Informed Consent Can Be a Driver of Inequity

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September 27, 2022

Health Leads

Health, well-being and dignity for every person in every community.

We partner with communities and health systems to address systemic causes of inequity and disease. We do this by removing barriers that keep people from identifying, accessing and choosing the resources everyone needs to be healthy.

Introduction

__The expansion__ of social care programs to address social determinants of health __increased demand__ for health information technology __to collect, store and share data__.

Healthcare investments in “social determinants of health” programs are on the rise…

- Billions now flowing into parallel healthcare social needs segment:
  - *Public sector investment:* $250 million in CMS’ Accountable Health Communities and CPC+ pilots
  - *Private sector investment:* Social needs tech market valued at $88 million to $92 million, with 12-15% adoption increase by 2023*
- Health Leads saw a significantly increased inbound request for expansion and / or technology

U.S. News & World Report

“Some Hospitals Prescribe Food, Take Other Steps to Fight Food Insecurity”

Houston Chronicle

“Texas lawmakers look to Uber, Lyft to transport Medicaid patients”

Forbes

“To Keep You Healthy, Health Insurers May Soon Pay Your Rent”

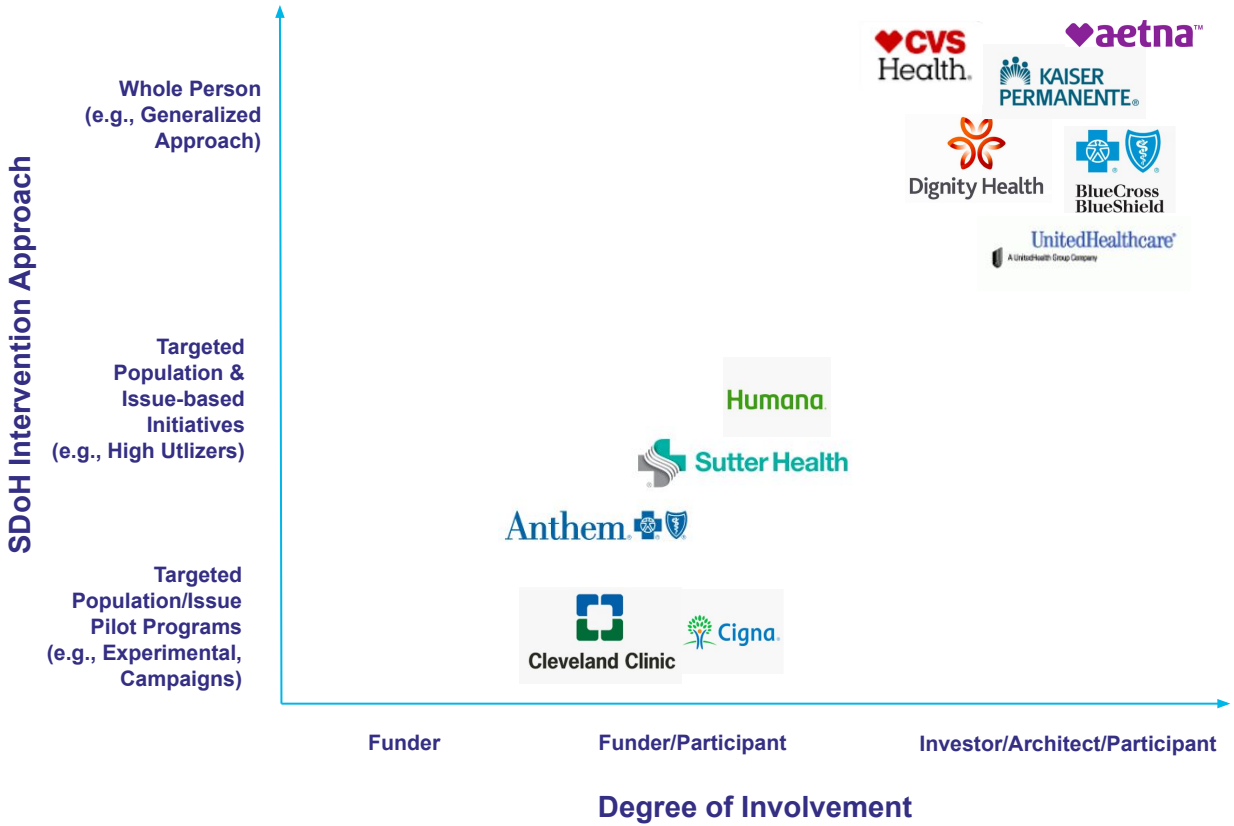
CNBC

“CVS pledges $100 million for community health programs”

*https://www.patchwiselabs.com/sdoh

…but the sector is still learning how to optimize their investment

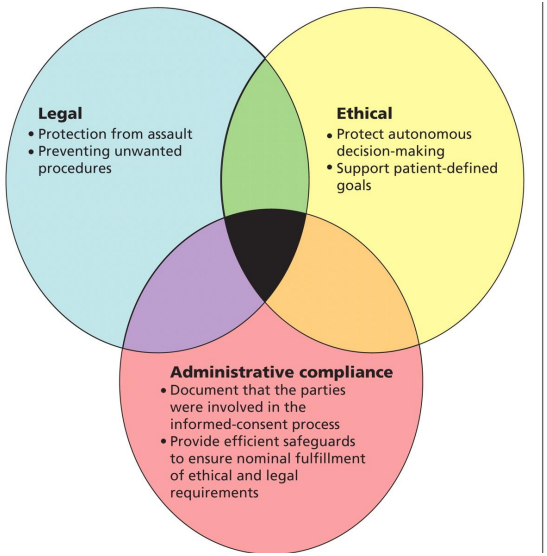
ILLUSTRATIVE ONLY

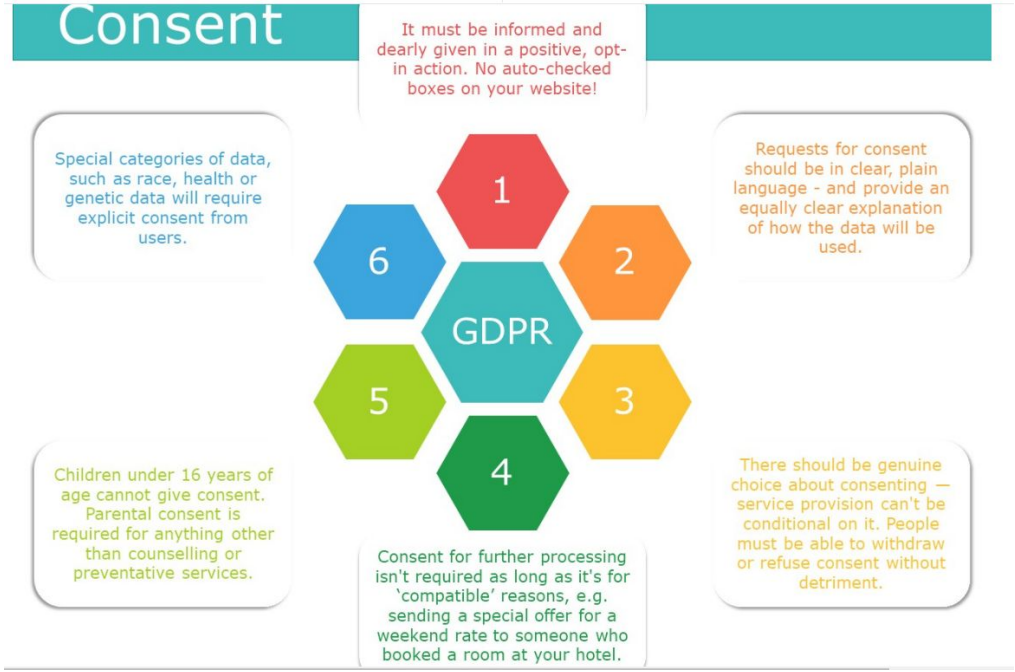


Key Observations

- Most investments have historically centered around a specific program (e.g., focus on specific population or targeted issues such as high utilizers, or those that are food insecure)
- Majority of programs are focused on enhancing screening and referral capabilities in the form of ad-hoc “pilot projects”
- Significant gaps in connecting a diverse set of investments initiatives together, or soliciting community input to inform program design
- More recently, payors and providers have begun to explore new ways to deepen their engagement with community in hopes of gaining better access and ownership over community

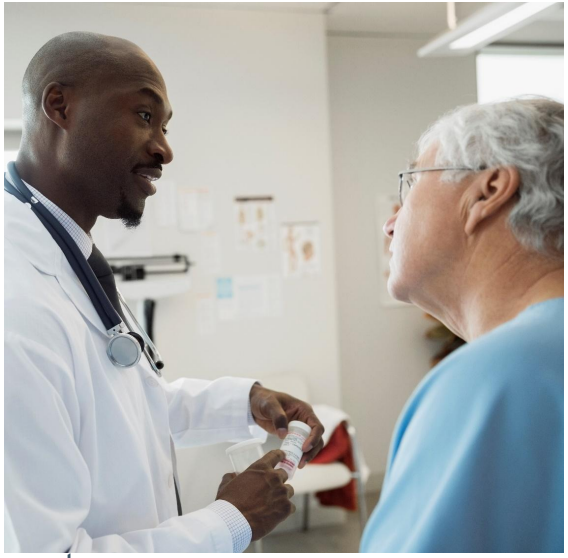
Informed Consent





Informed Consent for Clinical Treatment. Daniel E. Hall, Allan V. Prochazka, Aaron S. Fink
CMAJ Mar 2012, 184 (5) 533-540; **DOI:** 10.1503/cmaj.112120
https://elearning.bits.vib.be/courses/writing-a-data-management-plan/lessons/privacy/topic/informed-consent/

Case Study Exploration



Explore how Community Referral Networks manage Consent:

- Case Studies in:
  - Community Information Exchange (CIE)
  - Community Referral Network (CRN)
  - Health Information Exchange (HIE)

Using Focus Groups and Interviews:

- CBOs and patients identified issues and gaps with current processes
- Identified ways to rearchitect Informed Consent

Case Study: 211 San Diego CIE

"The informed consent process involves three key features:

(1) disclosing information needed to make an informed decision;

(2) facilitating the understanding of what has been disclosed;

(3) promoting the voluntariness of the decision about whether or not to participate.

In addition to legal compliance, the community driven governance structure includes an ethics workgroup to consider additional elements of consent and data sharing to build into CIE policies for participating partners and users.

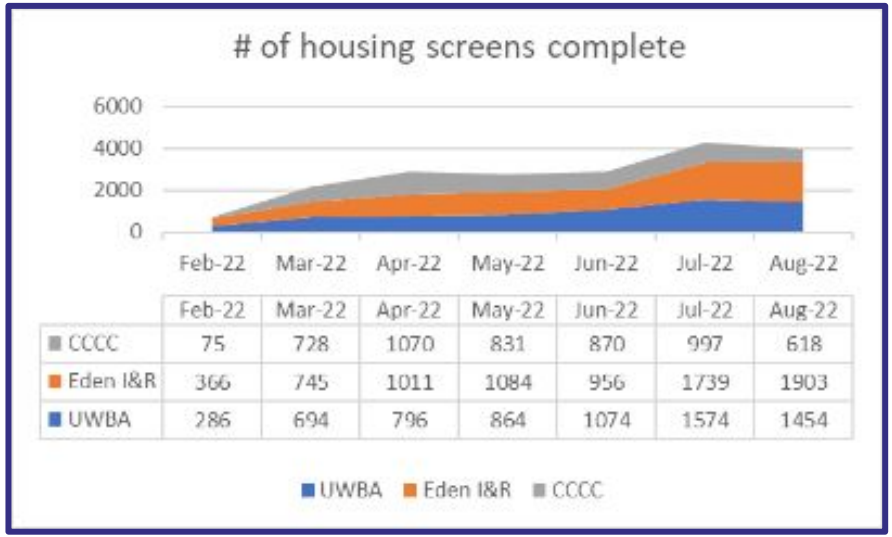
Source: 211 SD/CIE Toolkit (2019)

Case Study: Housing is Health

- Network is supporting individuals/families with housing rights information to prevent homelessness
- There were a three points of consent:
  - Call Center staff to administer proactive housing security questions
  - Incoming callers agreeing to answer the questions
  - Incoming callers agreeing to receive services to support resource gaps
- Call Center staff:
  - Identified that callers are waiting long periods of time before having to answer too many questions;
  - Concern of the lack of services available to meet identified needs

Solutions

- Obtain input from Incoming Callers on consenting to answer questions and received referrals
- Adjust when the housing security questions are implemented in the call;
- Implement simple workflow solutions to utilize the wait time to help surface potential housing security needs and triage the individual to the appropriate team (telephone tree)



	Feb-22	Mar-22	Apr-22	May-22	Jun-22	Jul-22	Aug-22
CCCC	75	728	1070	831	870	997	618
Eden I&R	366	745	1011	1084	956	1739	1903
UWBA	286	694	796	864	1074	1574	1454

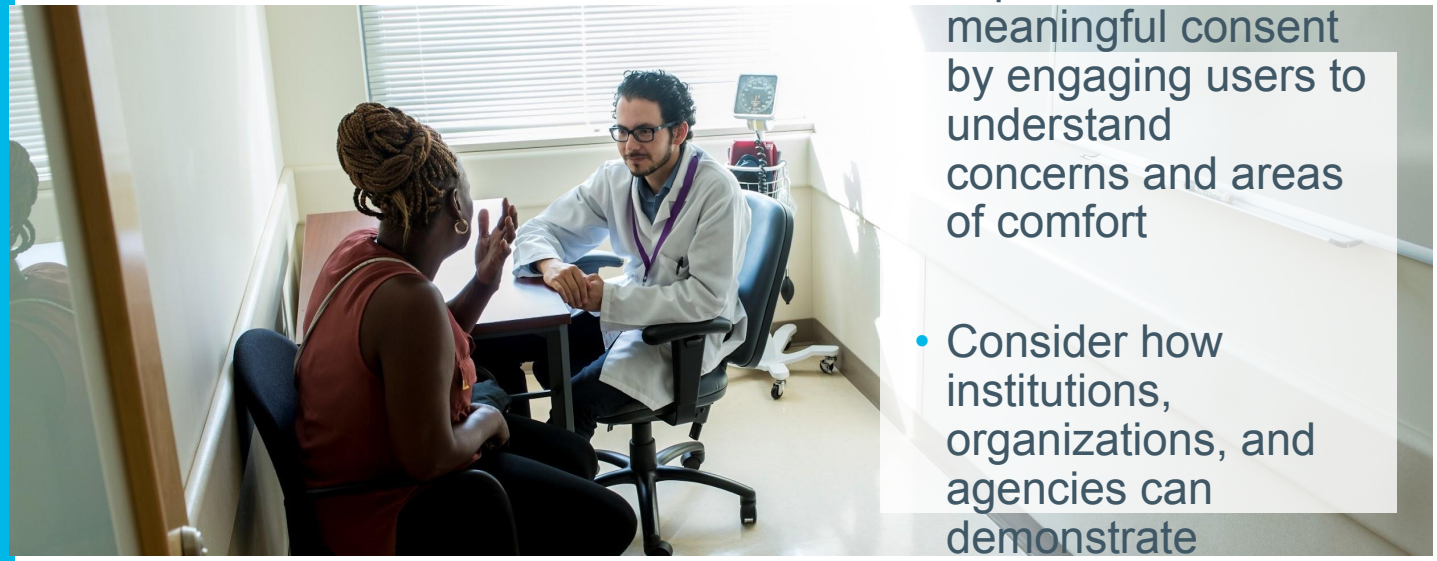
Case Study: HIE - NJ

- HIE seeks to expand participation in HIE network.
- Community Based Organizations & Local agencies
  - Consent varied – majority ‘blanket’ consent
  - Concern: who has access to the data
- Community members (experts)
  - Concern: Consent wasn’t meaningful; unclear meaning and perceived as a gate to receiving service
- Individual staff interviews (CBO & HIE)

Proposed Solution(s)

- Peer support to help patients navigate informed consent processes
  - Clear descriptions of the purpose of the consent
  - How data will be used
  - How data will be accessed
- Re-design the process for introducing informed consent to patients

Conclusion: Recommendations & Future Considerations



- Identify improvements to meaningful consent by engaging users to understand concerns and areas of comfort
- Consider how institutions, organizations, and agencies can demonstrate accountability