

AI in medicine and care from the perspective of patients

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Executive Summary

AI promises great potential for the healthcare system – for prevention, patient-specific diagnoses and therapies. Physicians and nursing staff can be effectively supported in their work in the future by AI-based assistance systems. The Plattform Lernende Systeme has already dealt with various aspects of the introduction of AI-based assistance systems in the healthcare system in several publications (see [Müller-Quade et al. 2020, 2019](#); [Plattform Lernende Systeme 2019](#); [Beck et al. 2019](#)). All technological advances must focus on the needs of those affected. A central concern of the working group Health Care, Medical Technology, Care of Plattform Lernende Systeme is therefore to also take the perspective of patients into account when discussing the opportunities and challenges of AI in the healthcare system.

Members of the working group therefore [organized a round table with representatives of various stakeholder groups](#) in October 2019 to identify and discuss their assessment of the opportunities and challenges for the use of AI systems in healthcare.¹ Within the event, 16 patient representatives were able to interactively discuss positions in the form of a World Café in a qualitative group discussion and jointly prioritize issues.² The central results of this discussion as well as the assessments of patient representatives on the opportunities and challenges of AI systems in the healthcare were summarized in a [conference report](#).

¹ The event was organized by Plattform Lernende Systeme in cooperation with the German Research Center for Artificial Intelligence (DFKI) and the Charité Berlin.

² The selection of the patient representatives was made under consideration of as many different clinical pictures as possible.

The qualitative survey of patient representatives shows that the perception of potential opportunities for AI in the healthcare system outweighs the assessment of risks: The majority of the patient representatives participating hope that AI systems will help them to provide more personalized treatment, networked treatment with cross-sector processes and more comprehensive and faster diagnosis. Of particular importance is also the access by patients to their electronic patient files. The health data from regular care stored on them is considered a valuable source of data to ensure the sensible and high-quality use of AI-based assistance systems in medical and nursing care. New possibilities for participation and inclusion in the treatment process are also considered promising.

The representatives of the various associations see the greatest threat in the use of AI systems in the healthcare sector in the lack of data security and in the subsequent problems of data misuse and cybercrime. They want stable IT security to prevent this and sanction options to be able to take action against data misuse.

Health data are elementary for developing and utilizing AI-supported assistance systems. Prudent data protection is therefore a prerequisite for patient representatives to strengthen AI-supported care and protect the data donors. In this context, the patient representatives also consider informational self-determination and specifications for data storage to be important (e.g. confidentiality, availability, legal validity, access rights). Otherwise, it is feared that data may be collected without consent or that the right to forget is no longer guaranteed. In addition, a contact point for legal assistance should be created so that those affected can assert their rights in a self-determined manner. It is also feared that human interactions will be restricted and that AI-based medical devices will be developed without patient participation. In this context, they endorse greater participation of affected persons in research, development and application of AI technologies in the health care system and legal assistance and educational opportunities on issues of data protection and the management of health data.

The fear of incorrect or discriminatory therapy decisions by medical or nursing staff based on AI technologies was also mentioned by patient representatives as a major challenge. Above all, they fear that wrong decisions or decisions that are disadvantageous for those affected will be made, either through incorrect interpretation of the IT results or through poor quality of the data sets or algorithms, for example due to insufficient traceability of the algorithm decision or training with irrelevant data points. This requires a critical analysis of the data sets in terms of purpose, quality and size, but lacks generally accepted metrics and standards.

Along the analysis of the fictitious application scenario [With Artificial Intelligence against Cancer](#), patient representative Barbara [Baysal commented on the opportunities and challenges of AI in cancer prevention](#), diagnosis and therapy. Here, too, the focus is on the transparency of decisions made by AI systems in medicine and the self-determination of patients.

It's 2024 and Anton Merk (65) has developed lung cancer. He is one of the first patients to be treated using a medical AI assistance system. In the future, all attending physicians will be able to use this technology – for screening, diagnosis, treatment and even follow-up care. Mr. Merk and other patients will therefore have a much greater chance of survival and recovery.



Screening

Mr. Merk has an appointment with his family doctor. She has access to his digital **patient records**, which – as consented to by Mr. Merk – contain information about previous illnesses and other matters such as on his past work in a coal-fired power plant. The **AI-based assistance system**, which the doctor is using to access this data recommends a medical check-up by a lung specialist.

AI better meets the diverse treatment requirements: Today's lung cancer diagnosis focuses primarily on smoking as the main risk factor. With AI, we would have the **opportunity** to include many other factors such as asbestos or dust exposure in a more comprehensive risk assessment.

Diagnosis

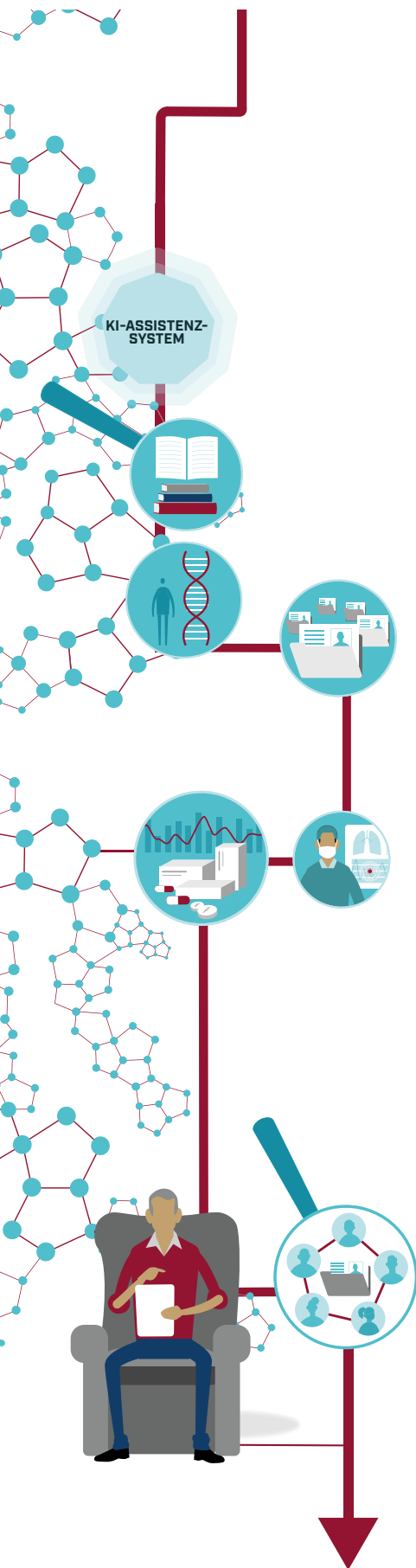
Mr. Merk goes to see a lung specialist, who performs a computerised tomography (CT) scan on his lungs. The **AI assistance system** also helps the lung specialist, this time in assessing the CT images. After the scan and further examinations in a lung clinic, the doctors have reached a diagnosis – he has lung cancer.

Appropriate data storage: It should be ensured that the data is stored in a sensible, appropriate and traceable manner. For example, a dentist does not need access to my lung findings.

AI and reimbursement: AI examination results must not be used against the patients. For example, it would not be justifiable if certain services were no longer reimbursed simply because an AI system did not recommend them. An AI system alone cannot decide whether a service is sufficient and appropriate.

Communication: There is a danger that risk assessments of AI systems can be unsettling if they are passed on to affected persons unfiltered become. It is very important that medical personnel are psychologically trained so that they can communicate the results of AI systems in a patient-adequate manner.

Improved diagnostics: The great opportunity of presorting images by AI is that more tumors can be detected even with simple X-ray examinations. Through the more precise risk identification more people can participate in the CT examinations.



Treatment

The **AI assistance** system reviews the findings and **recommends** surgery to remove the tumour. Lung specialists, oncologists, radiation therapists and surgeons set up for a consultation team – known as a tumour board – and recommend that Mr. Merk should undergo the operation. After the successful procedure Mr. Merk discusses with the lung specialist what medication he should take. The specialist consults the **AI assistance system**, which **predicts** how successful different **treatments** would be based on comprehensive guidelines, the genetic characteristics of the tumour and patient data from across the globe. Together, Mr. Merk and the specialist opt for the form of chemotherapy expected to strike the optimum balance between effectiveness and side effects.

Sufficient data basis: The benefit of AI assistance systems is crucially linked to the database. Only if the AI can use meaningful data, information will be generated that will benefit the tumour board.

Voluntary and protected data sharing

The treatment is a success. The collected data of the last months flow into Mr. Merck's **digital patient file** and are dedicated to research made available in anonymized form. Then are his illness and the treatment completely documented and possible abnormalities in the future can be made available at an early recognize. In addition, he has given a **voluntary and protected data release** agreed: His pseudonymized data are thus also available to research and may open better chances for further lung cancer patients in the future. The servers, on which these data are stored in accordance with data protection regulations, are located in Germany.

Sufficient database: The release of pseudonymized data is not a one-way street. Patients should be informed regularly on request about the use, purpose and results of data evaluation.

The discussion with patient representatives shows that the development of AI technologies with increased patient participation is of great importance for patient representatives. Consistent consideration of those affected can improve the sustainable introduction of digital and AI-based technologies in medicine and care and increase the benefits of these new technologies. This is the only way to ensure accessibility and participation of all population groups. Similarly, the effectiveness of the new treatment methods can only be ensured by good user-friendliness. For this reason, the patient representatives interviewed call for a stronger structural integration of patient interests in all areas of the healthcare system and a critical discussion of the development of AI-based medical devices. By exchanging and involving representatives of various groups of stakeholders, Plattform Lernende Systeme aims to contribute to the dialogue process on AI in the healthcare system.

Imprint

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