

Multiple Choice Comprehension Assessment for Biobanking: Full Length

This tool was originally developed as a True/False quiz to reflect content identified as essential by an expert Delphi panel, and was used to assess comprehension among individuals given a simplified versus traditional biobank consent form. For details, please see:

- Beskow LM, Dombeck CB, Thompson CP, Watson-Ormond JK, Weinfurt KP. Informed consent for biobanking: consensus-based guidelines for adequate comprehension. *Genet Med*. 2015 Mar;17(3):226-33. doi: 10.1038/gim.2014.102.
- Beskow LM, Lin L, Dombeck CB, Gao E, Weinfurt KP. Improving biobank consent comprehension: a national randomized survey to assess the effect of a simplified form and review/retest intervention. *Genet Med*. 2017 May;19(5):505-512. doi: 10.1038/gim.2016.157.

The present version was developed to reflect the same substantive content, following best practices for writing multiple choice test questions:

- <https://cft.vanderbilt.edu/guides-sub-pages/writing-good-multiple-choice-test-questions/>

and refined iteratively through 41 cognitive interviews.

****As with any consent template materials, be sure to customize to your needs before using!****

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FULL LENGTH MULTIPLE-CHOICE ASSESSMENT

Here are a few questions to help make sure we did a good job explaining what people need to know about taking part in a biobank.

*** PLEASE NOTE: THERE ARE TWO KINDS OF QUESTIONS BELOW ***

- **Pick One** – choose the *one* answer option that you think is correct
- **True/False** – tell us whether you think the statement is true or false

1. What is the purpose of this project?

- To collect and store samples and health information for use in future research
- To collect samples and health information for one study, then discard them
- To collect and store only samples, not health information, for use in future research

Answer Explanation:

CORRECT! [or] INCORRECT

The purpose of the Biobank is to collect and store samples and health information for future research. Researchers need both—samples and health information—to learn more about health and disease. Rather than using them for just one study and then throwing them away, the Biobank will keep them so they can be used for many studies in the future.

2. Which one of the following is something the Biobank will NOT do?

- Ask me for some basic information about myself
- Have someone available to answer my questions
- Provide me with medical care

Answer Explanation:

CORRECT! [or] INCORRECT

The Biobank will ask you for basic information, such as your name, age, race and family health history. If you have any questions about the Biobank, now or in the future, the Biobank will have someone available who can answer them. **One thing the Biobank will not do is provide you with medical care.**

3. **True or false: You will have blood drawn as part of this project.**

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

If you agree to participate in the Biobank, **we will draw about 3 tablespoons of blood from your arm.**

4. **True or false: The Biobank will collect information from your medical records.**

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

If you agree to participate, **the Biobank will get information about your health from your medical record.**

5. **True or false: The Biobank will let researchers study your samples and health information.**

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

The Biobank will let many kinds of researchers use the stored samples and health information for approved studies.

6. Someone from the Biobank might contact you for all of the following reasons EXCEPT:

- To update my basic information
- To let me know every time my samples and information are used in a study
- To see if I am interested in participating in other research

Answer Explanation:

CORRECT! [or] INCORRECT

The Biobank will contact you from time to time to update your basic information. The Biobank might also contact you to tell you about other studies you might want to join. **One thing the Biobank will not do is notify you every time researchers use your samples and information.**

7. True or false: If you participate in the Biobank, you will get personal health benefits from the research.

- True
- False

Answer Explanation:

CORRECT! [or] INCORRECT

You will not get any direct health benefits from participating in the Biobank. The main reason you may want to join is to help researchers learn things that could improve health care for people in the future.

8. **True or false:** Unless you decide to stop taking part, there is no limit on the length of time the Biobank will keep your samples and information.

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

There is no limit on the length of time the Biobank will keep your samples and information. The Biobank will go on letting researchers use them unless you decide to stop taking part.

9. **True or false:** Some of your genetic and health information might be put into a database outside the Biobank.

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

Some information about your genetics and health might be put into scientific databases outside of the Biobank, along with that from many other people.

10. **The chance that someone could get access to your information or trace it back to you is:**

None, because the Biobank guarantees it will protect my privacy

Small, because the Biobank will take many steps to protect my privacy

Big, because there is nothing the Biobank will do to protect my privacy

Answer Explanation:

CORRECT! [or] INCORRECT

The Biobank will take many steps to protect the privacy of your personal information. Even so, **there is still a small chance that someone could get access to the information we have stored about you.**

11. True or false: The Biobank will give researchers information that easily identifies you.

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

The Biobank will not give researchers your name or other information that could directly identify you. Information that directly identifies you will also not be placed into scientific databases outside the Biobank.

12. True or false: There are no laws to protect against discrimination based on your information.

True

False

Answer Explanation:

CORRECT! [or] INCORRECT

The Genetic Information Nondiscrimination Act (GINA) makes it illegal for employers and health insurers use your genetic information to discriminate against you. However, GINA does not protect you against discrimination if you apply for other types of insurance, like life, long-term care, or disability insurance.

13. If research using your sample helps lead to any new products or treatments:

- I will not get any of the profits
- I will get part of the profits
- I will get all of the profits

Answer Explanation:

CORRECT! [or] INCORRECT

Some research done using the samples and information stored in the Biobank may lead to new tests, drugs, or other treatments. If this happens, **you will not get any profits.**

14. If the researchers use your sample and information in a study:

- I will get my individual results
- My individual results will be sent to my doctor
- I should not expect to get my individual results

Answer Explanation:

CORRECT! [or] INCORRECT

Research is not the same as medical care. **You should not expect to get individual results from studies done using your stored materials.**

15. Once you sign up for the Biobank, can you change your mind?

- Yes, but the Biobank cannot get back samples and information from studies that have already begun
- Yes, and the Biobank will get back my samples and information, even from studies that have already begun
- No, once I sign up, I cannot leave the Biobank

Answer Explanation:

CORRECT! [or] INCORRECT

Taking part in the Biobank is your choice. **If you choose to take part, you can stop at any time.** The Biobank cannot get back samples and information already given out for study. But if you decide to stop taking part, we won't use them in any more future studies.