eConsent Community of Practice: Bringing Industry Together

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Point-of-Care Partners

Point-of-Care Partners Overview

Point-of-Care Partners (POCP) is a leading health IT management consulting firm that helps healthcare stakeholders develop and execute winning management and information technology strategies in an evolving electronic world.

POCP Advantages:
- Multi-stakeholder projects **across many segments of healthcare**
- Rich directory of people in all segments willing to **add perspective** to projects
- Experienced staff of consultants with **diverse healthcare backgrounds**
- On leading edge of the evolution of health care IT and its application to health care for **18 years**
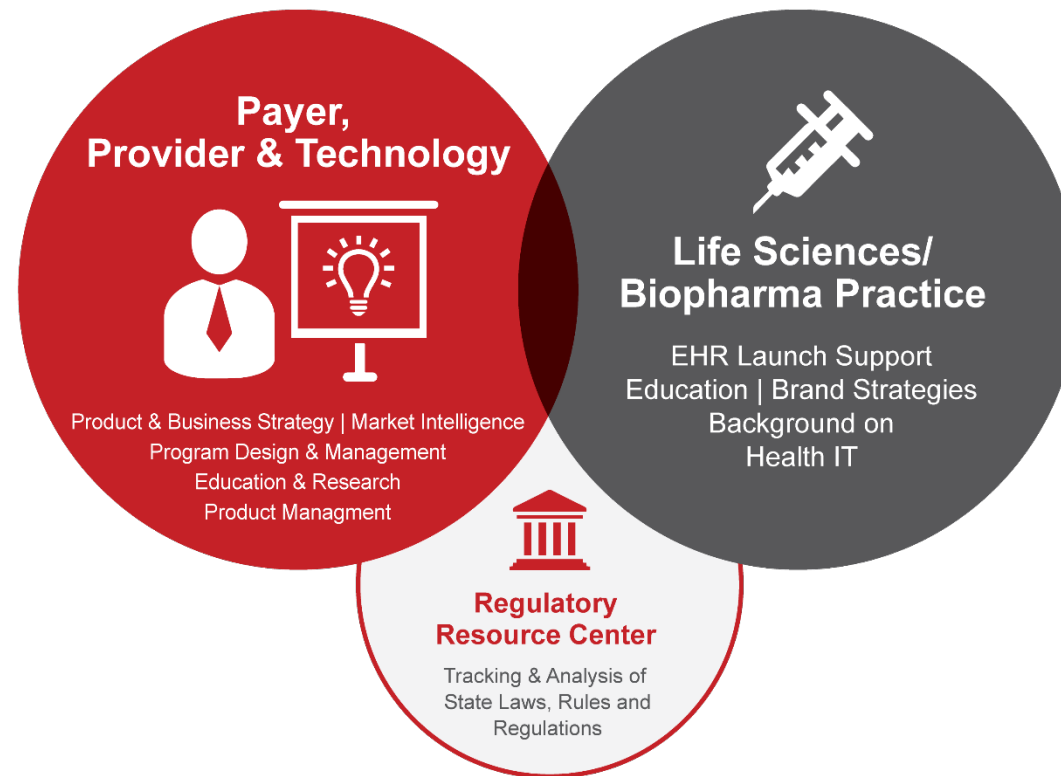
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Subject Matter Experts In …

- Interoperability, APIs and Transactions in Support of Value-Based Care
- ePrior Authorization (device, procedure)
- eMedication Management
  – ePrescribing & Related Transactions
  – Specialty Pharmacy Automation
  – Medication Therapy Management
  – ePrior Authorization (drug)
  – Biosimilars (track/trace, reporting)
- Clinical Decision Support/Clinical Messaging
- Electronic Health Records (EHRs)
- Health Information Exchange
- Long-term, Post-Acute Care

The Way We're Organized Today…

Payer, Provider & Technology

Product & Business Strategy | Market Intelligence
Program Design & Management
Education & Research
Product Managment

Life Sciences/ Biopharma Practice

EHR Launch Support
Education | Brand Strategies
Background on
Health IT

Regulatory Resource Center

Tracking & Analysis of
State Laws, Rules and
Regulations

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Healthcare Informed Consent

Healthcare Informed Consent: A record of a healthcare consumer's choices that permits or denies identified recipient(s) or recipient role(s) to perform one or more actions, within a given policy context, for specific purposes and periods of time

Four Types of Informed Consent in Healthcare

Privacy: agreement to collect, access, use, or disclose (share) information

Research: consent to participate in research study

Medical Treatment: consent to undergo a specific treatment/procedure (or record of refusal to consent)

Advance Care Directives: consent to access instructions for potentially needed medical treatment (eg, DNR)

Healthcare eConsent Evolution

DRIVERS: Industry and ONC Funding and Rule-Making

Research consent to participate in research or clinical trials

eConsent for Medical Treatment

Industry and ONC push for *informed consent* vs. implied consent

eConsent for Record Sharing

ONC Final Rule requires EHRs to share patient record based on patient consent

SAMHSA 42 CFR Part 2 protection of Substance Abuse Disorder

ONC funding eConsent and FHIR research projects

Open Questions Around eConsent

Legal

Technical

Ethical – Revoke?

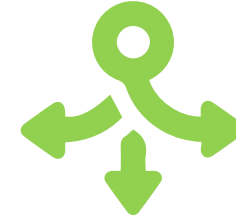Payers/Providers see risk in sharing data

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eConsent Best Practices

Patient-Centered eConsent Model

Patient-to-Many Approach for Informed Consent

Shared Decision-Making Model

Reference: Brandner, A. et al. (2016). The Patient Portal of the Personal Cross-Enterprise Electronic Health Record (PEHR) in the Rhine-Neckar-Region. Exploring Complexity in Health: An Interdisciplinary Systems Approach, A. Hoerbst et al. (Eds.) [Citation:] O. Heinze and B. Bergh. A model for consent-based privilege management in personal electronic health records. Stud Health Technol Inform 205(2014): 413-7.
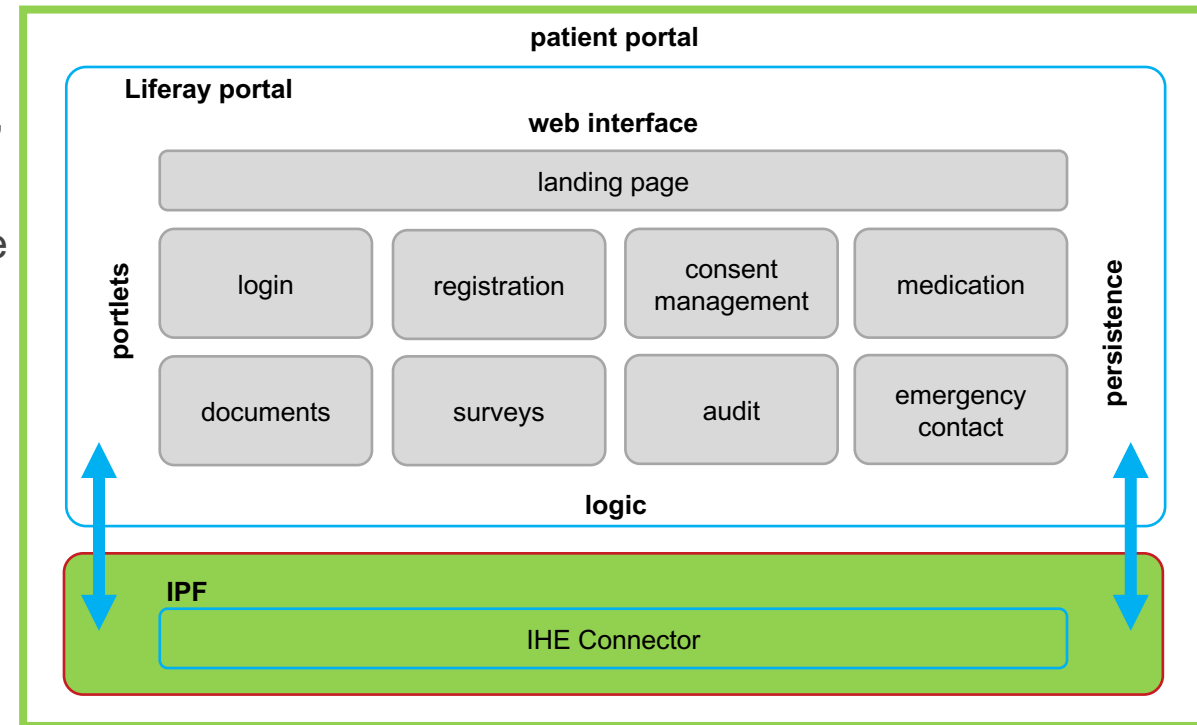
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Patient-Centered eConsent Model

Consent-based Privilege Management Model

- Patient access via a portal connected to a "personal cross-enterprise EHR" (PEHR)

- Patient creates a "personal healthcare team," selects providers on the team, and then chooses "document classes or types" that the team can access
  - Can restrict time period
  - Patient can view who has accessed what documents

- Interoperable with IHE-based architectures

Architecture of the patient portal

Reference: Brandner, A. et al. (2016). The Patient Portal of the Personal Cross-Enterprise Electronic Health Record (PEHR) in the Rhine-Neckar-Region. Exploring Complexity in Health: An Interdisciplinary Systems Approach, A. Hoerbst et al. (Eds.) [Citation:] O. Heinze and B. Bergh. A model for consent-based privilege management in personal electronic health records. Stud Health Technol Inform 205(2014): 413-7.

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Patient-to-Many Approach for Informed Consent

Industry shift to ACO models and growth of Patient-Centered Medical Homes are leading healthcare organizations to play a greater role in care delivery. This shift should also lead to a change in how informed consent should work

Instead of traditional patient-to-physician, informed consent should be between the patient and the organization, with other healthcare professionals involved in the patient's care included

"

"Complexity of process requires collaboration of members, case mgt, providers, community resources."

~Director, Regional Health Plan

Reference: Campbell, K. & Parsi, K. (2017). A New Age of Patient Transparency:
An Organizational Framework for Informed Consent. The Journal of Law, Medicine & Ethics, 45, 60-65.

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Shared Decision-Making Model for HIE and ACP

- Research conducted to develop a user interface with iterative end-user feedback

- eConsent application intended for use by the patient to inform the patient of benefits and risks of sharing personal health information via an HIE

- Effectiveness of application-based eConsent only
  - 70% had moderate to low comprehension of HIE and implications of granting consent (ie, not well-informed)

"The legal doctrine and ethical norm of informed consent and its deficiencies, particularly its concentration on physician disclosure of information rather than on patient understanding, is what led to the development of shared decision-making as a way to enhance informed consent…"

Reference: Ramos, S.R. (2017 Nov). User-Centered Design, Experience, and Usability of an Electronic Consent User Interface to Facilitate Informed Decision-Making in an HIV Clinic, CIN

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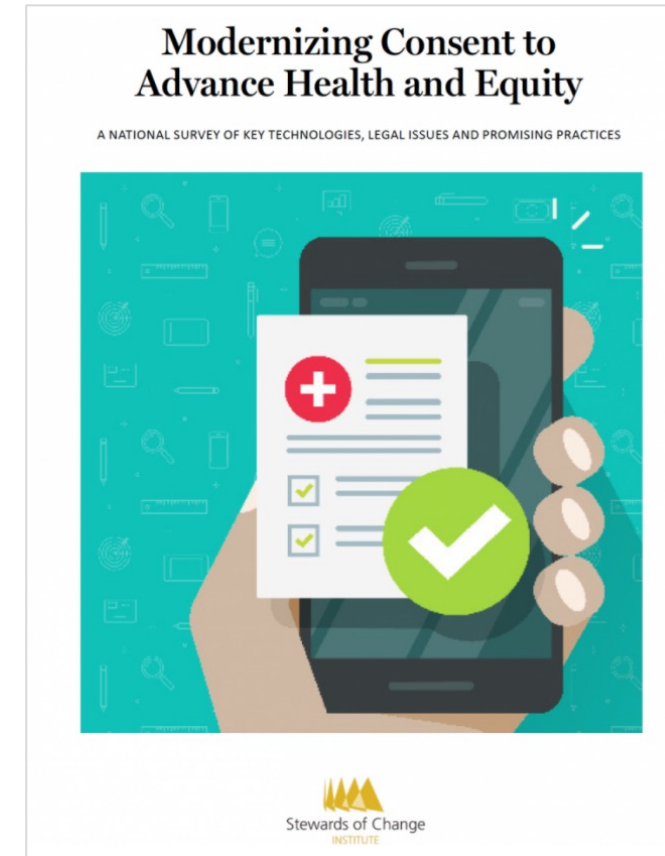# Stewards of Change Institute Consent Scan

The Problem

- Antiquated consent processes and information distributed across the web in myriad systems that are not easily accessible

- Current systems obstruct information sharing within and across sectors

- A critical need to improve racial equity, socioeconomic disparities and outcomes
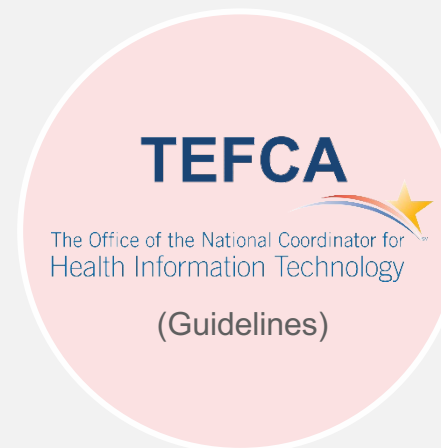
The Goal

- Improve health, well-being and equity by significantly advancing consent services

The Need

- First examination/aggregation of consent-related activities in a decade

- Urgency in obtaining and utilizing learnings to inform action/implementations

Modernizing Consent to Advance Health and Equity

A NATIONAL SURVEY OF KEY TECHNOLOGIES, LEGAL ISSUES AND PROMISING PRACTICES

Stewards of Change
INSTITUTE

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SAMPLING of eConsent Activities

Is the timing right for an eConsent Community of Practice?
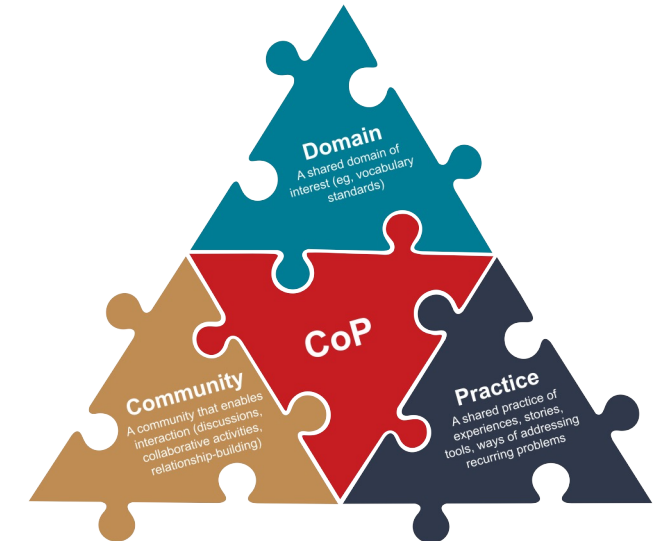
What is a community of Practice?

What is a Community of Practice?

- A ***Community of Practice*** is a group of people who share a concern, a set of problems or a passion about a topic and who deepen their knowledge and expertise in this area by interacting on an ongoing basis

- **Domain** — the shared interest that provides the incentive and passion for the group to come together.

- **Community** — the group of people who come together with a common interest, who share their perspectives and knowledge with one another.

- **Practice** — the agreed upon ways of formalizing and implementing the collectively developed knowledge and solutions that further the community's mission.

- This includes ***developing and implementing new technology or best practices, innovation and problem solving, conducting research, and developing standards.***

Domain
A shared domain of interest (eg, vocabulary standards)

CoP

Community
A community that enables interaction (discussions, collaborative activities, relationship-building)

Practice
A shared practice of experiences, stories, tools, ways of addressing recurring problems

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Potential Use Cases in eConsent Community of Practice

Advance Care Planning

Social Services/Health Equity (Project Unify)

Maternal and Infant Health

Thank You

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