Advancing SDOH Interoperability: Enabling Privacy and Consent through Standards and Implementations

Part 2 – Implementers Testing and Leveraging Standards

June 2, 2021
Meeting Etiquette

• Attendees are muted by default. Please keep your phone on mute.

• This webinar is being recorded and will be made available at the Advancing SDOH Health IT Enabled Tools and Data Interoperability Confluence site: https://oncprojecttracking.healthit.gov/wiki/display/ASHIETDI/Advancing+SDoH+Health+IT+Enabled+Tools+and+Data+Interoperability+Home

• The slide deck is accessible under the handouts section of the GoToWebinar widget. It will also be made available at the Confluence site above.

• Use the “Questions” feature for your questions and comments
  • We will be moderating and addressing them at the end of the webinar during the Q&A portion
# Agenda

<table>
<thead>
<tr>
<th>Topic</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening Remarks</td>
<td>Samantha Meklir&lt;br&gt;Office of the National Coordinator (ONC)</td>
</tr>
<tr>
<td>Introduction to Protecting Privacy to Promote Interoperability (PP2PI) Workgroup</td>
<td>Hannah K. Galvin, Chief Medical Information Officer, Cambridge Health Alliance</td>
</tr>
<tr>
<td>Enforcing Patient Consent: A Report from the ONC LEAP Patient Consent Project</td>
<td>Mohammad Jafari, ONC LEAP Project Director, San Diego Health Connect</td>
</tr>
<tr>
<td>Advancing SDOH Interoperability</td>
<td>Jake Thomson, Director of Interoperability, Unite Us</td>
</tr>
<tr>
<td>Privacy in Whole Person Care</td>
<td>Leslie Paith, Product Lead &amp; Mike Wolf, Engineering Lead, NowPow</td>
</tr>
<tr>
<td>SDOH Engagement</td>
<td>Greg White, Security Risk Solutions, Inc.</td>
</tr>
<tr>
<td>Q&amp;A</td>
<td></td>
</tr>
</tbody>
</table>
Opening Remarks

Samantha Meklir
ONC
Introduction to Protecting Privacy to Promote Interoperability (PP2PI) Workgroup

ONC Advancing SDoH Webinar Part 2

Hannah K. Galvin, MD, FAAP, FAMIA
Chief Medical Information Officer, Cambridge Health Alliance
Assistant. Professor of Medicine, Tufts University School of Medicine
Disclosure

Dr. Galvin has no conflicts.
Protecting Privacy to Promote Interoperability Workgroup

- Formed in 2018, formalized in 2020
- Supported by HIMSS, IHE USA and The Drummond Group
- Multidisciplinary workgroup of > 160 industry experts
Stakeholders across the U.S. healthcare ecosystem

- Healthcare Provider Organizations/Institutions
- Professional Societies
- Standards Development Organizations
- Health IT Vendors
- Health Information Exchanges
- Interoperability Frameworks
- Payers
- Government
- Government and Non-Government Contractors
- Privacy Law and Ethics Experts
- Patient Advocates
Nadie

- 31 y/o presents for PCP f/u for depression.
- At previous visit, clinician detected potential red flags of IPV and recommended 3rd party app, “SmartScreen” for screening and education.

- Nadie screened positive for IPV via app.
- FHIR integration pulls score/interpretation discretely into PCP’s EHR.
Nadie

- Provider discusses with patient, documents in visit note.
- Nadie is not ready to leave partner at this time.
- Safety plan discussed.

- Dx of T74.91XA “Unspecified adult maltreatment, confirmed, initial encounter” recorded on problem list to ensure other providers are aware of SDoH concern.
Nadie

- Nadie’s partner, James, is EHR portal proxy.
- She expresses concerns that he could view note, problem list and other data via the portal.
- Provider uses EHR-specific functionality to hide this data from portal.
Nadie

- Nadie’s health insurance is through James’ employer. EOB sent to James includes billing dx T74.91XA.

- Nadie is able to intercept mailing.
Nadie

- In order to fund free services, “SmartScreen” app sells patient data to market research firm.
- Nadie unknowingly agreed to this as part of Terms and Conditions.

- Nadie begins receiving IPV PSA messages to her e-mail address, which James has access to.
- James becomes agitated and violence escalates. Nadie presents to ED unconscious with multiple contusions.
Defining the Problem

Sharing of information private health care information between healthcare providers, organizations/institutions and patients/families can only be accomplished freely when there is agreement on:

- Need for privacy vs. need for patient safety
- How to identify sensitive information
- How to tag sensitive information
- How to protect sensitive information (home record/shared)
- How to display sensitive information
- How to share/re-share sensitive information
Why Are Standards Such A Challenge?

- Many different stakeholders
- Many different types/flows of data (both internal and external)
- Questions of data ownership
- Access control definitions
- Questions of patient safety vs. right to individual privacy
- Development/implementation of standards complex

Industry: “Too big to tackle”
Current State

- Many organizations enable blunt privacy protections to comply with state laws
  - Patients must choose to share ALL or NONE of their data
  - Concern for “data blocking”
  - May be inadvertently producing healthcare disparities
Previous Efforts

- Data Segmentation for Privacy (DS4P) and Consent 2 Share (C2S) adoption as lagged due to:
  - Lack of financial or regulatory stimulus
  - Inability to meet many high-priority clinical use cases
  - Implementation not easily scalable across organizations
  - Issues related to patient safety and usability not adequately addressed by pilots
How we are approaching things differently?

1. Building off of previous work
2. Expanding scope of use cases to more widely encountered situations
3. Cross-industry stakeholder representation
4. Focus on consensus-driven implementation guide as a key deliverable
5. Leveraging advances in technologies such as NLP
Workgroup Deliverables and status

- Develop set of nationally-acceptable use cases
  - Adolescent/reproductive health
  - Geriatric/mental health
  - Adult Social Determinants of Health
  - Maternal/baby

- Draft minimal set of potentially-sensitive data elements

- Standards gap analysis and revision

- Develop consensus-driven guidance
  - Terminology value sets
  - Recommendations for role-based vs. user-based security
  - Visualization of redacted data
  - Utilization of redacted data in decision support
  - Policies/procedures for break-the-glass access to data
Workgroup Structure

Foundational sub-groups

- Clinical
- Usability
- Implementation
- Standards & Terminology
- Policy

Overarching sub-groups

- Patient perspective
- Legal
- Ethics
Progress In 2020 And Beyond

- **May 2020**: Launched PP2PI WG
- **June**: Developed consensus around the WG charter as well as establish logistics.
- **July**: Proposal of WG guiding principles and use cases
- **August**: Proposal for sub-groups and organization to move towards WG deliverables
- **Sept**: Create sub-groups, identify chairs, and subgroup output
- **October**: Sub-group charter and first meetings
- **November**: Early subgroup deliverables
- **December**: Progress towards clinical use cases and other subgroup charters
Clinical team has developed 4 initial use cases.

Finalize SDoH use case with feedback from Gravity Project.

Adjust use cases as needed based on feedback from other subgroups.

S&T builds sensitive data element story around each use case.

Identify/update terminology value set to fit use cases.

S&T work with HL7 Security WG to ballot for standards revision, starting w/ 1 use case.

U&I turn use cases into persona usability pieces and storyboard these.

Develop questions for implementation guidance to prepare for Delphi Method v1.0.

Build basic prototypes for helping advance work towards sandbox-MVP.
Use cases
Standards & terminology
Usability & Implementation

Consensus on Implementation Guidance via Delphi Methodology

Sandbox demonstration
Implementation guide
Real-world demonstration

2022

2023
How to Get Involved

For More Information, Contact:

Serena Mack
Program Administrator
Drummond Group, LLC

serena.mack@drummondgroup.com
hagalvin@challiance.org
Enforcing Patient Consent

Report from the ONC LEAP Patient Consent Project

Mohammad Jafari, Ph.D.
ONC LEAP Consent Project Director, San Diego Health Connect (SDHC)
Patient Consent Challenges

- Patient Consent is often captured in paper form
  - Challenge: searching and retrieval based on metadata

- when it is captured in electronic form, it is often not in an interoperable form (e.g., a PDF attachment)
  - Challenge: consolidation from multiple sources

- when it is captured in standard electronic form, it is often not computable
  - Challenge: automatic enforcement (without manual steps)

- when it is computable, it often only allows for a binary decision
  - Challenge: consents are often reduced to a binary ("share" or "don't share") without allowing more nuanced choices
Goals

Patient Consents that are:

• Interoperable
  • FHIR Consent resource and a standard access API
  • An aggregation service to retrieve applicable consent from all sources

• Computable
  • A consent decision service to parse and process patient consents
  • An API for query/response about consent decisions

• Applicable
  • Different Types of Consent
    • Privacy, Research, Treatment, Advanced Health Directive
  • Proof of concept for various use-cases
    • HL7v2 Exchange, eHealth Exchange, Direct Exchange, FHIR (embedded and proxy)
High Level Architecture
Consent Management Service

A service for patients to create, modify, revoke, and reinstate consents.

demo: https://leap-gui-yop72tkfq-uc.a.run.app
Consent Decision Service

A service to determine whether, in a given context, requested access is permitted or denied and whether any obligations apply

- Consent discovery
- Query processor
  - Query processor,
  - Validation service
  - Provision processor
  - Obligation service
  - Conflict resolution service
- Audit Service
- API interface
  - Clinical Decision Support Hooks & eXtensible Access Control Markup Language (XACML)
Consent Enforcement Service

Individual modules integrating with different application contexts to enforce consent decisions
Consent Enforcement Service

- Capture and report the context of the workflow (a LEAP-CDS query)
- Send the query to the Consent Decision Service
- Receive and process the response
- Apply and enforce the decision in the local environment
  - Block access,
  - Modify the data based on obligations

examples: https://github.com/sdhealthconnect/leap-demos
Thank You

Contact Me At
Mohammad Jafari, Ph.D.
jafarim@gmail.com
Unite Us: Advancing SDOH Interoperability

Jake Thomson, MBA
Director of Interoperability, Unite Us
Roadmap for Today

- Brief Overview of Unite Us
- Unite Us Interoperability and Demonstration of HL7 FHIR SDOH Clinical Care IG
- Protecting Sensitive Data & DS4P
Unite Us: Brief Introduction
The only end-to-end solution for social care

Creating an efficient system of care within the community to improve health

- Predict needs
- Serve the individual
- Invest in social care
- Enroll in services
- Measure network impact
The pillars that enable impactful social care coordination

Protect data

- Securely sharing client level information is **vital** to connecting health and social care.

Integrate systems

- Create one seamless experience across the community with leading **practices** and **technology** for interoperability.

Evaluate impact

- Identify and prove the **real-world impact** of social care for every step of the journey.
Unite Us
Interoperability & FHIR Implementation
# Unite Us Interoperability to present day: Person-centric community exchange

<table>
<thead>
<tr>
<th>Year</th>
<th>Milestones</th>
</tr>
</thead>
</table>
| 2013 | • Company founded  
       • Unite Us Platform first developed as person-centric community care coordination network |
| 2018 | • First SMART on FHIR-based exchange with leading EHR |
| 2019 | • NC statewide resource directory as public utility, demonstrating OpenReferral-based ingestion process |
| 2020 | • SMART on FHIR exchange live with thousands of users across the USA  
      • Investment in Unite Us Interoperability as distinct product organization with focus on advancing secure, standards-based exchange for health-social care team |
| 2021 | • 300% + YTD increase in interoperability product partnerships with leading platforms in both health and social care and adopt FHIR  
     • Implementation of new advanced privacy features  
     • Development of first school-based use case with Student Information System  
     • Implementation of HL7 SDOH Clinical Care Implementation Guide |
| 2022+ | • Scaling FHIR-based exchange with more partners and organizations  
       • Ongoing demonstration of new use cases for standards-based exchange (e.g. Bidirectional Screenings; Unite Us Payments Use Cases) |
Demonstration of HL7 FHIR® SDOH Clinical Care Implementation Guide

Community Organizations

- Unite Us Web Application
  - Send and Receive Referrals
  - Gain Consent
  - Screen
  - Track Referral Status
  - Track Client Outcomes

Resource Directory

Vendor-specific specifications

OpenReferral/HSDS

External Sources

Data
Demonstration of HL7 FHIR® SDOH Clinical Care Implementation Guide

Community Organizations
- Unite Us Web Application
  - Send and Receive Referrals
  - Gain Consent
  - Screen
  - Track Referral Status
  - Track Client Outcomes

Community, payer & health platforms
- SMART on FHIR®
- EHR
- SMART on FHIR® compliant EHR
- Case Management
- SMART on FHIR® compliant Case Management

External Sources
- OpenReferral/HSDS
- Vendor-specific specifications

Resource Directory
- Data

Unite Us Web Application
- Send and Receive Referrals
- Gain Consent
- Screen
- Track Referral Status
- Track Client Outcomes

Smart on FHIR® compliant Case Management

Smart on FHIR® compliant EHR

EHR

Case Management

Community, payer & health platforms

Community Organizations

External Sources

Resource Directory

OpenReferral/HSDS

Vendor-specific specifications
Interoperability takes industry focus

Accelerating Adoption

- Vendor adoption will be critical, especially in social domains
- Unite Us favors a programmatic approach – **How can the industry create programs that incentivize care coordination, payment and focused technology demonstration?**
  - Examples: Innovative Care for Kids (CMMI); NC Healthy Opportunities (1115 Waiver)

Incremental Approaches to Demonstration of Standards

- **SDOH technology is not a fixed space, many different solutions**
  - Resource data ("the phonebook") can become more of a public utility
  - Advanced exchange requires person-centricity
- **Crawl, Walk, Run:** smaller organizations will need help

Interagency Collaboration on Data Capture Standardization

- Recommend **more inter-agency collaboration** to reduce overlapping data collection, especially for community organizations
Protecting Sensitive Data & DS4P
We enable secure, meaningful data exchange across sectors.

Certifications
- HITRUST
- SOC 2 Type 2
- NIST

Regulations
- HIPAA
- 42 CFR Part 2
- FERPA

Access & Permissions
- Organization, program, and user-level roles and permissions to satisfy HIPAA/NIST standards
- Personalized onboarding for each partner
- BAAs, where applicable

Infrastructure
- Hosted via AWS’ fully certified and compliant cloud servers
- Native permissions engine
- Data secured and encrypted at rest and in transit
- Audited technical, physical, and administrative safeguards
- Annual penetration testing and audit by third party
- Continuous vulnerability monitoring and alerting
- USA based data centers
Consent

Unite Us’ consent is obtained once and saved in the client record before the first referral is created. The Unite Us consent outlines the ways in which client information may be shared in order to connect them to services.

- Compliant with Health Insurance Portability and Accountability Act (HIPAA) requirements, including Administrative, Technical, and Physical Safeguards, and Breach Notification Rules
- Sensitive information (e.g. SUD treatment information) is restricted from view based on organizational and user level permission configurations
- All data is encrypted in transit and at rest, with continuous vulnerability monitoring

Housing

Client

Transportation

Behavioral Health

Legal Services

The Office of the National Coordinator for Health Information Technology
Unite Us is well positioned to support privacy standards, such as DS4P

**DS4P Standard designed to prevent further disclosure of sensitive information**

- Offers segmentation at multiple levels
  - Document
  - Section
  - Data Element
- Generally implemented for CCDA-based exchange
- Adoption still nascent

**Unite Us well-positioned to support sensitive information standards**

- Unite Us already segments data within care coordination platform in this way
  - Sensitive information automatically limited to the sender and the recipient
  - Subject to the individual’s consent
- Generally focused on FHIR-based exchange
  - Respects our permission engine
  - Support for consent FHIR Resource
Connect with Unite Us

www.UniteUs.com

Jake Thomson
Director of Interoperability
jake@uniteus.com

Follow Us

LinkedIn  Facebook  Instagram  Twitter
Privacy in Whole Person Care

Leslie Paith, MPH, Product Lead and Mike Wolf, Engineering Lead
NowPow
Whole person care
Whole communities

NowPow is a personalized community referral platform that powers communities with knowledge

Sharing information is core to what we do
  • 3 types of referrals with varied levels of info sharing
  • Tailored interventions and network design
  • Workflow privacy features
Protecting Sensitive Information is Paramount

We believe:

• It’s more than compliance with regulation; it’s about transparency and respect for the person being served
• Ambiguity around regulations and lack of granular privacy controls leads to unnecessary information restriction, creating disparities and inequities for those with complex needs
• We must meet today’s demands with solutions that support individual choice, regulatory compliance, and tiered visibility
• We must also drive collaboration to implement and adopt standards so that information sharing is easy across systems
NowPow Provides Enhanced Privacy

Multi-dimensional approach to ensuring privacy across use cases

**Role based access control**
- Separate roles for PII/PHI, referrals, screening, and reporting
- Network providers only see longitudinal records for people they’re working with

**Flexible consent options**
- Consent from source system or in NowPow
- Simple verbal consent confirmation
- Signature consent with custom content and electronic capture
- Auto-enforcement for expiration and revocation

**Advanced workflow configurations**
- 42 CFR Part 2 disclosure notice
- Dynamic listing of referral partners in consent form to align w/ state mental health privacy law

**Sensitive service types**
- Sensitive service type referrals excluded from longitudinal record
- Configurable to meet intervention
- User has flexibility to make any referral sensitive to respect the individual
Complex Technical Design Required to Meet Today’s Privacy, Transparency and Data Sharing Needs

A multi-tenant, separate database data architecture keeps source system data private. Consent capture, privacy and data-sharing policies configured at customer level.

- User confirms point-in-time data sharing via referral process
- Integrated patient digital consent enables data sharing
- Coordinated referral networks with identity resolution share screenings and referrals across tenants using configured privacy settings
- Our rich set of FHIR APIs enable data sharing, but real interoperability requires adoption of consent and privacy standards
Multiple Standards have to Align to Create the Complete Infrastructure

A coordinated system for information exchange with FHIR, Gravity, DS4P, HEART, and SMART on FHIR is possible

- FHIR + DS4P enables clinical providers to safely share data
- Gravity + FHIR + DS4P allows referral platforms and CBOs to exchange data with privacy restrictions and respect clinical data sharing regulations
- HEART + SMART on FHIR allows patients to control and configure policies to protect the privacy of their personal data
- Multiple stakeholders need to align to create this ecosystem
Our Vision

• Create a privacy infrastructure and automate workflows to meet regulations and respect individual privacy so that information sharing is easy

• The person is empowered with transparency and the ability to authorize information sharing at key events in their care journey and on-demand

• Maria’s experience in our vision:

  Maria wants her need for immigration services private; she places controls on this specific information

  Sharing of her immigration and behavioral health information triggers her authorization automatically, minimizing user burden

  Maria decides to removes access from an organization where the service was unsuccessful
Contact Us

Leslie Paith, MPH
leslie.paith@nowpow.com
www.linkedin.com/in/lesliepaith/

Mike Wolf
mike.wolf@nowpow.com
www.linkedin.com/in/mikedwolf/
Opportunities to Engage

Greg White
Security Risk Solutions, Inc.
Engaging in Enabling SDOH Privacy and Consent through Standards Development

• HL7 Security Work Group
  • Main call is on Tuesdays 3 – 4 PM ET
  • https://us02web.zoom.us/j/82546740051?pwd=WIZwN3BzMWdOUitXS0tmTjVnOTHhUT09
  • Meeting ID: 825 4674 0051
  • Passcode: 712852

• HL7 Patient Care SDOH Clinical Care FHIR IG Work Group
  • https://confluence.hl7.org/display/GRAV/FHIR+IG+Work+Group+Meetings#FHIRIGWorkGroupMeetings

• HL7 Community Based Care and Privacy (CBCP) Workgroup
  • Tuesdays 12:00 – 1:00 PM ET
  • https://us02web.zoom.us/j/89234543086?pwd=anE3djgyQXFYbkFYTEZCNVBPyVzZz09
  • Meeting ID: 892 3454 3086
  • Passcode: 873496

• HL7 Work Groups Call Information
  • http://www.hl7.org/concalls/CallDirectory.aspx

• Kantara User Manager Access (UMA) Work Group
  • https://kantarainitiative.org/groups/user-managed-access-work-group/
Engaging in Enabling SDOH Privacy and Consent Projects and Testing

• Join the Gravity Project
  • [https://confluence.hl7.org/display/GRAV/Join+the+Gravity+Project](https://confluence.hl7.org/display/GRAV/Join+the+Gravity+Project)

• Join the Protecting Privacy to Promote Interoperability Work Group
  • Contact Serena Mack at serena.mack@drummondgroup.com

• Participate or Observe Connectathon Testing
  • HL7 May 2021 Connectathon SDOH Clinical Care IG Track Report Out with ZeOmega – Aunt Bertha Demo Recording [https://hl7.org.zoom.us/rec/play/EODqCguvS1duNorPUHfNREs1hB1hA_HY2RfEzsOgmj1hMm2S7xqncVPtOThBbVO9bAPz4DBpwmnxqP-K.Gt58S4rm5Pn4qEkL?startTime=1621452832000](https://hl7.org.zoom.us/rec/play/EODqCguvS1duNorPUHfNREs1hB1hA_HY2RfEzsOgmj1hMm2S7xqncVPtOThBbVO9bAPz4DBpwmnxqP-K.Gt58S4rm5Pn4qEkL?startTime=1621452832000)

  • Upcoming Connectathons

• Consent Management, Decision and Enforcement Services Testing Leads
  • Duane Decouteau ddecouteau@saperi.io, Mohammad Jafari jafarim@gmail.com

• SDOH Clinical Care IG Testing Leads
  • Bob Dieterle rdieterle@enablecare.us, Corey Smith corey.smith@ama-assn.org, Monique van Berkum Monique.VanBerkum@ama-assn.org
Thank you for joining!