Patient-Centered Outcomes Research Institute

Workshop to Advance the Use of Electronic Data for Conducting PCOR

Lessons from the Field:

HMO Research Network Virtual Data Warehouse

pcori

Contents

HMO Research Network Virtual Data Warehouse (HMORN VDW)

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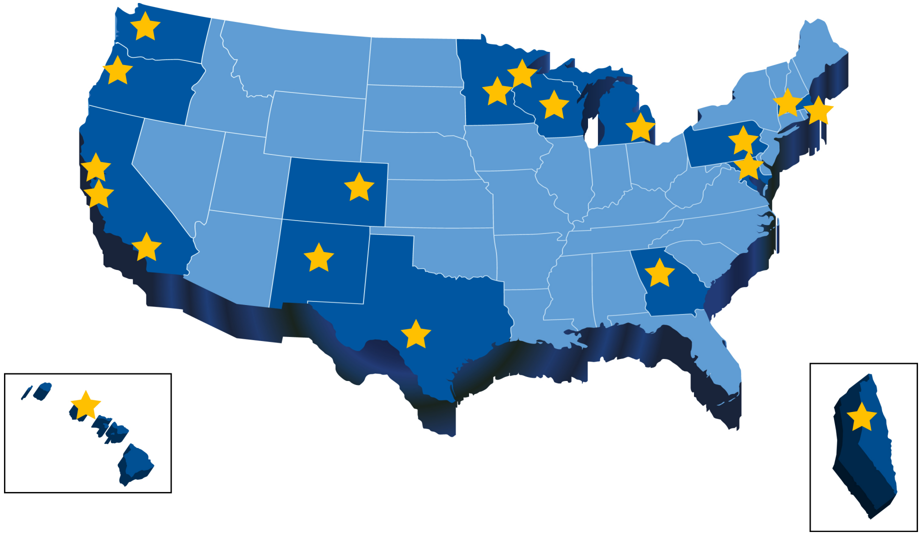
Background of the HMORN VDW

The HMORN is a consortium of 19 health systems with affiliated research centers committed to “closing the loop” between research and clinical care delivery



Founded in 2003, the HMORN VDW was originally created by one of the HMORN’s consortium projects – the NCI-funded Cancer Research Network (CRN), in order to:

- **Reduce resources** needed to create high quality data sets for each new study
- **Promote understanding and valid use** of complex real-world data

Background of the HMORN VDW

Now governed and supported by the HMORN Board, the HMORN VDW’s **expanded breadth and depth** allow the model **to support research on virtually any disease topic**

Research activities supported by the HMORN VDW include:

- Behavioral and mental health
- Cancer
- Comparative effectiveness
- Complementary and alternative medicine
- Communication and health literacy
- Dissemination and implementation
- Epidemiology
- Genomics and genetics
- Health disparities
- Health disparities
- Health informatics
- Health services and economics
- Infectious and chronic disease surveillance
- Drug and vaccine safety
- Primary and secondary prevention
- Systems change and organizational behavior

HMORN VDW at a Glance

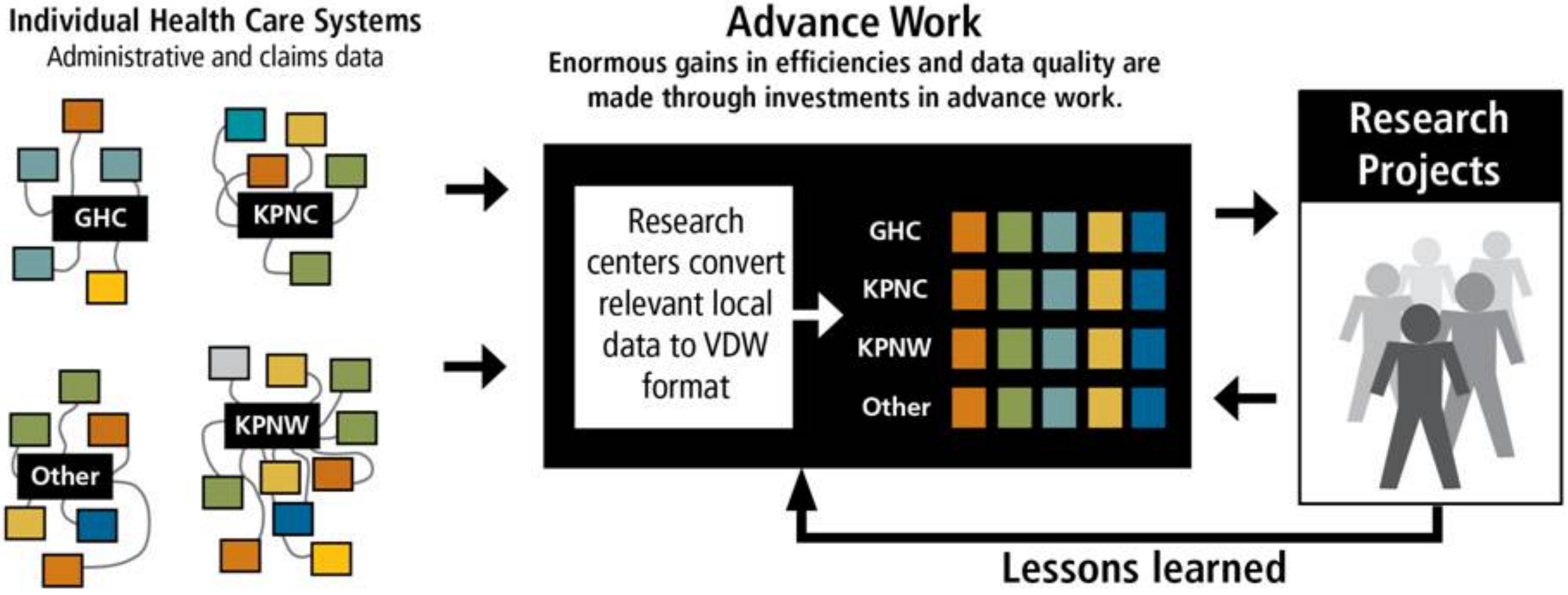
- A **distributed data model**, not a centralized database
- Applicable for multi-center health services and population health research (currently, **16.5 million covered lives** in total)
- **Facilitates multi-center research** while protecting patient privacy and proprietary health practice information
- **Data remain at each institution** until a study-specific need arises and ethical, contractual and HIPAA requirements are met
- **Data sourced from clinical systems** including those used in pharmacy, lab, pathology, disease registries, radiology, and modern Electronic Health Records (EHR) in all care settings
- Clinical data are **supplemented by data from health plan systems** (e.g. claims, enrollment, finance/accounting)

HMORN VDW at a Glance

Participating sites agree on data to make available for research and standard definitions and formats

Sites map **rich and complex data** to agreed upon standards

Data model is standardized; the data themselves are not



Individual Health Care Systems
Administrative and claims data

Advance Work

Enormous gains in efficiencies and data quality are made through investments in advance work.

Research centers convert relevant local data to VDW format

HMORN VDW at a Glance

HMORN Governing Board provides overall policy direction about content, resources and access

VDW Operations Committee (VOC) manages cross-site development activities, with technical and scientific input

VDW Workgroups for specific data areas define, maintain and interpret data file specifications, propose specification changes, perform quality assurance, and aid sites in implementation

VDW Implementation Group (VIG) extract information from local systems, convert it to standard VDW structures, ratify specifications and share best practices

VOC staff financed by HMORN operating budget; member sites contribute workgroup and VIG members

HMORN VDW at a Glance

Use published **data standards** (e.g., NDC, ICD-9/10, CPT-4, DRG, ISO) where available and create our own when necessary

Each site needs **hardware and software** to store, retrieve, process, and manage datasets

HMORN VDW data tables are designed and optimized to **meet research needs**

Sites contribute to **data documentation** (e.g., source of variable, variations) on a password-protected web site

For **quality control**, periodic checks look at ranges, cross-field agreement, implausible data patterns, and cross-site comparison

Accomplishments

The HMORN VDW is **used by major consortia**:

- Cancer Research Network (CRN) – NCI
- Cardiovascular Research Network (CVRN) - NHLBI
- Mental Health Research Network (MHRN) - NIMH
- Center for Education & Research on Therapeutics (CERT) - AHRQ
- Surveillance, Prevention, & Management of Diabetes Mellitus (SUPREME-DM) – AHRQ
- Mini-Sentinel – FDA
- Medication Exposure in Pregnancy Risk Evaluation Program (MEPREP) – FDA

The CRN alone has **284 publications**

Accomplishments

- Health plans and care delivery systems increasingly use the HMORN VDW for **internal reporting, analysis, and disease management** (registries)
- **Patient care, clinical guidelines, policy, and quality metrics** are frequently impacted indirectly via research findings
- The HMORN VDW has **great potential** to more directly impact patient care, guidelines, and policy, but has not yet established a formal process to receive and carry out such inquiries

Expansion and Growth Opportunities

The VDW has expanded in terms of…

- **covered population** (10 million to now 16.5 million)
- **geographic / institutional diversity** (11 to now 19 sites; rural and urban; HMO and traditional indemnity)
- **breadth of data** (e.g. death, laboratory results, vital signs, social history)
- **depth of data** (e.g. additional variables in each area)
- **quality of data** (dedicated quality improvement operations)
- **history of data** (allows further longitudinal analyses)
- **online query tools** (e.g., PopMedNet used by SPAN, PEAL, and other networks)

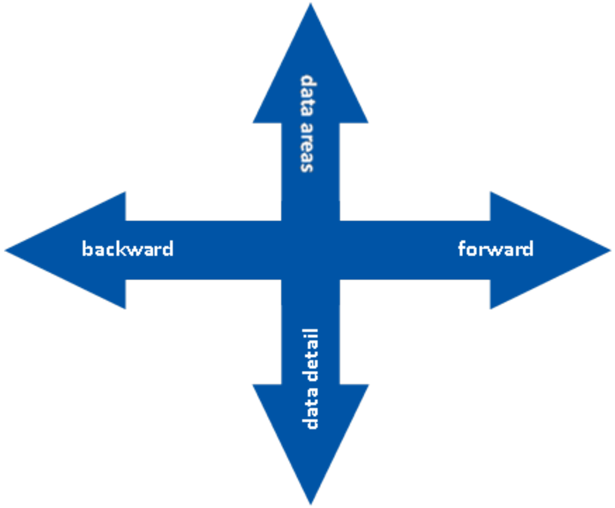
Expansion and Growth Opportunities

Breadth, depth, quality & tools can continue to be expanded as resources become available

Patient-reported outcomes (e.g., risk factors, HQ-9, etc) are an example of available patient-centered data not yet incorporated into the VDW

The HMORN VDW as a data model is at once **broad and deep**, **longitudinal and prospective**

The VDW is a powerful tool for conducting outcomes research, but does not yet meet the far reaching goals of PCOR



Expansion Potential: Facilitators

The VDW model is **public** and has a **strong community** of active developers and users

Successful infrastructure, governance, and collaborative oversight exist to aid in implementation, quality assurance, and development of the model

Participating sites typically have **strong ties** with their health systems which aids in the development and expansion of content

Expansion Potential: Barriers

Underlying data are collected for treatment, payment, and operations – not specifically for research

Source systems vary substantially within and across sites

It takes time (and resources) to:

- Agree on the need for a new variable or data area
- Develop clear specifications to guide implementers and end-users
- Implement new variables at each site
- Verify and document the implementations
- Consult with users throughout

Expansion Potential: Barriers

Health plans continually change their information systems, often requiring **adaptation or re-implementation** of the VDW at sites (e.g., ICD-10)

Limited largely by the **availability of funding**; VDW Operations already accounts for > ½ of the HMORN's annual operating budget

Project-specific grant funding does not support the level of cross-site and cross-project upkeep and knowledge sharing that is needed for a Network-wide resource

Sharing data beyond project collaborators is complicated for technical, regulatory, and political reasons

HMORN VDW and PCORI

The HMORN VDW:

- Covers a **large and geographically diverse population** (including pregnant women, children, elderly, under-served)
- **Captures clinical and administrative data** over multiple decades
- **Supports a broad range of research activities**, including feasibility work, surveys, focus groups, chart reviews, recruitment, individual and cluster randomized trials
- Has a **collaborative** governance and data development model
- Directly **links to clinical delivery systems** and health plans, though this is variable
- Is **highly affordable** by leveraging data already acquired; maintenance and development are primary costs

Low degree of patient engagement overall in HMORN research activities and VDW at the present time

Lessons Learned

Technology is rarely the limiting factor – privacy, regulatory process, and proprietary interests often the greatest barriers

Function over form – the VDW model focuses on what works for a wide audience, not on advancing the field of Informatics

Linking HMORN VDW data with clinical text in the EHR and using Natural Language Processing (NLP) – holds great potential to improve accuracy and efficiency in research

Patient involvement – challenging to attain when dealing with large databases, and without incentives from traditional funders

Explicitly endorsed **expanded data sharing** (e.g., PopMedNet) in Collaboratory – short of a broad partnership there is little incentive to do so; some sites may never fully buy in hmo research network

QUESTIONS?