Project Unify: Consent Service Utility
Overview and Update
June 27th, 2022
Agenda

• Welcome and Introductions
• CSU Status Update
  • Business Case for CSU
  • Demonstration Sites & Learning Partners
  • Use Cases (Early Intervention, Housing)
  • Architecture and Technology Overview
• ONC eConsent Discovery Workshop (8/16)
Presenters

Daniel Stein, President, Stewards of Change Institute

Mary-Sara Jones, Senior Business Development Exec, Health & Human Services at Amazon Web Services

Brian Handspicker, Project Unify Fellow, Stewards of Change Institute

Jim St. Clair, Executive Director, Linux Foundation for Public Health
Stewards of Change institute

National Interoperability Collaborative

NIC
NATIONAL INTEROPERABILITY COLLABORATIVE

National Action Agenda for Health Equity
an initiative of NIC

Project Unify
an initiative of NIC

InterOptimability Training and Certification Curriculum
ITCC is a project of NIC

Consent Service Utility
CSU POC Sites & Learning Partners

- New York State, DOH, Montefiore Health Systems, BE-InCK, Early Intervention
- Hennepin County/Health, MN
- San Diego County, CA HHS & CIE
- New Jersey, Hackensack, InCK
- Colorado CDHS
- California HHS, Center for Data Insights and Innovation
- Dell Medical School, The University of Texas at Austin (LEAP CDS II)
- Linux Foundation for Public Health
- Office of the National Coordinator
- Amazon Web Services
- Interoperability Institute (MELD)
- Network for Public Health Law
- HSLynk
- Center for Democracy and Technology
- Point of Care Partners
- Connecting for Better Health (BluePath Health)
“Shovel Ready” Sites Are Committed to Piloting the Consent Utility:

- **Bronx, New York** (Department of Health; Montefiore Health Systems, Bronx RHIO, Integrated Care for Kids/CMMI; Early Intervention Use Case)
- **Hennepin County Health, MN** (Model of Care Advancement; Housing/Healthcare Use Case)

Implementation Sites and Learning Partners

- **Doug Fish, MD**, Medical Director, New York Department of Health
- **Paul Meissner, Director, Research Program Development, CMO, Montefiore Health**
- **Connor T Johnson, Model of Care Coordinator**
  - Housing Stability, Hennepin County
- **Kristine McCoy, MD, MPH, Sr. Visiting Scholar; Robert Graham Center for Policy Studies in Family Medicine & Primary Care**
Other Potential POC Sites and/or Learning Partners:

- San Diego, California DHHS (expand LEAP CDS into social care) & HHSA DNII
- Monmouth/Ocean County, NJ (Integrated Care for Kids/CMMI)
- Solano County, CA (Whole Person Care/AB 133)
- Colorado DHS (Rules Engine)
- Dell Medical School, The University of Texas at Austin (LEAP CDS II; exchange with social services)
CSU Proof of Concept Timing and Development Status

Timeframe for MVP (minimal viable product) & POC

- Year 1: MVP sites will demonstrate the viability of the Consent Utility with synthetic data
- Years 2 & 3: MVP sites will transition to formal POC pilots and may add programs.
- Year 4: transition to government support for customization and broader replication.

Potential Funding Partners

- CDC Foundation
- Philanthropy (outreach underway to multiple foundations, Associations)
- Federal Agencies (CMS 90/10; ONC Cooperative Agreements; ARP/CURES)
- Pilot Sites, State Funding (1115 Medicaid Waivers, Other)
- National Science Foundation (Open Knowledge Network)
- US Digital Services 18F
ONC eConsent Discovery Workshop (8/16)

- Convergence emerging with respect to health and human services
- Facilitating nationwide data sharing coupled with empowering individuals with their own data
- Leveraging/reusing technical design patterns to create innovative and more convenient user experiences
People need to navigate multiple systems and programs to acquire services.

Secure, responsible, accurate and ethical data exchange is critical for decision making, care coordination, and for addressing disparities.

There are few tools for obtaining and managing informed consent, without which impedes trust.

New mind sets, models, tools and competencies are needed to support innovation and work across silos.
The Problem:

- Processes to obtain consent from people are typically not user-friendly, hard to understand, often paper-based, and do not engender trust.
- Helpers (nurses, educators, social workers, etc.) often face paper-based, non-standard processes spread across many systems, which are not accessible.
- The lack of informed consent impedes data sharing, limits access to benefits, care coordination, and service delivery - which can deepen inequities.

Goals:

- Put people in the (data) driver’s seat.
- Help helpers, help.
- Build trust, improve decision-making, enhance care-coordination.
Voices from the Community about Consent and Trust
Multi-Domain Consent Challenge

- Student Information System
- Justice
- Job Training
- Job Placement
- Electronic Health Records System
- Social Care Case Management
- WIC Health Agency
- State SNAP Agency
- Homeless Shelter
- Child Care CBO
- SNAP
- Student Information System
- Family Court
- Children, Youth and Family Services
- Housing Choice Voucher
- Equal Housing Opportunity
- New Jersey WIC
- Every Child Deserves a Healthy Start
Consent/Authorization Required by Many Programs

- Socialcare Case Management
- WIC Health Agency
- State SNAP Agency
- Child Care CBO
- Electronic Health Records System
- Housing Choice Voucher
- Homeless Shelter
- Job Training
- Job Placement
- Justice
- Student Information System
- Family Court
- Children, Youth and Family Services
Consent & Authorization Are Required and Always Preferred
Objectives:

- Design and test a “minimally viable product” (MVP) using synthetic data, for specific use-cases. (Early Intervention, Housing)
- Transition the MVP to open-source, standards-based, replicable, proof-of-concept pilots using tools that meet/exceed legal, ethical, security, infrastructure requirements. (No data sharing at this phase)
- Engage people with lived experience and apply human centered design principles to create a common look/feel for all consent types, and that work on all devices.
- Build a configurable “rules engine” that meet federal & state laws/policies.
- Prove value with proof-of-concept implementations to encourage government investment to build, test, replicate and maintain efforts.
Consent architecture is based on business process workflows and data governance that incorporates both individual business roles, data attributes and individual permissions.

- **Role Based Access (RBAC)** - user's role (such as a clinician or social worker) and organization determines what data the user can access according to organizational policies.

- **Attribute Based Access (ABAC)** - includes the limited data elements from other systems that will improve the decision-making ability of the user AND locks data based on local, state and federal policies. This is the bucket of additional data elements to be added to data bucket.

- **Client Consent** unlocks the attributed based access controls
San Diego LEAP-CDS Consent Model

Source: San Diego LEAP-CDS (https://github.com/sdhealthconnect/leap-cds)
Opportunity: Extend LEAP-CDS

Strengths:
• Common Consent Service Model - not encapsulated in individual systems
• Not Specific to Healthcare – generalizable to socialcare, education, justice, etc.
• Well Designed Architecture Model – flexible, adaptable, modularized
• Open-Source Implementation – extensible, replaceable services

Additional Opportunities:
• Identify Management – needs attestation, validation, matching, deduplication
• Explicit Record Locator – has consent discovery which implies record location
• Explicit Record Exchange – implies record exchange for the consent decision service
• Support for non-healthcare domain privacy and consent rules, e.g., for socialcare
Unify Consent Service Model (Draft)
WHY? Law of Unintended Consequences

LAW OF UNINTENDED CONSEQUENCES

OFTEN SEEN WHEN:

A SIMPLEx SYSTEM TRIES TO REGULATE A COMPLEX SYSTEM

It's simple, see?

ACTION → ??

sketchplanations
Potential Contributing Technology Partners For Scalability and Sustainability

• MELD & Synthetic Personas/data (Interoperability Institute)
• LEAP CDS: healthcare record location (healthcare only, currently)
• AWS Magellan prototype: record location
• AWS: consent store, other
• Sovereign Identity: identity attestation and validation
• Cardea: record location & consent system
• Direct PEHRLS: record location standard
• National Human Services Interoperability Architecture (NHSIA-update)
• Graph Technology (NSF)
“In the California State Assembly, we are interested in the potential of our public systems to better serve families through local collaboration. Only recently have we begun to appreciate how our siloed policymaking, often aimed at serving the same people, can unintentionally create barriers to local collaboration and information sharing. We have started discussing how to align our policymaking to reduce these barriers and support collaboration. Stewards of Change Institute’s pilot projects that demonstrate innovative solutions to enable data sharing would help the State Assembly advance our vision of integrated systems. It could also illuminate points of friction in state law which we, as policymakers, are in a position to address.”

- Tanya Lieberman, Chief Consultant, California Assembly Education Committee
Discussion & Next Steps
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