



The  
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# **Supporting working carers of people living with dementia**

**The potential of technologies for combining work and care**

**By Alice Spann**

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# Acknowledgements

*“A bend in the road is not the end of the road... unless you fail to make the turn.”*

*– Helen Keller*

This journey has been a long and hard one, but ultimately so rewarding. I learned, a lot, laughed a lot, cried a lot, and grew so much. Thank you to everyone I met along the way, who shared their stories, their knowledge, their insight, and their friendship with me. Thank you to everyone who has been walking beside me my entire life, for their unconditional love and support.

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To my family: words are not enough...

To Liv and Tassilo: the sky is the limit!

Alice Spann




May 2022

## Declaration

I, Alice Spann, the author, confirm that this thesis is my own work and that the work described in this thesis was carried out solely by me unless otherwise stated (see *Introduction, III. Contributions and thesis structure*).

This thesis contains chapters which are published in peer-reviewed journals or presented in a publication-ready format. These publications are acknowledged in the *Introduction* chapter (*III. Contributions and thesis structure*) and at the beginning of each respective chapter. The contributions of the author (Alice Spann) and co-authors are detailed in the *Introduction* chapter, *III. Contributions and thesis structure*. All co-authors permit the inclusion of these publications in this thesis. This declaration is co-signed by the supervisors of this PhD project to confirm the author's (Alice Spann) contributions to each publication as detailed in the *Introduction* chapter, *III. Contributions and thesis structure*.

I am aware of the University's Guidance on the Use of Unfair Means<sup>1</sup>. This work has not previously been presented for an award at this or any other university.

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## List of abbreviations

**AAIC:** Alzheimer's Association International Conference

**ADL:** Activities of daily living

**BPSD:** Behavioural and psychological symptoms of dementia

**CRE:** Care-related emergencies

**GSA:** Gerontological Society of America

**HCP:** Healthcare and/or social care professional

**IADL:** Instrumental activities of daily living

**ICT:** Information and communication technology

**LA:** Local Authority

**NHS:** National Health Service

**PD:** Participatory design

**PwD:** Person/people living with dementia

**PRC:** Person/people receiving care

**SC:** The Sustainable Care Programme

**UK:** The United Kingdom of Great Britain and Northern Ireland

**WDC:** Working dementia carers



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## Abstract

**Background:** Carers of a person with dementia are faced with unique challenges when combining paid work and unpaid care. Technology can address some of these challenges. This PhD project aims to explore and identify technologies which have the potential to support working dementia carers and to map these technologies onto the work-care reconciliation challenges they express.

**Methods:** Scoping reviews and a participatory design approach were used to explore A) the problem, and B) the solution. Semi-structured interviews with 16 working dementia carers helped to identify what work-care-reconciliation challenges carers wanted solutions for. A comprehensive review of the technology landscape then identified technologies – currently available and emerging – which could address these work-care reconciliation challenges. Technology experts from academia, industry, and social care commission validated the findings. Finally, a custom-built website was used to get feedback from those intended to use these technologies.

**Findings:** Work-care reconciliation challenges carers wanted solutions for included i) care management, ii) attending appointments, iii) entertainment and companionship, iv) psychological and psychosocial stress, v) safety concerns, vi) accessing information, and vii) personal care. A total of 83 technologies, deemed to address the work-care reconciliation challenges carers had identified, emerged from the technology landscape review. These were mapped onto carers' work-care reconciliation challenges (technology map). Most of these technologies were thought to be useful by participants of the online technology evaluation. However, technologies' effects on other stakeholders, especially people with dementia, were important considerations.

**Conclusion/implications for practice:** The technology map can be used as a reference by working dementia carers and those aiming to support them (i.e., their employers, carer or dementia support organisations, and local authority adult social care departments) to identify technological solutions to their challenges. Furthermore, it could be used by technology providers as a guide for further research and development.

**Keywords:** working carers; dementia carers; technology; self-help tool; participatory design.

# Introduction

## I. Overview of the problem

This thesis is primarily concerned with how technologies can support working carers of people living with dementia to reconcile their paid work and unpaid caring responsibilities. Unpaid care, provided by family members, friends or neighbours, has always been the biggest pillar in the care of people living with sickness, frailty or disability (Buckner & Yeandle, 2015). As the social care system in the UK is increasingly under pressure, many carers and people with dementia do not receive the support they need and carers risk their employment, their relationships, financial security, and wellbeing (Atkins et al., 2021; Carers UK & Age UK, 2016; Humphries et al., 2016; Yeandle & Buckner, 2007). Technology has the potential to empower carers to seek solutions to their work-care reconciliation challenges outside and independent of strained public services. Many working carers, however, do not consider technology when looking for solutions for their challenges, do not know that technological solutions exist, or do not know where they can get them from (Carers UK 2013a; Spann et al. 2022, see chapter 4.3.3.1.). This thesis aims to explore, identify, and map technologies, currently available and emerging, which have the potential to help working carers of people with dementia to better reconcile work and care. The project is associated with the ESRC-funded Sustainable Care Programme – Connecting People and Systems (SCP)<sup>2</sup>, which provided funding for some of the research activities presented here.

## II. Publication Format Thesis

This thesis is presented as a Publication Format Thesis, as described in the University of Sheffield's Code of Practice (The University of Sheffield, n.D.). A Publication Format Thesis allows PhD candidates at the University of Sheffield to include materials which have been published, accepted for publication, or are in a format suitable for future publication (e.g., in a peer-reviewed journal) as individual chapters or comprising most of their thesis. These materials can be authored solely or partly by the PhD candidate, in which case the contributions of each co-author must be clearly established.

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<sup>2</sup> The Sustainable Care Programme (SCP) was a 2017-2021 multidisciplinary project, headed by Professor Sue Yeandle at the University of Sheffield, and funded by the Economic and Social Research Council (award ES/P009255/1, Sustainable Care: connecting people and systems, 2017-21, Principal Investigator Sue Yeandle, University of Sheffield). With a future-oriented and internationally comparative view, it aimed to investigate how social care can be made sustainable in the UK while developing wellbeing outcomes for adults living in their own home with disabilities or chronic health conditions and everyone involved in their care

### III. Contributions and thesis structure

Chapter one, the background, presents the multiple pressures on the adult social care system which lead to many people who need care and support having to go without and their family, friends, and neighbours having to fill this gap. An overview is then provided over the situation of carers in the UK in general, and those of carers who must combine unpaid care with paid work in particular. To provide some context for the interviews with working dementia carers, discussed in chapters 5 and 6, which have been conducted in Scotland, the relevant legislative conditions affecting carers in Scotland are highlighted. Furthermore, it is briefly discussed what it means to provide care for people with dementia. The concept of technology is introduced along with a definition of how the term is used in the context of this thesis and why it is considered a potential solution to the challenges working dementia carers face. The chapter concludes with a discussion of the rationale, research aim, and objectives.

Chapter two presents the methodology, starting with the research paradigm and participatory design approach and concluding with an overview of the relevant ethical considerations.

The main body of the thesis is divided into four parts, representing five original studies<sup>3</sup> that were conducted to explore the potential of technology to support working dementia carers. Each of these four parts is introduced with a preface and the study's rationale. Where relevant, additional information that did not fit within the publication-ready format of a chapter is also presented in this introduction, along with additional references. The four parts are as follows: I) scoping reviews, II) interviews with working dementia carers, III) technology landscape review, and IV) online technology evaluation.

- I. Two scoping reviews are presented in part I. The first review was conducted at an early stage of the project and aimed to find out what was already known about the challenges working carers experience when combining work and care and which support and solutions have been identified in the literature. A conceptual framework that highlights how potential support and solutions for carers' work-care reconciliation challenges can lead to further, secondary challenges, was the outcome of this research. The study is presented in chapter 3 as the accepted manuscript of the following paper: Spann, A, Vicente, J, Allard, C, Hawley, M, Spreeuwenberg, M, de Witte, L. (2020): Challenges of combining work and unpaid care, and

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<sup>3</sup> To ensure consistency, figures, tables, chapters, and pages were consecutively numbered, thus do not match the numbering of the published papers.

solutions: A scoping review. *Health & Social Care in the Community*. 28: 699– 715. <https://doi.org/10.1111/hsc.12912>

**Authors' contributions:** The candidate (AS) took the lead in developing the review protocol. The supervisors (MH and LdW) reviewed and approved the protocol. AS and a fellow PhD candidate (JV) screened and selected the relevant articles and resolved disagreements by discussion and seeking opinions from another PhD candidate (CA), and the supervisors (MH, MS and LdW). AS extracted and analysed the data and drafted the manuscript. MH, MS and LdW contributed to the subsequent drafts and the final manuscript. All authors reviewed and approved the final manuscript and agree to the inclusion of this paper in this thesis.

The second scoping review, presented in chapter 4, was conducted to examine what was already known about technologies used by working carers to address their work-care reconciliation challenges. The purpose for which technologies had been used was examined and the conceptual framework developed in the first scoping review was used as an analytic framework to explore the benefits and barriers and/or limitations of these technologies that carers expressed. The study is presented as the accepted manuscript of the following paper: Spann, A, Vicente, J, Abdi, S, Hawley, M, Spreuwenberg, M, de Witte, L. (2022): Benefits and barriers of technologies supporting working carers—A scoping review. *Health & Social Care in the Community*. 30: e1– e15. <https://doi.org/10.1111/hsc.13421>

**Authors' contributions:** The candidate (AS) took the lead in developing the review protocol. The supervisors (MH and LdW) reviewed and approved the protocol. AS and a fellow PhD candidate (JV) screened and selected the relevant articles and resolved disagreements by discussion and seeking opinions from another PhD candidate (SA) and the supervisors (MH, MS and LdW). AS extracted and analysed the data and drafted the manuscript. JV, MH, MS and LdW contributed to the subsequent drafts and the final manuscript. All authors reviewed and approved the final manuscript and agree to the inclusion of this paper in this thesis

- II. Part II presents a qualitative study. Semi-structured interviews have been conducted with working carers of people with dementia in Scotland. The findings of this study are presented in chapters 5 and 6 in a publication format. Additional themes that did not fit the scope of these two manuscripts but are relevant for the discussion of this thesis are presented as an addendum in chapter 7. The themes discussed with interviewees were influenced by gaps in the evidence identified through the scoping reviews.

Interviewees provided insight into the challenges they faced and currently used, wanted, or needed technological solutions for (chapter 5). This chapter is presented in a publication-ready format and will be submitted to *Dementia* or a similar journal as Spann, A, Spreeuwenberg, M, Hawley, M, de Witte, L (n.D.). *Dementia family carers' needs and wants for technological solutions to their work-care reconciliation challenges: Semi-structured interviews in Scotland* [Unpublished manuscript].

**Authors' contributions:** The candidate (AS) conceived the design of the study with input from the supervisors (LdW and MH). AS conducted the interviews and transcribed the audio recordings with support from professional transcribers. AS analysed the transcripts and discussed emerging themes with LdW and MH. AS drafted the manuscript. The supervisors (LdW, MH, and MS) helped revise the manuscript. All authors reviewed and approved the final manuscript and agree to the inclusion of this paper in this thesis.

Interviewees furthermore shared their experience on how their autonomy at work impacted their ability to manage care-related emergencies and how they were able to use technology to that end (chapter 6). Chapter 6 presents the submitted version of the following published paper: Spann, A, Allard, C, Harvey, A-C, Zwerger, K, Spreeuwenberg, M, Hawley, M, de Witte, L (2022). The impact of autonomy at work on dementia family carers' ability to manage care-related emergencies: Semi-structured interviews in Scotland. *Community, Work & Family*, [online preprint] doi: 10.1080/13668803.2022.2117589

**Authors' contributions:** The candidate (AS) conceived the design of the study with input from the supervisors (LdW and MH). AS conducted the interviews and transcribed the audio recordings with support from professional transcribers. AS analysed the transcripts and discussed emerging themes with LdW, MH, and fellow PhD candidates (CA, AH, and KZ). AS drafted the manuscript with input to the discussion from CA, AH and KZ. LdW, MH, and MS helped revise the manuscript. All authors reviewed and approved the final manuscript and agree to the inclusion of this paper in this thesis.

- III. The fourth study, a review of the technology landscape, is presented in part III, chapter 8. The work-care reconciliation challenges identified in chapter 5 were used as the starting point to review currently available or emerging technologies which have the potential to address these challenges. The thus identified technologies were categorised according to their use-case, using a carer-centred approach, and mapped against the previously established work-care

reconciliation challenges. This study is presented in a publication-ready format with plans for submission to *Human Technology, Health and Social Care in the Community*, or similar journals as Spann, A, Spreeuwenberg, M, Hawley, M, de Witte, L (n.D.): *Supporting working dementia carers: Mapping technology-based tools and services on dementia carers' work-care reconciliation challenges*. [Unpublished manuscript].

**Authors' contributions:** The candidate (AS) conceived the design of the study with input from the supervisors (LdW and MH). AS conducted tiers 1) and 2) of the search and analysed the data. AS, LdW, and MH discussed the emerging use cases and technology groups. AS produced the videos for the expert webinar with editorial advice from LdW and MH. AS, LdW, and MH recruited technology experts for the webinar. The webinar was led by AS with support from LdW and MH. AS drafted the manuscript. LdW, MH, and MS helped revise the manuscript. All authors reviewed and approved the final manuscript and agree to the inclusion of this paper in this thesis.

IV. Part IV, chapter 9, presents the final study which used a custom-built website to get feedback on the technologies identified in chapter 8 from working carers of people with dementia and those most likely to be affected by these technologies (people with dementia, care workers, employers). This is the only study not presented in a publication-ready format.

Chapter 10 is the final chapter of this thesis. It contains a discussion of the findings and examines whether the research objectives have been met. Strengths and limitations are discussed and an outlook on further research is provided. The thesis concludes with an exploration of the practical implications of its findings.



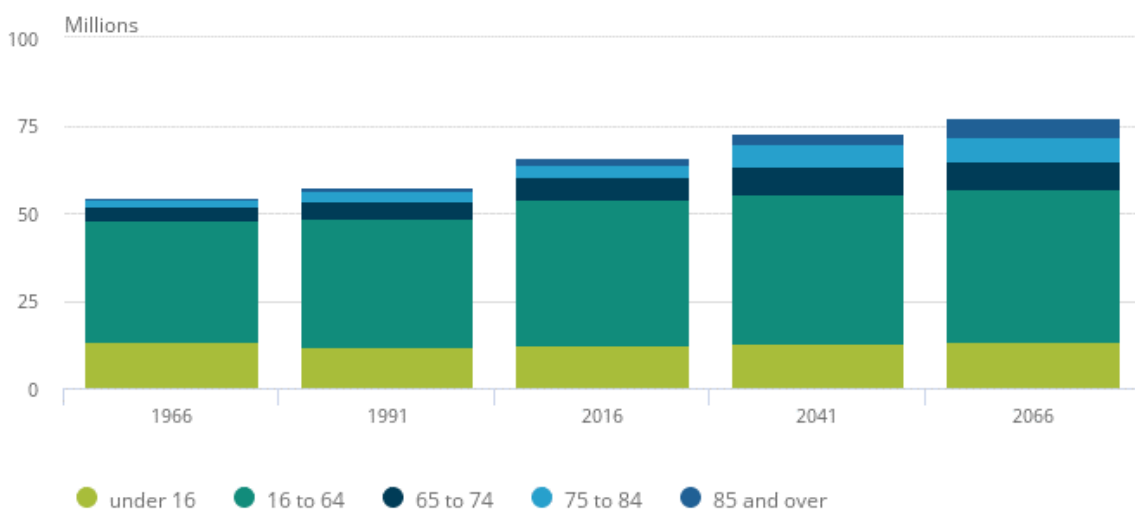
# 1. Background

This chapter provides the necessary background to understand the relevance of the research topic. Relevant concepts like technology and working carers are introduced and defined. The social care crisis in the UK and its impact on unpaid carers is discussed. An overview is provided on what it means to be an unpaid carer, to combine unpaid care with paid work, and to provide care for people with dementia. The chapter concludes with a discussion of the thesis' rationale, aims, and objectives.

## 1.1. Social Care in the UK – at a tipping point(?)

Care needs are growing. One of the most important sources of increasing care needs is an ageing population. Population ageing results from a combination of decreasing fertility rates and increasing life expectancy, causing a shift in the age structure of societies (United Nations Department of Economic and Social Affairs, 2020). This is a global phenomenon and considered a gradient of economic and social progress. According to the UN, the proportion of people aged 65 and above is set to increase from currently around 9.3% to 16% globally by 2050 (United Nations Department of Economic and Social Affairs, 2020). The ONS (2018) expects the British population aged 65 and older to increase by about 50% from 2016 to make up 26% of the total population by 2041, and among them the amount of the so-called “oldest old”, people aged 85 and above, to double from currently 2 to then 4% of the total population. This contrasts with the projected 2% increase in people aged 16 to 65 in the same period and predicts a shift in the UK's age composition, which is illustrated in figure 1 below.

Figure 1: Projections of UK population developments by age group, selected years (ONS, 2018, p. 3)



As modern medicine continues to extend lives, more people may be expected to live with increasingly complex long-term conditions which limit their quality of life and increase their need for care (Foresight, 2016). People with physical limitations might come to require assistance to a varying degree regarding their activities of daily living (ADLs; i.e. personal hygiene, toileting, moving around, feeding themselves) or instrumental activities of daily living (IADLs; e.g. medication management, shopping, preparing meals) which are more complex and required for an independent life (Mlinac & Feng, 2016). Additionally, some people might require emotional support or somebody to monitor their health or ensure that they don't come to any harm.

The degree to which societies see long-term care needs as a public or private issue reflects cultural norms and attitudes regarding family and is manifested in their arrangements and legislation regarding social care. Accordingly, countries which view care as a family issue tend to have low public involvement whereas countries which see it as a public responsibility provide either financial support, which can be used to finance privately organised care or publicly funded services (Bettio & Plantenga, 2004). Although traditionally emphasising the provision of health- over social care (Glasby, 2017), the UK had, in the past, relatively high levels of community and residential care provision compared to other nations (Bettio & Plantenga, 2004). However, the UK government's austerity programme in the wake of the global economic crisis of 2008 led to severe cuts in public expenditure on social care services, with a real-term reduction of 37% from 2011 to 2016 – despite growing numbers of people needing care – which has led to severe accessibility issues of social care services (Atkins et al., 2021; Humphries et al., 2016). Deusdad et al. (2016) argued that tendencies of privatisation and deinstitutionalisation as they have been occurring in the UK are a regular consequence of financial crises. Deinstitutionalisation, receiving care in their community rather than a care home, is encouraged under the government's "Ageing in Place" policy. Apart from lower costs to the public purse, this policy emphasises benefits to the cared-for person regarding wellbeing, independence, and social participation. However, the reality for some people might hold reduced opportunities for well-being as they might experience social isolation, inadequate housing, or insufficient or low-quality care provision (Sixsmith & Sixsmith, 2008). Only recently has the government started to reverse its austerity policy regarding adult social care, with total spending in 2019/2020 returning to 2010/2011 levels but still remaining well below the minimum the UK Homecare Association recommends (Bottery & Ward, 2021). Since then, though, the Covid-19 pandemic has further exacerbated the precariousness of the UK health and social care sectors, despite further budget increases (Bottery & Ward, 2021; Care Quality Commission, 2021; Charles & Ewbank, 2021).

Despite the UK government's most recently expressed commitment to reforms of the social care system (Department of Health and Social Care, 2021; HM Government, 2021), including much needed

financial reform, there is little reason for optimism in light of the long history of more or less successful reform attempts (Glasby, 2017; Humphries et al., 2016; Jarret, 2018). In addition, there are unprecedented challenges to recruit care staff for an already short-staffed, underpaid, and undervalued workforce put under even more strain during a global pandemic (Care Quality Commission, 2021). Brexit, too, is contributing to staff shortages as the care sector heavily relies on EU citizens who now face immigration restrictions (Elgot, 2021; Holmes, 2021). Devolution, which saw the reinstatement of regional governments in Wales, Northern Ireland, and Scotland in 1999, led to regional differences in the organisation, provision, and accessibility of social care (Atkins et al., 2021). Furthermore, as social care provision falls into the remit of local authorities which might have different resources and spending priorities, the availability and accessibility of care services can resemble a “postcode lottery” (Glasby, 2017; Humphries et al., 2016).

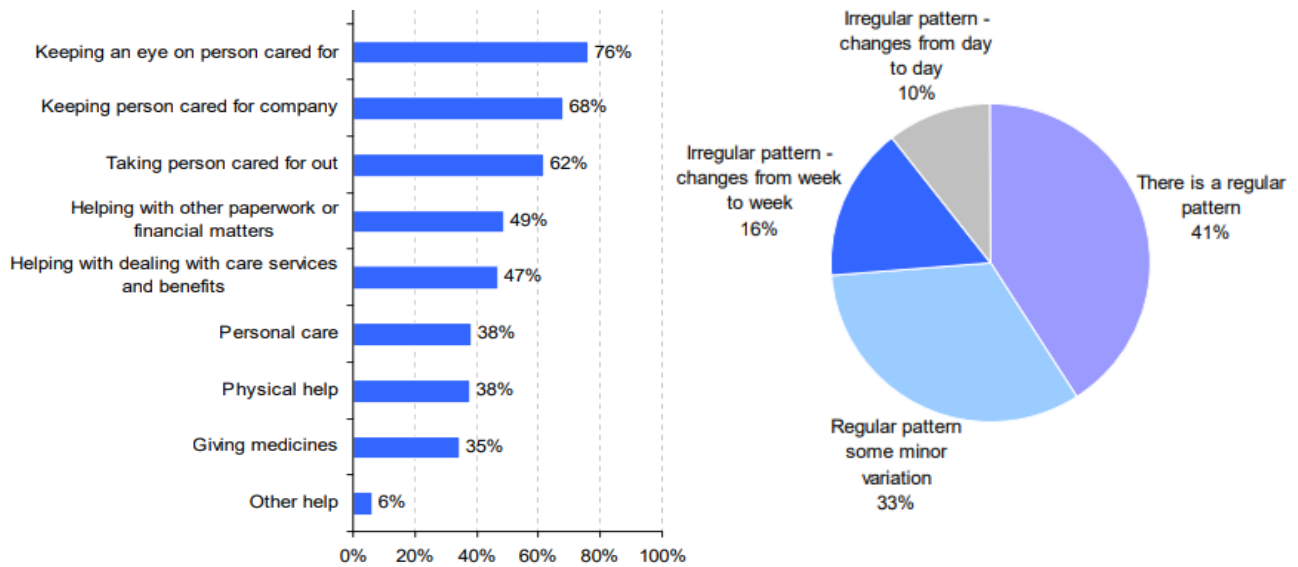
As fewer social care services are available and accessible, and fewer people receive publicly funded care, more and more people have to pay for their care out-of-pocket and care needs go unmet on a massive scale (Atkins et al., 2021). Accordingly, families are increasingly under pressure to bridge this gap in care provision.

## 1.2. Being an unpaid carer

Care that is provided to an ill, frail or disabled person by family members, friends or neighbours rather than formal services is generally considered unpaid, even if the carer receives financial support from the government (i.e., carer’s allowance) or other sources. Before the Covid-19 pandemic, Carers UK (2019b) estimated that around 17% or 8.8 million adults provided care in the UK. Since then, the number has drastically increased to an estimated 13.6 million people (Carers UK, 2020; Phillips et al., 2020). However, as many carers view their contribution as a normal part of their relationship with the person they care for and “just helping out” rather than labelling it as caring (Hamblin & Hoff, 2012; McCartney, 2016; Skills for Care, 2013), it can be expected that the actual number of carers is a lot higher. The care these carers provide saves the economy around £132bn. per year – which is roughly the same amount as total annual public spending on the National Health Service (Buckner & Yeandle, 2015). Caring situations are usually very diverse and dynamic. Care is provided *by* people of all ages, socioeconomic and ethnic backgrounds and both genders, although women care more often (20% of women and 13% of men are carers) and the likelihood of becoming a carer increases with age (Carers UK, 2019b; NHS, 2010). Zhang, Bennett, and Yeandle (2019) found that the likelihood of becoming a carer at some point in one’s life is 65% for people in the UK, 60% for men and 70% for women. Care is provided *for* people of all ages with varying degrees of physical, mental, and emotional support needs

who either live with their carers or in their own homes (NHS, 2010). Care and support needs can be very varied and fluctuate (figure 2).

Figure 2: Type and regularity of care provided (NHS, 2010, p. 42; 46)



Most carers are between the ages of 16 and 64 and thus of working age (NHS, 2010; ONS, 2011). Thus, many have to reconcile their unpaid care with their paid work responsibilities.

### 1.2.1. Combining work and care

Slightly more than half of the carer population, 4.87 million, were combining caring for a loved one with paid work – a number that yet again has increased, to about 7 million, since the onset of the Covid-19 pandemic (Carers UK, 2020; Phillips et al., 2020). Carers UK (2020) note that people providing care during the pandemic are more likely to be working than before and that 2.8 million, one in ten, working adults in the UK have started to provide care during the pandemic. This means that already at least 26% of all people in paid work are carers (Carers UK, 2020). This number is, however, expected to increase even further in the coming years as more people require care, not enough formal services are available or accessible, and more people are needed in the job market for longer to support an ageing society – especially women who provide care more often (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Care Quality Commission, 2021; Round, 2017; Ward, Ray, & Tanner, 2020; Yeandle & Buckner, 2007).

Combining work and care is a very complex issue (Spann et al., 2020, see chapter 3.3.3.). Demands and resources can originate from the caring, work, and personal spheres. Demands from the caring sphere could, for example, be the support needs of the cared-for person, while resources could be

appreciation for the care provided, a stronger bond between carer and cared-for person, a sense of accomplishment, and formal care support. Demands from the work sphere could be a demanding and time-intensive job, while resources could be emotional support from co-workers and employers. Demands from the personal sphere could be family responsibilities such as caring for a child in addition to caring for an ageing parent (so-called sandwich carers), while resources could be emotional and practical support. Having to reconcile caring and work can have massive impacts on carers' mental and physical health, their relationships, and their employment (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). King and Pickard (2013) found that providing care for ten hours a week or more significantly impacted the likelihood of the carer remaining in paid work. Carers UK (2019b) has calculated that the number of people who have given up work to care has increased by 12% from 2013 to 2.6 million, equating to 600 carers a day. Not only does that affect the long-term financial situation of carers, but it also negatively impacts the economy and the public purse. Lost tax revenue and increased spending on benefits to support carers cost the UK economy £1.7bn a year (Pickard et al., 2018). Additionally, there are costs to employers in terms of loss of skilled labour, recruitment, and training expenses (Carers UK, EfC & DoH, 2013). Combining work and care should not be problematised per se as many carers want to do both. Caring can give them a sense of purpose, and an opportunity to reciprocate and support their loved one in their need (Bourke et al., 2010; Eldh & Carlsson, 2011; Hamblin & Hoff, 2012). Work, on the other hand, is not merely a source of income but offers respite from caring, a sense of accomplishment, and social connections outside caring (Bourke-Taylor et al., 2011; Bruns & Schrey, 2012; Calvano, 2013). However, if not sufficiently supported, combining care and work can create significant demands on carers – specifically their time – which can negatively affect their health, relationships, and employment (Carers UK, 2014; Wang et al., 2011; Wang et al., 2013; Wang et al., 2020; Wittenberg et al., 2019).

Role theory has long been an important theoretical framework to explore the underlying dynamics between work and family life and the strain resulting from role conflict (Edwards et al., 2002; Goode, 1960; Greenhaus & Beutell, 1985; Lavassani & Movahedi, 2014; Rozario et al., 2004). Time-based role conflict arises when the demands of one role (e.g., work) make it physically impossible to address the demands of another (e.g., caring), or through being too preoccupied with one role to meet the demands of the other, even while attempting to do so (Greenhaus & Beutell, 1985). Examples of working carers' time-based role conflict include care management; coordinating and attending medical or similar appointments; and worrying about and managing care-related emergencies (CRE; e.g., falls, accidents and injuries; home environment hazards like fires, floods, electricity or heating blackouts) (Spann et al., 2020, see chapter 3.3.3.).

As social care is a devolved issue in the UK, the four nations have responsibility for how they regulate support for carers. Due to austerity and inadequate implementation, however, many carers don't receive the support they need (Atkins et al., 2021; Carers UK, 2018). The interviews that form part of this research (see chapters 5-7) have been conducted in Scotland. Hence a brief overview of carers' situation in Scotland is now presented here.

### 1.2.2. Caring in Scotland

Since devolution of the Scottish Parliament in 1998, Scotland's ability to self-organisation and -control has increased. Importantly for the context of this thesis and in contrast to social care, employment law is not devolved and legislation in that regard, to Scotland's dismay, is still made by the UK government in Westminster (Scottish Government, 2017). The Scottish National Party, SNP, in government since 2007, has a strong political commitment to social issues in general and care and carers in particular (Scottish National Party, 2021). Despite being poorer than England, Scotland provides more state-funded care which, according to Atkins et al. (2021), is a sign of the Scottish government's high prioritisation of social concerns. The UK census of 2011 identified a total of 492,031 unpaid carers in Scotland (Carers UK, 2019a). The Covid-19 pandemic increased the total percentage of unpaid carers from an estimated 16% to now 25% of the total Scottish population. This means that already, more than 1.1 million people in Scotland provide unpaid care (Carers UK, 2020), a number Scotland's most influential carer organisation Carers Scotland had expected not to be reached before 2037 (Carers Scotland, n.D.-b). Of those carers, at least 56% are in paid work (Carers Scotland, n.D.-b). In a country where 98% of its landmass is classified as rural, 17% of Scots live in rural and 6% in very remote areas (Scottish Government, 2021), which can impact the availability and accessibility of care services.

Some of the most significant policies and government initiatives affecting carers in Scotland are:

**Personal and nursing care has been free for all adults** since 2019, however, the cost has not been able to keep up with demand and there have been real-term social care spending cuts for older people of 9% between 2010/11 and 2018/19 (Atkins et al., 2021), meaning that there are long waiting lists for care services and care needs go unmet (Age Scotland, 2019).

In 2013 the Scottish Government introduced the **Social Care (Self-directed Support) (Scotland) Act** (Scottish Parliament, 2012) which places a duty on local authority (LA) social work departments to offer people eligible for social care a range of choices over how they receive their support. This includes either receiving support arranged and financed by LAs, support selected and/or arranged by the cared-for person and financed by LAs, or direct payments with which cared-for people can procure care services as they see fit. There remain severe issues with the implementation of this scheme though,

stemming from insufficient funding and availability of care providers or lack of flexibility from LAs (Audit Scotland, 2017).

The **Social Security (Scotland) Bill** was introduced in 2018 which transferred control over carer's allowance from the UK to the Scottish government, resulting in a 13% rise in carer's allowance for Scottish carers (Scottish Government, n.D.-b).

Health and social care were integrated in 2016 and **Integration Authorities and Health and Social Care Partnerships** were established. These are responsible for consolidating the funding of local NHS boards and LAs are expected to respond holistically to the health and care needs of the people living there. Additionally, there are carers' centres in every LA which provide support, information, and advice for carers (Scottish Government, n.D.-a).

The **Carers (Scotland) Act 2016** entails a duty for LAs to provide support to carers, based on their needs which meet the local eligibility criteria, a carer support plan to identify carers' needs and personal outcomes, and a requirement for LAs to have an information and advice service for carers on, amongst other things, emergency and future care planning, advocacy, income maximisation, and carers' rights (Scottish Parliament, 2016).

The **Carer Positive Employer Programme**, set up in 2013, is an employer recognition scheme for carer-friendly employers, funded by the Scottish Government, and operated by Carers Scotland (Carers Scotland, n.D.-a).

To summarise, Scotland's strong commitment to improving the lives of carers and those they care for is noteworthy and commendable. However, these efforts are hampered by budgetary constraints, inadequate or incomplete implementation, and chronic care worker shortages, exacerbated by Brexit and the Covid-19 pandemic (Care Quality Commission, 2021).

### 1.2.3. Caring for people living with dementia

Carers in full-time work are most likely to care for people living with dementia (Carers UK, 2013). At present, 1 million people with dementia are living in the UK, roughly 90,000 of those in Scotland (Carers UK, 2014; Prince et al., 2014; Scottish Government, 2016; Wittenberg et al., 2019). An old estimate put the total of unpaid dementia carers in the UK at around 700,000 (Lewis et al., 2014). Precise numbers of how many people currently combine work and care for people with dementia are not known but are likely to see a drastic rise due to the projected doubling of the prevalence of dementia in the UK by 2050 (Prince et al., 2016; Prince et al., 2014; World Health Organization, 2017), the availability and accessibility restrictions of social care services detailed in chapter 1.1., and rising retirement ages (Round, 2017), as the likelihood of becoming a dementia carer increases with age.

Dementia refers to degenerative processes of the brain which are generally progressive in nature. Symptoms include emotional, psychological, cognitive, and behavioural issues like anxiety, depression, aggression, disorientation, memory loss, etc. (commonly referred to as behavioural and psychological symptoms of dementia, BPSD), which can affect the ability of people with dementia to continue living independently (World Health Organization, 2017). Most people with dementia in the UK live in their communities where they are supported and looked after by unpaid family carers (Alzheimer's Research UK, 2015; Prince et al., 2014). Unpaid care provided to people with dementia in residential and home care was valued at approximately £11.6 billion in 2014, 44.2% of the total societal cost of dementia. Strikingly, however, this percentage rises to 74.9% for people with dementia living in the community in contrast to merely 6.7% living in residential care settings (Prince et al., 2014). This highlights the importance of unpaid carers and can be interpreted as reflecting the high levels of care people with dementia need, and the lack of home care services provided.

Care needs of people with dementia can involve anything from assistance with their activities of daily living and personal care, so-called instrumental activities of daily living (e.g., shopping, financial and household management, etc.), social and emotional support, and ensuring their safety and comfort. These needs can fluctuate but usually intensify when the dementia progresses (Gallagher-Thompson et al., 2020). Because of the complex and unpredictable nature of the condition, caring for people with dementia has been found to be more challenging than caring for someone with other diseases or disabilities (Matsumoto et al., 2007; Newbronner et al., 2013): dementia carers provide more care overall, and caring for people with dementia is particularly emotionally challenging due to having to come to terms with the slow decline and changing personality of a loved-one, frequent interpersonal conflict with the person with dementia, and having to be constantly vigilant to manage the behavioural and psychological symptoms of the condition and to ensure the safety of people with dementia. Accordingly, dementia carers have been found to have more stress, physical and mental health problems, and generally, a worse quality of life (Carers UK, 2014; Huang et al., 2012; Koyama et al., 2017; Kuo et al., 2014; Moon & Dilworth-Anderson, 2015).

Support for working dementia carers is urgently needed yet hard to come by in light of the adult social care crisis.

### 1.3. The potential of technology

In a chronically under-resourced social care system as outlined in chapter 1.1., technology can offer carers urgently needed solutions for their work-care reconciliation challenges they can acquire and use independently of any authorities. This view seems to be shared by the Scottish Government, who, in their updated Digital Health and Care Strategy, committed to improving the accessibility of digital



devices, services, and infrastructure for all people living in Scotland (Scottish Government & COSLA, 2021). Investment in Scotland's digital infrastructure is urgently needed, as access to the internet at home only averages 87% of households (Scottish Government, 2021), compared for example to 91% average in the European Union (Statista Research Department, 2021). Internet access is a prerequisite to using most of the technologies discussed in this thesis. Technology, especially web-based, plays an increasingly important part in our public, social, and personal lives, enabling us to get information, communicate and connect, be entertained, and conduct official or private business. Thus it is all the more striking that as many as 62% of carers are unaware of technology that can help them to care, and 26% of carers who are aware do not know where to get it from (Carers UK, 2012).

The rapid development of technologies produces a plethora of terms aimed at classifying and defining them, such as robotics, information and communication technologies (ICTs), social media, monitoring technology, and artificial intelligence – to name but a few. In the context of health and social care, terms like telehealth, telecare, telemedicine, digital health, E- and M-Health, etc. are used which are notoriously ill-defined (see e.g., Linskell & Dewsbury, 2019 for an insight into the discussion on the term 'telecare'). What makes these terms so difficult to use, apart from vague definitions, is that they can summarise an array of technologies that are different in appearance, capabilities, basic function, and intended purpose. In this thesis, technology is thus used in a broad and open sense to refer to any device or system that is electronic and/or digital in nature, not limited to physical appearance (hardware) or programming (software). Technologies can be mainstream or specifically designed for the care context. A further definition or classification of technologies according to basic function and intended purpose, as relevant to working carers of people with dementia, will be an outcome of this research.

In the context of social care, technologies have been developed that aim to increase the independence of people in need of care, either by compensating for physical or cognitive limitations (e.g., fully automated toilets or medication reminders), helping them to manage their condition (e.g., diabetes apps) or by ensuring that help is available in case of emergencies (e.g., fall detectors, personal alarms, environmental alarms). Approximately 182,000 people are currently supported by a telecare emergency service in Scotland (Scottish Government & COSLA, 2021). Additionally, robots are being developed to keep people company who are isolated and lonely. On the other end of the caring dyad, technologies have been created to support the physical (e.g., mobile patient lifts) and supervising (e.g., activity sensors or care cameras) aspects of caring. The body of research on technology for carers (see e.g., Bergström & Hanson, 2017; Smith, 2008; Sriram et al., 2019; Wasilewski et al., 2017) and technology for people with dementia (see e.g., Astell et al., 2019a; Astell et al., 2019b; Lorenz et al., 2019; Yellowlees, 2020) continues to grow. However, little attention has yet been given to technology

that can help carers in general, and carers of people with dementia in particular, to better combine work and care. The scoping review on technology for working carers conducted as part of this thesis (Spann et al., 2022, see chapter 4) only identified one paper that explicitly focused on working carers of people with dementia (Beauchamp et al. 2005). While technology may have the potential to help working carers manage and resolve some of the challenges they face, they need to have autonomy, i.e., the ability to self-directedly use these technologies at work. More research is needed on carers' priorities regarding technologies to support their efforts to reconcile work and care and their ability to use these technologies when at work.

#### 1.4. Thesis rationale

Carers have always been an indispensable cornerstone of the UK social care system. Even more so after more than a decade of austerity, chronic underfunding of the social care system, workforce shortages, and an ongoing global pandemic. Nevertheless, carers deserve support to live a fulfilling life of their own, to have a satisfying family and social life, employment, and financial stability. Combining work and caring for people with dementia is particularly stressful, due to the effect dementia has on the ability of people with dementia to live independently, the amount of supervision required to keep them safe and comfortable, and the physical, mental, and emotional impact of caring. Technology, although no panacea, can have the potential to relieve some of the pressure on carers while they reconcile unpaid care with paid work. Yet, little is known about which technologies can be useful for working carers of people with dementia. This translates into technologies not being promoted enough to carers as potential solutions for them to consider. Furthermore, to realise the full potential technologies can offer them, carers need to be able to reflect on the implications they might have on other stakeholders, including people with dementia, employers or clients, and care providers.

#### 1.5. Aim and objectives

This PhD project aims to explore, identify, and map technologies, currently available and emerging, which have the potential to help working carers reconcile work and care. An outcome will be a framework which maps technologies onto work-care reconciliation challenges, and which highlights technologies' functionality and purpose for working dementia carers. This framework can then be used as a reference for those who aim to support them (e.g., employers, carer or dementia support organisations, and local authority adult social care departments), to identify technologies which can help working carers of people with dementia in their individual situation. The project has the following objectives:

- **Objective 1:** To investigate which challenges working carers of people with dementia face when combining work and care and how their autonomy at work impacts their ability to manage care-related emergencies. The following questions will be addressed:
  - a. *What do working carers of people living with dementia experience as particularly challenging when combining work and care and what support needs do they articulate?*
  - b. *How does their autonomy at work, more specifically dementia carers' control over their work hours, workplace, and break times, impact their ability to manage care-related emergencies and use technology for that end?*
  
- **Objective 2:** To explore which technologies working carers of people with dementia are using or would like to use to support their work-care reconciliation efforts, and what their experiences are with these technologies. The following research questions will be addressed:
  - c. *Which technologies do working carers of people with dementia (want to) use to reconcile work and care, and for what purpose?*
  - d. *What are their experiences with these technologies?*
  
- **Objective 3:** To identify promising technologies, currently available or emerging, and map them onto the previously identified work-care reconciliation challenges, taking into account how people with dementia, employers/clients, and care workers may be affected. The following research questions will be addressed:
  - e. *Which technologies, currently available or emerging, have the potential to address the identified work-care reconciliation challenges?*
  - f. *What are the views of working carers or those potentially being impacted by these identified technologies (i.e., people with dementia, care workers/providers, employers)*

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## 2. Methodology

The previous chapter served to introduce the research topic by outlining the rationale for conducting this research. The UK social care crisis has been discussed and how it impacts on the rising pressure put on unpaid carers. What it means to be a carer in general, and a working carer and carer for people with dementia in particular has also been discussed. The term “technology” as it is used in the context of the thesis has been defined and a rationale provided, why it is important to investigate technologies as potential solutions to carers’ work-care reconciliation challenges. The chapter concluded with the research aim and objectives. This current chapter now outlines how these aims and objectives were met. The research paradigm and research approach are discussed in detail, followed by a section on the researcher’s reflexivity. It concludes with a discussion of ethical considerations. The detailed design of each study is presented in the respective chapter.

### 2.1. Research paradigm

The choice of study design and research methods are heavily influenced by the researcher’s underlying philosophical views of the nature of reality and knowledge, their research paradigm – be that conscious or not. As this influences the generation and interpretation of knowledge, researchers should ideally reflect on their philosophical stance before developing their research questions and corresponding study design (Barbour, 2014; Creswell, 2007; Kivunja & Kuyini, 2017). Bunniss and Kelly (2010) described the logic of deliberations which connect the researcher’s philosophical stance to the choice of research methods: ontology impacts epistemology, which in turn determines methodology and the development of the study design.

*Ontology* refers to assumptions regarding the nature of reality and truth. The positivist paradigm, for example, postulates an objective truth and sees reality as static and fixed, independent of human observation (Realism). The interpretivist or social constructivist paradigm, on the other hand, sees reality as subjective and constantly changing and rejects the notion of ultimate truth (Idealism) (Creswell, 2007). Research disciplines can have dominant paradigms, for example, medical research traditionally adopts a more positivist worldview (Bunniss & Kelly, 2010; Kivunja & Kuyini, 2017). It can be challenging for researchers embarking on multidisciplinary research to reconcile competing paradigms. This PhD project’s emphasis is on developing specific solutions for specific problems, which shows a pragmatic worldview. Pragmatists, according to Creswell (2007), are not committed to a specific ontology but rather adopt a viewpoint which serves their objectives at the time. Reality can thus exist both within and outside the mind.

*Epistemology* refers to beliefs regarding how reality or truth can be known. Positivist epistemology assumes that hypotheses can be generated and tested to measure how the world works. These should be generalisable and unbiased. Interpretivism sees knowledge as subjective and interpreted and assumes that there is no real or correct “knowing”. “Reality” can thus only be understood through how it is experienced and expressed by the observer (Bunniss & Kelly, 2010; Creswell, 2007). Pragmatism acknowledges that there is an objective reality but that it can only be accessed through the interpretation of the individual, which is dependent on context – social, political, historical, or other. It is, however, more interested in the process and outcomes of research and its practical implications (Creswell, 2007; Lewis & Ritchie, 2003).

*Methodology* refers to the logic of how knowledge is generated and is influenced by the underpinning ontological and epistemological stance of the researcher. The positivist paradigm is associated with quantitative research methods where statistics are used to test generated hypotheses. Interpretivism uses qualitative methods to gain access to the “inner world” of respondents, their beliefs, experiences, and motivations (Barbour, 2014; Bunniss & Kelly, 2010; Creswell, 2007). In the pragmatic paradigm, researchers focus on open-mindedly investigating a practical problem and choose the methods which are most suitable to answer their questions (Creswell, 2007). This approach is thus a good fit with participatory design, which seeks solutions to practical problems (Steen, 2014).

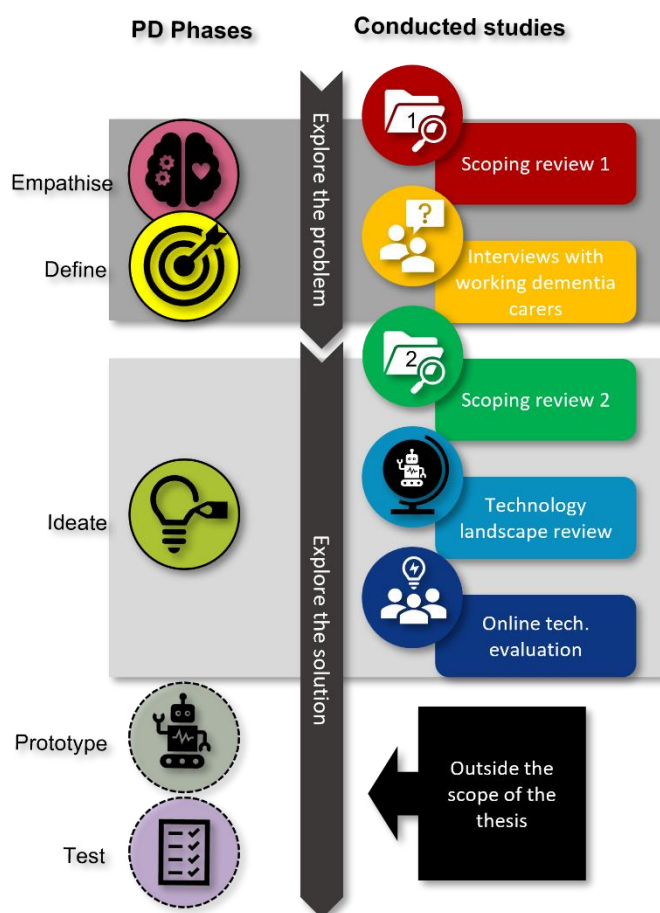
## 2.2. Participatory design (PD)

This project aims to develop a framework that maps technologies onto the work-care reconciliation challenges identified by working carers of people living with dementia. Ultimately, this framework can be used as the basis of a self-help tool that working dementia carers and those aiming to support them can use to identify technological solutions to carers’ work-care reconciliation challenges. This research follows a participatory design approach. Participatory design, or PD, is a research approach that can be used to develop practical solutions to practical problems together with the people who experience these problems and who are expected to use the developed solutions (Clemensen et al., 2007; Sanders, 2003; Steen, 2014; Van der Velden et al., 2014). Sanders (2003) highlighted that PD is pre-eminently an attitude towards conducting research. As such, it represents an evolution from user-centred design, which traditionally seeks solutions for rather than with people. Regarding the role of research participants, Simonsen and Robertson (2013) state that “*participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users’ situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them*” (p. 2). Similarly to participatory action research, from which it evolved, PD is problem-centred, future-oriented, democratic, and inclusive (Barbour, 2014; Clemensen et al., 2007). Done well, PD has the potential to create more innovative solutions that are more useful and beneficial

for those intended to profit from them (Mitchell et al., 2016; Trischler et al., 2017). According to Steen (2014), PD can be organised in two main phases: 1) exploring the problem, wherein the focus should be to *empathise* with the people one is designing for, and to let them *define* their problem, and 2) exploring the solution, wherein *ideas* are collected to address the defined problem(s) and *prototypes* are developed and *tested*. This can be achieved through a variety of means. To explore the problem, researchers have, for example, conducted interviews, focus groups, workshops, consultations, or surveys with the people experiencing a problem, whereas solutions are usually developed in co-design workshops (Clemensen et al., 2007; Hanson et al., 2007; Hendriks et al., 2014; Lindsay et al., 2012; Mayer & Zach, 2013; Rodgers, 2018; Steen, 2014; Tseklevs et al., 2018). PD is described as an iterative process where the development and evaluation of solutions can lead to further exploration of problems (Clemensen et al., 2007). Solutions can be specific devices or services and should be a product of the co-design process (Steen, 2014).

This PhD project is inspired by the PD approach to first explore the problem, i.e., which work-care-reconciliation challenges dementia carers need and want technological solutions for, and then to explore the solutions, i.e., which technologies, currently available or emerging, have the potential to address these challenges. To *explore the problem*, carers' voices were given centre stage. An initial review, *scoping review 1*, provided an introduction to the issue and presented an overview of what is already known about the challenges carers face when combining work and care and which solutions or support have been identified (see chapter 3). *Interviews with working dementia carers* have then been conducted so that carers could

Figure 3: Illustration of the PD approach as it was applied for this thesis.



themselves define their priorities for technological support (see chapter 5) and to explore under which conditions at work these technologies would have to be used (see chapter 6). To *explore the solution*, another review, *scoping review 2*, provided insight into the technological solutions already studied for and with working carers (see chapter 4). The interviews with working dementia carers also shed light

on carers' experiences with technology they already used and their needs and wants regarding technology in general to support them to better combine work and care (see chapter 5). The work-care reconciliation challenges carers expressed in chapter 5 were then used as an analytic lens for a *technology landscape review*, which explored currently available and emerging technologies that have the potential to address these challenges (see chapter 8). The outcome of this study was a technology map that connects technologies to dementia carers' work-care reconciliation challenges. The technologies thus identified were then presented as blog posts in an *online technology evaluation* study to get stakeholders' (working dementia carers, people with dementia, employers, care workers) views on these technologies. Combined, these studies form the first phases of the PD process (exploring the problem: empathising with the people experiencing the problem and letting them define their problem; and exploring the solution: ideating potential solutions). The later stages of the PD process, developing and testing a prototype of the solution, fall outside the scope of this PhD project. Figure 3 illustrates the PD approach as it was applied for this thesis. The two phases that fall outside the scope of this thesis, prototyping and testing, are still depicted to illustrate how the findings of this project can be used to eventually co-design a useable self-help tool based on the technology map presented in chapter 8, which working dementia carers and those aiming to support them (e.g., employers, carers and dementia support organisations, and local authorities) could use to identify technological solutions for carers' individual situation.

### 2.3. Research reflexivity

Every researcher approaches an issue with their own expectations and preconceptions (Finlay, 2002). These can be the product of a researcher's biography, their being-part of the societal, historical, and/or political context in which the research takes place, and not least because undertaking research usually involves some level of engagement with the pre-existing literature (Davis, 2020; Finlay, 2002). These preconceived notions can impact decisions concerning a study's design, the data generation process, and analysis of the data, and can thus influence the findings (Barbour, 20014). Randall and Phoenix (2009) further highlight the interaction between researcher and participant, which is a core trait of qualitative research. For example, the interview setting and rapport between interviewer and interviewee can influence how comfortable interviewees feel to discuss their views and experiences (Barbour, 20014; Randall & Phoenix, 2009). Barbour (2000) thus advises to recognise and accept the researcher as active part of the qualitative research and encourages researchers to reflect on their preconceived views and expectations and the impact they have on the decision they make regarding their research.

My background as a nurse has provided me with a lot of personal experience with caring for people with dementia. Nurses are trained to view their patients holistically. This means that we don't just see

a patient's illness and consequent deficits in their activities of daily living that nurses seek to compensate, rather we aim to situate their current condition in the context of their lives and work to activate their resources. These resources can be physical, cognitive, emotional, or social. Ideally, a nurse's work is always in cooperation with their patient and their support system. Where possible, nurses' actions and interventions should be oriented towards patients' priorities for their own wellbeing and planned and regularly evaluated with patients.

These values of peoples' right to self-determination and participation regarding decisions about their own care have influenced my approach to my research. I generally view technology as tools that can empower people to live the lives they want to live. In the case of people with dementia, this could mean delaying or preventing having to leave their own home to live in a care home. It can mean taking back some control over their lives, e.g., by using reminders or technology that can make certain activities simpler. For carers, technology can relieve them of some of the burden of feeling they always have to be present to ensure the safety of the person they care for. The most important aspect of technology in my view, however, is that people themselves can decide which technology they want to use, how they want to use it, for what purpose, and whether to use it at all. To be able to make informed decisions about technological support concerning their care, however, people must first be encouraged to reflect on their own needs and be made aware of all the technologies that are available to them – including any potential downsides to using them.

My belief that people should be empowered to become the masters of their own fate not only influenced my research questions but also my methodology. The decision to conduct interviews with working dementia carers to let them define their own needs for technological support does not only stem from gaps in the literature but also from this personal value. Similarly, it was important to me to let the people most likely to be impacted by the technologies I found in chapter 8 themselves express their views on them, rather than to look for expert opinions from other researchers or practitioners. The value of self-determination is also reflected in smaller decisions such as to let interviewees themselves decide when and where they wanted to be interviewed. This decision is also influenced by my personal experience as an occasional working carer for family members. This taught me on a very personal level that working carers often struggle to make time for anything outside their responsibilities as a carer and employee, and that the people they care for are never far from their minds. It also reinforced the idea that work-care challenges can be very diverse which is why one-fits-all technological solutions cannot exist. This belief is reflected in my open approach to discussing carers' challenges during the interviews and on my approach to analysing the data. A further insight I gained from being a nurse and occasional family carer is that carers might not have a lot of opportunity to vent and talk about themselves. Thus, I made a conscious effort on some occasions to just let

interviewees talk, even if they did not directly respond to my questions. I also expected that interviewees might become emotional when talking about their difficulties. When this happened, I reacted according to the situation (e.g., putting my hand on theirs, offering my sympathies and understanding, giving them time to collect themselves) and offered them to pause the interview. I had also prepared a list with resources and organisations that provide support to carers to hand to interviewees after the interview had concluded.

My work as a nurse had included daily evaluations of the care plan with patients. These evaluations were essentially in the format of semi-structured interviews, in that a topic guide was used to help patients reflect on their needs and wishes regarding the care they received. Having this experience helped me to quickly feel comfortable in an interview situation and to establish rapport with interviewees. It did, however, make it difficult not to immediately give interviewees my professional advice during interviews when they described challenges that I was aware support and solutions were readily available for. Once the interview had concluded, I asked these interviewees whether they wanted any advice from me and shared any information available to me with them.

After some deliberations I decided to focus on my role as a researcher when introducing myself to my research participants, rather than to emphasise my background as a nurse. This was a difficult decision though as I value transparency very much. However, I did not keep my identity as a nurse a secret when interviewees wanted to know more about my credentials. The idea was that carers might respond differently to my questions if they perceived them as coming from a healthcare professional rather than a researcher. I was concerned that interviewees, e.g., could have censored themselves out of fear of being judged or being too polite to discuss their criticism of the health and social care system in front of a nurse. Ultimately, I decided that gaining a rich and uncensored understanding of the challenges working dementia carers face would be of greater benefit to my interviewees than my being up front with my background.

#### 2.4. Ethical considerations

Ethical approval for the project has been granted by the SchARR Research Ethics Committee (Reference 022994). Ethical considerations primarily concerned confidentiality and participants' consent. All participants were able to consent and withdraw their consent at every stage of the data generation process. Experts taking part in the stakeholder consultations to discuss the findings of the two scoping reviews (see chapters 3 & 4) and the webinar to comment on the comprehensiveness of the identified technologies (see chapter 7) were not required to complete a consent form as they were only asked for their opinion and no personal data was generated in the discussions.

The legal basis for collecting and using the information provided by participants was that the research is “a task in the public interest”. The potential harm for participants resulting from taking part in the interviews was assessed to be minimal. Interview discussion topics were about carers’ caring role and combining this with paid work and the ways technology could enhance and/or support their efforts to reconcile work and care. Some carers showed signs of emotional distress during their interview. When this was the case, interviewees were asked if they wanted to pause the interview. All interviewees were made aware of the possibility to abort the interview at any time without consequence, but no one made use of this option. To minimise the demand on carers’ time, interviews were undertaken at their convenience. Upon initial contact over the phone, participants were asked to name a time and place they felt most comfortable.

Possible harm from taking part in the online research was expected to potentially arise from participants unintentionally revealing personal and identifiable details when leaving their comments or from participants showing disrespect for different views and opinions of others. Participants were asked during registration to select a pseudonym to protect their identity, abide by the Chatham House Rules, and respect others’ views and opinions. However, this concern proved unfounded. PwD were among the stakeholder groups whose feedback and comments were sought, although ultimately no PwD registered for the research website. Dementia support or advocacy organisations, which were approached to help with the recruitment of people with dementia, were asked to act as gatekeepers and forward the invitation only to people who were known to have the capacity to consent or who could be supported during the research by a carer, family member, or friend.

In advance of any fieldwork, participants were provided with written information regarding the project. The participant information sheets, and consent forms (see appendices A-C) explicitly stated that participation was voluntary and that participants were free to withdraw at any time without giving a reason and without any further consequences. The information sheets and consent forms also outlined the data storage and anonymity arrangements. All interviewees were asked to sign two copies of the consent form (appendix A), one for their records and one for the research team. Participants for the online research indicated their consent upon registration for the website. All interviews were audio-recorded on an encrypted digital recorder, provided by SchARR, and the files were transferred securely to the SchARR Transcribers Group who have signed a nondisclosure agreement. Once the transcripts were returned, any identifiable information (i.e., names, places, etc.) was removed, and each interviewee was assigned a pseudonym to protect their identity. An anonymisation log was created and stored in an access-restricted folder on the University’s shared networked file store and destroyed at the end of the project. With the interviewees’ and online research participants’ consent, the anonymised interview transcripts and website comments have been archived at ORDA, the



University of Sheffield's data repository, to make them available for other researchers (Spann et al., 2021; 2022).

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# Part I

## Scoping Reviews

### I.a. Preface

The previous chapter provided insight into the development of the research project. Important reflections on the underlying research paradigm, the background and preconceptions of the researcher, and ethical considerations have been provided. Participatory design has been introduced as the methodological and ideological framework of this thesis.

The following two scoping reviews have been conducted at a very early stage of this project. The purpose of these reviews was to get a firm understanding of the research topic and to identify any gaps in the available literature. The first scoping review aimed to explore what is already known about the challenges carers face when combining work and care and what support and solutions have been identified to address these challenges. It contributed to the *exploring the problem* phase of the PD process. The review was not limited to dementia carers but included those caring for people of all ages with all kinds of long-term diseases or disabilities. The outcome was a conceptual framework which considers challenges which are the direct result of work-care reconciliation efforts (primary challenges) and challenges which result from intended solutions and support (secondary challenges). It is thus useful to consider potential consequences of intended solutions and support which can help to design better solutions in the future. The review revealed that high and unpredictable care needs and challenging behaviour on part of the person receiving care – often associated with caring for people living with dementia – can be particularly difficult for working carers. This insight has led to refocusing the remaining project from working carers in general to working carers of people with dementia. What follows in chapter 3 is the accepted version of the full article: Spann, A, Vicente, J, Allard, C, Hawley, M, Spreeuwenberg, M, de Witte, L. (2020): Challenges of combining work and unpaid care, and solutions: A scoping review. *Health & Social Care in the Community*. 28: 699– 715, which has been published in final form at <https://onlinelibrary.wiley.com/doi/10.1111/hsc.12912>. This article may be used for non-commercial purposes in accordance with the Wiley Self-Archiving Policy [<http://www.wileyauthors.com/self-archiving>].

The first review demonstrated that technology plays a part in supporting working carers. However, it is often merely a sidenote and not explored in more depth. The purpose of the second scoping review thus was to identify any literature, both academic and grey, that focused on working carers and explored technologies of any kind to support them. The conceptual framework developed in the first scoping review was used to explain what technologies were used for and what potential shortcomings (secondary challenges) have been identified. This review contributed to the *exploring the solution* phase of the PD process and is published as Spann, A, Vicente, J, Abdi, S, Hawley, M, Spreeuwenberg, M, de Witte, L. (2022): Benefits and barriers of technologies supporting working carers—A scoping review. *Health & Social Care in the Community*. 30: e1– e15. <https://doi.org/10.1111/hsc.13421>.

The insight gained from these scoping reviews significantly shaped the design of the remaining studies, particularly the interview study presented in part II. The decision to focus on working carers of people with dementia rather than on working carers in general and the inclusion of the issue of autonomy at work are the most significant results from the work on these scoping reviews.

#### I.b. Rationale

The growing importance of evidence-based practice in health and policy resulted in a dramatic increase in the number of published systematic reviews (Dixon-Woods et al., 2006). Apart from giving practitioners and policymakers quick and easy access to up-to-date knowledge, a systematic review allows researchers to have a good understanding of their field of research and can help to identify any gaps in the evidence base (CRD, 2009; Seers, 2015; Umscheid, 2013). There is a plethora of methods to synthesise knowledge from a variety of primary sources, differing for example in the kind of question they want to address, whether their source material is homogeneous or their approach to assessing the quality of reviewed material (Whittemore et al., 2014). One of the newer methods for evidence synthesis is the scoping review, first described by Arksey and O'Malley (2005). This method can be used to summarise and characterise an emerging or established field of research and is particularly useful as it allows to synthesise heterogeneous source material, including academic and grey literature (Colquhoun et al., 2014). The two scoping reviews conducted for this thesis are presented in chapters 3 and 4. The following section I.c. provides additional and more detailed information on the stakeholder consultations presented in sections 3.2.3 and 4.2.3 as part of the accepted manuscripts of the two scoping reviews which have since been published.

#### I.c. Stakeholder consultations

The methodological framework of the scoping review includes stakeholder consultations as an optional final step (see table 1 on page 48 for an overview of the complete scoping review framework) (Arksey

& O'Malley, 2005; Davies et al., 2009). The purpose of these consultations is to “*add value, additional references and valuable insights*” (Davies et al., 2009, p. 1388) from experts in the field. A total of four stakeholder consultations (two in the UK and two in the Netherlands) and two one-on-one consultations with experts (both in the Netherlands) were held between October and December 2018, after the data analysis had been completed for both scoping reviews. Participating stakeholders were members of carer support organisations and academics who specialised in studying and/or working with carers (N=12). During these consultations, the findings of the reviews were presented in two separate presentations. After each presentation stakeholders were asked whether these findings were in alignment with their personal and professional knowledge and experiences and whether they would like to add anything. Stakeholders were also asked of their opinions on the conceptual framework presented in chapter 3.3.2, i.e., whether it was understandable, useful, and representative of their understanding of the issue. Stakeholders were generally in agreement that the findings represented their own knowledge and experiences with the challenges working carers face, confirming the findings of the first scoping review. Their comments and suggestions greatly improved the design and presentation of the conceptual framework. Stakeholders agreed that the framework was a valuable and useful way to conceptualise carers’ challenges and available support and solutions aiming to address these challenges. The few stakeholders that had knowledge of and experience with technologies for working carers confirmed the findings of the second scoping review and highlighted how little was known at the time about that topic and how urgently further research was needed. Finally, discussions with stakeholders influenced the construction of the interview topic guide (see appendix G).

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### 3. Challenges of combining work and unpaid care, and solutions: A scoping review

#### **Abstract**

The number of people who combine work and unpaid care is increasing rapidly as more people need care, public and private care systems are progressively under pressure and more people are required to work for longer. Without adequate support, these working carers may experience detrimental effects on their wellbeing. To adequately support working carers, it is important to first understand the challenges they face. A scoping review was carried out, using Arksey and O'Malley's framework, to map the challenges of combining work and care and solutions described in the literature to address these challenges. The search included academic and grey literature between 2008 and 2018 and was conducted in April 2018, using electronic academic databases and reference list checks. Ninety-two publications were mapped, and the content analysed thematically. A conceptual framework was derived from the analysis which identified primary challenges (C1), directly resulting from combining work and care, primary solutions (S1) aiming to address these, secondary challenges (C2) resulting from solutions, and secondary solutions (S2) aiming to address secondary challenges. Primary challenges were: A) high and/or competing demands; B) psychosocial/-emotional stressors; C) distance; D) carer's health; E) returning to work; and F) financial pressure. This framework serves to help those aiming to support working carers to better understand the challenges they face and those developing solutions for the challenges of combining work and care to consider potential consequences or barriers. Gaps in the literature have been identified and discussed.

**Keywords:** Working carers, unpaid care, challenges; support and solutions, conceptual framework, scoping review; international.

**Abbreviations:** PRC: person receiving care; HCP: healthcare professional; UK: United Kingdom.

#### **What is known about this topic:**

1. There are currently about three million working carers in the UK, and the number is increasing.
2. Combining work and care is a very complex, dynamic and diverse commitment.
3. If not properly supported, it can put carers' employment, relationships and wellbeing at risk.

#### **What this paper adds:**

1. This paper is the first to comprehensively map the international literature on working carers' challenges and solutions.
2. It introduces a conceptual framework which helps to better understand their challenges and how solutions can create additional challenges.
3. Several areas have been identified where more research is required.

#### 3.1. Background

Global population ageing and medical progress see more people, of all ages, living with increasingly complex care and support needs (Cohen et al., 2011; Foresight, 2016; WHO, 2015). Caring situations are usually very diverse and dynamic. Care needs can fluctuate and include everything from assistance

with activities of daily living (ADLs; i.e. personal hygiene, toileting, moving around, subsistence), complex instrumental activities of daily living required for an independent life (IADLs; e.g. medication management, shopping, preparing meals), social or emotional support, or monitoring health and safety in the home (Mlinac & Feng, 2016; NHS, 2010).

The 2008 financial crisis led to extensive austerity measures in the UK which affected the provision of home care and community-based services and access to publicly funded care (Deusdad, Pace, & Anttonen, 2016; Humphries, Thorlby, Holder, Hall, & Charles, 2016;). As fewer people receive publicly funded care, families are increasingly under pressure to bridge this gap in service provision. 6.5 million people, roughly 10% of the general population, currently provide unpaid care to an ill, frail or disabled family member, friend or neighbour in the UK (Carers UK, 2015; Kelly & Kenny, 2018). (In this article, the term “carer” refers to family members, friends or neighbours providing care unpaid. The terms “formal care” or “care worker” will be used explicitly to describe care provided by a person who is paid and formally employed.) This saves the economy £132bn per year which is near the total public spending on the National Health Service (Buckner & Yeandle, 2015). Most carers are of working age (NHS, 2010; ONS, 2011). According to the 2011 census, around 3 million people, about half the carer population, were combining caring for a loved-one with paid work (Carers UK, 2015). This number is expected to increase in the coming years as more people require care, less formal services are available or affordable to address their needs due to austerity, and more people are needed in the job market for longer to support an ageing society – especially women who provide care more often (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Round, 2017; Yeandle & Buckner, 2007).

Combining work and care is a very complex issue and can have massive impacts, both negative and positive, on carers’ mental and physical health, their relationships, and their employment (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). King and Pickard (2013) found that providing care for ten hours a week or more significantly impacted the likeliness of the carer to leave work. Carers UK (2019) have calculated that 600 carers on average left work to care every day over the past two years and total numbers of carers leaving employment have increased from 2.3 to 2.6 million since 2013. Giving up work not only affects the long-term financial situation of carers; it also negatively impacts the economy and the public purse. Lost tax revenue and increased spending on benefits to support unemployed carers cost the UK economy £1.7bn a year (Pickard, King, Brimblecombe, & Knapp, 2018). Additionally, there are costs to employers in terms of loss of skilled labour, recruitment, and training expenses (Carers UK, EfC, & DoH, 2013). Combining work and care should not be problematised in general as many carers want to do both. Caring can give them a sense of purpose, an opportunity to reciprocate and to support their loved-one in their hour of need (Bourke, Pajo, & Lewis, 2010; Eldh & Carlsson, 2011; Hamblin & Hoff, 2012). Work, on the other hand, is not merely a source of income but



offers them respite from caring, social support, and an opportunity for fulfilment outside of caring (Bourke-Taylor, Howie, & Law, 2011; Bruns & Schrey, 2012; Calvano, 2013). However, as both care and work can create significant demands on carers, it is essential that they receive the support they need to be able to fulfil both their roles without risking their own wellbeing.

Adequately supporting working carers requires a comprehensive understanding of the challenges they face, and which solutions can address them. This review thus aims to find out what is already known about the challenges of combining work and care and support or solutions which address these in the international literature and to identify any gaps. Although the knowledge base on working carers is steadily growing, there has been, to date, no comprehensive review to that end. Previous reviews have addressed specific solutions, namely workplace-based support and technology, or looked at the challenges of combining work and caring for an older person (Andersson, Erlingsson, Magnusson, & Hanson, 2017b; Calvano, 2013; Ireson, Sethi, & Williams, 2018). This review takes a more inclusive approach, not limiting itself to any specific solutions or age of people needing care. Furthermore, it includes both academic and grey literature, as some solutions might only have been reported on by non-peer-reviewed sources. This article does not discuss the role legislation and public policy could play in supporting working carers; this is discussed elsewhere, for example in Bouget et al. (2016), Jungblut (2015), Kröger and Yeandle (2013), Yeandle (2017) and Yeandle and Buckner (2017).

### 3.2. Methodology

The scoping review, first described by Arksey and O'Malley (2005), is a method for evidence synthesis of heterogeneous source materials. This method can be used to summarise and characterise an emerging or established field of research and is particularly useful as it allows to synthesise both academic and grey literature (Colquhoun et al., 2014). It typically starts out with a broad research question and is characterised by an iterative yet systematic approach to reviewing the literature (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Daudt, van Mossel, & Scott, 2013). The main steps are displayed in table 1.

*Table 1: Summary of the scoping review framework (adapted from Davis et al., 2009)*

<b>Stage 1</b>	<b>Identify the initial research questions</b> , determine which aspects of the question are particularly important to facilitate the most appropriate search
<b>Stage 2</b>	<b>Identify the relevant studies</b> , comprehensively answer the central research question(s) including any time, date, budget constraints and range of sources
<b>Stage 3</b>	<b>Study selection</b> , similar to systematic review but from the outset adopts greater flexibility with eligibility criteria, as familiarity with data progresses search terms may be redefined (iterative process)
<b>Stage 4</b>	<b>"Charting" the data</b> , takes a broader approach than data extraction in a systematic review. Uses a narrative descriptive-analytical framework method but does not attempt to "weigh" the methodological quality of evidence

<b>Stage 5</b>	<b>Collate, summarise and report the results</b> using a framework approach
<b>Stage 6</b>	Optional <b>consultation with key stakeholders</b> has the potential to add value, additional references and valuable insights

### 3.2.1. Constructing and running the search (stages 1-3)

A review protocol described the search strategy and operationalised the major concept. Table 2 presents the operationalised concepts which were used to create the search terms, as well as the corresponding inclusion and exclusion criteria.

*Table 2: Operationalised concepts and corresponding inclusion & exclusion criteria*

Concept	Explanation
Working carer	A person in paid work who provides unpaid care <sup>†</sup> for a relative, friend or neighbour; care is understood as providing assistance with ADLs (activities of daily living) and IADLs (instrumental activities of daily living) as well as social or emotional support and monitoring the health and safety of the cared for person; no restriction in terms of condition of the person receiving care (e.g. carers of stroke survivors);
Included	Unpaid or "informal" carers: no formal training; no monetary reimbursement*; carer is not employed with a care provider or hired by the care recipient or their relatives;
	Carer is in paid employment or self-employed or had to give up work to care; no restrictions in terms of work hours or workplace;
Excluded	Publication is focused on the challenges of combining work and care
	"Normal" childcare (bringing up a healthy child); short-term care (acute illness or accident); voluntary work; domestic work;
Needs	Publication doesn't focus on reconciling work and care
Solutions	What do working carers struggle with; how do they experience their dual responsibility; Holistic view: physical, emotional, social, financial (safety), esteem, self-actualisation needs;
Included	Interventions/ solutions/ strategies which have been identified to address their needs;
Excluded	Support carers currently receive or want (e.g. workplace interventions, technology, community initiatives, public or private care services, etc.);
Also excluded	Publications which only focused on government legislation or policy (e.g. carer leave schemes) <sup>‡</sup> ;
	Non-English publications; incomplete references; film or book reviews; protocols;

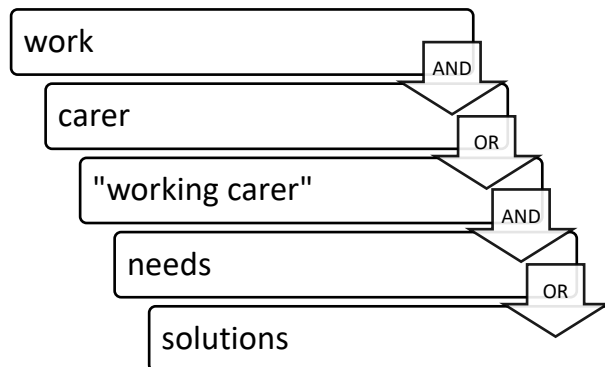
<sup>†</sup>In some countries, carers may receive carers allowance or people receiving care may support them financially. These carers are still considered "unpaid" as they are not in official employment of a care provider or the person they care for.

<sup>‡</sup>Due to the temporal and spatial context-specificity of government policies and legislation relevant for working carers (e.g. regulation of flexible work and care leave) it was decided that they fall outside the scope of interest.

A pilot search revealed that the search terms used to capture the "working carers" concept, consisting of terms used for "work" and "carer", were, by necessity, so broad and unspecific, that a large number of articles were picked up which used these terms in irrelevant contexts. Hence, to increase the

precision and relevance of the search, the “needs” and “solutions” concepts were incorporated and combined with Boolean operators. The search construct is displayed in figure 4<sup>4</sup>.

Figure 4: Search construct

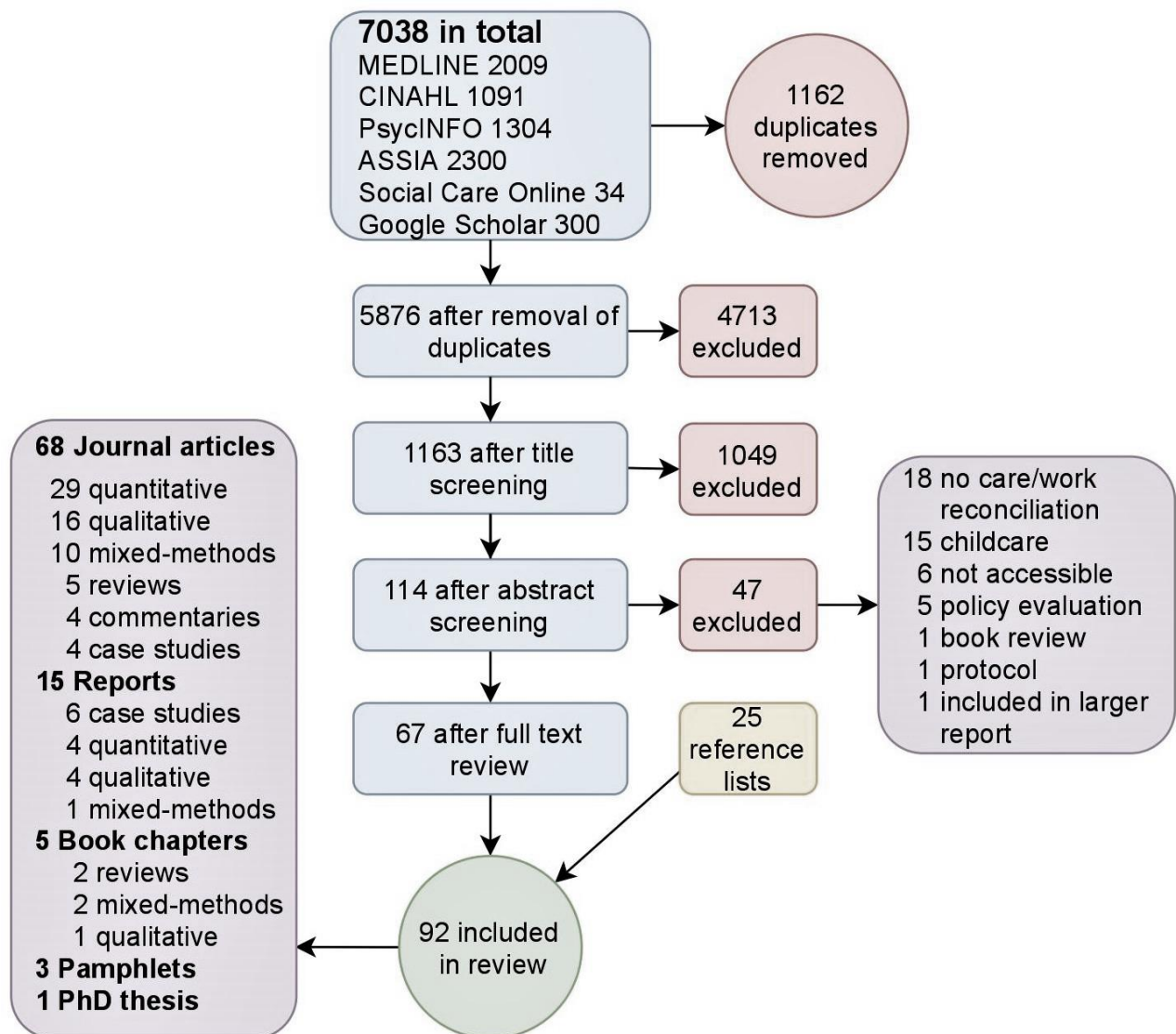


The search was conducted between 2008, the start of the financial crisis which contributed to austerity in the UK and increased the pressure on families to provide care in the community, and the day of the search, the 25<sup>th</sup> of April 2018 in the MEDLINE, CINAHL, PsycINFO, ASSIA, Social Care Online, and Google Scholar databases. It was limited to literature published in English and, where possible, restricted to papers with an

available abstract. This search identified a total of 6738 publications (The term “publications” is used hereafter to refer to both peer-reviewed articles published in academic journals and grey literature, i.e., non-peer-reviewed research reports, book chapters, theses, pamphlets). After removal of duplicates, the references were imported into MS Excel for the screening of titles and abstracts. The titles were screened to eliminate publications which did not focus on working carers and to formulate the eligibility criteria (see table 2 and decision tree in appendix D). A second reviewer screened the titles independently to validate the developed eligibility criteria and to ensure that they were employed consistently. The weighted Cohen’s Kappa was 0.62, indicating substantial inter-rater agreement (Landis & Koch, 1977). This process reduced the eligible publications to 1163, which either addressed combining care and work explicitly or where this could not be ascertained from just the title. The abstracts of these 1163 publications were again screened by both reviewers (Kappa=0.65) which developed the eligibility criteria further. A third reviewer resolved any disagreements. The 114 publications remaining after this stage of the screening process were read in full by the first reviewer, which excluded 47 publications. Screening the reference lists of the remaining 67 identified 25 publications which were added to the final selection. Figure 5 depicts the search process.

<sup>4</sup> The numbering has been adjusted for this thesis to ensure consistency

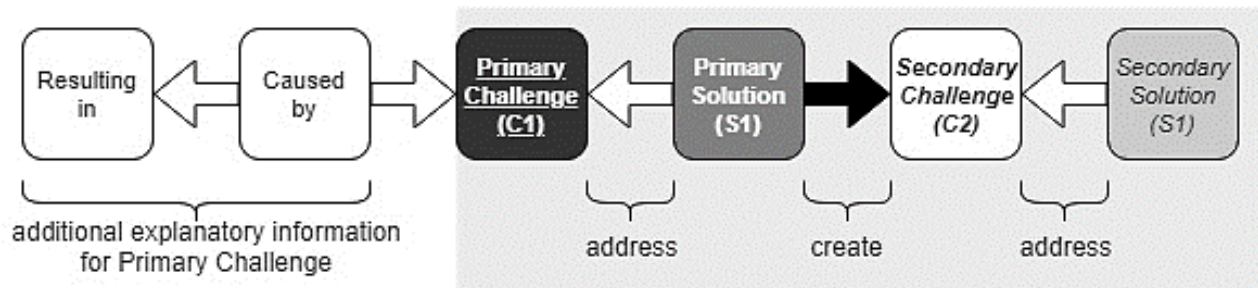
Figure 5: Flowchart of the search process



### 3.2.2. Data analysis/synthesis (stages 4&5)

The selected publications were charted to capture their key aspects. Information charted includes authors, date of publication, study location, study design and discipline as well as more specific information including research aims, carers and people receiving care (see appendix E). NVivo Pro 11 software was used for thematic analysis of the included publications. Relevant content, namely any information relating to challenges of combining work and care and solutions and support, was analysed inductively. The result was a framework which is illustrated in figure 6.

Figure 6: Illustration of the conceptual framework of primary and secondary challenges and corresponding solutions/support



### 3.2.3. Stakeholder consultations (stage 6)

As per Davis, Drey, and Gould's (2009) suggestions, stakeholder consultations have been held to get feedback on the findings of the review. Discussions have been held with members of carer support organisations and academics specialised on carers in the Netherlands and the UK between October and December 2018. Ethical approval and consent from stakeholders were not required as they were approached solely to validate the findings of the review and provide feedback on the structure, design, usability and ease of use of the developed framework.

## 3.3. Results

### 3.3.1. Description of the included publications

Of the included publications, 68 were journal articles: 29 quantitative, 16 qualitative, 10 mixed-methods studies, five reviews, four commentaries, four case studies. Of the 15 reports, six were case studies, four each were qualitative and quantitative, and one was mixed-methods. Five book chapters were included: two reviews, two mixed-methods and one qualitative study. Additionally, three pamphlets and one quantitative PhD thesis were included in the analysis. Studies had been conducted in a variety of disciplines, including health sciences, social sciences, psychology, business studies, and economics. The majority originated from North America (n=46), followed by Europe (n=31), Australasia (n=6) and Asia (n=5), as well as four multinational studies. Regarding the cared-for person, 39 publications focused on older people, ten on adults, 12 on children with special needs, eight on a combination thereof, and 23 did not specify this. It should, however, be noted that authors used different age-limits to define these groups. The complete data chart is presented in appendix E.

### 3.3.2. Conceptual framework of challenges and solutions

During analysis, it became clear that the relationship between the identified challenges and solutions was not straightforward. The conceptual framework illustrated in figure 6 resulted from this observation. **Primary Challenges (C1)** incorporate challenges which originate directly from combining

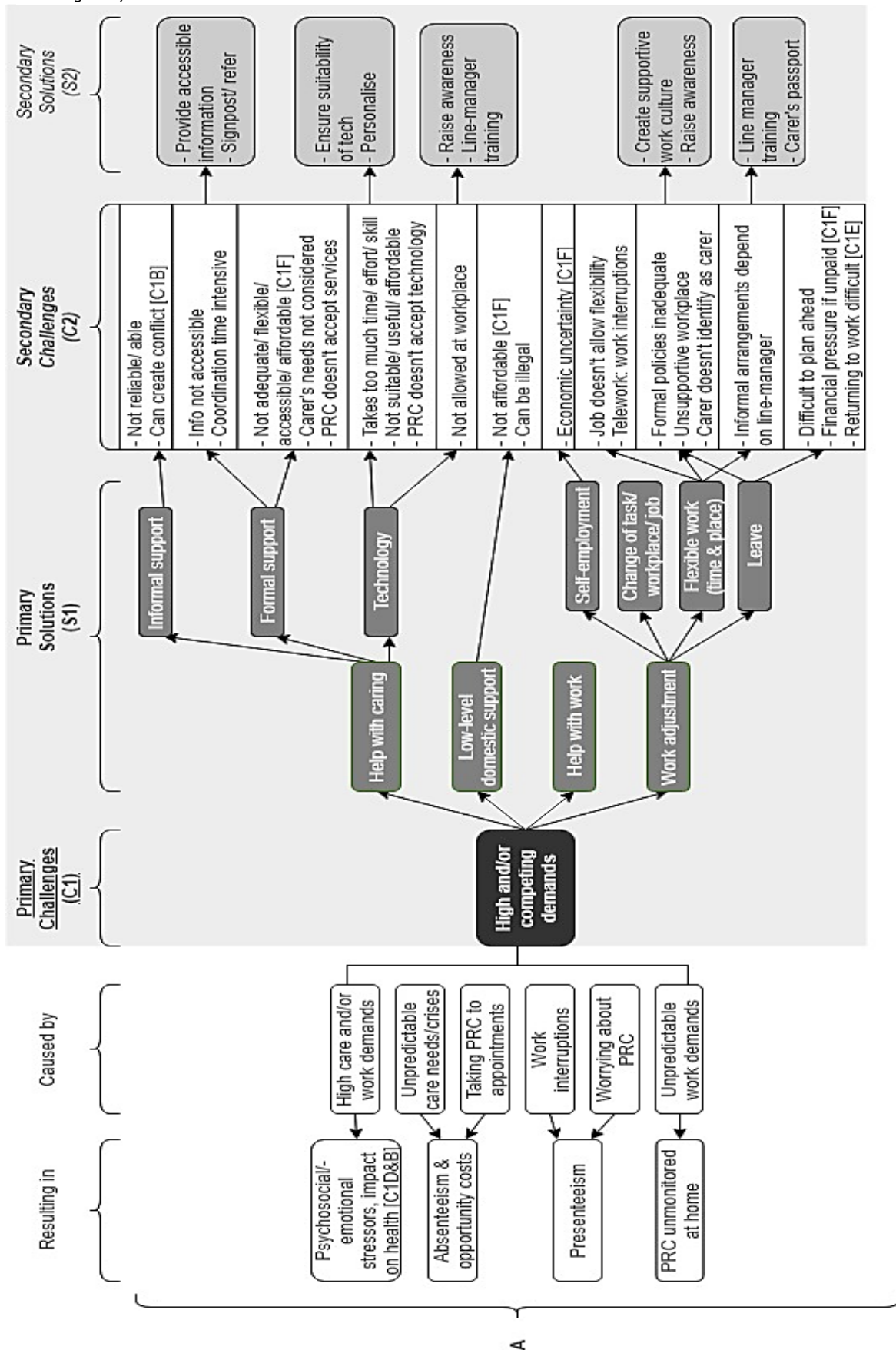
work and care. These are A) high and/or competing demands; B) psychosocial/-emotional stressors; C) distance; D) carer's health; E) returning to work; and F) financial pressure. Additional explanatory information for Primary Challenges include causes and consequences and are presented on the left side of the diagram. **Primary Solutions (S1)** describe solutions or support which aim to address Primary Challenges. Some of these can create additional challenges for carers (**Secondary Challenges, C2**), mostly resulting from accessibility issues. In a few cases, *Secondary Solutions (S2)* are described which aim to address Secondary Challenges.

The order in which Primary Challenges are now presented, together with a diagram, does not represent prioritisation and it should be noted that combining work and care is a dynamic effort. Consequently, carers might experience different, and indeed multiple, challenges from one day to the next and their priorities for solutions may change accordingly. The framework will not be representative of every working carer's individual experience but rather represents an abstract generalisation onto which challenges individual carers face and solutions which aim to address these can be mapped.

### 3.3.3. Thematic findings

#### **C1A) High and/or competing demands**

Figure 7: Application of the framework for Primary Challenge C1A "High and/or competing demands" (PRC= person receiving care)



Caring created particularly **high demands** if the cared-for person required time-intensive care,

especially at night, had to be monitored constantly to ensure their safety and survival, was severely limited in their mobility or exhibited demanding behaviour. Cohabitation often increased the pressure on carers' time, making them feel that they were never "off-duty". Paid work too created high demands, especially if it required long work hours. Added up, these demands left little time to take care of personal needs including health [see C1D] and spending time with friends and family, leading to a decline in the quality of relationships and isolation [see C1B]. **Competing demands** arose when the work interfered with caring and vice versa. Unpredictable, fluctuating care needs, and emergencies were one significant source of these demands leading to absenteeism as the carer unexpectedly had to stay home or leave work to attend to the cared-for person. Caring could also compete with work if the carer had to take the cared-for person to medical or similar appointments. Although these could be scheduled in advance, carers still had to take time off as consultations often coincided with their work time. The resulting absenteeism could have a detrimental impact on carers' career prospects or ability to remain in work. Constantly worrying about the safety and wellbeing of the person they cared for and exhaustion could lead to presenteeism, meaning that carers were not able to concentrate and work productively. Care-related presenteeism also occurred when carers were continuously interrupted at work by calls of the cared-for person or members of their care network, or when they had to coordinate appointments or services with restricted business hours. Carers often incurred opportunity costs. For example, they were unable to participate in job training, networking opportunities, or company events relevant for their career progression were unavailable for overtime or business trips or felt unable to accept promotions because they feared that they would not be able to cope with the additional demands and responsibilities. Work could also create unpredictable demands such as unplanned extra-shifts or overtime. This could lead to difficulties with the care arrangement and could result in the cared-for person being unmonitored or unsupported at home.

**Help with caring**, either providing "hands-on-care" (assisting with ADLs and IADLs), monitoring the cared-for person's wellbeing or taking them to appointments, was identified as a very valuable solution for carers, enabling them to concentrate on work. **Informal** help was provided by family members, friends, or neighbours. Sometimes, their **ability to care could be limited**, for example if care needs were so complex that they required special training or if care needs persisted over a long time, leading to the loss of informal support if members of the care network moved to a different place, became too old to provide care or died. Some carers experienced their **informal support as unreliable**, predominantly where siblings cared for their ageing parents [see C1B]. This could lead to difficulties in distributing care-related information and conflict over how best to provide care and share responsibilities.



**Formal** services were either privately funded or provided by the community (e.g. home care services, day-care centres, meals-on-wheels, and transportation services). Schools played an important part in the support of children with special needs. Carers often found that **information on availability, accessibility, and entitlement was hard to obtain**. This and the fact that service provision was often fragmented made it very **difficult and time intensive for them to organise and coordinate** the support they required. *Providing easily understandable information and signposting or referring* to available services was highly valued support. Some employers provided these services on their company intranets, organised information and networking events, provided carer-specific assistance through their EAPs (employee assistance programme), or employed case managers who provided personalised assistance and information. Charities or publicly accessible websites too could help carers to identify and coordinate services by informing them directly or connecting carers to peers and enabling them to share information online. Carers often found that formal services, where they lived, were **inadequate for their needs** or unavailable. This problem appeared to be particularly prevalent for carers living in rural areas and carers of children with special needs, especially if they suffered from rare or “invisible” conditions that affected behaviour (e.g. autism, attention deficit hyperactivity disorder). Cultural norms could also determine the availability of support and societies that traditionally saw caring as a personal matter made it harder for carers to receive help. Services which had been sought to enable carers to work could thus create additional demands as carers were often contacted at work when problems arose that these services were not qualified to handle. Some services were **unaffordable** or could increase financial pressure [see C1F] and publicly-funded services were **not always accessible** due to strict eligibility criteria. Many carers also found services **did not consider their own needs** and were **not flexible** enough, specifically regarding business-hours, which often conflicted with carers’ work hours. This meant that they had to come to work late or leave early, especially if there was no suitable transport available to bring the cared-for person to services and back home. Carers who were themselves healthcare professionals (double-duty carers) often felt that they were viewed as a resource by service providers rather than someone seeking support. Even if carers finally found adequate help with caring, they might find that the **cared-for person did not accept** any outside help. Equally, some carers did not trust anyone else with caring for their loved-one or thought it would take too much time to delegate. Carers of terminally ill people, especially children, sometimes did not seek help with caring and decided to quit their job or take an extended leave of absence as they wanted to spend as much of the time they had left with their loved-one as possible.

**Technology** helped carers in different ways. Monitoring technology could reassure people needing care that help would be readily available, thus increasing their confidence to be more active and take care of their own needs. This could decrease the demand on carers. Additionally, monitoring the cared-for person while at work could offer peace of mind, allowing carers to concentrate on their work in the

knowledge that they would be notified if necessary. It was also used to communicate with their loved-one and to coordinate their care arrangement. Technologies could create additional challenges too, as carers and cared-for people were **required to have the necessary abilities and skills** to use them and it could **take a lot of time and effort** to operate them properly. Some carers found that technology, often offered to them by local authorities or healthcare professionals, was **unsuitable** for their needs, was too **expensive** or was **not accepted by the cared-for person**, highlighting the need to *ensure the suitability* of technologies and to *personalise* them for individual needs and preferences. Some carers found that technology created problems at work, for example, repeated phone calls could cause work interruptions. Some **employers did not allow their use** at work. *Training line managers and raising their awareness* as to why it is important for carers to have access to technology helped in some cases. Enabling carers to take **short breaks** from work to check on the person they cared for could also help carers to worry less and focus more on their work.

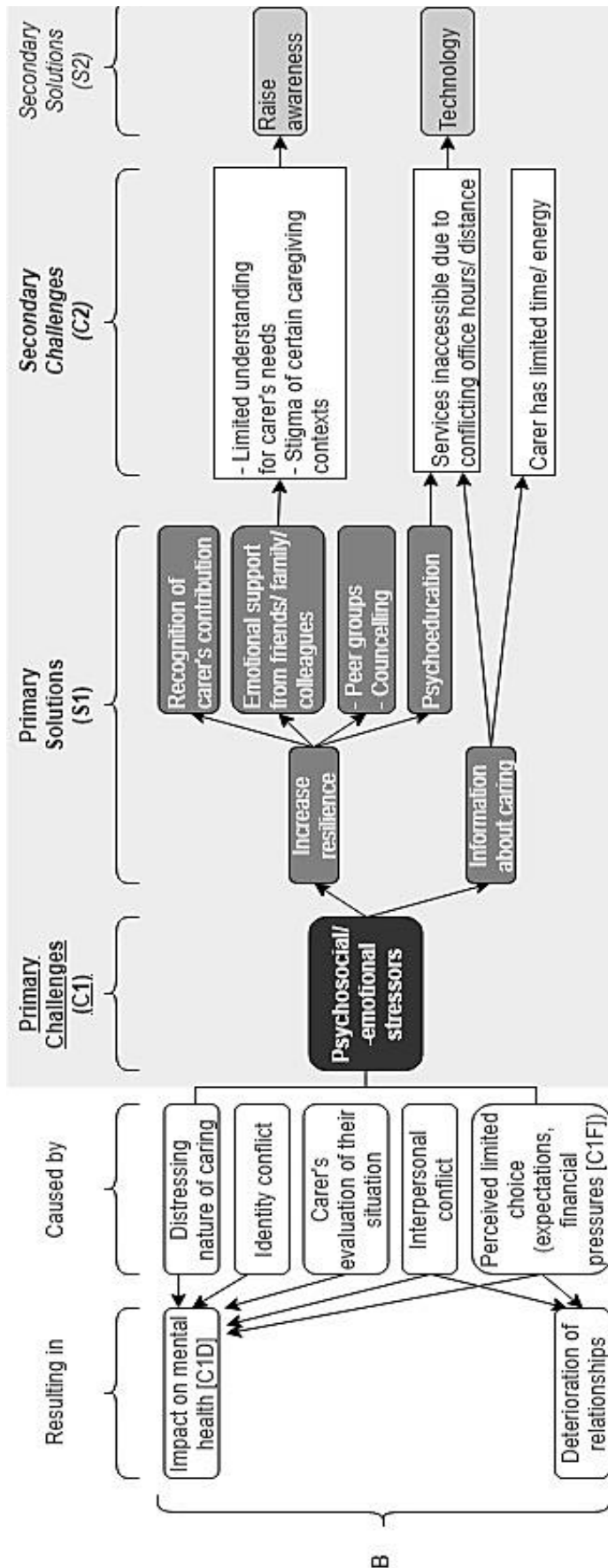
In some cases, **adjusting their work situation** was the only option carers had. Flexibility regarding their work hours, workplace and the ability to take leave when necessary without having to fear for their job were highly valued solutions. **Flexible work hours and the option to work from home** were of course **not always possible**. In some cases, employers found a different task or role for carers which allowed for more flexibility. Having no access to flexible work meant that some carers had to use sick or annual leave to be able to provide care. This could create or exacerbate health problems in the long run if carers could not use this time for their own needs [see C1D]. Working from home to tend to the cared-for person could be challenging as carers could find themselves distracted, **work interruptions** could occur, and they could feel guilty that they did not pay more attention to their loved-one. Some organisations developed different models and policies regarding flexi-time and **carer leave**, (e.g. paid or unpaid, emergency leave, differences in the number of days a carer can take leave). Due to the unpredictable nature of caring however, carers found it **difficult to plan ahead** and predict how long they would need leave for. Long-term leaves could make it **difficult to return to work** [see C1E] and unpaid leave could cause **financial difficulties** [see C1F]. Some workplaces, typically larger companies, had formal policies in place which regulated eligibility for flexible work and leave. Although these ensured equal access, **formal policies were often inadequate** or too rigid to address the needs of carers, especially if they were universal policies originally designed for parents of healthy children. *Raising awareness* of the diversity of caring situations and having a carer's champion in the workplace to lobby for the interests of carers was found to help improve these policies. An **unsupportive workplace** and the view that caring is a private rather than a public issue had an impact on the availability of support and meant that **carers often did not openly self-identify** and request support for fear of negative career consequences. They were also reluctant to talk about their caring role because they did not want to be seen as a "shirker" or getting special treatment or did not want to be

labelled, particularly in male-dominated workplaces. *Creating a supportive work culture* could enable carers to access the practical and emotional support they needed. Some carers worked hard to build up good relationships with co-workers so that they would **help them at work** and cover for them in case they needed to take time off to care. Smaller companies often preferred to make individual arrangements. While these could ensure greater flexibility and a better fit for the needs of the carer, these ***individual arrangements were also highly dependent on the line-manager/employer***. Line-managers were often described as gatekeepers to workplace support and carers could feel indebted or obliged to work extra hard to reciprocate. Some carers experienced a loss of the support they had individually arranged with their line-manager if they had to change departments inside the company or if they got a new line-manager. Thus, some companies developed a *carer's passport* (which lists the support a carer had been able to negotiate) and provided line-manager training to sensitise them to carer issues. Some carers found that the only way for them to reconcile work and care was to ***change their task, workplace or job***. Having to change job was challenging for carers as they often had no time for the job search or feared that future employers might not offer the flexibility they required. Restricted employment opportunities were particularly problematic for rural carers. **Self-employment** theoretically provided a maximum of flexibility and autonomy. However, it could mean ***financial uncertainty*** and increased pressure to work as they had no access to many employment rights and benefits. They were thus particularly vulnerable to care-related work interruptions which could harm their business development.

**Low-level domestic support**, for example, help with shopping, housework or looking after their children while they were at work or caring was a big help for some carers. In some countries, carers employed migrant care workers to help them with looking after the cared-for person. This could be considered semi-formal help with caring as these care workers were paid but often not officially employed or adequately trained. This form of support was ***not affordable*** for everyone as care workers lived with the cared-for person 24 hours a day. These care workers were not always officially employed or even registered which ***could be illegal*** in some countries.

### **C1B) Psychosocial/-emotional stressors**

Figure 8: Application of the framework for Primary Challenge C1B  
 "Psychosocial/-emotional stressors" (PRC= person receiving care)



Carers often faced several **psychosocial/-emotional stressors**. Caring could be very distressing, especially when carers had to deal with their loved-one being in pain or displaying difficult behaviour (e.g. children with behavioural disorders or older people with dementia). Some people described the gradual decline of their ageing parents and the reversed parent-child roles as very confusing and distressing. Fluctuating care needs too caused stress as carers found it difficult to plan ahead. End-of-life care was upsetting not only because of the loss of their loved-one but also because it could mean the sudden loss of state support and benefits, which could push carers into an existential crisis on top of an emotional one [see C1F]. Apart from financial difficulties, cultural or familial expectations limited carers' perceived choice whether they wanted to be more involved in caring or work and was strongly related to gender and the relationship with the cared-for person. Filial piety in many Asian countries expects children to care for their parents when they age. There was generally a greater expectation of women to provide care which could make it difficult for male carers to talk about their caring role and get the support they needed. Family and personal expectations played an important part in determining roles and responsibilities and often depended on the type and quality of the relationship with the cared-for person. While spouses typically assumed the caring role without question, decisions regarding involvement with caring for a parent were often not straightforward for

siblings. Proximity, both emotional and locational, was a factor in this, as was employment status. Those with no job or greater opportunities for flexibility were expected to take on the role of main carer. This was also the case for siblings who worked in the (health-) care sector (double-duty carers). Parents of children with special needs usually negotiated roles and responsibilities, some finding more rigid role assignments and some sharing them more equally. Some, particularly double-duty carers, had difficulties with their identity. They were unsure whether they were primarily carers or workers and had trouble prioritising one role or the other, although women, especially mothers often prioritised caring. Double-duty carers additionally had trouble separating their professional carer role from their informal one, causing confusion and uncertainty. Conflict was an additional source of distress. Relationships with friends and family, which could be an important source of emotional and instrumental support, often suffered due to the carer's lack of time and attention. Family members who were only peripherally engaged with caring could create conflict when they criticised the carer or tried to interfere with the care arrangement. Caring could sometimes exacerbate underlying family conflicts. The cared-for person could create conflict if they rejected the care arrangement, made additional demands on the carer's time, were unappreciative or generally had a difficult relationship with the carer. Conflict at work could arise from negative attitudes of employers and co-workers with a limited understanding of the carer's situation. Carers' own evaluation of their situation could further impact their psycho-emotional well-being. They often described feeling guilty for having to prioritise work over care and vice versa. Many also expressed resentment for the situation they were in and feelings of being abandoned and not appreciated for what they contributed. Carers sometimes struggled with their confidence, many doubting their ability to successfully combine work and care, feeling that they were unprepared and did not know enough about caring, or perceiving themselves as unreliable at work.

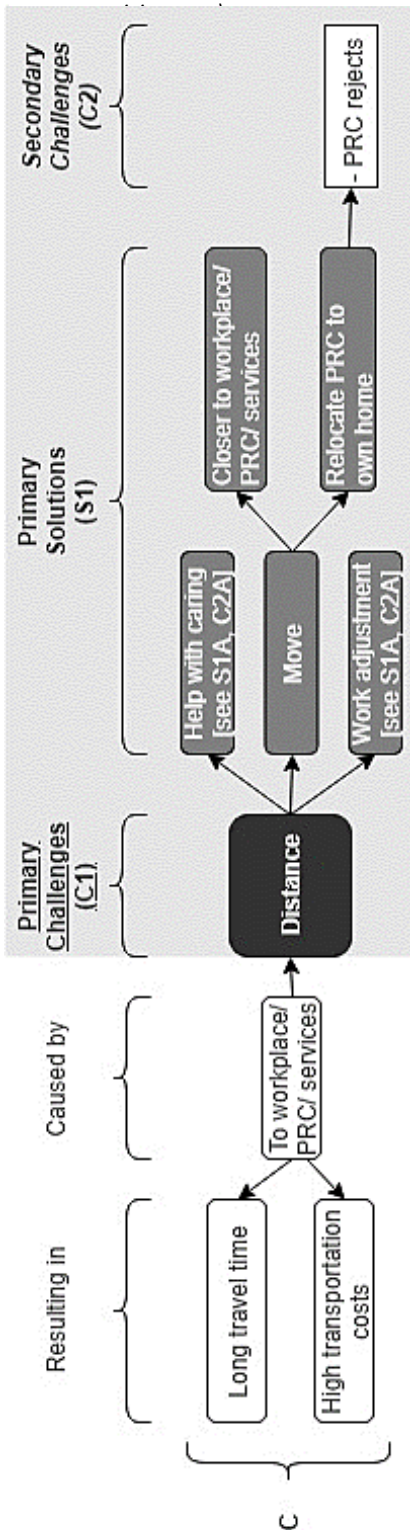
**Increasing carers' resilience** was seen as very helpful and several strategies have been identified to that end, such as **emotional support**, often provided informally by friends, family and colleagues. A supportive culture at work had a massive impact on carers' wellbeing. Often, however, carers found **limited understanding for their needs** and concerns and the **stigma associated with some caregiving contexts** meant that this form of support was not always very effective. *Raising awareness* on a societal level could lead to greater understanding for carers and eliminate stigma. **Peer groups** in the community and at work, both online and in the physical world, created a safe space and helped carers share their experience and get support from people in similar situations. **Counselling**, either privately organised or provided at the workplace, also helped people get emotional support and increase their resilience. On top of enabling them to access required support, **recognition of their contributions** by their families and society made carers feel better about their situation.

**Psychoeducation** by professionals or specifically developed programmes helped carers to increase their resilience, confidence and self-efficacy, develop organising and coping skills, and deal with personality traits such as perfectionism. These programmes could help carers change their attitude towards their situation and focus on the positive aspects of caring, improving their wellbeing. Some found that caring gave them a purpose and were proud and grateful that they were able to support their loved-one. Others found strength in their faith or culture. Psychoeducational programmes delivered in a community peer group setting were often ***inaccessible due to conflicting office-hours or distance***. *Technology* was a solution, delivering these programmes via web-based platforms.

Receiving personalised **information about caring** and targeted advice could increase carers' confidence in their abilities. This information was provided directly by healthcare professionals, case managers employed by their workplace, information events organised by employers, or peers. Getting the required information could be challenging for carers due to ***limited available time and energy*** and some services were ***inaccessible due to conflicting office-hours or distance***. *Technology*, dedicated websites and discussion fora, can provide these services independent of time and location.

#### **C1C) Distance**

Figure 9: Application of the framework for Primary Challenge C1C "Distance" (PRC=



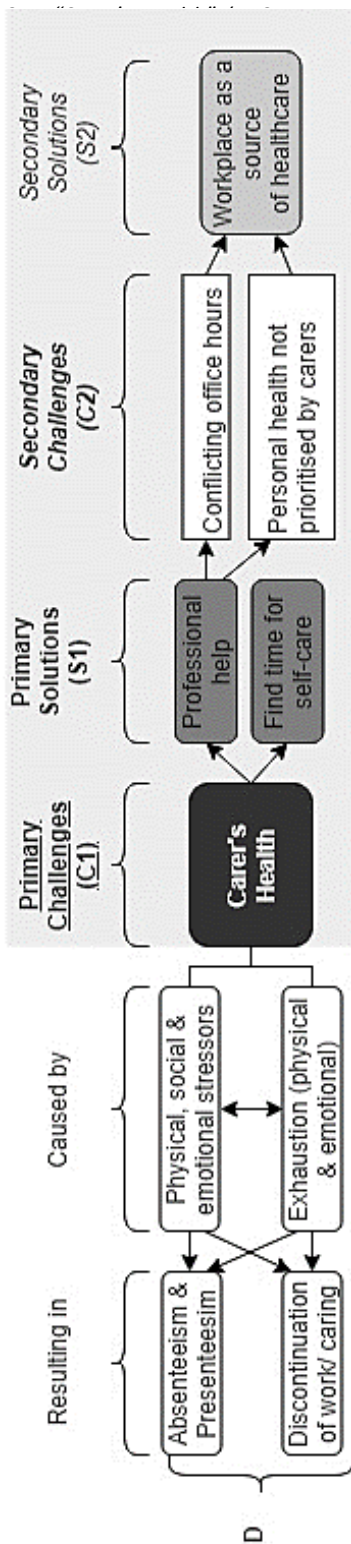
Challenges arose from the physical distance between the workplace and place of residence of the cared-for person. Having to travel between these places and their own home could take up a lot of time and travel costs could start to add up [see C1F]. If services were used to help with caring, e.g. day care centres, the distance between those, workplace and place of residence could also create difficulties, especially if there was no adequate transportation for the cared-for person and business-hours conflicted with carers' work hours. This meant that they were often late for work or had to leave early. Distance was an important aspect to consider regarding carers' ability to respond to emergencies at home. Carers who worked and lived at a substantial distance from the person they cared for found that commuting daily was not possible. Caring at a distance, their role was primarily the management of any care arrangement they had organised. This could be very time-intensive and difficult, as they were not able to solve arising issues or respond in person to emergencies. Carers experienced feelings of guilt as they were not able to be more present for their loved-one. Constantly worrying and investing a lot of time in care management could result in presenteeism. Many carers saved up their vacation or weekends, which they might have needed for recreation, to travel to the cared-for person.

**Help with caring** could be a solution for carers, as were **work adjustments** [see S1A]. Some long-distance carers found that they had to **move** so that they lived closer to either the person they cared for, the services they needed to help with caring or their workplace. **Relocating the cared-for person** into their own home could present another solution, but **they could reject** this idea, and even if they did not, cohabitation could mean greater potential for interpersonal conflict [see C1B].

#### C1D) Carer's health

**Carers' health**, physical and mental, had a big impact on their ability to work and care. Health problems might have already existed before they started caring or developed because of chronic physical and emotional exhaustion. Carers often described having trouble to get enough sleep. Being unhappy with

Figure 10: Application of the framework for Primary Challenge



their current situation or worrying about their future and their loved-one caused them sleepless nights. Caring could also disrupt sleep, for example, some carers of people with dementia reported continuous calls as their loved-one was disoriented or lonely or monitoring equipment they used kept them awake (e.g. bed sensor alarms). This chronic exhaustion could lead to decreased productivity at work and increase the risk of accidents or mistakes. It could also result in carers having to take sick leave.

Seeking medical or **professional help** would be important but many carers **did not prioritise their personal health** as caring for their loved-one did not leave them enough time. **Conflicting office hours** of professionals posed an additional access restriction. The *workplace could be a valuable source of healthcare* through occupational health services and initiatives which aimed to increase the wellbeing of workers, such as yoga or relaxation classes. Some carers also made an effort to **find time for self-care** which could range from spending time with friends to “pampering” or even just a few minutes every day for themselves.

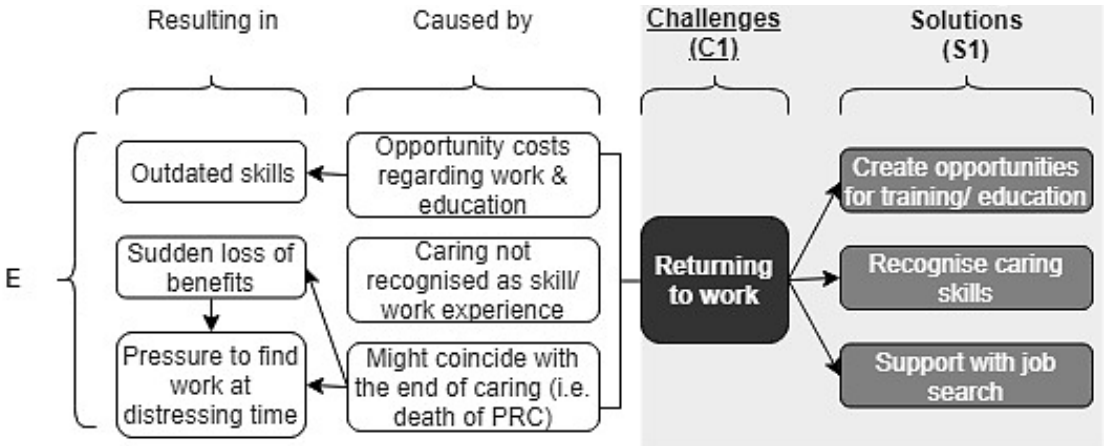
#### C1E) Returning to work

**Returning to work** or finding a job was difficult for carers who had had to leave work or had never had a job due to their caring responsibilities. Carers expressed concerns about the gap in their career and that their skills had become outdated. People who had become carers early in life might have experienced opportunity costs regarding their education. This could have long-term consequences on their careers as well as their confidence. Some carers expressed dismay that caring was not recognised as a skill in the job market. Additionally, returning to work might only be possible when caring ends, which might mean the death of the cared-for person. This could be a very distressing time and the sudden



loss of benefits received to support caring could create enormous additional pressure for carers in mourning to find work quickly.

Figure 11: Application of the framework for Primary Challenge C1E “Returning to work” (PRC= person receiving care)

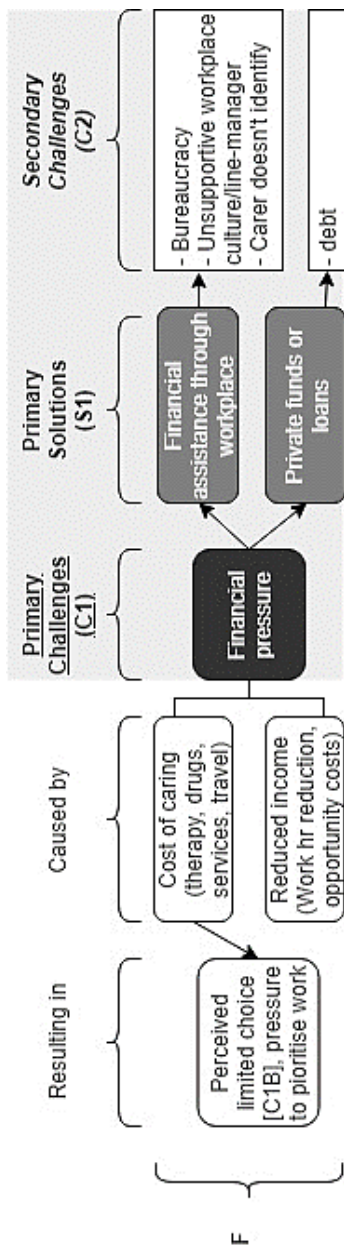


**Creating opportunities for training and education**, sensitive to the interests, needs, and resources of carers, as well as the needs of the job market, were very helpful for carers looking for work. Access to further and higher education and support in developing ambitions and perspectives for their careers and lives were important for young carers. Work placements specifically designed for carers helped people gain valuable job experience and on-the-job training which could be organised around their caring responsibilities. Some employers, particularly in markets where qualified labour was in short supply, played a crucial part in enabling carers to return to work by maintaining close contact to their (former) employees and including them in job training. Many carers desired the **recognition of caring skills** (e.g. social skills, management skills) on the job market and valued support to identify their skills. Carers looking for work after a long absence might profit from **support with the job search**, building up skills, confidence and self-efficacy, helping with CV writing, and job interview training. Supporting carers to develop business ideas and transition into self-employment was also mentioned as a potential solution.

**C1F) Financial pressure**

**Financial pressure** was a frequently mentioned problem. Travel costs for long-distance carers, therapies, and especially care services could add up substantially. Some carers had to reduce their work hours to meet the needs of the cared-for person, which meant a reduction of income. Having to take unpaid leave or exit the job market meant that carers often had no income at all. This could also impact on their pension entitlements and insurance protection. Many carers thus felt that they had no choice but to work even though they needed more time to care which could affect their health [see C1B&D]. Some carers had to use up their **private funds or take out loans** to meet the costs and often incurred **debt**.

Figure 12: Application of the framework for Primary Challenge



Some workplaces provided financial assistance in the form of benefits, special insurance schemes or subsidised care services. An **unsupportive workplace culture or line-manager** limited the accessibility of these solutions as carers did not feel confident to ask for them or **did not identify as carers**. **Bureaucracy** also restricted access to financial assistance.

### 3.4. Discussion

This paper comprehensively reviewed the challenges of combining work and care and solutions described in the literature to address these challenges. The outcome is a conceptual framework which serves to better understand the complexity of work-care reconciliation. The framework links challenges to potential solutions while also highlighting any consecutive challenges which can potentially arise from these solutions. The framework can thus be used by those supporting or developing support for working carers to better understand their needs and potential shortcomings or barriers to solutions.

The analysis revealed that the workplace as a source of both challenges and support appears to be relatively well researched and understood. Flexibility regarding work hours and workplace, as well as the ability to take leave when required, were essential for carers. This reflects findings from a recent Carers UK (2019) report which identified flexible work and paid care leave as the second and third most desired solutions for working carers. However, flexible work was not always possible or accessible if the organisational culture or line-managers were unsupportive. Many carers were unwilling to self-identify at work

because they feared negative career repercussions, making workplace carer support inaccessible. Ireson et al. (2018) investigated available workplace carer support in different sectors and found organisational values an important factor, determining availability and accessibility. Similarly, a supportive line-manager/employer was the most desired solution identified by Carers UK (2019). The importance of autonomy and social support at work to mediate the effects of high job demand on emotional wellbeing has been described in the job demand-control and job demand-control-support models (Johnson & Hall, 1988; Karasek, 1979). There is a gap in the literature regarding different levels of autonomy at work – particularly regarding work schedule, working from home and taking breaks – and how these impact on the challenges carers face and the solutions and support they can access.

Flexible work does not automatically mean autonomy over one's work schedule. Working from home too warrants closer examination. Kossek, Lautsch, and Eaton (2006) found that teleworking could decrease work-family conflict if workers employed adequate boundary management, but their study did not focus on carers who might find boundary management more difficult. Additionally, more research is needed to understand the challenges of self-employed or gig-working carers and those on zero-hour contracts.

High caring demands, taking up too much time and energy and impacting on productivity, and unpredictable care needs, making it difficult to plan ahead, were identified as important challenges by many working carers, irrespective of the age or condition of the cared-for person. It appeared that the kind of care need (e.g. constant monitoring, challenging behaviour) and the amount of time spent caring had a substantial impact on carers' ability to remain in work. Pickard et al. (2018) too established a connection between time spent caring and security of employment, stating that providing ten hours of care or more per week put carers' employment at risk. In the reviewed publications, a significant difference between caring for a child with special needs and caring for an adult was the availability of adequate formal and informal help with care. Parents of children with special needs, especially mothers, appeared to find it more difficult to find suitable help and were often faced with stigma (Bourke-Taylor et al., 2011; Brennan, Rosenzweig, Jivanjee, & Stewart, 2016; Bruns & Schrey, 2012; Chou & Kröger, 2014; Home, 2008). It is likely that cultural context influences the availability of support, particularly cultural assumptions regarding the role of a mother and family in general, the responsibilities of the state, and the visibility and acceptance of illness and disability in society. The degree to which societies see care as a public or private issue reflects cultural norms and attitudes regarding family and is manifested in their arrangements and legislation regarding social care. Accordingly, countries which view care as a family issue tend to have low public involvement whereas countries which see it as a public responsibility provide either financial support, which can be used to finance privately organised care or publicly funded services (Bettio & Plantenga, 2004). A closer investigation of potential differences when combining work and care for a child or adult with special needs in different cultural contexts could contribute to a greater awareness for the necessity of solutions to be sensitive to different caring situations.

Carers' health, appraisal of their situation, and coping strategies were important in their ability to manage work and care. Cultural norms and expectations as well as interfamilial and -personal dynamics impacted on this. Interventions that aimed to increase carers' resilience and improve management and coping strategies were seen as beneficial to increase carers' psycho-emotional well-being. Carers often described a lack of care-related knowledge. Despite potentially positive impacts of increased knowledge on caring, Alzheimer's Research UK (2015) found that, sometimes, knowing more

about the condition of their loved-one and their prognosis can interfere with carers' coping strategies. It might be helpful in such cases to provide information in connection with professional or peer support. Additionally, a cultural shift would be required that no longer views carers as a resource but acknowledges their contribution and enables them to access the solutions and support they need to care, work, return to work, and fulfil their own life goals. Finally, technology has been mentioned by many publications as playing a part in support for working carers, although often only as a side-note. More research is needed to understand which and how technology can help people to better combine work and care.

This review has several strengths and limitations. The search was not limited regarding work and care context and includes publications from different cultural settings, providing a broad view on challenges and solutions of combining work and care. Limiting the search to English, however, could have limited further understanding. Influential carer support organisations such as Carers UK produce research which is not published in peer-reviewed journals but provides invaluable insight into issues relevant for working carers. Including grey literature in the analysis is thus a distinct strength of this review. However, it comes at the price of not being able to assess the quality of included publications due to their diversity, although this is not necessarily required for a scoping review (Pham et al., 2014). Another limitation of the scoping review methodology is that it does not allow the measurement of effect sizes and provides limited opportunities for direct comparison of findings of different studies. Thus, although including diverse work and care contexts in this review provides a more inclusive view on working carers' challenges, statements regarding the specific nature of the challenges which arise from these different caregiving contexts are limited. The feedback from stakeholder consultations on content and design was invaluable in constructing the conceptual framework from very complex data.

### 3.5. Conclusion

This review provides a framework which links challenges of combining work and care with potential solutions and serves to highlight additional challenges resulting from these solutions. Owing to the diversity of caregiving contexts and available solutions, reconciling work and care is often a very complex effort. When aiming to support working carers it should be considered whether the offered solution is accessible to carers, whether it could create additional challenges for carers and whether and how other stakeholders such as the cared-for person, employers, and members of the care network are impacted.

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### **ii. Conflict of Interest statement (for all authors)**

All of the authors confirm that they have no competing interests.

### **iii. Funding or sources of support in the form of grants, equipment, drugs etc**

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### **iv. Authors' contributions**

AS took the lead in developing the review protocol. MH and LdW reviewed and approved the protocol. AS and JV screened and selected the relevant articles and resolved disagreements by discussion and seeking opinion from CA, MH, MS and LdW. AS extracted and analysed the data and drafted the manuscript. MH, MS and LdW contributed significantly to the subsequent drafts and the final manuscript. All authors reviewed and approved the final manuscript. 2

### **v. Ethics approval and consent to participate**

N/A

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## 4. Benefits and barriers of technologies supporting working carers – A scoping review

### **Abstract**

Combining work and care can be very challenging. If not adequately supported, carers' employment, wellbeing and relationships may be at risk. Technologies can be potential solutions. We carried out a scoping review to find out what is already known about technologies used by working carers. The search included academic and grey literature published between January 2000 and June 2020. Sixteen relevant publications were analysed and discussed in the context of the broader discourse on work-care reconciliation. Technologies discussed can be classified as: a) web-based technologies; b) technologies for direct communication; c) monitoring technologies; and d) task-sharing tools. Technologies can help to make work-care reconciliation more manageable and alleviate psychosocial and emotional stress. General barriers to using technology include limited digital skills, depending on others to use technologies, privacy and data protection, cost, limited technological capabilities, and limited awareness regarding available technologies. Barriers specific to some technologies include work disruptions, limited perceived usefulness, and lacking time and energy to use technologies. More research into technologies that can address the needs of working carers and how they are able to use them at work is needed.

**Keywords:** Working carers, employment, technology, scoping review, barriers, benefits.

**Abbreviations:** HCP: healthcare professional; ICT: information and communication technology

### **What is known about this topic:**

1. About 15% of all adults in paid work in Europe have unpaid caring responsibilities.
2. If not properly supported, combining work and care can put carers' employment, relationships, and wellbeing at risk.
3. Technology plays a part in most peoples' lives but is rarely considered as a solution to support working carers.

### **What this paper adds:**

1. The majority of studies about technologies to support working carers focus specifically on web-based technologies, leaving other types of technologies underexplored.
2. Technology can be beneficial for working carers; however, barriers to accessing and using technology need consideration.

#### 4.1. Background

Prior to the ongoing COVID-19 pandemic, around 16% of the European working-age population had provided unpaid care to a frail, sick or disabled family member, friend, or neighbour (Eurofound, 2015) – a number which has since increased dramatically (Carers UK, 2020; Power, 2020; United Nations, 2020). This unpaid care work is of substantial economic value; for example, Buckner and Yeandle (2015) estimated that unpaid care saves the UK economy roughly the same amount as total annual public spending on their National Health Service (~£132 billion). More than half of the European carer population currently combine unpaid care with paid work, meaning that about 15% of all people in

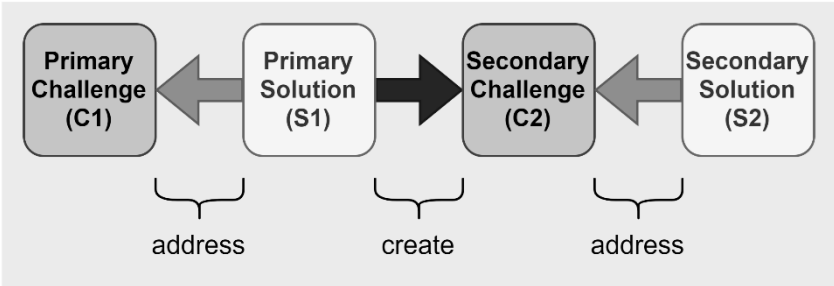
paid work are so-called “working carers” (Carers UK, 2019; Eurofound, 2015). Even before the COVID-19 pandemic, this number was expected to increase as more people require care, fewer formal services are available or affordable due to public funding constraints, and more people are needed in the job market for longer to support an ageing society – especially women who provide care more often (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Round, 2017; Yeandle & Buckner, 2007). Juggling caring and work can have substantial impacts on carers’ health, relationships, and employment (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). According to King and Pickard (2013), providing care for ten or more hours a week significantly increases the likelihood of a carer dropping out of the labour market. This negatively impacts on carers’ long-term financial situation, the labour market in terms of loss of skilled or experienced labour, and the economy and the public purse (Carers UK, EfC, & DoH, 2013; Pickard, King, Brimblecombe, & Knapp, 2018). Work can offer a stable income, respite from providing care, and social support (Bourke-Taylor, Howie, & Law, 2011; Bruns & Schrey, 2012; Calvano, 2013). Caring is often seen as an opportunity to reciprocate, support a loved one in need, and gain a sense of purpose (Bourke, Pajo, & Lewis, 2010; Eldh & Carlsson, 2011; Hamblin & Hoff, 2012). However, to avoid negative impacts on carers’ wellbeing, they must receive the support they need to be able to fulfil both roles.

4.1.1. Challenges faced by working carers

4.1.1.1. Conceptual framework of working carers’ challenges and solutions

We recently conducted a comprehensive review on carers’ work-care reconciliation challenges and potential solutions for them (Spann et al., 2020). That review resulted in the development of a conceptual framework that connects challenges to their potential solutions and highlights that solutions can create additional challenges (see figure 13). The framework is a useful tool for those supporting or developing support for working carers to better understand the complexity of work-care reconciliation, identify carers’ needs, and recognise potential shortcomings or barriers to solutions.

Figure 13: Conceptual framework of challenges and solutions of combining work and care (adapted from Spann et al., 2020).



Challenges directly originating from combining work and care are conceptualised as Primary Challenges (C1). Primary Solutions (S1) refer to solutions or support aiming to address Primary Challenges. Secondary Challenges (C2), in turn, can arise from these solutions – most of them resulting from accessibility issues – while Secondary Solutions (S2) aim to address these Secondary Challenges.

#### *4.1.1.2. External challenges*

External Primary Challenges usually arise when work and care demands are in direct conflict, forcing carers to prioritise one over the other. In our previous review (Spann et al., 2020), we classified these as C1A, high and/or competing demands; and C1C, distance. Fluctuating and unpredictable care needs, worrying about the cared-for person's safety and wellbeing when at work, and having to manage care from a distance, can lead to work interruptions, loss of productivity, and absenteeism. Unpredictable work demands such as overtime or extra shifts can make it more difficult to manage caring. S1 include receiving help with caring – both paid/formal and unpaid/informal – adjusting one's work situation (e.g., reducing work hours, requesting flexible work arrangements, looking for a more flexible job, or becoming self-employed), taking leave from work, and using technology. All these solutions can create additional challenges (C2), including the time-intensive coordination of the care network, information about support and how to access it being hard to obtain, an unsupportive workplace, and formal care services being inadequate, unaffordable, or not accessible.

Carers who delayed their entry into the job market or who must take leave from work for care-related reasons might find it difficult to return or find a new job (C1E) due to having a gap in their résumé and finding their skills and knowledge insufficient or outdated. S1 include providing accessible opportunities for training and education, recognising caring skills on the job market, supporting carers to look for a new job or develop their business ideas, and enabling carers on leave to stay in close contact with their workplace.

Many carers face financial pressure (C1F) resulting from care-related expenses or having to reduce work hours, take on more flexible but lower-paid work or having to take unpaid leave or even exit the job market. S1 include financial assistance like benefits, special insurance schemes or subsidised care services provided by the workplace or government (Bouget, Spasova, & Vanhercke, 2016; Eurofound, 2015; Kröger & Yeandle, 2013; Yeandle & Buckner, 2017; Yeandle, Wilson, & Starr, 2017). C2 include carers not self-identifying, thus not seeking or making use of available financial support, or bureaucracy.

#### *4.1.1.3. Internal challenges*

We found that internal Primary Challenges arise from the psychosocial-emotional experience of combining work and care (C1B) (Spann et al., 2020). They are often caused by interpersonal conflicts

at the workplace, with the cared-for person or the care network, identity conflict, the distressing nature of caring, lacking confidence in their care skills and knowledge, perceiving themselves as unreliable at work, and carers' general evaluation of and perceived limited choice in their situation. These psychosocial and -emotional stressors can lead to or exacerbate existing health concerns (C1D), especially if they persist over a long time and are inadequately addressed. S1 aim to strengthen carers' resilience by providing information and advice on caring, emotional support, and psychoeducational programmes to help carers develop better coping and self-management skills and build up their confidence and self-efficacy. Finding time for self-care or seeking professional help for physical or mental health problems is also beneficial. C2 can result from carers not prioritising their wellbeing, having no time or energy to seek and engage with this kind of support, or services being inaccessible due to distance or conflicting business hours.

#### 4.1.2. Review aim

Our previous review demonstrated that technology plays a part in supporting working carers – although it is often merely a sidenote in a broader discussion about support for working carers and rarely explored in depth (Spann et al., 2020). The present review takes a closer look at the role technologies play. A growing body of research addresses technology for carers (Bergström & Hanson, 2017; Smith, 2008; Sriram, Jenkinson, & Peters, 2019; Wasilewski, Stinson, & Cameron, 2017). However, little is yet known about whether and how carers use these technologies to reconcile work and care, and how work impacts carers' experiences with technology. Andersson, Erlingsson, Magnusson, and Hanson (2017b) reviewed research using Information and Communication Technologies (ICTs) to support working carers. Their review, however, was restricted to carers of older family members and included articles that did not focus exclusively on working carers. Furthermore, technologies were restricted to ICTs, although a broad definition was used. Our review aimed to identify literature, both academic and grey, that explores the use of electronic and/or digital technologies of any kind to support working carers. Our focus is on identifying which technologies working carers used and on understanding their experiences with them, i.e., which benefits they derived and which barriers to accessing and using the technologies they encountered. Furthermore, we aim to situate our findings in the general discourse around work-care reconciliation. These broad questions necessitate a wide-ranging and exploratory yet systematic review approach, best accomplished by the scoping review methodology (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Daudt, van Mossel, & Scott, 2013). To understand technologies in the complex context of the challenges working carers face, we will relate our findings to the findings of our previous review (Spann et al., 2020), using our conceptual framework as an analytic aid.



## 4.2. Methodology

Our research follows Arksey and O'Malley's (2005) scoping review approach, a method for evidence synthesis of diverse source material, including grey literature. It can be used to summarise and characterise an established or emerging field of research, thus highlighting gaps in existing evidence (Colquhoun et al., 2014). The main steps of the scoping review are displayed in table 3.

Table 3: Summary of the scoping review framework (adapted from Davis, Drey, & Gould, 2009)

<b>Stage 1</b>	<b>Identify the initial research questions</b> and determine which aspects of the question are particularly important to facilitate the most appropriate search.
<b>Stage 2</b>	<b>Identify the relevant studies</b> to comprehensively answer the central research question(s) and consider any time, date or budget constraints and range of sources.
<b>Stage 3</b>	<b>Select studies</b> systematically but allow for flexibility with search terms and eligibility criteria which may be redefined as familiarity with the data progresses (iterative process).
<b>Stage 4</b>	<b>"Chart" the data</b> , using a narrative descriptive-analytical framework method. Do not attempt to "weigh" the methodological quality of the evidence (broader approach than data extraction in a systematic review).
<b>Stage 5</b>	<b>Collate, summarise and report the results</b> using a framework approach.
<b>Stage 6</b>	Optional <b>consultation with key stakeholders</b> has the potential to add value, additional references and valuable insights.

### 4.2.1. Constructing and running the search (stages 1-3)

The operationalised major concepts used to construct the search and the corresponding eligibility criteria are displayed in table 4. Search terms used to capture the "working carers" concept, consisting of terms used for "work" and "carer", were connected to search terms for the "technology" concept using the Boolean operator AND. The "technology" concept was intended to be as comprehensive as possible. We indexed all potentially relevant electronic and digital technologies and translated them into search terms. Potentially relevant technologies were identified from key publications and consultations with technology scholars. Publications (referring to both peer-reviewed and non-peer-reviewed literature) were eligible if they focused on working carers or had at least a distinct section or chapter on working carers, and if they mentioned any kind of technology in either the title or abstract. A pilot search in the Web of Science database found a very high number of publications using terms relating to "work" and "caring" in an irrelevant context. Therefore, after consultation with a librarian,

we decided to limit the “working carers” concept to the titles to ensure that identified publications were more relevant to the research question.

Table 4: Operationalised concepts and corresponding inclusion and exclusion criteria

Concept	Explanation
Working carer	A person in paid work who provides unpaid care <sup>†</sup> for a relative, friend or neighbour; care is understood as providing assistance with ADLs (activities of daily living) and IADLs (instrumental activities of daily living) as well as social or emotional support and monitoring the health and safety of the cared-for person; no restriction in terms of the condition of the person receiving care (e.g. carers of stroke survivors);
Included	Unpaid or "informal" carers: no formal training; no monetary reimbursement <sup>‡</sup> ; carer is not employed by a care provider or hired by the person receiving care or their relatives;
	Carer is in paid employment or self-employed or had to give up work to care; no restrictions on working hours or workplace;
	Publication is focused on the challenges of combining work and care
Excluded	“Normal” childcare (bringing up a healthy child); short-term care (acute illness or accident) <sup>‡</sup> ; voluntary work; domestic work;
	Publication does not focus on reconciling work and care
Technology	Technology is understood as any electronic and/or digital solution and can refer to both hardware and software;
Included	Any electronic and/or digital technologies used in the context of combining work and care
Excluded	Non-electronic and/or -digital technologies
	Technologies that are not used in the context of combining work and care
Also excluded	Non-English publications; incomplete references; film or book reviews; protocols;

<sup>†</sup> In some countries, carers may receive a carers allowance or people receiving care may support them financially. These carers are still considered “unpaid” as they are not in the official employment of a care provider or the person they care for.

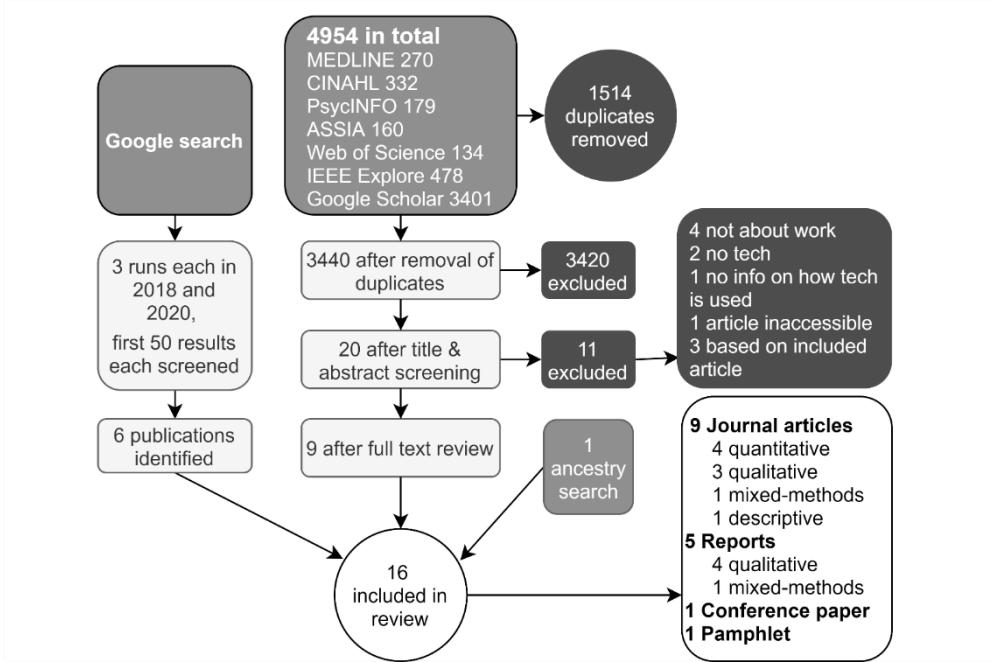
<sup>‡</sup> Short-term care may also lead to work disruptions. However, these disruptions are usually confined to a relatively short time with a foreseeable end and thus tend to have fewer long-term implications for carers’ career, health, relationships, and financial stability.

The search was conducted in the MEDLINE (biomedical literature), CINAHL (nursing and allied disciplines), PsycInfo (psychology), Web of Science Core Collection (science, social science, arts and humanities), ASSIA (sociology), IEEE Xplore (technology) and Google Scholar (multidisciplinary) databases. As Google Scholar restricts the number of search terms that can be used in one search, multiple searches had to be run to cover all technology search terms used in the other databases – for each of these searches, the first 100 results were extracted. The final search was conducted between May 30<sup>th</sup> and June 4<sup>th</sup>, 2018 and updated between June 8<sup>th</sup> and 15<sup>th</sup> 2020. It was limited to English and restricted to literature published after the year 2000, as the pilot search revealed no relevant literature before that. We also conducted an ancestry search of eligible publications and “standard Google” searches. Google searches are not generally part of the scoping review methodology. However, many organisations supporting carers and people needing care commission or conduct research which we aimed to capture through the standard Google searches. We constructed three separate runs, using the most relevant search terms identified from the eligible publications. For each of those runs, the first 50 results were screened for relevance.

An example search string used in MEDLINE and the search terms used in the “standard Google” search are supplied as supporting information (appendix F).

The search identified a total of 4954 publications, which were imported into EndNote referencing software and screened for duplicates. Titles and abstracts of the remaining 3440 publications were screened independently by AS and JV, thereby ensuring the consistent application of the eligibility criteria (see table 4). A Kappa of 0.82 was achieved, indicating a very high agreement (Landis & Koch, 1977). Any disagreements were resolved by SA. A total of 20 publications were identified from the academic databases, eleven of which were excluded after full-text review: two were conference abstracts whose corresponding full-text journal article was among the selected publications; one was a book chapter based on an included article; one was inaccessible, and the remaining seven were excluded because they did not fit the scope of the review or provided insufficient information on how technology was used. This left nine publications to be included in the final selection. One further publication was identified through the ancestry search and six through the Google searches. Figure 14 displays the flowchart of the search process.

Figure 14: Flowchart of the search process



4.2.2. Data analysis/synthesis (stages 4&5)

Key aspects of the selected publications were charted using a data extraction sheet which was adapted throughout the process. General information (i.e. authors, date of publication, study location, study design), as well as more specific information including research aims, methods, and results were mapped. NVivo Pro 11 software was used to enable thematic analysis (Braun & Clare, 2006). We first

coded information about the kind of technology used and its intended purpose, and carers' perceived benefits of using the technology. We then related our findings to the broader context of the work-care reconciliation discourse to understand what Primary (C1) or Secondary (C2) work-care challenges these technologies provide solutions for. For that, we used the conceptual framework we developed (Spann et al., 2020) and described in the background section of this paper. Lastly, we analysed information on the perceived shortcomings of technologies or barriers to using them.

#### 4.2.3. Stakeholder consultations (stage 6)

Stakeholder consultations were conducted with members of carer support organisations and academics who specialise in studying carers in the Netherlands and the UK (n=12) between October and December 2018. Ethical approval and consent from stakeholders were not required as they were approached solely to validate the findings of the review and provide feedback.

#### 4.3. Findings

Nine of the included publications (56%) were peer-reviewed journal articles (JA) and seven (44%) non-peer-reviewed publications: five research reports (RR), one conference paper (CP) and one pamphlet (P) arguing for a technology-enabled future of care. Three journal articles were from Sweden, five from the USA, and one from the UK. All included reports originated from the UK, as did the pamphlet. The conference paper came from the USA. Five of the included publications focused exclusively on carers of older adults, three on carers of people with chronic conditions and/or people with cognitive impairment, and eight did not specify this. Table 5 lists the publications and their main attributes. Table 6 presents an overview of the findings which are now discussed in detail.

Table 5: Main attributes of publications

No	Reference	Pub. type	Country	Participants	Aim of Publication	Tech used/described
1	Andersson et al. 2016	JA, Qual.	SWE	HCPs operating tech for working carers of older people	describe nursing and support staff's experiences of using ICT for information, e-learning and support of working carers of older people	Web-based "Anhörigstödportalen" & "Gapet"; Tech for direct communication: email & SMS;
2	Andersson et al. 2017a	JA Qual.	SWE	Carers of older people (full time employed and seeking a job)	describe working carers' experiences of having access to web-based family care support network 'A good place' (AGP) provided by the municipality to support those caring for an older family member	Web-based "A Good Place (AGP)"; Tech for direct communication: email & SMS;
3	Andersson et al. 2019	JA Quant.	SWE	Carers of older people (65+ years); self-employed or in paid employment/ work	describe the perceived value of different forms of support among Swedish working carers of older people, with a focus on ICT-mediated support	Web-based, Monitoring Tech, Tech for direct communication
4	Arksey 2002	JA Qual.	UK	Employed, self-employed or in full-time education	explore the extent to which the needs of employees with caring responsibilities are supported in the workplace	Tech for direct communication: Telephone
5	Beauchamp et al. 2005	JA Quant.	USA	Carers of people with Dementia; employed at least part-time outside the home	evaluate the efficacy of a multimedia support programme delivered over the Internet to employed family carers of persons with dementia	Web-based "Caregiver's Friend: Dealing with Dementia"
6	Carers UK 2012a	RR Mixed	UK	Employed, no further specification	exploring in more detail the evidence and opportunities afforded by telecare and telehealth technologies and the barriers to greater take-up from the carer's perspective	Monitoring tech: Telecare & Telehealth
7	Carers UK 2012b	P -	UK	Not specified [chapter on technology & work]	survey the current landscape of technology for care and explore ways in which we can start to build a technology-enabled vision for the future of care	Web-based, Tech for direct communication; Monitoring tech; Task-sharing tools;
8	Carers UK et al. 2013	RR expert groups	UK	Employed, no further specification	explore ways in which carers can be supported to combine work and care	Monitoring tech: medication reminders; fall detectors
9	Jarrold and Yeandle 2009	RR Qual. & review	UK	50% in employment (special chapter on work & care)	carers' experiences of telecare	Monitoring tech: Telecare
10	Klemm et al. 2014	JA Quant.	USA	Carers of people with chronic diseases (full or part-time employed)	evaluate psychosocial outcomes in employed family carers of people with chronic disease, who participate in non-/actively in	Web-based: online support groups

					online support, and whether psychosocial outcomes differ based on the format of online group support	
11	Kuhn et al. 2008	JA Quant.	USA	Carers of older people with chronic diseases (employed in big corporations)	describe a pilot programme aimed at enhancing the self-efficacy and minimizing the distress of employees who care for relatives with chronic medical conditions	Web-based "Powerful Tools for Caregivers Online (PTC online)"
12	Mahoney 2004	JA Descript.	USA	Carers of older people with chronic disease or cognitive impairment (Low-status occupational workers were specifically targeted)	development and testing of an innovative telecare system designed to support working caregivers concerned about vulnerable adults or older adults at home	Web-based "Worker Interactive Networking (WIN)"; Monitoring tech: wireless sensors "Nursense"
13	Mahoney et al. 2008	JA Mixed	USA	Carers of older people (primarily "blue-collar" workers)	determine the feasibility of and receptivity to the first computerized workplace-based direct caregiver intervention and to assess the effects on businesses, working family caregivers, and their elderly relatives	Web-based "Worker Interactive Networking (WIN)"; Monitoring tech: wireless sensors "Nursense"; Tech for direct communication: email
14	Pickering and Thompson 2017	RR Qual.	UK	Employed, no further specification	raise the profile of working carer, the difficulties they encounter and the impact this has; develop approaches to supporting working carers; promote the positive outcomes of support; provide solutions for culture change and promote positive attitudes of employers; co-produce 'Top Tips' to help employers retain working carers;	Monitoring tech: panic alarms, GPS technology, fall detectors; Task-sharing tools: "Rally Round"; Web-based; Tech for direct communication: telephone
15	Wilson et al. 2018	RR Qual.	UK	Carers in semi-skilled; professional; skilled; and unskilled roles;	examine 'what works' in supporting carers to remain in or return to employment by testing a range of support interventions (technology among them)	Monitoring tech: Telecare; Task-sharing tools: "Jointly" & "Rally Round"; Tech for direct communication: phone or email;
16	Wingrave et al. 2012	CP Descript.	USA	Carers of people with cognitive impairment	examine the design of a smart carer support system and how it is extended in a new system to support working carers	Monitoring tech: sensors, Artificial Intelligence; smartphone

JA= journal article; RR= research report; P= pamphlet; CP= conference paper; Qual.= Qualitative Research; Quant.= Quantitative Research; Descript. = Description

Table 6: Overview of findings

Technologies used/described	Source	Purpose of technologies	Perceived benefits of technologies	Specific barriers	General barriers
<b>Web-based technologies†</b> Training, information & resources; Peer networks; Care data storage; (mentioned: "A Good Place (AGP)", "Anhörigstödportalen", "Gapet", "Caregiver's Friend: Dealing with Dementia", "Powerful Tools for Caregivers online (PTC online)", "Worker Interactive Networking (WIN)")	P [1], P [2], P [3], P [5], N [7], P [10], P [11], P [12], P [13], N [14]	<i>For care:</i> peer and professional support; psychoeducation; information on caring and available support; store and share care-related information.  <i>For work:</i> Stay connected to the workplace; flexible training;	<i>For external challenges</i> <ul style="list-style-type: none"> <li>Staying connected to the workplace</li> <li>Accessible information</li> <li>Care management</li> </ul> <i>For internal challenges</i> <ul style="list-style-type: none"> <li>Save time and money</li> <li>Improve resilience &amp; mental health</li> <li>Improve care relationship</li> </ul>	Work disruptions  No additional benefit perceived  Having no time/energy to use technology	Limited digital skills  Using technology depends on others  Cost  Privacy & data protection  Limited technological capabilities
<b>Technologies for direct communication</b> Telephone, email, SMS, video-call technology	P [3], P [4], N [7], P [13], N [14], N [15]	communicate with the cared-for person, peers, HCPs, care network and workplace; arrange appointments; coordinate care	<i>For external challenges</i> <ul style="list-style-type: none"> <li>Staying connected to the workplace</li> <li>Peace of mind</li> <li>Care management</li> </ul> <i>For internal challenges</i> <ul style="list-style-type: none"> <li>Save time and money</li> <li>Improve resilience &amp; mental health</li> <li>Improve care relationship</li> </ul>	Work disruptions	Limited technological capabilities  Limited awareness of technologies
<b>Monitoring technologies</b> Telecare (mentioned: personal alarms, fall detectors, medication reminders, various sensors, GPS technology), cameras and telehealth devices	P [3], N [6], N [7], N [8], N [9], P [12], P [13], N [14], N [15], N [16]	<i>Telecare and cameras:</i> ensure the cared-for person's safety at home; <i>Telehealth:</i> self-management of disease;	<i>For external challenges</i> <ul style="list-style-type: none"> <li>Peace of mind</li> <li>Decrease the demand on the carer</li> </ul> <i>For internal challenges</i> <ul style="list-style-type: none"> <li>Improve care relationship</li> </ul>	Work disruptions  No additional benefit perceived	Limited awareness of technologies
<b>Task-sharing tools</b> (mentioned: "Jointly", "Rally Round")	N [7], N [14], N [15]	coordinate and share care tasks; store and share care-related information; communicate with care network;	<i>For external challenges</i> <ul style="list-style-type: none"> <li>Care management</li> </ul>	No additional benefit perceived	Limited awareness of technologies

† web-based refers to websites or -portals; P Peer-reviewed; N Non-peer-reviewed.

#### 4.3.1. Description of technologies

The following grouping of technologies was derived from the analysis: a) web-based technologies, b) technologies for direct communication, c) monitoring technologies, and d) task-sharing tools. Web-based and monitoring technologies were referenced the most, each referred to in ten publications. Interestingly, most peer-reviewed publications were concerned with web-based technologies (Andersson, Erlingsson, Magnusson, & Hanson, 2017a; Andersson, Magnusson, & Hanson, 2016; Andersson, McKee, Magnusson, Erlingsson, & Hanson, 2019; Beauchamp, Irvine, Seeley, & Johnson, 2005; Klemm, Hayes, Diefenbeck, & Milcarek, 2014; Kuhn, Hollinger-Smith, Presser, Civian, & Batsch, 2008; Mahoney, 2004; Mahoney, Mutschler, Tarlow, & Liss, 2008). Monitoring technologies and technologies for direct communication were mostly discussed in non-peer-reviewed, and only in four peer-reviewed publications (Andersson et al., 2019; Arksey, 2002; Mahoney, 2004; Mahoney et al., 2008) and task-sharing tools only in non-peer-reviewed sources (Carers UK, 2012b; Pickering & Thompson, 2017; Wilson, Marvell, Cox, & Teeman, 2018).

#### 4.3.2. Perceived benefits of technologies

##### 4.3.2.1. *Technologies can make work-care reconciliation more manageable (external challenges)*

**Staying connected to the workplace:** Web-based technologies and technologies for direct communication can facilitate carers working remotely (S1 to C1A and C1C), enabling them to provide care while still staying connected to their workplace and participating in meetings and online training. This can also help carers return to work after a longer care-related leave (S1 to C1E) (Carers UK, 2012b).

**Peace of mind:** Monitoring technologies can give carers peace of mind that the cared-for person is safe and well when they cannot be physically present themselves (S1 to C1A and C1C) (Andersson et al., 2019; Carers UK, 2012a; Carers UK et al., 2013; Jarrold & Yeandle, 2009; Mahoney, 2004; Mahoney et al., 2008; Pickering & Thompson, 2017; Wilson et al., 2018; Wingrave, Rowe, & Greenstein, 2012). Andersson et al. (2019) found that the higher the work-care reconciliation conflict, the more carers value monitoring technologies. This was generally true for most kinds of support though, technological, or otherwise. Monitoring technologies include cameras, telecare, and telehealth. Telecare refers to technologies that help to keep an eye on the home and movements of the cared-for person. Some of these devices allow carers to view status reports of the collected data via web-portals (Mahoney, 2004; Mahoney et al., 2008) or on smartphones, using artificial intelligence to interpret the data (Wingrave et al., 2012). Telehealth devices allow carers to check on the health of the cared-for person from afar and alert healthcare professionals (HCPs) when measurements are unusual (Carers UK, 2012a).



Technologies for direct communication enable carers to check in with the cared-for person and care network and respond to any potential crises or alarms raised by monitoring technologies (Arksey, 2002).

**Decrease the demand on carers:** Monitoring technologies can decrease or eliminate the need for carers to continuously check in with the cared-for person (S1 to C1A and C1C). Additionally, they can increase the independence of cared-for people by providing reassurance that help is available if needed (Pickering & Thompson, 2017). Furthermore, telehealth can help slow down or halt disease progression and avoid adverse events (e.g., hospital admission), thus potentially preventing more demanding care in the future (Carers UK, 2012a, 2012b; Jarrold & Yeandle, 2009; Wilson et al., 2018).

**Care management:** *Task-sharing tools* can make it easier for carers to coordinate their care network and share information (S2 to C2A) (Andersson et al., 2016; Carers UK, 2012a, 2012b; Pickering & Thompson, 2017). Carers value using *web-based technologies* to store personal and care-related information which makes it easier to share and coordinate with HCPs (Andersson et al., 2016; Andersson et al., 2019). *Technologies for direct communication* enable carers to participate in medical appointments and care planning from a distance (S1 to C1A and C1C) (Andersson et al., 2019).

**Accessible information:** Community or workplace operated *web-based technologies* can provide easily accessible information on available support (e.g., care services, financial support, worker's rights) and how to access it (S2 to C2A and C2F) (Andersson et al., 2017a; Carers UK, 2012b; Pickering & Thompson, 2017). Andersson et al. (2019) found that carers particularly value information that can help them to have some rest and time for themselves, such as information on respite care.

#### 4.3.2.2. *Technologies can help with psychosocial/-emotional stress (Internal challenges)*

**Improve resilience and mental health:** *Web-based technologies* can provide information on caring in the form of peer-support groups and customisable care-related disease- or disability-specific educational resources (e.g., webinars, videos, podcasts, literature, and news items; S1 to C1B) (Andersson et al., 2017a; Andersson et al., 2016; Beauchamp et al., 2005; Carers UK, 2012b; Kuhn et al., 2008; Mahoney, 2004; Mahoney et al., 2008; Pickering & Thompson, 2017; Wilson et al., 2018). Carers UK (2012b) suggested that employers can provide this kind of information via their company's intranet. Carers also receive advice on caring and emotional support from peers and professionals via *technologies for direct communication* (Andersson et al., 2017a; Andersson et al., 2016; Andersson et al., 2019; Carers UK, 2012b; Klemm et al., 2014; Mahoney et al., 2008; Pickering & Thompson, 2017; Wilson et al., 2018). Andersson et al. (2016) stated that this kind of support can help to improve carers' mental health and prevent potential physical, mental, or emotional breakdown as carers can be reached earlier by HCPs (S1 to C1D). *Web-based psychoeducational courses* can reduce participants'

depressive symptoms and stress levels and improve their overall quality of life (Beauchamp et al., 2005; Kuhn et al., 2008; Pickering & Thompson, 2017). Klemm et al. (2014) found that *web-based* support groups, both professionally facilitated and peer-directed, can equally help carers to achieve this, but only if they participate actively. For some carers, self-identification as a carer and public expression of emotions are problematic. Andersson et al. (2019) found that 25% of carers in their study preferred to be anonymous when meeting other carers. *Web-based technologies* allow them to preserve their anonymity, as well as their autonomy and take charge of their individual needs for support and information (Andersson et al., 2017a; Andersson et al., 2016; Kuhn et al., 2008).

**Save time and money:** A distinct benefit of especially *web-based technologies*, and *technologies for direct communication*, is that they are available at any time and place (Andersson et al., 2017a; Andersson et al., 2016; Andersson et al., 2019; Beauchamp et al., 2005; Kuhn et al., 2008; Pickering & Thompson, 2017). This helps carers save time as well as money as they do not have to spend it on travel and resources but can access support – generally for free – online (S2 to C2B and C2D; S1 to C1F) (Beauchamp et al., 2005). However, Andersson et al. (2019) found that carers value *web-based* social support slightly less than community peer groups which they attributed to limited digital skills and the impersonal nature of online interaction. *Web-based* resources, however, are valued because they can be revisited at any time (Kuhn et al., 2008). Personalising and individually tailoring information and educational content can also help carers save time (Andersson et al., 2016; Beauchamp et al., 2005; Carers UK, 2012b). Carers appreciate websites that are either themed to ensure that they can access the information most relevant to their specific caring situation (e.g., specialised on dementia (Beauchamp et al., 2005) or chronic conditions (Klemm et al., 2014; Kuhn et al., 2008)) or receive access to closed specialised online peer-groups through their referring HCP (Andersson et al., 2017a; Andersson et al., 2016).

**Improve care relationship:** *Monitoring technologies* enable carers to check up on the cared-for person without having to call them all the time, reminding them of their dependence. These devices thus have the potential to improve the relationship between carer and cared-for person because conversations can revolve around more personal and meaningful topics (S1 to C1B) (Jarrod & Yeandle, 2009; Mahoney, 2004; Mahoney et al., 2008). Andersson et al. (2016) also highlighted that some people receiving care might feel guilty for or threatened by support services offered directly to carers. In this case, *web-based technologies* and *technologies for direct communication* may offer an unobtrusive way for carers to get the support they need without upsetting the cared-for person.

### 4.3.3. Perceived barriers to uptake of technologies

Despite the demonstrated benefits of technologies for working carers, they are no panacea. There are various barriers to accessing or using technologies, some general, some specific to certain technologies.

#### 4.3.3.1. General barriers

**Limited digital skills:** Carers' ability to use any kind of technology strongly depends on their confidence and digital skills (Andersson et al., 2017a; Andersson et al., 2016; Andersson et al., 2019; Mahoney, 2004; Pickering & Thompson, 2017; Wilson et al., 2018). Some carers, especially those with limited experience with digital technology, can be intimidated by the thought of having to use *web-based technologies* to access support or embarrassed by their lack of digital skills which can lead to avoidance (Andersson et al., 2017a; Andersson et al., 2016). Digital literacy also poses a barrier for HCPs expected to use web portals and webchats to offer advice and support (Andersson et al., 2016). Digital skills do not appear to be such a big barrier for *monitoring technologies*. In the study conducted by Carers UK (2012a) only 5% of carers who were unhappy with devices reported them as being too complicated. Regardless, Wilson et al. (2018) have highlighted the importance of ongoing technical support.

**Using technology depends on others:** *Monitoring technologies* often require active operation (e.g., wearing a device or activating it) by the person being monitored. Their ability to use technologies as intended determines whether they can fulfil their purpose. Inhibiting conditions mentioned were severely limited mobility or cognitive impairments which meant that people forgot to use devices or were frightened by sensor technologies that changed their environment and routines (Carers UK, 2012a; Jarrold & Yeandle, 2009; Wilson et al., 2018). The cared-for person may also reject technologies out of fear, distrust or perceiving them as unnecessary, intrusive, or dehumanising (Carers UK, 2012a; Jarrold & Yeandle, 2009; Wilson et al., 2018). In the study by Mahoney et al. (2008), carers' siblings opposed *monitoring technologies* for a parent, which the authors attributed to the acting out of historic sibling rivalries or conflicts. Moreover, an unsupportive workplace is a substantial barrier to carers' ability to use *technologies for direct communication, web-based or monitoring technologies* (Arksey, 2002; Mahoney, 2004; Mahoney et al., 2008). Mahoney et al. (2008) cited employers' concerns about data security, potential damage to IT equipment or increased demand on their IT support personnel, and potential loss of productivity through carers looking up information online or checking on monitoring technologies back home. Their research, however, demonstrated that these concerns were largely unfounded.

**Cost:** The cost of technologies, especially *monitoring technologies* and connected services, can be a substantial barrier to their uptake (Carers UK, 2012a, 2012b; Jarrold & Yeandle, 2009; Mahoney et al., 2008) and can exacerbate financial pressure on carers.

**Privacy and data protection:** Some carers are concerned about the protection of sensitive data that they share or store online via *web-based technologies* and are uncertain about what, and how much, personal information to reveal in online discussions with HCPs (Andersson et al., 2017a; Andersson et al., 2016). Especially for *monitoring technologies*, privacy is an important issue. Cameras are often rejected by carers as too intrusive (Mahoney, 2004; Mahoney et al., 2008; Wingrave et al., 2012). In Mahoney's (2004) study, this concern was so strong that carers rejected *monitoring technologies* despite the assurance that no cameras would be used. Interestingly though, in a later study, the authors found that carers suggested cameras as an addition to the unobtrusive sensors installed as part of the study, albeit only in non-sensitive areas of the home (not bedrooms or bathrooms) (Mahoney et al., 2008). The authors reasoned that this might have been due to carers having established trust in the equipment and its operators. Jarrold and Yeandle (2009) similarly found that worries regarding the intrusiveness of *monitoring technologies* were allayed once people had been using them for a while. According to Mahoney (2004), ensuring maximum customizability and control of carers and cared-for people over the decision of which technology to use, how, and when, is key to people using it.

**Limited technological capabilities:** The limited capabilities of technologies were seen as problematic by Mahoney et al. (2008) and Wingrave et al. (2012), although rapid technological advancements in recent years may have taken care of most of these issues. In Mahoney et al.'s (2008) study, for example, the authors experienced difficulties with mobile network coverage when implementing their intervention. Another issue identified was the management and interpretation of data collected by *monitoring technologies* (Mahoney, 2004; Mahoney et al., 2008; Wingrave et al., 2012). Technologies can record and generate an almost limitless amount and variety of data, including audio, video, motion and acceleration, pressure, and temperature; however, processing all these data can be difficult and expensive. Careful consideration should thus be given to the aspect(s) of the life of the cared-for person that requires monitoring, with suitable technologies selected accordingly. Wingrave et al. (2012) suggested using artificial intelligence to aid the interpretation of monitoring data. At present, an underdeveloped market and lacking sufficient consumer demand and investment hinder technologies from reaching their full potential to support working carers (Carers UK, 2012b; Mahoney et al., 2008). Also, some carers may be unable to use *web-based technologies* or profit from *monitoring technologies* if they have no internet access (Mahoney, 2004). Ultimately, technologies that do not operate reliably (e.g., often produce false alarms) can limit the trust of carers and cared-for people

(Carers UK, 2012a, 2012b; Jarrold & Yeandle, 2009; Pickering & Thompson, 2017; Wingrave et al., 2012).

**Limited awareness of technologies:** A major barrier is carers being unaware of technology's existence and how to access it, and limited understanding of the potential benefits it can offer (Andersson et al., 2016; Carers UK, 2012a, 2012b; Carers UK et al., 2013; Jarrold & Yeandle, 2009; Mahoney et al., 2008). Carers UK (2012a) found that 62% of British carers were unaware of available technology. Of carers who were aware of technology, 26% wanted to use it but did not know where to get it from. Andersson et al. (2016) assigned HCPs a vital role in raising carers' awareness of the existence and potential of technologies to support their roles. Employers, as trusted sources of information, can help to assuage carers' concerns regarding technologies and help them access them (Carers UK et al., 2013). Local government or social care services too can play a role in making carers aware of technologies and helping them to access them. This can, however, depend on their staff's knowledge and resources regarding technologies (Andersson et al., 2019; Carers UK, 2012a; Jarrold & Yeandle, 2009). Carers UK (2012a) has thus called for a culture change in which service providers and local government staff should automatically check for suitable technological support for carers when they get in contact and where carers themselves are encouraged to think about technology when they take up their caring role. Carers as users of technologies may thus create the demand required for the currently underdeveloped market to produce more suitable products (Carers UK, 2012b; Mahoney et al., 2008).

#### 4.3.3.2. *Specific barriers*

**Work disruptions:** *Technologies for direct communication* and overseeing *monitoring technologies* can create additional demands on carers and potentially cause work disruptions (Wingrave et al., 2012). *Monitoring technologies* must be suitable for the cared-for person, and who to connect them to, and who is best suited to respond are important considerations to avoid additional challenges for carers, particularly if they work a long way away (Carers UK, 2012a, 2012b; Wilson et al., 2018). Andersson et al. (2017a) found that carers generally did not use *web-based technologies* at work as they felt that they interfered with their jobs.

**Having no time or energy to use technology:** Many carers may not find the time or energy to engage with *web-based technologies*, despite being aware of their potential benefits (Andersson et al., 2017a; Andersson et al., 2016; Kuhn et al., 2008; Mahoney et al., 2008). In the study by Mahoney et al. (2008), this affected predominantly low-income carers from an ethnic-minority background.

**Perceiving no additional benefit:** Some carers see no additional benefit to using technologies. *Web-based* resources, information, or discussion forums can be seen as a waste of time if they are not relevant to the carer's situation (Andersson et al., 2017a). Some carers prefer face-to-face to online

consultations with HCPs, in parts due to previous experiences of long response times to online queries or requests (Andersson et al., 2017a), HCPs facing challenges in maintaining a personal touch when managing high numbers of online interactions, and difficulties in explaining complex issues and emotions in a restrictive online format (Andersson et al., 2016). Webchats can also make carers feel pressured to interact with peers (Andersson et al., 2017a) or be difficult to sustain if not enough carers actively participate (Mahoney et al., 2008). *Monitoring technologies* may be seen as insufficient, especially if care needs are substantial (Jarrod & Yeandle, 2009; Wilson et al., 2018). As carers may feel that they can leave the cared-for person alone for longer periods, some carers worried that *monitoring technologies* could unintentionally increase the social isolation of the cared-for person (Wilson et al., 2018). Wilson et al. (2018) found that some carers did not perceive any additional benefit from using *task-sharing tools* and preferred to communicate directly with their care network or use mainstream social media like WhatsApp.

#### 4.4. Discussion

This review provides an overview of the existing literature on technologies used by working carers. Not much is yet known about this subject despite a growing body of evidence on technology for carers (Bergström & Hanson, 2017; Smith, 2008; Sriram et al., 2019; Wasilewski et al., 2017). Andersson et al. (2017b) conducted a review on ICT-based solutions for working carers of older people that identified 14 articles. Their work focused on how ICTs can reduce burden and improve working carers' well-being. For the present review, we have taken a more comprehensive approach with our inclusion criteria, not limiting the kind of technology to be included or the kind of care provided. Furthermore, we applied a more holistic outlook, using our conceptual framework from our earlier review (Spann et al., 2020) to relate our findings to the general work-care reconciliation discourse.

Our search only revealed 16 relevant publications within a 20-year period, six of which published more than ten years ago. This indicates that technologies as support for working carers have been identified long ago, but that a lot more research is needed to better understand which and how technologies can help to better reconcile work and care. Furthermore, the fact that seven of the included publications came from non-peer-reviewed publications highlights that a lot of important information within the informal care field is published in non-scientific literature. Despite most of the identified publications being very old, which is of particular concern in the rapidly progressing field of technology, there are still valuable conclusions to be drawn regarding how technologies can benefit working carers, which barriers must be considered when using them, and where further research is needed.

For this review we classified technologies as a) *web-based technologies*; b) *technologies for direct communication*; c) *monitoring technologies*, and d) *task-sharing tools*. However, as there are many

gaps in the literature on which this classification is based, it might prove to be incomplete as technologies for working carers continue to be researched and better understood.

Apart from three studies which included *monitoring technologies* and two which included *technologies for direct communication*, one of those a very early study that mentions the importance of telephones, peer-reviewed articles focused on *web-based technologies*. These were used to enable professional and peer-support, store and share care-related information, and provide psychoeducational resources, information on caring and available support. It is unclear, however, if these resources and information were generally relevant for all carers or if the content was specific to working carers' challenges (e.g., how to manage workplace conflicts and ask for support for caring at work, strategies on how to balance work and care, etc.). This should be explored further, and future interventions should employ a co-design approach whereby working carers define their own information needs and priorities. In any case, it was established that working carers profited from these interventions, particularly as they were available independent of time and location. Further research on other technologies, notably *monitoring technologies* and *task-sharing tools* is much needed in the context of combining work and care.

Although it was not the express purpose of this review to evaluate the challenges-solutions framework developed in our earlier work (Spann et al., 2020), we found it useful to better understand the benefits and barriers of using technology in the broader work-care reconciliation discourse. Developers and distributors of technology for working carers should not only be aware of their advantages but should also consider potential shortcomings or unintended consequences. Data management, privacy and data security are important matters to consider, as are carers' digital skills. The literature highlights that using technologies can often depend on others, including people receiving care. Cared-for people often had difficulty operating devices or did not want to use them, rendering technologies useless or even leading to conflict. Spann and Stewart (2018) identified several factors which influenced older people's decision to adopt technology, among them the impact of technologies on their sense of self and their self-efficacy. As *monitoring technologies* need to be useful, usable, and acceptable – ideally even enjoyable – for carers as well as the person they care for, both sets of views and experiences need to be considered in the development and deployment of technologies. Often, carers did not see any additional benefit from using technologies, as was the case with *task-sharing tools* (Wilson et al., 2018). Empirical evidence regarding their usefulness for working carers is needed.

In the context of work-care reconciliation, technologies need to be usable at work. Line managers have been identified as the main gatekeepers for carers' access to resources and support at work (Carers UK, 2019; Spann et al., 2020). This finding has been echoed in this review with an unsupportive workplace presenting a major barrier to carers' ability to use technology at work. As highlighted by

Mahoney et al. (2008), employers and line managers might have valid concerns regarding employees using technologies. However, as they have also demonstrated, these concerns might prove unfounded. Indeed, morale might even improve as employees feel better understood and supported by employers who enable them access to technologies. To allay any concerns employers might have regarding their carer employees' usage of technologies, it might be prudent to raise awareness and start a dialogue. The impact of job characteristics, i.e. the ability to take breaks when needed or leave the workplace, on workers' capacity to use technology and respond to care-related emergencies also need to be considered. More research is needed to understand which technologies are useful for working carers and how their work impacts their ability to use these technologies.

One additional area where more research is needed is telework or telecommuting, meaning carers using technologies to enable them to work from home while caring. Such technologies have not yet been discussed in detail. However, technologies are not necessarily the focus of interest when looking at telework. Hamblin and Hoff (2012) found that carers were frequently distracted when working and caring at home and Keck and Saraceno (2009) found that they often felt guilty when they had to prioritise work over keeping the cared-for person company (and vice versa). These findings were only side notes in their research though and warrant closer examination. Kossek, Lautsch, and Eaton (2006) identified work-family boundary management and psychological appraisal as important factors regarding interpersonal conflict and mental health of teleworkers but their work did not focus on working carers. Future research should address this evidence gap. The COVID-19 pandemic has forced many people to work from home these past few months. It will be interesting to see how working carers have been impacted by this situation.

One subject identified by several of the publications included in this review is carers' limited awareness of technologies. Carers UK (2013) found that while technology played a part in the lives of 98% of adults in the UK (e.g. for leisure, banking, shopping or communicating), only 30% of the general population used it to support health and care and 43% said that technology was the last thing they would consider as a potential source of help with caring. Limited awareness of technology prevents usage which in turn hinders further development and improvement of technologies that could be useful for working carers, because necessary user evaluations are missing, and developers and providers might not see the benefit of investing in them. Signposting carers to available technological support is urgently needed. This kind of support can be provided by HCPs, employers, carer support organisations or local authorities and other government departments.



#### 4.5. Strengths and limitations

This review has several strengths. The scoping review methodology is uniquely suitable to synthesise evidence from both academic and grey literature. This was particularly useful as it allowed the inclusion of non-peer-reviewed sources exploring technologies used by working carers that had not been addressed by peer-reviewed publications. It was thus possible to get a fuller and more inclusive picture of technologies that might be useful to working carers and which could be investigated further. Situating our findings in the context of our earlier review (Spann et al., 2020) allowed for a better understanding of the benefits and barriers of technologies, contextualised in the broader work-care reconciliation discourse.

The review also has a few limitations. Considerable efforts have been made to ensure that all publications that addressed technologies for working carers would be captured in the review. These efforts included a vast array of technology-related search terms, a broad range of academic databases, an ancestry search of included publications, and a Google search. However, the decision to limit the literature search to the English language, the “working carers” concept to the titles and the possibility that authors might have used terms to refer to technology that have not been captured in the search means that relevant additional publications might have been missed. It should be noted that all included publications originated from either the USA, UK, or Sweden. How both work and caring are organised in any given country strongly depends on the historical, cultural, and political context (Bettio & Plantenga, 2004; Bouget et al., 2016; Eurofound, 2015; Kröger & Yeandle, 2013). Although technologies, insofar as they are available and accessible, can transcend political and cultural restrictions, it is unclear whether our findings are transferable to other countries.

#### 4.6. Conclusion

This review synthesised existing evidence relating to the technologies currently used by working carers. There is a dearth of research regarding technologies suitable to address the challenges faced by working carers. Peer-reviewed publications are mostly concerned with *web-based technologies*. Other technologies such as *technologies for direct communication, monitoring technologies* and *task-sharing tools*, are mainly addressed in non-peer-reviewed publications which discuss many benefits and limitations. More robust research is needed to fully understand how working carers can benefit from these technologies.

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## CONFLICTS OF INTEREST

All of the authors confirm that they have no competing interests.

## AUTHORS' CONTRIBUTIONS

The lead author (AS) is a PhD student at the School of Health and Related Research at the University of Sheffield. AS took the lead in developing the review protocol. MH and LdW reviewed and approved the protocol. AS and JV screened and selected the relevant articles and resolved disagreements by discussion and seeking opinion from SA, MH, MS and LdW. AS extracted and analysed the data and drafted the manuscript. JV, MH, MS and LdW contributed significantly to the subsequent drafts and the final manuscript. All authors reviewed and approved the final manuscript.

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# Part II

## Interviews with working carers of people with dementia

### II.a. Preface

The two scoping reviews presented in the previous chapters provided a valuable overview of the state of knowledge in the areas of carers' work-care reconciliation challenges, available support and solutions, and technology. To add to the existing evidence, address some of the identified gaps (i.e., concerning autonomy at work and technology), and gain a first-hand understanding of the challenges working dementia carers face and their needs, wants, and experiences regarding technology, semi-structured interviews have been conducted. Working dementia carers themselves thus defined their problem and their priorities for technological support which is in accordance with the problem-centred and democratic principles of participatory design (PD) (see chapter 2.3.). In addition, the interviews provided insight into how carers' autonomy at work impacted their ability to respond to care-related emergencies when at work and use technology to that end. This study thus contributed to the *exploring the problem* and the *exploring the solution* phases of the PD process. Two manuscripts were drafted from the interview data. The first, Spann, A., Spreeuwenberg, M., Hawley, M., & de Witte, L. (n.D.). *Dementia family carers' needs and wants for technological solutions to their work-care reconciliation challenges: Semi-structured interviews in Scotland*. will be submitted to *Dementia* or similar journals. The second manuscript, Spann, A., Allard, C., Harvey, A.-C., Zwerger, K., Spreeuwenberg, M., Hawley, M., & de Witte, L. (2022). *The impact of autonomy at work on dementia family carers' ability to manage care-related emergencies: Semi-structured interviews in Scotland*. has been published in *Community, Work & Family* in September 2022.

The first manuscript, presented in chapter 5, provides an overview of the work-care reconciliation challenges dementia carers wanted and used technologies for and constitutes the basis of the technology framework developed in chapter 8. It builds on the findings of the second scoping review, which revealed that a bottom-up approach to investigating technology for working carers is needed, starting with their wants and needs. The second manuscript, presented in chapter 6, explores the impact of working carers' autonomy at work on their ability to manage care-related emergencies when

working, and use technology to that end. It also addresses gaps in the evidence identified in both previous scoping reviews and provides valuable insight into the context in which potential technological solutions would have to be used. Three further themes from the interviews with working carers, addressing their views on and experiences with technology, did not fit the scope of the manuscripts but are relevant for the research questions this thesis aims to address. They are thus presented as an addendum in chapter 7.

## II.b. Rationale

To explore the problem, empathise with working dementia carers, and gain a first-hand understanding of and let them define their problem, semi-structured interviews have been conducted. Carers were asked which work-care reconciliation challenges they experienced and wanted and needed technological solutions for, which technologies they already used, for what purpose, what their experiences were with them, and how their autonomy at work impacted their ability to respond to care-related emergencies when at work and use technology to that end.

Rather than merely quantifying the challenges carers faced and the kind of support they received, this study was interested in carers' experience and their views on technology. Interviews allow researchers to gain an understanding of people's lived experiences, thoughts, and motivations and are thus uniquely suitable to provide answers to these questions (Barbour, 2014; Bunniss & Kelly, 2010). Narrative interviews are concerned with the story and experiences of participants. The researcher usually takes the backseat and empowers participants to lead the narrative, highlighting issues important to them while disregarding others (Barbour, 2014). Semi-structured interviews, on the other hand, provide a balance between the necessary structure to discuss predefined issues with research participants but also flexibility to ask follow-up questions for a more in-depth understanding and to explore any arising issues which might previously not have been considered (Barbour, 2014; Witzel, 2000). As discussed in chapter 1.2.1, most working carers don't experience work-care reconciliation as static, primarily due to fluctuating care needs. Furthermore, the arrangements they make to support them in fulfilling both their roles vary, depending on available resources and preferences. Acknowledging this complexity, no consensus was sought from participants regarding the prioritisation of challenges and support, which could be achieved by conducting a Delphi study. Rather, the aim was to offer people a variety of potential solutions they might find helpful for their individual situations. A longitudinal approach could provide insight into how carers adapt their strategies to combine work and care, different challenges they might experience along the way and whether, how, and why their priorities for support change. Adopting a longitudinal approach, interviews would ideally be conducted at multiple important stages throughout the carer's care career, such as becoming a carer or after important events like significant changes to the cared-for person's condition (e.g., hospitalisation,

deterioration, or improvement of health), to the carer's employment situation (e.g., promotion, job change, change to work hours) or to the care arrangement (e.g., people with dementia moving in with carer or receiving care through additional services). However, this approach was not feasible for this PhD project with its limited time resources but should be considered for future studies.

An alternative to conducting interviews would have been focus group research. As it offers insight into how groups of people sharing specific characteristics or experiences shape their collective ideas and understandings (Barbour, 2014), this method could have shed light on whether working carer groups formulate the same priorities for support and how any consensus is achieved. However, as stated, rather than trying to find consensus, this thesis is concerned with identifying and mapping technologies onto all challenges carers identify and want solutions for when combining work and care, not just a selection. The power dynamics generally present in focus groups (Barbour, 2014; Farnsworth & Boon, 2010) could lead to a false picture of which work-care reconciliation challenges and technological solutions are a priority for any given group, as there is a risk that more dominant voices could drown out others. Furthermore, as discussing carers' struggles when reconciling work and care could be deeply personal and complex, a group setting might not be the best way to make people feel comfortable enough to share their experience and ultimately get a deeper and faceted understanding of their situation. Additionally, it was anticipated that the logistics involved with asking people to come to a specific place at a specific time to participate in these groups would not have been feasible for most working carers, as time pressure and conflicting hours are significant issues for many of them (Spann et al., 2020, see chapter 3.3.3.). One-on-one interviews allow for much greater logistic flexibility. To overcome the logistical challenge of asking working carers to travel to a specific place at a specific time, online techniques could have been employed (Barbour, 2014). Online research is determined by the researcher's conceptualisation of the internet as either inexorably linked and interwoven with the physical world, a place of social interaction, or a tool for data generation (Markham & Stavrova, 2016). As a tool, online group discussions could have been initiated, for example, or interviews via chat or email. The former would have to have been conducted synchronously, i.e., in real-time, but participants would not have been required to travel. The latter could have taken place asynchronously, allowing carers to respond at their convenience. There are, however, several issues with this approach, including difficulties to express complex issues in writing and limited opportunities for active engagement between researcher and participants. Most importantly though, it was hypothesised that not all working carers might have access to or are experienced in using the required technologies (Andersson et al., 2017; Andersson et al., 2016; Spann et al., 2022, see chapter 4.3.3.1). In a research project that centres around technology, it would have been detrimental to exclude these people as they could provide insight into why technology might not play a part in their work-care reconciliation strategy.



For all the reasons outlined above, it was decided to conduct semi-structured interviews with working carers of people living with dementia, following the problem-centred approach described by Witzel (2000).

#### II.c. Procedure

The problem-centred approach by Witzel (2000) is an interview technique that puts a specific topic or problem at the centre of the conversation and uses a topic guide to prompt respondents' narration. It thus enables the in-depth exploration of the topic while ensuring that the required themes are addressed. The topic guide used for the interviews with working dementia carers included talking points on i) *the challenges carers faced when combining work and care*; ii) *the support or solutions they used to mitigate these challenges*; iii) *technologies they already used to help with care and/or work and their experiences with them*; iv) *currently unaddressed technological support needs they identified*; and v) *the impact their autonomy at work had on their ability to use technology and respond to care-related issues when at work*. As Carers UK (2013) have pointed out, many carers are not aware of technologies as (potential) part of their support system. To stimulate interviewees not aware of or currently not using any technologies to think about which support they might find useful that technology could offer, the question "If you had a magic wand, what would you like technology to do for you?" was used.

Additionally, a brief questionnaire was administered to capture predefined key data including age, and background which were used to ground the data in the context of participants' lives and allowed for meaningful comparison of groups of people within the sample who share specific characteristics (Witzel, 2000). As part of the purposive sampling strategy, parts of this questionnaire (i.e., those dealing with autonomy at work) were administered upon initial contact with prospective interviewees to ensure that a broad range of these characteristics was represented in the sample. See Appendix G for the complete topic guide and questionnaire.

A pilot interview was conducted to confirm that the topic guide was adequate – the data from this pilot interview was not included in the analysis. This pilot interview confirmed that some carers might find the interview a valuable opportunity to vent and talk about their general situation and their worries. Ensuring enough time and privacy was thus emphasised when scheduling the interviews with participants. Interviews took place between March and July 2019 and interviewees were encouraged to suggest a time and place most convenient and comfortable for them: nine chose their own home, five chose neutral places like pubs, cafés, or meeting rooms, and one requested a phone interview. Interviews lasted between 35 and 120 minutes (mean: 1.5 hours). All interviews were audio-recorded and observational notes were taken during and after.

A purposive sampling strategy (Barbour, 2014) was used to ensure that participants had varying levels of autonomy at work, that all sexes were included, and that a broad age range was represented. Considerable, although ultimately fruitless, efforts have been made to recruit people working in the gig economy (e.g., contacting unions, agencies, and organisations known for using or providing gig-work like UBER directly, via email, and via their social media channels and asking them to distribute the recruitment flyer to everyone working or associated with them). Carers were eligible if they:

**1. were in paid work for at least 20hrs./week,**

**2. provided care for at least 5hrs./week,**

→ 1.&2. to ensure that they had enough experience being both in paid work and unpaid care and to increase the likelihood that combining those roles presented them with challenges (King & Pickard, 2013).

**3. had been a working carer for at least six months,**

→ Carers very early in their care-and-work career might face unique challenges as it may be assumed that they are still in the process of getting to terms with their new roles and setting up their support system.

**4. cared for person with dementia living outside of institutional care settings in Scotland,**

→ Dementia is a condition with increasing prevalence which requires high levels of, mostly informal, care. Unpredictable care needs and BPSD are typical characteristics which can be particularly challenging for working carers (see chapter 1.2.3.).

→ Residential care settings have been excluded as paid care professionals are primarily responsible for caring for people with dementia which reduces the demand on working carers.

**5. had sufficient English language skills.**

Researchers have pursued a variety of strategies to recruit working carers. To name but a few, Barnett et al. (2009) recruited via four employers and reported response rates between 6 and 27% for their survey, their final sample consisting of 572 carers. To recruit carers for their interviews, Eldh and Carlsson (2011) approached employers through local projects which assisted them to support their carer employees. Boezeman et al. (2018) asked carer support organisations to help with recruitment and approached labour unions and patient organisations, and posted on hospital message boards. Arksey and Glendinning (2008) too used carer organisations, in addition to accessing local authority records of people receiving carers' allowance or seeking a job and recruiting through employers and snowballing. Snowballing was found to be the most effective strategy by Bourke et al. (2010) in their qualitative study on self-employed female carers, noting that their attempts to recruit through advertisements and mail lists of the chamber of commerce or similar organisations were not as

successful. Authors are generally vague on the success of their recruitment strategies, but from their combined efforts, it seemed that a multipronged approach was needed.

Recruitment flyers were designed that contained a brief description of the project, the eligibility criteria as defined earlier, and the researcher's contact details, and asked carers to get in touch if they wanted to participate. To ensure that even working dementia carers could be reached who previously had not recognised themselves under this term, the recruitment flyer addressed them as people *in paid work and looking after a family member, friend, or neighbour living with dementia*. Carer organisations, the chamber of commerce, trade unions, the researchers' professional network, and a random selection of businesses operating in Scotland were asked to distribute the flyers among their clients, contacts, and employees and to post an advertisement for the study on their social media channels. Flyers were also pinned to several community notice boards, handed out at dementia support groups, and placed at dementia daycare centres. Carers were invited to contact the research team if they fit the eligibility criteria and wanted to get involved. The most successful of these strategies was the collaboration with one carer organisation which acted as gatekeeper and forwarded the contact details of interested clients, with their consent, whom they had approached on behalf of the researcher. Snowballing was also a helpful strategy.

To analyse the interview data, interviews were transcribed and read multiple times to ensure familiarity with the texts. The data was then broadly structured around the three main interview topics: i) *carers' work-care reconciliation challenges*, ii) *carers' experiences with technology*; and iii) *carers' autonomy at work*. Data were analysed using the thematic analysis approach described by Braun and Clarke (2006). Thematic analysis, according to Braun and Clarke (2006), is a "foundational method for qualitative analysis" (p.78) and can be used independently of epistemological stance and theory to summarise and manage qualitative data. An inductive, iterative process to identify themes and connections between them was used throughout. Emerging themes were discussed within the research team and with other work-care scholars. Each participant was sent a short summary of their interview and asked whether they wanted to add, clarify, or amend any of the information. Where this was the case, clarifications or additional information were included in the ongoing analysis. A more detailed description of the analytic procedure can be found in chapters 5.2.4. and 6.2.4. Appendices H and I provide an overview of the themes and subthemes that emerged from the analysis, accompanied by sample quotes. Any quantifiers or semi-quantifiers (e.g., some, many, all, few) used in the presentation of the findings in chapters 5-7, when referring to participants' statements, only relate to the study population. These (semi-)quantifiers serve to accentuate patterns in the data (i.e., regularities, peculiarities, etc.). No generalisations can be made as to the prevalence of any of the described challenges beyond the study population. See Neale et al. (2014) for a discussion on the legitimacy and use of (semi-)quantifiers in qualitative research.

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## 5. Dementia family carers' needs and wants for technological solutions to their work-care reconciliation challenges: Semi-structured interviews in Scotland

### **Abstract**

Most people with dementia are cared for by family, friends or neighbours in the community. Many of these unpaid dementia carers have to balance caring with paid work which can present them with several challenges. Technology can offer potential solutions, independent of an already strained social care system. This qualitative study aimed to explore working dementia carers' needs and wants regarding technological solutions for their work-care reconciliation challenges. We conducted semi-structured interviews with 16 (10 women, 6 men) working carers of community-dwelling people with dementia in Scotland. Data were analysed thematically to identify key themes. Carers wanted solutions for seven main issues: i) care management; ii) attending appointments; iii) entertainment and companionship for the person with dementia; iv) dealing with psychological and psychosocial stress; v) safety concerns; vi) accessing information, and vii) personal care. Technological solutions most carers had experiences with were aimed at care management, their safety concerns, and accessing information. Few if any carers had experience with technologies for entertainment and companionship for the person with dementia, their own psychological and psychosocial wellbeing, attending appointments, and personal care. Some carers made suggestions for technologies they were not aware already existed, highlighting the need for effective signposting to technological solutions for their individual needs. Our findings are relevant for employers and organisations seeking to support working carers, and local governments tasked with providing technologies for care-related reasons.

**Keywords:** Working carers; technology; challenges; dementia; interviews; wants and needs.

### 5.1. Background

Dementia refers to degenerative processes of the brain which are generally progressive in nature and will affect 75 million people worldwide by 2030. Symptoms include emotional, psychological, cognitive, and behavioural issues, which can affect the ability of people living with dementia to continue living independently (World Health Organization 2017). Most people with dementia in the UK live in their communities where they are supported and looked after by unpaid family carers, i.e., family, friends, or neighbours (Alzheimer's Research UK 2015; Prince et al. 2014). Roughly 4.9 million people in the UK combine unpaid care with paid work, which amounts to one in seven people in paid work (Carers UK 2019). This number has since sharply increased due to the Covid-19 pandemic (Carers UK 2020; Phillips et al. 2020). Carers in full-time work are most likely to care for people with dementia (Carers UK 2013b). Precise numbers of working dementia carers are currently not known but are likely to see a drastic rise due to the projected doubling of the prevalence of dementia in the UK by 2050, severe availability and accessibility restrictions of UK health and social care services resulting from ongoing public funding constraints – further exacerbated by Covid-19 (Charles and Ewbank 2021), and rising retirement ages

(Broese van Groenou and De Boer 2016; Buckner and Yeandle 2015; Care Quality Commission 2021; Prince et al. 2016; Prince et al. 2014; Round 2017; Ward et al. 2020; World Health Organization 2017; Yeandle and Buckner 2007).

Care needs of people with dementia can involve assistance with their personal care, instrumental activities of daily living (e.g., shopping, financial and household management, etc.), social and emotional support, and ensuring their safety. These needs can fluctuate but usually intensify when the dementia progresses (Gallagher-Thompson et al. 2020). Because of the complex and unpredictable nature of the condition, caring for people with dementia has been found to be more challenging than caring for someone with other diseases or disabilities (Matsumoto et al. 2007; Newbronner et al. 2013): dementia carers provide more care overall and caring for people with dementia is particularly emotionally challenging due to having to come to terms with the slow decline and changing personality of a loved one, frequent interpersonal conflict with the cared-for person, and having to be constantly vigilant to manage the behavioural and psychological symptoms of the condition and to ensure the person with dementia's safety. Accordingly, dementia carers have been found to have more stress, physical and mental health problems, and generally, worse quality of life than other carers (Carers UK 2014; Huang et al. 2012; Koyama et al. 2017; Kuo et al. 2014; Moon and Dilworth-Anderson 2015). There are, however, positive sides to caring as well: it can offer a sense of purpose and a chance to reciprocate to a loved one in their need (Bourke et al. 2010; Eldh and Carlsson 2011; Hamblin and Hoff 2012). Despite work also offering benefits to carers like a sense of personal achievement and social contacts outside of caring, respite, and financial security (Bourke-Taylor et al. 2011; Calvano 2013; Utz et al. 2012), balancing both work and care can create significant challenges for carers (Spann et al. 2020, see chapter 3.3.3.) which can negatively affect their health, relationships, and employment if they are not sufficiently supported (Carers UK 2014; Wang et al. 2020; Wang et al. 2013; Wang et al. 2011; Wittenberg et al. 2019; Yeandle and Buckner 2007).

In a chronically under-resourced social care system (Charles and Ewbank 2021; Ward et al. 2020), technology can offer carers urgently needed solutions for their work-care reconciliation challenges. Technology in the context of this study is defined as any electronic and/or digital device or application. While technology for carers (see for example Bergström and Hanson 2017; Smith 2008; Sriram et al. 2019; Wasilewski et al. 2017) and people with dementia (see for example Astell et al. 2019a; Astell et al. 2019b; Lorenz et al. 2019; Yellowlees 2020) are increasingly investigated, little attention has yet been given to technology that can help carers of people with dementia to better combine work and care. In a recent review, we identified 16 publications, academic and grey, addressing technological solutions for working carers (Spann et al. 2022, see chapter 4). Most of these aimed to evaluate specific technologies we classified as web-based technologies, technologies for direct communication,

monitoring technologies, and task-sharing tools. Carers used them to have peace of mind, manage their care network, stay connected to their workplace when working from home, decrease the care demand, access information, improve their mental health, resilience, and relationship with the cared-for person, and save time and money. However, we could not find a single publication that took a bottom-up approach and explored which challenges working carers wanted and needed technological solutions for. In light of the fact that many carers are not aware that technological solutions for their challenges exist and where they can procure them (Carers UK 2013a), the growing number of websites in the UK which collate these technologies are welcome signposting tools. These include [www.atdementia.org.uk](http://www.atdementia.org.uk), [www.alzproducts.co.uk](http://www.alzproducts.co.uk), [www.dementia.livebetterwith.com](http://www.dementia.livebetterwith.com), [www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk), and [meetadam.co.uk](http://meetadam.co.uk). However, while most of these sites enable carers to filter technologies for specific needs, none of them yet include filters specific to the challenges carers face when combining work and care for people with dementia. To fill this gap and to better understand whether existing technologies can address the challenges working carers of people with dementia face, it is essential to understand the needs and wants for technological support they express. Thus, in this paper, we explore which work-care reconciliation challenges working dementia carers want, need, and use technological solutions for. The findings of this study will feed into the development of information products for carers.

## 5.2. Methods

For this qualitative study, we conducted semi-structured interviews which allow researchers to gain a first-hand understanding of people's lived experiences and views (Barbour, 2014; Bunniss & Kelly, 2010). We used Witzel's (2000) problem-centred approach which employs a topic guide to prompt interviewees' narration on central issues, thus facilitating the in-depth exploration of the issues while ensuring that essential themes are addressed. In addition, a brief questionnaire is administered to capture interviewees' contextual demographic data.

The topic guide included questions on what the most difficult aspects of combining work and care were for carers and how care affected their work and vice versa. Further questions pertained to whether technology played a part in carers' support system, and if yes, which technology and how they used it. And finally, carers were asked, if there were no limitations, what would they want technology to do for them. A pilot interview confirmed the topic guide's suitability. Interviews were conducted in Scotland between March and July 2019 at a place most convenient for interviewees: nine chose their home, five neutral places like pubs, cafés, or meeting rooms, and one requested a phone interview. Interviews lasted between 35 and 120 minutes (mean: 90 minutes). All interviews were audio-recorded and observational notes were taken during and after.

### 5.2.1. Ethical approval

Full ethical approval was granted by the ScHARR Research Ethics Committee at the University of Sheffield (Reference 022994). All participants were fully informed about the study, including their right to withdraw at any point without consequence, and gave their explicit consent before the interview started. Confidentiality was ensured throughout the study and data were stored securely. All participants received a pseudonym to ensure their anonymity.

### 5.2.2. Participants

We used a purposive sampling strategy (Barbour 2014) to ensure that both sexes and a broad age range were represented and that participants had varying levels of autonomy at work (defined as control over workhours, workplace, and breaktimes) which we reasoned would impact their ability to manage care-related issues and use technology when working. Carers were eligible if they: i) were in paid work for at least 20h/week; and ii) provided care for a person with dementia for at least 5h/week. They also iii) had to have been working carers for at least six months, and iv) care for a person with dementia living outside of residential care settings in Scotland.

### 5.2.3. Recruitment

We used a multipronged recruitment approach. Carer organisations, the chamber of commerce, trade unions, the researchers' professional network, and a random selection of businesses operating in Scotland were asked to distribute our recruitment flyers among their employees, clients, and contacts and to post an advertisement for the study on their social media channels. Flyers were also pinned to several community notice boards, handed out at dementia support groups, and placed at dementia daycare centres. Carers were invited to contact the research team if they fit the eligibility criteria and wanted to get involved. One carer organisation forwarded the contact details of interested clients with their consent, who were then contacted by the research team. We also asked participants to forward our recruitment flyer to other carers they knew who fit the inclusion criteria.

### 5.2.4. Analysis

Interviews were transcribed and read multiple times to ensure familiarity with the texts. The data were analysed using the thematic analysis approach described by Braun and Clarke (2006). We used an inductive, iterative, descriptive process to identify themes. The research aims were used to guide the analysis and to discover relevant themes. We first coded the initial five transcripts using NVivo 12 software. Codes were then revised and used to code the remaining transcripts. Codes were added and revised throughout the process and ultimately combined into clusters of meaning to form the themes



presented hereafter. Emerging themes were discussed within the research team and other work-care scholars. Appendix H provides a table with an overview of the themes, subthemes, and sample quotes. Each interviewee was then sent a short summary of their interview, using the themes that emerged from our analysis. Interviewees were asked to confirm whether this interpretation was true to their experience and views, and whether they wanted anything added, clarified, or amended. Six interviewees (37.5%) responded. Any clarifications or additional information they provided was included in the ongoing analysis.

### 5.3. Findings

In total, 16 working carers were interviewed (ten women and six men). The age range was 27 to 70 (mean: 50.6 years). Seven carers were employed full-time, six were self-employed, one partially retired, and two were small-business owners on top of their full-time employment. The hours of care they provided ranged from five and, in one extreme case, 75+h/week. It was difficult for most carers to settle on a definitive number of their weekly care hours as most of their caring was not plannable and they did not necessarily define some of it as caring (e.g., shopping and home maintenance for the person with dementia). Of the people with dementia (N=17), 13 were carers' parents (one cared for both parents), one a parent-in-law, one an uncle, and two a spouse. Three carers' situations had changed considerably just before the interview: two had changed from full-time employment to working less than 20 h/week on a self-employed basis for care-related reasons, and one carer just started to transition into retirement after caring had ended for them following the person with dementia's passing. Per the study's eligibility criteria, only their situation preceding these events was considered in the analysis. Table 7 presents an overview of the interviewees' characteristics.

Table 7: Participant characteristics

<b>CARER</b>		<b>Women (N=10)</b>	<b>Men (N=6)</b>	<b>total n (N=16)</b>
<b>Age</b>	<40	1	3	<b>4</b>
	40-60	7	1	<b>8</b>
	>60	2	2	<b>4</b>
<b>Employment status</b>	Employed	6	3	<b>9</b>
	Self-employed	2	2	<b>4</b>
	Employed & self-employed	1	1	<b>2</b>
	Partially retired, employed	1	0	<b>1</b>
<b>Weekly workhours</b>	<35hrs	1	1	<b>2</b>
	35-40hrs	7	2	<b>9</b>
	>40hrs	2	3	<b>5</b>
<b>Caring for yrs.</b>	0.5-2yrs	3	2	<b>5</b>
	3-6yrs	2	3	<b>5</b>
	>6yrs	5	1	<b>6</b>
	<10hrs	2	2	<b>4</b>

Weekly care hours	10-20hrs	4	1	5
	21-40hrs	3	2	5
	>40hrs	1	1	2
<b>People with dementia</b>				<b>total n (N=17)</b>
Relationship to carer	Parent			13
	Parent in-law			1
	Other parental generation			1
	(Ex-) Spouse			2
Age	<70yrs			4
	70-80yrs			3
	>80yrs			10
Dementia Diagnosis	Alzheimer's			5
	Vascular			3
	Fronto-temporal			2
	No official diagnosis			1
	N/A			6
Dementia Stage (CDR)*	Moderate			5
	Moderate-severe			4
	Severe			8

\*CDR=Clinical Dementia Rating Scale, staging based on participants' descriptions (Waite et al. 1999)

Our analysis produced seven themes representing challenges carers wanted solutions for. These were i) care management; ii) attending appointments; iii) entertainment and companionship; iv) psychological and psychosocial stress; v) safety concerns; vi) accessing information, and vii) personal care. The order in which these challenges are presented (see rainbow diagram in figure 15 for an illustration) does not constitute any prioritisation. Not every carer<sup>5</sup> described experiencing every challenge, but all of them reported experiencing or having experienced more than one. Many carers we interviewed did not experience their work-care reconciliation efforts as static due to fluctuating care needs and changing circumstances at work (e.g., getting a new line manager, business trips, meeting deadlines). Accordingly, the challenges they experienced could change and with them their priorities for support. Appendix H provides an overview of the identified work-care reconciliation challenges carers wanted solutions for, along with sample quotes.

<sup>5</sup> Any quantifiers or semi-quantifiers (e.g., some, many, all, few) used in the following presentation of the findings when referring to participants' statements only relate to the study sample. These (semi-)quantifiers serve to accentuate patterns in the data (i.e., regularities, peculiarities, etc.). No conclusions can be made as to the prevalence of any of the described challenges beyond this study's population. See Neale et al. (2014) for a discussion on the legitimacy and use of (semi-)quantifiers in qualitative research.

Figure 15: Rainbow diagram of carers' work-care reconciliation challenges



### 5.3.1. Care management

#### **Coordinating the care network**

Care networks included unpaid (i.e., family members, friends, neighbours) and sometimes paid (i.e., live-in care workers, personal assistants, and assisted living facility manager) members. Carers needed to coordinate responsibilities with their care network and exchange information about people with dementias' condition, habits, mood, or upcoming appointments. Some arrangements with care network members were stable and reliable, requiring little managerial effort. Other carers had to rely on family members who had considerable care needs themselves or manage their care arrangement on a day-by-day basis, which could cost a lot of time and effort and lead to work disruptions.

*"She [spouse of person with dementia] is exhausted, she is 88, she is exhausted, she is getting tinier by the day [...] That's my thing with her, is what you could give her. He [person with dementia] is long gone. It's about her as a carer; that is our focus, it's her that we have to look after. It's the damage on her, the wear and tear of her and if she hurts herself, we think [person with dementia] would just be like [asking her] 'Why are you there?' We don't know, we know he wouldn't know how to lift a phone now and or what to do and that's why we have to have this permanent contact."*  
(Sue)

Carers used their phone to text, call or email their network. Many carers appreciated instant messenger apps for allowing them to communicate with their whole network at once, exchange documents, images, and videos, and store records of their exchanges.

Some carers wanted reassurance that a member of their care network had been to check in with the person with dementia to make sure they were alright (see also 3.5. safety concerns). However, Ian found that some network members did not want or know how to use even easy-to-use technology such as texting and wondered if there was yet simpler technology that could let him know if someone had been in to check on the person with dementia.

“Well, I'm always asking them to text me but they're not so good at texting. They either don't want to spend the money, or they just forget or whatever but yeah, I mean I always want those like ‘Guys, talk to me, talk to me’, [...] So yeah, a lot of the time you just haven't got a clue what's going on.” (Ian)

### **Coordinating care providers**

For many carers, the process from councils approving care packages to people with dementia receiving them took many months which some attributed to social care budget constraints:

“There's a package of care but no carers to carry it out” (Rose)

Some carers felt that the care provided by services was sometimes inadequate and that their instructions were not followed. Maggie described her frustration over having to interrupt her work to help her mother's home care workers.

“The carers can't cope, so I have to help them to change her [person with dementia] and do a little personal care. I have to be there to, you know, sometimes there's new carers [...]. So, I have got to be there, to tell them where everything is and how to do everything. And sometimes I get really frustrated and I think I might as well do this myself.” (Maggie)

Registering their complaints (e.g., via phone or email) and continuously having to explain what they wanted care workers to do could be time-intensive and cause conflict. Theresa wanted remote access to an online version of care workers' logbook reports, which they needed to complete after each care visit, and which were kept in hardcopy form in the person with dementia's home.

“If carers [home care workers] were able to input into that portal as well with a daily report, it also means on the days that I don't get to see mum I could just log in and see what they've said today [...]. I know they would ring me if there was an issue – I know they would ring me – but, sometimes it's useful just to see a little comment that they've put or sometimes they might write that I need to collect more, I need to collect something from the chemist or more nutritional drinks or something like that.” (Theresa)

Max, who used his lunch break to head home and help his mother eat her lunch, was frustrated that he had no way of knowing when care workers would arrive and make him wait for them to finish their tasks before he could help his mother and get back to work. He suggested that technology could inform him when exactly care workers would arrive so he could make his arrangements accordingly.

“We've no idea when they're [care workers] gonna be there roughly. No, we know roughly they're coming between this and this hour. But if you've taken your lunch off and then you have to wait for it for ages. [...] They've probably no real way of knowing unless I suppose you could say if they had a list of houses that they were going to visit and when they've left the house previous to that, if there was some way of communicating that through an app or something.” (Max)

Carers who privately hired care workers suddenly found themselves as employers with all the associated responsibilities. This required a lot of administrative effort and could be overwhelming for carers with no experience managing employees.

“For everything I do there has been an initial time which is gathering the information, understanding what I might need to do, I need to communicate with, particularly in the original set up of the care plan, because I wrote both the job descriptions for the carers, submitted the plan which had to be approved for by the local authority in order that I could make use of the budget that was provided to me.” (Gavin)

### 5.3.2. Attending appointments

#### **Attending medical and similar appointments**

Conflicting hours of health- and social care professionals (HCPs) were a challenge for carers.

“I’ve had social workers like going ‘Oh yeah we’ll do it before you go to work!’ and you go ‘Well, I leave at 7 o’clock’ and they go ‘Ok wish I’d never said that now!’ So, it tends to be that for those kinds of meetings, the flexibility has to come from my side. [...] It’s the same with doctors’ surgeries. You know, they must know that a huge part of the population works.” (Hannah)

Medical or similar appointments made well in advance presented relatively few problems as carers could either arrange for time off work or for their care network to accompany the person with dementia. Some appointments, however, could be very short notice.

“The hospital appointments are not so bad because they’re quite far in advance but things like the district nurses, they just turn up on your doorstep and expect you to be there.” (Rose)

Carers with limited autonomy over when and where they worked depended on the goodwill and understanding of their line managers or on colleagues taking over for them to be able to attend the appointment. Some carers found it difficult to attend if they had deadlines and needed to prioritise work or lived too far away.

“You can’t really say to somebody who’s organised something bank-wide, say, “Look, can you move this ‘cos I need to go and take my mum to the doctor.” (Hannah)

### **Attending business meetings**

Carers working from home sometimes needed to attend business meetings, for which many used videoconferencing software. Betty particularly appreciated these software’s chat functions which allowed her to unobtrusively communicate to her colleagues if she needed to leave a meeting for care-related reasons.

“As well as having the facility to work from home, the instant message [name] technology that we have for doing quick messages meant I was able to tell someone in the meeting I was going to have to drop off the call, needing to make some calls for my dad and they were able to know why I wasn’t contributing.” (Betty)

### **Arranging medical or similar appointments**

Arranging appointments with HCPs was challenging for carers as the conflicting hours meant they needed to find time to do this while at work. Theresa wanted to be able to communicate with HCPs via email rather than phone as that would save her time and be easier to accommodate.

“I would like to have access to the GP and the carers through technology. I don’t even have email access to them, so that would be really useful, you know. That’s quite basic technology, but at the moment that all has to be done by phone and for me, actually, email’s easier than phone, especially when you’re working. You can just bang out a quick email rather than having to go and do the whole phone call palaver.” (Theresa)

## **5.3.3. Entertainment and companionship**

### **Providing entertainment and companionship**

People with dementias’ continuous cognitive decline and social withdrawal were big concerns for carers.

“Sometimes I think that while there is no denying the progress of her disease and the reality of it, sometimes I think that if she could be more stimulated, she wouldn’t have deteriorated so quickly”. (Maggie)

Many, particularly carers who worked and cared simultaneously, felt guilty for not being able to keep the person with dementia more company (see also 3.4. psychological and psychosocial stress). One carer felt that entertainment like TV or radio was not stimulating enough while also musing that the person with dementia could find it difficult to learn using new technology. George remembered the positive effect a small dog had had on his wife in terms of providing companionship:

“It was being classified as an [emotional support] dog or something [...]. And my wife certainly liked it being there.” (George)

### **Enabling active participation in society**

Some carers wanted the person with dementia to actively participate in society.

“If I had a magic wand, I’d just want something to get them out to, and be happy.” (Jasmin)

James suggested a website that could collate information on dementia-friendly events in the neighbourhood, while Jasmin talked about self-driving cars:

“There’s so many groups but a way to combine everything would be quite useful. Just to like ‘Ok, where do I go? What’s available on Monday in Scotland?’” (James)

“I’d like technology to... you know how you have driverless cars, I’d like to have that, and I would like to have pavements which are disabled access, and I’d like to have more, you know, access for people that have disabilities, [...] to give them a better cause in their life.” (Jasmin)

### **Enabling people with dementia to communicate**

Dementia massively impacted some people with dementias’ ability to communicate. Some could no longer give coherent responses, others appeared to have lost the ability to speak altogether. Their carers expressed a desire for technology that could enable them to communicate with the person with dementia again.

“I’m for the days when people are embedded with a chip, you know, really, I think, that we can communicate telepathically.” (Maggie)

#### **5.3.4. Psychological and psychosocial stress**

Carers reported having to deal with complicated emotions. A prominent emotion was guilt, e.g., for having to prioritise work over caring and vice-versa, for not being able to give their family as much time as needed, or for considering moving the person with dementia to a care home as they felt they could no longer cope.

“But because they [workplace] are supportive, when I’m having to take time off like these last few weeks, I feel as if I’m letting them down. But, when I’m there, I feel as if I’m letting my parents down. And it’s, that conflict is there all the time, whether it’s in one way or another.” (Flora)

While some carers managed to find positive sides to their situation, others felt overwhelmed or alone. Some reported having conflicts with siblings who refused to get more involved with caring for their

parents. Almost all carers talked about having to make personal sacrifices they sometimes felt sad or resentful about.

“I worry about the fact that I can’t spend as much time with people and doing things that I enjoy, I worry about the length of time this is going to take, this chunk that it takes out of my life.” (Maggie)

Relationships with romantic partners, friends, and family often suffered and some carers felt abandoned by their social network.

“People try and help and, but it’s just complete opposite from what you need from people, you know. It’s interesting as well because some male friends just vanish. [...] I think a lot of female friends sort of get it, but I think guys just don’t know what to say, don’t know what to do.” (James)

Role reversal and people with dementias’ changing personality, caused by dementia, were often difficult to accept, as was getting to terms with slowly losing their loved one. Dementia could sometimes exacerbate already difficult relationships between the carer and the person with dementia. The person with dementia, or in one case their spouse, refusing help (in the form of e.g., home care services, day-care-centres, technology) could be a great source of conflict and frustration.

“Where to draw a line between being respectful of what she [spouse] wants and saying, ‘You’re being absolutely ridiculous’, you know? ‘You’re missing out on something here which is detrimental to him because of your views’.” (Sue)

Emotional labour and constantly being ready to spring into action were very exhausting for carers and many already experienced adverse health effects caused by exhaustion.

“So, I would say the combining it [work and care] is, is you know the risk that you, you put too much demands on yourself mentally and physically and you end up running yourself down.” (Betty)

Accordingly, some carers made a conscious effort to find time for their own health and wellbeing, for example by doing sports, going on walks, taking counselling, etc.

Dealing with these emotions and finding emotional and social support, technology did not seem to be a solution that carers typically considered. One younger carer used social media to vent and explore the humorous side of caring, and to reconnect with friends who had limited understanding of his situation:

“I use [social media] a lot in terms of like it’s, they’re funny, but my updates are also like, nobody could possibly say to me ‘I don’t know what’s going on with you’ like it’s there, ‘this is what happened today, this is what mum did’, you know. And I twist it in a sort of funny way but it’s also just educating people.” (James)

Several carers noted that there were support groups organised by dementia or carer organisations, but that they either conflicted with their work, that they did not find the time or energy to attend, or that they worried that they did not have much in common with the target audience.

“They’re all a bit elderly and really, I don’t really have a lot in common apart from the fact that we all look after somebody with dementia.” (Rose)

#### 5.3.5. Safety concerns

All interviewed carers expressed concern for people with dementias’ safety.

“You just have to wait and see what happens every day and deal with every situation. So, you are always firefighting, you can’t plan anything.” (Maggie)

If their work allowed it, many carers used their phone to check in with their care network or the person with dementia. However, some people with dementia had difficulties using a phone due to dexterity issues, hearing or remembering how to use it. Frequent calls by carers could put a strain on the relationship with the person with dementia as they could feel patronised by carers’ attempts to check on them.

“It’s easy for me to pick up the phone and just prompt, but you know, it’s frustrating for the person who’s forgetting, almost kind of the sense that they’re being told what to do and they’re being monitored. And my dad’s always been a pretty free spirit, so the idea that I’m on his case, checking this, that, and the next thing irritates him.” (Betty)

### **Managing accidents and emergencies**

All interviewed carers worried about potential accidents like falls or other emergencies in the home. Gavin used a system of interconnected sensors in the person with dementia’s home to monitor their movement. Unusual activity could trigger an alert and be monitored via an app or online portal. Despite generally viewing this system positively, Gavin noted issues with the interpretation of the transmitted data, particularly if there was more than one person at home:

“You just have to be careful about what conclusions you develop from them, from the data.” (Gavin)

Ian, who worked from home and cared simultaneously, suggested a traditional baby phone to hear when his mum needed assistance but did not get one for fear of disturbing her:

“Should we get these baby things that you plug into the sockets and, but then I’ve got no peace because if I want to listen to music she’s gonna hear and be bothered by it, especially if it’s a two-way thing, I don’t know if there’s a one-way thing, but yeah, you get over sensitized cause every single little sound goes ‘Oh, is mum calling for me?’ and you jump up like this.” (Ian)

Cameras were mentioned by many carers, although few had experience using them. Those who did, found cameras with two-way audio transmission, controlled via an app, very useful as it took them mere seconds to check and have peace of mind. Others thought cameras would be too invasive.

“At any point in the day through an app on our phone, we can check in on her and make sure she’s OK. [...] It takes the stress levels down a wee bit because as I say you get peace of mind you don’t need to leave your work and go up as much.” (Max)

“I wouldn’t like to go down that route internally unless it really became strictly necessary. And I don’t think it is. It is too invasive.” (Gavin)

Many people with dementia were issued community alarm systems by the council, i.e., small wearable panic buttons connected to an emergency response call centre via a home base. While some carers were grateful for the technology giving them peace of mind, many others pointed out that people with dementia might not use or forget to use it when needed. Gavin worried that call centre operators’ disembodied voices coming from the home base could be distressing. Other issues raised were devices’ limited range and the time between setting off the alarm and help arriving.



"The weakness is really the intercom communication between the client and the call centre. Ideally, you'd want something in every room. And for the person to be comfortable that they know 'Where's that sound coming from? Who's that?'" (Gavin)

"She'll [spouse] call the people from the community alarm and it'll take them, in the middle of the night, three or four hours sometimes. So, in the meantime she's got him a cover, he's sleeping on the floor and she's sitting beside him wide awake." (Sue)

Falls alarms were highly appreciated as they sent an automatic alarm to the call centre when detecting a fall. There were, however, concerns about people with dementia forgetting to wear them, their reliability, and their limited range. One carer suggested an integrated communication function which would make the home base obsolete and increase the range. One person with dementia had been issued a bed occupancy alarm from the council which would alert the call centre if they were out of bed for too long. However, the device produced frequent false alarms, causing the carer many work disruptions and a lot of frustration trying to get the device fixed and diminishing the trust that it would work properly when needed:

"Technology that works is good, technology that doesn't work is just frustrating and time-consuming." (Maggie)

Furthermore, the carer described the traumatic experience of the person with dementia being woken in the middle of the night by the rescue workers dispatched by the call centre:

"These enormous, big blokes come into the house in the middle of the night and wake her up and she's terrified." (Maggie)

### **Reminding**

Carers wanted solutions for reminding people with dementia of certain tasks like taking their medication, imminent appointments, and eating and drinking regularly (some also need instructions on how to prepare their food). They also wanted confirmation when such tasks had been completed. One carer found they needed to see what the person with dementia was doing when reminding them to take their medication so they would not take the wrong pills by accident. Regarding automated pill dispensers or recorded messages, carers cautioned that the person with dementia might not hear the notification or hear it but not know what to do about it and get distressed. It was also remarked that pharmacies might refuse to refill automatic dispensers. Carers who worried about people with dementia getting dehydrated or malnourished wanted technology that could monitor their nutritional and hydration levels. Carers who needed people with dementia to attend appointments on their own wanted solutions to remind them where they needed to be and what they needed to do to get there. Another concern was people with dementia causing fires or floods if they forgot to switch off cookers or faucets.

### **Managing disorientation**

Carers worried about people with dementia becoming disorientated and distressed. Some carers found dementia clocks or talking watches helpful. One carer of a person with severe dementia found

that video phoning helped soothe them when they were very distressed. People with dementia being at risk of getting lost when out for a walk was a common concern. One person with dementia regularly forgot to pay when shopping, causing their carer to have to disrupt work to sort out the issue with law enforcement. Mobile phones were no viable solution for people with dementia who did not know how to operate them or forget to bring them along. One carer mentioned a door alarm to be notified when the person with dementia leaves home but ended up not using it for fear of frightening them. Many carers suggested GPS tracking devices, but none had any experience with them. Some thought the person with dementia might forget to bring the device along. Flora was seemingly so concerned that she half-jokingly suggested implanting her father with a trackable chip:

“My dad goes wandering and it would be quite good to have him chipped just so that we can just sort of go, ‘Right, he’s down the road’, so we donae lose him’, because we do-, he’s walked this area all his life and he’s always enjoyed walking and you didnae want to take that away from him [...] I don’t know what human rights people would say...” (Flora)

### **Preventing crime**

Carers were concerned about how vulnerable people with dementia were on their own. They specifically mentioned worrying about scammers. Several carers had power of attorney and managed people with dementias’ finances. Hannah was so worried that she installed a security camera outside her mother’s home:

“And she’d let this guy into her house, given him £100 and then rung me up and said, ‘I don’t think I should have done that, should I?’ [...] And at that point I did go and look at technology in [department store] where you have some kind of CCTV that links to your phone.” (Hannah)

She suggested a doorbell with facial recognition to prevent her mother from admitting strangers:

“There was something on [social media] not so long ago about an 11-year-old boy who had a Great Aunt with dementia, and they had similar problems. She was letting people in. So, he has set up some facial recognition door alarm where it’s stored the, the facial combination of, I dunno, a number of approved people. And if you’re not on that list, you don’t get in.” (Hanna)

#### 5.3.6. Accessing information

### **Finding information**

Several carers reported not knowing what support was available and where to turn for help. Many had not received any information or guidance on dementia, what to expect when caring for a person with dementia, or on caring in general. Others had received information but at a time when they were ill-equipped to understand and process it, found that the information did not fit their needs, or were too exhausted to work through all the information:

“That is one of the biggest challenges with this actually, is understanding everything that’s out there and who you need to speak to and what you need to do. And I mean [carer organisation] have been good and [dementia organisation] have been good but they both sent me piles and piles of leaflets and information and they’re still sitting unread at home because I’ve either been really busy at work or by the time I’ve got home I’m so exhausted that I don’t want to sit there and read through fifteen different leaflets.” (Theresa)

Carers wanted easily understandable information about the availability and accessibility of benefits, entitlements, and services including care providers, specialist therapists, day-care-centres, lunch clubs, and technology. Carers expressed wanting practical advice from someone in a similar situation or with experience caring for people with dementia. This could include advice on talking about care-related issues at work which many found difficult, but which could be essential for accessing support. Carer or dementia organisations or peer groups provided valuable information and guidance but were often difficult to access because their hours conflicted with carers' work schedules and some carers described only learning about them by accident.

"They've [carer organisation] got some amazing courses about understanding dementia, you know, how to deal with all the things that are coming. I just can't get to them because I have work." (Theresa)

Carers who used the internet to look for information sometimes found this overwhelming as they often did not know what to look for. One carer got information from a social media channel on dementia care and used the comments section to get advice from peers but found that the content was only mildly relevant due to being from a different country.

### **Fighting for information**

For many carers, dealing with the council or organisations involved in aspects of people with dementias' care was cumbersome, bureaucratic, and time-consuming. One frustration was the perceived fragmentation of services. Maggie, for example, described how local councils prescribe a telecare product, technology suppliers provide it, and contractors install and maintain it – with little to no communication between them. This required her to hunt down those responsible for providing a specific aspect of a service, keep calling for updates, and repeat her concerns again and again whenever she was forwarded to someone else.

"I am astonished by the lack of organisation in the national health service and the council. They are unbelievably disorganised. They can't coordinate anything, they can't communicate with each other, and so much of my time is spent on the phone trying to get people to do the things that are their jobs, that they should be doing seamlessly without any reference to me at all." (Maggie)

Maggie suggested these organisations could use software to coordinate and work on cases together:

"My partner works in construction, and they have a programme called [redacted] which is a platform that everybody has access to, password-protected, anybody can log into [programme], and all the drives for the buildings that they build are on there, and all the comments that everybody makes go into a central place and everybody can see it, at any time. And that's what they [council and national health service] need. And it already exists. They just need to buy it and use it." (Maggie)

Some carers found it very difficult to get the information they needed from the council, for example, information on Scotland's self-directed support scheme. In Maggie's case, the council had installed movement sensors in her mother's home to better understand her care needs. Weeks after the technology had been taken down again, Maggie still had not received the results:

"After it [technology] had been there for a month, I phoned them [council] up and I said, 'Can you tell me what the data is from this device?'. 'Well, she moved around a bit in the last month'. And so then, the guy came back who'd fitted it.

Had another chat with him. He said, 'I'm going to speak to the other chap and get him to contact you'. I never heard from him. That was weeks ago," (Maggie)

While some carers were inclined to excuse councils for being understaffed and overworked, others felt that councils did not know themselves what support was available or how it worked and that obstacles were deliberately put in their path to prevent them from accessing benefits or other forms of support.

"Everything's a state secret really (laughs) it really is! They will give you no advice and they will give you-, they'll not sort of say to you, 'Well, you're not entitled to this but you might be entitled to that'. They never tell you that. They just tell you 'You're not entitled to that' and you've got to find out things." (Flora)

One carer suggested using a voice recorder app to have a record of the conversations with the council in case they were challenged about what had been agreed.

### **Exchanging information with HCPs**

Sometimes people with dementia were able to and preferred to attend appointments with HCPs on their own, in which case carers might worry that they do not get all relevant new information if they do not attend themselves. Exchanging information with HCPs could be especially challenging due to conflicting work hours. Theresa suggested a secure online platform where everybody involved in the person with dementia's care could store and share relevant data like test results, prescriptions, care plans, etc.

"It would be useful to have some kind of platform where, you know, we had information about all the people that were involved in mum's care or even access to her care plan. You know, at the moment, it's just a file hidden in her flat [...]. I personally would find that useful to have one place to go for absolutely everything, whether it's the memory centre information, carers information, the GPs information, the hearing centre's information. Because, you know, I don't know when her next appointment is for her hearing aids 'cos I've not been, you know." (Theresa)

#### 5.3.7. Personal care

Many carers provided intense personal care, even if they received help from care services. In their efforts to reconcile work and care, providing personal care however was only relevant for carers who worked and cared at the same place or who worked close enough to care during their lunch breaks. Most personal care (i.e., preparing meals and helping people with dementia to eat, drink, and take their medication; helping them with grooming; etc.) was plannable and could be arranged around work.

"I'll do a couple of hours, clear the emails. And I'll go and give my mum her breakfast. [...] and then I'll go back to, well I'll go the gym for a wee while, go back to work, then make sure that I'm there for lunch [...] After I prepare dinner, cook it, and lay it out, I'll go back to work for a couple of hours." (Iona)

Toileting presented a bigger challenge, particularly if people with dementia suffered incontinence or severely limited mobility, as this could not be planned, took a long time, and was often very uncomfortable for carers.

"It is really challenging because it's your own parent. I mean, it's bad enough doing that for anybody at all that you are not connected with but to do it for your own parents, it's such a very difficult and emotional thing." (Maggie)

One carer thought about how personal care might be more automated in the future, for example by robots, but also expressed trepidations regarding AI and robots and believed that the person with dementia would prefer the human touch.

“Maybe in 20 years’ time people are used to that and they find a way of dealing with it. And it’s just because we are on the cusp of that development that we find it frightening. But at the moment, you know, I might say, ‘Well, I would really like it if an automated carer could deal with the incontinence stuff’, for example. But that’s for my benefit. But mum, how would she feel about that?” (Maggie)

#### 5.4. Discussion

In this study, we aimed to explore which work-care reconciliation challenges working dementia carers needed, wanted, and used technological solutions for. Combining work and care is a very dynamic effort, impacted by fluctuating care needs typical for people with dementia and changing work demands like upcoming deadlines, business meetings, work trips, etc (Gallagher-Thompson et al. 2020; Matsumoto et al. 2007; Newbronner et al. 2013; Spann et al. 2020). Furthermore, the arrangements carers make to support them in fulfilling both their roles vary, depending on available resources and preferences (Spann et al. 2020, see chapter 3.3.3.). Hence it is unsurprising that carers experienced a multitude of challenges they sought technological solutions for i) care management; ii) attending appointments; iii) entertainment and companionship for the person with dementia; iv) dealing with psychological and psychosocial stress; v) safety concerns; vi) accessing information, and vii) personal care. To preface this discussion, it should be highlighted that while technologies can have a transformative effect on the lives of those who need them, carers and people with dementia alike, they must not come to be seen as a substitute for proper and urgently needed investment in health and social care in the UK (Eccles 2021).

Our interviews showed that carers had experience with technology in some areas, particularly regarding the “safety concerns” challenge, while few had considered potential technological solutions for other challenges such as their “psychological and psychosocial stress”. The interview situation itself and the discussion of their challenges prompted many of them to reflect and creatively think about what technology might offer them. This was equally the case for our younger and older interviewees and echoes the findings of previous research (Andersson et al. 2016; Carers UK 2012; Carers UK 2013a; Jarrold and Yeandle 2009).

Managing the care network was a significant challenge many carers expressed. This included coordinating, communicating, and keeping all members of the care network informed but also receiving the required information from care services and reassurance that the care had been provided according to the agreed-upon care plan. All the technological solutions carers used or wanted (phone, email, texting, generic messenger apps, secure platforms for care providers to access care plans and daily reports, technologies to let carers know if and when care network members have been looking

in on the person with dementia) are dependent on care network members' agreement and active participation. Care services would also be required to procure and implement software packages, revise workflows, train their employees, and above all, ensure compliance with data protection which could be a barrier given the current social care funding and personnel crisis in the UK (Care Quality Commission 2021; Ward et al. 2020). Customisable software solutions to help carers administrate their privately organised and paid for care workers are also needed and would have to be regularly updated to conform with any legal changes and be easy to understand and use. Secure online platforms were also suggested as a solution for carers unable to attend medical or similar appointments with people with dementia due to work to ensure they retain all relevant information. Again, the accessibility of this technology along with others to facilitate appointment coordination (e.g., answer phones, email, online appointment system, etc.) and remote (phone or video) consultations depends on their implementation by others, i.e., the healthcare system or individual HCPs. Already the Covid-19 pandemic has necessitated the shift to more remote consultations (Joy et al. 2020) but issues such as carers' ability to participate when at work and people with dementias' ability to participate when on their own need to be addressed.

People with dementias' entertainment was a big concern and caused a lot of guilt for many carers who worried about the effect of the lack of adequate stimulation and companionship on the progression of people with dementias' symptoms and quality of life. Apart from radio and TV, however, which were often seen as too passive, carers had not considered technological solutions for this challenge. In any case, what people with dementia experience as entertaining and stimulating might depend on their personality, ability, and preferences which might require carers to reflect on their own views on how people with dementia should spend their time and accept that they might have other ideas. Thus, technology for entertainment would have to take people with dementias' experience with and ability to use technology, and their preferences into account (Lorenz et al. 2019). Groenewoud et al. (2017) found that people with dementia can enjoy games on tablet PCs and can play them without help, provided these games are appropriate. Reminiscence apps (Moon and Park 2020) have also been found to be stimulating and beneficial for people with dementia. To be useful for working carers, people with dementia must be able to operate these technologies on their own. An increasing number of studies explore the use of companion robots for people with dementia (Jung et al. 2017; Moyle et al. 2016; Pike et al. 2021). Issues like the safety of the technology, affordability, and acceptability will have to be addressed. Similar concerns need to be considered for driverless cars – if and when they are commercially available – which some carers hope could combat the social isolation of people with dementia. As dementia progressively affects the brain's neural networks, some form of language and communication impairment is common in people with dementia (Weekes 2020). Technology which could help compensate for these impairments would have to consider that their exact causes and

expression can vary. However, carers' wish for technological solutions to help communicate with people with dementia might be more an expression of a desire to resurrect the relationship they once had with their loved one, rather than about the act of exchanging verbal information. Accordingly, carers might benefit more from help with accepting and coping with this loss rather than complex technologies.

An almost universal concern for working carers was ensuring people with dementias' safety. This challenge seemed to be the one most carers had experienced technological solutions or wanted them for. Carers wanted technologies that alerted them or their care network to potentially dangerous situations, accidents, or emergencies to ensure a prompt response. Technologies would have to be appropriate for the specific need (e.g., crime, accident, and emergency prevention/response, reminding, disorientation), be responsive to people with dementias' abilities and preferences regarding technology use (i.e., technology requiring active use or prompting to action vs. passive monitoring technology), provide options as to whom to alert to the situation (i.e., carer, care network members, or emergency call centre) in case carers don't have the autonomy at work to manage themselves (see chapter 6), provide an adequate range so as not to inadvertently lock people with dementia into a "safe zone", and provide information that is quickly and easily accessible and interpretable for carers to have peace of mind at work. Technologies aiming to remind or alert people with dementia should also have additional haptic, audio and/or visual accessibility features. Before using this technology though, it needs to be assessed whether people with dementia would be able to act on these alerts and not be frightened by them. An important issue with technologies that need to be carried or worn by the person with dementia is the potential that they may forget to do so. Lorenz et al. (2019) highlight that people with dementias' ability to interact with technology depends on the progression of their disease. Technology that requires people with dementia to actively use it thus requires regular evaluation if it is still fit for purpose. From our interviewees' descriptions, it appears that the process by which people with dementia are issued technology by local authorities for their safety needs requires revision. Most people with dementia received community alarm systems by default despite not being able to actively operate the device when needed or inappropriate or untimely responses by emergency services. There was also a pronounced lack of coordination between organisations tasked with prescribing, providing, and maintaining technologies which presented significant additional challenges for carers. For many carers, their need for safety conflicted with people with dementias' need for privacy and independence. There is, however, some evidence to suggest that technology might improve people with dementias' independence by increasing their confidence and sense of safety – future research should seek to expand on these findings using more robust methods, including larger sample sizes (Meiland et al. 2017).

For the challenges of managing their psychological and psychosocial stress and accessing information, online sources can provide valuable solutions. Interestingly, only one carer thought to seek emotional support from social media – that includes the younger carers we interviewed. Online peer networks can provide both emotional and practical support, independent of time or carers' location. Dementia or carer support organisations can help carers identify peer groups suitable to their needs and wants. Psychoeducational online programmes can increase carers' resilience and coping skills and reduce stress and negative affect (Beauchamp et al. 2005; Klemm et al. 2014; Kuhn et al. 2008). These programmes should include practical advice for challenges unique to working carers such as how to talk to line managers and co-workers about their caring responsibilities, how to be assertive when it comes to negotiating autonomy at work, etc. Ideally, when developing such interventions, carers should be included in the design process. As carers do not have a lot of time and energy, information on dementia, caring, and available support needs to be easily understandable and accessible, customisable, up to date, in one place and certified by trusted sources. Carers struggling to receive the required information from fragmented service providers would benefit from increased system thinking and networking software solutions. These technologies could streamline these organisations' workflow, thereby helping to preserve scarce resources. However, this is yet another technological solution carers have no influence over.

Regarding the provision of personal care, only toileting is of immediate relevance to carers' efforts to reconcile work and care as all other activities could be planned and worked around – and only for carers who work and care simultaneously or provide care during their lunch breaks. Carers wanted solutions for toileting and especially for incontinence issues which they experienced as very uncomfortable and difficult. This seems to be an area where much research and development of technology are needed. Care robots did not seem to be an option for carers who thought that people with dementia would prefer personal interactions.

#### 5.4.1. Strengths and limitations

To the best of our knowledge, this was the first study seeking to explore which work-care reconciliation challenges dementia carers wanted, needed, and used technological solutions for. In light of increasing pressure on working dementia carers, this research thus provides valuable insight into how carers can use technology to help themselves address some of their challenges and overcome the availability and accessibility limitations of publicly funded and organised support. A strength of the study is the purposive sampling strategy we used to recruit carers with a broad variety of traits regarding age, gender, and employment status. Recruiting carers in their twenties and thirties meant that we could include the perspectives of a generation that grew up using the internet and came of age in the era of the smartphone, for whom it might feel more natural to consider technology to solve their problems.



Furthermore, representing a broad spectrum of employment situations is likely to provide a more complete picture of the work-care reconciliation challenges carers face and the technologies they might find useful as a result. However, despite substantial efforts, we were not able to recruit carers in “insecure work” such as the gig economy. Further research should explore if their work-care reconciliation challenges align with our findings. While we are confident to have reached data saturation regarding the work-care reconciliation challenges dementia carers face and seek technological solutions for and discussed our analysis with other work-care scholars, further discussions of our findings with key informants like carer support organisations could strengthen the credibility of our analysis.

Future studies should seek to employ a longitudinal approach which could provide insight into how carers adapt their work-care reconciliation strategies over time, different challenges they might experience along the way and whether, how, and why their priorities for technological support change. Ideally, interviews could be conducted at important stages throughout carers’ care career, including becoming a carer or after important events such as significant changes to the person with dementia’s condition (e.g., hospitalisation, deterioration, or improvement of health), to the carer’s employment situation (e.g., promotion, job change, change to work hours) or to the care arrangement (e.g., people with dementia moving in with the carer or receiving care through additional services).

Our findings are limited to the situation of carers of people with dementia living in Scotland and may not be transmissible to other countries.

#### 5.4.2. Implications for practice

Our findings can help those aiming to support working carers (i.e., their employers, carer or dementia support organisations, local authorities, etc.) better understand dementia carers’ needs regarding technological solutions. Many carers still do not think about technology when looking for solutions to their challenges, even if promising options exist. Working dementia carers should thus be encouraged to reflect on the challenges they experience when combining work and care and assisted in looking for technological solutions if there are no other resources or solutions available (e.g., care services, support from their community, etc.). Local authorities involved in the procurement of technologies should consider that technology is not a one-fits-all solution and that particularly people with dementia, depending on the progression of their disease, might not be able to use technologies as intended (Lorenz et al. 2019). Thus, not only carers’ needs but also the implications for people with dementia must be considered when looking for technological solutions. We identified several issues carers wanted solutions for, which require other stakeholders (i.e., local authorities, care providers, HCPs) to change their practices and implement technologies (e.g., to decrease the fragmentation of

services and organisations involved in care provision). While that would require an initial investment and system change and learning, organisations might ultimately also benefit from more streamlined workflows and interactions with carers. Further research is needed to explore which technologies are currently available that have the potential to address the challenges carers expressed in this study. To be truly empowering, the aim should be to offer solutions to all challenges working dementia carers face, without prioritisation, as many will experience several if not all these challenges at some point in their career as workers and dementia carers.

## 5.5. Conclusion

Dementia carers face many challenges when combining paid work and unpaid care for people with dementia. Technology can offer solutions independent of a strained social care system or any authorities, thus empowering carers to help themselves. These technologies must be used in a complex context where their impact on people with dementia, carers' work environment, and everyone involved in people with dementias' care (i.e., the care network, care services, healthcare providers, local authorities, etc.) must be considered.

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## 6. The impact of autonomy at work on dementia family carers' ability to manage care-related emergencies, and use technology to that end: Semi-structured interviews in Scotland

### **Abstract**

Most people with dementia (PwD) are cared for by unpaid family carers, many of whom must balance caring with paid work. This regularly entails dealing with care-related emergencies (CRE). This study aims to explore the impact of carers' autonomy at work regarding breaks, schedule, and place on their ability to manage CRE, and use technology to that end. We conducted semi-structured interviews with 16 working carers of PwD in Scotland. Data were analysed thematically to identify key themes. Autonomy at work appeared on a spectrum from no to complete autonomy. Carers' position on this spectrum was often dynamic and determined by the nature of their work, their workplace culture and regulations, and the support of their line managers – or clients in the case of self-employed carers. Break autonomy allowed carers to use technology to be notified of and delegate the CRE response. Schedule autonomy allowed for an in-person response to CRE. Place autonomy allowed carers to work and care simultaneously, which enabled them to manage CRE immediately but presented them with additional challenges. Distance between the workplace and PwD's residence impacted carers' ability to manage CRE, despite having complete autonomy. Implications for healthcare professionals, service providers, employers, policymakers, and technology developers are presented.

**Keywords:** Working carers; autonomy at work; care-related emergencies; dementia; interviews; technology.

**Authors' note:** We recognise that using abbreviations when referring to an individual or a group of people is derogatory. The use of PwD as an abbreviation for a person or people living with dementia in this paper should improve readability and is not meant to disrespect this already marginalised group.

### 6.1. Background

People who work full-time while also providing unpaid family care<sup>6</sup> are most likely to care for people with dementia (PwD) (Carers UK, 2013b). The experiences and related challenges PwD live through are well-documented, can affect their ability to continue living independently, and include affective and cognitive issues commonly referred to as behavioural and psychological symptoms of dementia (BPSD) (World Health Organization, 2017). Most PwD are primarily cared for in their communities by unpaid carers – family, friends, or neighbours (Alzheimer's Research UK, 2015; Prince et al., 2014). There are approximately 700.000 unpaid dementia carers in the UK (Lewis et al., 2014). Although their exact number is unknown, current societal trends are likely to increase the number of working dementia carers: retirement ages – especially women's – are extending, the prevalence of dementia in the UK

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<sup>6</sup> Care in this context refers to the assistance provided to sick, frail or disabled people and not to childcare if the child in question has no special healthcare needs.

will double by 2050, and public funding constraints limit availability and accessibility of care services (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Prince et al., 2016; Prince et al., 2014; Round, 2017; World Health Organization, 2017; Yeandle & Buckner, 2007). Already, the Covid-19 pandemic has led to a sharp increase of working carers (Carers UK, 2020; Phillips et al., 2020) which is likely due to the intensified precariousness of the UK health and social care sectors (Charles & Ewbank, 2021).

Both work and caring can positively and negatively impact carers (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). However, if not sufficiently supported, combining care and work can create significant demands on carers – specifically their time – which can negatively affect their employment, health, and relationships (Carers UK, 2014; Koyama et al., 2017; Kuo et al., 2014; Wang et al., 2011, 2013, 2020; Wittenberg et al., 2019). Caring for PwD is very challenging due to the unpredictable and complex nature of the condition (Matsumoto et al., 2007; Newbronner et al., 2013). PwD's care needs can fluctuate, increase with the progression of their condition, and include everything from care management, assistance with (instrumental) activities of daily living, social or emotional support, and monitoring of their safety (Gallagher-Thompson et al., 2020).

Role theory has long been an important theoretical framework to explore the underlying dynamics between work and family life and the strain resulting from role conflict (Edwards et al., 2002; Goode, 1960; Greenhaus & Beutell, 1985; Lavassani & Movahedi, 2014; Rozario et al., 2004). Time-based role conflict arises when the demands of one role (e.g., work) make it physically impossible to address the demands of another (e.g., caring), or through being too preoccupied with one role to meet the demands of the other, even while attempting to do so (Greenhaus & Beutell, 1985). Examples of working carers' time-based role conflict include care management; coordinating and attending medical or similar appointments; and worrying about and managing care-related emergencies (CRE, e.g., falls, accidents and injuries; home environment hazards like fires, floods, electricity or heating blackouts; BPSD-related issues) (Spann et al., 2020). Hereafter, we focus on CRE as their unplannable nature is particularly problematic to reconcile with carers' work.

Technology, herein defined as any electronic and/or digital device, can play an integral part in managing CRE. Spann et al. (2022) found that working carers used monitoring technologies to ensure the cared-for person's safety, and technologies for direct communication and task-sharing tools to coordinate and communicate with their care network, healthcare professionals, and the cared-for person. Technology thus can be an important tool for notifying carers of and managing CRE when at work. This, however, requires carers to have autonomy, i.e., the ability to self-directedly use technologies at work. There is an evidence gap on the impact of autonomy at work on carers' ability to use technology for care-related reasons (Spann et al., 2021).



Autonomy is a long-debated concept in the work context, especially regarding workers' well-being and empowerment, and organisational management (see Gagné & Bhave, 2011 for a brief overview). Broadly speaking, autonomy at work is "the control workers have over decisions within their job" (Wheatley, 2017, p.297) and can be separated into job control, i.e., autonomy over work tasks and conduct, and schedule control, i.e., autonomy over work schedule and place (Wheatley, 2017). Autonomy at work hereafter explicitly refers to schedule control. Flexible working is often used synonymously and encompasses "a wide range of arrangements that allow workers to work more flexibly" (Chung, 2017 p.4) like compressed hours or working from home. Flexible working is one of the most discussed and sought-after solutions for working carers' time-based role conflict (Carers UK, 2014, 2019a; Spann et al., 2020). However, whereas schedule control implies workers' power to self-direct, flexible working is a neutral term, revealing no information on underlying power dynamics. Yet it is this power to self-direct that is likely to have a big impact on how carers can deal with CRE at work. While UK employees have the statutory right to request flexible working, it is their responsibility to demonstrate the effect on their employer and can be rejected on that basis (Carers UK, 2019b). Similarly, employees have the right to time off for CRE (GOV.UK, n.d.) but duration, frequency, and pay are left to employers' discretion. This does not apply to self-employed people, who may have more autonomy but also do not have the same employment rights.

In this paper, we aim to address the evidence gap identified by Spann et al. (2022) and explore how working dementia carers experience the impact their autonomy at work has on their ability to manage CRE and use technology to this end. This study is part of a research project investigating how technologies can support working carers of PwD. The interviews conducted for this study (Spann et al., 2021) also addressed work-care reconciliation challenges carers wanted solutions for (e.g., care management, safety concerns, providing entertainment and companionship for PwD, etc.) and their experience with technology. These findings will be published elsewhere.

## 6.2. Methods

Interviews allow researchers to gain an understanding of people's lived experiences (Barbour, 2014; Bunniss & Kelly, 2010). We conducted interviews following Witzel's (2000) problem-centred approach, which centres on a specific topic and uses a topic guide to prompt respondents' narration. This enables the in-depth exploration of the topic while ensuring that the required themes are addressed. A brief questionnaire captured participants' contextual demographic data.

We conceptualise autonomy at work as break ("Do you have control over your break times?"), schedule ("Do you have control over when you work?"), and place autonomy ("Do you have control over where you work?"). Participants were asked how these concepts affected their ability to combine work and care and use technology (see table 8).

Table 8: Relevant questions and prompts from the interview schedule

<b>Can you tell me about your current work situation?</b>	
Prompts	<ul style="list-style-type: none"> <li>• You indicated that you                             <ul style="list-style-type: none"> <li>○ Have high/low control over your work schedule</li> <li>○ Can/can't work from home</li> <li>○ Can/can't take breaks whenever you need to</li> </ul> </li> </ul> <p>...how does this affect your ability to combine work and care?</p>
<b>Does technology play a part in your support?</b>	
Prompts	<ul style="list-style-type: none"> <li>• If yes, which technology?</li> <li>• How? What do you use it for?</li> </ul> <hr/> <ul style="list-style-type: none"> <li>• Are you able to use technology at work?                             <ul style="list-style-type: none"> <li>○ What is your line manager's attitude?</li> <li>○ How does your level of autonomy at work (see above) impact your ability to use the technology?</li> </ul> </li> </ul>

A pilot interview confirmed the topic guide's suitability. Interviews took place in Scotland between March and July 2019 at a place most convenient for interviewees: nine chose their home, five neutral places like pubs, cafés, or meeting rooms, and one requested a phone interview. Interviews lasted between 35 and 120 minutes (mean: 90 minutes). All interviews were audio-recorded and observational notes were taken during and after.

#### 6.2.1. Ethical approval

Full ethical approval was granted by the SchARR Research Ethics Committee at the University of Sheffield (Reference 022994). All participants were fully informed about the study, including their right to withdraw at any point without consequence, and gave their explicit consent before the interview started. Confidentiality was ensured throughout the study and data was stored securely.

#### 6.2.2. Participants

We used a purposive sampling strategy (Barbour, 2014) to ensure participants had varying levels of autonomy, and that both sexes and a broad age range were represented. To ensure participants had enough experience being both in paid work and unpaid care, carers were eligible if they: i) were in paid work for at least 20hrs./week; and ii) cared for at least 5hrs./week. To ensure carers had had enough time to come to terms with being a working carer and set up their support system, they also iii) had to have been working carers for at least six months. As caring for PwD living in residential care settings can look vastly different, carers were eligible if they iv) cared for a PwD outside of residential care settings in Scotland.

### 6.2.3. Recruitment

Working carers are difficult to recruit due to generally being very short on time, (see e.g., Arksey & Glendinning, 2008; Barnett et al., 2009; Boezeman et al., 2018; Bourke et al., 2010; Eldh & Carlsson, 2011). Hence, we used a multipronged recruitment approach. Carer organisations, the chamber of commerce, trade unions, the researchers' professional network, and a random selection of businesses operating in Scotland were asked to distribute our recruitment flyers among their employees, clients, and contacts, and to post an advertisement for the study on their social media channels. Flyers were pinned to several community notice boards, handed out at dementia support groups, and placed at dementia daycare centres. Carers were invited to contact the research team if they fit the eligibility criteria and wanted to get involved. One carer organisation forwarded the contact details of interested clients with their consent, which were then contacted by the research team. We also asked participants to forward our recruitment flyer to other carers they knew who fit the inclusion criteria.

### 6.2.4. Analysis

Interviews were transcribed and read multiple times to ensure familiarity with the texts. The data was analysed using thematic analysis (Braun & Clarke, 2006). The question *"How does break, schedule, and place autonomy at work impact dementia family carers' ability to manage care-related emergencies and use technology to that end?"* was used to guide the analysis. Relevant text passages were coded in an inductive, iterative process. Codes were then organised into clusters of meaning that formed the themes and subthemes and the relationships between them (see figure 16). An overview of the codes, themes and subthemes, and example quotes, are provided in appendix I. Emerging themes were discussed within the research team. To confirm the soundness of our analysis, we sent each interviewee a summary of the analysis of their interview, to which six participants (37.5%) responded. Their clarifications and added details helped to improve the interpretation of the data.

### 6.3. Findings

A total of 16 carers participated (ten women and six men). The mean age was 50.6 years (27-70). Seven were in full-time employment (>35h/week), six self-employed, one was partially retired, and two full-time employed while also having a small business on the side. Three carers' situations had changed drastically shortly before the interview: two had resigned from their full-time employment for care-related reasons and now worked significantly less than 20hrs./week on a self-employed basis, and for one carer, caring had just ended due to the PwD's passing and they just started to transition into retirement. Per the study's inclusion criteria, only their situation before these events was included in the analysis. Care hours varied between five and, in one extreme case, 75+h/week. Most carers could

only estimate the number of weekly hours they cared for as most were not plannable and sometimes did not even register as caring (e.g., shopping and home maintenance). Of the PwD, 13 were carers' parents (one cared for both parents), one in-law, one uncle, and two (ex-) spouses. Table 9 presents an overview of participants' characteristics.

Table 9: Participant characteristics

<b>CARER</b>		<b>Women (N=10)</b>	<b>Men (N=6)</b>	<b>total n (N=16)</b>
<b>Age</b>	<40	1	3	4
	40-60	7	1	8
	>60	2	2	4
<b>Employment status</b>	Employed	6	3	9
	Self-employed	2	2	4
	Employed & self-employed	1	1	2
	Partially retired, employed	1	0	1
<b>Weekly work hours</b>	<35hrs	1	1	2
	35-40hrs	7	2	9
	>40hrs	2	3	5
<b>Caring for yrs.</b>	0.5-2yrs	3	2	5
	3-6yrs	2	3	5
	>6yrs	5	1	6
<b>Weekly care hours</b>	<10hrs	2	2	4
	10-20hrs	4	1	5
	21-40hrs	3	2	5
	>40hrs	1	1	2
<b>Work sector</b>	Public	4	3	7
	Private	6	2	8
	Public & private	0	1	1
<b>Industry sector*</b>	K: Financial and insurance activities	4	0	4
	L: Real estate activities	1	1	2
	M: Professional, scientific and technical activities	0	1	1
	O: Public administration and defence; compulsory social security	2	3	5
	Q: Human health and social work activities	3	1	4
	R: Arts, entertainment and recreation	1	0	1
<b>PwD</b>				<b>total n (N=17)</b>
<b>Relationship to carer</b>	Parent			13
	Parent in-law			1
	Other parental generation			1
	(Ex-) Spouse			2
<b>Age</b>	<70yrs			4
	70-80yrs			3

	>80yrs	<b>10</b>
<b>Dementia Diagnosis</b>	Alzheimer's	<b>5</b>
	Vascular	<b>3</b>
	Fronto-temporal	<b>2</b>
	No official diagnosis	<b>1</b>
	N/A	<b>6</b>
<b>Dementia Stage (CDR)**</b>	Moderate	<b>5</b>
	Moderate-severe	<b>4</b>
	Severe	<b>8</b>

\*UK Standard Industrial Classification ((ONS), n.D.)

\*\*CDR=Clinical Dementia Rating Scale, staging based on participants' descriptions (Waite et al., 1999)

### 6.3.1. Autonomy at work – a spectrum

All carers had experience with CRE at work, ranging from accidents in the home (e.g., falls, leaving the stove on, taking the wrong medication), to the PwD getting into trouble when out and about (e.g., getting lost or picked up by police for shoplifting), to having to manage issues with the care network (e.g., network members needing help to manage BPSD or a breakdown of the care arrangement).

“You are always firefighting; you can't plan anything” (Maggie)

Carers' break, schedule, and place autonomy appeared as a spectrum with “complete” and “no autonomy” at the extremes (see figure 16). Complete autonomy allowed carers to generally manage CRE well and use technology. However, the distance between carers' workplace and the PwD's residence could make it physically impossible to manage CRE in person, even if their autonomy would have allowed it. No autonomy, on the other hand, meant that carers were generally unable to manage CRE or use technology.

Where carers landed on this spectrum seemed to be impacted by the nature of their work, workplace culture and regulations regarding flexible work or technology-use for private reasons, and the support of line managers or clients. Workplace culture in turn could affect line managers' attitudes, and regulations their ability to offer carers support.

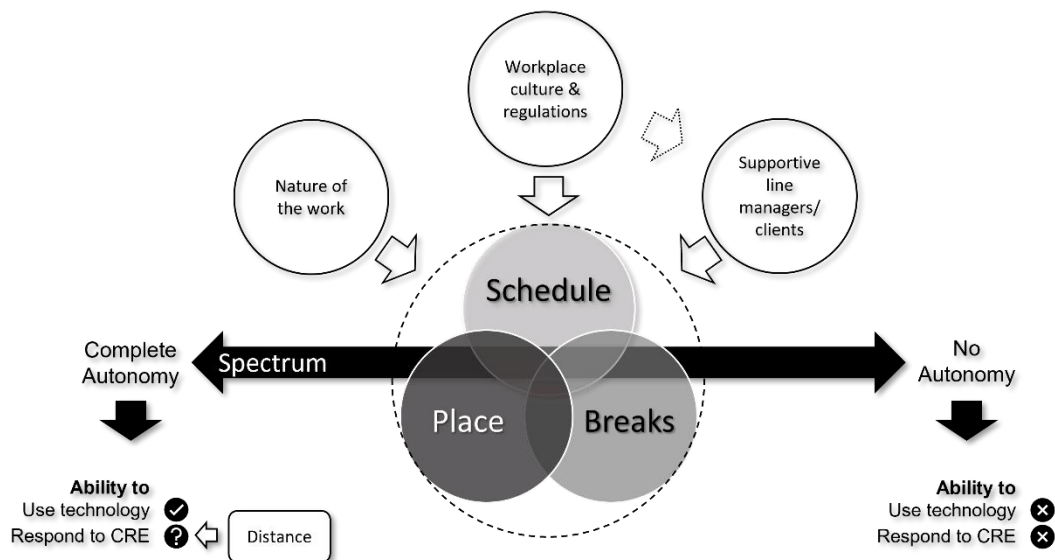


Figure 16: Illustration of the autonomy-at-work spectrum (CRE = care-related emergencies)

Three interviewees were at the no-autonomy and six at the complete-autonomy end of the spectrum. The remaining seven were somewhere in between. Carers did not necessarily experience their position on the spectrum as static. Hannah, for example, transferred to a different department in her company and got a new line manager who was much more understanding and supportive:

“My previous role I was finding it a real challenge. They weren’t that understanding. My current manager couldn’t be more understanding. We’re two weeks in but I, I just get the feeling that she, she is much more understanding in general. Much more compassionate, empathetic, and much less a micro-manager. So, I think it will work better in every respect.” (Hannah)

Similarly, Theresa became very unsure about her autonomy when she got a new boss:

“I feel, rightly or wrongly, to ring this new boss in [location] who doesn’t know me and say ‘Listen, my mum’s not very well. I need to go and spend the afternoon with her’, I feel as though I would get a black mark for that.” (Theresa)

Carers who normally experienced high autonomy could find their position on the spectrum change temporarily, e.g., when they needed to attend business meetings or go on business trips.

“The only way I wouldn’t, I wouldn’t do that [leave work for a CRE] is if I was sort of in a video conference and I didn’t have my phone with me for instance and I was in the middle of a discussion with someone.” (Max)

#### 6.3.1.1. Break autonomy

Autonomy over when, how often, and how long they could take breaks was essential for carers’ ability to use technology for care-related reasons. Complete break autonomy allowed carers to use technology when needed.

“We’ve all got our mobiles so I mean I can go out for a cigarette break. As long as I take the time off my flexi-time, it’s my own time.” (Flora)

At work, carers’ most important technology was their (smart-)phone. They used it to communicate with their care network and the PwD’s healthcare professionals via phone calls, texts, emails, or messenger apps, and to check in with the PwD to see how they were doing or remind them of

upcoming appointments, or to take their medication. Some carers also used their phone to manage other technologies like cameras or sensors installed in the PwD's home for their safety.

Some carers needed only a few seconds to periodically check on messages or monitoring technologies. Break autonomy meant that carers could be notified of CRE – by the PwD, care network or emergency services – manage some of them immediately or delegate the response to their care network. However, some carers had to find enough privacy to take a call.

“This open plan environment, you can't just sit there and pick up the phone. I have to find a meeting room, make the call privately.” (Theresa)

No break autonomy meant that using phones was limited to fixed break times.

“So apart from being able to make the odd phone call in a break period, that was about it” (Gavin).

Not being able to use their phone when needed meant that these carers could not even be notified of CRE, let alone manage them, making them highly dependent on their care network. This was problematic as some carers had to rely on people who had considerable care needs themselves while many others had to get by without professional help due to long waiting lists for care services. Some carers arranged to be called via their workplace in case of CRE.

“[Workplace] has my [department] phone number. So, if that rang then I would be able to answer that, yes.” (Rose)

However, technology could still help carers with no break autonomy and no care network to have peace of mind. Some PwD had personal alarm wristbands connecting them to a call centre to coordinate the emergency response. Gavin expressed the wish for automated solutions:

“Maybe if there was something that was more automated, that could provide a kind of a robotic approach, that could in some way, in a compassionate- you know it could even replay my voice perhaps to her. Just giving her the message, you know ‘Are you still up, mum? It might be time to go to bed. I'm working at the moment, but I will speak to you in the morning’.” (Gavin)

#### 6.3.1.2. *Schedule autonomy*

Schedule autonomy meant that carers could manage their work time, taking time off or rearranging their work hours. This enabled them to manage CRE in person. Carers who had some levels of schedule autonomy generally had complete break autonomy and thus no problems using technology. Conversely, carers with no schedule autonomy did not automatically also have no break autonomy, i.e., having fixed start and end times could still allow them to take breaks when needed. The only option available to carers with no schedule autonomy to still manage CRE *in person* was co-workers taking over their shifts and responsibilities.

“My colleagues I work with on my rota, they all know about my home situation. And they wouldn't hesitate if we were fully staffed and probably even if we weren't. They would muck in and take over.” (Rose)

One carer changed her work pattern to night shifts because her care network could look after the PwD at night and the likelihood of CRE coinciding with her work was reduced. This, however, meant that she had to manage daytime care when she needed to catch up on sleep.

“No dayshifts anymore. I used to do the odd dayshift. But I can't leave [PwD] for that length of time anymore.” (Rose)

Carers somewhere in the middle of the schedule autonomy spectrum had varying levels of control over their start and finish times. Some could take time off and make it up another day, allowing them to leave work when needed to manage CRE.

“With the nature of the role there is, there is flexibility [...] other than the meetings, the work doesn't necessarily need to be done at a specific time of day.” (Hannah)

Complete schedule autonomy meant that carers had no restrictions on how they arranged their work hours. These carers could usually integrate work and care more easily.

“My work situation lends itself very well to the situation with my mom. So, I haven't had any problems really. If I need to go out, I just go out. (Max)

However, business trips or meetings could be fixed points in their schedule even they had limited control over. Upcoming deadlines and stressful, performance-driven work environments could make it difficult to prioritise caring.

“Even if work said, ‘Yeah, you can have all the time off you want, actually’, that's fine, but my workload doesn't go anywhere from having all that time off.” (Theresa)

Some carers thus described trying to figure out whether they needed to deal with a CRE themselves and leave their workplace.

“Last week she'd overmedicated. So, you know, some other call to take when you're in a meeting or whatever just to say, you know, and then there's that - is she okay? Do I need to go? Do I need to stay?” (Theresa)

#### 6.3.1.3. *Place autonomy*

Place autonomy meant that carers could control where they wanted to work. Complete place autonomy meant also having complete break and schedule autonomy and the ability to use technology freely. Some carers' place autonomy was limited by needing to get permission every time they wanted to work remotely or having fixed days at the office. It could also be temporarily limited by business meetings or trips. Working remotely could make it easier to manage CRE. It also had the additional benefit of freeing up time otherwise spent on commuting. Technology was an essential tool to stay connected to work.

“It [working from home] means that I can stop work and I could pick up the phone and speak, whereas if that was at work, I'd have to find somewhere to do it or if I was in a meeting or whatever.” (Betty)

“If I haven't slept until really late during the night because I've been worrying, trying to figure out what the next thing is, I could be really tired. If I'd had to travel in the next day... But if I start, if I log on later, I just know that I'll just finish later and it just helps even in that subtle way, you know.” (Betty)

“As long as I can get my, those two days in [city] it is just enough. Everything else can be done off Skype, email, phone and I could be anywhere.” (Ian)

Place autonomy did not automatically mean that carers worked where they cared. While some lived too far away from the PwD, others did not see the need as they worked close to the PwD's residence.

“I would work from home if need be, but it makes no sense to me whether to work from home. I work from here because I'm so close anyway.” (Max)



"I would prefer to be up here [with PwD] more often but I don't want to take the micky, you know. This isn't where I'm based. So, and I have meetings in [town] and things like that and I really should be in the city that my job is located in." (Iona)

Carers who worked and cared at the same place were generally able to ensure the PwD's safety.

"If she wandered around during the day when I was there, I would be able to look out for her." (Maggie)

"In that time with mum just sitting there sleeping, not doing anything, I would do some work but obviously every five, ten minutes I get up and check she's all right and come back, do a bit more work." (Ian)

Some carers cohabited with the PwD, sometimes just briefly before returning to their own home. Others only spent their workday together and returned home in the evening. While these carers could often prevent CRE or manage them promptly, they were faced with unique work-care reconciliation challenges. They often provided high levels of personal care, despite some receiving help from care services. Work interruptions occurred frequently, and some carers felt they had to be constantly vigilant to keep the PwD safe. This required them to be very organised, yet flexible.

"It's absolutely understanding what's needed. Not just what you want to do, what's actually best for you, your mum, and your customers. Yeah. So, there's, there's no way you can structure it." (Ian)

Self-employed carers could face financial pressure if caring took up too much time.

"I might have an eight-hour working day and I might get two hours of work done in that time. But I have to live on the money that I make in my job. And if I'm only working two hours a day, I can't live on that." (Maggie)

Working and caring from the same place required boundary management. Some carers felt pressure to keep the PwD company and provide entertainment and expressed feeling guilty if they prioritised work over care and vice-versa.

"I often felt guilty getting on with work when I felt I should be with my wife and also felt guilty when I was with my wife, and I knew that I needed to be doing something for work." (George)

"I would see her walking past the studio door towards her bedroom and I'd say to her, 'oh are you away to bed mum?' and she'd just look at me and she'd say 'what else is there to do', you know. And she's, I know she didn't mean it to come across like that, but there was an element of, not blame but well, you know, 'you're ignoring me, you're working, what am I going to do, there's nothing for me to do', it wasn't just you know, it was, there was a resentment in her voice, about it that she had nothing to do and she was bored and she was just going to go to sleep." (Maggie)

One carer found the constant rapid role-switching between business and providing intense personal care very difficult.

"You're sort of having that [business] conversation to going and wiping poo off the floor or whatever it is, you know. A complete role switch. And you're going from being a nanny to being a bloke in a pin-striped suit in the city, to almost, not quite almost, to being a nurse. It's the constant switching between the two that is quite bizarre." (Ian)

### 6.3.2. Factors influencing carers' position on the autonomy spectrum

#### 6.3.2.1. *Nature of the work*

The nature of their work, i.e., characteristics inherent to some or all activities associated with a specific job, was a very important determining factor. All interviewees on the no-autonomy end of the spectrum worked in client-facing roles in the public sector (i.e., as telephone mental health advisor, airport security officer, and care home assistant). The nature of their work required them to be at a

certain place at a certain time and always focused on their work. Technology could only be used during official break times:

“I have to say that the nature of the work I was doing required pretty much 100% concentration. So, whilst deployed it would not have been, it wouldn't have been appropriate, and it probably wouldn't have been supported, to know that somebody could potentially be distracted in that way.” (Gavin)

Carers who had some schedule autonomy but were required to work at a specific place were employed in the public or private sector – one was a self-employed childminder. Some had client-facing roles (support worker, childminder, fire safety advisor). This determined their place of work which could vary depending on their client. Others had a desk job with no or limited client contact (civil servant, customer support, privacy officer at a bank) who needed to handle sensitive data or infrastructure only provided at their desk.

“If my job allowed me, I could physically work from home no hassle, but my actual job, my role just now isn't a work-from-home role.” (Sue)

Bigger teams, less specialised work, and non-client facing roles seemed to make it easier to take time off for CRE.

“There's enough people that if I go it doesn't have an impact, right? Me disappearing and nearly 200 people in the bit that I'm in, it doesn't kill the business. That's where working for the bank has been my saving grace.” (Sue)

“For a huge number of people that are working in office-based roles, I can see that that would work. But yeah, no, equally I can see that there are kind of customer-facing type roles where people go ‘No sorry, you're not doing that’.” (Hannah)

Carers on the complete-autonomy end of the spectrum were predominately employed in the private sector (project manager, bank clerk), or self-employed (art restorer, property manager, consultant). Their work was often project-based and not client-facing, apart from business meetings. As long as they got their work done on time, there was little scrutiny.

“I've got a lot of flexibility, as long as I get it finished for whenever people need it. But it means that if I need to talk to a doctor on a morning, I can do that and just build my time up later in the day.” (Betty)

Business trips or meetings could temporarily change the nature of these carers' work and their position on the spectrum.

“If I were in a meeting, I wouldn't obviously get my phone out and check the [care] camera, or I wouldn't get my phone out and go on the [care network] WhatsApp group.” (Iona)

#### 6.3.2.2. *Workplace culture and regulations*

For some, it appeared that the nature of carers' work would have allowed for more autonomy than they ended up having. For example, some carers explicitly stated that they were not allowed to use or have their phones on them, even when using them would have been possible without impacting their work. It is unclear whether that was due to their workplace's culture, i.e., the emotional and social environment created by explicit or implicit values, traditions, management style, etc., or explicit regulation.

“I have got time but it [using phones] is, it's not, you can feel it's not looked upon kindly.” (Jasmin)

“We’re not allowed mobiles. It would be in my bag” (Rose).

Some organisations did have explicit flexible working regulations. While some of these regulations had a positive effect on carers’ autonomy, others appeared needlessly restricting.

“We can please ourselves any time between seven in the morning ‘til nine at night. So that’s the sort of space. And in that time, we have to work [at least] three hours.” (Flora)

“There were some shift-swap options so, but they were pretty limited because you could only swap with people on the same sort of pattern as such.” (Gavin)

Hannah acknowledged the difficulty for large organisations to draft regulations fit for everyone, while Theresa pointed out that regulations could be good in theory, but a workplace’s culture – a high-stress and productivity-oriented culture in her case – could make it difficult to benefit from them in practice.

“Because we’re an organisation where that policy fits across everybody from people in back-office roles to people that are standing in a branch, they’re never going to be able to introduce a policy that is that broad and that flexible.” (Hannah)

“On paper, we have a very good flexible and agile working policy. In reality, it’s just not always possible. It just depends. Again, it depends on the deadlines I’ve got, it depends on the meetings I’ve got. Next week I’ll be able to work from home a couple of days, so that’s fine. This week I just can’t at all cos I’ve got too much on.” (Theresa)

Some carers found that their workplace culture was not understanding, unsupportive, or too performance-oriented for them to disclose their carer status for fear of unfavourable treatment or being seen as unreliable. This could prevent them from seeking more autonomy or disclosing the full extent caring impacted their work, and vice-versa.

“Now, have I gone and asked my employer if I can go do that? No, I haven’t. Why not? I don’t know. You know, because I’m thinking they’re either going to say no, or they’re gonna think I’m slacking, you know, shirking my responsibilities at work.” (Theresa)

“There maybe was a fear they could question ‘what are you doing’ you know, ‘you can’t be going up there [to PwD]’. I don’t know, I just thought what they don’t know won’t harm.” (Liam)

“I wouldn’t want any special dispensation or to be, you know, looked at, not looked upon as a charity case but kind of in that sense, if you know what I mean. To be, maybe not be considered for certain things like trips away or things like that.” (Iona)

Workplace culture and regulations did not impact the autonomy of the self-employed carers we interviewed.

### 6.3.2.3. Supportive line managers/clients

While often bound or shaped by workplace culture and regulations, line managers were a decisive factor for carers’ autonomy, clearly demonstrated by getting a new line manager.

“Unfortunately, my previous manager didn’t interpret it [flexible work regulations] that broadly. My current one does.” (Hannah)

Supportive line managers could mitigate restrictive regulations, for example by allowing carers to use their phones despite official guidelines.

“I would say to my boss ‘I’m gonna have my phone, there’s something going on’ and that would be fine, because we’re not supposed to have our- data protection and all that, we’re not supposed to have our phones out.” (Sue)

Hence, some carers felt it was essential for line managers to know their carer status.

"You have to let your employers know what's going on, you have to be honest and say, 'This is the situation and I am the carer, I'm responsible for these people'." (Sue)

Others seemed to feel they had to earn their autonomy by proving their reliability.

"I guess if you've worked here for years and have proven yourself to be a reliable and committed employee, they're gonna give you a bit more leeway, aren't they?" (Theresa)

Some self-employed carers depended on the understanding and support of their clients.

"But they understood because they've got fathers that are now failing themselves. And so, they were actually very, very understanding when last week, for example, when I said, it was the first time ever, 'I'm not gonna be able to come down, mum's gone into hospital'." (Ian)

### 6.3.3. Distance

For some carers, having complete autonomy was not enough to effectively manage CRE, due to the distances between their workplace and the PwD's residence.

"The phone would go saying, you know, 'Your mum's double-dosed her medication' or 'She's fallen' and I'm thinking 'I've just arrived in [office]', you know. I cannot physically, you know, I can jump on a train and come back, but by the time I do..." (Theresa)

If the distance was too great, their caring role was reduced to managerial tasks, and they could only delegate the CRE response to their care network or emergency services. In the case of business trips, distance could be a temporary issue. Some carers permanently worked at a great distance which they experienced as practically, financially, and emotionally difficult.

"I am close to 400 miles away. So, a journey here is not something I can make in a week and back. Apart from the expense, it's the time." (Gavin)

"I've got this unbelievable rack of guilt that I'm not here and all that is on my brothers and sisters. So, I try and come home at least once, one week every month." (Iona)

Conversely, having no autonomy at work, Gavin found that the great distance helped him to let go of some of the responsibility.

"One of the advantages of being so far away is that I found it easier to compartmentalise, that I knew there was nothing I could do. I couldn't just jump in my car to render help. I had to rely on local services." (Gavin)

Place autonomy allowed carers to travel to the PwD, and resume work there. Those with no place autonomy either had to get creative with their schedule or take extended leave.

"They were long shifts, and it was only generally about a four-day week. It did enable me to add quality breaks to long weekends to make five, six or seven days so I could use effectively a week to make a trip up. So that's what I did. Or I took holiday onto it, I took a couple of weeks." (Gavin)

Some carers went to considerable lengths and made personal sacrifices to reduce the distance. Ian, for example, moved cross country and in with his parents. Theresa moved her mother from a different town into sheltered housing near her home. And Maggie had to maintain a long-distance relationship with her partner and keep postponing their life together.

## 6.4. Discussion

This study aimed to explore how working dementia carers experience the impact of their autonomy at work on their ability to manage CRE and use technology to that end, thus addressing an evidence gap identified by Spann et al. (2022). Where the neutral term *flexible working* is often employed in the work-care reconciliation discourse, we suggest using *autonomy at work* as this better describes the underlying power dynamics, i.e., whether the worker has the power to self-direct. Autonomy at work, conceptualised as break, schedule, and place autonomy, can be viewed on a spectrum with ‘complete’ and ‘no autonomy’ at the extremes.

Break autonomy, the ability to take breaks when, for how long, and as often as needed, seemed to be the deciding factor in whether carers could be notified of and manage CRE, at least from afar, e.g., by delegating the response to their care network or emergency services. For this, carers mostly used their (smart-)phones: to coordinate and communicate with their care network and the PwD’s healthcare professionals, and to check in with the PwD by calling or checking on monitoring technologies in their home. Break autonomy allowed carers to do that freely. Still, technology could play a part in helping carers with no break autonomy to manage CRE, e.g., by connecting the PwD via a personal alarm system to an emergency response call centre. However, carers need to be sure that PwD are able and comfortable with actively using these technologies (Spann et al., 2022). Many carers are not aware of technological solutions to their work-care reconciliation challenges (Carers UK, 2013a; Spann et al., 2022) and would benefit from employers, support organisations, healthcare professionals, etc. raising awareness and providing advice and guidance on that matter.

Schedule autonomy enabled carers to manage CRE in person by coming in late, leaving early, or rearranging their schedules. Yet, carers working in a stressful or productivity-driven environment, or self-employed carers paid by the hour, might feel pressured to work, and thus not be able to benefit from their theoretical schedule autonomy.

Place autonomy allowed carers to work and care from the same place, meaning they could prevent or manage CRE instantly. However, these carers were faced with additional work-care reconciliation challenges: they provided a substantial amount of personal care, felt they needed to be constantly vigilant to prevent CRE, and experienced many work disruptions. While much of the personal care they provided could be planned around work, they needed to be highly organised yet flexible to accommodate any CRE. Kossek et al. (2006) found that working from home could decrease role conflict if adequate boundary management was employed. Our carers found boundary management very difficult as they felt guilty when they needed to prioritise work over caring and could not keep the PwD company, and vice versa. One carer also described rapid and frequent role-switching as very challenging.

Break autonomy seemed to only exist in its extremes (either complete or no autonomy), whereas schedule autonomy seemed to have many in-betweens, e.g., flexible start and finish times, banking overtime hours, compressed hours (e.g., working longer days to have a shorter workweek), etc. At first glance, place autonomy appears more in line with break autonomy – either carers can work remotely or not. However, their autonomy could be limited by regulations on remote work or having to ask permission every time they wanted to work remotely.

Carers' position on the spectrum was not always static. Business meetings or trips could temporarily reduce their autonomy whereas a new line manager could change it permanently. A carer passport, i.e., a record that allows carers to carry over negotiated flexibility and support to new roles or line managers, can help preserve carers' autonomy (Carers UK, 2017). Line managers' compassion for carers' situations and trusting them to manage could be just as helpful as bending or generously interpreting official regulations about flexible working or using technology. This finding is echoed in the literature where line managers have been identified as the main gatekeepers for carers' ability to access support and resources (Carers UK, 2019a; Spann et al., 2020) and use technology for care-related reasons (Arksey, 2002; Mahoney, 2004; Mahoney et al., 2008). According to Milasi et al. (2020), workers' access to place autonomy specifically depends on line managers' trust. Ireson et al. (2018) found that workplace culture also determines the availability and accessibility of support for carers. Some of our interviewees did not want to tell their employers about their caring responsibilities or ask for more autonomy for fear of career consequences and being viewed as unreliable. Chung (2017) concurs that this flexibility stigma hinders employees from requesting more flexibility, especially in highly competitive workplaces. This is despite evidence that flexibly working employees are more productive, not least because they often feel the need to reciprocate their employers for accommodating their situation. Previous studies have also found that carers made changes to their careers or passed on job advancement opportunities if it awarded them less flexibility (Bernard & Phillips, 2007; Edwards, 2014).

The nature of their work seemed to have a decisive impact on carers' autonomy. Client-facing roles and jobs requiring carers to work highly focused and at specified times and places seemed to offer the least autonomy. Milasi et al. (2020) concurred that some occupations do not allow much autonomy. However, there appears to be a strong cultural aspect to how much autonomy is afforded in specific sectors, highlighted by varying autonomy levels in the same occupations in different European countries (Milasi et al., 2020). It appears that culture, in general, can influence workplace culture which in turn impacts carers' autonomy. Our interviews further suggest a gender aspect to autonomy in certain work sectors. All but one of our interviewees who had very little to no autonomy, both male and female, worked in traditionally female sectors (child, social, and health care – the exception being airport security). Although inconclusive due to our small sample size, this finding is consistent with

previous research on autonomy at work and gender. A Europe-wide study by Chung (2019) concluded that traditionally female sectors have worse working conditions and less schedule flexibility. Larger studies should seek to quantify which work sectors afford which levels of autonomy to carers, based on the nature of the work. Self-employment did not automatically afford complete autonomy as some self-employed carers had to work at a specific time and place. However, none of them had any limitations in using technology to be notified of and manage CRE. If caring took up too much of their time, self-employed carers' income could be at risk, especially for those who did project-based work. Despite considerable efforts, we have not been able to recruit carers in 'insecure' work like agency or gig work or zero-hours contracts. Many of these casual workers have no access to employment rights or paid leave which might force them to prioritise work over caring even if they have schedule autonomy.

Distance between the carer and the cared-for person is a well-documented challenge (e.g., see Bernard & Phillips, 2007; Koerin & Harrigan, 2003; Manthorpe, 2001; Spann et al., 2020). Maintaining a close distance was a priority for many of our interviewees, even at a personal cost in terms of relocating themselves or the PwD, putting their romantic relationships on hold, or frequently travelling for hundreds of miles. Distance carers generally value flexible work arrangements and are known to often have to take leave to travel long distances for care-related reasons (Bernard & Phillips, 2007; Edwards, 2014; White et al., 2020). However, little is yet known about the specific interaction of autonomy at work with distance caring. Our findings show that place autonomy can allow carers to overcome distance and manage their work and care responsibilities from the PwD's home. In contrast, regarding CRE response, distance could make even high levels of schedule autonomy meaningless. Larger investigations should seek to confirm and expand upon our findings.

Future studies should also explore the impact of financial issues on carers' autonomy, which were not part of our investigation. Milasi et al. (2020), for example, found that well-paid employees had greater access to jobs with high place autonomy. Having less financial pressure may mean that carers have greater choice in the job market and can prioritise high-autonomy jobs even if they offer lower pay. It may also enable them to reduce their work hours or take leave to dedicate more time to care. Having more financial resources may make it easier to afford private care providers or monitoring technologies for peace of mind.

Milasi et al. (2020) found that around 40% of workers who had worked remotely during the Covid-19 pandemic did so because of the pandemic. Before that, remote workers had primarily been high-skilled workers with high autonomy levels who mostly worked on computers. The pandemic has suddenly made working from home possible – necessary – for many workers where this has previously been unthinkable. It has also led to a sharp increase in working carers in the UK (Carers UK, 2020; Phillips et

al., 2020). These carers had to deal with a suddenly drastically different work-life while providing even higher levels of care with very little support or guidance, many of them also home-schooling their children and supporting other vulnerable relatives (Milasi et al., 2020; Phillips et al., 2020). The effects of reconciling work and care for PwD during the pandemic should be further explored, particularly regarding how many carers' newfound autonomy affected their ability to combine work and care under these very difficult circumstances.

#### 6.4.1. Implications for practice

Our findings have implications for employers, policymakers, and technology developers. Employers should be mindful of their employees' caring responsibilities and recognise the importance of using technology such as their phones for managing CRE. They should revise their regulations to ensure that their employees can have a maximum of autonomy and create a workplace culture where carers feel supported to request more autonomy. Enabling carers to manage CRE could prevent their exit from the labour market which could save employers a lot of money otherwise spent on recruitment and training of replacements for carers. Many carers seem unaware of existing technologies like monitoring technologies which could make it easier for them to reconcile work and care and manage CRE. Employers are ideally positioned to signpost carers to these technologies. Line managers should be encouraged to support carers and use carer passports. Currently, when requesting more flexibility at work, UK employees must prove to their employer that granting this flexibility won't negatively impact their business (Carers UK, 2019b). Policymakers in the UK should learn from the push towards working from home during the Covid-19 pandemic and take this burden of proof off employees. They should also ensure that social care services are available, accessible, and affordable, particularly for carers who have no autonomy at work to respond to CRE and have no care network to fall back on. Provisions should also be made for self-employed carers whose work is impacted by caring. Healthcare professionals and service providers working with PwD and/or their carers should consider carers' autonomy at work when scheduling appointments and accommodate them where possible (e.g., adjusting their own business hours, providing asynchronous and remote channels of communication like email or video consultations, scheduling appointments well in advance and with carers' prior consultation, etc.). Further, they are well suited to raise awareness and advise carers on potential technological solutions to their work-care reconciliation challenges. Smartphones are today's Swiss army knives, offering carers many functionalities including messenger apps to coordinate their care network and to manage monitoring technologies in the PwD's home. Technology developers seeking to innovate for working carers need to consider whether and how carers can use their phones when at work. Technology is often the last resort for carers seeking to reconcile caring with work, particularly considering severe accessibility challenges to social care services. Innovative technologies that can



autonomously ensure the PwD's safety and wellbeing, provided that they are able and comfortable to use these technologies or have them in their home, can help carers with no autonomy at work to have peace of mind.

#### 6.4.2. Strengths and limitations

We have employed a purposive sampling strategy to recruit carers with a broad range of characteristics in terms of their age, gender, and autonomy at work, both employed and self-employed. However, our sample size is relatively small and despite considerable efforts, we have not been able to recruit carers working in 'insecure' work such as the gig economy. Future research should address this gap. We used member checking to increase the trustworthiness of our analysis. Our findings are specific to the context of carers of PwD living in Scotland and may not be transferrable to other countries.

#### 6.5. Conclusion

Autonomy at work appeared as a spectrum where carers with no autonomy were generally not able to manage CRE and use technology to that end, and carers with complete autonomy were generally able to do so well. Break autonomy seemed to be most influential for carers' ability to use technology, primarily their (smart-)phone at work and manage CRE by delegating the response to their care network. Schedule autonomy enabled them to manage CRE in person. Place autonomy meant that carers could work and care at the same time. While this allowed them to prevent or manage CRE instantly, it also presented them with unique challenges such as problems with boundary management and frequent work interruptions. The nature of carers' work, their workplace culture and regulations, and the support of their line managers or self-employed carers' clients influenced carers' position on the autonomy spectrum. While distance could make high schedule autonomy meaningless for in-person CRE response, place autonomy could allow carers to overcome distance and work and care from the PwD's home. The findings have implications for employers, policymakers, and technology developers.

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## 7. Addendum: Working dementia carers' experience with and views on technology they use or want to use to better reconcile work and care

Analysing the interview data and drafting the manuscripts for publication in a peer-reviewed journal, three themes remained which did not fit the scope of these manuscripts, but which are relevant for the scope of this thesis. The first theme, *carers are not aware of potential technologies*, echoes findings from the second scoping review and has implications on how the technology framework developed in chapter 8 could be distributed to finally address this issue for good. The second theme, *technology's impact on people with dementia*, provides further insight into issues carers might have to keep in mind when looking for solutions that impact people with dementia. The final theme, *priorities not always for work-care reconciliation*, empathises that many carers seem to think about technology first and foremost in regards to what it could do for or how it could affect people with dementia rather than considering their own needs.

### 7.1. Carers are not aware of potential technologies

When asked about their experience with technology, many carers thought of devices intended to keep people with dementia safe. Many had personal alarm systems provided by their council, or in one case by their sheltered housing. Although almost all interviewed carers used their phone to help them manage aspects of caring and reconciling work and care, many had to be prompted to reflect on their use of phones to become aware of the role they played. Even younger carers who considered themselves to be quite tech-savvy had not considered using certain technologies like online peer support for the needs they expressed. Many carers criticised that they had received no advice on technology or that technologies they might find useful were insufficiently or inadequately advertised:

"If there was something like 'dementia camera', now that would be simple, that's a really good business idea for someone to you know, come up with. Whereas what you've got to do is instead of typing in [an online search engine] 'dementia camera', which doesn't exist, you've got to go 'camera', you know, 'to be linked in with Wi-Fi that you can speak through' -laughs- you know, you've got to really think outside the box and find something that's designed for something else." (Liam)

Interestingly, many carers described wanting technological solutions, like care cameras, GPS tracking devices or fall detectors, which they had no idea already existed. Some carers stressed how little time and energy they had to work through information. Thus, it was very frustrating for them to get information on technology that did not fit their or the needs of the person with dementia or to only learn about technology that could have helped when it was already too late for it to be useful.

Asked where they would expect information on technology to come from, carers mentioned charity organisations, their council, and their healthcare professionals. However, most had to rely on their personal networks or their own initiative and creativity for technological solutions to their challenges.

Recommendations or suggestions from friends, family or co-workers could help carers get ideas and research suitable technologies. Working in the care sector could mean that carers had some experience with certain technologies from work. The internet was a valuable source where carers went to look for technology, although, as mentioned, some found it difficult to find the right search terms for what they were looking for. One carer mentioned that online peer groups could help to suggest technologies but had never considered this option before the interview. One carer had visited a technology showroom advertised through their workplace, which had showcased many potentially helpful technologies.

## 7.2. Technology's impact on people with dementia

Chapter 5, specifically the section on "safety concerns", details the experience carers had with technologies that needed to be used by people with dementia (i.e., people with dementia forgetting or not knowing how to use technology, devices potentially frightening or confusing them, connected services being inadequate, etc.). However, even if people with dementia were able to use technologies, some carers found that they just did not want to use them. Some people with dementia did not want to burden anyone:

"I don't know how many [location] ladies you know of this generation, but they're very independent and strong-willed and she would not pull a pull cord unless. You know, she wouldn't do it because that would be causing a fuss and you don't want to cause a fuss." (Theresa)

Others did not want to wear devices because of their impact on their self-image:

"So, he did have the pendant, but he kept taking it off. Yeah. He kept saying 'I'm not wearing a necklace'." (Rose)

"She wouldn't wear it. She's still quite vain, so, she won't wear her hearing aids because she's vain, she won't wear her glasses cause she's vain, anything like that." (Theresa)

Some carers worried that technology could be frightening to people with dementia, like false alarms, devices emitting sounds or disembodied voices that people with dementia have difficulties placing. Robots or AI were particularly concerning concepts.

"When I get to the age where I might have dementia or care needs, I'm sure we will have robots by then, as carers. Another 10, 20 years, whatever and I think that would scare me to death, to have an inanimate object coming in and it could go wrong and what would happen, you know." (Maggie)

The acceptance of and comfort of the person with dementia with the technology was an important issue for many carers. Cameras, for example, were thought of by some as too invasive on the privacy of people with dementia. However, knowing that people with dementia were safe when carers could not be physically present was an even bigger concern for many interviewees. Some carers described trying to include people with dementia in decisions on using technology that impacted them directly, for example by using persuasive arguments. James remarked that there was no resistance from the person with dementia anyway because of their condition, while also noting that information needed to be kept simple for them:

“The interesting thing with her dementia is, it’s made her really placid, really so she’s fine with it. And all I’m going to say to her is, ‘Look, it’s just to keep you safe and it’s just in case you ever got lost or you ever sort of got on the bus and didn’t know how to get home, where we could find you again.’ I think that would be enough for her.” (James)

Importantly, if people with dementia did not live alone (e.g., with a partner or spouse), using technology also had to be negotiated with their cohabiter.

“Where to draw a line between being respectful of what she [spouse] wants and saying, ‘You’re being absolutely ridiculous, you know? ‘You’re missing out on something here which is detrimental to him because of your views’.” (Sue)

### 7.3. Priorities are not always for work-care reconciliation

Asked what they wanted technology to do for them if they had a magic wand, many carers seemed to prioritise solutions that would improve the person with dementia’s condition and quality of life or the relationship they had with them above their own challenges when combining work and care, despite specifically being asked about the latter.

“Something to stimulate her mind and that would be quite good. So, I wouldn’t, you know, I would feel that she was getting something out of her life. Cos at the moment I feel her life isn’t worth living, there’s no quality of life there for her.” (Maggie)

Some carers worried that technology might not be compassionate and were very critical of and could even decide not to use technology, despite its promise to make life easier for themselves if it meant a loss in quality of life for the person with dementia.

“So, a carer [service provider] will go in and they’ll have their iPad, they’ll ignore their patient completely because that’s what they’ll do.” (Ian)

“When I’m out doing the shopping with my dad-, I mean I can-, we could do it online and then technology would do that for us, but there’s a part that- it’s the only time to get my dad out away from my mum. So, and it just lets him interact whether he meets somebody when we’re out shopping and that sort of thing, it just gives him a bit of fresh air.” (Flora)

Some carers felt that technology could help to free up time they could then spend on providing better care and having better interactions with the person with dementia.

“And then you could free up money and time to do the stuff that technology can’t do. Cos, I think there really isn’t much technology-use in this situation unless you are going futuristic robots and all that stuff, but if you are talking about right here and now, the reality of what existing technology can do, then yes, it can free up people to do a better personal human job.” (Maggie)



# Part III

## Review and mapping of the technology landscape

### III.a. Preface

The previous three chapters presented the findings from in-depth interviews conducted with working dementia carers. Their needs, wants, and experiences with technology were discussed as well as how their autonomy at work impacted their ability to use them when working and to respond to care-related emergencies. The interviews have thus contributed to the *exploring the problem* phase of the participatory design (PD) approach described in chapter 2.2.

The following chapter presents the technology map, which is one of the most important outcomes of this thesis. The work-care reconciliation challenges working dementia carers expressed in the interviews in chapter 5 have been used here as the basis to conduct an extensive review of online resources and grey literature. The aim was to map currently available and emerging technologies onto the challenges working dementia carers identified. This study contributed to the *exploring the solution* phase of the PD process and is presented in a publication-ready format as Spann, A, Spreeuwenberg, M, Hawley, M, de Witte, L (n.D.): *Supporting working dementia carers: Mapping technology-based tools and services on dementia carers' work-care reconciliation challenges*, with plans for submission to *Human Technology, Health and Social Care in the Community*, or similar journals.

### III.b. Rationale

To explore potential technological solutions for working dementia carers and map them onto their work-care reconciliation challenges, a review of the technology landscape and a technology expert consultation were conducted. With a similar aim, Lorenz et al. (2019) used a rapid review of the peer-reviewed literature, expert interviews, and user reports to map technologies onto the dementia care pathway. However, their search terms referring to technology were limited to a handful of concepts. Aiming to find all potentially relevant technological solutions necessitates a more open approach. As outlined in chapter 1.3. of this thesis, technology herein is conceptualised as any device or system that is electronic and/or digital in nature. There are no limitations to physical appearance (hardware), or programming (software) and technologies can be mainstream or specifically designed for the care

context. The experience from conducting the scoping review on technologies for working carers (chapter 4) showed that another review of peer-reviewed evidence to identify suitable technological solutions for dementia carers' work-care reconciliation challenges, based on the example of Lorenz et al. (2019), would be unpractical and unfeasible. A vast array of search terms to capture the open conceptualisation of technology produced thousands of search results, despite limiting the search to working carers. However, to explore not only technologies already investigated with and for working carers but all potentially relevant technologies, a review based on dementia carers' work-care reconciliation challenges would have to be as open as possible and could not be limited to any user or technology group. Thus, it would be nigh impossible to define suitable search terms and parameters for such a search and the results would likely be unmanageable. In addition, Lorenz et al. (2019) designed their rapid review to include evidence on the effectiveness, cost, and benefit of technologies, for which it makes sense to use peer-reviewed publications. Rather than evaluating specific technologies, often prototypes which might not be commercially available anytime soon (if at all), this study aimed to provide a broad overview of all current or soon-to-be-available technologies. An alternative approach to the one outlined presently would have been to conduct a Delphi study with experts working with technologies in a variety of areas. Delphi studies are often employed to seek the consensus of experts regarding a specific issue (McKenna, 1994). As such, experts could have been provided with vignettes describing each work-care reconciliation challenge (as were later used in the expert consultation, see chapter 8.2.5.), and asked which technologies they considered most promising to provide solutions. However, rather than reaching a consensus regarding specific technologies and their application in supporting working carers, this study aimed to get as comprehensive a picture of the current and emerging technology landscape as possible, to analyse the potential use-cases of these technology groups, and to map these use-cases and technology groups onto the work-care reconciliation challenges dementia carers identified. It was thus decided to use a two-tiered approach to searching the technology landscape and to get technology experts' feedback on the comprehensiveness of the findings in a webinar (a more detailed description is presented in chapter 8.2.).

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## 8. Supporting working dementia carers: Mapping technology-based tools and services on dementia carers' work-care reconciliation challenges

### Abstract

**Background:** Reconciling paid work and unpaid care for people with dementia can be very challenging for individual carers. Technology can offer solutions independent of a strained social care system. This paper aims to examine the landscape of currently available and emerging technologies, classify the identified technologies according to their use case, and map them onto dementia carers' work-care reconciliation challenges.

**Methods:** We used a two-tiered approach to examine the technology landscape between October 2019 and January 2020: 1) currently available technologies using online care technology databases and app stores; 2) emerging technologies using conference proceedings and the IEEE Xplore database. Technologies with similar functions were clustered into technology groups and their use-cases analysed using the seven work-care reconciliation challenges identified by Spann, Spreeuwenberg et al. (n.D.) as the analytic framework. A webinar with 14 technology experts validated the comprehensiveness of the findings.

**Findings:** The search identified 83 individual technology groups and 30 use-cases for Spann, Spreeuwenberg et al.'s (n.D.) seven work-care reconciliation challenges: I) care management; II) attending appointments; III) entertainment and companionship; IV) psychological and psychosocial stress; V) safety concerns; VI) accessing information, and VII) personal care.

**Conclusion:** Technologies can offer much-needed support to carers of people with dementia who struggle to reconcile work and care. Our technology map can be used to examine carers' work-care reconciliation challenges and explore potential technological solutions. Several ethical, legal and practical implications need to be considered when using these technologies.

**Keywords:** technology, working carers, dementia, review, expert consultation.

### 8.1. Background

At least 7 million working people, that is 26% of all people in paid work in the UK, also provide unpaid care for a sick, frail, or disabled family member, friend, or neighbour (Carers UK 2020; Phillips et al. 2020). Although precise numbers of working dementia carers are unknown, Carers UK (2013b) state that carers in full-time work are most likely to care for people with dementia. Dementia describes progressively degenerative processes of the brain and affects peoples' emotional, psychological, cognitive, and behavioural capabilities and their ability to live independently (World Health Organization 2017). People with dementias' care needs can be very complex, unpredictable, and challenging (Gallagher-Thompson et al. 2020; Matsumoto et al. 2007; Newbronner et al. 2013). Balancing both work and care can create significant challenges for carers (Spann et al. 2020; Spann, Spreeuwenberg et al. n.D.; see chapters 3.3.3. and 5.3.). This can have significant effects on carers' health, relationships, and employment if they do not receive the support they need (Carers UK 2014;

Wang et al. 2020; Wang et al. 2013; Wang et al. 2011; Wittenberg et al. 2019; Yeandle and Buckner 2007).

The adult social care system in the UK is currently under pressure and many people must do without the care and support they need (Charles and Ewbank 2021; Ward et al. 2020). Technology has the potential to empower carers to seek solutions to their work-care reconciliation challenges outside and independent of strained public services. Many working carers, however, do not consider technology when looking for solutions for their challenges, do not know that technological solutions exist, or do not know where they can get them from (Carers UK 2013a; Spann et al. 2022; see chapter 4.3.3.1.). There is a growing number of websites in the UK which collate and signpost technologies for carers and people with dementia, including [atdementia.org.uk](http://atdementia.org.uk), [alzproducts.co.uk](http://alzproducts.co.uk), [dementia.livebetterwith.com](http://dementia.livebetterwith.com), [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk), and [meetadam.co.uk](http://meetadam.co.uk). Technologies on these sites are categorised into specific applications or use-cases which can be filtered by users. There are, however, no such filters for work-care reconciliation challenges. Not much is yet known about technologies working carers use to better combine work and care and most of the available evidence is on evaluating specific technologies (Spann et al. 2022, see chapter 4). In a recent study, we took a bottom-up approach and identified several work-care reconciliation challenges working dementia carers wanted and used technologies for (Spann, Spreeuwenberg et al. n.D., see chapter 5.3.).

An increasing number of reviews address what technologies are available, users' experiences, and their effectiveness for carers and people with dementia (see, e.g., Evans et al. 2015; Gibson et al. 2014; Godwin et al. 2013; Lorenz et al. 2019; Sriram et al. 2019; Yellowlees 2020). Andersson et al. (2017) and Spann et al. (2022, see chapter 4) reviewed the existing literature on technologies used by working carers. However, to date, no review explored what technologies are available for dementia carers' work-care challenges. Lorenz et al. (2019) mapped technology-based services and devices onto the dementia care pathway. In a similar fashion, we aim to address this gap in the evidence by examining the landscape of currently available and emerging technologies, classifying them according to their use-case for working dementia carers, and mapping them onto the work-care reconciliation challenges carers identified (Spann, Spreeuwenberg et al. n.D.; see chapter 5.3.).

## 8.2. Methods

### 8.2.1. Defining "technology"

The rapid development of technologies produces a plethora of terms, like robotics, information and communication technologies (ICTs), social media, monitoring technology, and artificial intelligence. In the context of health and social care, terms like telehealth, telecare, telemedicine, digital health, E- and M-Health, etc. are used. Definitions are often vague or inconsistent (see, e.g., Gibson et al. 2014;

Linskill and Dewsbury 2019; Sriram et al. 2019), and can summarise various technologies that are different in appearance, capabilities, basic function, and intended purpose. In this study, we thus refrained from using these terms in our search and defined technology in a broad and open sense, referring to any device or system that is electronic and/or digital in nature, not limited to physical appearance (hardware) or programming (software). Technologies could be mainstream or specifically designed for the care context. The terms used to refer to the technology groups (see appendix J) resulting from this study were selected with a carer-centred perspective to most accurately describe their basic function or purpose.

### 8.2.2. Framework for data collection and analysis

To ensure that the technologies meet the needs of working dementia carers, the search and emerging classification is organised around working dementia carers' work-care reconciliation challenges, identified by Spann, Spreeuwenberg et al. (n.D.; see chapter 5.3.). These include seven main challenges: i) care management; ii) attending appointments; iii) entertainment and companionship; iv) psychological and psychosocial stress; v) safety concerns; vi) accessing information; and vii) personal care. These main challenges are made up of several subchallenges. An overview is presented and described in table 10.

*Table 10: Framework for data collection and analysis: work-care reconciliation challenges of working dementia carers (adapted from Spann, Spreeuwenberg et al. n.D.; see chapter 5.3.)*

Subtheme	Description
<b>CARE MANAGEMENT</b>	
Coordinating the care network	<ul style="list-style-type: none"> <li>• WDC need to coordinate responsibilities with their care network.</li> <li>• WDC need to exchange care-related information with their care network.</li> <li>• WDC need reassurance that someone has checked on the PwD.</li> </ul>
Coordinating care providers	<ul style="list-style-type: none"> <li>• WDC need to set up and coordinate care services.</li> <li>• WDC need to know when care providers arrive at the PwD's residence so that they can manage work around it.</li> <li>• WDC who privately hire care workers need to manage their responsibilities as employers.</li> </ul>
<b>ATTENDING APPOINTMENTS</b>	
Attending medical and similar appointments	<ul style="list-style-type: none"> <li>• WDC need to attend appointments with HCPs, which is challenging due to conflicting hours.</li> </ul>
Attending business meetings	<ul style="list-style-type: none"> <li>• WDC working from home sometimes need to attend business meetings.</li> </ul>
Arranging medical and similar appointments	<ul style="list-style-type: none"> <li>• WDC need to arrange appointments with HCPs, which is challenging due to conflicting hours.</li> </ul>
<b>ENTERTAINMENT AND COMPANIONSHIP</b>	
Providing entertainment and companionship	<ul style="list-style-type: none"> <li>• WDC want to minimise PwDs' cognitive decline and social withdrawal.</li> <li>• WDC want PwD to have more company when they need to work.</li> </ul>
Enabling active participation in society	<ul style="list-style-type: none"> <li>• WDC want the PwD to be able to actively participate in society.</li> </ul>
Enabling PwD to communicate	<ul style="list-style-type: none"> <li>• WDC want to be able to communicate with PwD whose ability to speak is affected by dementia.</li> </ul>
<b>PSYCHOLOGICAL AND PSYCHOSOCIAL STRESS</b>	

Dealing with psychological and psychosocial stress	<ul style="list-style-type: none"> <li>WDC need to deal with complicated emotions, emotional situations, and decisions (e.g., feeling unprepared or abandoned, having to make personal sacrifices, having to manage adverse effects on their health caused by emotional labour and constant vigilance, etc.).</li> <li>WDC need to deal with interpersonal conflict and difficulties (e.g., role reversal and the slow decline and changing personality of the PwD, difficult relationships between carer and PwD exacerbated by dementia, PwD or their spouse refusing help, etc.).</li> </ul>
<b>SAFETY CONCERNS</b>	
Managing accidents and emergencies	<ul style="list-style-type: none"> <li>WDC need reassurance that the PwD is safe (e.g., accidents, falls or other emergencies).</li> </ul>
Reminding	<ul style="list-style-type: none"> <li>WDC need to remind PwD of certain tasks or activities (e.g., taking medication, appointments, eating and drinking, etc.) and want confirmation when tasks are completed.</li> <li>WDC need to remind PwD to switch off appliances which could e.g., cause fires or floods.</li> </ul>
Managing disorientation	<ul style="list-style-type: none"> <li>WDC need to ensure PwD remain orientated to avoid distress.</li> <li>WDC need to be able to find PwD who are at risk of getting lost when out for a walk.</li> </ul>
Preventing crime	<ul style="list-style-type: none"> <li>WDC need reassurance that PwD are safe from crime (e.g., scammers, burglars, etc.).</li> </ul>
<b>ACCESSING INFORMATION</b>	
Finding information	<ul style="list-style-type: none"> <li>WDC need access to easily understandable information on dementia, caring, benefits, entitlements, and services.</li> <li>WDC want practical advice from peers or someone with experience caring for PwD.</li> </ul>
Fighting for information	<ul style="list-style-type: none"> <li>WDC need reliable information from organisations which can be difficult if more than one organisation is involved.</li> </ul>
Exchanging information with HCPs	<ul style="list-style-type: none"> <li>WDC need to exchange relevant information with HCPs when PwD attend appointments on their own, which is challenging due to conflicting hours.</li> </ul>
<b>PERSONAL CARE</b>	
Toileting/ incontinence care	<ul style="list-style-type: none"> <li>WDC want solutions for helping PwD to the bathroom, especially incontinence care.</li> </ul>

Abbreviations: WDC= working dementia carer; PwD= person/people with dementia; HCP= healthcare professionals

### 8.2.3. Data collection

Data for the mapping of technologies was collected using a two-tiered approach: 1) to identify suitable technologies which are currently available, we searched the complete catalogues of online care technology databases and App stores, and 2) to identify suitable emerging technologies, we searched conference proceedings. We then conducted an expert consultation to get feedback on the comprehensiveness of the technologies we had identified. Table 11 provides an overview of tiers 1 and 2 and the respective exclusion criteria used.

Table 11: Overview of tiers 1 & 2 searches with exclusion criteria

Searched	Total entries	Excluded
<b>TIER 1) CURRENTLY AVAILABLE TECH.</b>		
<b>Online technology databases</b>	<b>N=12,902</b>	<ul style="list-style-type: none"> <li>Technology is not digital and/or electronic</li> <li>Technology does not address any of WDCs' challenges</li> </ul>
<a href="http://atdementia.org.uk">atdementia.org.uk</a>	n=403	
<a href="http://alzproducts.co.uk">alzproducts.co.uk</a>	n=863	
<a href="http://dementia.livebetterwith.com">dementia.livebetterwith.com</a>	n=373	
<a href="http://livingmadeeasy.org.uk">livingmadeeasy.org.uk</a>	n=11,263	
<b>App stores (ST: "dementia")</b>	<b>N=432</b>	<ul style="list-style-type: none"> <li>App does not address any of WDCs' challenges</li> <li>Dementia screening, prevention, or therapy</li> <li>Games not suitable for PwD</li> <li>Not in English</li> <li>Aimed at HCPs or researchers</li> </ul>
<a href="https://play.google.com/store/apps/details?id=com.dementia">Google Play</a>	<u>n=250</u>	
<a href="https://apps.apple.com/gb/app/dementia/id1441111111">Apple App Store</a>	<u>n=182</u>	
<b>TIER 2) EMERGING TECH.</b>		
<b>Conference abstracts</b>	<b>N=21,345</b>	<ul style="list-style-type: none"> <li>No technology mentioned</li> <li>Technology does not address any of WDCs' challenges</li> </ul>
<a href="#">AAIC</a>	<u>n=14,036</u>	

GSA Annual Scientific Meeting  
IEEE Xplore (ST: "dementia")

n=7,309  
N=781

- Dementia screening, prevention, or therapy
- Aimed at HCPs or researchers
- Prototypes not yet for sale

Abbreviations: AAIC= Alzheimer's Association International Conference; GSA= Gerontological Society of America; HCPs = healthcare professionals; PwD= person/people with dementia; ST= search term; WDC= working dementia carer

#### *8.2.3.1. Tier 1): currently available technologies*

We selected online technology databases based on consultations with carer and dementia support organisations. We searched the complete catalogues of [atdementia.org.uk](http://atdementia.org.uk), [alzproducts.co.uk](http://alzproducts.co.uk), [dementia.livebetterwith.com](http://dementia.livebetterwith.com), and [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk) between October and November 2019. These online databases each collate various technologies available in the UK which are relevant for caring, both mainstream technologies as well as those specifically intended for caring. Individual products are sorted into various functional categories, unique to each website, meant to make it easier for customers to find what they are looking for. This means that a product can appear in more than one category if it has multiple functions. The websites provide a brief description of each product and either allow customers to purchase them directly or redirect them to the provider's website. At the time of our search, these online databases had a total of 12,902 entries, which we screened in total. Many products were offered in more than one database, and many were listed more than once in the same database but under different functional categories. We excluded technologies if they were not digital or electronic or if they did not address any of the relevant work-care reconciliation challenges. We then searched the Google Play and Apple App Store between December 2019 and January 2020. Using the search term "dementia" we identified a total of 432 apps. Apps were excluded if their description was not in English, if they did not address any of the relevant work-care reconciliation challenges, if they aimed to prevent, diagnose, or treat dementia, or if they exclusively targeted healthcare professionals or researchers. Names and descriptions of all products and apps were extracted into MS Excel for analysis.

#### *8.2.3.2. Tier 2): emerging technologies*

To identify trends in technology development, which could give an indication of which technologies might soon become widely available for working dementia carers, we looked at conference proceedings. The search was conducted between October and December 2019 and limited to abstracts published from 2015 to 2019. We included the Alzheimer's Association International Conference (AAIC) and the Gerontological Society of America (GSA) Annual Scientific Meeting. Both conferences were carefully chosen for their reputation, size, international audience, and relevance to the field. The AAIC describes itself as "the largest and most influential international meeting dedicated to advancing

dementia science” with a focus on clinical and care research (Alzheimer's Association 2022). We selected this conference for its expertise in dementia and its inclusion of dementia care. The GSA refers to itself as the “oldest and largest interdisciplinary organization devoted to research, education, and practice in the field of aging” and as the “driving force behind advancing innovation in aging — both domestically and internationally” (The Gerontological Society of America 2022). We selected this conference for its focus on care-related issues [note that conference abstracts for the year 2017 were not available for unknown reasons]. In addition, we also searched for abstracts which might have been presented at other conferences through the IEEE Xplore database, which focuses on technology and engineering, using the search term “dementia”.

Titles and abstracts were extracted into MS Excel. We first screened the titles and then proceeded to read the full abstract of those deemed relevant. Abstracts were excluded if they did not present any digital and/or electronic technology, if they did not address any of the relevant work-care reconciliation challenges, if they aimed to prevent, diagnose, or treat dementia, or if they exclusively targeted healthcare professionals or researchers. Research prototypes were only included if similar technologies were discussed, thus representing a trend that could shed light on technologies soon to become commercially available (e.g., different prototypes of social robots). Prototypes were excluded if no similar technologies were mentioned by any other abstract (e.g., smart glasses for wayfinding).

#### 8.2.4. Data analysis

We first used MS Excel to group individual products describing similar basic designs and functionalities in their product description or abstract together (i.e., various products/abstracts describing wearable devices which could be pinged to locate the wearer on a digital map were grouped as “person locators”). We then created a short vignette for each of these product groups, based on an abstraction of all available product descriptions/abstracts. These vignettes contained a description of the *technology group* (“what does it do?”) and their possible *use-case(s)* in the work-care reconciliation context (“what can it be used for?”). Next, we used NVivo software for qualitative data analysis to analyse these use cases. We coded the use-case descriptions of the technology groups and clustered similar use cases together. We then mapped the emerging use-case clusters onto the work-care reconciliation challenges we used as an analytic framework (see table 10). Finally, we created a descriptor (hashtag) for each use case and added them to the technology group vignettes (see appendix J).

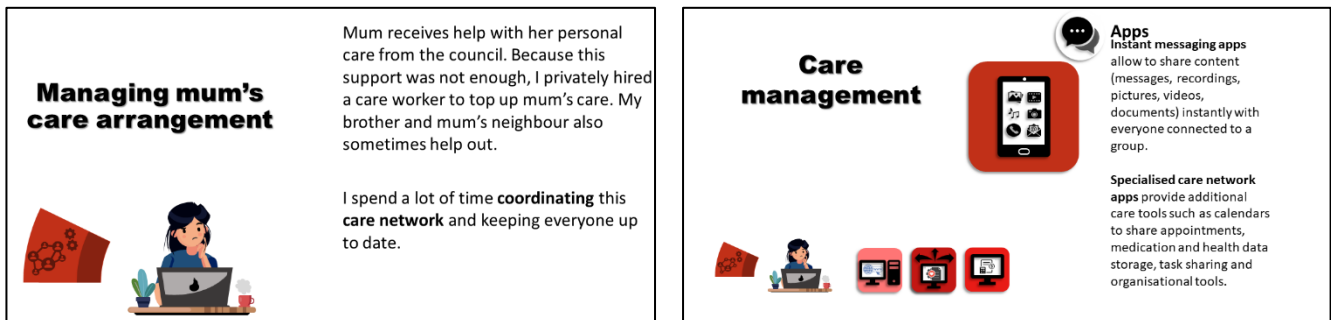
#### 8.2.5. Expert consultation

To get feedback on the comprehensiveness of our findings, we conducted a webinar with 14 technology experts from academia, social service commission, and industry in the UK. Ethical approval



was granted by the SchARR Research Ethics Committee at the University of Sheffield (Reference 022994). We used a convenience sample of experts who were recruited through the professional network of the research team and snowballing. In preparation for the webinar, experts were sent a total of ten short videos (30 min in total, ranging from 1.5 to 6.5 minutes). Each video contained a scenario portraying the work-care reconciliation challenge in question and then listed all the technologies that were identified to address the challenge (see example in figure 17).

Figure 17: Screenshot of the video on the care management challenge for the technology expert consultation



Experts were asked to take note if they knew of any technologies that were missed. These potentially missing technologies as well as the relevance of the technologies presented in the videos were then discussed in an online webinar which was held with 14 experts in March 2020. A further four experts could not attend the webinar and provided feedback via email. Experts' suggestions were discussed among all participants and, if deemed relevant, included in the developing technology catalogue.

### 8.3. Findings

#### 8.3.1. Overview of the identified use-cases and corresponding technology groups

A total of 83 technology groups (see appendix J) and 30 use cases could be identified (see table 12). Of these technology groups, 57 were identified exclusively through tier 1, eight exclusively through tier 2, and nine exclusively through the expert webinar. The remaining nine technology groups were identified through more than one source. By far the most use-cases (n=11) and technology groups (n=51) could be mapped onto the "safety concerns" work-care reconciliation challenge. The mean for technology groups associated with each "safety concerns" use case was also highest for this challenge (mean=7). For the "care management" challenge we could identify four use-cases and twelve technologies (mean=4.3), for "attending appointments" three use-cases and nine technologies (mean=4), for "entertainment and companionship" five use-cases and 20 technologies (mean=6.6), for "psychological and psychosocial stress" two use-cases and seven technologies (mean=5), for "accessing information" three use-cases and ten technologies (mean=3.6), and for "personal care" two use-cases and three technologies (mean=1.5). The use-case with the most assigned technology groups (n=13) was "reminders". Of all identified technology groups, 13 can be viewed as emerging. Five of

these technology groups (Personnel Management Software [13\*], Wayfinders [43], AI booking assistant [44], Guide apps [72], GPS arrival notification [60]) are well established but for different users (e.g., Guide Apps for blind people), or in other areas (e.g., GPS Arrival Notification for deliveries) but could be adapted to suit the needs of working dementia carers and people with dementia. Eight technology groups (Care Cameras [6], Wearable Hydration Reminders [9], Self-driving Cars [46], Talking Microwaves [59], Ambient Activity Monitor [73], Full Bladder Detector [76], Automatic Hip Protectors [77], Wearable Activity Monitors [81]) are new technologies which are not yet widely available or might only be available in certain countries (e.g., Full Bladder Detectors were only available in Japan at the time of the research).

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\* These numbers in brackets refer to the ID number assigned to each technology group in appendix J

Table 12: Overview of the identified use-cases and corresponding technology groups, mapped onto the work-care reconciliation challenges (left column) identified by Spann, Spreeuwenberg et al. (n.D., see chapter 5.3.). N (right column) refers to the number of technology groups assigned for each use case. The total number of technology groups for each main challenge is different from the sum of the technologies for the use cases because some technologies can be used for more than one use case.

Subtheme	Use-case	Technology group**	N
<b>CARE MANAGEMENT</b>			<b>12</b>
Coordinating the care network	Care network coordination	Social Media [2], Email, Phones, Answer Phones [32], Instant Messaging and Care Management Apps [53]	3
	Visitor notification	Smart Speakers [11], Security Cameras [36], Fob or ID Card Scanners [50], Smart Intercoms [57], QR Code Scanner [70]	5
Coordinating care providers	Care service management	Care Management Software [3], Personnel Management Software* [13], Email, Phones, Answer Phones [32], GPS Arrival Notification* [60], Care Finder Apps [75]	5
<b>ATTENDING APPOINTMENTS</b>			<b>9</b>
Attending medical and similar appointments	Teleconsultations	Smart Screens [1], Care Tablets [24], Electronic Health Records [33], Video Call Software [39], Telepresence Robots [49]	5
Attending business meetings	Telework	Video Call Software [39], Business Software and Hardware [42], Telepresence Robots [49]	3
Arranging medical and similar appointments	Appointment Coordination	Email, Phones, Answer Phones [32], Electronic Health Records [33], Online Booking Systems [34], AI Booking Assistant* [44]	4
<b>ENTERTAINMENT AND COMPANIONSHIP</b>			<b>20</b>
Providing entertainment and companionship	Entertainment	Smart Screens [1], Smart Speakers [11], Social Robots [17], Care Tablets [24], Simple TV Remote Controls [25], Simple Music Players [35], Musical Soft Toy [45], Talking Photo Albums [69], Video and Computer Games [71], Self-care Apps [80]	10
	Stimulation	Smart Screens [1], Smart Speakers [11], Aromatic Oil Diffusers [15], Social Robots [17], Care Tablets [24], Musical Soft Toy [45], Sound (and Light) Devices [66], Talking Photo Albums [69], Video and Computer Games [71], Self-care Apps [80]	10
	Companionship	Smart Screens [1], Social Robots [17], Care Tablets [24], Musical Soft Toy [45], Robotic Soft Toy [56], Simple Smart Phone Apps [63], Picture Button Phones [65], Smart Camera TV Attachments [82]	8
Enabling active participation in society	Social participation	Wayfinders* [43], Self-driving Cars* [46], Guide Apps* [72]	3
Enabling PwD to communicate	Communication	Communication Boards and Apps [61], Talking Photo Albums [69]	2
<b>PSYCHOLOGICAL AND PSYCHOSOCIAL STRESS</b>			<b>7</b>
Dealing with psychological and psychosocial stress	Psychoeducation	Social Media [2], Online Training Programmes for Carers [12], Information Apps and Websites [51], Self-care Apps [80]	4
	Self-care	Social Media [2], Banking and Shopping Apps [4], Email, Phones and Answer Phones [32], Information Apps and Websites [51], Call Services [64], Self-care Apps [80]	6
<b>SAFETY CONCERNS</b>			<b>51</b>
Managing accidents and emergencies	Calling for help	Barrier Alarms [5], Stationary Personal Alarms [7], Smart Speakers [11], Wearable Person Locator [52], Mobile Phones [54], Wearable Personal Alarms [62], Simple Smartphone Interface Apps [63], Picture Button Phones [65], Automatic Hip Protectors [77], Smart Watches [83]	10
	Injury prevention	Pressure Sensors [40], Proximity Alert [74], Automatic Hip Protectors* [77]	3

	Environmental hazard management	Automatic Switch-offs [8], Environmental Hazard Detectors [18], Smart Thermostats [28]	3
	Communicate emergency information	Care Management Software [3], Emergency Information Storage Device [10]	2
	Activity monitoring	Barrier Alarms [5], Care Cameras* [6], Fridge Cameras [16], Motion Detectors [21], Indoor Cameras [26], Door and/or Window Alarms [31], Pressure Sensors [40], Smart Power Sockets [41], Baby Monitors [55], Ambient Activity Monitor* [73], IoT – The Internet of Things [78], Wearable Activity Monitor* [81]	12
Reminding	Reminders	Smart Screens [1], Wearable Hydration Reminders* [9], Smart Speakers [11], Stationary Hydration Reminders [19], Motion Detectors [21], Care Tablets [24], Pocket Pill Dispensers [38], Pressure Sensors [40], Electronic Pill Dispensers [48], Call Services [64], Portable or Wearable Reminders [68], Dementia Clock and Reminder Apps [79], Smart Watches [83]	13
	Instructors	Smart Screens [1], Smart Speakers [11], Video Call Software [39], Recordable Instructors [58], Talking Microwaves* [59], Talking Photo Albums [69], Guide Apps* [72],	7
Managing disorientation	Dementia clocks	Smart Screens [1], Smart Speakers [11], Care Tablets [24], Digital Dementia Clocks [27], Electronic Day Planner Whiteboard [29], Analogue Dementia Clocks [37], Talking Clocks and Watches [47], Dementia Clock and Reminder Apps [79]	8
	Person locators	Missing Person App [14], Wearable Person Locators [52], Wearable Activity Monitors* [81], Smart Watches [83]	4
	Home Leaving Notification	Barrier Alarms [5], Motion Detectors [21], Door and/or Window Alarms [31], Security Cameras [36], Pressure Sensors [40], Wearable Person Locators [52], Wearable Personal Alarms [62], Wearable Activity Monitors* [81]	8
Preventing crime	Security	Banking and Shopping Apps [4], Stationary Personal Alarms [7], Motion Detectors [21], Door and/or Window Alarms [31], Security Cameras [36], Smart Intercoms [57], Call Blockers [67]	7
<b>ACCESSING INFORMATION</b>			<b>10</b>
Finding information	Accessing information	Smart Screens [1], Social Media [2], Smart Speakers [11], Online Training Programmes for Carers [12], Email, Phones, and Answer Phones [32], Information Apps and Websites [51], Call Services [64]	7
Fighting for information	Chasing information	Case Management Software [22], Call Recorder Apps [23]	2
Exchanging information with HCPs	Exchanging health-related information	Email, Phones, and Answer Phones [32], Electronic Health Records [33]	2
<b>PERSONAL CARE</b>			<b>3</b>
Toileting/ incontinence care	Toileting assistance	Automatic Toilets [20]	1
	Continenence management	Enuresis Sensors [30], Full Bladder Detectors* [76]	2

\*\* Number in brackets refers to technology group ID number in appendix J

\* Emerging technology

PwD = person/people with dementia

### 8.3.2. Description of the identified use-cases

The 30 technology use cases are now described in more detail. The numbers in brackets refer to the corresponding technology group, which are detailed in appendix J.

#### 8.3.2.1. Care management

Technologies can make the **care network coordination** easier by allowing the exchange of information with care network members. Technologies enable carers to communicate with their entire care network at once, exchange relevant documents and media (e.g., photos or videos), and retain a record of their conversations [2, 32, 53]. Care Management Apps [53] can offer useful additional tools like schedules or medication lists. **Visitor notification** technologies allow carers to know when care network members or care providers visit the person with dementia, thus giving them peace of mind. Technologies can require visitors to sign in at the person with dementia's residence by scanning an identifier on a device [50, 70] or announcing their presence [11, 36, 57]. Carers can receive visitor notifications via app. Technologies for **care service management** allow carers to view and exchange information with care providers [3, 32]. GPS Arrival Notification [60] is software currently used by some care providers to track the location of their care workers. Access to this information can let carers better plan care and work around care workers' arrival. Care Finder Apps [75] can help carers find and hire care providers or care workers while Personnel Management Software [6] can help them manage their responsibilities as employers of privately organised and hired care workers.

#### 8.3.2.2. Attending appointments

Technologies enable carers to attend virtual **teleconsultations** with healthcare professionals [1, 24, 33, 39, 49] or to **telework** by remotely attending business meetings [39, 49] or accessing programmes they need for work [42]. Other technologies allow carers to asynchronously **coordinate appointments** with healthcare professionals when their work hours collide [32, 33, 34, 44].

#### 8.3.2.3. Entertainment and companionship

Technologies facilitate people with dementias' **entertainment**. Some make it easier for people with dementia to access music or TV [25, 35, 45]. Smart Speakers [2] and Social Robots [17] can provide a variety of entertaining functions such as audiobooks, telling jokes, etc. Under the right circumstances, Video and Computer Games [71] and Self-care Apps [80], especially gaming apps, can also be entertaining for people with dementia. Technologies can also **stimulate** people with dementias' senses and cognitive abilities. Technologies can use sound, light, and/or scent to affect people with dementias' mood and help to invigorate or relax [2, 15, 17, 45, 66, 80]. Technologies for reminiscence [1, 24, 69] and virtual games [71, 80] can be entertaining and cognitively stimulating, the latter

promoting people with dementias' sense of accomplishment. Technologies for **companionship** can make people with dementia feel more connected to other people by making it easier to use a phone [63, 65] or through video calls [1, 24, 82]. Friends and family can send messages, photos, and videos to be displayed [1, 24], thus making people with dementia feel more involved and connected. Certain technologies can provide companionship through their physical presence [17, 45, 56]. Other technologies can enable people with dementias' active **social participation** by helping them get where they want to [43, 46, 72]. Some technologies can facilitate people with dementias' **communication** by using symbols or images connected to a recording of the associated word or phrase [61, 69].

#### *8.3.2.4. Psychological and psychosocial stress*

Technologies facilitate **psychoeducation** by allowing carers to learn coping strategies and skills to better deal with their psychological and psychosocial stress, and providing valuable information and advice from peers [2, 12, 51, 80]. **Self-care** technologies allow carers to take care of their own psychological and psychosocial needs by connecting them to healthcare professionals or peers to vent and receive emotional support [2, 32, 51, 64]. Banking and Shopping Apps [4] can free up time that carers can then use on themselves. Self-care Apps [80], especially relaxation or exercise apps, can help carers unwind or let off steam. Mental health self-test apps can alert carers of risks to their mental health and encourage them to seek professional help.

#### *8.3.2.5. Safety concerns*

Technologies enable people with dementia to **call for help** in case of emergencies like falls. By pressing a button or pulling a cord, an alert is sent to a predefined phone number(s) [5, 7, 52, 62, 63, 65]. Smart Speakers [11] can send an alert if the person with dementia calls out for help. Some technologies have integrated sensors which can autonomously detect a fall and send an alert [52, 54, 62, 77, 83]. Technologies can also help to **prevent serious injuries** of people with dementia by either alerting carers to people with dementia getting up from chairs or beds so they can render assistance [40, 74] or by providing protection if a fall does occur [77]. Other technologies can help to **manage environmental hazards** like fires, heating failure, flooding, etc. [18, 28] and alert the person with dementia, carer, and/or emergency services. Automatic Switch-offs [8] can turn appliances like cookers, faucets, and power tools off after a certain time or if a hazard is detected (e.g., smoke). Some technologies can be used to store and **communicate emergency information** like emergency contacts or medical information that first responders can access [3, 10]. **Activity monitoring** technologies allow carers to monitor certain behaviour or activities of the person with dementia. They can allow carers to quickly check in and look out for unusual sounds or activity [26, 55], detect when an area has been entered or left [5, 21, 31, 40] or if/when appliances have been used [16, 41]. Some technologies use machine

learning to detect abnormal events or behaviour [6, 73, 81]. IoT – The Internet of Things [78] can connect and analyse data from multiple different connected sensors. Carers can monitor these devices for example via smartphone app. **Reminders** are technologies that can help to remind people with dementia of certain tasks or activities. Some devices are only for specific tasks [9, 19, 38, 48] while others can be programmed to display [1, 24, 79] or readout [11, 79] any reminder messages to people with dementia at pre-set times. Some of these technologies vibrate or use audio-visual cues to prompt people with dementia to complete certain tasks [68, 83] while others can require people with dementia to confirm whether they completed the task/activity [1, 24]. Some Motion Detectors [21] and Pressure Sensors [40] can be recorded with messages, e.g., not to forget the keys when leaving the house. Call Services [64] can be arranged to call and prompt people with dementia at pre-set times for defined activities. **Instructors** can help people with dementia navigate certain tasks or activities, for example by giving step-by-step instructions for certain activities [1, 11, 59] which can also be recorded by carers and accessed by people with dementia by pressing a button [58, 69]. Technologies can also connect people with dementia to others to receive instructions if they need help with tasks or activities [39, 72]. **Dementia clocks** can help people with dementia to remain orientated by displaying date, time and/or time of day and support this with images like sun or moon [1, 24, 27, 37] or by announcing it at defined times or when pressing a button [11, 47]. Some technologies use a list of daily tasks to guide people with dementia through the day [29, 79]. **Person locators** allow carers to locate people with dementias' whereabouts. People with dementia need to carry a device [52, 81, 83] which carers can ping to locate on a digital map. Missing Person Apps [14] send a missing-persons-alert to all app users in a region to help find that person. **Home Leaving Notification** technologies can notify carers if people with dementia leave their home or a designated area [5, 21, 31, 36, 40, 52, 62, 81]. Notifications can be received for example via smartphone app or text message. **Security** technologies allow carers to keep people with dementia safe from crime by deterring scammers [4, 57, 67] or home intruders [21, 31, 36]. Stationary Personal Alarms [7] fixed next to the door allow people with dementia to call for help if someone tries to force entry. Alerts can be sent to carers' phones via text message or app or directly to emergency response services. Some technologies can activate a loud localised alert.

#### *8.3.2.6. Accessing information*

Technologies allow carers to **access information** on dementia, caring, and available support [1, 2, 11, 12, 51] and connect carers to peers to exchange information and practical advice [2, 51] and to professionals for one-on-one consultations [32, 64]. Technologies can help carers to **chase the information** they need from service providers, making interface management easier for different collaborating departments and service providers [22], and letting carers keep records of verbal

information they might need to refer to later [23]. Technologies also allow carers to view and **exchange** people with dementias' **health-related information** with healthcare and service providers [32, 33].

#### *8.3.2.7. Personal care*

Technologies can help carers **assist** people with dementia with **toileting** and hygiene after visiting the toilet and can even enable people with dementia to retain their independence [20]. **Continence management** technologies can alert carers of people with dementias' need to visit the bathroom [76] or to change incontinence products [30].

### 8.4. Discussion

This paper aimed to examine the landscape of currently available and emerging technologies, classify the identified technologies according to their use-case for working dementia carers, and map them onto the seven work-care reconciliation challenges identified by Spann, Spreeuwenberg et al. (n.D., see chapter 5.3.). In total, we could identify 83 technology groups and 30 use cases for the seven work-care reconciliation challenges. Interestingly, most use-cases and technology groups and the highest average number of technology groups for each use-case could be identified for work-care reconciliation challenges directly impacting people with dementia, namely "safety concerns" (11 use-cases and 51 technology groups, mean=7) and "entertainment and companionship" (five use-cases and 20 technologies, mean=6.6). On the other hand, "personal care" – the only remaining challenge also directly impacting people with dementia – has the least technology groups in total and on average per use-case (two use-cases and three technologies, mean=1.5). However, the "personal care" challenge in the context of combining work and care is only relevant for carers working and caring at the same time and limited to assistance with toileting and incontinence care. These findings echo those of Sriram et al. (2019) who found most technologies in their categories corresponding to our "safety concerns" and "entertainment and companionship" and the least for the category corresponding to our "personal care". Furthermore, it is concerning that we could only identify three technologies, all of which can be classified as emerging, that aim to facilitate people with dementias' active participation in society. Gibson et al. (2014) also found that technologies promoting people with dementias' quality of life or assisting them with their personal care are curiously rare. This could indicate where the priorities for the development and distribution of technologies currently are. It should be questioned whether the relative plethora of technologies available for some use-cases but not for others are representative of the needs, preferences, and priorities for technological support people with dementia and working dementia carers express, and if not, who decides which needs are prioritised when researching, developing, and distributing technology for people with dementia and their carers.



In any case, most of the technologies we identified will have an impact on people with dementia – and other stakeholders like members of the care network, care providers (services and individual care workers), carers’ employers, healthcare professionals, and local authorities. Where technologies concern people with dementia, most “entertainment and companionship” technologies we identified require them to at the very least *want* to use them actively, while many in the “safety concerns” category could be used without their active participation, consent, or even knowledge (i.e., technologies for environmental hazard management, to communicate emergency information, for activity monitoring, home leaving notification, and security). There could be an ethical dilemma between carers’ need to have peace of mind and people with dementias’ right to autonomy and self-determination – a conflict that is well documented (see, e.g., Bennett et al. 2017; Fetherstonhaugh et al. 2013; Howes and Gastmans 2021; Mort et al. 2013; Robinson et al. 2007; Smebye et al. 2016). It further needs to be considered, that some technologies needing to be worn or carried (e.g., wearable personal alarms) could threaten people with dementias’ sense of self, e.g., by making them feel more vulnerable or frail (Gibson et al. 2014; Spann and Stewart 2018). Privacy and confidentiality of data collected by various monitoring technologies is another concern (Niemelä et al. 2021; Spann and Stewart 2018; Wrede et al. 2021). Gibson et al. (2014) categorised technologies for people with dementia according to underlying power-dynamics: i) used *by* people with dementia (i.e., typically supportive technologies to be used independently by people with dementia, e.g., reminders or instructors), ii) used *with* people with dementia (i.e., technologies which emphasise collaboration and interaction with others or the technology, e.g., games, social robots), and iii) used *on* people with dementia (i.e., technologies monitoring or intervening in aspects of people with dementias’ lives to keep them safe, e.g., environmental hazard detectors, person locator, etc.).

An additional consideration is people with dementias’ ability to use technologies, especially if carers need to rely on them for safety. Spann, Spreeuwenberg et al. (n.D., see chapter 5.3.5. and addendum 7.2.) found that many people with dementia were issued wearable personal alarms by their council which did not suit their needs and abilities. Dementia is an umbrella term for various disease patterns affecting people in different ways (World Health Organization 2017) resulting in different care needs and effects on how people with dementia interact with technology. As dementia progresses, people with dementias’ needs and abilities to interact with technology can change and some technologies might outlive their usefulness while others become more relevant (Lorenz et al. 2019). Sriram et al. (2019) differentiate between technologies requiring people with dementia to use them actively or passively. We suggest introducing a third mode of use: i) active use (i.e., person with dementia must actively use the technology, like pushing a button or using a voice command, e.g., stationary personal alarms, phones, etc.), ii) passive use (i.e., person with dementia has to wear or take the technology with them but does not have to push any button or activate the technology in any other way, e.g.,

person locators or wearable reminders), iii) ambient use (i.e., person with dementia does not have to interact with the technology in any way, e.g., environmental hazard detectors, cameras, etc.). To summarise, when carers want to use technology to mitigate their work-care reconciliation challenges, which directly impact people with dementia, they should consider whether and how this technology would affect people with dementia on a personal level, i.e., their self-determination and sense of self, as well as whether and how people with dementia would have to actively use the technology. Technology when used for and with people with dementia must not be a quick-fix solution but require an ongoing, empathetic, and careful evaluation and negotiation with people with dementia and their cohabiters, centred on people with dementias' needs, preferences, and abilities.

Some technologies require other stakeholders' permission or collaboration. For example, monitoring technologies like cameras could collect data on care workers. Wrede et al. (2021) found that care workers were not very concerned about being monitored themselves, especially if technologies could be temporarily deactivated. This however implies that care workers are informed about these technologies. Where such technologies are used without care workers' knowledge and consent, especially when monitoring sensitive areas like bathrooms, there might be legal issues to consider. Care management technologies like messenger apps or visitor notification systems require care network members' or care workers' active use. GPS arrival notification software, although already in use by some care providers and not illegal as long as employees consent to being tracked by their employer (McAllister 2018), raise questions regarding the potential of coercion of employees already overworked and under a lot of time pressure (Health and Social Care Committee 2021). There are even some technologies which completely depend on others (e.g., healthcare or service providers) procuring, implementing, and using them (e.g., AI or online booking systems, case management software, electronic health records, etc.). This means that whether these technologies have the potential to solve carers' work-care reconciliation challenges depends to a large extent on others. Stakeholders should not only consider implementing these technologies for working carers' benefit but also for their potential to increase efficiency in interface management and save them time and resources.

As the technologies we identified would have to be used in the context of combining caring with work, the impact of using these technologies on carers' work needs to be considered. Technologies such as those addressing carers' "psychological and psychosocial stress", for "accessing information" or for "entertainment and companionship" for people with dementia, do not have to be used by carers when working but others, especially those for "care management" and "safety concerns", do. In a previous paper, we investigated the impact of carers' autonomy at work on their ability to use technology and respond to care-related emergencies (Spann, Allard et al. 2022, see chapter 6): some carers have the autonomy to use technology and leave work when needed to respond to emergencies, some carers

cannot leave work but use technology freely to manage emergencies remotely, some carers work from home and care simultaneously, and some carers do not even have the autonomy to use their phone when needed, thus cannot even be notified of emergencies. These findings have clear implications for the design and delivery of technologies and connected services. Solutions, especially for carers' safety concerns, are needed that take all these different scenarios into account. Additionally, employers should recognise the importance of technology for carers of people with dementia and enable them to use it as freely as possible. Feeling understood and supported by their employer can alleviate a lot of stress for carers and can help employers retain their carer employees (Carers UK 2019; Spann et al. 2020).

We found various technologies which can be viewed as emerging. If the five technologies we found which are already established for other user groups or in other areas (personnel management software, wayfinders, AI booking assistants, guide apps, and GPS arrival notifications) were to be further developed or adapted to be used by people with dementia or working carers, issues including data protection, usability, and the impact on other stakeholders (as already discussed) need to be considered. Most of the other eight remaining emerging technologies, except for self-driving cars and talking microwaves, have been specifically developed to address issues concerning health and social care. Apart from rigorous person-centred research to evaluate their usefulness and usability, their success will be determined by how information about them is disseminated. If the people intended to use these technologies don't know they exist, there will be no required user feedback to improve the design to better suit their needs, no spreading the word about the potential of the technology, and probably no further investment in improving designs and services. It was the express aim of this study to map, not to evaluate, the identified technologies. However, there are countless studies evaluating several aspects of many of the technologies we could find (see, e.g., Ienca et al. 2017; Sriram et al. 2019; Stavropoulos et al. 2020). Aspects which require attention when evaluating our identified technologies are, for example, whether and how they can contribute to carers remaining in paid work for longer, their impact on carers' and people with dementias' overall wellbeing, their impact on people with dementias' autonomy and sense of self, the degree to which people with dementia must interact with them (i.e., active, passive, ambient use), whether carers' autonomy at work permits them to use them at work, whether and how they impact on other stakeholders like care workers or service providers, etc. Using a person-centred design approach and including working carers and people with dementia in the design process should ensure that technologies meet their needs and potential shortcomings are identified and addressed.

#### 8.4.1. Implications for practice

Working dementia carers and people who aim to support them (e.g., their employers, carer or dementia support organisations, and local authorities) can use the technology map presented here to think about potential technological solutions to dementia carers' work-care reconciliation challenges and look for available and accessible technology products. Efforts should be made to signpost working carers to these technologies and carers should be encouraged to share their experiences with others in similar situations. Local authorities tasked with procuring and providing technological solutions to people needing care and their carers should be reminded that technology is no panacea but is often the last resort in an under-resourced care system (Eccles 2021; Gibson et al. 2014). Efforts should not only be made to improve working dementia carers' information on and access to technologies to allow them to address their own challenges, but also to invest in the social care sector and ensure that required services are available and easily accessible.

#### 8.4.2. Strengths and limitations

To the best of our knowledge, this is the first study that uses a carer-centred, bottom-up approach to map currently available and emerging technologies onto the work-care reconciliation challenges working dementia carers express. The broad and open definition of technology allowed us to identify a diverse array of technologies which we described and categorised according to their work-care reconciliation use-case. We used technology databases available in the UK and app stores to identify currently available, and conference proceedings to identify emerging technologies. Using additional sources like reports of relevant technology research institutes or a systematic review of academic, peer-reviewed literature might have produced further insight. To mitigate this risk, we consulted with various technology experts from academia, industry, and social service commissioning to get their feedback on the comprehensiveness of our findings. Despite this broad approach, however, we cannot guarantee that no relevant technologies have been missed. Additionally, the development of technologies is rapidly advancing, which means that our findings could already be dated. However, as most developments are likely to build on or advance already existing technologies and due to the development of our 30 use-cases, connected to the work-care reconciliation challenges identified by working dementia carers, it is likely that the basic framework we developed here will remain relevant and that new developments can be mapped onto it. Further research is needed to test the usefulness of this framework and to gather the views of working dementia carers and other potentially impacted stakeholders on the technologies we identified. The framework we present here is based on the challenges working dementia carers in Scotland identified (Spann, Spreeuwenberg et al. n.D.; see chapter 5.3.) and on technologies we found primarily in technology databases in the UK. Further

research should ascertain whether the work-care reconciliation challenges that form the basis of the framework we present and the technological solutions we identified are transferable to other countries and other cultures.

## 8.5. Conclusion

Technologies can offer much-needed support to carers of people with dementia who struggle to reconcile work and care. We examined the landscape of currently available and emerging technologies, classified them according to their functionality and use-case, and mapped them onto the work-care reconciliation challenges dementia carers identified. A total of 83 technology groups – 13 of which can be viewed as emerging – and 30 use cases could be identified. This technology map can be used by working dementia carers and those aiming to support them to examine their work-care reconciliation challenges and explore technologies that have the potential to offer solutions. Most of these technologies must be used by, with, or on other stakeholders, including people with dementia, care workers, and healthcare and service providers. Several ethical, legal, and practical implications need to be considered when carers contemplate using technologies to address their work-care reconciliation challenges.

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# Part IV

## Online technology evaluation

### IV.a. Preface

The previous chapter introduced the technology map which is firmly rooted in the work-care reconciliation challenges working dementia carers themselves wanted and needed technological solutions for (see chapter 5). The following chapter presents the final study of this thesis. Here, a custom-built website was used to get working dementia carers' and other relevant stakeholders' (i.e., people with dementia, employers, care workers) views on the technologies identified in chapter 8. As such, it contributed to the *exploring the solution* phase of the participatory design process presented in chapter 2.2. This is the only study not presented in a publication-ready format.

### IV.b. Rationale

The purpose of this study was to get feedback from working dementia carers and other relevant stakeholder groups (people with dementia, employers, care workers) on the technologies identified in the technology landscape review (see chapter 8.3.). Participants were asked for their views on these technologies' usefulness and limitations, and ideas for their further improvement and development. Initially and following the participatory design approach, it was planned to achieve this as well as co-design a useable self-help tool based on the technology map (see table 12) by conducting a series of in-person workshops. However, the outbreak of the Covid-19 pandemic and the first UK-wide lockdown orders in March 2020 prohibited any kind of research where participants and researchers would have had to meet face-to-face. Consequently, plans to co-design the aforementioned self-help tool had to be cancelled. Still, in order to round off the research presented in this thesis, there was a lot of pressure to either come up with an alternative research method or not get any feedback at all from those intended to use or potentially be impacted by the identified technologies. An option was to conduct further literature reviews, this time on peer-reviewed evidence from technology users' experiences. There is a growing body of research investigating people with dementias' and their carers' views and experiences with certain kinds of technologies (see, e.g., Groenewoud et al., 2017; Olsson et al., 2012; Scerri et al., 2021; Sriram et al., 2019, 2020; White et al., 2010). However, few if any studies include the views of carers who combine caring for people with dementia with work (Spann et al., 2022). It is questionable whether a review for all the identified technologies would have been feasible

in the remaining time and whether there would even have been any evidence of the experience of our defined stakeholder groups, especially as some of the technologies were emerging and some have not yet been implemented for people with dementia or their carers. Furthermore, conducting a review rather than exploring stakeholders' views directly is not in alignment with the democratic principles of the PD approach. Thus, online methods to get stakeholders' views were explored. A series of online focus groups, similar to the webinar conducted as part of the technology expert consultation after the technology landscape review (see chapter 8.2.5.), were briefly considered. Synchronous and asynchronous online focus groups have been used successfully for different research purposes (Fox et al., 2007; Stewart & Shamdasani, 2017; Stewart & Williams, 2005). However, it was reasoned that the high number of technologies for which feedback was needed would make synchronous focus groups unfeasible, even if organised as a webinar series rather than a one-off event. As the only viable alternative, a research website was custom-built using the free wix.com website builder. Using online tools is a relatively new but promising approach for conducting research requiring participants' creative input (Følstad et al., 2016; Friedrich, 2013; Zancanaro et al., 2018). This method did produce promising insight from our stakeholder groups, but participant engagement was very challenging which impacted the quantity and thus quality of the findings. A detailed description of the procedure and its strengths and limitations can be found in chapter 9.

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## 9. Working dementia carers' and other relevant stakeholders' views on the 83 identified technologies

### 9.1. Methods

Ethical approval for this research was granted by the SchARR Research Ethics Committee. The research website was constructed between April and May 2020 using the free wix.com website builder which provides a broad range of useful functional and creative tools. Among these tools is a ready-to-go blog which was used to create the technology blog posts participants were asked to comment on, as well as a star-rating and comment function. The website was created solely by the author with feedback on content, design, and functionality provided by the supervisory team, academic peers, and the personal network of the author. A professional web-designer was hired to customise the comment function and ensure that participants' comments were stored securely on the websites' backend. The website consisted of a) a publicly accessible section, containing general information on the research, research team, purpose of the study, and the participant information sheet, and b) the research section, only accessible to registered research participants, containing the technologies participants were asked to comment on.

To register, participants needed to indicate their consent to participate before being asked to create a unique username to protect their identity, consisting of a combination of a colour and animal. They were then asked to define which stakeholder groups they identified most with, using the prompt: I am participating in this research as someone who is (selection)

- a. a working carer of a person(s) living with dementia
- b. a person living with dementia
- c. representing the views of a person(s) living with dementia
- d. working in the care sector
- e. an employer or line manager
- f. working for a carer support organisation or an adult social care department

Each of the 83 technologies (see chapter 8 and appendix J) were presented in a short blog post that contained an icon for visualisation, a brief (1-2 minutes reading time) description of the purpose of the technology ("what does it do?") and a description of the potential use-cases for working carers ("what can it be used for?"). These 83 blog posts were presented to a test audience to ensure they were easily understandable. Figure 18 presents a screenshot of one of these blog posts. The use cases were hyperlinked so that participants could see the other technologies classified as serving the same

purpose. To make the large number of technologies participants were asked to look at more manageable, the technology blog posts were randomly arranged into groups of ten.


Figure 18: Screenshot of one of the 83 technology blog posts

# 19 STATIONARY HYDRATION REMINDER

Session 2

## What does it do?

Stationary hydration reminders can be placed on a glass or mug to monitor the drink frequency of the user. Built-in tilt sensors monitor how often the user has taken a drink and the device prompts the user to have a drink if the measured drink frequency is too low. Prompts can be recorded but there are also pre-set notification options. The prompts can also be set to specified intervals.



## What can it be used for?

[#Reminder](#) Stationary hydration reminders can remind the cared-for person to drink regularly. This can help to prevent dehydration.

Please leave a comment and rate this technology

Let us know how much you like this technology by clicking on the stars



Show guide

Please leave a comment. Click on "Show guide" for suggestions.

Submit comment

[I'm done with this technology](#)

[Read previous comments](#)

#### CONTACT

#### FREQUENTLY USED TERMS

This website is part of an ongoing research project supported by the University of Sheffield and Zuyd University of Applied Sciences

[contact\\_aspannl@sheffield.ac.uk](mailto:contact_aspannl@sheffield.ac.uk) or [sustainablecare@sheffield.ac.uk](mailto:sustainablecare@sheffield.ac.uk)



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This website is best viewed on a computer. Viewing it on a phone or other mobile device might affect the viewing experience.

Participants were asked to rate the technology (“Let us know how much you like this technology by clicking on the stars”) between one (“don’t love it”) and five (“love it”) stars. They were then asked to comment on their views of the presented technologies with prompts like:

- *If you have previous experience with this technology, what is your experience?*
- *If you do not have previous experience with this technology, please try to imagine what it might be like using it:*
  - *Do you see any benefits for yourself?*
  - *Do you see any drawbacks or downsides?*
- *In what way could this technology be improved?*

A further section of the research part of the website invited participants to suggest technologies that were not presented as a blog post. The public part of the website went live in May 2020 and the data collection period officially went from the beginning of June to the end of August 2020. Participants’ contributions were securely stored in the website’s backlog and extracted once the data collection period ended. The research part of the website was taken offline after the official data collection period and safely deleted.

#### 9.1.1. Participants and recruitment

We aimed to include members of the following stakeholder groups: i) working carers of people with dementia, ii) people with dementia or those representing their views and interests (e.g., their carers or representatives of dementia support and advocacy organisations), iii) employers/HR, iv) care workers, and v) representatives of carer support organisations and adult social care departments. We designed recruitment flyers (print-out and online version) for each of these stakeholder groups. We asked various dementia and carer organisations throughout the UK and the extended network of the research team of the Sustainable Care Research Programme (CIRCLE 2018) to distribute our flyers among their contacts. In addition, we created a short recruitment video we asked our partners to circulate on their social media channels. Furthermore, we worked with Join Dementia Research, an online self-registration service that connects researchers with volunteers with memory problems or dementia and their carers who have an interest in taking part in research. We also invited our former interviewees to take part in this study. Recruitment started in May 2020 and took place continuously until the research concluded at the end of August 2020.

#### 9.1.2. Data analysis

The data was analysed individually for each separate work-care reconciliation challenge (see chapter 5). All technology groups and corresponding comments that were assigned to each of the seven work-

care reconciliation challenges were separately uploaded into QSR NVivo12 software for qualitative data analysis. As many of these technology groups have multiple use cases and are assigned to more than one work-care challenge, comments have been excluded from analysis if they were not made for a use case relevant to the work-care challenge under discussion. Thematic analysis (Braun & Clarke, 2006) was used to inductively explore participants’ comments. In addition, the star ratings participants left for each technology were summed up and the average rating for each technology group was calculated.

9.2. Findings

In total, 26 people registered for the research website. However, only ten people participated actively, i.e., left at least one comment and/or star rating for at least one of the technology blog posts. Five of the ten registered as a working dementia carer, one as representing the views and interests of people with dementia, and two each as working in the care sector and working for a carer support organisation or adult social care department. One of the working dementia carers clarified that they currently did not provide care anymore for the person with dementia but had done so in the past. No one registered or participated as a person with dementia or an employer. Table 13 presents an overview of the ten registered participants who actively participated, the stakeholder group they associated themselves with, and the total number of comments they left overall.

Table 13: Overview of participants and total number of comments per participant

Stakeholder group	Participant ID	Total N comments
Representing the views and interests of people with dementia	Violet Tiger	25
Working for a carer support organisation or an adult social care department	Green Dog 1	3
	Red Dog 2	13
Working dementia carer	Burgundy Cat 1	1
	Green Cat 1	24
	Green Dog 2	4
	Purple Cat	84
	Blue Dog 1	10
Working in the care sector	Lavender Loris	2
	Blue Dog 2	6

In total, 173 star ratings and 172 comments were left by participants (mean=2.07 comments and mean=2.08 star ratings per blog post), ranging from one to ten comments and ratings left for individual posts. In most cases, participants left a comment and a rating. The average star rating for each technology blog post and total number of ratings left are displayed in table 14. Due to the small total of ratings overall – 36 of the 83 (43%) posts were rated by only one participant – the ratings are merely displayed but not analysed further.

Table 14: Overview of star ratings left per technology blog post

ID	Tech	Stars* (votes)
1	Smart Screens	3.6 (10)
2	Social Media	3.6 (8)
3	Care Management Software	3.4 (5)
4	Banking & Shopping Apps	3.4 (5)
5	Barrier Alarms	3.8 (6)
6	Care Cameras	3.3 (4)
7	Stationary Personal Alarms	2.3 (4)
8	Automatic Switch-Offs	4.3 (4)
9	Wearable Hydration Reminders	3.3 (4)
10	Emergency Information Storage Device	2.4 (5)
11	Smart Speakers	3.5 (2)
12	Online Training Programmes for Carers	4.6 (3)
13	Personnel Management Software	1.5 (3)
14	Missing Person App	1.5 (3)
15	Aromatic Oil Diffusers	2 (2)
16	Fridge Cameras	2.3 (3)
17	Social Robots	3.5 (2)
18	Environmental Hazard Detectors	5 (2)
19	Stationary Hydration Reminders	2 (2)
20	Automatic Toilets	2 (2)
21	Motion Detectors	3 (3)
22	Case Management Software	4 (1)
23	Call Recorder Apps	2.5 (2)
24	Care Tablets	2.5 (2)
25	Simple TV Remote Controls	3 (2)
26	Indoor Cameras	2 (2)
27	Digital Dementia Clocks	4 (1)
28	Smart Thermostats	2 (1)
29	Electronic Day Care Planner Whiteboard	3 (1)
30	Enuresis Sensor	5 (1)

31	Door And/Ro Window Alarms	3 (1)
32	Email, Phones, Answer Phones	3 (1)
33	Electronic Health Records	3 (1)
34	Online Booking Systems	4 (1)
35	Simple Music Players	5 (1)
36	Security Cameras	3.5 (2)
37	Analogue Dementia Clocks	3 (1)
38	Pocket Pill Dispensers	3 (1)
39	Video Call Software	3 (1)
40	Pressure Sensors	3 (1)
41	Smart Power Sockets	2 (2)
42	Business Software and Hardware	3 (1)
43	Wayfinders	3 (1)
44	AI Booking Assistant	3 (2)
45	Musical Soft Toys	3 (1)
46	Self-Driving Cars	4 (1)
47	Talking Clocks and Watches	3 (1)
48	Electronic Pill Dispensers	3.6 (3)
49	Telepresence Robots	3 (1)
50	Fob Or ID Card Scanners	4 (1)
51	Information Apps And Websites	5 (1)
52	Wearable Person Locators	3 (2)
53	Instant Messaging and Care Management Apps	3 (1)
54	Mobile Phones	4 (1)
55	Baby Monitors	3 (1)
56	Robotic Soft Toys	4 (1)
57	Smart Intercoms	4 (1)
58	Recordable Instructors	2 (1)
59	Talking Microwaves	3 (1)
60	GPS Arrival Notification	4 (1)
61	Communication Boards and Apps	3 (1)
62	Wearable Personal Alarms	3 (1)
63	Simple Smartphone Interface Apps	3 (1)
64	Call Services	3 (1)
65	Picture Button Phones	3.5 (2)
66	Sound (And Light) Devices	5 (1)
67	Call Blockers	4.5 (2)
68	Portable Or Wearable Reminders	3.5 (2)

69	Talking Photo Albums	3.3 (3)
70	QR Code Scanners	2 (2)
71	Video And Computer Games	2.5 (2)
72	Guide Apps	2.5 (2)
73	Ambient Activity Monitors	3 (2)
74	Proximity Alerts	3 (2)
75	Care Finder Apps	3.3 (3)
76	Full Bladder Detectors	3.5 (2)
77	Automatic Hip Protectors	3.5 (2)
78	IoT - The Internet Of Things	2.5 (2)
79	Dementia Clock and Reminder Apps	3.5 (2)
80	Self-Care Apps	4 (2)
81	Wearable Activity Monitors	3 (2)
82	Smart Camera TV Attachment	3 (1)
83	Smart Watches	3.5 (2)

\* Votes were between 1 (I don't like this technology) and 5 stars (I like this technology very much)



The following paragraphs present the themes that were synthesised from participants' comments on the technology blog posts as they refer to each of the main work-care reconciliation challenges identified in the interviews with working carers (Spann, Spreeuwenberg et al. n.D.a; see chapter 5). The numbers in brackets refer to the technology group ID (see table 14 or appendix J). Any quantifiers or semi-quantifiers (e.g., some, many, all, few) used in the presentation of the findings when referring to participants' comments only relate to the study population. These (semi-)quantifiers serve to accentuate patterns in the data (i.e., regularities, peculiarities, etc.). No conclusions can be made as to the prevalence of any of the described views and experiences beyond the study population (Neale et al., 2014).

### 9.2.1. Care management

Participants viewed technology to organise and exchange information with care network members [2, 3, 53] as invaluable, "a quick and easy way to connect with paid carers and family alike" (Purple Cat, on [2]), and thought that these technologies are likely to become increasingly important for carers. People with dementias' ability to engage with these technologies was questioned, however. Care management software [3] was also seen as very useful but Violet Tiger believed it was not yet advanced enough:

"I think it is essential that proper records are held by professionals, but don't think there are many places where the technology is advanced sufficiently for records to be shared with service users or carers. More still needs to be done on sharing records between professionals." (Violet Tiger, on [3])

Apart from data protection, participants were concerned about who would have access to these records. It was noted that it would be mutually beneficial for service providers and carers to have access and to add to people with dementias' records, and to keep each other informed of recent developments and people with dementias' needs and preferences.

Visitor notification technologies were received with mixed opinions. Participants liked that they would give them insight into when, for how long, and by whom people with dementia were visited [36, 50, 57, 70]. However, Purple Cat felt uneasy about using security cameras [36]:

"I just always felt that it was spying." (Purple Cat, on [36]).

For QR code scanners [70], the placement of the QR code sticker appeared an important concern, and it was noted that they would need constant replacement and could mark people with dementias' residences as vulnerable when placed outside the home. It was also remarked that while this technology would let them know that service providers had been to see the person with dementia, it could not provide insight into the quality of the care delivered. Care finder apps [75] were thought to be a good idea if run by a major company:

"Depends how dominant the tech company behind the app is. If it is a LinkedIn style app back by Google/Facebook etc then fine. Otherwise it will remain irrelevant." (Green Cat 1, on [75])

GPS arrival notification technology [60] was also received positively, with participants noting that it should be logistically possible but that they were unsure how service providers would view it. Personnel management software [13] was viewed with indifference, with participants noting that they did not need it or used other technology like spreadsheets, but that it would probably be appreciated by those who need it if designed in a user-friendly way.

### 9.2.2. Attending appointments

Participants generally viewed technologies positively [33, 34, 39, 44]. Online booking systems [34] were appreciated for their potential to save time and be more efficient than phone calls and preserve carers' and people with dementias' privacy when appointments needed to be arranged at the office:

“It also means that such appts [appointments] can be made at work online without work colleagues hearing personal business.” (Purple Cat, on [34])

It was remarked that using video call software [39] for teleconsultations with healthcare professionals would spare people with dementia from having to travel and allow them to remain in their usual environment. However, multiple participants noted that people with dementia would not be able to use technology for teleconsultations [1, 24, 39, 49] on their own except at very early dementia stages, that they might not want to use these technologies, or that they might be confused or scared by a virtual presence:

“Many of the people I work with have had various devices set up by their families and know that the device is doing something but they're not quite sure what. E.g. [sic!] trying to turn the TV on with phone, or being upset because a face is looking at them and they're not sure who it is or why they're there.” (Lavender Loris, on [1])

It was highlighted, that at a certain point in the dementia trajectory, carers should no longer care remotely.

Regarding electronic health records [33], participants had concerns regarding data protection and who would be able to access these records, noting that they and people with dementia would need to have access to ensure that records were accurate and complete. Participants noted that some technologies [42, 44], although they liked them in theory, would not help solve their problem: business software and hardware [42] could not eliminate the conflict of needing to prioritise caring over work and vice versa and AI booking assistants [44] could not make the choice between multiple offered appointments.

### 9.2.3. Entertainment and companionship

As most of these technologies would have to be used by people with dementia, many participants considered how people with dementia would interact with and be affected by them. Regarding people with dementias' interaction with technology, a common concern was whether they were able or want to use technologies. Participants thought people with dementia could forget (how) to use technologies

or have difficulties learning to use new ones. Many technologies were thought to be useful, but only at an early dementia stage [1, 11, 24, 43, 46, 63, 72, 82]. Participants believed that familiarity with technologies before being diagnosed with dementia would make it easier for people with dementia to use them.

“Mum always had soft toys, even pre dementia, sitting on her bed (and so do I) so this is not a great leap to think something like this may have been a comfort to her.” (Purple Cat, on [45]).

Some technologies were thought to require the presence of someone else to operate them and ensure they were used safely [1, 15, 66]. Others remarked that technologies [1, 35, 72, 82] needed to be easy to use.

Regarding technologies’ effect on people with dementia, some technologies were highlighted as being potentially amusing and entertaining [17, 24, 66, 69, 71], some, especially those having a physical presence, were thought to be potentially soothing and comforting [11, 17, 24, 45, 49, 56, 66, 69, 82], and some were thought to enable people with dementia to have a good time [1]. One carer commented that talking photo albums [69] could enable people with dementia to have more meaningful interactions with carers, which would of course not solve the issue of providing entertainment and companionship to people with dementia when carers need to work. Two technologies were thought to be enabling for people with dementia, in that they made it easier for them to watch TV [25] and participate in video calls [82]. Some technologies, however, were seen as potentially frightening and distressing [1, 11, 17, 49, 72, 82], especially those with disembodied sounds and voices or video conferencing devices.

Participants remarked that some technologies could be inaccessible due to high cost [17], could cause a lot of work to set up [69], or could be open to abuse [69, 72]. In two cases, the potential positive [56] and negative [15] effect of technologies on pets was highlighted. It was also noted that some technologies could be dehumanising [72, 82] and could not fully replace human interaction [61].

“However, most useful for communication remained our knowledge of her and also the human touch, holding her hand, making eye contact.” (Purple Cat, on [61])

In one case, a participant misinterpreted the intended purpose of smart TV attachments [82], thinking they would be used for surveillance, rather than as a means of communication – highlighting the need for precise descriptions of technologies and their intended purpose.

#### 9.2.4. Psychological and psychosocial stress

Technologies were valued for letting participants connect to peers and making them feel understood and less alone [2], for letting them vent [64], and for receiving emotional support [2, 64]. One carer remarked that feeling thus supported would make them a better carer [2]. Social media [2] was thought to play an even more important part in caring in the future, although the comment did not

specify in what way. Time was also an aspect some participants considered: technology could free up time for themselves [4], allowed participants to access support when they needed it [80], and could be used at their own pace [12]. Interestingly, some participants seemed to think of the value of some of these technologies only from the perspective of people with dementia, even when the technology description explicitly stated, that they were meant to be used by the carer [2, 4, 80]. One carer remarked that they did not want to use social media [2] because they did not want to connect with others further along in the dementia carer journey.

#### 9.2.5. Safety concerns

Most technologies were viewed favourably by participants. They specifically highlighted the potential to give carers peace of mind [5, 6, 18, 48, 57], preserve people with dementias' independence [18, 68, 79], better understand people with dementias' care needs [6, 73], and save carers time and effort [4, 6]. Participants thought that some technologies could be beneficial for everyone, not just people with dementia [9, 11, 38, 48, 63, 68]. However, they also noted that several technologies would only be useful in the early dementia stages [1, 9, 11, 18, 24, 27, 29, 37, 38, 47, 48, 52, 58, 63, 64, 68, 72, 79, 81, 83]. On the other hand, some technologies were thought to be useful to people with dementia throughout the dementia trajectory [5, 8, 18, 83] and that having used technology before becoming ill might make it easier to use it after:

“This would benefit folk who grew up using technology or who had been around technology quite a lot.” (Blue Dog 1, on [1])

There was also an expectation that future generations might be more used to technology when growing older. Participants noted that people with dementia might not know how to use technology as intended or respond when the technology prompted them to do something [1, 6, 7, 19, 29, 52, 54, 59, 64]. Technology that had to be carried or worn was viewed critically, with participants noting that people with dementia might not want to or forget to do so [5, 7, 10, 52, 62, 68, 77, 81]. Equally, it was seen as problematic that people with dementia might have to find the technology before they could use it:

“I’m not sure how successful this would be as a way of reminding someone how to carry out a task as they would first need to locate the book.” (Purple Cat, on [69])

While some participants acknowledged the usefulness of certain technologies, they remarked that they did not fit the needs or abilities of the person with dementia they were looking after:

“My friend has young onset dementia so falls are not yet a concern.” (Violet Tiger, on [6])

Several technologies were also seen as potentially distressing or frightening for people with dementia, especially if they emitted sudden noises or disembodied voices [1, 11, 21, 47, 52, 72]. Participants noted that if certain technologies [28, 26, 48, 74] were needed to keep people with dementia safe,

they would not feel comfortable with them being on their own anymore. Other technologies were thought to only be useful if the carer was nearby to respond to alerts raised by the technology [5, 26, 31, 36, 40, 55, 74]. Some participants questioned how the data collected by certain technologies would be interpreted [21, 55], especially if people with dementia did not live alone [6, 21]. There was a concern that some technologies, while useful in theory, would not be able to address the real issue [1, 8, 16, 19, 28, 41, 77]:

“This could play a part in ensuring someone is eating but won’t actually tell you if the person ate what they took out the fridge. Also everything that people eat is not kept in the fridge.” (Violet Tiger, on [16])

Participants noted that some technologies would depend on other stakeholders [10] or even the general public [14, 63] to be usable and useful.

“This relies on the successful uptake of the app and more specifically, in your area – not something that can be guaranteed.” (Purple Cat, on [14])

Participants had several concerns regarding the cost [83], potential for false alarms [5], and data protection [3, 78]. A big concern was the potential for abuse [4, 72, 78] and the perceived intrusiveness of certain technologies [6, 26, 36, 72, 73, 78], especially cameras. It was also thought that some technologies could make carers feel they need to constantly check in with the person with dementia [26, 36]. Participants noted that some technologies would also require constant updating [3, 67, 83] and one worried about the storage space on their phone taken up by monitoring data [16]. One participant was worried that technology could be used as a pretence by local authorities to withhold additional care:

“I fear that local authorities may see them as a way of delaying residential care for individuals that should no longer be living alone.” (Purple Cat, on [58])

#### 9.2.6. Accessing information

Technologies [2, 12, 51, 64] were valued for giving participants access to information on dementia and available support. Participants noted that technologies could save them time [51] and enable them to learn at their own pace [21]. However, one carer remarked that advice from peers on social media [2] could be culture and context-specific, and Green Dog noted that they acknowledged the benefits of social media but did not want to engage with it because:

“I do not really want to talk to other people who may be further on in the journey” (Green Dog 1, on [2])

Technology for chasing information and exchanging health-related information was valued and thought to make caring easier [22, 23, 33]. However, data protection [22, 33] and who would be able to access health-related information [33] were a concern. Email and answer phones [34] were seen as better than nothing and preferred over phoning healthcare professionals, as this could save time and effort, but participants noted that their messages were not always responded to promptly.

Participants did not comment on smart speakers and screens [1, 11] regarding their access to information, although they were marked as potentially useful to them in this capacity.

#### 9.2.7. Personal care

Two of the three technologies were viewed quite positively [30, 76]. Participants thought that they could reduce conflict and distress for people with dementia [30] and preserve people with dementias' dignity [76]. One carer also thought there might be potential for saving them time [76]. However, it was noted that enuresis sensors [30] could only be useful at a specific stage of the dementia trajectory, and that full bladder detectors [76] would need additional note keeping to, e.g., detect urinary tract infections. Automatic toilets [20] on the other hand were viewed very critically. Participants acknowledged the potential benefit for themselves but thought that people with dementia might be distressed by introducing this technology. They also remarked that this technology was not widespread in their culture which could impact people with dementias' acceptance.

### 9.3. Discussion

This chapter provides insight into stakeholders' views of the technologies identified by Spann, Spreeuwenberg et al. (n.D.b; see chapter 8.3.). Most technologies were viewed favourably by participants. Particularly the potential to save carers time and effort and be accessible when they needed was highlighted regarding technologies for care management, attending appointments, psychological and psychosocial stress, and accessing information. This is in line with the findings from the second scoping review (Spann et al., 2022; see chapter 4.3.2.). It is interesting to note that participants regularly appeared to emphasise technologies' benefits for and effects on people with dementia rather than considering these issues for their own efforts to reconcile work and care. As many technologies need to be used by, with, or on people with dementia (Gibson et al., 2014), it is perhaps unsurprising that participants would consider people with dementias' interests. However, on some occasions, participants thought primarily of people with dementia even if the technology's description explicitly stated that it was intended to be used by carers (e.g., banking and shopping apps [4]). While participants' considerations for people with dementia provide much-needed insight into the perspective of people with dementia – as sadly no person with dementia registered or contributed to the research themselves – this is slightly disappointing considering the dearth of evidence on technologies for work-care reconciliation (Spann et al., 2022). Similar observations were made when interviewing working dementia carers (see addendum 7.3.). While it needs to be stressed, that this study is limited by the small number of actively contributing participants, it could be interesting to investigate this phenomenon further. Specifically, it should be explored whether there really is a tendency by working carers to emphasise people with dementias' needs and interests above their own

and how this phenomenon could be explained. Similar to Furlong and Wuest's (2008) investigation into carers' self-care practices, it could be the case that the dynamic and unpredictable process of caring for people with dementia could lead to carers hyperfocusing on people with dementias' needs, thus losing sight of their own. As caring is still largely a private issue that often goes unnoticed, especially in the workplace (Carers UK, 2019; 2020), it might also be the case that carers don't reflect enough on the challenges they face when combining work and care and thus have difficulties to consider the value of technology as a potential solution.

Where technologies needed to be used by, with or on people with dementia (predominately technologies for attending appointments, entertainment and companionship, and safety concerns), participants questioned whether people with dementia would be able to use these technologies as intended. Forgetting to wear or carry a technology, forgetting where they kept the technology, and forgetting (how) to use the technology when needed were frequent comments. Regarding reminders and prompts, participants questioned if people with dementia could interpret prompts correctly and act accordingly. These findings are echoed by the working carers interviewed earlier (see addendum 7.2.). Many technologies were viewed as useful and usable by people with dementia, but only in the early stages of dementia with very few being viewed as potentially useful throughout the dementia journey [5, 8, 18, 83]. Lorenz et al. (2019) also found that some technologies can become less and others more useful as dementia progresses and people with dementias' needs and capabilities to interact with technology change. However, as some participants noted, having been avid users or accustomed to certain technologies before becoming ill could help people with dementia to keep using them or adapt to new ones more easily. This could have implications for future generations who have lived most, or all their lives using all kinds of technology. Further, this means that the uptake, usefulness, and usability of technologies for people with dementia could be improved by incorporating functionalities into technologies they are already familiar and comfortable with (e.g., integrating fall detectors and person locators in watches). Further investigation is needed to substantiate this assumption. Another issue to consider is whether people with dementia want to use certain technologies, especially if they need to be worn or carried. As participants highlighted, some technologies could be frightening or confusing while others could impact on people with dementias' sense of self (Gibson et al. 2014; Spann and Stewart 2018).

Participants had various practical and ethical concerns, including data protection, ensuring that (only) the right people had access to people with dementias' data, the cost and potential intrusiveness of certain technologies, the need for information accessed via technology to be context and culture-specific, technology maintenance and reliability, and the potential to increase rather than resolve the demand on carers. Some participants noted that while they could see the benefit of a technology, they

personally had no need for it. Others commented that some technologies, while sounding promising in theory, did not address their or people with dementias' needs. This as well as some participants misunderstanding the purpose and intended users of technologies highlights the need for precise descriptions and complete transparency regarding benefits and all potential downsides when advising carers on technologies. Several technologies were thought to only be useful when carers were close by to either help people with dementia use them safely and correctly or to respond to technologies notifying carers of certain events. Consequently, these technologies are only useful to carers who work and care at the same place or work very close to the person with dementias' residence and have the schedule autonomy to leave work, when necessary (Spann, Allard et al., 2022; see chapter 6.3.1.), and should be specifically marked as such.

Finally, participants remarked that at a certain point in the dementia trajectory, people with dementia should no longer be on their own, despite some technologies' (e.g., activity monitors or person locators) potential to address some of the challenges people with dementia and carers could face. One participant expressed concern that technology could be used as an easy and cheap way for local authorities to delay or avoid having to finance adequate residential care provision. Gibson et al. (2014) also highlight the dangers of viewing technology as a quick-fix solution to the UK's ongoing social care funding crisis (Bottery & Ward, 2021; Care Quality Commission, 2021; Charles & Ewbank, 2021). Local authorities or others advising carers on technologies (e.g., carer or dementia support organisations, employers, etc.) must take carers' concerns regarding technologies seriously, accept that technologies might not be suitable or desirable options for some people, and ensure that adequate care services are available, affordable, and accessible.

### 9.3.1. Strengths and limitations

Under the circumstances, this method was the only one that allowed me to gain any first-hand insight into stakeholders' views on the technologies identified as potentially useful for working dementia carers. Apart from keeping everyone safe during a global pandemic primarily affecting older and vulnerable people (Alzheimer's Society, 2020), this method had the benefit that participants did not have to travel and could participate in their own time.

However, recruitment and participant engagement in the research proved to be very difficult. In total, only 26 people registered for the website but not all of them participated actively. None of the participants registered as people with dementia or employers, although one person registered as someone representing people with dementias' views and interests and participants frequently commented with people with dementias' interests in mind. Only a small number of those registered for the research website ended up leaving any comments or star ratings, and for many technologies,



only a single participant left any comments or ratings at all. To try and increase participant engagement, a “technology of the week” newsletter was sent once a week to all registered participants – with limited success. The comments that were left are very insightful even though many stem from a single participant. Participants very rarely engaged with each other’s comments, and other stakeholder groups’ views (i.e., care workers, people with dementia, employers) are underrepresented. It is possible that the number of technologies participants were asked to comment on was overwhelming, despite efforts to keep this manageable by clustering them into groups of ten and keeping the descriptions as brief and to the point as possible. Working carers seldom have spare time available and might have prioritised spending that time with family, friends, or on themselves. Particularly during a global pandemic, it is possible that participating in this kind of research was not a priority for our participants or that they did not find the time to do so. The “technology of the week” newsletter mentioned earlier has only been sent to registered participants via email to try and increase their engagement. This newsletter could also have been distributed via the social media channels of the organisations that helped with recruitment to try and recruit additional participants. Furthermore, incentives such as gift vouchers for participants and special prizes for participants with the highest number of comments might have increased participation and engagement in the research. Another way to keep participants engaged could have been to construct the website in such a way that participants are redirected to a new blog post automatically after submitting a comment. It is possible that some participants might have kept reading and engaging for a bit longer once they started reading about the next technology. Extending the time the research part of the website was accessible could also have contributed to increasing the number of registered and actively engaged participants. Despite the huge efforts this research method cost in terms of creating the website, getting ethical approval, recruitment, and engagement of participants and the slightly disappointing outcome, it remained the only viable option to conduct this kind of research during a pandemic.

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## 10. Discussion and concluding remarks

This thesis aimed to explore, identify, and map technologies, currently available and emerging, which have the potential to support working carers of people living with dementia to reconcile work and care. The findings of each study are discussed in detail in each respective chapter. This discussion serves to draw all findings together and explore how they contributed to addressing the main objectives of this thesis.

To preface this discussion, it should be highlighted that technologies must not come to be seen as a substitute for proper and urgently needed investment in health and social care in the UK (Eccles, 2021; Gibson et al., 2014). Technologies can be empowering and have a transformative effect on the lives of those who need them, carers and people with dementia alike. Yet there is a danger of them becoming coercive rather than liberating if the under-resourced social care landscape offers no alternatives to using them.

However, that this kind of research is needed is demonstrated by the fact that many carers are not aware that technological solutions for their challenges exist and where they can get them from (Carers UK, 2013; Spann, Vicente, et al., 2022; see chapter 4.3.3.1.) Thus they are not even in a position to consider whether technologies are suitable for their and people with dementias' situation. This was also a finding of the interviews conducted with working dementia carers as part of this thesis. Even carers who considered themselves tech-savvy had not thought of technology as a solution to some of their challenges, and many were not aware that the technologies they wished for already existed (see addendum 7.1.).

Despite a growing body of evidence on technology for carers and people with dementia (see, e.g., Bergström & Hanson, 2017; Evans et al., 2015; Gibson et al., 2014; Godwin et al., 2013; Lorenz et al., 2019; Smith, 2008; Sriram et al., 2019; Wasilewski et al., 2017; Yellowlees, 2020) not much had been known about the topic of technology to support reconciling work and care for people with dementia. Only 16 publications could be identified that address technology for work-care reconciliation within 20 years, seven being non-peer-reviewed publications and only ten having been published within the last ten years. Further, most of these publications aimed to evaluate technology (prototypes) or examine carers' experience using certain kinds of technology (Spann, Vicente, et al., 2022; see chapter 4). Only one publication (Beauchamp et al., 2005) was aimed at working carers of people with dementia and none took a bottom-up approach to investigate working carers' need for technological support (Spann, Vicente, et al., 2022; see chapter 4). This indicates that while technologies have been identified as potential solutions for working carers for more than 20 years, more research is needed to better

understand which and how technologies can help them to better reconcile work and care for people with dementia.

This thesis introduces a technology map (see chapter 8.3.1., table 12) whereby technologies have been grouped according to their functionality, classified according to their use-case relevant for working carers, and mapped onto the work-care reconciliation challenges working dementia carers identified (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5.3.). This technology map can be used by working carers and those aiming to support them (e.g., employers, carer or dementia support organisations, and local authority adult social care departments) to identify potential technological solutions to carers' individual work-care challenges. Together with this technology map, this thesis had three main objectives which are now discussed in detail.

### 10.1. Objective 1

Objective one was to investigate which challenges working carers of people with dementia face when combining work and care and how their autonomy at work impacts their ability to manage care-related emergencies.

A scoping review (Spann et al., 2020; see chapter 3) was conducted to get a comprehensive overview of what was already known about the challenges carers face when combining work and care, and which solutions have been described to help them manage these challenges. This review resulted in the development of a conceptual framework that not only considers challenges directly resulting from having to reconcile work and care (primary challenges) but also acknowledges that potential solutions aiming to address these primary challenges (primary solutions) can result in secondary challenges. This framework can help those supporting working carers to have a clearer understanding of the difficulties carers face when combining work and care, and that potential secondary challenges need to be considered when offering carers solutions. The primary work-care reconciliation challenges identified through the scoping review were A) *high and/or competing demands*; B) *psychosocial/-emotional stressors*; C) *distance*; D) *carer's health*; E) *returning to work*; and F) *financial pressure* (Spann et al., 2020). This framework has been proven to be a useful analytic lens when conducting the second scoping review (Spann et al., 2022, see chapter 4) and reviewing the evidence on barriers and benefits to technologies carers use to better reconcile work and care. The first scoping review was not limited to carers of people with dementia. Thus, more focused exploration of the work-care reconciliation challenges carers of people with dementia face was warranted.

Following the democratic and person-centred philosophy of the participatory design approach (see chapter 2.2.), working dementia carers were interviewed so they could themselves identify the challenges they experienced when reconciling work and care and the technological support they

required or desired (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5). Combining work and care for people with dementia is very challenging and complex due to fluctuating and often unpredictable care needs (Gallagher-Thompson et al., 2020; Matsumoto et al., 2007; Newbronner et al., 2013; see chapter 1.2.3.) and work demands. As established in chapter 3.3.3., findings from the first scoping review, not just the amount of time spent caring but particularly unpredictable care needs that require a lot of monitoring of the cared-for person's safety and wellbeing can have a substantial impact on carers' ability to remain in work. Adding to the complexity are unstable care arrangements which require a lot of management, and which often depend on available resources and preferences (Spann et al., 2020; see chapter 3.3.). Hence it is unsurprising that interviewed working dementia carers experienced a multitude of challenges: i) *care management*; ii) *attending appointments*; iii) *entertainment and companionship for the person with dementia*; iv) *dealing with psychological and psychosocial stress*; v) *safety concerns*; vi) *accessing information*; and vii) *personal care* (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5.3.). There are clear similarities to the work-care reconciliation challenges identified in the scoping review in chapter 3. *Care management, attending appointments, entertainment and companionship for the person with dementia, safety concerns, and personal care* align with primary challenge A) *high and/or competing demands* (Spann et al., 2020; see chapter 3.3.), in that they all relate to time-based role conflict. According to Greenhaus and Beutell (1985), time-based role conflict occurs when addressing the demands of one role (e.g., work) makes it impossible to deal with the demands of another (e.g., caring), for example through being physically unable or cognitively too preoccupied with one role to meet the demands of the other. The *personal care* challenge, however, also had a clear psychological component, in that carers found it emotionally difficult to deal with incontinence and intimate hygiene. Thus, along with dementia carers' challenge of dealing with their own *psychological and psychosocial stress, personal care* also correlates with primary challenges B) *psychosocial/-emotional stressors*, and D) *carer's health* (Spann et al., 2020; see chapter 3.3.). Dementia carers' challenge of *accessing information* is, however, conceptualised as a secondary challenge in the scoping review's findings, in that it forms a significant barrier to carers' ability to access the support they need (Spann et al., 2020; see chapter 3.3.). The primary challenges E) *returning to work*; and F) *financial pressure* (Spann et al., 2020; see chapter 3.3.) have no clear counterpart in the interviews with working dementia carers. The last remaining challenge, C) *distance* (Spann et al., 2020; see chapter 3.3.), however, is an important factor when discussing the impact of dementia carers' autonomy at work on their ability to manage care-related emergencies.

The complexity and unpredictability inherent in caring for people with dementia require carers to be flexible enough to manage care-related situations/emergencies (CRE) when they occur. Unsurprisingly, flexible work is highly valued by working carers (Carers UK, 2019; Spann et al., 2020; see chapter 3.3.3.). However, the neutral term flexible work can disguise underlying power dynamics (i.e., employers

requiring employees to be flexible rather than employees having the power to self-direct their schedule) and should thus be replaced by autonomy at work, more specifically schedule control (Wheatley, 2017) in the work-care-reconciliation discourse. In chapter 6 (Spann, Allard et al., 2022) it was found that autonomy at work, i.e., schedule control (autonomy of work breaks, schedule, and place), can be viewed on a spectrum where carers with no autonomy were generally not able to manage CRE and use technology to that end, and carers with complete autonomy were generally able to do so well. Break autonomy seemed to be most influential for carers' ability to manage CRE without leaving work, by using technology (primarily their phone) and delegating the CRE response to their care network. Carers without break autonomy could still manage potential CRE without their direct involvement, e.g., by connecting the person with dementia via a personal alarm system to an emergency response call centre. Carers who had schedule autonomy could generally manage CRE in person by coming in late, leaving early, or rearranging their schedule entirely – at least in theory, as some carers felt pressured to prioritise work over caring (e.g., through deadlines or a competitive work environment). Carers with place autonomy could work and care from the same place and thus prevent or manage CRE instantly. However, these carers found they needed to be highly organised yet flexible to accommodate any CRE, experienced frequent work disruptions, and some found the rapid and constant role switching (from carer to worker and vice versa) very challenging. Adequate boundary management, which Kossek et al. (2006) suggested could decrease role conflict, was thus very difficult for carers to employ and they often felt guilty when they needed to prioritise work over caring and vice versa. These findings, albeit merely a side note in their research, are echoed by Keck and Saraceno (2009) and Hamblin and Hoff (2012).

Several factors have been identified that influence carers' autonomy at work and their ability to use technology (Spann, Allard et al., 2022; see chapter 6.3.2.) The nature of their work often had a decisive impact. While there are certainly some occupations that necessitate work at specified times and places, Milasi et al. (2020) pointed out that there appears to be a strong cultural aspect to how much autonomy is afforded in specific sectors in different countries which became evident when the Covid-19 pandemic suddenly necessitated many employees to work from home where this was previously considered unthinkable. Similarly, Chung (2019) found that traditionally female work sectors have worse working conditions and less schedule flexibility, which is particularly problematic considering that women still provide more unpaid care (Zhang et al., 2019). Larger studies should seek to quantify which work sectors afford which levels of autonomy to carers and how much this is influenced by culture. Although self-employment did not automatically afford carers complete schedule and place autonomy, depending on the nature of their work, there did not seem to be any limitations to using technology when working. For employed carers, line managers appeared to be decisive in their level of autonomy and their ability to use technology, a finding that is supported by the literature (Arksey,

2002; Carers UK, 2019; Mahoney, 2004; Mahoney et al., 2008; Milasi et al., 2020; Spann et al., 2020). Workplace culture, too, was an important factor that determined whether carers felt comfortable asking for more autonomy and support (Chung, 2017; Ireson et al., 2018; Spann, Allard et al., 2022). Many carers feared they would be seen as unreliable, and thus tried to keep the extent to which caring impacted their work as secret as possible. However, flexibly working employees have been found to often be more productive (Choudhury et al., 2021; Chung, 2017) and employee morale might even improve as employees feel better understood and supported by employers who enable them access to technologies (Mahoney et al., 2008). As many work-from-home orders imposed during the Covid-19 pandemic (Milasi et al., 2020) are now revoked, it could become harder for employers to deny their employees the place autonomy they have become accustomed to and proven to work successfully.

Distance, identified as a primary challenge in the scoping review on carers' work-care reconciliation challenges (Spann et al., 2020, see chapter 3.3.3.), was a factor that impacted carers' ability to manage CRE even if they had complete autonomy at work (Spann, Allard et al., 2022; see chapter 6.3.2.). Although a well-documented challenge for carers for which they particularly value high autonomy at work (Bernard & Phillips, 2007; Edwards, 2014; Koerin & Harrigan, 2003; Manthorpe, 2001; Spann et al., 2020; White et al., 2020), the specific interaction of autonomy at work with distance caring remained relatively unexplored until now. The interviews with working dementia carers revealed that distance can make even high levels of schedule autonomy meaningless for managing CRE in person, but place autonomy can allow carers to overcome distance and manage their work and care responsibilities from the person with dementia's home.

## 10.2. Objective 2

The second objective was to explore which technologies working carers of people with dementia are using or would like to use to support their work-care reconciliation efforts, and what their experiences are with these technologies.

The scoping review presented in chapter 4 (Spann, Vicente, et al., 2022) revealed that the evidence on technologies for working carers is limited in both quantity and scope, and that technologies which have been explored thus far can be classified as *web-based technologies*, *technologies for direct communication*, *monitoring technologies*, and *task-sharing tools*. In the included publications, *web-based technologies* were used to stay connected to the workplace when on care leave, enable professional and peer-support, store and share care-related information, and provide psychoeducational resources, information on caring and available support, although it is unclear whether and how these resources and information were specific to working carers' challenges and not just for carers in general. Both *technologies for direct communication* and *task sharing tools* were used

to coordinate the care network. The former was generally used to communicate with the cared-for person, workplace, and everyone involved in cared-for peoples' health and care provision while the latter was also used to store care-related information. *Monitoring technologies* were used to keep an eye on cared-for peoples' safety and wellbeing. These findings relate to working carers in general and not specifically to those who combine work with caring for people with dementia.

This thesis took a bottom-up approach to explore not only the technologies working dementia carers already used and their experiences with them, but also which technologies they wanted to use and for what purpose. The interviews with working dementia carers (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5.3.) showed that carers had experience with technology in some areas, particularly regarding the *safety concerns* and *care management* challenges, while few had considered potential technological solutions for other challenges such as their own *psychological and psychosocial stress*. This is of particular interest because the scoping review revealed that while eight peer-reviewed publications address technologies aimed at the latter, only three respectively aimed at the former two (Spann, Vicente, et al., 2022; see chapter 4.3., table 6). No previous publication, peer-reviewed or not, addressed technologies for working carers' *attending appointments, entertainment and companionship, and personal care* challenges. This indicates that research interests might not align with working carers' needs and that future research should adopt a more carer-centred approach. The interview situation itself and the discussion of their challenges prompted many carers to start reflecting and becoming aware of the technologies they already used and to think creatively about what technologies they wanted. Importantly, many carers described wanting technologies they were not aware already existed (see addendum 7.1.) which is in line with previous research (Andersson et al., 2016; Carers UK, 2013) and highlights the need to support working carers in considering technological solutions for their challenges. Empowering carers to think creatively about how they could use technology to support their work-care reconciliation efforts might have the positive effect of them leading the way in the development of new, and improvement of existing, technologies to better suit their and people with dementias' needs.

When discussing carers' experiences with technologies, the challenges-solutions conceptual framework developed as part of the first scoping review (Spann, Vicente, et al., 2022; see chapter 3.3.2.) can be a useful tool, as demonstrated by the second scoping review (Spann, Vicente, et al., 2022; see chapter 4.3.). This framework encourages carers, those who advise them on technologies, and technology developers to consider not only the benefits of potential solutions to carers' work-care reconciliation challenges but also how these solutions can inadvertently create additional (secondary) challenges.



Regarding *care management* (see chapter 5.3.1.), many interviewed carers used instant messaging apps to coordinate their care network, which they generally found very useful. However, a secondary challenge is that all the technological solutions carers used or wanted, depend on care network members' agreement and active participation. Some technologies carers wanted, like online platforms where they could exchange information with care providers, would even require care providers to procure and implement software packages. This could be a barrier considering the UK's ongoing social care crisis (Care Quality Commission, 2021; Ward et al., 2020; see chapter 1.1.), and could raise questions as to who would have access to the data and who decides that.

Apart from using their phone to coordinate appointments with healthcare professionals, carers had no experience with technology for *attending appointments* (see chapter 5.3.2.). Already the Covid-19 pandemic has necessitated that more healthcare providers offer remote consultations (Joy et al., 2020) but issues such as carers' ability to attend when at work and people with dementias' ability to attend on their own need to be addressed. A major barrier, i.e., secondary challenge, to carers using their phone to coordinate appointments was that they needed to be used synchronously, so during carers' worktime and sometimes in front of their co-workers. Carers thus wanted technologies that allowed them to deal with this in private and at their convenience (e.g., email, answer phones), noting that this would again require others, in this case, healthcare professionals, to enable them access to these technologies. Many carers did use technology to attend business meetings when working remotely, which was generally appreciated.

The only technologies that were used for the *entertainment and companionship* of people with dementia (see chapter 5.3.3.) were radio and TV. Carers worried about the lack of adequate stimulation and the effect this could have on the progression of the symptoms of dementia. Many carers wanted technologies that could give people with dementia a better quality of life and enable them to take part in society (see addendum 7.3.), and many felt guilty that they could not keep people with dementia company when they needed to work. However, what people with dementia experience as entertaining and stimulating might depend on their personality, ability, and preferences (Lorenz et al., 2019) which carers should accept even if that means people with dementias' preferences for entertainment don't align with their own ideas. Nevertheless, carers should be encouraged to explore the many possibilities technology can offer for entertainment and companionship together with people with dementia. Once confirmed that people with dementia want to and are comfortable using these technologies, important secondary challenges to consider are whether they can do so safely and independently, as well as their affordability. Where people with dementias' speech was affected by their illness, carers wanted technology that would allow them to regain their ability to communicate. However, this might be more an expression of a desire to resurrect the relationship they once had with

their loved one, rather than about the act of exchanging information. In any case, technology that does compensate for impaired speech, which is common in people with dementia (Weekes, 2020), would have to consider that communication impairments can have different causes and expressions.

Almost all carers described experiencing *psychological and psychosocial stress* (see chapter 5.3.4.), but only one thought to seek emotional support via technology (i.e., social media). One of the younger carers who considered themselves quite tech-savvy even appeared surprised that they had not previously thought of the potential of social media to get emotional support from peers. Lack of awareness thus appears to be a major barrier to carers' access to these technologies, despite ample evidence of the benefits of online support such as peer networks or psychoeducational training programmes (see, e.g., Andersson et al., 2017; Beauchamp et al., 2005; Klemm et al., 2014; Kuhn et al., 2008).

Carers seemed to have the most experience with technologies for their *safety concerns* (see chapter 5.3.5.), where they also seemed to want the most technological solutions. They wanted technologies that alerted them or their care network to various potentially dangerous situations, accidents, or emergencies to ensure a prompt response, although many noted that these technologies often did not fit people with dementias' needs and abilities (see also addendum 7.2.). Lorenz et al. (2019) found that people with dementias' needs and their abilities to use technology can change along the dementia trajectory, thus requiring constant evaluation. Issues carers frequently described were people with dementia forgetting to use, wear, or carry technologies and some not wanting to use them. Another secondary challenge is that carers with little autonomy at work might not be able to use or respond to these kinds of technologies (Spann, Allard et al., 2022; see chapter 6.3. and previous discussion on objective 1) and that technologies with a limited range could inadvertently lock people with dementia into a "safe zone". Carers worried that technologies aiming to remind or alert people with dementia could be scary, confusing, or simply ignored and thus should have a range of optional accessibility features. For many carers, their need for peace of mind conflicted with people with dementias' rights to privacy and independence. There is, however, some evidence to suggest that (some) technologies might improve people with dementias' independence by increasing their confidence and sense of safety, although this evidence is methodologically limited (Meiland et al., 2017). An important secondary challenge experienced by some carers was the pronounced lack of coordination between organisations tasked with prescribing, providing, and maintaining technologies which regularly resulted in work interruptions and frustration.

Online sources were regularly used by carers to *access information* (see chapter 5.3.6.) with carers noting that content needed to be relevant to their situation as they often had limited time or energy to search for information online. Carers often described a lack of care-related knowledge and feeling

unprepared and overwhelmed. However, knowing more about the condition of their loved one and their prognosis can negatively impact carers' coping strategies (Alzheimer's Research UK, 2015) which indicates that information provided online has to be sensitive to this issue. It might be helpful to involve carers in decisions regarding which information is presented online and how. Some carers wanted practical advice from peers but only one carer had thought to use social media for that purpose. Carers struggling to receive the required information from fragmented service providers suggested organisations could use software solutions to improve their interface management and streamline their workflow. Secure online platforms were also suggested as a solution for carers to exchange people with dementias' care-related information with healthcare providers – yet again technological solutions that would have to be implemented by others and which carers have no influence over.

Regarding *personal care* (see chapter 5.3.7.), only toileting is of immediate relevance to carers' efforts to reconcile work and care as all other activities (e.g., preparing meals, grooming, etc.) could be planned and worked around – and only for carers who work and care simultaneously or provide care during their lunch breaks. Carers often experienced toileting and especially incontinence issues as very uncomfortable and emotionally difficult and wondered if technology could offer solutions. However, one carer noted that they would not want technologies like care robots to take over these tasks as they felt people with dementia would prefer personal interactions and might even be frightened by robots.

### 10.3. Objective 3

The third objective was to identify promising technologies, currently available or emerging, and map them onto the previously identified work-care reconciliation challenges, taking into account how people with dementia, employers/clients, and care workers may be affected.

In chapter 8 (Spann, Spreeuwenberg, et al., n.D.b), the seven previously identified work-care-reconciliation challenges (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5.3.) were used to conduct a comprehensive review of the landscape of currently available and emerging technologies. A total of 83 technology groups (see appendix J) – 13 of them considered emerging – were identified, classified according to their use-case for working dementia carers, and mapped onto the seven work-care reconciliation challenges (see table 12 in chapter 8.3.1.). Five of these emerging technologies are already established for other user groups or in other areas. When adapting them to be used by people with dementia or working carers, issues like data protection, usability, and the impact on other stakeholders need to be considered. Except for self-driving cars and talking microwaves, the remaining emerging technologies have been specifically developed to address issues concerning health and social care. Whether they will become widely available will largely depend on whether the intended users

learn of their existence and find them useful and usable. Overall, 30 individual use cases emerged from the analysis with many technology groups having more than one use case (see appendix J). Potentially suitable technologies could be identified for each of the seven work-care challenges. Most use cases and technology groups and the highest average number of technology groups for each use-case were identified for the *safety concerns* and *entertainment and companionship* challenges and least for the *personal care* challenge, a finding echoed by Sriram et al. (2019). Very few technologies could be identified that aim to promote people with dementias' active participation in society (all of them considered emerging) or assist them with their personal care, which was also found by Gibson et al. (2014). It should be questioned whether the relative plethora of technologies available for some use-cases but not for others are representative of the needs, preferences, and priorities for technological support people with dementia and working dementia carers express, and if not, who decides which needs are prioritised when researching, developing, and distributing technology for people with dementia and their carers.

To get working dementia carers' and other stakeholders' (i.e., people with dementia, employers, care workers/providers) views of these technologies, they were invited to rate and comment on each of the 83 technologies using a custom-built blog-style website. As detailed in chapter 9.3.1., participant recruitment and engagement were challenging. However, there are still some valuable insights which should be expanded on in larger studies. Particularly technology that does not concern people with dementia directly was generally viewed favourably by participants with them specifically highlighting their potential to save carers time and effort and be accessible when they needed them.

Where technologies do concern people with dementia (predominately technologies for *attending appointments*, *entertainment and companionship*, *safety concerns*, and *personal care*), Gibson et al. (2014) provide a useful classification: technologies used i) *by*, ii) *with*, and iii) *on* people with dementia. Following this classification, two arguments brought up by participants require consideration. The first relates to people with dementias' ability to interact with technology. Many participants questioned whether people with dementia would be able to use technologies as intended due to them forgetting to wear or (how) to use them, being overwhelmed by the technology, or not knowing how to respond to reminders or prompts, a finding that is supported by the literature (see, e.g., Lorenz et al., 2019; Sriram et al., 2019). This is a particular concern as the interviews with working carers suggest that technologies often appear to be introduced to people with dementia by local authorities with a one-fits-all approach and without considerations as to whether and how they are even able to use them (Spann, Spreeuwenberg, et al., n.D.a; see chapter 5.3.5. and addendum 7.2.). Despite not addressing the actual need, such an approach – if it is indeed widely practised – would be a waste of already scarce resources in the social care sector and should urgently be reviewed. Many technologies were thought

to only be useful to people with dementia in the early stages of the illness or that people with dementia might find it easier to use them if they had been avid technology users before becoming ill. Further research with people with dementia is needed to confirm if people who have been technology users all their lives find it easier to use them after becoming ill as this could have implications for the future development, design, and deployment of technologies for people with dementia.

The second argument requiring consideration following Gibson et al.'s (2014) classification is that of underlying power dynamics, i.e., who gets to decide if, which, and how technology is used. As participants highlighted, some technologies could be frightening or confusing for people with dementia while others could impact their sense of self (see also Gibson et al., 2014; Spann & Stewart, 2018). Many technologies in the *safety concerns* category could be used without people with dementias' active participation, consent, or even knowledge. Interview and website research participants thus were particularly wary of surveillance technology such as cameras or activity monitors due to their intrusiveness (Spann, Spreeuwenberg, et al., n.D.a; see chapters 5.3.5., and 9.2.5., and addendum 7.3.). This brings up the long-debated ethical dilemma between carers' need for peace of mind and people with dementias' right to autonomy, privacy, and self-determination (see, e.g., Bennett et al., 2017; Fetherstonhaugh et al., 2013; Howes & Gastmans, 2021; Mort et al., 2013; Robinson et al., 2007; Smebye et al., 2016). Some participants remarked that at a certain point in the dementia trajectory, people with dementia should no longer be on their own, despite some technologies' potential to address some of the challenges they or carers could face. One participant expressed concern that technology could be used as an easy and cheap way for local authorities to delay or avoid having to finance adequate care provision, a sentiment that is shared by Eccles (2021) and Gibson et al. (2014). When discussing technology with carers, they should be supported to consider these ethical issues as they pertain to their individual situation. Local authorities or others advising carers on technologies (e.g., carer or dementia support organisations, employers, etc.) must take carers' concerns regarding technologies seriously, accept that technologies might not be suitable or desirable options for everyone, and ensure that adequate care services are available, affordable, and accessible. To summarise, technology when used by carers for and with people with dementia must not be a quick-fix solution but require an ongoing, empathetic, and careful evaluation and negotiation with people with dementia and their cohabiters, centred on people with dementias' needs, preferences, and abilities.

An interesting observation made both during the interviews with working dementia carers (see addendum 7.3.) as well as during the online research (see chapter 9.3.) was that participants regularly appeared to emphasise technologies' benefits for and effects on people with dementia rather than considering these issues for their own efforts to reconcile work and care. This phenomenon warrants

further investigation as it might indicate that carers are hyperfocused on people with dementias' needs while neglecting their own, as has been found to be the case with carers' self-care needs (Furlong & Wuest, 2008).

Some general concerns participants had (see chapter 9) which are echoed by the findings from the technology scoping review (Spann, Vicente, et al., 2022; see chapter 4.3.3.1.), involve cost, reliability and maintenance of technologies, data protection, and ensuring that (only) the right people have access to people with dementias' sensitive data. They noted that technology providing information needed to be context-specific and that some technologies (e.g., for *safety concerns*) could inadvertently increase the demand on carers. Additionally, some technologies were thought to only be useful if carers were close by to ensure people with dementia interacted with technologies safely or to respond to potential alerts raised by technologies, thus only being useful for carers who work and care at the same place or who work close by and have enough schedule autonomy to leave work when needed (Spann, Allard et al., 2022; see chapter 6.3.1.). Some participants noted that while some technologies sounded promising in theory or that they could see the benefit of them, some did not address their or people with dementias' needs, or they personally had no need for them. This was also a finding of the technology scoping review (Spann, Vicente, et al., 2022; see chapter 4.3.3.2.). This circumstance, as well as some participants misunderstanding the purpose and intended users of technologies, highlights the need for precise descriptions and complete transparency regarding benefits and all potential downsides when advising carers on technologies.

Some technologies require other stakeholders' – e.g., care workers, healthcare professionals, or employers – permission or collaboration. Unfortunately, these stakeholders' views are widely missing from the data collected via the online research (see chapter 9.2.). Thus, the following deliberations are speculative and require further investigation. For example, ethical and legal issues need to be addressed when using technologies that can affect care workers (e.g., monitoring technologies including cameras or GPS technologies to monitor care workers' positions). Some technologies' (e.g., AI or online booking systems, case or care management software, electronic health records) potential to solve carers' work-care reconciliation challenges depends to a large extent on others (e.g., healthcare or service providers) procuring, implementing, and using them. These technologies' potential benefits such as increased efficiency in interface management and saving time and resources, could persuade these stakeholders to implement them not only for carers' sake. Similarly, employers could be persuaded to allow their employees to use technology for care-related reasons at work by reminding them that accommodating carers' needs to reconcile work and care is usually less expensive and cumbersome than losing experienced employees and that employees' productivity and

commitment to their workplace tends to increase if they feel adequately supported (Carers UK, 2019; Carers UK et al., 2013; Chung, 2017; Spann et al., 2020).

#### 10.4. Implications for practice and research

The findings of this thesis have several implications for practice and further research. A detailed discussion can also be found in each respective chapter.

##### 10.4.1. Implications for practice

The main outcome of the thesis, the technology map presented in chapter 8.3.1., table 12 (Spann, Spreeuwenberg, et al., n.D.b), can be used by working dementia carers and those supporting them (i.e., carer or dementia support organisations, employers, local authority adult social care departments) to identify suitable technological solutions to carers' individual work-care reconciliation challenges. Many carers still do not think about technology when looking for solutions to their challenges, even if promising options exist. Carers should thus be encouraged to reflect on the challenges they experience when combining work and care and be assisted in looking for technological solutions, in addition to helping with access to other resources or solutions (e.g., care services, support from their community, etc.). Employers, carer and dementia support organisations, local authority adult social care departments, and healthcare professionals are ideally placed to signpost carers to technologies which can be facilitated by using the technology map developed in this thesis.

**Employers** should be mindful of their employees' caring responsibilities and recognise the importance of using technology such as their phones for reconciling work and care. Where the nature of their work permits it, carers should be allowed to carry and use their phone for care-related reasons (or any other technologies they might require) at all times, not just during official break times, so that they can be informed of and manage any care-related emergencies. Employers should revise their regulations to ensure that their employees can have a maximum of autonomy and create a workplace culture where carers feel supported to request more autonomy. This could prevent carers' exit from their workforce which could save employers a lot of money otherwise spent on recruitment and training of replacements for carers. Furthermore, employees who feel well supported at work and who enjoy a maximum of autonomy are regularly more productive and committed to their workplace (Carers UK, 2019; Carers UK et al., 2013; Chung, 2017; Spann et al., 2020). Line managers should be aware of and refer carers to organisations in their local area which offer support. They should also be aware of the potential support technology can offer and encourage carers to reflect on their needs. The technology map presented in this thesis can be a useful tool for carers and line managers to facilitate this process.

**Carer and dementia support organisations** can use the technology map presented in this thesis when advising working dementia carers on available support and solutions to their challenges. Members of these organisations should be aware of potential downsides of these technologies and the effect they can have on others (e.g., people with dementia, care workers, etc.) and advise accordingly. They can add to the usefulness of the technology map by following up with the people they recommend certain technologies to and inquiring as to their experiences with them. This practical advice is highly appreciated by carers and can be used for future consultations.

**Local authorities** involved in the procurement of technologies must understand that technology is not a one-fits-all solution and that people with dementia, depending on the progression of their disease, might not be able to use technologies as intended (Lorenz et al., 2019). Thus, not only carers' needs but also the implications for people with dementia must be considered when offering technological solutions. Several issues carers wanted solutions for require local authorities to change their practices and implement technologies (e.g., to decrease the fragmentation of services and organisations involved in care provision). While that would require an initial investment, system change and learning, local authorities might ultimately benefit from more streamlined workflows and interactions with carers.

**Healthcare professionals** should be aware of carers' work situations and the multiple challenges that come with combining work and care. Information about these issues as well as technology as potential solution should be part of healthcare professionals' education and training. Trade unions could offer regular training courses which could also be an opportunity for healthcare professionals to share their experiences with technological support for their patients and their carers. A major issue working carers faced when interacting with healthcare professionals was their conflicting work hours. Offering early morning, evening, or weekend appointments could be a solution for these challenges as well as exploring options for remote consultations, aided by technology. Healthcare professionals should also be encouraged to adopt technologies that allow the secure storage and exchange of information with carers.

**Policymakers** should be reminded that technology is no panacea but often the last resort in an under-resourced care system (Eccles, 2021; Gibson et al., 2014). Providing technologies to carers and people with dementia must not be viewed as a substitute for proper investment and reform of the social care sector. However, funds should be made available to carers on a local level to acquire technologies they deem suitable and necessary to provide better care and to better reconcile caring with their work and other responsibilities. The Covid-19 pandemic has demonstrated that working from home can be feasible where this was previously thought unthinkable (Milasi et al., 2020). Policymakers in the UK



should learn from this before calling employees back to the office and consider the benefits of granting more autonomy to both employees and employers.

#### 10.4.2. Implications for research

The technology map presented in this thesis is based on the needs working dementia carers in Scotland identified in an interview study. It can be used to further explore working carers' needs for technology, using a longitudinal approach. Of particular interest would be to follow carers from the moment they become carers/when they receive the dementia diagnosis, throughout the dementia trajectory, up until the moment their caring role ends.

If the technology map proves to be useful in practice, efforts should be made to investigate the challenges carers not providing care for people with dementia face when combining work and care and whether the technology map has relevance for them as well.

Technology researchers and developers seeking to innovate for working dementia carers need to consider whether and how carers can use these technologies when at work. Innovative technologies that can autonomously ensure people with dementias' safety and wellbeing, provided that they are able and comfortable to use them or have them in their home, are needed to help carers with no autonomy at work to have peace of mind.

#### 10.4.3. Dissemination strategy

Efforts have been made and continue to be made to make the findings of this thesis available to an audience of academics and practitioners. Three papers have already been published in a well-regarded academic journal targeting health and social care professionals and a journal targeting social scientists and practitioners interested in the intersection of work, family, and the community. Two additional papers have been written in a publication-ready format and will be submitted to prominent academic journals in the field of dementia and/or social care. Furthermore, the findings have been presented at numerous national and international conferences.

However, additional efforts should be made to ensure that the findings of this thesis, especially the technology map, reach their target audience, i.e., working dementia carers and the people seeking to support them. Carer and dementia support organisations can play a pivotal role in this. The technology map could be used as the basis to develop a technology sign-posting website the likes of [dementia.livebetterwith.com](http://dementia.livebetterwith.com), [meetadam.co.uk](http://meetadam.co.uk), [atdementia.org.uk](http://atdementia.org.uk), [alzproducts.co.uk](http://alzproducts.co.uk), or [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk), or alternatively integrated into these websites. Leading and influential carer organisations like Carers UK or Employers for Carers could use the main findings of this thesis to create and distribute informational and training material for various stakeholder groups (e.g., employers,

healthcare professionals, social care workers, adult social care departments, etc.) which they can use to better advise and support working carers. Importantly, carer and dementia organisations can organise local events to raise the awareness of carers and people with dementia about the potential of technologies to improve their experience as working carers or people receiving care. Regular events like Dementia Cafés as organised by the Alzheimer’s Society or Alzheimer Scotland are particularly suitable for these kinds of events as they are generally well advertised and have a regular audience of both carers and people with dementia. Carer and dementia support organisations could also use their social media channels to raise awareness and to share the findings of this thesis.

## 10.5. Strengths and limitations

This thesis has several methodological strengths and limitations which are discussed in detail in each study’s respective chapter. As demonstrated, this thesis addresses an important gap in a still relatively under-researched field by taking a bottom-up and carer-centred approach to investigating which and how technologies can support carers of people with dementia to better reconcile work and care (Spann, Vicente, et al., 2022; see chapter 4.3.). Significant strengths of this research were the broad and open definition of the term “technology” and the participatory approach. The latter ensured that the technology map presented in chapter 8.3.1., table 12 (Spann, Spreeuwenberg, et al., n.D.b), was firmly rooted in the wants and needs for technological solutions that working dementia carers identified themselves. As this technology map is intended to be used by carers themselves and those supporting them (i.e., employers, carers and dementia support organisations, and local authority adult social care departments) to help them find technological solutions to their individual challenges, this might ultimately prove to increase the technology map’s usefulness. Semi-structured interviews proved to be a suitable method to define the challenges carers wanted solutions for. The problem-centred approach described in chapter II.c. was flexible yet structured enough to encourage carers’ narration while ensuring that all necessary conversation topics were discussed. A further strength is that the findings of the thesis have been shared and discussed on numerous occasions with experts on technology and work-care reconciliation from academia, industry, and the third sector (e.g., dementia and carer support organisations), and most importantly with the people most likely to use or be impacted by these technologies. Discussions with experts and/or fellow work-care scholars were held after the scoping reviews (see chapter I.c.), after the interviews with working dementia carers (see chapter 5.3.), and after the technology landscape review (see chapter 8.2.5.). Their feedback and insight directly affected the interpretation of the data and enhances the credibility of the research. The views and experiences of carers and other relevant stakeholders on the technologies identified as potentially relevant to working carers are addressed in the online technology evaluation study in chapter 9. Despite its limitations (see chapter 9.3.1.), the insight gained from this study furthers the

understanding of which and how technologies are useful to working dementia carers and which potential downsides must be taken into account.

This thesis has several limitations. The interviews with working dementia carers (Spann, Allard et al., 2022; Spann, Spreeuwenberg, et al., n.D.a; see chapters 5-7), although featuring a very diverse group of carers (i.e., in terms of gender, age, employment and caring situation, and autonomy at work) did not include carers working in the gig economy. This is despite considerable efforts that have been employed to recruit them. Gig work has been increasing in recent years and is characterised by gig workers' vulnerability to low pay, unstable and competitive work conditions, high stress, and limited to no access to certain employment rights like paid care leave (Freni-Sterrantino & Salerno, 2021). Although data saturation was reached with regards to the work-care reconciliation challenges interviewees described, this highly vulnerable group of workers may experience additional or different work-care reconciliation challenges. This should be investigated further. Data saturation has not been reached when asking carers what technologies they wanted if there were no limitations. As this is a question targeting carers' imagination and creativity, however, this circumstance is not too surprising. In any case, the use cases that underly these desired technologies do generally map well onto the challenges carers identified. What this demonstrates is that carers should actively be involved in the development and design of technological solutions to their work-care reconciliation challenges.

To construct the technology map (Spann, Spreeuwenberg, et al., n.D.b; see chapter 8), technology databases available in the UK and app stores were used to identify currently available technologies, and conference proceedings to identify emerging technologies. Using additional sources like reports of relevant technology research institutes or a systematic review of academic, peer-reviewed literature might have produced further insight. To mitigate the risk that relevant technologies could have been missed, various technology experts from academia, industry, and social service commissioning were consulted to get their feedback on the comprehensiveness of the technology landscape review. Despite this broad approach, however, it cannot be guaranteed that no relevant technologies have been missed. Additionally, the development of technologies is rapidly advancing, which means that the findings of the review could already be dated. However, as most developments are likely to build on or advance already existing technologies and due to the development of the 30 use-cases which are mapped onto working dementia carers' challenges, it is likely that the basic framework of the technology map will remain relevant and that new developments can be mapped onto it. Further research is needed to test the usefulness and usability of the technology map.

The Covid-19 pandemic severely impacted the final study presented in this thesis. Original plans to evaluate the technologies identified through the technology landscape review while also co-designing a useable self-help tool that uses the technology map as a basis had to be scrapped on very short

notice. The pandemic and consequent UK-wide lockdown orders in March 2020 prohibited any in-person workshops. The custom-built technology evaluation website conceived as a replacement for in-person workshops did produce valuable insight on the views of those intended to use or be impacted by the technologies identified in chapter 8. However, the findings are limited by difficult recruitment and low engagement of participants. Only a small number of those registered for the research website ended up leaving any comments or star ratings, and for many technologies, only a single participant left any comments or ratings at all. Participants very rarely engaged with each other's comments, and other stakeholder groups' views (i.e., care workers, employers) are underrepresented. No people with dementia participated themselves, thus the views on how technologies would impact people with dementia are only proxies provided by carers. Despite the huge efforts this research method cost in terms of creating the website, getting ethical approval, recruitment, and engagement of participants, and the slightly disappointing outcome, it remained the only viable option to conduct this kind of research during a pandemic. Plans to co-design the self-help tool based on the technology map had to be cancelled due to the pandemic and the uncertainty as to when in-person research would have been possible again. There was not enough time remaining to devise and design an online method to replace the planned in-person co-design workshops.

It was the express aim of this thesis to map, not to evaluate the identified technologies beyond the views of those intended to use or be impacted by them. However, there are countless studies evaluating several further aspects of many of the technologies we could find (see, e.g., Ienca et al., 2017; Sriram et al., 2019; Stavropoulos et al., 2020). Aspects which require attention when evaluating the identified technologies are, for example, whether and how they can contribute to carers remaining in paid work for longer, their impact on carers' and people with dementias' overall wellbeing, their impact on people with dementias' autonomy and sense of self, the degree to which people with dementia must interact with them (i.e., active, passive, ambient use), whether carers' autonomy at work permits them to use them at work, whether and how they impact on other stakeholders like care workers or service providers, etc. Using a participatory design approach that includes working carers and people with dementia in the design process should ensure that technologies meet their needs and potential shortcomings are identified and addressed.

The findings of this thesis are based on the challenges working dementia carers in Scotland identified and on technologies found primarily in technology databases in the UK. Compared to the rest of the UK, Scotland's current government has a strong commitment to carers and has implemented several unique policies that benefit them directly. Scotland's adult social care system is also organised differently from the rest of the UK (see chapter 1.2.2.). The findings from this thesis thus may not be transferable to other countries or cultures.

## 10.6. Conclusion

This thesis presents the findings of five separate studies which aimed to investigate how technologies can support carers of people with dementia to better combine paid work and unpaid care. The resulting technology map can be used by working dementia carers and those aiming to support them to identify technological solutions to their individual work-care reconciliation challenges. Combining work and care for people with dementia is a very complex endeavour and technologies used for this purpose can affect multiple stakeholders (i.e., people with dementia, care workers, employers). These and various practical and ethical issues need to be considered when thinking about using technology to better reconcile work and care.

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## Appendix A: Interviewee information sheet and consent form



### **Sustainable Care: Sustainability and wellbeing in our care systems**

The Sustainable Care Research Programme (2017-2021), based at the University of Sheffield in collaboration with the University of Birmingham and Kings College London, is investigating how social care arrangements can be made economically and ethically sustainable and produce wellbeing outcomes for everyone involved. It has been funded by the Economic and Social Research Council.

**Why have I been contacted?** The programme is made up of a series of research projects. You are being invited to take part in the project “**The potential of technologies to support working carers**”. This project, led by Professor Luc de Witte, is looking at what parts of working carers’ lives can be supported using technology. We are contacting you as someone who provides care for someone living with dementia and also works. We would greatly appreciate it if you could read this information sheet to decide if you would like to take part, and so that you can understand what your participation would involve.

**What would the research involve?** We would like to interview you to find out about your experiences and opinions of providing care while also working, what support you receive or would need and which (if any) part technology plays in your support system. The interview will last approximately one hour and will take place at the time and place most convenient to you. We will audio-record the interview and take some written notes throughout. The recordings will be transcribed after the interview and your personal data anonymised. If you wish to terminate the session at any point, let the researcher know and the session and recording will stop.

You will be interviewed by a member of the project team, Alice Spann.

**Do I have to take part?** It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can still withdraw at any time during the interview without there being any negative consequences and you don’t have to give a reason. If you wish to withdraw from the research, please let the researcher know either during your session or afterwards by emailing Alice Spann (redacted) or calling (redacted). If you want to withdraw afterwards, please ensure to let the researcher know within two weeks after the interview because after transcription your personal data will be anonymised, and it might no longer be possible to identify your contribution. If you withdraw or are withdrawn from the study for any reason, the research

team will retain the personal data already collected about you for a maximum five years after the end of the project (2021), unless you request, we delete it.

**What will happen to the information you give us?** Everything you say will be kept confidential and only accessible to members of the research team unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else. Your personal information (e.g. name, contact details) will only be accessible to members of the research team at the University of Sheffield. Our conversations will be recorded, if you agree. The researcher will also take some notes during the interview. The audio recordings and transcripts will be securely stored on the University's shared networked file store. In the transcripts, any information you provide which could reveal your identity will be removed, and you will be given a pseudonym. The person with the responsibility for transcribing the interviews will be subject to a confidentiality agreement. The document which notes which pseudonym you have been given will be stored in an access-restricted folder on the University's shared networked file store and will be destroyed within five years of the end of the project (2021). Excerpts from the session may be included in the project's outputs, for example in reports, web pages, and other research outputs. You will not be able to be identified in any reports or publications.

Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering their research questions. You can decide whether your anonymised data can be archived at the UK Data Archive and used in future research. Only authenticated researchers will have access to this data, only if they agree to preserve the confidentiality of the information on the archive. They may use your words in publications, reports, web pages, and other research outputs but will not include any information that would identify who you are.

**Are there any risks?** As pseudonyms will be used, you will not be identifiable. In the interviews, the focus will be on your everyday experiences and opinions. You are free to decline to answer questions and can withdraw your consent to be interviewed at any time.

**How can I find out more?** If you have any questions about the study or just want to talk to someone about it, you can contact Alice Spann anytime. You can also call us, send us an email or a letter:

Alice Spann

The Innovation Centre, University of Sheffield, 217 Portobello, Sheffield, S1 4DP,

Phone: redacted

Email: [redacted](#)

**Please feel free to contact us at any time. We will be happy to give you further information.**

**Note:** This study has been reviewed and given favourable opinion by the Research Ethics Committee of the School of Health and Related Research (SchARR) at the University of Sheffield. If you wish to discuss the study with the person responsible for the research, please contact the Sustainable Care Programme leader, Professor Sue Yeandle. Address: CIRCLE (Centre for International Research on Care, Labour and Equalities), Faculty of Social Sciences, The University of Sheffield, ICOSS, 219 Portobello, Sheffield S1 4DP, Tel. (redacted). If you have a complaint, please contact the Dean of SchARR, Professor John Brazier. Address: SchARR, The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Tel. (redacted).

The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is ‘a task in the public interest’. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University’s Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

If you wish to contact the Data Protection Officer at the University please write to: Anne Cutler, The University of Sheffield, Edgar Allen House, 241 Glossop Road, Sheffield, S10 2GW or e-mail her at [redacted]. Requests to withdraw from/ remove data from the project should be addressed to the researcher in the first instance and then to the Data Protection Officer. If you are not satisfied with the response you receive from the University you have the right to lodge a complaint with the Information Commissioner’s Office (ICO): <https://ico.org.uk/concerns/>. Freedom of Information requests should be sent via email to [foi@sheffield.ac.uk](mailto:foi@sheffield.ac.uk).



**Sustainable Care: Sustainability and wellbeing in our care systems Consent Form**

<b>Taking Part in the Project</b>	Please initial
I have read and understood the project information sheet dated 11/09/18 or the project has been fully explained to me. (If you will answer No to this question, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean).	
I have been given the opportunity to ask questions about the project.	
I agree to take part in the project. I understand and agree that taking part in the project will include taking part in an interview which will be audio-recorded.	
I understand that my taking part is voluntary and that I can withdraw from the study at any time; I do not have to give any reasons for why I no longer want to take part and there will be no negative consequences if I choose to withdraw.	
<b>How my information will be used during and after the project</b>	
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named.	
I understand that if I want to withdraw from the project after I participated, I must do so within two weeks, as my responses will be transcribed and anonymized thereafter.	
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	
I agree for the data I provide to be archived within an approved Data Archive	
<b>So that the information you provide can be used legally by the researchers</b>	
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	

Name of participant [printed]

Signature

Date

Name of Researcher [printed]

Signature

Date

Project participant ID number:

**Project contact details for further information:** Professor Luc de Witte, The Innovation Centre, The University of Sheffield, 217 Portobello, Sheffield, S1 4DP, phone: redacted, email: redacted.

**If you wish to discuss the study with the person responsible for the research,** please contact the Sustainable Care Programme leader, Professor Sue Yeandle. Address: CIRCLE (Centre for International Research on Care, Labour and Equalities), Faculty of Social Sciences, The University of Sheffield, ICOSS, 219 Portobello, Sheffield S1 4DP, Tel. redacted

**If you have a complaint,** please contact the Dean of SchARR, Professor John Brazier. Address: SchARR, The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Tel. redacted.

**If you wish to contact the Data Protection Officer at the University please write to:** Anne Cutler, The University of Sheffield, Edgar Allen House, 241 Glossop Road, Sheffield, S10 2GW or e-mail her on (redacted). Requests to withdraw from/ remove data from the project should be addressed to the researcher in the first instance and then to the Data Protection Officer. If you are not satisfied with the response you receive from the University you have the right to lodge a complaint with the Information Commissioner's Office (ICO): <https://ico.org.uk/concerns/>. Freedom of Information requests should be sent via email to [foi@sheffield.ac.uk](mailto:foi@sheffield.ac.uk).

## Appendix B: Technology expert information sheet



### Sustainable Care: Sustainability and wellbeing in our care systems

The Sustainable Care Research Programme (2017-2021), based at the University of Sheffield in collaboration with the University of Birmingham and Kings College London, is investigating how social care arrangements can be made sustainable. It has been funded by the Economic and Social Research Council.

**Why have I been contacted?** The programme is made up of a series of research projects. You are being invited to take part in the project **“The potential of technologies to support working carers”**. This project aims to examine specific aspects of working carers’ lives they find particularly challenging and identify technology-based solutions which have the potential to overcome these challenges. We are contacting you as someone with expertise in technology and would greatly appreciate it if you could read this information sheet to decide if you would like to take part, and so that you can understand what your participation would involve.

**What would the research involve?** We would like you to take part in an online roundtable event (webinar) with members of the research team and about 10 to 15 other participants like yourself. The aim is to get your feedback regarding the comprehensiveness of an extensive review of online sources and grey literature regarding technologies, currently available and in development, which may support working carers. Prior to the webinar, we will ask you to have a look at a series of brief videos (10 in total, most under 3 minutes long) presenting the findings of the review. These are contained in a Google Drive for which you will receive an invitation weblink. The webinar will take place using video conferencing software, for which you will receive access details. The researcher will take notes of any additional technologies you might suggest without referring to you personally. The webinar will last approximately 2 hours. You can terminate your participation in the webinar at any point by exiting the video conferencing software.

**Do I have to take part?** It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can still withdraw at any time during the webinar without there being any negative consequences and you don’t have to give a reason. If you wish to withdraw from the research, please let the researcher know before the webinar by emailing Alice Spann (redacted) or simply by exiting the video conferencing software. Please note that withdrawal after the webinar is not possible as your contributions are noted anonymously and will not be identifiable. We will not collect any personal data from you.

**What will happen to the information you give us?** Everything you say will be kept confidential and only accessible to members of the research team. Your name and contact details used to

contact you will only be accessible to members of the research team at the University of Sheffield. The researcher will also take some notes during the interview. We will take note of any additional technologies you identify, and they might be added to the findings of the review and may be included in the project's outputs, for example in reports, web pages, and other research outputs.

**Are there any risks?** This study does not deal with any sensitive subjects of a personal nature, nor are any personal data collected. In the webinar, we will focus on your experience and opinions. You are free to decline to answer questions and can withdraw your consent to be involved in the webinar at any time before and during the event.

**How can I find out more?** If you have any questions about the study or just want to talk to someone about it, you can ask me now. You can also call us, send us an email or a letter:

Alice Spann

The Innovation Centre, University of Sheffield, 217 Portobello, Sheffield, S1 4DP,

Phone: redacted

Email: redacted

**Please feel free to contact me at any time. I will be happy to give you further information.**

**Note:** This study has been reviewed and given favourable opinion by the Research Ethics Committee of the School of Health and Related Research (ScHARR) at the University of Sheffield. If you wish to discuss the study with the person responsible for the research, please contact the Sustainable Care Programme leader, Professor Sue Yeandle. Address: CIRCLE (Centre for International Research on Care, Labour and Equalities), Faculty of Social Sciences, The University of Sheffield, ICOSS, 219 Portobello, Sheffield S1 4DP, Tel. (redacted). If you have a complaint, please contact the Dean of ScHARR, Professor John Brazier. Address: ScHARR, The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Tel. (redacted).

The University of Sheffield will act as the Data Controller for this study. This means that [the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has



not been handled correctly), can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

If you wish to contact the Data Protection Officer at the University please write to: Luke Thompson, The University of Sheffield, University Secretary's Office, Western Bank, Sheffield, S10 2TN or e-mail [dataprotection@sheffield.ac.uk](mailto:dataprotection@sheffield.ac.uk). Requests to withdraw from/ remove data from the project should be addressed to the researcher in the first instance then to the Data Protection Officer. If you are not satisfied with the response you receive from the University you have the right to lodge a complaint with the Information Commissioner's Office (ICO): <https://ico.org.uk/concerns/>. Freedom of Information requests should be sent via email to [foi@sheffield.ac.uk](mailto:foi@sheffield.ac.uk).

## Appendix C: Online technology evaluation participant information sheet and consent form



### Can I take part?

We are looking for people who

- provide care for a person living with dementia and also work or had to give up work to care
- live with dementia or represent the views of a person living with dementia
- employ people who have unpaid caring responsibilities
- work in the care sector
- represent carer or dementia support organisations or adult social care departments.

### What would the research involve?

We would like you to please provide your views and opinions via the designated comment sections on

- a number of technologies we identified which might be useful for someone combining paid work and unpaid care
- the design of a self-help toolkit which signposts working carers to these technologies.

To access the research material you have to register. Upon registration, you will be asked to choose a pseudonym so that your identity is protected. You can enter the website and leave comments repeatedly and at any time, using your log-in information. Your contributions can be viewed under your chosen pseudonym by the research team and other participants like yourself who register to use the website. You are not required to comment on all the content you will find on the website but we would ask you to please comment on as many as possible, particularly if you have personal experience with the content presented.

You may be contacted by the research team via the email address you provided during registration to invite you to elaborate on comments you made on the website. You are free to choose whether you prefer this to be via email, phone or video call and at a time that is convenient to you. You are also free to decline this invitation.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, please save this information sheet on your computer or print it for your records. Upon registration for the website, you will be asked to tick the boxes on a consent form. You can still withdraw your contributions at any time without there being any negative consequences and you don't have to give a reason. If you wish to withdraw from the research, please let the researcher know by emailing Alice Spann. If you withdraw or are withdrawn from the study for any reason, the research team will retain the personal data already collected about you for a maximum five years after the end of the project (2021), unless you request we delete it.

## **What will happen to my information?**

Everything you contribute under your chosen pseudonym will be kept confidential and only accessible to members of the research team and other registered users of the website. Any personal information (e.g., contact details) you submit upon registration will only be accessible to members of the research team at the University of Sheffield. The website will be taken offline at the end of the study (at the end of August). Your contributions will be copied to an access-restricted folder on the University's shared networked file store. The document which connects your pseudonym to your personal information will be stored in an access-restricted folder on the University's shared networked file store and will be destroyed within five years of the end of the project (2021).

Excerpts from your contributions may be included in the project's outputs, for example in reports, web pages, and other research outputs. Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering their research questions. You can decide whether your anonymised contributions can be archived at the UK Data Archive and used in future research. Only authenticated researchers will have access to this data, only if they agree to preserve the confidentiality of the information on the archive. They may use your words in publications, reports, web pages, and other research outputs but will not include any information that would identify who you are.

## **Are there any risks?**

There is no risk that your contributions are identifiable due to the use of a pseudonym for any of your activity on the website. During registration, you will be asked to choose a random pseudonym which does not allow you to be identified. We will ask for comments on your experience and opinions. You are free to decline to comment and can withdraw your consent to be involved in the study at any time.

You and the other website users will be asked to abide by the Chatham House Rules and we will ask you to respect your fellow participants and not reveal any personal information they may reveal in their contributions to others.

## How can I find out more?

If you have any questions about the study or just want to talk to someone about it, please feel free to contact us at any time. We will be happy to give you further information.

### Note

This study has been reviewed and given favourable opinion by the Research Ethics Committee of the School of Health and Related Research (SchARR) at the University of Sheffield.

If you wish to discuss the study with the person responsible for the research, please contact Professor Luc de Witte, The Innovation Centre, The University of Sheffield, 217 Portobello, Sheffield, S1 4DP, phone: redacted, email: redacted.

If you have a complaint, please contact the Dean of SchARR, Professor John Brazier. Address: SchARR, The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Tel. 0114 2220726.

The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice.

If you wish to contact the Data Protection Officer at the University please write to: Luke Thompson, The University of Sheffield, University Secretary's Office, Western Bank, Sheffield, S10 2TN or e-mail [dataprotection@sheffield.ac.uk](mailto:dataprotection@sheffield.ac.uk).

Requests to withdraw from/ remove data from the project should be addressed to the researcher in the first instance then to the Data Protection Officer. If you are not satisfied with the response you receive from the University you have the right to lodge a complaint with the Information Commissioner's Office (ICO). Freedom of Information requests should be sent via email to [foi@sheffield.ac.uk](mailto:foi@sheffield.ac.uk).

## Consent Form and Questionnaire

To complete registration, please fill out this consent form and answer a few brief questions about yourself. This will help us to provide some context to your contributions on the research website. Your information will be treated strictly confidential.

Please repeat the email address you used to register for the website

Please enter the username you created for the website.

The username should be a combination of a colour and an animal (e.g. Purple Hamster)

Please indicate that you consent to take part in the research.

Please ensure that you have read the Project Information and contact [aspann1@sheffield.ac.uk](mailto:aspann1@sheffield.ac.uk) if you have any questions.

I have read and understood the project information or the project has been fully explained to me. I have been given the opportunity to ask questions about the project. I understand and agree that taking part in the project will include commenting on content presented on a secure website. I understand that my taking part is voluntary and that I can withdraw from the study at any time; I do not have to give any reasons for why I no longer want to take part and there will be no negative consequences if I choose to withdraw. I understand that I can withdraw any and all of my contributions from the project after I participated by emailing the project team under [aspann1@sheffield.ac.uk](mailto:aspann1@sheffield.ac.uk). I agree to respect the other people participating on the website and abide by the Chatham House Rules, meaning that I will not reveal their personal information to others. Violation of these rules may result in my exclusion from the research. I understand my personal information will not be revealed to people outside the research team. I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named. I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form. Other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. I agree for the data I provide to be archived within an approved Data Archive.

I understand and agree to take part in this research project

I agree to be contacted by the research team via the email address I provided to invite me to elaborate on comments I make on the website.

Yes

No

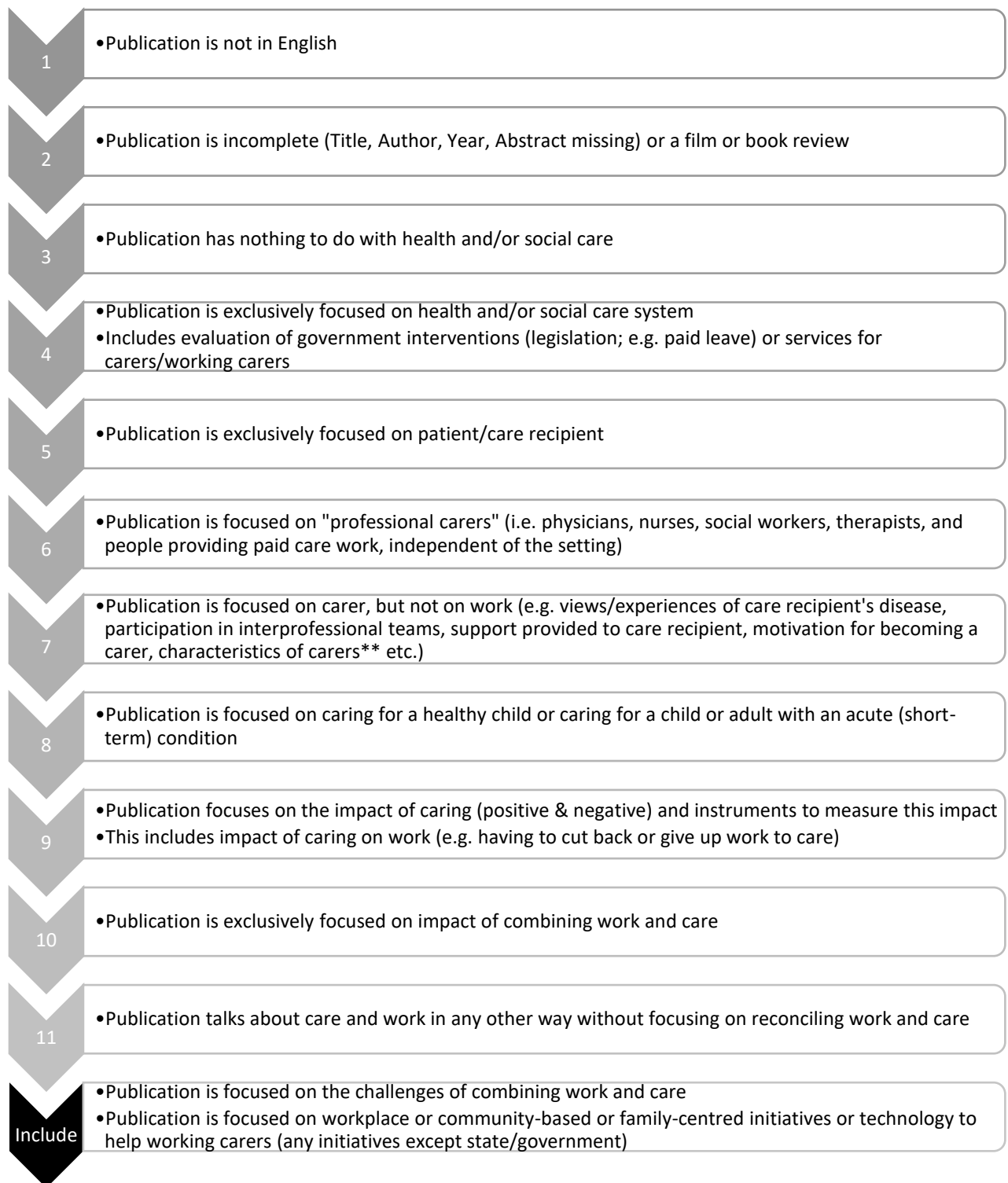
I agree to assign the copyright I hold in any materials generated as part of this project to the University of Sheffield so that the information I provide can be used legally by the researchers.

Yes

No (Answering No will mean that your contributions cannot be used in the research)

## Appendix D: Decision tree for selection of publications – Scoping Review 1 (see chapter 3.2.)

This decision tree was developed by the first author during the screening of titles and abstracts of publications identified in the literature search. It was used by the second and third authors to aid in the selection of eligible publications.



\*\*characteristics of carers may include anything that describes carers (e.g. gender, age, ethnicity, relationship to care recipient but also employment status)

Appendix E: Data chart – Scoping Review 1 (see chapter 3.3.)

No.	Author	Year	Pub. type	Design	Journal/Discipline	Loc	Carers	total no carers	PRC	Aim	C1	S1	C2	S2
1	Andersson et al.	2016	Journal Article	qualitative (interviews)	Scandinavian Journal of Caring Sciences Nursing	SWE	Employed, not further specified	n/a	not specified	describe HCPs' perception of ICT support for WCs	B	B C	A	A
2	Andersson et al.	2017	Journal Article	Review	International Journal of Care and Caring Nursing	[SWE]	employed, unemployed, sometimes not clear in included articles	n/a	older people	ICT-mediated support for WCs of older people	A C	A B C	A B	A B
3	Andersson et al.	2017	Journal Article	qualitative (interviews)	Scandinavian Journal of Caring Sciences Nursing	SWE	Employed	9	older people	WCs experience with web-based ICT	B	A B C	A B	B
4	Ang & Malhotra	2018	Journal Article	quantitative (cross-sect survey)	Aging & Mental Health Sociology, Health Services & Systems research	SGP	Employed	662	older people (75+)	if social support from family and friends moderates the association of care-related work interruptions	A B	A B	A B	A
5	Arksey & Glendinning	2008	Journal Article	qualitative (interviews)	Social Policy and Administration Social Policy Research	UK	employed & not employed	80	not specified	How rural carers manage care & employment	A B C D E F	A B C	A	A
6	Barnett et al.	2009	Journal Article	quantitative (cross-sect survey)	The Psychologist-Manager Journal Management, Psychology, Women's studies	USA	Employed	572	older people (55+)	estimate a mediational pathway between usable flexibility at work, elder caregiving concerns, and planned job changes	A	A	A	A

7	Boezeman et al.	2018	Journal Article	quantitative (RCT)	European Journal of Public Health Occupational Health	NL	Employed	128	various (parents, siblings, children, other)	evaluate WC role-focused self-help intervention to reduce stress	A B	B E	B	
8	Bourke et al.	2010	Journal Article	qualitative (interviews)	New Zealand Journal of Employment Relations Economics, Management	NZ	self-employed (women)	8	older people (parents/-in-law)	examining the lived experience of elder care on the work-life balance of self-employed women	A B C	A B	A	
9	Bourke-Taylor et al.	2011	Journal Article	mixed-methods (survey & telephone interviews)	Journal of Intellectual Disability Research Occupational therapy/Rehabilitation	AUS	employed, not employed (women)	152	children (school age), developmental disabilities	Health & work participation of mothers of children with developmental disabilities	A B D E	A E	A	A
10	Brennan et al.	2016	book chapter	Review	n/a	USA	employed, not employed	n/a	children, special needs	map research on family care demands onto studies of available family, workplace, and community support	A B F	A B F	A	A
11	Brown	2014	Journal Article	quantitative (cross-sect survey)	Journal of Child and Family Studies Psychology	USA	employed, parents	51	children, developmental disabilities	impact of worker & child characteristics & workplace support on work-family conflict among parents of atypically developing children	A F	A F	A	
12	Bruns & Schrey	2012	Journal Article	"Mixed-methods" (survey & open-ended questions)	International Journal of Developmental Disabilities Educational Psychology	USA	employed, not employed	20	children (3-30yrs), rare trisomy	Parent perspectives on in-home care needs and work responsibilities	A B F	A	A	



13	Calvano	2013	Journal Article	Review	The Academy of Management Perspectives Management	(USA)	Employed, not specified	n/a	older people	examine state of literature on relationship between eldercare & work	A B	A B F	A B	A
14	Carers UK	2014	Pamphlet	n/a	n/a Social Policy	UK	Employed, not specified	n/a	not specified	Inform employers & employees	A C	A		
15	Carers UK	2014	Report	quantitative (survey)	n/a Social Policy	UK	employed, not employed	6828	not specified	Annual State of Caring report Carers UK	C	A E	A	
16	Carers UK & EfC	2012	Report	quantitative (survey)	n/a Social Policy	UK	employed, not employed, sandwich carers	1009	adults (& healthy children <18yrs)	understand pressure of dual caring responsibilities on families and their implications	A B E F	A B C D	A	A
17	Carers UK et al.	2013	Report	quantitative (survey)	n/a Social Policy	UK	Employed, not specified	n/a	not specified	explore ways in which carers can be supported to combine work and care		A B	A	A
18	Carmichael et al.	2008	Journal Article	mixed-methods (survey & interviews)	Feminist Economics Economics	UK	employed, not employed	272 (survey) 26 (interviews)	various (parents, siblings, children, other)	consider the impact that caring responsibilities have on women's employment	A B C E	A	A	A
19	Chou et al.	2012	Journal Article	quantitative (cross-sect survey)	Journal of Intellectual & Developmental Disability Policy, Public Health, Sociology	TWN	employed, not employed (women)	487	children (4-42yrs), intellectual disability	WC difficulties of mothers of children with ID	A B D F	A E	A	
20	Chou et al.	2013	Journal Article	qualitative (interviews)	Journal of Applied Research in Intellectual Disabilities Policy, Sociology	TWN	employed/working (women)	15	adult children (18+yrs), severe intellectual disabilities	WC difficulties of mothers of adult children with ID	A B C D F	A B	A	A

21	Chou & Kroger	2014	Journal Article	qualitative (interviews)	Health & Social Care in the Community Policy, Social Sciences	TWN	employed/working (women)	11	adult children (20-33yrs), intellectual disabilities	social capital for WC reconciliation for lone mothers of adult children with ID	A B D	A B	A	A
22	Cullen & Gareis	2011	Report	Case studies	European Foundation for the Improvement of Living and Working Conditions Policy	EU	Employed, not specified	n/a	not specified	EU employers' support for WCs	A B C D E F	A B D E F	A	A
23	Dembe & Partridge	2011	Journal Article	Case studies	Journal of Workplace Behavioral Health Health Services Management, Policy	USA	employed (white-collar, professionals)	n/a	older people	characteristics of best practice employer eldercare programmes	A	A B D F	A	A
24	Dembe et al.	2011	Journal Article	quantitative (cross-sect survey)	International Journal of Workplace Health Management Health Services Management, Policy, Public Health	USA	Employed	447	older people	WCs evaluation of sponsored elder care programmes	A	A B F		A
25	DeRigne & Porterfield	2010	Journal Article	quantitative (cross-sect survey)	Social Science & Medicine Social Work	USA	employed (parents)	38569 [children, 23380 married parents, 8814 single mothers ]	children, special needs [<18a]	examine factors affecting parents' employment change decisions and whether having a medical home influences these decisions	A D F	A B	A	A

26	Duxbury et al.	2009	Report	mixed methods (survey, interviews)	n/a business	CAN	employed, carers & non-carers	32800 (survey), 30 (interviews)	various (parents, siblings, children, other)	increase understanding of what it means to be a WC in CAN	A B C D F	A B D	A B	A
27	Earle & Heymann	2011	Journal Article	quantitative (cross-sect survey)	Social Science & Medicine Health, Social Policy	USA	Employed	2455	adults & children with special health care needs	how work environment mediates WC health	A B D	A B F		A
28	Eldh & Carlsson	2011	Journal Article	qualitative (interviews)	Scandinavian Journal of Caring Sciences Health Sciences	SWE	Employed	11	older people (parents/-in-law)	experience of WC of ageing parents	A B C D F	A B C	A	A
29	Employer Panel for Caregivers	2015	Report	mixed methods (questionnaires, roundtables)	n/a Social Policy	CAN	Employed, not specified	n/a	not specified	provide recommendations for CAN businesses to support WCs	A	A B C	A	A
30	Evans et al.	2016	Journal Article	Case studies	PLoS ONE [Electronic Resource] occupational therapy	AUS	employed, sandwich carers (women)	18	parents/-in-law & children <18yrs (healthy or chronic disease)	understand working sandwich carer women's role balancing strategies	A B D	A B D	A	
31	Evans et al.	2017	Journal Article	mixed methods (Q methodology)	Scandinavian Journal of Occupational Therapy Occupational Therapy	AUS	employed, sandwich carers (women)	31	parents/-in-law (& healthy children <18yrs) (in-law)	most helpful role balancing strategies for WC sandwich women	B D	A B D		
32	Fast et al.	2014	Report	quantitative (cross-sect survey)	Research on Aging, Policies and Practice Social Policy	CAN	Employed	5960	adults	examine care-related employment consequences in Canada	A B	A	A	
33	Fine	2012	Journal Article	Review	Ageing International Sociology	(AUS)	Employed, not specified	n/a	not specified	examine impasse concerning those who are employed and seek to provide care, current and future support for reconciliation		A		

34	Fletcher	2010	Journal Article	qualitative (interviews)	Issues in Comprehensive Paediatric Nursing Nursing	CAN	employed, not employed (women)	9	children (<17yrs), cancer	cost of caring for a child with cancer	A D F		A	
35	Gaugler et al.	2018	Journal Article	mixed methods (survey, focus groups)	International Journal of Aging & Human Development Health Sciences	USA	employed, carers & non-carers	880 (370 carers)	adults (18+)	impact of caregiving and caregiving-work conflict on WCs well-being	A B C D F	A B	A	A
36	Gordon et al.	2012	Journal Article	quantitative (cross-sect survey)	Journal of Family Issues Management	USA	employed (women)	583	older people	Antecedents and consequences of bidirectional work-care (role) conflict	A B D	A B	A	A
37	Greaves et al.	2015	Journal Article	quantitative (cross-sect survey)	International Journal of Aging & Human Development Psychology, Management	AUS USA IND	Employed	123	older people	examined the interactive effect of core self-evaluations & supervisor support on turnover intentions of WCs	B D	A B		A
38	Gwyther & Matchar	2015	Journal Article	commentary	Generations Health Services	USA	Employed, not specified	n/a	older people	describe employee support programme	A B C	B	A	A B
39	Gysels & Higginson	2009	Journal Article	qualitative (interviews)	BMC Health Services Research Nursing, Health Research	UK	employed, not employed (women)	15	adults (spouses), advanced illness	meaning and consequences of WC wives of husbands with advanced illness	A B D F	A B D	A	
40	Hamblin & Hoff	2012	Report	qualitative (interviews)	n/a Policy (?)	UK	employed, carers & former carers	41 (carers), 9 (former carers)	not specified	understand challenges of WC & how employers can support	A B C D E F	A B D	A	A
41	Heitink et al.	2017	Journal Article	qualitative (interviews)	Work Occupation & Health	NL	employed (double-duty carers)	16	not specified	challenges of double-duty WCs	A B D F	A B D	A	A

42	Hoff et al.	2011	Report	qualitative (interviews)	n/a (Policy ?)	UK GER POL ITA	Employed	226	not specified	compare reconciliation strategies of WCs in GER, UK, POL, ITA	A B D F	A B C D F	A B	A
43	Holzappel et al.	2014	Journal Article	commentary	Generations unclear	USA	Employed, not specified	n/a	older people	Inform on workplace support	A	A B	A	A
44	Home	2008	Journal Article	"Mixed-methods" (survey & open-ended questions)	Social Work and Social Sciences Review Social Work	CAN	employed (women)	197	children, hidden disabilities (e.g. ADHD)	rewards & challenges of mothering children with hidden disabilities	A B D	A	A	
45	Jimenez et al.	2017	Journal Article	Pilot	Journal of Applied Gerontology Psychiatry, Behavioural Sciences	USA	Employed	71	older people (50+)	Pilot psychosocial Tec based support for WC	A B	B D	A B	A B
46	Keck & Saraceno	2009	Report	qualitative (interviews)	n/a Social Sciences	GER	Employed	26	older people (parents/-in-law)	detecting constraints & resources of WCs in the second half of their life	A B D E F	A B	A	A
47	Keeling & Davey	2008	Book chapter	mixed-methods (survey, focus groups)	n/a Sociology	NZ	Employed	3809	older people	examine the „zones of care“, intersections between formal & informal care & gaps	A B C F	A	A	A
48	Kim et al.	2013	Journal Article	quantitative (cross-sect survey)	Journal of Applied Gerontology Economics	USA	employed (white-collar)	642	older people	Influence of informal support on relationships among caregiver stress, work interruptions, and work performance appraisal	A B D	A B F	A	A
49	Klemm et al.	2014	Journal Article	quantitative (randomised longitudinal)	CIN: Computers, Informatics, Nursing Nursing, Health Sciences	USA	Employed	86	adults, chronic disease	evaluation of professionally-led vs moderated peer support web-based intervention		B		B

50	Koerin et al.	2008	Journal Article	Review	Journal of Gerontological Social Work Social Work	(USA)	Employed, not specified	n/a	older people	trends in family caregiving, gov's role in supporting family caregivers, outline family-friendly workplace strategies & policies	A B D	A B D F	A	A
51	Kossek et al.	2017	Journal Article	quantitative (RCT)	Journal of Occupational Health Psychology Management	USA	employed (HCPs), carers & non-carers	931	children & adults	test effects of an organizational intervention to increase supervisor social support for work and nonwork roles, and job control	A B D	B D		A
52	Kuhn et al.	2008	Journal Article	Pilot	Journal of Workplace Behavioral Health unclear	USA	Employed	155 (49 completed study)	adults (18+), chronic conditions	describe a web-based program for WCs aimed at improving self-care & reducing negative work-related outcomes		B		B
53	Larson & Miller-Bishoff	2014	Journal Article	mixed methods (interviews, questionnaire)	Frontiers in Psychology Occupational Therapy	USA	employed, not employed	39	children (<18yrs), disabilities	WC of children with disabilities psychological well-being & orchestration of daily routines	A B F	A B	A	
54	Lashewicz	2011	Journal Article	Case studies	Work Community Health Sciences	CAN	not employed	1	parent	Sibling's prioritisation of care vs career work	A B D E	A B	A	
55	Lilly	2011	Journal Article	discussion paper	Healthcare Policy = Politiques de sante Health Economics	CAN	employed, not specified	n/a	not specified	Workplace support for low-intensity WCs	A B C D E F	A B F	A	A
56	Mahoney et al.	2008	Journal Article	quantitative (feasibility)	Telemedicine Journal & E-Health Nursing	USA	employed (mostly blue-collar)	19	older people	feasibility & receptivity to computerized workplace-based direct caregiver intervention	A B	A B	A	

57	McCartney	2016	Report	mixed methods (survey, online focus groups)	CIPD (Professional body for HR & people development) (management?)	UK	employed (junior to senior)	23	not specified	explore the situation of WCs & employers' support practices	A B C D F	A B E F	A	A
58	Miller & Canada	2012	Journal Article	mixed methods (survey, focus groups)	Family & Community Health	USA	employed, not employed	50	not specified	explore the situation of WCs & employers' support practices	A B D F	A B	A	A
59	NAC & Center for Productive Aging at Towson University	2008	Report	mixed methods (survey, telephone interviews, follow-up survey after 6 months)	n/a (economics?)	USA	employed, carers & non-carers	1786	older people	examining the extent to which workplace caregiving programs helped the employees who used them	A B	A B	A	A
60	Neal et al.	2008	book chapter	Review	n/a (gerontology?)	USA	employed (distance carers)	n/a	older people	challenges & solutions for distance WC	A B C F	A B C	A	A
61	Okumura et al.	2009	Journal Article	quantitative (cross-sect survey)	Paediatrics Paediatrics (Medicine)	USA	employed, parents	40723 [children]	children, special health care needs	determine how child- and family-level factors and the medical home are associated with work loss	A F	A B	A	A
62	Oldenkamp et al.	2018	Journal Article	quantitative (cross-sect survey)	Health & Social Care in the Community Health Sciences, Sociology, Epidemiology, Geriatrics	NL	Employed	333	older people (parents/-in-law)	types of work arrangements used & characteristics of users	A F D	A B E	A	A
63	O'Sullivan	2015	Journal Article	commentary	Work Occupational Health	USA	employed, sandwich carers	n/a	older people, children (healthy)	challenges & solutions for sandwiched WCs	A B C D	A B D F	A	A

64	Phillips & Bernard	2008	book chapter	mixed methods (survey, interviews)	n/a Gerontology	UK	Employers	204 survey, 48 interviews	older people	Work, care, distance!	A B C	A B C	A	A
65	Pickard et al.	2015	Journal Article	quantitative (cross-sect survey)	Journal of Social Policy Economics, Political Science	UK	employed, not employed	6304	adults (18+)	effectiveness of paid services in supporting unpaid carers'	A	A	A	
66	Pickering & Thompson	2017	Report	mixed methods (interviews, FGs, survey, webchats, workshops, consultations)	n/a (Social Policy?)	UK	Employed, not specified	n/a	not specified	raise awareness for WC & develop (workplace) support strategies	A B C D E F	A B D E	A	A
67	Plaisier et al.	2015	Journal Article	quantitative (cross-sect survey)	Human Resource Management Journal Social Sciences	NL	Employed	1991	various (parents, siblings, children, other)	How support at the individual & organ level facilitate work & care	A B	A B	A	A
68	Ramesh et al.	2017	Journal Article	Case studies	Social Science & Medicine Geography (!?)	CAN USA UK AUS	Employed, not specified	n/a	not specified	Examine available WC workplace support in Canada & internationally	A B E	A B D	A	A
69	Randall	2017	Journal Article	qualitative (interviews)	Comprehensive Child & Adolescent Nursing Nursing	UK	employed, not employed	24	children, life-limiting/threatening illness	restructuring working lives to accommodate the care of a child with life-limiting/ threatening illness	A B E F	A C E	A	
70	ReACT et al.	2014	Pamphlet	n/a	n/a (management?)	USA	Employed, not specified	n/a	not specified	assist front-line managers and HR executives in supporting their employee caregivers	A B	A	A	A



71	Sakka et al.	2016	Journal Article	quantitative (cross-sect survey)	Industrial health Nursing	JPN	employed, carers & non-carers (women)	82 (carers), 386 (non-carers)	older people (parents/-in-law)	examine differences in CIW spillover between employed women carers & non-carers & relationship between CIW spillover & caring appraisals	A B	A B		A
72	Schneider et al.	2013	Journal Article	quantitative (cross-sect survey)	Health Economics Economics	AUT	employed, carers & non-carers	471 (carers), 431 (non-carers)	older people	whether eldercare predicts job change or exit and which aspects of work and care shape these intentions	A B D F	A		A
73	Schroeder et al.	2012	Journal Article	Review	Ageing International Gerontology(?)	(CAN)	employed (older employees)	n/a	not specified	overview of current research on older WCs in CAN	A B C D F	A B D	A	A
74	Sellmaier	2016	Thesis	quantitative (cross-sect survey)	Social Sciences	USA	employed (men)	122	children, special needs	types of job, home, and community resources relevant for WC fathers of children with special needs	A B	A B	A	A
75	Sethi et al.	2017	Journal Article	qualitative (interviews)	Diversity & Equality in Health & Care Social Work, Geography	CAN	employed (Chinese immigrants)	13	older people (parents/-in-law)	perspectives on caregiving of Chinese immigrant CEs & explore WC management	A B C D E F	A B D	A	A
76	Sethi et al.	2017	Journal Article	qualitative (interviews)	International Journal of Workplace Health Management Social Work, Geography	CAN	employed (double-duty carers)	n/a	not specified	employers' experiences with WC & workplace support	A B D	A B D	A	A

77	Sherman and Reed	2008	Journal Article	quantitative (cross-sect survey)	Journal of Leadership Studies Management	USA	Employed	100	older people (65+)	what affects the job performance of elder WCs	A	A B F		A
78	Sherwood et al.	2008	Journal Article	quantitative (cross-sect survey)	Psycho-Oncology Nursing, Health	USA	employed, not employed	80	age not specified, cancer	Identity factors influencing cancer WCs employment	A B			
79	Skills for Care	2013	Pamphlet	n/a	Skills for Care	UK	Employed, not specified	n/a	not specified	Inform employers	A B D E	A B E	A	A
80	Stewart	2013	Journal Article	quantitative (cross-sect survey)	Journal of Family Issues Health, Social Work	USA	employed, carers & non-carers ("normal" childcare)	1902	children & adults, disability or chronic illness; healthy children	comparison of WIC & CIW on WC & normal childcare	A B F	A B	A	A
81	Tomkins & Eatough	2014	Journal Article	qualitative (interviews)	Organization Psychology	UK	employed (women)	8	various (parents, siblings, children, other)	identity work at the work/life interface of WCs	A B	A B	A	A
82	Trukeschitz et al.	2013	Journal Article	quantitative (cross-sect survey)	Journals of Gerontology Series B: Psychological Sciences & Social Sciences Economics, Social Policy	AUT	employed, carers & non-carers	492 (carers), 446 (non-carers)	older people	Association between care & work-related strain, hypothesis testing	A B D	A B D	A	A
83	Utz et al.	2012	Journal Article	mixed methods (interviews, time-log)	Journal of Applied Gerontology Sociology	USA	employed, not employed	48	older people (50+)	time use during respite for employees & non-employed carers	A B F	A B D	A	
84	Vuksan et al.	2012	Journal Article	qualitative (focus groups)	International Journal of Workplace Health Management Geography	CAN	Employed, not specified	n/a	family members at end-of-life	Helpful workplace & WC characteristics that help in End-of-Life Care from the POV of employers	A	A	A	
85	Wagner et al.	2012	Report	qualitative (telephone interviews)	n/a management / social policy (?)	USA	employed, not specified	n/a	older people	identify current trends & innovations in workplace policies & practices that support WCs	A	A B D F	A	A

86	Ward-Griffin	2008	book chapter	qualitative (Interviews, focus groups)	n/a nursing	CAN	employed (double-duty carers)	37	older people	analysis of paid & unpaid caregiving experience of double-duty carers in Canada	A B	A B	A	A
87	Ward-Griffin et al.	2015	Journal Article	qualitative (telephone interviews)	Journal of Family Nursing Nursing	CAN	employed (double-duty carers = DDC)	32	older people	social processes of DDC and boundary-blurring changes (oscillation) within 3 DDC prototypes	A B D	A B	A	
88	Wilson et al.	2018	Report	mixed methods (various descriptive project data, interviews)	n/a Employment studies	UK	employed, not employed	70	not specified	'what works' in supporting carers to remain in or return to employment	A B C D E F	A B D E F	A B	A
89	Zacher & Schulz	2015	Journal Article	quantitative (cross-sect survey)	Journal of Managerial Psychology Psychology, Management	GER	Employed	100	older people	the extent to which perceived workplace support for eldercare reduces WC's strain	B	A B		A
90	Zacher & Winter	2011	Journal Article	quantitative (cross-sect survey)	Journal of Vocational Behavior Psychology	GER	Employed	147	older people	stressor-strain-model of eldercare strain as mediator of the relationship between care demands and work	A	A B D F		A
91	Zacher et al.	2012	Journal Article	quantitative (cross-sect survey)	Journal of Occupational Health Psychology Psychology	GER	Employed	165	older people	examine a model of care demands, mental health, & work performance.	A D	A B D		A
92	Zuba & Schneider	2013	Journal Article	quantitative (cross-sect survey)	Journal of Family and Economic Issues Economics	EU CHE NOR TUR	employed, carers & non-carers	24526 (15% carers)	adults	effects of workplace characteristics on WC time conflicts	A B	A B		A

Appendix F: Example search and “standard Google” search terms – Scoping Review 2 (see chapter 4.2.1.)

Herein contained is an example of the search string as it was used for the MEDLINE database. The search was adapted for the CINAHL, PsycINFO, ASSIA, Web of Science, IEEE Xplore, Google Scholar, and Social Care Online databases. Additionally, the search strings for the three “standard Google” searches are presented.

1. exp Caregivers/
2. ((informal or family or spous* or unpaid) adj3 (care* or caregiver* or "care giver*" or caretaker*)).ti.
3. carer*.ti.
4. (caregiver* or care-giver* or "care giver*").ti.
5. (caretaker* or care-taker* or "care taker*").ti.
6. 1 or 2 or 3 or 4 or 5
7. exp Employment/
8. (occupation or job or career).ti.
9. ((paid or gainful or salaried) adj3 (work or employment or job or occupation)).ti.
10. 7 or 8 or 9
11. 6 and 10
12. "working carer*".ti.
13. ("working caregiver*" or "working care giver*" or "working care-giver*").ti.
14. ("working caretaker*" or "working care taker*" or "working care-taker*").ti.
15. ((work* or employ* or self-employ*) adj3 (carer* or caregiver* or "care giver*" or care-giver* or caretaker* or "care taker*" or care-taker*)).ti.
16. 12 or 13 or 14 or 15
17. 11 or 16
18. limit 17 to english language
19. (((step* or walk*) adj3 (count* or meter*)) or fitbit or actigraph* or pedometer* or actigraph* or acceleromet* or ((physical or physiolog* or perform* or fit* or train* or activ* or endur* or exercise) adj3 (track* or monitor* or measur* or device* or app*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
20. exp Accelerometry/
21. (((mobile or phone or telephone or techn* or "portable electronic" or "portable software") adj1 app*) or app*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
22. Mobile Applications/
23. (AI or ((artificial or machine or comput*) adj1 intelligence) or "intelligence agent*" or knowbot*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
24. exp Artificial Intelligence/
25. ((assist* adj3 (device* or organiser* or technolog* or system* or service* or tool* or equipment)) or "self-help device*" or (techn* adj3 (aid* or assist*)) or (external adj1 (aid* or system*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
26. Self-Help Devices/
27. (computer or PC or "personal computer" or "computer program*" or (computer adj1 (assisted or based or mediated or generated)) or computeri#ed or "user-computer interface").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
28. computers/ or computer peripherals/ or computer storage devices/ or computer terminals/ or modems/ or computers, analog/ or computers, hybrid/ or computers, mainframe/ or computers, molecular/

29. ("electronic care" or e-care or ecare).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
30. ("electronic health" or ehealth or e-health or "digital health").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
31. ((electronic or automated or computeri?ed) adj1 ("medical record*" or "medical record system*" or "health record*" or "patient record*")).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
32. exp Medical Records Systems, Computerized/
33. ("electronic mail" or "e mail*" or e-mail* or email*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
34. Electronic Mail/
35. ("electronic mentoring" or ementoring or e-mentoring or "remote consultation*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
36. ("electronic pharmacy" or epharma* or e-pharma* or telepharma*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
37. (HIT or "health information technolog*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
38. (software or informatics or interactive or (interactive adj3 (program* or software or media or technolog* or communication or health*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
39. exp Software/
40. exp Medical Informatics/
41. (internet or web-based or "web based" or website* or portal* or hypermedia or hypertext or online or on-line).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
42. exp Internet/
43. Online Systems/
44. (ICT or ((electronic or digital or information) adj1 "communication technolog*") or "communications media" or "electronic communication").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
45. communications media/ or exp telecommunications/
46. (text* or "text messag*" or SMS or "short messag* service" or MMS or "multimedia messag* service" or "web messag*" or whatsapp or chat* or "instant messag*" or messenger or "instant messenger").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
47. ("mobile health" or mhealth or m-health).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
48. (((smart or cell* or mobile) adj1 (phone* or telephone* or technolog*)) or cellphone* or smartphone* or phone or telephone* or telecommunicat* or (mobile adj1 (communicat* or telecommunicat*)) or iphone*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
49. exp Cell Phone/

50. (((mobile or electronic* or handheld or hand-held) adj1 (technolog* or tool* or device* or monitor* or computer*)) or "mobile electronic device" or (wireless adj1 (technolog* or communicat*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
51. exp Wireless Technology/
52. (microcomputer* or "micro PC" or micro-computer* or ((handheld or hand-held or "hand held") adj1 (computer* or PC or device* or monitor* or console* or technolog*)) or ipad* or pda or "personal digital assistant*" or "personal data assistant*" or tablet* or "tablet PC" or minicomputer* or "mini PC" or minicomputer* or blackberry* or android* or "palmtop computer*" or "palm top computer*" or "palmtop PC" or "palm top PC" or laptop* or "pocket PC" or "pocket computer*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
53. exp microcomputers/ or minicomputers/
54. Reminder Systems/
55. reminder system*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
56. (robot* or "man-machine system*" or automat* or ((mechan* or electro-mechan* or electromechan*) adj3 (device* or equipment))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
57. Robotics/
58. Automation/
59. ("smart home" adj3 (technolog* or system* or device* or solution* or gadget* or tool* or sensor* or equipment or service*)) or "controlled environment").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
60. ("social media" or facebook or twitter or instagram or (virtual adj3 (life or lives or living or world or communication)) or blog or blogging or vlog or vlogging or ((online or on-line) adj1 (discussion or forum or platform*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
61. blogging/ or social media/
62. (Telecare or "tele care" or tele-care).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
63. (telecommuting or "virtual team*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
64. ("video recording*" or videoconference* or teleconference* or videoconsult* or "video consult*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
65. exp Videoconferencing/
66. exp Video Recording/
67. (Telehealth or Telehealthcare or "tele health" or tele-health).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
68. (Telemedicine or "tele medicine" or tele-medicine or "remote care technolog*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
69. exp Telemedicine/
70. (Telemonitoring or "tele monitoring" or tele-monitoring or e-monitoring or eMonitoring or "patient monitor* device*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

71. monitoring, ambulatory/ or exp telemetry/
72. (virtual or augmented or simulation or "computer simulation" or ((virtual or augmented) adj1 (reality or environment)) or VE or VR or "reality system*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
73. computer simulation/ or virtual reality/
74. ("voice assistant*" or "voice assistant technolog*" or "smart voice assistant*" or "smart voice assistant technolog*" or Alexa or Siri or Cortana or "virtual assistant*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
75. ((wearable adj1 (sensor* or technolog* or device*)) or smartwatch* or "smart watch*" or wearable* or ((pendant or wrist or wrist-worn or "wrist worn" or wearable or personal) adj1 alarm) or "fall detector*" or "wearable electronic device*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
76. exp Wearable Electronic Devices/
77. (bluetooth or "blue tooth" or "bluetooth technolog*" or "blue tooth technolog*" or pager or ((3G or 4G) adj1 system*) or "global position* system*" or GPS or gerontechnolog* or technogenerian).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
78. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77
79. 18 and 78
80. limit 79 to (abstracts and english language)

Google search No. 1: "working carer technology"
Google search No 2: "working caregiver technology"
Google search No. 3: "informal care employment job technology"

## Appendix G: Working Carer Interviews: Topic Guide<sup>7</sup>

- ✓ Re-iterate purpose of project
- ✓ Request permission to use tape recorder and ask them to sign two consent forms; one for them to take away and one for the records

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### Can you tell me something about your role providing care - how did this come about?

#### [Prompts:]

- Who do you care for?
- When did you start to provide care?
- Why did you start to provide care?
- Does [PwD] have a diagnosis of dementia? When did you receive the diagnosis?
- Are you the main carer? Why you and not another family member?
- Do you live with [PwD]? If not, where does he/she live? [distance to your place of residence]
- How do you support [PwD]/what tasks do you perform?
- How many hours a week do you usually spend on these tasks/**caring**?
- Why do you personally provide care?

### Can you tell me about your current work situation?

#### [Prompts:]

- Could you describe your current job? (occupation, type & size of employer, **work hrs/week**)
- **Can you take me through a typical day where you are combining work and care?**
- What is the most difficult aspect of combining work and care for you?
- Does providing care affect you **at work** on a day-to-day basis in any way?
  - How? Challenges? Conflict with colleagues or line manager (do they know you are a carer)? Concentration?
- Does your work affect your ability **to care** in any way?
- Which of these affect you the most? For which do you want support/solutions for the most?
- You indicated that you
  - Have high/low control over your work schedule
  - Can/can't work from home
  - Can/can't take breaks whenever you need to
- ...how does this affect your ability to combine work and care?
- How do you feel about your situation as a working carer?

### What (if any) support/services do you use to overcome these problems (or at least attempt to) and reconcile work and care?

- Do you receive any support from...?
  - Family
  - Council
  - NGO/voluntary organisations

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<sup>7</sup> Topic guide is based on Hamblin, K. & Hoff, A. (2009). *Carers@Work*. <http://www.carersatwork.tu-dortmund.de/>



- Private care
- Workplace
- Other
- If yes, how do they help you?

**Does technology play a part in your support? (keep the term open, only suggest examples if participants can't think of any technology)**

- If yes, which technology?
  - How? What do you use it for?
  - Does technology make it easier for you to combine work and care?
    - If yes, how?
    - If no, why not?
  - Are you satisfied with the technology you use?
    - If not, why not?
  - Does the technology suit your needs or do you see room for improvement?
    - If yes, how?
  - Are you able to use the technology at work?
    - What is your line manager's attitude?
    - How does your level of autonomy at work (see above) impact your ability to use the technology?
  - If you met someone else who combines work and care, would you suggest the technology to them?
    - Why?
    - Why not?
- If no, why not?

**If you had a magic wand, what would you like technology to do for you?**

**What else would make reconciling work and care easier for you?**

**WRAPPING UP:**

- What are the most difficult and most positive aspects of combining work and care for you?
- In light of your experience, if you met someone combining work and care, what advice would you give them?
- What are your wishes for the future? In a year's time?

<b>Brief Questionnaire for Context (if not already addressed in the interview)</b>	
	● Age
	● Marital status
	● Who do you live with?
	● If partner: Are they in paid work? Do they help you with caring?
	● Highest level of education achieved
	● Age of person you provide care for
	● Hours of care you provide on average per week
	● Is there a confirmed diagnosis of dementia? If yes, when was it diagnosed
	● How many hours/week do you work?
	● Are you or have you ever provided care for anybody else (including children)?

Appendix H: Sample quotes for themes and subthemes – Working carer interviews chapter 5 (Dementia family carers’ needs and wants for technological solutions to their work-care reconciliation challenges)

WDC= working dementia carers; PwD= person/people living with dementia; HCP= healthcare professionals.

Theme	Subtheme	Description	Example Quotes
CARE MANAGEMENT	Coordinating the care network	WDC need to coordinate responsibilities with their care network.	“Do you know what makes the difference? WhatsApp. WhatsApp, because that’s literally a group [...] and I will put into that, [...] ‘Somebody needs to stop by your gran’s’ or ‘I’ve had to go to [work], can one of you pick up with her’, and that’s generally it.” [Sue]
		WDC need to exchange care-related information with their care network.	“I just use it [WhatsApp] simply just to, to share, share important notes or it can be anything such as ‘Shall I get some potatoes on the way’ if I’m up here, to communication that relates to an appointment to the doctors.” (Gavin)
		WDC need reassurance that someone has checked on the PwD.	“I always want those [members of the care network] like ‘Guys, talk to me, talk to me’, [...] So yeah, a lot of the time you just haven’t got a clue what’s going on.” (Ian)
	Coordinating care providers	WDC need to set up and coordinate care services.	“The guy who runs the team, I’m in contact with him so frequently, phoning in, emailing him, [...] ‘Can you, erm, can you not do this, can you please do that...’.” (Maggie)
WDC need to know when care providers arrive at the PwD’s residence so that they can manage work around it.		“We’ve no idea when they’re [care workers] gonna be there roughly. No, we know roughly they’re coming between this and this hour. But if you’ve taken your lunch off and then you have to wait for it for ages. [...] that’s the kind of, someone, some of that kind of stress that we have if we take our time off and then you want to give her [mum] her lunch and then you end up waiting for ages and then you have stuff to go back at work.” (Max)	
WDC who privately hire care workers need to manage their responsibilities as employers.		“For everything I do there has been an initial time which is gathering the information, understanding what I might need to do, I need to communicate with, particularly in the original set up of the care plan, because I wrote both the job descriptions for the carers, submitted the plan which had to be approved for by the local authority in order that I could make use of the budget that was provided to me.” (Gavin)	
ATTENDING APPOINTMENTS	Attending medical and similar appointments	WDC need to attend appointments with HCPs, which is challenging due to conflicting hours.	“I’ve had social workers like going ‘Oh yeah we’ll do it before you go to work!’ and you go ‘Well, I leave at 7 o’clock’ and they go ‘Ok wish I’d never said that now!’. So, it tends to be that for those kinds of meetings, the flexibility has to come from my side. [...] It’s the same with doctors’ surgeries. You know, they must know that a huge part of the population works.” (Hannah)  “The hospital appointments are not so bad because they’re quite far in advance but things like the district nurses, they just turn up on your doorstep and expect you to be there.” (Rose)
	Attending business meetings	WDC working from home sometimes need to attend business meetings.	“Where I think it’s harder is when you’ve got meetings set up with your team, and you’re the person that’s supposed to be going to, I don’t know, some big governance meeting of umpteen people. Where you’re either gonna have to find

			somebody else to represent the team or you know. You can't really say to somebody who's organised something bank-wide, say 'Look, can you move this cos I need to go and take my mum to the doctor'." (Hannah)
	Arranging medical or similar appointments	WDC need to arrange appointments with HCPs, which is challenging due to conflicting hours.	"I would like to have access to the GP and the carers through technology. I don't even have email access to them, so that would be really useful, you know. That's quite basic technology, but at the moment that all has to be done by phone and for me, actually, email's easier than phone, especially when you're working. You can just bang out a quick email rather than having to go and do the whole phone call palaver." (Theresa)
ENTERTAINMENT AND COMPANIONSHIP	Providing entertainment and companionship	WDC want to minimise PwDs' cognitive decline and social withdrawal.  WDC want PwD to have more company when they need to work.	"Sometimes I think that while there is no denying the progress of her disease and the reality of it, Sometimes I think that if she could be more stimulated, she wouldn't have deteriorated so quickly". (Maggie)  "I would see her walking past the studio door towards her bedroom and I'd say to her, 'Oh are you away to bed mum?' and she'd just look at me and she'd say, 'What else is there to do', you know. And she's, I know she didn't mean it to come across like that, but there was an element of, not blame but well, you know, 'You're ignoring me, you're working, what am I going to do, there's nothing for me to do'. It wasn't just, you know, it was, there was a resentment in her voice about it, that she had nothing to do, and she was bored, and she was just going to go to sleep." (Maggie)
	Enabling active participation in society	WDC want the PwD to be able to actively participate in society.	"If I had a magic wand, I'd just want something to get them out and be happy." (Jasmin)
	Enabling PwD to communicate	WDC of PwD whose ability to speak is affected by dementia want to be able to communicate with the PwD	"I'm for the days when people are embedded with a chip, you know, really, I think, that we can communicate telepathically." (Maggie)
PSYCHOLOGICAL AND PSYCHOSOCIAL STRESS	Dealing with psychological and psychosocial stress	WDC need to deal with complicated emotions, emotional situations, and decisions (e.g., feeling unprepared or abandoned, having to make personal sacrifices, having to manage adverse effects on their health caused by emotional labour and constant vigilance, etc.). WDC need to deal with interpersonal conflict and difficulties (e.g., role reversal and the slow decline and changing personality of the PwD, difficult relationships between carer and PwD exacerbated by dementia, PwD or their spouse refusing help, etc.).	"I'm either feeling guilty about it and I'm not doing my work, guilty about something I'm not doing for my mum or guilty that my kids have had to move down the queue." (Hannah)  "The physical, I couldn't care less about cutting the grass, picking mum up out of a chair. That's nothing. (I: So, it's the emotional labour?), yes, it's emotionally exhausting." (Ian)  "It's like looking after a toddler, but when you are looking after a toddler they are always learning and growing and it's also a positive beautiful thing. And when you are looking after a toddler like this, they are deteriorating all the time and they are becoming less and less capable and it's, and to see that happening to your parent [sighs]." (Maggie)  "Where to draw a line between being respectful of what she [spouse] wants and saying, 'You're being absolutely ridiculous', you know? 'You're missing out on something

			here which is detrimental to him because of your views'." (Sue)
SAFETY CONCERNS	Managing accidents and emergencies	WDC need reassurance that the PwD is safe (e.g., accidents, falls or other emergencies).	"There's even the sort of, me sitting at work and I know that my mum's not well, so I'm maybe not concentrating at much and that has a big effect." (Flora)
	Reminding	WDC need to remind PwD of certain tasks or activities (e.g., taking medication, appointments, eating and drinking, etc.) and want confirmation when tasks are completed.	"I'm still working full time and as I say if I didn't have the phone there to check my dad, albeit he gets quite irritated with me checking you know, checking your tablets he'll go 'I'm not two' I'll go 'no, but you do forget, so it's easy for me to pick up the phone and just prompt'." (Betty)
		WDC need to remind PwD to switch off appliances which could e.g., cause fires or floods.	"There've been quite a few instances where mum's forgotten she's put a pan on the stove, um, and they have a system where as soon as the smoke alarm goes off the fire brigade just come." (Theresa)
	Managing disorientation	WDC need to ensure PwD remain orientated to avoid distress.	"Anything out of his routine, the repercussion's awful he's so unsettled afterwards. So, he has a complete fixed routine." (Sue)
		WDC need to be able to find PwD who are at risk of getting lost when out for a walk.	"He'll go for wanders, so you lose him, you don't know where he is and then you've got to sort of like try and find out where he is." (Mary)
Preventing crime	WDC need reassurance that PwD are safe from crime (e.g., scammers, burglars, etc.).	"And she'd let this guy into her house, given him £100 and then rung me up and said 'I don't think I should have done that, should I?' [...] And at that point I did go and look at technology in [department store] where you have some kind of CCTV that links to your phone." (Hannah)	
ACCESSING INFORMATION	Finding information	WDC need access to easily understandable information on dementia, caring, benefits, entitlements, and services.  WDC want practical advice from peers or so. with experience caring for PwD.	"We felt that we've been left to fend for ourselves in the sense that we have to do our own investigation and chance conversations, Google searches for things, thinking outside the box, you know." (Liam)  "Sometimes you just need somebody to say well 'Is this normal?', you know? Somebody to say, 'Well is this normal, is this part of the process' or, you know, 'Is there something else, you know, sort of going on?'" (Mary)
	Fighting for information	WDC need reliable information from organisations which can be difficult if more than one organisation is involved.	"They [council] would assess my mum and then see how much they were prepared to pay for her care. And I was like, 'How long does that take?', and she says, 'Oh, I can't give you a time', and I says, 'Well, is it an hour, a month or is it six months?', and she went, 'Well, it'll not be six months'. And that's what I was left with. And after that, I just kept phoning them and pestering them, which you didn't want to do because you know that they're struggling, but every time I phoned, I got a different story. I even said to them, 'Well how much do you, so that we can work out our finances, how much do you pay an hour?', and it went from anything from £13 to £16." (Flora)  "So, you have the council, they run the [telecare] system but they out-source the maintenance to a company called

			[name], they out-source the supply of the hardware to a different company called [name]. So, these three people, they are all trying to maintain the same system and they don't talk to each other [...]. That [coordinating these services] totally wasted, inefficiency wastes my time, about an hour every day, maybe more, things that don't need to be." (Maggie)
	Exchanging information with HCPs	WDC need to exchange relevant information with HCPs when PwD attend appointments on their own, which is challenging due to conflicting hours.	<p>"It's no good asking my dad for a summary of what happened because you don't get any information. If they leave information with him, it's not necessarily gonna get passed on unless I go look for it or ask for it." (Betty)</p> <p>"I would like to have access to the GP and the carers through technology. I don't even have email access to them, so that would be really useful, you know. That's quite basic technology, but at the moment that all has to be done by phone and for me, actually, email's easier than phone, especially when you're working. You can just bang out a quick email rather than having to go and do the whole phone call palaver." (Theresa)</p>
<b>PERSONAL CARE</b>	Toileting/ incontinence care	WDC want solutions for helping PwD to the bathroom, especially incontinence care.	"It [incontinence care] is really challenging because it's your own parent. I mean, it's bad enough doing that for anybody at all that you are not connected with but to do it for your own parents, it's such a very difficult and emotional thing." (Maggie)

Appendix I: Sample quotes for themes and subthemes – Working carer interviews chapter 6 (Impact of dementia family carers’ autonomy at work on their ability to manage care-related emergencies and use technology to that end)

CRE = care-related emergencies; PwD = person/people with dementia

Theme	Subtheme	Codes	Example Quotes
Autonomy at work – a spectrum	Autonomy can be temporarily limited	Autonomy can be temporarily limited due to business trips or meetings, or upcoming deadlines	<p>“I have a pattern where I try and routinely work a Wednesday at home. For example, this morning we had members of our team from other cities up yesterday/today, so we did have a team meeting this morning. So, I did go in this morning, back this afternoon – I tramped back at lunchtime.” (Hannah)</p> <p>“If I were in a meeting, I wouldn’t obviously get my phone out and check the [care] camera, or I wouldn’t get my phone out and go on the [care network] WhatsApp group.” (Iona)</p>
	Break autonomy (BA)	BA enables carers to use tech. when needed	“We’ve all got our mobiles so I mean I can go out for a cigarette break. As long as I take the time off my flexi-time, it’s my own time.” (Flora)
		No BA makes it hard to use tech. and be notified of and manage CRE	“No, I shouldn’t take a phone call. I could see if there was somebody who tried to reach me, the message service, so I would try as much as I could to at least be alert to any issues. My wife at home would have been able to have taken messages if there was anything urgent.” (Gavin)
		Tech. could still help carers with no BA	“Maybe if there was something that was more automated, that could provide a kind of a robotic approach, that could in some way, in a compassionate- you know it could even replay my voice perhaps to her. Just giving her the message, you know ‘Are you still up, mum? It might be time to go to bed. I’m working at the moment, but I will speak to you in the morning’.” (Gavin)
	Schedule autonomy (SA)	SA enables carers to manage CRE in person	“It’s flexible, so if I need to go up to the house [to PwD] and I don’t have a meeting or something or some sort of deadline or whatever I can go up whenever I want.” (Max)
		Carers with no SA rely on co-workers or swap shifts to still manage CRE in person	<p>“My colleagues I work with on my rota, they all know about my home situation. And they wouldn’t hesitate if we were fully staffed and probably even if we weren’t. They would muck in and take over.” (Rose)</p> <p>“No dayshifts anymore. I used to do the odd dayshift. But I can’t leave [PwD] for that length of time anymore.” (Rose)</p>
	Place autonomy (PA)	PA does not automatically mean that carers work where they care	<p>“I would work from home if need be, but it makes no sense to me whether to work from home. I work from here because I’m so close anyway.” (Max)</p> <p>“I would prefer to be up here [with PwD] more often but I don’t want to take the micky, you know. This isn’t where I’m based. So, and I have meetings in [town] and things like that and I really should be in the city that my job is located in.” (Iona)</p>
		Carers who work where they care can prevent CRE	“If she wandered around during the day when I was there, I would be able to look out for her.” (Maggie)

		Carers who work where they care need to be organised and flexible	"It's absolutely understanding what's needed. Not just what you want to do, what's actually best for you, your mum, and your customers. Yeah. So, there's, there's no way you can structure it." (Ian)
		Self-employed carers face financial pressure if caring takes up too much time	"I might have an eight-hour working day and I might get two hours work done in that time. But I have to live on the money that I make in my job. And if I'm only working two hours a day, I can't live on that." (Maggie)
		Carers who work where they care must employ boundary management and rapid role switching	"I often felt guilty getting on with work when I felt I should be with my wife and also felt guilty when I was with my wife, and I knew that I needed to be doing something for work." (George)  "You're sort of having that [business] conversation to going and wiping poo off the floor or whatever it is, you know. A complete role-switch. And you're going from being a nanny, to being a bloke in a pin-striped suit in the city, to almost, not quite almost, to being a nurse. It's the constant switching between the two that is quite bizarre." (Ian)
Factors influencing carers' position on the autonomy spectrum	Nature of the Work (NoW)	NoW can determine PA, SA, and tech. use	"If my job allowed me, I could physically work from home no hassle, but my actual job, my role just now isn't a work-from-home role." (Sue)
		Client-facing roles, work sector, team size, and specialisation impact on level of autonomy	"For a huge number of people that are working in office-based roles, I can see that that would work. But yeah, no, equally I can see that there are kind of customer-facing type roles where people go 'No sorry, you're not doing that'." (Hannah)  "There's enough people that if I go it doesn't have an impact, right? Me disappearing and nearly 200 people in the bit that I'm in, it doesn't kill the business. That's where working for the bank has been my saving grace." (Sue)
	Workplace culture and regulations (WC&WR)	WC&WR can be liberating or needlessly restricting	"We can please ourselves any time between seven in the morning 'til nine at night. So that's the sort of space. And in that time, we have to work [at least] three hours." (Flora)  "I have got time but it [using phones] is, it's not, you can feel it's not looked upon kindly." (Jasmin)  "There were some shift-swap options so, but they were pretty limited because you could only swap with people on the same sort of pattern as such." (Gavin)
		WR don't always fit everyone	"Because we're an organisation where that policy fits across everybody from people in back-office roles to people that are standing in a branch, they're never going to be able to introduce a policy that is that broad and that flexible." (Hannah)
		WR can be good in theory, but WC can make it difficult to benefit in practice	"On paper, we have a very good flexible and agile working policy. In reality, it's just not always possible. It just depends. Again, it depends on the deadlines I've got, it depends on the meetings I've got. Next week I'll be able to work from home a couple of days, so that's fine. This week I just can't at all cos I've got too much on." (Theresa)
		WC can deter carers from asking for more autonomy	"Now, have I gone and asked my employer if I can go do that? No, I haven't. Why not? I don't know. You know, because I'm thinking they're either going to say no, or they're gonna think I'm slacking, you know, shirking my responsibilities at work." (Theresa)

	Supportive line managers (LM)/clients	LM can mitigate restrictive WC&WR	<p>"Unfortunately, my previous manager didn't interpret it [flexible work regulations] that broadly. My current one does." (Hannah)</p> <p>"I would say to my boss 'I'm gonna have my phone, there's something going on' and that would be fine, because we're not supposed to have our- data protection and all that, we're not supposed to have our phones out." (Sue)</p>
		Carers can feel they have to earn LM's support	"I guess if you've worked here for years and have proven yourself to be a reliable and committed employee, they're gonna give you a bit more leeway, aren't they?" (Theresa)
		Self-employed carers can be depended on clients	"But they understood because they've got fathers that are now failing themselves. And so, they were actually very, very understanding when last week, for example, when I said, it was the first time ever, 'I'm not gonna be able to come down, mum's gone into hospital'." (Ian)
Distance		Distance can make complete autonomy ineffective when managing CRE	<p>"The phone would go saying, you know, 'Your mum's double-dosed her medication' or 'She's fallen' and I'm thinking 'I've just arrived in [office]', you know. I cannot physically, you know, I can jump on a train and come back, but by the time I do..." (Theresa)</p> <p>"I am close to 400 miles away. So, a journey here is not something I can make in a week and back. Apart from the expense, it's the time." (Gavin)</p>
		PA allows carers to travel to the PwD and resume work there	"I'm a project manager and I'll just do my day-to-day job whilst I'm in [town]. When I'm at home [PwD's home] it's a bit more difficult, obviously working, a full-time job and doing all the meal sorts and the pills and just checking on her in general, but I will make it work. [...]that's only a week out of every month, [mm] every six weeks so, I don't mind." (Iona)
		Having no PA requires getting creative with the work schedule or taking extended leave	"They were long shifts, and it was only generally about a four-day week. It did enable me to add quality breaks to long weekends to make five, six or seven days so I could use effectively a week to make a trip up. So that's what I did. Or I took holiday onto it, I took a couple of weeks." (Gavin)
		Some carers go to considerable lengths and make personal sacrifices to reduce the distance	<p>"So, I took the decision in 2017 that I would move up here, quit [city 3] and move in with Mum as her full-time carer." (Ian)</p> <p>"I mean there's no way we would have been able to manage that whilst she was so far away. [...] I think we maybe just got there in time so at least she knows where she is, she's aware of her surroundings, and I think the thought of moving her now would just be very complicated." (Theresa)</p>



## Appendix J: Catalogue of technologies for working dementia carers

### 1 Smart Screens

#### What does it do?



Smart screens are internet-enabled touchscreen devices with a built-in speaker and voice assistant. Voice assistants can talk to the user (e.g., to read out notifications or reminders) and receive verbal instructions. Smart screens usually offer a range of functions and are highly customisable with downloadable programmes ("apps" or "skills"). Some smart screens can be used as #IoT hubs [see 78].

#### What can it be used for?

**#Reminder #Instructor** Carers can programme regular or one-off reminders and prompts (e.g. to drink regularly) on the smart screen via a smartphone app or online portal. These reminders or prompts are then read aloud or text on the screen at the pre-set time. Some apps or skills can guide people with dementia through an activity (e.g., taking their pills). Some smart screens can be set to require people with dementia to acknowledge the reminder, either by pressing a button on the screen or by acknowledging it verbally.

**#DementiaClock** Smart screens can display the time, date, day and/or time of day. The time of day is usually accompanied by a picture (e.g., the sun for daytime, moon for night-time). Dementia clocks can help people with dementia to remain orientated by letting them know what time of day it is.

**#Teleconsultations** Smart screens can be used for video calling. Callers can call the device via a smartphone app or online platform. Some healthcare professionals offer video consultations which people with dementia can attend via the smart screen. Smart screens can be set to "auto-answer". This means that people with dementia do not have to interact with the device to answer the call.

**#Entertainment #Stimulation** Smart screens can play audiobooks, music, and stimulating or relaxing sounds and images. Devices can be populated with people with dementias' photos and videos from their past. Carers can record short stories or add captions to go along with the photos and videos. Looking at the photos and listening to the recorded stories and music can be entertaining and stimulating and help people with dementia reminisce about their life. Voice assistants can tell jokes and stories. People with dementia can initiate this with a voice command or carers can activate the playback via a smartphone app. Routines can be set up on the smart screen to prompt the person with dementia e.g., to continue their audiobook or listen to music. Programmes are currently in development to allow users to have natural conversations with the voice assistant.

**#Companionship** Via a smartphone app or online portal, carers, family members and friends can send people with dementia messages, videos, and pictures to their smart screen. This can help to keep them informed and socially connected.

**#AccessingInformation** Users can ask smart screens for all kinds of information. This can include the time, weather or news or caring advice and information on dementia.

### 2 Social Media

#### What does it do?



Social media are websites and computer programmes that allow people to create online communities and share information, ideas, personal messages, and other content (like videos or photos).

#### What can it be used for?

**#Psychoeducation #SelfCare #AccessingInformation** Social media can be used by carers to connect to other people in similar situations. Dedicated channels can provide curated content and discussion groups where carers can exchange advice, information, and emotional support with their peers. Some of these groups are public on the internet while others are closed and require an invitation from the group administrator.

**#CareNetworkCoordination** Carers can set up closed groups on social media for themselves and their care network. They can use these groups to communicate and share care-related information such as updates, videos, photos, and other content.

### 3 Care Management Software

#### What does it do?



Care management software can be used by care providers to keep digital records of their clients. Amongst other things, care management software can be used by care workers (people who provide paid care) to keep a digital record of the care plan and to make their daily reports online via a smartphone app. These records are secured and can only be accessed by authorised persons. Some care providers allow carers access to these reports and the care plan via a smartphone app or online portal.

#### What can it be used for?

**#CareServiceManagement #CommunicateEmergencyInformation** Carers can use the care management software to get access to the person with dementia's care plan. Carers can see the daily care reports produced by care workers after their visits to the person with dementia. This can help them to have peace of mind that the agreed-upon care has been delivered and to receive an update on the person with dementia's wellbeing. Some care providers allow carers to use the software to upload information about the person with dementia. This can include emergency and medical information as well as the preferences and needs of the person with dementia. Care workers can use this information for their care plan and to develop a more personal care relationship with their clients.

### 4 Banking and Shopping Apps\*

#### What does it do?



A banking app gives the user instant access to their bank account via their mobile device. Users can check their balance, make transactions, and manage payments. The app is heavily secured and can only be accessed with a password or thumbprint.

Shopping apps allow users to do their shopping online and have it delivered to their doorstep.

#### What can it be used for?

**#Security** Carers can use banking apps to manage the financial affairs of the person with dementia. Banking apps can help to keep people with dementia safe from scammers or fraud. Managing someone else's financial affairs either requires that person's express permission or for carers to have power of attorney.

**#SelfCare** Banking and shopping apps can be used anywhere at any time, given the app has access to the internet. This can save carers time which they can then use for themselves.

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\* An app (application) is a computer programme or piece of software designed for a particular purpose. Apps can be downloaded via the internet and installed on smartphones or other mobile devices.

## 5 Barrier Alarms

### What does it do?



Barrier alarms are two-part devices which can be placed in doorways. The infrared beam between these two devices forms an invisible barrier. When someone passes through this barrier, the infrared beam breaks and activates an alert.

Barrier alarms can either raise a localised alert, send an alert or notification to a connected pager or place an automated call via a connected home base.

### What can it be used for?

**#HomeLeavingNotification #ActivityMonitoring** Barrier alarms can notify carers if the person with dementia enters or exits an area, room or residence. Carers can thus have an idea of the activities and daily routine of the person with dementia (e.g., when they get up in the morning). Notifying carers when the person with dementia leaves the home can be relevant for people who are at risk of getting lost when out for a walk on their own due to their illness.

### Optional features



Some barrier alarms can only be triggered by a wearable bracelet breaking through the barrier. This can be useful if more than one person or pets live in the same residence. Bracelets can have an integrated SOS button. Pushing this button can lead the connected home base to initiate sequential calls to designated emergency contacts until one of them answers the call.

## 6 Care Cameras

### What does it do?



Care cameras are indoor cameras that use a very sensitive motion sensor and machine learning to monitor and interpret movements. Care cameras can detect unusual activity and send an alert to a connected smartphone app. For privacy protection, persons in the live feed can be replaced by stickmen.

[Emerging technology: this technology is not yet widely available]

### What can it be used for?

**#ActivityMonitoring** Care cameras can notify carers when unexpected activity occurs. They can detect falls or unusually long periods of inactivity. The notification sent to the carer's smartphone app acts as a prompt for them to investigate. When the care camera's integrated motion detector is directed at the person with dementia's pill dispenser and the camera's parameters are set accordingly, the camera can notify the carer via the smartphone app if the person with dementia has forgotten to take their medication.

## 7 Stationary Personal Alarms

### What does it do?



Big, stationary buttons or pull cords are at a fixed location (e.g., the bathroom). They can be pushed or pulled to trigger an alarm and alert a carer about the need for assistance (e.g., to help mobilise the person with dementia to or from the bathroom).

Stationary personal alarms can either raise a localised alert or send an alert or notification to a connected pager.

## What can it be used for?

**#CallingForHelp** Stationary personal alarms can allow the person with dementia to alert the carer about their need for assistance. This can be helpful, for example, for people with limited mobility who need help moving around. This requires carers to be close to the person with dementia.

**#Security** Stationary personal alarms can be fixed next to the person with dementia's entrance door. When triggered, a silent alarm is sent (e.g., to a call centre). Operators can listen silently to judge the situation and take appropriate action. This can help people with dementia to receive timely assistance in case of a home invasion or harassment by cold callers and fraudsters.

## 8 Automatic Switch-Offs

### What does it do?



Automatic switch-offs can detect gas leaks or floods and automatically shut down the water flow or gas source. Some additionally trigger an alarm. Countdown plugs automatically switch off plugged-in devices after the pre-set countdown has run out. Stove switch-offs shut down the stove after the pre-set countdown or when they detect excessive fumes or heat. Stove switch-offs can raise a localised alert before switching off the stove.

### What can it be used for?

**#EnvironmentalHazardManagement** These devices can automatically deactivate appliances or devices after a pre-set time or when a hazard is detected. This can help to avoid accidents or emergencies in the person with dementia's home.

## 9 Wearable hydration reminders

### What does it do?



Wearable hydration reminders are integrated into regular fitness trackers which are worn on the wrist. They measure a person's hydration level by scanning the tissue via optical spectrometry. They then prompt the wearer via vibration and visual display to drink.

[Emerging technology: this technology is not yet widely available and has not been tested with people with dementia.]

### What can it be used for?

**#Reminder** Wearable hydration reminders can remind people with dementia to drink regularly to help prevent dehydration.

## 10 Emergency Information Storage Device

### What does it do?



Emergency information storage devices are usually small and can be worn on a wrist strap or necklace. The emergency information can be accessed by playing a recorded message on the device or by scanning a QR code with a smartphone which opens a secure webpage containing the information. Information can include important medical, personal, and care-related details as well as emergency contacts.

### What can it be used for?

**#CommunicateEmergencyInformation** Carers can record an emergency message or populate a secure webpage with relevant emergency information. This can ensure that first responders have access to all relevant medical and care-related information as well as emergency contacts if the carer is not available in case the person with dementia has an accident or other emergency.

## 11 Smart Speakers

### What does it do?



Smart speakers are internet-enabled speakers with a voice assistant. Voice assistants can talk to the user (e.g., to read out notifications or reminders) and receive verbal instructions. Smart speakers usually offer a range of functions and are highly customisable. Programmes ("apps" or "skills") can be downloaded. Some smart speakers can be used as **#IoT** hubs.

### What can it be used for?

**#Reminder #Instructor** Carers can programme regular or one-off reminders and prompts (e.g., to drink regularly) on the smart speaker via a smartphone app or online portal. These reminders or prompts are then read aloud by the voice assistant at the pre-set time. Some apps or skills can guide people with dementia verbally through an activity (e.g., taking their pills). Some devices can be set to require people with dementia to acknowledge the reminder verbally.

**#CallingForHelp** Via smartphone app carers can connect to the smart speaker and listen in or communicate with people with dementia. People with dementia can also use the smart speaker to make a call or call for help.

**#VisitorNotification** Visitors can announce their presence to the smart speaker. Carers can access the visitor log via a smartphone app or online platform. This may require a special programme.

**#Entertainment #Stimulation** Smart speakers can play (curated) music or audiobooks. Voice assistants can tell jokes and stories. People with dementia can initiate this with a voice command or carers can activate the playback via a smartphone app. Routines can be set up on the smart speaker to prompt people with dementia to do certain things (e.g., continue audiobooks or listen to music). Programmes are currently in development to allow users to have natural conversations with the voice assistant.

**#AccessingInformation #DementiaClock** Users can ask smart speakers for all kinds of information. This can include the time, weather or news or caring advice and information on dementia.

## 12 Online Training Programmes for Carers

### What does it do?



Online training programmes can deliver advice and information on care-related issues. Content is usually structured into individual lessons and can include caring skills, general information on dementia, cognitive and behavioural coping skills, and organisational skills.

The content can be presented using different media such as videos, podcasts, quizzes, and text. Lessons are usually designed to be accessed when and where needed, at the carer's own pace and can be revisited.

### What can it be used for?

**#Psychoeducation #AccessingInformation** Online training programmes can help carers to strengthen their resilience and to focus on the positive aspects of caring. Training programmes can improve coping, organisational, and caring skills, and knowledge about dementia.

## 13 Personnel Management Software

### What does it do?



Personnel management software is used by many care providers. Amongst other things, the software can manage staff schedules, pension and holiday entitlements and calculate their payment.

[Emerging technology: this technology is not yet available for carers but is established for care providers.]

### What can it be used for?

**#CareServiceManagement** A slimmed-down version of the personnel management software used by care providers could be used by carers to manage privately organised and funded care workers.

## 14 Missing Person App

### What does it do?



If a person goes missing, a missing person app can be used to notify the network of app users, upload a description of the missing person, and ask the network to keep an eye out.

### What can it be used for?

**#PersonLocator** Carers can use the app to ask the network of users for help to look for missing people with dementia. This can help carers to locate people with dementia in case they get lost when out and about.

## 15 Aromatic Oil Diffusers

### What does it do?



Aromatic oil diffusers release the scent of aromatic oils into the air. When activated, the device heats and diffuses the applied aromatic oil for a certain period. Different oils have different properties which can stimulate or relax.

### What can it be used for?

**#Stimulation** Oil diffusers can provide stimulation or relaxation for people with dementia. Applying the oil and switching the device on might require the carer to be present.

## 16 Fridge Cameras

### What does it do?



Fridge cameras can be installed inside a fridge. They take a picture of the inside of the fridge each time the door is closed. The picture is then sent immediately to a connected smartphone app. Fridge cameras act as a shopping aid by ensuring that the user is up to date with the content of their fridge, thus helping to reduce waste.

## What can it be used for?

**#ActivityMonitoring** Carers are notified immediately by the picture sent to their app when the person with dementia has used the fridge. The picture can also let them know what has been taken out of the fridge. This can let carers conclude whether, when, and what the person with dementia is eating. This can be relevant to investigate sudden weight fluctuations which can be caused by people forgetting to eat or how to prepare a meal due to their illness.

## 17 Social Robots

### What does it do?



A social robot can perform complex movements and interact with the user by responding to touch and commands or by initiating activities. The goal of a social robot is to create close and effective interactions with its user. It can provide assistance, companionship, and stimulation.

Robots can have a variety of shapes and sizes, some resembling animals, and some are more human-like. Some robots are very mobile, others are meant to be more stationary and require help to move around or have to be lifted and put in a different place when needed. Some robots have an integrated LCD touch screen to display content and enable video calls.

### What can it be used for?

**#Companionship #Entertainment #Stimulation** Social robots can act as a companion for people with dementia. They have a physical presence in people with dementias' homes and can respond to social cues. Depending on their programming, social robots can initiate conversations or activities or provide guidance for safe exercising (e.g., some robots can dance to music, tell jokes, or prompt the user to listen to an audiobook). Some robots have an integrated LCD screen which can be used for video calls with friends or family. This can help to combat loneliness and social isolation.

### Optional features



A new feature currently in development and already integrated into some social robot prototypes is fall detectors. Robots can use their sensors to detect if a person has a fall and initiate an emergency response.

## 18 Environmental Hazard Detectors

### What does it do?



Environmental hazard detectors can detect gas, smoke, heat and/or power cuts. Heat detectors can be placed near cooking stations where smoke detectors would not be helpful.

Environmental hazard detectors can either raise a localised alert or send an alert or notification to a call centre or smartphone app via the internet.

### What can it be used for?

**#EnvironmentalHazardDetection** These devices can alert people with dementia and their carer (or optionally an emergency response team via a connected call centre) to a potentially dangerous situation in their residence.

## 19 Stationary Hydration Reminder

### What does it do?



Stationary hydration reminders can be placed on a glass or mug to monitor the drinking frequency of the user. Built-in tilt sensors monitor how often the user has taken a drink and the device prompts the user to have a drink if the measured drink frequency is too low. Prompts can be recorded but there are also pre-set notification options. The prompts can also be set to specified intervals.

### What can it be used for?

**#Reminder** Stationary hydration reminders can remind people with dementia to drink regularly to prevent dehydration.

## 20 Automatic Toilets

### What does it do?



Smart toilets include either the whole unit with tank and bowl or just the seat which can be attached to an existing unit. Different models have different features such as automatic lifting and closing of the toilet lid and seat, a seat warmer, a bidet wand with adjustable water temperature and drying function, and an automatic flush.

### What can it be used for?

**#ToiletingAssistance** Smart toilets are more hygienic than using toilet paper. They are particularly beneficial for people with dexterity issues. People who suffer from incontinence or irritable bowel disease also benefit because the toilet's wash and dry functions eliminate the need for excessive wiping which can cause skin irritation. These toilets can help carers to deal more quickly and hygienically with helping people with dementia the bathroom.

## 21 Motion Detectors

### What does it do?



Motion detectors use passive infrared technology (PIR) to detect movement. Devices can be programmed for a specific range and to only activate at certain times (e.g., at night). Parameters can be set so that devices can raise alerts if activity or no activity is detected during a specified time.

Motion detectors can raise localised alarms or send an alert to a pager or via a connected home base. The home base sequentially calls the designated emergency contacts until one of them responds. Motion detectors can be part of an **#IoT** [see 78] solution, sending an alert to a smartphone app via the internet. Motion detectors can also be connected to other devices such as cameras or lights. As such, motion detectors can activate the connected device when movement is detected.

### What can it be used for?

**#ActivityMonitoring #Security #HomeLeavingNotification** Motion detectors can let carers know when the daily routine of the person with dementia changes, enabling them to intervene promptly. Devices can also be used as intruder alerts if positioned and set to be active during a time when movement from the person with dementia



is not expected. Used at the front door, devices can notify carers if people with dementia leave their home. This can be relevant for people with dementia who are at risk of getting lost when out and about on their own.

**#Reminder** Some motion detectors enable carers to record a brief message. When motion is detected, the device plays the message (e.g., to remind people with dementia to take their keys with them when leaving the home).

### Optional features



Some motion detectors can also detect sound.

## 22 Case Management Software

### What does it do?



Case management software can be used by service providers and organisations to collaboratively work on a case. The software can enable collaboration within and between organisations. This can make it quicker and easier for organisations to share information and reduce the risk of misinformation and time spent chasing up information.

### What can it be used for?

**#ChasingInformation** Case management software can reduce the time carers have to spend coordinating and chasing up information from organisations and individuals involved in the care of the person with dementia. It can eliminate the need for follow-up calls and reduce the risk of misinformation.

## 23 Call Recorder Apps

### What does it do?



Call recorder apps can record phone or even video calls made and received on the device they are installed on. Some apps even provide an automatic transcript of the recorded conversation.

### What can it be used for?

**#ChasingInformation** Call recorder apps allow carers to keep a verbatim record of conversations. This can be useful if they need to refer back to confirm specific details (e.g., any agreements made, or arrangements discussed). Call recorder apps can be helpful if carers have to talk to multiple organisations about care-related issues. They can help to manage potentially contradictory or conflicting information.

## 24 Care Tablets

### What does it do?



Care tablets are touchscreen devices with custom software. These devices usually offer a range of functions and are customisable to an extent. Other than regular off-the-shelf tablets, users cannot install additional apps or programmes.

Some care tablets can be part of an **#IoT** [see 78] solution.

### What can it be used for?

**#Reminder** Carers can programme regular or one-off reminders and prompts (e.g., to drink regularly) on the care tablet via a smartphone app or online portal. These reminders or prompts are then read aloud or text on the screen at the pre-set time. Some devices can be set to require people with dementia to acknowledge the reminder, either by pressing a button on the screen or by acknowledging it verbally.

**#DementiaClock** Care tablets can display the time, date, day and/or time of day. The time of day is usually accompanied by a picture (e.g., the sun for daytime, moon for night-time). Dementia clocks can help people with dementia to remain orientated by letting them know what time of day it is.

**#Teleconsultations** Many care tablets can be used for video calling. Callers can call the device via a smartphone app or online platform. Some healthcare professionals offer video consultations which people with dementia can attend via the care tablet. Some care tablets can be set to "auto-answer". This means that people with dementia do not have to interact with the device to answer the call.

**#Entertainment #Stimulation** Devices can be populated with people with dementias' favourite music, photos, and videos from their past. Carers can record short stories or add captions to go along with the photos and videos. Looking at the photos and listening to the recorded stories and music can be entertaining and stimulating and help people with dementia reminisce about their life.

**#Companionship** Via smartphone app or online portal, carers, family members and friends can send people with dementia messages, videos, and pictures to their care tablet. This can help to keep them informed and socially connected.

### Optional features



Some care tablets can have a voice assistant. Voice assistants can talk to the user (e.g., to read out notifications or reminders) and receive verbal instructions.



An emerging feature of care tablets is a small stationary robot. This robot is attached to the care tablet and uses lights and movement to go along with the care tablet's voice assistant.

## 25 Simple TV Remote Controls

### What does it do?



Simple TV remote controls have only the bare minimum of buttons required to operate the TV. This reduces the risk of users accidentally resetting their TV settings or getting lost in a channel list or menu.

### What can it be used for?

**#Entertainment** Simple TV remote controls make it easier for people with dementia to have control over their entertainment.

## 26 Indoor Cameras

### What does it do?



Indoor cameras can be installed inside a property. Most indoor cameras have an integrated microphone and speaker, enabling two-way communication. Audio and video are transmitted via the internet. Carers can control the camera and access a live feed or past recordings via a smartphone app or online portal. The smartphone app can be set to send email alerts or push notifications when movement is detected to prompt users to investigate.

## What can it be used for?

**#ActivityMonitoring** Indoor cameras allow carers to use their smartphone app to have a quick look to see whether the person with dementia is okay. This can take as little as a few seconds. The two-way communication function enables them to also listen in and speak to the person with dementia.

## 27 Digital Dementia Clocks

### What does it do?



Digital dementia clocks can display the time, date, day, and time of day. Some devices can be personalised to display some or all the above, others are pre-set. Some devices use pictures (e.g., of the sun or moon) to illustrate the time of day and set to automatically dim during nighttime. Some devices can also display a selection of messages to prompt or remind people with dementia (e.g., to drink regularly).

### What can it be used for?

**#DementiaClock** Digital dementia clocks can help people with dementia to remain orientated by letting them know what time of day it is.

## 28 Smart Thermostats

### What does it do?



Smart thermostats allow users to control central heating via the internet (e.g., a smartphone app).

### What can it be used for?

**#EnvironmentalHazardDetection** Carers can use the internet (smartphone app) to check whether the person with dementia's home is properly heated. Carers can also use the app to adjust the temperature remotely.

## 29 Electronic Day Planner Whiteboard

### What does it do?



An electronic day planner whiteboard is a magnetic whiteboard with an LED light strip from the top to the bottom. Different LED colours symbolise day and night. As the day progresses, more lights light up on the light strip, symbolising the passing of time. The whiteboard can be used to write routine activities (e.g., brushing teeth or having lunch) next to the light strip. Alternatively, magnetic plaques can be placed on the whiteboard, displaying pictures of the various routine activities. When the light on the light bar moves past the activity in writing or on the magnetic plaques, this indicates that this activity should take place now.

### What can it be used for?

**#DementiaClock** The differently coloured light strip helps people with dementia to remain orientated throughout the day and to retain their daily routine.

## 30 Enuresis Sensors

### What does it do?



Enuresis sensors are devices that can detect moisture. There are small wearable enuresis sensors which can be worn in the underwear and there are enuresis mats which are placed on the mattress. These sensors can detect when urinary incontinence occurs. The devices can raise a low localised alert or send a notification to a connected pager or smartphone app via the internet.

### What can it be used for?

**#ContinenceManagement** The sensors eliminate the need for carers to make physical checks for urinary incontinence, preserving the dignity and independence of people with dementia. This can help carers to manage incontinence when it occurs.

## 31 Door and/or Window Alarms

### What does it do?



Door and/or window alarms are two-part wireless, magnetic devices. One part is fixed to the door/window frame, and the other to the door/window. An alarm is raised when the door or window is opened or left open. Devices can be programmed to only raise alarms at certain times (e.g., at night).

Door and/or window alarms can raise localised alarms or send an alert to a pager or via a connected home base. The home base sequentially calls the designated emergency contacts until one of them responds. Door and/or window alarms can be part of an **#IoT** [see 78] solution, sending an alert to a smartphone app via the internet.

### What can it be used for?

**#ActivityMonitoring** Door and/or window alarms can let carers know when the daily routine of the person with dementia changes, enabling them to intervene promptly. Fixed to the fridge door the device can send an alert when the fridge door has not been opened within a specified time frame, letting carers know if the person with dementia has not had anything to eat yet.

**#Security #HomeLeavingNotification** Door and/or window alarms can act as an intruder alert and can notify carers if the person with dementia leaves the home. This can be relevant for people with dementia who are at risk of getting lost when out and about on their own.

## 32 Email, Phones, and Answer Phones

### What does it do?



Email, phone, and answer phones can be used to facilitate communication between carers, care network members, care services, and healthcare professionals.

### What can it be used for?

**#CareNetworkCoordination**      **#CareServiceManagement**      **#AppointmentCoordination**      **#SelfCare**  
**#AccessingInformation** **#ExchangingHealthRelatedInformation** Email, phones, and answer phones allow carers to get advice, support, and information from healthcare professionals, care network members, and care services. It is often difficult for carers to speak directly to healthcare professionals due to conflicting work hours. Email and answer phones allow carers to leave a message, e.g., requesting an appointment. Healthcare professionals can then reply in their own time.

## 33      Electronic Health Records

### What does it do?



Electronic health records are digital versions of a person's medical records. These can include information regarding a person's allergies, current and past health issues, medical and treatment reports, medication, and emergency contacts.

Electronic health records are digitally secured to prevent data breaches and can only be accessed with permission. Authorised healthcare professionals can access a person's electronic health records to view their medical history and to add test results, therapy recommendations, and reports.

Not all electronic health records are accessible by patients themselves, or their authorised representatives. Currently, there are several different systems in operation in the four nations of the UK, some allow patients access, and some don't. Where patients don't have access, they can usually request a print-out from their GP.

### What can it be used for?

**#CareNetworkCoordination** Carers who have access to people with dementias' electronic health records can view their medical reports and treatment recommendations online. This can be particularly useful for carers who cannot accompany people with dementia to their medical appointments and who are thus at risk of missing important information.

**#Teleconsultations** **#AppointmentCoordination** Some electronic health record systems allow users to book medical appointments directly online and some even enable teleconsultations with healthcare professionals.

## 34      Online Booking Systems

### What does it do?



Online booking systems can be used by healthcare professionals. Patients can view and select available appointments via the internet.

### What can it be used for?

**#AppointmentCoordination** Online booking systems can be used by carers to arrange appointments for people with dementia with healthcare professionals. This can be particularly useful for carers whose work hours make it difficult to arrange appointments via the phone.

## 35 Simple Music Players

### What does it do?



Simple music players have only the bare minimum of buttons and controls. Devices can play content from an SD storage card or tune into the radio. The buttons are usually big and easy to handle for people with sight or dexterity issues.

Some devices only have one button: an on/off switch. All other controls are concealed to prevent users from accidentally turning the volume up or down or switching to the wrong channel.

### What can it be used for?

**#Entertainment** Simple music players make it easier for people with dementia to have control over their entertainment.

## 36 Security Cameras

### What does it do?



Security cameras can be installed outside a property. Modern security cameras have a built-in motion detector which only activates the recording when movement is registered. Many cameras include a night-view mode.

Carers can access a live feed and past recordings via a smartphone app. Recordings are also stored on the camera itself. The smartphone app can be set to send email alerts or push notifications when movement is detected to prompt users to investigate.

Some cameras can enable users to have a two-way conversation or control the camera remotely via the connected smartphone app. This means that users can adjust the camera's perspective and view radius.

### What can it be used for?

**#Security** Security cameras can ensure the safety and security of the person with dementia's property. It can collect evidence of a crime and act as a deterrent if placed in a visible spot.

**#VisitorNotification #HomeLeavingNotification** The built-in motion detector can notify carers about visitors coming to see the person with dementia and when the person with dementia leaves the home. This can be useful for people who are often disorientated because of their disease and might be at risk of getting lost.

## 37 Analogue Dementia Clocks

### What does it do?



Analogue dementia clocks combine an analogue clock face with a digital date display or a rotating disk with pictures representing day- (sun) or night-time (moon).

Some clocks only show the day of the week and/or the time of day (e.g., morning, noon, afternoon, etc.).

### What can it be used for?

**#DementiaClock** Analogue dementia clocks can help people with dementia to remain orientated by letting them know what time of day it is.

### Optional features



Some analogue dementia clocks are combined with a whiteboard. Carers can use this whiteboard to leave notes or instructions (e.g., about appointments) for the person with dementia.

## 38 Pocket Pill Dispensers

### What does it do?



Pocket pill dispensers have a few compartments where medication can be sorted (e.g., all pills for one day). The device can alert people with dementia at pre-set times. Alerts can be audio-visual (beeping and blinking) and vibrate. Devices are small enough to be carried in a pocket on the move.

### What can it be used for?

**#Reminder** Pocket pill dispensers remind people with dementia to take their medication on time.

## 39 Video Call Software

### What does it do?



Video call software uses the internet to enable two or more people to have a video conversation. The software can be installed on any computer, smartphone or tablet PC that includes a camera, microphone, and speaker. Callers have to ensure that they use the same software.

### What can it be used for?

**#Teleconsultations #Telework** Some healthcare professionals offer video consultations which carers and/or people with dementia can join remotely. When working from home to look after the person with dementia, carers can use video call software to take part in business meetings remotely.

**#Instructor** Video call software allows carers to help people with dementia with tasks or activities (e.g., finding their pills).

## 40 Pressure Sensors

### What does it do?



A pressure sensor is a soft pad which can detect when weight is applied or lifted, i.e., when a person steps on it, sits/lies down, or gets up. Sensors can be programmed to only alert if the person has not returned after a certain time to prompt the carer to investigate.

Pressure sensors can either raise a localised alert or send an alert or notification to a connected pager or smartphone app via the internet.

### What can it be used for?

**#InjuryPrevention #ActivityMonitoring** Pressure sensors can be placed under a mattress or a chair cushion. They can notify carers when the person with dementia gets up, sits/lies down or enters or leaves a room or the house.

Carers can thus monitor people with dementias' activities and daily routines (e.g., when they get up in the morning). Carers can also be notified if anything is out of the ordinary (e.g., if the person with dementia gets up at night and does not return). Pressure sensors can help to prevent falls as carers are notified if the person with dementia gets up and can thus rush to their aid if they work from home. Some pressure sensors can be connected to a night light. This can reduce the risk of falling at night.

**#HomeLeavingNotification** Pressure sensors can be placed under a doormat. They can alert the carer when somebody enters or leaves the home. This can be relevant for people who are at risk of getting lost when out for a walk on their own due to their illness.

**#Reminder** Some pressure sensors have the option to record a short message which is played back when the sensor is triggered by somebody getting up. This can be used for example to remind the person with dementia to return to bed or not to leave the house at night.

## 41 Smart Power Sockets

### What does it do?



Smart power sockets can be plugged into a regular power socket. Smart power sockets can detect the use of plugged-in devices. This usage data can be accessed online via a smartphone app. Smart power sockets can be part of an **#IoT** [see 78] solution.

### What can it be used for?

**#ActivityMonitoring** Smart power sockets can enable carers to monitor which and when the person with dementia uses electronic devices. This can be particularly useful in the kitchen as it allows carers to see whether the person with dementia uses appliances (e.g., water kettle or microwave) to prepare food and drink.

## 42 Business Software and Hardware

### What does it do?



Business software can be computer programmes used by the carer's company and installed on their private devices. Business hardware can be company-owned laptops with preinstalled software required for work.

### What can it be used for?

**#Telework** Business software and hardware can enable carers to work remotely. This can enable them to look after the person with dementia while working from home.

## 43 Wayfinders

### What does it do?



Wayfinders can be stand-alone devices or apps. Wayfinders use GPS for visual navigation (e.g., a map or pictures of noticeable landmarks along the way) and/or voice instructions.

[Emerging technology: Wayfinders are a well-established technology. Wayfinders suitable for people with dementia are in development and not yet widely available.]

### What can it be used for?



**#SocialParticipation** Wayfinders can help people with dementia to navigate and orientate themselves when out and about. This can prevent them from getting lost, help them to increase their confidence, and enable them to participate actively in society.

## 44 AI Booking Assistant

### What does it do?



AI (Artificial Intelligence) booking assistants are online programmes which can be used to arrange appointments. Users tell the programme what, when, and where to book an appointment. The programme then calls the service provider to arrange the appointment according to the requested parameters. The AI's voice sounds like a real person. This technology requires that the contact information and business hours of the service provider are accessible

online.

[Emerging technology: this is a new technology which can currently be used to make reservations for restaurants or cinemas. It is not yet available to arrange appointments with healthcare professionals.]

### What can it be used for?

**#AppointmentCoordination** AI booking assistants could be used by carers to arrange appointments for people with dementia, for example with healthcare professionals. This can be particularly useful for carers whose work hours make it difficult to arrange appointments themselves.

## 45 Musical Soft Toy

### What does it do?



Musical soft toys are cuddly toys (e.g., a teddy bear) with an integrated music player. Music can be uploaded to an SD storage card which can be inserted into the musical soft toy. Playback is activated by pressing the toy's paw.

### What can it be used for?

**#Entertainment #Companionship #Stimulation** The musical soft toy can provide hours of musical entertainment for people with dementia. Depending on the uploaded content, the music can be relaxing or stimulating. The toy also invites its user to cuddle with it, thus potentially helping to combat loneliness.

## 46 Self-driving Cars

### What does it do?



Self-driving cars are vehicles which can drive with little to no human input. This is achieved through a variety of sensors which can perceive the car's environment, including street signs, pedestrians, other cars, etc. These sensors ensure the safety of the passengers and the car's surroundings.

[Emerging technology: self-driving cars are not yet commercially available]

### What can it be used for?

**#SocialParticipation** Self-driving cars can enable people with dementia who are no longer able to drive a car due to their illness to be more independent when wanting to travel. This can improve their social participation and combat loneliness.

## 47 Talking Clocks and Watches

### What does it do?



Talking clocks or watches can announce the time, time of day, and date at the push of a button.

### What can it be used for?

**#DementiaClock** Talking clocks and watches can help people with dementia to remain orientated by telling them the time whenever needed.

## 48 Electronic Pill Dispensers

### What does it do?



Electronic pill dispensers contain a person's pre-sorted medication. Alerts can be set to prompt the person to pick up the device. The alert stops when the device is tilted which releases the medication. Some devices can be locked to prevent accidental double-dosing. Alert options include an audio and/or visual signal (beeping and blinking) and a pre-recorded message. Some devices can send an automatic notification (autodial) to the carer or a call centre if the person with dementia does not respond to the dispenser alert by tilting it to release the medication.

### What can it be used for?

**#Reminder** Electronic pill dispensers remind people with dementia to take their medication on time.

## 49 Telepresence Robots

### What does it do?



A telepresence robot is a wheeled device that can be remote-controlled via the internet, using a smartphone or PC. Robots can be small to be used on a table or as tall as a person. These robots either have an integrated screen, microphone, speaker and camera or a smartphone or tablet can be attached which works with any video call software.

These robots can be manoeuvred remotely by the user to give them a virtual presence in the room. The robot's camera lets users see the remote location while its microphone and speaker let them have a conversation.

### What can it be used for?

**#WorkingRemotely** When working from home to look after the person with dementia, carers can use telepresence robots to have an active presence at their workplace. In this case, the robot has to be at the workplace.

**#Teleconsultations** Some healthcare professionals offer video consultations which carers and the person with dementia can join via the robot. Ideally, the robot will be at the residence of the person with dementia. Some

robots can be set to "auto-answer" which means that the person with dementia does not have to actively accept the call.

## 50 Fob or ID Card Scanner

### What does it do?



Visitors who have a special key fob or ID card can scan this at the person with dementia's residence. The scanners are usually part of an **#IoT** [see 78] solution. Scanning the fob or ID card on the device notes who enters the building at what time and creates an entry in the visitor log. Visitors can use the device again when they leave the residence. Carers can access the visitor log via a smartphone app.

### What can it be used for?

**#VisitorNotification** These devices allow carers to be notified when and who (e.g., a family member or care provider) visits the person with dementia. This can provide reassurance that the arranged care is provided as planned and that somebody has been in to check on the person with dementia.

## 51 Information Apps and Websites

### What does it do?



Websites and apps enable users to access information quickly and at any time. Some websites have algorithms to make information more relevant by guiding users through several questions. Some apps can be personalised or "learn" what the user requires.

### What can it be used for?

**#Psychoeducation #SelfCare #AccessingInformation** Information apps and websites can provide general information on dementia, available support and services, and caring advice, and can signpost to further information and resources. Many apps and websites have discussion sections where carers can connect with their peers and sometimes even service providers or healthcare professionals (either via the discussion section or via live chat or email).

## 52 Wearable Person Locators

### What does it do?



Wearable person locators are small devices which can be worn on the wrist, around the neck, in a bag, on a belt or in a shoe. These devices include GPS technology and many also include a SIM card. Carers can access the location of the wearer in real-time via a smartphone app or by calling the device. Some devices can enable two-way conversation.

### What can it be used for?

**#PersonLocator** Wearable person locators can allow carers to access the location of the person with dementia. This can help carers to locate the person with dementia in case they get lost when out and about.

**#CallingForHelp** Some devices include an SOS button. When the person with dementia presses the button, an alert containing the current location is sent. The alert is transmitted to the carer's smartphone or the wearable person locator initiates sequential calls to designated emergency contacts (autodial) until someone responds. Some devices include a fall detector which automatically raises an alarm via autodial in case of a fall.

**#HomeLeavingNotification** Some devices include a geofence function. This function automatically alerts carers when the wearer has left a predefined area.

## 53 Instant Messaging and Care Management Apps

### What does it do?



**Instant messaging apps** allow users to instantly share content (e.g., messages, recordings, pictures, videos, documents) via the internet with any of their contacts who also use the app. Content can be shared with only one person or whole groups at a time. These apps keep a record of conversations and shared content. This means that users can go back to their conversation log to look up previously shared information.

**Care management apps** provide this function and additional tools which can help manage the care network. These tools include calendars to share appointments, medication and health data storage, task sharing and organisational tools.

### What can it be used for?

**#CareNetworkCoordination** Carers can use instant messaging and care management apps to coordinate and communicate with their care network. Care management apps provide additional tools to better organise shared information. Communicating with a whole group at a time can save carers a lot of time and can ensure that all members of the care network have all the necessary information at once.

## 54 Mobile Phones

### What does it do?



Some mobile phones have special features which are potentially relevant for people with dementia. This can include accessibility features such as big picture buttons which can be programmed with one specific number each or hearing aid compatibility. Some mobile phones have an SOS button. And some have an integrated fall detector.

### What can it be used for?

**#CallingForHelp** These accessible mobile phones make it easier for people with dementia to make and receive phone calls, particularly when they are not at home. People with dementia may find it easier to call for assistance. Mobile phones with an SOS button initiate sequential calls to designated emergency contacts when pushed until one of these contacts responds to the call. The same call sequence can be initiated on a mobile phone with an integrated fall detector when a fall is detected. The phone additionally transmits its current location via GPS.

## 55 "Baby" Monitors

### What does it do?



Traditional "baby" monitors are a set of two devices which detect and transmit sound. The devices usually enable two-way communication. Newer devices can transmit the detected sound to a smartphone app. Some "baby" monitors can have an integrated indoor camera which allows carers to also check in visually with the person with dementia.

### What can it be used for?

**#ActivityMonitoring** Carers can use "baby" monitors to monitor people with dementias' safety and well-being. When the device is connected to a smartphone app via the internet, this can be done from anywhere. If the device is a more traditional "baby" monitor, the carer has to be close by as the transmission range can be limited.

## 56 Robotic Soft Toy

### What does it do?



Robotic soft toys are cuddly toys with various levels of robotic sophistication. Some can only vibrate to simulate purring. Others can perform more complex movements such as blinking, moving the head and body, and wagging the tail. Some of these robotic soft toys can respond to touch and even memorise which reactions the user likes as a response to touch or verbal cues.

### What can it be used for?

**#Companionship** Robotic soft toys can be soothing or stimulating companions for people with dementia. They are an alternative to pets as they don't need looking after (apart from recharging or changing the batteries now and again).

## 57 Smart Intercoms

### What does it do?



Smart intercoms have a camera, microphone, and speaker, and are connected to the internet. Users can receive a notification via a smartphone app when someone rings the doorbell. The app enables them to see and speak to the visitor, and to open the door remotely. Some smart intercoms have a sensor which can detect when someone approaches or knocks on the door.

### What can it be used for?

**#VisitorNotification #Security** Smart intercoms notify carers when visitors (e.g., care service providers, family members or friends) come to see the person with dementia. Smart intercoms allow carers to refuse unwanted callers entry to people with dementias' residences. This can help carers to protect people with dementia from cold callers or fraudsters.

### Optional features



Some smart intercoms have a new facial recognition feature. This feature allows the intercom to "learn" faces known to the resident and to recognise the person when they come to visit.

### What does it do?



Recordable instructors are large push buttons or dictaphones. Carers can record messages with instructions to help guide people with dementia in completing an activity. Pushing the play button on the device plays one instruction after the other. The large push buttons can be customised with a picture or message to prompt people with dementia to push it. Devices should be placed strategically (e.g., buttons giving instructions on how to use the coffee machine should be placed close by). Dictaphones can be carried around.

### What can it be used for?

**#Instructor** Recordable instructors can help people with dementia to complete complicated activities.

### What does it do?



Talking microwaves can speak the microwave settings and can give or receive verbal cooking instructions.

[Emerging technology: this technology is not yet widely available]

### What can it be used for?

**#Instructor** Talking microwaves can make it easier for people with dementia to prepare food.

### What does it do?



The service provider uses a GPS enabled device (e.g., a smartphone) which transmits their current location and lets clients know in real-time when they can expect the service provider's arrival. This technology is used by many delivery services. Some care providers use this technology to plan care workers' routes and have an overview of where they are at a given time.

[Emerging technology: this technology is well established with delivery services and some care providers. Technically, carers could be given access to this information].

### What can it be used for?

**#CareServiceManagement** GPS arrival notification technology can let carers know in real-time when care service providers will arrive at the person with dementia's residence. This can help carers to arrange work and their own care around care workers.

## 61 Communication Boards and Apps

### What does it do?



Communication boards are custom touchscreen devices. Communication boards and apps display big (customisable) pictures symbolising activities, moods, or objects. Users can point to these pictures to communicate or press them to activate voice recordings.

### What can it be used for?

**#Communicate** Communication boards and apps can be used by people with dementia whose illness affects their ability to speak<sup>8</sup>. The picture symbols can make it easier for them to communicate their wants and needs.

## 62 Wearable Personal Alarms

### What does it do?



Wearable personal alarms are small devices with an SOS button. The device can be worn on a lanyard around the neck, or a wristband or belt clip. To notify the carer of their need for assistance, the wearer has to press the SOS button to activate the alarm. Some devices are waterproof and can be worn in the bath or shower. Some devices include a fall detector which automatically raises an alarm in case of a fall. Wearable personal alarms can roughly be grouped into devices for indoor and for outdoor use.

**Indoor wearable personal alarms** can raise a localised alert or are connected to a pager or home base. The home base can be connected to the landline or internet. Once the alarm has been activated, the home base automatically calls the designated emergency contacts sequentially until one of them responds to the call. The home base can also be connected to a call centre which manages the emergency response. The home base acts as a speaker in the person with dementia's home and can be used to communicate with the responder if the person who pressed the alarm is in earshot. Indoor alarms have a limited range.

**Outdoor wearable personal alarms** include a SIM card and GPS technology, giving the device unlimited range. Once the alarm has been activated, it automatically calls the designated emergency contacts with an automated message requesting help. This call is sequential until one of the contacts responds to the call. The device also transmits the wearer's location. Some devices can enable a two-way conversation, and some include a geofence function. This function automatically alerts carers when the wearer has left a predefined area.

### What can it be used for?

**#CallingForHelp** Wearable personal alarms can allow people with dementia to alert the carer about their need for assistance. This can be helpful, for example, if people with dementia have a fall or other accident or emergency.

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<sup>8</sup> It should be noted though that dementia can affect people's ability to communicate differently. This means that communication boards might not be useful for everyone whose speech is affected by their illness.

## 63 Simple Smartphone Interface Apps

### What does it do?



Simple smartphone interface apps transform the home screen of a smartphone into an intuitive and user-friendly interface.

### What can it be used for?

**#CallingForHelp #Companionship** Simple Smartphone Interface apps can make it easier for people with dementia to use a smartphone. The app can be used to arrange the home screen with only content relevant to the user. This can include one-touch picture buttons for most important contacts, a large clock, and an SOS button which automatically dials the user's emergency contacts sequentially until one of them responds to the call. The app can make it easier for people with dementia to make and receive calls and to call for assistance when on the move.

## 64 Call Services

### What does it do?



Call services can be either generic machine voices, human callers (e.g., call centre operators) or recorded messages from the carer.

### What can it be used for?

**#Reminder** Carers can order calls from call services to remind people with dementia about regular or one-off events or activities. This can include calls to remind people with dementia to take their pills or to attend a medical appointment. These kinds of calls may require a monthly subscription.

**#SelfCare #AccessingInformation** Carers can use call services (helplines) to access emotional support or counselling or receive information about available support or caring advice. These helplines can be provided, for example, by carer or dementia support organisations.

## 65 Picture Button Phones

### What does it do?



Picture button phones have large keys which can be programmed for one-touch dialling. This means that pushing one of these keys automatically dials the number programmed on it. Each key can be fitted with photographs of the person whose number is programmed on it.

Picture button phones can be cord or cordless landline phones or mobile phones. These phones usually have several other accessibility features such as adjustable volume, visual caller notification, hearing aid compatibility, integrated call blockers, etc. Some picture button phones have an integrated, specially marked SOS button. This can be programmed to sequentially call the designated emergency contacts until one of them responds. Some phones even have a connected personal alarm button which can be worn around the neck or wrist.

### What can it be used for?



**#Companionship #CallingForHelp** Picture button phones can make it easier for people with dementia to make and receive phone calls. This can help to combat social isolation and loneliness. These phones can also make it easier for people with dementia to make a call or press the SOS button if they require help or assistance.

## 66 Sound (and Light) Devices

### What does it do?



These devices have a library of soothing music or nature and animal sounds. Some devices can also project colour-changing lights onto the wall or ceiling.

### What can it be used for?

**#Stimulation** These devices can be stimulating or relaxing for people with dementia.

## 67 Call Blockers

### What does it do?



Call blockers can be stand-alone devices which can be attached to a phone, or they can be integrated into landline and mobile phones. Call blockers usually have a large database of rouge numbers which are automatically blocked and an option to add numbers to be blocked. Blocked numbers are not able to connect to a phone protected by a call blocker. Some call blockers only allow calls from people with a password.

### What can it be used for?

**#Security** Call blockers can automatically protect people with dementia from unwanted and predatory phone calls.

## 68 Portable or Wearable Reminders

### What does it do?



Wearable reminders are typically integrated into a wristwatch. Portable reminders resemble a voice recorder or dictaphone and can be carried in a pocket. Reminders can be pre-set. Some devices only vibrate or beep, others also display a short message or replay a recorded message.

### What can it be used for?

**#Reminder** Portable or wearable reminders can be a good solution for people with dementia who need prompting for certain activities (e.g., to remember to take their medication on time or to drink regularly).

### What does it do?



Talking photo albums are photo books with a built-in voice recorder. Each page of the talking photo album has the option to record a short message or story for the photo or picture on the page. The message can be played by pressing the small play button on each page.

### What can it be used for?

**#Instructor** Carers can place snaps of each step of an activity (e.g., how to use the coffee machine) in the talking photo album and record additional voice instructions. This can help people with dementia to complete an activity by themselves.

**#Entertainment #Stimulation** Carers can use the talking photo album to record stories from the life of the person with dementia fitting the picture on display. Looking at the photos and listening to the recorded stories can be entertaining and stimulating and help people with dementia to reminisce on their life.

**#Communication** Carers can put photos of family members and friends, places and activities in the photo album and record their names and meaning. This can help people with dementia to remember. People suffering from speech difficulties can also use it to train their speech and communicate.

### What does it do?



Visitors can use their smartphone to scan a QR code ("Quick Response" code) at the person with dementia's residence. The QR code can, for example, be a sticker on the front door. Scanning the QR code notes who enters the building at what time and creates an entry in the visitor log. Visitors can scan the QR code again when they leave the residence. Carers can access the visitor log via a smartphone app.

### What can it be used for?

**#VisitorNotification** Scanning these QR codes allows carers to be notified when and who (e.g., a family member or care provider) visits the person with dementia. This can provide reassurance that the arranged care is provided as planned and that somebody has been in to check on the person with dementia.

### What does it do?



Video and computer games can be played on a TV via a video game console or on a computer. There are countless games with varying degrees of difficulty and for numerous interests. Some video game consoles enable active gameplay where users have to move around to influence and control the game.

### What can it be used for?

**#Entertainment #Stimulation** Games can provide hours of stimulating entertainment for people with dementia.

## 72 Guide Apps

### What does it do?



Guide apps connect users to a call centre. The call centre operator can use the back camera of the user's smartphone to see what they are doing and what they need help with and give them instructions and guidance accordingly.

[Emerging technology: This service has been developed for people with visual impairments. It is currently not available for people with dementia.]

### What can it be used for?

**#Instructor #SocialParticipation** Guide apps can guide the user in real-time through an activity (e.g. getting somewhere or using appliances). This can help them to complete activities and to find their way when out and about.

## 73 Ambient Activity Monitor

### What does it do?



Ambient activity monitors can detect and interpret movement. Movement creates ripples and waves in the sea of background radio signals left for example by wireless internet and mobile phone networks. Ambient activity monitors can sense these ripples and waves and use special computer programmes to analyse the movement. The monitored person does not have to wear or carry any device and movement can even be detected through walls. There are no cameras involved.

[Emerging technology: This technology is in development and not yet available in the UK].

### What can it be used for?

**#ActivityMonitoring** Ambient activity monitors can allow carers to have an overview of the activities and daily routines of people with dementia. The device can detect falls and immobility. Special computer programmes can detect small changes in the routine of the monitored person which can help carers to react earlier to potentially hazardous incidents.

## 74 Proximity Alerts

### What does it do?



Proximity alerts are small devices that have a cord which is connected via a small magnet. The other end of the cord can be clipped to a person's clothing. As the person gets up from their bed or chair, the clip will disconnect from the main unit and sound the alarm.

Proximity alerts can raise localised alerts or send a notification to a connected pager. Devices also allow carers to record a brief message (e.g., to ask the person to wait for assistance) which can be played together with the alert.

### What can it be used for?

**#InjuryPrevention** Proximity alerts can alert carers when someone who needs help moving about gets out of bed or a chair. These devices can thus help to prevent falls.

## 75 Care Finder Apps

### What does it do?



Care finder apps enable users to search resumes of local registered professional care workers and to advertise jobs that care workers can apply for. Users can book interviews and even facilitate care workers' payments through the app.

### What can it be used for?

**#CareServiceManagement** Care finder apps can make it quicker and easier for carers to find qualified care workers, even at very short notice. Care workers can be hired for short and one-off jobs or ongoing, regular arrangements.

## 76 Full Bladder Detector

### What does it do?



A full bladder detector is a small device that can be worn on the skin underneath the belly button, kept in place by medical tape. The device uses ultrasound to detect how full the bladder is and sends an alert to a connected smartphone app when it's time to go to the bathroom.

[Emerging technology: This device is not yet available in the UK. A similar device that monitors bowel and intestinal movements to help detect a full bowel and manage bowel incontinence is currently in development.]

### What can it be used for?

**#ContinenenceManagement** a full bladder detector can prompt people who don't feel the need to or forget to go to the bathroom. This can eliminate the need for carers to make physical checks for urinary incontinence, preserving the dignity and independence of people with dementia. This can help carers to manage incontinence before it occurs.

## 77 Automatic Hip Protectors

### What does it do?



Automatic hip protectors are soft belts with an integrated fall sensor and airbags. When a fall is in progress, the airbags are instantly inflated to cover the hips. Some automatic hip protectors can initiate an emergency call to a carer when a fall has been detected.

[Emerging technology: this technology is in development on not yet widely available.]

### What can it be used for?

**#InjuryPrevention** Automatic hip protectors can protect the wearer's hips from serious injury when a fall occurs. Hip fractures regularly lead to hospitalisation and can massively impact an older person's quality of life and life expectancy.

## 78 IoT - The Internet of Things

### What does it do?



IoT (Internet of Things) hubs can connect several compatible sensors<sup>9</sup> and devices, combine and interpret the received information, and allow users to control connected devices from a distance. All of this is done via the internet. An IoT hub can be a care tablet, a smart screen or speaker or a custom-built device. Monitoring parameters can be set for each sensor. IoT computer programmes use machine learning to detect and interpret patterns of behaviour from the collected sensor data. When changes or undesired events occur (e.g., a fall or doors left open at night), the IoT can send an alert. Carers can access the activity profiles of the monitored person and receive alerts in real time via a smartphone app or online portal.

### What can it be used for?

**#ActivityMonitoring** IoT devices can allow carers to have a detailed understanding of the activities and daily routines of people with dementia. Sensors and devices can be added and connected as required which makes IoT systems very customisable. As these devices can detect small changes in the routine of the monitored person, carers can react earlier to potentially hazardous incidents.

## 79 Dementia Clock and Reminder Apps

### What does it do?



**Dementia clock apps** can display the time, date, day and/or time of day. Some apps can illustrate the day period with pictures (sun for daytime, moon for night-time).

**Reminder apps** can remind the user of one-off or regular activities and events. They can also include routines which can be illustrated with photos or pictures to guide the user through the steps of an activity (e.g., getting dressed).

### What can it be used for?

**#DementiaClock** Dementia clock and reminder apps can help people with dementia to remain orientated by letting them know what time of day it is and what activity should take place at any given time.

**#Reminder** Carers can programme reminder apps with regular or one-off reminders and prompts (e.g., to drink regularly) or daily routines. These reminders or prompts are then read aloud or text on the screen at the pre-set time. Some apps can be set to require people with dementia to acknowledge the reminder or routine when completed.

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<sup>9</sup> Connected sensors or devices can include multiple motion detectors, window/door alarms, smart power sockets and cameras.

### What does it do?



There are numerous apps which can be used for self-care purposes, i.e., to increase the well-being of the user. Some apps are targeted at carers while others are more suitable for people with dementia. Some apps only have one purpose or function while others are multifunctional.

### What can it be used for?

**#Psychoeducation #SelfCare** There are several self-care apps which can benefit carers. **Relaxation apps** can include relaxing sounds and music and guide users through relaxation exercises. **Mental training apps** can provide programmes to strengthen carers' resilience. **Exercise apps** can guide carers through physical exercises to strengthen their body and prevent care-related injuries (e.g., back injuries from lifting). **Mental health self-test apps** can help carers to figure out the state of their mental health. This can help them to seek professional help for exhaustion and mental health issues earlier.

**#Entertainment #Stimulation** There are several dementia-friendly **game apps** which can be played on tablet PCs. **Reading assistant apps** have been developed specifically for people with dementia and provide various accessibility tools (e.g., magnifier, audiobook function). **Relaxation apps** collect nature sounds and soothing music. **Reminiscence apps** can be populated with favourite music, photos, and videos from people with dementias' past, along with captions or recordings describing the content. Some of these apps also offer content libraries which include images and music from certain eras, and which can help people with dementia to remember their childhood or youth.

### What does it do?



Wearable activity monitors are bracelets with several highly sensitive built-in motion sensors. These sensors can detect and interpret subtle movements and activities (e.g., eating and drinking). Additional sensors in the home detect where the wearer is which helps the device interpret the movements. Devices also include a SIM card and GPS. This means that devices can be worn outside the home.

Carers can access data transmitted by the device via a smartphone app or online portal. Parameters can be set to raise alerts, for example, if certain activities don't take place at a predefined time or potentially hazardous activities are detected.

[Emerging technology: wearable activity monitors are a new technology and not yet available in the UK]

### What can it be used for?

**#ActivityMonitoring** Wearable activity monitors can register and interpret a wide range of activities, including subtle ones. This can help carers to have an overview of the movements and activities of the person with dementia. Anything out of the ordinary can thus be detected and potential harm avoided. Wearable activity monitors are particularly useful in homes where more than one person lives which can make it impossible for ambient activity monitors to interpret the data correctly.

**#PersonLocator #HomeLeavingNotification** Wearable activity monitors include a SIM card and GPS as well as geofencing software. This means that the device can be worn outside the home. Carers can receive a notification if people with dementia leave a pre-defined area and can access their location via the smartphone app or online portal.

### What does it do?



Smart camera TV attachments can be connected to the TV to enable it to make and receive video calls. Some devices have an auto-zoom and auto-follow function which ensures that the caller is always in focus. Callers can video call the device with most mainstream video call software from any video call enabled device.

### What can it be used for?

**#Companionship** Smart camera TV attachments can be used by people with dementia to make and receive video calls on their TV. This can help to combat social isolation and loneliness.

### What does it do?



Smartwatches are wristwatches which can be linked via Bluetooth technology to a smartphone (which has to be close by). Through its connection with the phone and apps which can be installed on the smartwatch, the watch can have a variety of highly customisable functions and features. Some smartwatches are stand-alone. This means that they require a SIM card and can be used without having to connect it to a phone. These smartwatches enable two-way communication directly via the device without having to use the connected phone.

### What can it be used for?

**#CallingForHelp** By pressing a button on the watch, the person with dementia can use the smartwatch to call for help. The watch then calls the designated emergency contacts (via the connected phone) consecutively until one of these contacts answers the call. Some watches enable the user to have a conversation directly via the watch. Where this is not possible, the user has to use their phone. Some smartwatches include a fall detector. When the device registers a fall, it activates the emergency call

**#PersonLocator** Carers can request the current location of the wearer by calling the smartwatch or by accessing its location data via a smartphone app or an online platform. This requires them to have access permission. This can help carers to locate the person with dementia in case they get lost when out and about.

**#Reminder** Carers can programme regular or one-off reminders and prompts (e.g., to drink regularly) which are read out by the smartwatch or text on the screen. Some devices can be set to require the person with dementia to acknowledge the reminder.