

# Consumer Mediated Exchange

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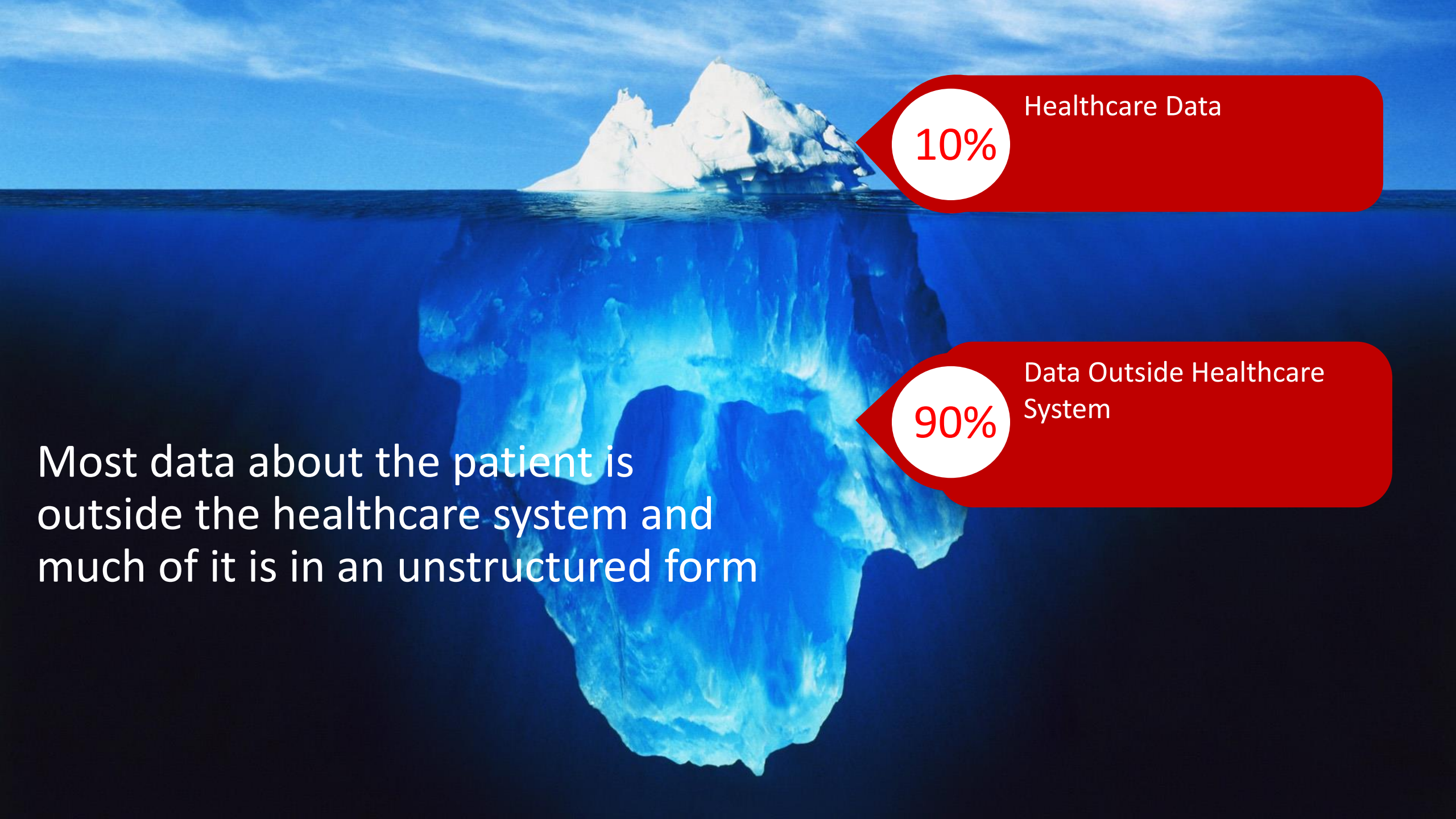
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# A Value-Based Care World is Uncharted and Filled with Risk and Uncertainty

<https://www.youtube.com/watch?v=skchMGisZTg>

- Barriers:
  - Longitudinal data (Claims and Clinical and Other)
  - Payment Models
  - Structural Issues in Healthcare
  - Patient Engagement
  - Interoperability
  - Data outside healthcare





Healthcare Data

10%

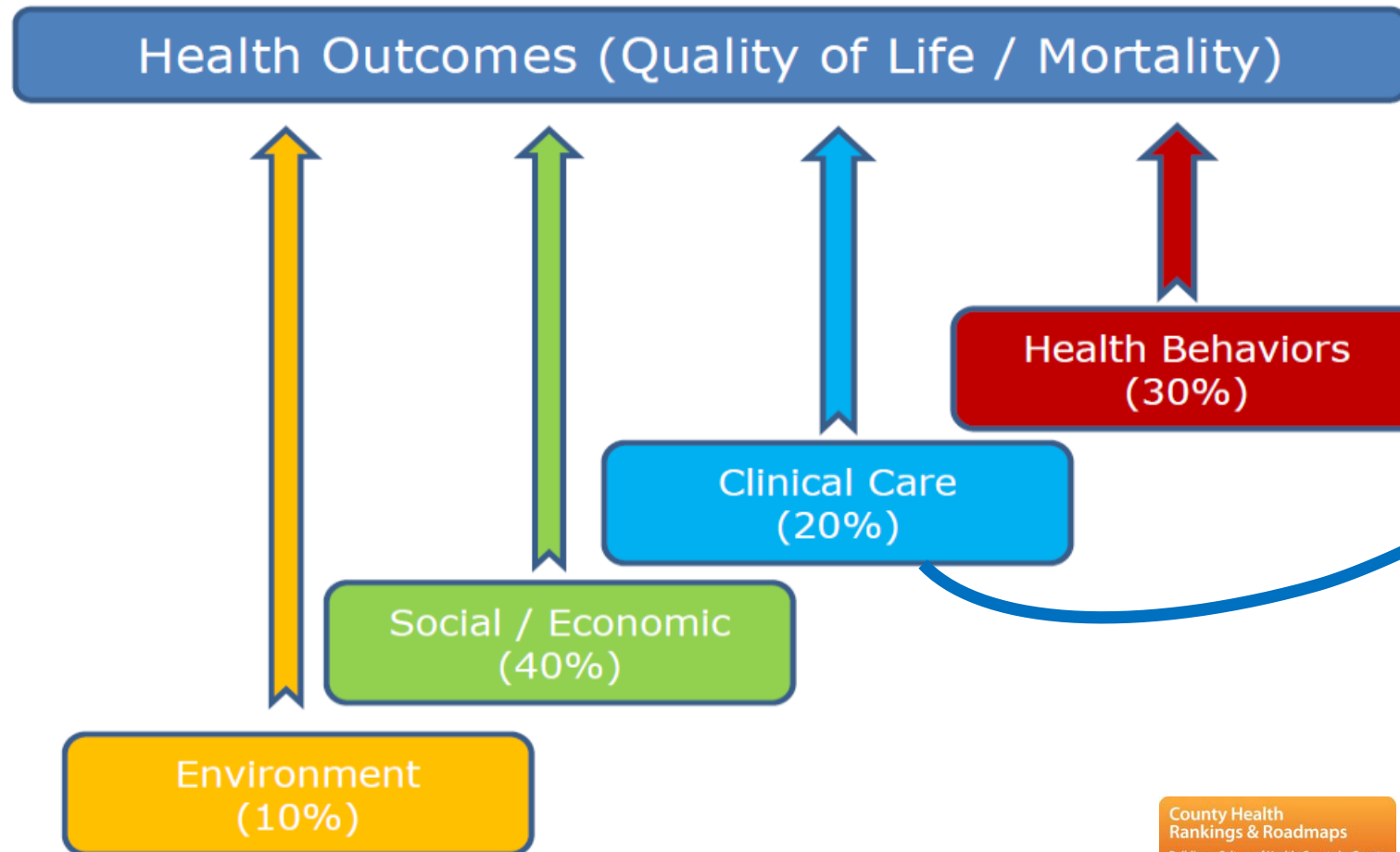
Data Outside Healthcare  
System

90%

Most data about the patient is  
outside the healthcare system and  
much of it is in an unstructured form

# Value-Based Care: It's More than Clinical Data

## Determinants of Health Outcomes – Clinical Care



Clinical Care is estimated to represent **only 20%** of overall outcomes (measured by length and quality of life).

Market needs a greater amount of actionable data, validated measurement and tools

## Accenture Consumer Survey on Patient Engagement

- 57% of consumers track their own health data
- **84% of consumers think they should have complete access to all of their EHR data**
- **40% of consumers would consider switching providers to obtain online access to their EHR data**
- 71% of consumers feel they should be able to **update** their electronic health records

Source: [http://www.himss.org/ResourceLibrary/genResourceDetailWebinar Reg.aspx?ItemNumber=27250](http://www.himss.org/ResourceLibrary/genResourceDetailWebinarReg.aspx?ItemNumber=27250)

# Agenda

- What is the state of consumer mediated healthcare exchange
- Regulatory changes that impact patient access to data
- Barriers to consumer mediated exchange
- How mobile technology can enable consumer ownership of their data

## Background: Interoperability

- The Health information exchange (HIE) market is projected to reach USD 1,545.0 Million by 2020 from USD 990.6 Million in 2015, at a CAGR of 9.3%.
- Existing HIE market largely grew thru funding from HITECH to address EHR interoperability, and it is largely provider focused and exist at local/regional or state level.
- Most are connected to a national HIE network (query based) and increasingly, large EHRs allow exchange thru this type of HIE or via a direct secure message (email).
- Most believe that HIEs are not fully mature or being widely used due to their limitations and lack of a sustainable business model.

# HITECH

- In March 2010, as part of the Health Information Technology for Economic and Clinical Health (HITECH) Act, the ONC [awarded](#) funds as part of the State Health Information Exchange Cooperative Agreement Program.
- State designated HIE entities received nearly \$548 million through this program, which funds states' efforts to rapidly build capacity for exchanging health information across the healthcare system both within and across states, according the ONC.



# **HIE: Solution to Interoperability**

## **Health Information Exchange was intended to address key issues surrounding**

- Quality of Care Improvement
- Cost Containment of Health Care
- Health Care Information Accessibility

## **Promise**

- Promoting the secure exchange, use and sharing of patient information
- Reducing the frequency of medical redundancy & errors
- Providing complete record of the patient's health encounters and interactions
- Improving patient outcomes individually at the clinical level and in aggregate at the public health management level
- Improving care coordination
- **Empowering patients to become more involved in monitoring and managing their own health care**

**YET.... Interoperability is still largely focused on providers and unsolved...**

# Forms of Health Information Exchange

## Query-Based Exchange

- Query-based exchange is used by healthcare professionals to search for clinical sources on a patient. This type of exchange is often used during emergency care.
- Limited based on knowing where patient has the data

## Directed Exchange

- Directed exchange allows healthcare providers to quickly and securely send patient information to other healthcare professional.
- Patient referrals, lab orders and results and prescriptions are easily and securely sent via the internet in encrypted files; it's as simple as sending an email.

## Consumer-Mediated Exchange

- Consumer-mediated exchange allows patients to manage their healthcare information online just as they would manage their finances online with banking.
- A consumer-mediated exchange allows patients to be in control of their vital information and can assist in coordinating care.
- Patients can provide other healthcare professional with their medical histories, assist in updating personal information and billing issues.

# Ongoing Challenges of Healthcare Interoperability

- **Technical View – Sharing of data is complicated:**
  - Medical records are voluminous and complex
  - Patient privacy - regulations vary by state
  - Security of patient information -- access controls in a mobile and disparate environment
  - Interoperability standards are still evolving
  - Patient Identification without a national standard
- **Business View – in search of a sustainable model:**
  - Paradigm shift – Competitors must be willing to share certain patient medical information with one another
  - Focus moves from who controls the patient data to how a larger pool of available patient data can be used to better treat the patient
  - **Business Model/ Sustainability is the ultimate challenge**

# Healthcare v. Banks

- **Do you know about an app that allows you to securely integrate multiple banking accounts into one view?**
- Many patients, particularly those with complex chronic or life-threatening conditions (e.g., transplant, advanced cancer), often have multiple portals from multiple provider organizations and specialists.

[How Close Are We to Consumer-Mediated Exchange?](#) Posted on [May 20, 2015](#) by [John Sharp, MSSA, PMP, FHIMSS](#) by **Sri Bharadwaj**, *president-elect, Southern California chapter of HIMSS; member, HIMSS Value of Provider-Patient Engagement Task Force; and director, information services, UC Irvine Health*

# HIPAA and Information Blocking

- **Under provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), providers must share patients' records within 30 days on request.**
- But health providers' data about their patients is a valuable economic asset that some doctors and hospitals are understandably reluctant to share with their competitors down the street.
- Many patients stick with clinicians and hospitals in part because that's where their records are. If the records can travel, so may patients, taking their business with them.
- **Also, many providers believe that they – not patients — own that information, and have no obligation to share it.**
- A recent [federal report cites this “information blocking” by providers](#) as an important obstacle to HIE. Legislative and regulatory remedies to information blocking are under review, but there may be another, equally powerful route to HIE: giving patients their records so they can decide who can have them and when.



## Mindset or Culture: Data is Power

- One impediment is a health system mindset or business model that sees patient data as a proprietary asset.
- Rather than creating affinity by offering an excellent experience, they want to do it by making it hard to move.
- Data are being sold in ways that bypass patient.
- We need to create a culture where this is done in a way that minimizes dependence on data holders/custodians
- The consumer should be in control. There needs to be stringent privacy and security, and no data moves without patient permission.

# 2017 ACI Transition Measure: View, Download, or Transmit (VDT)

Under the [Merit-based Incentive Payment System](#) (MIPS) pathway of the MACRA Quality Payment Program, the [Advancing Care Information](#) (ACI) category replaces the Medicare EHR Incentive Program (Meaningful Use).

**Patient Electronic Access: View, Download, or Transmit (VDT).** At least one patient seen by the MIPS eligible clinician during the performance period (or patient-authorized representative) views, downloads or transmits their health information to a third party during the performance period.

## Reporting Requirements

- **Numerator:** The number of unique patients in the denominator (or their authorized representatives) who have viewed online, downloaded, or transmitted to a third party the patient's health information during the performance period.
- **Denominator:** Number of unique patients seen by the MIPS eligible clinician during the performance period.

# Data Ownership: Legal Perspective

- **Patient Records: The Struggle for Ownership.** “There is no consensus on who owns medical records.
- The Health Insurance Portability and Accountability Act (HIPAA) does not specify ownership, and state laws are inconsistent.
- **Only New Hampshire has a law stating that patients own their medical records.** In 20 other states, providers own them. The rest of the states have no legislation addressing the matter, according to an analysis of state laws by Health Information & The Law, a project of the George Washington University’s Hirsh Health Law and Policy Program and the Robert Wood Johnson Foundation.
- Legal opinions on the matter differ as well. Daniel Shay, JD, an attorney with Alice Gosfield & Associates in Philadelphia, says, ‘The general understanding of the legal community is that patients own their records, or it’s their interests that are ultimately paramount.’
- Michael Bossenbroek, JD, a partner in Wachler & Associates, of Royal Oak, Michigan, says Michigan doesn’t have a clear rule regarding record ownership. ‘The default setting is that the records belong to the provider who has the control over it,’ he says.” ([Medical Economics, 12.10.15](#))

Is This Consumer Mediated Exchange Real?

# Consumer-mediated health information exchanges: the 2012 ACMI debate.

[J Biomed Inform.](#) 2014 Apr;48:5-15. doi: 10.1016/j.jbi.2014.02.009. Epub 2014 Feb 20.

- The American College of Medical Informatics (ACMI) sponsored a session on "Resolved: Health Information Exchange Organizations Should Shift Their Principal Focus to Consumer-Mediated Exchange in Order to Facilitate the Rapid Development of Effective, Scalable, and Sustainable Health Information Infrastructure."
- Those supporting the proposition emphasized the need for consumer-controlled community repositories of electronic health records (health record banks) to address privacy, stakeholder cooperation, scalability, and sustainability.
- Those opposing the proposition emphasized that the current healthcare environment is so complex that development of consumer control will take time and that even then, consumers may not be able to mediate their information effectively.



# **CARIN [Creating Access to Real-time Information Now through Consumer-Mediated Exchange] Alliance**

- Purpose: On July 7, 2016, David Blumenthal, David Brailer, Aneesh Chopra, & Leavitt Partners co-convened a multi-sector group
- Attendees: Over 45 participants representing the following sectors attended the meeting: Consumers, Providers, Payers, Government, etc
- As a follow-up to the inaugural meeting on May 26, 2016, this meeting focused on what the alliance is trying to achieve, the barriers that exist in consumer mediated health information exchange, and what the group can do to remove those barriers.

<http://carinalliance.com/wp-content/uploads/2017/08/CARIN-Community-Meeting-Summary-07072016.pdf>

# **CARIN Actions (not full list)**

## **Assessing the impact of CMS' APM regulations**

- As CMS continues to propose regulations related to MACRA, APMs, and MIPS, develop a strategy for responding to those regulations during the NPRM process to ensure the liberation of patient data will not be curbed.

## **Hackensack technology partnership**

- Develop an ecosystem of providers in the tri-state area who will begin to share data across organizations. Develop a case study regarding how Hackensack implemented their solution.
- **Work with other interested organizations on how Hackensack was able to build accessible consumer health information using the FHIR APIs.**

# Precision Medicine Initiative

<https://allofus.nih.gov/>

- The director of the Center for Outcomes Research and Evaluation at Yale-New Haven Hospital in Connecticut, Krumholz argues that putting the patients in control of their data and making it easier for them to participate in research has the potential to disrupt traditional models of research
- PMI is creating the ability for consumer-mediated exchange, he said. “It could be a means by which we can leverage a partnership with people and potentially decrease the cost of data acquisition and improve the accuracy and scope of data being collected.”

# NATE and CommonWell

- The National Association for Trusted Exchange (NATE) and CommonWell Health Alliance® announced that each would become a member of the other's organization.
- **They have agreed to establish a mutual synergistic and complementary relationship with the goal of enhancing cross-vendor interoperability to better assure provider and patient access to health data regardless of where care occurs.**
- NATE is a not-for-profit membership association focused on enabling trusted exchange among organizations and individuals with differing regulatory environments and exchange preferences...

## Consumer Mediated Exchange: HRBA

- The left-leaning Progressive Policy Institute and the right-leaning Heritage Foundation. These two organizations supported a bill in Congress that had bipartisan support entitled “[the Independent Health Record Trust Act of 2007](#).”
- Today, the original policy analysts for these organizations remain steadfast in their support of this concept as members of the [Health Record Banking Alliance Advisory Board](#) (HRBA), together with HIMSS Vice President Tom Leary and other leaders and chaired by Ted Shortliffe, MD, PhD, the former president and CEO of the American Medical Informatics Association (AMIA).
- <https://participatorymedicine.org/epatients/2014/04/its-time-to-c-me-see-me-consumer-mediated-exchange.html>



# What is an independent health record trust/bank?

- A health record bank (HRB) or trust is an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records, obtained from multiple sources, and assuring that the individual controls who accesses the records.
- Should Congress reconsider establishing such a regulated, bank-like infrastructure (with opportunities for multiple technical infrastructure vendors) that also facilitates value creation as shown by the SMART Platform work funded by HHS ([www.smartplatforms.org](http://www.smartplatforms.org))?
- With more opportunities for consumers (patients) to view or obtain their health information from separate “silos,” including genomic mapping and associated disease risk data, and the need to organize and share Patient Generated Health Data with physician/hospital EHRs, the timing has never been better to consider even better options for C-ME facilitation.

# Lessons Learned from Past Efforts

- Earlier efforts to create personal health records by companies such as Google, Microsoft and Dossia.
- Ultimately failures because they were more like scrapbooks with no way to move the data.
- They didn't focus enough on the use case of what patients would do with the data once they had it. Healthcare is local and Provider-Patient relationship is essential.

## Challenge: Unique Patient Identifier?

- The 1996 Health Insurance Portability and Accountability Act (HIPAA) called for a the creation of “a standard unique health identifier for each individual.” [national patient identifier (NPID)]
- **NPID:** Essentially a social security number (SSN) for medical records, a unique NPID would be assigned to every person in the U.S. and tied to their entire medical history, from birth to death.
- Unique medical IDs are not a new idea. Over 30 countries, including Singapore, Australia, and Britain,
- In 1998, Congress removed the provision of the unique patient identifier from HIPPA and even prohibited using federal funds to establish an NPID.

# Mobile enabled Consumer Mediated Exchange

- Mobile Devices/Wearables given its pervasiveness and proximity represents our best chance to collect data and engage our patients
- Mobility solution represent a key component to providing a portable and easy to use access and management of their data
- The challenge is the network effect... or lack there of...
- Technology Enablers like Block Chain combined with disruptors such as Apple provide some hope that some of the policy and cultural challenges could be addressed.

# ONC announced the Phase 2 winners of its Move Health Data Forward Challenge [Technology is there]

The ONC launched the competition to get companies working on “consumer-mediated exchange” of health information. Already, the ONC's Nationwide Interoperability Roadmap's 2015 to 2017 goals include enabling consumers to send, receive and otherwise use their health data.

- Some of the winners of the contest's second phase:
  - CedarBridge Group makes CareApprove, an app that lets patients give and take away their providers' access and ability to send and receive their health data. A plug-in allows providers to connect the app to electronic health records.
  - HealthToGo, created by software company EMR Direct, can be used to store healthcare data from multiple providers, thereby creating a longitudinal patient record. Like CareApprove, the app allows patients to grant or revoke access to the data.
  - Foxhall Wythe's Docket relies on end-to-end encryption for security and fast healthcare interoperability resources, or FHIR, a set of standards for interoperability, so patients can share information from multiple healthcare providers.
  - Lush Group's HealthyMePHR pulls data from patients' primary care EHRs. Through the FHIR-based platform, patients can choose how their information is shared by granting specific access.

## iShare Medical<sup>SM</sup>

- iShare Medical<sup>SM</sup> Messaging provides you with an iShareID Direct address that uniquely identifies you and can be used to get medical records from all your providers into one central location.
- In addition, iShare Medical<sup>SM</sup> Messaging can be used to safely and securely send and receive messages to and from your doctor or other medical providers.
- Your iShareID Direct address looks and works like an email address, but this is no email system. iShare Medical<sup>SM</sup> Messaging can only be used with your medical providers who have a secret key that will allow safe and secure exchange messages over an encrypted network.



## Health Companion<sup>®</sup>

- Health Companion is a tool to engage, empower, and inspire people to achieve better health at lower cost.
- Health Companion has four major features.
  - A secure life-long personal health record (PHR).
  - A personal, confidential health network to communicate with your providers, health coaches, specific communities, friends, and family. You are always in charge of your information and you decide how, when, and with whom it is shared.
  - A tool for managing your medical bills, insurance claims, and health accounts such as FSA and HSA.
  - A tool for personalized preventive health & wellness recommendations and follow-ups
- Health Companion is a certified Patient Portal under Meaningful Use, and an accredited provider of Direct messaging services as a HISP, CA, and RA.

## Secure Exchange Solutions

- Secure Exchange Solutions is the leader in Direct Secure Messaging for consumers.
- Over 10 million patients have access to Direct Secure Messaging through our network of patient portal and patient application partners.
- Secure Exchange was the first independent HISP to have a consumer anchor accepted as part of DirectTrust, empowering consumer health applications to exchange data with physician applications without the need for custom interfaces.
- They offer the most flexible deployment options for easy integration and rapid time to market



## **Humetrix: Mobile Health Platform for consumer Engagement, Value Based Care and Personalized Medicine** <http://www.ibluebutton.com/consumers.html>

- <https://medcitynews.com/2014/08/california-direct-selects-humetrix-mobile-ehr-app/> California HIE to use Humetrix iBlueButton app
- [With Cerner, Humetrix Demonstrates DIRECT and Mobile Enabled Provider-to-Patient EHR Exchange for Interoperability at Health 2.0 Fall Conference](#) - Santa Clara, October 1, 2017
- [Humetrix Focuses on Patient-Mediated Data Exchange Applications for Interoperability at ONC Direct Exchange Workshop](#) - Washington, DC - June 2, 2017
- [At HIMSS Humetrix Focuses on Patient-Mediated Data Exchange Applications for Interoperability](#) - Del Mar, CA - February 9, 2017
- [At CES, Humetrix Shows Technology to Help Consumers Drive Needed Healthcare Reform](#) - Las Vegas, January 5, 2017

# Health Wallet

- HealthWallet deploys a suite of best-in-class digital healthcare technology features to bring convenience and transparency to the already complex and confusing healthcare system.
- They put members in control of their health costs. Through on-demand access to providers and the ability to understand the cost for prescriptions and medical procedures before they get them.

<http://www.thehealthwallet.com/home>

# Argonaut Project on health records, interoperability could get the push it needs with Apple Healthkit

- Apple is said to be working with the Argonaut Project to integrate more electronic health data with the iPhone, a move experts say could go a long way towards advancing medical record interoperability.
- Participants in the Argonaut Project – an HL7-led initiative focused on expanding the use of open standards for health data exchange, notably HL7's FHIR specification
- Some of the industry's most notable vendors and providers: Accenture, athenahealth, Cerner, Epic, McKesson, Meditech, Surescripts, The Advisory Board Company, Beth Israel Deaconess Medical Center, Boston Children's Hospital, Intermountain Healthcare, Mayo Clinic, Partners HealthCare...

<http://www.openhealthnews.com/news-clipping/2017-06-27/apple-consulting-argonaut-project-health-records-interoperability-could-get>

## **To move forward with consumer-mediated HIE, several steps will be required.**

- First, the federal government needs to more aggressively enforce HIPAA's information-sharing provisions.
- Second, we need a new cohort of health-data stewards who can help patients manage their own data. Some process of private certification or public regulation will likely be necessary to assure that these new entities can be trusted to discharge this sensitive and complex responsibility.
- Third, we will need to perfect the technical ability of these new data stewards to access the electronic-data repositories of health-care providers.

# WHY DOES THIS MATTER ? Most current models treat Bob and Dave the same

(same sex, age, illness burden but different outcomes)

Bob

- **43yo**
- **Diabetes**
- **Hypertension**
- **COPD**

- Lives at home with his wife
- Employed with good health insurance
- Engineer who uses apps and spreadsheets to manage his conditions



Dave

- **43yo**
- **Diabetes**
- **Hypertension**
- **COPD**

- Lives alone
- Occasionally employed, no health insurance
- Low literacy
- Unsure how to manage his condition



**Difference in OUTCOMES**

**\$ COST \$\$\$**

Unmasking Social Determinants reveals inequity in resource utilization and outcomes.

# A Value-Based Care World is Uncharted and Filled with Risk and Uncertainty

**SOLUTION: INTEROPERABILITY** Focused on Consumers/Patients

**TECHNOLOGY:** Block Chains, AI, etc

**INDUSTRY DISRUPTION:** Apple and Google