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Tea, Technology and Me: a World Café approach to engage people with dementia and their carers about research priorities and policy development in digital technology and artificial intelligence

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Abstract

Digital technology and artificial intelligence (AI) use in health care is increasing, and it potentially offers significant patient benefit, such as independence, improved care and health care at home. Workforce benefits are apparent, for example, releasing time to see patients. However, are ethical and moral dilemmas of such technologies sufficiently unpacked by patients and understood by clinicians? A person living with dementia, and carers of people with dementia, alongside academics and clinicians, designed a public engagement World Café event for 20 people living with dementia and their carers. This process is described, as are reflections on a World Café approach to generate knowledge on a lesser explored topic. Working with a graphic recorder at the event proved a dynamic and engaging way of visually displaying feedback, served as an aide memoire and generated further

discussion. Three feedback themes are highlighted: (1) trust; (2) continuity of care; and (3) support and independence. The event's subsequent evaluation and impact, including a presentation to the House of Lords All-Party Parliamentary Group on Artificial Intelligence, are described. In conclusion, a suitable World Café approach enables people with dementia and their carers to voice exceptionally useful insights into a topic that already affects, or is very likely to, affect them.

Keywords dementia; public engagement; World Café; digital technology; digital health; artificial intelligence

Key messages

- Patients and the public, including people with dementia, should be involved in the design, acceptability and use of technological developments, with the support of specialist nurses to facilitate the involvement of patients who might otherwise struggle to engage.
- The benefits and risks of using technology should be carefully balanced, and clinicians and patients should work together in partnership in their use, and consider consent 'in advance' for artificial intelligence/digital health before sufficient competence for giving consent is lost. Technology will not be the solution for everyone, and it should not replace human interaction and care.
- We must be aware of further increasing the 'digital inequality' divide between patients, and be mindful of barriers to accessibility in areas where technology use is more challenging, for example, in more rural areas, due to poor broadband connection.

Background

We live in an ageing society, and consequently there are an increasing number of people living with dementia (Heese, 2015). The World Health Organization (WHO) references dementia as 'a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing' (WHO, 2020: n.p.). It affects memory, comprehension and thinking, among other cortical functions, and it can account for changes to a person's ability to control their emotions and/or social behaviour (WHO, 2020). There are currently just under one million people living with dementia in the UK (Wittenberg et al., 2019), and it is a condition which is thought will affect around 130 million people worldwide by 2050 (Prince et al., 2016).

The personal and financial cost to people living with dementia, and those looking after them, cannot be underestimated (Rapaport et al., 2020; Prince et al., 2015). Consequently, there is an impetus to consider ways of decreasing these burdens. One way this is already happening is via assistive technology, which is an overarching term covering 'any item, piece of equipment, product or system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain or improve capabilities of individuals with cognitive, physical or communication disabilities' (Marshall, 2000: 13).

The meteoric rise of assistive/digital technology and artificial intelligence is evidenced in the easy availability and relatively manageable cost of 'smart' devices such as Alexa and Google Home, which are in 22.4 per cent of UK homes (of internet users) (McNair, 2019). The COVID-19 pandemic has seen more people trying out technologies as a way of maintaining communication with loved ones, but also to complete essential activities, such as online banking and prescription requests. In April 2020, NHS Digital (UK) reported that 38 per cent of people had increased their use of National Health Service (NHS) technology since the start of the COVID-19 outbreak (NHS Digital, 2020).

The 'mainstreaming' of assistive technologies has already begun in dementia care, which is underpinned by a drive to improve people's quality of life (Gibson et al., 2019) and to reduce health

and social care costs (Ienca et al., 2017). Examples of such digital and assistive technologies evident in dementia care are telecare/telehealth/telemonitoring, safety interventions (for example, panic buttons, safer walking technologies) and communication/social interaction devices/systems, including social robots and 'smart' homes (for example, door sensors) (Lorenz et al., 2017). Artificial intelligence (AI) in dementia care involves machines specifically developed to behave like humans in the execution of cognitive functions such as decision making, voice and face recognition (Russell and Norvig, 2009). AI is currently being used to diagnose and monitor dementia, and it is also being developed to predict who might have the condition in later life, which adds its own ethical questions. Further, the development of sensors in the home to spot deteriorating health or risky behaviours is under way (Alzheimer's Society, 2020).

However, the push for such technologies in dementia care requires serious and considered thought to be given to the ethical and moral dilemmas they pose. Reviews have previously highlighted fundamental ethical concerns, such as informed consent, privacy, data security and affordability among people living with dementia (Wangmo et al., 2019; Novitzky et al., 2015; Zwijsen et al., 2011). Further concerns include social isolation, stigma and the question of whether or not human care could and should be replaced with technology (Wangmo et al., 2019; Felzmann et al., 2015). It is true, however, that some of these technologies are aimed at reducing social isolation. Ethical concerns have been raised relating to such technologies, especially those that are for monitoring purposes, and these need to be given due consideration (Bennett et al., 2017). Smith et al. (2018) voice concern that societal and psychosocial factors around the adoption of technology in dementia care have not been adequately addressed. Clearly it is imperative that the voices of those who are either using, or are the potential end users of, technologies must be heard in order for appropriate, sensitive, usable and affordable devices/systems to be developed. Any devices and systems should also be lawful and secure.

This paper describes how we involved lay people with experience of dementia in the planning of a public engagement event to discuss the use of technology in dementia care by those affected. The event itself and the main discussion will be highlighted, as will the key learning and subsequent impact of the event, alongside future directions for research and engagement. As this was a public engagement event to consider future research priorities and potentially influence UK policy, ethical approval was not sought. This is because attendees with personal and professional experience of the topics under discussion acted as advisers on research priorities and policy development, rather than as research participants. This decision was made with reference to the Health Research Authority and INVOLVE (2016) guidance on patient and public involvement and ethics, and we informed attendees that the World Café discussions were to inform future research topics and policies.

Methods

To ensure that the event was both relevant and accessible, a person living with dementia, a former carer of someone with dementia and an Admiral Nurse were involved in event planning, alongside university academics and NHS clinicians. The event was scheduled for January 2019, and the collaborative planning meeting took place in October 2018. Meeting attendees were reimbursed for out-of-pocket expenses, and refreshments were provided. We were also in email communication in the lead-up to the event. The event was funded by the National Institute for Health Research (NIHR) Kent, Surrey and Sussex, and clinical time to plan the event was funded by Higher Education England in the form of a Darzi Fellowship, a funded clinical leadership programme. The planned event was a public engagement exercise to elicit discussion on future research priorities and policy development, rather than a research method requiring ethical approval. Clearly, however, ensuring that activities were carried out in an ethical way was important to all involved (see Pandya-Wood et al., 2017 for a discussion of ethical issues in patient and public involvement [PPI]). An example of this is that when managing responses and responding to queries, we adhered to General Data Protection Regulation (GDPR) guidelines (legislation.gov.uk, 2018: c12), and

explained who had access to people's names and email addresses, in addition to how long we would keep that information and the strict purpose for holding that data. During the course of the event, general themes were recorded; at no time did we record attributable quotations from participants.

The notion of designing an event with lay people was novel to some clinicians, who remarked that it was initially difficult to 'let go' of power and share the reins of the design plans, particularly in the context of fixed deadlines and project budgets. This initial reluctance to 'let go' in collaborations between academics/clinicians and lay people has been documented in other public engagement processes (for example, Richardson et al., 2019). In time, however, clinicians realised the greater expertise of service users/patients, and the significant value in collaboration.

An essential part of this greater expertise and significant value was evidenced in the planning of specific details of the event to ensure that it was 'dementia friendly' – for example, the type of venue, its location, transport availability to reach the venue and the need to create a calm environment, as well as allocating a quiet room at the venue, separate to where the event was taking place, so that people had somewhere to go if they were feeling overwhelmed. We also designed event promotion that stated that it was specifically for people living with dementia, their family and carers. Consequently, and despite the limited time we had to plan the event with people affected by dementia, clinicians quickly realised the value of collaborating with 'experts by experience', and the need to be open to others' ideas with a view to working together for the benefit of all. The group planning process led to clinicians' recognition that co-creating ideas at the event pre-planning stage is essential to ensure relevance, accessibility and credibility. Therefore, we would recommend this approach to others, even if it adds complexity, cost and time, as its subsequent value cannot be overestimated.

The maximum number of attendees (24) was suggested so as not to overfill the room, as was the timing of the event, to coincide with optimum public transport availability (10.30 a.m. to 12.30 p.m.). The necessity of having a half-hour window (10.00 a.m. to 10.30 a.m.) for people to arrive, so that people could meet the organisers, orient themselves and enjoy refreshments, was agreed to be appropriate, as was a break halfway through the two-hour event. Finally, the collaborative meeting attendees suggested a list of organisations/groups who might be interested in attending the event, which was extremely helpful. We were grateful that the Admiral Nurse agreed to attend and support the event, as it was important to have a staff member with clinical expertise with people living with dementia present to ensure safety and well-being. She also advertised the event to colleagues and service users. Emails and the event flyer were subsequently sent to local dementia support groups, and to local NHS mailing lists. Bookings were taken online, with support provided for this, if needed.

Although there were a total of four event-planning meetings, and a large amount of email communication, we only had budget to meet once with service users and professionals as a group. Without these incredibly useful insights and offers of practical help from the public collaborators, it is unlikely that the event would have been designed in a way which best met the needs of those from whom we were keen to hear. Careful planning and targeted event promotion meant that the event was fully booked within a matter of weeks.

The event

The quest to learn more about technology and dementia care from those directly affected resulted in a plan to design and put on a World Café. As World Café (2020) guidance indicates, there are five basic elements to the World Café model. The first is the 'setting', whereby a café-style environment is created, with small round tables suitable for up to five people. The second element is a 'welcome and introduction' by the host/event organiser, who explains the World Café format, and who aims to encourage a relaxed approach to the event. Third, the 'small-group rounds' are the first of three 20-minute discussions, each with a different 'question' to focus on, which is the fourth element, designed to drive the discussion. Finally, the sharing of discussions is called the 'harvest', whereby an individual from each table is invited

Table 1. Event attendees (Source: Authors, 2022)

Self-identification	Number
Person living with dementia	6
Carer of a person living with dementia	5
Family member	1
Interested public members, health-care professional or member of professional carer organisation	8

to share the key discussion points with the rest of the World Café attendees. These points are typically shown in a visual way, for example, in a graphic recording.

The World Café approach was chosen as it is a well-utilised and effective method that increases delegates' knowledge of health topics in a relatively informal and enjoyable way (Bulsara et al., 2016), and as it has been successfully used with people affected by dementia (Gresham et al., 2019; Courtney-Pratt et al., 2018). An informal atmosphere to encourage discussion about health-related issues is also noted to work particularly well with seldom-heard groups (MacFarlane et al., 2017). As such, the group agreed to call the event 'Tea, Technology and Me' as a way of capturing the café format, of highlighting the topic of discussion (technology), and of stressing the 'me' part of the event in a way in which we hoped would lead people to feel a personal connection to the event.

The World Café took place at an accessible community venue in Canterbury, Kent (UK) in 2019, and it was well attended by people living with dementia, their carers and families. Twenty people attended (four people unfortunately stepped down on the day, due to illness and competing priorities) and identified themselves as shown in Table 1.

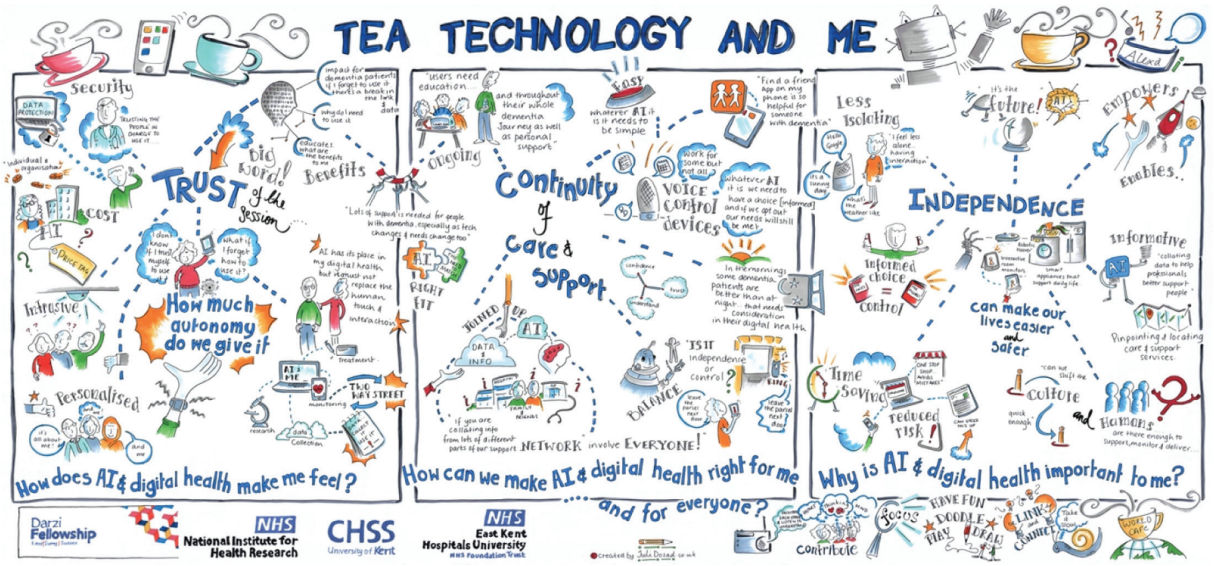
The room was laid out in a welcoming and informal café style, with four tables of five people. Attendees were able to enjoy refreshments throughout the activity, and there were volunteers on hand to ensure that people were comfortable, and had everything they needed, including access to a quiet area, and that they understood the format.

The event lead opened the café with a short presentation to describe the plan for the morning, and to reiterate why the topic was so important and why we needed to hear from those either directly or potentially impacted by technology use. General examples of technologies were mentioned in a neutral manner, so as not to lead the discussions, and the World Café guidelines were explained – for example, 'contribute your thinking', 'have fun' and 'facilitate yourself and others'. We purposely chose not to explain the technologies or AI, as the session was not to inform, but instead to capture the true understanding and concerns of attendees; imparting education about technologies and AI could have distorted this. Each of the tables had one question for discussion: (1) How does artificial intelligence (AI) and digital health make me feel?; (2) How can we make AI and digital health right for me and for everyone?; and (3) Why is AI and digital health important to me?

Each table had a host (along with a collaborator with dementia) who remained on the same table and facilitated discussion in line with World Café recommendations. Hosts clarified any ambiguities and double-checked key points with the group to ensure that nothing was being missed. Each table was provided with paper to aid note-taking. Each of the three questions was discussed for 20 minutes, and people were asked to move from one table to the next to consider all three questions. Delegates were encouraged to mix to facilitate cross-fertilisation of ideas and a different group dynamic for each topic, as per World Café guidelines (Burke and Sheldon, 2010). Hosts passed the key discussion points, typically on Post-it notes, to the event's graphic recorder, who was an artist visually illustrating the discussion, mostly in real time, and who also listened to the live discussions.

Towards the end of the event, a summary of topics discussed from each table was given by the hosts, with group members and the graphic recorder communicating frequently to ensure that salient points were captured both by the written word and as an illustrative graphic.

Figure 1. Tea, Technology and Me themes (Source: @ Juli Dosad)



Following a review of the feedback, the notes taken and the graphic recorder's illustration, it was clear that there was little understanding at the event of what AI was, but that there was clear enthusiasm for technology, despite a range of concerns. This discussion of attendees' enthusiasm and concerns led to the authors' subsequent refinement of initial ideas, resulting in three clear themes:

1. trust
2. continuity of care
3. support and independence.

These themes are explained in detail below. The output of the graphic recorder's illustration is shown in Figure 1.

Outcome: themes

Theme 1: trust

The issue of trust was a main theme raised by delegates, who had concerns that technology could be intrusive and invasive, which would be unwelcome and would add to feelings of mistrust.

People felt strongly that data use and storage should be safe, and also questioned if and how security can 'keep up' with technology developments. Alongside worries about trusting the technology, some people felt that they did not necessarily trust themselves to use the technology, and said that they may need extra help. There was a concern about what might happen if they forgot how to use it. It was stressed this could be a particular problem for people living alone, and that it may add extra stress for carers.

There was concern among the groups about their right to privacy, and they questioned who would have access to their health data; they would not wish it to be given to other organisations without their express permission. However, it was stated that digital health should be 'joined up', whereby data should be shared across places where people living with dementia attend, for example, ensuring that a GP has access to hospital information. Connected to this view was that any health data collected with permission would need to be used effectively.

It was questioned whether organisations can cope with the 'extra work' that comes from technology, and whether the technology will actually do what it says it will? There was an expressed need for integrating

technology with human input, in addition to its close monitoring. Monitoring, in particular, was seen as necessary to the success of technology, and to helping to enable trust of devices/AI.

Finally, some people stated that discretion (that is, devices not being easily visible) was important, and that some needs and concerns might be age-related.

Theme 2: continuity of care

Although people were generally open to the possibilities and uses of technology, the need for continuity of care underpinned by support and education was clearly articulated. Any technological support must be acceptable and tailored to the individual; it cannot be a 'one size fits all'. Therefore, any technological advancements must be planned and designed with the users, not simply for them. It was felt that people needed to know more about AI and digital health to facilitate its use: 'If we can see the evidence and the benefits of it, it will help people to use digital health and trust it more.'

People wanted to know what technologies were available, and how these technologies might help them. They felt that ongoing education and regular training were required about how to use technologies at home. Such education was seen as fundamental to allow people to make an informed choice about the use of these technologies in their health. It was notable at the event that attendees did not distinguish between digital health and AI, which in itself points to the need for education and support, and demonstrates the low level of understanding of AI at the outset of the event.

Some delegates stated that they wanted a choice whether their care would involve AI, and that their consent for more 'invasive' technologies such as trackers should be given before dementia becomes too advanced to make an informed choice.

Attendees felt that applications (apps), digital technology and AI should be easy to use, particularly for people not familiar with technology. They did note, however, that not everyone could use digital technology, as they may not have reliable internet access to use devices such as Alexa and Google Home.

Theme 3: support and independence

While different views about technology were apparent, with feelings ranging from apprehension to reassurance, attendees voiced the supportive benefits of AI and digital health for people living with dementia. Delegates cited telecare, sensors for falls, medication reminders and the automatic recording of important information as being very useful. Benefits of the remote monitoring of health status and location were seen as extremely important too, and technology was also considered to be something that could help improve the accuracy of diagnoses. However, the need for devices to be linked together was highlighted.

Devices and apps were also seen as useful for helping to remember things that they might otherwise easily forget, such as phone numbers and addresses. Some attendees remarked that they enjoyed the challenge of becoming familiar with different apps, devices and programs.

Some people were already using various devices and apps. For example, a device such as Alexa was seen as useful because it could act as a 'back-up brain' – 'Alexa never forgets'. Attendees also referred to apps such as Find My Friends on the iPhone, which they had adapted to their needs to find the nearest person, should they need help. This demonstrates digital disruption and innovation taking place in the community to find solutions which meet their needs, as well as demonstrating a perceived gap in current technology solutions.

For these reasons, technology was viewed by some as an enabler to freedom by helping them to live their lives, and to have more leisure time by freeing up time, in addition to making some people feel less isolated at home. However, the counterargument was that technology in the home could actually cause loneliness, and that interacting with a machine is emotionless. The resultant discussion led to perhaps the most powerful quotation from the whole event: 'AI has its place in my digital health, but it must not replace the human touch and interaction.'

Evaluation: delegates

Attendees were invited to complete an anonymous feedback form after the event, which had eight questions using a range of 'smiley faces' options to indicate answers. People were also invited to offer general comments. All attendees (n = 20) responded to the evaluation, and the majority said that the event was well organised and met expectations, that they had an opportunity to participate, and that they felt their voice was heard. The topics and subsequent discussions were felt to be interesting, relevant and important. There were a couple of criticisms of the event, with two people commenting upon the poor acoustics of the room, which we unfortunately were not aware of before the event and would seek to address if we were to run further activities. One person also felt that the questions put to each table could have been clearer. We are confident, however, that having a designated host at each table helped to appropriately guide the conversation; the depth of discussion, as evidenced by the themes, certainly demonstrates a genuine insight into the issues.

While comments were mostly positive, with words such as 'brilliant', 'enjoyable' and 'informative' used to describe the event, there were queries as to why more specific examples of the technology were not given and were not available to try out. Although it was not the aim of the event to trial various types of technology, it is noted that Hassan et al. (2017) and Meiland et al. (2014), among others, have successfully worked with people with dementia and their carers in the testing of devices, and it is encouraging that those with dementia and their carers are being involved in these important discussions about acceptability and usability. However, it should be noted that it was a specific decision not to provide education during the event, as we wished to capture a snapshot view of the general public to demonstrate the level of understanding of AI and digital health, and we did not wish to skew the findings with education about specific findings. This is something which could be considered for future work.

Evaluation: organisers

According to its creators, World Café events are a 'simple, effective and flexible format for hosting large group dialogue' (World Café, 2020: n.p.), and this is why this format was chosen. This method allowed for an open and engaging discussion between participants, and the round tables worked well to ensure that there were no hierarchical barriers between participants. In addition, we found that the use of increasingly 'powerful questions' allowed the provocation of 'thoughtful exploration and creative thinking' (Vogt et al., 2003: 5). There are logistical considerations around risk regarding mobility for more frail participants for World Café events, but these were carefully managed, and one participant remained at the same table throughout the session. In addition, World Café provide useful resources on their website, including checklists which greatly assisted a smooth planning process. Therefore, for our particular event, World Café provided a versatile and established method for exploring this topic in more detail.

The use of a graphic recorder enhanced both the processes of gathering and disseminating feedback at the event. This was discussed at the planning stage, and received good feedback. The main advantage of the graphic recorder was that the result was visually appealing and informative, and provided a highly accessible event summary. Anecdotal comments on the day demonstrated that participants enjoyed the 'live' creation in real time, with participants often approaching the graphic recorder directly to add comments. This is in contrast to the traditional approach of creating a summary after the event, which plays to the old model of event organisers holding control or 'power' over the outputs and results.

The main barrier to using this method in the future is cost. We were fortunate to receive NIHR funding and university department support which covered the cost of this, as well as funded clinical time through the Darzi Fellowship, but this might be prohibitive to organisers who may wish to run similar events. It is noted, however, that there is an Alzheimer's Society public engagement fund.

All delegates received a written report of the event, including details of the themes, which was produced in Plain English. They received a copy of the graphic recording, and it was also explained

that a presentation would be given to the House of Lords All-Party Parliamentary Group on Artificial Intelligence, and that there was the possibility of a written journal publication on the event.

Discussion

The collaborative approach to the World Café event was extremely successful, as it helped to ensure that the event was as relevant, accessible and informative as possible, with its promotion being made available to those who needed to know about it. The specific details of the event, as advised by people with experience of dementia, have been explained in detail. Attempting to put together an event such as this without their expertise would have been much harder, and it may well have 'missed the mark' in its appeal to those with whom we wished to connect.

The fact that the event was fully booked is testament to people with experience of dementia and their carers having much to say and wanting to be heard on this topic. This stance should therefore pave the way for additional events to be held, particularly for groups who are often marginalised/seldom heard, such as people with dementia.

Three clear themes were generated by the World Café discussions: (1) trust; (2) continuity of care; and (3) support and independence.

The first theme of trust taps into the literature review by Teipel et al. (2016), in which stakeholder values in technology developments were ascertained, and both trust and security were seen as important to both people with dementia and their carers. Identified barriers to technology included not trusting or understanding the technology, and the need for a personalised fit between the person using the device and the equipment/system itself. If expectations about the technology were not met, then lack of interest ensued (Thordardottir et al., 2019). Many studies have highlighted the need for trust in technologies – are they actually doing what they are meant to do? (for example, Greenhalgh et al., 2013; Lindqvist et al., 2013). Unfortunately, it appears that technology users and potential users have grounds to be wary of certain apps. In a review of dementia-related health apps, Rosenfeld et al. (2017) found that the majority of apps did not have a privacy policy, and that those that did lacked clarity. As Rosenfeld et al. (2017) stressed, providing appropriate projections, and communicating these in an accessible way, will foster the use of apps and facilitate more people to use potentially helpful apps.

It is important not to automatically assume that older people are sceptical of technology (Peine and Neven, 2018), as evidenced by the reference to the apps and devices already in use by some event attendees, and their enjoyment of them.

The second theme was continuity of care, as underpinned by the need for ongoing education and support. This was seen as critical by event attendees, and it has been evidenced in previous research, whereby technology users did not fully understand how a device worked. Therefore, technology users should not only be involved in technology developments, but should also receive ongoing support (Starkhammar and Nygard, 2008). Feedback sessions with people with dementia have previously worked well in terms of increased understanding, and being able to ask questions and provide recommendations for device improvements (Harrell et al., 2014). Concerns around the inadvertent decreasing of people's autonomy by a possible pressure to use technology have also been cited (Landau et al., 2010), which is worrying, as technology is meant to provide reassurance and helpful information (for example, monitoring). Again, it is paramount that people already using technologies in dementia support and care are continuously involved in decisions about whether to use such devices: informed consent is not a one-off discussion; it should be ongoing (Boger et al., 2019). Clearly, in view of the memory problems inherent in dementia, a careful discussion about consent should initially take place soon after diagnosis (Meiland et al., 2017).

The third and final theme was support and independence, whereby attendees posited the benefits of technology and AI as being a supportive enabler. Literature suggests that technology can promote the independence of people living with dementia, for example, sensor technology as a safety precaution

(Malmgren-Fänge et al., 2020). It can also result in decreased carer burden through feeling reassured that technology is assisting in the monitoring and management of the condition (for example, medication reminders, orientation devices and environmental detectors) (Boger et al., 2014). However, there was a clear expressed need that technology should not replace human care and interaction, and this concern should not be underestimated. The aim, as discussed in the literature (for example, Wangmo et al., 2019), should be that such technology augments care rather than replaces it, but people's concerns are clearly valid, and they need to be carefully and sensitively discussed.

In a systematic review of the acceptability and use of technologies by people with cognitive impairments (including dementia) and their carers, it was found that technologies that were familiar and straightforward to use (so had low technical demands) were facilitators for use, as were an improvement in care and increased feelings of safety. Further, the timing of when the technology was introduced, as well as the support for the introduction and maintenance of the technology, was instrumental (Thordardottir et al., 2019). These findings chime with the comments made by World Café attendees.

Limitations

The limited funding we had for the event meant that we were unfortunately unable to involve people with dementia and their carers in every step of the design and analysis of the event. While we maintain that this was a collaborative approach, we are not claiming it was co-production: a 'project that is co-produced is one in which researchers, practitioners and the public together share power and responsibility for the work throughout' (Hickey et al., 2018: n.p.). The event idea and its aims were driven by the event lead (Hadlow), and the feedback was analysed by Hadlow and Bates. Although there was a definite sense of the 'letting go' of power at the event design process, which reaped many benefits and was a key learning point in the project, more could have been done to collaborate further. In an ideal world, with more time and more funding, we would advocate a co-produced event in terms of the aims, design (including event flyer), management and analysis.

People with dementia and their carers were typically recruited via local support groups, as per the suggestion of our collaborators. While public engagement and involvement does not aim for representation, we are aware that those in support groups for those with dementia are likely already to be engaged with a range of services, and to have access to the latest knowledge and developments in dementia care. They are also a group who are mobile and able to travel to a community event, meaning that there will be voices of those who are homebound which were not heard. By promoting the event via email and digital flyers, we realise that it was biased towards people using technology, but this exercise was an important first step. A barrier to involvement was that, due to funding restraints, we were unable to pay for people's time or travel expenses to attend the World Café, which may have prevented some people from attending. This is something that we would seek to address in future engagement events to improve accessibility.

Our mode of communication was email, and people were asked to register for the event via Eventbrite. Therefore, those registering already had internet access and could navigate the registration process, although the organisers did offer to book directly for service users, and they did this for some participants. As such, the views around technology may be skewed a certain way, compared with those who do not have access to the internet or an email address. However, apprehension about technology and concerns about its security were strongly articulated at the event, so feedback was not all favourable, and we learnt about the challenges of ensuring that wide-ranging views are heard.

The event was oversubscribed and, again, limited funding and resource in terms of staff and volunteer time meant we had to turn people away despite clear appetite for further events. Additional events, with increased and sustained collaboration, could yield deeper insights which build on the knowledge already generated at this public engagement event.

Impact

An article on ethics and AI has already been published in New Statesman Tech (Hadlow and Farmer, 2019). Findings from the World Café event were presented at the House of Lords in February 2020 to senior decision makers in policy and research. This involved presenting the visual representation of the event, as well as discussing key themes and outputs from the event. Findings were presented by the event organiser (Hadlow) by way of a brief presentation to the All-Party Parliamentary Group on Artificial Intelligence, followed by a 50-minute Q+A session which offered an opportunity for parliamentarians, academics and other relevant and interested parties to ask questions. While the event was not specifically focused on health, the title of the session was 'Citizen Participation – AI and me', and therefore entirely matched the ambitions of the public engagement work. In addition, written evidence was submitted, which will be further disseminated, highlighting the key outputs of the engagement. As a result, the event organiser (Hadlow) was also invited to join the Citizen Participation taskforce of the All-Party Parliamentary Group on Artificial Intelligence. In addition, the public engagement work received interest on social media and, in addition to the article mentioned above, further articles were published in New Statesman Tech highlighting ethical dilemmas in digital health and AI.

Summary

This project demonstrates that people living with dementia and their carers are well placed and able to collaborate in public engagement event planning, promotion, participation and evaluation. It evidences that patients can act as agents of social change, and also adds weight to Alzheimer Europe's position paper, which calls for the increased involvement of people with dementia in research (Gove et al., 2018).

This paper has provided details of a useful template and structure for any researchers working in dementia research, engagement and involvement, alongside lessons learnt and a way forward. It has also reported a number of themes and considerations to be aware of when thinking about developing and using digital technologies for people with dementia. They, and their carers, must be an integral part of the design, trialling and evaluation of technologies to ensure that they are fit for purpose, and as relevant and useful as possible to those who seek to benefit from them.

Future work and recommendations

People with dementia should be involved in the design, acceptability and use of technological developments, in addition to prioritising research areas. This is not only ethical, but should also ensure relevance and acceptability of various technologies. The James Lind Alliance (JLA, UK) top 10 research priorities for dementia (research priorities of most importance to those with dementia, carers, and clinical and academic representatives) did not include technology (JLA, 2013). However, priorities will evolve and change as society progresses (the priority-setting exercise was carried out in 2013), and it is important for any research priority-setting exercise to be repeated after a given number of years.

The engagement work described in this paper also adds to Greaves et al.'s (2018) recommendation for data security standards, data management and ethics regarding new technology. Further, the publication of a framework for evidence of effectiveness and financial impact standards for digital health technologies is welcomed (National Institute for Health and Care Excellence, 2018). These aspects are crucially important, and they need to be given due consideration. In line with this, we have devised a list of ten recommendations for researchers and digital technologists working in the field.

The ten key recommendations borne out of the public engagement World Café event are:

1. Digital health should become part of everyday health conversations and planning, particularly around more controversial interventions, such as use of the Global Positioning System and cameras.
2. Consider how to integrate devices and joined-up care.

3. If data is collected, it should be used effectively, with a defined purpose.
4. Ensure that genuine, ongoing and deep public engagement, not token gesture 'focus groups', takes place – such engagement should be seen as a core component of innovation and regulation (but it does require funding).
5. Have a strategy (developed by patients and the public) about how to access 'real' patients.
6. To consider how regulation can keep up with innovation, it is imperative to strike a balance between the two.
7. Avoid being paternalistic as a health community.
8. People with dementia are not a homogeneous group; there are significant differences between age and disease areas, for example, and these differences should be borne in mind when creating AI/digital health.
9. Explore how to ensure equity of funding to avoid digital inequality. In that way, innovation and engagement can be encouraged across the UK, not just in the same areas/institutions.
10. Consider how to increase public education around these issues, and ask how much the average clinician/member of the public understands AI/digital health. Likewise, education about technology should never be a 'one-stop shop', and needs to be tailored and ongoing, particularly for people living with dementia.

Conclusion

If stakeholders can get it right for people living with dementia and groups who are traditionally left behind, we can get it right for everyone. For example, dementia-friendly communities are suitable for all. However, further public engagement activities are needed. They are hugely important to explore views not only regarding devices/technology currently in use, but also regarding innovation for future developments – for example, designing the right device, rather than retrofitting. Some stakeholders are actively engaging in this work, but there is much scope for improvement. We hope that this article offers a range of insights which will assist other stakeholders and researchers in the planning and carrying out of engaging events with the end users of digital technology, which can ultimately lead to real step-change differences in both policy and AI use.

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Declarations and conflicts of interest

Research ethics statement

The Chair of the Ethics Committee within the Division for the Study of Law, Society and Social Justice at the University of Kent has granted waiver status for this work as the content falls outside the definition of research and, as such, a research ethics review would not officially be required, according to NHS guidance.

Consent for publication statement

Not applicable to the article.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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