White Paper | 2025

Using AI for Shared Decision Making in Medicine

A Practical Guide

Contents

White paper voices

We are currently undergoing fundamental changes that open up great opportunities for better patient healthcare. Through an active exchange between healthcare and science, we can and should provide crucial ideas for tomorrow's health today.

Dr med. Sven Jungmann
Doctor and AI entrepreneur

This white paper provides a perfect basis for discussion for all stakeholders, regardless of whether they are persons concerned, HCPs or representatives from politics, industry or business. It is formulated succinctly, without unnecessary discourse, and appeals to all readers. In addition to discussing the fundamentals and benefits of the SDM, as well as digital possibilities, risks and opportunities in a scientific sense, it also explains all technical terms. Using everyday examples of fictitious people concerned, digital AI processes – from the exact prompt to the outcome – are displayed, as well as the interfaces, sticking points and possibilities of SDM. I think everyone should read this white paper!

Alexandra von Korff
Patient representative for breast cancer

Thank you very much for this great work. Many important aspects are explained here, as well as practical tips on how to use AI. For me, communication between doctors and patients is a vital pillar, and in this respect I think it is important to show patients that they should not expect everything to come from their doctor. No, quite the opposite. Communication must be clearly defined by both sides, and patients must know how to communicate their questions and needs. This is the only way to discuss and implement the upcoming treatment in the best possible way. You should also feel comfortable asking your doctor questions. This white paper contains helpful approaches and guidance.

Norman Roßberg
Patient representative for multiple myeloma

Christian Schepperle
Managing Director, Interessengemeinschaft Hämophiler e.V.
(Haemophiliac Interest Group)

Discover how AI provides personalised recommendations to help transform decision making and overcome information overload. Read more in this white paper.

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As a doctor and entrepreneur with extensive experience in AI-based healthcare innovation, Dr Jungmann combines sound clinical knowledge, regulatory expertise and practical knowledge of digital implementation. In addition to his own business activity in the field of AI and diagnostics, he has also advised various companies on digital innovation strategies and is also an angel investor, advising an established venture capitalist with a focus on digital health solutions. In 2017, Handelsblatt listed him among Germany's 100 brightest minds.

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Dario Madani is Managing Director of PRO RETINA Germany and has been completely blind for almost 20 years. As a blind person himself, he is committed to promoting research, disease management, self-determined living and better care for patients. He is committed to ensuring that patients make informed decisions for themselves and are also perceived as strong voices. Funding research in the field of degenerative retinal diseases is a matter close to his heart.

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Lars Masanneck combines clinical expertise with modern research as a clinician scientist at the Neurology Clinic of the University Hospital Dusseldorf. He co-leads the working group "Digital Translation in Neurology", completed a master's degree in digital health at the Hasso Plattner Institute and researches innovative approaches such as wearables, AI and digital therapeutics in clinical practice and clinical research. Lars Masanneck is currently the 1st Chair of the German Society for Digital Medicine.

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JENS ULRICH RÜFFER

Jens Ulrich Rüffer is an oncologist, film producer and communications specialist. Together with his team, he has produced numerous films on patient education, including for Deutsche Krebshilfe (German Cancer Aid). His focus of activity and research is shared decision making (SDM). From 2017 to 2021, as part of the Innovation Fund project “Make SDM a Reality” at the Kiel UKSH site, he converted an entire clinic to the SDM communication principle.

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Peter Schüller is a lawyer in the group law department of a global medical device company and Head of Global Legal Business Operations. His area of responsibility includes the legal management of AI strategy, digital products and research and development projects. As chairman of the committee “Legal Questions for the Use of Digital Methods and AI in Pathology” in the EMPAIA Consortium, a research project sponsored by the Federal Ministry for Economic Affairs on the AI innovation competition, he gained his first experience with the use of AI-supported systems in the healthcare system in 2020 – long before ChatGPT became public.

EVA STUMPE

Eva Stumpe is a lawyer and entrepreneur. As the mother of an adult daughter living with a rare genetic neuromuscular disease, she has been a volunteer nationally and at European level as a patient representative for more than 20 years. Up to now, her focus has been primarily on patient advocacy in the area of research, development and approval of new drug therapies. Since 2023, she has been part of the Roche Patient Council. By collaborating on this white paper on shared decision making and AI, she was able to bring in the patient perspective of people affected by rare diseases.

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As a specialist in neurology and psychotherapy, Alexandra Widmer combines clinical expertise with in-depth knowledge of digital health applications (DHAs). She actively uses digital solutions in patient care, has contributed to the development of several applications and supports companies in the successful introduction of digital innovations in healthcare. She is the founder of the docsdigital platform, which introduces doctors to practice-oriented digital tools for everyday clinical practice. Through the associated podcast and videocast, she brings innovative doctors together with health tech companies, creating a bridge between practice and digital innovation.

NELE VON HORSTEN

Nele von Horsten, née Handwerker, is a patient representative and media studies graduate and is writing her master's thesis for her degree in multiple sclerosis management studies on patient education. With her podcast and blog of the same name, MS-Perspektive (MS perspective), she informs those affected by the disease about how a full and self-determined life with the disease can be managed in the best possible way. Nele von Horsten has lived with a diagnosis of MS for over 20 years and brings her personal and accumulated experience as a speaker and advisor to the MS community. A specific example is the Roche Patient Council, where she has represented the perspective of those with by MS since 2024.

CARSTEN WITTE

Carsten Witte is a health educator and psycho-oncologist at the Centre for Radiotherapy in Freiburg. There, he advises patients on social law issues and provides psycho-oncological support – even after the treatment period. In addition, he is a volunteer as the Director of Jung und Krebs e.V. (Young and Cancer Association), which he founded and which supports young adults with and after cancer. As a patient advocate, he also advocates for more holistic healthcare and has been part of the Roche Patient Council since 2023.

SUMMARY

How AI revolutionises shared decision making in medicine

This white paper shows how artificial intelligence (AI) can support patients to take a more active role in treatment decision making. It shines a light on opportunities and challenges and provides concrete examples of how AI tools can improve shared decision making (SDM).

The integration of AI into medicine is opening up new opportunities for making informed treatment decisions. AI can provide medical information in an understandable way, help patients prepare themselves specifically for medical consultations and support doctors with a structured summary of relevant data. AI can provide an individually customised basis for decision making by taking into account clinical studies, research results and personal preferences. This is particularly valuable, as many patients often do not know which questions to ask or which factors are important for their treatment.

Are you curious?
Why not try it yourself? Share your experience with AI at #KI4patients on Instagram, TikTok or Facebook.

One illustrative example is the case study of Ms Müller, a passionate gardener with osteoarthritis of the knee. Originally, she planned to have a knee replacement without being aware of the long-term limitations. It was only through specific enquiries by her doctor that she realised that her actual goal was mobility in order to be able to garden. AI can help by asking relevant questions before the medical consultation, recording patient preferences and proposing personalised treatment options. It can also make complex medical situations easier to understand visually, so that patients can better understand their options.

This white paper makes it clear that AI can alleviate the burden on both patients and doctors by taking on routine tasks and creating valuable time for individual advice. At the same time, the use of AI raises ethical and legal questions, especially with regard to data protection, transparency and the preservation of patient autonomy. It is important that AI is not understood as a substitute for medical expertise, but as a supportive tool that enables informed and patient-centred decision-making.

Why this white paper is important

It provides practical guidelines for patients and patient organisations to enable them to immediately begin using AI tools in a meaningful way. AI can be used to provide comprehensive information for those who are faced with a health decision and prepare them as well as possible for conversations with their doctor. Read the entire white paper to learn how AI can support your treatment decision!

INTRODUCTION

History and background: How this white paper came about

This white paper is the result of close collaboration between the members of the Patient Council of Roche Pharma AG, which includes seven experienced patient representatives, as well as various experts from the healthcare sector and the technology industry.

Roche aims to prioritise people living with a disease and their needs. The Roche Patient Council was founded in 2023 to work together on strategically relevant topics such as early involvement of patients in clinical trial planning, the benefits of digitalisation for patients and accessibility in everyday work, and to find specific solution approaches to existing challenges.

One of the key questions asked by the Roche Patient Council was: how can the current rapid developments in artificial intelligence (AI) support patients and their care team in making informed decisions about their treatment and how to manage the disease?

To shed light on this question, the patient experts first conducted qualitative interviews with patients, relatives and healthcare professionals. The aim was to better understand how shared decision making [→ SDM, see Section 2] is currently implemented in the German healthcare system and what the challenges are for patients. The knowledge gained was consolidated and discussed in an interactive design

thinking process together with doctors, nurses and AI experts with the participation of the Hasso Plattner Institute d-school. Building on the prioritised “pain points”, the participants then developed possible solution approaches. The focus was on how AI can support patients in participatory decision making and overcome existing barriers.

One key takeaway from these discussions was that many of the challenges faced by patients and their families today could already be addressed using existing AI tools. However, knowledge of these tools and the expertise required to use them wisely are often lacking – even as the technology is rapidly evolving.

This dynamic affects not only patients and their environment, but also doctors, medical professionals, decision-makers in the healthcare system and the general public. This is because the integration of AI into healthcare can make a significant contribution to promoting informed treatment decisions, facilitating administrative processes and improving the quality of care in the long term.

In order to meet this need, the expert panel finally decided to pool the knowledge collected in the process and make it available to a broader audience as a white paper. The aim is to give patients and patient organisations better access to relevant information and to raise awareness among healthcare professionals and public health policymakers about the opportunities, challenges and reasonable use of AI in the SDM.

However, it must not be overlooked that SDM can only succeed in the healthcare system in close cooperation between all participants. In particular, doctors, nurses and therapists play a key role here. Although the white paper initially focuses on the perspective of patients and their options for action, it is essential that all stakeholders assume their responsibility and actively practise shared, participatory decision making.

Roche provided the platform for exchange and discussion and supported the organisational development of this white paper. The authors expressed their personal views in this context and were not compensated for their contributions. ●

SECTION 1

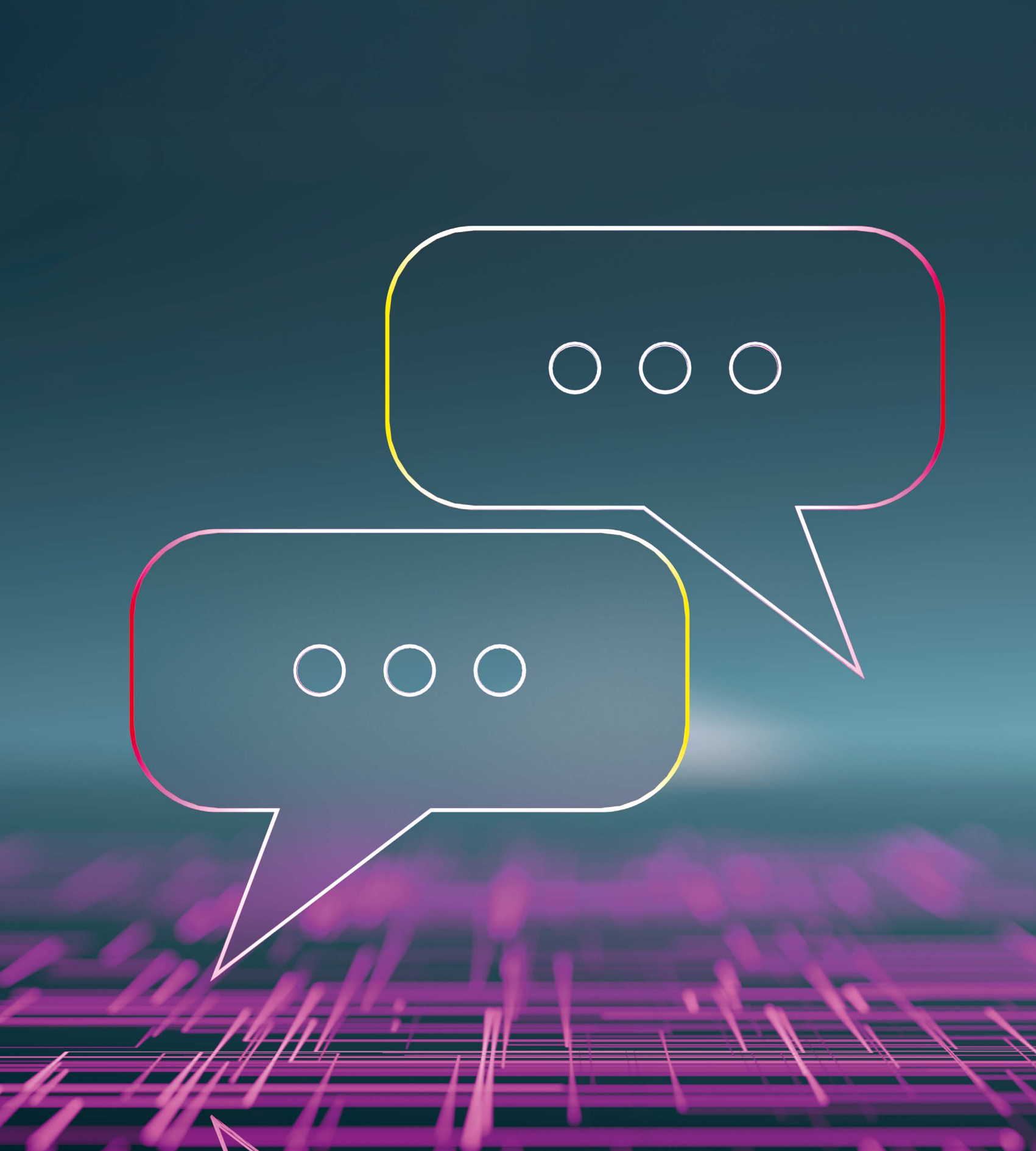
Practical tips on using AI in shared decision making

↗ see glossary: SDM

↗ see glossary: Large language models (LLM)

Shared decision making ([↗]SDM) is becoming increasingly important in the healthcare sector because patients want to be more involved in the decision-making process. At the same time, **large language models (LLMs)**[↗] – meaning AI systems like ChatGPT [https://chatgpt.com] – offer new ways to present knowledge quickly and so that it is easy to understand.

In this chapter, you will learn how LLMs can help to inform patients, support doctors in their research and strengthen both sides in dialogue. We will address **opportunities, risks** and **examples** and show how this technology can be used **responsibly** to improve patient care.



Basics: What are LLMs and why are they relevant for SDM?

An overview of large language models (LLMs)

LLMs are AI systems that have been trained on the basis of large amounts of text. They can create humanlike answers, translate texts, create summaries and explain complex facts in simple language. Some of the most well-known LLMs include OpenAI's ChatGPT.

With their ability to deliver information quickly and make complex content easily accessible, LLMs are an outstanding source of support for patients and doctors alike. In the best-case scenario, they supplement personal contact: patients can obtain information in advance and doctors gain more time for empathetic conversation.

Potential opportunities

- **Faster orientation:** patients and doctors can quickly receive an initial assessment of treatment options, symptoms or study results.
- **Overcoming language barriers:** translation functions and explanations in understandable language facilitate communication, including for those who speak a foreign language or who are less well-versed in medicine.
- **Targeted preparation:** LLMs can help structure information and collect relevant questions so that patients can prepare specifically for visits to the doctor.

Key risks

- **Data protection:** personal data (name, date of birth, exact address details) should never be entered in publicly available AI systems.

- **Hallucinations[↗] or misinformation:** LLMs often sound compelling but can still make false statements or rely on outdated information.
- **No substitute for healthcare professionals:** only doctors and qualified medical personnel make diagnoses and prescribe treatments. LLMs are a tool of support, no more, no less.

↗ see glossary: Hallucinations

Methodological notes: Handling LLMs in healthcare

Data minimisation and anonymisation

As patient data is particularly sensitive, it is advisable to remove any personally identifying characteristics (e.g. name) from texts before transmitting them to a freely accessible LLM. When working with highly sensitive information, you should check if there are any dedicated, **data protection-compliant** AI solutions that operate locally or in an appropriately secured environment.

Effectiveprompting

A “prompt” is the request you make to the LLM. For comprehensible, helpful answers, consider the following tips:

1. **Precise questions:** “Explain type 2 diabetes to me in simple words” is better than “Tell me about diabetes”.

2. **Provide context:** “Write a summary for a person who has never heard of epilepsy” or “Translate the following section into Turkish” helps the AI answer in more detail.

3. **Review results critically:** Read the answer carefully and, if in doubt, check with your healthcare professional or medical guidelines.

Review and validation

LLMs do not replace medical or scientific expertise. Patients should **make a note of** important points and bring them into the conversation with doctors, while doctors should always compare their research results from LLMs with official studies, specialist journals or databases.

Specific application examples for patients

Preparing for the doctor's visit

- **Example:** you can use AI to structure your symptoms and relevant information to make the conversation with your doctor more efficient. You want to compile a list of your symptoms and make sure you do not forget anything when you see the doctor. **Tip:** record the duration, frequency, intensity and possible triggers of your symptoms.
- **Prompt:** "Please help me summarise my symptoms and medical history for the next doctor's appointment. What information is most important?"
- **Result:** a structured overview of symptoms, pre-existing conditions and relevant data that will make your visit to the doctor more efficient.

Explanations in simple, comprehensible language

- ➜ **Example:** you receive a doctor's letter containing complex medical terms.
  Tip: ask specifically for individual terms and request an example to illustrate them; anonymise any form of personal identifiable information before entering it.
- ➜ **Prompt:** "Please translate the following doctor's letter into easily comprehensible language so that even laypersons can understand the content. Please explain any medical terms and present the text in a clear and structured way: `[insert text]`."
- ➜ **Result:** a translation of the terms into easily comprehensible language.

Replace the text in square brackets (including the brackets) with your own input.

Explanations in another language

- ➜ **Example:** you have a discharge letter in German and would like to make it understandable for a Ukrainian relative. In doing so, you will not provide any personal identifying information such as name, address etc.
- ➜ **Prompt:** "Please translate the following medical text into Ukrainian. Use easy-to-understand language: `[text]`."
- ➜ **Result:** a rough (anonymised) translation that conveys the basic content. If anything is unclear, you should consult a native speaker or expert.

Consideration of treatment options

- ➜ **Example:** you are considering whether you want to have surgery for a disease or would rather choose a drug therapy.
  Tip: find out the pros and cons of both options, including side effects and likelihood of success.

- **Prompt:** “What factors should I consider when deciding between drug therapy and surgery? What are the advantages and disadvantages of surgery and drug therapy?
  I have `[diagnosis X]`.”
- **Result:** An initial overview of advantages and disadvantages, possible side effects and general questions you could ask during the doctor’s appointment. It is important to have the result verified again by the doctor and to never make a decision based on the AI overview alone.

Treatment options at a glance

- **Example:** a person is looking for different treatment options for a disease.
  Tip: obtain an explanation of the available treatment approaches with modes of action and typical side effects. Find out more about the form of administration, the treatment interval and how easy it is to integrate into everyday life.
- **Prompt:** “What treatment options are available for `[disease or symptom X]`? Take into account the form of administration, the treatment interval and how easy it is to fit into everyday life.”
- **Result:** an initial overview of drug, surgical and alternative therapy options as well as their areas of application, form of administration, treatment interval and ease of integration into everyday life.

Comparison of treatments:
Patients want to better understand different treatment options and make informed decisions.

- **Example:** I want to compare an existing treatment with an alternative treatment method.
  Tip: obtain an explanation of the differences in terms of mechanism of action, mode of administration, side effects and prospects of success.

- ➔ **Prompt:** “What differences are there between `[treatment A]` and `[active ingredient B]`? What do I need to know as a patient about efficacy and safety?”
- ➔ **Result:** a comparison of the two treatment approaches with important factors for decision making.

Overview of patient services

- ➔ **Example:** you have been prescribed a specific treatment and would like to ask what additional services are available for these patients.
- ➔ **Prompt:** “What additional support services are available for patients with `[disease/treatment]` in Germany?”
- ➔ **Result:** an overview of available patient services (e.g. information materials, digital support, hotline etc.).

Note: it is advisable to tell others (e.g. patients, doctors or readers) that an LLM has helped to obtain information or write text. This makes it clear which sources are behind the statements and allows for an honest approach to potential errors or uncertainties.

`[→ See section 7 to find out more about the legal aspects of implementing AI-supported shared decision making.]`

Searching for clinical trials for possible participation

- ➔ **Example:** in the event of a lack of and/or insufficient treatment options, it can be helpful to ask whether there is an ongoing clinical trial you could join. But how can you find clinical trials for your area of disease in which you can participate?
  Tip: if you use AI search systems such as ChatGPT or specialised platforms such as ClinicalTrials.gov, you can use the same prompts and add additional filters if necessary.

- ➜ **Prompt:** “Find current clinical studies on [disease] in Germany or Europe. The studies should be in the recruitment phase and suitable for patients with [stage of the disease, e.g. metastatic breast cancer]. Search in trusted trial registries like ClinicalTrials.gov, the EU Clinical Trials Registry*, or DRKS**. If available, provide guidance on how patients can register for the studies or receive further information.”
- ➜ **Result:** an overview of contact points for available studies in Europe. This will allow you to find suitable clinical trials related to your disease and make informed decisions on participation together with the healthcare professionals.

* www.clinicaltrials-register.eu

** www.drks.de

Note: the studies mentioned are examples and are not intended to be exhaustive. Currently, there are no specific AI-supported platforms for patients to find clinical trials. However, work is being done to develop AI technologies that can support patients in finding suitable trials. Until such solutions are available, we recommend that you use the above-mentioned resources and seek advice from healthcare professionals.

Specific use cases for doctors and professionals

Researching and comparing treatments

- ➜ **Example:** you would like to know what treatment options exist for a specific indication and would like to gain a brief overview.
- ➜ **Prompt:** “What treatment options are available for [disease X] and how do they differ in terms of efficacy and side effects?”
- ➜ **Result:** an initial summary that doctors should subsequently validate through their own literature research or experience.

New medicines and study data

- ➜ **Example:** you want to know which new drugs have been approved for an indication.
- ➜ **Prompt:** “What are the latest approved drugs or treatments for `[indication Y]` and how does `[product name]` compare to other treatments?”
- ➜ **Result:** a rough overview of recent developments, which may need to be complemented by databases (e.g. PubMed, EMA websites).

Note: AI models for clinical decision support are still under development. The website `www.openevidence.com` is currently very helpful for this purpose.

Usefulness for clinical discussions

- ➜ **Example:** you are facing the question of which treatment is particularly suitable for patients with certain risk factors.
- ➜ **Prompt:** “What medications or treatments are particularly useful for older patients with `[disease Z]`? Please state your sources. Can you include `[product name]` in the comparison?”
- ➜ **Result:** an AI-generated assessment that serves as the basis for discussion for the interdisciplinary team or in case discussions.

Note: AI models for clinical decision support are still under development. The website `www.openevidence.com` is currently very helpful for this purpose.

Particular advantages of a product

- ➜ **Example:** you want to identify the best tolerated drug with the simplest dosage for your patients with chronic disease. **Tip:** pay attention to aspects such as frequency of intake, side effects and the handling of medication in everyday life
- ➜ **Prompt:** "What are the differences between `[active ingredient A]` and `[active ingredient B]` in terms of efficacy, tolerability and use in patients with `[disease Z]`? What factors influence the choice between different treatment options for `[disease Z]`, especially with regard to dosage, administration and patient preferences?"
- ➜ **Result:** a detailed comparison of the two drugs with regard to efficacy, tolerability, side effects profile and ease of use for patients. Doctors receive scientific and evidence-based information on relevant criteria with a focus on individualised treatment decisions without direct product advertising.

Notes:

- ➜ AI models for clinical decision support remain in development. The website `www.openevidence.com` is currently very helpful for this purpose.
- ➜ Strict rules apply in particular to medicines and their presentation, e.g. the German law on advertising in the healthcare sector (Heilmittelwerbegesetz) **(HWG)** or European guidelines on the advertising of medicines. For example, the HWG prohibits advertising of prescription drugs to laypersons as well as misleading or unobjective advertising statements to ensure the protection of patients and an independent medical therapy decision. Anyone using LLMs to obtain product information on certain medicinal products should be aware that LLMs do not comply with these laws. Therefore, product claims should be carefully reviewed.

New trends and innovations

- **Example:** you want to find out about the progress of a particular disease group before you delve deeper into the literature.
- **Prompt:** “What progress has there been in the treatment of `[indication X]`? Are there any new drugs or products such as `[product name/drug substance]` that stand out from previous treatments?”
- **Result:** a condensed summary, which should then be further supported by specialist publications.

Patient-centred communication

- **Example**: you want to understand which treatment options best fit the needs of a specific patient group.
- **Prompt:** “Which treatment option is best for `[Group A patients, e.g. children or elderly people]` with `[X disease]`? Can you include `[product name]` in the comparison?”
- **Result:** An AI-based list of considerations that can be incorporated into patient information in compliance with laws (e.g. the German law on advertising in the healthcare sector).

Are you curious?
Why not try it yourself? Share your experience with AI at #KI4patients on Instagram, TikTok or Facebook.

Conclusion

The **example prompts** shown here illustrate how diverse the potential of AI is in shared decision making, without replacing the human factor. However, it remains important that AI applications are always scrutinised critically, used in a way that ensures privacy and are not regarded as a replacement for healthcare professionals. By using the technology **responsibly**, SDM can be taken to a new level: patients become more confident in their decision making and doctors gain more time for patient-centred communication and empathetic conversation. Together, all parties involved can benefit from having access to relevant information made easier.

However, it is not only up to doctors or the healthcare system to advance SDM – patients also play an active role. They can help to increase the use of SDM by directly reaching out to their doctors and requesting information about all possible treatment options. They can then compare this information with their own preferences and needs and discuss it with their doctors. In addition, patients themselves are also responsible for learning the right way to use AI-based tools. One decisive factor, for example, is entering the correct “prompt”, which ensures that relevant information can be collected and used in a structured manner even before a doctor’s appointment. Through this active participation, SDM can be integrated more effectively into everyday medical practice and the quality of decision making can be sustainably improved. ●

SECTION 2

Opportunities and challenges for shared decision making in medicine

Lead author: Dr Sven Jungmann

A profound change has been observed in modern medicine over the past few decades: patients are increasingly being recognised as active partners in the treatment process. The concept of shared decision making (SDM) is a central approach that brings patients and doctors together as equals. This approach has been discussed in the medical community since the 1970s. [01] But what is behind SDM? Why is it so important, what methods are used and what challenges do we face in broad implementation?

01 Veatch RM. *Models for Ethical Medicine in a Revolutionary Age*. The Hastings Center Report. Vol. 2, No. 3 (Jun., 1972), pp. 5-7. https://doi.org/10.2307/3560825

What is shared decision making?

Although there is no uniform definition internationally, there is a wide consensus that SDM is a partnership process in which patients and doctors make medical decisions together. Both sides contribute their respective expertise:

- ➜ **Patients** contribute their personal values, preferences and circumstances.
- ➜ **Doctors** share their medical expertise as well as their experience.

The goal: an informed decision that makes sense medically and meets the patient's individual needs.

In principle, SDM can be used in almost any situation and in almost all medical decisions – especially if personal preferences play a role and there are several options for action with various advantages and disadvantages. Exceptions are acute emergencies, in which, for example, patients are no longer responsive or rapid action is necessary. This also applies to situations in which patients can no longer make their own decisions due to a long-term limitation of their decision-making ability – such as due to dementia or other neurodegenerative diseases. In such cases, medical decisions must be made taking into account advance directives, the assessment of relatives or legal caregivers and medical professionals. However, studies show that SDM can be successful even in situations with severely ill patients.[02]

02 Noteboom EA, May AM, van der Wall E et al. *Patients' preferred and perceived level of involvement in decision making for cancer treatment: A systematic review.* Psychooncology 2021; 30(10): 1663–1679. https://dx.doi.org/10.1002/pon.5750.

The problem of “silent misdiagnosis” [↗]

↗ see glossary: Silent misdiagnosis

Studies suggest that there may be differences between doctors’ assumptions about their patients’ wishes and their actual preferences.

➜ **Example from Great Britain:** doctors were convinced that 71% of breast cancer patients rated breast preservation as their top priority – in fact, only 7% did.[03]

Such discrepancies can lead to patients receiving treatments that do not meet their needs or values. This is often overlooked because patients do not dare to express their personal wishes or are unaware that there are alternatives. For ethical reasons alone, they need the freedom to actually request options based on their preferences – after all, it is their bodies and their lives.

03 Lee CN et al. *Development of instruments to measure the quality of breast cancer treatment decisions. Health Expectations.* 2010; Vol. 13, No. 3, pp. 258–72. doi:10.11 11/j.1369-7625.2010.00600.

Two fictitious examples to explain shared decision making

MARTIN JÜRGEN’S STORY

Part 1: A journey together

Mr Martin Jürgens, 65 years old and a retired teacher, has an active life: he enjoys hiking, plays tennis and volunteers in his community. During a routine examination, he is diagnosed with early-stage prostate cancer. Suddenly he is struck with fear, uncertainty and disbelief.

His doctor, Dr Schweigmüller, picks up on his anxiety and sits down next to him instead of at her desk. She explains that his tumour is localised and slow growing. She then introduces various guideline-compliant treatment options – from active monitoring to radiotherapy and prostatectomy (removal of the prostate) to hormone therapy – and explains their respective advantages and disadvantages.

Mr Jürgens expresses his fear about possible side effects that might limit his independence. Together, they discuss all options and agree on their personal preferences. They talk about what is most important to him in everyday life, such as staying mobile and independent. Finally, they agree on active surveillance with the option of reacting later should anything change during the course of the disease. When Mr Jürgens leaves the office, he feels heard, well informed and involved in the decision making process.

Part 2: A lonely journey

In an alternative scenario, Mr Jürgens receives the same diagnosis. This time, he meets Dr Steinbach, whose demeanour is matter-of-fact and aloof. Without any prior information, Dr Steinbach briefly explains that surgery to remove the prostate is necessary. He reacts evasively or curtly to the patient's questions. There is no mention of any alternatives.

Mr Jürgens feels insecure, but says nothing and agrees to the surgery. Subsequently, complications occur that he had not expected: incontinence affects his self-confidence and he withdraws from social activities. Later, he learns of an acquaintance who has opted for active surveillance. "So that would have been possible too?" he asks himself in frustration. He loses trust in his treating physicians and does not go to follow-up appointments.

Are you, like Mr Jürgens, facing an important health decision? In our "Practical tips" section, you will learn how AI can help you prepare for the conversation with your doctor and make a decision together that is right for you.

MARTA-LISAGRABOWSKI'SSTORY

Part 1: A good basis for making an informed decision

Marta-Lisa Grabowski is 29 years old when she feels a lump in her breast. She immediately contacts her gynaecologist, Dr Meyer. After further investigations, it is clear that this is an invasive tumour; a genetic test shows that Marta-Lisa Grabowski would benefit from chemotherapy. After her doctor tells her the news, the young woman is in shock. Dr Meyer takes her time and goes through various statistics with Marta-Lisa that show the impacts of her therapy decision.

Dr Meyer explains to Ms Grabowski the origins of the statistics, the data basis and answers all her questions about possible risks, possible side effects and long-term effects. The subject of wanting to have children is also discussed during the conversation, and Dr Meyer is also able to point out possible solutions in this regard too. The doctor does not pressure her to decide immediately – she gives her patient the opportunity to contact her with any questions. Marta-Lisa Grabowski gives herself a few days to think about things – she has been given all the information.

When she gets home, she searches the internet and finds a video on TikTok that presents cold wraps as an equivalent to her recommended therapy, but without the side effects. She sends the video to Dr Meyer, who classifies it as false information without a scientific basis. Marta-Lisa Grabowski decides in favour of the recommended therapy with full conviction.

Part 2: Social media and alternative facts

In an alternative scenario, Marta-Lisa Grabowski is given the same diagnosis. Her doctor Dr Jungblut opens the discussion with the statement: "You have to have chemotherapy, that is the only thing makes therapeutic sense in your case" – and begins to explain the treatment process to her patient. Marta-Lisa Grabowski is in shock and is unable to talk about her desire to have children. She feels overwhelmed. Arriving home, she goes on social media and finds videos that present cold wraps as an equivalent to her recommended

therapy, but without the side effects – she dives in and finds lots of short videos on alternative options. She can order some recommended herbs directly on the internet. She decides not to see Dr Jungblut again and to take the matter into her own hands. What she does not take into account is that not pursuing treatment in accordance with guidelines can significantly influence the course of the disease and increase the risk of complications.

Are you, like Marta-Lisa Grabowski, facing a medical decision and wanting to prepare yourself as much as possible for the discussion with your doctor? Our "Practical tips" section shows how AI can help structure your questions and make the most of your medical consultations.

Lessons from both stories

The different course of events illustrate the tremendous impact that patient-centred communication has on treatment and quality of life.

- ➜ **Empowerment through information:** in the first scenario, Mr Jürgens gets all the information he needs to make an informed decision.
- ➜ **The value of listening:** medical advice that also considers fears, values and life circumstances increases satisfaction and adherence to treatment.
- ➜ **Consequences of inadequate communication and patient involvement:** without proper dialogue and explanation, sub-optimal or undesirable treatment pathways can occur, with possible negative consequences for health and well-being.
- ➜ **Trust and relationship level:** SDM fosters a trust-based relationship between doctors and patients. In the absence of SDM, patients may doubt the medical decision, regret the procedure and likely avoid future treatments.

- **Social media and health literacy:** in the age of social media, patients are exposed to a particularly large amount of unchecked information. Lack of health literacy and trust can influence treatment decisions to their detriment.

Thenuancesof shareddecision making

These stories show that there is no one size fits all when it comes to medical decisions. They involve a complex interplay of clinical insights, patient values and lifestyle considerations.

- **Beyond medical facts:** while clinical expertise is critical, understanding a patient's personal circumstances can significantly affect the appropriateness of a treatment.
- **Emotional well-being:** coming to terms with anxiety and worries is as important as treating physical complaints. Emotional support can improve overall outcomes.
- **Patient autonomy:** when patients are involved in the decision-making process, they are more likely to be satisfied with their treatment and stick to the treatment plans.
- **Preventing regret:** successful SDM will prevent future regret by ensuring patients are fully informed about possible outcomes and side effects and have their preferences included in treatment planning.

Why is SDM important

SDM is not just an additional option – it is an important building block of modern, patient-centred medicine. SDM also meets the requirements of the Patient Rights Act[04] [↗]. This stipulates that patients must be fully informed about the disease and treatment options so that they can actively participate in their recovery. The method has many advantages:[05,06,07,08]

1 **Patient empowerment:** enables patients to actively participate in decisions by discussing the risks and benefits of different options, leading to a better sense of control over their health.

2 **Improved communication:** promotes a more open dialogue between patients and doctors and ensures a better understanding of patients' concerns and values.

3 **Higher satisfaction:** patients feel that they are taken seriously and respected. This not only improves the relationship with the treatment team – it also increases trust in the healthcare system as a whole.

4 **Greater adherence to treatment:** when patients are involved in decision making, they are more likely to adhere to treatment plans.

5 **Reduction of "silent misdiagnoses":** doctors often mistakenly suspect that they know what their patients want without actually asking about and taking into account their personal preferences. SDM reduces such misjudgements.

↗ see glossary: Patient Rights Act (Patientenrechtegesetz)

04 Act to Improve the Rights of Patients (Gesetz zur Verbesserung der Rechte von Patientinnen und Patienten) (§630c-h BGB) [online]. 2013 [accessed 05/01/2022]. URL: www.bgbl.de.

05 Mulley A et al. (2012). *Patients' Preferences Matter*. The King's Fund. https://cupfoundjo.org/wp-content/uploads/2014/10/patients-preferences-matter-may-2012.pdf

06 Veroff D, Marr A, Wennberg DE. *Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions*. Health Aff (Millwood) 2013; 32(2): 285-293. https://dx.doi.org/10.1377/hlthaff.2011.0941; Grote Westrick M, Volbracht E. *Überversorgung – Ausmaß, Ursachen und Gegenmaßnahmen [Overuse – Extent, Causes and Countermeasures]*. GG+W 2020; 20(2): 7-15; Decary S, Zadro JR, O'Keeffe M et al. *Overcoming Overuse Part 5: Is Shared Decision Making Our Excalibur?* J Orthop Sports Phys Ther 2021; 51(2): 53-56. https://dx.doi.org/10.2519/jospt.2021.0103; Shepherd HL, Barratt A, Trevena LJ et al. *Three questions that patients* ▶

6 **Reducing overuse and underuse:** a fact-based assessment of treatment options in the context of individual needs can minimise unnecessary or unwanted interventions.

7 **Less anxiety:** by providing clear information and awareness of concerns, shared decision making can ease the anxiety associated with medical decisions over the long term.

8 **Reduced legal conflicts:** shared decision making can result in a reduction of litigation.

9 **Greater satisfaction of the care team:** if patients are well informed and actively participate in discussions, this can lead to a more positive experience and increased satisfaction for doctors, nurses and therapists.

Approaches to implement SDM

To establish shared decision making in everyday practice in a sustainable manner, various measures that address both health care personnel and patients[09] are useful:

1 **Training and education:** Doctors and nurses should be specifically trained in patient-centred communication and SDM techniques. These include active listening, open-ended questioning techniques and conveying medical information in a way that patients can understand. These training sessions should be integrated into medical and nursing training and be offered regularly in continuing education and further study.

can ask to improve the quality of information physicians give about treatment options: a cross-over trial. Patient Educ Couns 2011; 84(3): 379-385. https://dx.doi.org/10.1016/j.pec.2011.07.022; Elwyn G, Frosch DL, Kobrin S. *Implementing shared decision-making: consider all the consequences.* Implementation Science 2015; 11(1): 114. https://dx.doi.org/10.1186/s13012-016-0480-9.

07 Schoenfeld EM, et al. *The Effect of Shared Decision-Making on Patients' Likelihood of Filing a Complaint or Lawsuit: A Simulation Study.* Ann Emerg Med. 2019;74(1): 126-136. doi:10.1016/j. annemerg-med.2018.11.017.

08 Slade M. *Implementing shared decision making in routine mental health care.* World Psychiatry. 2017 Jun;16(2):146–153. doi: 10.1002/wps.20412. PMID: 28498575; PMCID: PMC5428178.

09 Stiggelbout AM. *Shared decision making: Concepts, evidence, and practice.* Patient Educ Counts. 2015;98(10): 1172–1179. doi:10.1016/j. pec.2015.06.022.

They can be given by professional medical societies, universities, hospitals or independent training institutes.

2 **Development of decision-making aids:** patient brochures, online portals and apps can help to clearly show the advantages and disadvantages of various treatment options.

3 **Promoting health literacy:** patients should be encouraged to find out information about their disease and to ask specific questions. Improved health literacy levels support effective shared decision making. This should also enable them to classify information that they find on social media, for example.

4 **Adaptation of care structures:** practice and clinic procedures should be designed in such a way that there is sufficient time for consultation and discussions – for example, through longer appointment times or special consultation services.

Challenges with the broad implementation of SDM

Despite the many benefits of SDM, there are hurdles that hamper widespread, sustainable implementation: [10,11,12]

- **Patient related**
  - Lack of health literacy or understanding of medical information
  - Poor ability to make decisions in specific situations
  - Conscious rejection of an active role in decision making

- **Service provider related**
  - Time pressure during appointments and awareness that SDM means additional work (even if studies suggest that SDM does not necessarily require more time)
  - Lack of training in SDM techniques
  - Discomfort when uncertain or discussing multiple treatment options
  - Believe they are the “expert” and should make the decision

- **System related**
  - Lack of organisational support for SDM practices
  - Inefficient electronic medical records to facilitate SDM
  - Remuneration structures that do not provide incentives for SDM
  - Complex clinical situations with limited evidence-based options
  - Lack of resources for training and decision support

10 Muscat DM et al. *Equity in Choosing Wisely and beyond: the effect of health literacy on healthcare decision-making and methods to support conversations about overuse.* BMJ Qual Saf. 2024 Aug 22:bmjqs-2024-017411. doi:10.1136/bmjqs-2024-017411. Epub ahead of print. PMID: 39174336.

11 Elwyn G et al. *The limits of shared decision making.* BMJ Evid Based Med. 2023 Aug;28(4): 218- 221. doi: 10.1136/bmjebm-2022-112089. Epub 2022 Dec 15. PMID: 36522136; PMCID: PMC10423476.

12 Moleman M et al. *Shared decision-making and the nuances of clinical work: Concepts, barriers and opportunities for a dynamic model.* J Eval Clin Pract. 2021 Aug;27(4): 926-934. doi: 10.1111/jep.13507. Epub 2020 Nov 8. PMID: 33164316; PMCID: PMC8359199.

Conclusion

Shared decision making is a key step towards truly patient-centred medicine. When patients and doctors work together and make medical decisions together based on clinical facts and personal preferences, treatments become more individual, comprehensible and successful.

Recent developments in the field of artificial intelligence (AI) open up new opportunities to overcome existing obstacles and implement SDM more widely in practice. This could help to develop personalised decision support and alleviate the burden on healthcare professionals by automating time-consuming routine tasks. However, as is customary in evidence-based medicine, these innovations require systematic, transparent and reproducible scientific validation. The ideas presented here are therefore to be regarded primarily as suggestions and recommendations.

AI can be used with natural language and thus help to translate even complex medical topics in an understandable way for laypersons. AI applications offer the opportunity to integrate the largest and often unused resource of healthcare – the patients themselves – into the medical decision-making process and treatment process in a standardised manner.

Collective decision-making offers a great opportunity, especially in times of rapid technological progress, to prevent what are known as “silent misdiagnoses” and to really put the focus on patients. ●

Literature recommendations

An article on shared decision making as a treatment method [English]: https://ebm.bmj.com/content/28/4/213

An interesting series from the British Medical Journal on the theory and practice of shared decision making [English]: https://ebm.bmj.com/pages/shared-decision-making-and-evidence-based-medicine

An interesting approach to informing patients with fact boxes from the Harding Center: www.hardingcenter.de/de/transfer-und-nutzen/faktenboxen

Rummer A, Scheibler F. *Informierte Entscheidung als patientenrelevanter Endpunkt [Informed decision as a patient-relevant endpoint]*. Dtsch Arztebl Int 2016; 113(8): A322–A324. https://dx.doi.org/10.3238/arztebl.2016.0299b.

Geiger F, Hacke C, Potthoff J et al. *The effect of a scalable online training module for shared decision making based on flawed video examples – a randomized controlled trial*. Patient Educ Couns 2021; 104(7): 1568–1574. https://dx.doi.org/10.1016/j.pec.2020.11.033.

Schuldt A, Kuch C. *Projekt im hohen Norden: Pflegskräfte als Decision Coaches [Project in the far north: Caregivers as decision coaches]*. Pflegezeitschrift 73: 10–12.

Stacey D, Legare F, Lewis K et al. *Decision aids for people facing health treatment or screening decisions*. Cochrane Database Syst Rev 2017; 4: CD001431. https://dx.doi.org/10.1002/14651858.CD001431.pub5.

Danner M, Geiger F, Wehkamp K et al. *Making shared decision-making (SDM) a reality: protocol of a large-scale long-term SDM implementation programme at a Northern German University Hospital*. BMJ Open 2020;10(10):e037575. https://dx.doi.org/10.1136/bmjopen-2020-037575.

Geiger F, Novelli A, Berg D et al. *Klinik-weite Implementierung von Shared Decision Making: Erste Ergebnisse des Kieler Innovationsfondsprojekts zum SHARE TO CARE Programm [Clinic-wide implementation of shared decision making: First results of the Kiel innovation fund project regarding the SHARE TO CARE programme]*. Dtsch Arztebl Int 2021; 118(13): 225–226. https://dx.doi.org/10.3238/arztebl.m2021.0144.

Examples of existing aids:

- ➔ https://washabich.de
- ➔ https://patientenbriefe.de
- ➔ https://share-to-care.de

SECTION 3

The current status of AI and what to expect in the near future

Lead author: Dr Stefan Ebener

We are living in a time characterised by great technological strides that are encompassing and changing all areas of our lives. The way in which we work, communicate and collaborate, what we see, believe and know. Technology is ubiquitous and also – or even in particular – has an ever-growing impact on medicine. It revolutionises healthcare in many ways, from diagnosis to treatment to prevention. Looking back over the past 10 years, the rapid progress of medicine is particularly visible: the use of gene therapy to fight hereditary diseases, the use of personalised immunotherapy, 3D printing for the manufacture of prostheses, implants and organs, robotic surgery, precision medicine, telemedicine and finally the use of AI for areas including drug development, diagnostic procedures and personalised medicine.

The complexity of modern medicine multiplied by the variety of treatment options already exceeds the capacity of the human mind

The increasing complexity due to modern diagnostics and the use of novel medical technologies is coupled with an ever-broader range of treatment options and is fuelled by the accelerating gain in knowledge from new studies, guidelines and the scope for decision-making in medication. AI is intended to address the growing challenges and to provide doctors and patients with decisive support in the process.

Artificial intelligence (AI) is a technology that is currently difficult to define, the core of which is to imitate complex human behaviour or, if necessary, go beyond it. AI contains a number of concepts that are sometimes used interchangeably, but differ in important ways in terms of how they can be used and their capabilities:

Machine learning (ML): ML algorithms learn from data to detect patterns and make predictions. Examples of ML systems used in industry include predictive maintenance (PM) to prevent machine failures and quality control to identify defective products. In medicine, ML is used in areas including the analysis of X-rays, CT scans and MRIs to detect abnormalities [↗] and to support diagnoses. Examples are the detection of tumours in mammograms, the identification of lung nodules in CT scans or the risk assessment of heart disease.

↗ see glossary: Anomaly detection

Deep learning (DL): DL is a subtype of ML that uses artificial “neural” networks with many layers. Inspired by how the human brain works, these networks consist of interconnected nodes (“neurons”) that process information. DL is particularly good at recognising complex patterns and correlations in large amounts of data, such as images or sensor data. In industry, DL is used for object detection in robotics, for example, or for the analysis of production data. In medicine, e.g.

radiology (analysis of abnormalities such as tumours, fractures and other anomalies), pathology (analysis of tissue samples to identify and classify cancer cells), ophthalmology (analysis of retinal images to detect diseases such as diabetic retinopathy and age-related macular degeneration at an early stage) or dermatology (analysis of skin lesions in the diagnosis of skin cancer).

Large language models (LLMs): LLMs use artificial neural networks, in particular deep neural networks with multiple layers (hence a subtype of DL), to process and generate language as a priority, and are consequently trained on the largest possible body of text. They are multilingual and multimodal [↗]. Multimodality is the ability to understand and create videos, images, music, or program code. In medicine, they are now used in obtaining and synthesising information (diagnosis and treatment planning), generating medical reports (findings, doctor's letters and other medical documentation), but also in accelerating medical research (development of new drugs and therapies, analysis of research data etc.).

↗ see glossary: Multimodal AI

LLMs represent a paradigm shift in AI development and justify the continued hype surrounding AI

This paradigm shift stems from the ability of LLMs to perform tasks sufficiently well, even without explicit training. This form of generalisation allows the transfer of knowledge to new tasks through a data-driven approach. The context of information can now be captured better, relationships between words in a sentence can be taken into account and complex relationships can also be understood. As a result of this new approach (based on the transformer architecture developed by Google in 2017, which subsequently resulted in ChatGPT), a completely new market was created with diverse, freely available and independent language models.

In terms of medicine, two important developments can be derived from this:

1 The development of specific medical language models that can support and partially automate the work of experts (whether outpatient or inpatient)

2 The sheer range of potential fields of expertise in which they can add value (cf. images and listing).

The former is mainly driven by big tech companies such as Google, Microsoft, Amazon, Apple, Meta and Alibaba. The following language models, for example, show interesting approaches with impressive results: MedLM (model for answering medical questions) [↗], AlphaFold-2 (21 million parameters[↗] for protein structure prediction – awarded the Nobel Prize in Medicine), Amazon Comprehend Medical (US health privacy-compliant pre-trained model for extracting medical information from unstructured medical text), BioGPT (pre-trained AI model for the creation and analysis of biomedical text), BioNeMo (Cloud API [↗], which expands LLM use cases beyond language to scientific applications to accelerate drug research) and GatorTron (the largest clinical language model, which was trained with the Megatron framework[↗]).

↗ see glossary: MedLM

↗ see glossary: Parameters

↗ see glossary: Cloud API

↗ see glossary: Megatron

Domain-specific language models will revolutionise medicine

Example of MedLM: the advanced language model can be regarded as a medical expert that helps to understand complex information and prepare it for medical professionals and patients. MedLM achieved

an impressive accuracy of 91.2% on the MedQA benchmark[↗] for medical exams, demonstrating its ability to answer United States Medical Licensing Examination-style questions (USMLE[↗]) at a level comparable to human experts. This high level of accuracy highlights its potential to revolutionise medical training and practice. In addition to the dialogue-based approach[↗], MedLM is also multimodal. This is particularly crucial because of the multimodal nature of medicine. The model can process and integrate information from various sources, such as images (X-rays, mammograms), electronic health records, sensors, wearable devices, genomics, skin, retina and pathology data. This comprehensive approach has the potential to significantly improve patient care by providing doctors with a holistic view of patient information. From the perspective of patients and doctors, MedLM enables detailed, precise yet understandable answers to health questions. In particular, doctors and patients in a study preferred the answers from the model to those from the doctors themselves, which illustrates the potential of the solution to improve patient communication about symptoms, treatments or drugs, for example, and to provide reliable medical information in a targeted manner. And that's not all – the skills go beyond diagnosis and information retrieval. By automating tasks such as drafting doctors' letters, analysing medical records and designing personalised therapy concepts, it has the potential to optimise clinical workflows, reduce the administrative burden on healthcare professionals and improve efficiency in healthcare facilities.

↗ see glossary: MedQA benchmark

↗ see glossary: USMLE

↗ see glossary: Dialogue-based

Today, medical language models and the specialised language models derived from them, such as MedLM, GatorTron or PubMedBERT, enable a number of application examples that are currently being worked on and researched. It should be emphasised here that this is by no means a general LLM (GPT[↗]).

↗ see glossary: GPT

Use cases of LLMs along the patient journey

- **Administrative tasks**
  Streamline tasks such as scheduling and referrals with AI.
- **Chatbots**
  Chatbots provide support for patient care and health coaching.
- **Medical understanding**
  Improve patient understanding and communication with AI.

Chatbots

- → Triage for decision support – patients with low urgency and severity of health condition and classic clinical pictures, forwarding to information, providers etc.
- → Treatment of chronic diseases – daily measures to support patients, using devices – and self-reported information
- → Health and well-being coaching – fitness/sleep chatbot
- → Companionship – in case of loneliness or for the mental health of older people
- → Adherence to medication intake – patient follow-up

Medical understanding

- → Patient understanding – review provider notes and convert language so that patients can understand and follow the next steps
- → Educate patients with in-depth content about their disease and treatment
- → Answer queries from patients knowledgeably

Administrative tasks

- → Personalised recommendations – suggestions based on patient preferences
- → Scheduling – appointment scheduling, analysis of the patient's insurance and the provider's schedule
- → Referrals – streamline referrals (e.g. find a nearby cardiologist who accepts the patient's insurance, and arrange follow-up care)

Improving medical efficiency

- **Reduction of documentation**
  Reduces the time doctors spend documenting cases with automated notes and error detection.
- **Clinical care**
  Improves patient care through summaries, anomaly detection and personalised healthcare.
- **Administrative tasks**
  Simplifies insurance approval and content creation.

Reduction in documentation effort (according to Ärzte-Monitor 2023, doctors spend an average of 132 minutes per day, i.e. just over 2 hours, on documentation tasks, which corresponds to about 24% of their total working time):

- → Visit notes – auto-complete and “voice to text” transcription
- → Creating case summaries and treatment plans – propose plans based on the effectiveness of previous treatments and the current problem
- → Error detection – detect errors directly in the doctors’ treatment plan

Clinical care

- → Patient summaries and clinical insights – automatically summarise clinically meaningful findings/ insights for treatment teams or doctors (e.g. to support with diagnosis or treatment)
- → Detect abnormalities in CT or MRI scans – detect abnormalities and notify doctors
- → Personalised healthcare – create personalised treatment plans for patients by considering their medical history, genetic information, symptoms and other factors

Administrative tasks

- → Pre-authorisation and reimbursement – create responses in line with insurers’ guidelines and patient records; standardised medical codes used globally to classify diagnoses and diseases
- → Content creation – training and marketing – quickly and easily generate new content (such as videos)

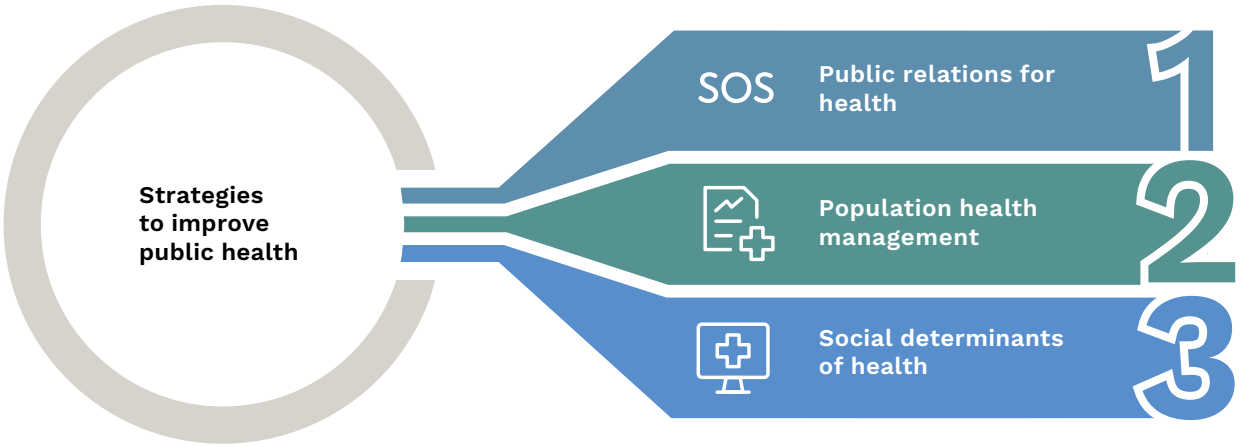
- **In silico testing**
  Computer simulation to evaluate efficacy
- **Synthetic data generation**
  Creation of AI modelling data
- **Recruitment campaigns**
  Targeted speech to participants
- **Personalised healthcare**
  Customising treatments to mitigate risk

Research and development support

- → Streamlined drug discovery and development – accelerated process by identifying potential drug candidates and testing their efficacy in silico (i.e. by using computer simulations) before starting clinical trials in animals and humans.
- → Synthetic training data – generate synthetic data to train and test AI models or simulate control populations in clinical trials
- → Clinical trial recruitment – develop effective recruitment campaigns (individual target identification, lead generation), screening and pre-sorting by reviewing inclusion and exclusion criteria
- → Personalised healthcare/treatment – early identification of potential harms to develop effective treatments

Exploring strategies to improve public health

- → Public health campaigns – develop effective public health campaigns (text, video, social media imagery, YouTube etc.) targeted to specific population groups (e.g. health literacy, cultural nuances).
- → Population health management – provide interactive interfaces for policy makers to couple databases (e.g. demographics, health) with environmental information (e.g. basic spatial models) and develop targeted public health initiatives.
- → Social determinants of health – query systems to determine whether a patient is suffering from food insecurity etc.



AI tools for healthcare – high barriers beyond technical feasibility

Broad adaptation of AI in medicine is subject to a number of challenges that are initially completely independent of the technology used (ML vs. DL vs. LLM). Of particular note are data-related, technical, regulatory and ethical challenges.

Models require large amounts of “high-quality data” in order to be effective. In medicine, high-quality refers to complete and curated data sets in particular. However, in reality, medical data is often dispersed, incomplete or difficult to access. Good data quality and data availability combined with data representativeness is an absolute requirement to avoid bias [↗] (distortions). It is important to map the entire population with all marginalised groups so that statements have a high degree of validity. If the protection of sensitive patient data is a top priority, the available data must be anonymised or pseudonymised accordingly. It should be noted that pseudonymised data is still considered personal data and is subject to the GDPR and the special protection provisions for health data. Anonymised data no longer has any personal reference. It is no longer covered by the General Data Protection Regulation (GDPR [↗]) and the special rules for health data (e.g. in the Federal Data Protection Act [Bundesdatenschutzgesetz, BDSG] or in social codes). It can therefore be used more freely, e.g. for research and statistics.

↗ see glossary: Bias

↗ see glossary: GDPR

Explainability and interpretability are some of the biggest challenges – especially for deep learning based models – as they sometimes act as “black boxes” and decisions are not transparent. At the same time, the embedded models in the overall system must have a high degree of robustness and reliability, which, due to the possibility of incorrect data and the necessity of guaranteeing interoperability and protecting against other faults, means that a considerable implementation outlay is required. The integration into clinical and outpatient systems and workflows is another complicating factor.

Independently of this, individual technologies pose specific challenges. For example, the phenomenon of “hallucination” can be found in language models (see glossary). This is remedied by “grounding”, a process that connects the model with real-world information and context to make its responses more relevant, accurate and reliable. These include a whole range of techniques, such as RAG*, external APIs**, or knowledge database usage. ●

* RAG (retrieval-augmented generation) is a method in AI that leverages existing knowledge from external sources to generate more accurate responses.

** External APIs (application programming interfaces) are interfaces to other services that are outside of one’s own system.

SECTION 4

How AI empowers patients to contribute to better shared decision making

Lead author: Dr Sven Jungmann

The transformative potential of AI for SDM

AI can analyse vast amounts of data and derive personalised, evidence-based recommendations from it. By processing clinical trials, research results and (where available) patient data, AI systems can deliver tailored information. This individualised recommendation is then achieved if it is possible to determine the needs and treatment preferences of the patients beforehand. There are certainly still some open questions here regarding the extent to which AI can actually reflect the personal weighting of a person's preferences. But it would be ensured that, in a first step, preferences are aligned with existing evidence-based options.[13]

13 Jungmann S et al. *Using technology-enabled social prescriptions to disrupt health-care.* J R Soc Med. 2020 Feb;113(2):59-63. doi: 10.1177/0141076819877541. PMID: 32031488; PMCID: PMC7068766.

This alleviates a central problem in SDM practice: the wealth and complexity of information that overwhelms many patients. Even if personal health data is not available, conversational AI solutions can flexibly adapt existing knowledge – for example, to the patient's respective previous knowledge, language or level of understanding. When this becomes a reality – it already seems technically possible –and then aligns with efforts to improve institutional health literacy, the likelihood of practising patient-centred medicine will increase substantially.

From a patient perspective, multimodal LLMs are a major opportunity. A big change lies in the naturalness in which AI can fit into communication and improve it – without hurdles, e.g. due to complicated operation and even without internet access in some cases. A recent example illustrates how far-reaching AI will be and how seamlessly it will soon fit into everyday life: OpenAI, the parent company of ChatGPT, has announced its intention to attract several billion users. The feature is able to communicate with ChatGPT in natural language via a phone call or via WhatsApp.[14]

14 https://help.openai.com/en/articles/10193193-1-800-chatgpt-calling-and-messaging-chatgpt-with-your-phone

Important note: This is primarily a discussion about potential, not necessarily reality as it is already experienced. Some scientific research is still pending on actual effectiveness and implementation.

Personalised data-based recommendations

Another far-reaching opportunity arises from the adaptability with which AI can process information to an audience in a customised way. After all, a crucial prerequisite for successful SDM is the provision of relevant and comprehensible information. AI can help by:

- **Presenting medical information in a comprehensible and personalised manner:** complex content (e.g. study results) and different therapy options are translated into easily accessible explanations that take into account the personal situation.

- **Offering multilingual support:** AI language models can impart the same knowledge in different languages or for different levels of expertise – in accordance with the patients' cultural and linguistic backgrounds, as well as their previous knowledge and general education.

- **Providing empathetic, feeling interactions:** unlike static information, AI can interact, enter into an exchange and participate in dialogue – this also creates trust and connection, so that questions that patients may not otherwise dare to ask are asked. Patients attach surprisingly high levels of empathy to AI responses, especially with long and explanatory answers.[15]

15 Tu T et al. *Towards conversational diagnostic AI.* arXiv preprint arXiv:2401.05654. 2024 Jan 11.

Intelligent assistance systems and chatbots

Intelligent chatbots and digital assistance systems can support patients even **before a doctor's appointment** by:

1. **Enquiring about symptoms and preferences:** patients provide information about symptoms, circumstances and goals at their own pace and can thus provide more complete information[16,17].

2. **Structuring information:** the answers are clearly summarised so that healthcare professionals can later focus on the specific questions and needs.

3. **Promoting understanding:** chatbots can provide basic knowledge and help patients formulate the right questions. They can adapt individually to the language and previous knowledge level as described above.

On the one hand, this contributes to reducing the burden on healthcare workers and, on the other hand, strengthens patient self-determination.

16 Veatch RM. *Models for Ethical Medicine in a Revolutionary Age*. The Hastings Center Report. Vol. 2, No. 3 (Jun., 1972), pp. 5-7. https://doi.org/10.2307/3560825

17 Ayers JW et al. Hogarth M, Smith DM. *Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum*. JAMA Intern Med. 2023 Jun 1;183(6): 589- 596. doi: 10.1001/ja-maininternmed.2023.1838. PMID: 37115527; PMCID: PMC10148230.

Unlike static information, AI can interact, it can enter into an exchange and participate in dialogue - and this also fosters trust and connection

Integrating patient preferences into treatment planning

AI systems are able to capture personal values, everyday circumstances and goals and to integrate them into possible treatment recommendations, including in an ongoing dialogue. In this way, a more patient-centred medicine is created, in which people and their individual concepts of life are taken seriously.

Benefits for patients and doctors

The integration of AI into the SDM process has the potential to provide several benefits:

- **Increased efficiency:** by gathering information in advance, valuable time during the doctor's appointment can be used optimally. AI reduces work for doctors by taking on routine tasks and highlighting important information.
- **Improved communication:** AI-based systems help to prevent misunderstandings and ensure that important patient preferences are taken into account.
- **Empowerment of patients:** by actively involving patients in data collection, they can be better seen and can better inform themselves.
- **Greater satisfaction:** patients whose personal situation is taken into account tend to be more satisfied with the course of treatment.
- **Improved outcomes:** the inclusion of individual targets can increase adherence and thus provide better long-term results, at least in theory.
- **Follow-up questions can be answered 24/7:** for example, when patients encounter topics in the sea of information that they would like to classify or when they think of things that they actually want to ask only after their doctor's appointment.

Real-world case study: Ms Müller and her knee

Ms Müller (pseudonym), a passionate gardener in her late 60s, has been suffering from severe knee pain for months. Her orthopaedist diagnoses knee arthritis. In the hope of rapid relief, she arranges an appointment with a specialist. She enquires among friends and on the Internet beforehand and learns about the possibility of an artificial knee joint, which she considers to be the ideal solution.

In the consultation room, she describes her symptoms in detail and reports her interest in a knee replacement. The orthopaedist listens to her, looks at the findings, and eventually says, “Yes, we can do the surgery.” He then briefly explains the course of the knee operation and says goodbye when the appointment is over.

On the way to the door, Ms Müller says to herself with relief: “Finally, I can get back to gardening again soon!” The orthopaedist stops and asks her to come back into the room. He goes into more detail to ask, “What exactly do you want to be able to do again?” Ms Müller replies, “This is my favourite hobby, I could just spend hours doing gardening.”

The doctor explains with empathy that although knee surgery can relieve pain, she will probably not be able to bend her knee as before. He suggests alternative treatments, such as targeted physiotherapy and gentle exercise that could improve her mobility without the limitations of an artificial knee joint.

After careful consideration, Ms Müller decides against surgery and chooses the conservative treatment programme. A few months later, she enters a regional garden competition painlessly and even wins an award for her lovingly tended flower garden.

The role of AI in shared decision making

The case study shows how important it is to include the individual wishes and circumstances of patients in medical decisions. However, in practice, there is often only a limited time to conduct detailed discussions and to record all relevant aspects. Furthermore, it is not always easy to comprehensively assess the importance of different treatment options in the context of individual lifestyles – such as hobbies, travel plans or everyday requirements.

Here, AI can make an important contribution:

- ➔ **Information capture in advance:** smart chatbots can collect detailed information from patients even before the consultation with the doctor. They ask questions about symptoms, daily activities, personal goals, family history and treatment experiences to date. Patients can respond at their own pace, research additional information or involve relatives.
- ➔ **Personalised data analysis:** AI systems can analyse the collected data and create a structured summary for doctors. In this way, the most important points can be discussed specifically within the limited time available for the consultation.
- ➔ **Aid in treatment planning:** by matching individual preferences with evidence-based medical guidelines, AI can generate personalised treatment suggestions. In the case of Ms Müller, the system can see that her main motivation is to kneel while gardening and can propose alternative therapy options accordingly.
- ➔ **Visualisation of treatment options:** AI can help to clearly present complex medical information. Interactive graphs or simulations can show, for example, how different treatments affect the ability to kneel or to carry out other specific activities.

The case study of Ms Müller illustrates how crucial it is to look at patients individually and to include their life goals in medical decision making. AI can help to optimise this process by gathering, analysing and preparing information in an understandable way.

The combination of human and artificial intelligence has the potential to revolutionise shared decision making. It increases both the efficiency and the quality of care without neglecting the indispensable human component. Through the responsible use of AI, we can create a healthcare system where patients like Ms Müller can receive the best possible support to make informed decisions that meet their individual life goals.

Source: this story is taken from a course given by Sir Muir Gray on "Healthcare Value" at Oxford University and has been altered slightly.

Are you facing a health decision or a medical appointment yourself and do you recognise yourself in Ms Müller's story? Read our section on "Practical tips" [→ Section 1, pg. 012] **to learn how you can use AI today to obtain comprehensive information and best prepare for the conversation with your doctor.**

Explainable AI (XAI) as a foundation of trust

↗ see glossary: Explainable AI

Particularly in the medical context, AI algorithms must be comprehensible in order to gain acceptance. Explainable AI [↗] (XAI) is a transparent way of showing how a system arrives at a recommendation or prediction. This reduces uncertainty in patients and creates a reliable basis for decisions[18]. There are different approaches to this and many are not yet ideal. However, much is happening in this field and AI can sometimes even reveal problems in existing systems, such as a systematic disadvantage of certain groups of people, which

18 Band S et al. *Application of explainable artificial intelligence in medical health: A systematic review of interpretability methods.* Informatics in Medicine Unlocked, Volume 40, 2023, 101286, ISSN 2352-9148, https://doi.org/10.1016/j.imu.2023.101286.

were not transparent before. For example, AI used in several US healthcare systems demonstrated a bias by prioritising healthier white patients over sicker black patients for additional care because it was trained on cost data rather than care needs.[19]

Moral significance

The explainability of AI is not just a technical, but above all an ethical challenge. When it comes to human health, transparency and comprehensibility of decisions are essential.

19 *James TA. Confronting the Mirror: Reflecting on our Biases through AI Healthcare. Harvard Medical School.* Trends in Medicine. 2024 Sep. https://postgraduateeducation.hms.harvard.edu/trends-medicine/confronting-mirror-reflecting-our-biases-through-ai-health-care

Current support from society

According to a representative survey commissioned by the digital association Bitkom[20], the majority of the population of Germany sees great potential in AI for medicine:

- ➜ **85%** see AI as a **huge opportunity**.
- ➜ **69%** favour **special support** for the use of AI in medicine.
- ➜ **51%** can imagine asking an **AI system for a second opinion**.
- ➜ **71%** believe that doctors should get support from AI **“whenever possible”**.
- ➜ Almost half (47%) believe that AI could even provide **better diagnoses** than a human being in certain cases.

20 Paulsen N. *Eine Zweitmeinung von Dr KI? Für 57 Prozent eine Option. [A second opinion from Dr AI? An option for 57%.]* Bitkom press release. (August 2024) www.bitkom.org/Presse/Presseinformation/Zweitmeinung-Dr-KI-Option

These figures show that there is a broad social willingness to continue realising the potential of AI in healthcare.

Conclusion

The consistent integration of AI in joint decision making has enormous potential to give patients more autonomy and direction and to relieve medical professionals in a targeted manner. There is also potential in terms of efficiency: by allowing patients to record their data themselves in advance, there is more time for empathetic conversations and in-depth advice during face-to-face appointments – and AI also offers huge opportunities for providing patients with safety in the aftercare sector, especially in the age of social media where they are exposed to an abundance of contradictory information. Studies and surveys show that many people in Germany are already open to using AI in a medical context. Robustly developed AI-based recommendations are based on a wealth of current scientific knowledge and can thus be very well-founded.

In summary, this means that the use of intuitively designed AI can overcome most of the known hurdles in SDM and be used widely, without complex training courses or expensive training documents.

It is important to ensure that new technologies are handled responsibly and transparently and to continue to gain and communicate scientifically sound knowledge about their benefits.

Next steps:

- **More in-depth research:** in particular, further studies are needed in the area of the efficacy of AI-based SDM, the involvement of patients and doctors, and explainability[21].
- **Pilot projects:** practical trials in clinics and practices help to test and develop specific application cases.
- **Interdisciplinary cooperation:** healthcare professionals, IT professionals and patient organisations should work together on concepts that integrate AI into the reality of care as needed.

Note: a more detailed discussion on how AI could change the role of doctors can be found in the following section of this white paper.

Overall, healthcare is on the threshold of an era in which AI is increasingly empowering patients to make informed and self-determined decisions. Technology alone will not replace human interaction – but it can make a decisive contribution to reducing obstacles to the flow of information and making decision making more transparent and individual. ●

21 Rahimi SA et al. *Application of Artificial Intelligence in Shared Decision Making: Scoping Review.* JMIR Med Inform. 2022;10(8):e36199. Published 2022 Aug 9. doi:10.2196/36199

SECTION 5

Accessibility in the era of artificial intelligence

Lead author: Dario Madani

The rapid development of AI has led to numerous technological innovations in recent years – from language assistants to automated translation tools. These developments can simplify the daily lives of millions of people and offer great potential for a more inclusive society. This article will focus on solutions for people with visual impairment, the use of easy language for people with cognitive impairment and the accessibility of digital technologies for older people. We will also look at the healthcare sector, where AI can not only support patients, but also integrate blind and visually impaired professionals.

Recent developments in accessibility through AI

Visual impairment and blindness

In recent years, people with visual impairments have been able to experience noticeable improvements in everyday life thanks to AI-based applications. Screen readers in Apple or Android operating systems use machine learning to identify and describe websites, documents and other content. This provides blind people with a more accessible digital environment.

Large technology companies such as Google are developing tools that use algorithms to analyse image content and generate “alt text”, i.e. short descriptive texts for visual elements. Microsoft’s “Seeing AI” app even takes it one step further by being able to recognise objects, text and even facial expressions.

Challenges

- ➔ Many websites still do not use manually created alt text, which means that the majority of internet content is still only accessible to a limited extent.
- ➔ In the case of complex images, AI-based systems often reach their limits when context or details are missing.

To further improve accessibility, it would be useful to refine image recognition algorithms – ideally complemented by better tools that allow users to create their own meaningful image descriptions.

Easy language and cognitive accessibility

Easy language plays a critical role for people with learning difficulties, older people with deteriorating cognitive abilities or non-native speakers. Many AI translation programs can already translate complex texts into simpler language variants. In turn, language assistants can provide information to users in easy language.

Challenges

- ➔ While automated text simplification is a great step forwards, it needs to be further optimised to accurately reflect cultural contexts and individual needs.

In future, AI systems could automatically adapt the difficulty level of texts to the particular language level of their users.

Accessibility for older people

Older people benefit in particular from intuitive user interfaces and voice controls. AI can make personalised adaptions in this regard, for example by automatically increasing font sizes or adjusting contrast ratios. Voice assistants also allow natural interaction with digital devices, without complex input using a keyboard or mouse.

Challenges

- ➔ Language assistants must be able to function reliably in noisy environments and recognise different accents.
- ➔ Organisations need to ensure that users have a positive and user-friendly experience regardless of their technical background.

Obstacles and challenges in development

Lack of awareness and interdisciplinarity

One of the biggest barriers to developing accessible AI solutions is a lack of awareness of the specific needs of people with disabilities. Accessibility is often viewed as a “nice to have” feature and is only implemented late in the development process. Ideally, developers should work with experts, psychologists and, above all, users themselves at an early stage to develop viable and sustainable systems.

Cost, time and competitive advantage

Implementing barrier-free technologies may increase development and testing costs. However, in the long term, this investment can be a competitive advantage when it reaches more people and improves overall user comfort. Looking ahead to the next few years, accessibility could become a key differentiator.

Regulation and legal framework

Ever-more stringent regulations, such as those in the EU (European Accessibility Act), require companies to make digital products accessible. These requirements can be an important driver for considering accessibility not just as an additional option, but as an indispensable development standard. Meeting regulatory requirements early will strengthen a company’s reputation as an inclusive provider.

Medical data accessibility

For blind and visually impaired professionals, AI can be a key to making complex medical data accessible. Machine learning, for example, analyses imaging methods (MRI, X-ray) and generates comprehensible text or speech output from them. In clinical research or the pharmaceutical industry, AI could also summarise clinical trial results automatically, making it easier for researchers with low vision to access key information.

Support for professionals with disabilities

Thanks to advancing AI, blind or visually impaired doctors and healthcare professionals can increasingly participate in everyday professional life – for example through voice-controlled assistants or automated documentation. AI systems can take on recurring routine tasks and allow professionals to focus on their core competencies without the need for a mandatory visual interface.

In the healthcare industry in particular, AI can help to break down barriers for both patients and professionals and realise truly inclusive care.

Future trends: Looking forwards

The coming years will show that accessibility is becoming increasingly established as an integral part of digital products. AI should play a key role in this and enable both automated and customised solutions.

1. **Even better image and text recognition:** machine learning models could describe emotions, gestures and complex scenarios even more precisely, which would enable visually impaired people to perceive images and videos more comprehensively.

2. **Broadened spectrum of easy language:** AI systems will be able to adapt text difficulty to audiences in real-time.

3. **Accessibility as a standard:** stricter legal requirements and greater awareness in society are likely to make accessible functionalities a standard feature of digital services.

Conclusion

Advances in the field of AI are opening up enormous opportunities to sustainably improve accessibility in digital applications – for people with visual impairments, as well as for people with cognitive impairments or older users. Particularly in the healthcare sector, AI can contribute to breaking down barriers both for patients and for specialists and to realising truly inclusive care.

Over the next few years, accessibility is expected to become an integral part of product development, rather than a extra that is added later. AI systems will be able to automatically translate an increasing amount of information into accessible formats and significantly improve digital participation for all people. If this development is recognised at an early stage and barrier-free functions are systematically integrated, this not only creates greater inclusion, but can also create a lasting competitive advantage. ●

SECTION 6

Ethics

Lead author: Prof. Dr Heiner Fangerau

The most important ethical principle of medicine is not to harm people. This principle applies to AI systems just as it does to other medical applications and technologies. For this reason, all AI applications must be tested for safety and the protection of patients before they are put to use. Furthermore, SDM aims to promote patient autonomy. AI must not simultaneously undermine this very objective. Last but not least, doctors must treat patients equally and fairly regardless of their origin, gender, social status or religion. AI must not undermine this principle either.

Harm due to lack of data protection and/or incorrect databases

The opportunities that AI brings for SDM also create ethical pitfalls and challenges. This starts with the development and research of AI and ends with its use in the course of SDM. Clear ethical guidelines and transparency in the handling of data are essential to maintain patient trust.

Since AI is based on large amounts of data collected from patients during development and application, there is a risk that data could be used for purposes other than SDM, e.g. to advertise medical devices, for social control and external steering of health behaviour (in the sense of gentle control or even linked to penalty systems) and personal adaptation of health insurance contributions (which should be the same for everyone in a solidarity-based insurance system– this is different to private insurance, which, for example, could be based precisely on the evaluation of data). Protecting sensitive health data is therefore of the highest priority. Techniques such as federated learning, i.e. the collection of data from different sources and devices, make it possible to train AI models without the need to centralise personal data. This ensures data protection and simultaneously promotes the further development of AI systems.

At the same time, there is a risk that AI systems will make recommendations that they have “hallucinated” due to a lack of data. For example, some common LLMs rarely, if ever, say they do not know something, but are programmed to always give an answer. It is helpful here and important for patient safety that AI systems in SDM can make their databases and decision-making bases transparent.

Respect for patient autonomy

In SDM, protection of patient autonomy is strongly linked to the protection of AI-generated data (but also its recommendations). AI has the potential to override analogous decision making because of the expectations that are associated with it for technical accuracy, prognostic power and validity. It may even deceive or persuade by communicating via an LLM and thus falsely reflect or adversely influence the patient's will. However, if the goal of SDM is to promote autonomy, AI should play a role in supporting decisions rather than in enforcing them. Patients must continue to retain the final authority to decide on their treatment.

All parties involved should also be given the opportunity to object in the sense that AI should improve communication between doctors and patients and not replace it. This includes the option to reject AI support in SDM. The use of AI must not lead to doctors or patients relying blindly on the technology, but should be viewed as a complementary tool to human expertise. This is also relevant for liability issues. AI systems, like other medical technologies, should support consultation and treatment, not replace it. Similarly to other technologies, doctors should never treat the AI, but rather their patients.

Questions of fairness

Conversely, given the opportunities that AI offers to improve SDM, all patients should also have equal access to AI-based tools in SDM, regardless of their social or economic status. The risk of a “digital divide”, i.e. being unable to use the technology due to lack of access, must be avoided. Similarly, it is important to keep in mind that AI systems can adopt unconscious bias from their training data or can themselves generate injustices depending on the target point. For example, if systems learn that people with higher attractiveness scores are given more time with their doctors and incorporate this time-related unfairness factor into their algorithms, this can lead to unfair treatment recommendations and reinforce existing inequalities. For many AI systems, the decision-making process takes place in secret. To prevent injustices, data sets must therefore be carefully reviewed, selected and continuously monitored by, for example, the initiators of data collection or medical professionals before entry, and algorithms must be implemented to minimise bias.

Similarly, it is important to keep in mind that AI systems can adopt unconscious bias from their training data or can themselves generate injustices depending on the target point.

Conclusion

Despite all the opportunities associated with AI in SDM, ethical risks and patient safety must not be forgotten. It is important to keep in mind that behind the AI, there are players with human interests. Current socio-ethical debates should be guided by freedom and autonomy, not by control, economic maximisation of profits or preventative health action at any cost. ●

SECTION 7

Legal aspects of implementing AI-supported shared decision making (SDM)

Lead author: Peter Schüller

According to the principles set out above, SDM is a partnership process in which patients and doctors make medical decisions together. To illustrate the legal aspects of implementing AI-supported SDM, it is assumed that patients and doctors will each use a publicly available **LLM chatbot** (such as ChatGPT, Claude or Gemini) separately.

The information in this section is not transferable if doctors offer a chatbot for their patients to use. Depending on the objective of such an offering, which would very likely be considered a **medical device**, in addition to compliance with data

protection, data security (GDPR) and cybersecurity (NIS2 Directive), the Medical Device Regulation (MDR) and the AI Act[↗] would also have to be observed.

↗ see glossary: European AI Regulation

Use of an LLM by patients

A relative reports: “My father is in hospital and has found out that lab test results are sent to the patient portal on his app. He takes the results, enters them into ChatGPT and makes a self-diagnosis before the nurses talk to him. A couple of times it was really important.”

1 **No medical diagnosis by the LLM**
Let’s start with the most important and hopefully well-known finding: a publicly available LLM is not suitable for making a medical diagnosis. OpenAI, the developers behind the LLM ChatGPT, warn even in their Terms of Use: “You must not use any Output relating to a person for any purpose that could have a legal or material impact on that person, such as making credit, educational, employment, housing, insurance, legal, medical, or other important decisions about them.” (emphasis added by author)

Although the systems provide accurate and detailed information due to their extensive knowledge base, their ability to capture complex medical facts remains limited. The information generated by an LLM is based solely on training data that is not individually validated, so it does not replace a diagnosis in terms of a medical assessment.

It is important to understand that an LLM is (merely) equivalent to the famous **stochastic parrot** who simply and succinctly calculates the next right word in the given context (the prompt) based on its training data – and sometimes determines it purely randomly according to **human thought principles**. You may remember the text recognition “T9”. It was a blessing in the first generation of mobile phones, where number keys had to be pressed multiple times in succession to generate a letter (for example, three times with the number 2 key for the letter “c”). Based on this knowledge alone, an LLM should **never be used for independent diagnosis** – not to mention treatment. Patients should therefore never exclude aspects in a subsequent treatment discussion for which they believe the LLM has already made an appropriate diagnosis or the correct treatment proposal.

Nevertheless, can it still be beneficial to use an LLM? Of course! Simply dealing with the facts and the input of the LLM can offer patients added value. It depends on the right “handling”. Staying with the example of the **lab values**, when patients ask the LLM to assess the values that have been identified, it is very likely that a conversation will develop about how to classify the individual values. And if the LLM is then asked to ask questions about possible causes for values that deviate from the norm, patients can reflect in advance and thus prepare comprehensively for the subsequent treatment discussion. In this way, where applicable, very different correlations can be explored than is the case in the typically short conversation with doctors. Therefore, the LLM is an **idea generator** for patients and should be used as such. Obtaining a medical diagnosis should not be the primary focus.

2 Particular hazards when using RAG

There are additional risks associated with the use of retrieval augmented generation (RAG) for information gathering. With RAG, the LLM does not just leverage knowledge acquired during training. It actively searches for additional information that it “retrieves”. This form of interaction with the LLM is also called **“chat with your own data”**. The retrieval takes place in documents provided by users, i.e. uploaded **laboratory reports**. This information (the lab report) is then used to generate more accurately tailored responses because the LLM primarily processes this information when instructed to do so by the prompt. **However, there is the risk that essential information will be incompletely recorded or incorrectly interpreted due to inaccurate vectorization**. Such inadequate data collection alone can cause important aspects to be overlooked, which in turn can have a negative impact on the outcome. The answers are usually astonishing. Because users recognise themselves immediately. This is not surprising. It is because the LLM has just been working with the data provided. However, this does not mean that the answer is actually correct. On the contrary, mixing user data and training data can lead to totally biased results that initially sound “good”. With the necessary caution, however, a significant gain in knowledge can be achieved. Because ultimately, this is the prime discipline of LLM: the lightning-fast processing of enormous amounts of information.

3 AI literacy

Article 4 of the AI Act requires companies that use AI systems to ensure that the personnel who use these systems on their behalf have what is known as AI literacy. Article 4 of the AI Act says somewhat cumbersomely: “Providers and deployers of AI systems shall take measures to ensure, to their best extent, a sufficient level of AI literacy of their staff and other persons dealing with the operation and use of AI systems on their behalf, taking into account their technical knowledge, experience, education and training and the context the AI systems are to be used in, and considering the persons or groups of persons on whom the AI systems are to be used.”

Even if this provision is not relevant for patients, the principles of this regulation can be used to ensure that patients receive the greatest possible benefit when using an LLM and are warned of the risks. This does not mean that patients should only use an LLM if they received appropriate training. But it helps tremendously. The possibility should therefore be considered that **patient representatives** could act as **AI ambassadors** and bring the necessary knowledge to the patient groups. This involves **teaching two key aspects** that underpin a foundation of AI literacy.

A The first aspect concerns **hallucination**. LLMs are designed to generate a response to every query, even if they not have enough information or no clear information exists. This “forces” an LLM to provide a plausible-sounding “answer” (the output) instead of signalling uncertainty or ignorance. This behaviour can cause the LLM to “hallucinate” information – make up details that are not based on verified data. Or to put it simply: LLMs always give an “answer” because they simply calculate the next word in the given context (the prompt). An exception only exists if an LLM is expressly trained not to answer individual questions to prevent hallucinations.

However, this is only the case for specially trained LLMs. As of today (March 2025), publicly available LLMs still hallucinate quite frequently, although the severity of hallucination varies widely depending on the context and the model.[22]

B The second and far more serious aspect is that LLMs are subject to what is known as bias because of how they work. This means that an LLM may unintentionally reproduce or reinforce bias in the "answers" when it is present in the training data.

Probably the most striking example of the bias of an LLM can be illustrated by the seemingly harmless use of the translation software DeepL. The German start-up is by far the best translation software. There is no doubt about that. And that is because of the underlying LLM. It is not just a dictionary that translates word by word. DeepL recognises the semantic context of the text to be translated, as is typical for LLM.

But where there is light, there is also shadow.
If you translate the German sentence:

„Die Ärztin wird von einem Team von Krankenpflegern unterstützt." ["The (female) doctor is supported by a team of (male) nurses."]

to Turkish and then back to German, you get the result:

„Der Arzt wird von einem Team von Krankenschwestern unterstützt." ["The (male) doctor is supported by a team of (female) nurses."]

22 Masanneck, L et al. *Evaluating base and retrieval augmented LLMs with document or online support for evidence based neurology.* npj Digit. Med. 8, 137 (2025). https://doi.org/10.1038/s41746-025-01536-y

The background is that the Turkish language does **not have grammatical genders**. In the case of the back-translation (and thus most probably also in many translations from Turkish into German), the translation software now “necessarily” fills this grammatical gap and calculates the gender of both professional groups on the basis of its training data – with a completely distorted and incorrect result. There is no indication that users should check the result. Give it a try.

4 Data protection and data security

If the interaction with an LLM occurs over the internet, questions about data privacy, data security and cybersecurity are inevitably raised. This is one of the reasons why some European data protection authorities have investigated the admissibility of ChatGPT. In fact, Italy temporarily banned the use of ChatGPT. In Germany, too, there is intensive discussion about how to deal with LLMs. As an example, we refer to the extensive **checklist of the Hamburg Representative for Data Protection and Freedom of Information**,[23] who urged caution when using LLMs. Caution is better than indulgence. The checklist includes the following points, some of which have already been presented above as essential knowledge in the AI literacy section:

- ➔ Secure authentication, so attackers cannot abuse the account
- ➔ No entry of personal data
- ➔ Opt-out of AI training (e.g. turn off “Chat history and training”)
- ➔ Check results for accuracy
- ➔ No acceptance of recommendations because it is not clear how a recommendation is made

23 Available at https://datenschutz-hamburg.de/fileadmin/user_upload/HmbBfDI/Datenschutz/Informationen/20231113_Checkliste_LLM_Chatbots_DE.pdf

Ultimately, the discussion regarding the admissibility under data protection law can be left aside if patients only process their own data. And even if the processing of the sensitive health data entered by patients by the provider of the LLM violates data protection law, the treatment relationship between doctors and patients remains unaffected.

However, patients should always be aware that the transfer of their data to LLM servers takes place without special contractual assurance of confidentiality. Anyone who is afraid of this risk should **anonymise every input**.

Therefore, it is critical to carefully evaluate the integration of LLM into medical practice to ensure it meets clinical needs and improves patient care.

Use of an LLM by doctors

1 No medical diagnosis by the LLM

For doctors, an LLM can only serve as an aid under professional law. And in fact as an aid whose **output cannot** be completely **controlled**. The output of a publicly available LLM is not reproducible, let alone fully traceable. The acceptance of an unchecked diagnosis “made” by an LLM is in **stark contradiction** to the **medical specialist standard** that must always be applied. As the **Hippocratic Oath** already states: “ I will prescribe regimens for the good of my patients according to my ability and my judgement (...)”. The **Declaration of Geneva** is somewhat more modern: “I will practise my profession with conscience and dignity and in accordance with good medical practice.” This oath, which is referred to as a soft law, is regulated in Germany in particular by the professional **regulations of the states**. In the case of the State of Berlin, for example, it says in section 11 para. 1 that: “Upon taking over treatment, physicians shall undertake to provide patients with appropriate examination and treatment methods in a conscientious manner.” *(Emphasis added in each case by the author.)*

The focus is on **reflective and empathetic human performance**. Doctors are more than aware of this duty. Violations can lead to the **revocation of their licence to practise medicine**.

2 Particular hazards when using RAG

If doctors use RAG, it is of utmost importance to review the LLM’s evaluation with extreme care and to classify it in the individual clinical context. Most of the time, **errors are not immediately recognisable**. The output is deceptive. Studies on the use of LLM in radiation oncology sometimes show high error rates.[24] However, other studies show the exact opposite. In his article, “When Doctors With A.I. Are Outperformed by A.I. Alone” [25], Eric Topol highlights recent studies showing that LLMs achieve better outcomes in certain medical tasks than doctors supported by AI.

24 https://healthcare-in-europe.com/de/news/chatbots-radioonkologie-studie-llm.html

One example is a study published in JAMA where ChatGPT achieved a diagnostic accuracy of 90%, while doctors achieved 76% with the support of an LLM and 74% without the support of an LLM. Topol attributes this finding to factors such as doctors' reservations about automation, lack of familiarity with LLM and the controlled environment of the studies, which do not reflect the complexity of everyday clinical practice. It underlines that these preliminary results may not be robust in real-world clinical situations. Therefore, it is critical to carefully evaluate the integration of LLMs into medical practice to ensure that they meet clinical needs and improve patient care.

25 Topol E and Rajpurkar P. *When Doctors With A.I. Are Outperformed by A.I. Alone. Interpreting Some Surprising Results* (February 2025) Ground Truths. https://erictopol.substack.com/p/when-doctors-with-ai-are-outperformed

3 **Obligation to inspect and controllability (human in the loop)**

The implementation of AI-supported SDM requires that the **decision-making responsibility** remains with the treating physicians. The "human in the loop" principle highlights that LLM is only a supportive tool and does not take over decision making. Doctors are obliged to thoroughly review all information generated by the LLM and to understand this as supplementary information. The final assessment must always be made taking into account all medically relevant factors and the **medical specialist standard** in order to identify and exclude risks that may arise from erroneous LLM output.

4 Data protection and data security

Unlike the use of an LLM by patients, before transferring personal data to a publicly accessible LLM, doctors must ensure that there is a legal basis for this in the form of express consent from patients (data protection). It is also necessary that all technical and organisational measures are taken to ensure the protection of the data (data security). It is the responsibility of the treating physicians to ensure that all data transfers meet the strict requirements of the GDPR and that potential risks from unsecured data transfers are avoided.

Due to the unclear processing of the data entered into an LLM to date, there are serious doubts as to whether doctors process patient treatment data in compliance with the GDPR, even if they supposedly have obtained consent. In the absence of sufficient patient informedness, their **consent** to the processing of their treatment data is likely to be **invalid**. The use of a publicly accessible, and moreover American, LLM with patient treatment data is therefore currently not possible for doctors.

Unlike patients, doctors face legal consequences in the event of **violations of the GDPR**. Doctors are therefore required to use an LLM **only with anonymised information**. Uploading identifiable treatment data is strongly discouraged.

5 Liability

In the event of errors resulting from the use of an LLM, any liability remains with the treating physicians. As the **final decision maker**, they are responsible and must adhere to the relevant medical specialist standard. Against the background of the functional principle described above, it may be doubted whether a consensual (i.e. as a result of patient consent) failure to meet the standard is even possible when using an LLM.

The treatment visit

1 **Informing the doctor about the risks of using an LLM**

It is the responsibility of the treating physicians to comprehensively inform the patients about the advantages and disadvantages of AI-based SDM. This explanation must encompass not only the mechanics and technical limitations of the LLM being used, but also the associated risks, such as the possibility of erroneous or incomplete information that can potentially negatively impact medical decision making. Legally, a **parallel can be drawn to remote treatment**, where a detailed risk assessment is also required on a case-by-case basis to ensure that patients understand the **limitations of the type of treatment** and are appropriately involved in the decision-making process.

2 **Obligation of the doctor to document: creation of a shared protocol**

Documenting the decision process is an essential building block for ensuring quality of care and minimising liability risks. It is essential that all relevant information generated through the AI-supported SDM is recorded in a **shared protocol**. This protocol should supplement the **doctors' existing documentation obligation**. The purpose of the protocol is to document the individual patient's wishes as well as the entire process in a transparent and comprehensible manner. In the event of disputes, a complete record of the decision-making process can be used as important evidence to understand whether patients have been **sufficiently informed** on a case-by-case basis and have given **effective consent** to treatment.

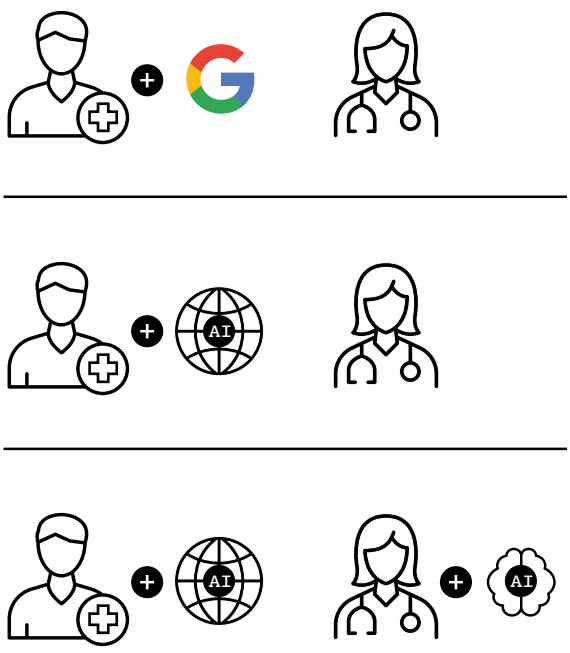
Conclusion

AI-supported SDM is not only legally challenging, but first and foremost a technological and ethical problem. Without sufficient AI literacy, patients and doctors will not be able to use an LLM to their mutual benefit. Development is still in its infancy and is still distorted for tasks as complex as a person's medical diagnosis and treatment. In the near future, **specialised LLMs** will be able to provide much more accurate individual diagnoses than doctors for many clinical pictures. However, there is one thing that is really difficult for LLM to do: use the **five human senses** (sight, hearing, smell, taste and touch) in treatment and therefore the part of medical care that only a human being can provide. The **future** is therefore almost certainly not human or machine, but **human and machine**. ●

SECTION 8

The transformation of the doctor's role with AI

Lead author: Dr Alexandra Widmer



Digitalisation is changing medical competence – a natural process?

Digitalisation is radically changing healthcare at a rapid pace. AI is increasingly finding its way into diagnostic processes, treatment decisions and communication with patients. This trend is seen by many experts as a great opportunity to improve the quality of medical care and reduce the workload of doctors. At the same time, it requires a consistent rethinking in medical practice, because the introduction of AI-based decision systems changes not only the way we practise medicine, but also the role we as doctors play in it.[26]

Traditionally, medical authority has been based on knowledge, experience and clinical judgement. We made decisions based on our own expertise, education and ability to grasp complex correlations in diagnostics and therapy. Patients were dependent on trusting our assessments or, if there was uncertainty, seeking a second opinion. With the advent of AI, this dynamic has changed.[27]

We are no longer only in direct contact with our patients, but increasingly also with machine recommendations that can suggest diagnoses, evaluate treatment options and even make prognostic assessments. This creates new challenges in terms of communication. On the one hand, AI could help to make more informed, objective and evidence-based decisions that are personalised for each patient. On the other hand, how does trust in medical expertise change when patients increasingly rely on AI-based recommendations? Or is this perhaps even considered equivalent or more reliable than the assessment of the treating physicians? [28]

We are no longer only in direct contact with our patients, but increasingly also with machine recommendations that can suggest diagnoses, evaluate treatment options and even make prognostic assessments.

26 Lorenzini G et al. *Artificial intelligence and the doctor-patient relationship expanding the paradigm of shared decision making*. Bioethics. 2023;37(5):424-429. doi:10.1111/bioe.13158

27 Čartolovni A et al. *Ethical, legal, and social considerations of AI-based medical decision-support tools: A scoping review*. Int J Med Inform. 2022;161:104738. doi:10.1016/j.ijmedinf.2022.104738

28 Sauerbrei A et al. *The impact of artificial intelligence on the person-centred, doctor-patient relationship: some problems and solutions*. BMC Med Inform Decis Mak 23, 73 (2023). https://doi.org/10.1186/s12911- 023-02162-y

From Google research to AI decision-making

The way patients obtain information has changed fundamentally in recent decades. In the past, patients came to the practice or clinic to receive a medical assessment without having much information about their disease. With the advent of Google and online health platforms, this has changed in an essential way. Patients began to self-educate themselves, to research symptoms and to search for diagnostic or treatment options on their own.[29]

Many doctors were initially sceptical of this development, because Google searches often led to unsafe, unfiltered or even false information. Nevertheless, over time, Google has become an accepted part of patient preparation. Doctors had to learn to deal with pre-informed patients, to address their questions and to correct misinformation.

Today we are facing a new transformation. Google was yesterday and AI is the future. Patients are increasingly relying on AI to obtain medical information. Instead of looking at search results from a variety of sources, they are given direct answers, often worded to suggest that they are evidence-based and personalised.

This change means that patients no longer come to us with individual information pieces of information, but with prepared summaries and treatment recommendations. AI-based health assistants analyse symptoms, assess disease risks and provide prognoses based on large amounts of data.[30]

This changes the way doctors talk, as we no longer only have to explain medical facts, but also assess the quality and reliability of AI-generated recommendations.

29 Kingsford PA and Ambrose JA. *Artificial Intelligence and the Doctor-Patient Relationship.* Am J Med. 2024;137(5): 381–382. doi:10.1016/j.amjmed.2024.01.005

30 Čartolovni A et al. *Ethical, legal, and social considerations of AI-based medical decision-support tools: A scoping review.* Int J Med Inform. 2022;161:104738. doi:10.1016/j.ijmedinf.2022.104738

As technology evolves, so too does medical literacy. A hundred years ago, it was a matter of course for doctors to carry out certain diagnostic tests themselves, which are now performed by machines. We are still able to read an ECG or EEG, but many colleagues already rely on automated findings without having to evaluate the raw data independently.[31]

It could be the same with clinical decision making in the future. The more doctors rely on AI-based support systems, the less they will use their own diagnostic and therapeutic skills. Dependence on machine recommendations could lead to losing certain skills because we no longer practise them regularly.

Perhaps this is a natural process of change. Throughout the history of medicine, there have been many episodes where new technologies have replaced the medical skills of doctors. The question is how we consciously shape this change so that doctors remain the central entity in medical decision-making and do not become mere moderators of AI recommendations.[32]

We are still in a transition period. Many of these developments are theoretical and their practical application in daily clinical care is still limited. Initial scientific studies suggest that AI can actually improve diagnostics and treatment planning by reducing systematic errors and providing a more objective basis for decision making. At the same time, there are concerns that doctors are less likely to make their own clinical judgements and rely more on algorithmic suggestions.[33]

31 Sauerbrei A et al. *The impact of artificial intelligence on the person-centred, doctor-patient relationship: some problems and solutions.* BMC Med Inform Decis Mak 23, 73 (2023). https://doi.org/10.1186/s12911-023-02162-y

32 Lorenzini G et al. *Artificial intelligence and the doctor-patient relationship expanding the paradigm of shared decision making.* Bioethics. 2023;37(5):424-429. doi:10.1111/bioe.13158

33 Čartolovni A et al. *Ethical, legal, and social considerations of AI-based medical decision-support tools: A scoping review.* Int J Med Inform. 2022;161:104738. doi:10.1016/j.ijmedinf.2022.104738

The challenge – redefining medical expertise and integrating AI in a meaningful way

The integration of AI into medicine is opening up new possibilities for data-based decision making. The key challenge is not to view AI as competition for medical expertise, but to use it as a tool that supports joint decision making between doctors and patients.

The question is not whether AI will replace medical judgement, but how we will handle these new sources of information. AI can help relieve us of the burden of routine administrative and diagnostic activities and create more space for individual consultations. At the same time, it brings with it new requirements. Doctors must learn to critically assess AI-generated recommendations, reflect on them with their patients and make viable decisions together.

How decision-making processes will change

The doctor-patient relationship has evolved through the centuries. While medical recommendations were previously often adopted unquestioned, it is now a matter of course that patients are actively involved in decisions. The introduction of AI will take decision making to a new level. Doctors and patients now have additional access to data-based recommendations. However, from different sources. The decisive question is not who will bear responsibility for treatment decisions in the future, but how the different perspectives of the doctors, patients and AI systems can be meaningfully linked together.

From the classic dyad to an expanded decision-making structure

For a long time, medical decision making has been a dyad. Doctors made diagnoses, gave therapy recommendations and patients made their choice based on this advice. This model has evolved with shared decision making. Today, it is self-evident that medical decisions are not only made on the basis of evidence, but also in a patient-centred manner.

As AI is integrated into decision making, the question is whether this dual relationship will continue or whether the process will evolve into a multiple decision-making structure.[34]

The triad

One possible scenario would be for doctors and patients to use the same AI platform. By having both of them access the same data sources, many decision-making conflicts could be reduced. In this model, AI would incorporate not only clinical evidence, but also patient-specific preferences.

In practice, this model has not really been feasible to date. Patients often use digital health apps, personalised diagnostic tools or second opinion systems based on different data sources than doctors' clinical decision-making systems. While medical AI systems are based on medical guidelines, large study cohorts and evidence-based databases, many patient AI systems are based more on personal empirical values, lifestyle data and health trends from online platforms.

For example, in multiple sclerosis research and treatment, work is being done on digital twins, which enable exactly such a triad of patient factors, biomarkers (such as MRI, sNfL etc.) and clinical data. The aim is to better understand the entire patient journey and make specific treatment adjustments in a data-based manner.[35]

34 Sauerbrei A et al. *The impact of artificial intelligence on the person-centred, doctor-patient relationship: some problems and solutions.* BMC Med Inform Decis Mak 23, 73 (2023). https://doi.org/10.1186/s12911-023-02162-y

35 Kingsford PA and Ambrose JA. *Artificial Intelligence and the Doctor-Patient Relationship.* Am J Med. 2024;137(5):381-382. doi:10.1016/j.amjmed.2024.01.005

The current evolution – two people, two AIs

What is actually emerging in clinical practice is a four-way combination. Both doctors and patients use their own AI systems. This will fundamentally change medical decision making. There are four key players in this structure

1 The **patient** uses an AI app that creates personalised therapy recommendations based on individual health data.

2 The **doctor** draws on clinical decision-making AI that is based on medical guidelines, evidence-based data and large study cohorts.

3 **Patient AI** takes into account personal factors, genetic analyses, lifestyle data and the experiences of other patients.

4 **Doctor AI** is based on scientific evidence, population-based data and regulatory requirements.

The challenge is not to define any of these perspectives as the right one, but to integrate the different sources of information into the joint decision-making process. Patients often have a clearer picture of their personal preferences thanks to their AI-based systems, while doctors bring in the medical-scientific evidence. The task will be to connect these different perspectives and empower patients to make an informed decision.

Shared decision making as a bridge between AI and medical expertise

The introduction of AI into medicine does not mean that our medical competence will be put into question. Rather, our role is shifting to one of moderation and advice in a data-driven decision-making environment. We must learn to not only interpret AI-generated recommendations, but also to include them in a joint discussion with our patients.

The future of medical decision making is not about AI making decisions, but how we will make better decisions together among doctors, patients and AI.

Case study – a patient with depression

A 42-year-old female patient with recurrent depression seeks medical advice on whether to begin drug therapy or to try psychotherapy first. Her patient AI suggests psychotherapy alone. It uses testimonials from other patients with a similar background and sees a high probability of success.
Based on current guidelines, the doctor's AI recommends a combination of psychotherapy and drug treatment. Data shows that patients with recurring episodes achieve better long-term treatment outcomes with this strategy.

The patient is inclined to follow her AI because she feels better understood by the individual analysis. However, the psychiatrist sees the evidence-based recommendation of her AI as a solid basis for combination therapy.

How can this decision be made jointly?

Shared decision making is not about which recommendation is more correct – it is about the patient making an informed decision.

The doctor discusses both recommendations with the patient and explains the basis on which the guidelines favour combination therapy. At the same time, she responds to the patient's preferences and asks:

- ➔ What are your concerns about drug therapy?
- ➔ What do you hope to gain from psychotherapy alone?
- ➔ How important is it for you to see an improvement as quickly as possible?

These questions actively involve the patient's perspective in the decision-making process. The doctor does not evaluate or correct the patient AI, but uses the AI information as the basis for discussion to make a joint decision.

Transforming the doctor's role in AI-driven decision making

The introduction of AI in medical decision making is not only changing the way diagnoses are made and therapies recommended, but also the communication between doctors and patients. A central element of shared decision making is that patients come to the consultation with clear treatment preferences. Doctors must learn to critically classify AI-based recommendations while taking the patient's perspective seriously.

AI will not replace medical advice, but will be an additional source of information that patients use to make their decisions.

Doctors face the task of jointly evaluating AI-based information with patients, comprehensively classifying medical knowledge and integrating the individual perspective of patients into the decision-making process.

As a result, the role of the doctor evolves. It is becoming increasingly facilitative and is guided by data-driven, patient-centred medicine, in which doctors bring together scientific findings and individual preferences.

Conclusion

The key question is not who is right, but how the patient comes to an informed decision. The role of doctors is not to weigh AI against patient opinion, but to integrate both perspectives into a joint conversation. AI does not abolish shared decision making, but rather increases its complexity. Doctors are more needed than ever to act as mediators between guidelines, technology and individual patient needs.

Conclusion

The integration of AI in medicine is fundamentally changing the relationship between doctors and patients and the role of doctors. While AI undoubtedly offers the opportunity to make diagnoses more precise and optimise treatment decisions in a data-driven manner, it also brings with it new complexity. In future, doctors will not only have to apply their own knowledge, but also learn to critically assess AI recommendations, reflect on them together with patients and include them in the medical decision-making process. At the same time, the task is to support patients in correctly classifying AI-based recommendations and making an informed decision on an equal footing.

Many of the developments represented here are assumptions and hypotheses, but one thing is already foreseeable: medical training and practice will change. The ability to reflect critically on digital decision-making systems will become increasingly important in medical education, specialist training and daily care. However, technological competence alone will not suffice. Communication, empathy and the ability to present complex relationships in a comprehensible manner to patients are becoming more essential than ever.

To this day, the art of conducting medical conversations has been mistakenly taken for granted, but it has not been systematically taught either during studies or in medical training. Incentives to encourage learning of this art through appropriate medical compensation are also, incomprehensibly, not utilised. This is despite the fact that the effects of successful doctor-patient communication are well known. As AI takes on more diagnostic and therapeutic roles, the doctor-patient conversation becomes the central place to clarify uncertainties, discuss preferences and make decisions together. During the conversation with patients, it will be a question of jointly evaluating AI-based recommendations, reflecting on uncertainties and making an informed decision.

This requires structural changes in medical training, in the remuneration of doctors and in the social perception of the role of doctors, but also within the medical profession.

The future of medicine will not only be determined by technological innovations, but also by the question of how doctors actively help to shape this change and integrate shared decision making into an AI-based practice. Who bears responsibility for medical decision making is not decided solely by algorithms, but by the ability of doctors to critically scrutinise new technologies, integrate them meaningfully into practice and simultaneously maintain the human dimension of medicine. ●

SECTION 9

Conclusion and outlook

Healthcare is at a tipping point: rapid advances in AI and the growing need for patient-centred care are opening up new opportunities for more effective shared decision making (SDM).

This white paper has shown that AI is much more than just a technological refinement of existing processes. Rather, it has the potential to fundamentally change the way doctors and patients make decisions together. Through AI-based information transfer, personalised advice and consideration of individual preferences, SDM can be made accessible to a broader group of patients and better integrated into everyday clinical practice.

However, there are also challenges to be kept in mind: the use of AI must comply with ethical and legal frameworks, ensure accessible solutions and enable trusting cooperation between humans and machines. SDM has long since ceased to be merely a theoretical concept – however, it lacks widespread implementation and acceptance. AI could act as a catalyst in this very context.

The use of AI in SDM is still in the early stages. To realise its full potential, interdisciplinary exchange is required. Patients should be given the opportunity to become familiar with AI-based decision-making aids and to be actively involved in their development. Doctors and healthcare providers can use AI to support individual consultations and make informed decisions together with patients.

Research and development are also needed to provide study evidence on the benefits and possible risks of AI-based SDM approaches through pilot projects. Technological innovations should aim to develop safe, understandable and personalised solutions that facilitate decision making and address the individual needs of patients.

This white paper is intended to provide a starting point for an open discussion. Digitalisation and the use of AI will significantly change healthcare. To ensure that these developments proceed in the interest of patients, now is the right time to take action. Let us seize the opportunities together and reimagine SDM as innovative, inclusive and patient centred. ●

GLOSSARY

Important terms

On shared decision making

Patient Rights Act (Patientenrechtegesetz) — Effective in Germany since 2013. It requires doctors, among other things, to provide comprehensive information about diagnosis and treatment, document medical measures and provide rights of access to the patient's records.

Shared decision making — A participatory approach in which medical expertise and patients' individual values, preferences and circumstances are combined to form a joint decision.

Silent misdiagnosis — A misdiagnosis that is not based on medical facts but on a failure to take into account patients' individual wishes, values and preferences. Knowing about and including these needs is essential for optimal treatment.

On artificial intelligence

Anomaly detection — Anomaly detection refers to artificial intelligence (AI) techniques that identify unusual patterns or outliers in data. In the healthcare sector, this can help to detect abnormal medical images or unusual vital signs at an early stage, for example, in order to diagnose diseases or risks more quickly.

Bias — Bias in AI refers to systematic errors or biases that result from unbalanced or unrepresentative training data. In healthcare, bias can lead to AI systems being less accurate in diagnosing certain populations or recommending treatments that pose ethical and practical problems. It is important to detect and mitigate bias to ensure fair and effective AI applications.

Cloud API — A cloud API (application programming interface) enables access to cloud services via standardised interfaces. In healthcare, developers can use cloud APIs to access AI models, databases or computing resources to build applications without having to worry about the underlying infrastructure. This facilitates the integration of AI functions into medical software and services.

Dialogue-based — Dialogue-based AI systems are designed to interact with users in natural language, similar to what happens in a conversation. In healthcare, such systems can act as virtual assistants to advise patients, answer questions or help healthcare professionals to make decisions.

GDPR — The General Data Protection Regulation (GDPR) is a European-wide regulation on the protection of personal data. It sets out how companies, authorities and other organisations in the EU may collect, store and process personal data. The goal is to protect people's privacy and give them more control over their own data.

Explainable AI — Explainable AI (XAI) refers to AI systems whose decisions and processes are comprehensible to humans. In medicine, this is particularly important, as doctors need to understand how an AI system has reached a certain recommendation or diagnosis to be able to include it in their decision making. XAI fosters trust in AI systems and facilitates compliance with regulations and ethical standards. (Caution: must be differentiated from the company xAI)

European AI Act — The planned EU AI Act aims to regulate artificial intelligence uniformly within the EU. It provides for AI systems to be classified according to risk (e.g. low or high risk) and lays down corresponding obligations for the development, use and monitoring of AI. The aim is to ensure the security, transparency and trustworthiness of AI applications.

Generative pre-trained transformer (GPT) — A generative pre-trained transformer (GPT) is a type of AI model that is based on the transformer architecture and was initially pre-trained on large amounts of text. “Generative” means that the model can generate new content. These models are particularly effective in natural language processing tasks and are used in applications such as chatbots, text summarisation or machine translation. In the medical field, they can help create patient reports or answer questions.

Hallucination — Describes the behaviour when the model generates information that is factually false, meaningless, or irrelevant to the given context even though it may sound fluid and convincing. This can happen due to insufficient training, bias in the training data, or simply due to the random processes underlying the model.

LLM — LLM stands for large language model. These are AI models that have been trained on large text sets and are able to generate or understand human-like text. Examples are Gemini and GPT-4. In a healthcare setting, LLMs can be used to process natural language, analyse patient data or aid in medical documentation.

MedLM — MedLM stands for “medical language model” and refers to specialised language models that have been trained on medical texts. They are designed to help with healthcare tasks such as interpreting clinical notes, aiding in diagnosis or answering medical questions.

MedQA — The MedQA benchmark is a data set or test environment to evaluate the performance of AI models in medical question-and-answer tasks. It is often based on questions from medical exams such as the USMLE and is used to measure how well an AI model understands and can apply medical knowledge.

Megatron — The Megatron framework is an NVIDIA software infrastructure designed to efficiently scale and accelerate training of very large language models across multiple GPUs and servers. It enables the training of models with hundreds of billions of parameters. In the context of healthcare, it can be used to develop specialised AI models for medical applications.

Multimodal AI — Multimodal AI is a form of AI that combines information from various data sources or modalities, such as text, image, audio and sensor data. In the medical context, multimodal AI can integrate patient data, medical images and electronic health records to enable more comprehensive analyses and more accurate diagnoses.

Parameters — In AI and machine learning, parameters are modifiable values within a model that are adapted during training to optimise the model. They determine how the model processes input and generates output. For large language models (LLMs), the number of parameters can be in the billions, influencing the model's capability and complexity.

USMLE — The United States Medical Licensing Examination (USMLE) is a multi-step assessment that doctors in the United States must pass in order to acquire their medical licences. It tests extensive medical knowledge and clinical skills. AI models being tested on the USMLE demonstrate their ability to process and apply complex medical knowledge.

Are you curious?
Why not try it yourself? Share your experience with AI at #KI4patients on Instagram, TikTok or Facebook.

APPENDIX

Conflicts of interest

INGA BERGEN

Inga Bergen does not state any conflicts of interest related to this publication. In the last 5 years, she has received fees from the following companies, or is a shareholder in them: Esteve Pharmaceuticals, AOK Plus, MEDICE, vitagroup health intelligence, AstraZeneca, Georg Thieme Verlag, Siemens Healthcare, GKV Spitzenverband (National Association of Statutory Health Insurance Funds), Janssen-Cilag, BITMARCK Holding, AOK Nordost, Roche Pharma, Verband Forschender Arzneimittelhersteller e.V. (Association of Research-Based Pharmaceutical Companies), MSD, AbbVie, Bundesverband der Arzneimittel-Hersteller e.V. (Federal Association of Pharmaceutical Manufacturers), Takeda, AktionsBündnis Patientensicherheit e.V. (German Coalition for Patient Safety), Pfizer Pharma GmbH, Asklepios Kliniken, Landesärztekammer Brandenburg (State Chamber of Medicine in Brandenburg), Doctolib, docdok. health AG, Sanofi, enovis, BKK VBU, Ärztinnenbund (German Medical Women's Association), SHL Telemedicine, TK, Tó, ALK-Abellelli Arzneimittel GmbH, Generali, Asklepios Medical School GmbH, Barmer, CyberConcept GmbH, Eterno Health, Lillian Care, Roclub, EY, Porsche Consulting, Helios.

Dr STEFAN EBENER

Over the past five years, Dr Stefan Ebener has directly or indirectly received fees from the following companies active in the healthcare market, or is a shareholder in them: Roche Pharma AG, GSK, Gesundheitsforen Leipzig GmbH, University Hospital Schleswig-Holstein (UKSH), DigiMed Bayern, Becton, Dickinson and Company, Smart Bridges GmbH. In addition, Ebener has contributed to various books and white papers, the proceeds of which have been remunerated in part.

Prof. HEINER FANGERAU

In the course of his duties as a professor, Prof. Dr Heiner Fangerau carried out research on the misuse of medicinal products by children and adolescents in the state of North Rhine-Westphalia between 1946 and 1980. This also includes trials and tests of medicinal products on children and adolescents who were institutionalised without consent and/or by taking advantage of their precarious, vulnerable situation. Before he took part in this white paper, he asked Roche to search for possible references to such studies in the company archives and to make them available. Roche had stated that it did not have such documentation. His participation in this white paper is not related to this process. In recent years, Heiner Fangerau has received lecture fees from Novo Nordisk, Roche Pharmaceuticals, Novartis and Alexion. The topics presented were not related to any medicinal products.

Dr SVEN JUNGMANN

In the last five years, Dr Sven Jungmann has received, directly or indirectly, honoraria from in the following companies active in the healthcare market or is a shareholder in them: AbbVie, Accessus Science Technologies, aiomics GmbH (registered company), Audi, Bayer, CapitalMind Investec, Coliquio, Coloplast, Daiichi-Sankyo, DHMS Direct Health Medical Services Ltd., Elsevier, Ferring, Gothaer Krankenversicherung (Gothaer Health Insurance), Halitus GmbH, Kassenärztliche Vereinigung Niedersachsen (Association of Statutory Health Insurance Physicians of Lower Saxony), Medice Arzneimittel Pütter, Medtronic, MNH Al Hajery, Mobile Healthcare Solutions, NaturalX Health Ventures, Novartis, OKG Capital, Pfizer, Roche, Samedi, SpeedInvest, Start2 Group, Theta Diagnostics, Thieme, Wellster Healthtech Group GmbH.

DARIO MADANI

Dario Madani claims to have no conflicts of interest in connection with this work. His employer, ProRetina, has received sponsorship for patient events and he has received fees and travel expenses to attend Roche's events, but outside of the scope of this work.

Dr LARS MASANNECK

Dr Lars Masanneck states that he has no conflicts of interest in connection with this work. He has received fees for lectures, consultancy and travel expenses to attend conferences of Biogen, Merck, Sanofi, argenx, Roche, Alexion, Neuraxpharm and Novartis, but outside of the scope of this paper. His research is sponsored by the German Multiple Sclerosis Society (DMSG), the B. Braun Foundation and the German Research Foundation (DFG) - 493659010.

PD Dr
JENS ULRICH RÜFFER

PD Dr Jens Ulrich Rüffer is a shareholder and Managing Director of Share-To-Care GmbH, whose aim is to introduce SDM throughout Germany. He therefore has a conflict of interest in collaborating on this white paper.

Additional activities without conflict of interest: as Managing Director of TAKEPART media + science GmbH, Professor Rüffer has received project funding and performed contract work for Amisar, AbbVie, Daiichi- Sankyo, Novartis, Roche, Bayer, Pfizer as well as Innovation Funds, Stihlstiftung (Stihl Foundation) and the German Federal Ministry of Education and Research (BMBF). As spokesperson of the Deutsche Fatigue Gesellschaft (German Fatigue Society), Professor Rüffer has received fees for lectures, consultancy and travel expenses for participation at conferences of Sanofi, Bayer, Roche, Alexion, PSO and Pfizer.

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Peter Schüller, LL.M., works at BIOTRONIK Corporate Services SE, where, among other things, he is responsible for legal advice on the digital products of the BIOTRONIK Group. He has no conflicts of interest. His contribution was not sponsored, authorised or influenced by the BIOTRONIK Group. It reflects only the personal opinion and experience of the author. Peter Schüller, LL.M., was asked to contribute the article by Dr Sven Jungmann, with whom he is a personal friend. Peter Schüller, LL.M., has received fees from the following companies in the healthcare market as a lecturer: SYNLAB Holding Deutschland GmbH.

EVA STUMPE

Eva Stumpe states that she has no conflicts of interest in connection with this work. Over the past 5 years, she has received direct and indirect fees (in these cases sent to the European Patients Organisation) from the following companies: Biogen, Novartis, Roche.

NELE VON HORSTEN

Nele von Horsten indicates that she has no conflicts of interest in connection with this work. Over the past five years, she has received fees, directly or indirectly, from the following companies in the healthcare market (in alphabetical order): Bayer, Biogen, Coloplast, Dawn Health, gtec, Medtronic, Merck, NeuroSys, Novartis, PwC, Rewoso, Roche. In addition, she received honoraria from the following institutions: Carl Gustav Carus Management, Medical Faculty TU Dresden, German Multiple Sclerosis Society (DMSG) Berlin, German Multiple Sclerosis Society (DMSG) Thuringia. Her podcast *MS-Perspektive* was supported by the Gemeinnützige Hertie-Stiftung (Charitable Hertie Foundation).

Dr ALEXANDRA WIDMER

Dr Alexandra Widmer declares that there are no conflicts of interest in connection with this work. She is a clinical specialist in neurology and a medical psychotherapist at Klinikum AMEOS (AMEOS Clinic) and also works on a freelance basis. She receives fees for lectures, consultancy and travel for Servier, Takeda, Pohl-Boskamp, Bayer and Besins. In addition, she also hosts the podcast and videocast docsdigital, which is not related to this work.

CARSTEN WITTE

Carsten Witte states that he has no conflicts of interest in connection with this work. He is employed as a health educator and psycho-oncologist at the Zentrum für Strahlentherapie Freiburg (Centre for Radiation Therapy Freiburg) and also works as a freelancer. Over the past five years, he has received fees, directly or indirectly, from the following organisations in the healthcare market (in alphabetical order): Charles River, dapo e.V., Elsevier, Ev. Deakoniekrankenhaus Freiburg, Fosanis, Kurvenkratzer GmbH, MSD, Pfizer, Roche, Siemens Healthineers, Takeda, Uniklinik Düsseldorf (University Hospital Düsseldorf), Uniklinik Freiburg (University Hospital Freiburg).

The project management was taken over by Belinda von Niederhäusern and Anja Thelen (Roche Pharma AG).

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