

Building Blocks for the Future PILAR III - HEALTH AND SOCIETY

# Human Centered Design for Living and Ageing with Data

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#### **About this white paper**

This document aims to compile and summarize the speeches, thoughts and bold ideas shared during the Open Sessions of the 2021 Annual Event of the Business and Innovation Network, recording, for future reference, the contribution of a group of impressive people from all over the world who gathered in Porto to share, evolve and create knowledge and visions for the future of Humanity. This was a collaboration between BIN@ Network and Everythink, a design company.

## About BIN@ Business and Innovation Network

Business & Innovation Network (BIN@) is an international network of academic and industry partners engaged in supporting open innovation and the creation of sustainable forum for sharing good practices and opportunities in innovation. BIN@ promotes a set of activities ranging from brokerage events to softlanding opportunities for startups. BIN@ has currently around 4500 delegates worldwide and so far has held 14 international events in Portugal, UK, Brazil, Romania, Poland and one fully digital event. You can see more about our activities on the official website:

www.businessandinnovation.net.

#### **About Everythink**

EVERYTHINK is an award-winning studio for creativity, design and innovation, established in 2008 in Porto. Through design, they put creative methodologies and strategic thinking at the service of companies' innovation, to create new services, products and experiences, impacting people in a positive, easy and happy way. Everythink's approach with customers, users, and stakeholders is key to create new products, services and experiences, with a positive impact on people's lives. The team works on different areas and outputs, offering diversity and experience in an effect of cross-pollination offering innovative insights, efficiency and time-to-market. Find more at <a href="https://www.everythink.com">www.everythink.com</a>

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### Human Centered Design for Living and Ageing with Data

A conversation with



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Ana Correia de Barros is a senior researcher at Fraunhofer Portugal, in the AICOS Assistive Information and Communication solutions center. She is the head of the Human Centered Department, a multidisciplinary team of researchers. Her main interests are in the field of human centered design applied to healthcare and, recently, to manufacturing, bringing healthcare to the workplace, shop floors, factories, and designing technology for these environments. Designing together with people, this team invests not only in devices but also in longitudinal studies about technology, how people are using appropriate technology.

It is very fortunate to work in a team where everyone is already evangelized about human centered design for healthcare and well-being. But we do have some of these experiences, sometimes with clients, trying to explain the value that we could bring. And I found that the most efficient way of doing this argument is through examples that we have. Examples of clients wanting something, going into the field and understanding that they have to redesign the problem, because they were about to put money in the wrong one. Or examples of data that we have collected when people were using health care technologies, and what they were interested in. In a project for Parkinson's disease, we had developed a solution for self management of the disease. We had lots of features that were asked from engineers and from the medical doctors. And then we have what the patients and the informal caregivers had asked us. What we saw, in a longitudinal study with logs of the use of the technology, was that the features that people asked for were the ones that were really used. These are small examples that we try to use to convey the value of user research and of human centered design.

#### Give the data back to users

It is key to invest on tools for remote monitoring of the technology. As people are using the technology, in longitudinal studies, data about that use is collected with people consent, and this is tremendously useful to identify events that are surprising or mysterious, and then use these data to go back to the participants and interview them to understand what is behind the behaviour found on data. This data could be used in two ways, one for research purposes and the other to give the data back to the users, and this is very impactful as people see themselves in a different lens. The design role is not just to select which kind of data to show, but also to work on beautiful and usable data visualizations for aging adults, novice technology users, or people with disabilities or chronic diseases. It's very important to invest on the usability of these visualizations. There are several examples of people thinking that they know how they behaved, and then there is a self confrontation with the visualizations. They get epiphanies. And this why we are giving back individual data.

#### **Digital literacy is evolving**

As you age, there is a natural aging decline in your abilities: sensory, cognitive, or motor abilities. But in terms of literacy and mental models associated with computers, being them smartphones, desktops, or tablet devices, we noticed that knowledge has grown. We have a technology called the Smart Companion. From the beginning, it was designed for someone who had never seen a computer, and the premise was that this person has to unbox it and use it immediately, being that intuitive. One of the things we did a lot was to break down tasks. For instance, scrolling was not intuitive and was not self discovered by the users, so we had to use buttons for navigation all the time. But then, as people began to interact with the devices, these strategies we designed just became annoying, taking a lot of time to complete tasks. People started scrolling and there was no scroll. It was broken down in so many steps when it could be done at once. So, it forced us to gradually design customizable solutions. We understood that there was this spectrum, it taught us to design solutions in the way people can customize them to their

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own needs. throughout time. It's really important not just to design technology, do usability studies and see if it works or not, but also to learn with people living with the technology, with the tweaks to our devices. And it's important for technology to accompany that progress in the learning.

#### Trust the technology

Whether the technology we are using are mobile devices, wearables, VR or AR, usability is something we will always have to care about. They are different, with different challenges, but it's doable. The challenge may lie precisely on the mental models and usability of these visualizations, and people grasping the meaning of the data. People will get access to more and more complex data about themselves, about the environment, but also very importantly, information about how the systems themselves work. And people need to understand this in order to trust these technologies, and the algorithms in the case of healthcare, because they provide predictions or recommendations. People need to know how these algorithms were built, whether to trust them, and how their data are being handled. And this, I think, will be one of our greatest challenges in the future. But we don't see people in everyday life concerned about this, not in Portugal at least, in some other countries

maybe a little bit. For instance, we see that in projects in Germany, older adults and people with chronic diseases are much more aware of these issues.

It's important for the future not just to think about how to convey this information, but also to convey it to the widest possible range of the population, thinking about an inclusive design. This is a really big challenge for many who don't know anything about artificial intelligence. But if you think of people who may have some kind of impairment, cognitive, sensory or motor, this is even more challenging. If we're going to do it, we should be thinking about the widest possible range of users.

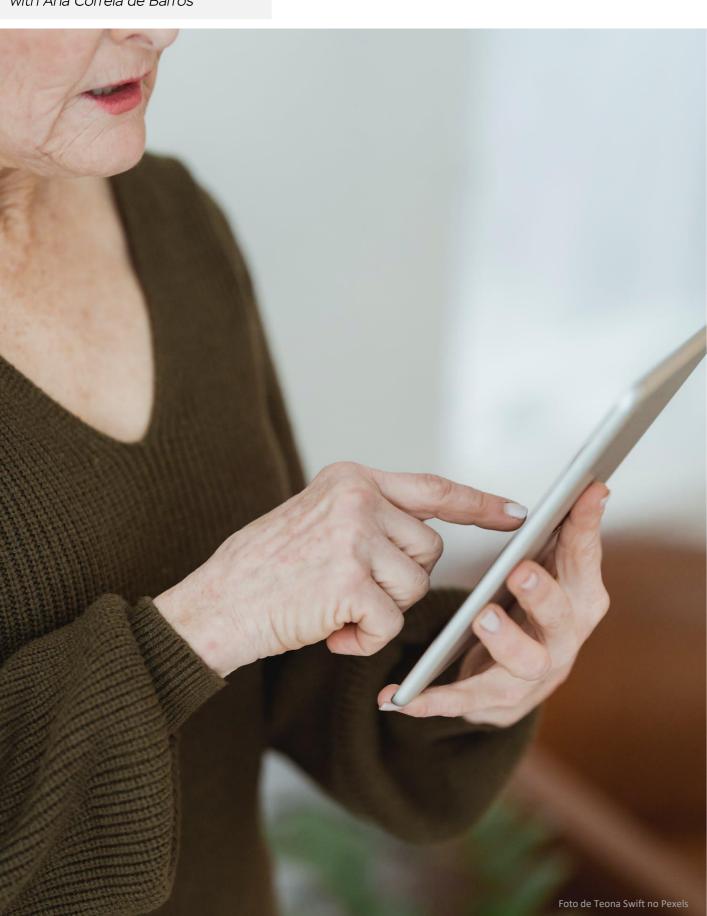
We are working on the mechanisms to audit the algorithms, to get a tool that anyone can use to see whether the algorithms may be biased and analyse the kind of data they were built upon. We also look at the end user side, trying to come up with mechanisms to explain the whole process of how an algorithm is built and how people can explore and make questions. That's the side of Human Centered Design, the parts of this meaningful experience. Another project by the Intelligent Systems group is on ways to certify datasets and algorithms, creating a pedigree of the process, which is traceable to support transparency and accountability.



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#### **Human Connection**

Sometimes we think we should abandon the screens and do something tangible so people can share it. There's the vision that technology may come to replace human beings, but there's the other vision, that technology can come precisely to help them, to bring them together and to create richer interactions. This is an actual discussion, and is what we like to think or to work on.

There is a longitudinal study to characterize a cohort of older adults in different places of the country, dozens of older adults that are living in residences or spend some time at day care centers. We wanted to see the impact in the long run, having then a psychologist in the team doing the assessment. We were going to be testing in person before and after the use and doing these neuropsychological assessments. But because of the pandemic, we had to introduce digital technology like video conferencing and tablet devices with cognitive games, and we had to adapt different instruments used in psychology to be able to work online.

We actually wrote a paper on the lessons learned, and technology was really powerful to enable this connection with the psychologist, which otherwise wouldn't happen. Besides interacting with us using technology, which was a new thing for them, people were so happy with this human

connection that we had to create extra sessions, not related to the research project, just to chat with the participants.

The need for social interaction is one of the main motivators for the use of digital technology. Even amongst older adults, the need to see their children or their grandchildren that may live abroad, or to know about their friends is a great motivator for using digital technology. In particular, Facebook and Skype are two main channels of entry. Now, with the pandemics, people would much rather prefer to have physical contact with one another. But, it was very powerful to use digital technology as an enabler of these social interactions that wouldn't happen otherwise. Even those people who didn't want to use technology at first, were available to talk online with different people, and they wanted even more.

#### New fields of research

For years we have been working with older adults, then with different chronic diseases, and then to the longitudinal studies, thinking about how people lived with technology.

More and more, you see people who are older and are working, and that is a really important part of our life:work. Because of my background, I have worked in a professional rehabilitation center, as well, I understood some of the challenges, that have

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to do with integrating people with different abilities in the workplace, and to get evidence on the impact of work on occupational diseases.

Combining all these experiences, we then started this new field of research of human centered technology for the shop floor. We have this MIT Portugal flagship project, called Operator, and we are using active and passive data to come up with ways to hopefully create better workplaces. We're trying to reconcile the vision of the companies with those of the workers. The companies are concerned with productivity rates, but this comes at the expense of workers' health, and we want to measure this. We want to measure in particular mental health, and collect some evidence on the really high rates of absenteeism, burnouts, or presenteeism. We are also collecting data on the environment, and the risks that people are exposed to. And then we can give back these visualizations, so that people can relate the data, and look at themselves in a different light.

We have plans of expanding this, looking into older adults, and people with disabilities at work. We started with shop floors because these are more challenging environments, even for Human Centered Design. It's really challenging to do these kind of activities, taking workers from the shop floor, who are,

or not, producing while they're talking to us, or doing our exercises. But it has been a rich experience so far, for us and for the companies.

There is a new project that we have called Anathema and which is looking at sexual health in older age. And this for Human Centered Design is challenging for many aspects. The strongest one being stigma. For us, this is completely new. There is almost nothing done around this field. So, this is something that I would like to highlight and get people thinking about.

We have also invited philosophers to discuss what are the limits of digital technology and whether it replaces important things, and still haven't reached a conclusion. We think that digital technology isn't value free. So, when we as designers, imprint some kind of values in the technology that we are designing, it can promote some values and demote some others. For example, when you have a medical device for doctors to use, you can promote the idea that the device knows more than a person or you can demote that idea. It is very tricky to try to speculate about the impact that this may have on users. There's actually a whole field of research on value sensitive design and, as a research institute, it is our job to try and bring philosophers to help us think about how we design values into technology.

There's the vision that technology may come to replace human beings, but there's the other vision, that technology can come precisely to help them, to bring them together and to create richer interactions.





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Translating Systems Thinking into Public Health Innovations Terry Huang – CUNY Human-centered Design for Living and Ageing with Data Ana Correia de Barros – Fraunhofer Portugal Healthy Ageing João Transmontano - Entogenex

#### **Building blocks for the future**

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