

Supplementary Materials

Appendix A: Case 1

Case Study 1: Hopes and Concerns

Lung Cancer Information Share

Lung cancer is the leading cause of cancer death and the second most common cancer among both men and women in the United States (U.S.). The Lung Cancer Information Share (LCIS) is the largest lung cancer database in the country, bringing together personal, genetic, and health care information from thousands of people. Information is collected by hospitals and commercial laboratories from around the country.



The information collected and in the database is de-identified, meaning that information that could be used to identify a person (such as name, date of birth, etc.) is removed to protect an individual's privacy.

A university in the U.S. runs the LCIS and gets federal funding to collect information and then do studies with the information. Studies focus on understanding both the causes of lung cancer as well as how to treat it more effectively. Other researchers interested in using the information need to get permission from the university. This means that researchers from universities, non-profit organizations (such as the American Lung Association), as well as for-profit companies (such as pharmaceutical companies) can access the information to conduct research as well as develop and market new lung cancer therapies.

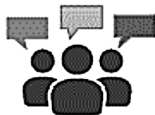
Meet Sue.

Sue is being treated for lung cancer. Her doctor tells her about the LCIS study and how she can participate. The findings from the project won't benefit Sue directly, but could help researchers find ways to better prevent, treat, and manage lung cancer.

The project asks Sue for:

- ✓ Access to her medical records that include information about her current and past health conditions, treatments, prescriptions, as well as her family medical history.
- ✓ Her personal information including her race, ethnicity, age, marriage status, sex, and gender.
- ✓ Access to her blood and tissue samples to analyze her DNA.

Before she can participate in the study, Sue will need to sign a consent form giving researchers permission to use her information.



As a group, discuss the following questions:

If you were Sue, would you give your information to the LCIS?

Why or why not?

Case 2

Case Study 2: Uses of a Medical Information Commons

GatherTogether

GatherTogether is a new medical information commons that will ask more than a million people in the United States (U.S.), with or without a diagnosed disease, to share their information for ongoing health research. People interested in participating will be asked to share various types of information, including:

- ✓ Medical records that include personal and family medical history
- ✓ Personal information including race, ethnicity, age, marriage status, sex, and gender
- ✓ Lifestyle information collected from surveys
- ✓ Medical claims data obtained from insurers
- ✓ DNA from samples of saliva, blood, or tissue
- ✓ Environmental data including water and soil samples from where someone lives or GPS data
- ✓ Internet activity such as social media posts and searches
- ✓ Other information including daily exercise tracking information from a smartphone or wearable technology



The information that is collected is de-identified in **GatherTogether**. It has the potential to be combined with existing patient disease registries, creating the largest medical information commons in the U.S.

Who might use **GatherTogether**?

Many organizations will want to use **GatherTogether** in their research. Here are some of the organizations who might want to access information:

- ✓ Government Agencies such as the National Cancer Institute or Centers for Disease Control
- ✓ Technology Companies such as Google, Apple or small start-up companies
- ✓ Pharmaceutical or Medical Test Companies such as Merck, Pfizer or small start-up companies
- ✓ Health Insurance Companies and Health Plans such as Aetna and Kaiser Permanente
- ✓ Law Enforcement such as Homeland Security, FBI, and local law enforcement
- ✓ Universities such as Stanford, University of Texas, and University of North Carolina
- ✓ Nonprofit Research or Advocacy Organizations such as the American Cancer Society or American Diabetes Association
- ✓ "Citizen Scientists," meaning anyone who wants to conduct research

Case 2 (continued)

Case Study 2: Uses of a Medical Information Commons

What could GatherTogether be used for?

The information will be available for researchers to use now and in the future – to help answer new research questions that come up over time. For example, researchers may want to:

- ✓ Study why people living in certain areas have higher rates of asthma than others
- ✓ Develop a test to help determine which chemotherapy treatment is best for each patient
- ✓ Identify which people in a company are exercising to provide them with a discount on health insurance
- ✓ See if people who are suffering from drug addiction, or their family members, have an 'addiction gene'
- ✓ Develop a new drug that will save millions of lives in another country
- ✓ See if people who use social media have more or less depression than others
- ✓ Identify someone who has committed a crime



GatherTogether is asking for input from States. You are part of the Texas Statewide Council that makes recommendations to the Governor's office.

Your group is tasked with deciding three things:

- 1) What type of information should GatherTogether collect and use?
- 2) What type of organizations should have access to GatherTogether?
- 3) What type of projects should be able to use information from GatherTogether?

Please be prepared to present your recommendations and reasoning to the larger group.

Case 3

Case Study 3: Participant Benefits

Participating in Data-Health

A start-up company is developing a new medical information commons called Data-Health. You are part of the advisory board for Data-Health and have been asked to come up with ways to encourage people to share their information.

Here are some things people may get in return for sharing their information. We identify some of the benefits and concerns to consider, but you may think of others.

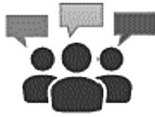


- **Receiving new health information. Benefit:** People could find out information that is medically actionable, such as learning they have a higher genetic risk for a disease. They could also have access to all of their information that has been collected. In each case, people can take their information to a genetic counselor or other healthcare professional to help them review and discuss their information. **Concern:** People may find out medical information about themselves or their family for which there is no current treatment. This can create stress for individuals and their families. It may also make it harder to get long-term or disability insurance.
- **Getting paid. Benefit:** People could get money for sharing their information. Money can be given as a one-time payment or given each time Data-Health uses their information. **Concern:** Paying people for the information they provide may drive up the costs of research and the prices of any products that are developed.
- **Having control over how your information is used. Benefit:** People can decide which groups using Data-Health have access to their information and for what purposes. People could also get permission to use the information in Data-Health to do their own research. **Concern:** Data-Health will need to ask people for their consent for each study. People may get annoyed by multiple requests and lose interest over time.
- **Helping others. Benefit:** For some people, knowing they are helping others and advancing medicine may be a benefit. Just like donating blood to the American Red Cross, people do it for the greater good of helping those in need, without any personal benefit. **Concern:** Data-Health could find that some groups of people may be more willing to share their information for the benefit of others, so the medical information commons may not represent everyone. Also, studies don't always benefit everyone equally.

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Case 3 (continued)

Case Study 3: Participant Benefits

**As a group, discuss the following questions:**

Your advisory board has been asked to decide what people should get in return for sharing their information, including:

- Receiving new health information
- Getting paid
- Having control over how personal information is used
- Helping others
- Others?

Please be prepared to present your reasoning to the larger group.