Consent Policy Design Group

Meeting #4

May 21, 2019

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Agenda

| Agenda Item	Time
Welcome & Introductions	1:00 pm
Public Comment	1:02 pm
Design Group Check-in	1:05 pm
Use Case Approach to Data Sharing (Part 2)	1:15 pm
Discussion	1:50 pm
Wrap-up and Meeting Adjournment	2:00 pm

Public Comment

Design Group Check-in

Use Case Approach to Sharing Health Data Part 2

Dr. Tim Pletcher & Dr. Lisa Moon

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Today's Objectives

- Brief review and question session about the prior data sharing concepts
  - "Push" and "Pull" and "Longitudinal Health Record"
  - Trust Framework
- Deep dive into the starting HIPAA Organizing Principle
- Develop policy position that can be leveraged for a statewide consent policy for the developing information exchange network
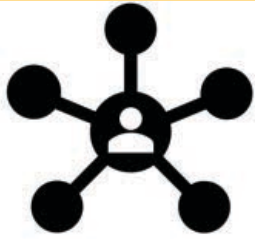
Reminder on HIE Continuum

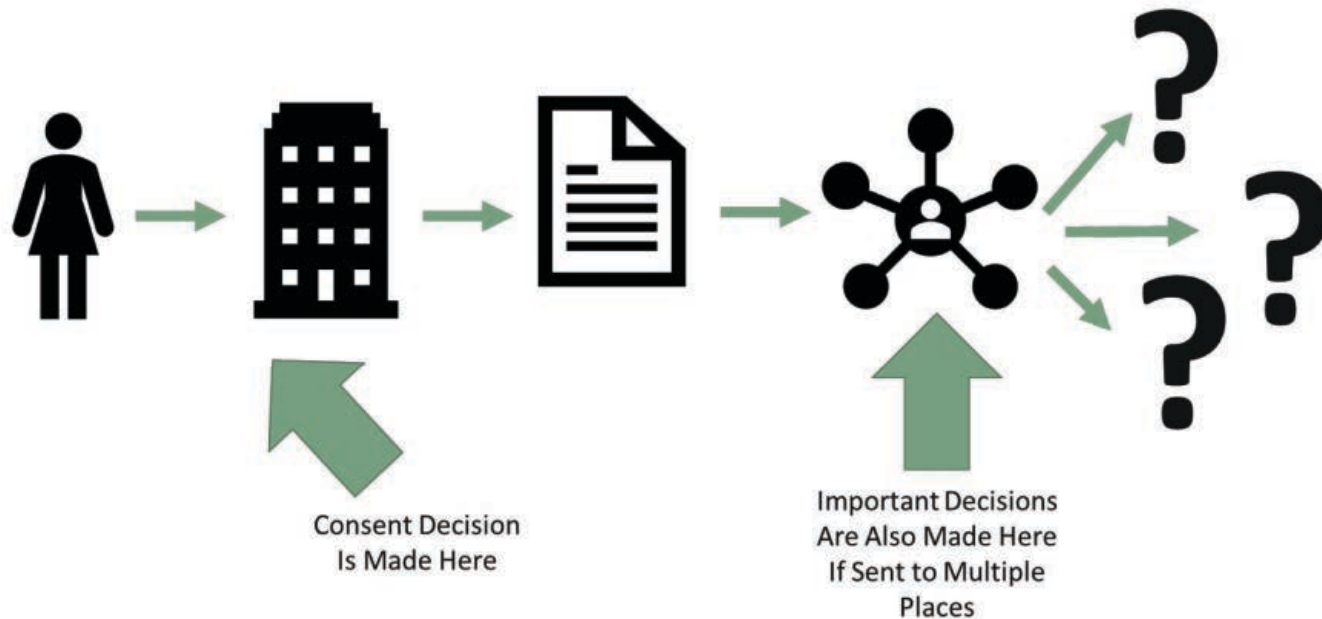**Network of Networks** ←――――――――――→ **Longitudinal Medical Record**

- Organizations tend to trust this model more because the HIE does not keep a pile of data that might be used for unintended purposes or be a cyber security risk

- Often less costly because they allow the data to be maintained at the source

- Generally, easier to make progress as there are lower expectations and concerns

- More like how the Internet works so more "future proof" in a world moving toward a web of interoperable systems

- Once everyone participates, it simplifies where to go for data

- Data is already available for new uses not previously envisioned

- Ability to do advanced analytics on the data

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Review From Last Time

Pushing Data to Multiple Endpoints

Consent Decision
Is Made Here

Important Decisions
Are Also Made Here
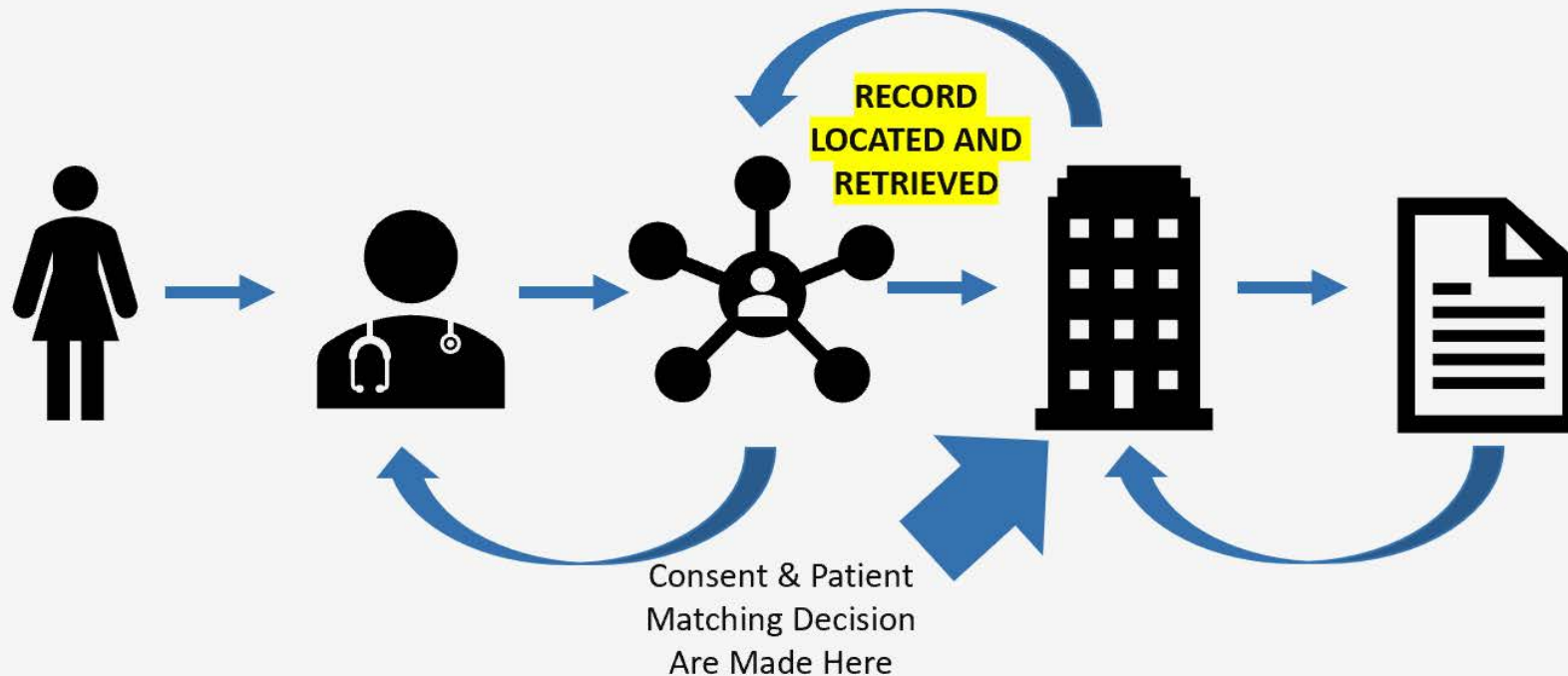If Sent to Multiple
Places

- Pushing data to one well known place is easy

- Pushing data from one place to multiple places is a little more complicated but the data source has a lot of control especially if the "subscribers" to the patient are discoverable

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Review From Last Time

Pulling Data Is More Complicated

RECORD LOCATED AND RETRIEVED

Consent & Patient Matching Decision Are Made Here

- Do we even know where to pull the data from?

- Is everyone involved confident the patient matching is accurate?

- How does the entity getting the request to release the information know the organization making it has consent?

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The legal framework separates joining the network from sharing data related to a Use Case.

Each Use Case Defines Primary & Permissible Use/s

USE CASE EXHIBIT

- Purpose
- Use Case Diagrams
- Definitions
- Use Case Details (Primary Use etc.)
- Service Interruptions
- Responsibilities of Parties
- Other Terms
- Use Case Implementation Guide Link

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Some Example Data Flow Purposes

1. **HIPAA**: Treatment, Payment, and Healthcare Operations (TPO)

2. **Public Health:** Immunizations, reportable conditions, syndromic surveillance

3. **Compliance Monitoring**: For example, Prescription Drug Monitoring Programs (PDMPs) for reducing prescription drug abuse and diversion

4. **Research**: Such as involved in human subjects study or the systematic investigation to develop or contribute to generalizable knowledge

HIPAA Organizing Principle for Data Sharing

Covered entities* with relationships in common may share individually identifiable health information

- Covered Entities include providers, health care organizations, health care clearinghouses and health plans
- Data sharing for treatment, payment or health care operations

So how do we know which covered entities have a patients in common?

Identity & Care Maps

ID&CM identifies the providers actively caring for a patient as well as the payers covering the cost of the patient's care to coordinate all the patient's electronic health information.

What exactly does Identity and Care Maps do?

- Lets providers **declare active care relationships** with patients by submitting patient rosters to HIN

- **Accurately routes information** to alert providers in active care relationships with patients

- **Enables updates to entire care team in real time** with any changes in a patient's status

- **Enables easy views of care team members** by authorized participants

Meet Millie

- 81 years old

- Has Congestive Heart Failure and recently diagnosed with diabetes

- Lives at home but in and out of local Skilled Nursing Facility

- Three sons who manage her healthcare

Millie's Care Team

Son

Son

Son

Care Coordinator

Nurse (SNF)

Dietician

Respite Care

Primary Care

Cardiologist

Endocrinologist

Podiatrist

Pharmacist

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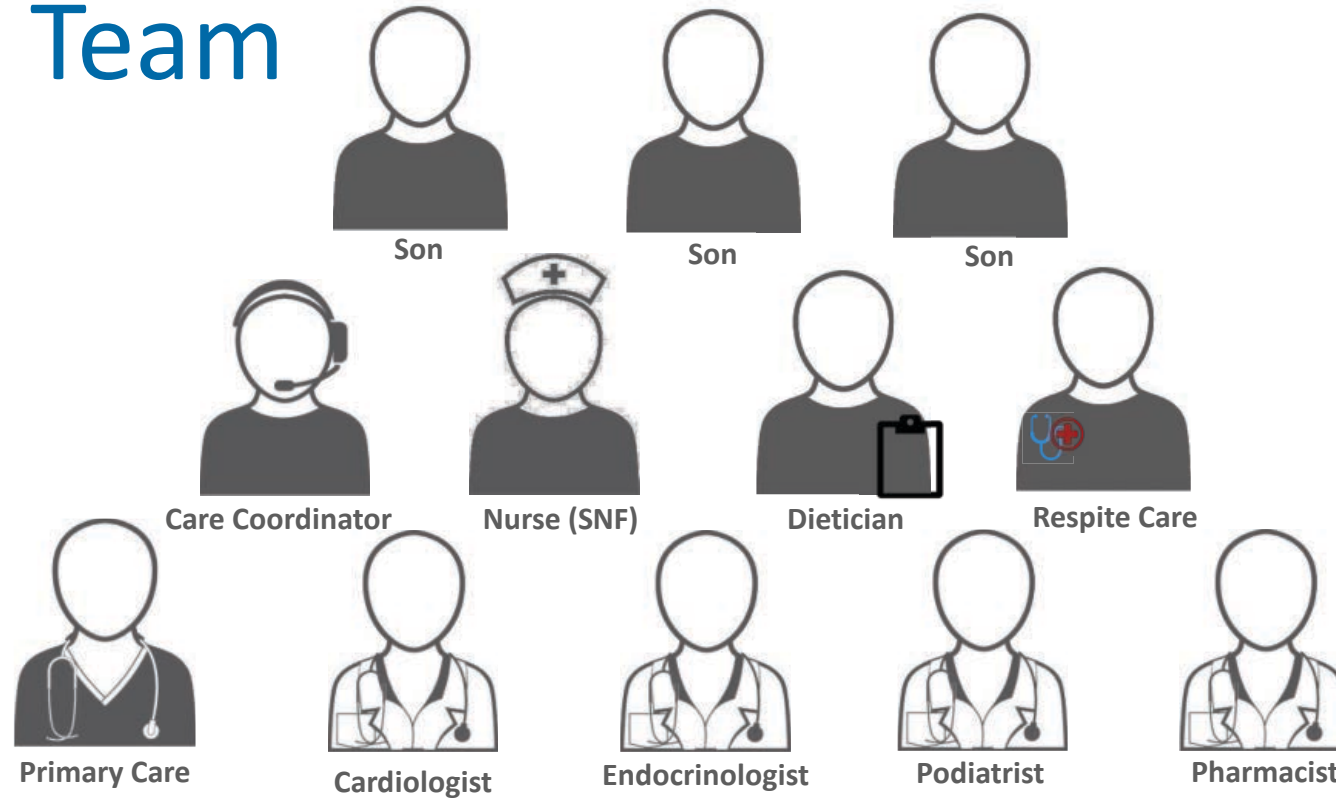
Many Organizations Provide ID & Care Map Info for Millie

Health Plans

Patient

Primary Care Provider

Specialist

Physician Organizations & ACOs

Hospital or SNF

Pharmacist

Community Based Services

Foster Care Program

Telehealth & Consumer Services

Research Study

Clinical Trial

Care Coordinator

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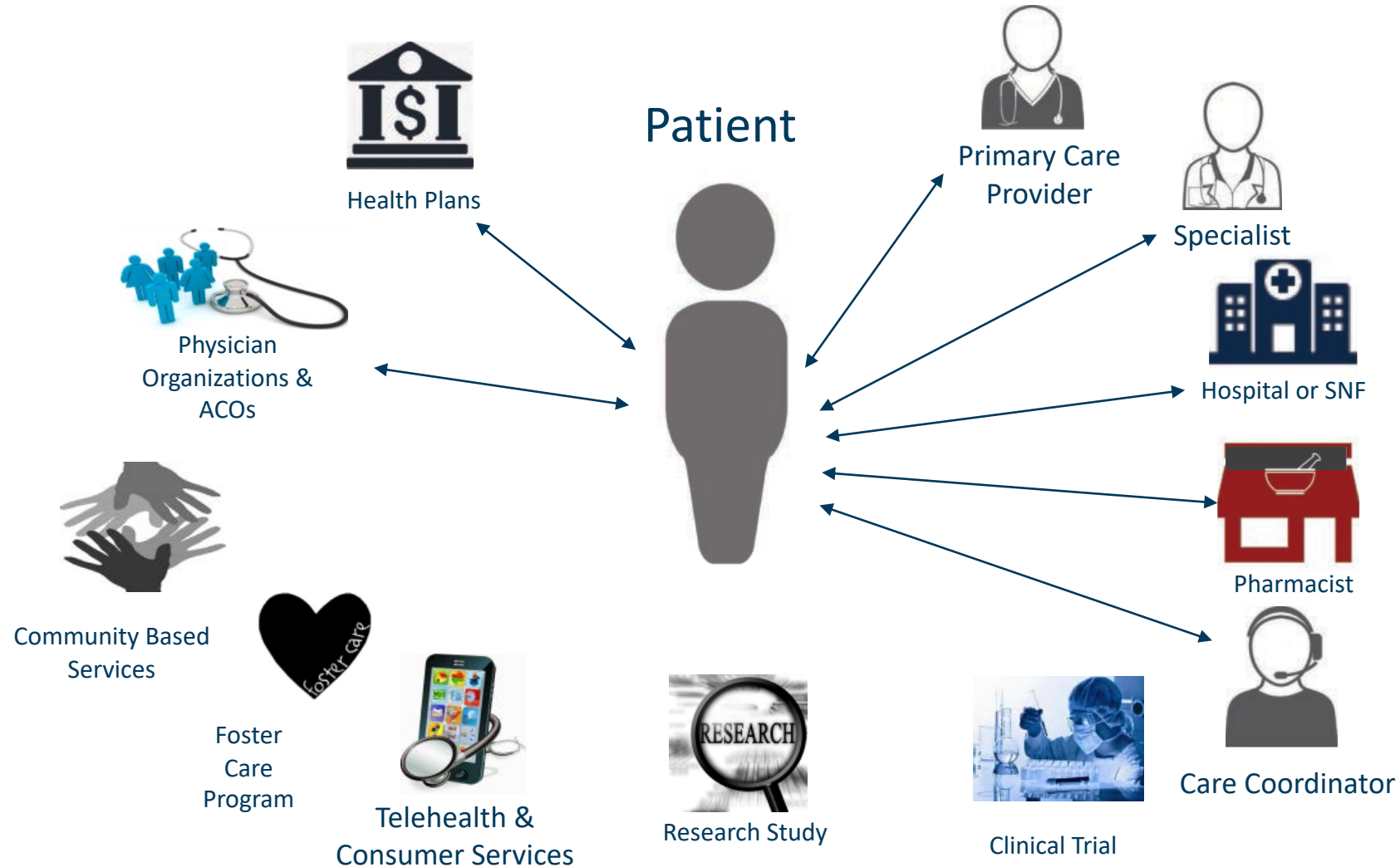
Care Summary "Push" Example

Send Data for Use Case to HIN Entity

CT HIN Entity

Declare linkages

Identity & Care Map

Patient Matching

Provider Info

Provider Directory

Receive Data From HIN Via ID & Care Map plus Provider Directory
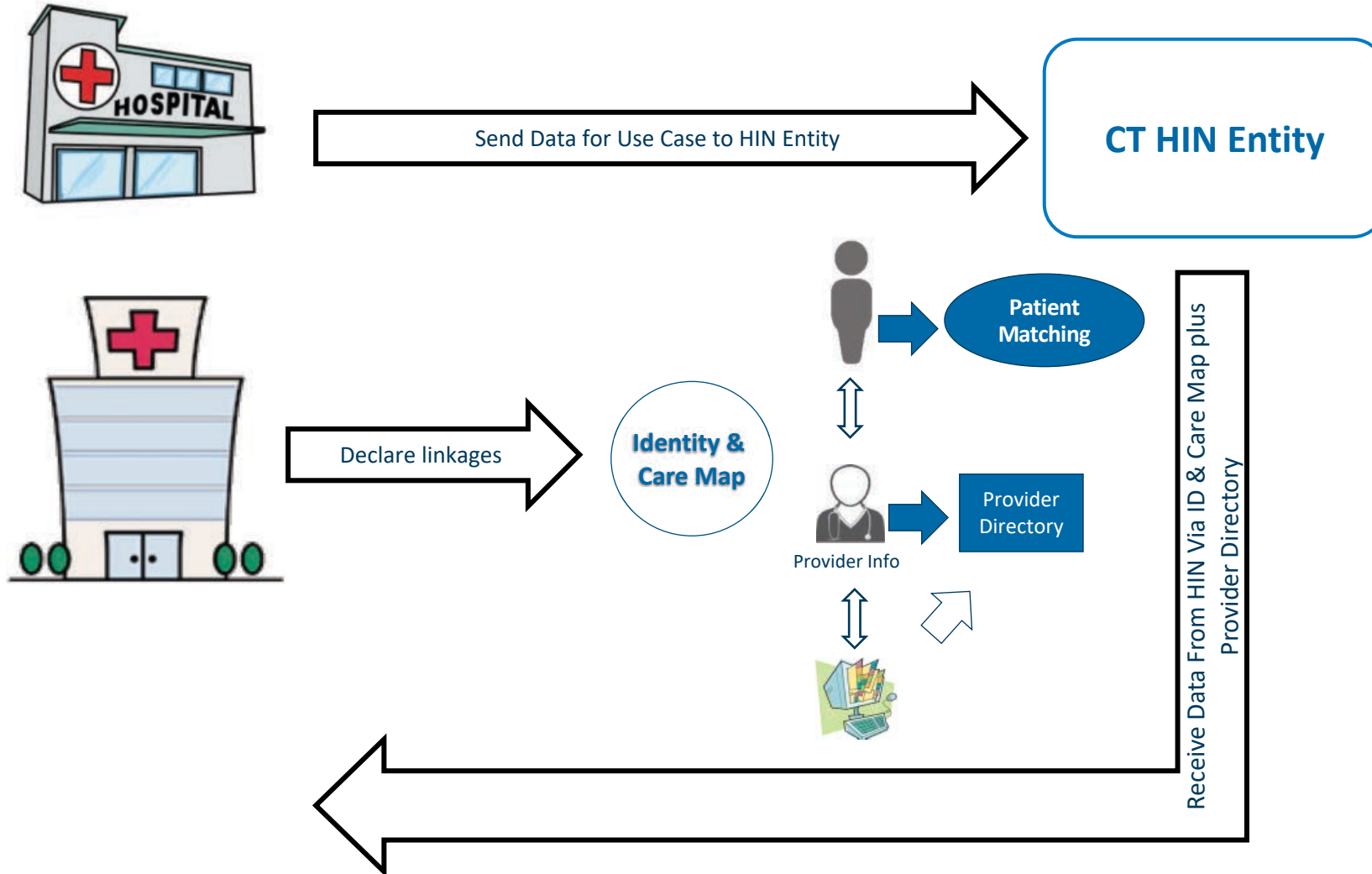
Care Map Enables Statewide Care Coordination

Now Millie's Care Team can be informed of major health events

ID & Care Map Works for "Pull" Too

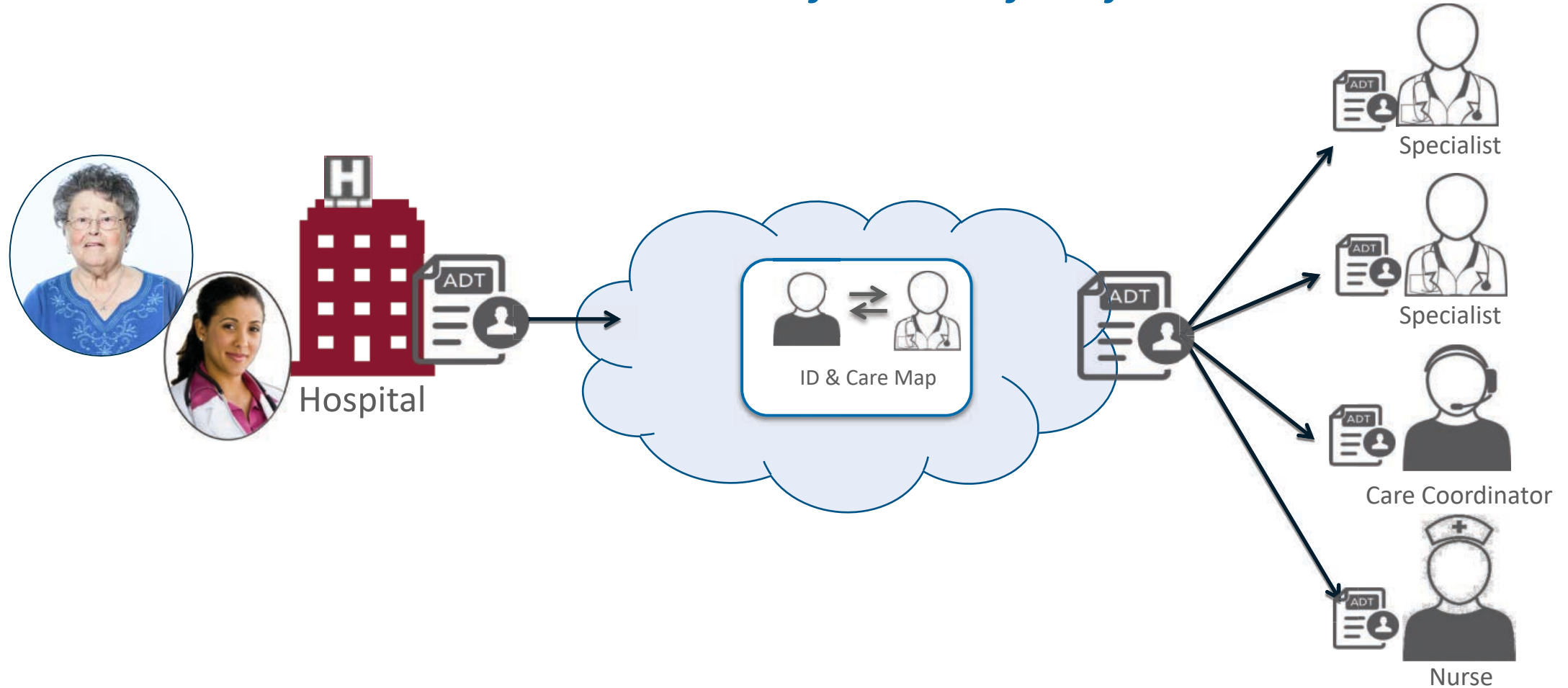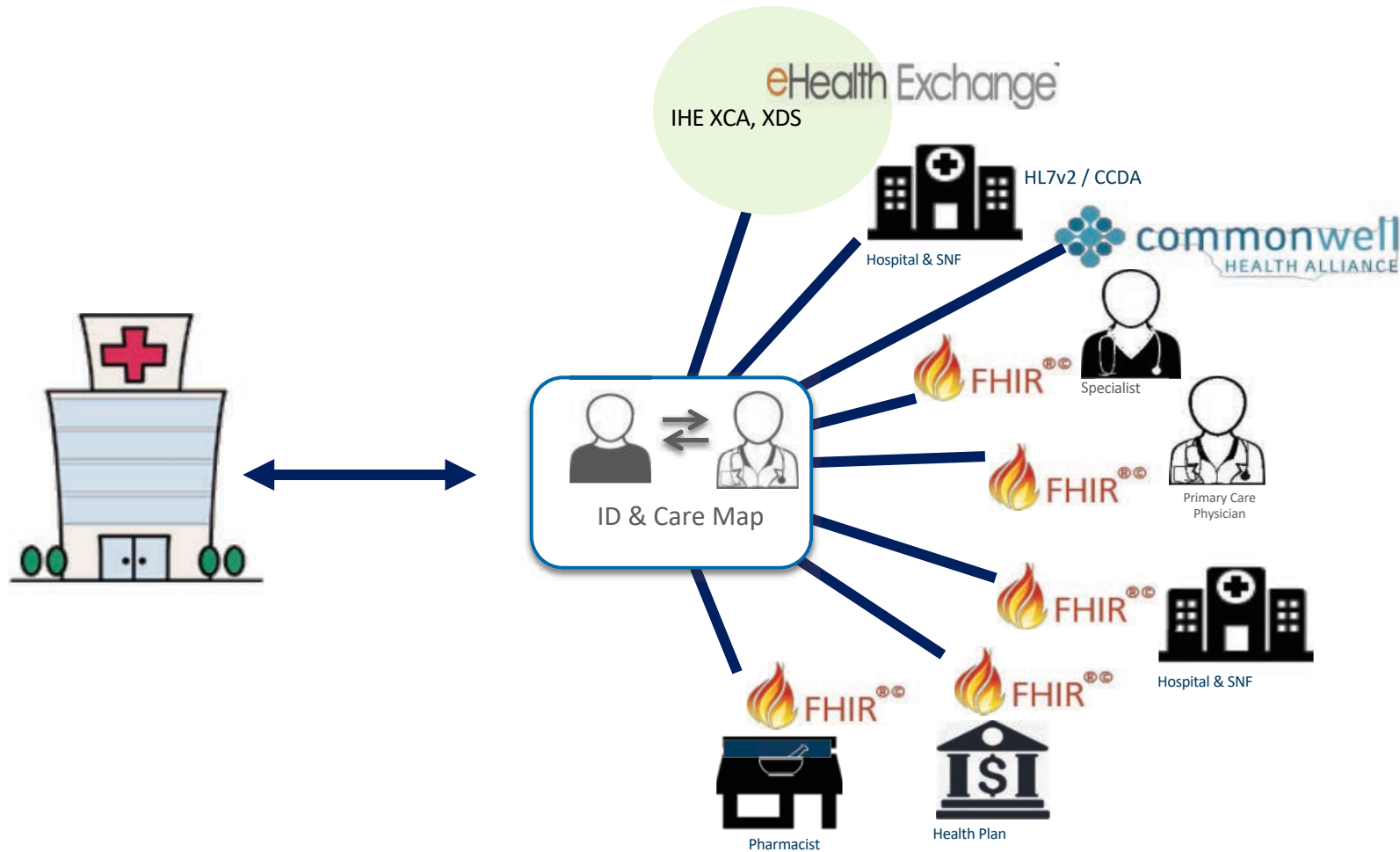eHealth Exchange

IHE XCA, XDS

HL7v2 / CCDA

commonwell HEALTH ALLIANCE

Hospital & SNF

ID & Care Map

FHIR®©

Specialist

FHIR®©

Primary Care Physician

FHIR®©

Hospital & SNF

FHIR®©

FHIR®©

Pharmacist

Health Plan

The Foundation for Other Services

Consumer Access

Query

Care Coordination

Quality Reporting

Public Health

Credentialing

Consent

Push & Alerts

Provider Directory

Identity

Patient Matching

Identity and Care Map
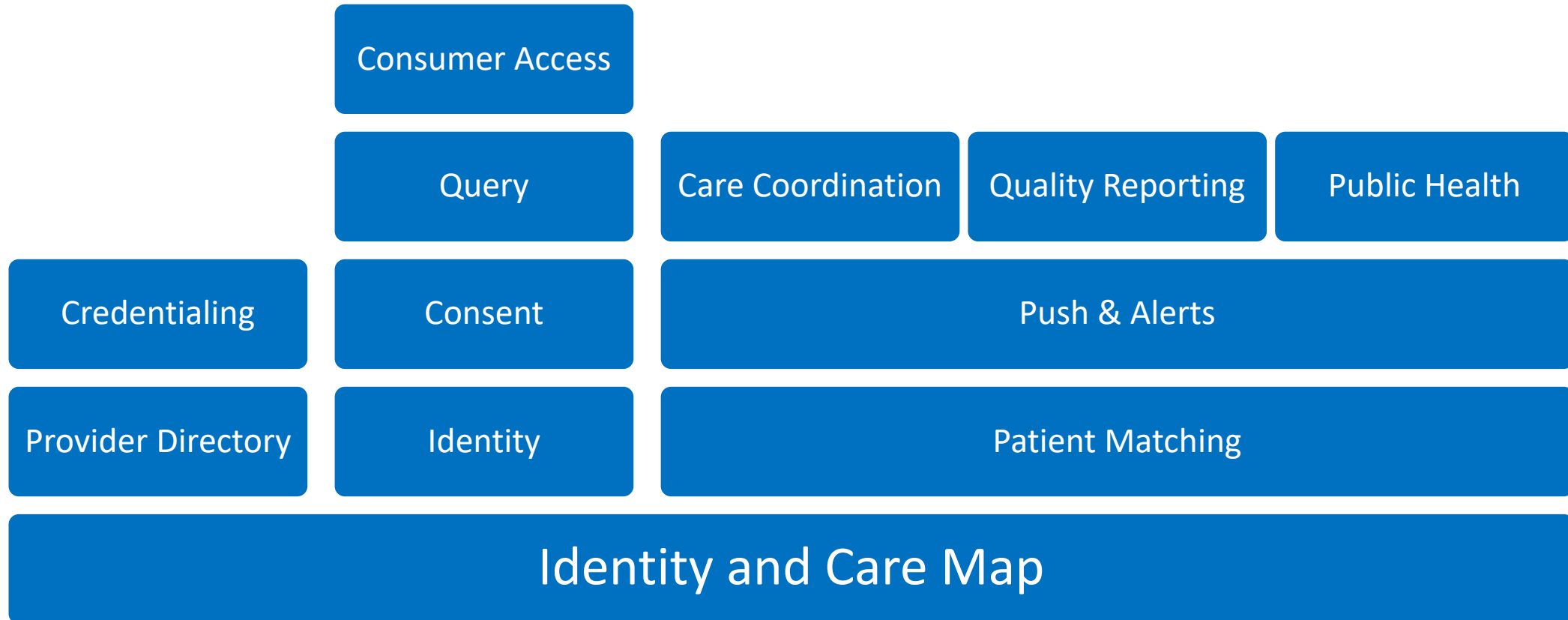
Recommendations to Consider

- Start with push model
- Concentrate initially on the HIPAA chain of trust for TPO as the formal staring place
- Focus on ID and Care Maps
- Build up and manage ID and Care Maps also sets up environment for pull
- Organizing principle of entities that have an individual in common may share data until there is a proactive consent model in place that can manage consent preferences for more advanced use cases

Developing A More Advanced
Data Sharing Policy

- As the information exchange network develops and new use cases are designed, the privacy workgroup could determine additional consent approaches

For example:

- Sensitive or Specially Protected Data
  - CFR 42 Part 2
- New sources of data are added that have additional requirements (e.g. PDMP)
- Research Data

Consent Policy Design Group – Workplan

Meeting Focus	Meeting Objectives
Meeting 1 – 4/9/2019 1pm – 2pm Kickoff and orientation	• Review and discuss project charter and proposed process for achieving desired outcomes • Orientation on relevant policies and procedures and semantic alignment / shared understanding of key terms
Meeting 2 – 4/23/2019 1pm – 2pm Current consent policies	• Establish understanding around current state of consent policies in Connecticut and bordering states • Consider draft language for a HIPAA TPO consent policy for recommendation to Advisory Council
Meeting 3 – 5/7/2019 1pm – 2pm Focus on TPO consent draft	• Review proposed process for the development of a consent policy framework, based on HIE use case requirements • Discuss stakeholder engagement and communication needs
Meeting 4 – 5/21/2019 1pm – 2pm Matching use cases to consent model	• Review and discuss received input from Advisory Council or other stakeholders • Review use cases where individual consent is required by state or federal law, or areas of ambiguity
Meeting 5 – 6/4/2019 1pm – 2pm Use Case A discussion	• Discuss the pros/cons of a statewide consent policy framework vs. HIE Entity consent policy framework to determine scope
Meeting 6 – 6/18/2019 1pm – 2pm Use Case B discussion	• Discuss the various ways that consent could be collected and possible roles for organizations in the consent process • Establish high-level understanding of technical architecture for electronic consent management solutions • Discuss workflows that could provide individuals with information and the ability to manage preferences
Meeting 7 – 7/9/2019 1pm – 2pm Review draft consent framework recommendations – structure and process	• Review and discuss strawman options • Develop draft recommendations for consent policy framework
Meeting 8 – 7/23/2019 1pm – 2pm Vote on draft recommendations	• Finalize and approve recommendations • Discuss stakeholder / general population engagement and communication process

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