

People with dementia In Public Space using Everyday Technology (PIPSET) (IRAS 215654)

This report has been prepared for research participants, community groups and wider stakeholders involved in, or interested in this research, and for clinicians and colleagues at the NHS recruitment sites.



All readers are welcome to circulate the report.

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Lay Research Report

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Background:

Everyday Technologies (e.g. microwave, ticket machine, smartphone, internet banking) are rapidly changing and expanding, both in and outside people's homes. This means there are additional demands on people, and expectations that people will, or must use Everyday Technologies to participate in everyday activities at home and in public space. Generally, society drives this expansion, since technologies are generally thought of as convenient, making life easier and tasks quicker. But for many people in society, Everyday Technologies can be burdensome and present challenges that hinder daily life activities. Research, mostly in Sweden, has shown that older adults and those with cognitive impairment, e.g. due to dementia, are more likely to have difficulties using Everyday Technologies than older adults without dementia or cognitive impairment. This may lead to them being at risk from being excluded from the technological aspects of society. To achieve dementia-friendly societies, it is important to develop new knowledge in other countries and in different contexts, such as urban and rural environments, as well as to look at the challenge and influence of technology on participation in places and activities in daily life, at home and in public space. Such knowledge can be used to make a technological landscape that is inclusive of all people's needs and supportive of how they live their everyday lives.

Aim:

To explore how participation in activities and places in public space interact with the access and ability to Everyday Technologies for people with dementia in the different countries. The findings can be used to improve support for people with dementia and to facilitate the development of dementia-friendly environments.

Recruitment and methods:

315 participants were recruited in three different countries (n=128 England, 73 Sweden, 114 U.S.A) between August 2015 and November 2017. In England, participants were recruited in London, Greater Manchester and Cumbria. Participants in Sweden and the US were recruited from Stockholm and Chicago.

Participants with dementia (n=99) were recruited from 5 National Health Service (NHS) research sites and memory investigation units. Participants without dementia

(n=214) were recruited via word of mouth, recruitment flyers in public places, or presentations given to community groups.

An occupational therapy researcher interviewed each participant in their home or another location based on their preference, spread over one or more occasions. All participants had capacity and gave written informed consent to take part in the studies.

Interviews included a) a demographic questionnaire (10 minutes), b) the Everyday Technology Use Questionnaire (ETUQ) (30-45 minutes), and c) the Participation in Places and ACTivities OUTside the Home Questionnaire (ACT-OUT) (40 minutes).

- a. The demographic questionnaire gathered information about age, gender, ethnicity, education and employment, driving status and travel passes, living situation and postcode.
- b. The ETUQ asks about the relevance of 90+ Everyday Technologies found in and outside the home. Respondents then rate their ability to use each relevant Everyday Technologies.
- c. The ACT-OUT lists 24 places older adults usually visit (i.e. supermarket, doctor's surgery, café, transportation centre), whether in the past, present or future. Follow-up questions ask for example; why they go, how often, how far, who they go with; and also about satisfaction, risk and challenge.

The interview data was analysed using statistical methods and content analysis of the free text responses. Regular Patient Public Involvement (PPI) consultation activities (further details in section 6) supported the development of recommendations from the analysis.

Outcomes:

Participation

- A pattern was revealed for participants with and without dementia to abandon places and activities for social participation (e.g. entertainment place, sports facility) to a higher degree.
- Places used for consumer activities or self-care (e.g. supermarket, doctor's surgery) were retained to a higher degree

- A small association was found between more Everyday Technology use outside home and increased social participation, for participants with and without dementia.
- Among participants with dementia, a small association was identified between deprivation in the living environment and social participation. There may be a link between a deprived living environment and reduced social participation for people with dementia, but more research is needed to understand this better.
- The findings showed motivators, considerations and management strategies for social participation outside the home, such as doing the activity with other people, planning and preparation.

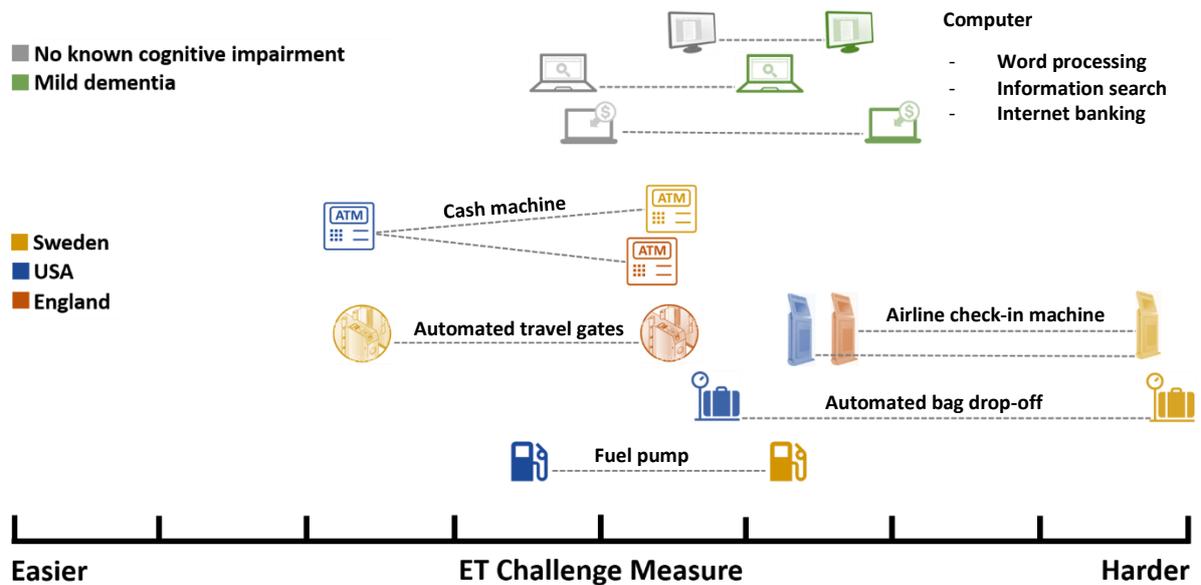
Technology and Participation

- A higher level of out-of-home participation was associated with higher probability that a person considers a higher amount of Everyday Technologies relevant, uses more of those Everyday Technologies, has a lower perceived risk of falling, has access to a concession travel pass, and lives in a relatively less deprived neighbourhood.
- Other types of perceived risk (getting lost; feeling stressed or embarrassed), together with age, gender, education, driving status, and rural or urban environment were not associated with out-of-home participation.
- Having a functional impairment (in addition to dementia for the participants with a dementia diagnosis) was associated with a low probability of a higher level of out-of-home participation.

Everyday Technology

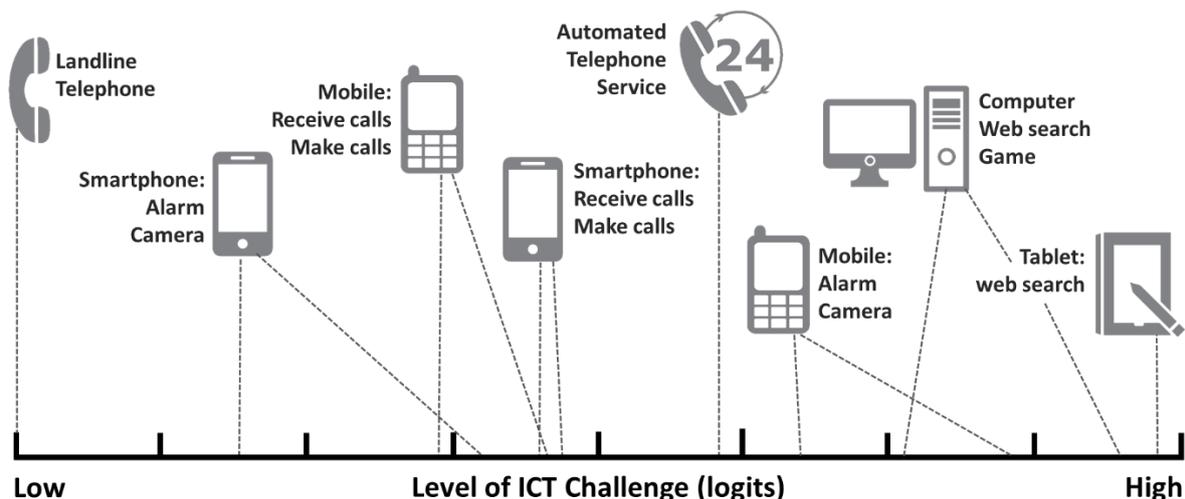
- Most Everyday Technologies were shown to be equally challenging to older adults in different countries, with or without dementia.
- 3 ICT computer functions (word processing, searching for information, internet banking) were more challenging to use for the group with dementia than the group without, and 5 public space technologies (i.e. ATM, fuel pump, automated ticket gate) varied in challenge level between country groups.

Figure showing the technologies that differed in challenge level:



- For participants with and without dementia, public space technologies (i.e. lift, ATM, door lock on public toilet, fuel pump), were used to a higher degree than 'portable' technologies which can be used both in and outside home (i.e. mobile phone alarm, camera, pedometer).
- The easiest to use ICT was the landline telephone, which nearly all participants owned and used. The most challenging was the tablet to search for information.

Figure showing how 69 participants perceived the challenge of a selection of ICTs:



- Among the group of people with dementia, a higher amount of relevant ICTs was related to having higher ability to use technology. No such relationship was found in the group without dementia.

Recommendations from the research



Screenshot from the dementia-friendly film (Gaber, Brorsson & Brave Teddy Oy Productions, 2019):

<https://vimeo.com/362114355>

1. Policy makers and service providers should consider strategies to enhance participation by providing offline and online choices for all services. This would counter the high challenge of some Everyday Technologies (particularly ICTs), and the stigmatising effect of not having access to, or not being a skilled user of technologies.

Target group: Policy makers and service providers in retail, public transport, financial, voluntary, and government services, cultural, recreational and spiritual centres, media.

2. Policy-makers and public transport providers should be more aware of barriers to access and consider adaptations to enable better accessibility for people with cognitive issues or disabilities living with dementia.

Target group: Transportation planners, transportation operators, policy-makers

3. Technology companies and developers should involve more diverse groups of people living with dementia or caring for people with dementia, in all stages of design, development and implementation of technologies. They should also consider existing contexts before introducing them, and use inclusive design that addresses cognitive usability to reduce the level of challenge.

Target group: Technology developers and providers, Non-governmental organisations (NGOs) and Think Tanks.

4. Occupational therapy interventions should take account of the technologies clients encounter in and outside home. They should offer tailored support to clients

wishing to adapt their technology use habits to match their changing abilities. They should be free to promote the more enabling features of particular technology designs and sites, and ensure adaptations made to a client's technologies are person-centred and evidence based.

Target group: Occupational therapy service, education providers, practitioners

5. Patient public involvement activities should include diverse individuals with dementia in ways that are adapted to people's abilities and tailored to fit the community and participatory context in which the activities take place.

Target group: Dementia researchers, service providers to people with dementia

Interdisciplinary Network for Dementia Using Current Technology (INDUCT)

The PIPSET research was part of the wider INDUCT research studies which were funded through H2020 Marie Skłodowska Curie Actions - Innovative Training Networks, 2015 (grant agreement number 676265). INDUCT aimed to improve technology and care for people with dementia, and to provide the evidence to show how technology can improve the lives of people with dementia.

Best Practice Guidance is available from: <https://www.dementiainduct.eu/wp-content/uploads/2019/10/D6.2-BPG-website-format-29-9-2019-v3.0.pdf>.

Patient and Public Involvement (PPI):

The European Working Group of People with Dementia have been involved from the outset of PIPSET, setting the priorities for this research at the fundraising stage with INDUCT's management team. Prior to ethical approval the group reviewed the recruitment materials, information sheets and consent forms, and went on to support the development of recommendations from the studies.

Consultations explored the ways in which Everyday Technologies can be both an enabler and disabler, among people living with dementia, or providing care for people with dementia, in different communities, including ethnic minorities living in Europe (i.e. Germany and Greece). The consultations highlighted the need for more contextually-relevant Everyday Technologies.

A variety of consultations and meetings with diverse stakeholders were undertaken across the London region. These included community-based groups such as the Hindu Society of Havering, Havering Museum Reminiscence Group, University of the Third Age, AgeUK and the Disabled Asian Womens' Network (DAWN). Based on the priorities reported by stakeholders, attention has been afforded to public transportation and community mobility, culminating in meetings with Kilburn Older Voices Exchange (KOVE) and Transport for London.

The Focus on Dementia Network group in Cumbria (formerly Service User Review Panel) have been consulted with regularly since recruitment opened in 2017. The group have brought in alternative perspectives on the findings, prioritised which findings should be shared, and identified local audiences for the research. This collaboration has moved towards co-authorship and led to new critical perspectives on PPI, particularly in rural contexts.

Dissemination

PIPSET dissemination activities included scientific publications, reports in policy and practice documents, oral and poster presentations at conferences, newsletter articles, podcasts, blogs, film. These are fully detailed in Annex 1. Complete Dissemination List.

Ethical Approval

In addition to approval in Sweden and the U.S., approval was received from the Health Research Authority: South West - Frenchay Research Ethics Committee on 27 April 2017 (IRAS project ID: 215654, REC reference: 17/SW/0091) and the study was registered with the National Institute of Health Research Clinical Research Network Portfolio (Study ID: 33163).

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Lancashire Care NHS Foundation Trust (formerly Cumbria Partnership NHS Foundation Trust)

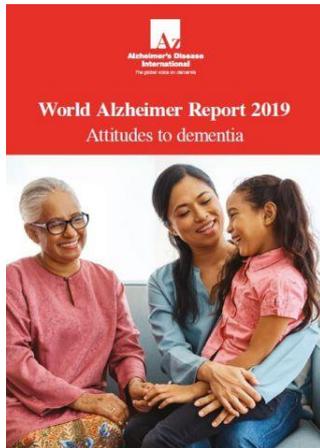
North East London NHS Foundation Trust

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South West London and St. George's Mental Health NHS Trust

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Annex. Complete Dissemination List



Screenshot from the World Alzheimer Report 2019. Please follow link for a case study based on the research (Gaber & Brorsson, 2019): <https://www.alz.co.uk/research/world-report-2019>

Scientific Publications

- Gaber, S. N., Nygård, L., Kottorp, A., Charlesworth, G., Wallcook, S. & Malinowsky, C. (in press) 'Perceived risks, concession travel pass access and everyday technology use for out-of-home participation: cross-sectional interviews among older people in the UK', *BMC Geriatrics*.
- Wallcook, S., Malinowsky, C., Nygård, L., Charlesworth, G., Lee, J., Walsh, R., Gaber, S.N., Kottorp, A. (2020) 'The perceived challenge of everyday technologies in Sweden, the United States, and England: exploring differential item functioning in the Everyday Technology Use Questionnaire', *Scandinavian Journal of Occupational Therapy*. Doi: 10.1080/11038128.2020.1723685
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- Wallcook, S., Malinowsky, C., Kottorp, A. & Nygård, L. (2019) 'The use of Everyday Information Communication Technologies in the lives of older adults living with and without dementia in Sweden', *Assistive Technology*. Doi: 10.1080/10400435.2019.1644685
- Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., Charlesworth, G., Wallcook, S. & Malinowsky, C. (in manuscript) 'Visualizing social participation in relation to Everyday Technology Use among older people with and without dementia in the UK: a mixed methods study'.

- Wallcook, S., Nygård, L., Kottorp, A., Gaber, S. N., Charlesworth, G. & Malinowsky, C. (in review) 'Kaleidoscopic alliances that shape the technological environment – revealed with statistical modelling'.

Policy and Practice Reports

- Alvarez, L., Wallcook, S., von Zweck, C, Timbeck, R., Ledgerd, R. (2019) 'Global indicators of assistive technology use amongst occupational therapists: Report from the World Federation of Occupational Therapists' Global Survey' In, Layton N, Borg J (ed.). Global perspectives on assistive technology: proceedings of the GReAT Consultation 2019. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO, p.411-423. Available from: <https://apps.who.int/iris/handle/10665/330372>
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Multimedia and other types of dissemination

- Gaber, S. N., & Brorsson, A. (2019). *Marie's Journey* [Video]. Turku: Brave Teddy Oy. Available from: <https://vimeo.com/362114355>
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International and national conferences, workshops and seminars

- Gaber, S. N., Nygård, L., & Malinowsky, C. (2021). *How do Contextual Factors and Everyday Technologies Foster Social Resilience in Participation among Ageing Communities Living with Health-related Vulnerabilities?* Council for Occupational Therapists in European Countries (COTEC), Prague; Sep. 2021
- Wallcook, S., Malinowsky, C., Nygård, L., Charlesworth, G., Lee, J., Walsh, R., Gaber, S.N., Kottorp, A. (2021) *The resilience of an occupational therapy tool to the changing technological environment*, 2nd COTEC-ENOTHE CONGRESS 2020, Prague; Sep. 2021.
- Gaber, S. N., Nygård, L., Kottorp, A., & Malinowsky, C. (2020). *Exploring the digital participation of older people living with and without dementia in Sweden and the UK*. Alzheimer's Disease International 34th International Conference, Singapore; Dec. 2020.
- Wallcook, S., Nygård, L., Kottorp, A., Gaber, S. N., Charlesworth, G. & Malinowsky, C. (2020) *Exploring the connection between emerging technologies, and the places outside home people with and without dementia go to*, Alzheimer's Society Annual Conference 2020, London; May 2020 (postponed).
- Wallcook, S., Focus on Dementia Network group Cumbria (2020) *To be an intervention, or not to be an intervention? Dementia-friendliness and the vulnerability of groups in rural places*, Alzheimer's Society Annual Conference 2020, London; May 2020 (postponed).
- Wallcook (2020) *Technological advances to promote social health in dementia from an occupational therapy perspective*, Dementia: Intersectoral Strategy for Training and Innovation Network for Current Technology (DISTINCT) training school, online; Apr. 2020
- Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., Wallcook, S., Charlesworth, G., & Malinowsky, C. (2019). *Everyday Technology: A Useful Servant but Dangerous Master for Participation in Society?* In the symposium entitled "Out and About? Participation in Out-of-Home Activities and Places among People with Dementia in Multiple Countries", Gerontological Society of America's (GSA) Annual Scientific Meeting, Texas; Nov. 2019.

- Rosenberg, L., Johansson, K., Brorsson, A., Gaber, S. N., & Cleeve, H. (2019). *Theoretical and methodological possibilities in studies of humans and environments*. Strategiska forskningsområdet vårdvetenskap (SFO-V) public seminar, Karolinska Institutet, Stockholm; Oct. 2019.
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- Gaber, S. N., Malinowsky, C., Brorsson, A., Kottorp, A., Roes, M., Reuther, S., & Nygård, L. (2019). *The Role of Contextual Factors and Everyday Technologies in Shaping the Burden of Disease and Inequalities in Participation, among Ageing Communities Living with Health-Related Vulnerabilities*. South Africa - Sweden University Forum (SASUF) Research & Innovation Week, Cape Town & Stellenbosch; May 2019.
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