



**Advancing  
Consent Management  
and Interoperability  
to Support Care  
Across the Continuum**

September 17, 2024





# #CIVITAS2024 UPDATES

The "Bridge Between Data and Doing" conference will be held October 15-17, 2024, in Detroit Michigan.

**Registration is Open!**

**Thank you to our platinum sponsor, InterSystems!**



# THANK YOU TO OUR CONFERENCE SPONSORS



## #CIVITAS2024 TEES & SWEATSHIRTS



*All proceeds directly benefit  
Alternatives For Girls nonprofit organization*

# ALTERNATIVES FOR GIRLS T-SHIRT FUNDRAISER

Our #Civitas2024 Annual Conference t-shirts and sweatshirts are available to support a great cause!

This year, we're highlighting Alternatives for Girls, a Michigan-based nonprofit organization dedicated to helping girls and young women experiencing homelessness and other risks. They work to prevent violence, early pregnancy, and exploitation while providing access to vital support, resources, and opportunities needed for safe and positive growth.

<https://www.bonfire.com/civitas-2024-annual-conference/>

# CIVITAS 2024 ANNUAL VIRTUAL PRECONFERENCE

**JOIN US ON 8/26, 9/11, AND 9/19!**

**These discussions are available exclusively  
for attendees of #Civitas2024**

MADE POSSIBLE WITH  
SUPPORT FROM OUR  
SPONSOR. THANK YOU!



## CIVITAS 2024 VIRTUAL PRECONFERENCE SESSIONS

Mark your calendars for the 2024 Virtual Preconference Sessions, which are made possible with support from Telligen!

- [Materials Available! | Session 1: Partnerships and Data Sharing with Emergency Medical Services and Crisis Response | August 26, 12:30-2:00 p.m. ET](#)
- [Materials Available! | Session 2: Advancing Equity in Maternal and Infant Health | September 11, 12:30 –2:00 p.m.ET](#)
- [Sign Up | Session 3: Using Networks to Improve State-Wide Systems and to Address Inequities | September 19, 3:00 – 4:30 p.m. ET](#)



## CIVITAS 2024 ANNUAL CONFERENCE ROOM BLOCK

Civitas 2024 Annual Conference attendees are eligible for discounted rates at the Detroit Marriott at the Renaissance Center.

Book early via our conference website to ensure you take advantage of these special rates!

**The discounted block ends on September 19, 2024, at 5:00 pm ET.**

*Please be advised: the conference is scheduled for October 15th-17th, with the room block available from October 11th-17th.*

# SPREAD THE WORD!

We appreciate your efforts in circulating the Civitas 2024 Annual Conference with your networks to further encourage cross-sector collaboration, increase robust opportunities for networking, cultivate creative solutions through knowledge sharing, and more.

You can find promotional content for social media, newsletters, and graphics in our digital toolkit. Please help us spread the word!

<https://civitasforhealth.swoogo.com/civitas2024/communicationstoolkit>

## Social Content for Conference Promotion

### Civitas Handles

- **X/Twitter** | @Civitas4Health [LINK]
- **LinkedIn** | Civitas Networks for Health [LINK]

✕	X/Twitter Content
in	LinkedIn/Facebook Content
📧	Newsletter Posts
☆	Social Media Content for Confirmed Event Sponsors
✕	Social Media Content for Confirmed Event Speakers

## Social Media Graphics

Click to download social media graphics below.

The following is intended for you to use as is or customize to fit your personal and organizational needs when promoting the event. We'd love to follow along and feature your posts on our channels, so please tag Civitas and use the event hashtag #Civitas2024!





# WE WANT TO HEAR FROM YOU!

We'd like to hear about your 2024 membership experience to continue delivering high-value member benefits and inform our programming.

Our Member Satisfaction Survey is now open! We encourage you to share this with other members of your teams who participate in Civitas offerings.

Civitas will be offering two \$100 Amazon gift cards and a top prize of one free registration for the 2025 Civitas Annual Conference.

<https://civitas.tfaforms.net/f/2024-Member-Satisfaction-Survey>

*Please note that only one prize will be awarded per organization.*





# Consent Management Workshop at the Conference

## Objectives:

- Acquire a deep understanding of the CSU and conceptual model;
- Learn about progress from key states developing approaches to managing consent;
- Discuss strategies for customizing and replicating the CSU for individual jurisdictions by aligning with current or planned HIE, HDU, CIE, and/or whole person care initiatives; and
- Discuss plans for launching a new Consent to Share Collaborative webinar series in 2025 with Civitas and SOCI.

**Tuesday, Oct. 15, at 8:00 a.m. and Thursday, Oct. 17, at 11:30 a.m.**

# **Advancing Consent Management and Interoperability to Support Care Across the Continuum**

**September 17, 2024**





# Agenda

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**Introduction**

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**Consent Concepts**

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**Interoperability Implications**

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**Planning for Consent in Action**

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# Introduction - Care Coordination & Privacy



Shared data is needed at multiple levels:

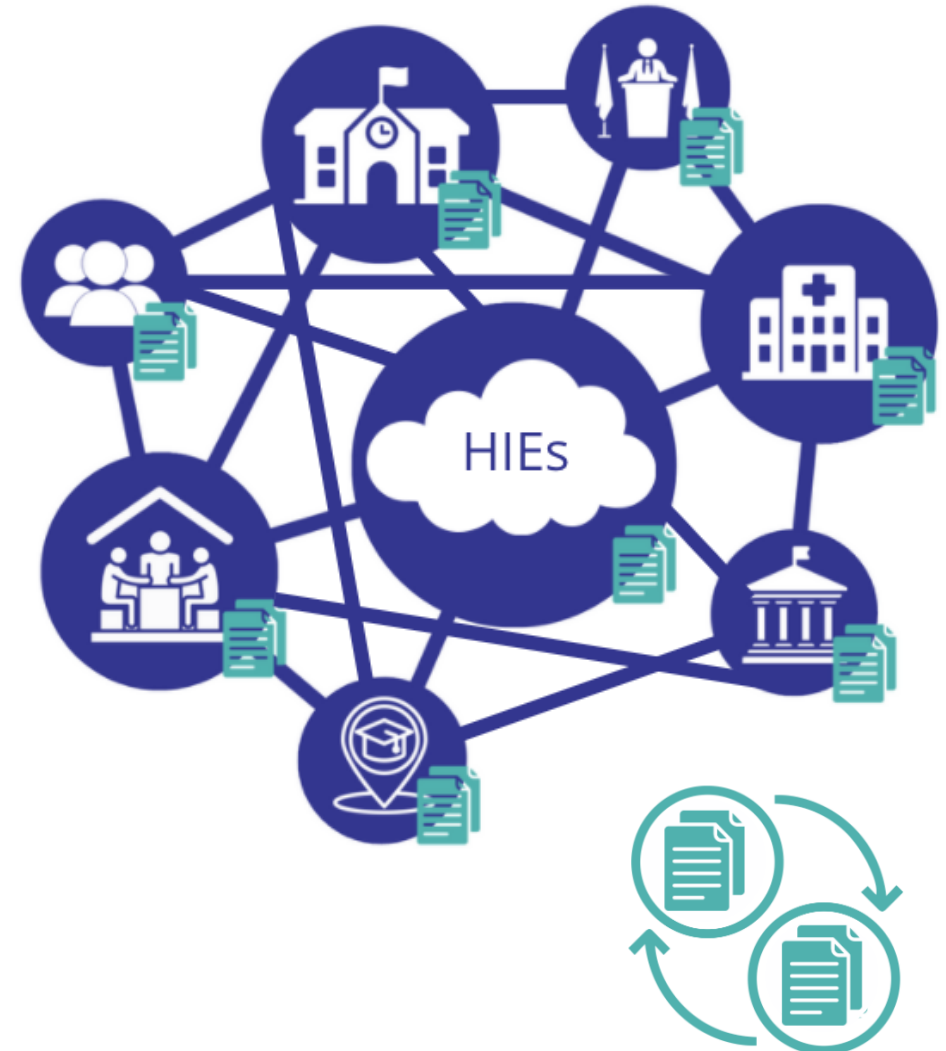
- **Direct service** – for care coordination and providing services
- **Program Administration** – for understanding how the program is operating and interacting with other programs and services
- **Program Compliance** - Meeting statutory, regulatory, and best practice standards
- ***Community Level*** – for legislators and public leaders to understand how funding, policies, and programs meeting the needs and challenges of populations and the community as a whole and evaluate their success

# Introduction - Care Coordination & Privacy



- More data is being collected from, and generated about, patients and clients than ever before
- Complex problems (SDoH, etc.) requiring data from multiple sources
- Easier, faster to share data, but paradoxically more complex – the more data we share, the more data we need to share to ensure we are sharing the right data, in the right way, with the right people, and then tracking the data we have shared

For today's presentation, we are focused on data sharing for care coordination and the delivery of social services (AKA non-clinical health and human services)



# Introduction - Care Coordination & Privacy



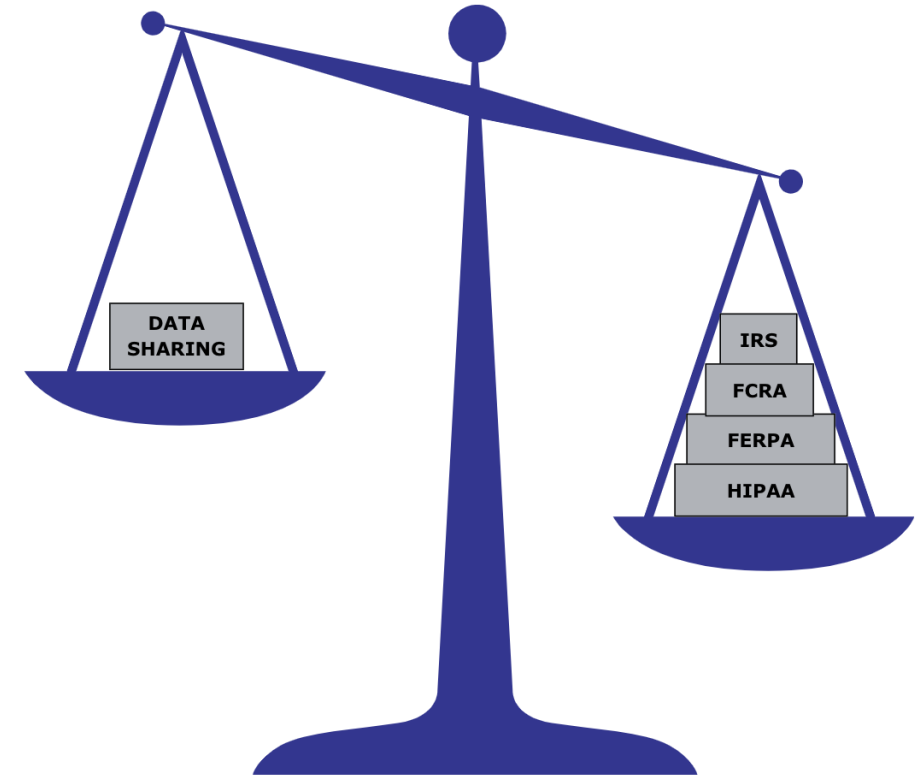
## Opposing Priorities

Strong desire for data to be shared:

- coordinate care and services,
- reduce friction of moving between providers and programs,
- better insights (360 view) on the client, program, and community levels

Statutory, regulatory, and principled need to protect privacy and ensure an individual's autonomy and agency over "their" data – the data they provide and the data collected and created about them.

- Reflected in the numerous laws governing privacy (HIPAA, etc.)
- A person's data is a proxy of the whole person. Therefore, the protection of a person's data should be regarded with the same level of care as you would the person themselves



***Consent is a mechanism for balancing these competing priorities***

# Introduction - Care Coordination & Privacy



Must be implemented at the **policy** level – privacy & consent regulations, data standards, etc.



Must be actively monitored and curated at the **program** level in the business process outside of the data systems – how the workers interact with patients and clients to inform and obtain consent



Must be implemented, managed, scaled, protected, and curated at the **technology** level – in the data system programming for how they deal with data to ensure



All pieces must work together to tackle the problem of effective consent management, governance, and interoperability

# Thinking about Consent



The term “consent” is used in many contexts, important to be clear

Generally, “consent” is an individual’s expression of their agreement, approval, or permission regarding some act or purpose; to be valid, the person granting consent must be informed of what they are agreeing to, free from coercion, and have sufficient mental capacity.

## INFORMED CONSENT

“Informed Consent” concept emerged from medical care, reflecting treatment focus...

Extended from treatment to cover data sharing with providers for treatment purposes (data sharing for research purposes is also generally covered under informed consent)

## CONSENT-TO-SHARE

“Consent-to-Share” is specific to data sharing for care coordination and the delivery of non-medical services, e.g. food assistance, transportation, etc.

Consent is an issue for the entire Health and Human Service ecosystem, and a wide range of programs



# Fundamental Principles of Consent



## Respect for Autonomy:

Respecting individuals' autonomy by ensuring they have the information needed to make informed decisions about their participation in public programs (Beauchamp & Childress, 2019).

## Dignity and Respect:

Obtaining consent demonstrates respect for the dignity of beneficiaries, acknowledging their right to make choices about their own lives and personal information (American Psychological Association, 2017).

## Ethics:

Informed consent in medical research ensures that participants are fully aware of the potential risks and benefits of the study, allowing them to make an informed decision about their involvement. This process respects their autonomy and upholds ethical standards in research (National Institutes of Health, 2020).

In the context of "consent to share", compliance with these general consent principles would mean and individual must know:

- What data is being shared
- For what purpose
- Who is sharing/requesting/receiving/viewing the data
- Their rights to modify or revoke consent

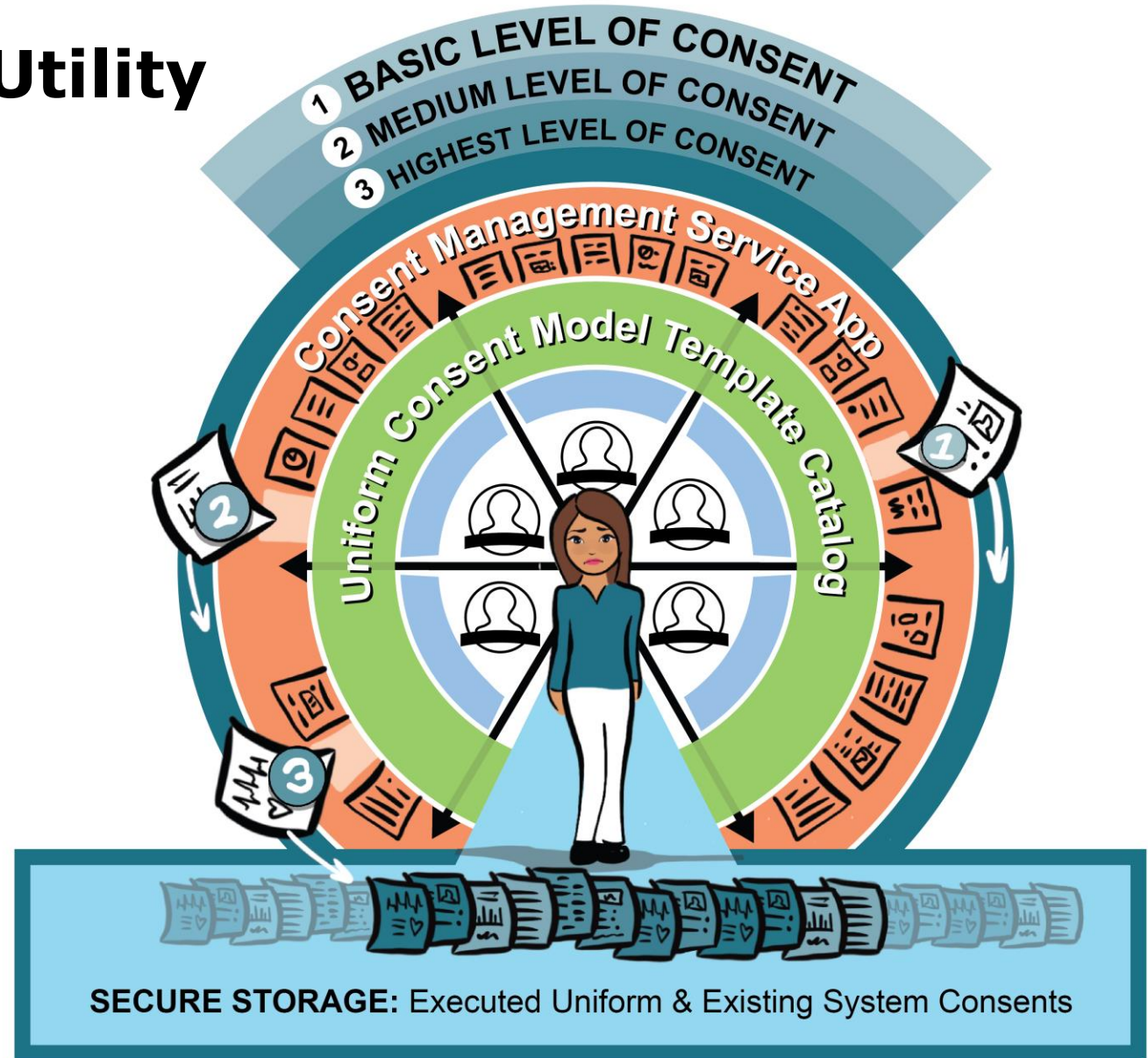


# Capture of Consent

- Ideally, Consent to Share should be:
  - **Dynamic** – individuals can provide, modify, or revoke consent at any time
  - **Granular** – individuals can indicate preferences for which data are
- Consent must be captured in some physical or digital form
  - it is not enough to capture “I agree to share”
- To be actionable, consent must be transformed into digital format so that the consent information may be understood, exchanged, and used by data systems (not just an image file)
- Many programs or providers capture some form of consent data today, but that data is generally specific to that program, use case, or system. It is NOT a Global policy.
- Data sharing across a community requires moving consent beyond any single program or privacy regime – it’s obtaining consent that will comply with (and be accepted by) all of the counterparties

# Consent Management Utility

- How do we manage consent across multiple programs and applications?
- Need a tool (or tools), internal or external, to track consent
- SOCI proposal - Shared Resource model consisting of:
  - Uniform Consent Model Template Catalog
  - Consent Management Service App
  - Secure Storage of Consents
- Other tools may also be deployed – how will they work together?



# Relationship between Consent & Interoperability



Consent opens the gate to allow data sharing, but implementing that consent – sharing the data – still requires interaction between two (or more) data systems – an interoperability problem

- These systems may be (and likely are) on different platforms, with different data formats, standards, definitions, etc.
- Consent data may also be managed in different formats
  - Without common understanding of consent terms and context, can't be sure you are complying with consent requirements
  - Without common understanding of underlying program data elements, consented data sharing still won't solve your problem – comparing apples and oranges
- Consent is an ongoing, dynamic process, not just a single opening of the gates
- Consent must be actively managed, curated, and governed within a framework that can be scaled and is elastic

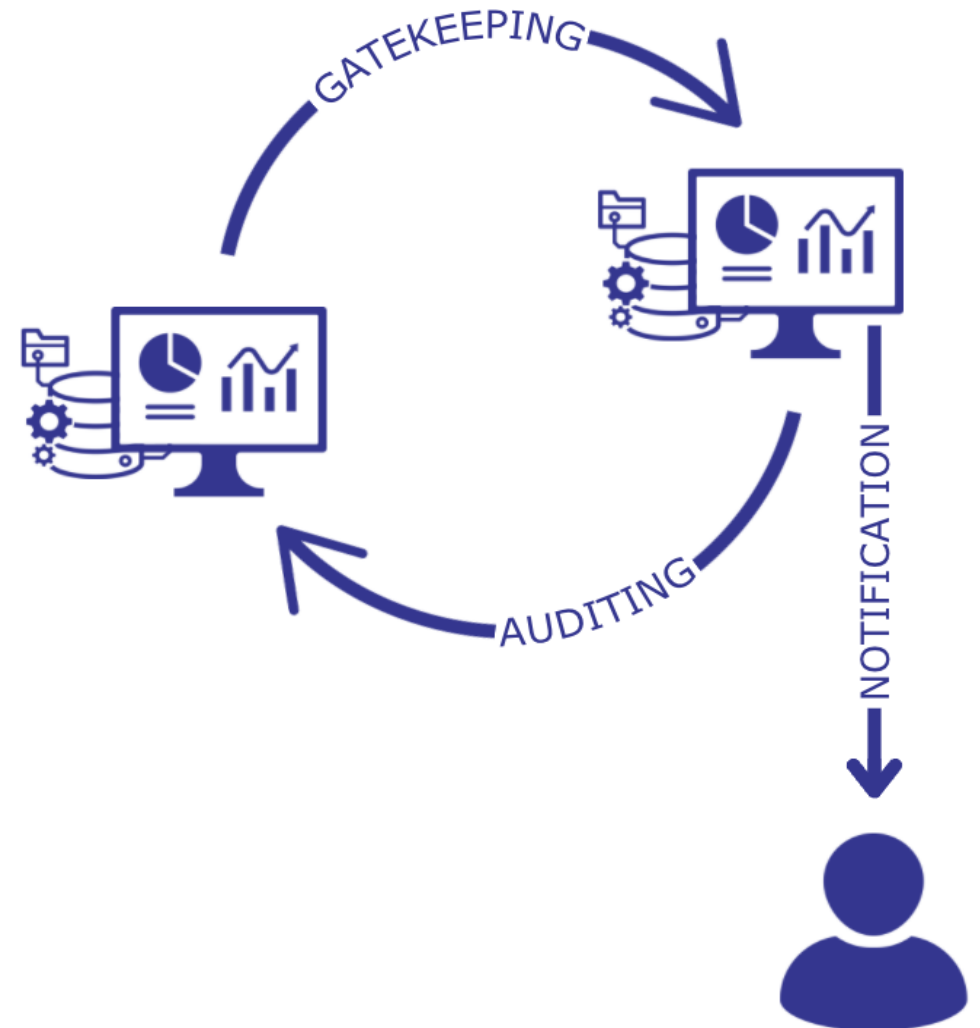
# Interoperability: Moving Consent from Concept to Action



Consent implementation requires two critical functions:

- **Gatekeeping** (monitoring and curation)
  - Validating the data sharing against the consent on an ongoing basis
  - Only authorized data, to authorized parties, for authorized purpose
- **Auditing** (standards, governance, model adherence, traceability)
  - Maintaining record of all data exchanges, so you can validate compliance with consent
  - Consent information needs to be captured for every data exchange transaction

**Client notification** (active or passive) is potential third requirement – allowing client to know when their data is being shared





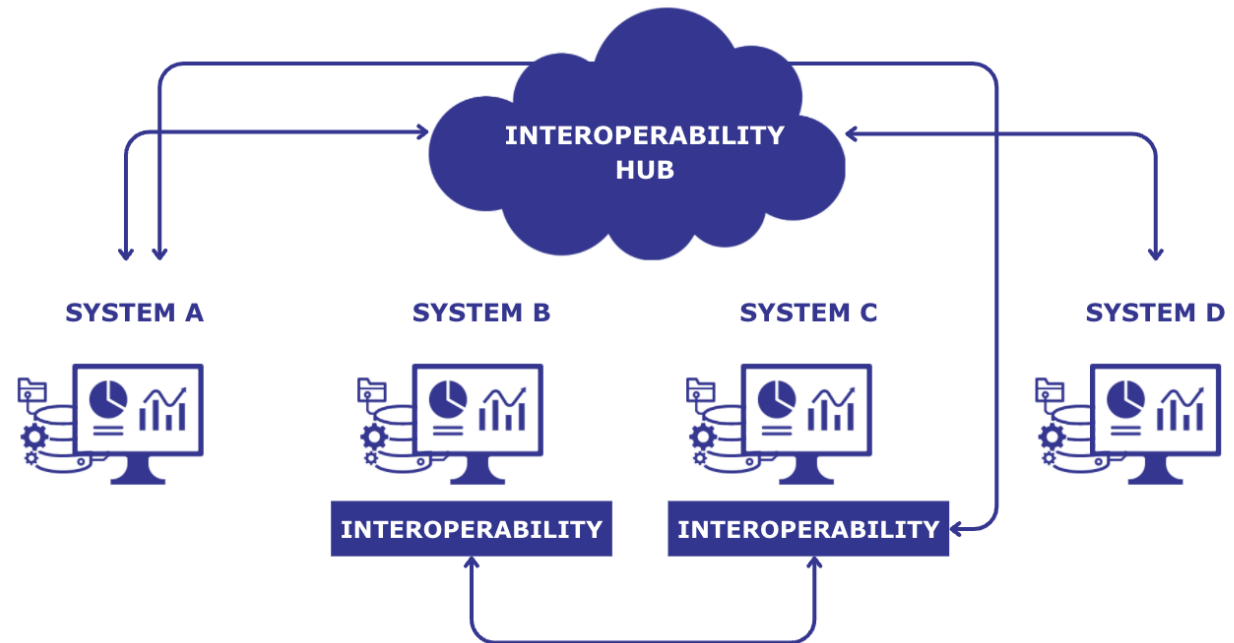
# Interoperability is Consent in Action

- The interoperability layer is where these problems get resolved
  - What is being shared with whom, and under what conditions?
  - Translating between systems – common understanding of the consent (and other) data being exchanged
  - Tracking transactions – gatekeeping, auditing, and notification
  - The interoperability layer is critical to managing consent, data sharing with context, and having reliability that consent standard are being adhered to.
- There are different ways that interoperability layer might be implemented for data sharing
  - Central hub performing translations
  - Interoperability layers built in/on existing program applications
  - Hybrid
  - Key considerations include scale (volume) elasticity (addressing complexity and seasonality), and how to curate (actively manage and evolve with business needs)
- Standards and a strong common data model are essential for all interoperability approaches
  - HL7 FHIR, etc.
  - Common taxonomy and lexicon
  - strong data definitions from each program of what the data means (e.g. variance on “household” definition by program - family members vs. all residents?)
- To effectively implement consent at scale, the data model is critical
- The data model must be extensible

# Implications for Implementation of Consent



- Solution must be able to deal with a high volume of data
- Solution must have a robust data model – granular, elastic, and extensible
- The more varied your consent to share practice model (number and types of partners sharing and data types being shared), the more complex interoperability challenge
- Need to think about where the interoperability is going to occur:
  - Physically, where will the interoperability activity take place within your information system
  - How will it be monitored, protected, and curated



# Thank you

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