

Supplementary Material 1.

## Survey on finding a balance between protecting data and limiting hurdles for research

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### Survey July 2024

You are invited to complete this survey asking about your thoughts on when extra government approval or data protection is needed when health data is used for research.

In Singapore, there is a lot of existing data that can be useful for research, such as administrative hospital data from the Ministry of Health and research data from universities. To promote research and allow researchers to make use of these existing data, **a national data platform** is being built in Singapore. Figure 1 illustrates the types of data that could be accessed via a national data platform.

There are layers of checks to prevent unwanted access and misuse of the data via the national platform. For example, all data that is accessed via the platform is **deidentified**. This means that personal identifiers (e.g. name, address, NRIC No.) are removed from the data so that data cannot directly be linked to a specific person. In some cases, it might still be possible to identify someone by linking several data points together. However, several measures are taken (such as the tracking of data use) to prevent researchers from trying to identify someone. The researchers will only be allowed to access the data they need for their research and no other data.

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Figure 1. Examples of data that can be accessed via a national data platform.

## [Next page] Approval process for use of the national data platform

Before researchers can use the data via the platform, they must obtain approval for their research project from a **MOH-led oversight committee**. It is mostly representatives from the main research institutes in Singapore who sit on the committee but there is also a lay person, a legal expert and an ethicist. This oversight committee reviews whether research projects are aligned with data safety policies in Singapore, legal requirements and whether the research is in the public interest.

In some cases, there might be reasons to ask the Ministry of Health to review the research as well or to put in extra data protection measures. For example, if the research uses sensitive health data, such as data on history of abortion or STDs. An example of an extra data protection measure is that researchers can only analyse the data on a computer in a room with CCTV.

The downside of requiring government approval of applying extra data protection is that it might require extra time and effort.

## Topic of the survey

**Your thoughts on what extra government approval or data protection is needed for health research.**

These research projects are fictional.

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### **[next page] Practical instructions**

This survey should take you about 15 minutes to complete. Your participation is completely voluntary and you may stop at any time for any reason. Unfinished surveys will not be taken up in the data analysis.

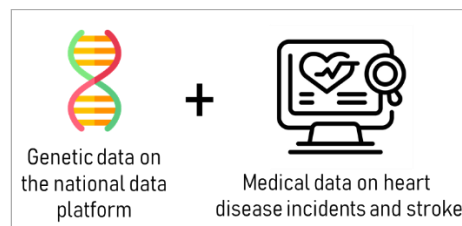
# Bioethical Considerations for Precision Health Research, Singapore and Trustworthy Data Governance

## **Part I: Does this research need MOH approval?**

In this survey, you are presented with two fictional research projects and you are asked if you think that extra approval by the Ministry of Health and extra data protection measures are required.

### **[Next page] Hypothetical Research project 1: Data use by MINDEF to predict medical risks during National Service (NS) training**

The Ministry of Defence (MINDEF) wants to request access to:



to link with



MINDEF's own data on medical incidents during National Service (NS) training

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*This research will be reviewed by the data platform's committee that consists of research experts, a lawyer, a layperson and an ethics expert.*

*The research is expected to take 3 years to complete.*

#### **Potentially beneficial elements:**

- With the aim to ensure that all men can serve in NS vocations that best suit their health (including any risks to cardiac health).
- To expand the Singapore Armed Forces (SAF) screening program to prevent injuries and potential death(s) during military training.

#### **Potentially controversial elements:**

- To prevent any medical risks during NS training, people with certain genetic markers would maybe not be able to acquire the health screening certificate that is required for some of the NS positions.

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**Question 1a. Do you think this research should have an extra review by the Ministry of Health? It will delay the research by 2 to 5 weeks. You can choose more than one option.**

<i>Yes, it should be reviewed by MOH</i>	<i>No, it does not need review by MOH</i>
There should be government accountability	I do not see the added value
MOH has the right expertise	I would not want the research to be delayed
MOH has the public interest in mind	MOH should not spend time or resources on this
Other reason(s): _____	Other reason(s): _____

**Are there any other government reviews (ministries or agencies) of the research you would like to see?**

- [Open text box]

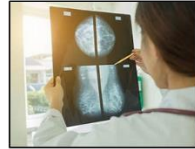
**Do you have any comments on this research proposal that you would like to share?**

- [Open text box]

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## [Next page] Research project 2: Data use by a private overseas company to support breast cancer screening

Private overseas company wants to request access to:



6000 images from breast cancer screening program on national data platform



Medical data on breast cancer from national data platform

*This research will be reviewed by the data platform's committee that consists of research experts, a lawyer, a layperson and an ethics expert.*

*The research is expected to take 3 years to complete.*

### Potentially beneficial elements:

- **Develop computer programs** to support breast cancer screening via artificial intelligence.
- If the program works, breast cancer could be detected in earlier stages and fewer doctors may be needed for screening.
- The current version of the computer program is trained on European data, which could lead to misdiagnosis and/or mistreatment when used in another population in Asia. By including the Singaporean data, the computer program could be better adjusted to the Singaporean population.
- Doctors in Singapore are interested in using this program to support their work.

### Potentially controversial elements:

- A private company is using the data.
- The company is based overseas.

**Question 2a. Do you think this research should have an extra review by the Ministry of Health? It will delay the research by 2 to 5 weeks. You can choose more than one option.**

*Yes, it should be reviewed by MOH*

*No, it does not need review by MOH*

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There should be government accountability	I do not see the added value
MOH has the right expertise	I would not want the research to be delayed
MOH has the public interest in mind	MOH should not spend time or resources on this
Other reason(s): _____	Other reason(s): _____

**Are there any other organisations that you would like to review the research?**

- [Open text box]

**Do you have any comments on this research proposal that you would like to share?**

- [Open text box]

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**Question 2b. The outcome of the research is unclear. We don't yet know if the computer program will successfully identify people with early breast cancer.**

**If the research is successful, individuals who took part in the study might be told about their breast cancer risk, but only if we had retained their contact details in the first place. However, if there would be a data leak, having kept people's contact information might be damaging.**

**The risk of a data leak is very small but it can never be fully prevented.**

**Should contact information still be kept? You can select multiple options.**

<i>Yes, personal information should be kept</i>	<i>No, personal information should not be kept</i>
It might lead to health benefits	I am worried about data leaks
Individuals might want to be informed about their cancer risk status	I do not see the added value
I am not worried about data leaks	It is unclear to me whether people have consented to be contacted for this reason
If participants explicitly consented to this, knowing all the potential benefits and risks	I do not believe this computer program will be helpful for breast cancer screening
Other reason(s): _____	Other reason(s): _____



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**[Next page] Research project 3: Data use by New York University (US) for research on a rare genetic disease that causes heart issues at a young age.**

**In Singapore, only around 80 people have the disease currently. No personal information is being kept in the dataset.**

*This research will be reviewed by the data platform's committee that consists of research experts, a lawyer, a layperson and an ethics expert.*

*The research is expected to take 3 years to complete.*

### Potentially beneficial elements:

- Linking data on this disease in several countries together, including Singapore, can provide new insights for developing treatments.
- The research can stimulate research collaborations between the US and Singapore.

### Potentially controversial:

- The data is shared with an overseas university.
- Even when personal information is not kept in the database, it might be possible to link the data to individuals because the disease is very rare (only 80 people in Singapore have this disease).

**Question 3. Do you think this research should have an extra review by the Ministry of Health? It will delay the research by 2 to 5 weeks. You can choose more than one option.**

<i>Yes, it should be reviewed by MOH</i>	<i>No, it does not need review by MOH</i>
There should be government accountability	I do not see the added value
MOH has the right expertise	I would not want the research to be delayed
MOH has the public interest in mind	MOH should not spend time or resources on this
Other reason(s): _____	Other reason(s): _____

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**Are there any other organisations that you would like to review the research?**

- [Open text box]

**Do you have any comments on this research proposal that you would like to share?**

- [Open text box]

**Question 3b. Because of the risk that the data might be linked back to individuals because of the small patient group, extra data protection measures might be taken.**

A data protection rule could be made to ensure that researchers can only analyse the data in a separate room with CCTV in Singapore. However, then it would be more difficult for researchers from the US to do this research.

**Would you be in favour of this data protection measure? You can select multiple options.**

<i>Yes, data should only be accessed in a room with CCTV</i>	<i>No, there is no need for this type of data protection</i>
It is important that the privacy of patients is protected	I am not worried about data leaks
I do not trust researchers from an overseas university	I do not see the added value for data protection
I am not worried about this data protection rule being a hurdle for researchers	This would make doing research more difficult
Other reason(s): _____	Other reason(s): _____

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## Research project 4: Data use by MOE to predict education level



*This research will be reviewed by the data platform's committee that consists of research experts, a lawyer, a layperson and an ethics expert.*

*The research is expected to take 1 year to complete.*

### Potentially beneficial elements:

- Predict educational level based on genomic data to better design educational programmes for children.
- The prediction levels are not able to predict how far one person goes in education, but they are considered to be valuable on an aggregated level. For example, if research shows that certain genes are associated with a lower education level, educational learning programmes could be adjusted to target children who have more difficulty reaching their full academic potential.

### Potentially controversial elements:

- Parents and children might start thinking of themselves differently when they are categorized as having more or less educational potential based on genomic information.

**Question 4. Do you think this research should have an extra review by the Ministry of Health? It will delay the research by 2 to 5 weeks. You can choose more than one option.**

Yes, it should be reviewed by MOH	No, it does not need review by MOH
There should be government accountability	I do not see the added value

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MOH has the right expertise	I would not want the research to be delayed
MOH has the public interest in mind	MOH should not spend time or resources on this
Other reason(s): _____	Other reason(s): _____

**Are there any other organisations that you would like to review the research?**

- [Open text box]

**Do you have any comments on this research proposal that you would like to share?**

- [Open text box]

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## **Demographics**

**Age (in years):** \_\_\_\_\_

**Gender:**

- Male
- Female

**Race:**

- Chinese
- Malay
- Indian
- Others (please specify): \_\_\_\_\_

**Highest education level:**

- No formal education
- Pre-Primary
- Primary
- Secondary
- Post-Secondary
- Polytechnic
- A Levels
- Other Diploma
- University- Bachelor's Degree
- University- Postgraduate Degree

**How would you rate your health?**

- Excellent;
- Very good;
- Good;
- Fair;
- Poor