

Running head: CHILDREN & YOUTHS' VIEWS OF AI IN HEALTHCARE

Understanding Children and Youths' views of Artificial Intelligence in Paediatric Healthcare.

Sarah Kiley-Watkins



This report is submitted in partial fulfilment of the degree of Master of Psychology (Health)

School of Psychology
University of Adelaide

October 2022

Word count: 7989

Table of Contents

Declaration.....	ii
Statement of Contribution.....	iii
Author's Acknowledgments.....	iv
Journal <i>Health Psychology</i> Cover Page.....	v
Abstract	vi
Introduction.....	1
Overview of AI and AI in healthcare.....	2
Public Perspectives in Clinical Decision-Making, Accountability and Patient Choice.....	3
The Current Study.....	8
Method.....	10
Participants.....	10
Materials.....	11
Vignettes.....	11
Design.....	12
Procedure.....	12
Reflexivity Statement.....	14
Results.....	15
Theme 1: While AI supports clinical decision-making, it remains the doctor's responsibility to communicate AI recommendations.....	15
Theme 2: Preservation of Patient Choice.....	16
Theme 3: Parental Influence in Consent and Decision-Making.....	17
Theme 4: Indecisions Around Accountability when AI makes Mistakes.....	18
Theme 5: Enthusiasm for AI Programs and Engaging in Health Research if information remains private.....	20
Discussion.....	22
Limitations.....	26
Conclusions.....	27
References.....	29
Appendix A: Ethics Approval Certificates.....	36

Declaration

This dissertation contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, contains no materials previously published except where due reference is made. I give permission for the digital version of my dissertation to be made available on the web, via the University's institutional digital repository, the Library Search and also through web search engines, unless permission has been granted by the School to restrict access for a period of time



Student ID: 

October 2022

Statement of Contribution

The current research project was completed by [REDACTED] (S.K.W), under the supervision of Associate Professor [REDACTED] (R.R) and [REDACTED] (G.M), while enrolled in the Master of Psychology (Health) program, at The University of Adelaide.

The research project was one of two student projects being led by R.R and included Ms [REDACTED] [REDACTED] (N.W).

The ethics application was completed by S.K.W and N.W with the assistance of R.R and G.M and was approved by the Women's and Children's Health Network (WCHN) Human Research Ethics Committee on 8 February 2022 and the University of Adelaide Ethics Committee on 31 March 2022. A site-specific assessment for the WCHN was also approved on 25 February 2022.

The specific aims, study design and choice of measures were pre-determined by the team at SickKids Toronto, with Dr. [REDACTED] (M.C) as the principal investigator. The specific research questions for this project were determined by S.K.W with input from R.R and G.M. The method and data analysis plan were in collaboration with N.W, R.R and G.M.

S.K.W and N.W were responsible for recruitment which involved interviewing participants and transcribing audio files verbatim. S.K.W was solely responsible for data analysis in this research project, which involved highlighting codes and identifying themes.

The written material presented here is the author's own work, with support and guidance from R.R and G.M.

I Sarah Kiley-Watkins, hereby declare that the above statement of contribution is true and accurate.

Author's acknowledgements

I would like to thank my primary supervisor Associate Professor [REDACTED] for her support and guidance throughout this process. I would also like to thank my secondary supervisor, [REDACTED], for his expertise on artificial intelligence. Additionally, I would like to thank the team at SickKids Toronto, specifically Dr. [REDACTED] and [REDACTED] [REDACTED] for their assistance in providing the necessary measures and tools to complete the study. Lastly, I would like to thank Ms [REDACTED], particularly for her contribution in the recruitment process and ongoing support.

Understanding Children and Youths' views of Artificial Intelligence in Paediatric Healthcare.

Sarah Kiley-Watkins¹

¹School of Psychology, The University of Adelaide

Author Note

There is no known conflict of interest to disclose.

Correspondence concerning this article should be addressed to [REDACTED], The University of Adelaide, North Terrace Adelaide, SA 5005

This article is intended for submission to the American Psychological Association Journal, 'Health Psychology' which adheres to the APA 7th edition reference style. At present, the article has been written according to the Master of Psychology (Health) thesis requirement of 6,000-8,000 words but will be edited prior to submission to meet the 30 pages specified by Health Psychology.

Abstract

Objectives: Artificial Intelligence (AI) is changing medical practice. Given patients are the intended beneficiaries of health AI, understanding the views of patients and families is essential to AI being adopted and accepted into healthcare settings, as well as ensuring implementation is done so ethically. While studies have focussed on adult perspectives of health AI, none have yet examined the views of children and youth. This study therefore explored how children and youth view the use of AI, with particular focus on ethical concerns regarding clinical decision-making, accountability, and preservation of patient choice.

Methods: In this qualitative study, children and youth were recruited from April to August 2022, through the Women's and Children's Health Network, Adelaide, South Australia. Three vignettes that sought participants views on hypothetical situations around potential AI applications were used and presented in semi-structured interviews. **Results:** Participants ($N = 6$) demonstrated mixed but mostly positive views of AI in healthcare. There was general support for AI tools to support clinicians in decision-making, but most emphasised the need for human oversight. Accepting AI into healthcare was also contingent on patient choice, with unanimous agreement that patients under the age of 18 had the right to choose if AI comprised part of their healthcare. There were mixed views around accountability of mistakes but general enthusiasm for engaging in health AI research and trialling novel AI programs. **Conclusions:** Overall, this research identified critical areas for regulators to ensure perspectives of children and youth are included in implementation plans of health AI.

Keywords: Children and youth, artificial intelligence, patient perspectives, medical ethics

Artificial Intelligence (AI) is changing medical practice. AI and its subfield, machine learning (ML), enables computers and machines to learn how to perform complex tasks autonomously (Australian Institute of Machine Learning [AIML], 2022). This has the capacity to meaningfully impact millions of patients by providing support to clinicians in clinical decisions, disease diagnosis, and treatment management (Davenport & Kalakota, 2019). While there is enthusiasm for the use of AI in healthcare from both patients and service users alike, how these technologies are implemented into clinical practice ethically remains a central concern (McCradden et al., 2020). Healthcare is a complicated, safety-critical field in which technological failures can lead to patient injury (Habli, Lawton & Porter, 2020). Therefore, current trends in AI use have brought about ethical concerns regarding patient choice, autonomy and accountability, as digital tools introduce ambiguity into clinical practice (Naik et al., 2022). The success of AI in clinical practice largely depends on acceptance from the public (McCradden et al., 2020). Consequently, an understanding of the public's views and beliefs around the potential benefits and harms of AI is fundamental.

There has been increasing engagement with patients and service users who will be impacted by AI in healthcare (Richardson et al., 2021). However, these studies have largely focussed on adult views and perceptions (McCradden, Sarker, & Paprica, 2020; Nelson, et al., 2020; Ongena, Haan, Yakar, & Kwee, 2020), with few studies focussing on adolescent views (Aicken et al., 2016). To date, no research has explored the views of children and youth (from here referred to as young people and reflects people under the age of 18) regarding AI in paediatric healthcare. Given patients are the intended recipients of AI innovations (McCradden et al., 2020), this population should be involved in the AI research agenda to ensure that their needs are addressed in an ethical way and considered during the development phase of digital tools. This study therefore aims to explore young peoples' values, beliefs and understanding of AI in healthcare. The research is intended to set an

agenda for education and engagement, with particular focus on young peoples' ideas around ethical concerns of clinical decision-making, accountability, and preservation of patient choice.

The subsequent sections in this chapter will be set out as followed. First, a review of AI and AI in healthcare. Second, a discussion of the public perspectives around clinical decision-making, accountability, and patient choice. Third, the current study will be outlined, followed by the research questions.

Overview of AI

Modern AI has accelerated in the last decade. Driven by an increase in availability of data sets, advanced algorithms, and developments in storage such as cloud computing (Gerke, Minssen, & Cohen, 2020), AI has become a popular tool, particularly in the field of ML (SAS, 2022; Isbanner, O'Shaughnessy, Steel, Wilcock, & Carter, 2022). For this paper, AI will be broadly conceptualised consistent with the AIML as a 'form of ML that involves teaching computers what to do by feeding examples of data and information' (AIML, 2022). By providing the computer with extensive examples, AI examines patterns of 'big data' and improves future decisions with the aim that the computer will learn automatically, complete complex problems, and perform tasks without human assistance. This automation has created advancements in every sector from marketing, agriculture, customer service and healthcare (Davenport & Kalakota, 2019).

While initially slow to adopt AI, there has been rapid exploration and development of ML across the field of medicine (Isbanner et al., 2022; Nelson et al., 2020). Clinical fields in areas of decision-making, disease diagnosis, and treatment management have seen particular advancements in AI (Davenport & Kalakota, 2019), given early detection, accurate diagnoses, and proper medical management can have lifesaving potential and reduced

healthcare costs (Sunarti et al., 2021). Certainly, AI has been advantageous in supporting clinical practice and informing best practice patient care, as these technologies provide clinicians with up-to-date medical information (Jiang et al., 2017). However, the ability to examine and learn large volumes of medical and patient data sets means that AI has the potential to perform as a human would, but more efficiently, effortlessly and at a reduced cost (Sunarti et al., 2021; Wadden, 2021). This has led to debates between experts and academics as to whether AI may eventually replace specialised doctors altogether (Hazarika, 2020).

Public Perspectives in Clinical Decision-Making, Accountability and Patient Choice

It is unlikely that AI will replace humans in the foreseeable future, however, these arguments raise the question of whether AI could be superior to the medical team in making clinical decisions and diagnoses. Clinical decision-making is a balance of expertise, collecting evidence, understanding patient symptoms, and performing physical examinations to make an informed decision (Liu, Keane & Denniston, 2018). While clinicians are skilled in clinical decision-making, Simpkin, Vyas and Armstrong (2017) argue that humans are susceptible to cognitive bias, inadequate knowledge, and fallible memory. Conversely, AI bases decisions on evaluations of masses of data and medical evidence relevant at that point in time (Simpkin et al., 2017). While AI can assist clinicians to make improved decisions, Davenport and Kalakota (2019) argue it has the potential to be more effective in providing highly accurate and credible diagnoses while replacing human judgement altogether. Accordingly, AI could eventually outperform human clinicians in both speed and precision when making clinical decisions.

Certainly, accuracy and efficiency are fundamental in decision-making, however effective decisions also require careful consideration of a patients hopes, fears and expectations (Liu et al., 2018). This requires open-ended, empathetic, and meaningful

conversations with patients, which no existing AI has yet to skilfully master. Consequently, the central question may not be 'Can this machine make a diagnosis' but 'Do I want this machine to make a diagnosis?' Lie et al. (2018) argue that at some point AI will be able to simulate empathetic listening; however, it is necessary to ask, as the patient, 'Do I want to share my information with a machine?' and more importantly, 'Do I want a machine to be the first to tell me about a serious diagnosis?' In answering these questions, it is therefore fundamental to understand patient perspectives in the adoption of AI in clinical decision-making, as this could ultimately affect how people engage in healthcare and manage treatment plans.

Several studies have explored the attitudes of patients towards AI in clinical decision-making. A qualitative study by Nelson et al. (2020) found a dominant theme amongst focus groups was the importance of a mutual relationship between humans and AI, where AI should only be used as a tool to provide second opinions. Similarly, a large-scale Australian study by Isbanner et al. (2022) found respondents considered human contact to be fundamental in healthcare; while they respected the idea of accurate diagnoses made by AI, they greatly valued human connection. A systematic review of 23 studies by Young, Amara, Bhattacharya and Wei (2021) found most participants envisioned AI as a second opinion for clinicians and a means to double-check recommendations to ensure safety. A web-based questionnaire found overwhelming support for AI in healthcare, with respondents expressing confidence in AI decision-making. However, most believed it should not replace a clinician. A study on cancer patients in China by Yang, Zeng, Peng, and Jiang (2019) found that despite having confidence in treatment advice made by AI, if the advice from a human clinician was different, patients would be more willing to take the clinician's recommendation. In contrast, a study by Xu, Bryant, and Howard (2018) found participants would be willing to blindly trust a robot to guide them through a rehabilitation program.

Arguably, this finding was the result of using an interactive robot that represented a human interaction and not expressed as a computer (i.e., nonhumanoid). Taken together, the literature proposes that patients consider AI to be a tool that requires human oversight. While AI can support humans in clinical decision-making, it is ultimately the responsibility of the doctor to relay information to ensure patient safety.

The prospect of patient harm caused by decisions made by AI is challenging standard clinical practices. While the medical team is held accountable for their actions, it is less clear when AI makes mistakes considering AI in itself cannot be held accountable for misdiagnosis or suggestions that result in patient injury (Esmailzadeh, Mirzaei & Dharanikota, 2021). Habli, Lawton, and Porter (2020) argue it is unreasonable to always hold human clinicians accountable for patient harm when AI is used in decision-making. First, clinicians do not retain direct control over AI recommendations. Second, many AI systems are 'opaque', meaning recommendations cannot often be explained. Alternatively, Naik et al. (2022) argue that clinicians hold some responsibility should they implement suggestions made by AI. Given then the use of technology limits the ability to attribute blame and take ownership of clinical decisions (Tigard, 2020), AI could result in vague understanding of who to hold accountable when harm is done. Esmailzadeh et al. (2021) argue that this could ultimately discourage patients from choosing AI in their healthcare and discourage service providers from applying AI to their decisions.

To understand this further, studies have explored patient and provider perspectives around accountability in AI decision-making. A qualitative study by Richardson et al. (2021) found adult patients were comfortable with AI having some responsibility in clinical decision-making, however many felt strongly that it was the doctor's responsibility to make the final checks over treatment plans, as this would likely mitigate any potential harm that might result from a mistake made by AI. A qualitative study by Lai, Brian and Mamzer

(2020) found that physicians (i.e., surgeons, radiotherapists, dermatologists) were willing to accept responsibility for mistakes made by AI, only if they could clearly understand and interpret the recommendations. For them, AI was a tool to support clinicians with their decisions, not replace them. Moreover, a study by Esmailzadeh et al. (2021) exploring differences between patients with acute and chronic conditions found that patients with acute conditions were significantly more concerned about accountability when using only AI clinical applications that did not have clinician oversight. Arguably because acute conditions have distinct symptoms that require urgent or short-term care; therefore, patients potentially felt anxious not knowing who was responsible for reliable treatment plans. Lastly, a qualitative study by McCradden et al. (2020) exploring the views of patients and caregivers found that half of participants expected mistakes to happen but felt it inappropriate to delegate responsibility to AI, advocating for shared decision-making. Altogether, these studies highlight the importance of clinicians having final oversight to ensure patient safety. From patients to service users, it appears that the general view is that the patient-doctor relationship should remain central to patient care.

Patient-centred care is fundamental in providing safe, high-quality healthcare. Rather than a passive bystander, patients are considered active partners in treatment planning, with the right to choose and control their medical decisions (Amann et al., 2020). A central component of patient-centred care is shared decision-making, where a clinician and patient engage in open conversation about best treatment options for the patient (Barry & Edgman-Levitan, 2012). With the clinician outlining risks and benefits associated with suitable treatment options and the patient expressing their values and priorities, patients can make informed and autonomous decisions (Bjerring & Busch, 2021).

Patient autonomy is one of the core principles of medical ethics. Autonomy refers to a person's right to make decisions about their own medical care and is represented by informed

consent, where a patient chooses to authorise a doctor to perform a medical treatment after all risks and benefits are outlined (Pugh, 2020). At present, there is no ethical consensus as to whether disclosing the use of AI algorithms should be mandatory of informed consent (Amann et al., 2020; Naik et al., 2022). However, Amann et al. (2020) argue that a failure to disclose the use of AI in healthcare would undermine a patient's autonomy and adversely impact the doctor-patient relationship. In turn, this could negatively impact people's perceptions of AI, as well as reduce compliance with clinical recommendations (Naik et al., 2022). Trust in technology is therefore critical given the information it provides might have life and death implications. Subsequently, Triberti, Durosini and Praverttoni (2020) argue a condition of shared decision-making is full autonomy of the patient, which can only be achieved if the patient is offered a variety of meaningful options, are informed about the technologies being used, and given the right to choose if AI forms part of their healthcare.

Currently there is limited research exploring patient choice around AI in healthcare. Additionally, the few studies that have explored patient perspectives have limited sample sizes. In a qualitative study with 87 adult participants, Richardson et al. (2021) found that preservation of patient choice was fundamental. The right to choose or reject AI involvement, as well as dispute or correct AI recommendations was important for participants overall comfort of incorporating AI into healthcare. Similarly, in a qualitative study with 41 adult participants, McCradden et al. (2020) found most people felt it fundamental that they be fully informed of AI tools so that they can provide informed consent and be given the option of opting out. Together these studies propose that people want the right to choose if AI is applied to their treatment. Furthermore, their willingness to trial and trust AI depends on understanding what technologies are being used, as well as allowed the option to 'opt-out' should they choose.

Given patients are the intended beneficiaries of health AI, understanding their views and beliefs are essential to AI being adopted within healthcare settings. Isbanner et al. (2022) argue that for any significant change in service provision, the perspectives of consumers should be considered both before and during implementation of AI, if it is to be supported and trusted amongst the public. Furthermore, Richardson et al. (2021) argue that policymakers require high-quality evidence around what people consider acceptable and unacceptable if AI is to be implemented in an ethical way that improves patient care. Consequently, there is an ethical responsibility to ensure that the public's views, perspectives, and values are considered in health AI implementation plans.

The current study

Recently there has been an increase in studies exploring adult views on ethical issues concerning health AI. Studies have focussed on the views of AI in health professionals from dermatologists (Polesie et al., 2020), radiologists (Eltorai, Bratt, & Guo, 2020) and general practitioners (Blease et al., 2019). Studies have asked patients to imagine using AI in skin cancer diagnoses (Jutzi et al., 2020; Nelson et al., 2020); neurosurgery (Palmisciano et al., 2020) and diabetes screening (Keel et al., 2018). Further studies have explored public perspectives of health AI in Canada (Paprica, De Melo, & Schull, 2019); China (Yang et al. 2019); and most recently Australia (Isbanner et al., 2022). While the literature has provided meaningful views of adults, none have yet explored the views of AI in healthcare amongst young people.

Childhood studies have highlighted that young people are often excluded from participation in research based on dominant developmental paradigms which consider young people 'too immature' or 'incapable' to contribute to decisions that affect them (Green & Hogan, 2005; Wall, 2010). To overcome this, adult populations are often investigated to

generate knowledge which is then used to generalise to younger populations (Carnevale, 2021). However, this dominant paradigm disregards young people's experiences, autonomy, and moral status, as well as imposes adult frames of reference (Gheaus, Calder, & De Wispelaere, 2019). Given young people are key informants and experts on their own lives (Harris & Manatakis, 2013), they are likely to hold different views and values regarding ethical issues of autonomy, decision-making and choice, particularly as parental involvement is greater in clinical care (Aarthun, Oymar, & Akerjodet, 2019). It is therefore critical that young people are meaningfully engaged in research to help shape the future of AI in paediatric healthcare and help guide education initiatives that reflect their voices.

The aim of the current study was to therefore understand how young people view the use of AI in healthcare. To identify sources of excitement and concern about AI, this research intends to set an agenda for education and engagement of this population. Research questions centred around dominant ethical concerns regarding clinical decision-making, accountability, and patient choice.

Research questions:

- Whose opinion do young people trust in making clinical decisions (i.e., the doctors or AI)?
- What are concerns/ hopes about using AI to make clinical decisions?
- When AI makes mistakes in clinical decisions, who do young people consider responsible?
- What should be considered around patient choice, if decisions around the use of AI conflict with parents/ the medical team?
- What do young people consider important in understanding choice and autonomy when using novel AI programs?

Method

Participants

Participants were recruited from April to August 2022, through the Women's and Children Health Network (WCHN) Adelaide, South Australia. The WCHN has both a Consumer Advocate Group (CAG) and Youth Advisory Group (YAG) who have previously been invited to participate in studies. The CAG consists of 82 adults; 18 are current consumers; 27 are a relative/ parent of a consumer; and 37 sit on regular committees. The YAG consists of seven young people, under the age of 18, who provide comment, ideas and research on areas relating to paediatric healthcare (Standfield, 2020).

To be eligible for the current study, participants had to be at least ten years of age and no older than 18 years. They were currently or had previously received care at a paediatric hospital or rehabilitation clinic related to any medical condition. They needed to communicate independently, have access to technology to complete the virtual interview and capacity to consent to research. Exclusion criteria were over 18 years of age and not fluent in English (given the nature of the semi-structured interview). No prior relationship existed between the participants and the interviewers. Participants were aware that the interviewers were students (S.K.W and N.W) from the University of Adelaide completing a Master of Psychology (Health) research project in AI and healthcare, as part of a larger study with the AIML and WCHN. Participants were also aware that a parallel study was being completed with SickKids Toronto who have collected their own data. Any aggregated themes will be compared between sites, and this will be completed by the AIML. Following the interview, participants were reimbursed a \$35 gift card, issued by the School of Psychology at the University of Adelaide.

From ten people who expressed interest in the study, six participants (girls = 66%, $M = 13.6$, $SD = 3.01$), were included in the sample. Two potential participants did not respond after initially signing the consent to contact form, while two did not respond to further correspondence following the consent phone call.

Materials

Semi-structured interviews were conducted by either student (S.K.W and N.W.) (both women). Interviews were completed virtually through Microsoft Teams or Zoom with each participant individually. Interviews were approximately one hour in length. Interviews included collection of baseline demographic information (age, year of school, postcode, and experience in the health care system), followed by a short presentation introducing AI and three vignettes (described below). All participants provided written informed consent. For young people under the age of 16, parent/ caregivers (from here referred to as parents) also provided written consent for their child to participate.

Vignettes. Age-adjusted vignettes (stories) with accompanying images were used to engage participants on the central themes of the study. Three vignettes were used and included hypothetical situations that could occur with the use of AI in healthcare. Each vignette took approximately 15 minutes to discuss and introduced three patients aged between 12 to 16 who were in hospital for varying conditions (i.e., depression, lung problems and food poisoning). The first introduced the concept of AI research and consent for using patient information. The second discussed incorporating novel AI programs into healthcare and patient choice. The third discussed accountability when AI makes mistakes in clinical decision-making. The method of introducing vignettes allowed for realistic problem-centred engagement and had been used previously for qualitative research on ethical issues in AI (McCradden et al., 2020; Aitken, De St. Jorre, Pagliari, & Cunningham-Burely, 2016).

Interview themes included 1) AI research (i.e., consent and sharing patient information); 2) hopes and fears about AI (i.e., preservation of patient choice when introducing novel health AI programs); and 3) clinical decision-making (i.e., responsibility when AI makes mistakes).

Participants were asked about their knowledge of AI prior to introducing the vignettes. Following the vignettes, they were informed that each scenario was an example of realistic but hypothetical AI-enabled research. They were then asked how they thought characters and family members would react and feel. Interviewers refrained from offering and seeking supplementary information beyond the details identified in the interview guide.

Design

The study adopted a participatory hermeneutical framework (Montreuil & Carnevale, 2018). This framework recognizes the moral agency of children and young people in the development of healthcare initiatives, as well as recognizes this populations experiences, views, and values as priorities in developing normative recommendations (Montreuil & Carnevale, 2018).

Thematic analysis was completed following Braun and Clarke (2006). A deductive approach was used to examine the data and identify some common themes, topics, and patterns that were relevant to the research questions. Coding occurred by highlighting sections of text and identifying common phrases or sentences that appeared frequently in the interview transcripts. No coding software was used, and the data were managed with Microsoft Excel and Microsoft Word 2021.

Procedure

Ethics approval was obtained from the WCHN Human Research Ethics Committee on 8 February 2022 and the University of Adelaide Ethics Committee on 31 March 2022. A site-

specific assessment for the WCHN was also approved on 25 February 2022 (See appendix A for the approval certificates).

The Director of Consumer and Community Engagement (D.S.M), at the WCHN, emailed the CAG and YAG with a plain language summary of the study and consent to contact form on 26 April, 1 May, and 30 June 2022. The summary described the aims of the study, background about AI, reimbursement, and the interview process. Additionally, student S.K.W presented at the YAG on 3 August 2022, to further introduce and discuss the study. All interested participants signed a consent to contact form which were either emailed directly to the research team or by D.S.M. Consent to contact forms allowed the research team (S.K.W and N.W) to contact participants directly to complete consent phone calls where the study was discussed, allowed potential participants to ask questions, as well as sign the consent form. For young people under the age of 16, an information sheet outlining the study and the interview process was also emailed to their parents. Parents were given the opportunity to participate in the consent phone call and asked to provide written consent for their child to participate in the interview. They were also given the opportunity to be present for the interview.

Upon completion of consent phone calls, interviews were scheduled with interested participants. S.K.W and N.W completed individual virtual semi-structured interviews with participants. Reimbursement was emailed to the participants upon completion of the interview.

Interviews were audio-recorded and transcribed verbatim with consent from participants. All identifiable information (i.e., name) was converted to anonymous ID's, ensuring all information provided was only identifiable by code. This was followed by the completion of thematic analysis which involved checking and re-checking transcripts to

refine themes (Braun & Clarke, 2006). While both students were involved in the data collection phase, the data was used to address different research questions.

Identified themes were emailed to participants on 27 September 2022 which allowed them the opportunity to provide written or verbal comment. This was to promote trustworthiness of results and provide opportunities for verification and further refinement. From the six participants, one person responded with feedback.

Reflexivity statement

The researcher conducting this analysis acknowledges that they do so through a lens of having lived experience of hospital admissions as a child, as well as a child who has engaged with the paediatric unit. The researcher reflected on their personal experience while undertaking this study, aware of any influence this may have in data analysis, however also with the understanding, interest, and appreciation of the diversity of others' experiences.

Results

A total of six participants (4 girls and 2 boys) were enrolled in the study. The age of participants ranged from 10 to 17 ($M = 13.6$, $SD = 3.01$). The length of interviews ranged from 50 minutes to 1 hr 15 minutes ($M = 60$, $SD = 8.94$). Most participants self-reported experience in the health care system, with four (66%) participants reporting more than one overnight experience in hospital. Participants were all in school; Year 5 (33%), Year 9 (16%), Year 10 (16%), and Year 11 (33%). All participants had a basic understanding and knowledge of AI but no prior experience with AI in healthcare.

The analysis identified mixed views of AI in general. Five major themes were identified (i) While AI supports clinical decision-making, it remains the doctor's responsibility to communicate AI recommendations, (ii) Preservation of patient choice, (iii) Parental influence in consent and decision-making (iv) Indecision around accountability when AI makes mistakes; and (v) Enthusiasm for novel AI programs and engaging in health research if information remains private.

Theme 1: While AI supports clinical decision-making, it remains the doctor's responsibility to communicate AI recommendations.

In general, participants felt that AI was useful in supporting clinical decision-making, however most felt strongly that it was the doctor's responsibility to relay AI recommended information to the patient. They felt an AI algorithm should never act autonomously and stressed the importance of human provider care in supporting them to feel valued as a patient.

AI doesn't necessarily have that like human-to-human contact, where you can sense that something else is going on... Talking about stuff is really important... it would make me feel safer... or more important I guess that someone is taking their time to come and talk to me about my treatment (P06).

Participants related past experiences of not being seen in person as invalidating and impersonal, highlighting the importance of doctors not relying on AI to express medical recommendations.

One time when I was in a hospital quite a few years ago... well I was in ICU, the [allied health] would not come to see me... she just never came... I [felt] annoyed (P01).

Participants also believed it was the responsibility of the doctor to seek 'second opinions' and consult with other medical experts before basing medical care exclusively on AI recommendations.

I would have felt disappointed that the doctor just didn't ask another doctor that knows a lot more... He should use that [specialist doctor] before he does AI (P02).

Additionally, participants acknowledged the benefits of using AI in healthcare to support clinical decisions, however, most maintained the doctor had more experience in decision-making and would therefore trust recommendations made by a doctor over AI.

There are certain procedures that humans can't do, or AI does better... but I feel like AI has a very standard protocol... Like a doctor is able to make a better judgment and form a better opinion whereas AI... If AI says you need to stay in hospital for a few days, it's not like telling you why. Whereas a doctor would be like due to this we would recommend that you stay in the hospital for a few days, and I would trust that a lot more than just like a robot coming up to me and telling me you have to stay here for a couple of days. I would be like no (P05).

Theme 2: Preservation of patient choice.

Preservation of patient choice was an important factor in participants' overall comfort with sharing information and accepting AI in healthcare. This was particularly important

given the age of patients, acknowledging that although patients were under the age of 18, they still had the right to choose.

Uh, no, I think 16 is old enough [to decide] that they should listen to her (P01).

Participants also acknowledged that parent consent may be required for medical treatment when a patient is under the age of 16, however, the choice to incorporate AI into their healthcare remained the decision of the patient.

I think at the end of the day her parents have to sign [consent] first, but it should still be her [decision] because she needs to choose if she wants to do this (P03).

Additionally, patient choice continued to be an integral factor when patients' opinions conflicted with parents and doctors. Participants reported that if parents wanted to use AI, but the patient did not, then the patient should have the final say.

Then no, they can't have access to it because it's not his parents' information... He should have a choice in what he wants... I feel 14 is still pretty old, by that time most people have an idea of what they want and what they don't want (P05).

Theme 3: Parental influence in decision-making when using AI

In general, participants reported that the most important people to consult around using health AI were their parents. Participants acknowledged that parents particularly needed to be included in the decision-making process because they were under the age of 18.

She is still underage in a way. Even though she can consent to her own like medical care her parents are still like obviously a part of it (P05).

However, participants also expressed the importance of their parents' opinion and the value they placed over their own decision-making.

I think under the age of 18 they always need to ask the parents because you aren't really old enough to make big decisions and stuff... they should probably just ask my mum because I might make the wrong decision and, like... my mum can make the right decision to do it (P03).

Parental influence was also greatest when the patient was under the age of ten, as participants felt strongly that young children were not as capable of making clinical decisions around their healthcare.

People who are younger, are not necessarily going to be able to take in all the information and process it... So a doctor can tell you what's going on, but whether you process that enough to be able to make a decision confidently is... Like necessarily unknown, especially with young kids like 5 to 10... So that's where like the parents or guardians, their decision is crucial (P06).

Finally, participants acknowledged that when patients were making decisions around accepting the use of AI in their healthcare, they could also seek further medical advice from a specialised doctor or nurse. However, they considered the opinion of their parents most helpful.

You could talk to a really smart doctor as well but probably just the parents [will be most helpful] (P02).

Theme 4: Indecision around accountability when AI makes a mistake

In general, there were conflicting opinions as to whether a doctor or AI was responsible for mistakes in clinical decision-making. Some participants felt neither AI nor the doctor were responsible for the mistake, particularly if the doctor was correctly analysing the data provided by AI.

No one's fault, I guess... well I guess that AI made a mistake, but you know, it could happen without an AI... I don't think if the doctor's used it correctly then I don't think it's their fault (P01).

Other participants felt both AI and the doctor were responsible, specifically if AI lacked the knowledge to properly diagnose and treat the condition and the doctor lacked the skills to understand the recommendations.

Well. It's pretty much both. Because the AI didn't know enough to answer that question properly, and the doctor didn't really know what to do with it (P02).

Other participants felt the doctor was accountable, however they also felt uncertain if AI should be used in clinical decision-making for minor conditions (i.e., food poisoning). It was considered that AI should be used as an aid in clinical decision-making for severe conditions, where more scans and tests may be required.

I think it's the doctors... cause the AI is just making suggestions but like I feel like they didn't have to use AI to make the decision. Like if it's just food poisoning, I feel like it's not necessary... like I feel like if it was a tumour or something and they needed to do like scans and stuff and they couldn't quite figure out what was wrong then they could use AI as like a backup (P05).

Participants also felt it was the responsibility of the doctor to report mistakes made by AI, to mitigate future mistakes occurring in patient care.

If the doctor makes a mistake for a patient, they should probably report that. So, then they know not to make that mistake again with another person (P02).

Additionally, participants felt that if AI made mistakes in clinical decision-making that this would cause some hesitancy around using AI in the future.

If it was [a decision] solely based on AI, then I would feel like I would be a bit worried how reliable it is... It would just leave a bad taste in my mouth about the entire hospital (P04).

Theme 5: Enthusiasm for novel AI programs and engaging in health research if information remains private.

Participants largely reported they would be willing to trial novel AI programs and provide their personal information for AI research. However, they emphasised the need to de-identify information to ensure patient privacy.

I'd probably be willing to let them [researchers] have access to everything, including the notes, as long as my name isn't attached to it (P01).

Participants generally reported enthusiasm to engage in research, and trial novel AI programs, particularly if it could help people, now or in the future.

I think I'd say that you should give it a go because there is probably the same amount of chance that it will help you than it won't and hopefully, you're going to be helping people either now or in the future when they can work on it to actually help people (P03).

Other participants were more sceptical of providing all their personal information to researchers indicating a level of distrust in organisations stealing their identify.

You don't wanna give too much information... otherwise they might start, like giving it away so that everyone knows who you are... They could steal your identity (P02).

This distrust was further emphasised when discussing private companies. Participants felt sceptical of providing any information to private companies, believing their main aim was to make profits, not ensure patient privacy.

Researchers just have the main goal of finding out new information, whereas that's not the main goal of the private company... If researchers [were from a] private health company might be more concerned about privacy... [private company] aims to make money (P01).

Others were ambivalent about incorporating health AI programs. They reported their willingness to try new programs would depend on the severity of their condition, indicating that they would be more likely to agree to AI if their condition was critical.

If I had a 50/50 percent chance of surviving then I would want the best odds but if I was like 5 percent survival rate then I would be like yeah go for it... because by that point I'd probably be like oh yeah, I might as well just try it (P05).

Lastly, safety was an important factor for participants in determining whether to incorporate AI into healthcare. Participants wanted to know first and foremost if there were any potential risks of harm before consenting.

I would want to know if it would like directly harm me. Am I safe from it? (P04)

Discussion

The purpose of the current study was to explore young peoples' perceptions of AI in healthcare. To date, the literature has focussed on adult views of health AI, but none have yet explored young peoples' perspectives. Given this population are also intended beneficiaries of health AI, are key informants and experts on their own lives, and are likely to share different perspectives and opinions to adults, it is crucial that young people are meaningfully engaged to help shape the future of AI in paediatric healthcare. Current trends in AI have brought about ethical concerns regarding clinical decision-making, accountability, and preservation of patient choice, particularly as these tools introduce ambiguity into clinical practice. Therefore, questions centred around these three topics.

After discussing the three AI vignettes, participants shared a variety of concerns that will likely shape their perceptions of AI applications in healthcare. While most generally had positive views of AI in medicine, this was contingent on proactive oversight of clinicians to mitigate patient harm potentially caused by technology. Consistent with previous research (Isbanner et al., 2022; Young et al., 2021), participants considered clinician oversight to be crucial in maintaining patient-centred care, with most believing AI should never act autonomously. It was vital for their overall comfort of AI applications that doctors see the patient in person and to not rely on AI to relay information. To do so would make participants feel invalidated and unimportant.

Furthermore, participants felt it essential that doctors consult specialised doctors for second opinions before basing their medical decisions purely on AI. Indicating perhaps people have more trust in human clinicians over AI. This finding was consistent with Nelson et al. (2020) which found when AI and humans reached conflicting diagnoses, 60% of participants would trust the doctor over AI and 42% expected second opinions to be sought

from another doctor. Moreover, a study by Longoni and Morewedge (2019) also demonstrated in a series of experiments that people trust human clinicians over AI for procedures ranging from skin cancer screening to pacemaker implants. In one experiment with 700 participants, they found that most preferred a human over AI, even when AI was designed to outperform the clinician. Arguably this was due to a belief that AI does not account for people's idiosyncrasies and individual circumstances. Certainly, participants in the current study acknowledged AI could make faster and more accurate diagnoses, however they believed AI was black and white in its decision-making. This meant participants were more likely to trust recommendations made by a human, as they believed doctors could form clearer judgements by explaining 'why' and 'how' they came to that conclusion. This was important for participants in accepting treatment recommendations. To therefore overcome resistance of AI, this finding highlights the need for providers to mitigate patient concerns around being treated as another number by increasing the perceived personalisation of treatment delivered by AI, as personalisation could be crucial to people accepting AI delivered care.

Similarly, accepting AI care was dependent on patient choice. Autonomy is one of the core principles of medical ethics (Singer, Pellegrino & Siegler, 2001) and participants were clear about patients having the right to choose if AI formed part of their healthcare. There was unanimous agreement amongst participants that a patient 16 years of age had the right to accept or refuse the inclusion of AI in their healthcare. This view remained strong even when the patient's views conflicted with parents, emphasising the importance of the patient having the final say. While exploring different demographics, this finding was consistent with Richardson et al. (2021) which found adults also considered the option to choose AI as crucial. This suggests that if AI were to operate covertly in the background, that this could result in significant breaches of public trust and negative perceptions of AI should a patient

who does not want AI to form part of their healthcare discover it was being used. Effective policy responses should therefore inform patient's roles in relation to AI so that individuals are aware of their position to reject AI treatment where possible.

While participants stressed the importance of patient choice, they also acknowledged that parents were central to decision-making when considering AI in healthcare. All agreed that parent involvement was necessary given the patients were under the age of 18. Interestingly however, participants emphasised the significance they placed on parent decisions. Some believed that for 'big decisions' such as trialling novel AI programs, that parents should always have final discretion because they were more capable of making judgements. This finding could be the result of participant ages, as younger participants (i.e., 12) particularly emphasised the importance of their parent's decisions over older participants (i.e., 17). It is likely that a 12-year-old is still dependent on their parents for medical advice, while a 17-year-old is exercising more autonomy. This was also highlighted when discussing patients under the age of ten, with participants unanimously agreeing that parents were crucial to decision-making. All believed young children were not capable of making decisions about their healthcare, particularly in terms of integrating AI. This finding highlights to policymakers to perhaps view children and adolescents differently, with more autonomy given to older adolescents to make choices around incorporating AI programs into healthcare.

Interestingly, some participants in the current study found that incorporating AI into healthcare should not always be necessary, particularly for decisions around minor conditions. For them, AI was only a tool to support clinicians in decision-making for critical conditions (i.e., cancer). They felt it was unethical for clinicians to rely solely on AI recommendations and held clinicians accountable for any mistakes made by AI. However, other participants were less concrete in their views around accountability. They believed a

clinician was not responsible for mistakes if they were using the technology correctly and that those who programmed the algorithm could also be held accountable.

Mixed views of accountability are consistent with previous research with a study by McCradden et al. (2020) reporting mistakes made by AI were attributed to those who developed the algorithm, those who input the data and senior management. In general, it is thought that the public is yet to fully comprehend the numerous accountability and responsibility considerations associated with AI (Duan, Edwards & Dwivedi, 2019). This is likely due to the number of stakeholders involved in the implementation of AI from developers, government agencies, health professionals and patients (Esmaeilzadeh et al., 2021). Thus, when AI is widely accessible, governing agencies and medical institutions will require clear policies identifying each stakeholder's responsibility. Nonetheless, despite uncertainty around accountability, participants in the current study were generally clear that for any mistakes made by AI, it was the clinician's responsibility to report the error. As this would help to mitigate future mistakes that could result in patient harm.

Mitigating risks to patients is of central importance. Health related data is often regarded as comprising the most sensitive information about a person, given its association with well-being and personal identity (Vayena, Blasimme & Cohen, 2018). Protecting a person's data to avoid risk of harm is therefore fundamental (Esmaeilzadeh et al., 2021). The findings from the current study reinforced themes around privacy and confidentiality identified in a systematic review by Aitken et al. (2016) which examined 25 publications from the United States, Canada, the UK, and other countries. Consistent with the review, there was general support for contributing health data, however this came with a caveat of ensuring patient information was de-identified to protect confidentiality. Furthermore, there were general concerns around privacy and security, with less trust around private companies. Certainly, the current study found mixed feelings as to what information should be provided

to researchers, with some participants sceptical of providing too much personal data (i.e., patient case notes, blood work, scans/ x-rays) for fear that companies could sell their identity. However, this scepticism grew when sharing personal information with private companies, with participants generally feeling that private companies were more concerned with making profits than ensuring patient privacy and safety.

Despite this, there was general enthusiasm amongst participants for trialling novel AI programs and engaging in AI research. Overall, participants derived a sense of altruism for participating in research, signalling a sense of duty to contribute their data to help people in the future. However, this could be representative of the current sample, given participants were involved in the CAG and YAG at the WCHN where they had provided previous consent to engage in research. Thus, research is likely considered important to this group.

Limitations

Although this study provided insight into young peoples' views of AI in healthcare, a population that has previously been overlooked, it is not without limitations. First, the sample only included six young people, who had previous involvement in the health care industry. Furthermore, they were registered consumers of the WCHN, indicating that advocating for health research was important to this group. Therefore, the findings are likely to have limited generalizability. It is also possible that increasing the number of participants could have resulted in the identification of different themes. However, the responses provided are consistent with the literature, indicating that many central concepts of clinical decision-making, accountability and choice could be general concerns shared by the public and less likely due to sampling bias. It is recommended that future studies explore the views of young people who have limited engagement in the health care industry and are not registered group members, as this would strengthen the findings to the general population.

Second, the interviews were completed by two members of the research team but coding and identifying themes were done individually. While the researcher acknowledged their own experiences and made every effort to analyse the data objectively, results could have an element of bias.

Third, while the interview guides and vignettes have been used in previous studies, the open-ended nature of the semi-structured interviews could have potentially led to bias. While effort was made to stick to the interview guide, the flexibility of asking participants to clarify, elaborate or rephrase may have resulted in leading questions, biasing responses. Moreover, participants may have provided answers to questions that they thought the researchers wanted to hear, leading to social desirability bias. This said, a strength of our design was the use of vignettes that were purposely structured to provide neutral responses and avoid normative valence in the language used. The vignettes also allowed the researchers to remain on topic and ask pre-determined questions which provided comprehensive data that allowed for comparisons between participants. Nonetheless, future studies could seek to clarify young peoples' perceptions of AI using questionnaires or surveys. This would provide objective predictions about the frequency and possible impact of ethical concerns, which would be useful for legislators.

Conclusion

AI, and its subfield ML, has seen rapid exploration and development across the field of medicine. There is enthusiasm for the implementation of AI, as this technology has the capacity to support clinicians in clinical decision-making, disease diagnoses and treatment management. The adoption of AI in medical institutions depends on the public's support and trust of these technologies. Therefore, it is imperative that the public is meaningfully engaged

before and during implementation to ensure AI enhances patient care ethically and responsibly.

In exploring young peoples' views of health AI, the results of the current study found mixed views but general support and enthusiasm for health AI. Participants generally considered AI as a useful tool to support clinicians in decision-making but emphasised these tools require clinician oversight. Accepting AI was also contingent on choice, with unanimous agreement that patients should have the right to choose if AI comprised part of their healthcare. While mixed reviews around accountability was consistent with previous research, participants generally felt clinicians were responsible for reporting any mistakes made by AI to mitigate future patient harm. The current findings also reflected previous studies around privacy and confidentiality, with participants generally willing to engage in health research and trial novel AI programs, only if their data was de-identified. Overall, this research identified critical areas for policy makers to ensure perspectives of young people are included in implementation plans of digital tools. However, there remains an urgent need to meaningfully engage this population in AI research to ensure their needs are addressed in an ethical way and considered during the development phase of health AI.

References

- Aarthun, A., Øymar, K. A., & Akerjordet, K. (2018). Parental involvement in decision-making about their child's health care at the hospital. *Nursing Open*, *6*(1), 50–58. <https://doi.org/10.1002/nop2.180>
- Aicken, C. R. H., Fuller, S. S., Sutcliffe, L. J., Estcourt, C. S., Gkatzidou, V., Oakeshott, P., Hone, K., Sadiq, S. T., Sonnenberg, P., & Shahmanesh, M. (2016). Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study. *BMC Public Health*, *16*(1). <https://doi.org/10.1186/s12889-016-3648-y>
- Aitken, M., De St. Jorre, J., Pagliari, C., Jepson, R., & Cunningham-Burley, S. (2016). Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. *BMC Medical Ethics*, *17*(1). <https://doi.org/10.1186/s12910-016-0153-x>
- Amann, J., Blasimme, A., Vayena, E., Frey, D., & Madai, V. I. (2020). Explainability for artificial intelligence in healthcare: a multidisciplinary perspective. *BMC Medical Informatics and Decision Making*, *20*(1). <https://doi.org/10.1186/s12911-020-01332-6>
- Artificial Intelligence – What it is and why it matters*. (2022). www.sas.com. https://www.sas.com/en_us/insights/analytics/what-is-artificial-intelligence.html#:~:text=The%20term%20artificial%20intelligence%20was
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared Decision Making — The Pinnacle of Patient-Centered Care. *New England Journal of Medicine*, *366*(9), 780–781. <https://doi.org/10.1056/nejmp1109283>
- Berman, S. (2011). *Clinical Decision Making - an overview* / *ScienceDirect Topics*. [Sciencedirect.com. https://www.sciencedirect.com/topics/nursing-and-health-professions/clinical-decision-making](https://www.sciencedirect.com/topics/nursing-and-health-professions/clinical-decision-making)

- Bjerring, J. C., & Busch, J. (2020). Artificial Intelligence and Patient-Centered Decision-Making. *Philosophy & Technology*. <https://doi.org/10.1007/s13347-019-00391-6>
- Blease, C., Kaptchuk, T. J., Bernstein, M. H., Mandl, K. D., Halamka, J. D., & DesRoches, C. M. (2019). Artificial Intelligence and the Future of Primary Care: Exploratory Qualitative Study of UK General Practitioners' Views. *Journal of Medical Internet Research*, 21(3), e12802. <https://doi.org/10.2196/12802>
- Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Carnevale, F. A. (2021). Recognizing Children as Agents: Taylor's Hermeneutical Ontology and the Philosophy of Childhood. *International Journal of Philosophical Studies*, 29(5), 791–808. <https://doi.org/10.1080/09672559.2021.1998188>
- Caulfield, J. (2019, September 6). *How To Do Thematic Analysis*. Scribbr. <https://www.scribbr.com/methodology/thematic-analysis/>
- Davenport, T., & Kalakota, R. (2019). The potential for artificial intelligence in healthcare. *Future Healthcare Journal*, 6(2), 94–98. ncbi. <https://doi.org/10.7861/futurehosp.6-2-94>
- Duan, Y., Edwards, J. S., & Dwivedi, Y. K. (2019). Artificial Intelligence for Decision Making in the Era of Big Data – evolution, Challenges and Research Agenda. *International Journal of Information Management*, 48, 63–71. <https://doi.org/10.1016/j.ijinfomgt.2019.01.021>
- Eltorai, A. E. M., Bratt, A. K., & Guo, H. H. (2019). Thoracic Radiologists' Versus Computer Scientists' Perspectives on the Future of Artificial Intelligence in Radiology. *Journal of Thoracic Imaging*, 35(4), 255–259. <https://doi.org/10.1097/rti.0000000000000453>
- Esmailzadeh, P., Mirzaei, T., & Dharanikota, S. (2021). Patients' Perceptions Toward Human–Artificial Intelligence Interaction in Health Care: Experimental Study. *Journal of Medical Internet Research*, 23(11), e25856. <https://doi.org/10.2196/25856>

- Gerke, S., Minssen, T., & Cohen, G. (2020). Ethical and legal challenges of artificial intelligence-driven healthcare. *Artificial Intelligence in Healthcare*, 295–336. <https://doi.org/10.1016/B978-0-12-818438-7.00012-5>
- Gheaus, A., Calder, G., & De Wispelaere, J. (2019). *The Routledge Handbook of the Philosophy of Childhood and Children*. Routledge & CRC Press. Retrieved September 30, 2022, from <https://www.routledge.com/The-Routledge-Handbook-of-the-Philosophy-of-Childhood-and-Children/Gheaus-Calder-Wispelaere/p/book/9780367733889>
- Green, S., & Hogan, D. (2005). *Researching Children's Experience - SAGE Research Methods*. (2011). Sagepub.com. <https://methods.sagepub.com/book/researching-childrens-experience>
- Habli, I., Lawton, T., & Porter, Z. (2020). Artificial intelligence in health care: accountability and safety. *Bulletin of the World Health Organization*, 98(4), 251–256. <https://doi.org/10.2471/blt.19.237487>
- Harris, P., & Manatakis, H. (2013). *Children's Voices*. https://www.education.sa.gov.au/sites/default/files/childrens-voices-framework.pdf?acsf_files_redirect
- Hazarika, I. (2020). Artificial intelligence: opportunities and implications for the health workforce. *International Health*, 12(4). <https://doi.org/10.1093/inthealth/ihaa007>
- Isbanner, S., O'Shaughnessy, P., Steel, D., Wilcock, S., & Carter, S. (2022). The Australian Values and Attitudes on AI (AVA-AI) Study: Methodologically Innovative National Survey about Adopting Artificial Intelligence in Healthcare and Social Services (Preprint). *Journal of Medical Internet Research*. <https://doi.org/10.2196/37611>
- Jiang, F., Jiang, Y., Zhi, H., Dong, Y., Li, H., Ma, S., Wang, Y., Dong, Q., Shen, H., & Wang, Y. (2017). Artificial intelligence in healthcare: past, present and future. *Stroke and Vascular Neurology*, 2(4), 230–243. <https://doi.org/10.1136/svn-2017-000101>
- Jutzi, T. B., Krieghoff-Henning, E. I., Holland-Letz, T., Utikal, J. S., Hauschild, A., Schadendorf, D., Sondermann, W., Fröhling, S., Hekler, A., Schmitt, M., Maron, R. C., & Brinker, T. J. (2020). Artificial Intelligence in Skin Cancer Diagnostics: The

- Patients' Perspective. *Frontiers in Medicine*, 7.
<https://doi.org/10.3389/fmed.2020.00233>
- Keel, S., Lee, P. Y., Scheetz, J., Li, Z., Kotowicz, M. A., MacIsaac, R. J., & He, M. (2018). Feasibility and patient acceptability of a novel artificial intelligence-based screening model for diabetic retinopathy at endocrinology outpatient services: a pilot study. *Scientific Reports*, 8(1). <https://doi.org/10.1038/s41598-018-22612-2>
- Laï, M.-C. ., Brian, M., & Mamzer, M.-F. . (2020). Perceptions of artificial intelligence in healthcare: findings from a qualitative survey study among actors in France. *Journal of Translational Medicine*, 18(1). <https://doi.org/10.1186/s12967-019-02204-y>
- Liu, X., Keane, P. A., & Denniston, A. K. (2018). Time to regenerate: the doctor in the age of artificial intelligence. *Journal of the Royal Society of Medicine*, 111(4), 113–116.
<https://doi.org/10.1177/0141076818762648>
- Longoni, C., & Morewedge, C. K. (2019, October 30). *AI Can Outperform Doctors. So Why Don't Patients Trust It?* Harvard Business Review. <https://hbr.org/2019/10/ai-can-outperform-doctors-so-why-dont-patients-trust-it>
- Machine Learning*. (n.d.). Australian Institute for Machine Learning (AIML) | University of Adelaide. <https://www.adelaide.edu.au/aiml/our-research/machine-learning>
- McCradden, M. D., Baba, A., Saha, A., Ahmad, S., Boparai, K., Fadaiefard, P., & Cusimano, M. D. (2020). Ethical concerns around use of artificial intelligence in health care research from the perspective of patients with meningioma, caregivers and health care providers: a qualitative study. *CMAJ Open*, 8(1), E90–E95.
<https://doi.org/10.9778/cmajo.20190151>
- McCradden, M. D., Sarker, T., & Paprica, P. A. (2020). Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research. *BMJ Open*, 10(10), e039798. <https://doi.org/10.1136/bmjopen-2020-039798>
- McDougall, R. J. (2018). Computer knows best? The need for value-flexibility in medical AI. *Journal of Medical Ethics*, 45(3), 156–160. <https://doi.org/10.1136/medethics-2018-105118>

- Montreuil, M., & Carnevale, F. A. (2018). Participatory Hermeneutic Ethnography: A Methodological Framework for Health Ethics Research With Children. *Qualitative Health Research, 28*(7), 1135–1144. <https://doi.org/10.1177/1049732318757489>
- Musbahi, O., Syed, L., Le Feuvre, P., Cobb, J., & Jones, G. (2021). Public patient views of artificial intelligence in healthcare: A nominal group technique study. *DIGITAL HEALTH, 7*, 205520762110636. <https://doi.org/10.1177/20552076211063682>
- Naik, N., Hameed, B. M. Z., Shetty, D. K., Swain, D., Shah, M., Paul, R., Aggarwal, K., Ibrahim, S., Patil, V., Smriti, K., Shetty, S., Rai, B. P., Chlosta, P., & Somani, B. K. (2022). Legal and Ethical Consideration in Artificial Intelligence in Healthcare: Who Takes Responsibility? *Frontiers in Surgery, 9*, 862322. <https://doi.org/10.3389/fsurg.2022.862322>
- Nelson, C. A., Pérez-Chada, L. M., Creadore, A., Li, S. J., Lo, K., Manjaly, P., Pournamdari, A. B., Tkachenko, E., Barbieri, J. S., Ko, J. M., Menon, A. V., Hartman, R. I., & Mostaghimi, A. (2020). Patient Perspectives on the Use of Artificial Intelligence for Skin Cancer Screening. *JAMA Dermatology, 156*(5), 1–12. <https://doi.org/10.1001/jamadermatol.2019.5014>
- Ongena, Y. P., Haan, M., Yakar, D., & Kwee, T. C. (2019). Patients' views on the implementation of artificial intelligence in radiology: development and validation of a standardized questionnaire. *European Radiology, 30*(2), 1033–1040. <https://doi.org/10.1007/s00330-019-06486-0>
- Palmisciano, P., Jamjoom, A. AB., Taylor, D., Stoyanov, D., & Marcus, H. J. (2020). Attitudes of Patients and Their Relatives Towards Artificial Intelligence in Neurosurgery. *World Neurosurgery*. <https://doi.org/10.1016/j.wneu.2020.03.029>
- Paprica, P. A., Melo, M. N. de, & Schull, M. J. (2019). Social licence and the general public's attitudes toward research based on linked administrative health data: a qualitative study. *CMAJ Open, 7*(1), E40–E46. <https://doi.org/10.9778/cmajo.20180099>

- Polesie, S., Gillstedt, M., Kittler, H., Lallas, A., Tschandl, P., Zalaudek, I., & Paoli, J. (2020). Attitudes towards artificial intelligence within dermatology: an international online survey. *British Journal of Dermatology*. <https://doi.org/10.1111/bjd.18875>
- Pugh, J. (2020). Informed Consent, Autonomy, and Beliefs. In *www.ncbi.nlm.nih.gov*. Oxford University Press. <https://www.ncbi.nlm.nih.gov/books/NBK556864/>
- Richardson, J. P., Smith, C., Curtis, S., Watson, S., Zhu, X., Barry, B., & Sharp, R. R. (2021). Patient apprehensions about the use of artificial intelligence in healthcare. *Npj Digital Medicine*, 4(1), 1–6. <https://doi.org/10.1038/s41746-021-00509-1>
- Simpkin, A. L., Vyas, J. M., & Armstrong, K. A. (2017). Diagnostic Reasoning: An Endangered Competency in Internal Medicine Training. *Annals of Internal Medicine*, 167(7), 507. <https://doi.org/10.7326/m17-0163>
- Singer, P. A., Pellegrino, E. D., & Siegler, M. (2001). Clinical ethics revisited. *BMC Medical Ethics*, 2(1). <https://doi.org/10.1186/1472-6939-2-1>
- Standfield, S. (2020, April 16). *Women's and Children's Health Network Advisory Group*. Youth Action Plan. <https://www.youthactionplan.sa.gov.au/connect-and-grow/womens-and-childrens-health-network-advisory-group/>
- Sunarti, S., Fadzul Rahman, F., Naufal, M., Risky, M., Febriyanto, K., & Masnina, R. (2021). Artificial intelligence in healthcare: opportunities and risk for future. *Gaceta Sanitaria*, 35, S67–S70. <https://doi.org/10.1016/j.gaceta.2020.12.019>
- Tigard, D. W. (2020). There Is No Techno-Responsibility Gap. *Philosophy & Technology*, 34(3), 589–607. <https://doi.org/10.1007/s13347-020-00414-7>
- Topol, E. J. (2019). High-performance medicine: the convergence of human and artificial intelligence. *Nature Medicine*, 25(1), 44–56. <https://doi.org/10.1038/s41591-018-0300-7>
- Triberti, S., Durosini, I., & Pravettoni, G. (2020). A “third wheel” effect in health decision making involving artificial entities: A psychological perspective. *Public Health*, 8. doi: 10.3389/fpubh.2020.00117

- Vayena, E., Blasimme, A., & Cohen, I. G. (2018). Machine learning in medicine: Addressing ethical challenges. *PLOS Medicine*, *15*(11), e1002689. <https://doi.org/10.1371/journal.pmed.1002689>
- Wadden, J. J. (2021). What Kind of Artificial Intelligence Should We Want for Use in Healthcare Decision-Making Applications? *Canadian Journal of Bioethics*, *4*(1), 94. <https://doi.org/10.7202/1077636ar>
- Xu, J., Bryant, D. G., & Howard, A. (2018). Would You Trust a Robot Therapist? Validating the Equivalency of Trust in Human-Robot Healthcare Scenarios. *2018 27th IEEE International Symposium on Robot and Human Interactive Communication (RO-MAN)*. <https://doi.org/10.1109/roman.2018.8525782>
- Wall, J. (2010). *Ethics in Light of Childhood* | Georgetown University Press. (n.d.). [Press.georgetown.edu](http://press.georgetown.edu). Retrieved September 30, 2022, from <http://press.georgetown.edu/book/georgetown/ethics-light-childhood>
- Yang, K., Zeng, Z., Peng, H., & Jiang, Y. (2019). Attitudes Of Chinese Cancer Patients Toward The Clinical Use Of Artificial Intelligence. *Patient Preference and Adherence*, *Volume 13*, 1867–1875. <https://doi.org/10.2147/ppa.s225952>
- Young, A. T., Amara, D., Bhattacharya, A., & Wei, M. L. (2021). Patient and general public attitudes towards clinical artificial intelligence: a mixed methods systematic review. *The Lancet Digital Health*, *3*(9), e599–e611. [https://doi.org/10.1016/s2589-7500\(21\)00132-1](https://doi.org/10.1016/s2589-7500(21)00132-1)

Appendix A

Ethics Certificates

Women's and Children's Health Network Human Research Ethics Approval

Approval date: **08 Feb 2022**

Dear [REDACTED],

Thank you for submitting the following Human Research Ethics Application (HREA) for HREC review;

2021/HRE00359: ExplAIn 4 Kids: Engaging Children & Youth in Artificial Intelligence in Paediatric Healthcare

HREA version: 1.02

Submission date: 07 Feb 2022

Your response has been reviewed by the Chair of the WCHN Human Research Ethics Committee. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The approval is for a period of **3 years from the date of this e-mail (08 Feb 2022)**, on condition of the submission of annual reports for both ethics and governance applications.

This project has been approved to be conducted at the following sites:

- Women's and Children's Health Network

The following documentation was reviewed and is included in this approval:

- Carer Consent Form-2-13-Dec-2021
- Consent-to-Contact-Form-1-08-Oct-2021
- Distress Protocol for managing participant distress in interviews-1-13-Dec-2021
- Draft of content for face to face recruitment-1-08-Oct-2021
- Email draft for recruitment-1-08-Oct-2021
- HREA
- Interview Guide Questions-1-08-Oct-2021
- Participant consent form-2-13-Dec-2021
- Participant-information-sheet for Older Children-3-07-Feb-2022
- Participant-information-sheet for Parent./Guardian-2-13-Dec-2021
- Participant-information-sheet for Youth-3-13-Dec-2021
- Presentation To Guide Questions-1-08-Oct-2021
- ProjectRegistration
- VERSION 2 Protocol_ExplAIn (1) (1).docx

[Application Documents](#) - (Please note: Due to security reasons, this link will only be active for 14 days.)

This HREC is constituted and operates in accordance with the National Statement on Ethical Conduct in Human Research (2007) (Updated 2018). The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council. Confidentiality of the research subjects must be maintained at all times as required by law.

This letter constitutes advice on ethical consideration only. You must not commence this research project at a site until you have obtained separate research governance approval from the site concerned.

At the WCHN, or any other SA Health site, separate authorisation from the Chief Executive or delegate of that site must be obtained through a Site Specific Assessment (SSA) request. For information on this process at the WCHN, please contact the WCHN Research Governance Officer, Dr [REDACTED] (telephone [REDACTED], email [REDACTED]@sa.gov.au).

I remind you approval is given subject to:

- immediate notification of any serious or unexpected adverse events to participants;
- immediate notification of any unforeseen events that might affect continued ethical acceptability of the project;
- submission of any proposed changes to the original protocol. Changes must be approved by the Committee before they are implemented;
- immediate advice, giving reasons, if the protocol is discontinued before its completion;
- submission of an annual report on the progress of the study, and a final report when it is completed to the WCHN Research Governance Officer. It is your responsibility to provide these reports, without reminder. The proforma for the report may be found on the WCHN Research Governance and Ethics website.

Please contact us if you would like to discuss any aspects of this process further.

The WCHN HREC wishes you every success with your research.

Yours sincerely

Dr [REDACTED]

Chair, WCHN Human Research Ethics Committee

Site-specific Approval for the Women's and Children's Health Network

Date of Decision Notification: 25 Feb 2022

Dear Dr [REDACTED],

Thank you for submitting the following Site Specific Assessment (SSA) for governance review;

2021/SSA00807: ExplAIIn 4 Kids: Engaging Children & Youth in Artificial Intelligence in Paediatric Healthcare

The Application has been reviewed by the Chief Executive/Delegate who has determined the application is now authorised at this site:

Women's and Children's Hospital

The following documentation is included in this authorisation:

- Carer Consent Form-2-13-Dec-2021
- Consent-to-Contact-Form-1-08-Oct-2021
- Distress Protocol for managing participant distress in interviews-1-13-Dec-2021
- Draft of content for face to face recruitment-1-08-Oct-2021
- Email draft for recruitment-1-08-Oct-2021
- Interview Guide Questions-1-08-Oct-2021
- Participant consent form-2-13-Dec-2021
- Participant-information-sheet for Older Children-3-07-Feb-2022
- Participant-information-sheet for Parent./Guardian-2-13-Dec-2021
- Participant-information-sheet for Youth-3-13-Dec-2021
- Presentation To Guide Questions-1-08-Oct-2021
- VERSION 2 Protocol ExplAIIn
- WWCC for [REDACTED] and [REDACTED]
- WCHN HREC Approval Email, 8 Feb 2022

Application Documents (Please note: Due to security reasons, this link will only be active for 14 days. The approved documents are also available to download from forms section of this project in GEMS)

Period of authorisation: 25 Feb 2022 to 8 Feb 2025

The Principal Investigator must abide by the following conditions of authorisation:

- Authorisation is limited to the site/s named in this communication and is granted for the term specified on the proviso that HREC approval remains current.
- Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, should be provided to the Research Governance Officer via Research GEMS
- Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the Research Governance Officer using the appropriate notifications form available on Research GEMS
- In light of the August 2018 directive from the South Australian Chief Medical Officer, access to case notes without consent at the WCHN must **only** be by a member of the team directly caring for the patient, unless approved otherwise by WCHN HREC.
- Any non-WCHN staff or students working on the Study, whether identified in the initial SSA submission or in future, who visit the WCHN site for any amount of time or who have access to any identifiable WCHN patient information (WCHN patients under the age of 18 years) **must** provide the Research Governance Officer with evidence of a current Department for Communities and Social Inclusion (DCSI) Child-Related Employment Screening check or more recently a Department of Human Services (DHS) Working with Children Check

(WWCC), in accordance with SA Health policy and WCHN Human Resources requirements. Non-WCHN staff or students are not authorised to be on the site or access any identifiable WCHN patient data (WCHN patients under the age of 18 years) without the Research Governance Officer reviewing and approving a current Child-Related Screening check.

- Any project-specific agreements, including confidentiality agreements and overarching project agreements including clinical trial research agreements, must be finalised and submitted to the Research Governance Officer before the project is able to commence.
- If conducting a clinical trial, the Principal Investigator must not commence the trial named in this communication until the Clinical Trial Notification (CTN) has been submitted to the Therapeutic Goods Administration (TGA) using the online form.
- If conducting a clinical trial, the Principal Investigator must provide a copy of their Good Clinical Practice (GCP) certificate to the RGO and ensure the associate investigators and trial coordinators have a valid GCP.
- The study must be conducted in accordance with the standards outlined in the National Statement on Ethical Conduct in Human Research (2007, including any future updates) and the Australian Code for the Responsible Conduct of Research (2018, including any future updates), along with applicable SA Health research policy requirements including the SA Health Research Governance Policy (current version, including any future updates)
- You are required to provide annual progress reports and a final report for the project, using the reporting forms available on Research GEMS. The annual report must be submitted on, or prior to, the anniversary of project authorisation.
- If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

Additional condition of WCHN research governance authorisation – Data access and information disclosure

WCHN provides no consent for the data it has provided for this study to be used for any purpose which can generate a financial return from a third party either by the use of the data as standalone data or as a collection of data, except or unless WCHN has provided express written consent for such purpose to occur.

We wish you all the best with the study and remind you that any changes to the application and safety reports will need to be submitted via GEMS and authorised by the approving HREC prior to implementation.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Yours Sincerely,

, PhD
Research Governance Officer

Human Research Ethics Committee, University of Adelaide Ethics Approval

Review Outcome

This page provides the outcome of the reviews by the Human Research Ethics Secretariat and Insurance Office.

Outcome of Review of Notification Form:

Accepted: The University of Adelaide has accepted this notification of Human Research Ethics Committee approval(s). The University of Adelaide's involvement will be indemnified by The University of Adelaide's insurance(s).

Project Title:

ExplAIIn 4 Kids: Engaging Children & Youth in Artificial Intelligence in Paediatric Healthcare

University of Adelaide Notification Reference Number:

35634

Date notification processed:

31/03/2022

End date of the primary Human Research Ethics Committee's approval:

08/02/2025

Notification of Human Research Ethics Approval Conditions:

Researchers are required to conduct this project in accordance with the ethics approval(s) received. They are also required to comply with the [National Statement on Ethical Conduct in Human Research \(2007\)](#), the [Australian Code for the Responsible Conduct of Research](#), the [University of Adelaide's Responsible Conduct of Research Policy](#). University of Adelaide researchers must notify the [HREC Secretariat](#) by email of any adverse events or changes to their project in accordance with the [University of Adelaide's reporting requirements for notifications](#).