

Supplemental Online Content

Spector-Bagdady K, Trinidad G, Kardia S, et al. Reported interest in notification regarding use of health information and biospecimens. *JAMA*. Published August 2, 2022.
doi:10.1001/jama.2022.9740

eAppendix. Reported Desire for Notice Regarding Use of Health Information and Biospecimens

This supplemental material has been provided by the authors to give readers additional information about their work.

eAppendix. Reported Desire for Notice Regarding Use of Health Information and Biospecimens

I. Definitions provided to participants previously in the survey

The healthcare system: “The healthcare system” refers generally to the healthcare system in this country.

Healthcare providers: Health care providers include people such as doctors and nurses who provide medical treatment.

II. Survey narrative and questions

Respondents first watched a 2-minute educational video (regarding a fictionalized patient named Florence) describing: 1) the value of research with biospecimens and health information, 2) what kinds of information this might include, 3) how biospecimens are collected, 4) clinical and other research uses of these materials, 5) that there are laws to protect some identified information. All underlined words were defined previously in the survey and via hover text each time they are used.

Now that you’ve heard Florence’s story and seen how health information can be shared, we’d like to know what you think about the use and sharing of health information.

The next questions are about the use of your health information for research.

Your health information is information about you and your medical treatment history including diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and test results.

Your health information can be “de-identified.” This means that “identifying information” about you is removed from your health information. Identifying information includes things like your name, address, date of birth, etc. De-identified information can then be given to researchers to study things like healthcare costs, quality, and diseases.

University researchers are people who work for colleges or universities. These researchers might use health information to understand how people use the healthcare system, how healthcare providers treat patients, and a wide variety of other health related topics. University researchers might also use biospecimens for research on how illness works, which treatments are most effective, or how genetics affect illness. University researchers may or may not be connected to your hospital in some way.

For you, how true are the following statements? [attributes randomized, there was also an additional partner question for all below that asked about comfort that we did not use for this analysis]

Q18B – I would like to be notified if university researchers will use my de-identified health information

Response options for all questions:

- Not true
- Somewhat true
- Fairly true
- Very true

Your health information can be identified. This means that “identifying information” about you is linked to your health information. Identifying information includes things like your name,

address, date of birth, etc. Identified information can then be given to researchers to study things like healthcare costs, quality, and diseases.

For you, how true are the following statements? [variables randomized]

Q19B – I would like to be notified if university researchers will use my identified health information

Your biospecimens may be collected during the course of your treatment. Biospecimens include blood from a blood test, or tissue samples from a biopsy. Your biospecimens contain your DNA. Sometimes when there are biospecimens left over from your healthcare (such as blood or urine left over from a diagnostic test) that otherwise would be thrown away, those leftover biospecimens might be used for research.

Biospecimens can be de-identified. This means that “identifying information” about you is not linked to your biospecimens. Identifying information includes things like your name, address, date of birth, etc. De-identified biospecimens can be given to researchers to study things like healthcare costs, healthcare quality, and diseases.

For you, how true are the following statements? [variables randomized]

Q20B – I would like to be notified if university researchers will use my de-identified biospecimens

Biospecimens can be “identified.” This means that “identifying information” about you *is linked to* your biospecimens. Identifying information includes things like your name, address, date of birth, etc. Identified biospecimens can be given to researchers to study things like health care costs, quality, and diseases.

For you, how true are the following statements? [variables randomized]

Q21B – I would like to be notified if university researchers will use my identified biospecimens

(Intervening questions ask about comfort and notification of quality analyst use)

The next questions are about the use of your health information by commercial companies.

Commercial companies are third-party companies that are not part of a hospital. For example, a third-party commercial company may conduct genetic tests and analyze information for a hospital or healthcare provider for a fee when a hospital is not be able to conduct the test on their own. Commercial companies may keep the information for their own use.

For you, how true are the following statements? [attributes randomized]

Q24B – I would like to be notified if commercial companies use my de-identified health information

Q24D – I would like to be notified if commercial companies use my identified health information

Q24F – I would like to be notified if commercial companies will use my de-identified biospecimens

Q24H – I would like to be notified if commercial companies will use my identified biospecimens