"Your future doctor may not be human", investigating artificial intelligence in healthcare

Patient Perspectives and Robot Doctors: Probing Participation with Artificial Intelligence in Health Care

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Abstract

Artificial Intelligence tools are increasingly used in healthcare to help with decisions and treatment recommendations. The perspectives of patients are integral in shaping AI innovation, yet what patient participation should look like requires further examination. This study investigates how patients can and should be informed about and involved in the implementation of AI-supported technologies in healthcare. This paper presents a focus group proposal, developed during a four-month research-based course at Maastricht University, aimed at finding new ways to learn from and about patients. Through creative activities like a taboo game and collective mind mapping, participants are provided with a platform for open deliberation and collaborative learning. The suggested format aims to foster democratic and emancipatory patient empowerment by establishing mutually beneficial researcher-patient relationships and ascribing intrinsic value to patient participation.

Keywords: artificial intelligence, patient participation, patient empowerment, focus groups

1. Introduction

Artificial Intelligence (AI), which refers to technologies meant to mimic human cognitive functions (Jiang et al., 2017), has found its way into many different sectors of contemporary society. From helping consumers to find the right restaurant to predicting earthquakes, the possible uses and promises are vast (Castro & New, 2016). The development and application of AI in healthcare is of particular interest. AI is already being used in some fields, especially in medical imaging, to assist with diagnosis and treatment recommendations (Davenport & Kalakota, 2019). Through machine learning, a collection of techniques in which the machine analyses training data and then makes predictions on new data sets (Balthazar et al., 2017), AI tools are becoming increasingly efficient at classifying images. Topol (2019) has argued that clinicians, health systems, and patients alike will benefit from such AI usage as image interpretation will become faster and more accurate. However, one of these key stakeholders – patients – is currently not sufficiently considered in the design and implementation processes of AI technologies.

Gaining insight into patient perspectives is important as this knowledge shapes the preconditions for AI development in healthcare (Haan et al., 2019). Being directly subjected to these technologies, patients are greatly affected when certain factors are not adequately

considered prior to AI implementation. A series of AI systems in the field of medical imaging already have shown harmful potential. For example, certain algorithms can read a patient's race from medical images, and marginalised groups have been found to be underdiagnosed when AI-based X-ray prediction models were employed (Banerjee et al., 2021; Seyyed-Kalantari et al., 2021). To avoid such problems, it is integral to consider a diverse range of patients and their needs, expectations, and preferences when developing and employing AI technologies. This can be done by actively involving patients in these processes, yet it ought to be examined what such patient participation should look like. Our research is thus guided by the question how patients can and should be informed about, and involved in, the implementation of AI-supported technologies in healthcare. During the four-month period of a research-based course, we have developed a proposal for a focus group format through which we aim to learn about perceptions of – and education about – care practices and AI. This paper first provides background on existing research on patient perspectives in a literature review. We then outline the methodology which led us to our proposal, followed by the suggested focus group format itself. Lastly, we consider limitations of our proposal and possibilities for future research.

2. Literature Review: Patient Perspectives on AI in Healthcare

Citizen science, the inclusion of non-professionals in scientific studies, has gained momentum in medical research (Fiske et al., 2019). The involvement of patients is seen as potentially benefitting processes and outcomes of health research and can be enacted in several ways. For instance, Beier et al. (2019) identify three levels of patient participation in medical research: individual consent, through which patients willingly participate in studies and provide biomaterials and data; consultation, whereby patients engage in the research process and voice their own preferences; and co-operation, where patients are included as co-decision-makers and co-researchers. In the context of AI in healthcare, with AI referring to technologies aimed at recreating human decision-making and behaviour (Jiang et al., 2017), co-operation would prove difficult. Active participation in research requires patients to possess knowledge of AI they currently lack (Beier et al., 2019; Haan et al., 2019). As such, individual consent practices like participation in interviews, and consultation regarding patient needs and preferences have been widely used in present AI healthcare research. However, questions about patient participation revolve around not only how patients can be incorporated in development and

implementation processes, but also to what ends their perspectives are used. Prainsack (2018) thus distinguishes between four types of patient empowerment: (1) individualistic empowerment, which considers patients empowered when they have the power of free choice between different options; (2) instrumental empowerment, which involves patients for the purpose of helping AI innovation; (3) democratic empowerment, which ascribes intrinsic value to patient perspectives and emphasises the inclusion of underserved groups; and (4) emancipatory empowerment, which aims to liberate people from oppressive power structures. The motives for research in the literature discussed below are not always made explicit yet tend to primarily be of instrumentalist nature, which raises certain practical and ethical concerns.

Several scholars have researched patients' views on the implementation of AI in various medical imaging fields. In line with Beier et al. (2019), studies thus far have focused their attention on individual consent practices and consultation methods. Data on individual patient experiences are thus collected through surveys or semi-structured interviews. Haan et al. (2019) conducted interviews with patients, sometimes in the presence of their loved ones, who were recruited directly after undergoing a Computed Tomography (CT) scan. Amongst the key findings were patients' concerns regarding the depersonalization of healthcare practices and their scepticism towards the accuracy of AI systems. Participants thus expressed a wish for a second reading from a radiologist. Continuing this study through a survey with 155 respondents, Ongena et al. (2020) found similar patterns as patients expressed a strong need to keep human interaction. Furthermore, Ongena et al.'s (2021) research on women's preferences regarding mammography revealed that most sampled women did not support a fully independent use of AI-based diagnostics. Instead, a combination of radiologist as first, and AI system as second reader was found to be most acceptable. These studies were conducted to gain an understanding of patients' levels of knowledge on AI and which key domains are of concern to them, and to subsequently test their technology acceptance towards AI systems in clinical practice. Ongena et al.'s (2021) research partially adheres to democratic empowerment, as the researchers investigate the perspectives of and give a voice to an underserved group, in this case women. Nevertheless, the overarching incentive behind all these studies is to improve AI development. The enacted patient participation thus slips into what Prainsack (2018) coins instrumental empowerment: listening to patients' voices for the sole purpose of refining AI.

Within dermatology, Nelson et al. (2020) found similar results when conducting semi-structured interviews with 48 patients. Perceived benefits included increased diagnostic speed and more accurate diagnosis, as AI is considered to draw on more data than humans. On the other hand, patients feared a loss of human social interaction and perceived less accurate

diagnosis to be equally likely due to inaccurate training sets or a potential for false-negatives and false-positives. Patients thus perceived a symbiotic relationship between humans and AI, in which AI provides a second opinion to a human first reader, as most desirable. How patients came to be knowledgeable about issues like inaccurate training sets and were able to articulate these concerns, however, was not explained. It is unclear to which extent the posed questions during the interviews may have prompted such responses. Moreover, Nelson et al. (2020) ascribe value to patient perspectives, as they will be the stakeholders most affected by AI implementation in clinical practice. However, their study cannot be classified as democratic empowerment, which places emphasis on the inclusion of marginalised groups, since the study population predominantly consists of white and highly educated patients.

Although there has been an emergence of patient-focused studies, previous research is not without shortcomings. As their focus mainly lies in AI improvement rather than patient voices, in several studies patients were sampled while in a vulnerable state of currently undergoing medical procedures (Haan et al., 2019; Nelson et al., 2020; Ongena et al., 2020). Patients may be less likely to respond accurately or be willing to share their thoughts while in a difficult position and setting. Moreover, contrary to Prainsack's (2018) notion of emancipatory empowerment, these studies may add to existing power imbalances. Fiske et al. (2019) point out that medical research projects making use of citizen science often fail to create reciprocal relationships between researchers and participants. While the surveys and interviews conducted in the examined prior research have been beneficial to the researchers, there was no explicit value for the patients. Instead, considering they were subjected to the studies in vulnerable states, research participation may have been a negative experience for participants.

The studies we examined furthermore confronted patients with specific AI tools of which they had little practical knowledge and experience (Haan et al., 2019; Nelson et al., 2020). For instance, Haan et al. (2019) found that patients' views on radiology and AI were rather general, sometimes incorrect, and therefore limited. They propose that patients may need to be educated on these topics, so that researchers may gain relevant patient input on how best to use AI systems in medical imaging, and other studies strengthen this argument. For example, Yang et al. (2021) conducted a scoping review on publications regarding attitudes towards AI in diagnostic imaging. They identified different stakeholders' perspectives on AI use in radiology and found that radiologists, medical students, and patients expressed a lack of knowledge on AI. Skovgaard et al. (2019) similarly reviewed studies on attitudes towards reuse of health data among people living in the European Union. Patients were found to express general opinions on the topic and a concern that data may be used to their disadvantage, but

they did not know the specificities of how health data were being used. Respondents therefore indicated a desire to be better informed about how health data are stored and reused.

These studies and reviews are relevant since they point to a clear gap in patients' knowledge on AI tools, health practices and data. Moreover, they raise important considerations for patients' role as stakeholders: How may they be involved in the implementation of AI technologies if they do not know what AI entails? How much do patients need to know, or should know, about AI tools in healthcare? And how can studies follow democratic or emancipatory empowerment practices, rather than adhering to instrumentalist approaches? This study seeks to answer these questions by designing new ways to learn from patients which align with democratic and emancipatory empowerment. Finding ways of putting patients and considerations about patient perspectives to the forefront is thus of great concern in our research. We propose a focus group format in which patients are prompted to explore their prior ideas and knowledge about AI through interactive group activities. For this purpose, we design probing kits composed of simple and playful tasks, such as a collective mind mapping, to elicit responses and stimulate discussion in a non-hospital setting (Burgess-Allen & Owen-Smith, 2010; Mattelmäki et al., 2016). Additionally, we present them with a specific case study in order to gauge more concrete views on AI decision-making tools. Throughout the group discussions, participants will be able to share their perceptions, existing knowledge as well as an absence of knowledge on AI in general and AI in healthcare. We therefore aim to develop a mutually beneficial relationship with participants (Fiske et al., 2019), in which they can learn more about AI in healthcare through engaging in the focus group.

3. Methodology

Our research design comprises a mixed-methods approach, in which the first step was a literature review on prior studies regarding patient perspectives. Relevant, recent articles were identified through keyword searches (e.g., *patient perspectives, artificial intelligence, patient participation*) and sourced from databases such as PubMed and Science Direct. We identified problems in the approaches of prior research, namely a lack of democratic and emancipatory patient empowerment, as well as the conducting of surveys and interviews in hospital settings. We subsequently decided to use a qualitative method in our own research to gain in-depth understanding of patients' attitudes and beliefs towards AI in healthcare. In contemplating whether to use one-on-one interviews or focus groups, we considered focus groups particularly

useful as they allow an investigation of collective priorities and emotional concerns (Berg & Lune, 2018). They furthermore provide a platform which can empower participants who find strength and comfort in numbers (Lloyd-Evans, 2006), which is especially useful when dealing with vulnerable participants such as patients. As a focal point of our research concerns patient education, a discussion and knowledge exchange between participants was also deemed valuable for their individual development. The proposed framework is thus a focus group format wherein patient perspectives on how AI should, or should not, be implemented in healthcare practices and the state of patient education are of primary interest.

In designing a focus group, we included the following elements as outlined by Berg and Lune (2018): a statement of the interview guidelines; an opening or introductory question; and special activities and exercises to stimulate discussion. As our aim was to find out more about patient attitudes and their existing knowledge, the focus when designing the activities was on experience and knowledge exchange. During this process, we conducted a trial focus group which involved five volunteer, non-patient candidates affiliated with Maastricht University and found through convenience sampling. The purpose was to test the effectiveness of our initial focus group design and to determine whether the included activities led to the kinds of responses that would inform our research question. The trial focus group consisted of several activities aimed at stimulating discussion amongst the candidates about AI and healthcare. The trial focus group began with an introductory question of how AI is portrayed in literature, art, or films that the candidates may have encountered in the past, and whether these portrayals shape the way candidates currently view AI. The next activity we carried out was a 'taboo game', where participants had to describe a certain AI-related word presented on a card without using a particular list of five words. The final activity of our trial focus group was a collective mind mapping exercise, where candidates were asked to brainstorm concepts, issues, and questions related to AI and healthcare.

The trial focus group was an integral part of the design process of our focus group, because it allowed us to test whether the included activities were effective, and whether these activities generated the kinds of responses that would inform our research on patient perspectives of AI in healthcare. The trial focus group helped us realise several changes we needed to make to our focus group design. One raised concern was that the procedure of the focus group was too unclear during the trial. As Beier et al. (2019) point to the importance of making the aim and extent of patient participation clear and transparent, a more explicit explanation for patients was needed. During the taboo game, words like 'algorithms' and 'image recognition' were guessed rather rapidly due to some of the participants' background

in AI-related research, yet a term like 'machine learning' was more difficult to explain. We decided to keep the level of difficulty the same in our final proposal since patient backgrounds may vary and their explanations hence cannot be easily predicted. Most importantly, during the mind mapping exercise most terms revolved around AI (see Figure 1). We realised that the trial focus group was too heavily focused on AI itself, and not sufficiently focused on the application of AI in healthcare. Therefore, we decided to incorporate more healthcare related words into the taboo game. We further recognised that we needed to stimulate more specific discussions about the application of AI in healthcare, as the conversations throughout the trial were rather general and unfocused. To do this, we decided that a case study was needed to learn about perspectives on the promises and risks of the application of AI in healthcare without steering them in any direction. A case study has thus been implemented in our final proposal to gauge attitudes towards a particular scenario.

Figure 1

Mind map created in the Trial Focus group
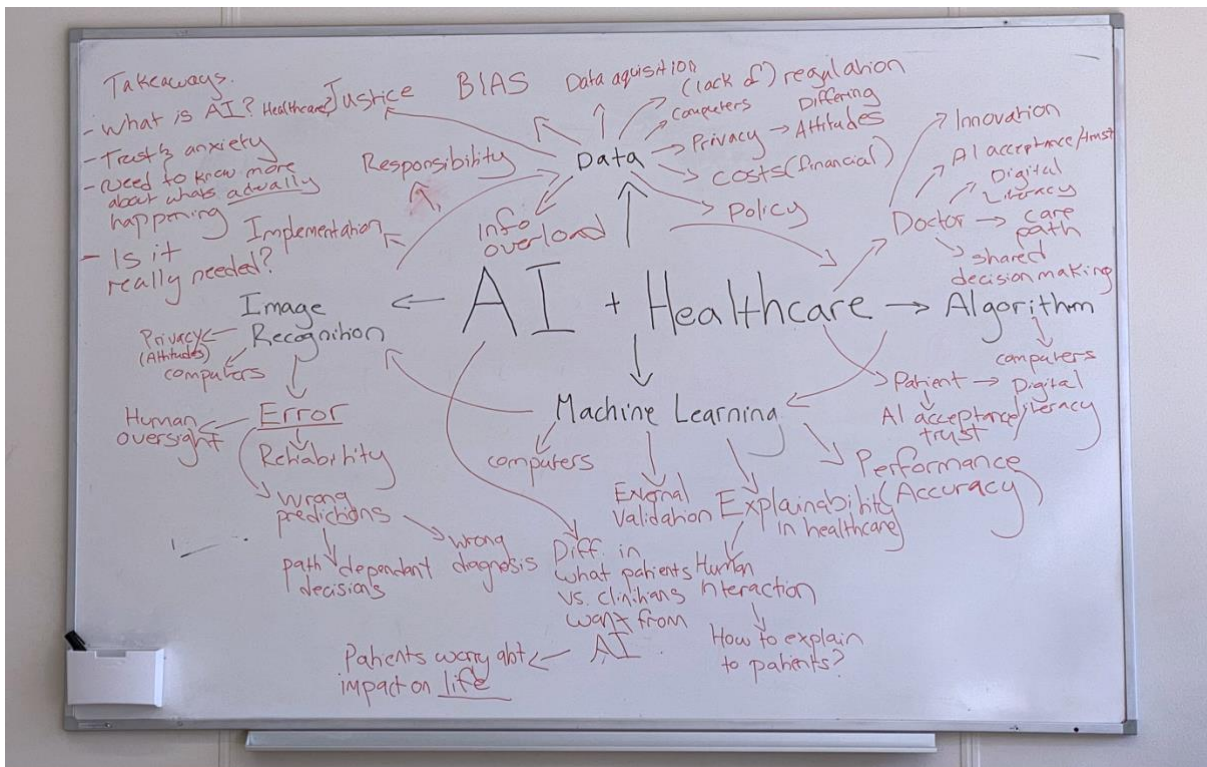
After reflecting on the trial focus group and re-evaluating our research design, we scheduled a meeting with a PhD candidate in radiotherapy at the Faculty of Health, Medicine,

and Life Sciences at Maastricht University. The purpose of this meeting was to gain further insight into a new type of therapy, namely proton therapy, as a treatment for cancer patients. We were particularly interested in the application of AI in selecting which patients are eligible for this type of therapy. During the meeting, we discussed the role of AI in selecting patients for the therapy. We found that patients are selected based on their likelihood of developing certain complications when treated with a photon or a proton treatment plan, and that this selection is done entirely by a computer. Furthermore, we discussed the patient's role in the selection process, and whether they are informed about the use of AI prior to undergoing the therapy. We found that there is difficulty determining what exactly is regarded as AI. In the case of proton therapy, the AI used is just a model, and what happens in the model is clearly shown. Additionally, this procedure is still relatively new, so patients are simply informed when they are eligible and are given the choice whether they want to undergo the therapy or not. However, proton therapy is becoming increasingly prominent, and patients often read about the therapy and want to find out whether they are eligible. Therefore, once proton therapy is sufficiently utilised in clinical settings, the issue of AI selecting which patients get to undergo the therapy and which patients do not will become critical. This decision-making AI serves as a good case study for our focus group as it will stimulate a more focused discussion on AI applications in healthcare.

4. Proposal for a Focus Group Format

4.1 Position in Patient Participation and Empowerment Context

To cope with the pressing issue of how to inform patients about the involvement of AI in healthcare, a framework that investigates patients' attitudes will be proposed in this section. So far, patients appear to be rather neglected regarding the consideration of their views and concerns. Thus, literature on the inclusion of patients in the process of developing and implementing Artificial Intelligence in healthcare is rather limited. However, to determine attitudes and concerns by patients it is vital to have actual input from the people affected by AI in healthcare, be that the treatment of a disease, the analysis of a disease or the selection or prioritisation of treatment. Citizen science highlights this importance and shows that citizens', in this case patients', input is valuable and fruitful (Sok et al., 2009). It puts citizens to the foreground and sees them as part of solving the problem. This also relates to the different types

of patient empowerment outlined by Prainsack (2018), whereby this proposal specifically focuses on the types of democratic and emancipatory empowerment of patients. Democratic empowerment entails an extension of the amount and variety of decision makers, which means more people are invited to the table to make decisions that not only concern doctors but especially patients. Meanwhile, emancipatory empowerment deals with breaking down oppressive hierarchies. Here, the focus lies on the power of a patient. An empowered patient could, for example, own their health data and deal with it themselves.

This proposal aims to encourage patients into such directions, as it is important for affected people to participate in decisions that influence them, their lives, and their social environment. By using the suggested framework, it can be investigated how patients are positioned in the current situation to then determine what needs to be done to possibly become a democratic or emancipated patient. A focus group has thus been developed which aids in finding out how patients view issues surrounding the mentioned topics. Focus groups are beneficial for this respective research because they do not only give insight into how something is happening but also why (Berg & Lune, 2018). Rather than merely finding out what patients think of AI in healthcare, this might help researchers to investigate the reasons behind certain attitudes. For example, one could more easily find out why patients have a rather positive, negative, or neutral stance on AI in the outlined healthcare processes and services. The proposed focus group further aims to stimulate discussion amongst patients about their understanding of AI and healthcare and comprises several activities which can in turn educate patients about AI and its potential use in healthcare. We thereby strive to establish a mutually beneficial relationship between researchers and participants. The following will describe the outline of the proposed focus group and the respective steps that are taken to investigate patients' attitudes.

4.2 Step-by-Step Overview of the Focus Group

It is proposed that the sampling for the focus group should not solely rely on patients but be extended to patients and their loved ones. These are an integral part in the development or treatment of and coping with certain diseases. Moreover, the sample should include people from different backgrounds, as to allow for a diverse range of perspectives and to be representative of the patient population. The proposed setting is, if possible, outside of a hospital due to the negative connotations an ill person or their loved ones might have. This

way, they should be more open to the posed questions and prompts and are not exposed to a setting which could negatively affect their experience of participating. Researchers following the framework should be free to decide whether patients and loved ones are included into one universal focus group or be separated into respective ones. Before the focus group starts, the interviewers must assure every participant of anonymity and confidentiality and ask for consent to document or record information disposed by participants. Illness being a rather personal and sometimes private topic which may arise during the case study element, the option to not answer should be provided at any stage of the focus group. Additionally, transparency about the research aims and extent of participation is crucial (Beier et al., 2019), hence the explanations preceding the questions must clearly outline the procedure of the focus group.

The first aim is to understand what participants think AI is and does. The proposed focus group therefore begins with an introductory discussion round. Here, participants are prompted to have an open and plenary discussion about their respective conceptions of Artificial Intelligence. They are prompted with the question whether they have encountered AI in art, movies, books, or other media before, and if so, how AI was portrayed. Through this, researchers can determine variances in patients' definitions already and see whether some might need aid in understanding certain concepts revolving around AI. A follow-up question inquires whether the encountered narratives have shaped the way participants look at AI. The introduction round thus points to how patients are experiencing the depiction of AI and how that might shape their perspective on it. As we are dealing with patients, we consider it best to keep the opening question general and AI-focussed as to not immediately bring up the potentially sensitive topic of healthcare and related issues.

Rather than having participants answer pre-determined survey or interview questions, our aim after the introduction is to provide them with a platform for open deliberation. As such, the following activities are simple and foster a collaborative learning process (Mattelmäki et al., 2016). First, a so-called taboo game is proposed. Inspired by the actual game *Taboo* (*Taboo*, n.d.) participants in this exercise should explain words without mentioning certain phrases or words. In this respective case, the terms should revolve around AI, healthcare, and AI in healthcare. The aim is to gain insight into how patients describe and explain concepts to others, which exposes their pre-existing or lack of knowledge on the topics. Especially with rather vague terms such as AI, this is highly informative. Example words such as 'machine learning' (Figure 2) that were used in our trial focus group showed that many people struggle with explaining terms revolving around AI and the restriction of using words such as 'data' or

'algorithm' reinforced that. Researchers conducting this focus group may choose different words or adjust the level of difficulty.

Figure 2

Taboo Game – Proposed cards containing AI and Healthcare terms

Algorithm	Machine Learning	Image Recognition
Data	Artificial Intelligence	Artificial Intelligence
Network	Algorithm	Automation
Artificial Intelligence	Robot	Computer
Programming	Data	Algorithm
Social Media	Neural Networks	Machine Learning

Healthcare	Radiologist	Treatment	X-Ray
Domain	Doctor	Therapy	Bones
Doctors and Nurses	Radiology	Cure	Scanning
Illness / Disease	Scanning	Disease	Radiology / Radiography
Hospital / Clinic	Cancer / Toumours	Doctors and Nurses	Radiation
Medicine	Medical Imaging	Hospital / Clinic	Machine

After the taboo game, researchers could use specific examples where AI is used in healthcare. A case study functions as an illustration of what has been discussed thus far in the process and should prompt participants to a more specific and concise description of their opinion. Because neutrality is a rather hard to obtain goal in such discussions, especially after some input has been given already, we propose to outline two scenarios, one rather negative and one rather positive. Wording can easily change the perception (Labrador et al., 2014) of participants which is why it was decided to go into both directions. One such case study may be the use of AI in decision-making on proton therapy, as is the case at a radiation therapy clinic in Maastricht. A simple example for two vignettes could be the description of this selection process. In one scenario, one could describe how patients get carefully selected through a scheme that determines who is most eligible for a treatment based on risk factors (positive). In another scenario, one could state that an algorithm decides who will be prioritised and who will be left waiting for treatment (negative). When confronted with both negative and

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positive framings, a collective exploration can be conducted in which participants together investigate which factors influence their position.

The respective insights from these sections are to be gathered in the end with a collective mind map. Concepts and questions that arose during discussions, or which participants find important in hindsight, are put on the board. Everything that has been discussed might be stated again by participants and they have room to describe their stances and opinions on topics that come up. The development of this step is different per focus group because of the individuality of the previous discussions. Depending on the case study, results for the mind map might differ, too. Overall, this activity allows for a visual expression of what patients know about AI in healthcare, what they have learnt from their participation, and in which areas they still lack knowledge or information. Together, these steps (Figure 3) build our proposed focus group and aid researchers in investigating notions, stances and opinions of patients and their loved ones. The execution of the framework might differ from this proposal for different researchers and purposes, yet this serves as a solid base of orientation.

Figure 3

Proposed Steps for the Focus Group

1: Introduction	2: Taboo game
"Have you encountered AI in (fictional) media before? If so, how was it portrayed?" "How have these narratives shaped the way you look at AI?"	Explaining AI- or Healthcare- related concepts without using 'forbidden' words
3: Case study	**4: Mind mapping**
Collaborative exploration of positive and negative framings of AI in healthcare	Collective visual representation of concepts, questions, and prior discussion

5. Conclusion

AI tools are becoming increasingly prominent in various clinical applications, especially in the recognition and interpretation of medical images. Patients are likely to greatly benefit from AI usage in healthcare in the future as AI offers many promises of speed and accuracy. However, the harmful potential of using AI systems in medical imaging is a pressing issue. Patient perspectives on the implementation of such AI in health practices are still neglected in existing literature. Moreover, research often follows an instrumental empowerment approach to patient participation, whereby the primary incentive is improving AI innovation. Our study instead aims to find ways of putting patients and their concerns first. As such, this paper has presented a focus group proposal aimed at gathering the in-depth perspectives of patients and their loved ones through a series of activities. We suggest the following exercises: an introductory discussion about participants' experience with AI narratives; a taboo game of explaining AI- and Healthcare-related concepts; a collective exploration of a specific case study on AI applications in healthcare; and collective mind mapping. The suggested format stimulates critical discussion about the application of AI in healthcare and fosters individual education in participants through knowledge exchange within discussions. The purpose of this study is to empower patients and to give them a voice in decision-making processes that ultimately concern their well-being.

The limitations of the suggested proposal are as follows. Firstly, the application of AI is relatively new, so the scenarios presented in the focus group are not concrete, but more abstract and future orientated. Secondly, patient perspectives vary across geographical locations, levels of education, socio-economic backgrounds, as well as personal outlooks. Thus, the results of this study may vary significantly across different samples. Thirdly, the time constraints of the focus group may affect the results, as patients will have a limited time to reflect on the issue and form their opinions. Finally, access to the research subjects may pose a problem for data collection, as patients may be unavailable or simply refuse to participate in a focus group study, especially if they are undergoing treatment for various conditions.

The focus group proposal provides opportunities for future research. To get more insight on patient education regarding AI technologies, it could be beneficial to conduct in-depth interviews with doctors. Doctors may provide their perspectives of how (hypothetical) AI may fit into existing practices. They could furthermore reveal what conversations between doctors and patients look like, and how patient perspectives may be influenced by doctors' own standpoints towards AI applications in health practices. Moreover, future studies may

investigate alternate activities to stimulate focus group discussions depending on the researchers' needs or study population. Our taboo game provides a platform for patients to explore their conceptions of AI and share these verbally. This allows insight into their understanding of difficult concepts and how they use language and vocabulary to reason their ideas. Visual methods, such as conceptualisation through LEGO bricks, may instead allow participants to easily communicate and share ideas without the potential pressure of having to verbalise the perfect answer to a complex issue. It could ground their ideas in models, thus enabling them to work out their thoughts through physical interactions with bricks.

The results from studies using this framework could inform healthcare institutions to what extent key stakeholders, namely patients, accept the use of AI in clinical practices, as well as where they draw the line regarding the risks involved. Most importantly, the format provides grounds for democratic and emancipatory patient empowerment. Participants from diverse backgrounds can come together and exchange their pre-existing knowledge. Researchers gain insight into the reasons behind patient preferences and needs, while the participants themselves benefit by learning from discussions with peers and having a voice in critical debates. This may enable a move from individual consent and consultation practices for instrumentalist purposes, to involving patients as co-decision-makers and ascribing intrinsic value to patient participation.

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