Global dialogue on technology: Transcript

The dementia landscape project

4 March 2021
Co-chairs

Jeremy Hughes CBE

Jeremy Hughes works in health and social care and is former Chief Executive of the Alzheimer's Society in the UK, where he led the charity in its five-year strategy “The New Deal on Dementia 2017-22”. He chaired the Dementia Technology Working Group for the UK Department of Health & Social Care, and he was awarded the CBE for services to older people in the Queen's Birthday Honours 2015.

Dr Vaibhav Narayan

Dr Vaibhav Narayan is currently Vice President of Digital Health Innovation, Science for Minds, at Johnson & Johnson (J&J). 'Science for Minds' is a newly launched initiative at J&J to address the significant unmet need surrounding neuropsychiatric and neurodegenerative disorders, with a focus on three key areas: 1) serious mental health disorders, especially those impacting adolescents, 2) dementia, and 3) holistic mental health care. Prior to this role, Vaibhav was Head of Data Science for the Neuroscience Therapeutic Area at Janssen, the pharmaceutical division of J&J. In these roles, Vaibhav has led internal programs, industry collaborations and public-private partnerships to discover and validate digital solutions for early detection, disease progression monitoring and relapse prediction in Alzheimer’s, Mood and Schizophrenia. An integral component of this digital and data driven strategy has been 'disease interception': i.e., deflecting trajectory of CNS diseases through remote monitoring and early detection and integrated pharmacological/ non-pharmacological solutions that modify disease and develop resilience.
Speakers

Dr Amanda Lazar

Amanda Lazar is an assistant professor in the College of Information Studies at the University of Maryland, College Park. She received her PhD from the University of Washington in the Department of Biomedical Informatics and Medical Education. Her research examines the design of technology for older adults – and in particular, older adults with dementia – to support social interaction and engagement in activities. Her work is supported by the National Science Foundation (NSF) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

Professor David Sharp

Professor David Sharp is a neurologist and Centre Director of UK DRI Care Research & Technology, focusing on using technology to enhance the lives of people living with dementia. He is also Scientific Director of the Imperial College Clinical Imaging Facility and Associate Director of the Imperial Centre for Injury Studies. His research programme aims to improve clinical outcomes after dementia and traumatic brain injury (TBI), focusing on common cognitive impairments in domains such as memory and attention. He uses cognitive neuroscience and advanced neuroimaging to investigate the effect of brain injury on brain network function and the effects of inflammation and neurodegeneration. His has explored how new treatments of cognitive impairment can be personalised and his current work focuses on harnessing neurotechnology development to improve the lives of those living with dementia and the effects of brain injury.
Dr Allison Sekuler

Dr Allison Sekuler (FSEP, FPS, FAPS) is the Sandra A. Rotman Chair in Cognitive Neuroscience and Vice-President Research at Baycrest Health Sciences, and Managing Director of the Rotman Research Institute and the Centre for Aging + Brain Health Innovation (supporting innovators in Ontario, across Canada, and globally). A graduate of Pomona College (BA, Mathematics and Psychology) and the University of California, Berkeley (PhD, Psychology), Dr Sekuler holds faculty positions in the Department of Psychology, Neuroscience & Behaviour at McMaster University and the Department of Psychology at the University of Toronto. Her research uses behavioural and neuroimaging approaches to understand how the brain processes visual information, with specific interests in face perception, motion processing, perceptual learning, neural plasticity, aging, and neurotechnology. Her research was the first to show conclusively that older brains “rewire” themselves to compensate for functional changes.

Lenny Shallcross

Lenny Shallcross is executive director at the World Dementia Council. Prior to that he was Head of Community Engagement leading programmes across the UK to establish Dementia Friendly Communities. This includes the Dementia Friends programme which is the biggest health social movement campaign delivered by 10,000 volunteers that have recruited 2 million individuals through a community, digital and corporate offer. Before working for Alzheimer’s Society he worked in the UK government as a political adviser at DCMS and the DoH, as well as working in Parliament and for the Labour Party.
So thank you and welcome everyone. I know some of you have already participated in some of our workshops but for those of you who I have not met, which is not many of you, I am Lenny Shallcross, Executive Director of the World Dementia Council. As you will know, the World Dementia Council was established following the London dementia summit that was hosted here in the UK as part of the UK's presidency of the G8, as was. The Council is chaired by Harry Johns, President and CEO of Alzheimer's Association in the US. There are 24 members of the Council. Alongside the members there are a number of governments, and WHO and OECD are also members.

At the 2013 summit the international community committed to make progress across research, care, awareness and risk reduction. And the committed to a series of goals that would be delivered by 2025. The council was established after that meeting by the UK government with the purpose of supporting and challenging the international community to deliver on those commitments.

As I mentioned at the top, this is a fourth in a series of workshops we are holding over the first half of this year, reflecting on where we are and the dementia landscape. Later in the year we will produce a report evaluating the progress that has been made on the 2025 goals and identifying how that progress can be accelerated. And our intention, Covid-19 allowing, and given these slightly unusual circumstances where I am talking to you from my living room, which is the new normal, is to revert to the old normal and hold an in-person summit meeting later this year where we will launch the report. As I said, Covid-19 allowing.
These workshops are designed to get input into the report from international experts in the field reflecting on where we have come from, where we are, where we need to get to and how we will get there. After this meeting we will circulate to you all a transcript and we will follow that up with a discussion paper based on the conversation today. As I said we will send that to you and will very much welcome your comments on it.

As you might notice on the top of the screen, we are recording the meeting but that is for the purpose of producing that transcript. Before handing over to the co-chairs just a reminder to mute and unmute yourself which we are all very used to. We will have the chat function open throughout the meeting and I would encourage you to use the chat function to share your thinking. As you will have seen from the programme, we will have circulated we will have a lot of time for discussion, and I would encourage you to share your perspectives. If you do want to take part live in the meeting, use the chat function to indicate you want to speak, raise your hand or just wave. We will be keeping a look out.

With that I would like to introduce the co-chairs.

- Jeremy Hughes, former Chief Executive, Alzheimer’s Society and former chair, Dementia Technology Working Group for the UK Department of Health & Social Care
- Dr Vaibhav Narayan, Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

With my thanks to them both, I will now hand over to Jeremy to take the meeting forward.

Jeremy Hughes
Former Chief Executive, Alzheimer’s Society and former chair, Dementia Technology Working Group for the UK Department of Health & Social Care

Thank you, Lenny, and thank you for making today happen together with Josh from the World Dementia Council.

I was reflecting on the journey we have come on since 2010. Then the UK was one of the first countries in the world to adopt a dementia strategy. And I remember when we looked at the priority actions that were in that strategy – and there were 19 of them so it was fairly comprehensive – we didn’t really look at technology at all. There was technology implicit but not explicit. In the discussions that led up to that strategy, technology didn’t feature particularly strongly. Even at the G8 Dementia Summit which led to the formation of the World Dementia Council, 11th December 2013, we barely touched on technology as a subject matter.

So I think we have come a long way to recognize that technology is a key driver, not least in the last year when technology has become such a key part of everyday life. And that is why it is very important that in the review that the World Dementia Council is doing this year, we have this particular workshop on technology to focus on what we can learn and what we need to build into the achievement of the 2025 goals and beyond.
But technology isn’t confined to this workshop and I have sat in the other workshops and seen how it has been addressed. To pick up on a couple of examples. Mary Sano from the Mount Sinai School of Medicine in the care workshop reflected in a survey 2016 while 71% of people in care were interested in using technology for care only 7% did so and only 4% had access to telehealth. Now that has begun to change. Another reflection from that workshop is looking at the appropriateness of technology and accessibility. This was also picked up in a workshop here in the UK by the organization of people with dementia. The issue of technology also came up in the prevention workshop where Neerja Chowdhary from the World Health Organization talked about launching a new app for dementia prevention and using technology to reach across communities that don’t have access to traditional face-to-face healthcare that you see higher income countries. And Charles Alessi from Healthcare Information & Management Systems Society (HIMSS) highlighted the importance of digital technology in potentially addressing inequalities.

So I think we have a much higher recognition than before that technology has a part to play. But equally technology can disenfranchise people who don’t use it. It can lead to remoteness not accessibility if you don’t get it right. And I think that is particularly relevant when you talk about technology and dementia. So I think it is important that we use today to inform and shape the conversation going forward.

Now Vaibhav and I, when we were planning the workshop, wanted to make sure that it wasn’t too broad ranging. Because it could go in different directions. And there were three key themes that came out of our discussions. One is around technology and prevention. One around improving the daily functioning around people with dementia. And one around patient centred health and social care systems. So, I hope we will be able to pick up those themes in the discussion that Vaibhav will be leading following the introductory speakers. So, I am delighted to be able to introduce one by one our three speakers who come with different perspectives on the theme of technology. I am sure they will inspire a lot of discussion. And as Lenny said, please use the chat function to put down your thoughts as we go through the speakers and then we will have a chance to have some live discussion as well. We will be capturing all the discussion – both live and in the chat function – in the report that follows. So, I am delighted to invite first Dr Amanda Lazar to be our first speaker. Amanda is the Assistant Professor, College of Information Studies, University of Maryland and her research particularly looks at the design of technology to support older adults, and particularly older adults with dementia, to support their interaction and engagement. So over to you Amanda.
Thank you so much. I will be talking about technology for brain health, risk reduction as well as early detection.

**RISK REDUCTION**

*Where does technology fit?*
- Consumer health informatics
- Personal informatics
- Patient portals & EHRS
- Telemedicine
- Information resources
- Educational technology
- Behavior change technology
- Technology for attitudinal change on a societal level

*Issues to consider:*
- Minimise diabetes
- Treat hypertension
- Prevent head injury
- Stop smoking
- Reduce air pollution
- Reduce midlife obesity

- Maintain frequent exercise
- Reduce occurrence of depression
- Avoid excessive alcohol

- Treat hearing impairment
- Maintain frequent social contact
- Attain high level of education

*Dementia prevention, intervention, and care: 2020 report of the Lancet Commission*
So, I know you previously had an entire session on prevention at the World Dementia Council, so we are not going to get into the detail but start at the idea that there are these documented lifestyle factors that appear to affect the risk of dementia and appear to be able to be modified. And I have those in the box to the right. So where might technology fit into these? Everywhere right. Researchers have been looking into the role that technology can play in each of these domains. Not necessarily with the goal of affecting dementia but for other populations. So, for example text messaging for smoking cessation to sensors that detect and alert to air pollution. And of course this last year we have seen the major role the technologists are playing in education as well as social connection.

So, in thinking about reducing the risk of dementia using technology you don’t have to start from scratch. There are entire bodies of literature that exists on these different topics. Even though they haven’t been framed in terms of dementia and that might be a good thing because many of these risk factors are meant to be modified at an earlier point in the lifecycle not when we get to a certain age or when we have cognitive symptoms. We are meant to be addressing these earlier.

And, as we had in the introduction from Jeremy, I am going to make the point that technology isn’t always the solution and it can be the problem. So we don’t always need to see technology as the thing to come in and "solve" what we are working on. We also want to see it as something we need to modify and there are these larger deeper societal problems we need to fix. Deeper than what technology can do.

So researchers are realising that when we work on health technology we also need to move beyond technological innovation as our only goal. Innovation needs to happen in other spaces that can feel pretty mundane. Places like service provision, supporting
people with technology, the usability issues that were discussed and more. I can best speak from a US context in nothing that those who are experiencing inequitable access to technology because of cost, internet connection, economic segregation or structural racism, these are individuals more likely to go on and develop dementia in part due to those modifiable risk factors that I spoke about. So if our interventions are going to require resources that these groups are deprived of than that is going to amplify those already existing disparities. Of course what we do about this needs to go beyond technology alone but we are here to speak about technology so we will.

I will give you an example about virtual reality (VR). I am really excited about virtual reality as a way to get at this embodied learning that is linked to dementia onset. Things like learning to play a musical instrument or dancing. You can imagine VR being really perfect for that. And that is exciting. We also need innovation on the service side, but the user of technology does not need to access a more costly and harder to use system. So as one example Robin Brewer at the University of Michigan is doing all this innovative work using telephones where the users are using telephones and she is doing all the complex technical stuff on her side. So she has done work supporting older adults in doing blogging she is now starting a senior centre where all the services are via phone. Even something like zoom can create an insurmountable barrier. There is lots of innovation to be had that do not include costly technology and services.

I am finally going to talk briefly about the role technology can play in detection. People are really excited about early detection as a way to identify and get in there and do interventions that can perhaps slow cognitive decline. Pharmacologically speaking people think perhaps we are going in to late and if we can get in earlier that is when we can make a change potentially. And technologists are really eagerly responding to this technology prevention. I would say every week through my google alerts I am seeing to create solutions to achieve better health equity.

Professor Dag Aarsland
How can we transfer the wonderful Techs that are available into the memory clinics- i.e. solve the regulatory and data protection issues hindering data flow into Electronic journals

Foteini Orfaniotou
What we know about long term adherence with the different technologies and different stages of the disease? How can we increase long term adherence if those are deployed in clinical practice?

Dr Jennifer Lynch
Working on a monitoring sensor project at the moment, the issue of acceptability has always been critical; although it’s worth noting that some of people’s hesitancy has waned during
another piece of technology that might be able to detect early signs of dementia. So we are not just seeing sophisticated algorithms on MRI for example but also technology that is folding into our smart homes or internet of things technology landscape. So for example one study is measuring voice features that appear alongside early stages of dementia and we can easily imagine how the ubiquity of voice systems in our homes might fold into this to really scale dramatically. And one thing to note about these technologies is that they can only measure something that can be detected so we are not trying to detect really early changes in the brain that don’t affect our behaviour yet. This is where something can be detected even if someone might not be able to assess it themselves. And here too innovation is not enough. Researchers are drawing attention to the fact we need to work on topics like the ethics of finding out and informing someone they have what is currently an incurable disease and there is major work on stigma, societal stigma, we need to do to make it safe to receive a diagnosis. And also note there is research on stereotyping or self-fuelling beliefs about cognitive and physical decline are really important things to think about here.

So thank you for coming with me on this whirlwind tour and I am excited to hear the other speakers.

Jeremy Hughes
Former Chief Executive, Alzheimer’s Society and former chair, Dementia Technology Working Group for the UK Department of Health & Social Care

Amanda thank you very much for getting us off to a flying start. There are some really profound issues you raise there about wider social problems, that we can’t just look to technology to solve everything. Whilst we look to technology to find solutions it is also important to recognise that it can be an impediment as well. Your introductory talk reminded me of the importance of providing some kind of technology ‘buddy’ who supports the person with dementia to access the technology. There is a particular role for volunteers who are technically savvy, technologically knowledgeable to provide that support because otherwise access can be denied. So some really interesting points you’ve raised around the boundaries and the opportunities that are there.

I would like to now move on to our second speaker, Professor David Sharp from Imperial College London. One of my proudest moments at ten years at Alzheimer’s Society was the creation of the Dementia Research Institute which is a virtual institute involving six universities across the UK, funded by the UK Government with the main two UK charities contributing as well. One of the high points of that was the agreement that we would set up a really groundbreaking care and technology institute as part of that. And we had some really stunning applications for who would win the prize for the funding of that centre. I was delighted David Sharp came through with his team at Imperial where he is not only the director of the DRI for care and technology but also director of the clinical imaging facility and associate director of Imperial centre for injury studies. So David over to you to set in the wider context some of the work we have been doing on dementia and technology.
Professor David Sharp
Professor of Neurology, Imperial College London, and Centre Director of UK DRI Care Research & Technology

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Thank you very much for the introduction. And it is quite right Jeremy was completely instrumental in setting up the centre that I have the privilege to lead at the moment. It has been a whirlwind 18 months really. We kind of launched June 2019 so for the majority of time we have been going we have had the Covid-19 pandemic and that has thrown all sorts of things up in the air but certainly one that has been exciting. I am going to give you a bit of a flavour of what we are doing. It is going to be focused on the work that we are doing but I have put it in the slightly larger context.

So as Jeremy said we have now the UK DRI. Six universities, seven centres spanning a whole range of work. Much of the work is very basic science so it is focused on drug discovery, new targets, molecular understanding. But the centre that I am leading the is one of the few silver linings of the pandemic.

Dr Seb Kohler
For primary prevention, behaviour change is a very ambitious goal since multiple risk factors are involved. mHealth might be one tool within an integrated strategie for increasing awareness/knowledge transfer and nudging. In our survey, 80% of 40-75yr olds indicated willingness to use mHealth for dementia risk reduction: https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7010-z

Dr Allison Sekuler
There’s also the issue of cultural differences - we’ve seen that in differences in wearing masks during COVID. Some cultures are more focused on personal
Care Research and Technology Centre is very much focused on patients who are affected by dementia now, what we can do to improve the situation, to try and drive technological and engineering innovation through to dementia care.

**The Challenge**

- How do we improve quality of life for patients affected by dementia?
- How can we use new technology to stay at home for as long as possible?
- Can we use new technology to reduce medical risks for patients affected by dementia?

So I think we have a number of challenges. One is how do we improve the quality of life for people affected by dementia? And I have put that at the heart of what we try and do. And with a real focus on technology. So, how can we use technology to help people stay at home for as long as possible and live as full a life as possible I would hope. And aligned to that is a medical aspect of what we are doing. So, can we use technology to reduce medical risks for patients affected by dementia of various kinds. Can we stop unnecessary hospital admissions? Can we improve brain health, or at least slow the decline in brain health, for people affected by dementia? And finally an important goal is can we access new treatments or interventions more accurately. What would it look like if we had a system that allowed us to accurately measure changes in the environment or social care in a more personalised way.

**Programmes**

- **Biosensors**
  - Electrical Eng.
  - Low-cost, noninvasive, handheld device that predicts measures of **Behavior**.
- **P&O Diagnostics**
  - Synthetic Biology
  - Develop new approaches to detection, diagnosis and tracking of antibiotics
- **AI agent Interface**
  - Robotics
  - Integrate robotic devices into the home to improve quality and quality of life.
- **Sleep and Circadian Disruption**
  - Produce new approaches to identifying sleep and circadian rhythm in the home.
- **Behavior & Cognition**
  - Measure behavior in the home and support clinicians in the care of the individual.
- **Healthy Home**
  - Digital platform to integrate data collected in the home to guide care and clinical decisions.

Dr Lampros Kourtis
To add to Vaibhav’s 3 points I wanted to add digital phenotyping for early detection.
Respecting privacy is possible using on site, device-based analytics, without transmitting PII.

Professor Martin Orrell
We need to understand cultural concepts of dementia risk and causation

Dr Allison Sekuler
A number of our CABHI programs are focused in that area.
So we heard a little bit touched on about sensors and the internet of things that we are living in. So that is at the heart of some of the things that we are doing. So we are interested in developing a smart home and intelligent environment where we can measure things that are relevant to a patient’s life in a limited and private way. So these might be things such as medication use, behaviour, sleep, infections, potentially brain activity. And we might integrate that information into a system that allowed us to augment decision making be that care decision making or medical decision making and allow us to make personalised interventions in a much more intelligent way. We have a system set up, we have a range of monitors in the home that is being used in this way, and then we have a rich engineering and computer science set of programmes that are feeding into this real-world test bed for dementia technology. So our goal on the clinical and care side are really in part is to integrate with hospital, general practice, social care and public health. So we don’t want to replace these systems but find a way to augment what is going on there. We want to use digital health and data science and AI to directly link to clinical care. We want to deliver holistic research programme with an aim to improve quality of life, reduce hospital admissions and personalise social care. We are focusing on very common problems such as infections and sleep disturbances and social isolation and the way we deliver care in a complex environment.

So very briefly it is really important we think about how we connect across the different institutions and bodies that are providing care. So part of that challenge is how do we integrate information. So this is a little diagram of the integration system we are doing in west London. We have our own system where we are monitoring in the home, we are linking that through to primary care and hospital care but also importantly to our partners in social care delivered by Hammersmith and Fulham Council. And that is with a goal of trying to predict patient need and plan responses to be more responsive in care delivery.

- ensuring there are culturally safe solutions for older adults in Indigenous communities, in the Black community, in Southeast Asian communities, etc.

The needs and interests can vary and we need to adapt to their needs, not ask them to adapt to ours.

Dr Heather Snyder
@Lampros - what would you include in digital phenotyping or what sort of technologies would you envision capturing this data?

Dr Lampros Kourtis
Passive, continuous unbeknownst to user, biomarkers

Dr Ioannis Tarnanas
There is a big discussion about virtual companions or assistants (A.I. agents) and how can they help improve interaction and adherence for prevention,
To deliver that we have a multi-disciplinary team. So I think that is really important. We have people who are clinicians, like me. So I am a neurologist dealing directly with patients. But also engineers like Tim Constandinou who is developing new sensor systems – he is focused on radar development. We have Paul Freemont, and he does synthetic biology work, and he is looking a new infection biosensors that can be deployed into the home and would allow us to look at say UTI risk or we been looking at Covid-19 risk in recent months. We have a robotic programme led by Ravi Vaidyanathan that is looking at conversational agents and voice and robotic devices deployed into patients’ homes. We have a sleep programme led by Derk-Jan Dijk that is looking specifically at how we best measure and understand and intervene and treat sleep at home. I lead a programme around behaviour and cognition and then Payam Barnaghi is the scientist who has built the system that we are using and is also developing the machine learning and AI that we need to do the work.

Now lastly this is the pipeline that we are going through. So, we are starting off with the clinical care problem in part identified from population data – so we are looking at the monitoring and interaction with People with Dementia. The design choices there are very important. We have a position paper in this area.

Dr Heather Snyder
@Ioannis - these technologies/assistants continue to evolve; one of the challenges are measures impact. What would you suggest about outcome measure to evaluate these tools?

George Vradenburg Trust. Credit card companies watch all of my transactions and warn me if ‘out of pattern’ use of my card. Took a while, but most of us regard that as a trusted ‘surveillance’ system

Dr Guy Boersma
Great to hear about human rights and implementation issues. Both benefit from labour-intensive support
affects of dementia at population level. And we are looking at developing technology that is fit for purpose to meet care needs. Validating that technology in particular cohorts so initially in a living lab-controlled environment but getting that through to patients’ homes as quickly as possible. Then doing clinical evaluation in larger cohorts. Our end goal obviously is to try and influence the way we are delivering care and to do that in an integrated way and to do it in a way that links not just to hospital care, but primary care and particularly social care. We are working out new ways to deliver care that promotes well being and reduces risks for patients living with dementia.

We are doing that really in partnership. So that all of our strands of work are really a partnership between clinicians who are directly involved in care, scientists and engineers who are providing the technical support, designers who are guiding us on the development of the right systems but also importantly people affected by dementia themselves these are the patients themselves but also the carers who have been affected. They are a central part of the programme we are running and that is to try and avoid developing systems and technologies that doesn’t have a place to work.

So that was it. Thank you very much.

Jeremy Hughes
Former Chief Executive, Alzheimer’s Society and former chair, Dementia Technology Working Group for the UK Department of Health & Social Care

David thank you for that. And a very clear demonstration about what inspired us when setting up the DRI Centre. It was that one of the great things that Imperial could bring was that multi-disciplinary team, bringing together people who might not have worked before in dementia. So it is really great to see that happening.

One interesting reflection from some other work that I am doing is the importance of involving the business community: There is a programme now happening in the middle of England covering a number of counties led by Eon who is one of the big electricity suppliers. It looks at how you make sure that the smart home technology that they are putting in place – that has nothing to do with health or dementia – can be used to support people with dementia. So really helpful to have your contribution.

So let’s move on to are final introductory speaker who is Dr Allison Sekuler, Vice President, Research, Baycrest Health Sciences Center and has been particularly focused in her work on the brain processing of visual information and has been one of the first to show the link between older people’s rewiring of themselves to compensate for functional changes. I know Allison is going to take a slightly broader perspective in her presentation this afternoon. Allison over to you and thank you for joining us.

and engagement with people living with dementia and their carers. The work I’ve done with David Sharp’s team in the DRI from Kent Surrey Sussex Academic Health Science Network taught me how with thoughtful engagement, people are keen to receive the benefits and reassurance of ‘home monitoring’.

Professor Rhoda Au
“High touch” interactive tech can provide a means of providing care to complement and supplement family/ caregiver and medical care.

Professor Dag Aarsland
Re improving life of PWD; one key problem is psychiatric / behavioral changes; agitation; Tech can help monitoring these, sleep/ nighttime etc, and monitor light,
Thank you for having me it is a real pleasure and I have really enjoyed hearing the perspective of folks so far. Amanda opened by talking about some areas of stigma and ageism. I just want to stress that that is not a new concept.

For as long as there’s been the written word, people wrote about the stigma of aging and they have been expressing ageist views. So Shakespeare wrote in As You Like it “The last scene of all, that ends this strange eventful history is second childishness, and mere oblivion. Sans teeth, sans eyes, sans taste, sans everything.” It’s a really depressing view of aging. And when we think of aging, and dementia in particular, it summons up feelings of deterioration and diminishment and decay.
But at Baycrest, we have a much different view of aging — our vision of aging is a world where every older adult enjoys a life of purpose, inspiration and fulfilment. That is a pretty big goal to try and reach. And a pretty big goal in the best of times. But we have been living in the Covid-19 times that are a little bit different. Covid-19 has introduced as you have heard a number of opportunities to accelerate the development and adoption of technologies.

Historically, though, there was a huge innovation gap in those areas for the seniors. And this was the impetus for my predecessors Dr Randy McIntosh and Ron Riesenbach to create of the Centre for Aging + Brain Health Innovation, or CABHI, back in 2015.

Today, CABHI is 100% focused on doing everything we can to get the best innovations into the hands of people who need them as quickly as possible, working in the design and development, validation, the mobilisation and adoption, working with a whole range of different stakeholders. With generous support from the Public Health Agency of Canada, the Ontario Government, Baycrest Foundation, and working with partners like the Institute for Aging at the Canadian Institutes for Health Research – we’ve now

Care Strategic Advisory body we have lots of real life stories of how Technology is making a huge difference to people’s lives not only as a prevention tool but also to support people through to end of life care to support people to live as well as they with dementia.

Dr Katarzyna Hess-Wiktor

The common hardship in disease prevention and introducing healthtech is indeed behavior change - and changing behavior begins with introducing improvement to existing behaviors in a stepwise way, bit by bit, building on current habits. Individualizing the intervention - whether low or high tech, has to start with existing habits. Assistive tech might actually be where interventions may
been able to invest about $120M in hundreds of projects now having a real impact on the healthcare of older adults not just in Canada but around the world.

So what is it that allows some of these solutions to succeed and what is it that is most needed in the time of Covid-19 and how can we put those two elements together? As everyone knows when Covid-19 hit one of the biggest impacts was visitors were banned from hospitals and long-term care. So our team at Baycrest put together what we call these t-carts, technology-cards that included things like iPads and virtual stethoscopes. And they immediately set into practice this new eVisit system that you can see in the pictures on the right that helped to bring families and friends directly into patients’ and residents’ rooms, virtually even if they couldn’t be there in really life. And it really did enhance the quality of life for our residents in the hospital and long-term care facility.

And those same carts allowed physicians to move virtually from room to room when they couldn’t be there in person. And this is one of our neurologists, Dr Morris Freedman, who is also know as “the virtual dementia whisperer” for the work that he has been start - as their aim is often to support in the everyday life, i.e. routines. Failure of scaling high tech often seems to depend on them being too far from what’s “the usual” way of living.

Dr Allison Sekuler
In thinking about what technologies are needed to help people living with dementia, its key to think about what PLWD feel they need. In our large scale discussions with people, one key element is restoring a sense of control and helping people recognize that dementia does not define the person. Depending on disease stage there are lots of technologies that can help. But back to the issue of stigma, if we don’t address that we will face an uphill struggle in meeting the needs of PLWD.
doing virtually for his dementia patients. And one of the noticeable things here is as virtual care has expanded it has brought the care that you might find in big city centres into different areas. So now for example Morris and his colleagues are able to work with people who are living with dementia in the North in rural areas and that has done wonders for addressing some of the health inequities we see in Canada and see around the world as well.

Of course sometimes it is helpful to have ongoing care and in this case some of the AI-based solutions are really helpful on that front. This is just one example, MindfulGarden, where a display changes in response to a patient’s activity level and their voice. So it engages and calms the patient and can be used in delirium and dementia.

AI-based solutions can be used in many other areas for addressing other critical issues, including the detection and prevention of pressure ulcers and the detection and prevention of falls.
When we think about the holistic approach for people, we want to get beyond thinking about healthcare and thinking about engagement as a whole. How do we keep people living in long term care homes engaged and feeling like it is their home and not a medical facility? One of the sorts of approaches taken here is shown by LinkedSenior where they have been able to digitalize and personalize engagement plans for individuals so that people can increase their engagement, decrease their use of anti-psychotics, and also increase staff efficiency.

Within Baycrest we have taken an approach building something called Baycrest@Home and Ron Riesenbach my colleague is helping to lead this as well. And what they do there is to create a whole range of virtual activity programmes, including a virtual dance program we developed in collaboration with Canada’s national ballet school. You can access that one for free going to the national ballet school site as well as the Baycrest site. So I encourage you all to check that out. And Baycrest@Home is also building on these online clinical and social supports to bring the clinical environment into the home so that people don’t have to come to clinical settings themselves.

adherence and tracking/intervening with other lifestyle related behaviors.

Professor Jane Rylett
@Katarzyna the issue between intervening and interfering and how this is assessed and resolved on an individual level will be critical to acceptance

Dr Allison Sekuler
Also want to stress that there are many solutions that are NOT technologies, but are equally effective and often much more scalable and accessible.

Dr Ioannis Tarnanas
Really good point @Foteini. Actually, post validation new tech is quite well accepted by the clinicians - at least to my experience. Of course, completing a high quality validation isn’t easy :-)
As was already mentioned virtual reality is a critical new area and is being used in care as well as some of the other settings you have heard about. So if you are under lockdown and want to travel somewhere or have new experiences than virtual reality is a critical way to do that. So it is keeping residents engage and helping them grow. It is helping them exercise and, in some cases, develop new hobbies. And for people who can't wear headsets, they can still experience virtual reality with devices like Broomx. It is a terrific new solution and can project virtual reality onto any three-dimensional space.

Virtual reality is also critical in training as we've heard. In this case I am showing a couple of examples that help increase empathy in caregivers but you can also use VR to stimulate experiences which is really important in scaling up rapidly care workers and other support workers in the long-term care sector. We are working with companies to address the urgent need of society in upskilling and redeployment for example.

Dr Allison Sekuler
Excellent point @ Jane

Dr Heather Snyder
To pick up on another thread in the discussion around VR in Dementia ...
ISTAART Tech and Dementia professional interest area wil be hosting a discussion on VR in Dementia on April 22 - Drs Felix Clay and Joe Strong to provide overviews (Dr. Julie Robillard to moderate). Happy to share more info on registration with Lenny to share if interested.

Dr Dennis Chan
Behaviour change in medicine is often challenging because the desired outcome (stop smoking - lower risk of MI, healthier lifestyle - lower risk of dementia) is too distant to be incentivising. So one question is: how can
And of course once you have got caregivers you want to make sure they are being taken care of as well. And technology can play a roll there through chatbots for example, and this device that I have here because I use it all the time InteraXon Muse — which uses real time neurofeedback to improve people’s meditation practices and sleep.

Finally I want to address why some of these innovations succeeded while others fail. David addressed the issue of user engagement earlier in his prevention and I want to emphasise that. From the very beginning in CABHI we always had a very strong Seniors Advisory Panel a group of very engaged individuals. Building on that we wanted to scale that up.

So in a couple of weeks we are launching a platform that is in some sense a of virtual community engagement center but I think of it also as a learning, engagement and innovation acceleration platform and we are calling it Leap. We’ll be launching Leap with its first thousand members in a beta version, and we are hoping in the next few years to scale it up to at least a million members. And this is a place where older adults can be
interacting with innovators, with policy makers, with researchers, to help to drive the work that is being done while they are also learning, and they are also co-developing. And we think this is one way to scale up what we have learnt and to help others succeed on a much bigger scale.

And I want to just finish by coming back to this issue of stigma that Amanda raised and highlight that this is an old problem, but it is not going anywhere just now. This is actually a picture of my dad. He is 82. He’s not decaying — he’s not even retired. He’s still a neuroscience professor teaching and publishing in journals like Nature and Science, and he celebrated his 80th birthday by cycling 26 miles. As the pandemic started, like many men, he started to grow this scruffy pandemic beards.

But as the pandemic continued, he started to shave his beard and I asked him why. And he said it was because in his areas of Boston the hospitals were openly talking about using points systems to determine who would have access to ventilators if they ran out and who they would just let die. And older people had a couple of knocks against them. And he said in case he got Covid-19 he wanted to look as professional as possible because
being old he had one knock against him, and he didn’t want to have another because if he got sick, he didn’t want to be discriminated against. To me that was a really striking story. And I continue to hear stories like this when we talk about how fast we should re-open. People often say “Well, it only kills old people....” as if, even if that were true, somehow be ok. And obviously it is not true, and it is not ok.

What we are hoping is that we can get round this sort of stigma. Because when people are afraid of stigma, they are afraid to show any weakness. And with that perception it will be even harder for them to come forward when they experience cognitive decline, and we’ll be less able to provide the sorts of interventions we need to provide to prevent or delay the onset of dementia. So I am really concerned I would say that, combined with the fact that Covid-19 is having a very real direct impact on the brain directly, there's a danger that the current pandemic of Covid-19 will lead into to an echo pandemic of dementia.

And our hope is that solutions like Leap will help address the issue of stigma head on, showing that nobody has a best before date, showing that older adults can and do make real contributions to society — co-creating new solutions, new knowledge, and new policies. We want to show that, contrary to Shakespeare’s view, aging is not “Sans everything”. Ageing is avec wisdom, avec passion, and avec purpose. Thank you.

And our hope is that solutions like Leap will help address the issue of stigma head on, showing that nobody has a best before date, showing that older adults can and do make real contributions to society — co-creating new solutions, new knowledge, and new policies. We want to show that, contrary to Shakespeare’s view, aging is not “Sans everything”. Ageing is avec wisdom, avec passion, and avec purpose. Thank you.

Thank you, Allison that was really powerful. What I really liked was at the top of your presentation you weren’t talking about good ageing or better ageing but your vision at Baycrest was inspired ageing. And that word inspired changes the dynamic and changes the way you think about something just in one word. What you showed I think was that from covid we have driven some things fast forward, but we now need to learn from that. Think about the good things that we have learnt, such as the geographical reach to the remoter areas of Canada that you showed, but also some of the challenges and the risks involved.

Thank you, Allison that was really powerful. What I really liked was at the top of your presentation you weren’t talking about good ageing or better ageing but your vision at Baycrest was inspired ageing. And that word inspired changes the dynamic and changes the way you think about something just in one word. What you showed I think was that from covid we have driven some things fast forward, but we now need to learn from that. Think about the good things that we have learnt, such as the geographical reach to the remoter areas of Canada that you showed, but also some of the challenges and the risks involved.
So thank you to all three of our speakers for setting the scene so well. I would now like to hand over to Vaibhav to chair the discussion because this is your meeting and your opportunity through the chat function and the live discussion to input into the work of the Council. So Vaibhav over to you.

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Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you so much Jeremy. And hello everyone. I am happy to co-chair this meeting and lead the interactive part of the discussion which I hope will be very rich. And thank you Allison for sharing your story and David and Amanda as well. I just again hopefully we will get to the premise of technology and want to thank the speakers for reminding us of some of the pitfalls as well.

I just want to remind everyone we want to focus on three main areas. The first area is early in the journey around prevention and risk reduction. The second area is what we can do for patients already living with dementia how can we improve daily life. And the third area is how can we use technology to better provision medical care.

Starting with the first one just a few words. We all know that a lot has been done over the years for early detection of cognitive decline. The question really is can we move beyond detection to risk reduction. There has been a lot of emerging science now that much of dementia and cognitive decline is actually driven by modifying risk factors. And the question is can technology be used to track and improve these modifiable risk factors to engage people in a brain healthy lifestyle in a frictionless and scalable manner and enable large scale risk reduction. I will suggest to the group that there is a huge opportunity here, not only can we use technology for large scale risk reduction, but we can also use it to bring customised solutions to individuals and help people reduce their own personal risk based on their personal risk factors.

That leads us to the second area that we want to focus on. What about the people who are living with dementia, who already have cognitive impairment? There I would ask that in addition to focusing on the cognitive impairment and memory problems what can we do to bring technology to help them with the functional impairment in their daily lives? What can technology do to make them more independent in their daily lives, to reduce caregiver burden and to ultimately essentially increase the time they can live at home delaying entry into professional nursing homes and so on? So a huge role for technology in improving daily life and independence and functioning of people who are already living with dementia.

And the third point for discussion is the tremendous awareness that in fact covid has raised in the role of technology in the provision of person centric care for patients. We
know that we in the healthcare industry, in the pharma world, are now thinking harder about how we can make clinical trials much more virtual, much more patient friendly, reduce clinical visits etc. So the question for us collectively is how can we harness this heightened investment and awareness of technology to particularly help patients and help neurologists and physicians take better care of them? I would like to focus discussion not just on generic technologies like telemedicine but technologies that could be applied in a healthcare setting to dementia patients.

So again a reminder: risk reduction, improving the daily function of people and the healthcare setting. I would just say to acknowledge many of the challenges that were raised. Amanda you said that technology isn’t the only solution and that is true. David you pointed out the learning engines that can be developed. Allison you spoke quite a bit about the various technology initiatives. And those all point to challenges but also to opportunities. I think that one opportunity that technology gives us is to be both large scale but also very personalised and customised hopefully at low incremental cost. So this is something you should focus on. I do passionately feel that technology should be a force for democratization and not for further digital divides and so on.

So with comments we would really like to hear from the esteemed participants on this tech dementia meeting. I am happy to see a lot of familiar faces as well. We have about 40 minutes or so to hear from you. As Lenny said at the beginning we want to focus on where we are, where we need to go and how we get there. I think we should what we can do today as well as what we can do in the future. As a reminder we will be keeping an eye on the videos but please if you want to raise your hand virtually or you can mention in the chat you want to speak. But hopefully from now it will be an effortless discussion without much need for prompting around the real tremendous promise of technology for helping patients with dementia.

So I guess looking at the chat function Heather do you want to expand on the point you were making in the chat?

Absolutely, and thank you to the speakers those were really great presentations and really perfect way to set the stage for discussion. My question may be for all of you but particularly for you David around scalability and thinking about the in-home sensors. And this may be for identifying individuals at risk but also for those who have cognitive impairment. Maybe hearing from you a little bit around adoption or the possibility of scalability of these technologies.

Thank you very much it is a great question. I think probably at the heart of whether we can scale into real impact is whether you can accelerate into real scale. It is perfectly manage diabetes, one for medication reminders, one for cognitive engagement, each with different privacy settings and links to care teams. There is a need for integrated solutions that consider that PLWD are also likely living with other conditions.

@George and @Allison - the problem is with lonely senior citizens. What can be seen already in some countries - seniors without family might be especially vulnerable in accessing health services - e.g. when you have to register for a covid vaccine online.

@Julie integration of data is a large need - how can this be managed? by whom? interpretation in a timeframe that
possible to do things with a hand full of people. But to get to a larger scale you need to think about the cost of the system, how intrusive it is, whether it is providing wider benefits. And as Jeremy said who are commercial partners might be. We need to be working with companies who are capable of delivering these sensors into homes. But we have a massive opportunity because the internet of things is arriving in our homes in all sorts of ways, and it is already happening. The systems may not be for care, but they are coming in lots of other ways and this gives us an opportunity to build on that. So we are really focused on not very complicated sensors but perhaps sensors that are all around us that we can deploy at scale and perhaps piggyback on other systems that are already there. And the value of them partly comes from the data that we can derive from many many months and years. The final point is around accessibility, that is a big part of what we are concerned about. One thing we have steered away from at the moment is having cameras in people's homes. The obvious thing maybe is that we film everything but there are lots of problems with that people don’t really like that. We don’t have cameras in the system. The sensors we have are much less obtrusive. And the people who are taking part in the study don’t have a problem the sensors are very unobtrusive, and they feel well looked after rather than being intruded on.

Dr Allison Sekuler
Sandra A. Rotman Chair in Cognitive Neuroscience and Vice-President Research at Baycrest Health Sciences

Can I just add that on cameras, David’s right, so like the solution I mentioned to reduce falls does use cameras to detect falls, but it does it in a way that nothing is recorded, and the video is constantly overridden unless there is a fall. And then the information is absolutely critical because it helps you see did the person hit their head? And it helps you reorganize the home or the room to avoid falls in the future. So I wouldn’t count out camera all together, but I agree it can be difficult for some folks if they feel spied on, but it can be useful if it is dealt with in the right way.

The only other thing I would add is that we see a lot of these sensor solutions coming through CABI because we don’t just focus on long-term homes and hospitals but also ageing in a place of your choice and care continuation as well as cognitive and brain health. But one of the sticking points to getting us to where we need to get, and I assume Dave your group is working on it, is what do you do with the data? The data visualization component of it? If you have a lot of data and you don’t have it in a way that family physicians can deal with it or family members can deal with it, then it is not going to be useful. So you can have all the data in the world but until we come up with the right data analysis and the right data visualisation mechanisms that is going to be a limiting factor for us, and I think your group is working on that as well.

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you, David, and thank you Allison. This has brought up the question of privacy and trust and hopefully we can come back to that very important issue later in the
conversation. I do want to pick up on one point which is I think the natural trade-off between having very bespoke sensors and instruments for detailed measurements versus having something much more scalability that has widespread availability. I think there is room for both. But one concept that we need to pay attention to is how much can we reuse the data that people are already generating in their daily lives. How can we reuse data from commercial devises that people are already wearing, wearable sensors, smart phones and so on? Let the goolees and the apples do the marketing to get into people's home. And Jeremy you brought up the idea that an electric company is the way in to collect some new types of data. So there is a real opportunity to piggyback on the kind of things that are already going into people’s home. So this concept of re-use is an important one, this concept of re-using commercial devises for medical purposes is also going to be an important point in terms of overall scalability here.

With that said another point being brought up by Rohda is that it is all very well to think about technology and digital measures and I just talked about the fact we can reuse the data that is already being generated or we can have these bespoke sensors. I think there is a question about the validity of these measures. If you are predicting an event are you really predicting. What is the specificity, what is the sensitivity? Are you raising false alarms? Are you creating more anxiety? So maybe I will throw it back to others in the virtual room. What do you see about the trade-offs between getting more validity maybe getting the regulators involved versus doing something more pragmatic to help people today? And I guess part of the answer will be it will be a learning engine we will refine the algorithms as we go along. But we want to have an impact sooner rather than later. So any comments on that?

**Professor Rhoda Au**
Professor of Anatomy & Neurobiology, Neurology and Epidemiology at Boston University Schools of Medicine

Can I follow up on my comment? Because I want to point out that in the realm of prevention, where we are talking about symptoms, early early symptoms of detection, we now always talk about digital biomarkers. I want to point out that we already know about the heterogeneity of behaviour. So if we start to talk about biomarkers in the traditional sense, we are not going to get there with digital.

So I would like to point out that when someone is in the very early stages of memory impairment, they will have a series of different patterns of behaviour that leads you to think they have a memory impairment. So they will forget to turn off the stove for example, but they won't forget all the time. Or they will forget how to get to a familiar place. But they won't forget all the time. So when you ask a family member or a patient when they first noticed, they are not going around testing themselves. Rather what is happening is there is this fluid pattern of different behaviours that collectively come together to signal that there is a memory problem. And if we keep going down this path of validating digital biomarkers against existing gold standards which were based on collecting very sporadic information, we are just not going to get there in the prevention space.

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Dr Julie Robillard
@jane Important questions! Need tools that are vetted for quality and organizations that connect with each other to promote

Phyllis Ferrell
Per the convo between Lampros and Vaibhav, I have been trying to get my mom to do these “lifestyle modifications” for years and she just read this book and is finally doing them! she is tracking her steps and everything - I haven’t read this book yet, but there must be something in it that worked better than her daughter nagging her. Much Abides by Charles Edwards, Charlotte Memory Clinic https://www.amazon.com/Much-Abides-Survival-Guide-Aging/dp/1952248078/ref=sr_1_1?dchild=1&keywords=much+abides&qid=1614878386&sr=8-1
Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you Rohda. I think one point we do want to make is that we don’t want to look at one thing in isolation. We want to look at it in the context of other data whether it is coming from other fluid markers or other readouts to get the full picture.

Professor Martin Orrell
Director of the Institute of Mental Health

This discussion is concentrating a lot on how we track people, how we monitor them, how we have sensors and collect data and so on. And that is a very important part of the discussion. But we have to think about people’s human rights. I don’t think we can move away from what are people’s preferences, what do they want, what are their human rights. I worry that the discussion will go too much towards tracking people, monitoring this and monitoring that. It is very important stuff and could be transformative for health care. But on the other side of it is what people want, what their human rights are and so on. I want to introduce that into the discussion because otherwise I feel we will go too far the other way.

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you I think it is an important point well noted. I did mention the importance of trust and ownership of data and proper consent on how any of the data can be used but I think it is an incredibly important point.

Dr Chris Edgar
Chief Scientific Officer, Cogstate

You do raise an important point Martin. I would add you need not restrict the value of these digital technologies to their complete roll out to very widespread populations. There will be information you gain and learn from these relatively small studies that do inform things like prevention, things like care needs, that will apply to much wider groups of populations whether they are being monitored or not. So I think there is value in these studies in and of themselves even before wider roll out necessarily. The context here is that there are two important barriers that digital technologies create: access (we know many people do not have access to the internet or digital tools and technologies, or even if they do are not using them fully); and the potential to reduce needed face-to-face interaction (many folks including older adults want to be with another human being and experience isolation and loneliness and not have that interaction replaced by a digital...
I notice Sebastian you bring up an interesting point in the chat we are all talking about the promise of technology to reduce risk. And this goes back to a little bit to the value, right? We are not monitoring people for the sake of monitoring. Hopefully we are trying to collect data to help people themselves to manage their brain health better and reduce risk. The question that Sebastian is bring up in the chat is if we talk about modifiable risk factors, and we talk about behavioural change, we know from other fields of medicine that behavioural change is awfully hard! People don’t stop smoking even though it is obviously bad and increases the risk of lung cancer. How are we going to get people to reduce risk of cognitive decline or dementia based on technological intervention? The point being made by Sebastian is even raising awareness of what risk factors are and measuring them and helping people visualise them will go a long way to getting people to lead a healthy lifestyle. The brain is a special organ. People think of heart health, they think of liver health, but people are not tuned into how to measure and become aware of their brain health. Sebastian, I do not know if you want to expand on your point, but this is an important aspect. How do you get people to engage and change anything?

Yes, I agree and then to reach the right people. The people who are most in need of change in risk factor. This brings up the point in the chat that there is cultural sensitivity, also tailored towards the need of people in low socioeconomic position, that the messaging is clear, that they can handle the technology and that it is affordable. So if we are talking about prevention the question is who is going to pay for it in the end? If we are talking about tech it is always expensive to develop but no one wants to pay for health or prevention in the end. So this is the problem that we are facing.
Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

We are talking quite a bit around prevention, early detection and so on. So, I would be interested to hear from folks around the opportunities to help those who are already living with significant cognitive impairment. And I want to emphasise the point is it is not what you think it is right it is about what the patient really sees as limiting in their daily lives and what the caregiver sees as limiting in their daily lives. We tend to focus quite a bit on memory tests and cognition. But what inhibits people in their daily lives in functional impairment and the ability to stay independent. What adds to caregiver burden is things such as wandering, and agitation and aggression and so on. And maybe I would just like to invite the views of people on how we can help those today who are already experiencing significant cognitive deficits and maybe dementia?

Phyllis Ferrell
Vice President of the global Alzheimer’s team for Eli Lilly and Company

I think that your question should be about people who already have symptoms, and we shouldn’t jump all the way to the prevention space because there is this big group of folks in the middle who actually have cognitive symptoms but are not getting diagnosed until three to four years after symptoms begin. So there is this whole discussion around prevention, whether that is secondary prevention in therapeutics or risk reduction in lifestyle modifications, then there is dementia care. Both of these are good categories. But the place where we have the greatest opportunity to make a difference and have an impact now is in the middle catching people very very early in their symptom pathology because that is where these new therapeutics are going to have the greatest impact. Even without therapeutics those are the very people we are having difficulty finding in order to enroll in clinical trials, and the ones who can benefit through preparation and advocacy support. I think sometimes we go to the two poles but, I worry we miss that big group of people in the middle.

Dr Dennis Chan
Principal Research Fellow at the Institute of Cognitive Neuroscience, University College London

I mentioned earlier in the chat and I think it would be useful Vaibhav to expand on the second objective around people living with dementia. I think we need to distinguish between people who are living with dementia and people who are living with mild cognitive impairment. Because the needs are of course different. So you can imagine we are going to use different tech in different situations. So, for someone with dementia we are going to be talking about sensors to monitor falls, reduce risk of hospitalisation and so on. But for someone who has MCI the goals are different. The issues should focus more on how we help maintain their autonomy and how we keep them working because they can’t work so well. And this is much more about assistive technology. No one so far
has talked about assistive technology and that cover a huge range of different devices. And it would be very interesting to know whether you think it is in the scope of this call to talk about that. So not just those who are living with dementia but that middle space you mentioned just now. There is a world of stuff that could be done.

Dr Vaibhav Narayan  
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you very much your point is well taken and is very much in scope. I would almost call them functional prosthetics right because people have prosthetics for physical disabilities you could also have prosthetics for functional disability due to mild cognitive decline. And I think it is a massive, massive opportunity with massive scope for customisation and personalisation and scalability both. Assistive technology and robots and other technologies are very important in that space.

Dr Dennis Chan  
Principal Research Fellow at the Institute of Cognitive Neuroscience, University College London

So I think it is not necessarily something as complicated as robotics. We were talking about VR earlier and VR is limited by being pretty clunky at present. But consider instead augmented reality (AR). Everyone remembers Google Glass and that bombed partly because of a terrible initial presentation by the Google CEO. But fewer people know it was repackaged and is now used as Google Glass Enterprise. It is absolutely extraordinary. People use it on the BMW workfloor, they get a head-up display within their glasses and they see what they are supposed to do – like fitting a piston into the engine – via an AR schematic superimposed on the real-life engine. So I guess my point is these things are already out there and it is not a huge jump to go from the engineering space to the health space with such devices providing head-up assistance for people who have memory or navigation problems and so on.

Dr Vaibhav Narayan  
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

It is a point well-made and well taken. I do want to go to some other folks who have had their hands up. Louise.

Dr Louise Lafortune  
Senior research associate, University of Cambridge

We have moved on a bit but coming back to the implementation of technologies we have a view on the acceptability of technology from prevention to supporting people with point about the use of data by clinicians. It’s important that this is aligned with care pathways-- that we have an understanding of what data will be used in decision-making. What information SHOULD we be collecting about people, not just what we CAN collect. This has ethical implications as well as logistical ones.

Professor Jane Rylett  
@Allison - LEAP is an excellent creation and look forward to impact and outcomes

@katarzyna. You’re right of course, but a subset of the overall challenge.

Dr Louise Lafortune  
@Amanda - This is important everywhere. There is potential to integrate brain health in all health policies (e.g. as
care. But that comes from people that have engaged with us. But the reality in “real life”, beyond the environment of research where we take our insights into the areas we can intervene, I think it is a bit underestimated. I think there is more work to be done around preferences at a more general way at a population level so we have better understanding around what would be acceptable. So we can have great devises some of them very complex some simple but if we don’t take the extra step of stepping outside the discipline of dementia the overall where does technology fit in people’s home in people lives to understand where we can make the intervention in people’s lives that works.

The other point and it is different. It is building on the earlier point. We talk about robots and new complex technologies but there are very simple technologies out there for people with early cognitive challenges that area already used in day-to-day life but not for that purpose. So simple reminder functions and so on. So it is much more present in people’s lives than we think. So if we had a repository of ideas and how people use technology now to address problems, we might be able to address the challenge of using technology to help people right now.

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

I do want to emphasize that point because one of the advantages of technology is that it is very fast moving, and we want to make sure we are using technology to benefit people in the here and now as we develop new technologies for the future. Going back to your point there are some things that will be developed like sensors and so on but there are also technologies that are used in people’s lives and we can re-use that technology to make a difference today. And I think technology has to be scalable and very, very irrative in the impact we make.

I am happy to see a lot of messages in the chat and in the WhatsApp but as the powers invested in me as someone who is facilitating the discussion maybe the next point, I want to go to some Dag you are making is that we tend to focus on dementia and cognition and tend to assume these are the massive unmet need but if we look at the whole person care more often than not these patients have other co-morbidities that they are managing. So the biggest challenge may not be related to dementia and cognitive decline but there may be psychiatric conditions readouts that would be highly disabling and impairing. So maybe for folks who are engaged in caring for patients how do you see technology as not just providing for the dementia but for a whole person approach and addressing other comorbidities that may be present?

Professor Dag Aarsland
Professor and Head of Department of Old Age Psychiatry, Institute of Psychiatry, Psychology and Neuroscience at King’s College London

Vaibhav maybe I can start off. Thank you for that. Particularly in the later stages of dementia the non-cognitive symptoms are often the main problem both for the patient, the families and the care staff and I think technology has a role also in this domain of...
the illness both in terms of monitoring symptoms, agitation, movement, night-time issues and so on. But also, potentially, in terms of monitoring treatment. So, for example we are working on the effect of light – daylight – on sleep, mood and activity level. And by combining devices that can monitor movement and level of daylight it is possible to provide very relevant data that clinicians can use in their planning of therapy. So, I think that it is a fairly neglected area because all the technology has been focused on cognition and functional changes, but behavioural changes are also a huge area for potential changes through technology.

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

And Dag what about the issue of these folks not being able to take care of the other comorbidities that they have. They have diabetes, they have other issues, they are not able to engage in proper self-care or not able to adhere to their medication regime. How can technology, or functional prosthetics that we talked about, improve all these outcomes for our patients in a clinical care setting?

Professor Dag Aarsland
Professor and Head of Department of Old Age Psychiatry, Institute of Psychiatry, Psychology and Neuroscience at King’s College London

Yep. Short answer I think it is huge potential to have physiological measures. It is very easy to measure heart rate, blood pressure, blood sugar levels. All kinds of things that can be combined and integrated into the totality of the patient together with cognition function and behaviour. Obviously very complex, we don’t want to see our patients filled with devices. So, there are challenges. But there is also huge potential.

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Lampros?

Dr Lampros Kourtis
Consultant, Digital Health Innovation

I wanted to go back to something Phyllis mentioned. Early detection. In the chat there is a lot on that. The idea is: can we bring people in earlier into the treatment ecosystem? You got fifty, sixty-year-olds who are not likely to want to get checked for cognitive decline. And even if they wanted to, there are no sensitive enough instruments, tools and methods to evaluate these slight micro symptoms that might be manifesting in these early stages. So how can we do that? One way to do this is to have continuous

for a tiny change in someone cognitively normal, but especially if there is a treatment, how early should people begin to be actively evaluated and possibly treated?

Foteini Orfaniotou
@Jennifer also to add that some of those solutions would target GPs/PCPs and the integration in the workflow will be more tricky than in memory clinics based on heterogeneity and volume

Dr Louise Lafortune
From a prevention/risk reduction perspective, the public is a key stakeholder too I would think…Also, I think the public might be/would be more accepting of data sharing than we think, if there is transparency about who owns the data & who uses it…
passive evaluation. No one is going to take a test when they are fifty on their cell phone once a week. But can we actually measure these micro symptoms? So just as you have a measure of your physical activity on your iPhone telling you, you've made 10,000 steps today and your average heart rate was 65bpm, imagine if you have another parallel dashboard that is not shared with anyone - it just sits on your phone so privacy is contained. Can you have that information about your typing speed, your use of language, your driving behaviour, your dexterity, your hearing acuity? Things that might decline slowly but you need to have years of data to see. Everyone declines but the question is how fast. These kind of metrics introduced in a device you are already using. You don't have to buy a new device, you don't have to engage in testing. We are being tested by our devices all the time! For example, eye movements when we read on the phone – we read more often on a phone than in a book. So can we actually get those metrics?

Dr Vaibhav Narayan
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

I think it is a great point. I do wonder especially early on can we change the conversation from cognitive decline to brain health. Not a positive spin but a much more optimistic scenario that lets you know how you are doing on risk factors, how you are doing on actual read outs. The challenge will always be is that knowledge and awareness enough or do we need to provide specific interventions or specific solutions as well. And this goes back to the idea that we don’t want to measure for the sake of measurement, we also want to provide solutions. However the point you make that this is a private dashboard for the individual to use themselves and share it with who they want to maybe their primary care physician, goes a long way to addressing some of the trust and privacy issues. But I think that is a terrific point.

Professor Arlene Astell
Professor in Neurodegenerative Disease in the department of Psychology at the University of Reading

I want to make the point that for the majority of people around the world their experience of living with dementia is living at home supported by family and friends and communities. The majority of people are not in clinical settings or long-term care homes. And I think we have to be mindful about what we are trying to achieve when we are introducing technology. So for instance if we generate all this data and collect it, if that is possible because it seems to be for only some countries, what are we going to do with that? Because currently we don’t really do much with people, they get their diagnosis, they go home, and they get on with it. So we have to see it in that context. What is it we are going to be able to deliver people that we are not doing now? My experience using existing technology, things you can just get off the shelf, is that we can improve people’s daily life, their enjoyment and participation, reduce burden on families, with things that we already have, but we have not at present committed to making these things available at scale. So, I think we need to keep in mind the broader context around what people need and want and what we are hoping to achieve with some of these innovations because they are a very long way from what people are looking for anyway.
So I think there is a number of issues, I also think, and I know Martin said it earlier, that when we think about solutions, we need to think about what are the preferences of people who have a diagnosis versus what are their family members. Because these are two different groups of people with different wants. I think it is really important to keep the person living with dementia at the centre of these innovations.

Dr Vaibhav Narayan  
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

Thank you. Inherent in that challenge is how do you get advocacy and input from people who already have significant dementia, so we have to be particularly sensitive about the condition and make sure we are doing. Ioannis?

Dr Ioannis Taranas  
Chief Scientific Officer, Altoida

A couple of good points were raised earlier, one from Lampros about passive biomarkers and one from you Vaibhav about brain health. I would like to say something that might sound controversial. When we think about cognitive decline and dementia we usually think about older people or sometimes earlier like forty-five plus. I would say that when we discuss brain health, we should consider people of twenty and above. Continuous assessment through the life course. And on that point as well I would like to discuss the idea of a platform. Instead of isolated biomarkers and isolated apps combining everything into a platform might be a bit more ambitious as an idea but this might generate the trust we are discussing here, and this is what will collect all the vast amount of data in a single location. I don’t see any other way to join the dots unless we are going from the app to the platform approach. This is just a very early thought but happy to discuss more offline.

Dr Vaibhav Narayan  
Vice President of Digital Health Innovation, Science for Minds, Johnson & Johnson

The only thing I would say with a platform approach is we have to think about scalability and cost. So, there is a balance between maybe a platform for more research-intensive purpose and then re-using devices at home might be the way to go. But we should pick up on that. Jeffrey?
I want to pick up on what you just said. A lot of the discussion has been using words such as "technology", "scale", "the elderly", "demented", "the carer". These all are represented by large sub-categories or sub-groups. And when you get into technology there is huge variability. There are over 400 wearables. Similarly, apps, there are thousands of them. I think it is a very big challenge for us in these kinds of meetings and in other venues to drill down on the specific priorities. If you talk about scale this specificity is important. For example, just like the idea of universal internet access is a top-level idea that cuts across many different populations and technology challenges, we need to get down to more specifics about whether you are trying to deliver a prevention outcome for a health system or a series of biomarkers and an outcome for a particular focused registration trial. So I think this specificity of framing is a very important piece of context.

I think that is something that is going to need to be a focus of our discussion. I wanted to turn this comment to a very specific area that we should think about for the future, although I know we are winding down our time here. That is, consider that we think we will have a more effective treatment or treatments in the near future. Covid-19 has taught us a lot on being nimble and using technology particularly in telemedicine or virtual visits and that sort of thing. If we had for example an antibody treatment, how would that be delivered widely? Would we have the same kind of initial challenges of testing, monitoring, scaling? I don’t think we would have drive-thru infusion centres! But we need to consider the aspect of what digital approaches will facilitate scaling new therapies as a case of where we are going to be, not where we are now. What technologies would be best able to facilitate the widest use of new therapies is an important pressing question to answer.

I know you have thought a lot about the development of a technology that is scalable, that takes care of the noise, that can be deployed in people's homes. I fully agree with your comments on drilling down into the use questions, who the stakeholders are and what we are trying to address. We only have a few minutes left but I do think looking at the chat it is helpful to bring it back to the point of who the key stakeholders are. From my perspective, first of all the patient themselves. Whether they are pre-patient, at risk, have mild cognitive impairment or full-blown dementia. Then the caregiver, whether a professional caregiver or a familial caregiver. They are an important stakeholder. The third important stakeholder is the clinician, the healthcare system. So maybe one opportunity I want to ask is how much does this technology we are talking about have to integrate with the clinical care, with the physician and clinician actually looking at this data. The reason I bring this up is individuals' willingness to participate in a data regime, either to collect data or provide data or to use technologies that they see as something their healthcare system is also using and participating in. So, any thoughts
from folks who are developing solutions from the clinical side, how you see yourself interacting? The whole self-care solutions versus solutions that are interacting with clinical care pathways. Maybe I will make the point that we want to develop solutions that strengthen interactions between patient, carer and healthcare provider. Because one danger of technology is that it creates a barrier to human relations between patient and carer – whether familial or healthcare. I think that is an important issue in addition to the trust question and the digital divide issues that were brought up earlier.

With that I want to thank everyone for participating. We had a lot of incoming. We will carefully look at everything that got shared in the chat and make sure that gets incorporated into our thinking. We look forward to synthesising all of the conversation into an output. And with that back to your Jeremy.

**Jeremy Hughes**
Former Chief Executive, Alzheimer’s Society and former chair, Dementia Technology Working Group for the UK Department of Health & Social Care

Thank you. We have started a conversation of people who might not talk together. If one thing has happened this afternoon LEAP has already spread to Sweden in the course of this afternoon so there are things happening! The one thing I would add is we need to think about the people who are not on this call. So, we have talked about Google and data management beyond health. I would go a bit beyond what Vaibhav said and say it is not just about health systems but about socioeconomic systems integrating people with dementia and using those wider systems and the cultural change that goes with that. So, thank you everyone and with that back to you Lenny to close us off.

**Lenny Shallcross**
Executive director, World Dementia Council

Thank you everyone. Briefly as we have overrun slightly. We will send you a transcript. I will leave you with a cheery thought that I was reflecting on something David Sharp said at the top about cameras. While some people may be reluctant to have cameras my apartment is covered with them so I can keep an eye on my dog wherever I am in the world. They have been rather redundant the last year but hopefully as we turn the corner on covid their utility will return. And that will be a time we can have not just virtual meetings, rich as the conversation was today, but meeting in person! So, with that I wish you a good remainder of your day whether it is for you the morning, afternoon or evening right now. Thank you.
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.

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