

# Summit 2021

Looking to the future:  
The dementia landscape



**World Dementia  
Council** Leading the Global Action  
Against Dementia

## Data sharing for dementia research

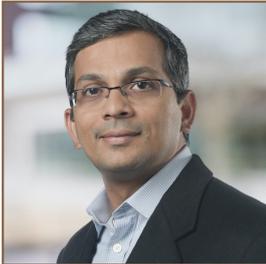
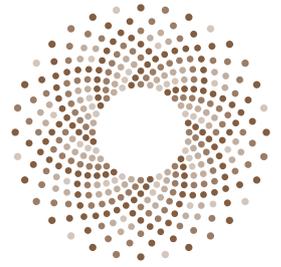
Transcript of a session from the  
World Dementia Council virtual summit  
6 December 2021

*Johnson & Johnson*

**SCIENCE  
FOR MINDS**

*Lilly*

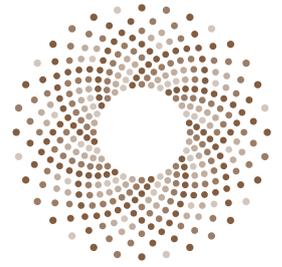
# Chair



## Dr Niranjana Bose

Dr Niranjana Bose is the Managing Director of Health and Life Sciences at Gates Ventures, where he serves as the Science Advisor to Mr. Bill Gates. Prior to this, he was the Chief of Staff to the President of the Global Health Program at the Bill & Melinda Gates Foundation. He was with the Gates Foundation from 2007 through 2014, which included a few years with their Enterics and Diarrheal Diseases (EDD) program strategy team, where he was responsible for managing a portfolio of investments, which included clinical development of enteric vaccines (rotavirus, cholera, enterotoxigenic E coli and shigella). Dr Niranjana holds a Ph.D. in biochemistry from Dartmouth College and an MS in biological sciences and BS in pharmaceutical sciences from Birla Institute of Technology and Science, Pilani, India. He also received the Business Bridge Diploma from the Tuck School of Business at Dartmouth.

# Speakers



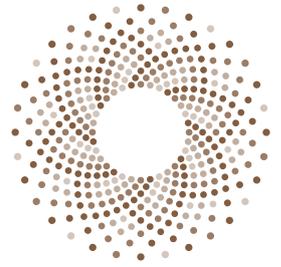
## Phyllis Barkman Ferrell

Phyllis Barkman Ferrell is the Global Head of External Engagement for Alzheimer's disease and Neurodegeneration at Eli Lilly & Company, where she previously served as the leader of the Global Alzheimer's disease development team. Ferrell's most recent prior position was Vice President of the Chief Commercial Services Officer for Eli Lilly and Company. Ferrell has been with Lilly for more than 25 years and has held many leadership roles throughout the organization. She has led efforts in medical affairs, medical development, commercial capabilities, sales, marketing, recruiting, business development, strategy, transformation, Six Sigma, and corporate financial planning. Ferrell received a Bachelor of Arts degree in economics and management with minors in computational mathematics and Asian studies from DePauw University. She graduated Phi Beta Kappa and with Magna Cum Laude honors in 1994. She received an MBA in general management and a certificate in public management from the Stanford University Graduate School of Business in 2001 and graduated with both Arjay Miller Scholar honors and as the Arbuckle Award recipient.



## Professor John Gallacher

John Gallacher is Professor of Cognitive Health at Oxford University and Director of Dementias Platform UK, a MRC-funded public-private partnership focused on accelerating research into the early detection and treatment of dementia. An expert on brain health and the use of big data in medical research, Professor Gallacher holds a visiting professorship at Imperial College London and an honorary professorship at the University of Hong Kong. He is the Principal Investigator for the Caerphilly Prospective Study and a member of the UK Biobank steering group, leading on cognitive and psychological assessment.



## Professor Miia Kivipelto

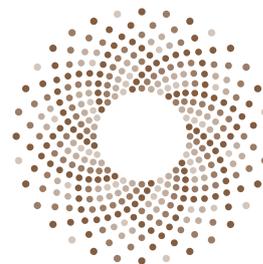
Miia Kivipelto, MD, PhD, is Professor in Clinical Geriatrics at Karolinska Institutet (KI), Center for Alzheimer Research and senior geriatrician and Director for Research & Development of Medical Unit Aging at Karolinska University Hospital, Stockholm, Sweden. Part of her Nordic Brain Network multidisciplinary research team (around 100 researchers and clinical staff) is located at University of Eastern Finland and Imperial College London, UK, where she has part time position as Professor. Her frontline research findings have been published in leading journals (330+ publications, H-index 75) and she has received numerous prestigious awards. Dr. Kivipelto's translational research focuses on the prevention, early diagnosis and treatment of cognitive impairment, dementia and Alzheimer's disease (AD). Through epidemiological studies, Prof. Kivipelto has identified various lifestyle and vascular risk factors for dementia and interactions with genetic factors and clarified underlying mechanisms. She is the PI of the landmark FINGER trial and founder and scientific leader of World-Wide FINGERS network. Professor Kivipelto is often invited to leading global dementia conferences and task forces.



## Dr Pierre Meulien

Dr Pierre Meulien is executive director of the Innovative Medicines Initiative (IMI), a €5 billion public-private partnership between the European Union and the European pharmaceutical industry. At IMI, he is responsible for the overall management of the program, which works to improve and accelerate the drug development process by facilitating collaboration between the key players involved in health research. Previously, Dr Meulien was president and CEO of Genome Canada, where he raised money and oversaw the launch of novel projects and networks in the field of genomics-based technologies. Prior to that, he was chief scientific officer for Genome British Columbia and was the founding CEO of the Dublin Molecular Medicine Center. Dr Meulien also worked with the French biotechnology company Transgene and with Aventis Pasteur (now Sanofi Pasteur). He has a Ph.D. in molecular biology from the University of Edinburgh and carried out a postdoctoral fellowship at the Institut Pasteur in Paris.

# Discussion transcript



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Hi Philip, all. Good morning, good afternoon. Greetings from Seattle. First off apologies, I am coming from my mobile phone because this morning I realized my Wi-Fi is down and 5.30am is not the time for a technician to respond! So, my apologies for being on a mobile phone but I'm glad I've been able to connect with all of you and thank you for this opportunity. Thanks to Philip, Lenny, Josh, and others for organising this panel, and recognising the importance of data sharing.

Today we're going to hear a diverse set of perspectives. From the perspective of a funder, we have Pierre Meulien, executive director of the Innovative Health Initiative. We have an industry perspective from Phyllis Ferrell from Eli Lilly and Company. She is the global head of external engagement for Alzheimer's disease and neurodegeneration. We have John Gallagher, professor of cognitive health from University Oxford and director of Dementia Platforms UK. So not only will we get an academic perspective from John, but also the perspective of somebody who's spearheading and leading a platform that stresses the importance of data sharing and more importantly how you bring that to translational and experimental medicine. And we will round out the panel with Miia Kivipelto, professor of clinical geriatrics at the Karolinska Institute, and again probably somebody who everybody knows very well. She heads up the Worldwide FINGERS Consortium. So, with that I am going to invite Pierre to share his perspectives from IHI, formerly known as IMI, and good morning, good to see you Pierre over to you.



**Dr Pierre Meulien**  
Executive Director, Innovative Health Initiative (IHI)

**Data sharing for Dementia Research and Innovation:**  
The Innovative Health Initiative Perspective.

Pierre Meulien  
06.12.2021 • WDC Summit 2021• Virtual

innovative health initiative

## Chat function

The chat function was available throughout the session for participants to ask questions of panellists and to hold discussion amongst each other. It began just under 10 minutes into the session and is displayed below. It does not necessarily correspond with the adjacent transcript in this document.



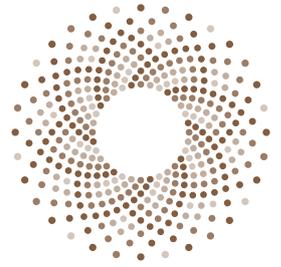
**Dr Greg Moore**

Great to see the progress and these new initiatives for data sharing!



**Dr Husseini Manji**

Indeed...we are going to make real progress by working together and sharing data



Terrific, thanks again Bose for inviting me to do this. As many of you know, we are now in the big transition from IMI to IHI and this is going to be a very interesting new partnership, with a significant joint budget between public/private of €2.4 billion over the next few years. I'm sure the neuro portfolio will figure well in this new venture. Bose asked me to just take you through a few principles under which we operate in terms of data sharing, and of course these are quite traditional in funding agencies.

## Data Sharing Principles in IMI/IHI

- Obligation to ensure open access (free online access for any user) to all peer-reviewed publications related to results of financially supported research
- Transparency and public access to clinical trial results funded through IMI/IHI. We also publish the protocols
- IMI/IHI supports the FAIR data principles (findable, accessible, interoperable and reusable)
- It is mandatory for each project to provide a Data Management Plan
- COVID – the EC and EMBL have created a European COVID-19 research data platform

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**Dr Maria Tome**

PIERRE MANY THANKS GREAT EFFORTS FROM IMI AND YOUR STAFF!!



**Dr Giovanna Lalli**

It will be very interesting to hear more about EPND - certainly an important need

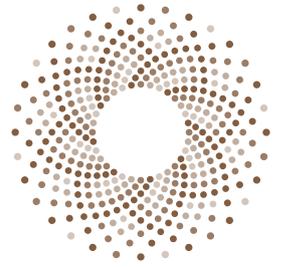


**Professor Derek Hill**

I have for many years been involved in critical path institute consortia seeking to advance regulatory science to advance the regulatory maturity of innovative technologies. There is a difference between data that is shared. And data that is shared and can be used in regulatory conversations. Billy Dunn of FDA has often made the point that data sharing is key. I wonder how much of the shared data we heard about today can be used in such regulatory conversations.?

We have an obligation to ensure open access to the research that's published. This of course means a lot of transparency and public access to clinical trial results funded through the programme. Also, we publish the protocols and methodologies, which are very important too. IHI will support, as IMI has done in the past, the FAIR data principles and we encourage everyone to use those principles - "findable accessible, interoperable and reusable" - and it's mandatory for each project to provide a data management plan and these are really important. And of course, the ugly word sustainability comes up a lot because this is one of the challenges that a lot of our big projects have, but we more and more find good solutions for this, but it remains quite a challenge.

Under Covid we have not only learned a lot, but other things have been experimented on. The European Commission and EMBL have created, as you will know, the European COVID-19 research data platform, which has been a fantastic tool in the integration of a lot of data coming from all over the globe.



Of course, we have a lot of experience in IMI/ IHI in big data projects. Presented on the slide, the European Health Data and Evidence Network (EHDEN) has been crucial in looking at interoperability and looking at the legal issues too. It has had a fantastic impact in responding to Covid because of the real-world evidence data is has been able to go through, looking at millions of datasets worldwide. This is going to be, I think, very crucial for many diseases that we're going to be dealing with.



**Professor James Rowe**

In addition and cohorts' and trials' data, resources for experimental medicines studies' outputs to be curated and shared will be important



**Sarah Lock**

Appreciate Miia's point that we should be using the data to assist clinical practice as well as research



**Professor Mary Sano**

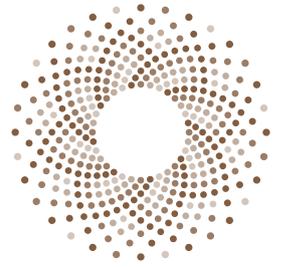
Congratulations to Miia for reminding us that sharing is not only via the "data" but via the sharing the research experience by investigators world wide

So back to neurodegeneration, and as you know, we have been very active. A lot of the audience will know lots of these projects, and some of you are involved in them. There have been some big data and what I call connecting the dots projects, like Roadmap that John will know very well, and these projects are trying to join dots between different real-world evidence projects and others. We also have the NeuroNet project which tries to build connectivity between the portfolio. And, of course, we try and go beyond our own silo. The last thing I want to do is to create an IMI or IHI silo. So, we need to link in with global initiatives like the ADDI, the Dementia Platform UK and so on and so forth.



**Dr Allison Sekuler**

Exciting initiatives all around. Would be great if there were a better way to coordinate the introduction of new measurements into different data



sharing initiatives, especially with the rapid pace of biomarker advancement



**Adam Smith**

We also know that significant amounts of data is generated in labs, and is disregarded - this could be captured, and organised (furthering the discussion about publishing negative results which we know is improving but could still be better).



**Professor Jane Rylett**

Excellent points on identification of challenges with development of platforms to accommodate different forms of data, construction of data sets and mechanisms for harmonization. How to integrate legacy data sets collected with different approaches? How to standardize for collection of future

## European Platform for data and sample sharing to accelerate the discovery and validation of biomarkers for Neurodegenerative Diseases



European Platform for Neurodegenerative Diseases

The European Platform for Neurodegenerative Diseases (EPND) will integrate existing initiatives and leverage elements of European infrastructures (BBMRI, EATRIS, ELIXIR and EBRAINS) and build, grow, and deliver a scalable and self-sustainable platform for storage and analysis of high quality clinical and biological samples and data collections.

<https://epnd.org/>



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I can't help but mention the newest kid on the block in terms of our portfolio, which is a fantastic big data project. It's close to a €20 million project for data and sample sharing called the European Platform for Neurodegenerative Diseases (EPND), and this is totally focused on neurodegenerative diseases. This will try and link in with other big initiatives, not only European infrastructures but well beyond into global outreach.

### EPND Partners



























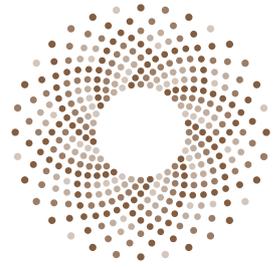






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We're very proud to have lots of fantastic partners in this project from the public and the private domain, and I have to acknowledge of course Gates Ventures under Bose's leadership as they are a major partner, a major funder of this initiative. So, we're so happy to be launching this! This is a brand-new project. It has just been launched and it is starting right now!



data sets to facilitate sharing?



**Dr Lucia Crivelli**

LatAm fingers is bringing together the data of 12 Latin American countries: sociodemographic data, clinical, cognitive MRI and biobank data. There are significant challenges when training people from different backgrounds on how to use the same platform (REDCap).



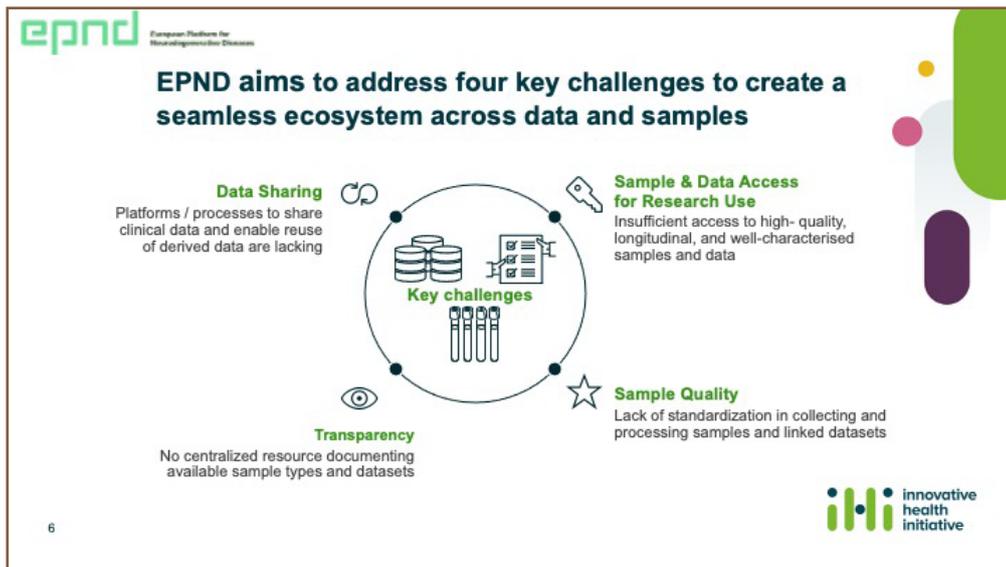
**Dr Nina Silverberg**

How do we assure inclusion of underrepresented/underresourced groups, including LMIC?



**Adam Smith**

Agree with John's points on education - both in understanding what data is available, where it sits, how to access that and also in training and education and attracting people to dementia research

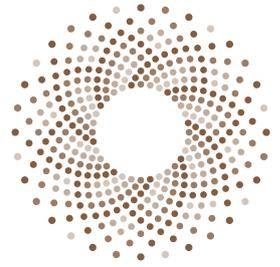


Its aims are really all-around data sharing. To process and share and make sure that data is reusable. There is lots to do on biological samples and linking high quality and large amounts of data to those samples and that will be open. The quality of the samples is important. The transparency with which all of this is put together is important. And I think that this is going to be a great project that will be able, as well, to link in globally to many different initiatives. I'm going to stop right there. I think I've used my four minutes and Bose back to you and I hope we can get into some of the more challenging areas of sustainability and moving forward and hoping to contribute to that part of the discussion as well. Thank you very much.



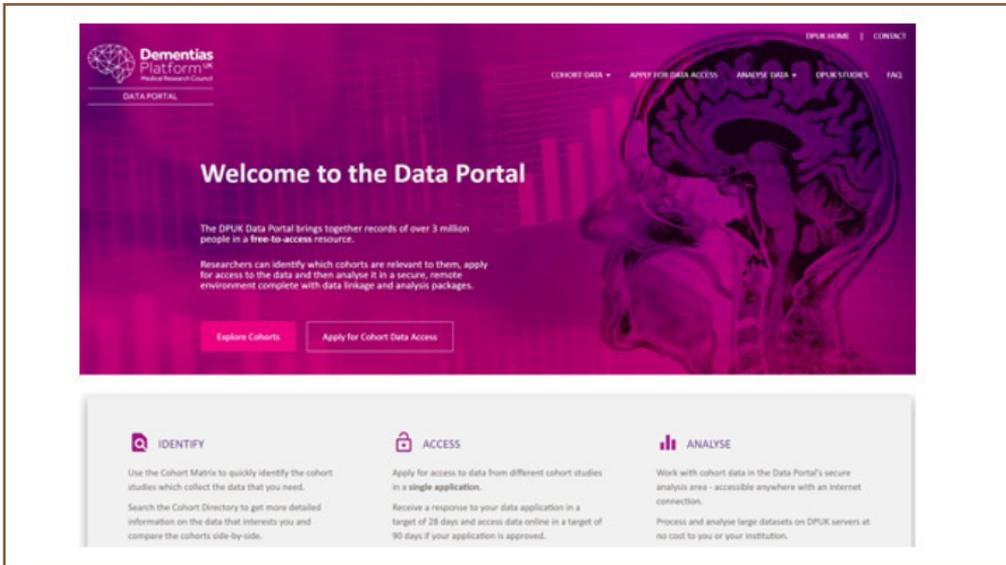
**Dr Niranjana Bose**  
Managing Director, Gates Ventures

Fantastic! Well thank you Pierre for that overview and we'll get to some of these aspects during our panel discussion. Let's turn over to Professor John Gallacher from Dementia Platforms UK and the University of Oxford to hear his perspectives. Over to you, John, thank you again.



**Professor John Gallacher**

Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK



who have healthcare data science backgrounds.



**Dr Lucia Crivelli**

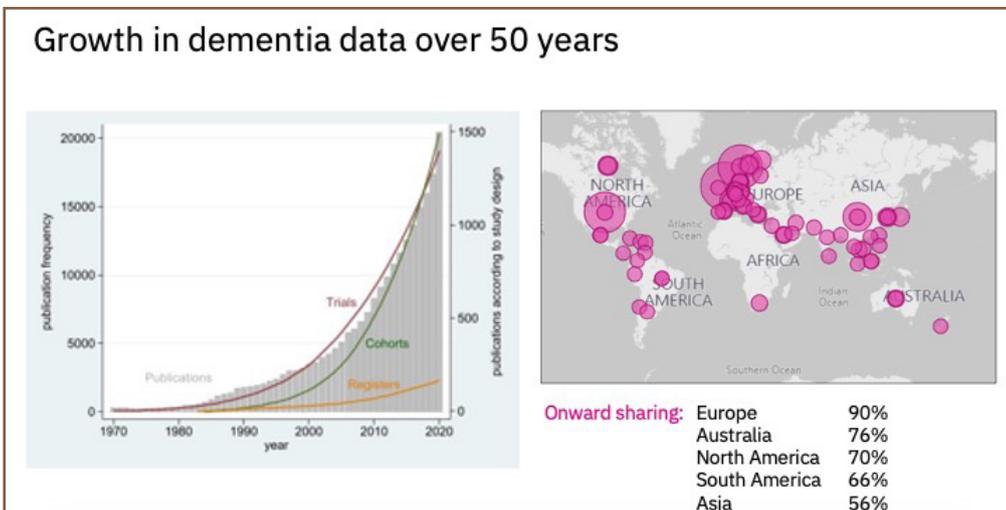
Dr. Kivipelto is right, its important to share experience on training and supporting the use of the platforms.



**Professor Cornelia van Duijn**

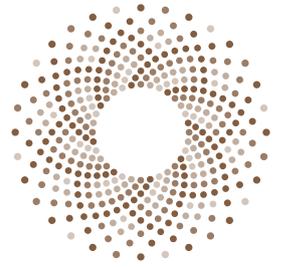
History in genetic research - GWAS in particular - has taught us that pooling data is not easy but can be done if we want this to happen to take science forward. I agree with John G that the biggest challenge is combining follow-up studies with multiple measurements. We should invest in this in view of the opportunities studying blood based biomarkers in these unique studies.

OK, thank you Bose. It's really good to see so many familiar faces. Lovely to see you again. This is the homepage for the Dementia Platform UK data portal. It's a discovery, analysis, and access platform. And the question is: why build it?

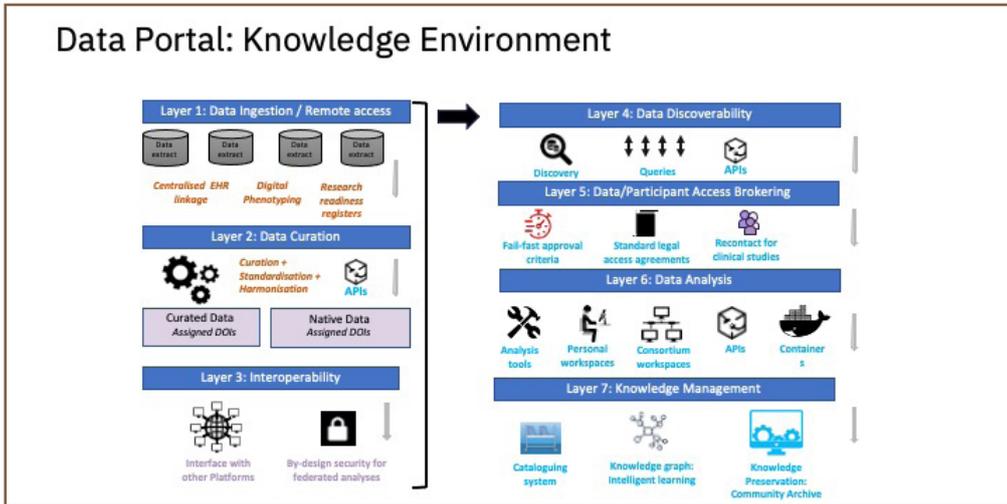


Well, if you have an idle moment in lockdown, you might want to look at the data landscape for dementia. You could go through the publications for the last 50 years and you see how they rise from under 300 a year to over 20,000 a year. If you then repeat the search looking at specific designs as a proxy for datasets, you'll see a similarly exponential rise and the issue here is these datasets all involve very different ways of approaching the problem.

Now these datasets are distributed mostly in Europe and in North America. What is really interesting, is that the data sharing cultures vary substantially in different



continents. In Europe there are explicit data sharing policies for 90% of datasets going down to 56% in Asia. This represents what may be described as a global exercise in entropy. Each of these datasets uses its own data model, its own metadata model, has its own agreements for data sharing, is typically under resourced for onward sharing, and frequently is under documented. So, what might we do in response?



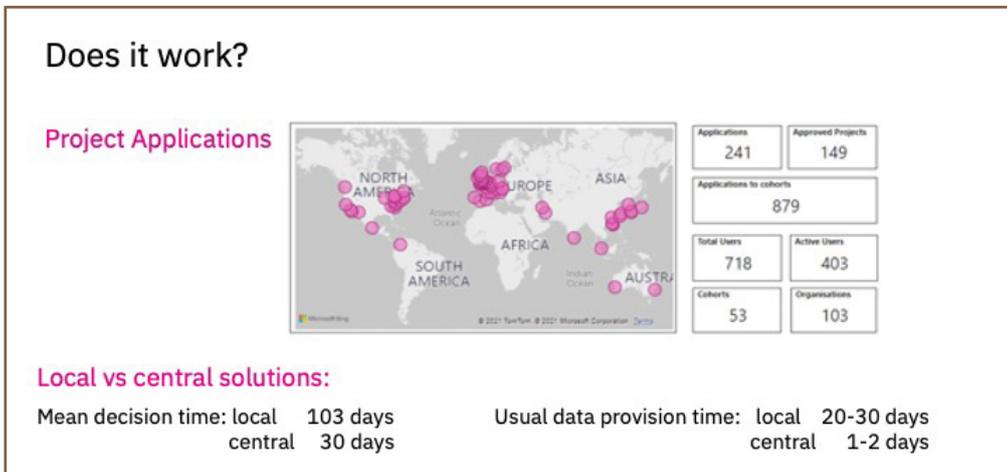
 **Professor Jane Roskams**

How big an emphasis is EPND approaching inclusion and diversity? It is clearly an issue with existing dementia datasets. Are there any direct plans to focus on this with respect to how EPND is set up?

Well, DPUK has been built as an end-to-end data management platform to address these issues. Looking at the slide, we have data ingestion. We then curate that data to research readiness, broker access between data controllers and third parties, and then provide a secure data analysis environment which allows multimodal analysis, machine learning, high performance computing. So, that's effectively a platform response.

 **Professor Rhoda Au**

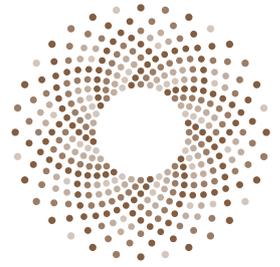
Can there be comment on thoughts related to digital data - 1) because technologies evolve and 2) because some digital data is considered inherently personal identifying, so what are solutions for robust accessibility and analysis of these data? What are lessons from genetic studies that can help deal with sensitive digital data?



Now the question is, does it actually work? Well, this is a pretty difficult question to answer, and it is largely because there's a lack of metrics available for comparison. What we could do is look at our usage. We've discovered over the last five years or so that we've had 241 data access applications resulting in 879 individual cohort access requests. And we have 718 registered users over five year we have retained 403 active users from 103 organisations in 27 countries. So there does seem to be an appetite for data access made easy if I can put it simply.

 **Dr Inez Jabalpurwala**

Nina, completely agree; the goal



We can also compare local solutions (those that are cohorts specific) with a centralised solution (the data platform). And we find that the mean decision time for a data access application is 103 days for local procedures versus 30 days for central processing procedures. Now this is obviously a very skewed distribution and I think this large number for the local access is due to one or two outlier values, but if we would take those away, we're down to about 60 to 80 days. If you look at the data provision time, it's 20 to 30 days for locally provisioned data, and one to two days for centrally provisioned data.

So, I think the take home story here is that there are multiple benefits from having centrally coordinated data access. Thank you.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Thank you, John, for that overview of DPUK and for reiterating the value of data sharing and coordination. Perhaps we will move on to our next panellist, I want to invite professor Miia Kivipelto to share her perspective as someone who's leading a large consortium, the Worldwide Fingers Consortium, and she can share her thinking on how it approaches harmonization and data sharing and data access. Miia over to you.



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Intitutet

Thank you, Bose. And hello everyone. So nice to see you all. What have we have learned from the Worldwide Fingers Consortium when it comes to data sharing? We all know that there has been great progress when it comes to risk reduction. The list of modifiable risk factors has been growing. So, there is a clear prevention potential. And importantly, we are moving from observation to action. Many countries are having these multidomain prevention trials.

We launched the Worldwide Fingers Network in 2017 to support different countries to best adapt and optimize these multidomain intervention model in various populations and settings. I'm very happy that today we have more than 40 countries from all continents who are part in the Worldwide Fingers network. Many of you who are here today are actively involved in in this network. As you know this network includes many low-and-middle-income countries which is important. This is really a truly global network.

What are our learnings? First, I would say that we have been trying, and I think it's very important, to create a culture and mindset supporting data sharing. And I would say it's not only data sharing, what we have been focusing on, it is also sharing experiences and lessons learned. There are many important lessons learned from the previous trials that we can use t when the new trials are starting so that they are not starting it in isolation. So, it's kind of constant feedback loop.

The second question is what data are we sharing and why? And what is the quality of the

of personalized medicine will never be fully realized if we leave behind most of the world's population. We also need to think about data that is "disease agnostic," to better understand common underlying mechanisms across diseases.



**Dr Nina Silverberg**

including how to do cognitive assessment in populations with lower levels of education. Inez, yes!



**Professor Cornelia van Duijn**

If we move to pooling 'Big' noisy data, should we move to AI to pool data and data mine?



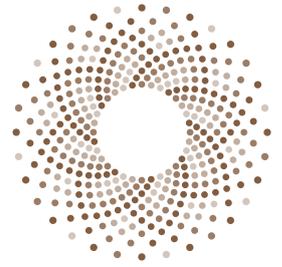
**Professor Chris Fox**

Sharing best practice in inclusion in data?



**Professor Arlene Astell**

Great questions Rhoda - is there a



data that we are sharing? And I would say that we have had a unique opportunity within World-Wide FINGERS for prospective data harmonisation. This has been earlier a big challenge in the dementia risk reduction field. The data has not been harmonised, and that's partly why the evidence has been not so strong. What we had been harmonising is of course the clinical outcomes, for example the cognitive scales. Also, the intervention components, how we are thinking with the 'Five Fingers' and the interventions. But also, biomarkers. We are collecting lot of biomarkers: blood, genetics, neuroimaging. Just having a harmonised view of that will create very nice global data.

Our World-Wide FINGERS Covid survey was a concrete example of how it is possible to harmonise and have a fully harmonized data. We have now done the Covid survey in 20 countries including 20,000 persons, and we can use that to adapt our interventions to this new normal landscape during Covid. One important question related to that has been how to use new technology to support the interventions and, in the monitoring, the concept e-Fingers.

When it comes to the actual data sharing, the landscape is quite complex, as you know, especially when we are thinking of global randomised trials. And there are different issues in different countries. In Europe we have GDPR and how that is interpreted in different countries. So, our lesson here is that we need the map, and we need to understand exactly what the landscape is, and what is needed for the data sharing. We are very happy for the support and collaboration with the ADDI, with the federated data set where the data is not travelling, no one is traveling nowadays, not even the data, but we can do still many things. So that's where we are now working to adapt to that and use platforms supporting global datasets sharing.

To sum up, I really think this is a very exciting opportunity where big data starts to meet clinical trials and we hope that the Worldwide Fingers can help to develop the infrastructure for large scale data sharing and joint analysis. This can help to really get the evidence on what is the most effective, feasible and scalable strategy for dementia prevention and risk reduction globally. And finally, we also hope that this infrastructure is helping us to use the data. We should not only collect and analyse the data but use the data. There is lots of data available that can be used and implemented in the clinical practice. Thank you so much.

group specifically dealing with both addressing these questions and harmonising approaches to digital data collection?



**Professor James Rowe**

Different countries - and different communities within a country - are at different levels with respect to Trust in data sharing between healthcare/ industry, or between government/ pharma, and across countries. We all need to keep working to ensure Trustworthiness of our data systems, and to help foster actual Trust.



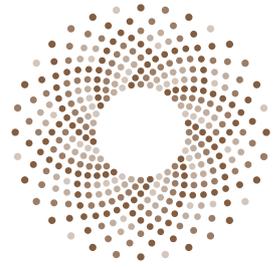
**Professor Henrik Zetterberg**

Dear all, This is a very relevant meeting, which will be quite hands-on, work-focused, and collaborative. It happens this week if you have not heard about it: <https://conferences.ncl>.



**Dr Niranjana Bose**  
Managing Director, Gates Ventures

Well, fantastic thank you Miia. With that perhaps we can transition over to our panel? I invite all the panellists to come back on the video and maybe I'll start with the question to Phyllis. And Phyllis, from your perspective, from Lilly's perspective, as we observed data sharing from industry, Lilly has been an exemplar in terms of data sharing, data access. Not the only exemplar, there are lots of others as well. But I wanted to pose a question to you: what are some of the drivers and what are their decision points that a company like Lilly faces before you decide to start sharing data or making data more broadly available for reuse and researchers?



**Phyllis Barkman Ferrell**

Global Head of External Engagement for Alzheimer's Disease and Neurodegeneration, Eli Lilly

Thanks Bose thanks for having me and it's a real honour to be on the panel with this group. I think it starts with the values of the company. Lilly does have a very, very deep commitment to data sharing. We see that in two ways. One is through publication of our data and what we call good publication practices. For us, publication is the final step of the research and discovery process. It's at the core of our business and we believe deeply in the timely sharing of important scientific knowledge and evidence that we acquire through our research.

For those of you in the Alzheimer's Disease community, you'll remember back at CTAD in 2016 we disclosed the Solanezumab Expedition3 study results only six weeks after last patient visit, which was just phenomenal. And it really only happened because of that deep commitment of the company, a team that worked overnight for a month, and also partnership with CTAD. Having partnerships with external organisations that will make space for us to bring in those kinds of late breaking data to the field is really critical. I think for purposes of the discussion today, we're really talking about sharing patient level data or clinical trial data, what we would call data transparency, and that's the other pillar of our two commitments. Lilly has a long history of commitment to transparency. In 2004 we were the first company to voluntarily disclose the initiation of our clinical studies and post study results in a publicly available registry. Now we do that with Vivli as a matter of course. When a study is completed, we have a process by which that data patient level data goes right to Vivli as a matter of course.

We were really excited to see that ADDI was going to partner with Vivli because, and Miia mentioned this calling it harmonisation of the data, what's also important is the interoperability of the data. So, the fact that ADDI is raising their hand and, saying, "we will work with Vivli so that data can move back and forth" is really important.

We recognize that sharing clinical study data has the ability to enhance public health. We need to do that while still safeguarding patient privacy, making sure that data is anonymised, and consents are appropriate. Respecting the integrity of the national regulatory systems and, of course, maintaining incentives for investments in biomedical research.

I think we come about that from several different angles. But specifically in Alzheimer's disease, we know this thing is a beast. And we know that we will not be able to cure this disease with one drug. Honestly, it's probably going to be medicines plus lifestyle modification and a whole lot of other things. So, we really recognise that collaboration and data sharing is going to be the centre of being able to achieve something here.

ac.uk/advascular/  
Related to the LMIC  
discussion, I meant  
to write,



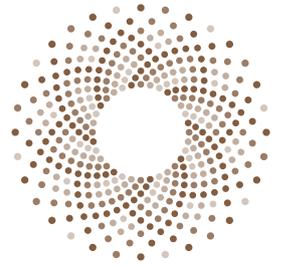
**Professor  
Jane  
Roskams**

The INCF has just created a globally accessible training space online that encompasses everything from understanding what FAIR data means, to complex ways to understand how to harmonize data, analyze imaging and multiple other data modalities, apply standards for normalization and harmonization. They also support training workshops and the development of specialized approaches for data integration, and forums for direct interaction around data analysis



**Dr Nina  
Silverberg**

Thank you Henrik!



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Fantastic well thank you Phyllis, for that perspective, and perhaps I'll go next to John to hear his thoughts, and I'd welcome Miia's thoughts as well on this. Both of you touched on aspects of data sharing/data access being under resourced, and the need for better coordination.

Also, Miia, you mentioned not just data sharing but the question of what you are sharing, why are you sharing and how will you be sharing, especially in terms of the data quality aspect. Let me first go to John to hear your thoughts on what more could be done to enable, facilitate and accelerate this for researchers?



**Professor John Gallacher**  
Professor of Cognitive Health, University of Oxford and Director,  
Dementias Platform UK

If I was to answer this at a high level, I'd say we need to reduce the transaction costs of collaboration. We're talking about the costs of finding partners, the costs of finding expertise, the costs of the technology, the costs of the legal agreements. This is not hard to do, but it does take political will to streamline and standardize our procedures.

Another experience we've had with DPUK is that many analysts are, frankly, undertrained to ask the questions that they're interested in, and particularly undertrained to ask them on a data platform which has technical issues associated with it. So I think training and education would also accelerate the exploitation of these data as they become more available.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

And Miia, your thoughts? What more could be done to enable data sharing and increased quality in data access?



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Institutet

The experience we have had with Worldwide Fingers is it's not only about the data sharing, but many countries are really struggling with the data management. It is quite a heavy lift from the data collection to the common data set. So many countries and teams, exactly like John is saying, are needing hands on support and concrete guidelines what to do.



**Dr Christopher Chen**

Achieving data sharing and equity requires considerable additional resources - who should provide this? the problem may be that ever increasing standards would discourage less well resourced sites and countries



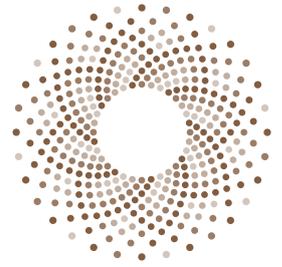
**Dr Andrea Slachevsky**

There is any strategy to share data recollect in clinical practice for research? It could be a strategy to obtain data of place with less resources for research and for patients that not-fulfill criteria of inclusion of research?



**Dr Greg Moore**

Federated learning and confidential compute may be helpful technical approaches in this space



We are now developing and implementing the Worldwide Fingers harmonization guidelines, including all these steps from common data elements, data collection and sharing. Of course, you need to adapt it to fit each country, but it is our experiences that help. Normally when you start the trial, you are very busy with your design and primary outcome and the clinical infrastructure needed. The whole part with data management and common data set is not often the primary focus. So, I think this joint effort and coordination is really needed.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

And if I can pick up on one aspect that you mentioned is how you helped set up a scientific helpdesk as part of the brain health institute? It might be early days but how successful has it been to have such a help desk?



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Institutet

Well, we have been really busy! We have had daily contact with various countries globally. When we started to develop these harmonisation guidelines, there was the need to ask and understand what exactly is needed? What kind of needs are there in the community? And actually, the needs are very different in different places. So, I would say that it has been very successful in terms of the interest is there and helping many new countries to get involved and start the harmonization process. A lot of manpower is needed for the support. I do think that after Covid people also have the mindset that this is the way of working, joint efforts and joint actions are needed. And of course, brain health and prevention seem to have increased importance and is attracting more interest. But clearly, having something concrete, like the harmonization guidelines and federated datasets is what is needed.



**Phyllis Barkman Ferrell**  
Global Head of External Engagement for  
Alzheimer's Disease and Neurodegeneration, Eli Lilly

Just building on one thing Miia mentioned, I think starting with the intentionality of sharing the data from the beginning, is really necessary. We put the GERAS data on the ADDI Platform. You'll recall that. And that was really exciting for us because that GERAS dataset is probably one of the largest, if not the largest, observational data set in Alzheimer's around the world. It's actually four studies, in Europe, Japan and the US. They're all Lilly studies. I thought "this is going to be easy, no problem". And then when putting it on with ADDI, we realised we didn't even have common data dictionaries across those four studies ourselves.



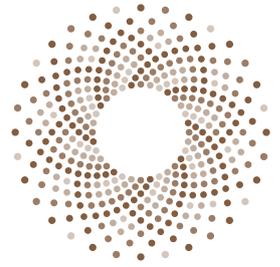
**Dr Inez  
Jabalpurwala**

Inclusion of different countries and cultural communities means inclusion in setting priorities. Part of the trust issue is moving from LMIC as a source of data to drive studies designed by developed countries, to studies designed to address their priorities.



**George  
Vradenburg**

@Nina Silverberg. Digital phenotypic using smartphones a promising route, given need for language independence and penetration of smart phones. Davos Alzheimer's Collaborative just initiated efforts in Malaysia where there is enormous racial/cultural diversity, many subpopulations with no written capability and a 200% penetration of smart phones.



And so, I think that the ADDI lens gave us insight into how we make sure we don't just check-the-box when we share data, but we make sure that that data is able to be used by someone who doesn't know the dataset as well as we do. I think the ADDI team members who are looking as outsiders at our data set and helping clean up the data dictionary and the definitions and all of those things was a real eye opening experience for us, at least for me. And so, I just want to echo what Miia's talking about there, which is you start from the intentionality of wanting to share at the beginning and making sure that things are common. I think we can do better as a field right now.



**Dr Nina Silverberg**

Thank you George, look forward to learning more!



**Dr Heather Snyder**

Perhaps Dr. Lucia Crivelli could comment on some of the opportunities and challenges on coordinating across LMICs?



**Professor Jane Roskams**

Could not agree more, George. Even beyond Malaysia, there is enormous penetration of cell phones throughout even remote communities in Africa, India and beyond. Structured appropriately, a couple of key studies in test case countries could be enormously powerful



**Professor Derek Hill**

What is the right way of involving medicines and medical device



**Professor John Gallacher**

Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK

I'd like to echo that. The trouble is though, many of our datasets are legacy data sets. And managing the complexity, especially when you have a cohort study with many waves and lots of new ideas going into each wave, is very challenging.

The only way we've managed to address this by having a what we would describe as a common data model that we apply retrospectively to data as they come in. It's labour intensive and a thankless task, but actually it does make data research ready for third parties who would otherwise have no idea what to do with it.



**Dr Niranjana Bose**

Managing Director, Gates Ventures

Pierre, I know IMI/IHI have had many enabling activities to promote and drive the reuse of data and more data access. And you spoke earlier about EPND, I want to acknowledge the partnership, thank you for bringing us along and I also want to give kudos to the academic partners and industry partners who have stepped in to join hands. EPND kicked off in November, so the project is only one month old. But I'm going to come to you to hear your thoughts on what other enabling activities could IHI or other funders help drive?

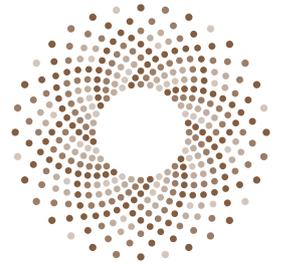


**Dr Pierre Meulien**

Executive Director, Innovative Health Initiative (IHI)

Thank you, first of all, I think the funders do have a vested interest that this happens. Obviously because every time you have a successful reuse of data or whatever, especially at scale, then this is a success factor for the funders too! So, we have a big, vested interest that this gets done.

In terms of the enablers, we can do a lot directly. So, we can do a lot and we do a lot, but probably not enough, in dissemination activities. This is about making sure our stakeholder community is actually aware that these datasets exist and then knows how



to use them. Of course, everybody will need a license, but that's only fair because the people who use this data need to be able to use it from a technical point of view and scientific point of view.

The second thing we can help with is this connectivity between individual projects and big infrastructure projects. In Europe, we have lots of things are going on, for example, we have ELIXIR and BBMRI. As many of you will know, ELIXIR is on the data front and BBMRI on the bio-sampling front. And there are others of course, these are just European examples. But these can become real beacons in being able to not redo things and become part of the sustainability answer.

And once again I come back to this sustainability word. The worst thing that could happen to one of our projects is that it begins, it ends and then all of this stuff falls off a cliff. That's in nobody's interest. I know there are real challenges about, follow on funding and all of the rest of it. And we get challenged. And please continue to challenge us as funders in these aspects! And with us try to find solutions for some of these sustainability issues where we all want to make these not only continue, but hopefully, get further linked into the connectome of where they should be.

So that's where we have a huge, vested interest, we have some enabling tools, but we would love to be challenged by the community to understand what else we can do. If it's a specific programme that you'd like to see and under IHI there will be lots of possibilities and potential to do something in neuro, and other diseases of course.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Fantastic and Pierre you mentioned EPND and EPND's dual purpose of data as well as sample access, can you speak a little bit to why the importance that IHI has brought to sample access as well?



**Dr Pierre Meulien**  
Executive Director, Innovative Health Initiative (IHI)

So, we love this idea of linking in with the BBMRI model and so on because it does simplify processes. And the other thing we love is that having samples linked with data rich data, scientific data, characterisation data and so on. And then having that as accessible as possible to the researchers whether they are on the public or private side. I think that's the potential for enriching the ecosystem.

If I can just mention on EPND, there's a whole ethical social and legal aspect to this project as well, which I think is really important because, you know, we're in Europe. I think Miia already mentioned GDPR. We do need to understand how different countries are approaching this so that we can have some principles that everybody could buy into. We have already some big data projects where the GDPR issues have really been

regulators into this data sharing discussion? They are ultimately gate keepers to some key uses of the results.



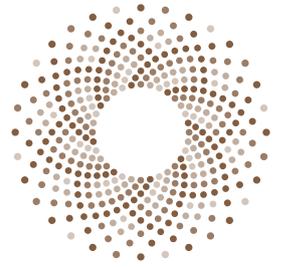
**George Vradenburg**

@Jane, totally agree. We are working in multiple countries and aspire to be ubiquitous globally. We are now working with 14 cohorts from 12 countries, another 10+ countries through NeuroNet will be involved as well



**Paola Barbarino**

There is great interest in Lower and Middle Income countries to participate in research but there are also challenges and barriers. From complex regulatory frameworks (or non-existing ones) to lack of funding or capacity to enter in research studies. It is important to bring all actors in a study at the same level



challenging. Admittedly, I think those have been more kind of centralised data projects and of course the world is now shifting to federated models because of this very issue.

I just want to say that for EPND the learnings from that will be applicable to other disease areas and I think we can all learn from that. And as you know, I'm really interested in this cross-project learning system within IMI that we have not done enough of. We need to do more of that and please challenge us on that too.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

We look forward to that journey with you on that. Miia, I think there is a question in the chat about what can be done in under resourced settings such as low-and-middle-income countries.

How can we enable folks that are trained, especially given the emphasis on privacy restrictions and compliance in data sharing? How can we enable more from LMIC settings? I know you've had a big emphasis along these lines, curious to hear your thoughts?



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Institutet

That's a very important issue. As we all know dementia is increasing even more rapidly in low-and-middle-income countries and these countries have been underrepresented in clinical trials. Stimulating the landscape on joint initiatives and data sharing is very important. And that's why I'm so happy that in the Worldwide Fingers study, many of the new countries are low-and-middle-income countries. But it's clear that support is needed, and this comes back to the point about concrete support. Not only helping with the data sharing but the steps before: data collection, data management, how to think through the ethical implications and informed consent and give training for the individuals who are doing this, so all these steps are there. I think this data from diverse populations can really help us to learn more about the demands on Alzheimer's disease and finding scalable and sustainable solutions globally.

I want to come back to the issues of how can we link these different projects? And I'm thinking immediately that Worldwide Fingers, EPND, EPAD and other projects should not be in silos, but we should really take the lessons learnt and find links. So, I was very happy to hear from Pierre that that could be the way forward. And I know we have started to plan that already, that for example, Worldwide Fingers data sharing and EPND, we should take and use the lessons learned from both of those.

and that requires support and time. See what happened in the Stride study at LSE. We continue to help organisations in LMICs to reach out to opportunities so if anyone has any let us know [p.barbarino@alzint.org](mailto:p.barbarino@alzint.org)



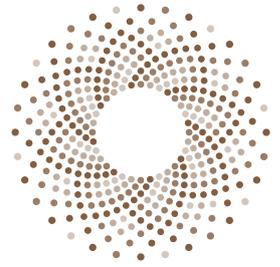
**Sarah Lock**

The collection of data also shows us what knowledge is available as well as what is not. The notice of what's lacking is very helpful for funders and policy makers in strategic planning.



**George Vradenburg**

@Paola, Davos Alzheimer's Collaborative .... Budgets of \$700M over 5 years to initiate global efforts involving LMIC's



**Professor John Gallacher**

Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK

Bose if I could add to that, if you look at both the maps I presented, there's a big gap in scientific activity in Africa. From a science equity perspective, the Dementia Platform enables equivalent access, and equivalent facilities, whether you are in Manchester or Malawi. The idea is to have all the security, governance, and analysis issues addressed centrally so that the data can be accessed remotely. You no longer have to be at a high-end institution in order to access the best data and test the best ideas. I think this is a fundamental issue actually, we do need to be sharing our high-end resources with our lower resourced neighbours.



**Professor Miia Kivipelto**

Professor in Clinical Geriatrics, Karolinska Intitutet

Fully agree. I was also thinking what we have with Worldwide Fingers in some African countries, but they have not yet been able to start the trials and intervention, though are conducting surveys and observational studies. So, there is that step as well. How can we stimulate clinical trials in these settings? Then if you have the system ready to support the data collection, management and sharing, that would be wonderful support.



**Dr Niranjana Bose**

Managing Director, Gates Ventures

Yes. And John coming back to you as you think of Dementia Platforms UK's enabling resources. I know in the last few years you've also embraced and engaged in interoperability conversations with other data sharing, data access, enabling platforms such as GAIN. Can you speak a little bit to how some of those best practices or resources can be made broadly available as a consortium?



**Professor John Gallacher**

Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK

Yeah, I think it operates at two levels. One is the sharing of technology, and the other is the interoperability between platforms. At DPUK we we've helped set up Dementia Platform Australia which is effectively saying to our Australian colleagues take what we've built and just stick it in your infrastructure and develop it how you like. That's a very efficient way of increasing capacity. But the other way is interoperability between platforms.



**Paola Barbarino**

We know about your great work George :-)  
we hope there will be more like you



**Professor Ricardo Allegri**

I agree, Data sharing and diversity must be the next step in research



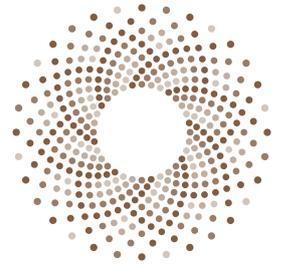
**Dr Nina Silverberg**

Experiences with hackathons to do more with the data? opportunities to get data scientists involved?



**Professor Rory Collins**

Paola: UK Biobank provides streamlined access to detailed data on all 500,000 participants (which includes genotype, exome and whole genome sequence data, and imaging data in 50,000 of a planned 100,000 subset, combined with health outcome data) on a cloud-based platform with free compute for LMIC researchers.



Each platform has its own history, its own primary goal, and its own technology development. And through ADDI, the AD Workbench in particular, we are able to link with GAAIN, EMIF and other platforms as well, and we look forward to building links with EPND, there's absolutely no question of that. But the issue then becomes technical; how do you most efficiently federate your data access whilst respecting jurisdiction and consent issues? Now there are no simple solutions, but the goal is, once you've solved them for one instance, you can apply that solution to many instances.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Fantastic segue John as I wanted to ask this question to Miia who mentioned federated sharing architecture that Worldwide Fingers is trying to embrace so they can try and overcome some of these challenges that you just alluded to. So, Miia I want to hear your thoughts on how that's going and what are some of the roadblocks or challenges you're facing there?



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Intitutet

I see this is a really great opportunity to overcome some of the challenges. We have started in Sweden and Finland adopting the AD workbench and seeing how it works. And now we are approaching various Worldwide Fingers countries, just to see what the requirements would be for these countries, and institutions, to take that next step. So, I'm optimistic that this can be the way to really support and facilitate data sharing in a good way. And we're just building now the guidelines on how to do that. Because we are dealing with trials, each PI and institute has the right to first analyse the results and do what needs to be done. And what would be the next level is to do joint analysis and start to plan what are the questions we want to answer?

So just as an example, we have got very different kind of responses from different countries. We have been talking with Singapore. We have been talking with UK and Spain. It depends on what country you are coming from and also what type of institute you are coming from, if it is a big university hospital or medical university, more private institution and so on. And how is your data, what is the informed consent, who are the funders? So, I would say there are a lot of complex questions and what we want to do is to map what are the specific questions from these countries? I would say there is not one size fits all solution, but you need to solve these practical questions in each country. But I believe that the federated dataset can absolutely facilitate that, and then it's up to us to find the way to discuss and clarify with each trial PI how the process goes and what can be shared that way.

And one more point. It helps when you have a vision and goal. What do we want to share? Why this is important? And then it's more the next level what could be important to analyse jointly? For example, in the Worldwide Fingers context it could be gene



**Professor James Rowe**

Anticipatory Consent will be key, with overt permission sought for flexibility in sharing across jurisdictions and across academic/industry/healthcare boundaries.



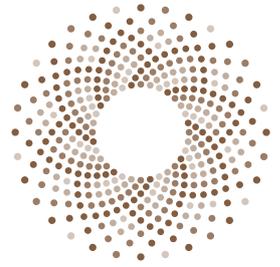
**Professor Jane Roskams**

@ninasilverberg - that is what has begun happening on the INCF training platform. We have been hosting global training and hackathons on targeted datasets



**Dr Jina Swartz**

What about special and neglected populations within LMICs, about which we know very little to nothing? How can we engage the global research community in working in this area, as well as engaging these populations - especially where there are high levels



environmental interactions. Is the effect of the intervention more if you have APOE4 or a high polygenic risk score? This may be something you can't answer in your own data set where the power is more limited. So having these concrete examples and study questions ready will make it easier for people to understand why and when we should share data.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Phyllis, go ahead, I was going to come to you.



**Phyllis Barkman Ferrell**  
Global Head of External Engagement for  
Alzheimer's Disease and Neurodegeneration, Eli Lilly

Having looked at this through the lens of the Davos Alzheimer's Collaborative, where we are talking to both low-and-middle-income countries and high resource countries, one of the things I want to add to this discussion, is I've been surprised, actually, how eager and willing the low-and-middle-income country flagship sites have been to do early detection.

We came in thinking that the early detection of cognitive symptoms would be something that was really only for high resource countries. They would want to do it because they could, potentially, have a therapy in the near future. I think one of the reasons that we've seen the low-and-middle-income countries lean in is they're thinking about this through the public health lens. And Miia has referenced this a couple of times. I mean, obviously she's led the field in some of the lifestyle modifications research. But if you're a low-and-middle-income country, even if you don't have a cyclotron around the corner, even if you don't think you'll be the first one for the antibodies, if you think that you can lean in and do some lifestyle modifications or put support around families before Alzheimer's becomes a crisis that's a good thing.

I think one of the challenges we have when we build these independent clinical research datasets is we pull things out of the public health system and, somehow, we have to make sure that we're able to do both. You need to do that, right? Because if you're going to do PET, you're going to use these biomarkers, and if you're going to do genotyping, you need to be in that research setting. But how do we make sure that we don't pull that totally out of the public health setting and that being perfect doesn't become enemy of the good? And we're continuing to collect some of these. Rhoda mentioned this in the chat, but digital technology is ultimately scalable. It can go into these public health settings.

The Global Dementia Observatory exists, and yet it's not getting all the data fed into in. So, I think, somehow, we have to make sure that we allow some of these learnings to move into this public health infrastructure as well, so that you are getting the benefits across the community. And then, of course, in these research settings you have this tightly more federated model. And that's a fine line to walk. But we've seen it in a lot

of mistrust and other priorities. I think, in particular, of the 50 million IDPs (Internally Displaced Persons) and 25 million refugees - where we have little to no understanding of the data or data gaps.



**Adam Smith**

UK National Centre for Research Methods also provides fantastic resources for training (funded by the ESRC) - <https://www.ncrm.ac.uk/>



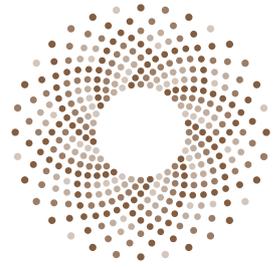
**Sarah Lock**

Thank you to the data sharing advocates and the great work of Gates ventures in making it happen



**Paola Barbarino**

We published a report on this in 2019, will give the link later. We also considered a lot of marginalised groups in the latest



of disease programmes already. We go in through the research lens, but really, if we're going to benefit the public health community and the broader community, especially in low-and-middle-income countries, we need to make sure that infrastructure gets trued up as well.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

Well said. I want to echo another comment that I saw in the chat from Greg Moore on the Microsoft side about federated learning and confidential compute. I think John this is something that you are also moving towards or embracing as additions to your platform, perhaps you could jump in and share your thoughts there.



**Professor John Gallacher**  
Professor of Cognitive Health, University of Oxford and Director,  
Dementias Platform UK

I think that there is an ongoing debate about the various benefits of federated versus pooled analysis, but they obviously both have their advantages and their constraints. Typically, with a federated data set you would reach out, do your analysis remotely, and then bring results back in. I think if we can do that efficiently then it opens a whole new avenue for global science.

Whether there are more technical solutions in being able to reach into datasets remotely and bring data together without apparently or actually bringing them out into a third space is I think a very interesting question. But currently the issue is how can we reach in, how we analyse, and how can we bring it out rapidly. I think rapidly is the issue here. We want low friction solutions rather than solutions which take 30 days for this legal requirement to be met and then another 30 days for a further legal requirement be met. This this is just unhelpful to science generally, so let's think of efficient solutions that we can apply globally across data platforms.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

And speaking of efficient solutions, perhaps this is a question I could address more broadly to the panel. One of the aspects that I've recently heard about being a challenge is who wants to be the commissioning body? For some of the datasets once they're completed it's time and resource intensive having a group that can adjudicate or give permission or not give permissions to persons requesting access. That seems to be one of the challenges. John your thoughts on how we could be more efficient and then I want to go to Miia and others as well who might want to share their thoughts on this question?

world alzheimers  
report on diagnosis



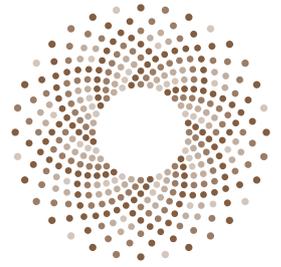
**Professor  
Hilikka  
Soininen**

Excellent  
discussion on  
an important,  
complicated issue,  
thank you!



**Dr Angela  
Bradshaw**

Fantastic discussions  
on data sharing!  
Alzheimer Europe  
published a report  
on data sharing  
earlier this year,  
highlighting the  
substantial EU  
investment in  
clinical research  
on dementia, and  
identifying key  
barriers and enablers  
for data sharing from  
this research. The  
clear message from  
research participants  
is the desire to  
be meaningfully  
involved in research,  
and in discussions  
on data sharing,  
so the value of  
their contribution  
to research can  
be maximised.  
If of interest, it  
can be accessed



here: <https://www.alzheimer-europe.org/reports-publication/2020-alzheimer-europe-report-data-sharing-dementia-research-eu-landscape>



**Professor John Gallacher**

Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK

So currently in DPUK we give data controllers complete freedom to choose whatever system they wish. Some systems go for we don't mind whatever you do effectively. Whilst some data controllers require a lot of collaborative discussion before a decision is made. I think there's a strong case for having defined constraints and criteria that can be ticked off rapidly on behalf of data controllers by data platform operatives. I just think it reduces the load on everyone. And provided the process is transparent, so that the data controllers have confidence that they retain full control over what is done, and rules are kept, it would accelerate access immediately.



**Dr Niranjan Bose**

Managing Director, Gates Ventures

Miia, welcome your thoughts.

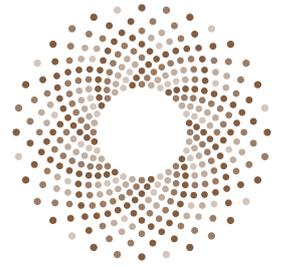


**Professor Miia Kivipelto**

Professor in Clinical Geriatrics, Karolinska Intitutet

I can just add them some reflections on the experience we have had with data sharing from our universities. It's time consuming. I think dealing with these issues, there are so many questions from lawyers and our universities. How do you deal with the GDPR and so on? It takes time! Sometimes I have a feeling that it would be easier for our universities to only work with their own data, because then you don't need to deal with these complex issues. So, I think having these, as I mentioned, dedicated work packages, dealing with the data issues like legal, ethical and regulatory is so important for all big calls and projects. Because it doesn't happen automatically. We need to have a dedicated team working on it.

The data control issue. It is of course a lot of responsibility when you think about sharing data. So, it's easy to understand why it takes time, and you have, as mentioned, informed consent and things you need to respect. And I think we need to think about the data that is already collected, and we need to do the best we can do with that. But we need to think prospectively about the new trial starting now, and this comes back to the teaching, we should try to use the knowledge available and try to have the informed consent that all these regulatory things are in place so that is we are freer to use the data.



**Dr Niranjana Bose**  
Managing Director, Gates Ventures

Although I know we're going to come up quickly on time so I want to go to the panel and pivot and ask what should we be doing differently going forward? Whether it's creation of enabling resources, harmonization tools, whether there could be a repository of some streamlined information? I know one size doesn't fit all, but I welcome the panels thoughts on what could we be doing now that could be seen as no regret activities for the future. I'll go to Phyllis first.



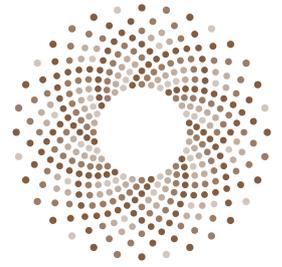
**Phyllis Barkman Ferrell**  
Global Head of External Engagement for  
Alzheimer's Disease and Neurodegeneration, Eli Lilly

Great put me on the spot! I think it was interesting listening to the conversation just then, about some of the challenges in data sharing. I don't think you're going to find many pharma companies fighting you to own and be the governor of that type of data. I think, for most of us, the best situation is to have a third party involved.

I think the tricky part, and this may be, Bose, your question about what to do next, is the layering, of which level of data sharing you allow. Everybody wants the active drug data arm. In reality that's going to be the most difficult thing to share, at least unless the drug failed, or until after it launches. So, for example, the Semagacestat data is now widely available. But once a drug is in a programme where it's got potential for regulatory review, getting that active data is going to be unlikely.

And to be honest, while there's a relatively small group of academics that are really going to want to play in that data, when you're talking about public health data the more impactful data is the placebo data, it's the data around biomarkers and fully characterised samples, how does the disease progress and so on. You know, that's the data that moves the field forward.

And so, I think you can look at what CPAD does. Typically, there's this layering of when I'm willing to share the data and which levels of data. And so, thinking through some generalities around what those layers are is important? Borrow, beg, and steal from ones that already exist. I don't think it's going to be is kind of a check-the-box exercise and not every company is going to come in and play the same way. But I think when you're talking about placebo data or fully characterized samples, things like that, you're going to make a lot more headway, a lot more quickly than if you're really talking about, say, the active arm of a drug study.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

I couldn't agree more. Pierre, I know I'm going come to you last because I'm going to John and then to Miia. I will come to you last because I would like to ask how might funders help going forward? John will come to you first and then go to Miia.



**Professor John Gallacher**  
Professor of Cognitive Health, University of Oxford and Director, Dementias Platform UK

Bose, I think it's very sensible to acknowledge that one size will not fit all. There is no way that we can come up with the master plan. But on the other hand, what we can do is make things easier for everybody as situations develop. For example, the idea of curating data to common standards and the idea of creating meta data to common standards. I would also raise the issue of governance arrangements in terms of access agreements. Simplify them, streamline them, and standardise them. It's very straightforward.

I think where funders can really help is in addressing the heavy lifting problems. For example, I will just pick data curation. Once it's done, it's done. And it is fantastic for everyone. But very few academics will, if you like, risk doing that off their own back, because it's difficult to get academic agreement for that, or even consensus on how it might be done.

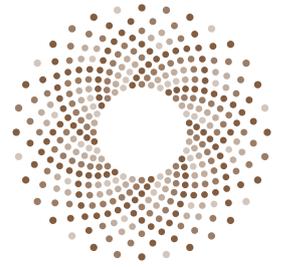
And one other thing I would do is reconfigure search engines so that you can search for datasets rather than findings. If you want to find a dataset and count how many independent datasets there are, it is extremely difficult and imprecise. But if you want to discover finding it's really easy there is a key term. So, I would go to the search engine developers and say look how can we develop your engines to identify independent datasets which are associated with particular findings, which are associated with particular ranges of literature.



**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Intitutet

If I continue, I fully agree. One size does not fit all. But we need to start somewhere. Firstly, I'd say what is important is having concrete examples and using that and then taking the next step. Harmonization I think and these common data elements, there are some basic things that are needed and this kind of help desk that we discussed. I believe many helpdesks and many types of support are needed, but it does not happen automatically, there needs to be more concrete support.

Secondly, I think what is important is that there are links between these different big initiatives so that they are not creating new silos and that there are these dedicated work



packages that are working with data regulation and ethical issues and so on. So, this is now more and more highlighted in all new projects.

And I think the third one for me is education. Why is this important? I don't just mean educating individuals but also educating at universities that data sharing and this kind of approach is the future. Yes, it is time consuming, but we need to have that mindset if we want to make progress in the future.

And that links to the final point I want to make. It is the importance of concrete examples. Why this is important, what we can achieve when we have these joint analysis or joint approach. And we already discussed a few examples of what we can't do without pooled data or shared data. The gene environmental example interactions, but even simple ones like sex or gender differences. Normally the individual datasets are too small. Finally, there more data driven analysis, machine learning, and so on and then you really need to have a lot of new data. So, I think having and highlighting concrete possible outcomes is what is needed.



**Dr Niranjan Bose**  
Managing Director, Gates Ventures

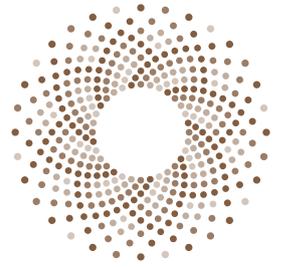
Well thank you Miia and now Pierre, the final word. Before I come to you, I want to thank all the panellists. Over to you Pierre.



**Dr Pierre Meulien**  
Executive Director, Innovative Health Initiative (IHI)

Thank you, thanks a lot. So obviously from a funder's perspective we see many challenges but also loads of things we can do. Where we see this is that we're very much on a journey. We could ask people, when they apply for funding for any kind of dataset, that they should really look at having a landscape mapping exercise as part of a part of their application. We could insist on certain aspects of governance and how important they are. What about the voice of the patient? The patient has an increasingly interesting role to play. They are the ultimate owners of the data and so we need to involve them more. And then make sure that that all of these things, in terms of data management, are resourced properly within the project. Which is something that sometimes is not. And including, of course, a very strong sustainability plan.

So, they're just some of the some of the things Bose. But you know, as I say, we're on a journey and we'd love to hear from a wide group of stakeholders. We will be organizing these kinds of events at the beginning of IHI, to help us design the programmes that will give rise to hopefully great big data projects.



**Dr Niranjana Bose**  
Managing Director, Gates Ventures

Well, thank you Pierre. A journey indeed. And I look forward to this journey with you, all of the other panellists, and others who participated with their comments and questions. These are true champions of data sharing and look forward to creating the enabling resources for the generations to come. Phillip, thanks to you and the World Dementia Council for this opportunity.

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](http://worlddementiacouncil.org)

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