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Opportunities and Risks of Digital Health: Older People's Perspective

Summary: The publication of the European Commission Strategy for Artificial Intelligence in April 2018 kicked-off a heated debate on healthcare tech. AGE Platform Europe joined the discussion with Europe's senior population at the forefront of their agenda.

Estelle Huchet
Project and Campaign Officer
AGE Platform Europe
Brussels, Belgium

estelle.huchet@age-platform.eu

@EsHuchet

@AGE_PlatformEU

Promising Outcomes, Threatening Systems

Artificial intelligence has become a key research area in many fields in Europe: be it machine learning algorithms capable of detecting behaviour related to early onset of Parkinson's disease (i-PROGNOSIS) or virtual conversational coaches providing real-time recommendations to support active and healthy ageing (NESTORE), the health sector is not outdone. As a representative of older Europeans, AGE has been invited to join several research and innovation projects developing solutions using artificial intelligence (AI) for ageing well.

These concrete solutions – though still under development – are illustrative examples of what could soon be part of our daily lives. Living with phones smart enough to identify signs of chronic diseases when we type a text, or home assistants like Google Home or Amazon Alexa capable of recommending what is best for you to stay fit are no longer sci-fi plots. Those so-called 'smart' solutions are being developed while we write this paper and could be on the market sooner than later for us to stay fit and healthy as long as possible.

The longevity challenge is a gold mine for the developers of those solutions. AI carries important promises of more personalised and preventive medicine, proposing interesting responses to the ambition of increasing life expectancy. The challenge remains to tap the potential of these new systems for sustaining healthy ageing without sacrificing people's fundamental human rights while we develop, operate or use these systems.

Human Support Cannot Be Replaced by Facebook

The report of the United Nations' Independent Expert on the impact of robotics and assistive technologies on older persons' enjoyment of human rights (July 2017) provides with an interesting perspective on how the current legal and policy frameworks fall short to ensure that technologies are used as enablers of autonomy, inclusion and participation in old age.

If Europe is at the forefront of data protection worldwide, as the European Fundamental Rights Agency recalls in its 2018 handbook on European data protection law, several risks remain in relation to lack of transparency and accountability when decisions are made by "black box" systems. As the lawyer Sandra Wachter stresses, we still lack biding legal provisions to enforce a broad "right to explanation" (Matsakis 2018) for how a machine came to a conclusion about your life.

These explanations are critical to provide recourse; they should cover both how the decision was taken and what could be done to reverse it in case it is proven discriminatory, or inaccurate. These risks of unfair decisions are especially high if no efforts are made to ensure machine learning algorithms are fed with representative datasets – a challenge that will not be possible to meet if we do not address the digital divides that keep many groups away from the most recent technologies.

Beyond those legal and technical considerations are a number of political ones: there is no question about the added-value digitally-enabled (especially AI) solutions can bring to society. As former AGE Platform Europe president, Liz Mestheneos writes: "AI does not get tired, sick, fed up nor does it forget: thus, it can act 24 hours a day to support humans, professionals and patient, with information and data" (Mestheneos 2019).

What we want to do with the human capital we will save with machines making decision for us is a political decision, however. Mestheneos writes: "AI, although discussed in terms of diagnosis, offers possibilities in reducing the current amount of time spent by doctors and health professionals in administration and allowing more face to face time and human contact" (Mestheneos 2019).

Is that the route we will take? Will we allocate more time to meet, look at each other, care for one another? "Even if AI turns out to be better at diagnosis and some kinds of treatment, the human support people need when in crisis and pain cannot be replaced by Facebook, robots, AI and its likes – though there is a role for these too."

Research shows that technologies are just another area reflecting the many socio-economic inequalities that already impact people's health. Those who would most need those technologies to adopt healthy behaviour, be diagnosed early, or receive care are also often those who are the least technically aware and/or have less financial capacity to access those technological solutions.

Major Shift Needed

Adopting a genuine ethical approach to health technologies is a bigger shift than it seems. It will imply to eradicate ageist assumptions that older people are technophobes and thus cannot be associated with the design, development and use of new technologies. It will be required from stakeholders in the field who are building and operating those technologies but also from those that are setting the frames for those technologies, be it law-makers, policy-makers, or standardisers. A recently-closed European project defined ethical underpinnings that should be considered in ICT standard development for active and healthy ageing (PROGRESSIVE).

It will also need to move away from the hierarchical dynamics that traditionally rule patient-doctor relationship: "We have to recognise that many of our health services are stuck within a top-down approach" writes Malcolm Fisk, Chair of Age Cymru in Wales, UK and coordinator of the PROGRESSIVE project. "Neither word (patient and delivery) allows for new ways of thinking that, perhaps, encourage more partnership approaches to health or suggest that people might, except in the most limited of circumstances, take responsibility for the management of their health conditions" (Fisk 2018).

The work conducted by AGE in the area of digital health relies on two legs: first, an active involvement in EU funded projects, like i-PROGNOSIS, FrailSafe or Maturolife; secondly, policy and advocacy work through initiatives like the European Innovation Partnership on Active and Healthy Ageing or the eHealth Stakeholders Group, with strong interconnections between the two.

Whatever the channel used, we do convey the same main messages:

- Solutions must be developed in sound and genuine partnership with users and not for users in order to make the most of the experience and expertise of older persons. As stated by the World Health Organization, "older people are the ultimate experts of their own lives" (WHO 2007).
- Any solution should comply with the 'triple A' rule: accessibility, affordability and availability. These criteria are crucial to close the digital divides and avoid creating further inequalities, including geographical ones. If the digitalisation of the healthcare sector can enhance access to services, it can also further exclude persons in vulnerable situations.
- Human rights impact assessment should always be included as a security net to make sure that the developed solutions respect key principles such as people's dignity, freedom and security, equality and non-discrimination.

AGE recently joined the European Alliance in Artificial Intelligence; this group will collect statements from different societal and economic stakeholders in Europe to steer the development of the EU policy frame around AI.

AGE also keeps strong partnerships with other societal NGOs and consumer organisations working on the issue. For instance, it joined the initiative coordinated by the European Consumers' Organisation (BEUC) and the Open Society European Policy Institute (OSEPI) to develop a "A Human Centric Digital Manifesto for Europe," a civil society compilation of the next wave of policies the EU needs for a digital transformation in the public interest.

The task is tremendous and requires more than just caution. The range of possibilities provided by artificial intelligence makes it compulsory to debate the topic widely. We cannot forgo this dialogue, and older persons as any other citizens, need to be part of it. ■

KEY POINTS

- AGE has joined several projects which use AI for ageing well.
- The current legal and policy frameworks for new technologies do not ensure inclusivity for older people.
- AI technologies cannot replace human interaction.
- Individuals most in need of new technologies for care are often unable to access them due to socio-economic inequalities.
- If we are to take an ethical approach to health technologies, we need to eradicate ageist assumptions.
- AGE aims to improve digital health by its involvement with EU-funded projects and through its policy and advocacy work.

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