

CHP Bright Spot

Developing a Collaborative Consent Process

The AcademyHealth Community Health Peer Learning (CHP) Program aims to advance progress toward population health improvements through the expanded capture, sharing, and use of electronic health data from diverse sectors. Engaging ten Participant Communities and five Subject Matter Expert (SME) communities in a peer learning collaborative, the CHP Program builds community capacity and supports the identification of data solutions, acceleration of local progress, and dissemination of best practices and lessons learned. This Bright Spot profile highlights a key community activity or achievement that is grounded in practical experiences, notes key lessons, and shares useful insights relevant to those working as part of local initiatives to improve population health. Bright spots are intended to tell the story of a discrete project component, and offer inspiration for others.

Background & Context

The North Coast Health Improvement and Information Network (NCHIIN) is a non-profit health improvement and health information exchange (HIE) organization located in Humboldt County, CA. NCHIIN's purpose is to provide health information exchange in Humboldt and Del Norte counties, and to lead community health improvement initiatives. In 2015, NCHIIN partnered with the Humboldt County Department of Health and Human Services (DHHS) Housing Programs to begin exploring local interest in and capacity for cross-sector data exchange – in part to better address the complex physical, behavioral, and social care needs of patients and clients who are identified as “super-utilizers.”

In Humboldt County, these individuals may interact with numerous organizations and care providers, but experience little to no coordination across their encounters with the healthcare, social care, and law enforcement systems. While various community efforts have developed local competency and experience in working across multi-organization and multi-disciplinary teams, efforts to share data across sectors and collaborate via care platforms are just emerging. Bolstering these efforts is essential to comprehensively supporting super-utilizer clients across multiple systems of care, and mitigating the high-cost, repeat encounters, as well as poor outcomes for some of Humboldt County's most vulnerable residents.

NCHIIN and DHHS have partnered to enhance care coordination and reduce emergency department utilization by high-need, vulnerable clients served by permanent supportive housing and shelter programs. Over an 18 month period, NCHIIN and DHHS studied existing data management systems, explored opportunities for data sharing, and ultimately decided to purchase and implement a care coordination platform called ACT.md - a browser-based and mobile-friendly program that enables case managers to receive healthcare encounter alerts (notification of admission, discharge, or transfer at local healthcare facilities) for their clients in real-time. It also serves as a task management and communication platform to support cross-sector case management coordination and collaboration of individuals involved in a client's care.

Challenge Issue

NCHIIN and the DHHS team knew that client consent would likely be a necessary part of the project. The housing program uses the Homeless Management and Information System (HMIS) consent which permits sharing of information among partner agencies for care coordination and service enrollment purposes. While the team was able to amend the HMIS consent early on to include NCHIIN's name as a participating organization, it soon became clear that a more robust process would need to be developed to work towards informed client consent – without which, clients might sign a release of information permitting participation in the

Developing a Collaborative Consent Process

project, and not understand that their case manager would be notified of their hospital encounters. Knowing that confusion around the intent of the project and this exchange of information could lead to mistrust that would have the potential to undermine the client-case manager relationship, the team proceeded with a more proactive and collaborative approach.

Approach to Resolution

On the recommendation of a CHP Program technical assistance provider, NCHIIN staff met with case managers and clients from the Multiple Assistance Center (MAC) several times throughout the fall of 2016 to discuss the project and co-design consent documents. An initial meeting with the case managers captured existing workflow related to obtaining client concern, as well as their concerns regarding communicating with clients about the data sharing project. Case managers also speculated about potential causes of client concern related to such information exchange, and requested details about the client opt-out process.

Following the meetings with case managers, NCHIIN staff met with 10 clients of the MAC to share a vision for the proposed effort, and to elicit their insights, questions, and concerns. Overall, clients saw the value of connecting members of their care team, with many reflecting on the challenges of receiving fragmented and uncoordinated care from their healthcare and social care providers. Discussion about event notification was particularly robust and insightful. Specifically, it became clear that while clients were okay with their case manager being notified of their hospitalization or ED encounter, they did not want their case manager to know the reason for the hospitalization or emergency department visit. Clients identified that sharing such information would be a deterrent to participation. Upon hearing this, NCHIIN removed this data element from its planned exchange protocol.



Clients also asked four primary questions, which became the basis for a client FAQ that staff assembled as part of the suite of communication products to support the consent. Clients asked NCHIIN to articulate:

- What types of information will be shared?
- How will the information be used?
- How will client information be protected?
- How can clients opt-out of the project?

NCHIIN assembled the responses to these questions and a brief description of the project with a project illustration in a two-page hand-out for clients.

Based on these conversations, NCHIIN also developed a script for Case Managers to use when reviewing the consent process with clients, as well as an opt-out package to round out the consent support documents. This set of consent document resources was made available to Case Managers and staff two months prior to the launch of the ACT.md platform.

Upshot & Impact

Allocating time and resource upfront to co-design consent rules and documents was a critical step in streamlining the consent process and communicate with clients about the project. To date, the project has 180 clients in the ACT.md platform (the pilot goal was 100 clients), and none have exercised their right to opt-out. More importantly, the project team has received no reports of client concern or refusal to participate in the data sharing project.

Working with clients and case managers to develop consent communication tools was a rich and rewarding process. Clients were eager and willing to participate, and their input led to the development of products that will serve the team well beyond the pilot phases of the project. Case Managers also provided useful insight and strategy suggestion, and the process of working with NCHIIN to develop documents helped establish a trusting and productive relationship which served the team well throughout the duration of the project.

North Coast Health Improvement and Information Network partnered with the Humboldt County Department of Health and Human Services to support cross-sector data exchange and care coordination efforts for individuals served in permanent supportive housing programs. NCHIIN uses exports of client information and housing status from the DHHS Homeless Management Information System (HMIS) and the health information exchange to create pathways to share alerts for client encounters at local emergency departments and hospitals.

[Read the NCHIIN community profile](#)

This Bright Spot was produced as a part of the Community Health Peer Learning (CHP) Program. In 2015, the Office of the National Coordinator for Health Information Technology (ONC) awarded AcademyHealth \$2.2 million to cooperatively lead 15 communities in the CHP Program. Through this two-year program, AcademyHealth is working to establish a national peer learning collaborative addressing community-level population health management challenges through expanded collection, sharing, and use of electronic data. Learn more at www.academyhealth.org/CHPhealthIT.