Article

Assistive Technologies to Address Capabilities of People with Dementia: From Research to Practice

Paul-Ariel Kenigsberg, Jean-Pierre Aquino and Alain Bérard
Fondation Médéric Alzheimer, Paris, France

François Brémond
CoBTeK Lab & INRIA STARS, Université Côte-d'Azur, Nice, France

Kevin Charras
Fondation Médéric Alzheimer, Paris, France

Tom Dening
Institute of Mental Health, University of Nottingham, UK

Rose-Marie Droës
Department of Psychiatry, VU University Medical Center, Amsterdam, The Netherlands

Fabrice Gzil
Fondation Médéric Alzheimer, Paris, France

Ben Hicks
Bournemouth University Dementia Institute, UK

Anthea Innes
Salford Institute for Dementia University of Salford, Salford, United Kingdom

Sao-Mai Nguyen
Lab-STICC, Institut Mines-Télécom Bretagne, Brest, France

Louise Nygård
Department of Neurobiology, Care sciences and Society, Karolinska Institute, Stockholm, Sweden

Maribel Pino
Laboratoire Lusage, Hôpital Broca, Assistance publique-Hôpitaux de Paris, France

Guillaume Sacco
Centre Mémoire de Ressources et de Recherche, CHU de Nice; Université Côte-d'Azur, CoBTeK, Nice, France

Eric Salmon
Department of Neurology, Liège University Hospital, Belgium

Henriëtte van der Roest
Department of General Practice and Elderly Care Medicine, Amsterdaù Public Health Research Institute, VU University Medical Center, Amsterdam, The Netherlands

Hervé Villet
Fondation Médéric Alzheimer, Paris, France

Marion Villez
Laboratoire LIRTES, Université Paris-Est-Val de Marne, Créteil, France

Philippe Robert
Université Côte-d'Azur, CoBTeK, & Innovation Alzheimer Association, Nice, France

Valeria Manera
Université Côte-d'Azur, INRIA STARS & CoBTeK, Nice, France

Abstract
Assistive technologies became pervasive and virtually present in all our life domains. They can be either an enabler or an obstacle leading to social exclusion. The Fondation Médéric Alzheimer gathered international experts of dementia care, with backgrounds in biomedical, human and social sciences, to analyze how assistive technologies can address the capabilities of people with dementia, on the basis of their needs. Discussion covered the unmet needs of people with dementia, the domains of daily life activities where assistive technologies can provide help to people with dementia, the enabling and empowering impact of technology to improve their safety and wellbeing, barriers and limits of use, technology assessment, ethical and legal issues. The capability approach (possible freedom) appears particularly relevant in person-centered dementia care and technology development. The focus is not on the solution, rather on what the person can do with it: seeing dementia as disability, with technology as an enabler to promote capabilities of the person, provides a useful framework for both research and practice. This article summarizes how these concepts took momentum in professional practice and public policies in the past 15 years (2000–2015), discusses current issues in the design, development and economic model of assistive technologies for people with dementia, and covers how these technologies are being used and assessed.

Keywords
dementia, assistive technologies, capabilities, empowerment, assessment, ethics, human rights, psychosocial model of disability, public policies, economics

Corresponding author:

Paul-Ariel Kenigsberg, Fondation Médéric Alzheimer, 30 rue de Prony, 75013 Paris, France.
Email: kenigsberg@med-alz.org

Introduction

Due to population aging, the number of people living with dementia—a major cognitive disorder with deficits sufficient to interfere with independence in activities of daily living (ADL)—is growing every year, representing a major challenge for the healthcare systems (Alzheimer's Disease International, 2014). Dementia can result from different causes, the most common being Alzheimer's disease (AD). Depending on the etiology and the disease stage, dementia can be characterized by cognitive, behavioral, motor, and/or functional symptoms. The biological processes involved in dementia are very heterogeneous, including neuroinflammation, gliosis, synaptic loss, neurodegeneration, cerebral atrophy, and alterations of the blood–brain barrier permeability (Raz, Knoefel, & Bhaskar, 2016). What the different forms of dementia have in common is that they lead individuals to lose the ability to perform independently and successfully everyday tasks (e.g., preparing a meal, taking their own medications, or making a phone call), thus bringing them to a dependency status. As there is no ultimate cure to dementia, research is focusing on one hand on ways to prevent—or at least delay—the dementia onset; and on the other hand, on ways to compensate for the individuals' physical and cognitive deficits, in order to promote their autonomy status, and to improve the quality of life of people with dementia and their caregivers.

Information and Communication Technologies (ICT) can play a role both in preventing cognitive and physical decline (Sacco et al., 2012), and in compensating for existing impairments, for instance through Assistive Technologies (ATs). ATs include any device or system that allows individuals to perform tasks that they would otherwise be unable to do, or increases the ease and safety with which tasks can be performed (Royal Commission on Long Term Care, 1999). These devices range from simple "low tech" items such as calendar clocks, to more complex "high tech" items such as automatic lighting, telecare sensors, and social robots. However, the complexity of technology embedded in a device is less relevant than the ease of use. AT became pervasive, and virtually present in all our life domains, including work (laptop, calculator, smartphone), ADL (microwave, coffee maker, heater), and social and leisure activities (mobile phone, TV, tablet). In all these contexts, ATs are meant to simplify our lives, and improve our ability to accomplish complex tasks in an error-free way, eventually compensating for acquired disabilities such as those emerging as a consequence of neurodegenerative diseases. However, while ATs are designed to reduce disabilities in older people, they may also represent an obstacle leading to social exclusion if the person is unable to employ AT successfully. For instance, using social networks through a smartphone can improve the social life of older people, allowing them to interact with their grandchildren more often, or to chat with friends. But being unable to use a smartphone can leave them out of the social circle, as more and more communication is made everyday through these ICT devices.

The role of AT in the domain of AD and related disorders is still debated, and the field would benefit from additional analyses. In this paper we will summarize the experience gained in the field of AT, and analyze the framework for their use by people with AD.

Methods

Gathering expert insight

Since 2007, the Fondation Médéric Alzheimer gathers external experts to: (a) develop an original, up-to-date, robust and valid conceptual framework on how the future context of dementia may unfold, to enrich strategic thinking; (b) engage with uncertainty, within

limits of scientific plausibility; (c) reframe complex problems, find a shared language, identify research themes; (d) enable a multi-disciplinary, open, progressive debate, of high scientific level, to create exchange spaces (research networking); and (e) explore promising issues, to produce practical guidelines. Since 2012, the group has met once a year. The thematic area in 2014 was: ''Technology & Alzheimer's Disease''. The present article stems from a one-day, multi-disciplinary expert group discussion initiated in December 2014 and updated in March 2017, with 20 participants from the fields of cognitive neurosciences, computer sciences, economics, ergonomics, geriatrics, neurology, occupational health, philosophy, psychiatry, public health, cognitive psychology, social psychology, social policy, sociology, and gerontology. To gather expert insight, several methods were combined. Session started with brainstorming on the needs of a person with AD. Then, 10 short oral presentations of 12 minutes each were used to update group knowledge on selected issues, followed by short questions to clarify a precise point. Technologies were discussed within the WHO framework of Functioning, disability and health. In-depth, structured group discussion with a moderator was organized in four sequences of 45 minutes. Discussion covered: unmet needs of people with dementia and their caregivers; domains of daily life activities where AT can provide help to people with dementia; the enabling and empowering impact of technology to improve their safety and wellbeing; barriers and limits of use; methods for technology assessment and ethical issues.

To gather further insight, expert discussion was extended, using input from scientific and professional literature. In this article, the angle chosen to present ATs is how they can address the capabilities of people with dementia.

The capability approach

Capabilities are defined as the opportunities that individuals have to achieve particular functionings. They are dynamically shaped by interactions between individuals and their environments, including their social relationships (Entwistle & Watt, 2013). People with dementia appear quite disadvantaged in their possibilities: their capability level (possible freedom) is comparable to that of people without cognitive disorders, but having at least five types of impairments in self-care and participation in domestic life (Le Galès, 2016; Tellez, Krishnakumar, Bungener, & Le Galès, 2016). It is also known that tailoring activities to the capabilities of dementia patients, and training families in activity use, result in clinically relevant benefits for patients and caregivers (Gitlin et al., 2008). The capability approach, largely diffused by the economist Amartya Sen (Nobel Prize 1998), appears particularly relevant in person-centered dementia care and AT development. The focus is not on the solution, rather on what the person can do with it: seeing dementia as disability, with technology as an enabler to promote capabilities of the person, provides therefore a useful framework for practice. We will analyze how these concepts took momentum in professional practice and public policies in the past 15 years (2000–2015). We will also discuss current issues in the design, development and economic model of technologies for people with dementia, and how these technologies are used and assessed.

The Human Rights based approach for people with cognitive disability

In 2002, the World Health Organization introduced the biopsychosocial model of disability (Figure 1): a biological, individual, and social perspective of disability and functioning, where engagement into an activity is influenced not only by the medical condition and
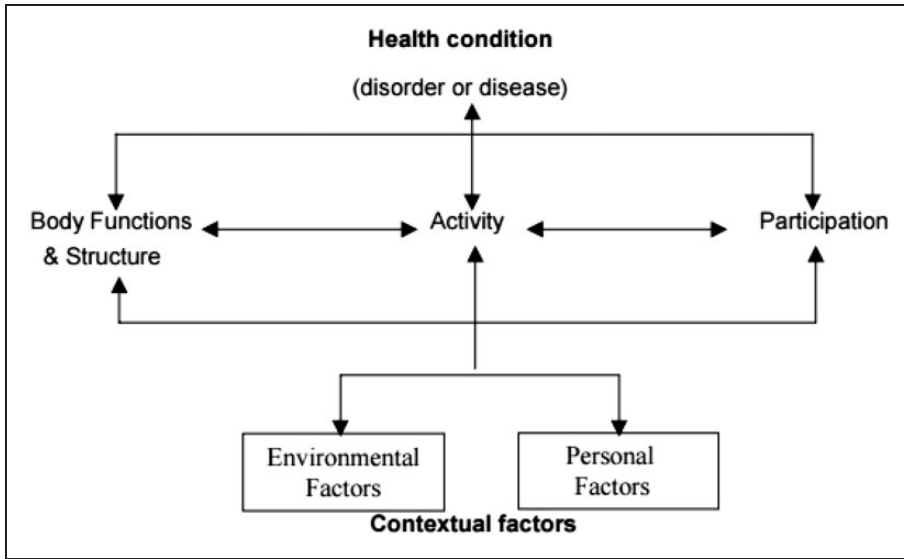
Figure 1. The WHO biopsychosocial model of disability.

possible impairments, but also by contextual factors linked to environment and the person (World Health Organisation, 2002).

The contextual factors explain why it is essential to recognize that each person with dementia is unique: the same AT device may be enabling, useful, useless or irritating depending on the person using it, for whom it is used, and in which conditions. It is also important to consider that incapacities to perform instrumental activities of daily living (IADL), are affected since the stage of mild cognitive impairment (Jekel et al., 2015), and may influence the appropriation and use of technology. The perceived ability to use everyday technology may actually predict overall functional level in people with mild cognitive impairment or mild AD (Ryd, Nygård, Malinowsky, Öhman, & Kottorp, 2016). More generally, tool use disorders in neurodegenerative diseases involve impairments in semantic memory and technical reasoning, besides motor capacity (Baumard et al., 2016).

The organizational approach

Industrial issues concerning technology development are discussed under the global approach of the value chain, a set of activities that an organization carries out to deliver a valuable product or service to its customers (Porter, 1985), value being defined as outcomes (ultimately, satisfaction of customer's needs) relative to cost (Porter, 2010).

Results

Unmet needs of people with dementia

An important starting point to understand how AT can help people with dementia is to identify their unmet needs. A Dutch survey conducted on 236 community-dwelling people

with dementia and 322 informal carers showed that most unmet needs are experienced in the domains of memory (support for memory problems), access to information about dementia, company, psychological distress, daytime activities, and eyesight/hearing (van der Roest et al., 2009). Reported reasons for unmet needs included a lack of knowledge about the existing service offer, a threshold to using services, and insufficient services offer.

How can technology help?

The Technology Charter for People Living with Dementia in Scotland (NHS Scotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue Service, Tunstall, Tynetec, 2015) identified three ways in which AT can help people with dementia: enabling and empowering; health and wellbeing; safety and independence (Table 1). For each point, we will discuss examples of AT, and explain how they can achieve the identified needs.

(a) Enabling and empowering

In order to maintain a good quality of life, improve self-esteem and mood, it is essential that people with dementia can maintain some autonomy in ADL as long as possible, and maintain a regular social activity. AT can provide useful tools to help people affected by physical and/or cognitive decline in that sense, while reducing caregiver's burden. For example, using a mobile telephone may be possible at an early stage of AD with specific learning techniques based on procedural memory, however after a three-month rehabilitation scheme (Lekeu, Wojtasik, Van der Linden, & Salmon, 2002). An assistive dressing system has been described, which continuously monitors the dressing state of the user, identifies and prompts correct and incorrect dressing states, and provides corresponding cues to help complete the dressing process with minimal caregiver intervention (Burleson et al., 2015). A growing AT area is that of socially assistive robots, which are perceived as useful solutions by people with dementia and their caregivers (Pino, Boulay, Jouen, & Rigaud, 2015). Despite several remaining usability problems, socially assistive robots represent promising solutions to assist with communication and reduce the impact of sensory loss, to reduce isolation and disconnection from personal and social communities, and to support the ordinary activities of daily life (Kramer, Friedmann, & Bernstein, 2009; Mordoch, Osterreicher, Guse, Roger, & Thompson, 2013; Tanaka et al., 2012). Communication can also be improved by using avatars, i.e., computer programs able to interact with users thanks to user inputs acquired through a set of sensors (cameras, microphones, touch screen, etc.) and a virtual character. Current applications are able to produce human-like communication behaviors by speaking and gesturing, and can be used also to assess people's cognitive status (Nonaka, Sakai, Yasuda, & Nakano, 2012).

(b) Health and wellbeing

The area of AT to improve safety and wellbeing is expanding, as evidence about the effectiveness and acceptability of AT for therapeutic purposes is increasing. For instance, several studies have been recently carried out on the use of serious games—videogames designed for purposes other than entertaining—for the cognitive and physical stimulation of patients with AD and related disorders (Robert et al., 2014). Several serious games targeting cognitive stimulation (e.g., multi-tasking ability) have been shown to improve cognitive functions in healthy elderly people (Anguera et al., 2014) and studies

Table 1. Three ways in which assistive technology can help people with dementia.

(a) Enabling and empowering	(b) Health and well-being	(c) Safety and independence
• To support what people can, and want to do for themselves.	• To maximize confidence, capacity, and capability of the individual to self-manage their dementia and any other health conditions they may have.	• To provide individualized solutions to concerns about safety, security, and independence.
• To increase choice and opportunity.	• To support physical and mental health and wellbeing through the use of technology enabled care.	• To reduce risk of fire and prevent accidents.
• To support what is important to the person with dementia and their families and carers.	• To help create or maintain routine.	• To support people with dementia to walk freely and safely both indoors and outdoors.
• To support the ordinary everyday activities of daily life.	• To support the search for information, advice, support, and help.	• To encourage going out and about and reduce the risk of being lost or the risks associated with being lost.
• To reduce isolation and disconnection from personal and social communities.	• To reduce the risks associated with falls and disorientation.	• To facilitate the person with dementia to communicate with a remote partner in care should clarity or reassurance be required.
• To maximize existing skills and abilities and support the development of new skills.	• To support reminiscence and life story work.	• To automatically alert a remote partner in care to the real time occurrence of a risk to the person or property.
• To assist with communication and reduce the impact of sensory loss. • To support memory, reasoning, judgment, and decision making. • To maintain social networks and enhance personal connection through social and digital media.	• To support medication regimes.	

Source: NHS Scotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue Service, Tunstall, Tynetec (2015).

are now extending to pathological populations. For instance, Ben-Sadoun et al. (2016) showed that *X-Torp*, a serious game designed to combine cognitive and physical stimulation, is well accepted and positively evaluated by both healthy elderly people and patients with MCI and early stages of AD. These studies suggest that serious games may represent a useful motivational tool to create entertaining trainings for patients with dementia-related disorders, to be used to complement standard pharmacological

treatments. In 2017, the *X-Torp* game was granted the status of medical device (Class 1-93/ 42/CE) from the French health authorities. Gamers will be able to access the game via an Internet platform. Virtual reality (VR) is now seen as another promising tool to create motivational trainings (Rizzo & Kim, 2005). VR cognitive trainings designed for people with dementia are generally well accepted, and preferred over classical paper pencil exercises even by dementia participants with scarce previous experience with ICT devices (Manera et al., 2016). Beyond supporting physical and mental health and wellbeing, VR can also be employed to support reminiscence and life story work. In a recent study we have shown that VR is a promising tool to improve reminiscence therapy in the elderly (Benoit et al., 2015): thanks to a high level of immersion in the virtual environment, which generates a feeling of presence, VR can successfully help triggering old memories. An emerging trend, which has recently generated a large public interest worldwide, is the use of VR on a mobile serious game (*Sea Hero Quest*) to collect a normative data set in healthy people to create a diagnostic test based on spatial navigation skills. This would help understand how the early symptoms of dementia can be differentiated from the consequences of natural ageing, to develop dementia prevention strategies and early interventions using gaming technologies (Morgan, 2016).

AT supporting the search for information, advice, support, and help are also emerging, targeting both people with dementia and their formal and informal caregivers. AT in this domain include both serious games designed for caregiver training (Manera et al., 2016); web-based blogs and platforms to facilitate and improve the communication between caregivers and healthcare professionals (Span et al., 2015); websites designed to provide information on dementia-related disorders targeting caregivers, patients with dementia, and professional organizations, such as *DEM-DISC,* a dynamic interactive social chart for dementia care (Droës et al., 2005); and e-learning platforms for carers, volunteers, and professionals, such as *Star course* (Hattink et al., 2015).

(c) Safety and independence

Several AT designed to improve safety and independence are already available on the market, and others are being developed. Social alarms can be defined as "devices (with or without some intelligence) located in the home, which, when activated, facilitate communication with a responder and the sending of information relevant to the user's well-being" (Fisk, 2003). These include smart smoke, gas and carbon monoxide detectors, which can be wireless connected and in case of an accident can alert people in the neighborhood through loud alarms, as well as local fire services and caregivers through automatic phone calls and text messages. The connected devices can be checked remotely for proper functioning (e.g., are they plugged in correctly? Is the battery charged? etc.). A survey conducted in England and Scotland confirmed that over 70% of elderly people have some form of social alarms installed in their homes, and that they are considered as generally acceptable (McCreadie & Tinker, 2005). These social alarms can help both to reduce the risk of fire and other common home accidents, and to automatically alert a remote partner in care to the real time occurrence of a risk to the person or property. Similar functions are covered by connected video monitoring systems. Thanks to automated video analyses techniques, video and RBD cameras can be employed to automatically detect accidents such as falls. Interestingly, algorithms are being developed to use cameras to improve the ecological assessment of ADL of older people. In the context of the European FP7 project *Dem@Care*, algorithms have been developed for the recognition and classification of everyday activities, such as
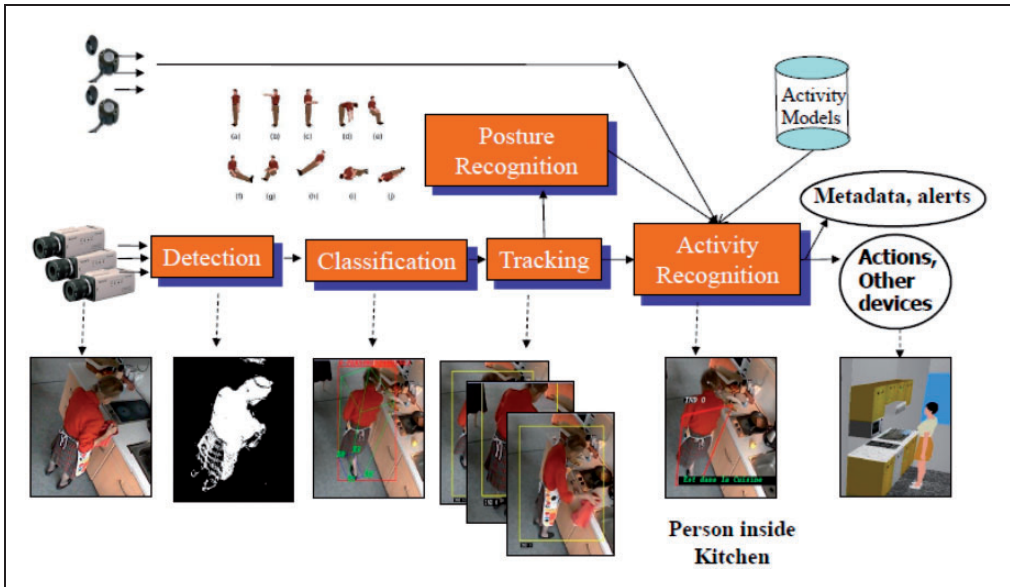
Figure 2. Ecological assessment of daily life activities and detection of accidents in the *Dem@Care* project.

sitting and waking up, preparing a meal, or going to bed (see Figure 2). Results collected on participants with mild cognitive impairment and dementia suggest that these algorithms are sensitive enough to accurately discriminate different ADL activities when participants follow a pre-defined activity scenario (König et al., 2015). They may therefore contribute significantly to home safety by creating personalized solutions enabling older adults to live longer, autonomously in their preferred environment.

Customized solutions are also being developed to support people with dementia to walk freely and safely both indoors and outdoors, to encourage them to go out and about, while reducing the risk of being lost and associated risks, and to facilitate communication of the person with dementia with a remote partner in care, should clarity or reassurance be required. For instance, the *COGKNOW Day* Navigator (Meiland et al., 2012), developed in a FP6 European project, is a holistic solution that assists persons with dementia within their own homes and outside. It increases independence and quality of life, while giving caregivers the relief of not having to monitor the person with dementia all the time. The service can be easily customized to address the individual needs of each person and their caregivers, for memory support, helping with daily activities, maintaining social contacts and increased safety. The main functionalities are: time indication, remotely configurable reminders, music, radio, picture dialing, activity assistance, house alerts for safety, and mobile navigation for going home.

How can technology be an obstacle?

Despite that an AT can simplify daily life and compensate for disability in several ways, it can sometimes be an obstacle and lead to exclusion, when people are unable to afford it,

learn how to use it, or forget how to use it (Damant & Knapp, 2015). As AT is so pervasive in our everyday life, it would be important to include assessment of AT use in the clinical assessment instruments. However, despite technology has changed our everyday activities, ADL/IADL assessment instruments remained mostly the same. For this reason, new clinical instruments assessing the ability to use everyday technology are being developed. The Everyday Technology Use Questionnaire (ETUQ; Nygård, Pantzar, Uppgard, & Kottorp, 2012; Rosenberg, Kottorp, Winblad, & Nygård, 2009) was designed to assess perceived difficulty in using everyday technology. Similarly, the Management of Everyday Technology Assessment (META; Malinowsky, Nygård, & Kottorp, 2011) evaluates the observed ability to manage everyday technology. Studies employing these instruments have shown that people with dementia and MCI have a greater difficulty to employ some everyday technologies, and thus the evaluation of AT actual use may be a sensitive way to detect early changes in cognitive decline (Ryd et al., 2016). Specifically, it is possible to create a hierarchy of action skills needed when handling everyday technology. This knowledge can be applied to design or adapt devices to reduce difficulty of use by people with cognitive impairment. Patomella, Kottorp, Malinowsky, and Nygård (2011) and Patomella, Kottorp, and Nygård (2013) have found that a technology is considered more difficult to use when: it is used less than once a week, has more complex design, requires more actions, requires that actions are used more frequently, and that more difficult actions are used more frequently, requires that actions are taken in particular sequences, gives more complex, mostly visual feedback and uses abstract symbols. Interestingly, this perceived difficulty appears independent of the user's age, gender, and of how long the AT had been used. The same authors found that many different aspects influence whether a piece of technology will be appropriated and used or not. These include the interests and attitudes of the person and the social context; the person's ability to use the technology; the level of challenge of the technology; and the context.

Design and development of technologies for people with dementia

Combining ICT and the social environment of older people, to support a widely self-determined autonomous life in their own homes, has led to the development of concepts, products and services for their daily life, under the European research program *Ambient Assisted Living* (AAL; Siegel, Hochgatterer, & Dorner, 2014). From 2008 to 2013, over 130 projects were launched, leveraging 620 million euros. But only a handful of solutions made it to market. This is largely explained, on one hand, by the difficulty to find a viable industrial business model, and on the other hand by the inadequation of these solutions to the real needs of end users. Although these solutions are not specific for people with cognitive disorders, they surround them and will challenge them over time in their everyday life (Rosenberg & Nygård, 2014). Three distinct research and development approaches can be observed, with distinct objectives and stakeholders involved. First, research on technologies specifically designed for people with dementia, mostly driven by multi-disciplinary academic/industrial teams and funded by national or international grants, usually results in the production of prototypes to demonstrate practical feasibility and attract further research funding. An example of such upstream research is a validated automatic video monitoring system for the detection of IADL in people with dementia (König et al., 2015). A second approach is to adapt existing technologies to new potential usage by people with dementia, usually funded by technology industrials seeking first sales or commercial target extension, with eventual support from local or regional partners. To gain customer confidence,

technologies are usually tested in reference centers before being promoted at a larger scale. For example, programs combining the use of GPS bracelets, databases of people with dementia, and police training have been effective in locating missing people faster (Petonito et al., 2013). A third approach is to adapt the competence of people with dementia to use everyday technology, i.e. electronic, technical and mechanical equipment, newly developed or common and well-known, in their living environment. Key professionals involved are occupational therapists and neuropsychologists. Family and volunteers may provide useful assistance to people with dementia about using the technology. One example is the use of recreational games: people with dementia, engaging with digital gaming technology in Tech Clubs, were able to challenge informal and formal caregivers' perceptions of their abilities (Cutler, Hicks, & Innes, 2016). Other examples include the use of existing electronic pads or music playing devices for reminiscence interventions or recreational purposes; and serious games, which stimulate executive functions and foster engagement in people with dementia, apathetic or not, while providing a pleasurable activity. Success or failure of these different approaches depends whether products are adapted to the capacities of people with dementia, respond to actual needs of the persons and caregivers, are endorsed by Alzheimer's associations and scientific societies, and provide relevant support services with a human assistance at the end.

Co-design of technologies with advice from people with dementia and their caregivers is an emerging trend (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). In understanding the limitations experienced by people with dementia, co-design activities allow developers to reduce challenges introduced by technology use, while empowering the persons. A positive impact is the increased caregivers awareness of their remaining abilities and reducing the potential of a person to be seen as a victim (Jury, 2016; Swaffer, 2014). AAL environments can be designed to support informal caregivers in fashioning "do-it-yourself" solutions that complement tacitly improvised care strategies and enable them to try, observe, and adapt to solutions over time, decide which activities to entrust to technology support, how a system should provide support and when adaptations are needed (Hwang et al., 2015).

Usages and appropriation of technologies by people with dementia

Within the biopsychosocial model of disability, technology can be viewed as an enabling tool to promote autonomy and citizenship of a person with dementia throughout daily life activities. Technology has multiple purposes, which can be summarized in a simple way, using the standards of the WHO International Classification of Functioning, Disability and Health (World Health Organisation, 2002). Nine domains of daily life activity appear relevant for technology: earning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; community, social and civic life; recreation and leisure (Table 2). Learning how to use technologies is key, given their multitude and ever-changing designs. How people with dementia strive to learn and maintain their skills and knowledge related to technology deserves further attention. A pilot study, involving people with mild to moderate stage dementia, suggests that they use different ways of learning in their daily life, relying on one's habituated repertoire of actions, on other people or on technology itself, or belonging to a learning context (Rosenberg & Nygård, 2014).

Table 2. Purpose of assistive technology for people with dementia: Domains of everyday life activity using the standards of the WHO International Classification of Functioning, Disability and Health (2002).

Domains of daily life activity
General tasks and demand
Communication
Mobility
Self-care
Domestic life
Interpersonal interactions and relationships
Community, social, and civic life
Recreation and leisure

Ethical, financial, and legal issues

Key ethical issues concern privacy, decision-making about the use of technology by people with dementia and financial access to technologies. In a guidance issued in 2015, the Mental Welfare Commission of Scotland states that "efforts must always be taken to support someone to make a decision whenever this is possible. This may include taking extra time to explain what is being proposed, involving advocacy, and using communication aids to help promote discussion and understanding." Advance planning can help to gather adequate willingful consent from the person with dementia about technology use, before severe cognitive impairments preclude this consent (Yang & Kels, 2016). Concerning financial access from a consumer perspective, cost of technology must include acquisition and rental costs, plus support and maintenance costs. AT services are subject to major variations in pricing in a mixed economy of multiple dementia care providers, including primary care, local authorities, private companies, and local or national resources dedicated to ATs (Gibson et al., 2016). Solvency of consumers is key to facilitate purchase of AT, and can partly be compensated by public policies. Affordability of technology can been quantified using willingness to pay approaches. A recent survey of American caregivers of older people showed that the mean amount they are willing to pay is approximately $50 per month for monitoring technologies and $70 per month for technologies that would both monitor and provide some assistance (Schulz et al., 2015). Younger caregivers, those caring for a person with AD, and caregivers with more positive attitudes toward and experience with technology are willing to pay more. However, 20% of the caregivers are not willing to pay anything. Most caregivers expect some financial help from the government or private insurance to have access to technologies. Ethical issues for equal access to technologies therefore involve some part of collective funding, eligibility of users being based on individual financial and social situation.

Key legal issues in using technology concern primarily contract obligations (who should be deemed responsible in case of device or support failure causing harm to the user?), conformity of technology to human rights and individual data sharing, both in research and practice. The use of mass data for research generated by monitoring behaviors in smart homes and serious games on mobile phones constitute a novel issue. The first large-scale in-home monitoring using pervasive computing technologies to give continuous access to AD

progression and intervention efficacy has been installed in Oregon (United States) in 500 homes, collecting data for up to eight years on gait and mobility, sleep and activity patterns, medication adherence, and computer use (Lyons et al., 2015). Patterns of intra-individual variation detected in each of these areas are used to predict outcomes such as low mood, loneliness, and cognitive function. The web game *Sea Hero Quest* intends to collect a normative data set on healthy people worldwide, to help create a cognitive diagnostic test based on spatial navigation skills. It may boost research on prevention of dementia by identifying early, subtle behavioral, cognitive, and executive changes, in a "massive online citizen science experiment" able to test 200 people in 1 minute (Morgan, 2016). Altogether, the development of a legal framework for AT in dementia remains a complex endeavor. It has been set as a long-term challenge (2020–2030) by the Japan Advanced Institute of Science and Technology (Sugihara, Fujinami, Phaal, & Ikawa, 2015).

Valuing technologies for people with dementia: Assessment and economic model

From a person-centered approach, a technology has a value if it satisfies the needs of people with dementia and their caregivers, at an individual level. But who assesses how technology and related technology support services satisfy these needs? From an organizational point of view, the value chain of AT for people with dementia can be broadly described using 10 basic processes: research, industrial development, production, marketing, distribution, technology assessment, prescription, purchase (co-payment), device use, data sharing, user assistance, and device maintenance. These processes involve multiple professionals from many different cultures, with no clear identification of who is concerned with individual needs and technology use assessment (Table 4). The overall economic model is not yet stabilized and depends in part of collective funding to facilitate access to AT. In this emerging field, industrials are moving towards norms and quality labels of technology solutions to increase confidence of potential users, that these devices will satisfy their needs. Some Alzheimer's associations and people with dementia have started hands-on demonstration of technology devices that may be of interest. Technology assessment also involves opinion leaders running clinical trials, professional societies, care operators, central purchasers, and public funders. Occupational therapists could give relevant individual advice, as they know about activity limitations of people with dementia, if properly informed, trained, and engaged in technology assessment (Jarvis, Clemson, & Mackenzie, 2016). A predictive model to differentiate between adopters and non-adopters of everyday technology aimed at people with dementia has been described (Chaurasia et al., 2016). Validated tools for assessing the ability to use everyday technology in a standard way, such as ETUQ (Nygård et al., 2012; Rosenberg et al., 2009) and META (Malinowsky et al., 2011) deserve a larger diffusion in clinical practice (Nygård, Kottorp, & Rosenberg, 2015).

From a broader perspective, should society as a whole invest in AT for people with dementia? In other terms, does AT for people with dementia bring social innovation, which means a novel solution to a social problem that is more effective, efficient, sustainable, or just than current solutions? If so, the value created would accrue primarily to society rather than to private individuals (Phills, Deiglmeier, & Miller, 2008). The approach of social return on investment is emerging. For example, in England, lifetime costs of dementia, including publicly and privately financed health and social care, average 200,000 sterling pounds per person and per year from diagnosis to end-of-life. A technology, along with accompanying assessment and services, would be cost-effective

Table 3. Values, principles, rights, and obligations: the Technology Charter for people living with dementia in Scotland.

Values and principles	People living with dementia have a right to:	Partners in care need to:
- Practice and service provision is rights-based, personalized and free from discrimination. - Unpaid carers and families are recognized and valued as equal partners in care. - Information and advice about technology is available in clear everyday language and in a variety of formats. - Routes and access to technology are ethical, equitable, simple, understandable and user-friendly. - Consideration of technology is embedded at all key points in the integrated dementia care pathway. - Technology augments—but does not replace—human intervention.	- Enjoy equity of service and service provision. - Participate in decisions that affect them. - Feel safe, take positive risks and enjoy freedom of choice. - Have their strengths and experience acknowledged and used to maintain and develop skills. - Attain and maintain maximum independence, health and wellbeing. - Enjoy access to recreational, leisure, and cultural life in their community. - Have a strong clear voice.	- Have the health, safety and wellbeing of people living with dementia at the heart of what they do. - Share information and data with all other partners in care who support people to live well with dementia. - Value the knowledge and experience of those living with dementia. - Include people living with dementia in the design and development of technology enabled dementia care. - Support positive risk-taking and agree and share risk and responsibility. - Ensure technology is considered and included in the design of internal and external living environments. - Be confident that everyone involved in delivering care and support is aware of, and up-to-date with, the positive benefits of technology.

from a societal perspective if it either reduced unpaid care hours by about 8% or improved caregiver quality of life by 0.06 to 0.08 quality-added life-years (QALYs) per year (Knapp, 2016).

Discussion

Development of AT to address capabilities of people with dementia has been shaped in the past decade by major conceptual shifts about daily-life risk perception; viewing dementia as a (potential) disability, which led to enable and empower people with dementia; a more positive communication about technologies, putting benefits forward; and understanding the appropriation process of AT, building on the individual experience of people with dementia.

Changes in daily-life risk perception

Performing an activity of daily life may expose the person with dementia to a number of hazards, minor or harmful. Technology may reduce the occurrence of such events. Within a

Table 4. The economic value chain of assistive technology for people with dementia: processes involve multiple professionals from many different cultures, with no clear identification of who is concerned with individual needs and technology use assessment.

Process	Stakeholders
Research	Engineers
	Expert professionals
	People with dementia
	Caregivers
Industrial development	Engineers
	Expert professionals
Production	Engineers
Marketing	Business to business marketers
	Business to consumer marketers
	Opinion leaders
	Journalists
	Social media users
Distribution	Specialized vendors
	e-commerce vendors
	Associations
	Central purchasers
Installation and user assistance	People with dementia
	Family caregivers
	Professional caregivers
	Assistance professionals
Prescription	Family and friends
	Health and social care professionals
	People with dementia
Purchase (co-payment)	Individuals
	Social welfare
	Insurers
	Local governments
Device use	People with dementia
	Family caregivers
	Professional caregivers
Data sharing	Engineers
	Data managers
	Health and social care professionals
	Families
	Control authorities
Device maintenance	Technicians
	Operators
	Maintenance companies
Technology assessment	Associations
	Opinion leaders
	Professional societies
	Operators
	Central purchasers
	Public funders

decade (2005–2015), the notion of risk has evolved and broadened: new expressions emerged, such as positive risk-taking and risk enablement, to account for potential benefits as well as disadvantages upon risk evaluation, to distinguish risk from danger. As the British Department of Health stated in a landmark risk guidance for people with dementia titled: ''Nothing ventured, nothing gained'', risks must be balanced with opportunities that are likely to follow risk-taking (Department of Health, Manthorpe & Moriarty 2010). However, professionals, carers, and people with dementia consider risk differently. Understanding different ideas about risk is the first step in developing an effective risk mitigation strategy. Decisions about risk should not assume that all people with dementia are ''at risk'' but should be based upon understanding of individuals and their own understanding of the risks they may face.

Much early research and communication about technology in dementia care has covered barriers to be overcome, raising concerns about potential detrimental effects, such as intrusion on privacy, stigma (with reference to tracking devices), reduced human contact, or reduced use of paid caregiving. According to the Nuffield Council of Bioethics, these issues have the potential to affect both a person's autonomy, for example through feeling controlled or devalued, and their well-being, for example through impoverished human relationships. Where the persons with dementia have the capacity to choose for themselves whether to accept or refuse a particular technology, their decision should be respected. Where a person with dementia lacks the capacity to decide for themselves whether to make use of a particular technology, the relative strength of a number of factors should be considered on an individual basis, including the person's own views and concerns, past and present, the actual benefit which is likely to be achieved through the use of technology, and the extent to which the caregiver's interests may be affected (Nuffield Council of Bioethics, 2009).

Dementia as a (potential) disability

In 2010, the European Dementia Ethics Network stated that it was essential to recognize dementia as a disability (or potential disability), as the first step towards ensuring the appropriate design of AT to be used by or for people with dementia, and towards ensuring that people with dementia have access to it when it would be of most benefit to them (European Dementia Ethics Network, Alzheimer Europe, 2010). Persons with disabilities include ''those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others'', according to the United Nations Convention on the Rights of Persons with Disabilities, an international legal framework ratified by 163 countries. This Human Rights based approach for people with cognitive disability is a new policy currently being promoted by the advocacy group *Dementia Alliance International,* chaired by Kate Swaffer, a young Australian woman living with dementia, and *Alzheimer's Disease International* (Dementia Alliance International, 2016). However, only a small number of countries do legally recognize dementia as being a disability, which would facilitate access for people with dementia to appropriate support, including ATs. In most countries, disability allowance is actually considered as a compensation benefit for people who are unable to work as a result of their incapacity. As dementia usually develops far beyond the legal limit of working age, the disability

approach is rarely considered for them. Scotland has been the first country to have included people with dementia in its implementation of this UN Convention and to have appointed in 2002 a *Scottish Dementia Working Group* of people with dementia to advise the government, with the support of *Alzheimer's Scotland*.

A positive approach to AT for people with dementia

In 2015, the Technology Charter for people living with dementia in Scotland introduced a globally positive approach to technology for people with dementia and their partners, putting benefits forward: enabling and empowering, health and well-being, and safety and independence (NHS Scotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue Service, Tunstall, Tynetec, 2015). Developed in consultation with people with dementia, it provides a general framework, easy to understand for all stakeholders, setting up values and principles as a guide to take position on ethical dilemmas. It stems from a dual perspective: the rights of the people living with dementia, and the commitment and responsibility from the care partners (Table 3). This approach is supported by notions of positive and shared risk-taking, freedom of choice, acknowledgement of strengths and experience of the person with dementia. The Charter also states that technologies in all their forms and applications are an integral part of life today, not just because they are available, but because people find them useful.

Usage and appropriation of AT by people with dementia

Yet, few professionals are studying usages of technology, and how people with dementia appropriate it for themselves. A recent review of commercially available AT for people with dementia identified 171 products and 331 services, which can be grouped in products used "by" people with dementia, "with" them or "on" them (Gibson et al., 2016).

More and more, people with dementia express themselves on blogs: most of them use non-specific technologies, such as smartphones or computers, generally with a positive experience. Negative experiences are about remembering passwords, or the purpose of the different alarms. Under stress conditions, people with dementia tend to disregard AT devices sensory cues (Teipel et al., 2016). Caregivers also use non-specific technologies, such as electronic pads, baby monitoring systems, smartphones, light sensors, and pillows equipped with loudspeakers. Furthermore, technologies change all the time and may be perceived as more difficult to use by people with dementia (Malinowsky, Kottorp, Patomella, Rosenberg, & Nygård, 2015). A major barrier to technology use is therefore the difficulty to obtain counseling and support (Knapp, 2016). In-depth interview with people with mild cognitive impairment shows that persons with mild cognitive impairment may relate to technology in various ways to meet needs of downsized doing, but are reluctant to adopt video-based monitoring technology intended to support valued occupations (Hedman, Lindqvist, & Nygård, 2016). People with dementia living in institution appear ambivalent about surveillance technology: on one hand, it gives them freedom to venture into new spaces; on another hand, they may be reluctant to use the technology provided, as they do not like to be observed (Niemeijer, Depla, Frederiks, & Hertogh, 2015). Concerning recreational use of technologies, a key outcome is the pleasure of people with dementia as a positive experience: pleasure of being enabled, pleasurable moments with significant others,

pleasure of just enjoying, playing, and having fun. The use of robotic animals may be beneficial, when introduced prudently after in-depth discussion with persons with cognitive disorders and families, to anticipate potential ethical dilemmas that may arise about values such as honesty, dignity, well-being, and personal choice (Gzil, 2015).

An emerging issue concerns the use of technology to create simulated, fictitious environments for reminiscence purposes, aimed at reducing anxiety and stress of people with dementia, such as a VR forest (Moyle, Jones, Dwan, & Petrovich, 2017), or a fake vintage train station and compartment, with a large television screen as a window, to create the illusion of a real railroad journey. Among people with dementia, the prevalence of those living with different realities and beliefs varies greatly from around 20% to 70%, in small part depending on the type of dementia a person has (Stokes & Kousoulis, 2017). Dilemmas with carers arise when the two realities meet. Truth or untruths can both cause unnecessary distress, but they can also create joy or necessary negative emotions. Approach must be flexible: person first, intervention second. Each perceived reality shall be explored with the carer, to make sense of the world together (Williamson & Kirley, 2014).

Access to technologies involves information, hands-on testing and learning, rapid and flexible procurement, and affordability. In the perspective of people with dementia and their caregivers, *Alzheimer's Scotland* has developed an initiative to find, test, and share information about domestic products to help people with dementia (clocks, telephones, mobile applications, etc.) These products are tested by the persons themselves and exposed in the resources centers of the association (Gray, 2016). Learning and using everyday technology are intertwined processes. It is therefore important to support continued use of everyday technology as long as it is valued and relevant to the person with mild cognitive impairment or AD (Rosenberg & Nygård, 2014). Rapid and flexible procurement of AT is required to provide a timely response to the changing needs of people with cognitive disability at the different stages of severity (European Dementia Ethics Network, Alzheimer Europe, 2010).

Finally, two outstanding examples of usage and appropriation of technologies to empower people with dementia, on an individual and collective level, are worth mentioning. On an individual level, Masahiko Sato (2014), in the first book ever written by a person with dementia in Japan, explains how, diagnosed with early-onset AD in 2005, he was able to live actively and independently during 10 years before moving to a retirement home in 2015, partly thanks to AT. He had worked as a systems engineer for a computer company before his diagnosis. He started using social media and an *iPad* a few years after he was diagnosed with AD. He made it a habit to turn his computer on and check his *Google* calendar when he gets up every morning, not to lose track of time. Before he goes out, he sets several timers on his mobile phone around the scheduled appointment. Using a train timetable and route finder software, he makes sure he gets an alert on his phone while on the train so he won't forget where to get off. He has more than 1,300 friends on *Facebook*, and makes frequent speeches around the country to share his experience. He recommends that other patients start using such tools in the early stages of their illness. On a collective level, *Dementia Diaries* is a UK-wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries. It serves as a public record and a personal archive that documents the day-to-day lives of people living with dementia, with the aim of prompting a richer dialogue about the varied forms of the condition. Project uses 3D-printed mobile handsets which are customized to be as simple as possible (Woodall, Suur, Kinsella, & Bunyan, 2016).

Conclusion

ATs are part of a global approach of non-drug interventions in dementia care. They deserve further attention in both research and practice. Within a psychosocial model of disability, AT can be viewed as an enabling tool to promote autonomy and citizenship of a person with dementia throughout daily life activities, in a positive way. This approach has started to influence public policies. Knowledge about these technologies must be developed among family and professional caregivers. Design and adaptation of AT must be based on individual needs of people with dementia. Validated tools for assessing the ability to use everyday technology by people with dementia deserve diffusion in professional practice. To be effective and respectful of people with dementia, technological innovation must build upon social innovation, with increased input from human and social sciences.

Declaration of Conflicting Interests

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Paul-Ariel Kenigsberg, PhD Biochemistry and MBA, is assistant manager of the coordination, prospective and strategy unit at the Fondation Médéric Alzheimer (Paris, France). He studied Prospective and scenario building at the University of Oxford. He is

chief editor of the national and international Press Review of the Fondation. This knowledge base, unique in its kind, established more than 10 years ago, allows prospective watch-keeping of the context of AD in its scientific, medical, technological, social, cultural, professional, political, economic, legal aspects, and spotting of innovative initiatives worldwide. He also leads the prospective expert groups of the Fondation Médéric Alzheimer. His current work focuses on the sensory approach in Alzheimer's disease and on technologies for people with dementia and their caregivers, early diagnosis and prevention.

Jean-Pierre Aquino, MD, specialized in Geriatrics and Public Health, is head physician of the Porte verte Medical Clinic in Versailles, technical advisor of the Fondation Médéric Alzheimer, he has been president of the French Society of Geriatrics and Gerontology (SFGG). Under these different titles, he participated in the Ménard Commission's work and in several working parties of the French Alzheimer Plan 2008–2012. As a President of the Committee on Advancing in age, prevention and quality of life, he provided a report to the government titled "Anticipate for a preserved autonomy: a societal issue", used to prepare the upcoming Law for adapting the Society to Ageing.

Alain Bérard, MD, specialized in Public Health, economist and jurist, is Deputy Director of the Fondation Médéric Alzheimer where he also manages the Coordination, Prospective and Strategy unit. His research work and publications focus on the needs of people of 65 years old and above, on the different professions working with people with dementia, on the social and asset management behaviors of people with young-onset dementia, and more recently on sensory impairments and Alzheimer's disease. He also performs evaluation of health, social and medico-social services for modeling and dissemination purposes.

François Brémond is research director at Inria and he is leading the STARS team at INRIA Sophia Antipolis. He designs and develops generic systems for dynamic scene interpretation. The targeted class of applications is the automatic interpretation of indoor and outdoor scenes observed with various sensors and in particular with static video cameras. These systems detect and track mobile objects, which can be either humans or vehicles, and recognize their behaviors. He is particularly interested in filling the gap between sensor information (pixel level) and recognized activities (semantic level). In 1997 he obtained his PhD degree at INRIA in video understanding and François Brémond pursued his research work as a post doctorate at USC on the interpretation of videos taken from UAV (Unmanned Airborne Vehicle). He has also participated to many European and industrial research projects in activity monitoring. François Brémond is author of more than 140 scientific papers published in international journals or conferences in video understanding. He is a co-founder of the Nice University team CoBTeK dedicated to the studies of ICT technologies to better understand behavioral disorders. More information is available at: http://www-sop.inria.fr/members/Francois.Bremond/.

Kevin Charras is psychologist and doctor in environmental psychology from University Paris-Descartes. His doctoral thesis focused on an enabling architectural environment for people with dementia and autism. He started his career as a psychologist in child psychiatry

in Rennes and joined the Fondation Médéric Alzheimer in 2007, first as Manager of the Studies Department and since 2010 as Manager of the Psychosocial Interventions Department. He developed and tested an intervention program or people with dementia, combining the architectural environment with the education of care professionals: *Eval'zheimer©*. He authored many articles on the impact of the environment on people with dementia and on psychosocial interventions in dementia care.

Tom Dening, MA MD FRCPsych, is professor of dementia research at the Institute of Mental Health, University of Nottingham, and Honorary Consultant in Old Age Psychiatry, Nottinghamshire Healthcare NHS Trust. 1991 to 2012, he was a Consultant Psychiatrist in Old Age Psychiatry in Cambridge and 2002–2011, Medical Director of the Cambridgeshire & Peterborough NHS Foundation Trust. His interests include the epidemiology and treatment of dementia and depression in older people, psychiatric services, dementia and technology, care homes and other clinical topics. He is an editor of the Oxford Textbook of Old Age Psychiatry, the leading international work in this field.

Rose-Marie Droës is professor of psychosocial care for people with dementia at the department of General practice and Elderly care medicine of the VU University medical center, head of the research program 'Care and support in dementia' of the department of Psychiatry and the Regional Institute for Mental Health Services GGZ-inGeest in Amsterdam. Her research program is part of the program Quality of Care and Common Mental Disorders of the EMGO Institute for Health and Care Research. Her research interests encompass quality of life in dementia, need of care and support of people with dementia and family carers in the community, support programs for persons with dementia and family carers, opportunities for ICT-solutions for unmet needs in dementia care, helpdesk for psychosocial care in dementia.

Fabrice Gzil is doctor in philosophy and manager of the studies department at the Fondation Médéric Alzheimer. In his doctoral thesis, which was awarded in 2008 the Prize of Academic Research by the newspaper *Le Monde,* he studied the history of the discovery of Alzheimer's disease, animal models of cognitive impairments related to ageing and moral philosophy issues raised by the progressive alteration of discernment and judgment (*La maladie d'Alzheimer: Problèmes philosophiques, Presses Universitaires de France,* 2009). At the Fondation Médéric Alzheimer, he is in charge of providing support to psychosocial research and research in human and social sciences. His current work focuses on care ethics and research in the context of dementia, as well as on the ways to promote rights, freedom and citizenship of people with cognitive disabilities.

Ben Hicks is lecturer in health psychology at Bornemouth University, and is involved in a number of research projects in the field of health psychology and the management of chronic health conditions. He undertook work on the Olympic Build, evaluating their Occupational Health facility and also for the Social Care Institute for Excellence (SCIE) where he managed a research project to develop guidance for care homes that wished to use ICT to improve the lives of people with dementia. After this project, he decided to undertake a funded PhD at Bournemouth University Dementia Institute (BUDI), exploring the impact of social clubs for older men with dementia in rural Dorset, England. These social clubs run activities for the men using commercial gaming technology such as iPads, Nintendo Wii, and Microsoft Kinect.

Anthea Innes, PhD in Sociology, is University of Salford's first professor of Dementia. She worked as a senior lecturer in Dementia Studies at the Department of Applied Social Science of the University of Stirling, before being the director of launched the Bournemouth University Dementia Institute. Her work explores the process of changing the culture of dementia care in care settings, of dementia provision in rural Scotland and how to elicit service users' views. She was a member of the groups advising the Prime Minister on rural dementia care and dementia friendly technology, while she also introduced the first worldwide postgraduate online program in Dementia Studies in Stirling.

Sao-Mai Nguyen is associate professor at Institut Mines-Télécom Atlantique-Bretagne-Pays de la Loire (Brest, France). After graduating from Ecole polytechnique in Informatics, she led research in Osaka University in Cognitive Robotics. She studied how robotics could help study cognitive impairments, with a focus on the theory of mind and autism. She then completed her PhD at INRIA on learning strategies for robots based on active learning and imitation learning. With Pierre-Yves Oudeyer, she studied how to combine curiosity-driven exploration and socially guided exploration to learn motor skills into an interactive learner. After two postdocs in Queen Mary University of London and University of Plymouth in computational neuroscience, she tries to bridge robotics, artificial intelligence, and cognitive science. Her interests lie in linking research of machine learning, robotic embodiment, developmental psychology, and neuroscience to make information and communication technology improve the everyday lives of the elderly and the disabled.

Louise Nygård, PhD, is professor of occupational therapy at the Division of Occupational Therapy at Karolinska Institutet (KI) in Stockholm, Sweden. She has conducted research in the field of dementia since 1990, with a particular interest in the experiences of persons with dementia, especially in the early and moderately severe stages. She finished her PhD at KI in 1996. Since then, she has established a research group of about 20 persons, Cognitive ACcessibility and Technology Use when aging in home and Society (CACTUS). She has published over 70 peer-reviewed papers and also reports and chapters in international and Swedish books. In recent years, her particular interest has been in the conditions for people with Mild Cognitive Impairment (MCI) or Alzheimer's disease (AD) as users of technology. Her research group has explored how people with MCI/AD manage the common everyday technology of today's society and how they can be supported by assistive technology. Her group has developed two assessment instruments of ability to use technology. These are being validated and increasingly used in both research and clinical practice. She has also continuously taken a strong interest in qualitative research methodologies, with qualitative studies in the real life contexts of people with dementia. She has also published on methodology on how we can access the experiences of people with dementia in research.

Maribel Pino, PhD in Cognitive Psychology/Ergonomics, is scientific coordinator of LUSAGE (Broca Hospital, Paris Descartes University), a Living Lab specialized in the design and assessment of Assistive Technology (AT) for older adults, particularly those with cognitive impairment due to Alzheimer's disease or related dementias, and their caregivers. Since 2009, Maribel Pino has been co-investigator in several French and European projects in the fields of Ambient Assisted Living and Healthy Aging. Her current research concerns Social Robotics, virtual agents, the psychology of engagement

in dementia, and theoretical frameworks for the design, selection, and assessment of AT and their integration within existing dementia care pathways.

Guillaume Sacco is geriatrician in the Memory Center of the Côte-d'Azur University Hospital in Nice (France) University Hospital. He also teaches Geriatrics and General practice at the Faculty of Medicine and is a medical expert for the CIU-santé (Center for Innovation and Uses in Health). He is currently preparing a PhD thesis with the CoBTeK (Cognition, Behaviour & Technology Unit) research team, about the interest of digital technology in assessment and treatment of the frail elderly.

Eric Salmon, MD, PhD, neurologist, professor, is head of the Memory Centre, Department of Neurology, University Hospital, Liege, Belgium; medical director of the Cyclotron Research Centre, University of Liege; principal investigator in the EC projects NEST-DD, European Alzheimer Disease Consortium (5th FW) and DiMI (6th FW), in Belgian InterUniversity Attraction Poles, in several clinico-pharmacological studies. Teaching in the Faculties of Medicine and of Psychology, University of Liege; involved in InterUniversity teaching programs. National and international research programs on neurodegenerative diseases, cognitive functions, and functional imaging.

Henriëtte van der Roest studied Social Psychology at VU University Amsterdam. Her PhD thesis, at the Department of Psychiatry, VU University medical center/GGZ Buitenamstel, focused on care needs in dementia and digital interactive information provisioning. From 2008 to 2009, she worked as a researcher at the Department of Mental Health of the University College London. Since 2009, she has been a researcher at the Department of Elderly Care Medicine, VU University medical center Amsterdam. She is currently involved in the SHELTER project, a European study that aims to validate a comprehensive assessment tool, the Minimum Data Set (MDS) for long-term care residents (InterRAI-LTCF) as a methodology to assess the provision of care in long-term care facilities in Europe. The study will ultimately lead to the creation of the first, cross-national European database of long-term care residents containing information previously not available on residents typology and outcomes, quality measures and services characteristics. She is also interested in dementia care and assistive technology for dementia.

Hervé Villet, MD, specialized in Public Health and Master in Health Economics, is assistant manager of the Observatory of Alzheimer's Disease Care Services at the Fondation Médéric Alzheimer. For the past 10 years, the Observatory has been conducting national surveys on the different services, in order to produce regular statistics and maintain a service directory, as well as thematic surveys on modalities of care and professional practices. His current work concerns the legal protection of people with Alzheimer's disease, social activities in gerontology and specific Alzheimer units. A national survey on sensory impairment and dementia will be launched in 2015.

Marion Villez, PhD in Sociology, is lecturer at the Interdisciplinary Research Laboratory on Education and Social Practice Transformations (LIRTES) of the University of Paris-Est-Créteil-Val-de-Marne (France). She worked previously as a Local Initiatives Department Manager at the Fondation Médéric Alzheimer. Her mission consisted in building up innovative issues to promote, support, and evaluate new initiatives dedicated to people

with dementia, their caregivers and professionals all around the country. Her PhD thesis focused on design and care practices of people with cognitive disorders in nursing homes.

Philippe Robert is professor of psychiatry at the Nice School of Medicine, Director of the Nice Memory Centre for Care and Research, Director of the Cognition, Behaviour & Technology Unit (CoBTeK) at the Côte-d'Azur University in Nice (France). He is the coordinator of the French National Alzheimer data bank. The CoBTeK unit aims to develop and transfer new technologies, developed for the benefit of clinical medicine and most particularly elderly subjects and others patients suffering from neuropsychiatric / neurodevelopmental disorders. CoBTeK provide an optimal partnership between engineers (INRIA) and clinicians (Memory center, CMRR) corresponding to the ''ICT or computer-to-clinic'' link.

Valeria Manera is a postdoctoral fellow at the CoBTeK unit of the Côte-d'Azur University in Nice (France). She has a Master degree in Clinical Psychology and a PhD in Cognitive Science. She spent long research periods at the University of Leuven (Belgium) and at the Stanford Psychophysiology Laboratory (California). Her domains of expertise include biological motion perception, emotion recognition and regulation, and dementia prevention. She is researcher in the French team of the In-MINDD project.