

Tool 6. Stakeholder Meeting Discussion Guide

6. Stakeholder Meeting Discussion Guide

PRIOR TO GROUP DISCUSSION: THE FACILITATOR WILL NEED TO SELECT 3 TO 5 OF THE SCENARIOS LISTED IN THIS GUIDE TO BE USED DURING THE DISCUSSION.

THE DECISION ON WHICH SCENARIOS TO CHOOSE SHOULD BE BASED ON THE OVERALL COMPOSITION OF THE GROUP. THE FACILITATOR WILL NEED TO WORK WITH THE LEADER OF THE INITIATIVE TO DETERMINE THE TYPE OF HEALTH CARE ENTITY EACH PARTICIPANT REPRESENTS AND THE PROFESSIONAL ROLE HE OR SHE MIGHT HAVE WITHIN THAT ENTITY.

Tentative Schedule

Welcome/Ground Rules/Consent	(5 minutes)
Introduction/Overview	(5 minutes)
Scenario 1	(20–30 minutes)
Scenario 2	(20–30 minutes)
Scenario 3	(20–30 minutes)
Scenario 4 (Time permitting)	(20 minutes)
Scenario 5 (Time permitting)	(20 minutes)
Conclusion/Wrap-up	(5 minutes)

Welcome and Ground Rules (10 minutes)

Welcome, everyone. Thank you very much for coming to this stakeholder meeting regarding health information exchange. Your ideas and opinions are very important to us.

I'm _____ and I'll be facilitating our group discussion today. That means I have a set of questions and discussion topics that I will be guiding us through. _____ will be helping me and taking notes during the group.

INTRODUCE SELF—WHERE YOU ARE FROM—OTHER RELEVANT INFORMATION.

NOTETAKER INTRODUCTION.

Group Objectives

Our goal today is to identify variations in business practices regarding privacy and security as they affect the exchange of health information. Today we will be looking at several scenarios or situations that require the exchange of identifiable patient health information. The goal of the exercises is to have you tell us the business practices that are relevant to the exchange of identifiable patient information, given the particular scenario. Walk us through your business processes for handling the described exchange of identifiable information. We are interested in identifying variations in privacy and security practices to better understand the environment in our state as the move toward the electronic exchange of health information gathers momentum nationwide. This group discussion will last about 2 hours.

Here are some ground rules that will help us work together:

1. First, I want everyone to know that there are no right or wrong answers. We want to know your honest ideas and opinions, and some of you may disagree. This is fine. We are here to learn from you, and we want to hear from everyone and learn what each of you thinks about the issues we will be discussing.
2. If you do not understand a question that I ask, please let me know. I'll try to rephrase it or explain what we are trying to address with the question.
3. *[Optional]* You have probably noticed the tape recorders in the room. They are here because we are audiotaping the group. We want to give you our full attention and not have to take a lot of notes. We will refer to the tapes when writing our report. However, your identity and anything you say here will remain private. Your names, addresses, and phone numbers will not be given to anyone, and study staff will not contact you after this group is over. No one except project staff will hear the audiotapes. When we write our report, we will report on what was said, but not on who said it.
4. Because we are taping, it is important that you try to speak one at a time. I may occasionally interrupt you when two or more people are talking at once in order to be sure everyone gets a chance to talk and that responses are accurately recorded. Sometimes I may need to move the discussion along to make sure we cover everything, and I may ask those people who have contributed a lot to the discussion to give others a chance to speak.
5. If you need to go to the restroom during the discussion, please feel free to do so, but we'd prefer that only one person is out of the room at any one time.

Privacy Statement

Your participation today is voluntary. If you feel uncomfortable at any time, you don't have to answer a question or you can refuse to participate further. As I mentioned, we will write a summary report of the findings from all the groups and interviews we conduct. Your name won't be used. Because these groups are private, we ask that you respect each other's privacy as well.

_____ will be passing out consent forms. Let's take a minute right now to read them and fill them out so [he/she] can collect them before we start. You will get two copies to sign. One copy is for you to keep; it has phone numbers to call in case you have questions later.

Any questions before we start?

Introductions (5 minutes)

To start things off, let's go around the room and introduce everyone. Please tell us your first name, your occupation, and your favorite hobby.

INTRODUCTION SHOULD MOVE QUICKLY—5 MINUTES.

Overview of Health Information Exchange

We are pleased to have all of you here today. I would like to begin by providing a little information on health information exchange. As mentioned, our goal is to develop plans to assess variation in business practices associated with privacy and security that affect health information exchange.

You might ask, “Why assess variation?” Assessing variation in organization-level business practices enables states and territories to identify the practices, policies, and laws that may pose barriers to interoperable health information exchange, as well as those that facilitate interoperable exchange. This, in turn, allows investigators to identify and propose practical solutions to barriers, while preserving the privacy and security of patients as governed by the local community and applicable federal and state laws, and to develop detailed plans to implement solutions.

As we refer to health information exchange, we are referring to the sharing of clinical and administrative data across the boundaries of health care institutions and other health data repositories. Many stakeholder groups (payers, patients, providers, and others) realize that if data could be more readily shared, health care processes would improve with respect to a number of indicators, including safety, quality, and cost. From a cultural and technical standpoint, sharing health data is not easy. Stakeholders have competing priorities. Financial concerns, unresolved issues related to data ownership, and privacy and security issues are among the hardest cultural barriers to overcome.

Let’s begin.

HOLD OFF ANY QUESTIONS AT THIS TIME... MOVE INTO DISCUSSION.

During this discussion, I will present a number of scenarios to you. For each scenario, I would like you to indicate whether a particular practice is a barrier to information exchange, assists in information exchange, or is neutral in that regard. Practices can originate from organizational business decisions, as well as state and federal laws.

Please keep in mind that we are not here to pass judgment on particular business practices. Our goal is to identify current business practices, barriers to health information exchange, and state and federal laws that may be relevant to each scenario.

BEGIN FIRST SCENARIO. HAND OUT SCENARIO TO EACH PARTICIPANT. HANDOUTS ARE LOCATED IN THE BACK OF THIS GUIDE. MAKE ENOUGH COPIES FOR EACH PARTICIPANT.

LIMIT DISCUSSION TO 20–30 MINUTES.

COMPLETE 3 TO 5 SCENARIOS.

Health Information Exchange Scenarios

1. Patient Care Scenario A

Overview:

The emergent transfer of health information between two hospitals that represent the 2 stakeholder organizations (ie, Hospital A and Hospital B) when the status of the patient is unsure. The actors are the staff involved in carrying out the request. The ER physician is requesting the information on behalf of Hospital A.

Stakeholder organizations and exchanges:

- Hospital emergency room in Hospital A is the organization requesting information.
- Hospital B is the organization releasing the information.

Scenario:

Patient X presents to emergency room of General Hospital in {fill state where discussion is being held}. She has been in a serious car accident. The patient is an 89-year-old widow who appears very confused. Law enforcement personnel in the emergency room investigating the accident indicate that the patient was driving. There are questions concerning her possible impairment due to medications. Her adult daughter informed the ER staff that her mother has recently undergone treatment at a hospital in a neighboring state and has a prescription for an antipsychotic drug. The emergency room physician determines there is a need to obtain information about Patient X's prior diagnosis and treatment during the previous inpatient stay.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. What would be the standard practice and policy for obtaining information sufficient to treat this woman?
3. What would be the standard practice for handling mental health information?
4. What would be the standard practice for securing data exchange?
5. What would be the standard practice related to authentication of the requesting facility by the releasing facility?
6. What would be the standard practice related to patient authorization for the release of information?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

2. Patient Care Scenario B

Overview:

The scenario involves the nonemergent transfer of records from a specialty substance treatment provider to a primary care facility for a referral to a specialist.

Stakeholder organizations and exchanges:

- Specialty substance abuse treatment facility (releasing sensitive clinical records)
- Primary care provider's organization (eg, doctor's office, community health center, public health agency) (requesting clinical records from the substance abuse facility, releasing information to specialist)

Scenario:

An inpatient specialty substance abuse treatment facility intends to refer client X to a primary care facility for a suspected medical problem. The 2 organizations do not have a previous relationship. The client has a long history of using various drugs and alcohol that is relevant for medical diagnosis. The primary care provider has requested that the substance abuse information be sent by the treatment facility. The primary care provider intends to refer the patient to a specialist and plans to send all of the patient's medical information, including the substance abuse information that was received from the substance abuse treatment facility, to the specialist.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. How would the releasing organization obtain authorization from the patient to allow release of medical records?
2. What is the process for handling substance abuse medical record data?
3. How does the releasing organization authenticate the health care provider requesting the information?
4. How is the data exchange secured?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

3. Patient Care Scenario C

Stakeholder organizations and exchanges:

- Hospital psychiatric unit (sending) and the skilled nursing facility (receiving)
- Physician (sending) and the transcription service (receiving)
- Transcription service (sending) and the physician (receiving)
- Physician (sending) and the skilled nursing facility (receiving)

Scenario:

At 5:30 p.m., Dr. X, a psychiatrist, arrives at the skilled nursing facility to evaluate his patient, recently discharged from the hospital psychiatric unit to the skilled nursing facility. The hospital and skilled nursing facility are separate entities and do not share electronic record systems. At the time of the patient's transfer, the discharge summary and other pertinent records and forms were electronically transmitted to the skilled nursing home.

When Dr. X enters the facility, he seeks assistance locating his patient, gaining entrance to the locked psychiatric unit, and accessing the patient's electronic health record to review the discharge summary, I&O, MAR, and progress notes. Dr. X was able to enter the unit by showing a picture identification badge, but was not able to access the EHR. As it is Dr. X's first visit, he has no log-in or password to use their system.

Dr. X completes his visit and prepares to complete his documentation for the nursing home. Unable to access the skilled nursing facility EHR, Dr. X dictates his initial assessment via telephone to his outsourced, offshore transcription service. The assessment is transcribed and posted to a secure Web portal.

The next morning, from his home computer, Dr. X checks his e-mail and receives notification that the assessment is available. Dr. X logs into his office Web portal, reviews the assessment, and applies his electronic signature.

Later that day, Dr. X's office manager downloads this assessment from the Web portal, saves the document in the patient's record in his office, and forwards the now encrypted document to the long-term care facility via e-mail.

The skilled nursing facility notifies Dr. X's office that they are unable to open the encrypted document because they do not have the encryption key.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. What would it take to develop an agreement for data sharing?
2. What would it take to establish access and role management policies and practices for temporary or new access?
3. What is your policy for determining appropriate access to mental health records?
4. Are you required to obtain authorization from the patient or patient representative prior to disclosing mental health records?

5. How would you secure unstructured, possibly nonelectronic patient data?
6. What concerns would you have about the reliability of another entity's or individual's security and privacy programs?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

4. Patient Care Scenario D

Overview:

The nonemergent transfer of health information

Stakeholder organizations and exchanges:

- Hospital mammography department (requesting health information)
- Outpatient clinic (receiving request)

Scenario:

Patient X is HIV positive and is having a complete physical and an outpatient mammogram done in the Women’s Imaging Center of General Hospital in _ {fill state where discussion is begin held} _____. She had her last physical and mammogram in an outpatient clinic in a neighboring state. Her physician in State A is requesting a copy of her complete records and the radiologist at General Hospital would like to review the digital images of the mammogram performed at the outpatient clinic in State B for comparison purposes. She also is having a test for the *BrCa* gene and is requesting the genetic test results of her deceased aunt who had a history of breast cancer.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. What is the current practice for authenticating entities and individuals?
2. What are the current processes and laws for release of genetic and HIV information?
3. Is an authorization required?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

5. Payment Scenario

Stakeholder Organizations and Exchanges:

- Health care provider (hospital or clinic)
- Health plan (payer)
- Patients

Scenario:

X Health Payer (third party, disability insurance, employee assistance programs) provides health insurance coverage to many subscribers in the region the health care provider serves. As part of the insurance coverage, it is necessary for the health plan case managers to approve/authorize all inpatient encounters. This requires access to the patient health information (eg, emergency department records, clinic notes).

The health care provider has recently implemented an electronic health record (EHR) system. All patient information is now maintained in the EHR and is accessible to users who have been granted access through an approval process. Access to the EHR has been restricted to the health care provider's workforce members and medical staff members and their office staff.

X Health Payer is requesting access to the EHR for their accredited case management staff to approve/authorize inpatient encounters.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Do you require patient consent before authorizing payer access to patient records?
2. Do you allow payers access to EHRs?
3. What is the method for enabling secure remote access, if allowed?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

6. RHIO Scenario

Note: Each stakeholder should participate in this scenario keeping in mind the type of data their organization anticipates exchanging with a RHIO.

Stakeholder organizations and exchanges:

- Multiple provider organizations (providing data)
- Multiple RHIOs (receiving data)

Scenario:

The RHIO in your region wants to access patient identifiable data from all participating organizations (and their patients) to monitor the incidence and management of diabetic patients. The RHIO also intends to monitor participating providers to rank them for the provision of preventive services to their diabetic patients.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. What barriers are there in utilizing medical record data to monitor disease management?
2. If the RHIO is managed as a third-party entity, are business associate agreements in place between the RHIO and participating entities?
3. Would you require authorization from patients to allow the RHIO to monitor their personal health information for disease management?
4. What would be the mode of transferring information?
5. What type of information—identifiable, de-identified, or limited data set—would be sent to the RHIO?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

7. Research Data Use Scenario

Stakeholder organizations and exchanges:

- Health care consumer (taking part in the study)
- Health care provider (distributing meds and collecting clinical data)
- Research investigator (receiving and analyzing clinical data)
- Institutional Review Board (IRB) (receiving reports on data collection)

Scenario:

A research project on children younger than age 13 is being conducted in a double-blind study for a new drug for ADD/ADHD. The research is being sponsored by a major drug manufacturer conducting a double-blind study approved by the medical center's IRB, where the research investigators are located. The data being collected is all electronic, and all responses from the subjects are completed electronically on the same centralized and shared database file.

The principal investigator was asked by one of the investigators if they could use the raw data to extend the tracking of the patients over an additional 6 months or use the raw data collected for a white paper that is not part of the research protocols final document for his postdoctoral fellow program.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. Having reviewed the content of this scenario and a few suggested business practices, we will now open this up to a discussion of your business practices regarding this scenario.

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

8. Scenario for Access by Law Enforcement

Stakeholder organizations and exchanges:

- Health care provider (providing health information)
- Law enforcement
- Patient
- Patient's family

Scenario:

An injured 19-year-old college student is brought to the ER following an automobile accident. It is standard to run blood-alcohol and drug screens. The police officer investigating the accident arrives in the ER, claiming that the patient may have caused the accident. The patient's parents arrive shortly afterward. The police officer requests a copy of the blood-alcohol test results, and the parents want to review the ER record and lab results to see if their child tested positive for drugs. These requests to print directly from the electronic health record are made to the ER staff.

The patient is covered under his parent's health and auto insurance policy.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. What is your business practice in terms of releasing copies of medical records for children who are no longer minors to parents, payers, and police?
3. What is your business practice in terms of asking such patients for permission to talk or give information to parents about their condition?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

9. Pharmacy Benefit Scenario A

Stakeholder organizations and exchanges:

- Pharmacy benefit manager (PBM) (requesting information)
- Outpatient clinic (receiving request)
- Patient X

Scenario:

The PBM has a mail order pharmacy for a hospital which is self-insured and also has a closed formulary. The PBM receives a prescription from Patient X, an employee of the hospital, for the antipsychotic medication Geodon. The PBM's preferred alternatives for antipsychotics are Risperidone (Risperdal), Quetiapine (Seroquel), and Aripiprazole (Abilify). Since Geodon is not on the preferred alternatives list, the PBM sends a request to the prescribing physician to complete a prior authorization in order to fill and pay for the Geodon prescription. The PBM is in a different state than the provider's outpatient clinic.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. How would you handle the sharing of information with the pharmacy benefit manager?
2. Do you currently have agreements for data sharing or business associate agreements?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

10. Pharmacy Benefit Scenario B

Stakeholder organizations and exchanges:

- Pharmacy benefit manager (PBM) (requesting information)
- Company A (providing claims information)
- Employees

Scenario:

A PBM (PBM1) has an agreement with Company A to review the companies' employees' prescription drug use and the associated costs of the drugs prescribed. The objective would be to see if the PBM1 could save the company money on their prescription drug benefit. Company A is self-insured and as part of their current benefits package, they have the prescription drug claims submitted through their current PBM (PBM2). PBM1 has requested that Company A send their electronic claims to them to complete the review.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Do you currently have agreements for data sharing or business associate agreements?
2. Having reviewed the content of this scenario and a few suggested business practices, we will now open this up to a discussion of your business practices regarding this scenario.

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

11. Health Care Operations and Marketing Scenario A

Note: This scenario could be modified to apply to any health care provider (physician group, home health care agency, etc) wishing to market services to a targeted subset of patients.

Stakeholder organizations and exchanges:

- Tertiary hospital (requesting study data)
- Critical access hospital (being asked to provide health information)

Scenario:

ABC Health Care is an integrated health delivery system composed of ten critical access hospitals and one large tertiary hospital, DEF Medical Center, which has served as the system's primary referral center. Recently, DEF Medical Center has expanded its rehab services and created a state-of-the-art, stand-alone rehab center. Six months into operation, ABC Health Care does not feel that the rehab center is being fully utilized and is questioning the lack of rehab referrals from the critical access hospitals.

ABC Health Care has requested that its critical access hospitals submit monthly reports containing patient identifiable data to the system six-sigma team to analyze patient encounters and trends for the following rehab diagnoses/procedures:

- Cerebrovascular accident (CVA)
- Hip fracture
- Total joint replacement

Additionally, ABC Health Care is requesting that this same information, along with individual patient demographic information, be provided to the system marketing department. The marketing department plans to distribute to these individuals a brochure highlighting the new rehab center and the enhanced services available.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. Having reviewed the content of this scenario and a few suggested business practices, we will now open this up to a discussion of your business practices regarding this scenario.

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

12. Health Care Operations and Marketing Scenario B

Stakeholder organizations and exchanges:

- Health care provider (hospital obstetrics department sending data)
- Hospital marketing department (receiving data)
- Local company (purchasing data from marketing department)
- Patients/consumers

Scenario:

ABC hospital has approximately 3,600 births per year. The hospital marketing department is requesting identifiable data on all deliveries, including mother's demographic information and birth outcome (to ensure that contact is made only with those deliveries resulting in healthy live births).

The marketing department has explained that they will use the patient information for the following purposes:

1. To provide information on the hospital's new pediatric wing/services.
2. To solicit registration for the hospital's parenting classes.
3. To request donations for construction of the proposed neonatal intensive care unit.
4. To sell the data to a local diaper company to use in marketing diaper services directly to parents.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Would you be able to release this information to the marketing department?
2. Would you be able to sell information to a local diaper company?
3. What steps would be necessary to conduct marketing using patient data?
4. What would be the mode of transferring information to the marketing department? To the diaper company?
5. What type of information—identifiable, de-identified, or limited data set—would be sent to the marketing department, assuming it was allowed? How about the diaper company?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

13. Bioterrorism Event

Stakeholder organizations and exchanges:

- Laboratory (collecting data)
- Health care provider (transmitting data to public health)
- Public health department (receiving data from provider, providing data to government agencies)
- Law enforcement (receiving data)
- Government agencies (receiving data)
- Patients

Scenario:

A provider sees a person who has anthrax, as determined through lab tests. The lab submits a report on this case to the local public health department and notifies their organizational patient safety officer. The public health department in the adjacent county has been contacted and has confirmed that it is also seeing anthrax cases, and therefore this could be a possible bioterrorism event. Further investigation confirms that this is a bioterrorism event, and the state declares an emergency. This then shifts responsibility to a designated state authority to oversee and coordinate a response, and involves alerting law enforcement, hospitals, hazmat teams, and other partners, as well informing the regional media to alert the public to symptoms and seek treatment if feeling affected. The state also notifies the federal government of the event, and some federal agencies may have direct involvement in the event. All parties may need to be notified of specific identifiable demographic and medical details of each case as they arise to identify the source of the anthrax, locate and prosecute the parties responsible for distributing the anthrax, and protect the public from further infection.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. What are your business practices in terms of the release of patient-specific information related to specific symptoms to law enforcement, CDC, Homeland Security, and public health in a situation where a threat is being investigated?
2. Is there a specific chain of command in place for such an event?
3. Faced with this scenario, what would be the first thing you would do?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

14. Employee Health Information Scenario

Stakeholder organizations and exchanges:

- Hospital emergency room (releasing health information)
- Employer human resources department (requesting health information)
- Employee

Scenario:

An employee (of any company) presents in the local emergency department for treatment of a chronic condition that has worsened but is not work related. The employee's condition necessitates a 4-day leave from work for illness. The employer requires a "return to work" document for any illness requiring more than 2 days leave. The hospital emergency department has an EHR and their practice is to cut and paste patient information directly from the EHR and transmit the information via e-mail to the human resources department of the patient's employer.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. What is your business practice in terms of releasing patient information to employers?
2. What are the *minimum necessary* elements that can be legally transmitted, if any?
3. How would you ensure that the data are securely transmitted?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

**15. Public Health Scenario A—
Active Carrier, Communicable Disease Notification**

Stakeholder organizations and exchanges:

- Health care provider (primary care physician)
- Public health department
- Law enforcement
- Patient

Scenario:

A patient with active TB, still under treatment, has decided to move to a desert community that focuses on spiritual healing, without informing his physician. The TB is classified MDR (multidrug resistant). The patient purchases a bus ticket—the bus ride will take a total of 9 hours with 2 rest stops across several states. {fill state where discussion is being held} is made aware of the patient’s intent 2 hours after the bus with the patient leaves. {fill state where discussion is being held} now needs to contact the bus company and other states with the relevant information.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. Having reviewed the content of this scenario and a few suggested business practices, we will now open this up to a discussion of your business practices regarding this scenario.

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

16. Public Health Scenario B—Newborn Screening

Stakeholder organizations and exchanges:

- Health care provider (sending initial data to public health and lab, receiving data on follow up/eligibility)
- State laboratory (receiving data)
- State public health department (receiving data, sending data for program eligibility)

Scenario:

A newborn's screening test comes up positive for a state-mandated screening test and the state lab test results are made available to the child's physicians and specialty care centers specializing in the disorder via an Interactive Voice Response (IVR) system. The state lab also enters the information in its registry, and tracks the child over time through the child's physicians. The state public health department provides services for this disorder and notifies the physician that the child is eligible for those programs.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, what would be the first thing you would do?
2. What is the state or local policy regarding the release of patient-specific information related to specific symptoms of a disease to a public health agency in a situation where a targeted disease is being investigated?
3. What barriers would be faced?
4. What would it take to remove these barriers?

PROBE: IS THERE ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

17. Public Health Scenario C—Homeless Shelters

Stakeholder organizations and exchanges:

- Primary care provider (sending) and hospital-affiliated drug treatment center (receiving)
- The hospital-affiliated drug treatment clinic (releasing) and the county program (requesting for purposes of reimbursement)
- The hospital-affiliated drug treatment clinic (releasing) and the shelter (requesting to verify the treatment)
- The family member (requesting) and the shelter

Stakeholder entities:

- Health care consumer/patient
- Primary care provider
- Hospital-affiliated drug treatment center
- Homeless shelter
- Patient relative/family member

Scenario:

A homeless man arrives at a county shelter and is found to be a drug addict and in need of medical care. The person does have a primary care provider, and he is sent there for medical care. Primary care provider refers patient to a hospital-affiliated drug treatment clinic for his addiction under a county program. The addiction center must report treatment information back to the county for program reimbursement, and back to the shelter to verify that the person is in treatment. Someone claiming to be a relation of the homeless man requests information from the homeless shelter on all the health services the man has received. The staff at the homeless shelter is working to connect the homeless man with his relative.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Would it be possible to release this information to the relative?
2. What barriers might be faced?
3. What could be done to overcome these barriers?
4. In what form would the information be released?

PROBE: IS THERE ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

18. Health Oversight: Legal Compliance/Government Accountability

Stakeholder organizations and exchanges:

- State university faculty (requesting health information)
- State public health agencies (asked to provide health information)

Scenario:

The governor's office has expressed concern about compliance with immunization and lead screening requirements among low-income children who do not receive consistent health care. The state agencies responsible for public health, child welfare and protective services, Medicaid services, and education are asked to share identifiable patient-level health care data on an ongoing basis to determine if the children are getting the health care they need. This is not part of a legislative mandate. The governor in this state and those in the surrounding states have discussed sharing this information to determine if patients migrate between states for these services. Because of the complexity of the task, the governor has asked each agency to provide these data to faculty at the state university medical campus who will design a system for integrating and analyzing the data. There is no existing contract with the state university for services of this nature.

Potential areas of discussion based on this scenario:

PARTICIPANTS SHOULD FOCUS ON THEIR CURRENT BUSINESS PRACTICES AND STATE AND LOCAL LAWS.

1. Faced with this scenario, how would your agency cooperate?
2. If permitted, how would the data be released (electronic or paper)?
3. Would authorization from patient representatives be sought?

PROBE:

- a. WHAT PRIVACY AND SECURITY BARRIERS CURRENTLY EXIST?
- b. WHAT WOULD IT TAKE TO REMOVE THESE BARRIERS?
- c. ANYTHING ELSE THAT MIGHT ENCOURAGE HEALTH INFORMATION EXCHANGE?

Closing (5 minutes)

We're all done for today.

Do any of you have any final comments regarding our discussion?

LIMIT DISCUSSION IF TIME IS AN ISSUE.

Thanks very much for your time. We appreciate that you came in here to meet with us for this group. Your comments and insights have been very helpful.

Scenario Handouts

MAKE ENOUGH COPIES OF THE SCENARIOS YOU SELECT FOR THE GROUP DISCUSSION FOR EACH PARTICIPANT.

1. Patient Care Scenario A

Patient X presents to emergency room of General Hospital in {fill state where discussion is being held}. She has been in a serious car accident. The patient is an 89-year-old widow who appears very confused. Law enforcement personnel in the emergency room investigating the accident indicate that the patient was driving. There are questions concerning her possible impairment due to medications. Her adult daughter informed the ER staff that her mother has recently undergone treatment at a hospital in a neighboring state and has a prescription for an antipsychotic drug. The emergency room physician determines there is a need to obtain information about Patient X's prior diagnosis and treatment during the previous inpatient stay.

2. Patient Care Scenario B

An inpatient specialty substance abuse treatment facility intends to refer client X to a primary care facility for a suspected medical problem. The 2 organizations do not have a previous relationship. The client has a long history of using various drugs and alcohol that is relevant for medical diagnosis. The primary care provider has requested that the substance abuse information be sent by the treatment facility. The primary care provider intends to refer the patient to a specialist and plans to send all of the patient's medical information, including the substance abuse information that was received from the substance abuse treatment facility, to the specialist.

3. Patient Care Scenario C

At 5:30 p.m., Dr. X, a psychiatrist, arrives at the skilled nursing facility to evaluate his patient, recently discharged from the hospital psychiatric unit to the skilled nursing facility. The hospital and skilled nursing facility are separate entities and do not share electronic record systems. At the time of the patient's transfer, the discharge summary and other pertinent records and forms were electronically transmitted to the skilled nursing home.

When Dr. X enters the facility, he seeks assistance locating his patient, gaining entrance to the locked psychiatric unit, and accessing the patient's electronic health record to review the discharge summary, I&O, MAR, and progress notes. Dr. X was able to enter the unit by showing a picture identification badge, but was not able to access the EHR. As it is Dr. X's first visit, he has no log-in or password to use their system.

Dr. X completes his visit and prepares to complete his documentation for the nursing home. Unable to access the skilled nursing facility EHR, Dr. X dictates his initial assessment via

telephone to his outsourced, offshore transcription service. The assessment is transcribed and posted to a secure Web portal.

The next morning, from his home computer, Dr. X checks his e-mail and receives notification that the assessment is available. Dr. X logs into his office Web portal, reviews the assessment, and applies his electronic signature.

Later that day, Dr. X's office manager downloads this assessment from the Web portal, saves the document in the patient's record in his office, and forwards the now encrypted document to the long-term care facility via e-mail.

The skilled nursing facility notifies Dr. X's office that they are unable to open the encrypted document because they do not have the encryption key.

4. Patient Care Scenario D

Patient X is HIV positive and is having a complete physical and an outpatient mammogram done in the Women's Imaging Center of General Hospital in {fill state where discussion is begin held}. She had her last physical and mammogram in an outpatient clinic in a neighboring state. Her physician in State A is requesting a copy of her complete records and the radiologist at General Hospital would like to review the digital images of the mammogram performed at the outpatient clinic in State B for comparison purposes. She also is having a test for the *BrCa* gene and is requesting the genetic test results of her deceased aunt who had a history of breast cancer.

5. Payment Scenario

X Health Payer (third party, disability insurance, employee assistance programs) provides health insurance coverage to many subscribers in the region the health care provider serves. As part of the insurance coverage, it is necessary for the health plan case managers to approve/authorize all inpatient encounters. This requires access to the patient health information (eg, emergency department records, clinic notes).

The health care provider has recently implemented an electronic health record (EHR) system. All patient information is now maintained in the EHR and is accessible to users who have been granted access through an approval process. Access to the EHR has been restricted to the health care provider's workforce members and medical staff members and their office staff.

X Health Payer is requesting access to the EHR for their accredited case management staff to approve/authorize inpatient encounters.

6. RHIO Scenario

The RHIO in your region wants to access patient identifiable data from all participating organizations (and their patients) to monitor the incidence and management of diabetic

patients. The RHIO also intends to monitor participating providers to rank them for the provision of preventive services to their diabetic patients.

7. *Research Data Use Scenario*

A research project on children younger than age 13 is being conducted in a double-blind study for a new drug for ADD/ADHD. The research is being sponsored by a major drug manufacturer conducting a double-blind study approved by the medical center's IRB, where the research investigators are located. The data being collected is all electronic, and all responses from the subjects are completed electronically on the same centralized and shared database file.

The principal investigator was asked by one of the investigators if they could use the raw data to extend the tracking of the patients over an additional 6 months or use the raw data collected for a white paper that is not part of the research protocols final document for his postdoctoral fellow program.

8. *Scenario for Access by Law Enforcement*

An injured 19-year-old college student is brought to the ER following an automobile accident. It is standard to run blood-alcohol and drug screens. The police officer investigating the accident arrives in the ER, claiming that the patient may have caused the accident. The patient's parents arrive shortly afterward. The police officer requests a copy of the blood-alcohol test results, and the parents want to review the ER record and lab results to see if their child tested positive for drugs. These requests to print directly from the electronic health record are made to the ER staff.

The patient is covered under his parent's health and auto insurance policy.

9. *Pharmacy Benefit Scenario A*

The pharmacy benefit manager (PBM) has a mail order pharmacy for a hospital which is self-insured and also has a closed formulary. The PBM receives a prescription from Patient X, an employee of the hospital, for the antipsychotic medication Geodon. The PBM's preferred alternatives for antipsychotics are Risperidone (Risperdal), Quetiapine (Seroquel), and Aripiprazole (Abilify). Since Geodon is not on the preferred alternatives list, the PBM sends a request to the prescribing physician to complete a prior authorization in order to fill and pay for the Geodon prescription. The PBM is in a different state than the provider's outpatient clinic.

10. *Pharmacy Benefit Scenario B*

A pharmacy benefit manager (PBM1) has an agreement with Company A to review the companies' employees' prescription drug use and the associated costs of the drugs prescribed. The objective would be to see if the PBM1 could save the company money on

their prescription drug benefit. Company A is self-insured and as part of their current benefits package, they have the prescription drug claims submitted through their current PBM (PBM2). PBM1 has requested that Company A send their electronic claims to them to complete the review.

11. Healthcare Operations and Marketing Scenario A

ABC Health Care is an integrated health delivery system composed of ten critical access hospitals and one large tertiary hospital, DEF Medical Center, which has served as the system's primary referral center. Recently, DEF Medical Center has expanded its rehab services and created a state-of-the-art, stand-alone rehab center. Six months into operation, ABC Health Care does not feel that the rehab center is being fully utilized and is questioning the lack of rehab referrals from the critical access hospitals.

ABC Health Care has requested that its critical access hospitals submit monthly reports containing patient identifiable data to the system six-sigma team to analyze patient encounters and trends for the following rehab diagnoses/procedures:

- Cerebrovascular accident (CVA)
- Hip fracture
- Total joint replacement

Additionally, ABC Health Care is requesting that this same information, along with individual patient demographic information, be provided to the system marketing department. The marketing department plans to distribute to these individuals a brochure highlighting the new rehab center and the enhanced services available.

12. Healthcare Operations and Marketing Scenario B

ABC hospital has approximately 3,600 births per year. The hospital marketing department is requesting identifiable data on all deliveries, including mother's demographic information and birth outcome (to ensure that contact is made only with those deliveries resulting in healthy live births).

The marketing department has explained that they will use the patient information for the following purposes:

1. To provide information on the hospital's new pediatric wing/services.
2. To solicit registration for the hospital's parenting classes.
3. To request donations for construction of the proposed neonatal intensive care unit.
4. To sell the data to a local diaper company to use in marketing diaper services directly to parents.

13. Bioterrorism Event

A provider sees a person who has anthrax, as determined through lab tests. The lab submits a report on this case to the local public health department and notifies their organizational patient safety officer. The public health department in the adjacent county has been contacted and has confirmed that it is also seeing anthrax cases, and therefore this could be a possible bioterrorism event. Further investigation confirms that this is a bioterrorism event, and the state declares an emergency. This then shifts responsibility to a designated state authority to oversee and coordinate a response, and involves alerting law enforcement, hospitals, hazmat teams, and other partners, as well informing the regional media to alert the public to symptoms and seek treatment if feeling affected. The state also notifies the federal government of the event, and some federal agencies may have direct involvement in the event. All parties may need to be notified of specific identifiable demographic and medical details of each case as they arise to identify the source of the anthrax, locate and prosecute the parties responsible for distributing the anthrax, and protect the public from further infection.

14. Employee Health Information Scenario

An employee (of any company) presents in the local emergency department for treatment of a chronic condition that has worsened but is not work related. The employee's condition necessitates a 4-day leave from work for illness. The employer requires a "return to work" document for any illness requiring more than 2 days leave. The hospital emergency department has an EHR and their practice is to cut and paste patient information directly from the EHR and transmit the information via e-mail to the human resources department of the patient's employer.

15. Public Health Scenario A—Active Carrier, Communicable Disease Notification

A patient with active TB, still under treatment, has decided to move to a desert community that focuses on spiritual healing, without informing his physician. The TB is classified MDR (multidrug resistant). The patient purchases a bus ticket—the bus ride will take a total of 9 hours with 2 rest stops across several states. {fill state where discussion is begin held} is made aware of the patient's intent 2 hours after the bus with the patient leaves. {fill state where discussion is begin held} now needs to contact the bus company and other states with the relevant information.

16. Public Health Scenario B—Newborn Screening

A newborn's screening test comes up positive for a state-mandated screening test and the state lab test results are made available to the child's physicians and specialty care centers specializing in the disorder via an Interactive Voice Response (IVR) system. The state lab also enters the information in its registry, and tracks the child over time through the child's

physicians. The state public health department provides services for this disorder and notifies the physician that the child is eligible for those programs.

17. Public Health Scenario C—Homeless Shelters

A homeless man arrives at a county shelter and is found to be a drug addict and in need of medical care. The person does have a primary care provider, and he is sent there for medical care. Primary care provider refers patient to a hospital-affiliated drug treatment clinic for his addiction under a county program. The addiction center must report treatment information back to the county for program reimbursement, and back to the shelter to verify that the person is in treatment. Someone claiming to be a relation of the homeless man requests information from the homeless shelter on all the health services the man has received. The staff at the homeless shelter is working to connect the homeless man with his relative.

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