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GLOBAL BRAIN HEALTH INSTITUTE

Brain Health & Housing
Seminar Series

Digital Technologies, Housing and Brain Health

GBHI/Respond Seminar Series on Brain Health and Housing

The Brain health and Housing seminar series is a joint initiative between the Global Brain Health Institute and Respond an Approved Housing Body (AHB) and service provider.

This series aims to advance our understanding of brain health as it applies to housing design, care provision and homeless services.

Conceptually, the overall intersection between brain health and housing can be divided into two interrelated meta-themes, that of the built (building, services, infrastructures), and that of the human (community, inclusion, social supports), with this series focusing on both these strands and how they interconnect.

Optimising one's environment, lifestyle and social community connection are both key factors in protecting brain health and preventing dementia, and generally contribute to individual and societal wellbeing. The value of approaching housing through the lens of brain health therefore, inherently touches on social justice, equity, community building and sustainable development.

Seminar 4: Digital Technologies, Housing and Brain Health

The fourth seminar in this series was entitled 'Digital Technologies, Housing and Brain Health'. Here speakers focussed on the concept of a 'smart society of interconnected information, devices and services' and what this transition means for society both overall and specifically, in terms of housing provision and brain health.

The seminar took place online on 7th November 2022 and the contributors included:

Opening statements

Declan Dunne - CEO, Respond

Keynote presentations

Alex Rothera – Entrepreneur, Designer and Inventor

Celine Fox – PhD Candidate, School of Psychology, Trinity College Dublin.

Panellists

Melissa Chan – Service Designer and Social Entrepreneur and Atlantic Fellow, GBHI

Richard Reilly – GBHI Faculty and Professor of Neural Engineering, Trinity College Dublin

Closing Remarks

Brian Lawlor – Deputy Executive Director, GBHI

Moderator

Áine Kerr – Journalist and Co-Founder of Kinzen

Introduction – Setting the Context

This seminar focused on our shift towards becoming a 'smart society' and the possible implications of this on society both overall and specifically, what this means for housing provision, our communities and brain health.

The speakers examined some key questions including:

- **How do we strike the balance between digital innovation supporting communities and individual wellbeing, and being a replacement for it?**
- **How do we ensure the vulnerable in our society can be supported through this transition and share in its benefits?**
- **How can we integrate technology to better understand, measure and protect our brain health across the life course?**

Summary of Ideas and Perspectives Presented

The main points and ideas presented by the contributors included:

Alex Rothera
Entrepreneur, Designer and Inventor

In relation to launching products and making creative things come to life, there are various frameworks that can help you understand and connect with people, when you're working in this space. One of the 'start-up rules' to focus on, is to talk to your customers or audience to create something they love.

Early on in the research/tech space the approach was to make something cool and futuristic and then look for a problem it solved. However the thinking and approach to this has now shifted around that question of 'how you design for the future'? So, instead of making something cool and then looking for applications for it, the approach is to really understand what the important problems are, and then finding the correct solutions for them.

How to understand and design for people

Through researching the area of young people experiencing loss, this highlighted that it is common for young people who are experiencing loss of a close friend and the associated feelings of this experience for the first time, to result in them feeling lost and isolated themselves. Their ability to talk about this experience with their friends' and in turn, their friends' abilities to listen to them are often quite low. This means they both recede and don't find the necessary support required.

As a response to this issue, you might then ask 'how do you provide the tools and start-ups for young people dealing with mental health issues?' This is how 'Cove', a music therapy App was developed with the NHS in the UK. It allows users to make music about how they are feeling. So, for people finding in difficult to talk about they are feeling, they can make a song and share their feelings that way instead. We are currently developing another App in this area, which is about digitizing art therapy that will allow users to share feelings and emotions, that may otherwise be 'untapped' if language was their only medium.

In terms of how to understand and design for people, it is really important to approach each project with a very rigorous research framework which has also been described as 'contextual design'. So how do you understand the 'context' of what you're launching a product in? The context can be much nuanced for example, the cultural context or age of users.

To demonstrate this, if we look at the video phone, you may not realise that it was first launched in 1970's at Bell Labs. It was very different to what we know as 'facetime' today and was a colossal failure at the time. On researching the reasons for its failure, it was found that users didn't want to be fixed to one spot. They wanted to be able to move around and continue doing errands whilst talking, which another product, the long corded phone allowed them to do.

Now we use frameworks like the one outlined in Figure 1 on next page, where we ask users 'what is important to you? and, 'what are your biggest pains and gains?'

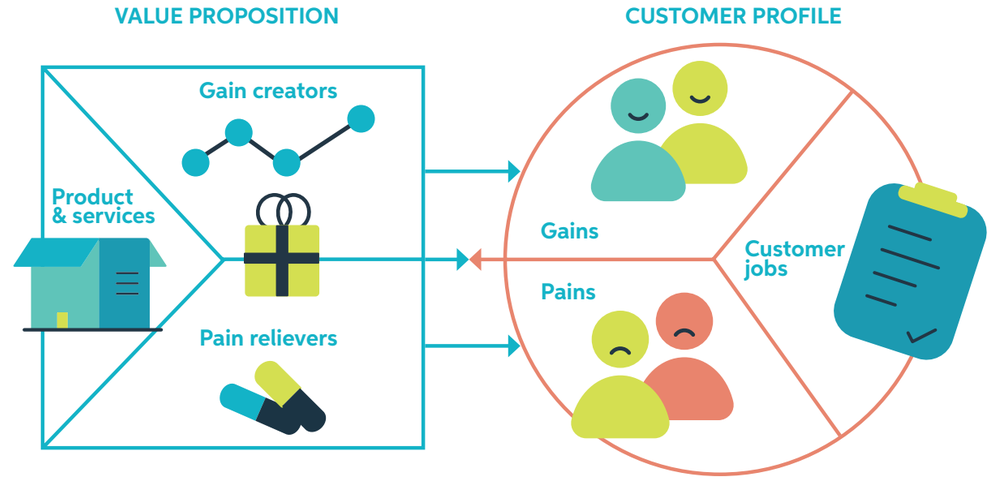


Figure 1

Emotional design

Another area to focus is to how do you design for delight and how do you add moments of spark and happiness to keep people engaged at different points of a service or product. A good example was the design of the first Sony Walkman, which had a heavily designed 'click' when you inserted a CD. This created delight when you knew you were about to listen to some music.

In the early days of product design, the approach was to create a 'minimum viable product' that was functional, reliable and usable, in the first instance. Then only later would the product be further developed to incorporate additional features to deliver 'emotional design' features. However, the approach has now changed to where you provide a slice of all these steps along the way so that users can have an emotional attachment to a 'minimum delightful product' from day one, as illustrated in Figure 2 below.

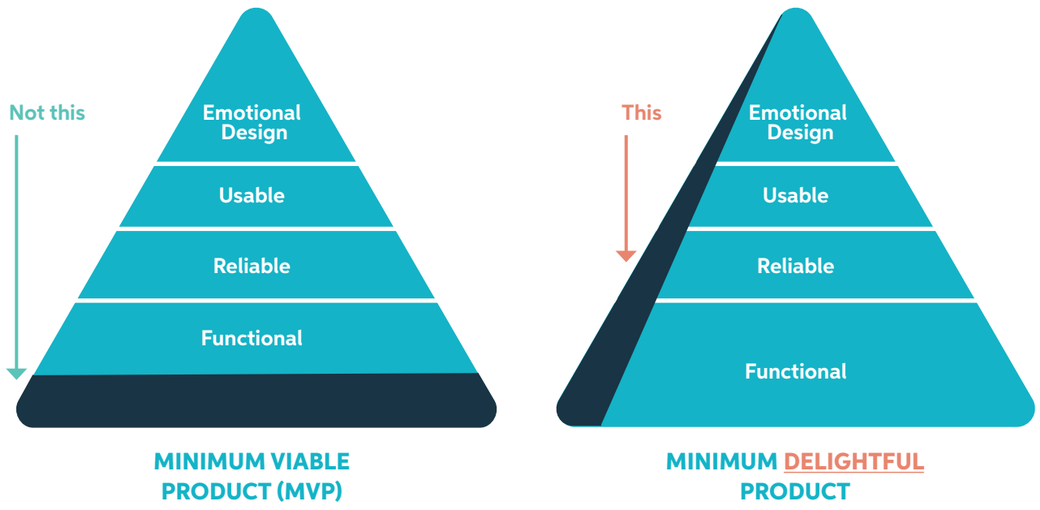


Figure 2

Another key aspect of product or service design is to think about the lifecycle of it, going from opening the product and first use and through its different stages and thinking about how you can infuse these with key moments of delight. For examples, at the beginning, you are welcoming or easing someone into the product. So you can maybe be a bit warmer, in order to get the users familiar with it, and then think about other key points when they need to become more familiar with the technology.

This could be applied in terms of housing and services where you think about how you ease someone into their home and what are the delightful moments that will make the process more approachable.

As an example, when designing products for Google, we realised that people had never had the experience of talking to a device. So by adding a feature for the device to be able to tell jokes was a great way to enable easing into the experience. On a more serious level when looking at more sober issues in developing 'Cove' for supporting mental health such as, 'every day 48 children lose a parent', we found out early on that when someone opened a music App and it was silent, this was quite scary as it felt like you were left alone. So the 'delight decision' that was made was to include a hum or other sound when starting the App so that you didn't feel alone or that you were starting from scratch.

Celine Fox
PhD Candidate, School of Psychology, Trinity College Dublin

Currently in Ireland, we know that mental health is a major problem. It is estimated that Ireland has the third highest rate of mental health illness in Europe. It is also estimated that 18.5% of people in Ireland report mental health problems at any given time. Also we know that these issues disproportionately affect those who are poor and other marginalised members of society. We also know that we cannot meet the need for treatment of mental health disorders.

Across Ireland and in many other countries, there are really long waiting lists for psychological services. In 2021, over 10,000 people in Ireland were waiting to see a Psychologist. It is estimated that over half of these people have been waiting longer than one year, demonstrating that this is a significant issue. In order to address this our work is ongoing, to harness the power of technology through use of internet based studies, and remote online data collection to really fill this gap, in order to get a better understanding of what's causing mental illness and how we can treat it better.

What treatments are going to work for whom?

A major question that we ask in the lab is, what treatments are going to work for whom? If you have a mental health disorder for example, depression anxiety or OCD and you present to a GP, they'll subscribe either face-to-face treatment or medication or digital treatment. You would assume therefore, that when you present with these disorders, the type of treatments you get will be chosen based on matching the best treatment for you, given your presentation and symptoms and profile. However that's not the way it's done and the reality is, that we actually don't have the tools to predict what treatment is going to work for each individual person. Therefore, it's a bit of a trial and error approach. Typically the treatments are chosen based on what the cost of them are and if whether or not they're available at the time, as opposed to whether or not they're actually the best treatment for that person. This leads to high rate of treatment non-response and people often have to go through lots of different treatments before they find the one that works for them.

Artificial Intelligence

In this scenario, we have started to investigate whether artificial intelligence could be a really powerful tool to gain a better understanding of what's going to work for whom. When developing an Artificial Intelligence (AI) model, we take a huge sample of data and then use all of that data combined, to generate a predicted outcome. So in the example of generating an image of mental illness, what we did was to take billions of images from Google, and using all of those images and facets of those images, we generated the few representative images of mental illness.
This is a pretty neat approach in this example of producing an image, but when we start to apply this kind of modelling to mental health we run into a problem. Currently, we don't have the volume of data to input and generate these kind of predictive outcomes.

It is estimated that Ireland has the third highest rate of mental health illness in Europe. It is also estimated that 18.5% of people in Ireland report mental health problems at any given time.

So for example in Ireland, it's estimated that about 100 to 150 clients will be seen by an individual therapist each year. Out of all of those people, only about ten of them will be interested in participating in research which makes sense, because if these people are quite unwell, then they're probably at their lowest point in their life and may not be motivated to come into a lab and get involved in extensive engagement for research. Their priority will be to get better.

Even out of those who do engage in research, only about seven of them will go on to complete the research project, so again we have this issue where we're actually really struggling to get enough data on people to predict who's going to respond to what treatments. This is where we took the approach of scaling up, so rather than getting people to come into the lab to undertake lots of the different assessments, we're going and reaching out to them by doing online internet-based research.

Collaboration with Silver Cloud

We've collaborated with Silver Cloud, which is an internet-based cognitive behavioural therapy (CBT) service. We recruited people as they were starting to use this internet-based CBT, to sign up for the study, where they completed a wide battery of assessments, all from the comfort of their own home, using their computer. They reported on things like their age, gender, lifestyles and medical symptoms. They also played games that tapped into their cognitive abilities. We then track and follow them through treatment. On each individual, we had over 600 measures. We also got a huge sample of people with over 700 people completing these assessments both at baseline and the follow-up.

This kind of scaling up using an internet based approach really facilitates the collection of not only of a greater depth of data (as we are collecting a lot of data on each individual person) but also a greater breadth of data in that we're getting these huge samples that have the power to track clinical effects. This means that we can then start to predict who each treatment is going to work for. What we've seen so far in this cohort, is that those people who seem to get better, are those who are exercising more, have a good diet, higher levels of education, are from a higher socioeconomic status and have more levels of social support.

Conversely, those people who are less likely to respond are those who are more unwell, have lower levels of social support, lower levels of education and higher levels of comorbidity. This, the idea is that if someone's presenting in clinic and they appear to have higher levels of symptomatology, they have lots of other issues going on and maybe, they demonstrate lower levels of education, that this internet-based treatment approach isn't the best option for them. It would point to trying to pursue other options that might suit them better. It means that at baseline, we can start to predict what's going to work for whom which is really interesting and allows us to start to see for each individual, the type of treatments they don't respond.

Citizen science approach

Something else we're really interested in is who's at risk of developing these kinds of disorders. What we've been doing is taking a citizen science approach, to understand the risk factors for dementia. Citizen Science is an approach where you get people from the general population to engage in research, not because they're financially motivated to do so, but because they have a genuine interest in those disorders and the aims of a research group really aligns with their with their goals in understanding these disorders and helping the cause. In terms of dementia this is an umbrella term, to describe those clusters or symptoms relating to issues like remembering, thinking and carrying our day-to-day activities,

The approach applied is that if we're collecting data through citizen science, we can actually reduce dementia incidence. In this regard we know that there are a myriad of risk factors for dementia and also that a high proportion of them are modifiable. So if at a societal and individual level, we're adjusting these factors, then we can actually lower the rates of dementia. These factors include, whether or not an individual is engaged in smoking behaviour; is drinking alcohol; experiences depression; experiences hearing loss; their cardiovascular health and education levels.

We know that if we can lower people's risk of these specific factors, we can then at a later stage, reduce their chances of developing dementia. Therefore we're hoping to get a better understanding of how all these risk factors evolve and influence each other over time, by using a smartphone App called Neureka. This App is free to download and it contains lots of quizzes and self-report skills games and behavioural trackers. We're using this information to get a better understanding of what drives mental illness and brain illness and but also how these things fluctuate over time. Currently, over 18,000 users have been registered and it's been downloaded across over 100 countries.

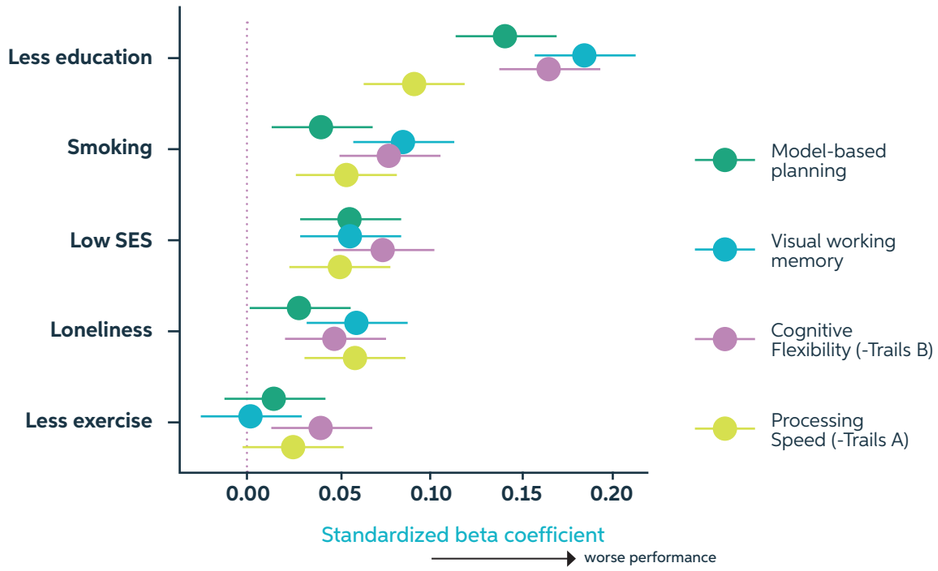
We're not just interested in measuring these risk factors at a single time point, but also looking at how they change over time and how these changes are associated with people's developmental supporters like dementia. For example, within the App we have behavioural trackers and mood trackers where people can self-report on their experiences, multiple times over the day. To demonstrate this, if we take smoking as a risk factor for development of dementia, we can start to see how smoking behaviour may be driving changes in cognition. When someone tracks their smoking behaviour charts over a number of days, and then we produce a graph of that behaviour and send it back to them, we can then start to try and understand what causes changes in smoking behaviour. For example for one person, stress could lead to increase in smoking, and then smoking could lead to increase in stress and over time these effects can have impacts on things like cardiovascular health, which increases risk of dementia.

In addition, we're really interested in looking at whether or not we can effect changes at population level and start to impact policy making. The graph below (Figure 3) shows that among the 18,000 users of Neureka, we can look at factors that are predictive of worse cognitive performance. For example, it shows that if someone has lower levels of education it's predictive of worse decision making. This is done by working mandatory target, flexibility and processing speed across lots of different games we have in the App into these cognitive abilities.

Although these clinical effects may be relatively small, if we start to think of these at a policy level by making for example, education more widely accessible to those who need it most, it may have small effects on an individual's clinical abilities, but at a population level this could really reduce the incidence of dementia. Similarly we see similar trends with things like exercise which again is like low levels in terms of implications for policy making.

Figure 3

LIFESTYLE RISK FACTOR ASSOCIATIONS CONTROLLING FOR GENDER AND AGE



As a final point to sum up, we really think that this digital approach has huge potential in terms of changing our understanding of these disorders, but also really facilitating earlier detection, who's at risk and treatments are best for whom. These tools are useful for clinicians in terms of predicting treatment but also determining the drivers of behaviour and mood space. It also empowers people, as one of the outcomes we deliver through Neureka, is giving data back to people. So, rather than just being passive data providers, where users give us information and they get nothing back, when they play these games on Neureka their scores are reported back to them by the data being graphed in these trackers. We also always inform our end users of any published research that we find with their data.

Therefore we're hoping to get a better understanding of how all these risk factors evolve and influence each other over time, by using a smartphone App called Neureka.

Melissa Chan

Service Designer and Social Entrepreneur and Atlantic Fellow, GBHI

‘Cara’ is a lifestyle membership platform that was developed to address the question of how we might support people living with dementia, to live in place for as long as possible. Drawing from the 2019 National survey on Dementia by the Singapore Management University and Dementia Singapore, it was found that three out of four people living with dementia feel rejected and lonely and nearly thirty percent of carers feel embarrassed while caring for their loved ones in public. ‘Wandering’ was also often a concern expressed by family carers, as it can be dangerous and even life-threatening. So the stress of ‘wandering’ or the risk of wandering weighs heavily on carers and family.

By working with service users, community partners and Dementia Singapore we co-created a digital solution to address these service gaps, via a scalable model. ‘Cara’ which stands for ‘community assurance rewards and acceptance’ was developed to further reduce the stigma of dementia, encourage people living with dementia and carers to live in place normally for as long as possible and enhance the assurance of a supportive community.

Cara provides access for people living with dementia and carers to connect to an ecosystem of solutions, via a mobile application. Some of the key functionalities include providing a unique identifier for people living with dementia; a safe return function to connect members of the public to family carers; care circle relationships being formed in the application; tailored rewards and access to the solutions and resources. It collaborates with the National Council of Social Service in Singapore, the agency for integrated care; the Land Transport Authority and the Singapore Police Force.

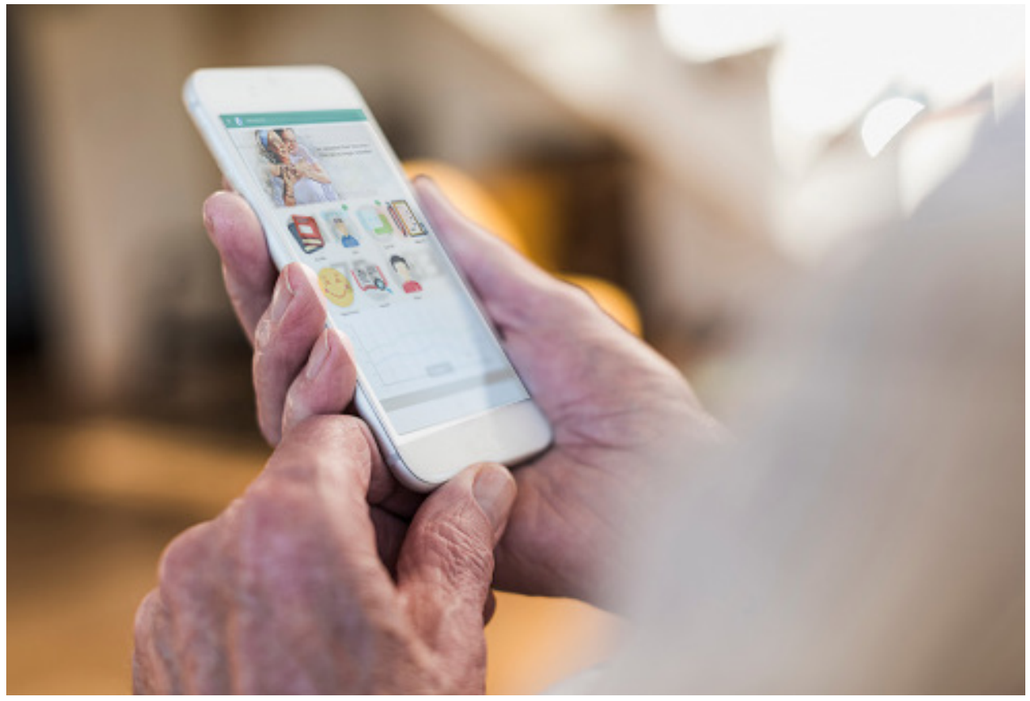
Kampung

When we were co-creating this In App we came across the word ‘kampung’ a lot. This is a local Malay word for ‘village’. So, there was always an idea of how do we bring the village model back into an urban environment to support people living with dementia, to live in place for as long as possible.

The platform brings players such as retailers, dining establishments, places of attraction down to members of the public, local transport agencies and social service agencies together and it blends the ‘online / offline’ model. Although it's delivered through a mobile application, the people living with dementia don't necessarily need to use the App if they don't want to. All users also receive a physical card with a unique QR code for identification.

Cara relies heavily on the gamification model through rewards and discounts to drive the behaviour change and to encourage people living with dementia and carers to remain active, engaged and to tap on the wider network of support. For example, we are partnering with a popular community attraction in Singapore called Gardens by the Bay. People living with dementia can now enter for free by showing their Cara card and carers get fifty per cent off. This really encourages family to using the technology kind of and access the supports or services that are available to them. Then with the reward model, trying to increase that action of moving around outside.

In terms of contextual design, a huge part of designing these digital care solutions for dementia is designing with end users. Therefore a large aspect of this work is building personas. This may not be relevant to all cases but in the work that we do, we see that the needs cut across a whole range of categories, from home and personal care, mobility, safety monitoring, tracking at home diet and nutrition, social engagement, family care and community support. Whilst all of this needs are often present for the end users that we're working with, the persona or, the type of users that we're working with are quite different. Therefore, we've categorized the users into the low maintainer; the active participant and those that are homebound. So when we design solutions by placing an importance on understanding the context and how the users will use the solutions.



Richard Reilly –
GBHI Faculty and Professor of Neural Engineering, Trinity College Dublin

Technology drivers that look to being increased even more in the future are sensors. We know that sensors are everywhere. For example we have our smart watches and we know those sensors are going to get even better in the next couple of years. Probably one of the big drivers are passive sensors in the house and being able to receive information from a small device that might be on the wall or in the kitchen for example, looking at hydration on the skin or watching a gate into a house. These are things that are going to be game changers for mental health and for brain health in general, from being able to see how we actually function in our own homes.

Acquiring data at scale with the huge opportunities that provides in terms of prediction of disease in the future, or disease progression is set to change because of the wide use of smartphones. This gives us huge opportunity to be able to gather more data from more sensors and do things in very different ways. Also our home Computing is going to change over the next couple of years. We're not going to probably have personal computers at home anymore or in the office as they'll all be in the server. We'll be sending data from those servers into our home and we will just be operating using screens.

Also, in the last couple of years, satellite communication, particularly precision for the kind of the GPS that we have in our car or the GPS we have on our watch or our phone has got infinitely better. That's going to be hugely advantageous for many individuals, it's going to be advantageous for transport use, maybe by predicting the quickest way home for us, but also for people who are who are challenged. For example, for somebody who is suffering from anxiety, you might be see maybe being able to choose a route that is more anxiety friendly as there less people there.

The issue of trusting the data is significant especially when used for basing clinical decisions. However, there's huge opportunities for this as we know in many countries, the healthcare system which is really struggling to deal with the volume. However, if we're able to use these passive sensors in the home and being able to acquire data at scale, then maybe we can accelerate the patient journey through the hospital and maybe even accelerate the discharge afterwards by knowing what kind of profile there is at home or the place you are going back to.

Acquiring data at scale with the huge opportunities that provides in terms of prediction of disease in the future, or disease progression is set to change because of the wide use of smartphones.

Conclusions and Recommendations

The best frameworks used in design and invention are when you create something to solve a problem.

It is also important to understand the context for the users and how they will actually use the product and what features are important to them. This will ensure the success of the product design and usability.

Ask how can you create moments of spark and delight to keep users engaged. This can be also be applied to housing settings from people moving into a new home and throughout their tenancy.

Constantly talk to users of your service to understand their experience and develop your products and services to continue delivering 'delight'.

The application of AI together with online, internet based research and applying a 'Citizen Science' approach has the ability to reach a large number of users compared to traditional approaches. This scale of research participants enables gathering of very in depth and broad datasets that enable you to extrapolate patterns and causal information to predict diagnosis and treatments.

Identifying and correlating, even minor causal links through large scale studies, allows for influencing policy decisions such as improvement in access to education, which may only have a minor effect on the individual user, but at a macro level has the ability to reduce the incidence of disorders such as dementia across populations. This in turn can have a significant impact in freeing up resources to address other health conditions.

Combining the innovative and inventive approaches used by new technological start-ups with the robust experience and oversight offered by established institutions such as the NHS in the UK, can result in creative and effective solutions.

Applying strict guidelines on data protection and ethics should be integral to all research and development of new technologies as this results in more appropriate solutions being developed for the end users.

The mix of an online/offline model for applications can be very effective for users and can demonstrate tangible outcomes. For example, in the development of an App for art therapy, bed bound people wear virtual reality headsets with a motion sensor on their hand and are able to move and throw the coloured balls to create their own painting. Afterwards, that painting is printed and can be taken away/hung up in their room.

There is growing need to develop new business models of how we provide care and the role of technology within that, as well as the data interpretation and security of that data.

Within the 'silver tech' industry a lot of devices that are being developed are not deemed to be medical devices. They are classed as commercial devices as they are readily available to all and not prescribed by a clinician. Trying to get these types of devices approved as medical devices is critically important, as we require information from large scale studies to formulate accurate predictions based on scientific information.

There is lack of education in evaluating technology that might be useful for allowing independent living. Currently, clinicians and physicians are trained to be experts at what they do and not to understand how technology can play a part. This is a different skills base that requires developing into the future.

Consideration must be given to the cost factor of developing new telecare and telemedicine devices and we must ensure they are developed and provided for everyone rather than just for wealthier people, populations and countries.

References

Material here is based solely on the seminar presentations and discussions.

More Information

For more details about the GBHI Respond partnership and Brain Heath and Housing seminar series please visit:
www.brainhealthandhousing.ie

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About Respond

Respond, a construction-led Approved Housing Body and service provider, has been working all around Ireland for over 40 years. Our vision is that every family and individual in Ireland will have high-quality housing as part of a vibrant and caring community. Housing and decent accommodation, in the areas where people want to live, are central to improving people's lives and enhancing the health and well-being of society.

17,008 tenants live in 7,761 properties across the 26 counties that we either own or manage. Respond also provide a range of services for families and individuals within our communities. This includes emergency accommodation with 24/7 support for families who are homeless in six Family Homeless Services, three Day Care Services for Older People, 15 Early Childhood Care and Education, Family Support and Refugee Resettlement services.
Our aim is to provide person centred services to support people to achieve their goals and reach their full potential.

www.respond.ie

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About the Global Brain Health Institute

The Global Brain Health Institute (GBHI) is a leader in the global community dedicated to protecting the world's aging populations from threats to brain health.

GBHI works to reduce the scale and impact of dementia in three ways: by training and connecting the next generation of leaders in brain health through the Atlantic Fellows for Equity in Brain Health program; by collaborating in expanding preventions and interventions; and by sharing knowledge and engaging in advocacy.

We strive to improve brain health for populations across the world, reaching into local communities and across our global network. GBHI brings together a powerful mix of disciplines, professions, backgrounds, skills, perspectives, and approaches to develop new science-based solutions.
We focus on working compassionately with all people including those in vulnerable and under-served populations to improve outcomes and promote dignity for all people.

GBHI is based at Trinity College Dublin and the University of California, San Francisco.
To learn more about GBHI, please visit us on gbhi.org or follow us on Twitter @GBHI Fellows.

Notes

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