

Assent (English) - v1.0

Name	John Dow
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Columbia University Biobank at NewYork Presbyterian (CUB-NYP)

We are asking children and adults who are patients at Columbia-NewYork Presbyterian Hospital to participate in a biobank. Before you decide to participate in the biobank, it is important for you to understand what a biobank is and what your participation will involve.

What is a research study?

A research study helps us to learn new things. We can test an idea. We can ask questions and try to find out the answer. A biobank is a place that stores samples, such as blood and urine, and health information. Scientists can use the samples and health information to help test their ideas.

Important things to know about participating in the biobank:

- It is your decision whether you want to be involved the biobank
- You can say no or you can say yes
- If you say yes, you can change your mind later
- Your doctors will take good care of you no matter what decision you make

Why are asking people to participate in the Columbia University Biobank?

We are asking children and adults to participate in the biobank so that we can help Columbia scientists with their research to understand different diseases or health conditions. Maybe the scientists will be able to create new ways to treat or to stop the diseases they are studying. A biobank can make it easier for scientists at Columbia to answer some of their research questions. A biobank can help scientists get answers needed to help people.

What do I need to do to join the biobank?

If you decide to join the biobank, you will need to do the following.

- Blood sample: You will need to provide a blood sample. To get the blood sample, we will need to poke you with a needle. Researchers will be able to use this blood sample to look at your DNA sequence and do research tests. Most of the tiny cells that make up your body contain DNA. The DNA gives our body the instructions it needs about how to develop and function.
- Doctor's records: We will look at the records that your doctors at Columbia enter into the computer



computer.

- **Questions:** In the future, we may send questions for you to answer. These questions could be on paper or on a computer.
- **Other research studies:** In the future, we may let you and your family know about other research studies conducted at Columbia University Medical Center. You do not need to agree to participate in these studies.

Could I get hurt by participating in the biobank?

When we use a needle to take the blood sample, it can hurt. Sometimes the needle poke will leave a bruise on your skin. We can use a cream on your skin so that it does not hurt as much. Sometimes people feel uncomfortable at the time of the blood draw. Occasionally, people feel faint or lightheaded. There is also a small risk of infection.

Loss of confidentiality

A risk of taking part in the biobank is the possibility of a loss of confidentiality. Loss of confidentiality includes having your personal information shared with someone who is not on the biobank team and was not supposed to see or know about your information. The study team plans to protect your confidentiality.

Will the biobank help me?

The biobank will not help you. The biobank will help scientists to answer research questions. We hope that by answering these questions children and adults who have health conditions or diseases may be helped in the future.

What about your privacy?

To protect you, the information collected in this biobank will be shared with Columbia University researchers and collaborators. Information will not be shared with anyone else unless required by law.

Will I be paid?

We will give you a \$20 gift card after you enroll in the biobank. If you are contacted in the future about other research opportunities, you may be paid depending on the research study.

What will it cost you to be in the biobank?

There is no cost to you or your parents for being in the biobank.

Do you have to participate in the biobank?

If you do not want to join the biobank, you do not have to. No one will be mad at you if you say no. You can also say yes now and change your mind later. Just tell the doctor or your parent/guardian that you want to stop.

Please talk this over with your parents before you decide if you want to be in the biobank. Your parents have said that it is ok with them if you are in the biobank. You can still say no even if your parents said that it is ok with them if you participate in the biobank.



If you sign this paper, it means that you want to participate in biobank. If you do not want to participate in the biobank, do not sign this paper.

What if you have questions?

You may ask questions at any time. You can ask now or later. You may talk to the researcher or someone else. Your parents/guardians have the information on who to call if you have questions after you go home.



Acknowledgment of verbal assent

Do you want to be in this biobank? Yes No

Name of Participant

John Dow

Signature of Participant



Name of Parent/Guardian

Test Guardian

Today's Date

07-14-2020



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