

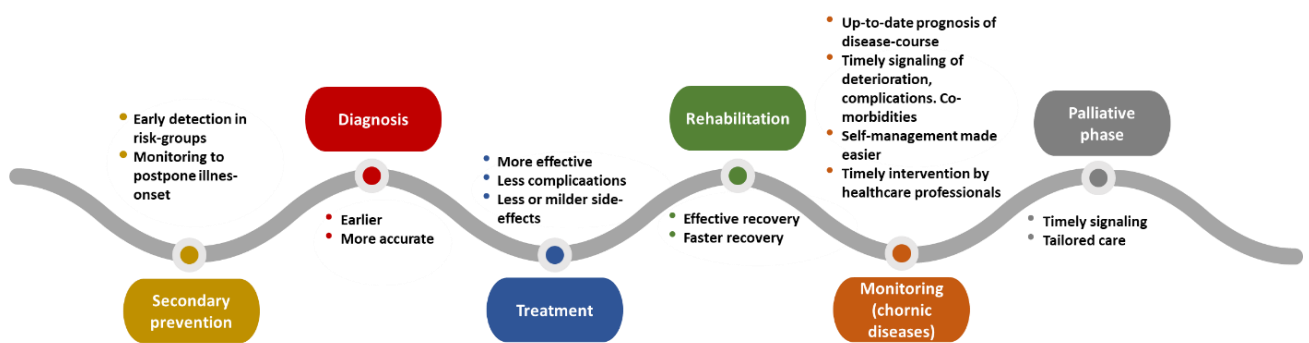
Patient participation for the embedment of artificial intelligence in healthcare

The accessibility and quality of care are under increasing pressure. Innovative technologies such as artificial intelligence can alleviate this pressure by making administrative work and care processes more efficient and by providing tailored care to individual patients. The result is a better health and overall better quality of life. Artificial intelligence is making its entrance in healthcare, but its implementation is still limited. For acceptance of this technology, warranties on safety and effectiveness are necessary. In addition, this technology presents ethical and social challenges, and adjustments or existing or the introduction of new laws and regulations are needed. The Netherlands and Europe are working on these challenges, but for acceptance and optimal embedding of artificial intelligence in healthcare, more is needed: resources, support, good examples that create trust among both healthcare providers and patients. The impact of this new technology will ultimately be experienced by patients: it will have to improve their health and quality of life. The Patient Federation of the Netherlands believes that patients should be given an essential role when embedding this technology in healthcare.

According to the Netherlands Scientific Council for Government Policy (WRR), the development of artificial intelligence (AI) is at a turning point: The transition from a laboratory environment to society is currently taking place. The social embedding of this technology is an immense task and will not happen on a very short term. To safeguard public values, it must be done carefully and in an inclusive manner¹.

Patients (organizations) know that AI as a technological and social innovation can not only add value to health and quality of life (see scheme below), but may also threaten or even erode it, as some recent examples show². Patients want and need to 'accompany' this promising technology into the consulting room, so that values important to them are not lost in the transition from lab to society. For patients important values might be at stake manifesting as ethical dilemmas, that can only be addressed together with patients. Without their participation, the risk of undesirable consequences of well-intentioned actions is real. History shows that the development and application of technological innovations can be accompanied by overconfidence, wishful thinking and short-sightedness, resulting in unnecessary human suffering.³

Patients can benefit from the application of artificial intelligence technologies at every stage of the care continuum



What do patients need?

To properly embed this technology, patient organizations need strengthening to inform and consult, train and activate their employees and patient representatives. The WRR opinion "Strengthen the capacity of civil society organizations to broaden their work into the digital domain, especially with regard to AI" hits the right nail on the head.

In the current transition phase, good examples are needed that give confidence in the technology: examples of AI applications that are embedded in the care process in the desired way, i.e. in collaboration with patients. Patients want safe and effective care in which they can participate, receive explanations in understandable language, and can trust the knowledge and skills of healthcare providers. They should be able to experience that care with AI is as good as the care they are used to, or preferably better. Good examples will strengthen patient (and caregiver) confidence in this technology

¹ Netherlands Scientific Council for Government Policy (WRR). Mission AI. The New System Technology, November 2021.

² Unprecedented Injustice. Report of the Childcare Allowance Parliamentary Inquiry; 17 Dec 2020, The Hague.

³ Carlson, E.A. Times of Triumph, Times of Doubt. Science and the battle for public trust. Cold Spring Harbor Laboratory Press, Cold Spring Harbor, New York, 2006.

and allay distrust and fears. Therefore, the WRR advice "Ensure good feedback between the developer of AI, its user and those who experience the consequences of it in practice" should be followed up.

To arrive at good examples, dialogue and collaboration with patients around concrete use-cases of AI applications is needed. Unraveling a number of representative cases for each phase of care (secondary prevention, diagnosis, treatment, monitoring, tertiary prevention and palliative phase) is necessary. Being able to recognize and address ethical dilemmas is crucial in this regard. In addition, patients need basic knowledge of AI and skills so that they know how to contribute meaningfully in projects and collaborations. This requires training of patients so that they can represent their peers in multidisciplinary collaborative processes around AI applications.

What needs to happen?

The following is needed in the transition phase from lab to society:

- Patients participation in development and implementation processes of AI applications expected to have direct impact on their health. This makes it possible to learn together how to create and implement good examples of AI applications. A growing number of such successfully embedded applications in the healthcare process will increase confidence in the technology.
- Such good examples has to be included in a Health Care Algorithms Knowledge Bank, yet to be established, with the aim of sharing practical knowledge gained during the multi-stakeholder collaboration and promoting the further implementation of AI applications.
- A review framework is being developed for inclusion of such good examples in this Knowledge Bank of Care Algorithms.
- Every successfully embedded AI application is to be provided with an explanation, understandable to patients about the function and role of the AI-tool in the care process (a.o)⁴.

In conclusion

As a society, we cherish values such as trust, privacy, respect for autonomy and equity in our health care. Patients are grateful whenever healthcare providers act in accordance with these values, but are also those who suffer the negative consequences when this does not happen (sufficiently). Therefore, it is of utmost importance that AI as innovative technology in the healthcare is co-guided with patients into the healthcare system: only patients and their representatives are able to bring the needs and values essential to them.

In time, AI will be part of the healthcare as other familiar technologies, such as ultrasound or X-ray. Then fear and doom-mongering will subside and the use of AI will no longer be questioned, because people will trust in the safety of the applications, knowing that the quality of these applications is monitored, and that there are rules for supervision and consequences if violating the regulations. European legislation is on its way, but will not come into force until 2025 at the earliest. Meanwhile, developments in the field of AI in healthcare are not standing still. It is the task of every civil society organization / NGO to contribute to the transition of AI from lab to society. The Netherlands Patients Federation does just that, together with its members, for and on behalf of all patients in the Netherlands.

Questions or suggestions?

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⁴ Complementary to the mandatory documentation for high-risk AI applications (Article 47 of the concept AI Act) by the European Commission (2021/0106(COD)).