radar visualisations of participation in **study three**, may not only be due to a decline or shrinking trend in participation but also based on a variety of other factors. Policies may benefit by acknowledging these other factors, in order to enable older people with and without dementia to participate in their chosen activities and places within public space, as a way to enact their citizenship. In **study four**, a framework of citizenship was used to facilitate a more nuanced three-dimensional contemplation of the underlying motivators for participation over time. This suggests that participation is a fluid way for older people with dementia to enact their citizenship rather than a static status or a passive shrinking phenomenon (Duggan et al., 2008). The synthesis of the findings revealed that the older people with dementia did continue to participate in a varied range of places within public space and in the longitudinal **study four** there was even an increase in the Swedish sample of older people with dementia's participation in some places.

The pattern of increasing participation was not only restricted to a place for medical care (e.g. the doctor's surgery), which may be expected considering the majority of older people with or without dementia had some type of functional impairment or comorbidity, in addition to their dementia diagnosis (Table 2). An increase in participation was also

observed in a place for recreation and physical activity (e.g. the forest, mountain, lake, sea) over time. In the case of increased participation in the forest, mountain, lake, sea it is worth considering local contextual factors. For instance, this is based on a Swedish sample from a mainly urban region of Stockholm. Whilst in other urban contexts, such as London this might imply limited access to nature, in Stockholm access to nature is in proximity to the urban centre (Samuelsson et al., 2018). Hence, the findings may also not be generalisable to the UK, or some other contexts, based on the right to freely access nature, which is a Swedish customary right, referred to as “everyman’s right” (allemansrätten) (Swedish Government Official Reports) [SOU], 1940, p. 268). This underlines the importance of exploring participation in a local context, on a micro-citizenship level and with regard to local policy, as one may argue that participating in nature is related to a person’s rights and citizenship in Sweden which cannot be directly extrapolated to other contexts. Whilst it is important to support the older person with dementia’s choice to participate in various places, including the forest, mountain, lake, sea, this must be considered in relation to perceived risks and the hazard awareness of the older person with dementia.

## **(ii) Relevance and perceived ability to use Everyday Technologies (ETs)**

### *Older people with and without dementia as users of ETs*

The findings indicate that the older people with dementia were able to use ETs and did use ETs, although to a lower degree than older people without dementia. Across the Swedish and UK sample, public space ETs tended to be used to a higher degree than portable ETs, especially ICTs, by older people with and without dementia and this trend was also evident among older people with dementia, over time in **study four**. This finding is striking when contextualised according to the plethora of research where technological interventions for older people with and without dementia are based on portable ETs, specifically ICTs (Astell et al., 2019; Pinto-Bruno et al., 2017; Palido Herrera, 2017; Kwan et al., 2020; Schaat et al., 2020). This is due to a narrower view of technologies focused on ICTs. Whereas this thesis takes a broader view of what technology is. A broader view of technology is more inclusive of the types of technology that older people, in particular those with dementia, use in their everyday lives (Emiliani, 2006; Nygård et al., 2016). This presents a potential opportunity to target interventions promoting health and social participation both through portable ICTs but also through a broader selection of ETs, such as public space ETs, and in combination with non-technological options.

The synthesis of the findings provides insight into not only the outcome of the studies but also the process of researching ETs with older people with and without dementia. The studies showed that older people with and without dementia were able to report and describe their experiences of using a variety of ETs and to relate this use to their participation in places within public space. This dispels the view of older people with and without dementia as passive recipients of ETs (Rosales & Fernández-Ardèvol, 2020), as well as the assumption that ET use forms a subsidiary or neutral role in their everyday lives

(Peine & Neven, 2020). Moreover, the Swedish sample of older people with dementia in **study four** were able to contribute their perceptions of ET use over the course of three years. This provides valuable insights into the patterns of stability and change in ET use among older people with dementia but it also testament to the potential ability of older people with and without dementia to play a greater role, actively participating in the consultation, design and development of the ETs that they are the users of.

### *Contextual factors for Everyday Technology (ET) use*

The tendency of the older people with and without dementia to use public space ETs to a higher degree than portable ETs in **studies two, three and four**, may be due to a multitude of reasons. On the one hand, research comparing everyday ICTs between eHealth use and general use, found that older people with cognitive impairment perceived technologies for eHealth use as less relevant compared to general use, suggesting that the purpose of technology use may impact the perceived relevance of it (Jakobsson et al., 2020a). Such research affirms the view of older people as *occupational beings* who need and desire to engage in meaningful or purposeful activities (Drolet, 2014; Wilcock, 1993). Thus, some types of ETs are perceived as more relevant than others. On the other hand, the findings in this thesis suggest that in order to understand the nuanced and dynamic nature of ET use, it is important to investigate its use over time, and to focus on not only performative aspects of participation based on the purpose of ET use. When ET use is abstracted from contextual considerations it risks perpetuating a fallacy of choice. The fallacy of choice suggests that ET use is dependent on the person's choice and preferences alone, as opposed to other interconnected factors which the synthesis of the findings showed were associated to the older person with and without dementia's participation in activities and places within public space. Other factors included the exploration of perceived risk in **study two** and social deprivation of the living environment in **study three**.

Research indicates that there are a variety of other contextual factors (Peek et al., 2016) associated with technology use and these may be linked to the propensity for a higher use of public space ETs relative to portable ETs, according to the synthesis of the findings. These include the inaccessibility and expense of private ownership of portable ETs, such as smartphones or tablets, as well as their reliance on a stable internet connection (Hunsaker & Hargittai, 2018). Research suggests that people with cognitive impairment, albeit due to acquired brain injury, use specific types of technologies, such as e-readers to a lesser degree than other types of technologies (Eghdam et al., 2016). Other studies emphasise that older people report lower trust and familiarity with newer, portable ICTs, such as smartphones which in part, may account for the relatively lower use of these types of ETs (Vaportzis et al., 2017). Within the privacy of the older person's home they may also be able to choose not to use ETs and may feel more comfortable to adapt their activities without recourse to ET use.

Within the context of public space, regardless of the intended purpose, there are instances where a person does not have the choice about whether to use public space ETs, or not. A lack of choice can be problematic and the inability to use ETs in public space may be



conspicuous and stigmatising (ADI, 2019). And yet, research indicates that there may be additional supports available for the older person when using ETs in public space, which may ameliorate the stigmatising effect of not being able to use ETs, such as receiving information and support from staff members, observing and imitating the actions of others, and the automation of technologies (i.e. smart travel passes) (Golant, 2017). Due to the ubiquity of public space ETs, older people with and without dementia may be dependent on using public space ETs, in order to participate in activities and places within public space. Thus, occupational injustices arise when the older person with or without dementia is not able to use public space ETs as this may inhibit their ability to enact their citizenship through participation in activities and places within public space (Hammel, 2017; Kottorp et al., 2016).

### *The journey as a natural continuation of participation in activities and places within public space*

The finding that the UK sub-samples of older people with and without dementia used ETs for preparatory and wayfinding activities may refer to the *touch points* that occur in the older person with dementia's journey (Boex & Boex, 2012). *Touch points* encompass temporal and spatial points where the older person interacts with their physical and social environment. Boex & Boex (2012) conceptualise the *touch points* from an architectural viewpoint, based on the experiences and feelings evoked for a person, as they participate in the journey. This may begin in a car park, then as the person navigates an entrance, and as they walk along a corridor to their intended destination (Boex & Boex, 2012). *Touch points* may serve as cues that enable participation, but they may also be barriers which disable or disrupt the continuum of participation. The findings from **study three** contribute to the concept of *touch points* by extending the understanding of participation to include the preparatory activities, which may be performed in the home, in advance of the participation in activities and places within public space.

*Touch points* may be located in the built environment but as the synthesis of the findings suggests, there are also technological *touch points*. An example of a technological *touch point* is the smart ticketing technology used in public transportation. In **study two**, access to a CTP, which may be in the form of a smart ticket pass, was positively associated with the probability of a higher level of out-of-home participation among older people with and without dementia. Technological *touch points* may also be used to enable preparatory and wayfinding activities. The preparatory activities involved ET use, and thus, technological *touch points* may include planning a route at home first or arranging support. This preparatory stage was viewed as one part of the journey, or continuum of participation. The findings are congruent with earlier research which indicates that preparatory activities need to be performed before subsequent participation in a desired activity within public space, these included preparatory activities such as using public transportation (Brorsson, 2013; Lindqvist et al., 2016). The need for support with preparing for public transportation is relevant for older people with dementia who may be reliant on public transportation due to driving cessation (Holden & Pusey, 2020; Sanford et al., 2020). In both the Swedish and

UK samples, there were fewer drivers among the older people with dementia than the older people without dementia (Table 2).

### **(iii) Associations between ET use, person-related, contextual factors, and participation in activities and places visited within public space**

The studies of this thesis constitute an unfolding exploration of participation in activities and places within public space. The synthesis of the findings show that whilst ET use may be a determinant of participation in activities and places within public space, there are a variety of other issues to consider including perceived risk of falling, access to a CTP, having a functional impairment, and social deprivation of the living environment. There was also a statistically significant association between social deprivation of the living environment and (social) participation in recreation and physical activity (Domain D) for the UK sub-sample of older people with dementia.

#### *Perceived risks and public space*

In spite of the portrayal of public space as a potentially hazardous and risk-inducing place (UD/MS, 2018), particularly for older people with cognitive impairments or dementia, no statistically significant association was found between the perceived risk of feeling stressed or embarrassed, or getting lost, with out-of-home participation among the UK sample of older people with and without dementia in **study two**. In the literature, one of the most frequently discussed concerns is the risk of older people with dementia getting lost (Bartlett & Brannelly, 2019; Peek et al., 2020). However, this was the least commonly reported perceived risk by the UK sample of older people with and without dementia (17.97%). The older people with and without dementia spoke about using preparatory or management strategies to manage problematic situations, such as getting lost. In **study three**, an older person with dementia described using a compass on the phone to help orientate himself when he got lost whilst participating in public space. Although this may indicate a lack of hazard awareness on the part of the older person with dementia, it also highlights the ability of older people with and without dementia to develop management strategies for participating in activities and places within public space. The synthesis of the findings, in particular **studies two** and **three**, revealed a potential contradiction between what the research proposes is a risk for older people within public space and what the older person with dementia is actually concerned about whilst participating in activities and places within public space. Thus, what constitutes a risk is indeterminate and may vary between people, environments, cultures, situations and time horizons. More research is required to understand how older people with and without dementia perceive risks whilst participating in activities and places within public space.

For the UK sample of older people with and without dementia in **study two**, the perceived risk of falling whilst participating in activities and places within public space was the most frequently reported perceived risk based on 43.75% of the sample. The findings also

showed that the perceived risk of falling was significantly associated with out-of-home participation among the UK sample of older people with and without dementia. Falls are commonly discussed in research with older people and particularly among older people with dementia due to the symptomology of dementia and the associated risk of falling (Fernando et al., 2017; Peek et al., 2020). However, research also emphasises the need to not only consider the fall as an observable event but also the fear of falling, in relation to the environment which has been shown to significantly influence the risk of falling (Landers et al., 2016). In **study three**, the older people with and without dementia did not describe intrinsic risk factors whilst participating in activities and places within public space. Notably, the older people with and without dementia also did not mention assistive technologies, such as fall alarms, to prevent their risk of falling. Instead both groups reported a need to pay extra attention to extrinsic risk factors in their physical and social context, ranging from uneven walking surfaces to disorientating alarms and disturbances from other people. The differences in the findings on perceived risk may support a departure from the quantification of observed risk events, in favour of the self-perceived risks by the older person with and without dementia (Stevenson et al., 2018).

#### *Perceived risks, social deprivation of the living environment and the neighbourhood*

As discussed in the earlier chapters of this thesis, the axiological assumptions and core values of occupational therapy present increased participation as a means for increased health and wellbeing. However, the synthesis of the findings also contribute a degree of complexity when considering participation, including social aspects of participation, which may have numerous benefits for the health and wellbeing of the person and their community but also more negative aspects such as perceived risks whilst participating in activities and places within public space. In **study two** and **three**, older people with and without dementia reported various perceived risks within their neighbourhoods and many of these were associated with their interactions with other people, such as crowds, feeling distracted by other people, or stressful situations associated with ET use. This suggests that the social aspects of participation may not always be perceived as positive. In **study three**, a statistically significant association was found between higher IMD, which refers to lower social deprivation of the living environment, and higher (social) participation in recreation and physical activity (Domain D) for the UK sub-sample of older people with dementia. The findings showed that the association was statistically significant for the older people with dementia but not for those without dementia. Whilst the association for older people with dementia was small, it was statistically significant and suggests that other factors beyond ET use may influence or co-constitute their participation in activities and places within public space. The investigation of social deprivation of the living environment, which encompasses aspects of crime, income, and access to housing and services, among others, and how this relates to social participation in **study three**, provided insights into the need to consider what it means to promote participation in activities and places within public space, in the context of perceived risks in one's neighbourhood or a relatively deprived living environment.

*Building on the insights about participation in activities and places within public space, through the lens of Everyday Technology (ET) use*

There is an impetus to cater for people with different needs or disabilities, and global phenomena such as climate change and the Coronavirus Disease 2019 (COVID-19) pandemic are a catalyst for redeveloping communities and cities to be more inclusive and sustainable (ADI, 2020; International Organization for Standardization [ISO], 2020). Internationally, there are discussions about planning and designing public space, for instance the Mayor of Paris has endorsed a “15-minute city” which envisions that all citizens are able to enact their citizenship and satisfy their everyday needs, by ensuring that places for work, shopping, health and cultural activities are situated within approximately a 15 minute walking distance from their own home (Handy, 2020). Similar approaches are being planned for other cities, including London and the influence of the post-war planning of the CIAM is evident (International New Town Institutet [INTI], 2018). The synthesis of the findings is relevant to these new conceptualisations of public space as they provide empirical insights into concrete patterns of participation in activities and places within public space, among older people with and without dementia, across different contexts and time horizons. The findings also contribute to the understanding of how the older person with and without dementia’s participation in activities and places within public space relates to their ET use, which is relevant for an increasingly technological society and envisioned smart cities, such as Stockholm (Kempin Reuter et al., 2019).

A discussion of the Swedish ABC-Stad (ABC-City) illustrates how this research may be applied to conceptions of public space. The CIAM model of compartmentalising urban space according to functionality is evident in the post-war planning model of the ABC-Stad in Stockholm (Boys, 2017; INTI, 2018). As a founding member of CIAM, Sven Markelius developed the prototypical ABC-stad in the Stockholm suburbs of Vällingby (1950s) and Farsta (1960s) (INTI, 2018; Pass, 1973). ABC-stad is an acronym for Arbete – Bostad – Centrum, which refers to three core compartments, work – housing – centre. The three core components were perceived as necessary in order for a suburb to act almost like a city providing all the basic needs of its residents, including access to a metro station and good transportation links (INTI, 2018). Despite the utopic vision to minimise the radius between functions and to build a self-sustaining suburb, the ABC-stad was predominated by housing rather than the other essential considerations, such as work (INTI, 2018). These historical and current proposals emphasise the functionality and proximity of the ideal community. However, this modular approach overlooks the nuanced and dynamic nature of human participation in activities and places, including temporal and social attachments to one’s neighbourhood (Jacobs, 1961). This thesis proposes that it may be more meaningful and efficient to plan and design a community, or city, according to the activities and places in which its citizens actually participate. There is a potential role for occupational therapists to work more closely with architects and urban planners, as well as the older people with and without dementia themselves, to build on existing patterns of participation in the older person with or without dementia’s community, fostering more inclusive communities (Iwarsson & Ståhl, 2004) rather than building separate age- or dementia-friendly communities (van Steenwinkel et al., 2019).

The synthesis of the findings provides a perspective from a population not traditionally included in the planning or design process of communities and cities (Houston et al., 2020; van Steenwinkel et al., 2019). This thesis suggests that by actively involving older people with and without dementia, they can share novel insights about their lived experiences (Houston et al., 2020), in particular concerning perceived cognitive accessibility issues whilst participating in activities and places within public space. A tool such as the ACT-OUT questionnaire could help a multidisciplinary team gain insight into the patterns of participation, from the perspective of activities and places. This approach could help understand what types of activities and places people participate in, frequency and temporal aspects, whether they participate alone or accompanied, their modes of transport, and their perceived risks. As this thesis demonstrates, the ACT-OUT questionnaire may also be used in conjunction with other tools such as the ETUQ, to underline the importance of considering ET use when planning and developing communities in an increasingly technological society.

## Methodological and ethical considerations

The critical reflection of the methods is based on two broad considerations – external validity and internal validity. External validity relates to the extent that the effects or findings of a study can be generalised; across populations (as in the case of population validity), or across settings as this pertains to ecological validity (Andrade, 2018). Internal validity refers to the degree to which the research design, data collection and data analysis of a study addressed the research questions, in a reliable and trustworthy way (Andrade, 2018). The chapter culminates in a discussion about the ethical considerations for the research in this thesis.

### External validity

#### *Population validity - sampling*

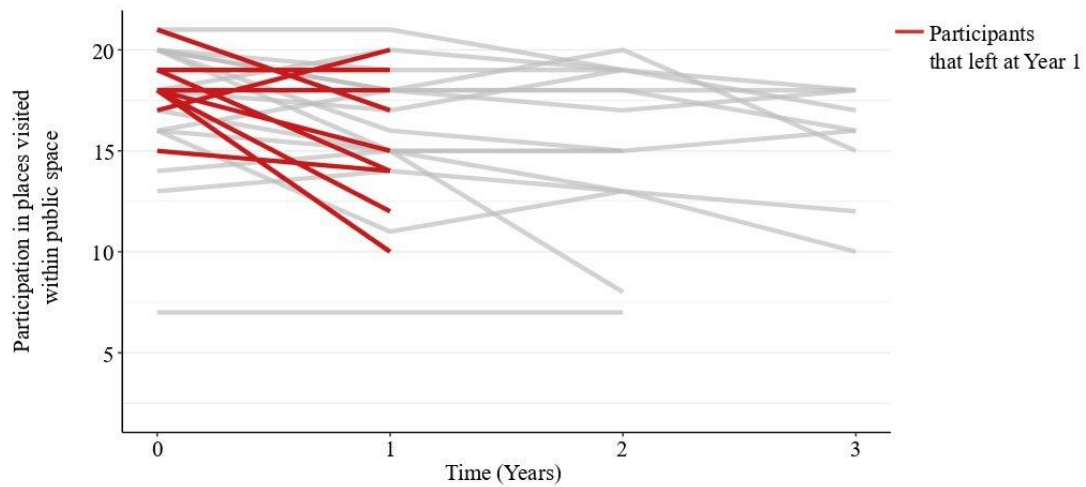
This thesis used a type of non-probability sampling referred to as purposive sampling. According to this sampling method, the researcher selects a participant based on specific, pre-defined characteristics that the participant possesses (Etikan et al., 2016). Purposive sampling was useful for this study as a way of including participants who are able to share insights and to inform the understanding of the research questions under investigation (Etikan et al., 2016). In other words, to recruit participants who were not users of ET, perhaps having never been users of ET, or who did not participate in activities and places within public space, would have been interesting but would not have contributed the required knowledge for this research.

Throughout the studies, consistent inclusion and exclusion criteria were used to attempt to match participants with dementia and participants without dementia, as a comparison group. The same matching variables, age, gender, years of education and living arrangements, were used in both the Swedish and the UK samples. For pragmatic reasons, due to time for data collection, convenience sampling approaches were also used, such as snowballing through word-of-mouth. Whilst the sub-samples of older people with and without dementia were generally well-matched according to the matching variables, there was a statistically significant difference in age and years of education among the UK sample. Whilst socio-demographic variables were not the focus of the research, such factors are necessary to consider. For instance, years of education is discussed in relation to the MoCA. Future research may build on this thesis by using randomisation and a larger population size, depending on power calculations, to enhance the generalisability of the findings (Andrade, 2018).

#### *Population validity - attrition*

Attrition and the missing data that follows a participant leaving the study is a common occurrence in longitudinal research, such as in **study four** (Fitzmaurice & Ravichandran, 2008). The research team anticipated that attrition would be an issue for research where the participants already had a diagnosis of dementia at recruitment. When undertaking research

with people with a progressive cognitive diagnosis such as dementia, it is difficult to determine whether data is missing completely at random or is due to the cognitive decline itself (Noorae et al., 2018).



**Figure 4.** Profile line plot of the response variable (participation in places visited within public space).

Note. The outlying profile line is attributable to one participant from the Swedish sample of older people with dementia who had comorbidities such as angina, hip pain, balance issues, dizziness, and impaired vision requiring glasses, in addition to a diagnosis of dementia. It is possible to infer that this may have contributed to the relatively low level of participation in places visited within public space (Gaber et al., 2020c).

Sensitivity analysis in study four revealed a statistically significant difference in cognition, according to the MoCA, between participants that remained in the study and those that left the study. This can lead to bias where participants who remain until the end of the study represent a selective group relative to the population, culminating in a final sample of 9 participants, by year three of the study. Sensitivity analysis suggested that the overall descending trend in participation in places visited within public space would have been in the same direction (i.e. a negative trend) but the magnitude may have been greater if it had been possible to prevent the potential attrition bias. This is illustrated through a profile line plot which highlighted steep, descending slopes for those participants who left the study by year one (Figure 4).

The missing cases could have been removed from the research as would be required in other data analysis methods such as ANOVA (Fitzmaurice & Ravichandran, 2008). However, this was avoided as it would not only reduce the power of the analysis but it would also neglect the time and contributions of the participants which were considered valuable, regardless of the duration of their participation in the study. For this reason, a multilevel model was used as it can include data assumed to be missing at random and the random intercept provided a trajectory line of participation over time, for each participant. In future research, efforts should be made to ensure a larger sample by the final year of the study because the small

sample size in year three prohibited the calculation of a person measure of ability to use ETs. To ensure stability, the ETUQ requires a count of at least 10 ratings per ET-item, to determine the person measure of ability to use ETs according to a Rasch model (Nygård et al., 2016). Four additional interviews were scheduled for the year three data collection, however, in compliance with the Declaration of Helsinki: ethical principles for medical research involving human subjects (World Medical Association, 2013) there was an ethical duty to protect groups and individuals who may be considered vulnerable. The interviews that were scheduled during the period coinciding with the COVID-19 pandemic (WHO, 2020) were postponed or cancelled and so were not included in **study four**.

Sample size calculations were performed in order to estimate the required sample size for future research using the ACT-OUT questionnaire. Pooled values from the Swedish and the UK data were utilised as a means of adjusting for variations between groups. Based on the pooled mean total participation in places visited within public space for the sub-sample with dementia (15.76) and the sub-sample without dementia (17.58), associated with a standard deviation of 3.28. This indicated a sample size of approximately 52 participants for each sub-sample ( $\alpha = .05$ ; power = .80).

It should be noted that estimations are somewhat speculative due to the exploratory nature of the research. Traditional sample size calculations depend on parametric approaches and yet, the variable in focus (total participation in places visited within public space) may not yet be assumed to follow a normal distribution. Given the exploratory nature of the research using the ACT-OUT questionnaire, which is a relatively new tool, the estimations may be used for hypothesis testing with sufficient power.

#### *Population validity – age*

The rationale for including people from 55 years old and above is that there was no logical reason for utilising the conventional cut-off of 65 years old. This conventional cut-off has been criticised as a conflation of chronological age and national pension eligibility and retirement (Higgs & Gilleard, 2014). Higgs and Gilleard (2014) contest that the construct and presentation of old age as a single, stable status can no longer be assumed due to changes in lifestyle, healthcare, technology, life expectancy and the organisation of society. As an increasing number of older people live and age in their own homes, this includes older people with dementia and research indicates that participation in social (Ngandu et al., 2015) and leisure (Fallahpour et al., 2016) activities in one's community is a modifiable risk factor for developing dementia. Dementia is a reality for people below the age of 65. Therefore, by including people from 55 years old, the research seeks to contribute to the field of health promotion and dementia prevention.

#### *Population validity – urban-dwelling participants*

The geographical areas for data collection were chosen to provide a broad investigation of out-of-home participation and ET use across different urban and rural environments of Sweden in **studies one** and **four**, as well as the UK in **studies two** and **three**. Initial research



suggests that technology use may differ for older people living in rural environments compared to those living in urban environments though there is a need to build up the evidence base about this topic. Whilst this thesis recognises the need to gather data on the experiences of older people with and without dementia in rural communities (Calvert et al., 2009), the data collected for this thesis was predominantly from urban, suburban, and some semi-rural communities in Sweden and the UK, with few participants from what can officially be classified as rural communities (Bibby & Brindley, 2013). It should also be noted that whilst urban and rural comparative studies are interesting, there is a need to be cautious of an urban-rural binarism, especially as other research based on the same UK sample showed that geographical location (i.e. urban or rural-dwelling participants) did not significantly moderate the association between amounts of relevant out of home ET and the amount of places people go to (Wallcook et al., 2020). On the one hand, future research may benefit from focusing on the recruitment of participants from rural communities where many older people with and without dementia currently reside. On the other hand, there is a need to be cognisant that the predominantly urban data contributes to the global population trend which is becoming increasingly urbanised and research, albeit before COVID-19, predicts that by 2050, two-thirds of all people will be living in cities or other urban centres (UN, 2019). Thus, more people will live and age in urban environments in the future and there has been a call for cities to be “at the heart” of sustainable development and public services (Andersdotter Fabre, 2017).

### *Ecological validity*

All data collection was performed in the home or another place chosen by the participant. Based on earlier research, it is recommended that research among older people with dementia is performed in a familiar and comfortable environment, such as the home (Nygård, 2006). However, the ecological validity of the research may have been improved by conducting the research within the public space that the participants were speaking about (van Cauwenberg et al., 2012). This could have provided relevant cues to support participants’ recall. Prior research among older people with dementia has been performed in public space, such as pedestrian crossings (Brorsson, 2013) or grocery stores (Brorsson et al., 2018). Such research provides insights into the real-life contexts and problematic situations that people with dementia encounter whilst participating in places within public space (Brorsson, 2013). In particular, walkalong interviews, whereby the interviewer records a semi-structured conversation in the participant’s neighbourhood or whilst using public transportation, may have been a useful compliment to the use of standardised questionnaires (Kullberg et al., 2017; van Cauwenberg et al., 2012). In hindsight the COVID-19 pandemic has highlighted that the risks of such an approach might outweigh the benefits for this population. Whilst the older person might not have been physically located in each of the places, this does not mean that they cannot speak or describe their experiences in a place. The purpose was not to validate the accuracy or reality of their physical participation but rather to explore the older person’s perception of their participation.

Pilot walkalong interviews were performed with two participants in London and these supported the interpretation and contextualisation of the findings. However, due to the time-

consuming nature of performing observational and participatory research in public space, a sub-sample would have needed to be selected for this in-depth approach. Hence, for practical reasons only two walkalong interviews were performed. Alternatively, photo or film elicitation methods may have been used, to gain insights into a person or a community's perception and experiences of the living environment. In future research, photos and film may be used within the home environment to help trigger memories and discussions about participation in activities and places within public space. It is salient to consider such alternatives, potentially as a substitute or in combination with face-to-face interviews at the participant's home, considering the COVID-19 pandemic. However, this does raise questions about the reproducibility of the research not only in terms of the validity of the methods but also due to changing attitudes and routines regarding ET use (Hedman et al., 2016) in relation to participation in activities and places within public space, among older people with and without dementia. Thus, it is possible to hypothesise that a number of the responses to the questions about participation of older people with and without dementia in activities and places within public space, in relation to ET use, may be different today following COVID-19 compared to the data collected before COVID-19. However, this cannot be known.

### *Effect size*

The evidence-base for the topic under investigation in this thesis is emerging, and the majority of earlier research concerning participation in places within public space, in relation to the access and use of ETs is qualitative. For these reasons, the studies in this thesis were dependent on Cohen's (1988) conventional thresholds for interpreting the standardised effect size. The effect size refers to the measure of the strength of the relationship between two variables. These thresholds are omnipresent across all research disciplines; however, their use has been criticised as arbitrary (Cumming, 2012). Cohen devised the thresholds based on his research about human heights and intelligence quotients and he advised that they should be used cautiously as a frame of reference only. Cumming (2014) recommends that researchers use effect sizes that are relevant to their specific discipline and topic under investigation. As the evidence-base for the topics addressed in this thesis builds, it is important to report effect sizes to facilitate subsequent meta-analysis and crucially, the development of more specific, relevant and meaningful thresholds for the interpretation of findings.

## **Internal validity**

### *Self-report*

The perspective of the older person with and without dementia themselves was foregrounded in this thesis. The rationale is to not limit the view of the older person with dementia to solely their diagnosis of dementia (Swaffer, 2016; Taylor, 2007). Rather, this thesis draws upon not only a biomedical view of older people with dementia but also the disability and mere difference discourses which recognise the potential for older people with dementia to be able to share their own views about their everyday lives. For this reason, all of the studies utilised self-reported data from the questionnaires used in the semi-structured interviews with the

older person with or without dementia. There is contradictory research about whether the reports of older people with dementia match those of their significant others, their carers or their clinicians. Studies have revealed a discord between what the person with dementia prioritises as important compared with their carers or clinicians (Harmer & Orrell, 2008). Other research shows an overlap in reports about technology use by the older person with dementia and their proxies (Malinowsky, 2011; Jakobsson et al., 2020b). Moreover, based on the experience and evidence-base of the CACTUS research group, older people with dementia, particularly in the mild to moderate stage, have been shown to be able to speak about their experiences of everyday life and ET use, in interviews that are conducted in a supportive and flexible way (Nygård, 2006; Waite et al., 2019). Based on research indicating that older people with dementia can indeed report about their experiences themselves (Malinowsky, 2011; Jakobsson et al., 2020b), coupled with the potential discrepancies introduced by proxy reporting, this thesis posits that older people with dementia should be supported to participate in the research themselves. This approach is aligned with advocacy efforts such as those by the Alzheimer's Society, Alzheimer's Disease International (ADI) and DEEP, to ensure people with dementia are respected as active research participants rather than passive subjects (DEEP, 2020).

Whilst there is an ethical and moral imperative to perform research *with* people with dementia, as opposed to *on* people with dementia, this is not without challenges. Research suggests that there may be issues with self-report, due to intrinsic biases in questions which may elicit responses based on social desirability (Classon et al., 2016; Soubelet & Salthouse, 2011). In the field of dementia research, a specific limitation pertains to the person with dementia's potentially limited awareness or ability to provide insights into their capabilities and their participation in everyday life (Classon et al., 2016; Johansson et al., 2015; Lepore et al., 2017). Confabulation has for instance been shown to be an issue for accurate self-report among people with dementia (Robins, 2020). Confabulation refers to various disorders, deficits, and behaviors where voids in a person's memory are filled either consciously, or unconsciously, by misinformation (Örülv & Hydén, 2006; Robins, 2020). This may account for the fluctuations in self-reported participation in activities and places within public space and ET use, particularly in **study four**. However, to temper this, the standardised questionnaires used in this thesis, specifically the ACT-OUT questionnaire and the ETUQ, were developed with a dementia audience in mind and according to best practice recommendations for working with older people with dementia (Margot-Cattin et al., 2019). A distinctive feature of both questionnaires is the use of concrete questions and clear examples to support the concrete reasoning and recall of the older person with dementia. The interviewer would then record the response alternative based upon the older person with or without dementia's response. Based on the findings, the older people with dementia were able to recall their participation between the past, present and future, and to also report an awareness of different types of risk, as indicated in **studies two and three**.

As a further precaution to mitigate recall bias, observations may have also been used to validate whether the self-reports correspond to observations. There is a current research concern with checking how closely self-report and observations overlap and the outcome of such research is the recommendation that a combination of self-report and observation should be used in clinical practice (Bartels et al., 2020). Whilst it is important to validate different

approaches, it should be noted that observations, even among clinicians are not free from biases (Kuhn, 1962; Saposnik et al., 2016). For instance, issues with inter- and intra-rater reliability, or the Hawthorne Effect which refers to a change in behaviour by the person under observation, based upon the act of being observed (Porta & Last, 2018). The time and cost efficiency of recommending multiple approaches in a clinical context is also questionable. The ACT-OUT questionnaire and the ETUQ are currently developed for a research context. Prior to their implementation into a clinical practice context, rigorous psychometric testing is advised as this may help to promote the efficiency and reliability of the questionnaires.

The purpose of the research was not to validate whether the participant's *perceived* participation, ET use, or risks, were objectively accurate, or to identify a universal and causal relationship between participation in activities and places within public space, with ET use, or other factors such as perceived risks. Rather, the purpose was to inquire, and to gain increased understanding, about the *perceived* participation, ET use, or other factors such as perceived risks, within, and between, the samples of older people with and without dementia, across different contexts and situations. It is also important to be mindful of potential biases towards *doing* and action. Hitch et al. (2014) emphasised the need for occupational therapists and scientists to be aware of a bias towards *doing* and *being* compared to the more underdeveloped concepts of *becoming* and *belonging*. Whilst Wilcock's (1999) conceptualisation of *doing* in the Occupational Perspective of Health (OPH) is not in focus in this thesis, it prompts an interrogation of the bias towards *doing* which may be inherent in occupational therapy and occupational science (Cutchin & Dickie, 2013; Njelesani et al., 2013). Thus, motivating the focus on *perceived* participation in this thesis.

### *Montreal Cognitive Assessment (MoCA)*

The MoCA was used throughout all data collection. In a practical sense, it is relatively quick and easy to administer, and it was the preferred tool used by clinicians at the research sites for this thesis, in Sweden and the UK. However, there are a number of limitations and important considerations intrinsic to brief cognitive screening tools, such as the MoCA. The MoCA was originally developed in a memory clinic setting among a highly educated, normative population and with a focus on AD (Julayanont et al., 2017). Due to the normative development of the MoCA, research from different countries and contexts has revealed a potential demographic effect on MoCA's performance (i.e. the effect of education, age or gender) (Borland et al., 2017; Hayek et al., 2020; Julayanont et al., 2017; Kang et al., 2018). On the one hand, studies have indicated that the MoCA is age and gender independent (Bernstein et al., 2011; Hayek et al., 2020; Wong et al., 2009). For the purposes of this research and based on earlier studies, a correction of one added point for education of 12 years or less was used to counter the education effect (Nasreddine et al., 2005).

### *Harmonisation and translation of the data collection tools and procedures*

The harmonisation process was multifaceted and iterative, comprising opportunities for collaboration in an international team but also challenges and compromises. The creators of

the questionnaires, the data collectors and the broader research team worked together to ensure a degree of harmonisation among the data collection tools (i.e. questionnaires and manuals), procedures and between the data collectors in Sweden and in the UK. The research team included fluent British English-speaking, fluent Swedish-speaking and bilingual members. Harmonisation was an important consideration to achieve parity between the Swedish and British terminology but also with the intention of achieving congruence in the procedures used to collect the data, as a way to ensure that the data were comparable between the different countries. Efforts to ensure harmonisation included using the same data collection tools, in the same order, and administered by occupational therapists following the same training in the use of the data collection tools.

The development of the ACT-OUT questionnaire involved cognitive interviewing with 27 older people, including those with dementia (Margot-Cattin et al., 2019). In addition to the cognitive interviews (Willis et al., 2005), the data collectors also engaged in pilot interviews in the UK, with feedback from the older people who were interviewed in the pilot interviews, in order to check the utility of the data collection tools for a British audience. During this iterative process, a British English version of the ETUQ was developed with American English ET items substituted for British English, for instance *lift* instead of *elevator* and *mobile phone* in the place of the *cell phone*. Similarly, the demographic questionnaire was adapted to include contextually relevant information, for instance the concession travel pass, which is called *The Freedom Pass*, in the London region. Regarding the MoCA, an English language copy of the MoCA version 3 was used with copyright permission for the doctoral education research.

A benefit of involving older people with dementia in the development of ACT-OUT questionnaire was that their feedback could be harnessed to refine and improve the questionnaire, in particular ensuring that it was tailored to the needs of older people with dementia and to support their participation in the interviews. The ACT-OUT questionnaire is a relatively new questionnaire and therefore information about its psychometric properties is underway, including a forthcoming Content Validity Index study and the findings from this research project which will contribute to the ACT-OUT questionnaire's evidence base.

The relatively homogenous sample focused on key variables, whilst controlling for other potential confounders, which can promote the internal validity of research, but more efforts could have been made in the data collection to promote inclusion from diverse and marginalised communities. For instance, all interviews in Sweden were conducted in Swedish and all interviews in the UK were performed in English. Translation services can be costly and time-consuming; however, these are recommended for future research.

## **General ethical considerations**

### *Involvement of older people with and without dementia in research*

There is an assumption that older people with dementia and older people more broadly, are not the typical or ideal research participant. Until the 1990s, older people with dementia did not have an active role in research and their perspectives were not prioritised (Hubbard et

al., 2003). This is based on a broad generalisation that older people, especially people with dementia, are not capable of managing the cognitively demanding processes of participating in research. This has led to a reliance on proxy reporting to compensate for a biomedical perspective of neuropathology that assumes that the older person with dementia is not able to share reliable reports about their personal history, social interactions, abilities or needs (Lepore et al., 2017; Novek & Wilkinson, 2019). Obtaining informed consent is perceived as particularly challenging in research with older people with dementia. Whilst this approach may be well-intentioned as a means of reducing the apparent burden of participating in research, it may also reduce the clinical outcomes and agency of the older person with dementia to choose to participate, or not (Lepore et al., 2017; Watts, 2012). There is also a concern that research with older people is complex and multidimensional due to the prevalence of “noise” introduced by a population that has such a high rate of comorbidity and polypharmacy (Gaber et al., 2020a; Ritchie et al., 2015). However, this negates the diversity of abilities, experiences, and needs of older people with dementia (Lepore et al., 2017). Whilst there is a tendency for research to only include “healthy” older participants, the research in this thesis sought to include participants with different types of functional impairments, in addition to a dementia diagnosis, as a more accurate representation of the target population.

#### *Integrity of data management*

Based on training in Medical Research Ethics, a data management strategy was devised to safeguard the collected data and as an acknowledgment of the time and resources that the various stakeholders had contributed. The data management plan was developed through consultation with lawyers at Karolinska Institutet, with a view to the protection of the personal and confidential information using informed consent, anonymisation and controlled access to the data. The plan outlined steps to be taken for the ethical storage, transfer and management of the data, in accordance with the NHS Code of Confidentiality (2003), the Caldicott Report (1997), and the requirements of the principles of the Data Protection Act (1998) (Department of Health and the Caldicott Committee, 1997). For the statistical analysis, data was presented at the group level to help maintain anonymity. Finally, due to the international design of this thesis, careful consideration was given to the secure storage, transfer, and process of data, including no international transfer of personal data (The European Parliament and of the Council, 2016).

## CONCLUSION AND CONTRIBUTIONS

The main take-home message of this thesis is to contribute complexity to our current conception of participation in activities and places within public space, as perceived by older people with and without dementia. Based on the empirical findings, this thesis offers a more nuanced conception of participation, as *a dynamic process of enacting one's citizenship through a continuum of social interactions in activities and places within public and private space, involving varying degrees of person-related and contextual factors, such as perceived risk and Everyday Technology (ET) use.*

This thesis has discussed the complexity of participation through the lens of ET use, as well as problematising other interconnected person-related and contextual factors. On the one hand, this thesis recognises the rights of older people with and without dementia to participate in an increasingly technological society, which is supported by policies and legislation such as the CRPD (UN, 2006). This is aligned with a disability discourse which advocates for older people with and without dementia to have the right to choose and access resources like all members of society. On the other hand, as the constituent studies of this thesis illustrate, there is a need to understand participation on a more granular level, not simply based on frequency of participation but also social aspects and the older person's perceived underlying motivators. These are considerations requiring extra attention, and management strategies for participation. The former focuses on aspects of doing, access, and rights of older people with and without dementia on a community and policy level. Whereas the latter is more concerned with the older person's being, belonging and becoming manifested by the ways that they enact their micro-citizenship through the process of participating in activities and places within public space.

This thesis harnesses the theory and methods from a diverse range of sources, emblematic of my training in occupational therapy and occupational science, architecture, as well as data visualisation. The thesis statement concludes that participation in activities and places within public space, as situated in the contemporary milieu, is inseparable from the relevance and perceived ability to use ETs. To speak of promoting participation for older people with and without dementia, as envisioned by age- and dementia-friendly policies, is to assume universal access to, and proficient use of, ETs. By focusing on the concrete patterns of participation in activities and places within public space as well as ET use, this thesis contributes to the evidence and knowledge base for the design and development of more inclusive and sustainable places, technologies, and services. Based on the findings, contributions from each study are outlined in this chapter.

## Clinical practice and education

- To enable equitable participation for older people with and without dementia, occupational therapists and other healthcare professionals may benefit from increased awareness of the relationship between the older person's decreased ability to use ETs and their decreased participation in places visited within public space (**All studies**).
- Through interdisciplinary collaboration, with architects, urban planners and other stakeholders, occupational therapists can support the planning and development of inclusive communities (i.e. age- and dementia-friendly communities) as well as helping to facilitate participation, through increased awareness of the types of places retained by older people with or without dementia (**All studies**).
- The centrality of participation in the neighbourhood for older people with and without dementia underlines the value of community-based practice placements and curriculum to educate the next generation of occupational therapists about the importance of enabling participation both in a person's home environment and public space, such as the neighbourhood (**All studies**).
- Whilst there are challenges associated with undertaking research with older people, particularly those with dementia, an ethical, flexible and inclusive approach can help to increase the evidence base and health outcomes for older people with and without dementia and to enhance opportunities for their participation in research (**All studies**).
- To achieve a more nuanced understanding of participation among older people with and without dementia, it is important to give increased consideration to the types of places that are most frequently abandoned, including not only those places pertaining to health and survival such as the hospital, health centre or doctor's surgery, but also those places related to other facets of one's everyday life, such as social participation (**All studies**).
- Social participation is a modifiable determinant of health and thus, in order to promote social participation among older people with and without dementia, clinicians can support not only basic, self-care ADLs in the home but also social participation within public space and the community (**Study three**).

## Policy

- National and international policies concerning inclusive communities may benefit from adopting a health promotion approach to consider ways to make those places at risk of abandonment more accessible, such as those related to social participation, in particular social, spiritual and cultural places as well as places for recreation and physical activities (**All studies**).
- Policymakers can enhance the contextualisation and relevance of their digital policies and agendas through an awareness of the local and national social deprivation of the living environment, especially among older people with dementia (**Study three**).
- To provide more targeted health and social care planning, consideration may be given to the influence of perceived risks, access to a concession travel pass (CTP) and use of



ETs for out-of-home participation, among older people with and without dementia (**Study two**).

- Amidst potential occupational injustices, such as budgetary cuts limiting access to subsidised travel in the UK, it is necessary for policymakers to recognise the link between access to a CTP and a higher level of out-of-home participation among older people in the UK (**Study two**).

## **Design and service provision**

- Utilising this research and other evidence-based approaches can support ongoing or prospective urban developments to be more compatible with the needs and preferences of their ageing users, including those with dementia (**All studies**).
- During the planning and development of inclusive communities, and smart cities, urban planners and architects need to consider the significant effect of ET use on the older person with or without dementia's ability to enact their citizenship, through participation in activities and places within public space over time (**Study four**).
- Accessible and usable transportation is integral to the older person with and without dementia's ability to participate in their chosen activities and places within public space, hence transportation providers should endeavour to optimise not only physical accessibility but also cognitive accessibility of their transportation service options (**Studies two, three and four**).
- Technology designers, developers and service providers would benefit from basing their innovations on the types of technologies that older people with and without dementia perceive as relevant and use over time (**All studies**).
- According to the research in Sweden and the UK, older people with dementia use public space ETs to a higher degree than portable ETs. Thus, service providers should consider whether it is more beneficial to develop interventions (such as, eHealth apps) on public space ETs rather than solely on portable ETs (**Studies two, three and four**).

## Future research

### International and interdisciplinary collaborations

The research based on the Swedish and UK data contributes to the international network of researchers working with the ACT-OUT questionnaire in Switzerland, Canada and the USA. The findings from the studies in this thesis reveal similarities and differences across national and international contexts, for instance across urban and rural differences within the UK sample. This is in addition to the similarities and differences in the activities and places that people participated in, and the ETs used, in the Swedish sample compared with the UK sample. It would be pertinent to investigate whether the associations and patterns identified at a national level also exist at an international level according to pooled data. This highlights the contextually- and culturally-specific factors associated with participation in activities and places within public space. These include aspects of citizenship in relation to differences in policy, the structure of healthcare, national policy, access to public transportation, attitudes to technology, and population-based indices. An example of the latter is the IMD used in **study three**.

Research using the ACT-OUT database may help to identify overarching patterns, theory and policy implications related to participation in activities and places within public space. Future research utilising the ACT-OUT database or as part of the broader ACT-OUT research network can yield an international and collaborative approach. This is conducive to building a discourse around participation in activities and places within public space. It is also potentially important to work with different disciplines, and across varied settings. Peine and Neven's (2020) model of the co-constitution of ageing and technology calls for a closer collaboration between the natural scientists, engineers and designers on one side of the 'Latourian divide', and the social scientists on the other side. Such collaborations may harness the skills from the different disciplines, as well as including clinicians, healthcare researchers, architects and service providers, in order to research and develop technologies with the in-depth understanding of the older people and the ageing process (Latour, 1993; Peine & Neven, 2020). These collaborations may occur in research institutes but also in other settings such as, design studios, laboratories, offices of technology companies, ministries for policymaking, and of course, within public space to promote ecological validity.

### Considering both the *what* and the *why* underlying participation in a technological society

The existing ACT-OUT research focuses on part one and part three of the ACT-OUT questionnaire, except for **study three** in this thesis which also investigated part two. Such research is useful for providing insights into *what* questions, such as what are the patterns of participation according to the different types of places? Or what is the most frequently perceived risk whilst participating in public space? However, the analysis of only parts one and three does not provide information about the *why* questions. For instance, less is known about why people retain or abandon specific places or why they are motivated to travel to some places independently and other places with company. Due to the scope of this thesis,

analyses focused primarily on places and to a lesser degree on activities, with the exception of **study three**. This is in part due to the theoretical foundation of the ACT-OUT questionnaire which conceptualises activities as embedded within places that the older person participates in within public space. However, future research may benefit from building on the mixed methods approach used in **study three**, in order to integrate more qualitative and quantitative insights about participation in activities as well as places within public space.

## **Longitudinal insights into the *process* of participation in a technological society**

Participation in activities and places within public space was explored in relation to time, including aspects of stability and change, as perceived by the older person with and without dementia. Insights about stability and change contribute to an increased understanding of the types of places which were abandoned or retained over time as well as how this relates to other factors over time, such as use of ET outside home. The findings across all of studies point to the value of investigating temporal aspects of participation, specifically the evolving process of participation through longitudinal research.

**Study four** in this thesis offers a unique contribution as the first longitudinal study using the ACT-OUT questionnaire. **Study four** provides statistical insights into the association of ET use outside home and participation in places visited within public space over time. However, the longitudinal data collection also included rich data in the form of free text responses in part two of the ACT-OUT questionnaire. The free text responses were consulted in order to triangulate and contextualise the analysis of the statistical data but they were not included in the **study four** publication. Due to the scope and focus of **study four**, it was sufficient to focus on statistical analyses, however, a qualitative longitudinal study harnessing the free text responses in the ACT-OUT questionnaire would be a valuable and organic elaboration of this thesis.

During analyses of the longitudinal data in **study four**, different statistical models were explored. For instance, a statistically significant association was found when the response and explanatory variables were reversed (i.e. use of ET outside home as the response variable and participation in places visited within public space as an explanatory variable). This suggests potential reciprocity in the relationship between use of ET outside home and participation in places visited within public space, but this should be interpreted with caution. The choice of statistical model in **study four** was grounded in the theoretical perspective and relevance of the research aim and hence, participation in places visited within public space was the chosen response variable. The question of reciprocity may be worth investigating in future research.

## Final reflections on the social impact of the research

Throughout my doctoral education and research project, efforts were made to ensure that where possible, the research was accessible. Open access and outreach activities were integrated into the dissemination plan. These activities encompass the “third task”. At Swedish Universities there is a “third task” in addition to research and education (Jacob et al., 2003). The “third task” encourages researchers to share their research beyond academia and to co-operate with other members of society, including the general public, about research goals and outcomes. This is especially important with respect to publicly funded research where there has been a shift from solely measuring the impact of research according to bibliometrics in peer-reviewed publications or citations by academic experts, towards a broader measure of the ways in which research can positively impact everyday life and society (Bornmann, 2013). This drive towards impacting society is known as social impact. However, social impact has been criticised - for its ambiguity, meaning different things within different contexts (Curry, 2018). The exploration of citizenship in this thesis is more closely aligned with civic science aspects of social impact. Civic science is defined as “broad public engagement with issues that arise at the many intersections between science and society” (Christopherson et al., 2018, p.49). A civic science imperative is distinguishable from other approaches, based on its emphasis of engaging various stakeholders, including the researcher, to enact their citizenship in various ways, such as participation in research and the exchange of knowledge which may benefit people and their communities (Christopherson et al., 2018).

The impetus for exploring a civic science imperative is that my doctoral research project was partially related to a larger research project, funded by a grant from the Kamprad Family Foundation for a larger project exploring participation outside home. The grant application focused on a dissemination plan which aimed to provide new knowledge to guide actions that facilitate participation in activities and places in public space among older people, especially those with cognitive impairment due to conditions such as dementia (Grant reference number: 20180057). To address this aim, I participated in training in Dissemination Science at the German Centre for Neurodegenerative Diseases (DZNE) in Witten, Germany. Building on this training, an initial mapping was performed in order to determine the existing ways that my research group (CACTUS) disseminated research and to plan potential new opportunities for dissemination. As my research is situated within public space, I identified a need to foster relationships and improved communications with everyday stakeholders in public space, such as public transportation providers, supermarkets, libraries, places of worship, community centres, and cultural institutions such as museums.

The mapping of the CACTUS research group’s outreach activities informed my data collection approach in North East London and South West London. Outreach activities were embedded within the data collection process, particularly the initial stages of informing local communities about the study and the opportunity to participate. Outreach activities included presenting information about the study, as well as raising awareness about the topics investigated in the study. This process required grading to adapt to different audience capabilities and interests. The audience included people with dementia or a cognitive

impairment, caregivers with limited time, older people who displayed issues with not only technological literacy but also health information literacy, and people from diverse ethnic communities who spoke about the stigma associated with dementia in their communities. I am still in contact with many of these people and I value the time I spent getting to know the people and communities that contributed to the research project. I am proud of the initiative that many of the groups have taken, including one mosque which has started having younger members of the congregation support older members with various technology issues and regular discussions about health and ageing. A lay report summarising the outreach activities and dissemination outcomes based on the data collected from the UK was created with my supervisors and a fellow doctoral student (Gaber & Wallcook, 2020). The lay report was shared with the multilevel stakeholders involved in the research, including clinicians and older people with and without dementia. The process of elucidating the key findings of the research and sharing these as a lay summary also helped to inform my contribution to the INDUCT Best Practice Guidance on Human Interaction with Technology in Dementia (INDUCT, 2020).

With a view to sharing my research in a memorable and accessible way, I collaborated with a co-researcher (Anna Brorsson, AB) to develop communication materials incorporating data visualisations and a case study published in the World Alzheimer Report (ADI, 2019). We also created a short educational film about inclusive communities, in collaboration with a filmmaker (Brave Teddy Oy) and filmed on location in Stockholm with ICA supermarkets, Jernhusen's Central Station in Stockholm, and Stockholm's metro service (MTR) (<https://vimeo.com/362114355>). The short film harnesses the research findings to present one older person with dementia's journey, as they participate in activities and places within public space, in relation to the use of ETs and perceived risks. The short film has been presented at international conferences, in teaching, and as a launchpad for a collaboration with KI Innovations AB and my co-researcher (AB). In particular, the synthesis of the findings in this thesis have revealed a knowledge gap and potential need because whilst the older people with and without dementia perceived value in enacting their citizenship through social participation, there was a tendency to abandon activities and places for social participation. Moreover, these types of activities and places have not been given sufficient attention in policy. To further develop the social impact of the research, and to implement the dissemination plan, I will continue to foster an ongoing collaboration with KI Innovations AB. In short, to promote social participation among older people with and without dementia, through the lens of ET use.

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