AQUA

Pseudonymised, Patient-Linked Public and Population Health Data

Goal

AQUA is the Latin word for Water. AQUA is a CH-MRC initiative that, like water, evolves activities and research processes adapting as technology disrupts disciplines, organizations and jurisdictions to build resilient communities able to respond rapidly to threats and opportunities. Our goal is to enable public health, population health, and healthcare providers with access to privacy-protected, comprehensive health data and reduce burdensome data entry.

Overview

CH-MRC's AQUA initiatives address the technical, business, compliance, legal and ethical aspects with a goal of enabling the use of patient-linked, de-identified, detailed data for multiple purposes while protecting the privacy and interests of individuals. The work products of this AQUA effort will provide valuable insights and feedback to further population health, public health, precision medicine, whole-person care, clinical trials and community health.

The CH-MRC AQUA Initiatives identify and define the challenges and potential solutions to enable health data liquidity while protecting individual rights, privacy and complying with state and federal regulations. It is a regional multi-jurisdiction, a cross-sector effort spanning data from healthcare, state and local public health, and other data provided by statute or voluntarily. Combinations of policies, legacy and proprietary information systems, the quality, and consistency of data classification, and resources create health data silos.

Public health receives many different types of data, some very detailed with patient, family and provider information. This "Protected Health Information" (PHI) is critical for public health to receive and for researchers, academia and industry to use. Healthcare partners and the public must trust that all safeguards are in place, and continuously updated, to ensure privacy.

The traditional process to share health data between organizations is to execute more data use agreements and IRB Protocols with greater detail, controls, and accountability. However, this model is burdensome and increases the risk of exposure and the cost of overseeing, logging and auditing.

Multiple stakeholders from a broad spectrum of organizations and interests are participating in CH-MRC AQUA. This includes state and federal organizations, industry, academia, research organizations, NGOs, compliance, pharma and privacy rights advocacy to name a few. The AQUA initiatives provide three critical services for these organizations. The network enforces all policies, permissions and confidentiality requirements.

1. Collect quality health data and associate it appropriately to eliminate the need to recollect.
2. Link comprehensive data by providing permission at the attribute level to facilitate patient and organizations' policies, permission, confidentiality, and to aggregate the privacy protected data.
3. Curate the data to maximize actionable health information presenting it to the right people at the right time.

Background

Public health uses data provided for many purposes, including vaccination campaigns, infectious disease management, chronic disease studies and health improvement programs. Most of the analysis to transform data into actionable information occurs within public health with the remainder performed by outside organizations. These organizations range from small companies to research and academic institutions that negotiate specific agreements with public health, such as Data Use Agreements and Institutional Review Board (IRB) Protocols. Execution of these transactions can be costly and time-consuming, but they are critical to safeguarding data and the privacy of individuals.

Recently, Accountable Care Organizations and Precision Medicine began to demonstrate the potential of using health data in new ways to improve care, lower cost and evaluate quality and effectiveness on an ongoing basis. AQUA extends this to improve preparedness, population, and public health.

Participants

The process has started slowly based on funding/resources in Solano County and being expanded to Alameda County. Below are the leaders of the effort with internal resources and funding from the California County Medical Services Funding. :

- Dr. Bela Matyas (Solano County Public Health Officer),
- Dr. Michael Stacey (Solano County Medical Services Officer, FQHC),
- Alvaro Fuentes (Contra Costa-Solano Community Clinic Consortium) and
- Dr. Muntu Davis (Alameda County Public Health Officer)

Primary jurisdictions committed to accelerate and support are public health officers from Alameda, Contra Costa, Marin, Napa, San Mateo and Solano Counties as well as the public health officer from the City of Berkeley (separate health jurisdiction). Observing and ascertaining how and when to participate are Monterey, Santa Cruz, Santa Clara, San Francisco, Sonoma, Lake and Mendocino county health officers. Given the significant progress made, demonstrated value to date, and taking advantage of the potential incentives of Meaningful Use Stage 3, discussions have re-started with Nevada, Butte, Shasta, San Diego, Yuba, Yolo and Sutter County health officers.

Process

CH-MRC AQUA initiatives use surveys along with mandatory reporting to bridge data silos. The method of collection, delivery, and content of the surveys pushes the boundaries of traditional access to information to include patient-linked, and privacy protected mental health, reproductive health, substance use, immunizations data sets. Aggregating data from these surveys enable real “neighborhood and community-based” analysis with pseudonymised data across entire populations/sub-populations regardless of a care provider. Out-of-jurisdiction generated data (care provided elsewhere) is included within the scope and will be completed as funds and resources allow.

AQUA starts with one county with multiple Hospitals, Federally Qualified Health Centers, Military Health and Veteran Health that already receive health data. Once the initial operations in the county are in place, it will expand regionally. Currently, five counties have agreed to participate with eight more interested in evaluating their ability to engage.

The first step is to initiate the discovery and demonstration projects, engage with existing stakeholder collaborations spanning the impact areas, and define detailed pilot projects for the three Use Cases leveraging existing efforts: Certified Electronic Health Technology, California Initiatives such as the California Cancer Clinical Trials Program, and advances in public health data structure.

These surveys will augment other public health data (Core) including: immunizations, encounters (superset of syndrome surveillance to include observations, diagnosis, treatments), electronic public health case reporting (eCR), cancer case incidents, and electronic public health laboratory reporting (identified positives, de-identified negatives).

Surveys

1. Common information: Patient, Provider, Demographics, De-Identified and patient-linked (all)
2. Community Health Indicator Data (tobacco, exercise, smoking, A1C, Lipid Levels)
3. Social Determinants of Health (superset of NACHC PREPARE with community context)
4. Child autism screening (i.e. M-CHAT)
5. Child development challenges screening (i.e. Ages and Stages)
6. Behavioral health screening with follow-up screenings
7. Cancer Screening (identified positives, de-identified negatives)

Measurements of success

1. Core public health reporting, Meaningful Use, situation awareness and surveillance:
    a. Patient-linked
    b. Provider-linked

2. Common demographics and coding spanning data sets

3. Identification of potential candidates for clinical trials, starting with Cancer
   Identification of individuals in emergencies to provide medications and enhance prioritized care delivery

4. Patient and Healthcare system rights and privacy, establishing common Compliance and HIPAA guidance statewide and for research purposes

Health Impact in Five Area

1. **Cancer** with an initial focus on infectious and rapid impact (melanoma) cancers
2. **Asthma** – chronic care and improvement
3. **Infectious disease**s – with a focus on the ability be better scope the impact of, and mitigation effectiveness including Hep-A, Measles and STDs
4. **Behavioral health** – identification of at-risk individuals, and those at highest risk
5. **Disaster and Emergency** medical response and recovery

Workflow

Workflow and the impacts on the clinic, clinician AND THE PATIENT are critical for success. For each of these questionnaires, many companies provide some but not all. To avoid 4-5 tablets with questionnaires at the beginning of a visit, one tablet with prioritized questions is desired. That data can then be used to:

- Update the clinician, care worker or LCSW
- Obtain patient data to “confirm” from the EHR, and update afterwards
- Provide results/summaries in PDF or HTML for viewing and as documents in the EHR
- Provide patient-linked pseudonymised data for community, population and public health purposes
- Enable real-time, bi-directional algorithms to make recommendations to clinicians while protecting patient privacy (not batch)
- Enable research with de-identified data and “break glass” capability by the source

The project engage with ONC, CMS and NIH/NLM to ensure standardized result sets. All interfaces will be published as Open APIs to enable/encourage as much participation and innovation as possible.

CALIFORNIA HEALTH MEDICAL RESERVE CORP

California Health Medical Reserve Corp (CH-MRC) is a unit of the US Medical Reserve Corps, one of 991 units tapping 200,000 volunteers across the nation whose purpose is to strengthen public health, improve emergency response capabilities and build community resilience.

Based in Palo Alto, California, our members work with the Stanford University Center for Population Health Science and the technology community on health information aggregation and analytics in support of the MRC purpose. Health data collection and exchange at the community level improves when networked with other communities: We engage other counties and not for profits in the advances and pioneering by Solano County Public Health in California. By sharing lessons learned, we pursue opportunities to improve lives by better research and application of science and technology at the community level.

CH-MRC'S AQUA is a formalization, continuation and enhancement of numerous independent efforts in order to accelerate the application of information, communications and technology to meet Preparedness, Population and Public Health needs. Solano County California has become the base of this activity building off many direct and indirect grants and funding, best practices, lessons learned and innovation including:

- CDC Public Health Information Network and public health efforts across the Country
- CA State CalREDIE, CAIR and California Cancer Registry
- HHS HITECH and Meaningful Use
- The ONC San Diego Beacon Community / San Diego Health Connect
- DoD Uniformed Services University Regional Information Sharing and Situation
- Awareness (RISSA) program
- Arizona MEDSIS and SIREN Programs
- The DoD / HHS Federal Health Futures Group
- CA Cancer Data Modernization Program
- Kentucky Health Information Exchange
- Solano / CA County Medical Services Program Pilot project with Solano FQHCs