

Perceptions, Attitudes, and Likely Behaviors of the Public Towards Donation and Storage of Biological Specimens and Health Information for Biobanking Research for Subject

DATA COLLECTED FROM THIS STUDY ARE CONFIDENTIAL AND WILL BE USED FOR SCIENTIFIC PURPOSES ONLY.

What is this survey about? This survey is about your views on taking part in medical research. We want to understand what you think about having your biological samples and copies of your health information being stored in a central location (often called a “biobank”) and used for medical research. Health information may include information from your medical record such as test results and information about diseases. It may also include information from your blood, tissues, and other samples, as well as genetic information (DNA). By completing this survey you will help inform how biobank research should be conducted in the future.

A. Personal Background Information:

Country of Residence

District

Residence:

- Urban
- Rural

Medical condition:

- Any inherited diseases
- Other
- Acute or Chronic disease

Gender:

Male
 Female

What is your age

Highest level of education completed:

University degree (B.A./B.S.)
 Postgraduate degree (M.D., M.Sc.Ph.D., J.D., etc.)
 Other (please specify):

Religion:

Muslim
 Christian
 Other (please specify):

Marital Status:

Single
 Married
 Divorced
 Widowed
 Other:

Do you have children

Yes
 No

How religious are you?

Not religious
 Somewhat religious
 Very Religious

Have you ever participated in medical research?

Yes
 No

If Yes, which of the following studies have you participated in before (check all that apply)?

	Yes	No
Drug Clinical trial:	<input type="radio"/>	<input type="radio"/>
Blood samples donation:	<input type="radio"/>	<input type="radio"/>
Genetic research:	<input type="radio"/>	<input type="radio"/>
Questionnaire/Interview study:	<input type="radio"/>	<input type="radio"/>
Do not know	<input type="radio"/>	<input type="radio"/>

Which of the following research would you consider volunteering for in the future (check all that apply)?

	Yes	No
Drug Clinical trial:	<input type="radio"/>	<input type="radio"/>
Blood samples donation:	<input type="radio"/>	<input type="radio"/>
Genetic research:	<input type="radio"/>	<input type="radio"/>
Questionnaire/Interview study:	<input type="radio"/>	<input type="radio"/>
Urine samples donation	<input type="radio"/>	<input type="radio"/>
Saliva donation	<input type="radio"/>	<input type="radio"/>

Have you previously heard of the term “biobank” before today?

- Yes
- No
- Not sure

B- Perceptions and Attitudes about Biobanks:

Please state whether you support the following statements by answering Yes, No, or Not sure

Donation

	Yes	No	Not sure
Biobank research can lead to better medical treatments for future generations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank research can lead to improvement in an individual's health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People will have to spend money to donate biological samples.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank research will only benefit private drug companies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Storage

	Yes	No	Not sure
People who donate their biological samples will not be able to request to have their samples destroyed in the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biological specimens given to a biobank can be sold to anyone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Privacy

	Yes	No	Not sure
Personal medical information stored in a biobank will remain private.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Personal medical information stored in a biobank might be revealed to unauthorized people.

Data Sharing

	Yes	No	Not sure
Biological samples can be shared with researchers in other institutions in my country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is acceptable for samples to be shared with researchers at other institutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The legal authorities should have the right to obtain my genetic results when necessary.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Researchers should receive governmental approval prior to exporting samples out of the country.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Research

	Yes	No	Not sure
Researchers are more interested in making money from donated biological samples than doing good research.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A person might be cloned if he/she donates a biological samples to a biobank.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biological samples will be used for the production of biological weapons.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Return of Results

	Yes	No	Not sure
Researchers will contact people if the analysis of their biological specimens shows risk for disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C. Preferences toward Types of Biobanks

Condition 1: Broad Consent and Coded Database

- You agree that your biological samples and medical information to be used for any type of medical research in the future (unspecified) without the necessity of you given any further consent. Review of future research will be under the oversight of a research ethics committee.
- A coded database will be used in which the biobank will remove your personal information such as name, address, national ID number, and birth date and replace it with a code (a number linked to your name) before it is given to other researchers. Biobank officials will have access to the code that can link back to your identity. The coding will enable the biobank to re-identify your medical information in case a result of testing that can improve your health that will be communicated to the treating physician to discuss with you. Also, being able to re-

identify your information will allow for the addition of your follow-up medical information to the biobank that increases the value of the research. However, there will be a small possibility that an unauthorized person obtains the code and be able to identify your medical information.

- Most Likely
- Not Sure
- Definitely Not

Condition 2: Broad Consent and Irreversibly Anonymized Database

- a. Same as above, you agree that your biological samples and medical information to be used for any type of medical research in the future (unspecified) without the necessity of you given any further consent. Review of future research will be under the oversight of a research ethics committee.
- b. The biobank will permanently remove your personal information such as name, address, national ID number, and birth date from your samples and medical information (information will be irreversibly anonymized).

- Most Likely
- Not Sure
- Definitely Not

Condition 3: Tiered Consent and coded samples

- a. Instead of being asked to consent to "any" type of future research, a Tiered consent will be asked, in which you will be given a choice as to what types of medical research you will allow your biological samples and medical information to be used. For example, you can choose whether you want future research to be restricted to only your health condition, restricted to illnesses that are in the same category of your illness, or no restrictions on the types of medical research that can be performed in the future. For each choice, it will not be necessary for you given any further consent. Review of such future research will be under the oversight of an ethics committee.

- b. This type of database will be coded.**

- Most Likely
- Not Sure
- Definitely Not

Condition 4. Tiered Consent and Irreversibly Anonymized Database

- Most Likely
- Not Sure
- Definitely Not

Thank you very much for taking the time to complete this survey! Your answers are very important to us and we really appreciate your time.

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