Module 4-P1: Cross-border transfer of sensitive health data for mobile digital technologies: Outcomes from a mixed method modified Policy Delphi in Singapore

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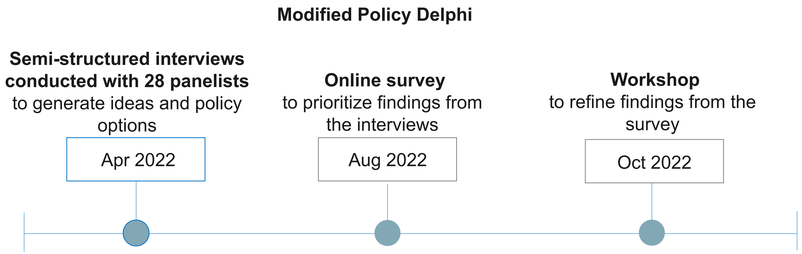
Background

Scalable mobile digital health technologies using big data, artificial intelligence and robotics can promote health and community care.[1,2] Development of these technologies requires the collection, storage, curation and use of data that may be highly personal and potentially sensitive.[3] Researchers developing digital technologies within international collaborations need to transfer parts or all of these datasets across jurisdictional borders to partner institutions for analysis. However, to date, there is no consensus on what data should count as 'sensitive' or when to trigger higher levels of restrictions and data security. Thus, the evidence on what data, and the conditions in which they may be collected in Singapore and shared with institutions overseas remains unclear.

Study objective and method

- Our study aims to develop ethical guidance for research being conducted at the Singapore-ETH Centre Future Health Technologies (FHT) programme.
- We engaged a panel of stakeholders in a mixed methods modified Policy Delphi[4] designed to deliberate on questions about data sensitivity and acceptable cross-border transfer. The panel consist of data contributors, data resources, data facilitators, data generators and professional data users.



Importance

- The legal and ethical provisions that would facilitate the cross-border transfer of potentially sensitive datasets are unclear.
- Legislation that exists for the protection of personally identifiable data generally do not apply to de-identified datasets that may contain sensitive information about cohorts of research participants.
- The transfer of data between Singapore and Switzerland must not only comply with the relevant data protection laws and regulations in both countries but should also align with cultural norms and expectations.

Findings

Findings from stakeholders' interviews and survey revealed that some data are considered sensitive (e.g. HIV infection status, history of suicide or attempted suicide, history of child abuse etc). Some of these data are classified as sensitive by Singapore's Ministry of Health (MOH). Additionally, the panel considered genome sequencing data and genetic test results as sensitive, which are currently not listed as sensitive by the MOH. The panel also considered data such as geo-location and direction-finding ability as sensitive despite de-identification.

A majority of the panel agreed with a range of desirable and feasible values and guiding statements related to data transfer such as obtaining informed consent prior to every data transfer (autonomy), ensuring appropriate accreditation of research partners (accountability), promptly reporting breaches to security protocols (transparency), recognising the value of health data as a public good (stewardship), and not selling data to third parties (integrity). However, less than half of the panel agreed with the desirability and feasibility of transferring data for research that can benefit Singapore only (public benefit), or amending for harms arising from re-identified data (justice). Similarly, less than half of the panel thought that it is neither desirable nor feasible to involve data contributors in the design and conduct of the research (engagement), or communicating with them about research activities (engagement).

Further findings will be revealed after the conclusion of the workshop in October 2022.

References

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