BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039798
Article Type:	Original research
Date Submitted by the Author:	26-Apr-2020
Complete List of Authors:	McCradden, Melissa; Hospital for Sick Children Sarker, Tasmie; Vector Institute Paprica, P. Alison; University of Toronto, Institute for Health Policy, Management and Evaluation; Vector Institute
Keywords:	QUALITATIVE RESEARCH, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, ETHICS (see Medical Ethics)

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Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research

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Word count: 3480 [excludes the title page, abstract, tables, acknowledgements, author contributions, and references]

Supplemental Materials – Discussion Guide, Health AI Scenarios

ABSTRACT

Objectives: Given widespread interest in applying artificial intelligence (AI) to health data to improve patient care and health system efficiency, there is a need to understand the perspectives of the general public regarding the use of health data in AI research.

Design: A qualitative study involving six focus groups with members of the public. Participants discussed their views about AI in general, then were asked to share their thoughts about three realistic health AI scenarios. Data were analysed using qualitative description thematic analysis.

Settings: Two cities in Ontario, Canada: Sudbury (400 km north of Toronto) and Mississauga, (part of the Greater Toronto Area).

Participants: Forty-one purposively sampled members of the public (21M:20F, 25-65 years, median age 40).

Results: Participants had low levels of prior knowledge of AI and mixed, mostly negative, perceptions of AI in general. Most endorsed AI as a tool for the analysis of health data when there is strong potential for public benefit, providing that concerns about privacy, consent, and commercial motives were addressed. Inductive thematic analysis identified AI-specific hopes (e.g., potential for faster and more accurate analyses, ability to use more data), fears (e.g., loss of human touch, skill depreciation from over-reliance on machines) and conditions (e.g., human verification of computer-aided decisions, transparency). There were mixed views about whether consent is required for health data research, with most participants wanting to know if, how and by whom their data were used. Though it was not an objective of the study, realistic health AI scenarios were found to have an educational effect.

Conclusions: Notwithstanding concerns and limited knowledge about AI in general, most members of the general public in six focus groups in Ontario, Canada perceived benefits from health AI and conditionally supported the use of health data for AI research.

Keywords: Artificial intelligence, machine learning, public engagement, qualitative research, data sharing

STRENGTHS AND LIMITATIONS OF THIS STUDY

A strength of this study is the analysis of how diverse members of the general public perceive three realistic scenarios in which health data are used for AI research.

The detailed health AI scenarios incorporate points that previous qualitative research has indicated are likely to elicit discussion (e.g., use of health data without express consent, involvement of commercial organisations in health research, inability to guarantee anonymity of genetic data) and may also be useful in future qualitative research studies and for educational purposes.

The findings are likely to be relevant to organisations that are considering making health data available for AI research and development.

Notwithstanding the diverse ethnic and educational backgrounds of participants, overall the sample represents the general (mainstream) population of Ontario and results cannot be interpreted as presenting the views of specific subpopulations and may not be generalisable across Ontario or to other settings.

Given the low level of knowledge about AI in general it is possible that the views of participants would change substantially if they learned and understood more about AI.

TRANSPARENCY STATEMENT

P. Alison Paprica affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that there were no discrepancies from the study as originally approved by the University of Toronto Research Ethics Board.

FUNDING STATEMENT

This research was funded by the Vector Institute.

COMPETING INTERESTS STATEMENT

MDM has nothing to disclose.
TS has nothing to disclose.
PAP has nothing to disclose.

INTRODUCTION

Modern artificial intelligence (AI) and its subfield machine learning (ML) offer much promise for deriving impactful knowledge from health data. Several recent articles present summaries of recent health AI and ML achievements, and what the future could look like as more health data become available and are used in AI research and development[1-5]. Given that AI and ML require large amounts of data,[6] public trust in, and support for, using health data for AI/ML will be essential. Many institutions are exploring models for using large representative datasets of health information to create learning healthcare systems[7,8].Public trust and social licence for such work is essential[8] because, in contrast with clinical studies that have consent-based participation from data subjects, “big data” research is often performed without expressed consent from the data subjects[9]. Previous studies exploring the public attitudes toward data-intensive health research in general, i.e., without an AI/ML focus, found that most members of the mainstream public are supportive provided there are appropriate controls[10-13]. While underscoring the need to address the public’s concerns, studies in Canada, the UK, USA and other jurisdictions suggest that members of the mainstream public view health data as an asset that should be used as long as their concerns related to privacy, commercial motives and other risks are addressed[10-13].

However, we cannot assume that this general but conditional public support for data-intensive health research extends to AI/ML for several reasons. Foremost, research has shown that the members of the general public have low understanding of AI in general, alongside AI-specific hopes and fears including loss of control of AI, ethical concerns, and the potential negative impact of AI on work[14-18]. Secondly, while there is general trend toward support for health AI,[19] there is also recent negative press about large technology companies using health data for AI, including patients suing Google and the University of Chicago Medical Center[20] and the view of the National Data Guardian at the UK's Department of Health that the sharing of patient data between the Royal Free Hospital of London and Google DeepMind was legally inappropriate[21]. Thirdly, there is decreasing confidence that accepted approaches to de-identification are sufficient to ensure privacy in the face of AI’s capabilities[22].

To date, there has been limited scholarly research on public perceptions of health AI. Most published studies have focused on the views of patients who may not be representative because they stand to benefit from AI applications[16]. Further, most published studies have focused on computer vision health AI applications in radiology and dermatology, which represent only a small fraction of the potential applications of AI in health[23-25]. Additionally, there is a need to understand public perspectives versus patient perspectives, because health AI research may rely on large datasets that include information about people who do not have health conditions and/or do not stand to benefit directly from the research. Accordingly, the objective of this study was to learn more about how members of the general public perceive health data being used for AI research.

METHODS

Study Design

Focus groups were conducted using semi-structured discussion guides designed to prompt dialogue among participants (see supplemental materials). Each two-hour focus group had four parts: (i) warm-up exercise and participant views about AI in general, (ii) brief introduction of the Vector Institute for artificial intelligence (Vector) and plain language examples of AI/ML supplied by Vector, (iii) of participant views on realistic but fictional health AI scenarios (see supplemental materials), and (iv) time for questions with a Vector representative (PAP). The three scenarios were presented in varying order across groups per site, and included AI-based Cancer Genetics Test, an AI-based App to Help Older Adults Aging at Home, and an Accessible Health Dataset of Lab Test Results for AI. Participants were asked to make an independent written decision about the acceptability of each health AI scenario before the group discussion began to increase the likelihood that they would state their own initial views versus echo the views of others. The study was approved by the Research Ethics Board of the University of Toronto in Toronto, Ontario, Canada, protocol number 38084.

Setting

The sessions took place in October 2019 in facilities designed for focus groups with audio-recording capabilities and space for observation (PAP, MDM, TS) behind a one-way mirror. Three focus groups were conducted in northern Ontario (Sudbury, 400 km north of Toronto) and three in the Greater Toronto Area (Mississauga).

Participants

A total of 41 participants took part in the research (Table 1) – 20 participants in Sudbury, 21 participants in Mississauga. Participants were contacted through Canadian Market Research, drawing from a repository of individuals who had consented to be contacted for research. Purposive sampling was used to identify eight invitees for each focus group that collectively had variation in age, gender, income, education, ethnicity and household size[26]. Of the 48 people approached, one person arrived unwell and was compensated but sent home, and six did choose to attend (reasons not captured). To create an environment in which participants were most likely to be comfortable sharing their views, in each city there was an afternoon focus group with individuals ages 25-34 and mixed incomes, followed by 5:00 pm focus group with people ages 35-65 with lower incomes, and a 7:30 pm focus group with people ages 35-65 and higher incomes. For practical reasons, recruitment for all focus groups occurred at one time. As part of the recruitment process, participants were notified of the purpose of the focus groups, i.e., to learn more about how members of the public perceive the use of health data for AI research. Participants were also informed of the purpose of each focus group, in writing, as part of the process to obtain their written informed consent immediately before each session, and verbally at the start of each focus group. At the end of each session, participants were provided with a cheque for $100 CAD as compensation for their time.

Table 1. Characteristics of participants (N = 41)

Variable	**Median**	**Range**
Age (years)	40	25-65
	Percent	**Frequency**
Gender		
Male	51%	21
Female	49%	20
Ethnicity		
French	15%	6
Caucasian	12%	5
Carribean	12%	5
East and Southeast Asian	12%	5
Southern European	10%	4
North American Indigenous	7%	3
Black and African	7%	3
South Asian	7%	3
Mixed	7%	3
Northern European	5%	2
Eastern European	2%	1
Other North American	2%	1
Marital Status		
Married/common-law	71%	29
Single	19%	8
Divorced/widowed/separated	10%	4
Income		
≤ $29,999	5%	2
$30,000 - $79,999	53%	22
≥ $80,000	42%	17
Level of education completed		
High School	24%	10
College	42%	17
University	29%	12
Post Graduate	2%	1

Table 2. Characteristics of participants by focus group

	Sudbury 1	Sudbury 2	Sudbury 3	Missis-sauga 4	Missis-sauga 5	Missis-sauga 6
Number of participants	8	6	6	7	7	7
Median age in years (range)	48 (35-62)	33 (27-35)	48.5 (39-65)	55 (35-59)	30 (25-33)	44 (36-63)
Gender						
Male	4 (50%)	3 (50%)	3 (50%)	4 (57%)	3 (43%)	4 (57%)
Female	4 (50%)	3 (50%)	3 (50%)	3 (43%)	4 (57%)	3 (43%)
Ethnicity						
French	2 (25%)	1 (16.7%)	3 (50%)	-	-	-
Caucasian	1 (12.5%)	-	-	1(14.2%)	1(14.2%)	2(28.5%)
Caribbean	-	-	-	1(14.2%)	2(28.5%)	2(28.5%)
E and SE Asian	1 (12.5%)	1 (16.7%)	-	-	1(14.2%)	2(28.5%)
S European	-	1 (16.7%)	1 (16.7%)	-	1(14.2%)	1(14.2%)
NA Indigenous	2 (25%)	1 (16.7%)	-	-	-	-
Black/African	-	1 (16.7%)	-	2(28.5%)	-	-
South Asian	-	-	-	2(28.5%)	1(14.2%)	-
Mixed	-	1 (16.7%)	1 (16.7%)	-	1(14.2%)	-
N. European	1 (12.5%)	-	1 (16.7%)	-	-	-
E. European	1 (12.5%)	-	-	-	-	-
Other N. Am.	-	-	-	1(14.2%)	-	-
Marital Status						
Married/c. law	6 (75%)	5 (83.3%)	6 (100%)	5(71.4%)	2 (28.6%)	5(71.4%)
Single	2 (25%)	-	-	1(14.3%)	5 (71.4%)	-
Div./wid./sep.	-	1 (16.7%)	-	1(14.3%)	-	2(28.6%)
Income						
≤ 29,999	1 (12.5%)	-	-	1(14.3%)	-	-
30,000 - 79,999	7 (87.5%)	2 (33.3%)	-	6(85.7%)	5 (71.4%)	-
≥ 80,000	-	4 (66.7%)	6 (100%)	-	2 (28.6%)	7 (100%)
Education						
High School	3 (37.5%)	1 (16.7%)	2 (33.3%)	2(28.6%)	-	-
College	5 (62.5%)	3 (50%)	2 (33.3%)	2(28.6%)	4 (57.1%)	3(42.9%)
University	-	2 (33.3%)	2 (33.3%)	3(42.9%)	2 (28.6%)	4(57.1%)
Post Graduate	-	-	-		1 (14.3%)	-

Patient and Public Involvement

The central research question - how do members of the general public perceive the use of health data for AI research - was directly informed by the results of previous qualitative studies with 60+ members of the public. Before the research was started, the draft scenarios were reviewed and refined based on feedback from the Manager of Public Engagement at ICES and multiple members of the public, including students at the University of Toronto and friends and family members of Vector staff. The corresponding author, PAP, is co-author of the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research and the Lead for the Public Engagement Working Group of Health Data Research Network Canada. Through those and other initiatives, PAP has connections to multiple patient and public advisors, from whom the research team will seek advice when disseminating study findings, including through non-academic channels such as “The Conversation” and social media.

Data Collection

Focus groups were moderated by an experienced male focus group moderator employed by Edelman (10 years of professional experience, RIVA-trained) with no prior relationship with the participants. The moderator was hired to conduct the focus groups. He had no prior knowledge about AI/ML and had no vested interest in the outcome of this project. This information was disclosed to participants at the beginning of the session. Having an external facilitator enabled the research team to benefit from the experience of a skilled professional, provided an environment in which participants would be more likely to feel free to express negative opinions about AI and the Vector Institute than if a member of the Vector Institute staff were facilitating, and allowed the research team to focus on observing the participant discussion and taking field notes. The discussions followed a semi-structured discussion guide (see supplemental material) which allowed for free-flowing conversation as well as facilitated discussion of written scenarios, with prompts on certain questions. All members of the research team (MM, TS, PAP) observed every focus group from behind a one-way mirror and took independent field notes during the sessions. Focus group participants were informed that researchers were in attendance behind the one-way mirror, and that sessions were audio-recorded. Audio-recordings were transcribed verbatim by Edelman and participant names were replaced with a code (e.g., M01 for male 1) before the transcripts were provided to the research team for analysis.

Data Analysis

Data were analysed by MDM, TS and PAP using a qualitative descriptive approach which is a naturalistic form of inquiry that aims to remain “data-near” while inductively interpreting and thematically grouping and detailing respondent experiences, beliefs and expectations[27-28]. MDM, TS and PAP worked together to develop the descriptive coding framework based on the verbatim transcripts and field notes taken during the focus group sessions. The transcripts were read and re-read as coding was performed independently by MDM and TS using a combination of Microsoft Word and Microsoft Excel software. No software was used to supplement human qualitative coding. MDM, TS and PAP used an inductive analytic approach to derive themes based on the data and socialised and refined themes through group discussion. Differences in opinion between MDM, TS and PAP were resolved through iterative discussions. Review and coding of transcripts stopped when inductive thematic saturation was achieved, i.e., when MDM, TS and PAP agreed that additional coding and thematic analysis would not result in any new codes or themes. Though the sample was not designed or intended to provide information about variation in perspectives based on gender, location or age, the research team analysed the theme-coded statements for each of those characteristics and did not find any consistent or significant correlations. The research team was open to the possibility of recruiting additional participants for additional focus groups if there was insufficient data to identify themes; however, based on the finding that themes were strong and consistent across the focus groups, no additional participants were recruited. No formal participant feedback was sought, although the interviewer continually reflected focus group participants' views back to participants to ensure that their views were being captured adequately.

RESULTS

The analysis identified mixed, mostly negative views about AI in general. There were three major themes from the participants discussion of the realistic health AI scenarios, (i) participants had hopes for health AI and perceived benefits from it, (ii) they also identified AI-specific concerns and fears and (iii) they described the conditions under which they supported the use of health data for AI research. Finally, though it was not an objective of the study, the realistic health AI scenarios were found to have an educational effect.

Theme 1: Mixed, mostly negative views about AI in general

Participants had mixed views about AI, but mostly unfavourable perceptions (Box 1). Negative comments referred to the potential for job loss, lack of human touch, and humans losing control over AI, with multiple references to malicious robots (e.g., Terminator, HAL 9000). Several participants shared stories of advertisements being presented to them on their mobile phones after they had spoken about a topic, which they interpreted as proof of AI surveillance of their behaviour. Some participants expressed hope for AI in terms of autonomous vehicles, AI's perceived ability to increase convenience and the ways that AI could be useful in dangerous environments not suitable for humans. However, most of the participants who expressed positive statements about AI also noted concerns given uncertainty about how AI will affect society.

Box 1: Mixed, mostly negative, views about AI in general

1. I feel like it’s one of those things that we’d all be diving headfirst towards, but may be something that could have long-term implications for us as a society down the road that maybe we didn’t fully understand when we dove into it at first. (M015-Mississauga2)
2. So, when I think of AI, I have mixed feelings about it because I think about, "Will my job exist in the future, or will most jobs exist in the future?" …. I think very few of us actually know what AI could be in the next year, ten years, 50 years from now. (F017-Mississauga2)
3. Are we phasing ourselves out? (M008-Sudbury3)
4. I think it's impersonal. Not like that human touch. Where there's substance and feelings or emotions. (F002-Sudbury1)
5. It's portrayed as friendly and helpful, but it's always watching and listening… So I'm excited about the possibilities, but concerned about the implications and reaching into personal privacy (M007-Sudbury2)
6. You talk to somebody about something and then an ad will pop up on your phone for it. It's almost like you're being listened to (F008-Sudbury3)
7. Scary. Out of control… are they [AI] going to take over. It's going to be jobless. (F004-Sudbury1)

Table 3. Summary of main participant views on three realistic health AI research scenarios

Health AI research Scenario	Main Hopes and Perceived Benefits	Main Fears and Perceived Risks	Main Conditions for Scenario to be Acceptable
AI-based Cancer Genetics Test: Academic researchers applying ML to consented genetic data to study cancer cell evolution	Potential for AI to save lives by identifying origin of cancers so treatment can be tailored AI provides faster and more accurate results than would be possible with humans AI has capability to analyse more data than humans could	Risk of re-identification because genetic material can never be truly anonymous Concerns related to spread of AI application outside of beneficial cancer scenario (e.g., misuse of AI tool for inappropriate prenatal genetic screening)	AI must be used as a tool with a human (doctor) making the final decision Data must not be sold (reference to 23andMe partnership with Glaxo Smith Klein) Participants noted and responded positively to the fact that data subjects in the fictional scenario had provided consent for data to be used for AI research
AI-based App to Help Older Adults Aging at Home: Team of academic and industry researchers using ML to develop a mobile phone application (app) to help older adults self-manage chronic conditions and age at home	AI creates a useful tool that provides helpful information to patients AI helps address health human resource shortages AI is helpful for people who do not have family and friends to support them	Concern that machines and AI will inappropriately be viewed as a substitute for human interaction	AI-based app supplements versus replaces human care People using the AI app would need to be fully aware that it is capturing and using their data (transparency) People have the option/choice to not use the AI app
Accessible Dataset with Lab Test Results for AI: Creation of a large accessible de-identified dataset of unconsented laboratory test results to be used a foundation for multiple AI-related purposes	Ability to use AI to generate new knowledge from large amounts of data AI analysis faster and more efficient than humanly possible Utility of dataset for teaching AI	Absence of specific purpose or intended benefit from AI Concern about misuse when companies access health data	External organisation certifies that data are de-identified Some participants would only support scenario if data subjects provide consent

Theme 2: Hopes and perceived benefits of health AI

Participants perceived benefits from each of the three realistic health AI scenarios (Box 2). Perceived benefits were both epistemic (e.g., the perception that AI could generate knowledge that would otherwise be inaccessible to humans) and practical (e.g., the ability of AI to sift through data, perform real-time analyses and provide recommendations to health care providers and directly to patients). Of the three scenarios presented (Table 3) participants saw the greatest benefit of the AI-based Cancer Genetics Test, where it was perceived that AI could save lives. Participants also commented favourably on the benefits of an AI-based app for older adults helping people maintain independence and about the potential for a large laboratory test results dataset to support health AI training, education and discovery research (Table 3).

Box 2: Hopes and perceived benefits of health AI

1. There's just so much potential value... this can potentially save lives. (M017-Mississauga2)
2. It could be a help worldwide to see similar symptoms...it will be quicker because using AI in a computer, you'll be able to get that data and those analytics quicker. (F003-Sudbury1)
3. I think it’s fantastic. The more data they collect, the more they’ll be able to identify the patterns of these cancers and where they originate from. I think it’s just great. (F009-Sudbury3)
4. A lot of times doctors are very busy... So if they have a database or something where they could put in a particular disease or something they're suspecting, and then this database just brings up - narrows down what the possibilities are. That might be better. (F013-Mississauga1)
5. If I could do that as an elderly person and keep my integrity and pride and myself, like staying home instead of having to be placed in a long term care facility. And this little [AI-based] app can help me to stay home and not have a nurse come in my house two, three times a day. (F002-Sudbury1)
6. When you can reach out and have a sample size of a group of ten million people and to be able to extract data from that, you can’t do that with the human brain. A group, a team of researchers can’t do that. You need AI. (M018-Mississauga3)
7. You put everything into a data[set], somebody's going to learn something on that. (M002-Sudbury 1)

Theme 3: Fears and perceived drawbacks of health AI

Participants were primarily concerned that the health data provided for one health AI purpose might be sold or used for other purposes that they do not agree with (Box 3). They also expressed AI-specific concern about the lack of human touch when machines are deeply integrated into care, potential job losses and the potential for AI to lead to a decrease in human skills over time if people become “lazy” and overly reliant on computers. Some additional fears and concerns specific to the individual scenarios were noted including, inability to guarantee privacy when genetic information is used for AI, skepticism that older adults would be able to use an AI-based app, and concern about companies misusing or selling data.

Box 3: Fears and perceived drawbacks of health AI

1. There's no guarantee that they [the people developing AI] are going to have any kind of integrity or confidentiality or anything like that. (F003-Sudbury1)
2. Are they going to take my information, are they going to sell it? So, it kind of makes you scared when other companies are buying it. (F016-Mississauga2)
3. For me the big question is ownership of that data. (M018-Mississauga3)
4. I don't find it very appropriate. First of all, it's going to take jobs away from health professionals. If the app has to tell them, suggest things or whatever, there's no communication there, like face-to-face. (F010-Sudbury3)
5. But it also misses out on that human component where the [personal support worker] comes in and talks to you and things like that. (M007-Sudbury2)
6. The concern is always that you lose some of those soft skills. And how many times in the medical field have you heard that a nurse practitioner or a doctor went on a hunch and found out what the problem was. So that's a concern, that you lose some of those soft skills and that relies on intuition when you rely solely on AI, on computers and programs and algorithms. (M010-Sudbury3)

Theme 4: Conditions under which health AI scenarios are more acceptable

Many participants suggested specific conditions that would make health AI acceptable to them, the most common requirement was that AI be used as a tool that helps humans make decisions versus an autonomous decision-making system (Box 4). In addition, across multiple scenarios, participants stated the requirement for transparency about how data are used in health AI, often expressed in terms of their preference that data subjects be fully informed about how data will be used and given the option of providing informed consent or opting out.

Box 4: Conditions under which Health AI Scenarios are More Acceptable.

1. As long as it's a tool, like the doctor uses the tool and the doctor makes the call. As long as the doctor is making the call, and it's not a computer telling the doctor what to do. (M001-Sudbury1)
2. But I think that it should be stressed for the people that are going to be using it, that it should not be their primary source of health information. They shouldn't skip going to the doctors. This is to be used in conjunction with that. (F007-Sudbury2)
3. The data may be used for research, but they may not be fully aware of it. They may have clicked "I accept" and that part was like - I was like, "That's kind of tricky, kind of." (F002-Sudbury1)
4. That's the thing that threw me off... it was the fact that you didn't get to choose that your information gets used in this process... "Give me a choice." (M012-Mississauga1)
5. Transparency...Why are they even taking the data in the first place? How would it help people in the future? Just understanding the purpose behind all of this. (M017-Mississauga2)

Theme 5: Educational effect of realistic health AI scenarios

There was a significant difference between the dystopian and/or utopian statements of participants at the beginning of each focus group (Box 1) and their comments about the health AI scenarios (Boxes 2, 3, 4, 5 and Table 3) which tended to be more grounded in reality. In some cases, participants were direct in stating that the health AI scenarios had an educational effect for them (Box 5).

Box 5: Educational Effect of Realistic Health AI Scenarios

1. I think our discussion prior to any of these scenarios was more geared toward just generally based [AI], wasn't more toward the health... I didn't think it was so appropriate but then seeing the other two [health AI] scenarios with it [the third AI scenario], I think it could all go hand in hand in the healthcare system. I'm leaning more towards it than my opinion was before. (F006-Sudbury2)
2. I'm not usually that positive, but I'm pretty positive about all of it, everything that we read [the health AI scenarios] so far… I'm anti-computer… But everything I've seen so far... I think it's all good information and it's all good tools, but the keyword "tool." It's a tool. And I see this being an awesome tool as well. (M004-Sudbury1)
3. [Before Scenarios] You can create a Terminator, literally, something that's artificially intelligent, or the Matrix… it goes awry, it tries to take over the world and humans got to fight this. Or it can go in the absolute opposite where it helps… androids… implants... Like I said, it's unlimited to go either way. [After reviewing health AI scenario] I know what they're trying to get done. I agree with all these things. I think they're extremely beneficial for everyone… So now I can say, you know what, I'm confident that this is going in the direction of where I would like this to go because I can't find a downside to an app like this. (M020-Mississauga3)

DISCUSSION

Upon reflecting and discussing the health AI scenarios, participants demonstrated mixed, but generally positive views of the application of AI in health research, provided certain risks were mitigated and conditions were met. Consistent with the literature, this study found that members of the general public have little understanding of AI and ML in general. Given this low level of knowledge, dystopian and utopian extremes presented in the media, and uncertainty about the future of AI and ML which runs across society, the term “hopes and fears” is likely a better fit than “benefits and risks” to describe how members of society perceive AI[15,16].

Overall, participants’ perception of three realistic health AI scenarios were more positive than their perception of AI in general. Many of the views expressed by participants were similar to the findings from a systematic review of public views of data-intensive health research[10] which found general support for using of health data for research with some conditions, concerns about privacy and security, the requirement that there be a public benefit, more trust in public sector studies compared to private sector studies, and varying views on the need for consent. This study adds information about participants’ AI-specific hopes (e.g., potential for faster and more accurate analyses, ability to use more data), fears (e.g., concern that AI will be used for objectionable purposes, lack of human touch, decrease in human skills over time due to over-reliance on machines) and conditions for acceptability (e.g., a human must be in the loop for computer-aided decisions).

Consistent with previous studies of public perspectives about health AI[16,23-25], participants’ support for health AI scenarios was linked to their perceived public benefit of the scenarios, with people being most supportive when they believed that AI could bring an important new capability to a problem beyond what humans could contribute. Each of three health AI research scenarios were viewed as being acceptable by most of the participants of the focus groups (Table 3). Of the three scenarios, the AI-based Cancer Genetics Test was the most supported, with several participants linking their support to personal or family experiences with cancer. The next highest supported scenario was the AI-based App to Help Older Adults Aging at Home. Participants were generally supportive of the scenario focused on creating a large accessible dataset, but were direct in stating that the benefits from it were less clear to them. Though care was taken to construct scenarios focused on health AI research, participants’ support was mostly associated with the benefit expected from the final health AI application, even when scenarios highlighted the fact that there was no guarantee that the research would achieve its intended impact. Given the Gartner Hype Cycle,[29] this may present a risk for AI/ML research. If members of the public assume that health AI research will always be successful, there is increased likelihood of disillusionment, potentially leading to an AI winter and decrease in research funding for AI/ML.

In this study, many participants’ concerns with the health AI scenarios were not directly related to AI. As has been observed for data-intensive health research in general, people were concerned about lack of transparency, and potential abuses and misuses of their health data, particularly when companies work with health data[10,13]. High profile news stories about data breaches as well as coverage of lawsuits (e.g., related to Google[20,21]) can heighten these concerns. In addition, participants did have some fears and concerns related to health AI which were very similar to the concerns that they expressed about AI in general, e.g., fear that AI would take over decisions and/o result in job losses.

Consistent with the available small literature on public views about health AI,[15-19, 23-25] the main condition for the health AI scenarios to be seen as acceptable was that AI be used as a tool by humans, and that humans continue to be in the loop. This condition is not surprising given the general fears associated with all AI, and also aligned with the American Academy of Dermatology Position Statement on Augmented Intelligence (their preferred term over artificial intelligence) which refers to "symbiotic and synergistic roles of augmented intelligence and human judgment"[30]. Participants' support was also conditional on transparency about how data are used for health AI. Some were direct in stating that consent should be obtained before data are used for health AI, while other participants noted that current consent processes (e.g., long forms) are not the solution, and many emphasised the need for plain language explanations of how data are used for health AI, preferably delivered by a human. Again, this finding is aligned with the American Academy of Dermatology Position Statement which states "there should be transparency and choice on how their medical information is gathered, utilised, and stored and when, what, and how augmented intelligence technologies are utilised in their care process." In this regard, the views of the general public about health AI are similar to their views on data-intensive health research in general;[10,11] i.e., they have mixed views on consent with most people primarily wanting to know if, how and when their data were used for research.

Taken as a whole, the findings of this study and other qualitative research should influence health AI research and application. Given widespread uncertainty about exactly how AI will impact society, and increasing use of public data (including unconsented data) for AI, we need to understand which uses of health data for AI research are supported by the public, and which are not. Transparency and plain language communication about health AI research are necessary but not sufficient[31]. This is not simply a matter of informing members of the public about how health data are used in AI research. Consistent with the Montreal Declaration for Responsible Development of AI[32] the objective should be to take the science of health AI in directions that the public supports. By behaving in a trustworthy manner, respecting public concerns and involving members of the public in decisions related to health AI, we can align with the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research[33] to establish socially beneficial ways of using health data in AI research.

Limitations

This study has limitations. Foremost, results may not be generalisable across or outside of Ontario. It is possible that participants from other settings, e.g., rural Ontario, remote northern Ontario, specific sub-populations or other jurisdictions would have different views. Given the low level of knowledge about AI in general it is possible that the views of participants would change substantially if they learned and understood more about AI. There are many uses of health data for AI which were not included in the scenarios in this study, and it is possible that participants would have different views if the scenarios were different or altered.

AUTHORSHIP STATEMENT

All authors contributed to the design of the study, attended all focus groups, developed and refined the themes, contributed text directly to the manuscript, and approved the final version submitted for publication. Melissa McCradden and Alison Paprica led the literature review. Alison Paprica led the work to design the scenarios with contributions from Tasmie Sarker, Melissa McCradden and multiple other individuals who are acknowledged. Tasmie Sarker and Melissa McCradden both independently coded all transcripts. Alison Paprica reviewed all coding and performed analyses with Melissa McCradden and Tasmie Sarker to develop the descriptive coding framework and identify themes. Alison Paprica was the lead for preparation of the manuscript. All of the authors gave approval of the final version for publication and agreed to be accountable for all aspects of the work.

ACKNOWLEDGEMENTS

The authors thank Elham Dolatabadi, James Fernandez, Ian Gormely, Jenine Paul, Céline Moore, Andrea Smith, and Linda Sundermann for their contributions to the health AI scenarios.

DATA SHARING STATEMENT

All data relevant to the study are included in the article. All authors had access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. No unpublished data are available outside of the study team.

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Discussion Guide for: Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research

Melissa D McCradden PhD, Tasmie Sarker, P Alison Paprica PhD

WAIT ROOM ACTIVITY (15 MIN BEFORE THE GROUPS BEGINS)

Review and sign provided informed consent form when checking in

Welcome!

While you're waiting for the group to begin, take a moment to think about how you feel about the idea of Artificial Intelligence (AI) in the world today.

- Choose pictures from the magazines that represent how you feel and paste them in the space below.
    - Fill in the blanks to explain each picture.

      My feelings towards AI are like _______________ because _____________________

- Take some time with this and really try to capture how you feel.

DISCUSSION

A) INTRODUCTION (5 MIN)

- Moderator Introduction:
    - Thanks for coming, general topic (AI), agenda (review and discuss scenarios related to the topic)
    - Role as objective facilitator for the group, listen to all points of view, no wrong answers, build off each other
    - Guidelines: Talk one at a time, as loud as my voice, avoid side conversations, equal air time, don't be shy to say what you believe whether or not everyone agrees with you
    - Food/permissions: Ok to get up for food, go to washroom, but one person at a time
    - General disclosures: Microphones, video recording, info for research only, one-way mirror
    - If you feel uncomfortable and want to stop participating, you are welcome to leave at any time.

- Participant Introduction:
    - First name, who do you live with, what's a word your family/friends would use to describe you?

B) INITIAL ATTITUDES TOWARDS AI (5 MIN)

- Before we get to your waiting room activity, what first comes to mind when you think of AI?

- Tell me about the image/s that you chose and explain how they represent how you feel about AI
    - Probe/listen for positive and negative feelings, feelings around a lack of understanding or confusion

C) VECTOR AI INTRODUCTION (5 MIN)

This focus group is being conducted for the Vector Institute which is an independent research institute focused on AI. Vector is home to many world-class AI scientists. When people from Vector explain AI they describe it like this:

AI is the field of computer science that focuses on training computers to perform tasks which would usually require human intelligence.

Using AI, computers can self-adapt and learn based on data and observations. A computer that is trained on large amounts of data can find patterns in data and make predictions and decisions with human-like intelligence.
For example, using AI a computer might:

- learn how to predict new songs that you'll probably like based on what you listen to on Spotify
- present an advertisement on the internet that is likely to be of interest based on other websites that you have visited
- scan millions of x-ray images in seconds and retrieve 3-4 images to assist a doctor who is making a diagnosis based on a rare or unusual x-ray image
- process large amounts of real-time data and predict when a baby in the intensive care unit is going to have cardiac arrest 5 minutes earlier than most doctors or nurses could

For the rest of this session I'm going to present some health AI scenarios for you to discuss.
They are all fictional scenarios that resemble actual health AI activities that are happening somewhere in the world now.

They all contain some scientific information, but the goal isn't to have you learn the details.

The Vector Institute would like to know how you feel about the scenarios. For example, whether something stands out in a good or bad way, or if you have important unanswered questions after reading them.

Vector will use what they learn about public perspectives in their future communications and decisions.

At the end of the session, a representative from Vector will come in to answer any questions that you have.

D) SCENARIO REVIEW (90 MIN) - Order rotate scenarios with handout, 30 minutes of discussion each (note: the text may be modified in small ways to improve clarity)

Scenario 1: AI-Based Cancer Genetics Test
Scenario 2: AI-Based App to Help Older Adults Aging at Home
Scenario 3: Accessible Lab Test Results Dataset for AI

	Sudbury	Mississauga
Ages 35 – 65, lower income	Scenario 1, 2, 3	Scenario 3, 1, 2
Ages 25 – 34, mixed income	Scenario 2, 1, 3	Scenario 3, 2, 1
Ages 35 – 65, higher income	Scenario 2, 3, 1	Scenario 1, 3, 2

- Read the scenario, before we discuss it, I want you to:
    - Mark up the scenario by circling ideas that attract you, crossing out ideas that push you away, and placing question marks beside ideas you don't understand (write legend on flip chart) – we will collect them at the end of the session and share them with our client
    - In the space provided, circle how appropriate you feel it would be for AI to be used in this way

Very appropriate, Somewhat appropriate, Not so appropriate, Not appropriate at all

- What is the main idea you take away from this scenario?
- With a show of hands, who wrote Very appropriate? Somewhat appropriate? Not so appropriate? Not appropriate at all?
    - What makes you feel this would be an appropriate use of AI?
    - What makes you feel that this wouldn't be appropriate?
- [time permitting] What questions do you have about this scenario?
    - What brings up these questions for you?
    - How would you hope these questions would be addressed?
- [time permitting] Of all the things we've talked about for this scenario, what is the most important thought you have to share?

REPEAT FROM BEGINNING OF SECTION FOR NEXT SCENARIO

E) ATTITUDES TOWARDS AI RELOOP & WRAP UP (5 MIN)

- Now that we have reviewed these scenarios, what would you say was your biggest take away from what you read or what we discussed today?

- How do you feel about the role of AI as it pertains to health?
    - Are you leaning positively or negatively towards it?
    - What are the reasons for that?

- Check back room for additional questions

F) Q&A WITH VECTOR AI (10 MIN)

- At this point, I'm going to invite Alison Paprica from the Vector Institute, her role is Vice President Health Strategy and Partnerships and she is here to answer any questions that you have.

Health AI Research Scenario: AI-Based Cancer Genetics Test

Someone close to you has recently been diagnosed with cancer. Their doctor orders a biopsy of the tumour to analyze the cancer cell DNA and several other tests to help her determine the best options for treatment. The data generated by these tests could be used in artificial intelligence (AI) research studies.

AI research could help doctors and patients have better cancer treatment options in the future. Researchers are using AI to analyze very large amounts of data to identify patterns that tell them where a tumour originated in a patient's body. In some cases, AI can help identify where a tumour came from faster or more accurately than other methods. If doctors know where a tumour started in the body, they might recommend different treatments. For example, in the future, doctors might use an AI test to determine that the cancer found in someone's ovary originated in the colon, and the doctor might recommend a colon cancer drug for treatment as a result.

AI is just one of the methods that is being used to study cancer and improve treatments. There is no guarantee that the AI study will provide benefits for the person who is close to you, or to anybody else.

If your friend or loved one does decide to provide their data to the research study, identifying information like their name, phone number, address, and health card number would all be removed before the data are made available to researchers. All people with access to the data commit to not attempting to re-identify any person in the dataset. The risk of re-identification would be very low, but is never zero, particularly when genetic information is involved, because every person's DNA is unique.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

Health AI Research Scenario: AI-Based App to Help Older Adults Aging at Home

A group of private and public sector organizations want to use artificial intelligence (AI) research to develop an app that helps older adults self-manage chronic diseases like diabetes so that they can age independently in their own homes.

The research team includes AI scientists from universities and hospitals, physician researchers, app developers from a small company and staff from a not-for-profit organization that provides home care services for seniors. The research team plans to use AI to identify patterns in large amounts of data that help them predict when older adults are most likely to run into trouble living at home. They want to use the results of the AI research study to develop an app that provides advice and directs seniors to services before problems become serious.

The data they are using for the AI research study includes:

- information that older adults have already entered into websites and apps themselves, e.g., information they typed on social media platforms that members of the public can read
- data that the home care services not-for-profit organization gathers, e.g., how much help someone needed with bathing
- physician notes from family doctor's offices, e.g., notes about how a person's chronic condition appears to be affecting their mental health and well-being

In all cases the people who have data included in the study were informed that their data may be used for research, but they may not be fully aware of it. For example, people may have clicked "I accept" to terms on a website, or signed a form with fine print without reading all the terms. In other cases, people have been in an office that has a poster on the wall stating that data may be used for research, but they didn't notice the poster or completely process the fact that their data would be used for a research study like this.

If things go as planned, the AI research studies will lead to an app that will help older adults with self-management and direct them to healthcare services when they need them. For example, the app might send medication reminders to an older adult with diabetes and mild depression if the person's condition is stable, or suggest that they make an appointment to see their doctor if their condition is worsening. There is no guarantee that the AI research study will lead to an app being developed, or that the app will be effective.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

Health AI Research Scenario: Sample Dataset with Lab Test Results for AI

A group of not-for-profit research institutes is planning to create a health dataset that can be used for artificial intelligence (AI). The research institutes have large datasets that are strictly controlled for use in approved research studies. Their goal is to create a small sample of one of these datasets that can be accessed with fewer restrictions than the larger, controlled health dataset.

The research institutes will start with a large dataset that has laboratory test results and basic information about hospital visits for over 10 million people that live in Ontario. They will take a random 2% sample to create the “sample dataset” which means that it would include data for about 200,000 people out of the 10 million people. It also means that out of every 100 people who had lab tests performed in Ontario, two people will have their data included in the sample dataset. However, there is no way for the people who are included in the sample dataset to know that their data are being used. Your data could be in the sample dataset, but you wouldn’t know it.

The sample dataset will have all identifying information removed, including names, dates, geographic information and any details about services that might allow someone to re-identify an individual. In addition, the research institutes will remove all the data for people with rare conditions because those people might be easier to re-identify. The sample dataset will include data for people that are healthy and data for people who have common chronic diseases, like diabetes and high blood pressure. An external organization will certify that the sample dataset is de-identified before anyone is permitted to work with the data. Once the sample dataset is certified as “de-identified”, it will be put in a controlled environment where researchers, students and companies can access it once they have completed training. They will not be able to download the data.

With AI, it is sometimes hard to know what the benefits of data analysis will be in advance. The benefits of the sample dataset could be:

- Researchers use the sample dataset to learn about new relationships and patterns in the lab test data. For example, they might have a new discovery which shows that a patient is at risk when two different lab tests increase at the same time.
- A large number of students work the sample dataset to learn and improve their computer programing skills.
- Companies use the sample dataset to develop apps that patients use to track their own laboratory test results over time.

It is possible that none of these benefits of the sample dataset are realized, or that the sample dataset has other benefits that the research institutes haven’t thought of.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

PA Paprica, MD McCradden, T Sarker – see “Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research” for additional information

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039798.R1
Article Type:	Original research
Date Submitted by the Author:	05-Aug-2020
Complete List of Authors:	McCradden, Melissa; Hospital for Sick Children Sarker, Tasmie; Vector Institute Paprica, P. Alison; University of Toronto, Institute for Health Policy, Management and Evaluation; Vector Institute
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Health informatics, Qualitative research, Ethics, Health policy
Keywords:	QUALITATIVE RESEARCH, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, ETHICS (see Medical Ethics)

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Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research

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Word count: 3480 [excludes the title page, abstract, tables, acknowledgements, author contributions, and references]

Supplemental Materials – 1. Discussion Guide, 2. Health AI Research Scenarios

ABSTRACT

Objectives: Given widespread interest in applying artificial intelligence (AI) to health data to improve patient care and health system efficiency, there is a need to understand the perspectives of the general public regarding the use of health data in AI research.

Design: A qualitative study involving six focus groups with members of the public. Participants discussed their views about AI in general, then were asked to share their thoughts about three realistic health AI research scenarios. Data were analysed using qualitative description thematic analysis.

Settings: Two cities in Ontario, Canada: Sudbury (400 km north of Toronto) and Mississauga, (part of the Greater Toronto Area).

Participants: Forty-one purposively sampled members of the public (21M:20F, 25-65 years, median age 40).

Results: Participants had low levels of prior knowledge of AI and mixed, mostly negative, perceptions of AI in general. Most endorsed using data for health AI research when there is strong potential for public benefit, providing that concerns about privacy, consent, and commercial motives were addressed. Inductive thematic analysis identified AI-specific hopes (e.g., potential for faster and more accurate analyses, ability to use more data), fears (e.g., loss of human touch, skill depreciation from over-reliance on machines) and conditions (e.g., human verification of computer-aided decisions, transparency). There were mixed views about whether data subject consent is required for health AI research, with most participants wanting to know if, how and by whom their data were used. Though it was not an objective of the study, realistic health AI scenarios were found to have an educational effect.

Conclusions: Notwithstanding concerns and limited knowledge about AI in general, most members of the general public in six focus groups in Ontario, Canada perceived benefits from health AI and conditionally supported the use of health data for AI research.

Keywords: Artificial intelligence, machine learning, public engagement, qualitative research, data sharing

STRENGTHS AND LIMITATIONS OF THIS STUDY

A strength of this study is the analysis of how diverse members of the general public perceive three realistic scenarios in which health data are used for AI research.

The detailed health AI scenarios incorporate points that previous qualitative research has indicated are likely to elicit discussion.

Notwithstanding the diverse ethnic and educational backgrounds of participants, overall the sample represents the general (mainstream) population of Ontario and results cannot be interpreted as presenting the views of specific subpopulations.

Given the low level of knowledge about AI in general it is possible that the views of participants would change substantially if they learned and understood more about AI.

TRANSPARENCY STATEMENT

P. Alison Paprica affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that there were no discrepancies from the study as originally approved by the University of Toronto Research Ethics Board.

FUNDING STATEMENT

This research was funded by the Vector Institute. Award/grant number: Not Applicable.

COMPETING INTERESTS STATEMENT

MDM has nothing to disclose.
TS has nothing to disclose.
PAP has nothing to disclose.

INTRODUCTION

Modern artificial intelligence (AI) and its subfield machine learning (ML) offer much promise for deriving impactful knowledge from health data. Several recent articles present summaries of recent health AI and ML achievements, and what the future could look like as more health data become available and are used in AI research and development[1-5]. Given that AI and ML require large amounts of data,[6] public trust in, and support for, using health data for AI/ML will be essential. Many institutions are exploring models for using large representative datasets of health information to create learning healthcare systems[7,8].Public trust and social licence for such work is essential[8] because, in contrast with clinical studies that have consent-based participation from data subjects, “big data” research is often performed without expressed consent from the data subjects[9]. Previous studies exploring the public attitudes toward data-intensive health research in general, i.e., without an AI/ML focus, found that most members of the mainstream public are supportive provided there are appropriate controls[10-13]. While underscoring the need to address the public’s concerns, studies in Canada, the UK, USA and other jurisdictions suggest that members of the mainstream public view health data as an asset that should be used as long as their concerns related to privacy, commercial motives and other risks are addressed[10-13].

However, we cannot assume that this general but conditional public support for data-intensive health research extends to AI/ML for several reasons. Foremost, research has shown that the members of the general public have low understanding of AI in general, alongside AI-specific hopes and fears including loss of control of AI, ethical concerns, and the potential negative impact of AI on work[14-18]. Secondly, while there is general trend toward support for health AI,[19] there is also recent negative press about large technology companies using health data for AI, including patients suing Google and the University of Chicago Medical Center[20] and the view of the National Data Guardian at the UK's Department of Health that the sharing of patient data between the Royal Free Hospital of London and Google DeepMind was legally inappropriate[21]. Thirdly, there is decreasing confidence that accepted approaches to de-identification are sufficient to ensure privacy in the face of AI’s capabilities[22].

To date, there has been limited scholarly research on public perceptions of health AI. Most published studies have focused on the views of patients who may not be representative because they stand to benefit from AI applications[16]. Further, most published studies have focused on computer vision health AI applications in radiology and dermatology, which represent only a small fraction of the potential applications of AI in health[23-25]. Additionally, there is a need to understand public perspectives versus patient perspectives, because health AI research may rely on large datasets that include information about people who do not have health conditions and/or do not stand to benefit directly from the research. Accordingly, the objective of this study was to learn more about how members of the general public perceive health data being used for AI research.

METHODS

Study Design

Focus groups were conducted using semi-structured discussion guides designed to prompt dialogue among participants (see supplementary file 1). Each two-hour focus group had four parts: (i) warm-up exercise and participant views about AI in general, (ii) brief introduction of the Vector Institute for artificial intelligence (Vector) and plain language examples of AI/ML supplied by Vector, (iii) discussion of participant views on realistic but fictional health AI research scenarios (see supplementary file 2), and (iv) time for questions with a Vector representative (PAP). The three AI research scenarios were presented in varying order across groups per site, and included AI-based Cancer Genetics Test, an AI-based App to Help Older Adults Aging at Home, and an Accessible Health Dataset of Lab Test Results for AI. Participants were asked to make an independent written decision about the acceptability of each health AI research scenario before the group discussion began to increase the likelihood that they would state their own initial views versus echo the views of others. The study was approved by the Research Ethics Board of the University of Toronto in Toronto, Ontario, Canada, protocol number 38084.

Setting

The sessions took place in October 2019 in facilities designed for focus groups with audio-recording capabilities and space for observation (PAP, MDM, TS) behind a one-way mirror. This allowed the research team to take notes and discuss emerging findings in real time without distracting participants. Three focus groups were conducted in northern Ontario (Sudbury, 400 km north of Toronto) and three in the Greater Toronto Area (Mississauga).

Participants

A total of 41 participants took part in the research (Tables 1 and 2) – 20 participants in Sudbury, 21 participants in Mississauga. Participants were contacted by the Canadian subsidiary of Edelman (a communications company that conducts market research) drawing from a database of individuals who had signed up to participate in research studies which was established by Canada Market Research (a company that provides market research services and field service support). Purposive sampling was used to identify eight invitees for each focus group that collectively had variation in age, gender, income, education, ethnicity and household size[26]. Of the 48 people approached, one person arrived unwell and was compensated but sent home, and six did not choose to attend (reasons not captured). To create an environment in which participants were likely to be comfortable sharing their views, in each city there was an afternoon focus group with individuals ages 25-34 and mixed incomes, followed by 5:00 pm focus group with people ages 35-65 with lower incomes, and a 7:30 pm focus group with people ages 35-65 and higher incomes. Participants learned the first name and city or town of residence of other people in the focus group, plus whatever additional information participants chose to share about their work, family, education, etc.

For practical reasons, recruitment for all focus groups occurred at one time. As part of the recruitment process, participants were notified of the purpose of the focus groups, i.e., to learn more about how members of the public perceive the use of health data for AI research. Participants were also informed of the purpose of each focus group, in writing, as part of the process to obtain their written informed consent.. At the end of each session, participants were provided with a cheque for $100 CAD as compensation for their time.

Table 1. Characteristics of participants (N = 41)

Variable	**Median**	**Range**
Age (years)	40	25-65
	Percent	**Frequency**
Gender		
Male	51%	21
Female	49%	20
Ethnicity		
French	15%	6
Caucasian	12%	5
Carribean	12%	5
East and Southeast Asian	12%	5
Southern European	10%	4
North American Indigenous	7%	3
Black and African	7%	3
South Asian	7%	3
Mixed	7%	3
Northern European	5%	2
Eastern European	2%	1
Other North American	2%	1
Marital Status		
Married/common-law	71%	29
Single	19%	8
Divorced/widowed/separated	10%	4
Income		
≤ $29,999	5%	2
$30,000 - $79,999	53%	22
≥ $80,000	42%	17
Level of education completed		
High School	24%	10
College	42%	17
University	29%	12
Post Graduate	2%	1

Table 2. Characteristics of participants by focus group

	Sudbury 1	Sudbury 2	Sudbury 3	Missis-sauga 4	Missis-sauga 5	Missis-sauga 6
Number of participants	8	6	6	7	7	7
Median age in years (range)	48 (35-62)	33 (27-35)	48.5 (39-65)	55 (35-59)	30 (25-33)	44 (36-63)
Gender						
Male	4 (50%)	3 (50%)	3 (50%)	4 (57%)	3 (43%)	4 (57%)
Female	4 (50%)	3 (50%)	3 (50%)	3 (43%)	4 (57%)	3 (43%)
Ethnicity						
French	2 (25%)	1 (16.7%)	3 (50%)	-	-	-
Caucasian	1 (12.5%)	-	-	1(14.2%)	1(14.2%)	2(28.5%)
Caribbean	-	-	-	1(14.2%)	2(28.5%)	2(28.5%)
E and SE Asian	1 (12.5%)	1 (16.7%)	-	-	1(14.2%)	2(28.5%)
S European	-	1 (16.7%)	1 (16.7%)	-	1(14.2%)	1(14.2%)
NA Indigenous	2 (25%)	1 (16.7%)	-	-	-	-
Black/African	-	1 (16.7%)	-	2(28.5%)	-	-
South Asian	-	-	-	2(28.5%)	1(14.2%)	-
Mixed	-	1 (16.7%)	1 (16.7%)	-	1(14.2%)	-
N. European	1 (12.5%)	-	1 (16.7%)	-	-	-
E. European	1 (12.5%)	-	-	-	-	-
Other N. Am.	-	-	-	1(14.2%)	-	-
Marital Status						
Married/c. law	6 (75%)	5 (83.3%)	6 (100%)	5(71.4%)	2 (28.6%)	5(71.4%)
Single	2 (25%)	-	-	1(14.3%)	5 (71.4%)	-
Div./wid./sep.	-	1 (16.7%)	-	1(14.3%)	-	2(28.6%)
Income						
≤ 29,999	1 (12.5%)	-	-	1(14.3%)	-	-
30,000 - 79,999	7 (87.5%)	2 (33.3%)	-	6(85.7%)	5 (71.4%)	-
≥ 80,000	-	4 (66.7%)	6 (100%)	-	2 (28.6%)	7 (100%)
Education						
High School	3 (37.5%)	1 (16.7%)	2 (33.3%)	2(28.6%)	-	-
College	5 (62.5%)	3 (50%)	2 (33.3%)	2(28.6%)	4 (57.1%)	3(42.9%)
University	-	2 (33.3%)	2 (33.3%)	3(42.9%)	2 (28.6%)	4(57.1%)
Post Graduate	-	-	-	-	1 (14.3%)	-

Patient and Public Involvement

The central research question - how do members of the general public perceive the use of health data for AI research? - was directly informed by the results of previous qualitative studies with 60+ members of the public[10,11]. Before the research was started, the draft scenarios were reviewed and refined based on feedback from the Manager of Public Engagement at ICES and multiple members of the public, including students at the University of Toronto and friends and family members of Vector staff. The corresponding author, PAP, is co-author of the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research[27] and the Lead for the Public Engagement Working Group of Health Data Research Network Canada. Through those and other initiatives, PAP has connections to multiple patient and public advisors, from whom the research team will seek advice when disseminating study findings, including through non-academic channels such as “The Conversation” and social media.

Data Collection

Focus groups were moderated by an experienced male focus group moderator employed by Edelman (10 years of professional experience) with no prior relationship with the participants. The moderator was hired to conduct the focus groups. He had no prior knowledge about AI/ML and had no vested interest in the outcome of this project. This information was disclosed to participants at the beginning of the session. Having an external facilitator enabled the research team to benefit from the experience of a skilled professional, provided an environment in which participants would be more likely to feel free to express negative opinions about AI and the Vector Institute than if a member of the Vector Institute staff were facilitating, and allowed the research team to focus on observing the participant discussion and taking field notes. The discussions followed a semi-structured discussion guide (see supplementary file 1) which allowed for free-flowing conversation as well as facilitated discussion of written scenarios, with prompts on certain questions. All members of the research team (MM, TS, PAP) observed every focus group from behind a one-way mirror and took independent field notes during the sessions. Focus group participants were informed that researchers were in attendance behind the one-way mirror, and that sessions were audio-recorded. Audio-recordings were transcribed verbatim by Edelman and participant names were replaced with a code (e.g., M01 for male 1) before the transcripts were provided to the research team for analysis.

Data Analysis

Data were analysed by MDM, TS and PAP using a qualitative descriptive approach which is a naturalistic form of inquiry that aims to remain “data-near” while inductively interpreting and thematically grouping and detailing respondent experiences, beliefs and expectations[28-29]. MDM, TS and PAP worked together to develop the descriptive coding framework based on the verbatim transcripts and field notes taken during the focus group sessions. The transcripts were read and re-read as coding was performed independently by MDM and TS using a combination of Microsoft Word and Microsoft Excel software. No software was used to supplement human qualitative coding. MDM, TS and PAP used an inductive analytic approach to derive themes based on the data and socialised and refined themes through group discussion. Differences in opinion between MDM, TS and PAP were resolved through iterative discussions. Review and coding of transcripts stopped when inductive thematic saturation was achieved, i.e., when MDM, TS and PAP agreed that additional coding and thematic analysis would not result in any new codes or themes. Though the sample was not designed or intended to provide information about variation in perspectives based on gender, location or age, the research team analysed the theme-coded statements for each of those characteristics and did not find any consistent correlations. The research team was open to the possibility of recruiting additional participants for additional focus groups if there was insufficient data to identify themes; however, based on the finding that themes were strong and consistent across the focus groups, no additional participants were recruited. No formal participant feedback was sought, although the interviewer continually reflected focus group participants' views back to participants to ensure that their views were being captured adequately.

RESULTS

The analysis identified mixed, mostly negative views about AI in general. There were three major themes from the participants discussion of the health AI research scenarios, (i) participants perceived benefits when data are used in health AI research and, (ii) they identified concerns and fears about the use of data in health AI research and about potential negative impacts of health AI application, and (iii) they described the conditions under which the use of health data for AI research and AI application would be more acceptable. Finally, though it was not an objective of the study, the realistic health AI scenarios were found to have an educational effect.

Theme 1: Mixed, mostly negative views about AI in general

Participants had mixed views about AI, but mostly unfavourable perceptions (Box 1). Negative comments referred to the potential for job loss, lack of human touch, and humans losing control over AI, with multiple references to malicious robots (e.g., Terminator, HAL 9000). Several participants shared stories of advertisements being presented to them on their mobile phones after they had spoken about a topic, which they interpreted as proof of AI surveillance of their behaviour. Some participants expressed hope for AI in terms of autonomous vehicles, AI's perceived ability to increase convenience, and the ways that AI could be useful in dangerous environments not suitable for humans. However, most of the participants who expressed positive statements about AI also noted concerns based on uncertainty about how AI will affect society.

Box 1: Mixed, mostly negative views about AI in general

1. I feel like it’s one of those things that we’d all be diving headfirst towards, but may be something that could have long-term implications for us as a society down the road that maybe we didn’t fully understand when we dove into it at first. (M015-Mississauga2)
2. So, when I think of AI, I have mixed feelings about it because I think about, "Will my job exist in the future, or will most jobs exist in the future?" …. I think very few of us actually know what AI could be in the next year, ten years, 50 years from now. (F017-Mississauga2)
3. Are we phasing ourselves out? (M008-Sudbury3)
4. I think it's impersonal. Not like that human touch. Where there's substance and feelings or emotions. (F002-Sudbury1)
5. It's portrayed as friendly and helpful, but it's always watching and listening… So I'm excited about the possibilities, but concerned about the implications and reaching into personal privacy (M007-Sudbury2)
6. You talk to somebody about something and then an ad will pop up on your phone for it. It's almost like you're being listened to (F008-Sudbury3)
7. Scary. Out of control… are they [AI] going to take over. It's going to be jobless. (F004-Sudbury1)

Table 3. Summary of main participant views about three health AI research scenarios

Health AI research Scenario	Main Hopes and Perceived Benefits	Main Fears and Perceived Risks	Main Conditions for Scenario to be Acceptable
AI-based Cancer Genetics Test: Academic researchers applying ML to consented genetic data to study cancer cell evolution and develop new AI-based test	AI provides faster and more accurate results than would be possible with humans AI has capability to analyse more data than humans could Potential for AI-based test to save lives by identifying origin of cancers so treatment can be tailored	Risk of re-identification because genetic material can never be truly anonymous Concerns related to spread of AI-based test outside of beneficial cancer scenario (e.g., misuse of AI-based tests for inappropriate prenatal genetic screening)	Data must not be sold (reference to 23andMe partnership with Glaxo Smith Klein) Participants noted and responded positively to the fact that data subjects in the fictional scenario had provided consent for data to be used for AI research Once developed, AI-based test must be used as a tool with a human (doctor) making the final decision
AI-based App to Help Older Adults Aging at Home: Team of academic and industry researchers using ML and big data to develop a mobile phone application (app) to help older adults self-manage chronic conditions and age at home	Use of data in AI research creates a useful tool that provides helpful information to patients AI-based app would help address health human resource shortages AI-based app would be helpful for people who do not have family and friends to support them	Concern that AI-based app will inappropriately be viewed as a substitute for human interaction	People using the AI-based app would need to be fully aware that it is capturing and using their data (transparency) AI-based app supplements versus replaces human care People have the option/choice to not use the AI-based app
Accessible Dataset with Lab Test Results for AI: Creation of a large accessible de-identified dataset of unconsented laboratory test results to be used a foundation for multiple AI-related purposes	Ability to use AI to generate new knowledge from large amounts of data AI analysis of big data faster and more efficient than humanly possible Utility of dataset for teaching AI	Absence of specific purpose or intended benefit from AI research Concern about misuse when companies access health data	External organisation certifies that data are de-identified Some participants would only support scenario if data subjects provide consent

Theme 2: Hopes and perceived benefits of health AI research scenarios

Participants perceived benefits from the uses of health data in each of the three realistic health AI research scenarios (Box 2). Perceived benefits were both epistemic (e.g., the perception that health data combined with AI research could generate knowledge that would otherwise be inaccessible to humans) and practical (e.g., the ability of AI to sift through large amounts of data, perform real-time analyses and provide recommendations to health care providers and directly to patients). Of the three AI research scenarios presented (Table 3) participants saw the greatest benefit of the AI-based Cancer Genetics Test, where it was perceived that AI research could ultimately save lives. Participants also commented favourably on the benefits of research to develop an AI-based app for older adults in terms of helping people maintain independence, and about the potential for a large laboratory test results dataset to support health AI training, education and discovery research (Table 3).

Box 2: Hopes and perceived benefits of health AI research scenarios

1. It could be a help worldwide to see similar symptoms...it will be quicker because using AI in a computer, you'll be able to get that data and those analytics quicker. (F003-Sudbury1)
2. I think it’s fantastic. The more data they collect, the more they’ll be able to identify the patterns of these cancers and where they originate from. I think it’s just great. (F009-Sudbury3)
3. When you can reach out and have a sample size of a group of ten million people and to be able to extract data from that, you can’t do that with the human brain. A group, a team of researchers can’t do that. You need AI. (M018-Mississauga3)
4. You put everything into a data[set], somebody's going to learn something on that. (M002-Sudbury1)
5. There's just so much potential value... this can potentially save lives. (M017-Mississauga2)
6. If I could do that as an elderly person and keep my integrity and pride and myself, like staying home instead of having to be placed in a long-term care facility. And this little [AI-based] app can help me to stay home and not have a nurse come in my house two, three times a day. (F002-Sudbury1)
7. A lot of times doctors are very busy... So if they have a database or something where they could put in a particular disease or something they're suspecting, and then this database just brings up - narrows down what the possibilities are. That might be better. (F013-Mississauga1)

Theme 3: Fears and perceived drawbacks of health AI research scenarios

Participants were primarily concerned that the health data provided for one health AI purpose might be sold or used for other purposes that they do not agree with (Box 3). They also expressed concern that AI research could lead to AI applications that have negative impacts including lack of human touch when machines are deeply integrated into care, job losses and the potential for AI to decrease human skills over time if people become “lazy” and overly reliant on computers. Some additional fears and concerns specific to the individual scenarios were noted including: inability to guarantee privacy when genetic information is used for AI, concern about companies misusing or selling data, and skepticism that older adults would be able to use an AI-based app.

Box 3: Fears and perceived drawbacks of health AI research scenarios

1. There's no guarantee that they [the people developing AI] are going to have any kind of integrity or confidentiality or anything like that. (F003-Sudbury1)
2. Are they going to take my information, are they going to sell it? So, it kind of makes you scared when other companies are buying it. (F016-Mississauga2)
3. For me the big question is ownership of that data. (M018-Mississauga3)
4. I don't find it very appropriate. First of all, it's going to take jobs away from health professionals. If the app has to tell them, suggest things or whatever, there's no communication there, like face-to-face. (F010-Sudbury3)
5. But it also misses out on that human component where the [personal support worker] comes in and talks to you and things like that. (M007-Sudbury2)
6. The concern is always that you lose some of those soft skills. And how many times in the medical field have you heard that a nurse practitioner or a doctor went on a hunch and found out what the problem was. So that's a concern, that you lose some of those soft skills and that relies on intuition when you rely solely on AI, on computers and programs and algorithms. (M010-Sudbury3)

Theme 4: Conditions under which health AI research scenarios are more acceptable

Many participants suggested specific conditions that would make health AI research scenarios more acceptable to them (Box 4). These included assurance that privacy will be protected and transparency about how data are used in health AI, often expressed in terms of their preference that data subjects be fully informed about how data will be used and given the option of providing informed consent or opting out. In addition, participants repeatedly stated that AI research should focus on the development of AI applications that help humans make decisions versus autonomous decision-making systems.

Box 4: Conditions under which health AI research scenarios are more acceptable

1. I think if you can eliminate people's fear or risk about their information like the names and identity being removed so the fear of the data being hacked. (M016-Mississauga2)
2. I find de-identified is very loose terminology when you're talking about DNA and medical records. (M020-Mississauga3)
3. The data may be used for research, but they may not be fully aware of it. They may have clicked "I accept" and that part was like - I was like, "That's kind of tricky, kind of." (F002-Sudbury1)
4. That's the thing that threw me off... it was the fact that you didn't get to choose that your information gets used in this process... "Give me a choice." (M012-Mississauga1)
5. Transparency...Why are they even taking the data in the first place? How would it help people in the future? Just understanding the purpose behind all of this. (M017-Mississauga2)
6. As long as it's a tool, like the doctor uses the tool and the doctor makes the call. As long as the doctor is making the call, and it's not a computer telling the doctor what to do. (M001-Sudbury1)
7. But I think that it should be stressed for the people that are going to be using it, that it should not be their primary source of health information. They shouldn't skip going to the doctors. This is to be used in conjunction with that. (F007-Sudbury2)

Theme 5: Educational effect of realistic health AI research scenarios

There was a notable difference between the dystopian and/or utopian statements of participants about AI at the beginning of each focus group (Box 1) and their comments about the health AI research scenarios (Boxes 2, 3, 4, 5 and Table 3) which tended to be more grounded in reality. In some cases, participants were direct in stating that the health AI research scenarios had an educational effect for them (Box 5).

Box 5: Educational effect of health AI research scenarios

1. I think our discussion prior to any of these scenarios was more geared toward just generally based [AI], wasn't more toward the health... I didn't think it was so appropriate but then seeing the other two [health AI] scenarios with it [the third AI scenario], I think it could all go hand in hand in the healthcare system. I'm leaning more towards it than my opinion was before. (F006-Sudbury2)
2. I'm not usually that positive, but I'm pretty positive about all of it, everything that we read [the health AI scenarios] so far… I'm anti-computer… But everything I've seen so far... I think it's all good information and it's all good tools, but the keyword "tool." It's a tool. And I see this being an awesome tool as well. (M004-Sudbury1)
3. [Before Scenarios] You can create a Terminator, literally, something that's artificially intelligent, or the Matrix… it goes awry, it tries to take over the world and humans got to fight this. Or it can go in the absolute opposite where it helps… androids… implants... Like I said, it's unlimited to go either way. [After reviewing health AI research scenario] I know what they're trying to get done. I agree with all these things. I think they're extremely beneficial for everyone… So now I can say, you know what, I'm confident that this is going in the direction of where I would like this to go because I can't find a downside to an app like this. (M020-Mississauga3)

DISCUSSION

After discussing the health AI research scenarios, participants demonstrated mixed, but generally positive views about using health data in AI research, provided certain risks were mitigated and conditions were met. Consistent with the literature, this study found that members of the general public have little understanding of AI and ML in general. Given this low level of knowledge, dystopian and utopian extremes presented in the media, and uncertainty about the future of AI and ML which runs across society, the term "hopes and fears" is likely a better fit than "benefits and risks" to describe how members of society perceive AI[15,16].

Overall, participants' perception of three realistic health AI research scenarios were more positive than their perception of AI in general. Many of the views expressed by participants were similar to the findings from a systematic review of public views of data-intensive health research[10] which found general support for using of health data for research with some conditions, concerns about privacy and data security, the requirement that there be a public benefit, more trust in public sector studies compared to private sector studies, and varying views on the need for consent. This study adds participants positive views about the potential for health AI research to derive benefits from large amounts of data that might otherwise go unutilized because AI can produce faster and more accurate analyses. As has been observed for data-intensive health research in general, participants were concerned about risks to privacy, and potential abuses and misuses of their health data, particularly when companies work with health data[10,11,13]. High profile news stories about data breaches as well as coverage of lawsuits (e.g., related to Google[20,21]) can heighten these concerns. Participants' support for the scenarios was also conditional on transparency about how data are used for health AI. Some participants were direct in stating that consent should be obtained before data are used for health AI, while other participants noted that current consent processes (e.g., long forms) are not the solution, and many emphasised the need for plain language explanations of how data are used for health AI, preferably delivered by a human. This finding is aligned with the American Academy of Dermatology Position Statement which states “there should be transparency and choice on how their medical information is gathered, utilised, and stored and when, what, and how augmented intelligence technologies are utilised in their care process.”[30] In this regard, the views of focus group participants were similar to the general public’s views on data-intensive health research in general;[10,11] i.e., they had mixed views on consent with most people primarily wanting to know if, how and when their data were used for research.

Though care was taken to construct scenarios focused on using data in health AI research, participants’ support was often associated with the perceived benefits and risks of AI application, even when scenarios highlighted the fact that there was no guarantee that the research would lead to the successful development of an AI application. Given the Gartner Hype Cycle,[31] this may present a risk for AI/ML research. If members of the public assume that health AI research will always be successful, there is increased likelihood of disillusionment, potentially leading to an AI winter and decrease in research funding for AI/ML. Consistent with previous studies of public perspectives about health AI[16,23-25], participants’ support for health AI research was highest when they believed that the AI research could bring an important new capability to a problem beyond what humans could contribute. Each of three health AI research scenarios were viewed as being acceptable by most of the participants of the focus groups (Table 3). Of the three scenarios, the AI-based Cancer Genetics Test was the most supported, with several participants linking their support to personal or family experiences with cancer. The next highest supported scenario was the AI-based App to Help Older Adults Aging at Home. Participants were also generally supportive of the scenario focused on creating a large accessible dataset but were direct in stating that the benefits from it were less clear to them.

Participants expressed concerns that focused on health AI applications vs. health AI research. As has been reported in the literature,[15-19, 23-25] the main concern and condition for support of health AI research was that the AI application being developed be a tool used by humans and not used without humans “in the loop.” This condition is not surprising given the general fears associated with all AI, and also aligned with the American Academy of Dermatology Position Statement on Augmented Intelligence (their preferred term over artificial intelligence) which refers to “symbiotic and synergistic roles of augmented intelligence and human judgment”[30].

Taken as a whole, the findings of this study and other qualitative research should influence how data are used in health AI research and applications of health AI outside of research settings. Given widespread uncertainty about exactly how AI will impact society, and increasing use of public data (including unconsented data) for AI, we need to understand which uses of health data for AI research are supported by the public, and which are not. Transparency and plain language communication about health AI research are necessary but not sufficient[32]. This is not simply a matter of informing members of the public about how health data are used in AI research. Consistent with the Montreal Declaration for Responsible Development of AI[33] the objective should be to take the science of health AI in directions that the public supports. By behaving in a trustworthy manner, respecting public concerns and involving members of the public in decisions related to health data use we can align with the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research[29] to establish socially beneficial ways of using data in health AI research.

Limitations

This study has limitations. It is possible that participants from other settings, e.g., rural Ontario, remote northern Ontario, specific sub-populations or other jurisdictions would have different views. Given the low level of knowledge about AI in general it is possible that the views of participants would change substantially if they learned and understood more about AI. There are many uses of health data for AI which were not included in the scenarios in this study, and it is possible that participants would have different views if the scenarios were different or altered.

AUTHORSHIP STATEMENT

All authors contributed to the design of the study, attended all focus groups, developed and refined the themes, contributed text directly to the manuscript, and approved the final version submitted for publication. Melissa McCradden and Alison Paprica led the literature review. Alison Paprica led the work to design the scenarios with contributions from Tasmie Sarker, Melissa McCradden and multiple other individuals who are acknowledged. Tasmie Sarker and Melissa McCradden both independently coded all transcripts. Alison Paprica reviewed all coding and performed analyses with Melissa McCradden and Tasmie Sarker to develop the descriptive coding framework and identify themes. Alison Paprica was the lead for preparation of the manuscript. All of the authors gave approval of the final version for publication and agreed to be accountable for all aspects of the work.

ACKNOWLEDGEMENTS

The authors thank Elham Dolatabadi, James Fernandez, Ian Gormely, Jenine Paul, Céline Moore, Andrea Smith, and Linda Sundermann for their contributions to the health AI scenarios.

DATA SHARING STATEMENT

All data relevant to the study are included in the article. All authors had access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. No unpublished data are available outside of the study team.

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Discussion Guide for: Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research

Melissa D McCradden PhD, Tasmie Sarker, P Alison Paprica PhD

WAIT ROOM ACTIVITY (15 MIN BEFORE THE GROUPS BEGINS)

Review and sign provided informed consent form when checking in

Welcome!

While you're waiting for the group to begin, take a moment to think about how you feel about the idea of Artificial Intelligence (AI) in the world today.

- Choose pictures from the magazines that represent how you feel and paste them in the space below.
    - Fill in the blanks to explain each picture.

      My feelings towards AI are like _______________ because ____________________

- Take some time with this and really try to capture how you feel.

DISCUSSION

A) INTRODUCTION (5 MIN)

- Moderator Introduction:
    - Thanks for coming, general topic (AI), agenda (review and discuss scenarios related to the topic)
    - Role as objective facilitator for the group, listen to all points of view, no wrong answers, build off each other
    - Guidelines: Talk one at a time, as loud as my voice, avoid side conversations, equal air time, don't be shy to say what you believe whether or not everyone agrees with you
    - Food/permissions: Ok to get up for food, go to washroom, but one person at a time
    - General disclosures: Microphones, video recording, info for research only, one-way mirror
    - If you feel uncomfortable and want to stop participating, you are welcome to leave at any time.

- Participant Introduction:
    - First name, who do you live with, what's a word your family/friends would use to describe you?

B) INITIAL ATTITUDES TOWARDS AI (5 MIN)

- Before we get to your waiting room activity, what first comes to mind when you think of AI?

- Tell me about the image/s that you chose and explain how they represent how you feel about AI
    - Probe/listen for positive and negative feelings, feelings around a lack of understanding or confusion

C) VECTOR AI INTRODUCTION (5 MIN)

This focus group is being conducted for the Vector Institute which is an independent research institute focused on AI. Vector is home to many world-class AI scientists. When people from Vector explain AI they describe it like this:

AI is the field of computer science that focuses on training computers to perform tasks which would usually require human intelligence.

Using AI, computers can self-adapt and learn based on data and observations. A computer that is trained on large amounts of data can find patterns in data and make predictions and decisions with human-like intelligence.
For example, using AI a computer might:
- learn how to predict new songs that you'll probably like based on what you listen to on Spotify
- present an advertisement on the internet that is likely to be of interest based on other websites that you have visited
- scan millions of x-ray images in seconds and retrieve 3-4 images to assist a doctor who is making a diagnosis based on a rare or unusual x-ray image
- process large amounts of real-time data and predict when a baby in the intensive care unit is going to have cardiac arrest 5 minutes earlier than most doctors or nurses could

For the rest of this session I'm going to present some health AI scenarios for you to discuss.
They are all fictional scenarios that resemble actual health AI activities that are happening somewhere in the world now.

They all contain some scientific information, but the goal isn't to have you learn the details.

The Vector Institute would like to know how you feel about the scenarios. For example, whether something stands out in a good or bad way, or if you have important unanswered questions after reading them.

Vector will use what they learn about public perspectives in their future communications and decisions.

At the end of the session, a representative from Vector will come in to answer any questions that you have.

D) SCENARIO REVIEW (90 MIN) - Order rotate scenarios with handout, 30 minutes of discussion each (note: the text may be modified in small ways to improve clarity)

Scenario 1: AI-Based Cancer Genetics Test
Scenario 2: AI-Based App to Help Older Adults Aging at Home
Scenario 3: Accessible Lab Test Results Dataset for AI

	Sudbury	Mississauga
Ages 35 – 65, lower income	Scenario 1, 2, 3	Scenario 3, 1, 2
Ages 25 – 34, mixed income	Scenario 2, 1, 3	Scenario 3, 2, 1
Ages 35 – 65, higher income	Scenario 2, 3, 1	Scenario 1, 3, 2

- Read the scenario, before we discuss it, I want you to:
    - Mark up the scenario by circling ideas that attract you, crossing out ideas that push you away, and placing question marks beside ideas you don't understand (write legend on flip chart) – we will collect them at the end of the session and share them with our client
    - In the space provided, circle how appropriate you feel it would be for AI to be used in this way

  Very appropriate, Somewhat appropriate, Not so appropriate, Not appropriate at all

- What is the main idea you take away from this scenario?
- With a show of hands, who wrote Very appropriate? Somewhat appropriate? Not so appropriate? Not appropriate at all?
    - What makes you feel this would be an appropriate use of AI?
    - What makes you feel that this wouldn't be appropriate?
- [time permitting] What questions do you have about this scenario?
    - What brings up these questions for you?
    - How would you hope these questions would be addressed?
- [time permitting] Of all the things we've talked about for this scenario, what is the most important thought you have to share?

REPEAT FROM BEGINNING OF SECTION FOR NEXT SCENARIO

E) ATTITUDES TOWARDS AI RELOOP & WRAP UP (5 MIN)

- Now that we have reviewed these scenarios, what would you say was your biggest take away from what you read or what we discussed today?

- How do you feel about the role of AI as it pertains to health?
    - Are you leaning positively or negatively towards it?
    - What are the reasons for that?

- Check back room for additional questions

F) Q&A WITH VECTOR AI (10 MIN)

- At this point, I'm going to invite Alison Paprica from the Vector Institute, her role is Vice President Health Strategy and Partnerships and she is here to answer any questions that you have.

Health AI Research Scenario: AI-Based Cancer Genetics Test

Someone close to you has recently been diagnosed with cancer. Their doctor orders a biopsy of the tumour to analyze the cancer cell DNA and several other tests to help her determine the best options for treatment. The data generated by these tests could be used in artificial intelligence (AI) research studies.

AI research could help doctors and patients have better cancer treatment options in the future. Researchers are using AI to analyze very large amounts of data to identify patterns that tell them where a tumour originated in a patient's body. In some cases, AI can help identify where a tumour came from faster or more accurately than other methods. If doctors know where a tumour started in the body, they might recommend different treatments. For example, in the future, doctors might use an AI test to determine that the cancer found in someone's ovary originated in the colon, and the doctor might recommend a colon cancer drug for treatment as a result.

AI is just one of the methods that is being used to study cancer and improve treatments. There is no guarantee that the AI study will provide benefits for the person who is close to you, or to anybody else.

If your friend or loved one does decide to provide their data to the research study, identifying information like their name, phone number, address, and health card number would all be removed before the data are made available to researchers. All people with access to the data commit to not attempting to re-identify any person in the dataset. The risk of re-identification would be very low, but is never zero, particularly when genetic information is involved, because every person's DNA is unique.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

PA Paprica, MD McCradden, T Sarker – see "Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research" for additional information

Health AI Research Scenario: AI-Based App to Help Older Adults Aging at Home

A group of private and public sector organizations want to use artificial intelligence (AI) research to develop an app that helps older adults self-manage chronic diseases like diabetes so that they can age independently in their own homes.

The research team includes AI scientists from universities and hospitals, physician researchers, app developers from a small company and staff from a not-for-profit organization that provides home care services for seniors. The research team plans to use AI to identify patterns in large amounts of data that help them predict when older adults are most likely to run into trouble living at home. They want to use the results of the AI research study to develop an app that provides advice and directs seniors to services before problems become serious.

The data they are using for the AI research study includes:

- information that older adults have already entered into websites and apps themselves, e.g., information they typed on social media platforms that members of the public can read
- data that the home care services not-for-profit organization gathers, e.g., how much help someone needed with bathing
- physician notes from family doctor's offices, e.g., notes about how a person's chronic condition appears to be affecting their mental health and well-being

In all cases the people who have data included in the study were informed that their data may be used for research, but they may not be fully aware of it. For example, people may have clicked "I accept" to terms on a website, or signed a form with fine print without reading all the terms. In other cases, people have been in an office that has a poster on the wall stating that data may be used for research, but they didn't notice the poster or completely process the fact that their data would be used for a research study like this.

If things go as planned, the AI research studies will lead to an app that will help older adults with self-management and direct them to healthcare services when they need them. For example, the app might send medication reminders to an older adult with diabetes and mild depression if the person's condition is stable, or suggest that they make an appointment to see their doctor if their condition is worsening. There is no guarantee that the AI research study will lead to an app being developed, or that the app will be effective.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

Health AI Research Scenario: Sample Dataset with Lab Test Results for AI

A group of not-for-profit research institutes is planning to create a health dataset that can be used for artificial intelligence (AI). The research institutes have large datasets that are strictly controlled for use in approved research studies. Their goal is to create a small sample of one of these datasets that can be accessed with fewer restrictions than the larger, controlled health dataset.

The research institutes will start with a large dataset that has laboratory test results and basic information about hospital visits for over 10 million people that live in Ontario. They will take a random 2% sample to create the “sample dataset” which means that it would include data for about 200,000 people out of the 10 million people. It also means that out of every 100 people who had lab tests performed in Ontario, two people will have their data included in the sample dataset. However, there is no way for the people who are included in the sample dataset to know that their data are being used. Your data could be in the sample dataset, but you wouldn’t know it.

The sample dataset will have all identifying information removed, including names, dates, geographic information and any details about services that might allow someone to re-identify an individual. In addition, the research institutes will remove all the data for people with rare conditions because those people might be easier to re-identify. The sample dataset will include data for people that are healthy and data for people who have common chronic diseases, like diabetes and high blood pressure. An external organization will certify that the sample dataset is de-identified before anyone is permitted to work with the data. Once the sample dataset is certified as “de-identified”, it will be put in a controlled environment where researchers, students and companies can access it once they have completed training. They will not be able to download the data.

With AI, it is sometimes hard to know what the benefits of data analysis will be in advance. The benefits of the sample dataset could be:

- Researchers use the sample dataset to learn about new relationships and patterns in the lab test data. For example, they might have a new discovery which shows that a patient is at risk when two different lab tests increase at the same time.
- A large number of students work the sample dataset to learn and improve their computer programing skills.
- Companies use the sample dataset to develop apps that patients use to track their own laboratory test results over time.

It is possible that none of these benefits of the sample dataset are realized, or that the sample dataset has other benefits that the research institutes haven’t thought of.

[Discussion prompts, e.g., Do you think it is appropriate to use health data for AI research in this way? Why? Why not?]

PA Paprica, MD McCradden, T Sarker – see “Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research” for additional information

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.