

Stakeholder Survey: Perspectives on Biobanking and Tissue Sampling

General Population/Patient Population Questionnaire

- 1) As you know for lots of different health studies researchers collect biological samples, such as blood, tissue and urine, and health information, such as family medical history and genetic information. When these are collected, usually with consent, they are often stored for future medical research, which may not be known at the time of a collection.

Given this, imagine a scenario where researchers have collected and stored your biological samples and health information. When it came time for them to be used for research, do you think: (*Choose only one answer*):

- a) The researchers should ask you for your permission to use them every time they would like to do a new study _____
 - b) The researchers should only ask for your permission to use them once, thus allowing researchers to use them for as many studies as they would like _____
 - c) The researchers should provide you with options regarding the types of studies your stored samples and health information could and could not be used in. _____
- 2) How would you feel if you had to give permission to use your stored biological sample and health information before each new research study: (*Answer a through e with one of 5 options to choose from.*)
- a) I would feel that it was a waste of time and money
Strongly Disagree ___ Disagree ___ Indifferent ___ Agree___ Strongly Agree___
 - b) I would feel bothered
Strongly Disagree ___ Disagree ___ Indifferent ___ Agree___ Strongly Agree___
 - c) I would feel I have control
Strongly Disagree ___ Disagree ___ Indifferent ___ Agree___ Strongly Agree___
 - d) I would have more trust in the study
Strongly Disagree ___ Disagree ___ Indifferent ___ Agree___ Strongly Agree___
 - e) I would feel respected and involved
Strongly Disagree ___ Disagree ___ Indifferent ___ Agree___ Strongly Agree___
- 3) In a scenario where researchers had collected and stored biological samples (such as blood, tissue, urine and genetic information) and health information from you for future medical research, do you think you should have the right to withdraw your consent and sample at any time? (*Choose only one answer*)
- a) Yes _____
 - b) No _____

- 4) Suppose biological samples can be completely anonymized or de-identified. An anonymized sample is when there is no way to trace it back to the donor. A de-identified sample is when researchers do not readily know who the sample belongs to, but there is a person, or a few people, that can trace the sample back to the research participant. Anonymized samples are thought to best protect a research participant's privacy, but once a sample is anonymized it is impossible for him or her to withdraw their sample.

In your opinion, what do you feel is more important: (**Choose only one answer**)

- a) Having a sample anonymized _____
 b) Having a sample de-identified, providing the right to withdraw from the study _____

- 5) Imagine a scenario where a researcher does some tests on your sample and finds out information related to your health that is unrelated to the study for which you had originally provided your sample for. For example, consider the researcher discovered that you were at an increased risk for cancer or heart disease, or carry a gene that indicated a predisposition to depression.

What do you think researchers should do upon discovering this information? (**Choose only one answer**)

- a) Nothing _____
 b) Tell me _____
 c) Tell my doctor _____
 d) Tell both myself and my doctor _____

- 6) Imagine a scenario where a public healthcare worker could access your health information without your knowledge and identify if you were at risk for a chronic health condition, including obesity, diabetes, hypertension, or chronic kidney disease. How would you feel if a policy put a system in place that allowed this public healthcare worker to mail this information to you in order to warn you of your high risk health status. (**Answer a to d with one of the 5 options to choose from**)

- a) I would feel that it was a waste of time and poor use of our public health care dollars.
 Strongly Disagree __ Disagree __ Indifferent __ Agree __ Strongly Agree __
 b) I would be feel that my privacy was invaded
 Strongly Disagree __ Disagree __ Indifferent __ Agree __ Strongly Agree __
 c) I would feel indifferent
 Strongly Disagree __ Disagree __ Indifferent __ Agree __ Strongly Agree __
 d) I would consider the information useful
 Strongly Disagree __ Disagree __ Indifferent __ Agree __ Strongly Agree __

- 7) For various types of health research, biological samples (such as, blood, tissue, urine and genetic information) are often stored and collected. If you provided a sample that was part of such a collection, who do you think owns these samples? (**Choose only one answer.**)

- a) You _____
 b) The researcher conducting the research _____
 c) The institution where the research is being conducted _____
 d) The funder (or funders) of the research if different from above _____

- 8) For various types of health research, biological samples (such as, blood, tissue, urine and genetic information) are often stored and collected. If you provided a sample that was part of such a collection, this sample would contain your genetic information. Given this, do you think you have the continuing right to decide on what is done with your sample? (**Choose only one answer**)
- a) Yes ____
 - b) No ____
- 9) How much do you trust the following individuals, organizations or groups with the care and use your confidential health information? (**Answer a to i with one of the 4 options to choose from.**)
- a. Insurance industry ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - b. Government in your province ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - c. For profit Industry, for example, a drug company
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - d. Data collection organizations (Stats Canada/Canadian Institute for Health Information) ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - e. Disease based foundation (eg. Kidney Foundation, Heart & Stroke) ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - f. University researchers funded by government ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - g. University research funded by industry
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - h. Hospitals ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____
 - i. Doctors ____
A great deal ____ Somewhat ____ Not at all ____ Don't Know ____