

# What Do Health Service Users Think About the Use of Their Data for AI Development?

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**Abstract.** AI tools are being introduced within health services around the globe. It is important that tools are developed and validated using the available health information of the population where it is intended to be used. We set out to determine what patients thought about the use of their health information for this purpose. In interviews we found that the patients of a health service in Auckland, Aotearoa New Zealand, are generally comfortable with their health information being used for these purposes but with conditions (around public good, governance, privacy, security, transparency, and restrictions on commercial gain) and with careful consideration of their perspectives. We suggest that health services should take the time to have these conversations with their communities and to provide open and clear communication around these developments in their services.

**Keywords.** AI, machine learning, screening, patient perspectives

## 1. Introduction

Artificial Intelligence (AI) tools are starting to be used in clinical practice. Many of these initial implementations of AI involve images, for example, mammograms. In these cases, the AI ‘reads’ the images and detects any abnormalities which may be alerted to the clinician for confirmation or for follow up actions. While many of these AI tools are developed through research projects with appropriate approvals processes, it is the health services that are making decisions on whether to provide access to patient information for the development (training and testing) of these AI tools. Governance decisions may be made in the absence of understanding what their population or patient groups think about the use of their health information to develop such tools.

At Te Whatu Ora Waitematā we felt it would be important to ask our patient population for their perspectives. These perspectives would then inform an AI Governance Group which was reviewing proposals for the use of data hosted by Te Whatu Ora Waitematā as well as proposals for the implementation of AI tools in clinical practice.

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## 2. Methods

The aim of the wider study was to explore patient perceptions of the use of their health information for secondary purposes. This paper presents the results related to the secondary use of health information for the purposes of machine learning (ML) and AI. The full study including the results related to other secondary uses are presented elsewhere. Semi-structured interviews were conducted with current users of services within a large secondary care health district in Aotearoa New Zealand (NZ) (Te Whatu Ora Waitematā). Ethical approval for this study was obtained from the New Zealand Health and Disability Ethics Committee (20/NTA/2).

The inclusion criteria were (1) current user of Te Whatu Ora Waitematā services, (2) 16 years or over, and (3) able to provide consent to participate. Clinicians identified potential participants who were then contacted to discuss the study and obtain verbal consent to participate. Interviews were conducted by a trained interviewer over the phone or via zoom according to the participant's preference.

In these interviews, participants were presented with scenarios and prompted to discuss their thoughts and any concerns. Participants were also prompted to discuss whether their views would be the same if it was their family member's health information or if the health information continued to be used after they had passed away. A scenario on the use of health information for ML and AI development centered around the secondary use of mammogram images and results. This scenario described using the data of a large number of screening programme mammogram images to develop a software tool that could detect abnormalities making the future diagnosis of breast cancer more accurate, quicker, and cheaper than traditional methods. Within this scenario the following issues were also explored:

- Linking existing health information (e.g., past mammograms) with future health information (e.g., future diagnosis of breast cancer).
- External companies being involved in the development of the computer programme and using the health information to create other computer programmes for other health providers (e.g., hospitals in another country).
- External companies selling the computer programme to make a profit.

Interviews were audio-recorded, transcribed by an independent transcriber and de-identified before analysis. Transcripts were analyzed using thematic analysis [1].

## 3. Results

Participants (n=12) ranged in age from 25 to 77 years and were representative of key ethnicity groups, rural/urban populations, and at recruitment had been accessing a diverse range of health services (e.g. hematology, renal dialysis, emergency department, mental health services).

When presented with the scenario around using health information for ML/AI, participants described being comfortable with the use of their health information in this way because it would help others and was for the “greater good”.

*“If a computer is going to do a better job at diagnosing a person better than a human could then I’m going to think its a good thing.” [03]*

They described no change in their comfort with the use of health information for ML/AI if it related to their family health information or if the information was continued to be used in this way after they had passed away.

Participants described the benefits of this type of secondary use in terms of other patients receiving better or more timely care because of the AI, as well as the secondary benefits such as the freeing up of clinicians for other needs.

*“It sounds like if a program can do something better, so it’s more accurate, hopefully timing might be a bit quicker.” [05]*

Although comfortable they described a number of conditions of use:

1. That the information was stored securely and protected – related to concerns around hacking and cybersecurity;
2. That the data was de-identified and their personal identifiable information is not used.
3. That there would be no harms resulting from use - for example one participant discussed that it would be ok as long as there was capacity for the increased cancers detected to be treated.
4. That there was good governance and oversight. Participants described the importance of accuracy with rigorous testing before implementation. They commented that although independent governance (outside the health service) and audit may be necessary, the responsibility for the safety of use of health information in this way remained with the health service. Alongside good governance, the importance of clinician oversight was clear. Although they saw clear benefit to a future with AI in medicine, participants did not want to see clinicians removed from clinical care or a patient’s choice to see a human doctor face-to-face taken away. They felt that seeing their clinician’s oversight and support of the AI in practice would be encouraging and result in them being more comfortable.
5. That the health information remained in the health system and was not shared overseas. Participants mentioned that health information (in this case the images) needed to remain in their health record and were not duplicated in multiple places or sent externally.

Although very comfortable with the use of their health information in this way participants raised questions over who holds the information and the security measures around it.

*“Who manages the programming, how much are they audited?  
That sort of stuff; who actually has access to all that information,  
gets to see all that, who’s making money off that?” [08]*

Participants described an element of trust when their health information was used in this way. Some described that they did understand things like this (i.e. ML, AI) but that this didn’t mean that they couldn’t support it. They wanted to be able to trust that the health service would use their health information responsibly and ensure no harm was caused. They said that trust is something that is earned but once damaged would be difficult to repair.

Participants commented that if health information was to be used in this way that there should be transparency and communication around this in order to gain trust. Consent forms and documentation should include AI development as a possible use and

where the health information was obtained prior to the consent process being updated there needed to be clear transparency that this was now happening. This extended to the use of health information after someone has died, with communication extending to family and communities in this case.

Although participants were supportive of their de-identified health information being used in this way (with the conditions above met) without specific individual consent, a few participants commented on the importance of retaining individual autonomy over the use of their health information and the ability to opt out – while recognizing that this may not always be feasible.

*“It would be infeasible to retract it, but going forward, they wouldn’t be able to share any new information.” [06]*

When asked if an AI tool could continue to be linked to their future health information, they agreed that this would be acceptable as long as there was clear benefit and the conditions around security and governance remained.

*“Well, I think it’s part of the package, isn’t it? It’s not going to be particularly reliable or relevant information if you can’t track it going forward.” [10]*

Participants were less comfortable with the idea of sharing their health information with an external company. Many felt that sharing with third parties would require individual consent and reassurance around privacy, and that companies shouldn’t be able to profit off their health information without providing financial benefit back to the system or individuals.

*“Um, no I don’t think so cause I don’t um, because I don’t trust all these overseas companies and people.” [04]*

#### **4. Discussion**

Interviews with patients of health services in Waitematā (Auckland, NZ) has found that in general most people were comfortable with their de-identified health information – in this case, screening programme mammogram images – being used to develop AI tools. This is due to an understanding that the tools would be used for the good of other patients in NZ. They were also comfortable with their health information continuing to be used after they had passed away, or to approving the use of their family members’ health information.

There were several caveats or conditions to the use of their health information that included the health information being secure and privacy being maintained, the information being retained in NZ, and the financial benefits not being held solely by an international company. Participants also felt that the health service should retain some responsibility for the health information and should communicate with their patients about this type of use of their health information. In terms of the use of AI in the health service, participants felt there should be rigorous testing, some degree of independent governance, clinician oversight and that clinicians should remain available to patients.

Our findings are similar to those seen elsewhere in studies of groups of patients about the use of their health information for secondary uses [2,3]. That is, that they are

generally comfortable with this secondary use, as long as the intention is to benefit other patients or ‘the public good’ and as long as considerations such as privacy and security are taken seriously. Although there is very little published research around perceptions of secondary use specific to use in the development of AI tools. Findings may be slightly different between surveys of the general population and those conducted with specific patient groups who are more aware of the information collected and the use of the information in their health care. We found both similarities and differences when we conducted the same survey in patients at Te Whatu Ora Waitematā and then with a national general population sample [4,5].

These findings are being used in the health service to help guide an AI Governance Group that provides review and approval of AI research, development and implementation proposals within the health service. It has also prompted greater communication with the population about the potential use of their health information for the development of AI tools.

## 5. Conclusions

AI tools are being introduced within health services around the globe. It is important that tools are developed and validated using the available health information of the population where it is intended to be used. This research has found that the patients of a health service in Auckland, New Zealand, are generally comfortable with their health information being used for these purposes but with conditions and with careful consideration of their perspectives. We suggest that health services should take the time to have these conversations with their communities and to provide open and clear communication around these developments in their services.

## Acknowledgements

We would like to acknowledge the study participants and the individuals who assisted with recruitment. This study was funded through a PDH-HRC Postdoctoral Fellowship.

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