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Improving outcomes for people with long-term care needs through the use of innovative care models and technologies

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## Executive summary

### Introduction

In the face of population aging and the increased prevalence of multi-morbidity, as well as chronic and degenerative conditions such as dementia, the demand for long-term care (LTC) services to support activities of daily living over a prolonged period of time is on the rise. Challenges arising from the combination this increasing demand and constrained resources have prompted strong interest by policymakers in new ways to improve the productivity of care. The objective of this report is to synthesize policy developments across Europe, drawing on international evidence about the impact on costs and outcomes of innovative care interventions through a rapid review of literature. Given our special interest in evidence-based measures, we focus on two areas in particular:

**Personalization approaches** (e.g. personal budgets, direct cash payments and vouchers); and

**Information and communication technology (ICT)** (e.g. assistive technologies, ambient assisted living, telecare etc.).

In addition to reporting on established findings, we also highlight a number of recent developments in LTC across Europe identified as promising by policy experts participating in the present research project.

### Main findings

Extant scholarship on innovations in LTC identified through the study's rapid review point to mixed and limited results, particularly where questions of (cost-) effectiveness are concerned. Research tends to be marred by methodological shortcomings often involving an absence of experimental design that renders conclusions tentative, at best. Most studies refer to quantitative assessments of different outcomes and dissimilar target groups, complicating the comparability of findings and failing to provide in-depth insights. Research also tends to be geographically biased to the cases of the United States and England, making generalizability

problematic. Of the evidence to be had, the strongest findings related to personalization point to an increased level of satisfaction with care by users due to a better matching of care characteristics and individual preferences. Evidence on clinical outcomes, including psycho-social wellbeing, suffers from an absence of randomized control trials. Concerning the reduction of costs associated with personalization in the form of cash-for-care schemes, evidence is also mixed. Whereas personalization tends to lead to the greater take-up of benefits or services, it is not clear to what extent these benefits are being provided for care that would have been bought or provided in the absence of financial incentives. Moreover, incentivizing the role of informal carers – often women – through the use of cash benefits raises questions about the societal costs associated with reduced female labour market participation, the burden of psycho-social and economic costs of family caregiving, and also the quality of care received by users. Thus far, research on personalization fails to capture this larger picture of cost-effectiveness.

Similarly, extant scholarship on the cost-effectiveness of ITC at the service of LTC tends to be short-sighted and methodologically problematic. Most studies are geographically limited to the United States, are highly heterogeneous due to the diverse nature of ITC, and also refer to different target groups, making comparability problematic. Bearing this in mind, many studies do provide encouraging evidence that the use of ICT in LTC has led to improved quality of life, as well as a slowing in the progression of some disabilities, especially cognitive and emotional decline. The economic impact of ICT is difficult to gauge: any benefit introduced must be weighed against the costs of developing and implementing new technologies.

Recent developments across Europe reported by participating policy experts mainly involved increasing investment in ICT, which is indicative of the strong emphasis placed on this particular area

of innovation. However, the experts also pointed to new applications of long-standing policy tools such as cash payments, as seen in England, as well as a growing role for novel models of care involving integrated approaches to care management and monitoring.

### Conclusions

Extant evidence on the (cost-)effectiveness of personalization schemes and ICT brings to light the crucial need for better data that allows us to draw robust, generalizable and comparative conclusions. This necessitates inter-disciplinary cooperation with researchers capable of carrying out experimental research designs that are rooted in shared understandings of outcomes and researchers who can then translate that evidence into the basis for feasible policies. We may also wish to revise our interest in cost-effectiveness (difficult to define and measure) as an outcome. Instead new domains of outcomes could be preferred and a new

prioritization of policy objectives devised that could take a societal view to evaluating the success of a measure. Regardless of what approach is taken, we need to accept the reality of mixed findings while still making informed policy choices. This necessitates trade-offs and imperfect solutions. Of the various imperfect solutions in existence today, personalization schemes tend to respond to care recipients' need for greater autonomy and choice of services in the face of declining physical or mental autonomy. However, personalization generally implies a greater reliance on informal carers, which the future does not seem to allow. This places the onus on policymakers to fill this gap with other solutions, which are likely to involve ICT as the next best imperfect policy solution. The question then is, to what extent should investment in technological innovations take the place of greater financing for professional personnel – a question beyond the scope of the present study, but which is crucial for moving forward.

## Introduction

In the face of population aging and the increased prevalence of chronic and degenerative conditions such as dementia, as well as the complexity of comorbidity typically accompanying longer years of life (Rechel et al., 2013), the demand for long-term care (LTC) services to support activities of daily living over a prolonged period of time has been on the rise and is expected to continue to increase. While future trends in disability are difficult to gauge, demographic changes coupled with a decrease in the number of informal caregivers (due among other things to greater participation in the formal workforce by women and shrinking family sizes) will necessitate a growing reliance on the formal care sector (OECD 2011). Within the European Union (EU), where mortality has dropped dramatically since the 1970s (Preston et al., 1989), the proportion of those aged 65+ amounts to one-fifth of the population (19%) and is still growing (EUROSTAT 2017). The challenges arising from the combination of increasing demand for LTC and constrained resources have prompted strong interest by policymakers in ways to improve the productivity of care. One approach to increasing productivity is to develop and implement innovative care models that often rely on technological support for aging in place.

The objective of this report is to identify and synthesize developments across Europe, drawing on evidence about the impact on costs and outcomes of new care interventions. Given our interest particularly in evidence-based measures, we focus on two areas of innovation which have thus far been the subject of the greatest amount of research:

**Personalisation approaches** in LTC such as the use of personal budgets, direct cash payments and vouchers; and

**Information and communication technology (ICT)** based developments including, for example, assistive technologies, ambient assisted living, telecare and tele-rehabilitation.

In addition to reporting on established findings under these areas of innovation, in what follows we also highlight a number of recent developments in LTC across Europe which may not yet appear in academic literature, but which have been identified as promising by policy experts participating in the present study.<sup>1</sup> These developments mainly involve an increasing investment in ICT, which is indicative of the strong emphasis placed on this particular area of innovation. However, also to be found are new applications of longstanding policy tools such as cash payments, as seen in England, as well as a growing role for novel models of care that involve integrated approaches to care management and monitoring. In our report, we describe two examples underway in Germany and Italy.

## Background

In attempting to identify the role played by innovation in improving productivity, quality of care, cost-effectiveness or any other outcome measure of interest, the meaning of the term 'innovation' must first be addressed. Elsewhere, social innovation has been defined as the 'development and implementation of new ideas (products, services and models) to meet social needs and create new social relationships or collaborations' (European Commission, 2013). Social innovations are said to constitute new ways to empower individuals and to address societal challenges. This said, it is important to note that a product or service that might be regarded as new within one context may be considered established or even outdated within another. Hence, the term innovation is highly relative

<sup>1</sup> The present study is part of a larger research project entitled, 'European network on long-term care quality and cost-effectiveness and dependency prevention', financed by the EU under grant agreement No. VS/2015/0276. For an overview of the project, including participating partners, see [www.cequa.org/overview](http://www.cequa.org/overview).

Note that the discussions of recent developments across Europe (particularly in section "Promising developments across Europe" on p.10) draw on country reports which can be found on the project website under publications (see: [www.cequa.org/copy-of-all-publications](http://www.cequa.org/copy-of-all-publications)).

and cannot be defined in any singular way. For the purposes of this report, we draw on trends that, over the course of the past two decades, have emerged to reflect major shifts in the organization and delivery of LTC services. This translates to the focus mentioned above on the use of personalization strategies and a growing reliance on ICT. Generally speaking, the underlying aim of these developments has been to increase the cost-effectiveness of care by enabling better outcomes while working within a fixed budget. But how?

Personalization, known in many countries as person-centred care, is premised on the notion that if users (and/or their family members) receive services tailored to their actual needs and preferences, they will achieve better outcomes than in traditional, standardised services which do not consider and incorporate the perspectives of users (McMillan et al., 2013; Rijken et al., 2017). Personalization allows service users to pursue maximization of those outcomes which they personally value and to choose the types of care which they believe can best promote those outcomes and personal satisfaction. Care is therefore centred on the needs and preferences of the user and is argued to be more cost-effective through optimization of available resources and increased benefits for both patients and care organisations (Reid et al., 2009; Poitras et al., 2018). Strategies to realize personalization or person-centred care include a reorganization of care pathways and availability of more service options, as well as needs-related cash measures such as cash-for-care programs, care vouchers, and personalized budgets, which all aim to enable a greater autonomy of choice by users.

ICT developments in LTC and the treatment of chronic conditions benefit from a broader trend of progressive technological adoption and digitalization in public and private health services (Deloitte, 2015). Digital health services include a wide range of technologies and solutions that enable improved access to health data and information, enhanced ways of communication and interaction between

patients and care providers, supportive technological and digital aids for daily living, and continuous monitoring and analysis of health status for proactive interventions (Barbabella et al., 2017; Ejehiohen Iyawa et al., 2016; Stroetmann et al., 2010). Overall, these improvements (individually and combined) are said to have a direct positive impact on the quality of care, empowerment of patients (and their families), and efficiency of the care process (Sanyal et al., 2018; Barbabella et al., 2017). Often, they are expressly intended to support aging in place, support the continuation of individual lifestyles as long as possible, and enhance the care services received.

In addition to the increasing personalization of care and investment in ICT, it bears noting once again that innovations in care models are also emerging. These aim at providing alternatives to the standard processes or services offered within the traditional care-setting dichotomy of the home versus the institution. Such models may involve the production of domains of outcomes valued by service users and their carers but not particularly promoted by existing services. Innovative forms of daycare, for example, may be more effective than traditional forms of care in producing outcomes such as social participation, learning new life skills or reducing loneliness. At the same time, by moving care away from the individual's home to a group environment – at least for some part of the day – providers may also reduce substantial travel and coordination costs involved in having care follow the recipient.

## Methods

In what follows, we aim to go beyond the more speculative assumptions of (cost-) effectiveness, drawing on evidence of outcomes related to two specific areas of innovation as reported in extant scientific literature. More specifically, the present study identifies and synthesizes evidence concerning the impact of personalization measures and ICT. We do this in two steps. First, we summarize the findings of rapid reviews of literature that were carried out using a series of search terms pertaining to the two topics and in combination with

“long term care” (alternatively referred to as “social care” and “elder care” in searches) and “outcomes/effectiveness/cost-effectiveness”: for personalization, this included the terms “personalisation”, “personal budgets”, “cash for care”, “cash benefits”; for ICT, the terms “ICT”, “innovative technology”, “telemedicine”, “care robots” were used in combination with LTC.<sup>2</sup> Narrative reviews, systematic reviews and meta-analyses (in English) were searched for in the Cochrane Library of Systematic Reviews, Google Scholar, PubMed and other relevant websites. Academic and research reviews were included. The searches were conducted primarily in English, with participating researchers carrying out additional rapid reviews using a second European language to capture scientific and grey literature (e.g. policy reports, briefing papers, online information) otherwise not available in English. These secondary searches were carried out in French, German, Italian, Polish and Portuguese. However, as these subsequent searches did not yield much in the way

of new findings, especially as concerns studies on outcomes, the results reported on below mainly refer to English language literature. The searches were not restricted by age group or country and included documents published between 2006 and 2016. Results from the rapid reviews are summarized in section IV below.

In an effort to identify recent trends across Europe that may be un-reported or under-reported in the academic literature or which emerged only after the rapid reviews’ period of observation had been concluded, a series of workshops/meetings were held with participating experts from our network (both policymakers and academics)<sup>3</sup> to identify additional innovations in LTC. These country-specific innovations are showcased in section V. As in many cases developments are still underway and have not yet been evaluated for impact or effectiveness, we limit ourselves mainly to the description of innovations. These may subsequently serve as a point of reference for future research.

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<sup>2</sup> For a full listing of search terms used in the rapid reviews, please contact the project partners. Contact details available at [www.cequa.org/overview](http://www.cequa.org/overview).

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<sup>3</sup> For an overview of the project, including participating partners, see [www.cequa.org/overview](http://www.cequa.org/overview).

## Outcomes related to innovations in LTC – evidence from rapid reviews

### The effectiveness of personalization

While personalization has been a driving force in many of the reforms introduced in LTC systems in Europe, the evidence based on its benefits and especially cost-effectiveness is contradictory and marred by methodological limitations. Most existing studies have been conducted in the United States and England and there is a dearth of evaluations using experimental design or based on randomized control trials (Arksey and Kemp, 2008; Low et al., 2011). A recent systematic review of literature (Low et al., 2011), for example, found only three randomized control trials assessing outcomes of personalization (Meng et al., 2005; Carlson et al., 2007; Glendinning et al., 2008). Some of the studies carried out comprise schemes or initiatives that also included disabled people of working age.

Most of the studies refer only to quantitative assessments of different outcomes of initiatives or schemes. Regarding outcomes, arguably the least disputed finding is that personalization is associated with higher satisfaction with care (Benjamin et al., 2000; Mahoney et al., 2006; Wiener et al., 2007). Among the possible explanations for this is the better matching of the characteristics of caregiving to the preferences of users that personalization entails (i.e. better allocative efficiency). This is made possible through the possibility of purchasing different types of care, choosing specific people to provide the care, defining tasks or asking carers to carry out tasks that formal services providers would otherwise refuse to do (Benjamin et al., 2000; Foster et al., 2003; Breda et al., 2006; Carlson et al., 2007).

For clinical or health outcomes, such as improved ADLs or IADLs or quality of life, the evidence that personalization leads to improvements vis-à-vis conventional care allocated by social workers is much more mixed (Low et al., 2011). Regarding psychological wellbeing, research findings are also somewhat mixed. Quite a few studies report a higher sense of control and independence and feelings of confidence associated with the use of

cash-for-care or similar consumer-directed schemes (Arksey and Kemp, 2008). These benefits, however, seem to be highly dependent on the target group of personalization. The evaluation of the individual budget pilot scheme (forerunner to the personal budgets currently in place in England) found that frail older people reported lower psychological wellbeing than other groups of people with disability (Glendinning et al., 2008; Netten et al., 2012). One important aspect to consider is that, at least in the English case, the value of the personal budgets provided to older people is often low, which could limit the scope for achieving improved outcomes (Jones et al., 2012).

One argument commonly made for the cost-effectiveness of personalization is that it could reduce the use of more expensive types of care, particularly institutional care. In Germany and the Netherlands, for instance, where reliance on cash benefits is high, the cash alternative to in-kind benefits provides lower amounts for the same level of assessed needs (about 50% lower in Germany and 25% lower in the case of the Dutch personal budget). Despite this, the cost-effectiveness of personalization has not yet been established. One of the possible reasons is that personalization has often entailed higher use of services (Dale and Brown, 2007; Low et al., 2011), or increased take-up of benefits by people previously unable to access care services (White, 2011). In Germany, where cash benefits represent tax-free household transfers that may be used entirely at the beneficiaries' discretion, the take up of cash benefits is especially prominent, making up nearly 60% of all benefits (as of 2015, 45.7% receive cash-only benefits and an additional 14% receive a combination of cash and in-kind services) (Rothgang et al., 2016). As cash benefits are not strictly tied to care in Germany, the quality and/or effectiveness of services provided by informal carers incentivized by this scheme is not monitored, further contributing to the lack of data on outcomes related to personalization. The shortage of evidence available (beyond the situation in

Germany) can also be partially attributed to the methodological shortcomings of most of the evaluations carried out, which include failure to account for all costs of establishing and running the schemes or to account for the full societal costs (e.g. informal care provision leading to lower female labour force participation) (Gadsby, 2013).

Two often-voiced concerns regarding personalization in LTC are the risk of financial abuse, particularly in schemes that allow for the payment of relatives, or adverse care outcomes as a result of poor choices by users. Regarding the former, the risk of greater neglect or financial abuse seems to be relatively low (Foster et al., 2003), although more recent research in England partially contradicts this (Ismail et al., 2017). One may also speculate as to the role played by under-reporting or non-reporting of abuses among the elderly, particularly where family caregiving is involved. As for increased harm or worsening of health outcomes that could directly be attributed to poor choices, there is no consistent sign of this (Gadsby, 2013).

Finally, is a dearth of research on the possible equity impact of personalization. This is despite the concerns which have been raised about the possibility of increasing inequalities with the introduction of user choice in LTC (Gadsby, 2013). Although not directly affecting the issue of equity, there also seems to be some variation in the take-up of personalization, namely the cash option in some systems, by older people. While cash substitutes for in-kind benefits that allow for greater choice have proved very popular among older people in the Netherlands and Germany (Eichler and Pfau-Effinger, 2009; White, 2011), the same is not true for England, where take-up of the cash option among older people has lagged behind other user groups (ADASS, 2011). A crucial aspect in explaining these differences is the leeway that users are afforded to make choices (e.g. regarding payment of relatives) and the procedures required to take-up or manage cash benefits, as well as the relative generosity of benefits involved.

Further research should broaden the geographical

scope of existing evidence and assess cost-effectiveness in relation to the specific national LTC (or health and social care) system. Furthermore, equity considerations or distributional effects should be included in future evaluations to better ascertain the societal benefits of personalization. The current findings suggest that personalization has the potential to be well regarded by users, as well as to positively impact the outcomes of at least some dimensions of quality of life of users.

### Innovative technologies

The way innovation is adopted to improve the lives of LTC users is a major challenge for societies. In general terms the literature agrees on the need to promote the development of e-health in the context of public health intervention for independent aging (Reeder et al., 2013; Thomas et al., 2014). However, searching for general conclusions common to all works is not an easy task, due to the difficulty of defining the concept of innovative care in a homogeneous way, and the diversity of technologies that appear in this context (Siegel and Dorner, 2017). These include, among others, not only mHealth (mobile health) technologies, health smart homes and home-based consumer health technologies, but also information and communication technologies for communication in health care, internet-based interventions for diagnosis and treatments, and social care when patients are receiving health care for chronic conditions (Demiris and Hensel, 2008; Ekeland et al., 2010; Edirippulige et al., 2013; Kruse et al., 2017).

Different studies indicate that the use of innovative technologies remains a novel topic with insufficient validation of results and a preponderance of studies from the US. Research based on experimental and control groups can still be considered incipient, and more progress is required in the design of larger studies. Few robust randomized controlled trials assessing the effectiveness of telemedicine in long-term care facilities have hitherto been developed (Barlow et al., 2007; Edirippulige et al., 2013; Liu et al., 2016).

Some of the existing works refer mainly to the quantitative evaluation of different types of programs. For example, Hirani et al. (2014) find significant differences between telecare and usual care on mental component scores; De Luca et al. (2016) demonstrate the effectiveness of a novel telehealthcare model that appeared to lead to a statistically significant reduction in a geriatric depression scale; Alonso-Moran et al. (2015) find that multi-morbidity is more common in the elderly population and negatively affects health-related quality of life; Siegel and Dorner (2017) find that different e-health programs studied increase vitality, mental health and health perception for the individual; and Realdon et al. (2016) reported the efficacy of a technology-enhanced homecare service to preserve cognitive and motor levels of functioning.

However, other documents focus more on qualitative analyses related to characteristics of different types of interventions, and qualitative evaluations of the programs according to different aspects such as economics, feasibility, stakeholder satisfaction, reliability and service implementation. For example, Edirippulige et al. (2013) evaluate different clinical services provided by telemedicine; WHO (2016) describes the consequences of this emerging development in the European region in 2016; and Reeder et al. (2013) analyse the positive effect of a multicomponent technology approach which includes activity sensing, reminders and other technologies tailored to individual preferences.

Perhaps one of the most important limitations of the work carried out is the different typology of people included in the analyses (Edirippulige et al., 2013), and the difficulty to generalize conclusions given the heterogeneous characteristics of the respondents. In some studies, the intervention was generally categorized as monitoring, and mainly consists of a combination of measurement of vital sign(s) and personal contacts with people living at home (Van den Berg et al., 2012). In others, responses are mainly offered by caregivers (for example, Jackson et al. (2016) assess the effectiveness of

interventions delivered by telephone, internet or combined formats to support careers of community-dwelling people living with Alzheimer's disease, vascular dementia or mixed dementia). Studies that collect simultaneous opinion from all the agents involved (disabled persons, caregivers, institutions etc.) are lacking.

Sometimes analysis innovative care implies mixing assessments of health and healthcare with aspects of long-term care. Research is usually focused on older people (Barlow et al., 2007; Demiris and Hensel, 2008; Van den Berg et al., 2012; Reeder et al., 2013; Liu et al., 2016; Khosravi and Ghapanchi, 2016; De Luca et al., 2016; Realdon et al., 2016; Kruse et al., 2017). However, in a much more limited way, some analyses include the younger adult population (Rojas and Gagnon, 2008; Thomas et al., 2014; Siegel and Dorner, 2017). Although more research focuses on the effect that e-health has on specific disabilities, such as those associated with dementia, finding studies clearly focused on the measurement of the effect that these types of technology have in other chronic diseases, such as diabetes or heart problems, allows us to broaden the age spectrum by incorporating some early-age research (Barlow et al., 2007).

In their conclusions, most studies show how this type of action improves people's quality of life. It appears to have a significant influence on the life habits of patients (for example, they learn to control relevant values such as blood pressure by themselves, or to follow up diets) but it is more difficult to assess its preventive effects (Liu et al., 2016). Some studies reveal its relevance by measuring the effects of multi-morbidity (Alonso-Moran et al., 2015).

Measurement of the effects in terms of efficiency and cost-efficiency is basically carried out through three approaches: (i) measuring the impact in terms of the reduction of disabilities; (ii) measuring the impact in terms of the reduction of hospital needs and care (number of medical visits, stays, etc.); (iii) measuring the economic impact.

Some studies have shown efficiency in terms of reducing disability and diseases. For example, Siegel and Dorner (2017) present results for different programs in terms of increased vitality and mental health, increase in health perception, in physical health, in the capacity to perform basic and the instrumental life activities, as well as a decrease in the level of depression.

The impact that these new technologies have had on hospital activity, medical visits and care needs is collected in several studies, which present figures about the derived effects. For example, Liu et al. (2016) indicate that cost savings were achieved with regards to monitoring daily living activities (ADLs) and that benefits to caregivers were observed. WHO (2016) shows percentages of reduction in elective hospital admissions, reduction in bed days, reduction in accident and emergence visits and in mortality.

Finally, some evidence exists related to the effects in terms of cost savings (Van den Berg, 2012; Ekeland et al., 2010). However, as Reeder et al. (2013) remark, although a reduction in costs is expected over time, it is still not possible to speak about economic benefits because of the costs of implementing new technologies and the small scale at which the technology operates).

Future research should focus on how to adapt systems and resources to the individual needs of elderly patients within the specific frameworks of the respective national healthcare systems (by means of controlled interventions, focus on patients' and caregivers' perspectives, economic analyses of e-health innovations, formative assessments and collaborative achievements). The key outcomes provide evidence of an increasing appetite for e-health and indicate tangible progress in the mainstreaming of technology solutions across different countries.

## Promising developments across Europe

### Moving cash payments into the residential care setting in England

Local authorities in England have offered cash payments, known as 'direct payments', as an alternative to a package of care services since the 1990s. These payments have been available for community-based care but not for residential care (other than for short stays). In 2013, the UK government set out to test how direct payments would work for people in residential care in 18 local authority 'trailblazers'. More specifically, it commissioned an independent evaluation to understand how direct payments were being offered and used in residential care, whether they were making a difference to residents and their families, and how well they were working for councils and care homes (Ettelt et al., 2017).

The take-up of direct payments in residential care was much lower than expected, with only 40 in use at the end of the trailblazer programme (Ettelt et al 2018). The small number of residents with direct payments were generally satisfied with them and welcomed the opportunity to access additional or different services, and some family members said that they felt empowered by the sense of control direct payments gave them over their relative's care and support. Those declining the offer of a direct payment were mostly happy with their current care or did not want the burden of managing finances.

The findings also indicated that there remained substantial barriers to implementing direct payments, including concerns of providers about loss of income, a lack of clarity about the demand for direct payments among residents of care homes, and a lack of clarity about how the demand for choice of service provider intended to be facilitated by a direct payment could be met by the current supply of services available to publicly-funded care home residents (Ettelt et al 2017).

### Moving gerontechnologies centre-stage in France

**Telealarm** and **teleassistance** services were first introduced in France in the 1970s and developed progressively over the next two decades, first to address the needs of disabled people and subsequently broadened to support the needs of the elderly (Gucher et al., 2014). Even so, policies and initiatives incentivizing the use of teleassistance and other forms of ICT in LTC were very haphazard and uneven in their availability across France. This led to the issuing of a public statement by the French Centre for Strategic Analysis (CAS) in 2009 acknowledging that, compared to other European countries, such as the UK, Germany or Denmark, there was a significant delay in France in the development of **gerontechnologies** (CAS 2009). As analysed in a number of reports<sup>4</sup>, this delay has been attributed to various reasons: the weakness and lack of uniformity of this industrial sector, which is composed of a disparate mix of subsectors (mechanics, electronics, building and safety technology, pharmaceuticals, etc.) to the cost<sup>5</sup> of gerontechnologies for users given the low level of public subsidies; as well as to concerns related to the lack of evidence of their efficiency (CAS, 2009; see also Gucher et al., 2014).

The end of the 2000s, however, marked a critical turning point in the spread of gerontechnologies across France. In 2007, three different reports emphasising the potential of new technologies to improve both the professional practices of caregivers and the quality of life of care recipients –

<sup>4</sup> Riaillé, 2007; Picard, 2008; Boulmier, 2010; CAS, 2009; ALCIMED, 2007; Franco 2010, cited in Pennec 2012, p. 120.

<sup>5</sup> Users' fees for teleassistance and telealarm services goe from €15 to €50 per month, according to their earnings. Local authorities largely contribute to financing as 45% of the municipalities between 5,000 and 200,000 inhabitants offer such services, with 530,000 elderly people in 2013 using them (Ennuyer, 2014).

by Rialle<sup>6</sup>, ALCIMED<sup>7</sup> and Picard and Souzy<sup>8</sup> – helped move the use of new technologies in LTC centre-stage on the public agenda. In the same year, the French society of technologies for autonomy and gerontotechnologies (SFTAG)<sup>9</sup> was created, followed two years later by the national centre of reference, health at home and autonomy (CNR Santé), which became ‘France Silver Eco’ in December 2014. Its aim is to facilitate the development and the use of ICT in healthcare and for dependent people living at home. Two further public reports supporting the use of ICT in care – one by the minister of health and sports, Roselyne Bachelot (Lasbordes, 2009) and an international study for the Caisse des dépôts (2009) – were also released.

The year 2010 represents another policy milestone, as it saw the creation of the Association of innovative solutions for autonomy and gerontotechnologies (ASIPAG)<sup>10</sup> by a number of industrial entrepreneurs<sup>11</sup> and the launch of the mission ‘live in your own home’ by the secretary of state for elderly people, Nora Berra. Both initiatives explicitly target elderly people in need of care and put the emphasis on information technologies and services. Building on this development, another public report from 2013 recommended the professionalization of the sector and a simpler financing scheme for users’ fees (IGAS, 2014). Finally, the Broussy report – which prefigured the Act on Adapting Society to an Ageing Population from December 2015 – emphasised the necessity of developing a specific industrial sector for

technologies and services in the autonomy field (Broussy, 2013). In the same year, a report released by the General Commissariat for Planning and Forecasts<sup>12</sup> defined the scope of such an economic and industrial sector and acknowledged that its development would strongly rely on those elderly people with the highest purchasing power (CGSP, 2013). A month after the publication of the Broussy report, a new industrial field called the ‘silver economy’ was launched, represented by the then deputy minister for elderly people.<sup>13</sup> It established a ‘silver economy contract’ to orient the actions taken in the sector in the years to come. In September 2015, its national committee created five thematic groups to formulate proposals for the removal of obstacles to the participation of private actors to the development of the industrial branch.<sup>14</sup>

Running as a common thread through all these reports is the claim that ICT has the potential both to alleviate the workload of care professionals and to respond to the needs and preferences of the elderly and their families, particularly the wish to stay in their homes for as long as possible. But, above all, they underline the financial opportunity that lies in the ageing of the population as a promising source of economic growth. The Broussy report also acknowledged that the development of new technologies cannot be left to the private sector alone and recommended guiding the industry by creating a dedicated national agency (Broussy, 2013, pp. 24, 115, 122, 132).<sup>15</sup> It highlighted the need to develop appropriate public education of the elderly on the uses of such care technologies,<sup>16</sup> as

<sup>6</sup> Submitted to the minister of health and of solidarities (Philippe Bas) and prepared in his formal request.

<sup>7</sup> A prospective study, carried out by the company ALCIMED, on health technologies and autonomy and commissioned by the national research agency and the CNSA.

<sup>8</sup> General council for information technologies.

<sup>9</sup> Société française des technologies pour l'autonomie et gérontotechnologies.

<sup>10</sup> Association Solutions Innovantes pour l'autonomie et gérontotechnologies.

<sup>11</sup> In 2011, the ASIPAG produces a label related to the use of technologies for the economy.

<sup>12</sup> Commissariat général à la stratégie et à la prospective, CGSP.

<sup>13</sup> It is piloted at the national level by a strategic committee composed of 40 professional federations and public actors – particularly the regions – in charge of developing this branch on their territories.

<sup>14</sup> The committee acknowledged that half of the measures formulated in the contract from 2013 had been implemented, but mostly by public actors, [www.entreprises.gouv.fr/politique-et-enjeux/la-silver-economy](http://www.entreprises.gouv.fr/politique-et-enjeux/la-silver-economy), last accessed on 10 May 2017.

<sup>15</sup> This proposal was not included in the Act on adapting society to an ageing population from December 2015.

<sup>16</sup> See also Collos (2013); Brugiére (2011); Caradec (2001).

well as the need to develop national guidelines to accompany the development of this sector (*ibid*, p. 136).

The aforementioned Act on Adapting Society to an Ageing Population from December 2015 encompasses a number of guidelines and recommendations for the silver economy. In it, France's commitment to becoming a world leader in this industrial sector is affirmed. The Act also provides a broad definition of the silver economy to include the most sophisticated building and safe technologies (domotique) and robotics, the simplest technical aids and teleassistance services, as well as the housing, mobility or 'senior' tourism sectors. Among the various policy aims of the Act, the main strategy is that of making ICT and other gerontechnologies financially more accessible to users, especially those with low incomes. It targets, for example, the creation of means-tested public aid for the financing of a number of interventions aimed at preventing the loss of autonomy – such as technical aids, teleassistance services, housing accommodation, and building and safe technologies – to elderly people with the lowest incomes. The Act also places special emphasis on the issue of personal housing for the elderly, by increasing the number of people eligible for financial benefits for home adaptations – including gerontechnologies – from the Elderly Insurance Fund (CNAV). The law also created a system of 'microcredits'<sup>17</sup> for the adaptation of homes of those elderly people not eligible for regular bank loans, as well as expanding the list of home adaptations qualifying for tax credits.<sup>18</sup>

France's public embrace of ICT and gerontechnologies has attracted considerable criticism, especially since the passing of the 2015 law. Among the most substantial is that regarding the economic reality of this development: as in the case of a number of other measures created by the 2015 Act, despite great interest in incentivizing more

ICT use in health and LTC, public investment remains very low. For growth to occur, there is still a need for public funding, as many elderly people are not able to purchase costly devices to support aging in place. Meanwhile concerns arise as to the potential effects gerontechnologies may produce on the elderly people in contact with them, as well as regarding a number of ethical issues.

New technologies for elderly patients may be seen as a game changer for some advocates, as they should help elderly to stay at home safely and allow them to participate fully in life. However, where elderly people may not adapt or even accept the presence of a new technology, then the use of is likely to be problematic (Barnard et al., 2013). Research points to evidence of low acceptance levels among the elderly concerning new technologies and the stigmatisation effect they produce, thus accentuating their feeling of isolation and strangeness within their immediate environment (Raulet-Croset et al., 2010; Collos, 2013; Brugiére, 2011; Caradec, 2001). Other studies acknowledge that the use of such devices – such as telealarms – shows a deeper need for social inclusion and social contact rather than emergency care for which their introduction was initially intended (Roulet-Croset et al., 2010; Pennec and Gutierrez Ruiz, 2014).<sup>19</sup> Finally, a number of reports and academic work explore the ethical issues surrounding the development of gerontechnologies, especially when based on the participation of private providers (Ennuyer, 2014) or on the development of geo-tracking devices (CNBD, 2013; CNIL, 2013). These issues concern both professional and relatives' practices, especially for elderly people with cognitive disabilities, but are hardly touched on in the recent Act on Adapting Society to an Ageing Population (where just a single line mentions them). As highlighted by Gucher et al. (2014), the relevance of the use of new technologies in the field of care for the elderly is not yet a subject of debate on the political agenda. Given such developments in

<sup>17</sup> €40,000,000 over two years, press release, 2014.

<sup>18</sup> €4,000,000 over two years, press release, 2014.

<sup>19</sup> According to Ennuyer (2014), only 5% the calls are related to an emergency such as a fall or a feeling of discomfort.

France, it appears imperative to cultivate an approach to integrating ICT into LTC in such a way that accounts for outcomes that are both contradictory and complementary at once (Ennuyer 2014).

### Increased public financing for research and development in Germany

As part of a larger campaign ('Technik zum Menschen bringen') to increase social innovation through the use of technology and digitalization, the German Federal Ministry of Education and Research (BMBF) has provided financing since 2015 for various projects that introduce technical solutions to increase the mobility and thereby quality of life of the elderly (BMBF, 2015). One example is the project 'UrbanLife+'<sup>20</sup> which, through careful city planning, aims to improve the sense of security experienced by elderly people living with mobility problems in urban areas. The project seeks to extend the notion of ambient assisted living beyond the domestic context and into the public sphere, through implementing technology that makes for 'smarter' public infrastructure. Examples include interactive monitors and sensors that provide pedestrians with clearly visible/audible cues and information regarding nearby public restrooms, transport or other facilities. Neighbourhood-based technological support is also being developed to increase social inclusion by keeping elderly people abreast of local events and activities.

By 2022, the BMBF will have also invested €20 million in a research cluster referred to as 'Future of Care' or 'Zukunft der Pflege,' led by the Pflegeinnovationszentrum (PIZ) at the OFFIS institute in Oldenburg.<sup>21</sup> In cooperation with the University of Oldenburg, the University of Bremen, and Hanse Institute of Oldenburg, PIZ will engage in the evaluation of innovative technologies (existing and newly developed) that support all sectors of LTC, whether home-based or inpatient, as well as carry out extensive knowledge transfer activities.

<sup>20</sup> For more information, see [www.urbanlifeplus.de](http://www.urbanlifeplus.de).

<sup>21</sup> For more information, see [www.offis.de](http://www.offis.de)

As of 2018, PIZ also collaborates with four practice-based centres in the states of Baden-Württemberg, Bavaria, Berlin and Niedersachsen. This collaboration is intended to encourage exchange between research institutions and practice. Being located at OFFIS, the centre is also expected to benefit from research into the applications of robotics and augmented virtual reality in LTC. In June of this year, the PIZ hosted its first so-called 'cluster-conference,' bringing together various experts and collaborating partners to discuss the use of innovative technologies in LTC.<sup>22</sup> In a report from the conference, strong emphasis was placed on the ongoing reluctance to adopt new technologies in Germany due to a lack of expertise on the part of care professionals on the implementation of innovations, as well as an absence of communication between the developers of technological innovations and caregivers/users (Boll et al., 2018, p. 1). The latter has been said to lead to the creation of technologies that often offer little practical advantage in the LTC sector (*ibid.*).

Among various themes emerging at the conference, the potential and acceptance in the provision of LTC came to the fore. Conference contributors provided information on the advantages and drawbacks involved in using (semi-)automated robots to provide care, whether within the individual's home or within an institutional setting. For example, whereas robots may relieve caregiver burden regarding the more physical tasks of lifting, washing, or feeding dependents, thereby freeing up resources for social and emotional care, matters of legal accountability in the event of damages incurred during robotics-based services are problematic (Boll et al., 2018; see also Matthias, 2004). Moreover, an increasing reliance on such technologies necessitates the regular training of care personnel and users, implying a significant revision of the current education of LTC professionals in Germany. For care dependents who may be severely incapacitated,

<sup>22</sup> Conference proceedings and papers can be found online at: <https://srvg03.offis.uni-oldenburg.de/piz/wp-content/uploads/2018/06/Zukunft-der-Pflege-Tagungsband-der-Clusterkonferenz-2018.pdf>.

robotic care must be designed to allow for a basic level of control by the user in order to protect his/her agency as an individual. This might prove particularly difficult where significant cognitive impairment is involved or where dependents are simply reluctant to embrace the use of non-human care due to cultural expectations regarding care or a lack of familiarity with technological devices. The main task of the PIZ over the next few years will be to identify ways of better designing and integrating technologies to overcome such challenges and thereby address the growing demands placed on the German LTC system due to chronic personnel shortages and population ageing (Boll et al., 2018).

#### Shared housing arrangements in Germany as an innovative care model

One of the more innovative forms of care which has gained attention in recent years in Germany is shared housing arrangements or residential groups ('ambulant betreute Wohngemeinschaften'). Generally, a limited number of people in need of care, often people with dementia (if necessary, with the support of their relatives), rent private rooms while they share a common space, domestic support, and access to nursing care. The concept aims to provide a small-scale, home-like care facility with ample leeway for individual activities that differ from the daily routines of traditional nursing homes. The concept particularly supports residents in maintaining independence and autonomy. Further, shared housing arrangements seek to integrate care with support from relatives, friends, neighbours, voluntary workers or the community, alongside the purchase of professional services. Internationally, similar concepts are known as 'small-scale living' in the Netherlands, 'Cantou' in France, or 'Green House' and 'Woodside Place' models in the US and Canada (Verbeek et al. 2009).

In Germany, shared housing arrangements first developed in the late 1980s and 1990s as self-organized projects, with the first residential group founded in Berlin in 1996 (Wolf-Ostermann and Gräske 2014, p 17). The concept has since gained acceptance by public authorities, financing

institutions, as well as nursing care providers (Fischer et al., 2011). Shared housing arrangements are now included in the states' (Laender) laws that have replaced the federal Nursing Home Act ('Heimgesetz'); while the LTC Adjustment Act of 2012 ('Pflege-Neuausrichtungs-Gesetz') has introduced special grants to support the implementation of shared housing.

The states' laws generally discern self-organized shared housing ('selbstverantwortete Wohngemeinschaften') from provider-organized projects ('anbieterverantwortete Wohngemeinschaften'). The latter in particular are regarded as a promising approach between traditional domestic care and the traditional nursing home, combining a home-like environment with high quality round-the-clock care (Hasenau et al., 2016, pp 9–10).

Self-organized residential groups are characterized by a strict separation of the corporate body providing housing and the organization providing care and support. The residents exercise property rights and determine daily routines and are free to choose the amount of nursing care they receive. In theory, they can also choose care from different providers at once, although this is unlikely due to coordination problems. The providers of nursing care are not allowed to intervene in decisions of the residential group or the body of representatives set up by the group. The classification as 'self-organized' also means that the residential group is not affected by further regulations (e.g. 'Ordnungsrecht' or administrative law) beyond the general requirements that all providers of nursing care have to meet (Wolf-Ostermann and Gräske 2014, p. 23).

In provider-organized shared housing, the nursing care provider is responsible for housing as well as care and general assistance, or cooperates with housing associations. Despite this, housing contracts and contracts for general assistance have to be separate from contracts for nursing care in order to give residents leeway to define the amount of care purchased and organized by dependents or

friends. Provider-organized shared housing is covered by administrative law and the states' laws that have replaced the federal Nursing Home Act, thus there are building/structural requirements and sometimes the obligation to report the establishment of a residential group to the nursing care authorities. Groups are limited to a maximum of 12 participants and there are limits to the number of groups within a certain area.

Generally speaking, LTC reforms since 2008 have gradually improved the environment in which shared housing care models flourish. Most importantly, the government has increased financing for nursing care provided in an outpatient setting (§36 SGB XI, Pflegesachleistungen), in several steps. Residents also have the option to claim services jointly through social long-term care insurance. In 2013, the LTC Adjustment Act took effect, introducing a monthly lump-sum of €200 per resident (later increased to €214) to finance the coordination involved with residential groups. Further, financing for the combination of nursing care and daycare has been increased and involves highly profitable business models for nursing care providers. The latter have evoked criticism, since some providers have established models which tend to maximize income from the LTCI while failing to achieve the core aims of shared housing: maintaining independence and autonomy, flexible choice of care, and a home-like environment.

The number of residential groups has increased from about 143 (including groups for disabled people) in 2003 to an estimated 3,121 in 2015 (Fischer et al., 2011; Schuhmacher, 2016). Assuming an average size of 8-9 placements per group, this amounts to between 25,000 and 28,000 placements. This is about 3.6% to 4.0% per cent of people who claim outpatient LTC services or 2.9% to 3.3% of people in nursing care homes. Current surveys<sup>23</sup> point to around 3,900 shared housing arrangements, a rather cautious estimate since there is no general obligation to report the groups. In

Berlin and the northeast of Germany shared housing is more prevalent than in other parts of Germany although the numbers have increased largely in North-Rhine Westphalia, whereas the numbers in Bavaria appear to have tripled between 2012 and 2017. However, these figures and trends have yet to be validated.

To date, there is limited evidence about the quality of care provided within these settings. Most evaluation studies refer to residential groups for LTC-patients with dementia located in Berlin. Comparing residential groups with care units in nursing homes shows no significant advantage in quality of life (Wolf-Ostermann et al., 2012). Differences with respect to decubitus or injuries related to falls are likely to be a result of the different clientele choosing residential groups or more traditional nursing care (Klingelhöfer-Noe, Dassen and Lahmann, 2015). One study points to positive effects for nutrition of residents in shared housing compared to nursing homes (Meyer et al., 2014). Further, a qualitative survey suggests superior working conditions and job satisfaction in small-scale, home-like settings (Reimer and Riegraf, 2015). Integration of family members in the care concept can be difficult (Gräske et al., 2015; Wolf-Ostermann et al., 2012). Finally, residential groups for LTC-patients with dementia do not show cost advantages over nursing homes (Wübbeler et al. 2015).

#### From national to municipal innovations in the organisation of LTC in Italy

Most innovations in LTC over the last decade in Italy have focused on addressing specific chronic conditions such as diabetes (e.g. through the IGEA project) and respiratory diseases (e.g. the national implementation of the Global Alliance against Respiratory Diseases) (Melchiorre et al., 2015). At a national level, apart from general initiatives by the Ministry of Health (i.e., in earlier National Health Plans (Piani Sanitari Nazionali) and in the latest Pact for Health (Patto per la Salute), years 2014-2016, respectively), important developments have been the delivery of the National Plan for Chronic

<sup>23</sup> First results of a survey currently organized by a government funded research project at the SOCIUM, university of Bremen.

Diseases (Piano Nazionale Cronicità) in 2016 (Ministry of Health, 2016b) and the National Plan for Dementia (Piano Nazionale Demenze) in 2015 (Ministry of Health, 2015). The former plan, which sets out national guidelines for ensuring appropriate chronic care management for patients (including specific indications for a number of chronic diseases not yet explicitly considered by the health planning legislation), represents the first comprehensive governmental response in the field of chronic care. The core of this policy concerns the adoption of the 'chronic care model' and, in particular, of different key aspects: the patient-centeredness approach, the recognition of the multidimensional needs of the patient (medical, psychological and social), the integration of different disciplines and services involved in care provision, the need for better health education and empowerment of the patient and his/her family, and continuous monitoring of the health situation. The intended goal of chronic care is to maintain the patient at home, avoiding or delaying institutionalization for as long as possible.

As for the National Plan for Dementia, it constitutes an innovative step forward within the Italian context towards improving the network of healthcare actors engaged in the diagnosis, monitoring and treatment of dementia. The plan has four objectives which are seen as being achieved through related actions: to carry out health and LTC interventions; to create and manage an integrated network of services for the treatment of dementia; to implement strategies for monitoring the appropriateness of care; and to raise awareness and reduce stigma related to dementia in order to achieve a better quality of life for patients.

In addition to greater investment in chronic care and dementia, particularly as concerns the coordination and integration of services for users, an updating of benefits also took place in 2017 when the Italian government defined new essential levels of assistance (livelli essenziali di assistenza, LEA) (President of the Council of Ministers, 2017). This culminated in a revised list of healthcare services which all regions are obliged to guarantee to citizens

(the previous list entered into force in 2001). They include a reorganisation of some aspects of LTC, involving better integration of health and social services through individual care plans taking into account both health and social needs (art. 21); an enhanced list of the basic levels of community care services to be guaranteed nationwide (art. 3-20); better economic protection when people with high-intensity health needs are admitted to care institutions (the fees are to be entirely paid by the State) (art. 29); and a re-structuring of home care into four levels of intensity, with different characteristics and types of professionals (e.g., medical doctors, nurses, healthcare workers, social workers) involved (art. 22).

Concerning LTC specifically, which is mainly the responsibility of the municipalities, the main policy innovation in recent years has been the progressive encouragement of central government of cooperation between municipalities for the management and provision of social services. Policymakers established that small municipalities (under a minimum number of inhabitants) should work together to organise care (Banchero, 2015). This measure increased the agreements between municipalities, with more centralised services and expected financial savings and resource optimisation. Furthermore, a common trend in LTC in many municipalities is the development of voucher systems and local cash allowances granted to older people with LTC needs or to their family carers. The overall goal of these instruments is to reduce the burden of this target group on formal social care services, which usually cannot be satisfied entirely by in-kind services due to budget and staff shortages. Vouchers and allowances represent an innovative way to support older people and their families in covering the needs for assistance, used in practice either as a compensation measure (covering indirect costs of LTC resulting from the involvement of a family carer forgoing earnings) or a budget for paying for LTC services at home (mostly by migrant care workers) or in nursing homes.

In general terms all the innovations covered in this section represent either recent policy interventions or are otherwise fragmented measures that have not yet been evaluated in their actual implementation by local healthcare authorities, or for their cost-effectiveness and impact at different levels. As yet, it is difficult to provide specific evidence or recommendations on the possible benefits of these new and innovative policies. Effectiveness analysis is difficult considering the possible range of side-

effects that might be involved. For instance, the skewing of the LTC offer towards the provision of cash benefits such as vouchers and allowances instead of in-kind services might represent a resource optimization strategy for the public healthcare sector, but it could imply issues for the private employment of care workers in the parallel market, who have usually low salaries, no social insurance and low skills in LTC, with consequences for the appropriateness and quality of care provided.

## Making sense of the evidence on LTC innovations: policy implications and next steps for research

Thus far, scholarship on innovations in LTC specific to the use of personalization and ICT technologies point to mixed and limited results. This is especially the case where questions of (cost-)effectiveness are concerned. Here, research tends to be marred by methodological shortcomings often involving an absence of experimental design that renders conclusions that are tentative, at best. Most studies refer to quantitative assessments of different outcomes and dissimilar target groups, complicating the comparability of findings and failing to provide in-depth insights. Research also tends to be geographically biased to the cases of the United States and England, making their relevance for and generalizability to other national contexts problematic.

Of the evidence to be had, the strongest findings related to personalization point to an increased level of satisfaction with care by users due to a better matching of care characteristics and individual preferences. Evidence on clinical outcomes (e.g. improved ADLs), meanwhile, tends to suffer from the lack of randomized control trials employed by researchers. Similar methodological problems apply to research on psycho-social wellbeing: while numerous studies report a greater sense of control and autonomy by users of cash-for-care schemes, there is also contrary evidence depending on the country and target group involved (e.g., the frail elderly taking up Personal Budgets in England).

As concerns the reduction of costs associated with personalization in the form of cash-for-care schemes, evidence is also mixed. Whereas personalization tends to lead to greater take-up of benefits/services, it is not clear to what extent this may be a so-called 'woodwork effect' in which benefits are provided for care that would have been bought or made even in the absence of financial incentives. Moreover, incentivizing the role of informal carers – often women – through the use of cash benefits raises questions about the nature of

societal costs associated with reduced female labour market participation, the burden of psycho-social and economic costs of family care giving, and the quality of care received by users. Thus far, research on personalization fails to capture this larger picture of cost-effectiveness.

Much along the same lines, extant scholarship on the cost-effectiveness of ITC tends to be similarly short sighted and methodologically problematic. Most studies are geographically limited to the United States, are highly heterogeneous due to the diverse nature of ITC, and also refer to different target groups, making comparability problematic. Bearing this in mind, many studies do provide encouraging evidence that the use of ICT in LTC has led to improved quality of life, as well as a slowing in the progression of some disabilities, especially cognitive and emotional decline. The economic impact of ICT is difficult to gage, however, as any benefit introduced must be weighed against the costs of developing and implementing new technologies.

Taken together, extant evidence on the (cost-)effectiveness of personalization schemes and ICT brings to light the crucial need for better data that allows us to draw robust, generalizable and comparative conclusions. This necessitates interdisciplinary cooperation with researchers capable of carrying out experimental research designs that are rooted in shared understandings of outcomes, who can then translate that evidence into the basis for feasible policies. We may also wish to revise our interest in cost-effectiveness (difficult to define and measure) as an outcome. Instead, new domains of outcomes could be preferred and a new prioritization of policy objectives devised that could take a societal view to evaluating the success of a measure. Regardless of what approach is taken, we need to accept the reality of mixed findings while still making informed policy choices. This necessitates trade-offs and imperfect solutions.

Of the various imperfect solutions in existence today, personalization schemes tend to respond to care recipients' need for greater autonomy and choice of services in the face of declining physical or mental autonomy. However, personalization generally implies a greater reliance on informal carers, which the future does not seem to allow. This places the onus on policymakers to fill this gap

with other solutions, which are likely to involve ICT as the next best imperfect policy solution. The question then is, to what extent should investment in technological innovations take the place of greater financing for professional personnel – a question beyond the scope of the present study, but which is crucial for moving forward.

## References

ADASS (2012). *The Case for Tomorrow*, London: Association of Directors of Adult Social Services.

Arksey H, Kemp P (2005). *Dimensions of Choice: A narrative review of cash-for-care schemes. Working Paper No DHP 2250*. Social Policy Research Unit, University of York.

Alonso-Moran E, Nuno-Solinis R, Orueta JF, Fernandez-Ruanova B, Alday-Jurado A, Gutierrez-Fraile E (2015). Health-related quality of life and multimorbidity in community-dwelling telecare-assisted elders in the Basque Country. *Eur J Intern Med*, 26(3), 169–175.

Barbabella F, Melchiorre MG, Quattrini S, Papa R, Lamura G (2017). *How can we strengthen eHealth in caring for people with multi-morbidity in European countries?* Health Systems and Policy Analysis, Policy Brief n. 25. Copenhagen: WHO Europe. Retrieved from [www.euro.who.int/\\_data/assets/pdf\\_file/0007/337588/PB\\_25.pdf](http://www.euro.who.int/_data/assets/pdf_file/0007/337588/PB_25.pdf)

Barlow J, Singh D, Bayer S, Curry R (2007). A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. *J Telemed Telecare*, 13(4), 172–179.

Breda J, Schoenmaekers D, Van Landeghem C, Claessens D, Geerts J (2006). When informal care becomes a paid job: the case of Personal Assistance Budgets in Flanders, In: Glendinning C, Kemp PA (eds), *Cash and Care: Policy Challenges in the Welfare State*. Bristol: The Policy Press.

Carlson BL, Foster L, Dale SB, Brown R (2007). Effects of cash and counseling on personal care and well-being. *Health Services Research*, 42(1p2), 467–487.

Benjamin AE, Matthias R, Franke TM (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research*, 35(1 II), 351–366.

Dale SB, Brown RS (2007). How does Cash and Counseling affect costs? *Health Services Research*, 42, 1, part 2, 488–509.

De Luca R, Bramanti A, De Cola MC, Trifiletti A, Tomasello P, Torrisi M, . . . Calabro RS (2016). Tele-health-care in the elderly living in nursing home: the first Sicilian multimodal approach. *Aging Clin Exp Res*, 28(4), 753–759.

Deloitte (2015). *Connected Health: How Digital Technology is Transforming Health and Social Care*. London: Deloitte Centre for Health Solutions. Retrieved from [www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-connected-health.pdf](http://www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-connected-health.pdf)

Demiris G, Hensel BK (2008). Technologies for an aging society: a systematic review of “smart home” applications. *Yearb Med Inform*, 33–40. Retrieved from [www.ncbi.nlm.nih.gov/pubmed/18660873](http://www.ncbi.nlm.nih.gov/pubmed/18660873)

Edirippulige S, Martin-Khan M, Beattie E, Smith AC, Gray LC (2013). A systematic review of telemedicine services for residents in long term care facilities. *J Telemed Telecare*, 19(3), 127–132.

Eichler M, Pfau-Effinger B (2009). The “Consumer Principle” in the care of elderly people: free choice and actual choice in the German welfare state. *Social Policy & Administration*, 43(6), 617–633.

Ejehiohen Iyawa G, Herselman M, Botha A (2016) Digital health innovation ecosystems: from systematic literature review to conceptual framework. *Procedia Computer Science*, 100, 244–252, <https://doi.org/10.1016/j.procs.2016.09.149>

Ekeland AG, Alison B, Flottorp SA (2010). Effectiveness of telemedicine: a systematic review of reviews. *International Journal of Medical Informatics*, 79(11), 736–771.

Ettelt S, Williams L, Perkins M, Wittenberg R, Lombard D, Damant J, Mays N (2018). Explaining low uptake of direct payments in residential care: findings from the evaluation of the Direct Payments in Residential Care Trailblazers. *Journal of Social Policy*, 47: 505–522

Ettelt S, Wittenberg R, Williams L, Damant J, Lombard D, Perkins M, Mays N (2017). *Evaluation of Direct Payments in Residential Care Trailblazers: Final Report*. London: Policy Innovation Research Unit (PIRU).

Foster L, Brown R, Phillips B, Schore J, Carlson BL (2003). Improving the quality of Medicaid Personal Assistance through consumer direction, *Health Affairs* 22(suppl. 1 web exclusive), 162–175.

Gadsby E (2013). *Personal Budgets and Health: A Review of the Evidence*. Centre for Health Services Studies, University of Kent.

Glendinning C, Challis D, Fernández JL, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M, Wilberforce M (2008). *Evaluation of the Individual Budgets Pilot Programme*. London: Individual Budgets Evaluation Network.

Hirani SP, Beynon M, Cartwright M, Rixon L, Doll H, Henderson C, . . . Newman SP (2014). The effect of telecare on the quality of life and psychological well-being of elderly recipients of social care over a 12-month period: the Whole Systems Demonstrator cluster randomised trial. *Age and Ageing*, 43(3), 334–341.

Ismael M, Hussein S, Stevens M, Woolham J, Manthorpe J, Aspinal F, Samsi K (2017). Do personal budgets increase the risk of abuse? Evidence from English national data. *Journal of Social Policy*, 46(2), 291–311

Jackson D, Roberts G, Wu ML, Ford R, Doyle C (2016). A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community. *Arch Gerontol Geriatr*, 66, 218–236. doi:10.1016/j.archger.2016.06.013.

Jones K, Forder J, Caiels J, Welch E, Glendinning C, Windle K (2013). Personalization in the health care system: do personal health budgets impact on outcomes and cost? *Journal of Health Services Research & Policy*, 18, 2, suppl 59–67.

Khosravi P, Ghapanchi AH (2016). Investigating the effectiveness of technologies applied to assist seniors: a systematic literature review. *Int J Med Inform*, 85(1), 17–26.

Kruse CS, Mileski M, Moreno J (2017). Mobile health solutions for the aging population: a systematic narrative analysis. *J Telemed Telecare*, 23(4), 439–451.

Liu L, Stroulia E, Nikolaidis I, Miguel-Cruz A, Rios Rincon A (2016). Smart homes and home health monitoring technologies for older adults: a systematic review. *Int J Med Inform*, 91, 44–59.

Low LF, Yap M, Brodaty H (2011). A systematic review of different models of home and community care services for older persons. *BMC Health Services Research*, 9(11), 93.

Mahony KJ, Simon-Rusinowitz L, Simone K, Zgoda K (2006) Cash and counselling: a promising option for consumer direction of home- and community-based services and supports. *Journal of Care Management*, 7(4), 199–204.

McMillan SS, Kendall E, Sav A (2013). Patient-centered approaches to healthcare: a systematic review of randomized controlled trials. *Med Care Res Rev*. 70(6), 567–596

Meng H, Friedman B, Wamsley BR, Mukamel D, Eggert GM (2005). Effect of a consumer-directed voucher and a disease-management-health promotion nurse intervention on home care use. *Gerontologist*, 45(2), 167–176.

Netten A, Jones K, Knapp M, Fernández JL, Challis D, Glendinning C, Wilberforce M (2012). Personalisation through Individual Budgets: does it work and for whom? *British Journal of Social Work*, 42, 1556–1573.

Poitras M-E, Maltais M-E, Bestard-Denommé L, Stewart M, Fortin M (2018) What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC Health Services Research*, 18, 446.

Realdon O, Rossetto F, Nalin, M, Baroni I, Cabinio M, Fioravanti R, . . . Baglio F (2016). Technology-enhanced multi-domain at home continuum of care program with respect to usual care for people with cognitive impairment: The Ability-TelerehabILITation study protocol for a randomized controlled trial, *BMC Psychiatry*, 16, 425, 1–9.

Reeder B, Meyer E, Lazar A, Chaudhuri S, Thompson HJ, Demiris G (2013). Framing the evidence for health smart homes and home-based consumer health technologies as a public health intervention for independent aging: a systematic review. *Int J Med Inform*, 82(7), 565–579.

Reid RJ, Fishman PA, Yu O et al. (2009). Patient-centered medical home demonstration: a prospective, quasi-experimental, before and after evaluation. *American Journal of Managed Care*, 15(9): e71–e87.

Rijken M, Struckmann V, van der Heide I, Hujala A, Barbabella F, van Ginneken E, Schellevis F (2017). *How to Improve Care for People with Multimorbidity in Europe?* Health Systems and Policy Analysis, Policy Brief n. 23. Copenhagen: WHO Europe. Retrieved from [www.euro.who.int/\\_\\_data/assets/pdf\\_file/0004/337585/PB\\_23.pdf](http://www.euro.who.int/__data/assets/pdf_file/0004/337585/PB_23.pdf)

Rojas SV, Gagnon MP (2008). A systematic review of the key indicators for assessing telehomecare cost-effectiveness. *Telemed J E Health*, 14(9), 896–904.

Sanyal C, Stolee P, Juzwishin D, Husereau D (2018). Economic evaluations of eHealth technologies: a systematic review. *PLOS One*, <https://doi.org/10.1371/journal.pone.0198112>

Siegel C, Dorner TE (2017). Information technologies for active and assisted living-Influences to the quality of life of an ageing society. *Int J Med Inform*, 100, 32–45.

Stroetmann KA et al. (2010). *How can Telehealth Help in the Provision of Integrated Care?* Policy Brief 13. Copenhagen, European Observatory on Health Policies and Systems. Retrieved from [www.euro.who.int/\\_\\_data/assets/pdf\\_file/0011/120998/E94265.pdf](http://www.euro.who.int/__data/assets/pdf_file/0011/120998/E94265.pdf)

Thomas CL, Man MS, O'Cathain A, Hollinghurst S, Large S, Edwards L, . . . Salisbury C (2014).

Effectiveness and cost-effectiveness of a telehealth intervention to support the management of long-term conditions: study protocol for two linked randomized controlled trials. *Trials*, 15, 36.

Van den Berg N, Schumann M, Kraft K, Hoffmann W (2012). Telemedicine and telecare for older patients – a systematic review. *Maturitas*, 73(2), 94–114.

White C (2011). *Improvement in Practice: The Personal Touch. The Dutch Experience of Personal Health Budgets*, The Health Foundation.

Wiener JM, Anderson WL, Khatutsky G (2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontologist*, 47(6):763–774.

World Health Organization (2016). *From Innovation to Implementation: eHealth in the WHO European Region 2016*. Copenhagen: WHO Regional Office for Europe.