

SINGHEALTH DONATION OF HUMAN BIOLOGICAL MATERIAL FOR FUTURE RESEARCH INFORMATION SHEET

“Human Biological Materials” means any biological material obtained from the human body that consists of or includes human cells (eg, tissue, blood, cells, bodily fluids).

“Leftover Material” means any Human Biological Materials collected pursuant to the Purpose that is no longer necessary for the Purpose.

“Extra Material” means any Human Biological Materials collected pursuant to the Purpose that is in addition of what is required for the Purpose.

1. Where the Human Biological Materials are from:

Human Biological Materials may be collected for the following purposes (“Purpose”):

- Therapeutic or diagnostic procedures and/or,
- For a research project.

Collections done pursuant to therapeutic or diagnostic procedures: We understand that your Human Biological Materials have been or will be removed for a therapeutic and/or diagnosis purpose to help treat your clinical condition. Often times, the clinician/reporting pathologist who is responsible for your medical treatment will complete all necessary therapeutic or diagnostic procedures and will no longer require any part of the Leftover Human Biological Materials. Such Leftover Materials will generally be discarded as biological waste in accordance with best practices - usually destroyed by incineration.

Collections done pursuant to research project: We understand that your Human Biological Materials will be obtained as part of your participation in the Research Project. Leftover Material will generally be discarded as biological waste in accordance with best practices - usually destroyed by incineration.

Leftover Material can however be used for Future Research (defined below). Therefore, rather than discarding as waste, we would like to seek your consent to procure and store these Leftover Materials for Future Research.

At SingHealth, we would like to procure and store Leftover Materials to facilitate medical research to advance medical knowledge, which may be valuable in preventing, treating, and/or curing human diseases in the future.

You will be asked to give your consent to donate your Leftover Material by indicating and signing on the “Leftover and/or Extra Material Donation Consent Form”. Before you can provide your consent, it is important that you understand the purpose of the donation and what it will involve. Please take the time to read the following information carefully. If you refuse consent, it will not affect the standard of medical care you are currently receiving.

2. Who the Human Biological Materials will be donated to:

(Default will be SingHealth Tissue Repository, otherwise, the appropriate Tissue Bank will indicate below)

Singapore Health Services Pte Ltd
c/o SingHealth Tissue Repository
The Academia – Discovery Tower Level 10,
20 College Road, Singapore 169856
Tel: 65767117 / 65767118
Website: <http://research.singhealth.com.sg>
Email: tissue.repository@singhealth.com.sg

3. Donation for Future Research

Your Leftover and/or Extra Material and its derivatives may be shared, whether within or outside of SingHealth (defined below), for use in future medical research and development, medical education, training, publication, diagnosis and possibly the treatment of medical conditions on a commercial basis or otherwise (“**Future Research**”). Any release of your Leftover Material and/or Extra Material will always be in accordance with the Human Biomedical Research Act 2015 of Singapore (“**HBRA**”).

In some cases, researchers may wish to use the Leftover and/or Extra Material in restricted human biomedical research involving human-animal combinations. This type of research is strictly regulated and may only be conducted in accordance with the HBRA. Please indicate on the declaration form whether you consent to use of your Leftover and/or Extra Material in this area of research.

4. IRB Approval Required

All research studies conducted on the Leftover and/or Extra Materials will need to be approved by a relevant Institutional Review Board (“**IRB**”). An IRB is an independent committee formally appointed by hospitals and other organizations undertaking research to conduct initial and subsequent periodic reviews of research involving human subjects. Your Leftover and/or Extra Material may only be released to researchers upon obtaining written approval from the IRB.

5. Possible risks, compensation and treatment in the event of injury

Where Leftover Material is obtained from the Purpose, there should be no additional medical risks, discomforts or inconveniences to you.

Where Extra Material is obtained from the Purpose, your consent will be obtained to remove the additional amounts of Human Biological Material stated in your Declaration Form. Additional risk to you in such removals would be minimal and not affect your existing clinical care. If you feel uncomfortable with the Extra Material to be obtained, you have the right to say no. Please indicate on the Declaration Form whether you consent to the removal of Extra Materials.

In the event of injury arising from your participation in the process of Human Biological Material donation, SingHealth is not in a position to provide compensation and treatment.

6. Voluntary donation of Human Biological Material

This donation of Leftover and/or Extra Material is voluntary and there may be no direct benefit to you personally. You renounce your rights to the Leftover and/or Extra Material and any intellectual property rights that may be derived from use of the Leftover and/or Extra Material. We will not be able to return the Human Biological Material to you once you have donated it to SingHealth. You will not receive any personal financial reward either now or in the future. If a new test or treatment is developed using the Leftover and/or Extra Material, you will not receive any share of profits arising from the commercialisation of the developed technology or product.

7. Withdrawal of consent

After giving your consent to donate your Leftover and/or Extra Materials, you can withdraw your consent at any time if the Leftover and/or Extra Material is individually-identifiable and the Leftover and/or Extra Material: (a) has not been used for research; or (b) has been used for research but it is practicable to discontinue further use of the Leftover and/or Extra Material for the research. However, the information or data that have been obtained before your withdrawal of consent may be retained and used for research. Withdrawal of consent to use of your Leftover and/or Extra Material does not affect your access to treatment or medical care.

8. Anticipated Cost to Subjects

If you consent to donating your Leftover and/or Extra Material for the Purpose, there will not be any cost to you.

9. Use of Personal Data

In addition to the donation of your Leftover and/or Extra Material, we wish to have current and future access to your personal data (as defined in the Personal Data Protection Act (Act 26 of 2012 of Singapore), including but not limited to your medical conditions, medications used, investigations and treatment history (“**Personal Data**”). Personal Data about your condition and your treatment can increase the usefulness of the Human Biological Material in future research. By consenting to the donation, you agree to allow Singapore Health Services Pte Ltd and its related companies (collectively, “**SingHealth**”), as well as their respective representatives and agents (“**Representatives**”) to collect, use and disclose your Personal Data for the Future Research and you are confirming that you have read, understood and consent to the SingHealth Data Protection Policy (as applicable to you), the full version of which is available at <http://www.singhealth.com.sg/pdpa> (hard copies available on request). Personal Data will otherwise be kept strictly confidential and will not be disclosed outside of SingHealth and its Representatives except in accordance with the consent you have given.

You are free to withdraw consent for the collection, use and disclosure of your Personal Data for the Future Research, and your continuing medical care will not be affected in any way.

10. How long will my Leftover and/or Extra Material be stored?

The Leftover and/or Extra Material and Personal Data may be stored at SingHealth indefinitely. We require any remaining Leftover and/or Extra Material released for and used in any future research to be destroyed and discarded in an appropriate manner after the research project is completed.

11. Will you be contacted in the future?

Researchers who access the Leftover and/or Extra Material may wish to contact you in the future (such as for further consent to share your Personal Data outside of SingHealth or where otherwise lawfully required). For example, if the Leftover and/or Extra Material and/or Personal Data was collected from you when you were below 21 years of age and you did not consent to the donation jointly with your parent, once you attain the age of 21, your consent may need to be obtained to conduct future research involving the Leftover and/or Extra Material and/or Personal Data. Your contact information will be obtained through your treating physician. We seek your consent for this purpose.

12. Incidental findings

Incidental findings are findings that have potential health or reproductive importance to a research subject and are discovered in the course of conducting research but are unrelated to the purposes, objectives or variables of the study. We need to know whether you would wish to be re-identified in the case of any incidental findings if future research involving your Leftover and/or Extra Material provides for such re-identification. Please indicate your preference on the declaration form if you wish or do not wish to be re-identified in these cases.

13. Export overseas for research

Your Leftover and/or Extra Material may also be exported to researchers outside of Singapore. This is because the researchers who use your Leftover and/or Extra Material may be part of a large group working in collaboration with institutions or commercial companies. We would like to seek your permission on your Leftover and/or Extra Material to be exported or removed from Singapore to a place outside Singapore for research. Any Leftover and/or Extra Material to be exported overseas may only be released in accordance with the requirements of the HBRA, other applicable laws and the relevant IRB. Please indicate on the declaration form whether you consent to have your Leftover and/or Extra Material sent overseas for research.

14. Contacts

If you have questions about the use of your Personal Data, Leftover and/or Extra Material or want to withdraw your consent as indicated above or provide feedback, you can find the contact information listed under Section 2 of this Information Sheet.