

# Using Personal Health Information in Research: A Conceptual Model to Achieve Social Licence

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## HIGHLIGHTS

- Population health data is valuable to research but requires social licence.
- We examine the influence of risk and trust on willingness to give access to data.
- Performance, physical and privacy risks were identified as key dimensions of risk.
- A conceptual model of willingness to share health data in research is proposed [1].
- This model may help to gain or maintain social licence through targeted strategies.

## INTRODUCTION

Personal health information is a valuable resource to the advancement of research. To achieve a comprehensive reform of data infrastructure in Australia, both public engagement and building social trust is vital. Considering this, we conducted a study to explore the opinions, perceived risks and trustworthiness regarding the use of personal health information for research, in a sample of the public attending a tertiary healthcare facility. Most of what we know about the perceptions of health research have centered on matters of privacy protection, consent, autonomy and use of data [2-4]. In general, most research projects focus only on the specifics of the project or general field of research (i.e. genomics) with little consideration of more generalized use of data [5].

In 2018 at eResearch Australasia, we presented our initial findings from the Consumer Opinions of Research Data Sharing (CORDS) study. Understanding the public's perception of risk and trust associated with willingness to share personal health information, is a significant step towards targeted resources to build public trust and gain social licence. We proposed that a poorly informed understanding of the social licence and a failure to recognize that privacy protection and risk mitigation alone might not be enough to secure the social licence, is to the detriment of using personal health information for research purposes.

Few studies have investigated ways to motivate patients to share their health information and none have provided an understanding to key facets of risk that influence patient's decisions to share data. We present a conceptual model to achieve social licence to use personal health information in research [1]. This comes from the need to better understand factors which influence the public's willingness to give access to personal health information for the secondary use in research.

## METHOD

The Consumer Opinions of Research Data Sharing (CORDS) study was a questionnaire-based design with 249 participants who were attending a public tertiary healthcare facility located on the Gold Coast, Australia. The questionnaire was designed to explore opinions and evaluate trust and perceived risk in research that uses personal health information. Concept analysis was used to identify key dimensions of perceived risk.

## RESULTS

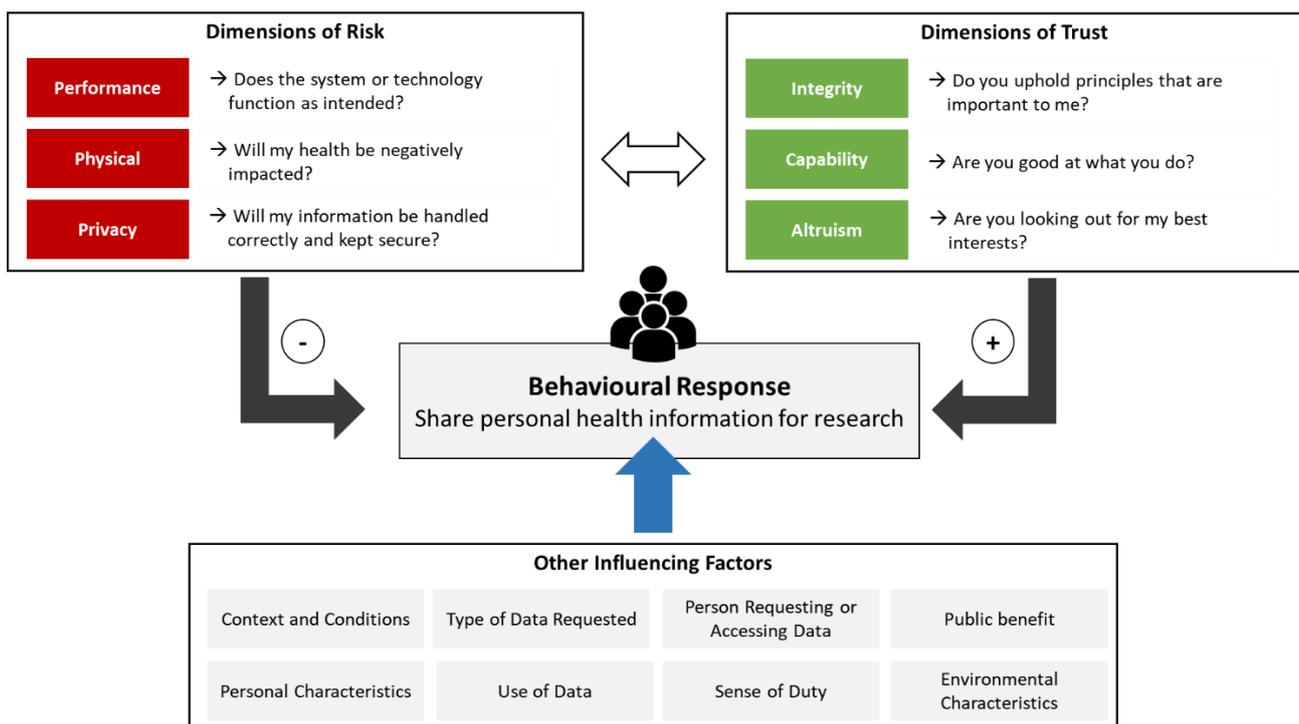
Qualitative analysis of the data extracted from the consumer survey led to the identification of three dimensions of perceived risk associated with sharing of personal health information for research:

- (1) Performance Risk: The risk that the system or technology does not function as intended, is not useful, or fails to deliver the desired results.
- (2) Physical Risk: The risk that participation will have a negative effect on one's health or peace of mind.
- (3) Privacy Risk: The risk of potential loss of control over personal information and/or inappropriate use with or without malicious intent.

Overall, perceived risk and trust have a complex interlaced relationship that ultimately impact willingness to share personal health information for research. Our study shows that this relationship is built upon a balance of multiple factors - relative advantage to negative consequence, the context and condition, or perhaps the trust and integrity in the person or organisations. All these factors are influential to producing the desired outcome or behavior.

## CONCLUSION

A conceptual model of willingness to share personal health information for research was developed. This helps us to better understand how the public’s perception of risk towards data sharing influence decision making, a finding that has not been previously described in the literature.



This conceptual model will be discussed to help inform strategies to mitigate perceived risk, build trust and ultimately sustain social licence among the public. For example, strategies might include: (i) building trust among the community that systems and technology are credibility (performance risk); (ii) establishing confidence in the research endeavor through a shared understanding of the benefits that flow from greater access and use of data will be achieved (personal risk); or (iii) addressing concern’s related to the sensitivity, regulation and privacy of different types of data (privacy risk).

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