



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

Part 2 – Implementers Testing and Leveraging Standards

June 2, 2021

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The Office of the National Coordinator for  
Health Information Technology



## 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):  
<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

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



# Opening Remarks

**Samantha Meklir**

ONC

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# 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

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## Disclosure

Dr. Galvin has no conflicts.



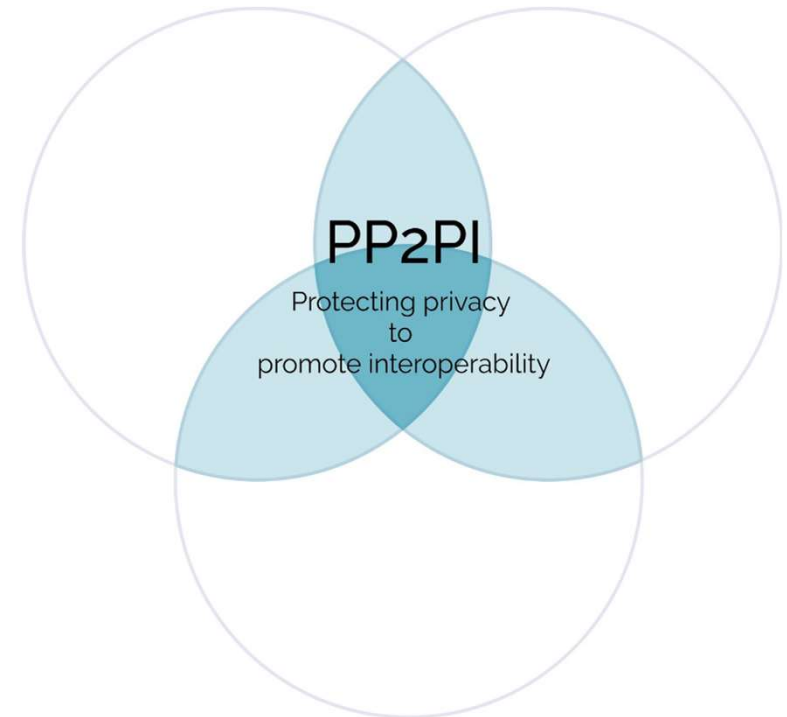
## Protecting Privacy to Promote Interoperability Workgroup

- 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 3<sup>rd</sup> 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?

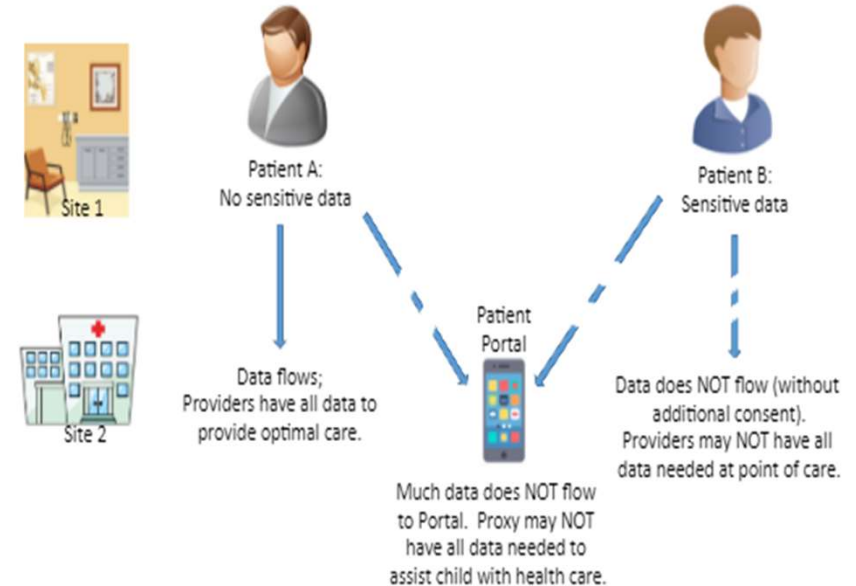
- Many different stakeholders
- Many different types/flows of data (both internal and external)
- Questions of data ownership
- Access control definitions
- Questions of patient safety vs. right to individual privacy
- Development/implementation of standards complex

**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



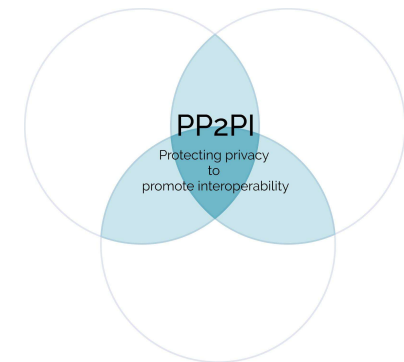


## Previous Efforts

- 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



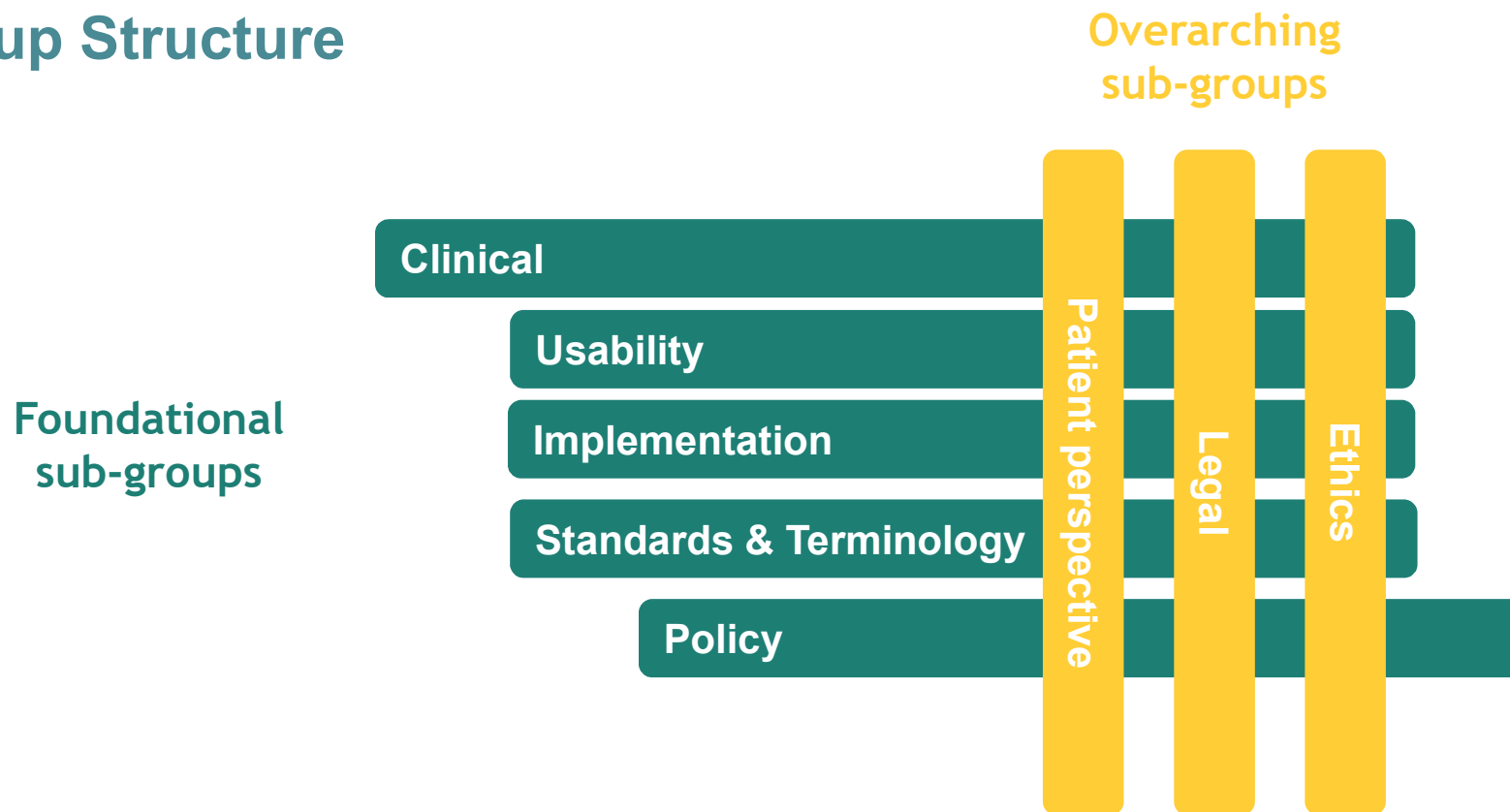
## Workgroup Deliverables and status

- 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

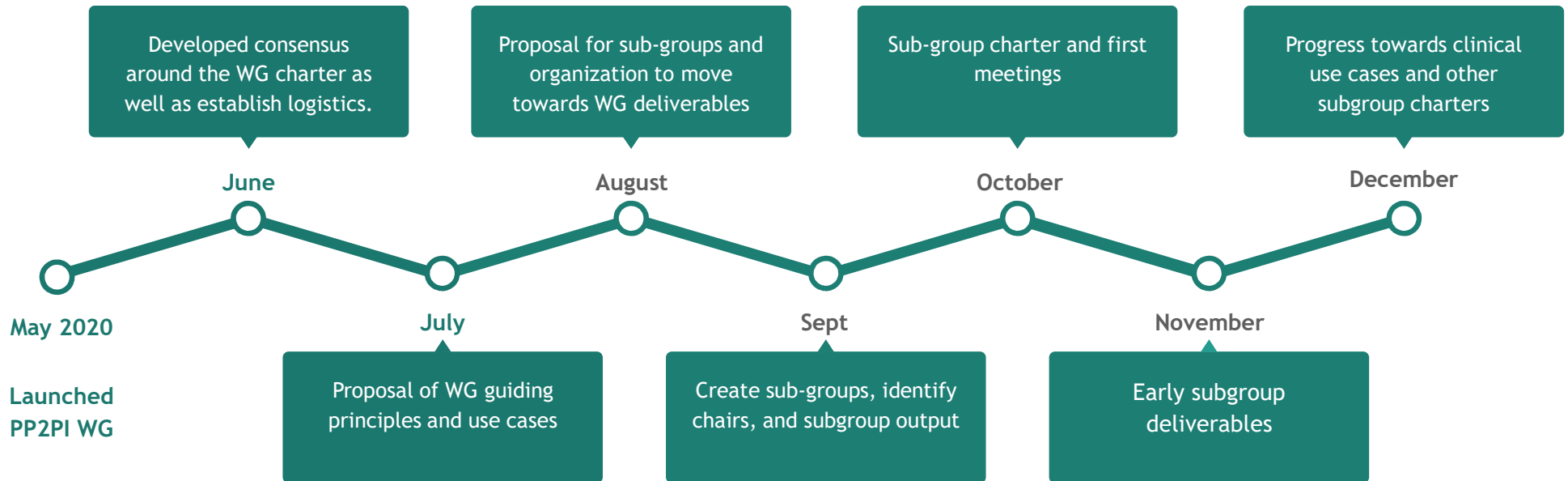




# Workgroup Structure



# Progress In 2020 And Beyond

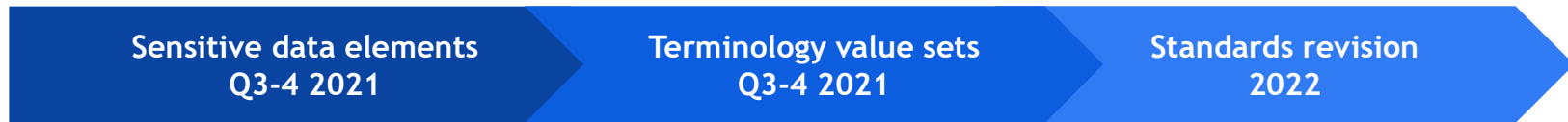




Clinical team has developed 4 initial use cases

Finalize SDoH use case with feedback from Gravity Project

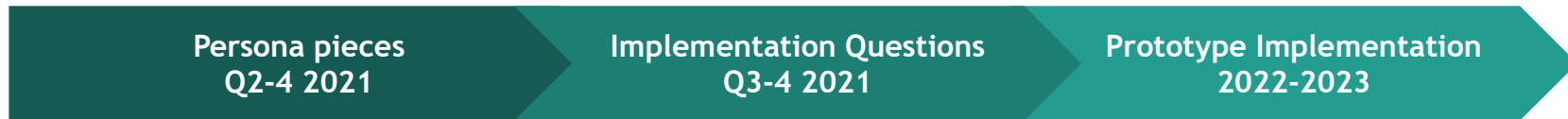
Adjust use cases as needed based on feedback from other subgroups



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

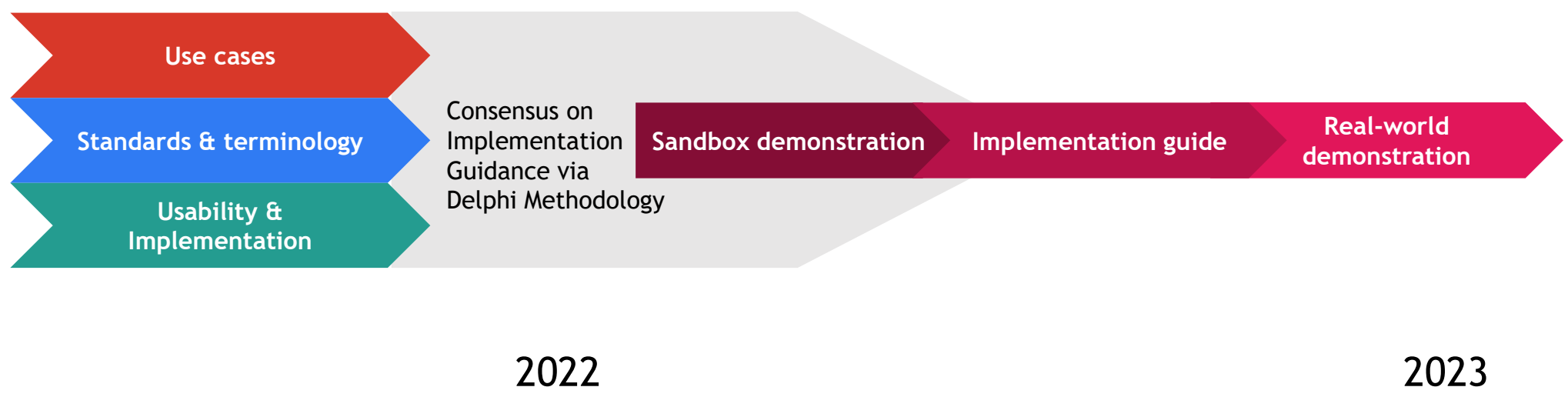


U&I turn use cases into persona usability pieces and storyboard these

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

Build basic prototypes for helping advance work towards sandbox-MVP



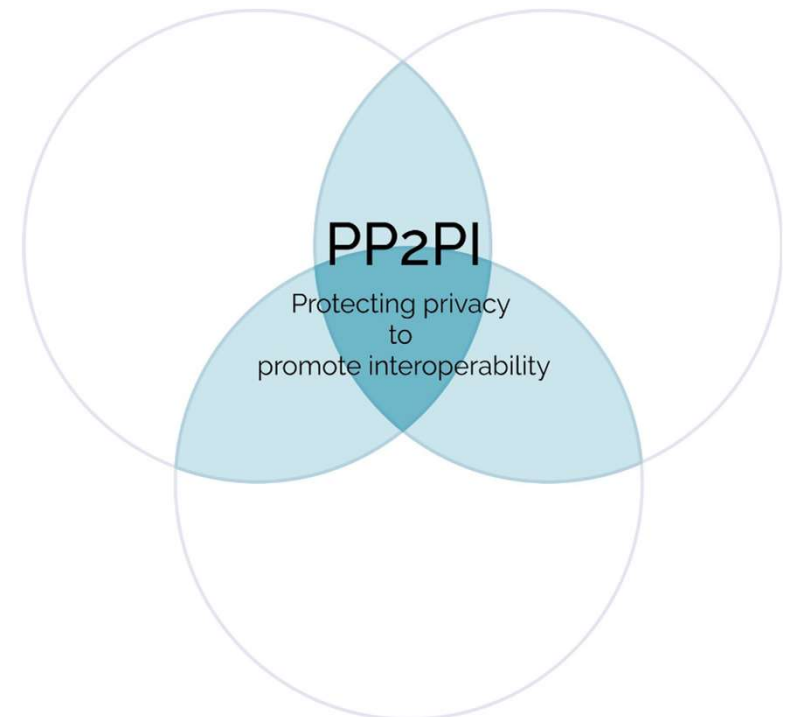


# How to Get Involved

For More Information, Contact:

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Drummond Group, LLC

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[hagalvin@challiance.org](mailto: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)

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## Patient Consent Challenges

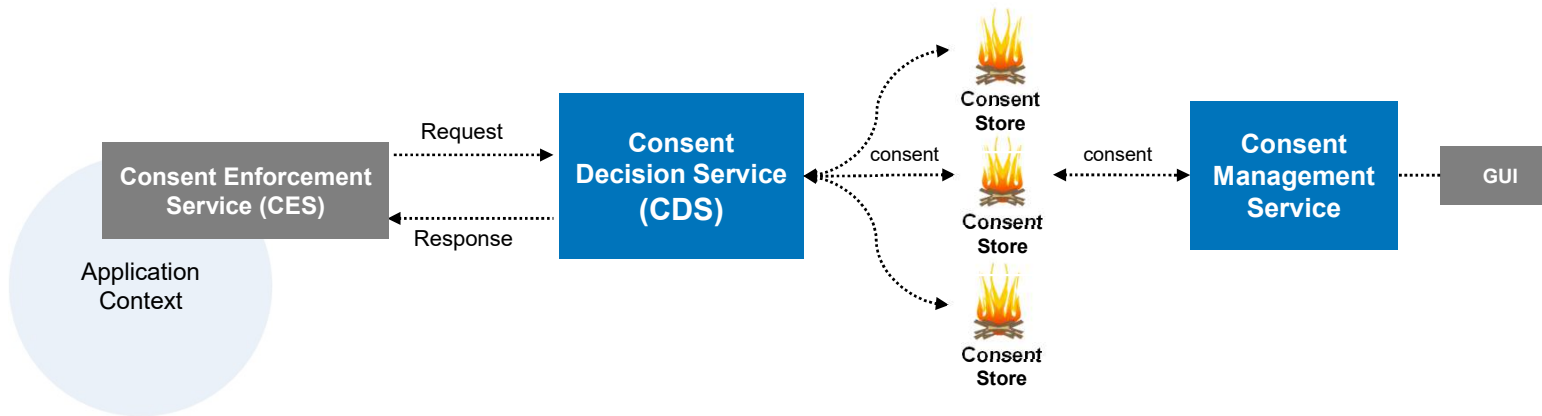
- Patient Consent is often captured in paper form
  - Challenge: searching and retrieval based on metadata
- when it is captured in electronic form, it is often not in an interoperable form (e.g., a PDF attachment)
  - Challenge: consolidation from multiple sources
- when it is captured in standard electronic 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:

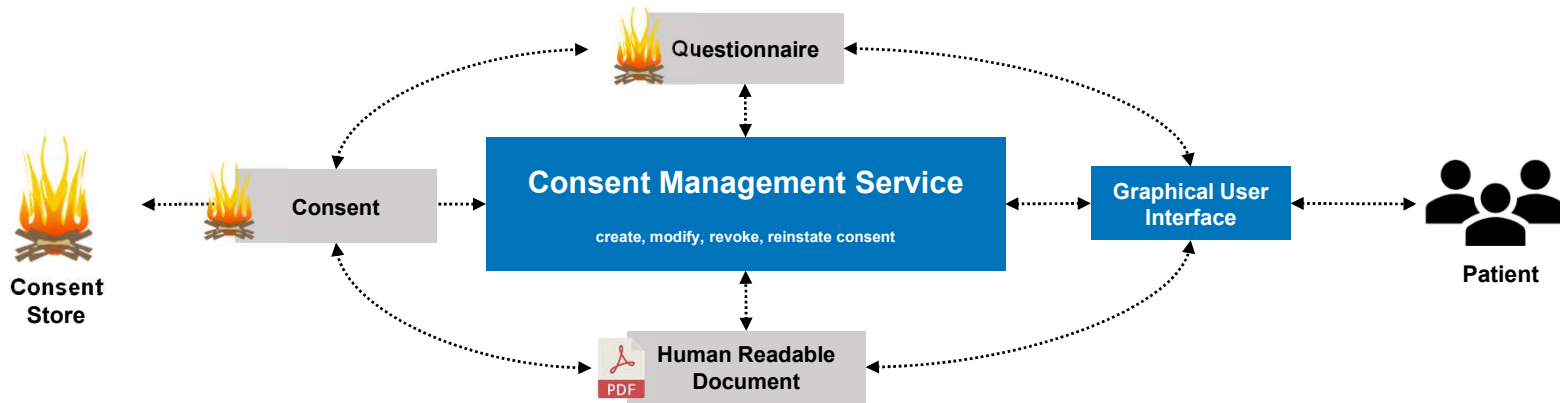
- **Interoperable**
  - FHIR Consent resource and a standard access API
  - An aggregation service to retrieve applicable consent from all sources
- **Computable**
  - A consent decision service to parse and process patient consents
  - An API for query/response about consent decisions
- **Applicable**
  - 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.



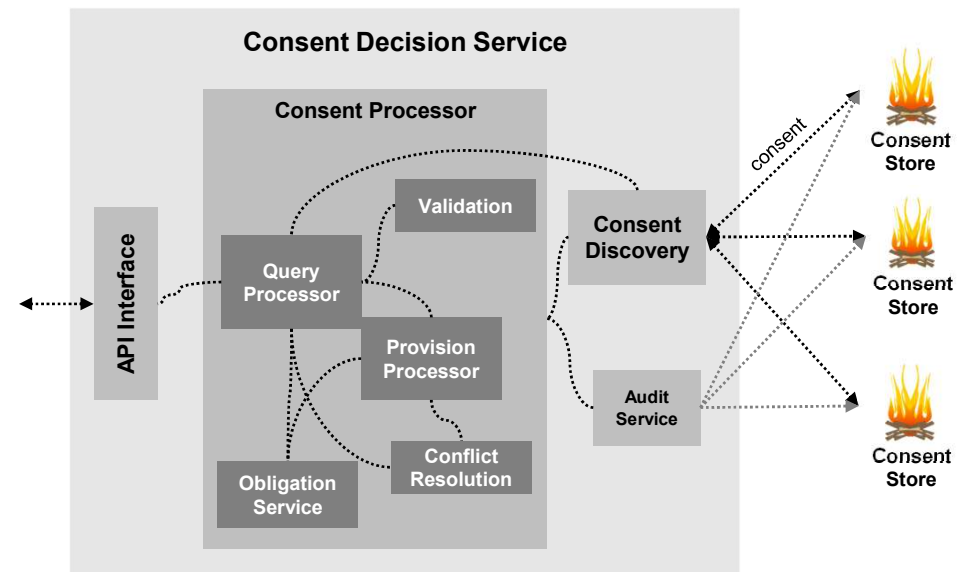
demo: <https://leap-gui-yop7t2tkfq-uc.a.run.app>

Custodian	Recipient	Effective Date	Expires On
Mariposa Community ...	HealthCurrent	Nov 01, 2019	Jan 01, 2022
		Jan 01, 2021	Jan 01, 2031
		Feb 17, 2021	Feb 17, 2022
		Feb 19, 2021	Feb 19, 2026
		Feb 19, 2021	Feb 19, 2022
		Feb 22, 2021	Feb 22, 2022
		Feb 22, 2021	Feb 22, 2022

## Consent Decision Service

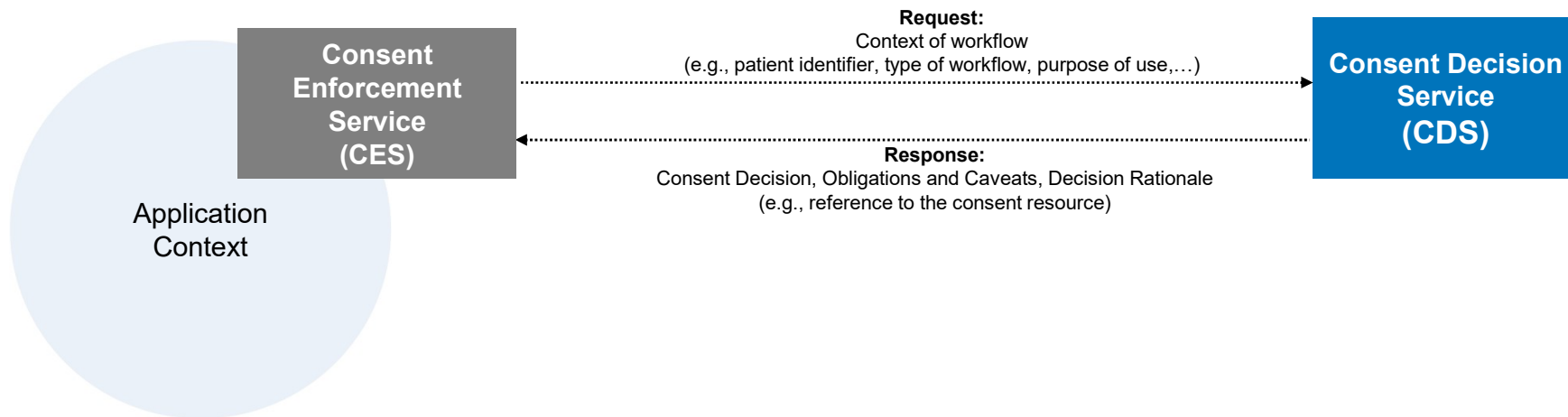
A service to determine whether, in a given context, requested access is permitted or denied and whether any obligations apply

- 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)*



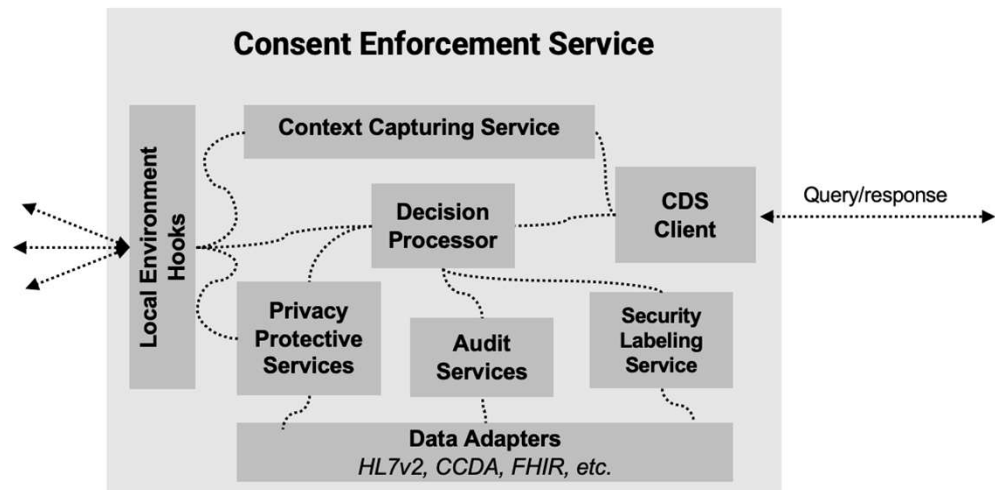
## Consent Enforcement Service

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.  
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# Unite Us: Advancing SDOH Interoperability

**Jake Thomson, MBA**

Director of Interoperability, Unite Us

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## Roadmap for Today

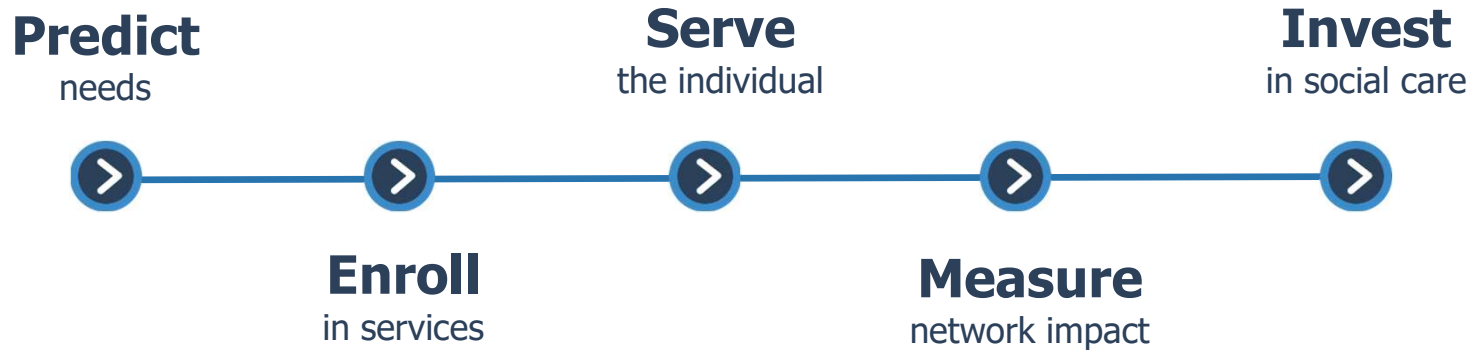
- Brief Overview of Unite Us
- Unite Us Interoperability and Demonstration of HL7 FHIR SDOH Clinical Care IG
- Protecting Sensitive Data & DS4P



# 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



# 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

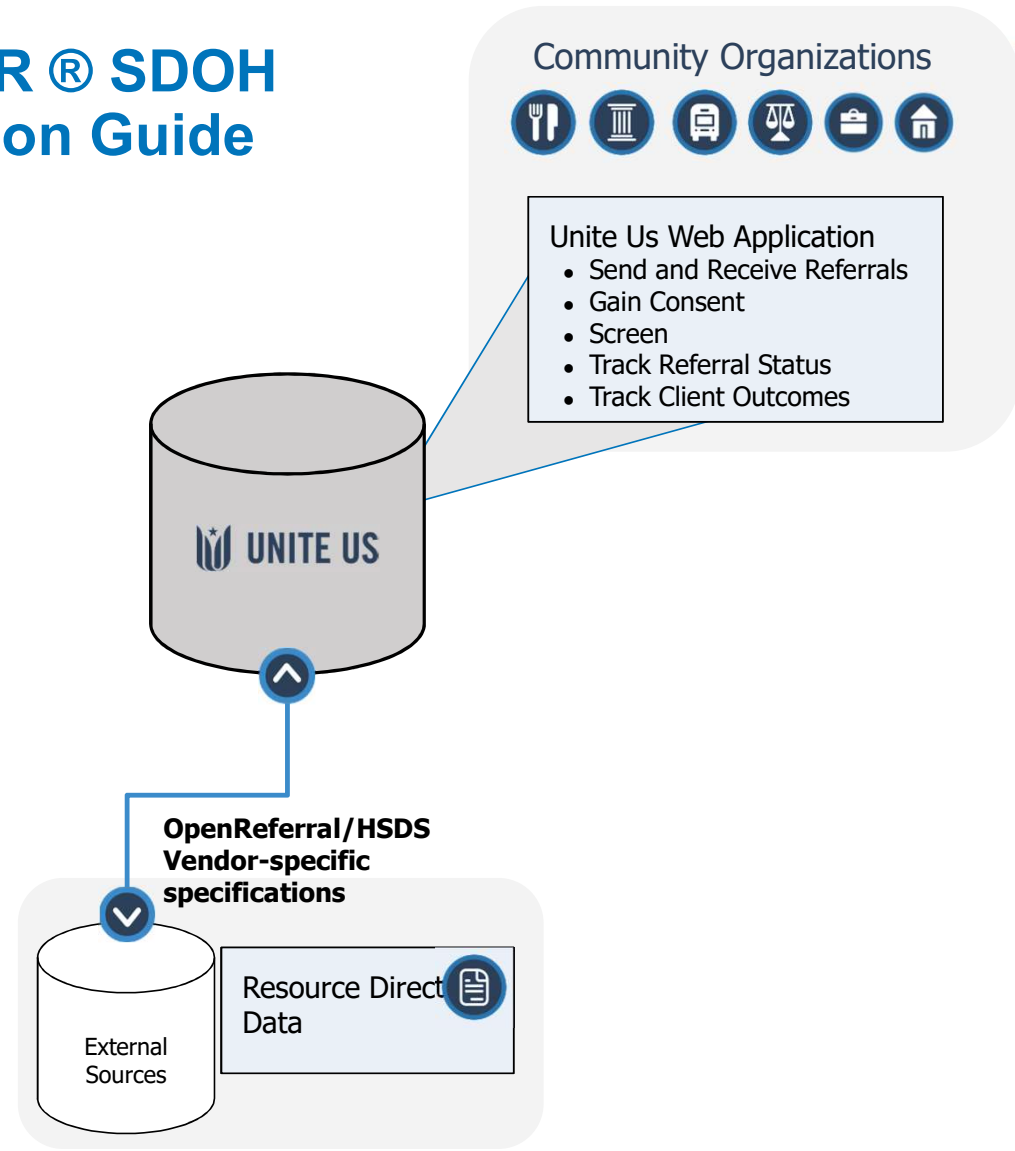
## Unite Us Interoperability to present day: Person-centric community exchange

Year	Milestones
2013	<ul style="list-style-type: none"> <li>• Company founded</li> <li>• Unite Us Platform first developed as person-centric community care coordination network</li> </ul>
2018	<ul style="list-style-type: none"> <li>• First SMART on FHIR-based exchange with leading EHR</li> </ul>
2019	<ul style="list-style-type: none"> <li>• NC statewide resource directory as public utility, demonstrating OpenReferral-based ingestion process</li> </ul>
2020	<ul style="list-style-type: none"> <li>• SMART on FHIR exchange live with thousands of users across the USA</li> <li>• Investment in Unite Us Interoperability as distinct product organization with focus on advancing secure, standards-based exchange for health-social care team</li> </ul>
2021	<ul style="list-style-type: none"> <li>• 300% + YTD increase in interoperability product partnerships with leading platforms in both health and social care and adopt FHIR</li> <li>• Implementation of new advanced privacy features</li> <li>• Development of first school-based use case with Student Information System</li> <li>• Implementation of HL7 SDOH Clinical Care Implementation Guide</li> </ul>
2022+	<ul style="list-style-type: none"> <li>• Scaling FHIR-based exchange with more partners and organizations</li> <li>• Ongoing demonstration of new use cases for standards-based exchange (e.g. Bidirectional Screenings; Unite Us Payments Use Cases)</li> </ul>

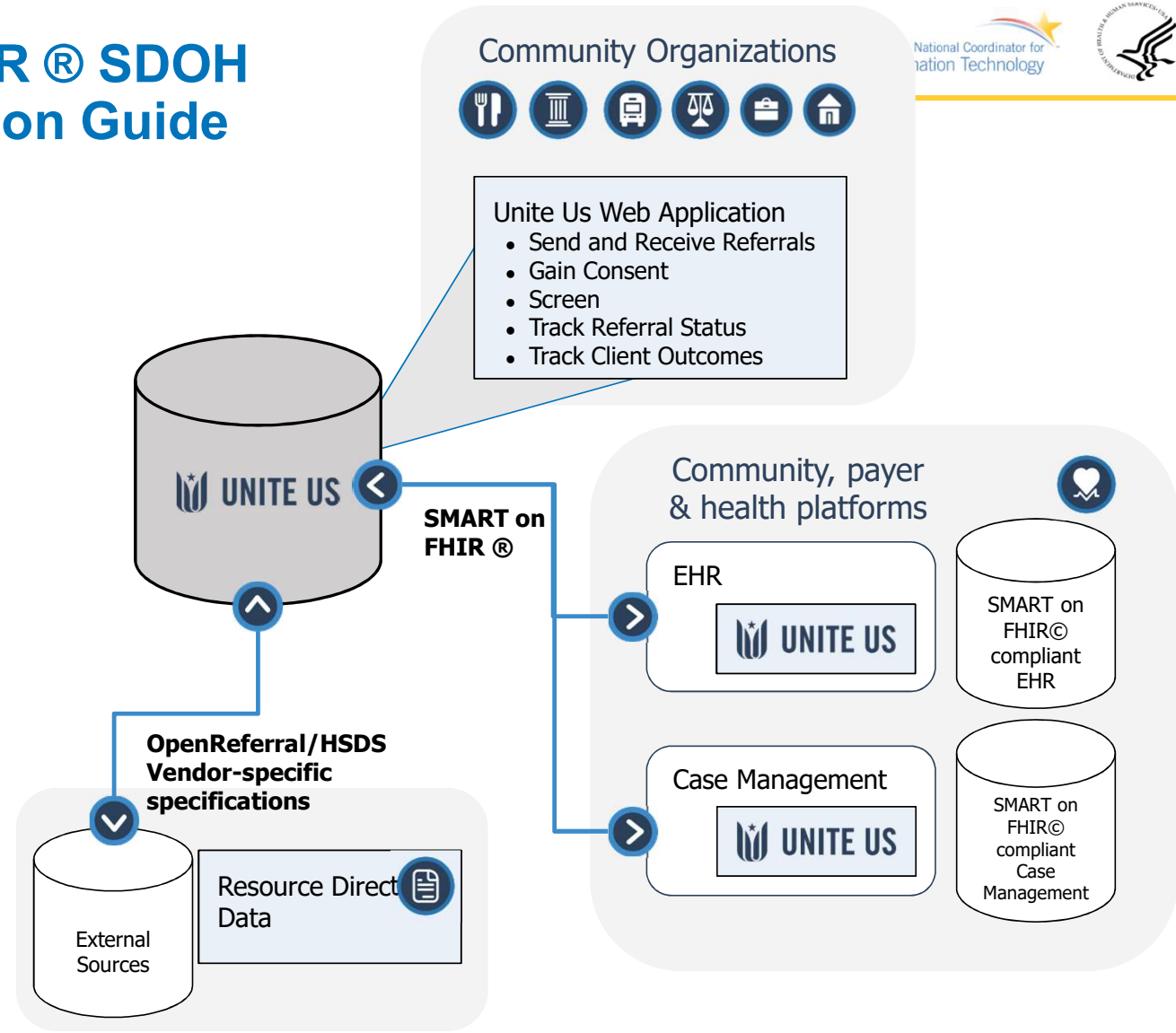




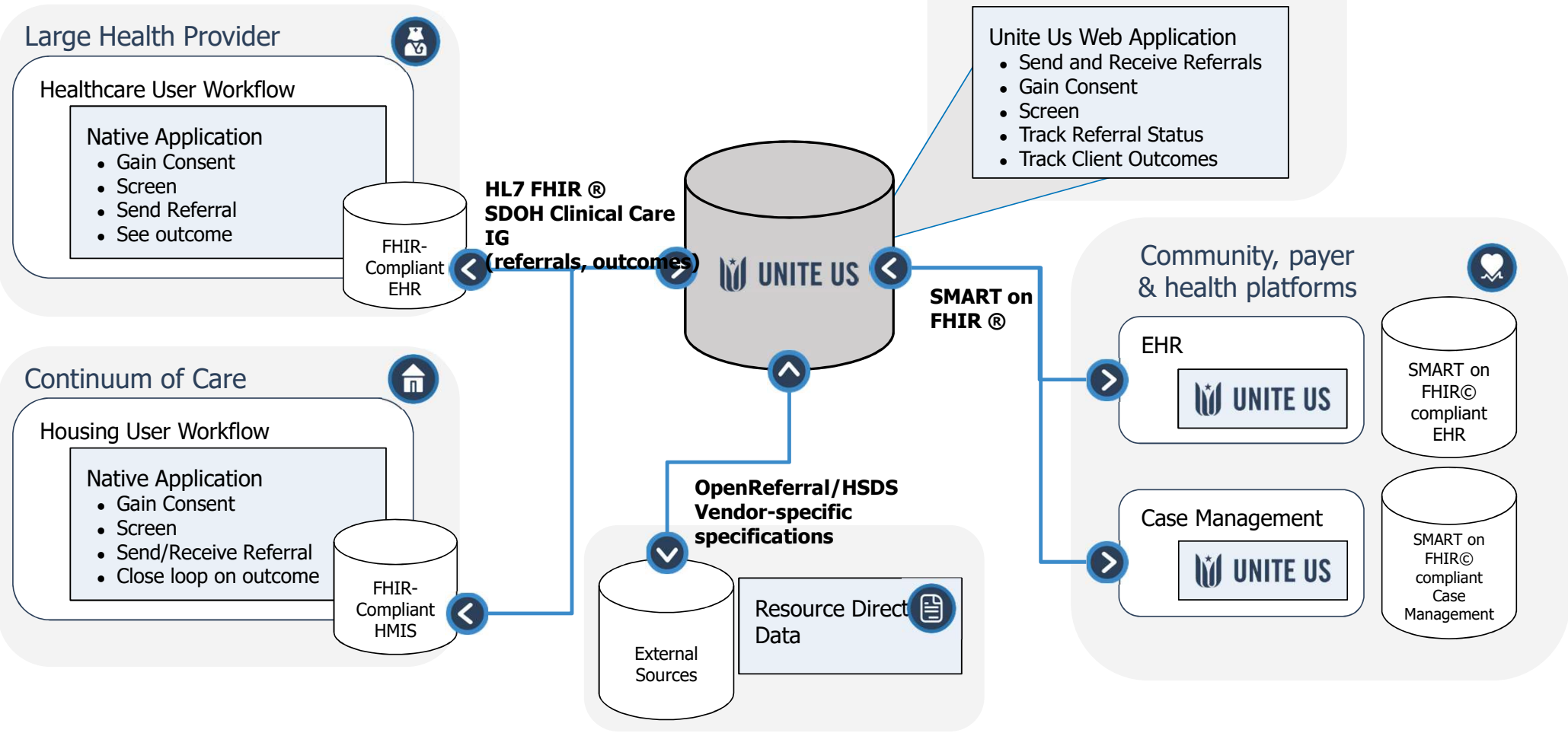
# 41 Demonstration of HL7 FHIR® SDOH Clinical Care Implementation Guide



# 42 Demonstration of HL7 FHIR® SDOH Clinical Care Implementation Guide



# Demonstration of HL7 FHIR® SDOH Clinical Care Implementation Guide



## 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


consent.uniteustraining.com

**INFORMED CONSENT FOR PARTICIPATION & INFORMATION SHARING**

Welcome to the community of service providers powered by Unite Us who will help you get the resources you need!

In order to begin, we will need some information from you and your consent to share that information across our network of service providers. Your personal information will be kept in strict confidence and will be used solely for the purpose of helping you obtain the services you have voluntarily requested from us. Our service providers are required to comply with federal, state and local privacy and data protection.

Please sign in the box below:



Clear Signature

**ACCEPT**

DECLINE



Client



Housing

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**.



Transportation



Behavioral Health



Legal 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

## 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 CCDAs-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](http://www.UniteUs.com)

### **Jake Thomson**

Director of Interoperability

[jake@uniteus.com](mailto:jake@uniteus.com)

## Follow Us





# Privacy in Whole Person Care

Leslie Paith, MPH, Product Lead and Mike Wolf, Engineering Lead  
NowPow

**NōWPōw**

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## 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



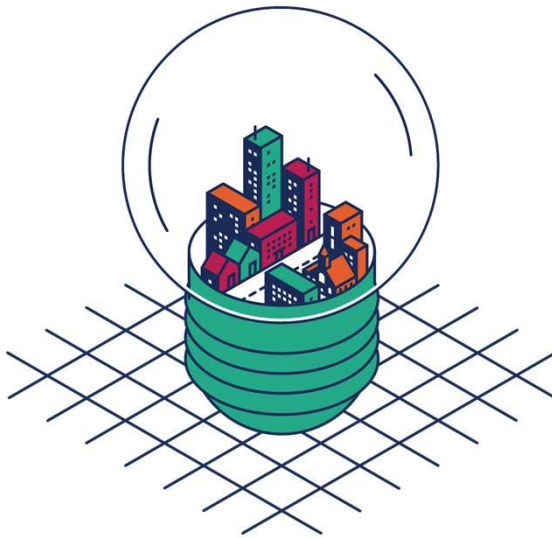
## Protecting Sensitive Information is Paramount

### 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

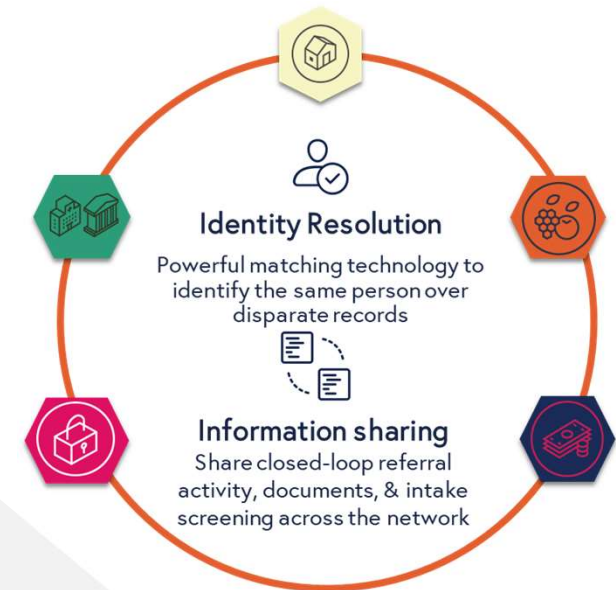
Configurable to meet intervention

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** remove access from an organization where the service was unsuccessful



## Contact Us

**Leslie Paith, MPH**

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**Mike Wolf**

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[www.linkedin.com/in/mikedewolf/](http://www.linkedin.com/in/mikedewolf/)



# Opportunities to Engage

**Greg White**

Security Risk Solutions, Inc.

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## 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-FHIRIGMeetings>
- HL7 Community Based Care and Privacy (CBCP) Workgroup
  - Tuesdays 12:00 – 1:00 PM ET
  - <https://us02web.zoom.us/j/89234543086?pwd=anE3djgyQXFYbkFYTEZCNVBPYkVzZz09>
  - 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>
- Join the Protecting Privacy to Promote Interoperability Work Group
  - Contact Serena Mack at [serena.mack@drummondgroup.com](mailto: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/EODqCguyS1duNorPUHfNREs1hB1hA\\_HY2RfEzsOgmj1hMm2S7xqncVPtOThBbvO9bAPz4DBpwmnxqP-K.Gt58S4rm5Pn4qEkL?startTime=1621452832000](https://hl7-org.zoom.us/rec/play/EODqCguyS1duNorPUHfNREs1hB1hA_HY2RfEzsOgmj1hMm2S7xqncVPtOThBbvO9bAPz4DBpwmnxqP-K.Gt58S4rm5Pn4qEkL?startTime=1621452832000)
  - Upcoming Connectathons
    - CMS HL7® FHIR® Connectathon, July 20-22, 2021, <http://www.hl7.org/events/cms/>
    - HL7 September 2021 FHIR Connectathon Sep 13-15, 2021, <http://www.hl7.org/events/index.cfm?showallevents>
  - Consent Management, Decision and Enforcement Services Testing Leads
    - Duane Decouteau [ddecouteau@saperi.io](mailto:ddecouteau@saperi.io), Mohammad Jafari [jafarim@gmail.com](mailto:jafarim@gmail.com)
  - SDOH Clinical Care IG Testing Leads
    - Bob Dieterle [rdieterle@enablecare.us](mailto:rdieterle@enablecare.us), Corey Smith [corey.smith@ama-assn.org](mailto:corey.smith@ama-assn.org), Monique van Berkum [Monique.VanBerkum@ama-assn.org](mailto:Monique.VanBerkum@ama-assn.org)



# Q&A



**Thank you for joining!**

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