Privacy and Consent: Mind the Gaps

the sequoia project

carequality

Panelists

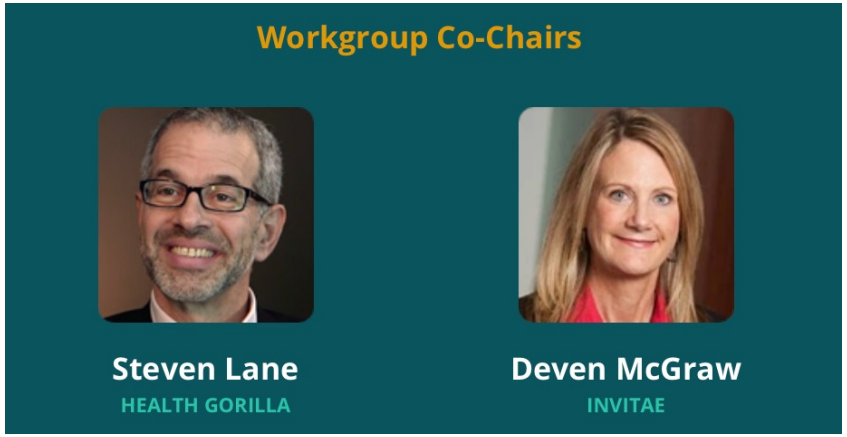
Chantal Worzala
Alazro Consulting
Moderator

Nichole Sweeney
CRISP

Mohammad Jafari
Senior Privacy Consultant

Dr. Steven Lane
Health Gorilla

Privacy & Consent Workgroup



- https://sequoiaproject.org/interoperability-matters/privacy-and-consent-workgroup/
- **Workgroup Purpose:** While information sharing has become the standard in U.S. health care, the inherently sensitive nature of health information creates significant operational challenges for health information exchange. The Workgroup will consider the broader needs of public and private sector stakeholders, while focusing on implementation-level and operational aspects of privacy and consent related activities.

Approach

- **Propelling the Healthcare Community Forward:** This Workgroup will serve as a Community of Practice by convening Sequoia Project's members and subject matter experts focused on information exchange that appropriately protects privacy.

- **Building on the Efforts of Others:** The Workgroup will begin with a landscape review to understand existing efforts and regulations. The intent is to leverage and learn from the efforts of others with a focus on identifying and addressing implementation concerns.

Health Data Sharing is a Shifting Paradigm

Emphasis on privacy and security

Emphasis on data sharing

Dobbs *highlights the tension between privacy and security and data sharing.*

FHIR and Consent

Mohammad Jafari

Consent Resource

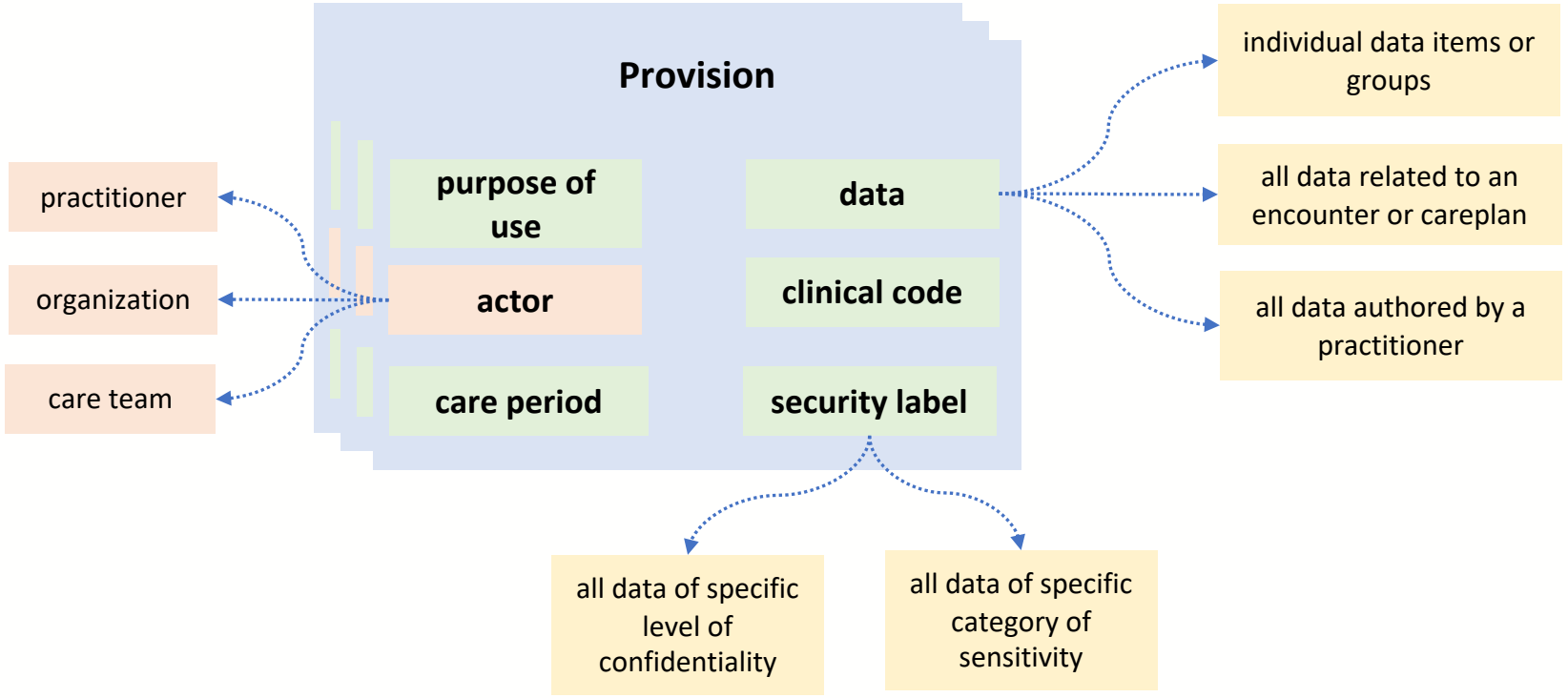
Consent Data Object

- Patient (subject)
- Grantor (patient or patient's representative)
- Grantee (organization or individual)
- Controller (enforcer)
- Period of effectiveness
- Status (draft, active, revoked, etc.)
- Granular Computable Rules

FHIR API

- Create, Retrieve, and Update Consents; Search based on various parameters

Consent Resource: Granular Rules



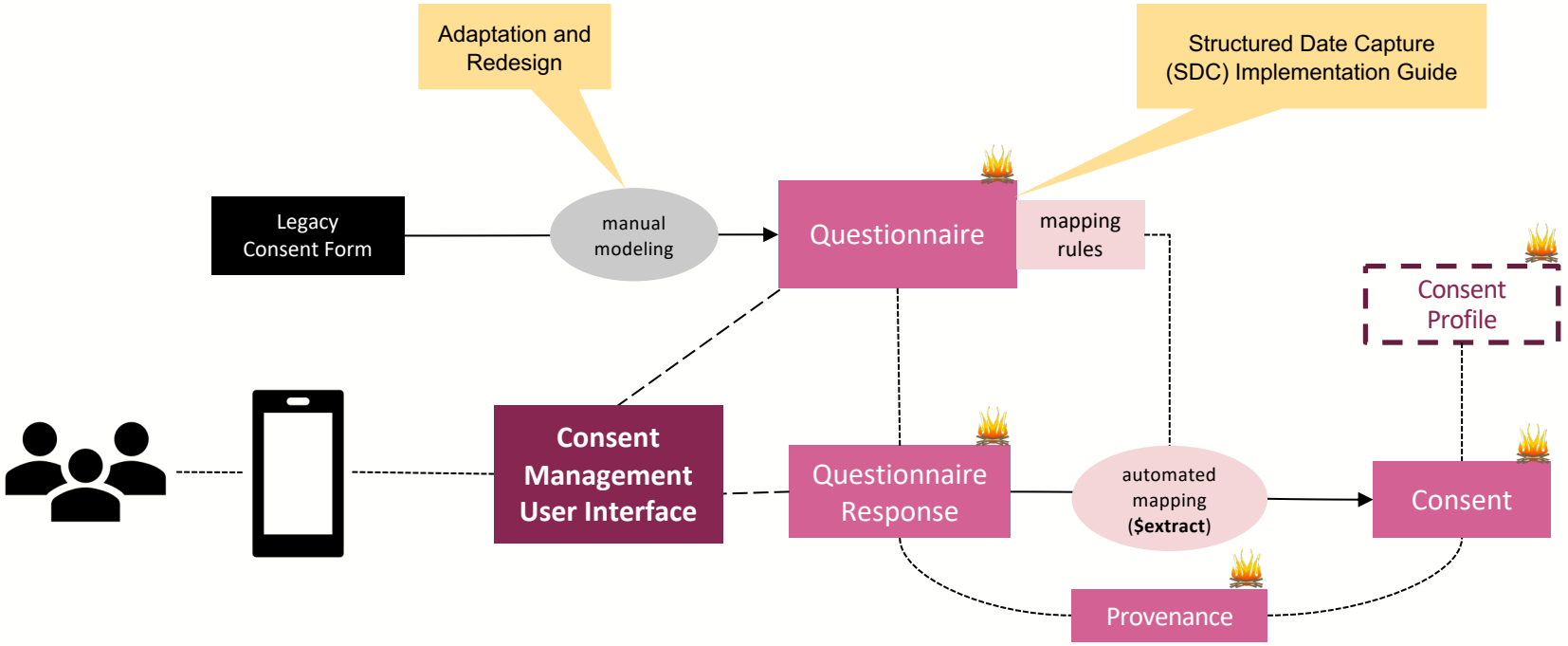
Consent Profiles

- Profiling the Consent resource for specific use cases
  - Required attributes
  - Binding of value sets
  - Transition of the resource based on transactions
- example: IHE Privacy Consent on FHIR (PCF)

Consent Management

- Request for consent
  - Triggered by workflow actor (e.g., clinician, administrative staff, scheduling service)
- Capture consent
  - Collect input from consumer/patient and store it in structured form Transform the input to computable FHIR Consent
  - Record provenance (e.g., link computable consent to the original response)
- Retrieve/Export
  - Human-readable/printable form
- Sign and Activate consent
  - By consumer/patient
- Revoke consent
- Audit
  - events authorized/prohibited by each consent
- Programmatic Access to Consent Management Function (API)
- Notifications
  - Consumer/patient accepts a request for consent
  - Consumer/patient signs and activates the consent
  - Consumer/patient revokes the consent
  - Consent expires
  - Event-based (e.g., patient is discharged)
  - date/time

FHIR Questionnaire and Structured Data Capture



Q&A