World Dementia Council

Leading the Global Action
Against Dementia

# Global dialogue on technology: Reflections

The dementia landscape project

Essays from international leaders in dementia
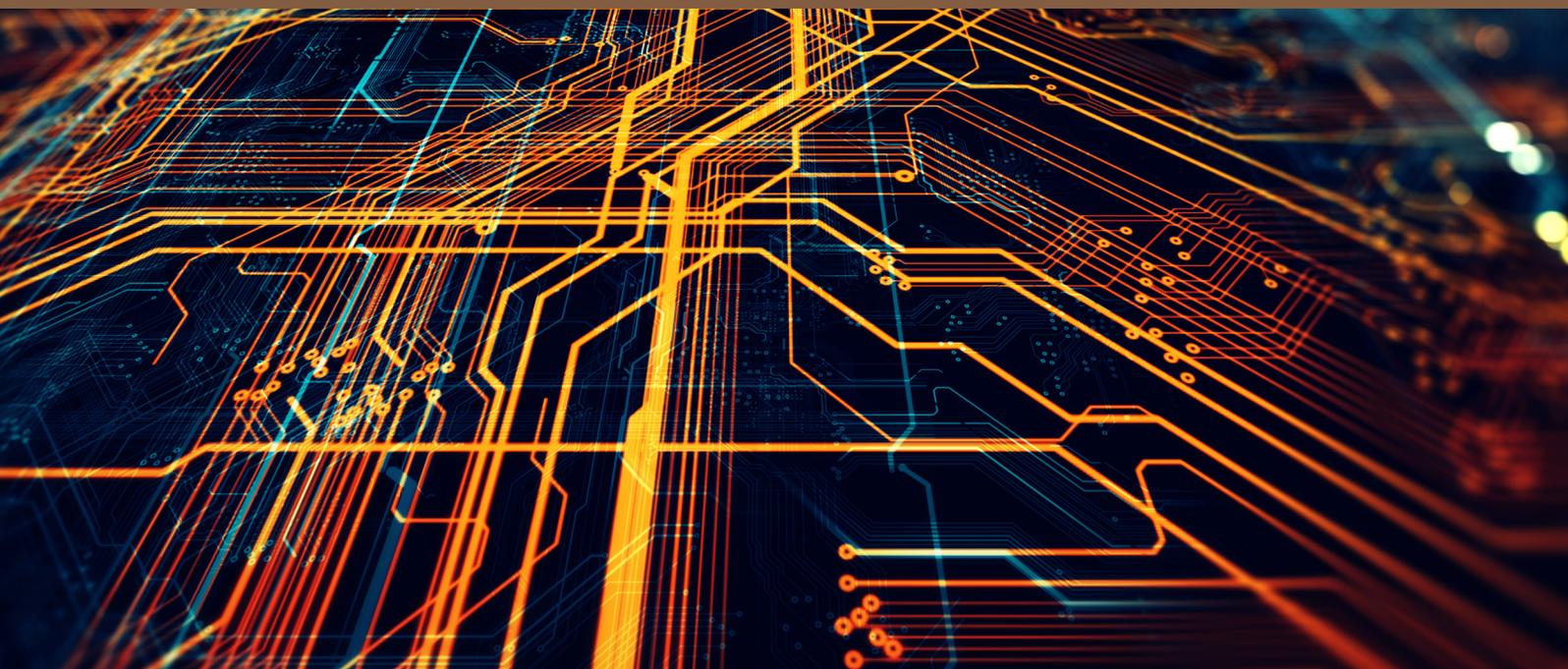
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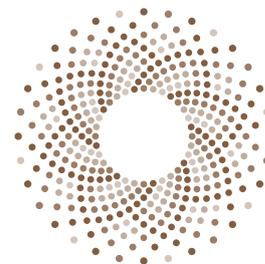
1. Introductions

## The promise of digital health and mobile computing for dementia prevention and care

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Science for Minds, Johnson & Johnson

Advances in digital health and mobile computing offer an unpreceded opportunity to transform dementia prevention, detection, intervention, and care. This is in part driven by increasing pervasiveness of digital technologies wherein data can be collected, analyzed, and transmitted in a frictionless way, thus making digital health solutions more accessible and usable across a broad spectrum of age and digital literacy. The COVID pandemic has further heightened awareness and acceptance of telemedicine and digital health, which is an opportunity that dementia researchers and providers should not miss.

While brain health and cognitive function are highly valued by individuals, particularly by those who perceive themselves at high risk for cognitive decline, there is a singular lack of information on how to measure and quantify brain health, let alone improve it. Technology provides an opportunity to raise awareness around cognitive health and dementia prevention at scale, across regions, in large swathes of population. Data collected passively from smartphones, wearables, and other objects of daily use can now be analyzed via machine learning to track memory and cognitive function continuously and unobtrusively. This 'internet of things' driven assessment of cognition will allow early detection of deviations from norms and expected decline, enabling earlier pharmacological and non-pharmacological interventions which is crucial for degenerative diseases such as Alzheimer's. Epidemiological studies and RCTs in the past decade have shed light on the most important modifiable risk factors for cognitive decline and dementia. Digital health technologies offer the possibility of translating this scientific understanding to practical and scalable solutions. For instance, digital data from individuals can now be used to track and monitor modifiable risk factors such as sleep, physical activity, social connectedness, depression etc., and based on observed deficits, a combination of nudges and customized remedial interventions can be pushed to alter lifestyle and behaviors that reduce risk of cognitive decline.

Beyond prevention and early detection, data science and technology are poised to make a significant impact in lives of those already diagnosed with cognitive impairment and dementia. An important area of impact will be the use of digitally captured measures
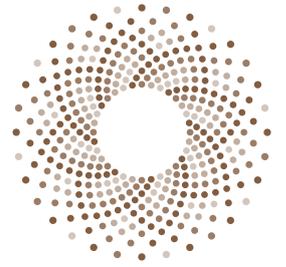
to assess real world impact of interventions. In this case, pervasive digital data will allow tracking of endpoints and outcomes that are most relevant to the patient and their caregivers in their daily lives, such as ability to use a computer, drive a car, or navigate successfully in unfamiliar surroundings. Assessing the impact of therapies on such real-world activities rather than abstract paper-pencil memory tests will incentivize development of therapies that make a meaningful difference and patients' lives and will help target the right interventions to an individual for maximal practical benefit.

In addition to better efficacy monitoring and treatment matching, digital technologies are well poised to directly benefit dementia patients and their caregivers by providing tools and solutions that help address memory and functional deficits (memory and functional prosthetics) leading to increased independence and higher quality of life. These solutions will range from digital memory aids to advanced robots that provide task help and address lack of stimulation and loneliness. Digital therapeutics can be developed that directly help address psychological and behavioral dysfunction related to advancing dementia. Furthermore, COVID driven surge in telemedicine provides a unique opportunity to develop telemedicine platforms that are customized for dementia patients. This would imply specific features to enable adoption by neurologists and 'accessibility features', co-designed with patients, that allow easy use of telemedicine services by individuals with dementia.

Finally, it should be emphasized that all digital, data and tech applications for dementia will need to be developed in close partnership with patients and their representatives adhering to the highest privacy and ethical standards to enable large scale adoption that is based on trust and multi-stakeholder value creation.
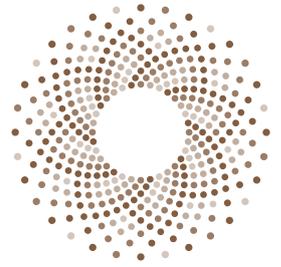
The opportunities of technology in dementia

Jeremy Hughes

Co-Chair, UK Prime Minister's Champion Group for Dementia Friendly Communities

Technological advance changes our understanding of dementia and the treatments we can develop. It supports knowing more about what causes dementia and how to prevent or delay its onset. It also can empower people with dementia to be more able to participate fully in society. But we do need to be careful not to embrace technological advance just because it is possible. It must genuinely improve the care and support for people with dementia.

There are three areas where this is particularly true for low and middle income countries and not just for the richer nations.

First, it is possible to bring specialist diagnostic and follow up support out of the hospital to people in their own homes. COVID 19 has brought about a revolution in the willingness to use online services to hold remote consultations. This can remove the stress and anxiety caused by the hospital visit. It can also bring services to those unable to access dementia specialists located in hospitals hundreds of miles away.

Second, the 'virtual meeting' means many people with dementia can come together far more easily. Webinars put on by Dementia Alliance International, and similar national organisations of people with dementia, attract large audiences and create lasting bonds of contact and support.

Third, technological advance provides the opportunity for people with dementia to be supported in their own homes, replacing or delaying a move into residential care. What's particularly exciting is that this support can be increasingly provided through the computer, smartphone and television people already have and are accustomed to using. This can replace the need for separate monitoring and support systems and the associate costs.

Whilst we should welcome and promote these ways technology can improve the lives of people with dementia, we must also be wary of new technology that might be undermine engagement for people with dementia. A good example is the sophistication increasingly needed to make everyday purchases and to manage your money, both on the High Street and online.

As technological advance continues at pace, we have the opportunity to ensure that it works to the benefit of people affected by dementia.
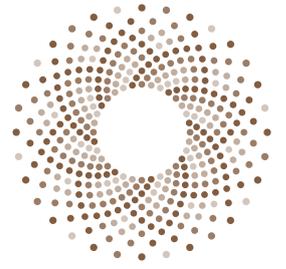
2. Detection and digital biomarkers

Digital biomarkers: The state of today and the promise of tomorrow

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Technological advances have enabled the integration of digital into the health sciences arena. A PubMed search of the words 'digital biomarkers' finds 1988 as the first time these words can be found in the same document.[1] Over the next 20 years, an additional 474 publications meet this same search criteria, before the numbers start to accelerate, more than doubling in the subsequent 5 years (n= 582; 2009-2014). Beginning 2015 to current (November 2, 2021) the number of publications exploded (n=2,920) with 1,273 publications in just these last nearly two years.

While these numbers reflect the accelerating interest in digital in clinical research context, they do not accurately reflect the evolution of "digital biomarkers" as a concept in of itself. A more precise PubMed search finds that 2014 is when "digital biomarkers" as an actual term was used.[2] It was not until 2017 that a review article summarizing a range of studies using digital sensors, mentioned digital biomarkers in the context of dementia.[3]

What these numbers provide is a publication pulse of how much interest in digital has been rising. Despite the recency of the specific term "digital biomarkers" entrance into the research lexicon and its relative nascent application in dementia, the concept is clearly here to stay. However, with this wider embrace, greater scrutiny is revealing that the idea is outpacing the science.

The question that remains unclearly answered is what is a digital biomarker? For some, the use of any digital device to measure a dementia-related symptom such as the cognitive domains of memory or executive function, eye scanning movements or EEG brain waves qualifies as such. Simple digital quantification meets the pragmatic need of immediate relevance to health-related technologies. Often, they provide more accurate

1. Bierman HR, Faith MR, Stewart ME. Digital dermatoglyphics in mammary cancer. Cancer Invest. 1988;6(1):15-27. doi: 10.3109/07357908809077025. PMID: 3365570.

2. Ponomarenko E, Baranova A, Lisitsa A, Albar JP, Archakov A. The chromosome-centric human proteome project at FEBS Congress. Proteomics. 2014 Feb;14(2-3):147-52. doi: 10.1002/pmic.201300373. PMID: 24285571.

3. Snyder CW, Dorsey ER, Atreja A. The Best Digital Biomarkers Papers of 2017. Digit Biomark. 2018 May 30;2(2):64-73. doi: 10.1159/000489224. PMID: 32095757; PMCID: PMC7015358.
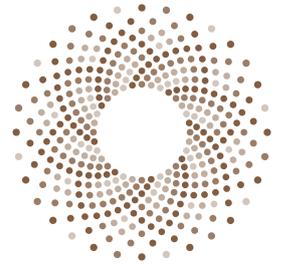
measures of pre-defined symptoms or behaviours, can do so at lower costs and produce results with minimal to no time delay. But defining digital biomarkers in this way is pushing much of its potential to the side.

Instead try to imagine a future vision of digital biomarkers that stretches beyond the current norm. It goes beyond what peer-reviewed science will find fundable or publishable. Beyond what the Food and Drug Administration will approve within current well-defined guidelines. Beyond what health insurance companies can conceive covering.

To start this mind-stretching discussion, the first step is to determine what will be the digital technologies needed to produce a digital biomarker? Given the heterogeneity of cognitive and behavioural symptoms of dementia, particularly in the earliest stages of disease onset, it is unlikely to be similar to a traditional biomarker; a consistent, reliable indicator of a disease or a measure of which, above or below some threshold, is not considered normal. It also unlikely to be produced from a single sensor nor will it be a single measure. Instead, digital biomarkers will likely emerge from multi-sensor inputs that will produce a dynamic flow of different signal patterns, where no one pattern will be the same and some may even appear as seemingly random. But in the aggregate, they will nonetheless provide a highly reliable diagnostic or prognostic metric.

This digital biomarker of the future will in essence capture the subjective reporting or clinical judgment that is often used to determine different stages of the disease. For example, it is common during an initial patient intake for a suspected case of dementia to include questions about when symptoms first emerged. The patient will often self-report experiential examples, such as forgetting to turn off the stove, misplacing an important document or confusion driving to a familiar location. What is important to note is that these experiences are not statically consistent. The person does not always forget to turn off the stove, does not always misplace important items and does not always get confused driving to a familiar location. Further, family report of history will likely produce a different set of examples from that of the patient. Family members as well as close friends may also recall distinct patterns that are unique from each other. Moreover, these self-reported experiences were not collected through formal testing methods typically used by trained clinicians. Rather, it is readily accepted practice that this reported flow of different behaviours can collectively be pulled together and interpreted that a memory impairment is evident. This information is also often used by a clinician to mark the earliest onset of disease.

This dynamic flow of constantly shifting and evolving behaviours is what digital biomarkers are going to have to mimic to achieve some level of diagnostic or prognostic accuracy comparable to that of traditional dementia-related blood or imaging biomarkers. But reaching the goal of a digital biomarker that also meets the validation standards of currently accepted disease biomarkers remains a significant barrier.

Applying current defined methods for validating traditional biological biomarkers to digital ones means adhering to existing standards that were based on collecting data more sporadically and potentially less accurately and will not push forward the idea of digital biomarkers as described above. Additionally, with increasing evidence that there are modifiable risk factors that reduce dementia risk,[4] the shift to prevention will be further attenuated if a new conceptualization of digital biomarkers as dynamic digital

4. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG, Dias A, Fox N, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Ogunniyi A, Orgeta V, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L, Mukadam N. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020 Aug 8;396(10248):413-446. doi: 10.1016/S0140-6736(20)30367-6. Epub 2020 Jul 30. PMID: 32738937; PMCID: PMC7392084.

signal patterns and the accompanying new methods for validating them does not take hold.

The future of digital biomarkers is not really as distant as it may sound. Advanced analytic methods are able to ingest large volume high-dimensional data and quantify them into predictive models with relatively high accuracy. Following the proposed shift in mindset will be the beginning of a major paradigmatic shift in how clinical research, and eventually clinical trials will be done and with that will be the realization of not only effective dementia treatments but also effective dementia prevention. It seems worth starting this revolutionary change now.
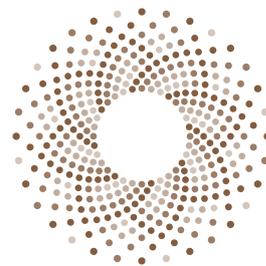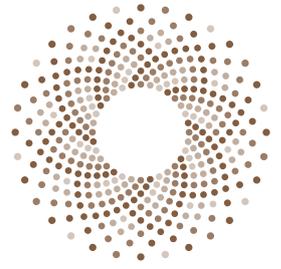
Can brain resilience be measured with digital biomarkers across the lifespan?

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Chief Scientific Officer, Altoida

For the last 2 years, COVID-19 prevention and control policies have been a major catalyst for change in the healthcare sector. The modern healthcare system has experienced a shock, especially as it relates to vulnerable individuals including with cognitive impairments and/or people living with dementia. The World Health Organization has taken notice and given interest to adverse mental health effects caused by the COVID-19 pandemic and as a response the healthcare systems accelerated the transition from the physical space, such as clinics, hospitals, in-person consultations etc, to the digital space, such as platforms, apps and virtual consultations. More specifically, the urgent need to collect all available quantitative data on the effect of COVID-19 on the cognitive, psychological and functional health of adults with neurocognitive disorders (NCD), triggered a "digital revolution" in healthcare. Especially in the field of "digital biomarkers" we experienced an unprecedented boom, as various digital health startups started investigating "digital footprints" or Digital Neuro Signatures (DNS)™ of behavioural and psychological symptoms (BPSD) such as, anxiety, apathy, sleep disturbance, agitation, and hallucinations providing insights into healthy and pathological patterns of brain health among older adults with cognitive impairments and/or people living with dementia.

When focusing on digital biomarkers being linked to patterns of brain health, it is crucial to accurately define both brain health and its determinants through a dynamic trajectory model incorporating risk factors and antecedents and also the term digital biomarker as a proxy for brain health outcomes. Brain health is an important focus for digital biomarkers due to its latent variables allowing individuals to function independently with a sense of purpose, to make their own decisions, to maintain social connectedness, to permit functional recovery from illness, and to cope with residual functional deficits. As part of global initiatives, such as The Alzheimer's Drug Discovery Foundation (ADDF), Hellenic Initiative Against Alzheimer's (HIAAD), Latin American Brain Health Institute (BrainLat UAI) and the Global Brain Health Institute (GBHI), we have been involved together with other researchers into a new definition of Brain Health, as a life-long dynamic state of cognitive, emotional and motor domains underpinned by physiological processes. This definition is multidimensional and can be objectively measured and subjectively experienced. It can also apply to communities beyond the level of the individual who is influenced by eco-biopsychosocial determinants, resulting in a continuum of quality of life and wellness.
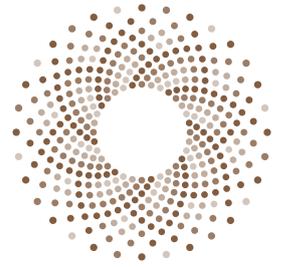
With such variables in mind, two avenues for a digital biomarker of brain health can be explored: (1) creating a digital biomarker platform based on "digital footprints" for brain function, physical function, social function, protective or risk factors, and mental health, or (2) identifying a lifespan Digital Neuro Signature (DNS)™ that exists as a proxy for all of brain health's constituent parts. To satisfy the first alternative, a digital brain health platform can be created to assess overall physical health, nutrition, sleep, physical activity, cognitive activity, socialisation and diet recorded via smartphones, wearables or other sources of the Internet of Things (IoT) and on the other side inferred casualty with various biological variables. Such platforms might contain different classes of digital biomarkers ranging from diagnostic, prognostic, monitoring, pharmacodynamic, predictive to safety and susceptibility digital biomarkers, depending on their unique structure. It should be noted that such platforms are still in their infancy and although they can create a metric that is easy for researchers to administer and for recipients to digest, further validation is still needed. In consonance with the second alternative, a lifespan DNS for brain resilience is being introduced here for the first time, in order to allow the quantification of subtle disbalances in the biological network associated with early progression toward disease, such as mild cognitive impairments and/or people living with dementia.

Brain resilience is a proxy measure that is sensitive to the various attributes of brain health, such as the brain age gap. Traditionally, the brain age gap is the difference between one's chronological age and an individual's brain age, as observed using neuroimaging magnetic resonance imaging (MRI), which examines the brain's structure, function and integrity. However, neuroimaging is a static biomarker, which represents sporadic, episodic and sparse data and limits representation from low socioeconomic regions and individuals from rural or medically underserved communities. On the other side we are proposing a dynamic digital neuro fingerprint (DNF) for brain resilience across the lifespan. Similar definitions of metabolic brain signatures of cognitive resilience in the 80+s have been proposed recently by researchers from the Department of Radiology, Mayo Clinic, Rochester, Minnesota, USA. Furthermore, rather than an introduction here with a limited focus at the presence or absence of disease such as dementia, we would like to share here a first conceptualization of the DNS brain resilience biomarker, based on continuous dynamical interpretation of brain health measurements, regardless of the starting point on the continuum of brain health. Brain resilience monitoring can be combined with personalized intervention strategies to improve individual health, lay the foundation to better understand the cultural relevance of brain health and operationalise it for research, policy and practice.

Predictors

B. Mechanistic Pathway
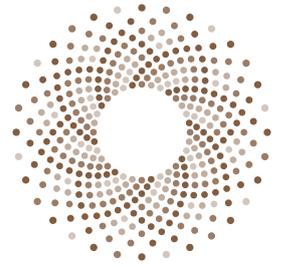
C. Outcomes

Lifespan eco-biopsychosocial determinants

Digital biomarkers capturing vascular health
Digital biomarkers capturing Fitness, mood and well-being

Resistance to Brain pathology
Aβ clearance mechanisms
Tau clearance mechanisms

Digital Neuro Fingerprint (DNF) of Brain structure,
Functional Networks - brain efficiency, capacity
Maintenance of Glucose metabolism

Resilience to pathology
Functional network - neural compensation

DNS Brain Resilience score
life-long dynamic state of cognitive, emotional and motor domains underpinned by physiological processes
Successful cognitive aging

Digital Neuro Signature brain resilience biomarker for successful cognitive ageing. Adapted from Arenaza-Urquijo and Vemuri (2018).

Further, an implication of this lifespan DNS for brain resilience is that it gives mechanistic insight into biological pathways and processes concerning health status and dynamics. Optimal brain resilience may be defined at any life stage as average performance levels among all people at that age who are free of known brain or other organ system disease in terms of decline from previously documented levels of function or as adequacy to perform all activities that the individual wishes to undertake, as an optimal capacity to function adaptively in the environment. The evidence collected through the DNS for brain resilience might also be fed back to policymakers and regulators to influence assessment, pricing, and reimbursement practices in line with emerging evidence on the impact of innovative therapies. The Clinical Trials Transformation Initiative in June 2017[1] has made some recommendations for digital health endpoints to reach such an ambitious goal. Lastly, an evidence collection infrastructure would also allow healthcare systems to refine patient populations eligible for treatment based on real-world data and experiences.

4. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG, Dias A, Fox N, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Ogunniyi A, Orgeta V, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L, Mukadam N. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020 Aug 8;396(10248):413-446. doi: 10.1016/S0140-6736(20)30367-6. Epub 2020 Jul 30. PMID: 32738937; PMCID: PMC7392084.
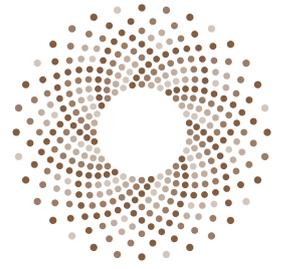
The moving landscape of digital diagnostics in dementia: The road from the lab to the clinic

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Dr Chris Kalafatis
Dr Andrew Owens
Dr Ta-Wei Guu
Department of Old Age Psychiatry, Institute of Psychiatry, Psychology and Neuroscience at King's College London

Digital technologies in dementia have the potential to greatly improve the diagnostic process and monitoring by allowing frequent or even continuous objective measurements compared to conventional methods. However, implementation in research and clinical practice has been, at best, partial. Among the various reasons for this delay has been the cost and availability of technological tools, slow uptake of translational research, the stereotyped view that older adults will struggle to adopt technology, and crucially, regulatory guidelines that can be prohibitively restrictive, particularly at proof-of-principle or piloting stage. The COVID-19 pandemic has acted as an inflection point for the deployment of remote digital technologies (RMTs), such as wearable sensors (wearables) and device applications (apps) in healthcare and clinical research.

Digital cognitive biomarkers, markers of function and detection of behavioural and psychological symptoms of dementia (BPSD) are now widely available and many have passed the important hurdle of the implementation, albeit at a small scale. Scalability however - which for digital biomarkers is a unique attribute - remains a challenge and limits their impact. As we are firmly entering the realm of risk-based population screening, digital diagnostics are best-placed to improve diagnosis and patient monitoring while delivering cost-effectiveness and improving health outcomes, a combination that is seldom encountered in clinical practice.

The climate is right, particularly for diagnostics that combine existing and expanding evidence base but also harness the capabilities that everyday devices (wearables, smartphones, web browsers etc) give. Off-the-shelf, consumer wearables and apps are now used to provide objective and continuous measurements of cognition and function, whilst being affordable and readily accessible to most, but not all. Inequity of access continues to present a challenge and should not contribute to health inequalities. In fact, as hardware costs are expected to continue to reduce and technologies are found to be valuable to health and social care systems, we envisage that such costs can be absorbed, particularly when collaboration with vendors is possible.

As patients and clinicians are becoming increasingly familiar with such technologies through personal and professional use, attitudes are also changing rapidly. In the next decade, the vast majority of our patients will already be casual users of the devices in
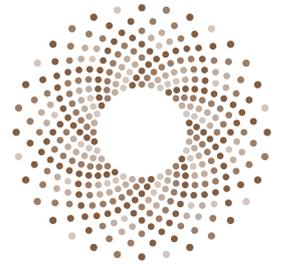
question. However, more real-world evidence is urgently needed to also improve their usability. Clinical uptake, however hindered, is actually on the rise. From our experience, a key component of this uptake stems from engagement with patient and carer groups to share the value of such approaches and discuss usability and data protection.

Virtual assessments and remote measurements have therefore entered clinical practice. Hybrid memory clinics have become inevitable during the pandemic and we are seeing coordinated efforts to standardise this practice and benefit from the inherent qualities digital tools bring, such as the ability of remote monitoring of mild cognitive impairment in the community, something that most service structures cannot currently provide. As brain health enters our clinical vocabulary, we are becoming more sensitive to our patients' lifestyle choices and our ability to promote healthy ageing, conversely, patients no longer feel that they are passive recipients of medical advice, but rather provide an active and informed role in their own wellbeing. We have recently developed a fully remote brain health clinic that harnesses digital biomarkers in tandem with typical clinical neuroimaging and protein-based biomarkers.[1] The clinic aims to improve diagnostic accuracy, monitor cognitive and functional trajectories - when we previously could not - and help prevent in anticipation of disease-modifying treatments for prodromal dementia.

Machine learning, now mostly prevalent in neuroimaging, is also a tool that has entered the clinic and is, no doubt, a promising contributor towards prediction. Predictive algorithms of neurodegeneration are in their infancy in clinical practice, but they are widely regarded as a revolution in diagnosis and patient management. However, for machine learning and artificial intelligence approaches to be fully potentiated, healthcare providers must make data access and formatting more suitable to data scientists, and dataset owners must do more than gesture promises of data access to appease grant awarding bodies once their funding has been secured. Highly publicised examples of data breaches in other research areas have not helped and societies can certainly do more to support policy changes and bring regulators up to speed with advances in research and new methods, such a swarm computing, to expand data sharing and blockchain technology to safeguard data privacy.

The continued application of digital tools is also dependent on permanent approval from test developers for these tools to be administered. This may require significant changes to how some services operate, and a financial commitment in order to assimilate existing technologies that have proven to be reliable, into their operational pathways. A multitude of digital diagnostic and monitoring tools are now past proof-of-concept. Wearables are used in combination with passive smartphone sensor data, such as phone usage and communication patterns to detect dementia, with minimal demand and input from patients.[2] Actigraphy is also employed in both dementia patients and carers to better monitor both BPSD and caregiver burden. Composite digital diagnostic biomarkers that reflect the probable multifactorial pathophysiology of dementia and can synthesize high-dimensional multisource data and may predict future cases, are a step closer to precision medicine. Here, "black-box" algorithms and algorithmic bias are challenges that researchers are tackling for clinical implementation.

As more novel digital diagnostics are being developed, online, research ready cohorts that cross geographic boundaries are becoming more prominent and in turn expand

1. Owens AP, Ballard C, Beigi M, Kalafatis C, Brooker H, Lavelle G, Brønnick KK, Sauer J, Boddington S, Velayudhan L and Aarsland D (2020) Implementing Remote Memory Clinics to Enhance Clinical Care During and After COVID-19. Front. Psychiatry 11:579934. doi: 10.3389/fpsyt.2020.579934

2. https://www.radar-ad.org/

their adoption.[3] These patient cohorts can facilitate knowledge sharing, offer deep phenotyping and support both industry-led and institutional multicentre trials at lower cost. Digital tools now enable remote research and hybrid clinical trials while also reducing participant burden, improving data collection, data flow and curation and potentially reducing the impact of screen failures.
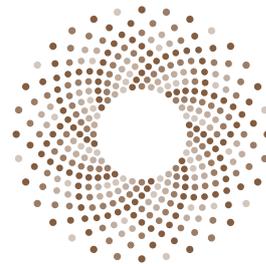
Ultimately, digital diagnostics in dementia are maturing and transforming our existing capabilities. Their added value, now evident to most in the field, ought to become a reality for our patients and their carers, now more than ever before.

3. https://www.protectstudy.org.uk/
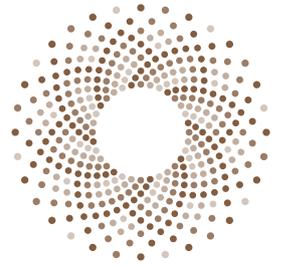
Tech-based detection and management of diseases causing dementia: Opportunities and challenges

Dr Dennis Chan

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There is a vogue among some commentators to frame the world of today as being at the beginning of a technological revolution, generating a societal change of tectonic magnitude not seen since the Industrial Revolution. While the aptness of the comparison is one for future historians to debate, there is little doubt that the advent of wearable tech and AI presents hitherto-unavailable opportunities to revolutionise healthcare. In principle, these opportunities can be applied to the entire spectrum of clinical practice relating to the diseases causing dementia, from detection of diseases in their earliest stages through to support of people with advanced dementia. However, as with any innovations that disrupt, any usage of tech-based solutions in practice will need to take into account not just the perceived benefits but also wider considerations such as their usability and acceptability in the general population, the risk of obsolescence associated with future technological advances and the risk that the requirement for tech will aggravate demographic and cultural inequalities in healthcare provision.

With that cautionary note in place, it is possible to identify a number of ways in which novel technologies may be used to address current needs. Detection of diseases in their earliest, preclinical, stages is a good (and logical) place to begin. As is the situation for introduction of innovations in any aspects of medical practice, first of all the case has to be made that the innovation delivers an improvement on current practice. This is especially relevant for technologies, to avoid the use of tech for tech's sake in the absence of a robust scientific or clinical rationale. However, for preclinical detection the argument is easily made; current methods are ill-suited to identify preclinical disease at the scale required to meet the need of the ageing population worldwide at risk of dementia. Traditional pen-and-paper tests of the kind used at present in clinical practice have low sensitivity and specificity for early stage disease and low ability for predicting progression to dementia. By comparison, CSF- or PET-based biomarker tests high sensitivity and specificity for early AD, but their high cost, invasiveness and limited availability preclude their usage at scale in the wider population. Furthermore, biomarker tests are at present not available for non-AD diseases, aggravating the difficulty of identifying these diseases in their earliest stages.

Disease detection based on wearable tech has the potential to overcome many of these current limitations. First of all, the multiple sensing capabilities of these devices allows acquisition of data relating to a variety of everyday activities known to be affected in early disease - such as sleep, navigation and social behaviour – but which cannot be measured using pen-and-paper tests. In addition to possessing ecological validity absent
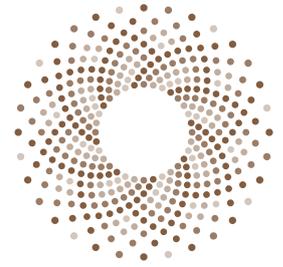
from legacy tests, the evaluation of naturalistic behaviours also brings major benefits in that the study of some behaviours that are common across animal species allows comparison of outcomes across animal models of disease and human cohorts, which is crucial for translational research and clinical trials. The range of activities measured can be expanded beyond historical cognitive domains to encompass new cognitive functions (such as human-device interaction) and non-cognitive activities including autonomic and motor functions, in turn improving knowledge of disease phenotype and awareness of disease impact on everyday life. Furthermore, the ability to track behaviours on an individual basis offsets the traditional drawbacks of interpreting data from traditional cognitive testing in light of demographic confounds (notably educational, linguistic and cultural differences) and identification of impairment by comparison against historically collected normative data. Finally, the ability of wearables to acquire data on multiple behaviours at a much higher frequency than is possible within the relatively infrequent assessments typically available in clinical practice will not only generate many more data points but will also yield high throughput multidimensional datasets of sufficient size to enable application of machine learning algorithms to extract additional diagnostic signal that that would be invisible to current data analysis methods.

Beyond the scientific case, consideration needs to be given to the practicalities of tech deployment, addressing a variety of operational challenges that are different to those posed by current practice. After identification of those activities of greatest value for preclinical detection, it needs to be established that they can be measured using current or next generation devices that are low in cost and scalable for future population-level application. Test validity (construct, content and ecological) will need to be determined, for instance by comparison of the outcome measures against current biomarkers of disease. Beyond scientific validation, it is critical that this new approach is acceptable from the user perspective, encompassing issues such as ease of use, device burden and privacy preservation. From a computer science perspective, the activities of interest need to measurable across a variety of hardware and software platforms, in such a way that is independent of future upgrades, to mitigate against the risk of obsolescence. Infrastructures will need to be set up that guarantee security of data capture and storage and deliver data in formats that are suitable for machine learning and other high level analytics, to extract maximal diagnostic signal.

The above worked example of disease detection outlines in some detail the specific opportunities and challenges associated with tech usage. However, the same general principles also apply to their potential future deployment in later stages of disease, given the numerous ways in which technologies could help maintain functional independence, quality of life and safety at home. Examples range from use of computerised cognitive training to help maintain cognitive function in people with mild cognitive impairment, using VR and other tech capable of simulating real life settings to ensure that cognitive gains transfer to real world function, through to passive (eg sensors) and active (eg wearable robotics) tech to track and support the activities of people with dementia and alert carers to falls or other acute medical problems in order to reduce risk of hospitalisation and support living at home.

As with preclinical detection, in all instances the overarching imperative is that any tech-based approaches provide added value above and beyond current options. Beyond that, the same considerations apply with regard to cost, scalability and user
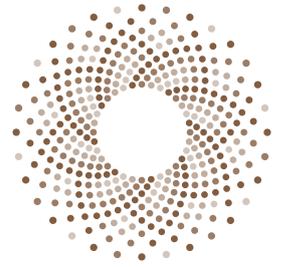
acceptability, with the latter being of particular significance given the extra challenge of using tech in people with significant cognitive impairment. Recent studies (such as the ATTILA trial in the UK) showing that current generation assistive technologies were of limited effectiveness when applied to people with dementia living at home not only illustrate the size of the challenge but also underscore the importance of design, to maximise usability of tech in order to improve compliance and clinical outcomes, and on the use of systems-based engineering principles* to guide implementation of such technologies in community and healthcare environments.

In conclusion, it is beyond reasonable doubt that new technologies will be integral to the future diagnosis and management of diseases causing dementia. Armed with this foresight, the challenge is to ensure that they are utilised cost-effectively across all stages of disease in ways that are acceptable to people of all demographics and cultures. By ensuring that any usage of tech-based approaches is founded upon robust scientific and clinical rationales, and that design and systems engineering principles are used to guide their deployment in clinical practice, it is possible to plan ahead and ensure that the use of tech in the diagnosis and management of diseases causing dementia will remain fit for purpose into the future.

*To illustrate the point about a need for systems-based approach, one could consider the replacement of ocean liners by airplanes for intercontinental travel. The development of airplanes itself does not suffice. Operation at scale required the installation of a system built around the plane, using airports instead of seaports, air traffic control in place of port authorities, airline crew etc etc.
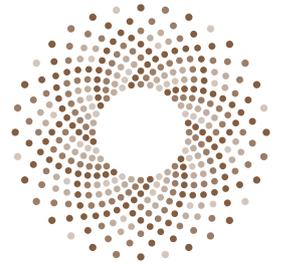
Pervasive computing to reinvent and accelerate clinical trials for Alzheimer's disease

Professor Jeffrey Kaye

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The key pathophysiologic mechanism leading to the clinical dementia syndrome of Alzheimer's disease remains unclear. This fact has dramatically affected progress in finding effective treatments. It has spurred a remarkable evolution of inquiry into the basic pathophysiology of the disease with many laboratories around the world using an array of biotechnologies (genetic engineering, high through-put 'omics, path or network analysis, etc.) to "invade" and map the cellular and molecular spaces of the brain in an attempt to more precisely elucidate the pathways of most importance. At the same time, clinical research and population science has provided many unique observations regarding risk factors that especially when aligned with more basic mechanisms provide multiple potential targets for therapy. On one level, this has created almost an embarrassment of riches reflected in what are collectively thousands of potential targets for therapies. On the other hand, limited by practical considerations of the immense resources and time necessary to bring treatments into practice, there remains a major challenge as to deciding which therapies might be most promising and practical to test using the trusted clinical trials pathways required to generate believable evidence that a therapy works meaningfully in the day-to-day world of affected individuals.

Currently there are over 125 drugs in active development for the treatment of Alzheimer's disease (AD).[1] Clinicaltrials.gov lists over 800 AD trials planned or active encompassing not only pharmacologic treatments, but non-pharmacologic therapies as well.[2] Whether these are symptomatic or disease modifying therapies, drugs or life-style interventions, all are welcome. However, most will fail to deliver on their promise. Simply stated, these will fail because the "go- no-go" decision to move therapy development down the evidence pipeline from early stage to later registration trials is based on a paucity of objective evidence available to development teams in order to make the leap from early-stage therapeutic trials to the currently required more expansive and expensive late-stage clinical trials. Much of this shortcoming lies in the outcome measures themselves which are tasked with gauging change that inherently unfolds slowly over many months or years. Current conventional measures of disease efficacy are insensitive to this subtle, slowly evolving pathologic and clinical change. Most importantly, they are unable to speak to whether the treatment will make a meaningful difference in the life of the person with AD.

This state of the science is reflected in particular in current US FDA guidance for the development of drugs to treat AD occurring before onset of overt dementia (i.e., those

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2. Clinicaltrials.gov, accessed November 4, 2021. Includes trials not yet recruiting, recruiting, enrolling by invitation, active, not recruiting. Interventions may be studies of approved drugs, biomarker outcomes, and non-pharmacologic therapies.
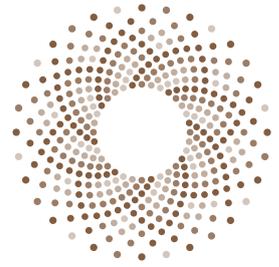
with in vivo AD pathology, but with no or subtle objective cognitive or functional deficits such as commonly observed as "MCI").[3] Current FDA guidance highlights the need for trial outcome measures that go beyond current metrics of cognitive performance of uncertain, stand-alone clinical meaningfulness, as well as demonstrate that a therapy favorably affects subtle functional deficits: "Ideally, the outcome measure used in this stage of disease will provide an assessment of meaningful cognitive function." The FDA encourages the "development of novel approaches to the integrated evaluation of subtle early AD (predementia) functional deficits/impact that arise from early cognitive impairment."[3,4]

The need for novel approaches for evaluating subtle cognitive and functional deficits is a product of the shortcomings of conventional AD trial outcome measures, largely rooted in legacy trial methodology. This methodology relies on assessing enrolled individuals with a combination of self-report measures (e.g., function, mood, adverse events), cognitive measures (e.g., psychometric batteries), and biomarkers (e.g., neuroimaging, fluid-based). These measures are typically collected at a baseline visit, followed by randomization to a placebo or treatment arm(s), with subsequent in-clinic follow-up assessments, often separated by large gaps of time. Even if assessments are conducted remotely by telephone, they remain necessarily brief and limited in scope. Thus, this assessment paradigm is inherently time-restricted, variable, proxy-based, and of low information content, generating data with important limitations. Key data related to cognition and function are not ecologically valid; patients are asked to perform tasks they never do in real life (e.g., memorize word lists) or describe how well they perceive they do a task at home, though actual daily performance on those tasks may be quite different than reported.[5] In early AD patients for whom changes in cognition and function are subtle, this approach lacks sensitivity to detect meaningful change. As a result, current trials may require thousands of volunteers followed for long periods of time to interpret if there is change in cognition or function.[6,7]

This state of affairs may be fundamentally transformed by using digital technologies focused on obtaining unobtrusive, cost-efficient, home-based, clinical assessments that take advantage of remote sensing, pervasive computing and high-dimensional data analytics. The use of such an approach or assessment platform allows objective, continuous, real-time, multi-domain, and ecologically valid data to be readily delivered.[8-12] The digital data are integrated into behavior and activity metrics ("digital biomarkers" or DBs) that include precise, time-stamped measures of physical activity, medication-taking behavior, sleep, socialization, and everyday cognitive function (e.g., computer use, driving). This comprehensive approach also incorporates regular on-line queries regarding internal states that inherently require direct report (e.g., pain, mood), home-based cognitive assessment, as well as the opportunity to capture adverse events and health economic data (e.g., falls, ER visits, clinical appointments). These DBs can be used to assay individual functions (medication taking, computer use, sleep, etc.), or aggregated into single composite functional measures that are real-world Digital Indicators of Active Life Status ("DIALS"). Importantly, these DBs and DIALS reflect tangible functions and everyday experiences that patients with mild cognitive impairment (MCI) and their partners rank higher in importance as treatment outcomes than their cognitive test scores.[13-15] They directly align with the FDA and other agencies recognition of using real world data to deliver real world evidence.[16] Crucially, the DBs and DIALS themselves can be traced back to their correlations with post-mortem AD

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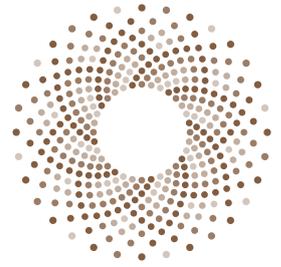
pathology itself [17,] thus linking the pathologic targets of therapies to the real-world evidence.

Further, in addition to delivering real world data, and yielding more patient-desired, meaningful outcomes, the approach provides unique improvements to trial conduct. The high frequency of the data captured at the individual level offers the opportunity to transform trial methodology by markedly reducing required sample sizes.[18-20] This not only improves the efficiency and cost of trials, but importantly also reduces the number of participants exposed to potential harm, as treatments may have serious adverse effects. Uniquely, this data improves the precision of the estimate of the trajectory of change at the person-level, providing intra-individual measures of change (verses conventional group change). It affords the opportunity not only to use these measures as endpoint outcomes, but also to stratify patients entering trials into those progressing more rapidly or not. This precision phenotyping of those more or less rapidly progressing, can further reduce sample sizes needed to show a divergence from a steeper change trajectory. In addition, at the end of a defined trial period, since the technology and online contact remains in place, important longer-term post-trial data can be readily captured.

In the above scenario, I have outlined the advantages brought to therapeutic development by digital real-world assessments focused on the critical use case of conducting studies of early pre-symptomatic AD. It should also be appreciated that this approach is not limited to the early stages of AD. The use cases immediately apply and generalize to the large number affected by other dementias whether secondary to vascular disease, traumatic injury or neurodegenerative disease (e.g., Lewy body dementia, frontal-temporal dementias). The use case also expands beyond early stages of disease. In fact, at the other end of the dementia severity spectrum, it should be noted that we also struggle to determine the efficacy of much needed symptomatic treatments of AD, especially addressing behavioral and psychological symptoms (BPS). Here the current challenge of showing clinical efficacy often presents with two major conundrums. First, the person with dementia may not be easily or even appropriately assessed because asking questions or hands-on examination of a severely affected person with dementia may in fact by itself precipitate BPSs. Second, relying on a care partner to provide timely observational data regarding home-based activity places added burden on an already strapped care provider.

The burden of assessment on care partners extends not only to their monitoring the efficacy of a therapy for the person affected with dementia, but to the care partner's ability to report on their own health and wellbeing resulting from interventions that are directed specifically to improve their own experience as a partner in care. Thus, the largely passive digital technologies described above are especially attuned to continuously assessing in the background key features of episodic behaviors and activities common in late-stage dementia, as well as caregiver health.[21-22] Again, as noted above, the high-frequency data lends itself to intra-individual analyses enabling use of for example n-of-one, individual symptomatic treatment cluster designs, further potentially reducing samples sizes while providing meaningful mapping of daily activities that are positively or negatively moved by the new therapy. In addition, in the area of care partner research, the digital, time-stamped data synchronously captured in-residence enables the opportunity to establish outcome efficacies based on the person

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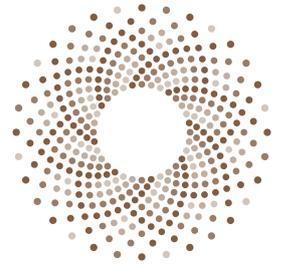
with dementia and their care partner considered together as an integrated life-dyad, rather than simply as independent actors.[23]

Finally, it should not escape notice, that the use of pervasive ambient computing methods for remote assessment at home facilitates greater inclusiveness of participants who may live in effective "clinical trial deserts", places where participation in research is hampered by living in a remote or isolated area or even when close to a trial center, still lacking a means to travel or be assisted regularly to participate in a trial. Further, the ability to reach out more widely to racially or ethnically underrepresented participants, as well as those who may be economically disadvantaged can also be further advanced by reducing the barriers to participate. Necessitated by the pandemic, fully remote deployment of home-based systems is now feasible.[24] Simply stated, where ever you live, you should be able to participate. It is clear that these under-represented in research participants are readily able to engage in home-based digital technology assisted assessment studies,11 and thus the remote, home-based assessment approach provides an opportunity to expand not only the total number of participants available for clinical trials, but the generalizability of therapies to be tested.

In summary, we have been blessed by the bounty of contemporary biotechnology, which has generated an abundance of potential AD therapies. Unfortunately, the vast majority of these promising therapies may fail to show efficacy or even to be advanced beyond the laboratory because the common clinical trials assessment paradigm is unable to provide timely, cost-effective readouts of meaningful outcomes. However, the status quo is about to change. Tremendous advances in pervasive computing and life analytic technologies now enable the opportunity for remote, continuous, long-term, and unobtrusive assessment in the real-world. These technologies when appropriately assembled to function in the everyday lives of persons with dementia and their care partners deliver needed ecologically valid outcome measures. The high frequency, and multi-domain integration of this data affords dramatic reductions in sample sizes facilitating the ability to test more therapies while at the same time, reducing the number potentially exposed to adverse events. The approach is highly flexible, capable of being tuned to a wide range of trial use cases such as presymptomatic dementia prevention, mediating BPS in late-stage dementia, or care provider interventions. By improving the efficiency and effectiveness of therapeutics development, not only may costs of development be moderated, and more meaningful outcomes be uncovered, but new basic knowledge about the lived experience of dementia in the community may be gained. Wise investment in this digital assessment enterprise to accelerate the trials testing pipeline will pay large dividends, magnifying our ability to establish highly valued therapies, while advancing and transforming our understanding of the basic behavioral biology of AD and related disorders across diverse communities.

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3. Behavour, inclusion and rights
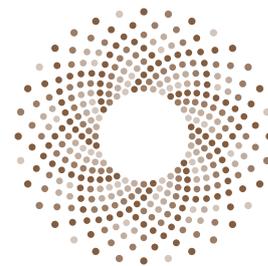
Three thoughts on behavioral change technology

Dr Katarzyna Hess-Wiktor
CEO and co-founder of Minnity

Prevention, supporting people with dementia to live well and independently and enabling better provision of health care is now irrevocably connected with technology. Digital tools allow us to perform, scale and evaluate health interventions. How can technology be used to increase awareness, spread knowledge and actually affect people's behaviors to lower their health risks? And once the first signs of dementia appear, how can technology effectively support the individual?

In this essay, I would like to share some insights inspired by the WDC round table on technology from the perspective of a psychologist specialized in dementia care training, working in the field of digital health and innovation.

The goal to introduce behavioral change through technology is an ambitious one. Because so many factors are involved, a digital intervention will always be only a piece of a larger puzzle, where social, cultural and individual components intertwine. There are three aspects to the design for behavioral change that I would like to highlight: co-creation to integrate the intervention with life, personalizing the experience and interaction, and evaluating the outcomes.

Co-creation. Technology, often devised by digital natives, may not take into account the habits of the older generations as well as hardships that they may experience in learning to operate new devices or software simply because of less experience with the digital world. Moreover, in case of individuals already experiencing some symptoms of dementia, progressive cognitive difficulties, including memory loss and orientation and problem solving undoubtedly affect the ability to uptake new and use old technologies. Just think of the many who realized that they had cognitive issues when they experienced difficulties in using a TV remote or an electric kettle. Designing behavioral change should thus be done in close collaboration with both the target group and their close ones, who often act as proxies and facilitators when adapting new technologies.
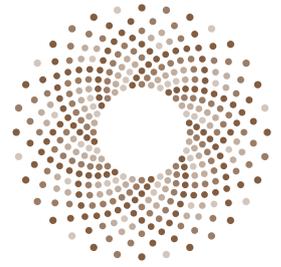
Research emphasizes the importance of including people with MCI or dementia together with their family members in product development, in order to learn about required design features to enhance usability and acceptability.[1] Good behavioral change technology is not designed in labs, it's co-designed with the users and stakeholders in the field, taking into account the ecological validity and cultural context of the solution.[2]
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Personalization. There is obviously no one-size-fits-all solution in behavioral change as our needs, personalities, social networks and environments vary immensely. The challenges for behavioral interventions using technology are connected both to their design and their implementation. Having an empathetic understanding of the challenges the users face is the basis of good design. It is rarely the case that the individual will adapt their environment and habits to technology - rather the opposite: the technology will only be used if its features and interface fit into the individual's everyday life.[3] Adding another layer of complexity, technology should take into account that care needs can rapidly fluctuate as a person experiences emerging limitations due to progressive dementia and new challenges arising for both the individual and the caregivers. In this case, technology can in fact be part of the problem, not only the solution. And if it cannot be adapted to how older adults and people with dementia wish to live their lives, they rather abandon it.[4] This is why designing user interfaces that are integrated with our habits and everyday activities is so valuable. For example, integrating measurements in everyday functions and interactions with the already used digital devices is a way to lower the threshold for technology. Voice user interfaces seem to be a promising area for exploration, too, as the verbal communication supported by technology has been around for almost 150 years.

Research shows also that the barriers to technology experienced by older adults are often lack of, or lack of clarity in, instructions and support, rather than skepticism to the technology itself.[5] It's important to point out that because sharing and interpreting instructions on how to use a device strongly relies on social relations, it is crucial to provide guidance in implementation of the tech solution, as well as to include other relevant individuals in its utilization. On that note, support for older adults who live independently and do not have an informal carer becomes an issue of societal responsibility and social care policies.

Evaluation. Design for behavioral change in dementia prevention and care should also be evaluated on multiple levels. Besides usability and acceptability, also other factors play an important role in the effectiveness of a digital intervention. Affordability and scalability might be obvious areas for evaluation - we want interventions to be cost-effective and available to many, but how does technology affect the user's self perception? When we implement monitoring, whose needs are we serving, the individual's, their caregiver's or the healthcare provider's - and what if they are contradictory? Does the used technology respect the integrity and dignity of the individual? We still have a lot to learn in this field as little is known about the consequences of technology use with regard to quality of life, occupational performance, or human dignity.[6] It is reported that technology may evoke stereotype threat and although this threat does not impair performance, it still changes self perception: older adults feel older after using some apps, especially unfamiliar ones.[7] How does this affect their well-being?

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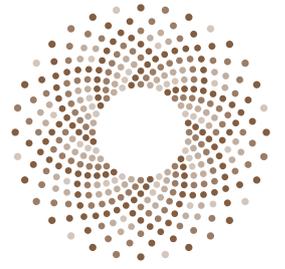
After all, the successful implementation of technology is measured by the scale of the positive effects it brings. That's why effective innovation should prioritize serving the needs of the users over the degree of novelty and technical advancement. This is sometimes overlooked in the healthtech world, where buzzwords like VR, algorithms and AI are more attractive to financiers than whether the innovation solves an actual problem with adequate means. Going the "easy", low-tech way, that has already proven to be helpful, may help us in developing behavior changing solutions also for those who do not have the capacity – or desire – to engage with demanding high-tech.[8] Designing together with the users, personalizing the solutions and implementation as well as evaluating the results of this process are key to creating behavior changing technology that works.

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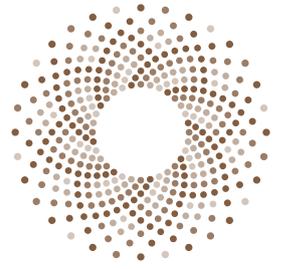
Technology: Hear to help

Professor Martin Orrell

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In the opening sequences of the film I Robot we are introduced to Asimov's laws of robotics and see Detective Spooner wrongly apprehend a Robot who is running with a handbag only to realise that it was not stealing but instead delivering an inhaler to a woman in need. Hence, technology is a force for good which still requires a degree of scrutiny.

The last twenty years has seen an ever increasing panoply of technology developed and marketed for people with dementia and their families. The tragedy of Covid-19 has dramatically accelerated the use of technology enabling families to keep in touch far beyond what was feasible 10 years ago. Even traditionally in-person psychosocial approaches such as group Cognitive Stimulation Therapy and group singing have been modified and implemented as a virtual format using Zoom or similar.
Hence, the technological tidal wave of new gadgets and apps has lead to high hopes for the future. However, in the excitement about the potential benefits of technology there remains a need to consider the rights, needs and preferences of the users and involve them from start to finish.

Though evidence is limited, policy-makers and researchers often see technology as promising solutions to promote societal inclusion, independence, autonomy and meaningful activities in people with dementia. The complex nature of how humans relate to and use technology is reflected in the difficulties of applications which aim to support people with dementia. The Technology taskforce of INTERDEM highlighted the need for high-quality studies on usability, effectiveness and cost-effectiveness, with timely involvement of people with dementia themselves.

Living at home means living in a technologically complex society, and research has shown that people with early stage dementia have decreased ability to manage everyday technology. Despite the wide variety of assistive technology available there remains a great debate about what technologies need to be developed and there are concerns about the lack of interactions between industry, health staff and the direct users of assistive technology: people with dementia and their carers. The EU funded ENABLE study with 5 countries using prototypes and qualitative methodology, concluded that whereas technology could promote independence it needed to be fully tested and operational prior to use in real life. Moreover, many innovative systems are not commercially available, and there is a need for independent research rather than 'in-house'
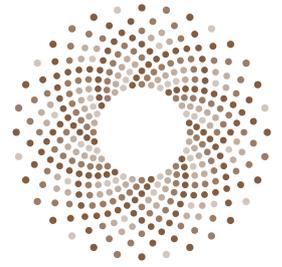
evaluations. Implementation of technology is not just impeded by lack of evidence of effectiveness but is influenced by stigma, perceptions and people's basic rights of autonomy and dignity.

People with dementia have been unable to fully benefit from technology because of the poor understanding in research and business of how people with dementia use technology in everyday life, with new applications being designed without an in-depth appreciation of people's needs, preferences and limitations. Research has been fragmented, with studies often poorly designed, in-house and small scale, with technology that does not meet people's needs making it hard to draw any conclusions on effectiveness. Lastly, there is little knowledge about practical, psychological and social barriers and facilitators to implementation to explain why people with dementia frequently do not use technology; and why it has been hard to get useful technology into more widespread practice.

So there is also a need to consider technology and human rights, and so the UN Convention on the Rights of Persons with Disabilities (CRPD) highlights the importance of respect, dignity, autonomy, non discrimination and acceptance of diversity, equality of opportunity, participation and inclusion in society. This is helpful to consider in the context of Kitwood's descriptions of the negative social psychology impacting on people with dementia.

Funded by two EU Marie-Curie Network grants INDUCT and DISTINCT employing 30 Early Stage Researchers we are pursuing a programme of research aiming to improve the lives of people with dementia and their carers through technology. The best practice guidance produced and has highlighted some of the complex issues relevant to human rights and technology. Marketing of Surveillance Technology, such as GPS tracking devices can undermine dignity by portraying people with dementia in a way that encourages stereotypes and contributes to a misunderstanding of dementia e.g. suggesting covert use for wandering people with dementia, children and pets. Also despite the lack of evidence for the effectiveness of brain training to prevent dementia there is evidence that engagement with it can lead to stigma by designating some people as 'successful' (or not) in cognitive ageing. The promotion of this technology suggests an individual responsibility to stay cognitively healthy risking anxiety, social exclusion, and implicit blame allocated to the condition and people who live with it.

Many countries and regions provide a disparate range of technology, creating inequality in access, so that implementation is severely limited. A recent review of ethical considerations of technology use in care homes identified three main themes: personal living environment (privacy, autonomy and obtrusiveness); the outside world (stigma and human contact); design of devices (individual approach, affordability and safety), and recommended that ethics should be studied in terms of the underlying concepts of privacy, autonomy, obtrusiveness, stigmatisation, human contact, individual approach, affordability and safety of technology.

Everyday technologies are increasingly vital in today's activities in communities and homes. Nevertheless, little attention has been given to the consequences of the increasing complexity and reliance on them. Technology may simplify our daily lives, compensate for disability and promote social inclusion. The rapid growth of
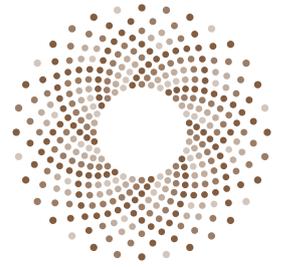
the technological landscape including robotics and smart home technology, has the potential to improve the cost-effectiveness of health and social services and facilitate social participation and engagement in activities. However, it also places people at high risk of exclusion if they fail to upgrade or maintain their competencies to manage technology. The older users' ability to manage products and services has been largely neglected or taken for granted. This has limited insights into how everyday technologies could be best designed and used, and how supportive dementia-friendly environments, private as well as public, should be designed to facilitate the participation of people with dementia.

Fundamental to all this is the imperative to hear the voice of people with dementia to involve them in all stages of design and development bearing in mind that lack of involvement can lead to faulty and unsuitable technology. Our recent review of 21 studies produced best practice guidelines on involvement. It is essential and feasible to involve people with dementia and this can be optimized by having the right prerequisites in place, ensuring that technology meets standards of reliability and stability, and providing a positive research experience for participants.

In the light of the technology race we also need to consider the limits and ramifications. In 'I Robot' the ideal robot may have been seen as an all purpose assistant. In contrast the robot in 'Ex Machina' was conceived as sufficiently 'lifelike' to pass the Turing test being hard to distinguish from a human. Technology should be a useful assistant and not replacement or substitute for real human contact.

Petbots may be viewed as more doll than a pet but (like pets too) will have their limits. Seeing people on zoom is palpably different from in person and we must always remember the need for real human contact for people with dementia to support their human rights, identity and humanity.

In the light of problems with the first 3 laws, Asimov also added the Zeroth law, to precede the others: A robot may not harm humanity, or, by inaction, allow humanity to come to harm. Technology is a good but not a universal one. To avoid harm, and to adequately benefit from technology we must hear the voice of people with dementia, respect the CRPD principles, and look for full user involvement in development, testing, evaluation and implementation.
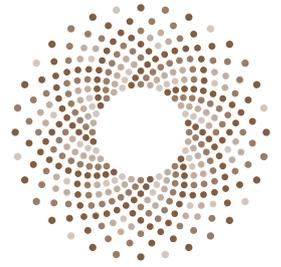
# Dementia technology: A human rights issue

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Since the potential of technology for dementia started to be recognised in the 1980s, its use has been inextricably linked with human rights. From access to and availability of technology, to its use in surveillance and restraint of people living with dementia, their human rights are central. The 'PANEL' – Participation, Accountability, Non-discrimination, Empowerment, Legality – guidelines were endorsed by the World Health Organisation (WHO), in 2015, to ensure the human rights of people living with dementia. How technology plays a part in this is a complex and often divisive topic.

There are many existing technologies with functionality to support people living with dementia to maintain participation in activities and connection with services. This includes cell phones, tablets and computers with apps that support text, video and audio calls and photograph and video sharing. Additionally, playing music and digital games are engaging activities that people with dementia can enjoy. However, affordability, availability and accessibility of devices continues to be a problem, particularly as these mainstream devices are not typically considered assistive technology. As such they are not provided by health or social care, leaving individuals and their families to self-purchase. On top of this is the cost of internet access through wifi or cellular services, which again falls on individuals or families. The fundamental importance of internet access for all, has been starkly highlighted by the COVID-19 pandemic, where multiple services and activities moved online, effectively excluding large sections of the population. This move to online services, highlights the importance of people with dementia having internet access and digital tools.

Access problems are compounded by the lack of knowledge and awareness among health and social care providers of the potential benefits of smart device functionality for people living with dementia. Additionally, the belief persists that people with dementia are unable to learn new skills, and so the concept of providing cell phones or tablets is still largely ignored. However, the evidence that people with dementia can continue to use smart devices or learn to use them for certain functions, for example, to call family or play games, is growing, along with recognition of the benefits to them and their families. Whilst this is to be welcomed, people living with dementia as end users, continue to be excluded from the technology development process. This is largely due to negative perceptions and low expectations of their ability to participate as equal partners. Consequently, there persists the tendency to work instead with family caregivers, and when they are not available ,which is frequently the case due to the demands of caregiving, with healthcare professionals. This is another example of the
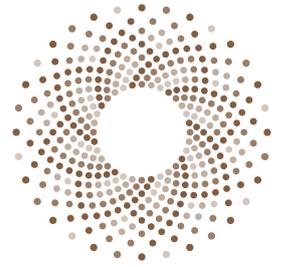
need for education about the abilities of people living with dementia, and practical tools for technology developers to engage with and co-produce digital solutions for people with dementia.

In addition to problems accessing digital resources to support the right of people living with dementia to participate in society, the use of technology itself can present a threat to their human rights. The most persistent example of this, is the use of GPS to track and monitor people living with dementia (Astell, 2006). For a variety of reasons, people with dementia may find wayfinding difficult, which can result in becoming lost, not returning home, or trying to make their way to a previous home. Sometime this has tragic consequences, with people being out overnight and occasionally dying from hypothermia or dehydration.

Technology could assist in addressing some of these challenges with wayfinding, while supporting the rights of people living with dementia to participation. GPS for example, could help them to find their route and stay on it. Over the past 30 years GPS on cell phones, electronic tagging, and other wearables have all been used to track people living with dementia. In 2004 the UK Alzheimer's Society said that any suggestion to use electronic monitoring - which at that time referring to tagging but currently could apply to apps on smart devices that track location - should be with the consent of the person with dementia. If an individual with dementia is deemed unable to consent, the decision to use GPS falls to whoever has legal responsibility for decision-making on their behalf. The system of legal guardianship or power of attorney varies across the world, but a key element is that decisions reflect the previously expressed views of the person with dementia. As such it is imperative that any use of GPS for tracking a person living with dementia, whether through a cell phone or wearable, is discussed as early as possible post-diagnosis. Otherwise, there is the very real risk of technology being used to constrain and confine them to certain locations rather than supporting continued participation.

In conclusion, current and emerging technology has vast potential to empower people to live well with dementia, through supporting continued participation in society. However, their rights must be kept at the forefront to avoid applications of technology that constrain their freedom under the label of keeping them safe and secure.

References

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The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org