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CLINICAL PRACTICE: CURRENT OPINION

Creating a consumer-driven global community of practice to support action within environmental design with people living with dementia: assistive technology challenges and opportunities

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Abstract

The environment, and assistive technologies as part of this, can play an important role in supporting the participation and wellbeing of people living with dementia. If not considered, environments can be overwhelming and disempowering. Disability approaches including environmental considerations and assistive technology were often not offered routinely with people living with dementia. Concerned by this, dementia advocates aimed to create change in this area. The Environmental Design-Special Interest Group (ED-SiG) of Dementia Alliance International was developed as an international consumer-driven community of practice bringing together people with different relevant expertise including living experience (people living with dementia, care partners), architecture and design, occupational therapy, rehabilitation and care provision. This practice opinion piece provides an overview of dementia, the need for collaborative practices within practice with people living with dementia, and the considerations of assistive technology, environmental design and the global context. The reflection provides insights into this international community of practice, with personal reflections of members with living experience of dementia, and benefits and opportunities in considering environmental design and assistive technology from the perspectives of members. This work demonstrates and advocates collaborations that centre the perspectives and expertise of people living with dementia.

Keywords: Dementia; assistive technology; consumer; community of practice

Introduction: Background of dementia, assistive technology and environmental design

Dementia

Dementia describes a syndrome causing neurodegeneration and changes to cognition, sensory perception and behaviour; and its symptoms can reduce a person's independence in daily life. Over 100 health conditions can cause dementia, including Alzheimer's disease and vascular dementia (Laver et al., 2016; World Health Organization, 2018b). It is anticipated that 75 million people worldwide will be living with dementia in 2030, roughly 5% of the world's older population, with a growing proportion (71% of new cases) occurring in low and middle income countries (World Health Organization, 2018b).

Currently, there are no curative treatments, but there are evidenced ways to reduce some symptoms; and a person-centred approach to clinical support is recommended (Laver et al., 2016). Evidenced approaches include: pharmacological and non-pharmacological support for dementia-related symptoms; education and support for people living with dementia and family carers; rehabilitation/reablement; support for psychological needs; aiming towards living well with dementia (Laver et al., 2016; World Health Organization, 2018b). With the focus on living well, independence in daily activities, participation and wellbeing, there is increasing attention towards inclusive and accessible communities and environments (Zeisel et al., 2020).

While dementia is now recognised as a major cause of disability and dependency in later life (World Health Organization, 2017a; World Health Organization, 2018b), it has not traditionally been considered a disability. Dementia has historically been classified in different ways, affecting the philosophy and approach to the care and services provided. Concerns about the quality of care and level of unmet needs have prompted calls for new approaches to supporting people living with dementia (Alzheimer Europe, 2017; OECD, 2015). International organisations, dementia advocates and health professionals are supporting the recognition of dementia as causing disability.

Recognising dementia as causing disability is anticipated to expand the nature of support approaches that are considered for people living with dementia, including rehabilitation/reablement; community-based living and goal-focused approaches to participation. Importantly, the conceptualisation also highlights the human-rights-based protections and approaches (Alzheimer Europe, 2017). These focus on supporting the development of inclusive communities, on applying the United Nations Convention on the Rights of Persons with Disabilities and on centring the perspectives of people living with dementia (Alzheimer Europe, 2017; Swaffer, 2020, 2021).

Collaborations with people living with dementia

Internationally, dementia advocates and organisations call for stronger inclusion of experts with living experience, that is, people who live with dementia. Historically, however, these dementia experts have often been excluded from participation, including in research projects, policy development, the design of assistive technologies they would like to use (O'Connor et al., 2022; Pachana et al., 2015; Swaffer, 2014). One reason for this exclusion lies in implicit associations and stereotypes about dementia including assumptions that people living with dementia might not be capable, interested or able to contribute to research or practice (Phillipson et al., 2019, Roberts et al., 2020; Rohra et al., 2021). Furthermore, existing infrastructures can also lead to exclusion due to the way research or design processes work, or how expertise is defined (World Health Organization, 2017a). Yet, living experience experts through providing their diverse and nuanced perspectives, can challenge assumptions and decrease stereotypes about dementia, driving forward research and practice. Collaboration over time can improve outcomes and foster a person-environment/technology fit (Gitlin, 2002; Liddle et al., 2022, Rohra et al., 2021). The engagement of living experience experts is a required aspect of many research, policy and service development processes. With this growth, the frequency of living experience experts in leading research, advocacy and change is increasing, creating advantages for researchers and improving outcomes (Kowe et al., 2022; Slattery et al., 2020).

Communities of practice

Communities of practice (CoP) describe an approach to networking, skill building and collaboration, where members focus around a shared purpose. Definitions indicate the importance of a shared endeavour and identity within group members as an approach to access knowing and learning about a topic (Wenger, 2011). CoP are activities- or practice-based, focused around problem solving, sharing experiences, coordinating action, collaborating and mapping gaps in knowledge. Regular interaction and sharing of experiences, resources and knowledge across contexts allow CoP to build identity, skills and action in its members. CoP vary according to their context and identified purpose (Ranmuthugala et al., 2011).

Assistive technology

Assistive technology is the umbrella term for the combination of assistive products and the services needed to ensure safe assessment, distribution and use of assistive products (AS/ISO, 2018). Assistive *products* are any product (including devices, equipment, instruments and software), used by or for persons with disability for participation, to protect, support, train, measure or substitute for body functions/structures and activities, or to prevent impairments, activity limitations or participation restrictions (World Health Organization, 2017b). Evidence exists about how effective these types of support are (Cho et al., 2016; Smith et al., 2018; de Witte et al., 2018), what people would like them to look like (Desmond et al., 2018), to do (Tebbutt et al., 2016) and how they could be developed further (MacLachlan & Scherer, 2018; Scherer et al., 2018). The scope of assistive products for people with disability (ISO 9999, 2016) and the outcomes possible (World Health Organization, 2001) are well articulated. Current clinical guidelines for supporting people living with dementia recommend occupational therapy services including assessment, prescription, advice or support for assistive technologies and home modifications to facilitate participation (Laver et al., 2016).

Environmental design

The important role of the built environment and its impact on the dignity and quality of life of people has been recognised in the World Alzheimer Report 2020 (Zeisel et al., 2020). This work emphasised the importance of considering human rights, participatory approaches and considering cultural contexts in environmental design. It demonstrates that design for dementia is 30 years behind design for physical disability (Fleming et al., 2020). It is essential to understand that the physical environment cannot be considered in isolation from the social environment; hence, it is important to understand how communities relate to both dementia and people living with dementia.

It has been argued that when the community is dementia-friendly, that is: aware, has policy, infrastructure and social readiness to meet the needs of people living with dementia, then the process of modifying the physical environment is easier and more sustainable (Frost & Fleming, 2020). Researchers argue that when the built and social environment fits the needs, aspirations and perspectives of people living with dementia, it is likely they can remain longer in familiar living environments, staying actively involved in the community and being confident when navigating familiar or unfamiliar environments despite challenges (Kuliga, et al., 2021).

Relationships between assistive technology and environmental design

Assistive technology and environmental design and modification are key strategies in supporting participation and quality of life for people with disability (Layton, 2017). One link between assistive products and environmental design can be viewed as a technology chain. On one end are assistive products placed into environments. These include, for example, a shower stool in a step-less shower recess; or fixtures and fittings, such as handrails, or wired smart-home technologies. At the other end of the chain are built features of the environment, which intersect with the embedded assistive products. These include ramps with handrails; or a no-sill doorway with ceiling track and hoist.

Assistive technology is embedded differently within each environmental scale, for example at a personal room level or in considering a shared building, or city. Assistive technology may be considered at the individual level or in shared environments, which can be large-scale, complex structures, (re-)designed over time, involving various stakeholders (with competing interests), where the needs of diverse users of space need to considered (Kuliga, et al., 2021). Given the interaction of assistive technology and environments, it is essential for designers, prescribers and users of technologies and environments to consider and address the needs of people living with dementia. Stronger advocacy and mandates for inclusive and dementia-enabling design principles are required (Kuliga, et al., 2021).

Following the World Alzheimer Report 2020, the Dignity Manifesto of Design for People Living with Dementia has been released and can be signed by those supporting its aims and vision (Design Dignity Dementia Team, 2021). The Environmental Design – Special Interest Group (ED-SiG) works towards creating awareness, and getting the agreement, adoption and adherence values into best practice for design, while following the recommendations proposed in the World Alzheimer Report 2020, and the Dignity and Design Manifesto. A description of the COP and authors' reflections and description of the motivation for beginning this CoP follows.

Assistive technology and environmental design have been relatively neglected within research and practice with people living with dementia (Fleming et al., 2020; Pagone & Briggs, 2021). This work serves to provide a brief overview of key considerations based on literature and authors' reflections (including living experience). It represents a collaborative reflection on current actions, challenges and opportunities from the perspectives of members of a community of practice (CoP).

The Environmental Design – Special Interest Group (ED-SiG)

Group structure

The Environmental Design – Special Interest Group (ED-SiG) is part of Dementia Alliance International (DAI; Dementia Alliance International, n.d.), an international advocacy and support group led by people living with dementia. DAI is a not-for-profit organisation with free membership for people living with dementia, relying on donations and sponsorship for its activities. Under ED-SiG, the focus on environment includes: the natural environment; built environment; rehabilitative environment; communal living environment; and sustainable environments. The intention of the ED-SIG group is to function as a CoP, identifying ways to discuss, use and incorporate environmental factors, such as assistive technology; architecture and design; aspects of the natural environmental, societal and attitudinal aspects of environment and related services, systems and policies, to improve the quality of life for people living with and affected by dementia. It was important to have people living with dementia together with experts from multiple disciplines like environmental design and architecture, occupational therapy, gerontology, neurology, ophthalmology, disability and accessibility, and care partners.

In May 2022, ED-SiG had 32 members from 5 continents – North America, Latin America, Europe, Asia and Australia. The full ED-SiG group and the steering committee (10 members) meet every two months via Zoom. Group membership happens mainly through referrals and interested individuals submit an Expression of Interest. There is no fee for membership and no specific income for ED-SiG, relying on voluntary steering committee and community membership. It is very important for the group to have a global representation of international experts, because Asia, Africa and Latin America are identified as regions expecting substantial growth in population with dementia, along with lower-middle-income countries (Prince et al., 2015). Environmental factors can be a huge barrier to improvement in quality of life.

Members of ED-SiG are change agents and mobilisers, and their role is to reach out to community leaders, researchers, policy-makers, healthcare professionals, architectural and design associations, to get them to consider and implement inclusive and dementia-enabling environmental design. ED-SiG will also provide expert support within resource constraints. The goal of ED-SiG is to work together with global and local partners to improve the quality of life for people living with dementia by making the environment accessible and accommodating.

Action plan

The group's initial action plan aims to create awareness and get the agreement, adoption and adherence to the values, environmental design best practices, and the recommendations stated in the World Alzheimer Report 2020 *Dignity, Design and Dementia*, and the Dignity and Design Manifesto in four objectives.

1. Curriculum and licencing-related education for (health and built environment) professionals to include design and dementia content.
2. The Convention of the Rights of Persons with Disabilities to recognise environmental design guidelines for people living with dementia
3. National Dementia Plans globally to include environmental design included as a nonpharmacological intervention.
4. National Dementia Associations to be better equipped with environmental design resources and information, making it a key advocacy item in the priority list.

Current group activities focus around the objectives. For Objective 1 and 4, ED-SiG seeks to compile the relevant resources and make it easily accessible for universities and national dementia associations to adopt and advocate changes. Objective 2 and 3 focus on reaching out to policy-makers and national dementia associations to include environmental design in their national dementia plans and advocate for inclusion with the United Nations.

Author's reflection: the Environmental Design-Special Interest Group as a Community of Practice

The International Classification of Functioning, Disability and Health (ICF) recognises environmental factors as one of the three components defining functioning and disability (World Health Organization, 2001). The complex interactions between an individual's health condition, internal personal factors and environmental factors influence how a person with dementia experiences their disability both at the functional level of what they can do in a standard environment and what they participate in their usual environment (World Health Organization, 2001).

When I (EO) was diagnosed with young-onset dementia in 2017, my greatest fear and concern was losing my independence and feeling 'imprisoned' by the environment. Gradual functional decline is a reality for us living with progressive, terminal Major Neurocognitive Disorders. People would over time lose their ability to do things from most complex cognitive tasks to simple tasks to self-care in the late stage. A familiar environment might become a nightmarish maze to navigate with the declining capacity to comprehend. A cosy and nurturing home environment will become a cold and disempowering place with restrictions and participation limitations.

Being an educator in disability, I soon realised that many of the difficulties I experienced are similar to those experienced by people with a disability. In other words, a large extent of the struggles encountered by people living with dementia is because of inaccessible and unaccommodating environments. I use public transport to get around, and a big issue I have is my audio and visual senses get overloaded and overstimulated by external environmental factors. The noise level at a busy interchange and information-dense cramped signages require effort that is hard to manage, creating disability.

In Norway, I felt so at ease because I didn't experience audio overload. At the concourse area, they have personnel stationed outside the passenger counter to assist. The train has an option of no talking in the cabin for someone like me who easily get overloaded with the noise level. While there are noise cancellation headphones they may be financially inaccessible and aimed at one individual rather than helping people generally.

The special interest group was started to look specifically into different aspects of the environment, its usages, the accommodations and accessibility needed to support the way people living with dementia interact and use the environment. Dementia Alliance International, as a consumer-run not for profit with expertise in advocacy, was well situated to provide the guidance, infrastructure and support for starting and running the ED-SiG, with involvement of co-founder Kate Swaffer.

Manner of collaboration

ED-SiG follows the international advocacy and action call for 'nothing about us without us' (Alzheimer Europe, 2013; Bryden, 2016; Ong, 2021; Rohra, et al., 2021). In terms of the level of involvement and participation (cf. Arnstein, 1969), the ED-SiG group is self-organised by living experience experts who set their priorities, topics and action plans. Members are people living with dementia, care partners, and researchers/practitioners from multiple disciplines, settings and practice areas.

ED-SiG has its share of challenges because it operates based on 100% volunteerism of the members. When there is a project to be done, members can decide if they are interested to take it up and work collectively. As living experience expert (EO) reflects: being an international community, to call for a meeting where everyone can attend, is a struggle. Hence, involvement of members is not limited to meetings but can also happen via e-mail correspondence. It is very tough on ED-SiG because I, as project lead, must manage all these correspondences, handling meetings and doing minutes without any administrative support, and I am a person living with dementia. Despite the challenges, ED-SiG was able to submit collective policy input for the Australian Residential Aged Care Framework (Department of Health, Australian Government, 2021).

Value of Engagement

Our experience with the ED-SiG has strengthened our belief that collaborative approaches between people with living experience (people living with dementia, family care partners), and others with relevant expertise are feasible and impactful. Members have various motivations but share a focus on making meaningful changes in the broader community to support inclusion and quality of life.

Working together advances the understanding and actions taken by bringing forward issues not previously considered, including practicalities and unintended consequences. It also amplifies the impact of any one member working on an issue, or creating a small scale inclusive environment. For example, a gerontology professor member in Canada, supported a living experience expert member with a local initiative in Singapore with wayfinding supports at public transport interchanges. In addition, working across diverse contexts has been important in understanding the range of ways of working, challenges in local environments, and impacts of policy, funding and culture.

Impact

The CoP, and its members in independent activities, create impactful change, as living experience expert (DF) indicates: I have a background involvement in developing dementia friendly communities, specifically Kiama (a coastal, regional town in Australia). As part of our early approach, we had a lot of input from individuals who had been working toward more dementia-enabling environments. One outcome of this was evidenced by our local Dementia Advisory Group being asked for input on new signage for a local public facility.

The ED-SiG fulfils a unique role in enabling all sorts of stakeholders in assistive technology and environments to come together and to say ‘what *good* looks like’. In our view, the voices of diverse communities must be heard to ensure our data, classification systems and policies are written with a full appreciation of the diversity of human experience. Significant research has been conducted on physical environments for physical impairments. To understand the design features which suit specific groups of people, whether this is dual sensory loss or dementia, will inform what works for people overall – and will tell us how design guidelines may need to be nuanced / different rather than universal.

Group Member Reflections: Challenges and Opportunities with Assistive Technology, Environmental Design and People Living with Dementia

In creating this reflection on the community of practice, group members were invited to contribute to writing this paper, consider their involvement, experiences, aims and practices and to identity key challenges and opportunities with assistive technology. Some authors engaged through writing, others through verbal discussion, and all contributed to the conceptualisation of key issues.

Acceptability of technology

There are many (sometimes contradictory) assumptions about assistive technology for people living with dementia. There seems to be an assumption that people living with dementia do not use technology. At the same time, it is assumed that everyone can and wants to use technology. In our view, both are false assumptions. A challenging area for practice is to confront assumptions and encourage richer understandings of what makes technology usable and acceptable for people. For example, CoP members indicate that technology should show clear benefits to users and help with things they identify as important. It should be transparent and ethical in how it collects, stores and shares data. It needs to also be able to be adapted and personalised so that it works for the user and those in their care network. Part of acceptability means looking into how the technology has been developed and evaluated – including the important inclusion of living experience experts.

One size doesn’t fit all

To address the current limitations in many technologies, ED-SiG members identified the need for recognition of the diversity of people living with dementia, including moving away from stereotypes, and solutions based on diagnosis, rather than individual strengths, needs and priorities. For instance, technology developers and prescribers need to recognise cultural diversity and diversity of environments of technology use, including remote and rural areas. It is important to also recognise that not everyone will want to use technology. Because the diversity of users, needs, contexts and use preferences are not currently well understood, there are concerns that diversity is not represented in big datasets. These datasets are driving future technology development and resource allocation (e.g., through machine learning and artificial intelligence). Lack of representation in these datasets risks rendering future technology and supports less relevant, less usable, and less acceptable to diverse users, missing opportunities to design supports that are seamless or joyful to use.

Technology replacing people

There was substantial concern that the focus of technology being marketed seems to centre around replacing human-based assistance. Many people living with dementia want connection and participation, rather than taking a focus on independence. The goals and values of technology use thus need further reflection and consideration. It is important that technology-based supports do not become mandated or the only option of support.

Tensions

CoP members identified a series of tensions experienced in their involvement in technology and environmental considerations with people living with dementia. Tensions ranged from that of being engaged in activism versus an objective researcher role; and the commercial pace and focus on profits, with associated pressures of technology development. The need to embrace complexity in considering different disciplines, perspectives and cultures was highlighted. Members also identified tensions with environmental and technology approaches developed for physical or sensory disability in heightening difficulties for people living with dementia. This included tactile marking and ramps making physical environments difficult to navigate; and multiple sensory streams (e.g., spoken, visual captioning, signing) making accessing information challenging.

Opportunities

The group has identified opportunities to focus upon; for example, aiming to raise the profile of issues for people living with dementia, including with organisations and individuals not historically associated with working directly with the group. This has included architects, lawyers, designers and technology developers. The CoP also identified opportunities to advocate, build skills and begin to conduct research together, across a range of contexts. Given the global focus, the opportunities within two international assistive technology related organisations are also noted. This includes a 'top down' network, the Global Cooperation on Assistive Technology (GATE; World Health Organization, 2018a), which is co-ordinated by the World Health Organization as a step towards realising the Sustainable Development Goals, and the Convention on the Rights of Persons with Disabilities. A 'bottom up' approach is the newly established a Global Alliance of Assistive Technology Organizations (GAATO, n.d.). GAATO is a non-profit association of legally established AT peak body or membership organisations.

Conclusions

The ED-SiG is a community of practice focused on action and creating change within an area of need. Many opportunities and challenges exist in considering assistive technology for people living with dementia. There is a great need for investment in participatory research and support programs with a focus on assistive technology and environment design with people living with dementia and cross-disciplinary teams. The contributions of people living with dementia within research, practice and advocacy have clear value, and funding research and advocacy approaches that are accessible and inclusive are essential. Taking a cross-disciplinary, international approach, which centres and respects the expertise of people with lived experience with dementia, is a distinct strength of the community of practice, which could be considered by other groups seeking to support action in inclusive practice.

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References

Alzheimer Europe. (2017). *Dementia as a disability? Implications for ethics, policy and practice. A discussion paper*. Alzheimer Europe. Retrieved 05.05.2022 from https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_ethics_report_2017.pdf.

Alzheimer Europe. (2013). “Nothing about us without us”. Retrieved 05.05.2022 from https://www.alzheimer-europe.org/Conferences/Previous-conferences/2013-St-Julian-s/Detailed-programme-abstracts-and-presentations/SS1.-Nothing-about-us-without-us.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, *35*(4), 216–224.

AS/ISO (2018). *ISO 9999 Assistive products for persons with disability—classification and terminology*, AS/ISO 9999.

Bryden, C. (2016). *Nothing about us, without us!: 20 years of dementia advocacy*. Jessica Kingsley Publishers.

Cho, H. Y., MacLachlan, M., Clarke, M., & Mannan, H. (2016). Accessible home environments for people with functional limitations: a systematic review. *International Journal of Environmental Research and Public Health*, *13*(8), 826. doi: 10.3390/ijerph13080826

Department of Health, Australian Government. (2021). New residential aged care standards. Retrieved from https://consultations.health.gov.au/ageing-and-aged-care/new-residential-aged-care-design-standards/.

Dementia Alliance International. (n.d.). The global voice of dementia. Retrieved 03.10.2022 from https://dementiaallianceinternational.org/.

de Witte, L., Steel, E., Gupta, S., Ramos, V. D., & Roentgen, U. (2018). Assistive technology provision: towards an international framework for assuring availability and accessibility of affordable high-quality assistive technology. *Disability and Rehabilitation: Assistive Technology*, *13*(5), 467–472. doi: 10.1080/17483107.2018.1470264

Design Dignity Dementia Team. (2021). The dignity manifesto of design for people living with dementia. Retrieved 05.05.2022 from https://designdignitydementia.com/manifesto-2.

Desmond, D., Layton, N., Bentley, J., Boot, F. H., Borg, J., Dhungana, B. M., . . . , & Scherer, M. J. (2018). Assistive technology and people: a position paper from the first global research, innovation and education on assistive technology (GREAT) summit. *Disability and Rehabilitation: Assistive Technology*, *13*(5), 437–444. doi: 10.1080/17483107.2018.1471169

Fleming, R., Bennett, K., & Zeisel, J. (2020). Design dignity dementia, In *World Alzheimer Report 2020. Design, dignity, dementia: dementia-related design and the built environment*. Alzheimer’s Disease International.

Frost, D., & Fleming, R. (2020). Moving toward a more dementia friendly world. In *World Alzheimer Report 2020. Design, dignity, dementia: dementia-related design and the built environment* (pp. 73–84, Alzheimer’s Disease International.

GAATO (n.d., GAATO Global Alliance of Assistive Technology Organizations, https://www.gaato.org

Gitlin, L. N. (2002). Assistive technology in the home and community for older people: psychological and social considerations. In M. J. Scherer (Ed.), *Assistive technology: matching device and consumer for successful rehabilitation* (pp. 109–122, American Psychological Association, 10.1037/10420-007)

AS/ISO (2016). *Assistive products for classification and terminology Class 18: Furnishings, fixtures and other assistive products for supporting activities in indoor and outdoor human-made environments*, AS/ISO 9999,

Kowe, A., Panjaitan, H., Klein, O. A., Boccardi, M., Roes, M., Teupen, S., & Teipel, S. (2022). The impact of participatory dementia research on researchers: a systematic review. *Dementia (London)*, *21*(3), 1012–1031. doi: 10.1177/14713012211067020

Kuliga, S., Berwig, M., & Roes, M. (2021). Wayfinding in people with Alzheimer’s disease: perspective taking and architectural cognition—a vision paper on future dementia care research opportunities. *Sustainability*, *13*(3), 1–24.

Laver, K., Cumming, R. G., Dyer, S. M., Agar, M. R., Anstey, K. J., Beattie, E., . . . , & Yates, M. W. (2016). Clinical practice guidelines for dementia in Australia. *Medical Journal of Australia*, *204*(5), e1–3.

Layton, N. (2017). Assistive technology. In M. Curtin, M. Egan, & J. Adams (Eds.), *Occupational therapy for people experiencing illness, injury or impairment: enabling occupation, promoting participation* (7th ed., pp. 648–670). Elsevier.

Liddle, J., Worthy, P., Frost, D., Taylor, E., & Taylor, D. (2022). Partnering with people living with dementia and care partners in technology research and design: reflections and recommendations. *Australian Occupational Therapy Journal*, *69*(6), 723–741. doi: 10.1111/1440-1630.12843

MacLachlan, M., & Scherer, M. J. (2018). Systems thinking for assistive technology: a commentary on the GREAT summit. *Disability and Rehabilitation: Assistive Technology*, *13*(5), 492–496. doi: 10.1080/17483107.2018.1472306

O’Connor, C. M. C., Liddle, J., O’Reilly, M., Meyer, C., Cartwright, J., Chisholm, M., . . . , & Bail, K. (2022). Advocating the rights of people with dementia to contribute to research: considerations for researchers and ethics committees. *Australasian Journal on Ageing*, *41*(2), 309–313. doi: 10.1111/ajag.13023

OECD. (2015). *Enhancing translational research and clinical development for Alzheimer’s disease and other dementias*, (OECD Science, Technology and Industry Policy Papers No. 22). Retrieved 05.05.2022 from https://doi.org/10.1787/5js1t57jts44-en.

Ong, E. (2021), NOTHING ABOUT US, WITHOUT US: MY JOURNEY AS A DEMENTIA ADVOCATE, Alzheimer’s Disease Association. Retrieved 05.05.2022 from https://alz.org.sg/nothing-about-us-without-us-my-journey-as-a-dementia-advocate.

Pachana, N. A., Liddle, J., Peel, N., Beattie, E., Juang, C., & Knight, B. G. (2015). Can we do better? Researchers' experiences with ethical review boards on projects with later life as a focus *Journal of Alzheimer's Disease*, *43*(5), 701–707.

Pagone, G., & Briggs, L. (2021). Royal Commission into aged care quality and safety. Final report: care, dignity and respect. *Commonwealth of Australia*. Retrieved 05.05.2022 from https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf.

Phillipson, L., Smith, L., Caiels, J., Towers, A.-M., & Jenkins, S. (2019). A cohesive research approach to assess care-related quality of life: lessons learned from adapting an easy read survey with older service users with cognitive impairment. *International Journal of Qualitative Methods*, *18*, 1609406919854961.

Prince, M. J., Wimo, A., Guerchet, M. M., Ali, G. C., Wu, Y. T., & Prina, M. (2015). World Alzheimer Report 2015 - the global impact of dementia: an analysis of prevalence, incidence, cost and trends. Retrieved 03.10.22 from https://www.alzint.org/resource/policy-brief-the-global-impact-of-dementia-2013-2050/.

Ranmuthugala, G., Plumb, J. J., Cunningham, F. C., Georgiou, A., Westbrook, J. I., & Braithwaite, J. (2011). How and why are communities of practice established in the healthcare sector? A systematic review of the literature. *BMC Health Services Research*, *11*(1), 1–16.

Roberts, C., Rochford-Brennan, H., Goodrick, J., Gove, D., Diaz-Ponce, A., & Georges, J. (2020). Our reflections of patient and public involvement in research as members of the European Working Group of People with Dementia. *Dementia*, *19*(1), 10–17. doi: 10.1177/1471301219876402

Rohra, H., Mann, J., Rommerskirch-Manietta, M., Roes, M., & Kuliga, S. (2021). Wayfinding and urban design from the perspective of people living with dementia - a call for participatory research. *Journal of Urban Design and Mental Health*, *7*(4), 1–18.

Scherer, M. J., MacLachlan, M., & Khasnabis, C. (2018). Introduction to the special issue on the first Global Research, Innovation, and Education on Assistive Technology (GREAT) Summit and invitation to contribute to and continue the discussions. *Disability and Rehabilitation: Assistive Technology*, *13*(5), 435–436. doi: 10.1080/17483107.2018.1471170

Slattery, P., Saeri, A. K., & Bragge, P. (2020). Research co-design in health: a rapid overview of reviews. *Health Research Policy and Systems*, *18*(1), 17. doi: 10.1186/s12961-020-0528-9

Smith, R. O., Scherer, M. J., Cooper, R., Bell, D., Hobbs, D. A., Pettersson, C., . . . , & Bauer, S. (2018). Assistive technology products: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. *Disability and Rehabilitation: Assistive Technology*, *13*(5), 473–485. doi: 10.1080/17483107.2018.1473895

Swaffer, K. (2020). Disability rights, enabling design and dementia, In *World Alzheimer Report 2020. Design, dignity, dementia: dementia-related design and the built environment*. Alzheimer's Disease International.

Swaffer, K. (2021). Chapter 1 - Rehabilitation: a human right for everyone. In L.-F. Low & K. Laver (Eds.), *Dementia rehabilitation* (pp. 1–13), Academic Press. doi: 10.1016/B978-0-12-818685-5.00001-5

Swaffer, K. (2014). *Dementia: stigma, language, and dementia-friendly*. London, England: Sage Publications Sage UK.

Tebbutt, E., Brodmann, R., Borg, J., MacLachlan, M., Khasnabis, C., & Horvath, R. (2016). Assistive products and the Sustainable Development Goals (SDGs). *Globalization and Health*, *12*(1), 79. doi: 10.1186/s12992-016-0220-6

Wenger, E. (2011). Communities of practice: a brief introduction. Retrieved 03.10.22 from https://scholarsbank.uoregon.edu/xmlui/handle/1794/11736.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.

World Health Organization. (2017a). *Global action plan on the public health responses to dementia 2017-2025*. World Health Organization.

World Health Organization. (2017b). Priority assistive products list (WHO/EMP/PHI/2016.01). World Health Organization. Retrieved 05.05.2022 from https://apps.who.int/iris/bitstream/handle/10665/207694/WHO_EMP_PHI_2016.01_eng.pdf.

World Health Organization. (2018a). Global cooperation on assistive technology. Retrieved 05.05.2022 from https://www.who.int/news-room/feature-stories/detail/global-cooperation-on-assistive-technology-(gate).

World Health Organization. (2018b). *Towards a dementia plan: a WHO guide*. World Health Organization.

Zeisel, J., Bennett, K., & Fleming, R. (2020). World Alzheimer Report 2020: design, dignity, dementia: dementia-related design and the built environment. Retrieved from https://www.alzint.org/resource/world-alzheimer-report-2020/.

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