

THE EMERGE SURVEY ON TAKING PART IN BIOBANK RESEARCH: VERSION C

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 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.**

What are the benefits of biobank research?

Biobank research using health information is done to learn the causes of human diseases and find better ways to prevent and treat diseases. The benefits of biobank research include understanding more about the causes of diseases like autism, cancer, and asthma, and finding better ways to prevent and treat these diseases.

Why is biobank research important?

Biobank research is important because research often works better when researchers from many different places work together and use information from many different people. Biobanks store and use information from large numbers of people, some who are sick and some who are not. Researchers compare information between people who are sick and people who are not sick. This helps them learn more about how to prevent and treat a wide range of diseases like autism, cancer, and asthma.

Does biobank research benefit the participants?

The purpose of biobank research is to help people in general. It does not help the people who take part in the biobank right away, but it may help them in the future.

What kinds of health information are collected and placed in biobanks?

If a person decides to take part in a biobank, copies of their health information are placed in the biobank. This health information is collected by doctors and researchers, and may include samples that are left over from tests that doctors have ordered. It may include information from the person’s medical record such as test results and information about diseases, as well as from blood, tissue, and other samples. It may also include their genetic information.

What do biobanks do with stored health information?

Biobanks share the stored health information with researchers who wish to do medical research with the information. The types of health information from the biobank that researchers use depends on the kinds of diseases or conditions that the researchers are studying. Some researchers may use the health information to develop products that can be sold, like new drugs or tests. If they do, they do not share the profits with the people whose health information is in the biobank.

Do biobanks share information that could identify someone?

Biobanks do not share information that could easily identify someone. Every person in the biobank is given a unique number. Biobanks share that number but they remove personal information such as names, addresses, social security numbers and birth dates before they share health information. Thus the chance that your health information could be traced back to you is extremely small.

What if someone agrees to take part and later changes their mind?

People can ask for their health information to be removed from a biobank at any time. However, if health information has already been shared, it is not possible to remove the information from ongoing studies.

On the following pages, we will ask your views about taking part in biobank research. Your answers to this survey are very important. Your answers will help us understand how people think and feel about having their health information stored, shared, and used in a biobank. This will inform how biobank research is done in the future.

SECTION 1. ATTITUDES TOWARDS TAKING PART IN A BIOBANK

In the following box is a description of one type of biobank. Please read the description of this biobank and answer the questions that follow.

SCENARIO 1

Please imagine that you have been asked to allow your health information to be placed in a biobank at your local hospital or healthcare organization. If you agree to take part in the biobank, the biobank will share your health information with researchers at your local hospital or healthcare organization who wish to use the health information in the biobank for research. In addition, this particular biobank will also place your health information in a large online database that anyone in the public can access. This is to make it easier for researchers across the world to do research with the health information. When you sign up, you will be agreeing for your health information to be used for all kinds of medical research. The biobank will remove your personal information such as name, address, social security number, and birth date that could identify you before it is shared.

Please answer the following question about the imaginary biobank described in Scenario 1.

	No definitely not	No probably not	Not sure	Yes probably	Yes definitely
1. If you were asked, would you take part in this biobank?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Next, please read the statements below about taking part in the imaginary biobank described in Scenario 1. Please check the boxes below to let us know how much you agree or disagree with each statement. Please answer all of these questions, regardless of how you answered Question 1.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. If I were asked to take part in this biobank...					
a) I would feel that taking part could lead to better medical treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I would worry about how researchers would use my health information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I would feel that I was helping future generations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I would worry that some research would be done that I did not want to take part in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I would feel that taking part could help my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I would worry about my privacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I would feel that taking part would help doctors where I get my medical care take better care of patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I would worry about my medical record being shared.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) I would feel that taking part could help me personally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I would worry about my genetic information being shared.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

k) I would worry that someone might make money using my health information.

Please also read the statements below about taking part in the imaginary biobank described in Scenario 1. Please check the boxes below to let us know how much you agree or disagree with each statement. Please answer all of these questions, regardless of how you answered Question 1.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
2. (cont.) If I were asked to take part in this biobank...					
l) I would want to know if my health information might be used by drug companies that make money.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) I would want to know how the biobank covers costs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) I would want to know the types of research my health information would be used for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) I would want to know who makes sure that my health information is used in the right way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) I would want to know who runs the biobank.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) I would want to know if my health information might be used by insurance companies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) I would want to know what would happen if a researcher misused the health information in the biobank.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) I would want to know what kind of knowledge would result from the use of my health information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 2. ATTITUDES TOWARDS ENROLLING YOUR CHILD IN A BIOBANK

3. Are you the parent or guardian of a child under 18 years of age?
- No (if “no” please skip questions 4, 5, and 6 in Section 2 and go to Section 3)
- Yes (if “yes” please continue with questions 4, 5, and 6 in Section 2)

Please only answer questions 4, 5, and 5 in Section 2 if you are the parent or guardian of a child under 18 years of age. If you are the parent or guardian of more than one child under age 18, please answer for your youngest child.

4. In what year was your youngest child born? _____

In the following box is a description of one type of biobank. Please read the description of this biobank and answer the questions that follow.

SCENARIO 2

Please imagine that you have been asked to allow your child’s health information to be placed in a biobank at their local hospital or healthcare organization. If you agree that your child can take part in the biobank, the biobank will share your child’s health information with researchers at their local hospital or healthcare organization who wish to use the health information in the biobank for research. In addition, this particular biobank will also place your child’s health information in a large online database that anyone in the public can access. This is to make it easier for researchers across the world to do research with the health information. When you sign up, you will be agreeing for your child’s health information to be used for all kinds of medical research. The biobank will remove your child’s personal information such as name, address, social security number, and birth date that could identify your child before it is shared.

Now please think about your youngest child under the age of 18 years and answer the following question about the imaginary biobank described in Scenario 2.

	No definitely not	No probably not	Not sure	Yes probably	Yes definitely
5. If you were asked, would you have your youngest child take part in this biobank?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Next, please read the statements below about your youngest child under the age of 18 years taking part in the imaginary biobank we just described in Scenario 2. Please check the boxes below to let us know how much you agree or disagree with each statement. Please answer all of these questions, regardless of how you answered Question 5.

	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly agree
6. If I were asked to have my youngest child take part in this biobank...					
a) I would worry about how researchers would use my child’s health information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I would feel that my child was helping other children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I would feel that taking part could help my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I would worry about my child’s privacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I would feel that taking part could help my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I would worry that some research would	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

be done that I did not want my child to take part in.

SECTION 3. ATTITUDES TOWARDS THE HEALTHCARE SYSTEM AND MEDICAL RESEARCHERS

In this section, we would like to know your thoughts and feelings about the healthcare system, medical researchers, and health information privacy. Please check the boxes below to let us know how much you agree or disagree with each statement.

When answering the question about your healthcare system, please think about the hospitals, clinics and laboratories that you and your family use.

	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly agree
7. I trust my healthcare system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I trust medical researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Health information privacy is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I worry about the privacy of my health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 4. HEALTH-RELATED ITEMS

11. Would you say your overall health is:

- Poor
- Fair
- Good
- Very good
- Excellent

12. Have you ever had a genetic test?

- Yes
- No
- Not sure

13. Have you ever been told by a doctor that you have a genetic disorder?

- Yes
- No
- Not sure

14. Has anyone else in your immediate family (parent, children, sibling, spouse) ever been told that they have a genetic disorder?

- Yes
- No
- Not sure

15. Have you ever been asked to take part in a biobank?

- Yes
- No
- Not sure

16. Have you ever taken part in a biobank?

- Yes
- No
- Not sure

The next questions are about your **youngest** child under the age of 18 years. If you only have one child under 18 years, please answer about that child. If you do not have any children under 18 years, please skip this section and go straight to Section 5 on page 8.

17. Would you say the overall health of your youngest child is:

- Poor
- Fair
- Good
- Very good
- Excellent

18. Has your youngest child ever had a genetic test?

- Yes
- No
- Not sure

19. Have you ever been told by a doctor that your youngest child has a genetic disorder?

- Yes
- No
- Not sure

20. Has your youngest child ever been asked to take part in a biobank?

- Yes
- No
- Not sure

21. Has your youngest child ever taken part in a biobank?

- Yes
- No
- Not sure

SECTION 5. DEMOGRAPHICS

Finally, we would like to ask you some questions about yourself.

22. What is your age?

- ___ years

23. Are you male or female?

- Male
- Female

24. Which one or more of the following would you say is your race? **(Check all that apply)**

- White or Caucasian
- Black or African American
- American Indian or Alaska Native
- Asian
- Pacific Islander
- Other
- Don't know

25. Are you Hispanic or Latino/a?

- Yes
- No
- Don't know

26. How religious do you consider yourself to be?

- Not at all religious
- Not very religious
- Somewhat religious
- Very religious

27. What is your current marital status?

- Now married **(SKIP to question 29)**
- Widowed
- Divorced
- Separated
- Never married

28. Are you currently living with a boyfriend/girlfriend or partner?

- Yes
- No

29. What is the highest grade or year of school you completed? (**Check only one response**)

- Never attended school
- Grade school (grades 1 to 8)
- Some high school (grades 9 to 12)
- High school graduate or GED
- Post high school training other than college (vocational, technical, or other types of training)
- Some college
- Bachelor's degree or equivalent
- Master's degree (MS, MBA, MFA, etc.)
- Doctoral or other professional degree (PhD, MD, JD or other)

30. What is your current work situation? (**Check all that apply**)

- Working
- Only temporarily laid off, sick leave or maternity leave
- Looking for work, unemployed
- Retired
- Disabled, permanently or temporarily
- Homemaker
- Student
- Other

31. What is your household's total combined income during the past 12 months? (This includes money from pensions, social security payments, jobs, net income from business, farm or rent, dividends, interest and any other income received by family members who are 15 years of age or older.)

- Less than \$15,000
- \$15,000 to \$29,999
- \$30,000 to \$44,999
- \$45,000 to \$59,999
- \$60,000 to \$89,999
- \$90,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or above

32. Including yourself, how many people currently live in your household?

___ people

33. How many children (including both biological and non-biological) do you have?

___ children

34. How many children under the age of 18 years currently live in your household?

___ children

35. Do you have health insurance or a health coverage plan? (Check all that apply)

- Yes, through my employer
- Yes, through someone else's employer
- Yes, a plan that I or someone else buys
- Yes, through Medicare
- Yes, through Medicaid or Medical Assistance
- Yes, through the military, CHAMPUS, or the VA
- Yes, through the Indian Health Service or the Alaska Native Health Service
- Yes, through some other source
- No, I don't have any coverage
- Don't know

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.