

The independent health care task force for equitable interoperability

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- Founded 2018, formalized 2020
- Mission: To advance safe, equitable, and patient-empowered sharing of health information.
- Vision: To further a health care ecosystem in which better standards for clinical data sharing increase trust between patients, providers, and caregivers to improve quality of care and health equity.



Governing Board

- American Medical Association
- American Academy of Pediatrics
- AARP (formerly known as American Association of Retired Persons)
- Integrating the Healthcare Enterprise USA
- Electronic Healthcare Records Association
- Drummond Group
- Office of the National Coordinator for Health IT (ex-officio)

State of Interoperability



Patient comfort with data use depends on range of sharing

Most comfortable	
My doctor's office	
	75.2%
Hospital or health system	
	64.2%
Least comfortable	
Social media sites	
	71.2%
Big tech	
	67.4%
Prospective employer	
	62.9%

Patient comfort with data sharing and equity indicators



59% of Patient Surveyed

Expressed concerns with their personal health data being used against them or their loved ones

Highly/Extremely Concerned Rates were higher in

Hispanic/Latinx, American Indian/ Alaskan Natives, and transgender individuals Almost 80% Desire the ability to opt-out of sharing some or all of their health data

Pew Charitable Trusts Focus Groups (summer 2019)

Location	Registered voter audiences	
Morristown, New Jersey	 Medicare beneficiaries age 65+ who are not eligible for Medicaid (9) Frequent users of the health care system (9) Caregivers of patients with chronic/serious illnesses (9) 	
Kansas City, Missouri	 Less frequent users of the health care system (9) Ages 40-64 (8) 	 _80 participants
Seattle	 Ages 23-39 (9) Frequent users of the health care system (9) 	
Nashville, Tennessee	 Medicare beneficiaries age 65+ who are also eligible for Medicaid (9) African Americans (9) 	
Online	• Patients with serious illnesses (18)	18 participants

Pew Charitable Trusts (2020)

Pew Charitable Trusts Focus Groups Conclusions

- Nearly all participants wanted access to their medical records; frequent health care users & patients with serious illnesses more likely to want to access electronically.
- Every group raised concerns about privacy and security of health data:
 - Some, particularly those of color, worried that easier access to data meant anyone in the hospital could see their personal information.
 - Concern that certain data elements could lead clinicians to prejudge them, which would negatively affect their treatment.
 - Cited apprehension about security of information in health care facilities and personal devices, citing recent data breaches.

Pew Charitable Trusts Focus Groups Quotes

"My concerns would be that the next doctor would be quick to take a look [at the record] without knowing the patient personally and judge them."

Medicare beneficiary, MORRISTOWN, NEW JERSEY

"If the doctor needs to know, I can tell him. I don't want to have it transferred on a profile for him that I am hungry or that I don't have a place to live at. I can tell him that if I need him to know that."

African American participant, NASHVILLE, TENNESSEE

Pew Charitable Trusts (2020) 9

Pew Charitable Trusts Recommendation

"ONC should continue to accelerate patient access to records while also focusing on increasing adoption of tools and policies to enable the exchange of individual data elements among providers, such as through standards-based API's."



Equitable Interoperability: Defining the Problem





Why Has this Problem Not Yet Been Solved?

- Technology is only part of the solution
- Implementation of technology must be informed by multiple stakeholders
- Multiple stakeholders must come to consensus on key issues to balance privacy and safety
- There are so many nuances and edge cases that are easy to get lost in
- To date there has not been alignment on the urgency to solve this problem



Limitations of Previous Pilots

- Mostly limited to 42 CFR Part 2 and few other selected use cases
- Did not make full use of available technology
- Set up within single regional system; not set up for interoperable scalability
 - Nationally stewarded and maintained VSAC value set would be required for this
- Implementation guidance re: controversial issues not available, so many of these issues not addressed



The Shift Approach

- Involve multiple (>200) stakeholders with differing viewpoints
- Vendor/stakeholder neutrality with patient focus
- Start with common high-impact clinical use cases
- Define possible solutions and drive toward proof of concept
- Build on existing frameworks and technology solutions
- Use the Delphi method to drive consensus re: controversial issues
- Limit POC scope in order to demonstrate what's possible; build sequentially
- Leverage expertise of legal, ethical, policy, patients through process



Volunteer Work Driven By Shared Understanding:

- Of the need for equitable interoperability.
- That not solving this problem worsens healthcare disparities.
- That the opportunity cost will have the most severe impact on historically. marginalized, underserved, and vulnerable patients and communities
- That the 21st Century Cures Act and recent Dobbs decision have underscored the urgency of solving this problem.



Shift Workgroups

Shift Task Force





Clinically Informed Use Cases

Phase I	1a. Older Adult Behavioral Health	-Behavioral health + SUD data protected by state law (non 42-CFR) -Shared with: portal proxy (HCA in waiting), recipient EHR, HIE, payer			
	1b. Adolescent Reproductive Health	-Reproductive health data protected by state law -Shared with: portal proxy (guardian), recipient EHR, ancillary services, payer			
Phase II	2a. Adult SDoH with Gravity	-SDoH data (IPV); working in conjunction with the Gravity Project -Shared with: portal proxy (partner), recipient EHR, 3rd party mobile app, payer			
	2b. Co-mingled Maternal/Infant	 -Includes: prenatal STI labs, maternal dx of postpartum depression -Accessed by: other parent, adult child in longitudinal record 			

Shift Use Case v2 Deliverables (Jan 2024)

- Build out simplified version 2 of use cases to support reference implementations, starting with:
 - Phase 1a: older adult BH
 - Phase 1b: adolescent reproductive health
 - Phase 2a: SDoH (with Gravity)
 - Phase 2b: linked mother/baby use cases
- Define granularity of semantic conceptual models for each

Shift: High Level Project Plan

А	В	С	D	E	F	G
Project	Task ,	Status 🚽	Start Date 🛛 👳	End Date 🚽 👳	# of Months \Rightarrow	Notes
Delphi 🔹	Informed Consent	In Progress 💌	1-Oct-2023	31-Oct-2024	13	
Technical 🔹	Seek Value Set Vendor/Steward	In Progress 💌	1-Oct-2023	31-Dec-2024	15	
Technical	Phase One Reference Implementations and Pilot		1 Oct 2022	21 101 2026	24	
	Participation	In Progress •	1-Oct-2023	31-Jui-2020	34	
Delphi	Redaction Safety and Ethics	Not Started	1-Jan-2024	31 Jan 2025	13	
Publication	Implications of ONC HTI-1 Final Rule	On Hold 🔹	1-Jan-2024	31-Mar-2024	3	Waiting for Publication
Technical 🔹	Compare DS4P CDA/FHIR and Shift Use Cases	Not Started 🔻	1-Jan-2024	28-Feb-2024	2	
Technical	Publish Phase 1 Use Cases with Granular Data Elements	In Progress 🔻	1-Jan-2024	31-Jul-2024	7	
Technical	Publish Phase 2 Use Cases with Granular Data Elements	On Hold 🔻	1-Jan-2024	31-Mar-2025	15	
Delphi 🔹	Intended Recipent Notification	Not Started 🔻	1-Apr-2024	30-Apr-2025	13	
Publication	Response to HTI-2 NPRM	On Hold 🔹	1-May-2024	30-Sep-2024	5	Waiting for Publication
Delphi 🔹	Clinical Decision Support	Not Started 🔻	1-Jul-2024	31-Jul-2025	13	
Technical	Phase Two Reference Implementations and Pilot Participation	In Progress 🔻	1-Jun-2025	30 Sep 2027	28	
Publication	Collaborate for VSAC Publication	Not Started 🔻	1-Jan-2026	31-Dec-2026	12	
Technical 🔹	Develop Phase Three Use Cases	Not Started 🔻	1-Jan-2026	31-Dec-2026	12	
Publication	Full Shift Companion Guide Publication Phase One	Not Started -	1-Aug-2026	30-Jun-2027	11	
Publication	HL7 Balloting or Collaboration Decision	Not Started 🔻	1-Jul-2027	31-Dec-2027	6	



1. Informed Consent

(Currently in round 3)

- 2. Safety and Ethics of Redaction
- 3. Notification to Intended Recipient
- 4. Use of Redacted Data in Decision Support Interventions



Shift Modified Delphi Process: Informed Consent

Use Cases:

- 1. EHR to Patient Portal (redaction from proxy)
- 2. EHR to EHR
- 3. EHR to HIE/EDW for pop health
- 4. EHR to 3rd party system (including mobile app)
- 5. EHR to Payer

Shift Modified Delphi Process: Informed Consent

Major Themes:

- Patient right to redact: 21st C. Cures vs. HIPAA.
- "Informed consent" framework needed.
- Patient-friendly definitions of complex concepts (portal proxy, use of pop health data)
- Scope questions (de-identified data, VBR data)
- Sharing with non-HIPAA CE's/apps may require additional education/consent.
- Need clear description of org-specific processes to opt out, pay out of pocket.

Shift Modified Delphi Process: Lessons Learned for Future Topics

- Balance appropriate stakeholder diversity across domains with forward momentum.
- Set clear process expectations and background framework with reference materials.
- Simplify survey questions as much as possible.
- Review survey questions with group and revise prior to first survey.
- Hold members accountable to continued participation.
- Drive toward high-level goal of consensus.

Shift Technical Workstream: Project Plan



Shift Technical Workstream: Proposed Sandbox Demonstrations

- Demo 1: EHR to sandbox HIE
 - SLS within the EHR
 - Filtering sensitive data
- Demo 2: EHR to EHR :
 - SLS within EHR
 - Sharing labeled data; access control in the recipient system.
- Demo 3: Incorporate patient preferences (consent decisions) in Demo 1 and Demo 2
- Demo 4: Integrate with consent management engine
 - Demonstrate enforcement of new consent
 - Demonstrate revocation of consent and its effect
- Future:
 - Real world demonstrations
 - Multi-vendor architectures



Shift Technical Workstream: Proposed Architecture

- Flexible and Scalable Architecture
 - Support various permutations of placing SLS/Consent Management with a) EHR system, 2) HIE, and 3) Third Party Services
- Standard-Based Components
 - Standard-based interfaces between SLS, Consent Management, and EHR/HIE: PCF
 - Consent Profile: PCF
 - Standard value sets for known categories of sensitive data including reproductive health and substance use.
- Granular Consent
 - Consent Profile

Shift Technical Workstream: Proposed Architecture



Shift Technical Workstream: Implementation Challenges

- Standard Value Sets for Sensitive Information
 - Uniform and consistent labeling of sensitive information such as:
 - Behavioral health
 - Reproductive health
- Pilot Test and Demo
- Patient Friendly Consent Management
- Maturity of Existing Specifications
 - More implementation and more extensive testing is needed

Questions

For more information: <u>http://www.shiftinterop.org</u> contact@shiftinterop.org