![France Assos Santé — La voix des usagers]

Artificial intelligence at the patient's bedside?

Manifesto for responsible, ethical and human-centred uses in healthcare

PART
②
For ethical uses in healthcare

➡ **Towards an ethical approach to the use of AI systems in the medical and administrative organisation of the healthcare system**

➡ **Towards an ethical management of health data used or generated by AI systems**

➡ **Towards an ethic of fair access to innovations based on AI systems**

France Assos Santé, the Union nationale des Associations Agréées du Système de Santé (UNAASS), is the leading organisation representing and defending the interests of patients and users of the healthcare system in France. It brings together nearly 100 national associations that work to defend patients' rights, access to healthcare for all and the quality of the healthcare system. It trains the 15,000 user representatives who sit on hospital and public health bodies. It plays an active role in public debate and puts forward concrete proposals to institutional and political players to improve the healthcare system.

Introduction

Artificial intelligence (AI) is transforming healthcare and the organisation of the health system as a whole. While it holds out the promise of earlier diagnoses, better patient monitoring and optimised resources, it also raises fundamental questions about how it should be managed and used.

Far from being a miracle solution, its development must be carefully thought through and be in line with the values of a humanistic, solidarity-based and ethical healthcare system. Our association is calling for rigorous and continuous reflections and significant actions based on three essential pillars to guide the deployment of these new technologies and uses: clear and ethical objectives and purposes, collective awareness-raising and fair access to innovations.
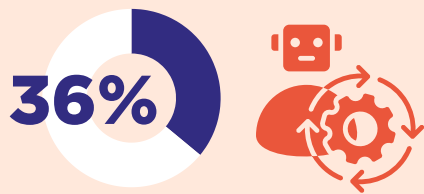
For what purpose should AI be deployed ? What about transparency ?

72

Algorithms used by a central administration or state agency listed by the Observatory of Public Algorithms.

source : Odap

36%

of health and social care activity could be automated by AI.

sources : Organisation Mondiale de la Santé

In public services, algorithmic tools are mainly used to automate certain administrative decisions (whether entirely or not), optimise the management of cases and detect fraud, particularly in the context of social benefits and health insurance. However, this deployment raises major questions in terms of transparency and human control, as algorithms increasingly influence users' access to social rights and therefore to healthcare.

At a time when we are witnessing a veritable algorithmisation, or even automation, of online public services, these algorithms are not being made public. The transparency obligations laid down by law in France (CRPA law) include exceptions that allow actions against social fraud to escape them. However, a number of investigations carried out by civil society have shown that the criteria used for automated targeting of individuals may precisely concern the most vulnerable and present serious risks of discrimination.

In the field of healthcare, diagnostic assistance in medical imaging, personalised treatment, detection of health risks and hospital flow management are all increasingly widespread uses. They also show that artificial intelligence can be put to good use in the general interest and to improve health. However, when it comes to individual care, the organisation of public health policies or preventive actions, targeting patients it can raise various concerns.

→ **Yet too few organisations that implement this type of tool and use provide concrete feedback on its real impact or involve the people concerned in identifying and anticipating potentially negative effects. This is despite the fact that they can have major consequences for people's health, access to healthcare and respect for their fundamental rights.**

Health data at the origin of the world of AI in healthcare

The performance of artificial intelligence, and therefore its value, is closely linked to the quantity and quality of the data used to develop it, particularly in the machine learning stages. If the data used is not representative of the population or if it is of poor quality, this can lead to major errors in the analyses produced by these tools: biases.
The challenges of AI are therefore inseparable from those of health data availability and uses.

128 000

Images of retinas needed to train an AI to detect retinopathy.

source : Inserm

However, the digital divide concerns 16 million French people and the reluctance of certain players to make an effort to provide information accessible to all regarding the shared health data they use and the associated rights remains a difficulty. AI and data sharing suffer both from a number of preconceived ideas and confusions fuelled by a certain opacity and a very negative collective imaginary. However, a shared confidence by people in health data sharing is in everyone's interest - users, researchers, AI designers and health professionals who use them, and all efforts and contributions in this sense would benefit to trust in AI uses.

➔ **This challenge needs to be tackled on a broader societal scale, in order to build confidence and trust among individuals and civil society, with more attention paid to the needs of the general public and messages tailored to the diversity of users and their perceptions and desire to get involved.**

The spread of AI: an opportunity and challenges for equity

Patients, regardless of their place of residence or socio-economic status, must benefit from AI innovations to improve the quality and safety of care. We must avoid a scenario where only certain territories or healthcare organisations benefit from advances in AI, while rural areas and the most vulnerable populations remain on the sidelines. Yet AI has enormous potential to improve access to high-quality, safe care, but its deployment must be designed with territorial equity in mind.

The widespread use of MRIs and scanners is a good example. These technologies have become an essential part of the care process, but access times are still considered too long and situations vary from region to region. The support of the French government and authorities has made it possible to speed up the provision of equipment on the ground while imposing conditions contributing to a fairer access for all.

32 days

average waiting time for an MRI scan (2018 France), compared with 15 days recommended by the 2009-2013 Cancer Plan

When it comes to deploying prevention pathways, there are also issues of dissemination, although the professionals or organisations who are going to deploy these tools and pathways will not always derive direct benefit from them. From a financial point of view, these benefits are more likely to be perceived by the payers in the healthcare system, primarily the National Health Insurance System, whereas the primary motivation for professionals in adopting AI remains saving time and relieving administrative burdens.

➔ **There may therefore be a lack of resources and incentives to ensure that professionals adopt these tools and their uses in a consistent manner to the benefit of a fair acces to AI's innovations improvement.**

Our proposals

Towards ethical and transparent uses in healthcare and public services

➡ **Secure that AI uses are designed with related healthcare services, and that impact and uses analyses of AI systems are publicised by health organisations.**

➡ **Involve health democracy bodies and civil society in the use of AI, particularly for population targeting and health crises management.**

➡ **Increase the transparency of public service's algorithms, and ensure that they are not used solely to combat fraud.**

Towards an information that reflects the diversity of users

➡ **Call on all the players in the data and AI chain to take part in educational information, built up with users.**

➡ **Strengthen the roles and resources of public agencies and supervisory authorities for support and control, and to ensure dedicated information missions.**

Ensuring fair access to innovations accross the country

➡ **Obtain governmental supports (financial, assistance, etc.) to support AI accross territories, for quality of care improvement and prevention interventions.**

➡ **Develop more detailed mapping and impact assessment initiatives.**

➡ **Involve health users in the transition from testing AI systems to widespread use (eligibility criteria, patient focus, clear framework).**

The expectations of healthcare users and our proposals can be found in detail in the full Manifesto (in french) online on the France Assos Santé website.

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