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# Comfort, trust and benefit

## Social licence for Artificial Intelligence training and implementation in health care

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## Research Summary

### Why was the research done?

Integrating Artificial Intelligence (AI) into healthcare requires a social licence to operate. The need for extensive health data to train AI, combined with shifting patient-clinician relationships, sparks critical debates regarding trust and benefits from AI innovations.

### What were the key findings?

While participants view the “AI turn” as inevitable, they express anxiety over a lack of agency about how this “AI turn” will progress. They expect to be included in setting the direction of this transformation. Claims of “push-button” efficiency are met with skepticism. Consumers fear this may lead to the oversimplification of complex health needs, further reduction in human resources and the erosion of human care. Participants recognize that AI is in its infancy and requires communal data contributions. However, they view this as reciprocal: powerful institutions cannot expect data access without giving the community a say in shaping the rules. Willingness to contribute data is often driven by expected future benefits, emphasizing the need for a Data Solidarity framework that prioritizes public value.

### What does this mean for policy and practice?

1. Anchor AI centric health care innovation in the Quintuple Aim for better health, better care, lower costs, clinician well-being, and equity. AI should reduce administrative burden and support care given by medical experts. Efficiency gains are to be reinvested into human relationships and improved health care experience. We call this the ‘**AI-in-the-Loop**’ principle.
2. Make explicit what data are being used, who uses the data, for what purpose and how. This serves to demonstrate that AI is feeding back into better care and minimizes exaggerated claims and unrealistic fears. Provide concrete and accessible examples of tangible benefits and acknowledge that AI is a tool to manage complexity, not a magic solution to oversimplify healthcare. We call this the ‘**Observability**’ principle.
3. Treat data as a public good. Establish partnerships where commercial engagements align with the core values encapsulated in the Quintuple Aim. Foster acceptance of individual costs (i.e., sharing data) among health consumers due to collective benefits that will be generated (i.e., the need for good care). We call this the ‘**Data solidarity**’ principle.
4. Move beyond consultation to active participation. Involve the community directly in defining the “rules of the road,” determining which AI innovations to prioritize, and deciding how the benefits of AI are distributed. We call this the ‘**Govern through Community Co-Design**’ principle.

## Citation

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We acknowledge the Traditional Custodians of the lands on which we work and live across Australia.  
We pay our respects to Elders past and present and recognise their continued connections  
to land, sea and community.

## CHAPTER 1. INTRODUCTION

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### 1.1 Rationale and Background

As technology advances, so does health care. Health interventions utilising Artificial Intelligence (AI) have the potential to transform health systems for consumers and care providers on an unprecedented scale. The adoption of AI in health care presents opportunities to enhance patient experiences and outcomes, reduce health system spending, improve clinician wellbeing and work towards greater health equity by addressing social determinants of health (Shah et al. 2024). However, the widespread implementation of AI requires large amounts of data from which AI models can learn in order to produce accurate input into care. Training and testing AI models can only occur by embedding AI in clinical decision-making which will lead to radical changes to health services. The long-term implementation and sustainability of AI in health systems requires health consumers' social licence, that is, the alignment between trust in, and perceived benefits from proposed AI innovations. In the context of AI in health care, social licence implies not only that health consumers are agreeable to the use of their personal data to train AI models but also attending to their hopes and wishes for how the integration of AI into their care should occur.

#### **The Evolving Landscape of AI in Medicine**

The integration of AI into health care is steadily moving toward clinical applications, with potential to significantly contribute to medical progress. AI tools can aid medical professionals in differential diagnostics, remote patient monitoring and clinical plan formulation (Bavli et al. 2025; Mendel et al. 2024; Zhang & Kamel Boulos 2023). Recent developments underscore the potential of 'agentic models' capable of autonomous decision-making and foundation models that can be applied to complex classification tasks, such as identification of biomarkers for diagnosis and treatment selection, audio classification for respiratory analysis, or classification of images (Teo et al. 2025; Zhang & Kamel Boulos 2023).

A recent rapid literature review indicates that beyond clinical care, expectations about the usefulness of AI in reducing administrative burden is a key predictor of its acceptance as a technology (Shevtsova et al. 2024). Enterprise solutions promise to free medical professionals' resources by assisting with documentation through real-time transcription and coding (Zhang & Kamel Boulos 2023). However,

Teo et al. (2025) caution that in proprietary systems like GPT and Gemini, hallucinations<sup>1</sup> and failures currently prevent effective clinical coding utilisation. Despite these challenges, tools like Ellen AI reportedly enhance physician-patient communication by transforming written notes into audio content, while integration with health record systems aims to automate administrative tasks (Zhang & Kamel Boulos 2023).

AI implementation in health care impacts both administration and clinical care. The integration of AI into medical processes and decision-making may give rise to concerns of undermining human aspects of care or making human professionals redundant. However, Teo et al. (2025) indicate that clinical decisions are superior when clinicians collaborate with or oversee AI. This ‘human-in-the-loop’ oversight is essential for safety, particularly as proprietary systems suffer from hallucinations, struggle with ambiguity in non-specific contexts, and carry risks of bias, all of which require professional scrutiny (Teo et al. 2025). How this augmentation model will affect the relationship between health consumers and healthcare providers is currently not well understood.

### **Trust, Benefit, and the Social Licence**

The successful integration of AI into health care requires a social licence to operate, which depends on understanding the public’s willingness to share health data and their confidence that the AI-generated outcomes will deliver genuine, equitable improvements to patient care (Woods et al. 2025). Meta-analyses reveal a correlation between perceived risks, trust, and technology acceptance (Wei et al. 2024). Trust serves as a crucial moderator, shaping how perceptions of risk and benefit influence behaviour (Ashrafi et al. 2024). While enhanced medical services are cited as factors for acceptance, ethical considerations like fairness and equitable distribution of benefits play a pivotal role (Shevtsova et al. 2024; see Davis & Williams 2025 on limitations of the fairness paradigm). Understanding the interplay between trust, risk, and perceived benefits is essential for predicting and working towards social licence for AI applications in health care.

Trust is the foundation for sharing one’s personal information as well as embracing care involving AI. Trust is fragile and influenced by many factors, most notably the perceived motivation of organisations using personal information. Patients are more inclined to share health data with healthcare providers and researchers than with government or private companies (Baines et al. 2024). Scepticism towards private companies often stems from concerns about data commercialisation, where profit-driven purposes are perceived to conflict with public good (Bavli et al. 2025). Mendel et al. (2024) found that

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<sup>1</sup> We use the term here to refer to information that has been fabricated by AI in response to a prompt.

fears of financial disadvantage, such as potential loss of insurance coverage, also hinder information disclosure.

Moreover, the risk-benefit calculus for AI in medicine may differ from other contexts. In e-commerce, social media or financial services short-term, concrete benefits are weighed against long-term, abstract risks (Kezer et al. 2022). Barth and de Jong (2017) characterize this distortion of the rational calculus as the ‘value of desired goal outweighs risk assessment,’ where risk concerns are nullified by the immediate desire for specific outcomes (e.g., connectivity in social media). In medical AI, risks to privacy and safety are perceived as concrete and immediate, while benefits can appear tenuous or distant (Wei et al. 2024).

### **The Privacy-Personalisation Tension**

The potential for personalisation of care is a key benefit associated with AI applications in healthcare. However, the delicate balance of risk-benefit analysis for AI in medicine is further complicated by a critical tension between the data needed for personalised and more accurate AI input and privacy concerns. In broader terms, Cloarec et al. (2024) describe this privacy-personalisation tension as a situation in which consumers, while expecting better personalisation, adopt strategies to share less information owing to privacy concerns, thereby hindering the effectiveness of service personalisation. In the medical field, a similar pattern is observed among patients who withhold critical information that could aid in diagnosis due to concerns about privacy and data misuse (Baines et al. 2024).

## **1.2 Aims and research questions**

Building on the concerns identified in the literature, this study aims to produce knowledge on health consumers’ comfort with AI models using their data for health care applications and AI implementation in their care. With comfort, we conceptually approximate social licence as the alignment between trust in and perceived benefits from a proposed innovation. This study was developed with the guiding principle that consumer input should orient health system design to better address their concerns and needs. Specifically, we aim to understand consumers’ perspectives on AI training and use in clinical settings with a view towards building social licence. We address the following research questions:

**RQ1** What is the range of concerns, comfort with, and expectations about health data use for training AI models for implementation in care among health consumers with diverse backgrounds?

**RQ2** How can AI healthcare systems and processes be designed to address diverse consumer concerns and build social licence?

## 1.3 Our approach

To answer these questions, we begin by outlining the research design and data sources through which we derived our analyses. As will be summarised in the next subsection, data were collected via a methodology called the 'The Comfort Board' where participants engage in workshops with distinct scenarios involving health data and AI. We then present three chapters summarizing our findings. First, we provide an overview of comfort levels in response to different scenarios among participants and what this means for social licence. Second, we focus on the themes we developed around trust and how they relate to understanding the processes of training and implementing AI in health care. Third, we explore the perceived benefits of AI use in health care and identify when and for whom benefits may materialize. We conclude by offering an overarching interpretation that good care underpins all considerations of trust and benefit and consider how findings can inform the development of practice guidelines which build social licence for AI in health care among health consumers.

### 1.3.1 Methods and data

We used a qualitative participatory design grounded in the interpretivist research tradition to explore participants' trust and perceived benefit regarding health care innovation driven by AI.

#### **Study Context**

The study was conducted in Queensland, Australia, a culturally diverse state, with over 22% of residents born overseas and 4.6% identifying as Aboriginal and Torres Strait Islander peoples (Queensland Government 2021). In line with Queensland's Digital Health 2031 strategy, AI in healthcare is a key priority to improve health outcomes for all Queenslanders (Queensland Health 2022, 2024). This study was conducted as part of the National Infrastructure for Real-time Clinical AI Trials (NASCENT) project, which aims to build Australia's national infrastructure for real-time clinical AI trials through advanced evaluation systems, workforce capability, and consumer partnerships. A team of social scientists from the SocioHealthLab and the Centre for Digital Cultures & Societies at UQ collaborated on the study of social licence associated with NASCENT project objectives.

#### **The Comfort Board**

All data for this report were produced as part of interactive workshops employing The Comfort Board methodology (Brown et al. 2019). In these workshops, participants were prompted to take the perspective of a fictional health care consumer in scenarios designed to elicit tensions surrounding the sharing of health data and the use of AI in decisions about care (see Callout boxes).

**Scenario 1: Imagine that you are Abi, living in suburban Queensland with your partner and two children. The following two scenarios take you through different fictional experiences at healthcare facilities in Queensland**

You've been diagnosed with type 2 diabetes about three months ago. Your GP referred you to a diabetes centre at a public hospital for care. You have been going there to see your doctor regularly, who helps you manage your blood sugar levels. To manage your diabetes, you do what your doctor says — taking three pills and two injections every day. You change your diet and exercise routines. You also wear a small device on your arm called a continuous glucose monitor (CGM). This device checks your blood sugar throughout the day and sends results to your phone and your doctor. It is not easy to keep up with all these changes. Some days are harder than others. But you are doing your best, and you really hope your blood sugar will be under control soon.

Today, you go to the diabetes centre for a check-up. Your doctor tells you that the hospital is working on a new way to help with diabetes care using artificial intelligence (AI). This AI is being trained using health data from all patients with diabetes in this hospital, including yours. Your doctor explains that before the data are used in AI training, the hospital removes your name and hospital identifier. This means the data will not be connected to who you are. The AI learns from things like age, symptoms, blood test results, diagnosis, and medicines.

Your doctor says that when the AI is ready in the future, it could help doctors find early signs of diabetes problems. It might also give advice on your care plan, especially your diet, exercise and other behaviours to help prevent these problems. These can make it easier to manage diabetes, based on what each person needs.

**1 A**

Context: baseline, outpatient suburban, routine visit, AI training  
Tensions: informed consent, anonymity, biometric data only  
Benefits: orientated towards the future and primarily community

One year later, you return to the hospital for another check-up. A nurse tells you about a new mobile app that can help you track and manage your diabetes.

You try the app and find it easy to use. This app quickly becomes part of your daily routine. The app feels like a virtual assistant. It gives you advice that fits your lifestyle and helps you make choices about food, exercise, and medicine. You feel like it understands your needs and gives helpful tips at the right time.

One day, while looking through the app's settings, you tap on 'About this app'. You find out that the app runs on the same AI tool your doctor mentioned last year. This AI is still learning from health data from all patients with diabetes in the hospital, including yours.

As you read more, you find out that the AI tool uses many types of information. This includes age, symptoms, test results, diagnosis and medicines. It also uses your daily blood sugar readings from the CGM, your diet and exercise, your social background, family history, and information from your mobile health apps.

**1 B**

Context: timelapse 1 year, outpatient suburban, routine visit, AI care  
Tensions: assumed consent, commercialization, comprehensive data use  
Benefits: orientated towards the present and primarily individual

**Scenario 2: Imagine that you are Toni, living in rural Queensland with your partner. These two scenarios take you through different fictional experiences at healthcare facilities in Queensland.**

A few days ago, you felt a bit tired and had a small cough. You thought it was just a cold, so you stayed home to rest. But tonight, while eating dinner with your partner, you suddenly feel very sick. Your chest hurts, you have a high fever, and your cough gets much worse. You feel weak and scared.

Your partner takes you to the hospital right away. The doctors say you have a serious lung infection and need urgent treatment. You are admitted to the hospital for care.

While you are being admitted, a hospital staff member at the front desk tells you that the hospital is working on a new way to improve care using artificial intelligence (AI). This AI is being trained using health data from all patients in this hospital, including yours.

The hospital staff member explains that before the data are used in AI training, the hospital removes your name and hospital identifier. This means the data will not be connected to who you are.

The staff member says when this AI tool is ready to use in the future, it may benefit you and other patients in the hospital. It could help doctors act faster when patients get worse. It might also give advice to help treat each patient safely and quickly, based on each person situation and needs.

**2 A**

Context: baseline, inpatient rural, acute visit, AI training

Tensions: informed consent, anonymity, biometric data only

Benefits: orientated towards the future and primarily community

Two years later, you return to the same hospital. This time, you are in severe pain — your right leg hurts more than anything you've ever felt before. You can't walk and need help right away. You are admitted to the hospital for care.

During your stay, you note the healthcare team acts fast, your test results come back quickly, and your treatment plan is made and put into practice rapidly. You start to feel better soon.

A few days later, as you are recovering in hospital you browse the internet to pass the time. You find out that the hospital is using the same AI tool the staff member mentioned two years ago to help with patient care. It occurs to you that the care you received a few days earlier, was based on a treatment plan produced by AI.

As you read more, you learn that the hospital is now working with a private company to make the AI tool better. This will help the AI learn faster and give better help to doctors. It may also help hospitals save money when they use AI for a long time.

**2 B**

Context: timelapse 2 years, inpatient rural, acute visit, AI care

Tensions: assumed consent, private company involvement

Benefits: orientated towards the present and primarily individual

Specifically, participants were asked to indicate their comfort related to a proposed scenario using a grid with two axes: benefit and trust, each ranging from 0 (lowest) to 7 (highest) (see Figure 1). Participants were then encouraged to explain why they rated their trust and benefit in this way. Following this, we facilitated discussions on how social licence for AI in healthcare could be strengthened, guided by the question “What would make you feel more comfortable in this scenario?”.

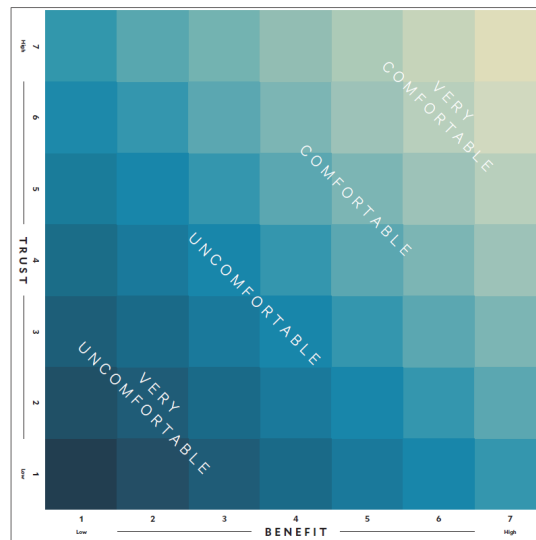


Figure 1. Comfort Board: trust (x-axis), perceived benefit (y-axis) on a 0–7 ordinal scale (7 = highest)

### Scenario development

A team of consumer representatives, clinicians, and researchers from the social, design, computer and health sciences developed two fictional scenarios followed by a prototype workshop which served to train facilitators and pilot the draft scenarios. Feedback from this workshop was used to refine scenarios for use in the comfort board workshops with health consumer participants. Finally, the team agreed on one scenario for outpatient care and another for inpatient care. Each scenario was further divided into two subsets to introduce prompts around privacy, consent, and commercialisation as well as trust and benefit over time.

### Sampling and recruitment

We took a purposive sampling approach to recruit health consumers from diverse cultural and socioeconomic backgrounds. Eligibility criteria included being aged 18 years or older, residing in Brisbane, and having received care in a Queensland healthcare facility within the past 24 months. Participants also needed to be able to understand and participate in written and spoken English. We advertised the study through newsletters in health consumer networks, social media, local community noticeboards and word of mouth. An expression of interest process was used to screen for eligibility.

Ethical approval was granted by The University of Queensland Human Research Ethics Lower Risk Panel (ID: HE001180). Participants who expressed an interest in the study were followed up by a member of the research team to provide participant information sheet, answer questions and identify any accessibility needs for participation in the workshops. All participants received a \$100 gift card to acknowledge their contributions to this study in line with Health Consumers Queensland guidelines. Where applicable, we also made travel arrangements or reimbursed parking and travel expenses. As part of reasonable accommodations, participants could opt to attend workshops by themselves or supported by a non-participant carer. They were also welcome to bring a companion animal. For participants with vision impairment, we provided a Braille version of the comfort board. We obtained written consent to take photographs during the workshops to record participants' positions on the comfort boards.

### **Data collection and sample**

Two in-person comfort board workshops with 34 health consumer participants were conducted on UQ's Herston campus in September 2025. Each workshop lasted approximately three hours and was co-facilitated by three members of the research team. Additional research team members, including health consumer representatives provided logistical support and observed the workshop. The workshops began by outlining the aims of the study and demonstrating the comfort board approach using a large grid mat (see Figure 2).



Figure 2 - Participants positioning themselves on the comfort board.

A structured workshop guide developed by the research team was used to ensure consistency across facilitators. Participants' positions on the comfort board were photographed, digitized, collated and visualized (see Figure 4). Group discussions were audio-recorded and transcribed verbatim using an AI-assisted transcription software, Otter.ai, then manually reviewed and verified by members of the research team. Thematic maps completed by participants were also collected and digitized at the conclusion of the workshops. All data were deidentified prior to analysis.

Most of the workshop participants were female (21F/13M) and between 31 and 60 years of age (16). About one-third were born in Australia, another one-third in East/Southeast Asia, and over a fifth in Europe. Around one-third identified as having a neurological, sensory, visual, psychosocial, or physical disability. Self-reported familiarity with AI in healthcare ranged from not familiar to very familiar (see Figure 3). A demographically diverse sample with varying levels of self-reported familiarity of AI allowed us to explore a breadth of perspectives.

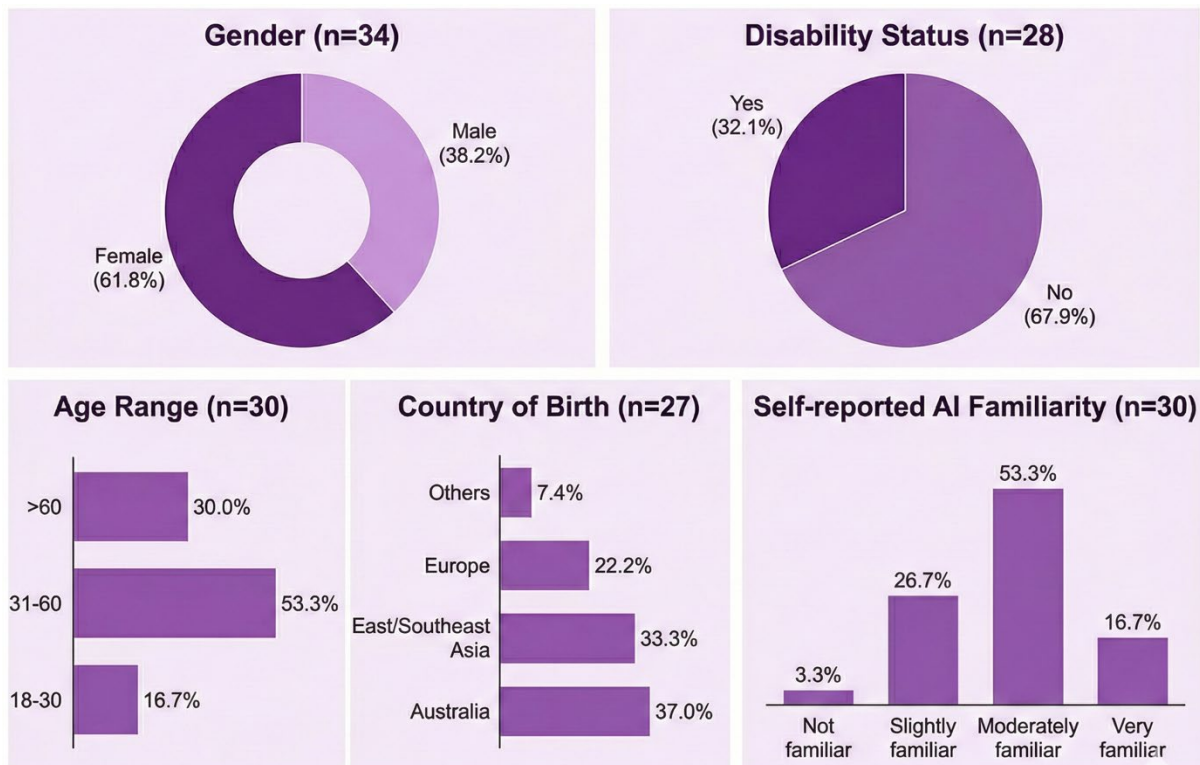


Figure 3. Sample description where participants provided information.

### Data analysis

Given this study's aim to explore social licence, we employed an abductive analytical strategy throughout the research. The design of instruments, facilitation of workshops and their interpretation were anchored in the concepts of trust and perceived benefit, while permitting open-ended

exploration by health consumers. Participants from diverse backgrounds might differ in their understandings but were able to situate themselves in the scenarios and prompts they were provided.

We analysed all qualitative data using reflexive thematic analysis (Braun & Clarke 2023) supported by NVivo 14. Research team members SP, MD, TD checked all transcripts for accuracy and familiarized themselves with their content, creating memos and annotations. Team members then discussed an initial set of codes and applied these codes independently to a selected transcript, refined codes and applied them to all transcripts non-exclusively. We also created a classification in NVivo to link codes to participant demographics. Finally, we grouped codes together in themes guided by the concepts of comfort, trust and benefit. Findings were discussed during research team meetings.

### 1.3.2 Reflexivity in our research practice

Our research practice was strengthened by multidisciplinary collaboration and ongoing reflexivity, features which permitted robust findings and critical reflection regarding the construction of knowledge. Within the social sciences, reflexivity is viewed as part of ethics in practice (Guillemin & Gillam 2004). The researchers in this study spanned creative arts, social, computer and health sciences. Working in such an interdisciplinary team made clear that from a clinical perspective, clinical interventions, outcomes and relationships were a key focus within analysis, whereas from a sociological perspective the structural context and ways health consumers made sense of health care systems were foregrounded. The project was also informed by consumer representatives who ensured that our interpretations were grounded in the lived experience of health consumers. This approach reflects broader trends towards interdisciplinary and multidisciplinary research in the social sciences as well as in research focused on health-related topics which recognise their greater explanatory power for understanding complex and multifaceted topics (Austin et al. 2008; Hesse-Biber 2016; Leahey et al. 2017).

Collaboration in this project required not only reflection on assumptions and flexibility but also time to develop shared languages and processes for working together. This reflects scholarly literature which has acknowledged the labour involved in communicating, coordinating and reaching consensus, given that epistemological and theoretical assumptions can differ across multidisciplinary teams (Bindler et al. 2012; Leahey et al. 2017). We approached these dynamics not as challenges to be overcome but as opportunities to develop appropriate scenarios, coder cross-checking processes and data reflection workshops through which there was iterative dialogue between sociological, clinical, and experiential perspectives. Such processes, and the interpretive tensions therein, offered productive sites for refining our understanding and yielded more nuanced and applicable findings than any single perspective could produce.

## CHAPTER 2. COMFORT

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We begin by presenting participants' perspectives on AI in general, an overview of comfort with our proposed scenarios for the training and adoption of AI in health care across the participant group and a case for social licence based in the data analyses.

### **“These are tools [they] are going to employ anyway”**

Health care is imbued with uncertainty, from determining a diagnosis, prognosis, treatment plans, to how someone may respond to specific treatment. Healthcare professionals use various tools to assist them in their attempts to alleviate uncertainty in healthcare delivery, with AI tools being the most recent. However, AI models need to be trained with high-quality data to produce accurate output. This includes live data from patients to support diagnostic and treatment decision-making on an ongoing basis. Essentially, AI training, development and implementation processes are iterative and inseparable from one another.

Many participants in our study recognised that AI is inevitably going to become part of healthcare or indeed already is. As this participant who received care for lung cancer shared:

When I have three monthly CT pet scans, exposure and brain MRI, I can see they're using computer diagnostic imaging to look at my lungs. Let's check and see. Are there any nodules there that need to be investigated? So, it's happening already, you know. (SL\_25)

There was a range of emotional responses to and considerations of personal and health data being used in this process. For some this was seen in a positive light with obvious benefits noted. However, for others, there was scepticism and apprehension about their data being used limiting their trust and overall comfort. These discussions often emerged in response to scenarios 1b and 2b in which we introduced a prompt highlighting benefits, such as personalisation and rapid commencement of treatment, but also necessary concessions around information and consent regarding how data are sourced. This participant explained:

We can't dispute the benefit of AI, because we know what an impact it's making, and to a point it's already in our hospitals and it's already been used to do things, it's just how it's doing that, and where we come in as human beings and consumers as to our input, as to how it should be used. (SL\_50).

Many participants recognised that AI is already widely in use, including in hospitals and General Practice. Yet this understanding does not reflect comfort with its use or imply a social licence to operate. Indeed, as this participant articulated, this was positioned as an opportunity for health

consumers to shape processes of AI use in health care for the future by establishing ethical practice. This was particularly noticeable in participants' reactions to scenario 1b, which proposed a fictional health consumer who had agreed to participate in an AI trial and later found out that personal and health data were used to train AI. Even though the benefits of the AI model we had built into the scenario were welcomed across the participant groups, some participants reacted with consternation or even expressed a sense of feeling betrayed. Other participants responded with resignation or cynicism. We observed a reduction in the overall comfort score across the sample, mainly due to the impact on trust and its flow on effects for the appreciation of potential benefits.

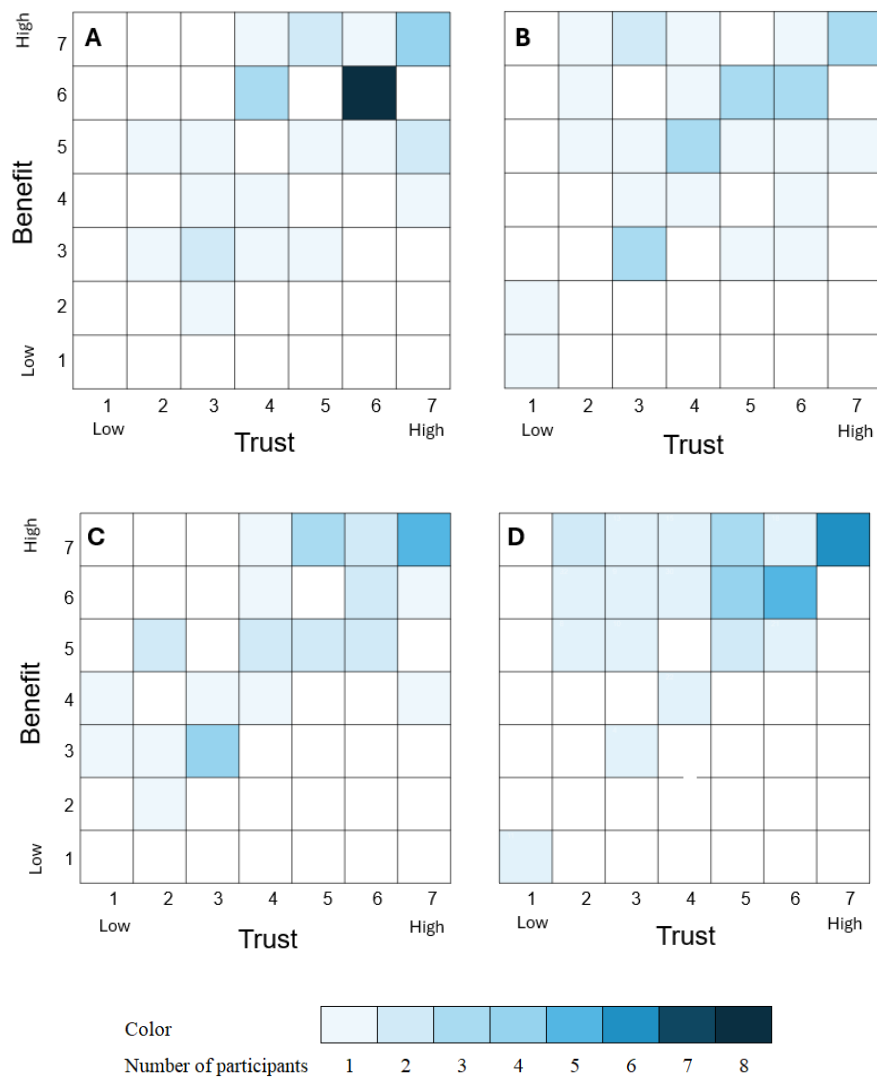


Figure 4. Comfort Board showing participants' levels of trust (x-axis) and perceived benefit (y-axis) on an ordinal scale from 0 (lowest) to 7 (highest). Scenario 1 is illustrated in Figures 4A–B, scenario 2 is represented by Figures 4C–D (darker colours indicating higher frequency)

Figure 4 illustrates how participants positioned their comfort levels across all scenarios. In scenario 1 (Figures 4A–B), participants most frequently located themselves toward the upper-right quadrant,

indicating relatively high perceived benefit and moderate-high trust levels, with the darkest cell (8 participants) suggesting a cluster of trust levels of 6 and benefit level of 6. By comparison, scenario 1b showed a more scattered distribution, with lighter shading overall and fewer responses in high-trust and benefit cells, alongside more cells at lower trust and benefit. This pattern reflects a downward trend of comfort level from scenario 1a to 1b.

In scenario 2 (Figures 4C–D), scenario 2a displayed moderate concentrations around trust levels of 4–6 and benefit levels of 3–5, suggesting mixed levels but generally mid-range comfort. In contrast, scenario 2b demonstrated stronger clustering in the high-benefit range (benefit 6–7) despite trust remaining mixed. The darker cells in Figure 4D indicate that more participants rated the perceived benefit of this scenario as high, even when trust was only moderate.

Importantly, participants seemed to respond particularly strongly to the fact that data were used beyond what had been agreed to in scenarios 1a and 2a. This highlights, that although many participants knew that AI is already in use and were not naïve to the fact that its integration is progressing, expectations regarding its use in healthcare and the requirement to share personal health data to facilitate ongoing training of AI models varied greatly. To work towards greater social licence will require reconfiguring mutual expectations and understandings around data privacy-as-control (El-Sayed et al. 2025), that transcend current models anchored in informed consent that have become enshrined in contemporary bioethics.

### **Health care at “the push of a button”?**

While privacy concerns around data use was one of the most common concerns amongst participants regarding the inevitability of AI use in healthcare, implications for care and the relationship between health consumers and health care providers were also salient. The analogy of care at the “push of a button” enabled by AI applications appeared in two separate small group discussions.

When you look at people with disabilities or people from different culture background, how much they understand, how much information do they require, and in which direction, which path they need to follow before they can build their confidence. “Oh, yeah. Look, I can press the button, go to the hospital, sit back, you know, and be quick” instead of raising questions. (SL\_37)

You tailor the intervention that you make to delivery based upon your experience and what’s going to work and you know your clinician experience... In medicine I feel more comfortable if there is clinician oversight... Many people are going to be uncomfortable with the idea of a button being pushed and treatment plan popping out. And I think it’s quite an unrealistic future. .... It’s not as simple. Care is not as simple. (SL\_25)

These participants approached AI implementation as an efficiency-enhancing tool in clinical practice, that is linked with a potential for greater health equity, as SL\_37 pointed out. Considerations such as these were particularly prominent in the discussions of scenarios 2a and 2b, which introduced a rural Queensland health consumer and highlighted the benefits of targeted AI implementation for presently constrained health care settings. Participants used the rural vs urban healthcare divide as a platform to discuss the possibilities of AI in addressing the social determinants of health and producing more equitable health outcomes across populations. These discussions included recognition of health data systems currently skewed by racial and ethnic bias, insensitivity to locally specific pathogens (e.g., the presence of tropical disease) alongside issues around staffing and equipment.

At the same time, as SL\_25's quote indicates, participants also recognized that there is more to care than "a button being pushed and a treatment plan popping out." This participant and others challenged understandings of AI as narrowly focusing on creating better care through efficiencies. Participants spoke here about and resisted oversimplifications of care. As many of them had personally experienced, clinical decisions and tailored treatment interventions are based on various forms of data, clinician experience and collaboration with other healthcare professionals. What this sentiment captures, is the fear that care would become less *caring*. As this participant noted:

That human element, for me, is really important. We can't lose that. ... It's a tool. It'll gather the information and it'll do it really quickly. So absolutely, [AI] can give you an excellent treatment plan, and it can do it really quickly. But is it the right thing for this person? (SL\_50)

Although many of our participants recognise that AI is already here and has potential benefits, we argue that acceptance or resignation and comfort do not equate. To achieve higher comfort levels amongst healthcare consumers, a greater sense of trust in AI must be fostered, whilst also building a reasonable understanding of the benefits of AI that allows all stakeholders to enjoy the returns of AI. As this participant warns:

It's like, "this is what [AI] will provide you." But is that what's going to happen? Because there's been lots of promises that health care will provide over time, and for people to like, want to trust that, because health care system is a form of authority. If we trust that, there's been very high personal, individual consequences. (SL\_22)

Based on participants discussions we expand our definition of comfort as the alignment of trust and perceived benefit from an intervention to acknowledge the emotional dimension to trust and benefit. Comfort is not only the result of a risk calculus, but it is also relational and embodied. Approaching social licence as attending to what health consumers *feel* comfortable with, our findings show that

health consumers need scope to be part of the processes of implementing AI in healthcare, that their expectations need to be understood, and the commitments to them honoured. We will explicate factors such as observability beyond informed consent that impact participant trust in greater detail in the next section.

## CHAPTER 3. TRUST

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Building trust in AI requires understanding the implications for AI use and sharing data for AI training. In this section we explore the factors that influenced participants' trust. Many participants were quick to identify potential and already existing benefits of AI use but nevertheless ranked low on trust in data use to train AI for health care delivery. We found that the early implementation stage in which AI applications currently are perceived to be at, set the context for participants' reasoning.

### **Like "raising a child"**

AI is currently still in the development stages and although some participants suggested that they perceived benefits already, the future of how AI will work in healthcare is still largely unknown. Participants in our study expressed how AI development or AI model training was a factor that influenced their trust and overall comfort with sharing their data.

AI will bring some new technology to make our life easier and convenient, but however, it's still new. So actually, the AI has come from the people, but it can make mistakes. (SL\_57)

We're still in the baby stage. Yeah, very much. (SL\_39)

I don't see that any difference there [to] actually raising a child. You know, because you teach your child, you can't teach your child everything. Some things they're going to trip over. They're going to stress their knees or whatever, going to get hurt, and you'll find a band aid for it. (SL\_37)

Some participants like the ones quoted above, recognised that AI was still developing and compared it to raising a child. Developing or training AI tools is a complex process, here portrayed as mirroring child development; it is reasonable to expect that AI would make mistakes but will likely learn from them.

There's going to be mistakes or people maybe, or organizations maybe might not have the right intentions at times, but I need to somehow try and help contribute to further... So, I do think there is potential benefit of having the data, because we might be able to use it. (SL\_22)

In the light of this, some participants considered that although the future is still unknown, the potential for more collective and future benefit of sharing their data outweighed the risks of harm and helped to increase their levels of trust. Feeling a sense of responsibility to contribute data for AI growth despite inevitable developmental stumbles. However, it is important to highlight that the evaluation of these errors is heavily dependent on inferred intentions. As SL\_22 implies, while technical mistakes are tolerable, the underlying motives matter; a distinction that becomes crucial when contrasting public healthcare (often seen as benevolent) with private organizations where profit motives might raise doubts about whether intentions are ‘right.’

So, I’m happy with, in terms of trust with them. I’m happy to give, like, if it was me to give my data, but I think just how it interprets the data is something I’d be more worried about, because it is something that is still learning. (SL\_49)

In turn, the potential for future benefits, did not alleviate concerns for some participants. The uncertainty of how AI will use their data or interpret it affected levels of trust. Some participants were still happy to share their data; others wanted more evidence or assurance that AI development would attend to safeguards.

My trust will decrease because this is the new AI still learning. .... I know that the current AI still have many limitations, related to ... hallucination and other things. So, with all the result and it’s still learning, not the major area yet, so still there’s some percentage or not correct with my personalized scenario. ... If the AI, become more mature with the publications, like I say, with the well-researched and I do trust more. (SL\_56)

The unpredictability, rapidly emerging evidence base and unknown issues with AI also resulted in lower trust for some participants.

My trust is sort of halfway, because, as SL\_49 said, AI is still unpredictable. It’s still learning, and we don’t know ... I’ve heard of different scenarios where the AI will actually come up with different scenarios that are not evidence based, but because it wants to please you, wants to give you the right answer. (SL\_50)

Participants recognised that it was important and beneficial for a broad spectrum of data to be collected to help train AI models, however the uncertainties about how AI would interpret their data to make decisions or what guidelines are in place to inform this, resulted in caution among participants. This was particularly noticeable among participants who considered the experience of Indigenous people and communities.

With cultures like that, or the mob, you need to involve the aunties. ... You need some sort of a champion. I think you need some people from that community, coming from that community, to speak on behalf of the community that has the level of authority to represent that community. If you try to convince, you know, like individuals, it will be very hard because, for example, these communities are very close-knit communities, and they listen to their elders. (SL\_47)

This participant believed a co-design approach to developing AI tools would not only help improve their trust but also play to the strengths of close-knit Indigenous communities. As has been shown elsewhere, the power dynamics surrounding data sharing and safety concerns related to harms from structural forces such as racism continue to be salient within Indigenous contexts and call for culturally appropriate methodologies (Watego et al. 2025). Strengthening social licence via increased trust requires tailored approaches that consider the current developmental gaps of AI models and social, historical and cultural contexts of health consumers whom these models are intended to serve.

At a broader level, some participants juggled the potential risk of AI doing harm, with the understanding that AI has the potential to progressively learn and provide more personalised recommendations and help improve their well-being and healthcare. Alongside this was the understanding that AI is constantly evolving, making it difficult for governance and regulatory systems to keep up. A paradoxical tension emerged between the wish for legislation and regulation of AI, and concurrent acknowledgment that these mechanisms will be ill-fitted if put in place without rigorous understanding of the specificities of AI data use and applications in health care. Some participants were willing to pay it forward in trust to allow for time to get the governance of AI right:

I don't have a crystal ball, and I can't look into the future, but I would hope in two years' time, there's enough information gathered to be able to be very confident that that will work... If nothing had changed in two years, if it was the same information as two years before, I would be questioning it. (SL\_39)

Notably, participants did not dismiss the need or feasibility of rules and safeguards around AI use in health care, but they made allowances for time to learn more and understand better how these mechanisms should work. This is an expression of trust that is conditional on making good use of time to progress on a matter that is important to health care consumers.

### **“Do no harm”**

While participants understood, and sometimes even made allowances for AI to learn and make mistakes, there was acute awareness for potential harms for communities and health consumers from

these mistakes. In other words, most participants did not perceive AI developments as a deliberate attempt to undermine their rights to privacy and care but felt nonetheless that there were risks stemming from uncertainty around the ethics of AI. Some participants explicitly contextualised such risks within medicine as a distinct ethical field, for which it was unclear how AI would fit into that.

Computer can't sign a Hippocratic Oath. It's not a Hippocratic Oath anymore. (SL\_45)

It is not acceptable use [AI] when it starts harming you. I think the first principle should be, 'do no harm'. (SL\_47)

The introduction of AI into health care brings with it significant ethical considerations for health services. Ethics in biomedicine have historically kept pace with the changing dynamics between health consumers and healthcare providers; yet, the commitment to an ethical principle to "do no harm" has persisted in medical professional ethics through the generations. Some of our participants' discussions evoked this principle with respect to AI driven health care transformations. The risk of harm to patients from sharing their data for AI healthcare applications influenced many participants' trust. Beyond AI systems still learning, potentially hallucinating or making mistakes due to inaccuracies or 'bad data', the concern here was about AI's ability to discern right from wrong, understand its limitations and to participate in care as an ethical actor.

When you see, there's people suing in America because basically their kids have suicided, because AI told them to. I have played with it myself. I have literally been on the internet, found an AI psychiatrist on a particular forum, and played with that myself to see. It's really disturbing because it doesn't pick up the nuances of your voice. (SL\_28)

Harm mitigation processes were deemed essential for increasing trust levels. 'Do no harm' was considered an essential guiding principle for developing AI applications. In these discussions, we found participants were often framing AI as an emergent technology during a period of growth. Healthcare providers were here positioned not only as supervisors or as a control mechanism, but also as mentors and guarantors adding professional values to AI augmented care. Such humans-in-the-loop were seen as part of a bigger picture of AI governance that would safeguard information and protect health consumers from harm.

It's safeguarding. I mean, if it does give you information that's life and death and it results in an adverse outcome, then who do we hold responsible? And how do we change that, if there's no one accountable? We can't do that. There has to be someone that looks at what's going on, understand what's going on, and sort of monitors. ... It's that ring fencing of going, 'this is the

information we fed it. We know what information is in there. It's not going to choose something from somewhere else and give us advice on that.' (SL\_50)

Against this background, participants acknowledged the role of different levels of government, and even the political system in Australia vis-à-vis other nations. Commercialisation of AI tools generated suspicion and mistrust for some. The outsourcing to private companies introduced in scenarios 1b via the introduction of a nominal fee for service raised concerns about who would be responsible for governance as part of AI development and management. Some participants perceived that the values of private companies would not be to protect patients, and therefore posed a risk for patient safety, and safety of their data, such as selling their data to insurance companies.

The professionals, they're making decisions based upon money, not from patients, patients, health ... My big worry is that you've outsourced everything to apply the company. You can't do that. You gotta be in public hands. (SL\_45)

I really am uncomfortable with this, for the reason there are just too many examples in the corporate world. Our world, around the West, show that private companies working with government firms tend to act unethically. (SL\_48)

As has been found elsewhere (Horn & Kerasidou 2020), in the context of health care, government appeared as the more trustworthy data custodian and care provider. We found that particularly participants born overseas were more inclined to 'trust the system', guided by the notion that the government's priority is to protect its citizens from harm.

I have high trust, especially Australian healthcare system and the government. I wouldn't be so fussed about this app going to the wrong hands, especially that names and hospitals are being removed, because my issue is whether insurance people will know about it, or the rental application. (SL\_63)

While this finding points towards important differences in how people with migration backgrounds might experience and feel about their relation to government, it is beyond our scope to offer an explanation for how this translates into greater comfort with AI data use and implementation in health care. However, this is an important research focus for follow-up that can contribute to better understandings of demographic influences on trust, benefit and, in turn, social licence. Another participant, SL\_34, spoke from a general position of trust in government, even though there is awareness of potential harms that come from mishandling personal data. They added that trust is not only based in facts and safeguards but also in *wanting* to trust the system due to immediate need.

[Abi] might have some faith in things like the code of conduct for clinicians, etc., in using AI. And there's a plethora of frameworks, and legislation review, safe and responsible artificial intelligence in health care. So, she might hope, as a citizen who votes and pays her taxes, that, you know, checks and balances would be in place larger than Queensland Health and all the rest of it. So, if it was me. I'd still be looking for that as a way to make this work for me, because I need hope, I'm sick. (SL\_34)

For some participants trust increased with the belief that the public health system has credible and trustworthy governance structures in place to protect their data. Similarly, participants who generally lacked trust in the public health system tended to be much more sceptical about trusting AI in healthcare. Scenario 1 was designed with current governance and safeguards such as consent and transparency around data sharing in mind. However, trust in due process remained a key focus for participants. As the scenarios progressed, components were introduced to create ambiguity. For some these were perceived as violations of shared understandings, for example when data were used more broadly than what participants had originally consented to. Yet, concerns around trust were directed primarily at the capacity of governments (rather than their intentions) to keep data secure from malicious actors.

Institutions generally, and that would definitely include politicians, all three levels of government. Definitely include Queensland Health are well behind the eight ball of the you know, universal hacker society... I wish I had more explicit faith. It's not that I lack faith in government. I'm a voter and participant in that process, as we all have to be.... I've just got very low level of faith that they will be ahead of the curve in what very clever hackers with, with really terribly adverse intentions about what they do with your data. (SL\_27)

The problem of capacity reveals the role of knowledge for trust in sharing data for use in AI-augmented health care applications.

#### **"Explain the black box"**

Our findings indicate that issues related to trust are intertwined with the different bodies of knowledge accessible to health consumers, healthcare providers, and other stakeholders. A longstanding tension between health consumer choice, lay expertise and biomedical knowledge has been interrogated in its implications for in patient-centred care (Pilnick 2023). Based on our analyses, trust in AI interventions can be seen as a continuation of such tension, exacerbated by uncertainties around what AI is, how it works and how it is (going to be) put to use:

[mRNA viruses] We would not have a cure or vaccine for anything if it wasn't for AI. So we need it. We need the data and all the rest of it .... The only thing that would increase my trust is if you tell me about the black box. ... How does chat, GPT or GeminiAI work? It's a black box. And nobody will be able to explain to me exactly how it works. But there should be principles and ethics and guidance along that and on those guidelines of actually how the data works to contribute this or that. For me was, if I wanted to increase my trust, is tell me how you're utilizing the information ... Explain the black box. (SL\_24)

The discussions across all scenarios throughout both workshops circled back to knowledge beyond distinctions between clinical or experiential knowledge. Factors identified as problematic were not limited to lack of understanding of AI generally. It included concerns about lack of transparency about what types of data are being used and for what purpose, lack of clarity around data governance and safety processes, commercialisation, the costs for keeping data secure, and the future of health consumer involvement in design and implementation of AI systems. In the previous sections, we have already identified the call for co-design approaches when it comes to Indigenous people and communities. Especially when considering these asymmetries in knowledge and power, we observe a similar desire among health consumers to have a say both in their own care but also in system design:

If there was options to understand, or, like, opt in and out of like, parts of that, go, 'No, I don't want you to know all of these details.' (SL\_19)

From the medical point of view, they need to build up an understanding and confidence in the consumer, in the services that they provide and the tools that are being used. I think that's what's actually lacking. (SL\_37)

Most participants could identify benefits for AI use in healthcare, however overall comfort with AI use and sharing their data for AI training was limited by factors lowering their levels of trust. Building on our approach to comfort as a set of feelings that complements the risk-benefit calculus, we see trust as forthcoming, where health consumers are brought into the process of furthering AI applications. Health consumers wish to feel that their knowledge and contributions are valued. Positive experiences with AI, but also with governance bodies and processes may help to build trust, further emphasizing the importance of careful integration. We explore the role of perceived benefits below.

## CHAPTER 4. BENEFIT

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In this section we discuss both what participants considered individual and collective benefits and what short- and long-term implications sharing their data to train AI models may have. We consider how perceived benefits of AI tools in healthcare improve the comfort with sharing data for training AI tools. We also consider what factors influence perceptions of benefit for sharing data for AI tool development. Here, personalisation, health system transformation and solidarity were foregrounded.

### “Like a virtual assistant”

AI models have the potential to complement human care with functions that can improve the diagnostic accuracy and management of health conditions and reduce the workload of clinicians. The benefits for patients were considered at both individual and more collective levels. In response to our outpatient scenario, for example, participants identified benefits for personal autonomy in their care, convenience and timeliness, potential efficiency gains in providing more targeted care and preventing exacerbation.

When you have the data, it's just trends, and we already kind of do that before. I think the benefit will be really high, just because something like diabetes can fluctuate so widely within a single day. So having that instant feedback versus waiting. Maybe it's a Friday afternoon if something is wrong, and you can't get easy or quick or cheap help until Monday. So that kind of benefit will be huge to those quick spikes. (SL\_29)

Another participant believed that, if AI could deliver more personalised care it would be beneficial for them as an individual in navigating their health condition.

This is exactly the type of product that I needed and wanted and couldn't access and would have found, personally very beneficial... it comes down to the outcome of what that personalization looks like, delivering the right kind of personalized care.... for us to make it feel like your virtual assistant, this is the information that's required. (SL\_18)

Tracking patient data with AI tools was suggested to have the potential to provide more objective and accurate care for managing health conditions than a doctor could, as well as assisting doctors in monitoring a persons' health condition.

The benefit is quite clear for me, because it can help me to tracking what a situation is and to notify the doctor. It is additional to the traditional way. (SL\_56)

[At] the hospital, and the doctor said, “How’s your diabetes going?” You can always show him the app. This is what’s been reading for the last month. (SL\_35)

Many participants, as we have demonstrated above, saw trust and benefit as interacting with one another.

I can see the benefits, because I’m, well, right? ... So that moves me up on the kind of the trust element, and, of course, in the benefit element as well. (SL\_24)

The new technology can help myself take care of myself, and can help me prevent some problem ... The hospital will remove the name and hospital identifier, so I don’t worry about that, but if it can use my data to analyze, I’m happy about that, because it can help to improve and solve problem. So, the most benefit increase, I think the trust increase. (SL\_57)

However, there were some concerns that AI models may not be able to provide personalised care for more people with more complex conditions or multiple conditions, or that it would take a textbook approach.

This app is going to be looking at the average, what’s the minimum, what’s the textbook say, rather than actually looking properly at the person and all their interfering issues. (SL\_30)

It’s going to give you things like, stop smoking, eat less sugary food, you know, like, that’s all pretty basic stuff. And I’d want it to be, yeah, more tailored to me ... Not just the general stuff, just the basic textbook stuff. (SL\_51)

There was consensus across the participant group that the potential of personalisation was a major area of benefit, where personal data are used to track an individual’s health, and offer tailored care. Some participants recognised that sharing their data was necessary to personalise care for themselves in this context. However, the prospect of more personalised and simplified care meant that some participants were willing to share their data also for future collective benefit to enable the development of AI for health care applications.

Life is very complex, and saying anything that will help me simplify my care, improve my care, inform treatment and prevent this for other people, I think is really, really meaningful. I do see AI as a means to better standardize care across patients. I see it interestingly, as being able to focus in on individual difference and account for individual difference in patient care better than I guess what I feel that I’ve currently experienced. (SL\_25)

We found that personalisation and the willingness to share data for this purpose was particularly pertinent in scenario 1, where outpatient care was presented as primarily in the hands of the health

consumer. This contrasts with discussions of scenario 2, where we presented inpatient care as led by the health care providers. Here, AI tools were seen as assisting clinicians with gathering and interpreting data, making decisions quicker when stakes for the patient were high.

What I think we can improve our trust and benefit already shown in this case, because if the benefits is very clear and already proved right in real case, it means that benefit to the patient and benefit to the doctor to get a faster result, and the AI after two years become major, is bringing you benefit. Yes, so that's the no doubt about the benefit. That's why I gave the max. (SL\_56)

The participant quoted above referred to the pace with which effective treatment was enabled due to AI-augmented care. Their willingness to rate this scenario with the maximum score for benefit, reiterates our argument that a strong evidence base to be built alongside the development and implementations process of AI models for health care, will be the main driver of comfort as a function of trust and benefit and ultimately lay foundations for a licence to operate AI-augmented health care.

#### AI as solving the health system crisis

Benefits of AI were also considered at a health system level, such as helping to address long wait times for specialist services. AI has been argued to have potential to help alleviate pressure on stretched health services, and overall foster progress towards the quintuple aim to improve health consumer and healthcare provider experiences, population health, economic viability and the social determinants of health (Shah et al. 2024). Some participants recognised the opportunities for AI to reconfigure health systems to better meet the needs of health consumers in a health system that is currently under stress.

They have to introduce new methods, new systems, new tools, to overcome the majority of the increase of people that are using the systems and services that we currently have in place. ... we can't get doctors, so we gotta get AI. (SL\_37)

Some participants suggested that AI had the potential to save money in health care by improving efficiency and accuracy, optimising staffing, and reducing the administrative burden on healthcare professionals. Another participant suggested that because doctors are over-loaded with work, AI tools could alleviate pressure on them by enabling patients to manage their conditions more independently or by decreasing reliance on healthcare professionals.

Nowadays, hospital and any healthcare provider is very overloaded with the work .... and maybe they don't, keep up with us. Like, get in touch on time. So, this is a great like, we can increase the deep independence that we can manage ourselves. (SL\_72)

Some participants recognised the health system as fragmented and saw AI tools as having potential to assist with developing a more unified system that could improve access to health records across the country.

Your health system actually gives the patient's account number. I use an account number so that you actually need to log into your account number to correspond with the health department, because if you have AI, it also means that your you should not be limited to one hospital. For example, in Australia, start with like Queensland. No matter where you go in Queensland, you should be able to pick up what you need, dosage or whatever should (SL\_44)

Potential benefits for health system equity were discussed primarily with respect to scenario 2, which introduces a rural health care context. AI has been argued to have potential to make healthcare more accessible particularly for rural areas where resources are more limited (Hains et al. 2025). Participants recognised accessibility issues that exist in the Australian context. Some participants spoke about how rural services have limited staffing and how AI tools could help relieve some of the pressure on rural services by providing additional support to doctors.

I think this helped me to check my health daily and avoid some emergency stay for me, because I live in in the rural Queensland that's been the medical facility is not as in the city. (SL\_57).

You're in a rural area. You've got not enough doctors around. I think having a tool that may be able to provide you some insight would be great. (SL\_50)

Participants who had experience working in rural areas highlighted that fact that there was less funding available and although they did not deem AI to be beneficial for them personally, the potential to improve access to care in rural areas was still considered beneficial.

I do also see a benefit to AI in that having worked as a health practitioner in rural areas, but the quality of care is different. There's much less funding in these small services. ... So look, I think anything that improves equity of care would be helpful. (SL\_25)

Participants expressed optimism that the lack of specialist care in rural areas could be addressed by AI tools. One participant suggested that AI tools could assist general practitioners in making decisions, or consulting AI tools. Relatedly, participants suggested that AI could act as a support system for clinical teams, enhancing diagnostic accuracy in areas like imaging without necessitating outsourcing or staff reductions. Furthermore, they noted that these capabilities could reduce the logistical burden and costs associated with flying specialists to rural and remote communities.

I'm aware of the barriers of somebody who lives quite far away to get health care, and sometimes that is not even their ability to access it at the hospital, but it's the travel to get there. I myself have worked up in the Cape of Queensland, where it's going to cost \$900 for somebody to fly to Cairns. (SL\_29)

Although technology like AI was considered to have the potential to improve patients experience accessing healthcare, for some participants, there was scepticism around AI's ability to substantially improve healthcare as well as about the consequences of commercialisation required to do so efficiently.

The private hospitals are the ones who are trying to make a profit, so they're going to probably be the first ones to take on AI because it means they can employ less doctors... You're going to see a difference between public and private, depending on which way you just lean. And you'll be deciding, potentially on that, like, you know, whether I want to see a real person or whether I just want an AI treating. ... Premiums people are paying for health ... because the health funds will be impacted by it as well. The flow on effects of that disparity will be enormous. (SL\_28)

There was also scepticism around cost saving initiatives. This was entangled with drive of the private sector to turn a profit. Instead of anticipating steps towards greater health equity in the wake of AI adoption for health care, this participant highlights concerns that indeed social divisions and faultlines along public and private health systems will deepen. Such considerations have the potential to undermine comfort and, in turn, social licence for AI-augmented health care. In response to such concerns, it is important to consider health systems in their complexity, anticipate undesirable side effects for access to health care and put in place social and policy solutions to the problem of health care alongside technological ones.

**"It takes the community and the collective to advance health care"**

Data collected or shared by patients to train AI tools may not directly benefit those patients. However, it does have the potential to improve care for patients in the future and the wider public. Participants accepted that while AI training might not offer them direct or immediate value, the potential benefits for the broader community made the effort worthwhile. In line with one of the common themes identified in the systematic review by Woods et al. (2025), for some, this altruism was specifically grounded in the hope of improving healthcare for future generations, including their own children. Yet, as we indicated in the first chapter, this also implies a very delicate balance between a promise of future benefits and concerns about present, concrete risks, particularly as AI continues to develop and grow, and requirements for data sharing along with it.

Some participants wanted to help others and were willing to share their data but were tentative about it. This suggests measures need to be in place to reassure patients that their data will be safe guarded but also information regarding how it will be used.

Is my data actually going to help others? ... If it's going to help others, then sure. It's like, I'll hand that information over.... data is like donating your organs. (SL\_19)

Another participant suggested that sharing their data is required to train the models and for future benefit. Therefore, they need to accept or take the risk, as refusing to share their data will not advance AI tools or healthcare.

The fact that there's potentially a long-term benefit in it makes it more marketable to me. If I don't accept it, if we all resist, it never happens. So, the benefit will happen by accepting it. ... You know, we've gotta join in to make it better. (SL\_20)

This was echoed by other participants who believed sharing their data was part of research and inevitable for advancing AI tools and managing health conditions in the future.

This delicate balance also raises questions about data governance: whose data is shared with whom? For which purpose and under which conditions will data being shared? Who do benefits accrue to and who is bearing any costs? For example, SL\_18 states, 'it takes the community and the collective to advance health care', suggesting that unless there is widespread acceptance and comfort with AI, it will not succeed in improving healthcare. At the same time, as we have shown, participants perceived the most benefits from AI, if these were tangible in their personalised care. In turn, anticipating benefits for oneself, was entangled with the willingness to share personal data for use in AI training. We found a tension here that we propose to address conceptually through the notion of data solidarity (El-Sayed et al. 2025).

Data solidarity revolves around public value as a guiding principle. Public value of patient data is assessed by weighing benefits and risks and ensuring equitable outcomes. This considers not only individual rights but also the broader impact on society. Data solidarity foregrounds data use over data type, aiming to incentivise types of uses that will be beneficial to the broader society and disincentivise uses that may produce undue risks and lead to unfair distribution of risks and benefits. As AI models develop, more data or different types of data may be required.

It comes down to assessing your comfort factor with sharing your personal information and what that looks like. Personally, I operate on a basis that everybody knows everything there is to know about me. (SL\_18)

Some participants recognised that there will be no immediate benefit to them, but future collective benefit meant they would be happy to share their data.

I see the benefits of this use of AI being less direct to me, but more broadly beneficial to the community. (SL\_25)

I don't particularly care either. If it's going to improve life for the epidemic of diabetes we have in Australia, let's do it. (SL\_34)

Despite a preference for individual benefits, many participants also saw value in sharing their data for future or collective good. Although they did not see that sharing their data would benefit them directly, they recognised a greater collective or public value.

## CHAPTER 5. DISCUSSION AND CONCLUDING REMARKS

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Social licence relies on building trust with health consumers and communicating the benefits for AI driven health care innovation. One in six people still feel AI will make healthcare worse, highlighting the need for greater public engagement to build social licence while strengthening authentic care (Woods et al. 2025). This report builds on the systematic review undertaken by Woods and colleagues (2025) to address the concerns regarding the impact of AI on health care it identified among health consumers. To inform the development of best practice guidelines, we used the comfort board methodology to address the following questions:

**RQ1** What is the range of concerns, comfort with, and expectations about health data use for training AI models for implementation in care among health consumers with diverse backgrounds?

**RQ2** How can AI healthcare systems and processes be designed to address diverse consumer concerns and build social licence?

We found that participants in The Comfort Board workshops responded to our prompts designed to gauge how they feel about privacy, commercialization and consent processes. They saw potential benefit in AI implementation and expressed their concerns in nuanced ways that demonstrate sophistication beyond a simple for/against stance towards AI. We conclude that there is widespread understanding that AI implementation is and will continue to progress in all domains of life including health care. Gaining and maintaining social licence requires attentiveness to health consumers' concerns and suggestions. Many participants had specific firsthand experiences of health care that

made them aware of the importance of empathetic, timely and high-quality care in periods of extreme vulnerability. The desire for good care underpinned their evaluations of trust and benefit.

As we demonstrated using The Comfort Board methodology, presenting realistic but concrete benefits may be crucial to promote understandings of individual and collective benefits of AI (Baines et al., 2024). A recent NHS trial of an AI-powered physiotherapy app demonstrated a 55% reduction in surgery waiting lists (Machin 2025). While initial scepticism existed among physiotherapy practitioners the realization of immediate access to care, without the replacement of professionals, significantly increased their satisfaction (Machin 2025).

However, to establish a social licence, benefits and risks must be thought together and addressed in their dynamic relationship with one another. Demonstrating the tangible benefits of AI applications in health care will take time during which health consumers are called upon to tolerate risks and place their trust into processes which are largely opaque and beyond their control. El-Sayed and colleagues (2025) argue that addressing these concerns requires moving beyond simple privacy as control over data models toward data solidarity. A solidarity-based governance approach focuses on maximising public benefit and minimising harm, potentially by disincentivising uses of data that prioritise private benefits to generate resources for public good (El-Sayed et al. 2025). It is crucial that the trust paid forward by health consumers is handled with care and leads to tangibly better health experiences and outcomes for all.

Concerns regarding AI tools and their ability to follow ethical guidelines and protect patients from harm influenced levels of trust and participants overall comfort with sharing their data or accepting AI involvement in their care. Some participants argued that AI models are unable to adhere to professional ethical standards and regulations. Further, some participants feared that the introduction of AI into health care could be harmful for patients and health systems if the correct processes are not in place to protect patients' data and data use.

In order to increase trust and overall comfort with AI in healthcare, strategies must be developed to provide patients with reassurance that healthcare professionals will be lead the interpretation of data, decision making processes and healthcare delivery while fostering genuine relationships with health consumers. By reducing administrative workload, AI has the potential to allow medical staff to devote more time to patient care (Zhang & Kamel Boulos 2023). In an NHS physiotherapy trial, for example, the technology allowed clinicians to be diverted to more complex cases that required face-to-face interaction (Machin 2025).

The acceptance of sharing data for AI and its use in clinical decision-making is often made contingent on human oversight, often referred to as "human-in-the-loop" (Goffin 2025). "Human-in-the-loop"

captures a governance angle on AI in healthcare. We expand on this conceptually and propose the notion of “AI-in-the-loop” (Natarajan et al., 2025) to capture the relation of AI and the human aspects of care. This aligns with the augmentation model, that recognizes that making professionals redundant is neither desirable nor feasible (Resh et al. 2025).

“AI-in-the-loop” is anchored in a vision for health care defined along five critical dimensions that correspond to the quintuple aim of health *care*:

1. If AI is used to reduce administrative tasks this will allow for better, longer human interactions. This may take the form of arriving at earlier diagnosis through AI consultation, personalising treatment plans, reducing administrative burden and enhancing communication across different points of care. **Patient experience** may thus be improved.
2. When used appropriately as an aid to health professionals and patients, AI has potential to improve accuracy of care. In this way, AI integration may lead to enhanced **population health**.
3. If AI efficiencies are deployed towards augmenting care and improving quality of care, **economic viability** of health systems may be strengthened.
4. If AI is used to support health care professionals in managing their workload and care responsibilities, this could assist them with efficiency and accuracy, potentially decreasing their cognitive load and offloading the administrative burden. **Health professionals’ experiences and well-being** may thus be improved, increasing job satisfaction and decreasing the risk of burnout
5. Through integration of AI in regional and rural areas where resources and staffing are limited, access to general and specialist care may be enhanced. This could include improvements for marginalised communities such as Indigenous, rural or migrant communities, by ensuring diverse data are used to develop and train AI tools. More equitable outcomes across populations broadly could be achieved, thus addressing the **social determinants of health**.

## Recommendations

Based on our findings, we recommend the adoption of the following four principles in all strategies aimed at building social license towards AI training and care involvement in health care settings.

1. Anchor AI centric health care innovation in the Quintuple Aim for better health, better care, lower costs, clinician well-being, and equity. AI should augment care and reduce administrative burden. Efficiency gains are to be reinvested into human relationships and improved health care experience. We call this the ‘**AI-in-the-Loop**’ principle.
2. Make explicit what data are being used, who uses the data, for what purpose and how. This serves to demonstrate that AI is feeding back into better care and minimizes exaggerated

claims and unrealistic fears. Provide concrete and accessible examples of tangible benefits and acknowledge that AI is a tool to manage complexity, not a magic solution to oversimplify healthcare. We call this the **'Observability'** principle.

3. Treat data as a public good. Establish partnerships where commercial engagements align with the core values encapsulated in the Quintuple Aim. Foster acceptance of individual costs (i.e., sharing data) among health consumers due to shared commonality in a relevant aspect (i.e., the need for good care). We call this the **'Data solidarity'** principle.
4. Move beyond consultation to active participation. Involve the community directly in defining the "rules of the road," determining which AI innovations to prioritize, and deciding how the benefits of AI are distributed. We call this the **'Govern through Community Co-Design'** principle.

### Concluding remarks

Experiential knowledge of ill-health and the health care system are a crucial factor for trust in AI data use and application. Observability, AI-in-the-loop and data solidarity can only be achieved if built on basic understandings of AI fundamentals in the general population. Dependence on the health care system because of acute need, is not a moment to explain the AI black box to enable health consumers' comfort with AI use. It is therefore necessary to address knowledge gaps not only by training health care professionals but also health consumers. Given that any person over their life span will at some point seek health care, this is a large-scale societal endeavour beyond the scope of a single trial of health promotion intervention. Understanding AI in health care and beyond needs to become a core curriculum item across educational settings.

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## APPENDIX 1 – PARTICIPANT DEMOGRAPHICS QUESTIONNAIRE

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**Date:** ..... **Location:** .....

**Participant name (Optional):** .....

Please tell us a little bit more about yourself. This will help us to better understand how different people may have different views on AI in healthcare.

Your completion of this form is voluntary. You can skip questions you don't want to answer. You can still participate in the workshop if you don't want to share this information.

**1. Which type(s) of healthcare services have you used in Queensland in the past 24 months? (Select all that apply):**

- Outpatient care (you received treatment or consultation but did not stay overnight)
- Inpatient care (you were admitted to a hospital and stayed overnight or longer)
- I'd rather not say

**2. Which Queensland Healthcare facility have you mostly used in the past 24 months?**

.....  
.....

**3. In your own assessment how familiar are you with AI technologies in healthcare? (Select one):**

- Not familiar at all – I know very little about AI
- Slightly familiar – I've heard about AI but don't fully understand it
- Moderately familiar - I understand basic concepts and applications
- Very familiar - I understand how AI works
- I'd rather not say

**4. What is your age?**

- 18–30
- 31–60
- 61 or over

**5. What is your gender?**

- Woman
- Man
- Non-binary
- I use a different term

(if you wish, please specify): .....

- I'd rather not say

**6. Were you born overseas? If your answer is 'Yes' please tell us where:**

.....  
.....

**7. Do you identify as being a person with a disability or impairment? If your answer is 'Yes' please tell us in what way:**

.....  
.....

**THANK YOU!**