The Health Care Systems Research Network: A Closer Look at the Capabilities, Resources and Benefits that Comprise Our Research Infrastructure

Sarah M. Greene, MPH
HCSRN Executive Director
What & Who We Are
Key Resources & Capabilities
Connecting & Collaborating
The Health Care Systems Research Network (HCSRN), formerly the HMO Research Network, brings together **18 research institutes** based in health care systems.

Founded in 1994 by 8 sites, HCSRN members conduct presearch to advance population health, utilizing electronic health record (EHR) data, very large patient populations, and the expertise of hundreds of scientists.

Member health systems provide care to commercially insured individuals and those insured via Medicare, Medicaid, and other financial arrangements.

We are committed to **public domain research** and advancing the notion of **learning health systems**, where research evidence informs practice, and clinical practice informs research.
Mission:
To improve individual and population health through research that connects the resources and capabilities of learning health care systems

Vision:
The HCSRN is the nation’s preeminent source of population-based research that measurably improves health and health care

Values:
- Scientific excellence
- Innovation and creativity
- Actionable research findings
- Collaboration and teamwork
- Transparency
- Efficiency
OUR 18 HC SRN MEMBERS

KP Washington Health Research Institute – Kaiser Permanente Washington Seattle, WA

Institute for Health Research Kaiser Permanente Colorado Denver, CO

Center for Health Research - Kaiser Permanente NW Portland, OR

Division of Research Kaiser Permanente Northern California Oakland, CA

PAMF Research Institute - Palo Alto Medical Foundation Palo Alto, CA

Department of Research & Evaluation Kaiser Permanente Southern California Pasadena, CA

Center for Health Research Hawai‘i Kaiser Permanente Hawai‘i Honolulu, HI

HealthPartners Institute HealthPartners – Minneapolis, MN

Essentia Institute of Rural Health - Essentia Health Duluth, MN

Marshfield Clinic Research Institute Marshfield Clinic Marshfield, WI

Center for Health Services Research; Public Health Sciences - Henry Ford Health System Detroit, MI

Meyers Primary Care Institute, UMass Medical School - Fallon Community Health Plan; Reliant Medical Group Worcester, MA

Harvard Pilgrim Health Care Institute, Dept. of Population Medicine Harvard Medical School Boston, MA

Geisinger Research Geisinger Health Danville, PA

Mid-Atlantic Permanente Research Institute - Kaiser Permanente Mid-Atlantic States Rockville, MD

Center for Research & Evaluation - Kaiser Permanente Georgia Atlanta, GA

Division of Research Baylor Scott & White Temple, TX

Institute for Health Services Research Maccabi Health Care Services Tel Aviv Israel
Virtual Organization in which member organizations voluntarily share resources to achieve a common set of goals

The HCSRN:

- Is not a legal or corporate entity
- Has no physical “bricks and mortar” office
- Has distributed, but no centralized staff
- Is supported by member dues, not grant funding
- Has a stable, yet adaptive structure
Governance & Operations

- HCSRN is led by a Governing Board comprised of research directors of each site, or their designee
  - Sets strategic direction, provides oversight, develops policies, vets prospective members
  - Governing Board chair serves 2-year term
  - Board members have full-time research/leadership jobs at their own institutes

- Board Committees expedite decision-making, oversee network assets and provide strategic advice about data

- Executive Director role created in 2015 to ensure business continuity, bolster visibility, manage day-to-day operations
  - “Virtual HQ,” based in Seattle

- 5 part-time staff assist with the Board, network operations, and management of the Virtual Data Warehouse
Board of Governors
(one representative/member site)

Executive Committee
Asset Stewardship Committee
Data Advisory Committee

Executive Director
Director, HCSRN Data Infrastructure
Technical Lead, Virtual Data Warehouse
Board Coordinator
VDW Coordination & Operational Support (2)
<table>
<thead>
<tr>
<th>Committee</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governing Board</td>
<td>Sets policy, budget and strategic direction</td>
</tr>
<tr>
<td>Executive Committee</td>
<td>Increases Board’s efficiency and agility. Manage Board policies and initiatives</td>
</tr>
<tr>
<td>Asset Stewardship</td>
<td>Inward facing, cross-project coordination. Create and maintain shared infrastructure</td>
</tr>
<tr>
<td>IRB Coordination</td>
<td>Develop and implement Network-wide ceding processes</td>
</tr>
<tr>
<td>Virtual Data Warehouse (VDW) Operations</td>
<td>Coordinate, support and oversee VDW development and management across sites</td>
</tr>
<tr>
<td>Research Administrators</td>
<td>Share best practices. Develop and implement HCSRN-wide administrative efficiencies</td>
</tr>
<tr>
<td>Scientific Interest Groups</td>
<td>SIGs are affinity groups of collaborators with common research interests, which form and evolve regularly as new scientific trends arise</td>
</tr>
<tr>
<td>Data Advisory Subcommittee</td>
<td>Standing subcommittee of the Governing Board formed to provide strategic guidance pertaining to the spectrum of issues related to HCSRN data infrastructure development</td>
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</tbody>
</table>
The Health Care Systems Research Network brings together research institutes based within some of the nation’s best and most innovative healthcare systems. Collectively, the HCSRN is comprised of >1,900 scientists and research staff with methodological and subject matter expertise from an array of disciplines and topic areas.
## Population Characteristics (2016)

### Total Membership

<table>
<thead>
<tr>
<th>Total Population, all US Sites, 2016: 16,840,294</th>
</tr>
</thead>
<tbody>
<tr>
<td>BS&amp;W</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>339,055</td>
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</table>

### Continuously enrolled*

<table>
<thead>
<tr>
<th>Age: 0-19</th>
<th>22.3%</th>
<th>24.0%</th>
<th>30.0%</th>
<th>22.7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-39</td>
<td>30.2%</td>
<td>22.3%</td>
<td>20.0%</td>
<td>24.9%</td>
</tr>
<tr>
<td>40-64</td>
<td>33.9%</td>
<td>33.1%</td>
<td>28.2%</td>
<td>40.9%</td>
</tr>
<tr>
<td>65+</td>
<td>13.6%</td>
<td>20.7%</td>
<td>21.9%</td>
<td>11.6%</td>
</tr>
<tr>
<td>Youth: 0 to 5</td>
<td>3.8%</td>
<td>7.6%</td>
<td>8.8%</td>
<td>5.4%</td>
</tr>
<tr>
<td>6 to 11</td>
<td>7.2%</td>
<td>7.0%</td>
<td>9.6%</td>
<td>6.8%</td>
</tr>
<tr>
<td>12 to 17</td>
<td>8.4%</td>
<td>7.1%</td>
<td>9.1%</td>
<td>7.8%</td>
</tr>
</tbody>
</table>

### Gender: Female

| 53.9% | 55.0% | 53.2% | 51.5% |

### Race: AS</25% college>

<table>
<thead>
<tr>
<th>Race: AS</th>
<th>0.4%</th>
<th>0.6%</th>
<th>0.6%</th>
<th>1.0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>BA</td>
<td>3.5%</td>
<td>1.4%</td>
<td>3.0%</td>
<td>1.7%</td>
</tr>
<tr>
<td>H/PI</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.3%</td>
<td>0.0%</td>
</tr>
<tr>
<td>NA/IN</td>
<td>0.1%</td>
<td>2.5%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>MU/OT</td>
<td>5.9%</td>
<td>0.2%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Unknown</td>
<td>51.4%</td>
<td>1.0%</td>
<td>25.7%</td>
<td>77.5%</td>
</tr>
<tr>
<td>WH</td>
<td>38.7%</td>
<td>94.3%</td>
<td>70.1%</td>
<td>19.8%</td>
</tr>
</tbody>
</table>

### Ethnicity: Hispanic

| Ethnicity: Hispanic | 4.4% | 1.0% | 3.7% | 0.9% |

### Non-Hispanic

<table>
<thead>
<tr>
<th>Non-Hispanic</th>
<th>95.6%</th>
<th>98.5%</th>
<th>66.4%</th>
<th>22.4%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>0.0%</td>
<td>0.5%</td>
<td>29.9%</td>
<td>76.7%</td>
</tr>
</tbody>
</table>

### Additional Observations

- **16.8 million individuals in total**
- **Stable enrollment at all sites**
- **Age and gender breakdown mirrors that of underlying population**
- **Availability of race data is improving, again, mirrors that of the underlying geographic area**
# Commonalities & Differences across HCSRN Sites

<table>
<thead>
<tr>
<th>Similar</th>
<th>Different</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research institutes affiliated with health care organizations</td>
<td>Degree of research center integration with its parent organization</td>
</tr>
<tr>
<td>Dedication to public domain, non-proprietary research</td>
<td>Size, complexity, and offerings of research institutes</td>
</tr>
<tr>
<td>Scientists value collaboration</td>
<td>Topical expertise</td>
</tr>
<tr>
<td>Access to comprehensive healthcare services data for a defined patient/member population</td>
<td>Organizational and staffing models</td>
</tr>
<tr>
<td>Willingness to share best practices and efficiencies for broader good of the Network</td>
<td>Proportion, size, and diversity of the defined populations</td>
</tr>
</tbody>
</table>
The **Virtual Data Warehouse (VDW)** is the HCSRN’s method for standardizing and pooling electronic health data for multicenter research. It maps disparate health data to a shared taxonomy and vocabulary.

- The HCSRN VDW is a common data model and approach, not a centralized database.
- Member sites agree on data to make available for research, and on definitions and standard formats to apply.
- Raw administrative, clinical, and claims data are transformed to the agreed upon set of agreed upon data standards at every HCSRN site.
- Each institution’s VDW data remain at their site until a study-specific need arises.
- The required study data are extracted after contractual, IRB, and HIPAA requirements are met.
Why Have a VDW?

Pre-2002: No VDW. Collaborative studies had each site doing its own custom programming. At project end—toss the data (!)

- Expensive
- Redundant
- Ad hoc
- Poorer quality
- Lessons lost
- Complicated Sources…

Creation of the VDW led to enormous efficiencies and it has become the HCSRN’s “crown jewel”
VDW Content Areas

Lab Results
- Person ID
  - Dates of order, collection & result
    - Test type, immediacy & location
    - Procedure code & type
    - Test result & unit
    - Abnormal result indicator
    - Ordering provider
    - Department
    - Facility
    - Etc.

Enrollment
- Person ID
  - Enrollment start & end dates
  - Insurance plan & type
  - Drug coverage
  - Primary care clinic & provider
    - Etc.

Demographics
- Person ID
  - Birth date
  - Gender
  - Race
  - Language

Tumor
- Person ID
  - Diagnosis date
  - Tumor type variables (many)
  - Tumor stage variables (many)
  - Treatment variables (many)

Pharmacy
- Person ID
  - Dispensing date
  - Dispensing MD
  - National Drug Code (NDC)
  - Days supply
  - Amount dispensed

Encounters
- Person ID
  - Dates of service
  - Provider seen
  - Type of encounter
  - Facility
  - Department
    - Etc.

Vital Signs
- Person ID
  - Date & time of measurement
  - Encounter date & type when measured
  - Height
  - Weight
  - Diastolic & systolic BP
  - BP type & position
  - Tobacco use & type
    - Etc.

Census
- Person ID
  - Geocode
  - Census data
  - Education variables
  - Income variables
  - Race variables
    - Etc.

Death
- Person ID
  - Date of death
  - Cause of death
  - Source
  - Confidence

EverNDC
- NDC
  - Generic and brand names
  - AHFS and GPI codes

Procedures
- Person ID
  - Dates of service
  - Procedure code & type
  - Encounter type & provider
    - Etc.

Diagnoses
- Person ID
  - Primary diagnosis flag
  - Diagnosis code & type
    - Etc.

Provider
- Provider ID
  - Specialty
  - Birth year
  - Gender
  - Race
  - Year graduated
Basic Snapshot of How the VDW Works*

Figure 1. Data Flow in and out of the VDW

Source: Ross T et al, eGEMS 2014
HCSRN Data Infrastructure & VDW Organizational Components

- Offer high-level strategic input for HCSRN data infrastructure
- Provide oversight & guidance to Infra Director & Technical Manager and connect VDW activities with HCSRN data infrastructure goals
- Lead development of the VDW and related resources in support of HCSRN strategic goals
- Provide subject matter expertise to inform VDW spec changes & new developments in their respective data areas
- Create site’s VDW according to specifications, maintain local knowledge about data availability, provenance & quality

HCSRN Executive Director
Asset Stewardship Committee Chair
Governing Board Liaison

Director, HCSRN Scientific Data Infrastructure AND Technical Manager, VDW Operations

Scientific & Technical Leads for VDW Data Area Work Groups:
Demographics & Enrollment, Lab, Census, Utilization, Vital Signs, Pharmacy, Tumor

VDW Site Data Managers

Data Advisory Subcommittee

VDW COORDINATORS
Assistance & logistical support for all activities

September 2018
VDW Organization & Operations

- Each Site has at least one site data manager, who is the “go to” for understanding your own local VDW
- Data Area Workgroup Leads provide specific subject matter expertise (lab, utilization, tumor, pharmacy, enrollment/demographics, census, vital signs/social hx)
- Site Data Managers and affiliated personnel meet monthly to review content issues that are discerned in the course of projects, review underlying changes in the source data, discuss QA procedures

“Data Get Better with Use”
Administrative Efficiencies

- Resulting from our many large condition-specific networks in cancer, mental health, aging, addiction and cardiovascular disease, we have developed strong trust fabric which supports operational efficiencies.
- Data sharing and data use agreements have been forged and templates available for use.
- Subcontract templates enable collaborative projects to get up and running more quickly than projects without similar shared templates.
- Find these on the hcsrn.org website.
Sub-Awards & Data Sharing

PRE-NEGO TIATED TEMPLATE AGREEMENTS

A list of HCSRN sites accepting each template below is included on the instruction sheet (page 1 of each document).

- **Version 3.1 Sub-Award Agreement Template** - this template has been shown to greatly minimize administrative start-up time for new NIH and other HHS grant awards in the HCSRN, formerly known as the HMORN. Version 3.1 includes updated OMB references. Instructions and FAQs are included.

- **Version 3.1 HCSRN DUA Template** - 3-page data use agreement (DUA) template can be used for projects with (a) straightforward data sharing schemes and (b) that use the HCSRN's pre-negotiated sub-award agreement template. Instructions and FAQs are included.

- **Version 1 HCSRN Reciprocal DUA Template** - For projects with reciprocal data sharing arrangements. Not linked to the HCSRN subaward template like the standard DUA template.

DUA TOOLKIT

- **HCSRN DUA Toolkit** - introductory toolkit covers when data use agreements (DUA) are needed, how to put a DUA in place, best practices and common pitfalls. Appendices include answers to frequently asked questions and
IRB Efficiency: Facilitated Review Process

- Early HCSRN collaborations (e.g., Cancer Research Network) paved the way for identifying ways to streamline or harmonize multi-site IRB review
- Significant work to develop inter-institutional trust, and inter-institutional agreements for a facilitated IRB review process
- IRB of the Lead Site (where PI resides) will serve as lead IRB, with participating sites having the option to cede
- Applicable to all studies, though most often used in data-only studies
- IRB Working Group has been active for ~10 years, and continues to meet and share effective practices, insights related to implementation of the new Common Rule
Inherent Attribute: Collaboration

- For a research network to succeed, need to enable collaboration between researchers at different sites, as well as between researchers and other health system stakeholders (patients, clinicians, leaders)

- Bidirectional communication and engagement are key

- Collaboration offers several benefits:
  - Cohesion and connection
  - Complementary skills/scientific expertise
  - Efficiency
  - Visibility
  - Potential for ↑ demographic & geographic diversity
  - Opportunities for participation in national networks
The Asset Stewardship Committee (ASC) is comprised of leaders of our large consortia and several site directors, as well as VDW and IRB working group leaders.

Among its functions are to identify collaboration opportunities and encourage cross-site connections.

Chaired by Greg Simon, MD, MPH (KPWHRI).

Great knowledgebase both at the leadership level and throughout the Committee.

ASC Helps us navigate the pragmatic and philosophical aspects of the multisite research in the HCSRN.
Scientific Interest Groups
– One of the Gateways

- Great way to find those with a shared affinity
- Listserv mechanism to connect people, share resources
- Activity level of interest group varies but does not typically result in huge spike in email traffic
- Current interest groups with a listserv:
  - Aging
  - Addiction
  - Disparities/Health Equity
  - Genomics
  - Natural Language Processing
  - Obesity
  - Patient Engagement in Research
  - Qualitative Research
  - Rural Health
  - Training & Mentoring

Plus, listservs for other groups, including IRB managers, research administrators, VDW, and project managers
More on the HCSRN’s Scientific Interest Groups

- Large projects such as Cancer Research Network & Mental Health Research Network have spinoff interest groups
- Many interest groups evolved into large collaborative projects (e.g., Obesity Interest Group → PCORnet Obesity Project)
- New groups can be created easily, provided there is a critical mass of researchers, and 1-2 individuals who can serve as content producers and assist with keeping the listserv vibrant
- To see the available listservs and join, visit: http://listinfo.kpwashingtonresearch.org/lists/lshome.asp
Important priority area for our Board Chair, Dr. Lucy Savitz (Kaiser Permanente Center for Health Research)

Our Training Interest Group (established mid-2018) is a newer venue for thinking through core competencies for health system based scientists, and exchanging effective practices across our sites

Postdoc and fellowship opportunities at various sites include AHRQ K12 Learning Health System scholars, Delivery System Science Fellowships, and other topic-specific traineeships

More to come on this particular area
Initiating Collaboration: Many Ways to Get Started

- Connect with your site’s Board representative and/or Asset Stewardship Committee member

- Contact our ("virtual") office to share ideas and interests
  - I can serve as ambassador, advocate and agitator!

- Happy to facilitate introductions and “matchmaking”

- Attend this monthly webinar to hear about other topics and other researchers’ work

- Sign up for HCSRN News Listserv to receive info on upcoming webinars, funding opportunities, and other content

Collaborations can take time to percolate and build, so a degree of patience and persistence is beneficial!
Ways to Connect with HCSRN Collaborators

Numerous entry points for connecting with researchers in the HCSRN community:

- HCSRN website, [www.hcsrn.org](http://www.hcsrn.org)
- News for the Network (~monthly bulletin)
- Existing projects
- Scientific Interest Groups
- Annual Scientific Conference, April 8-10, 2019 in Portland, Oregon

[www.hcsrnmeeting.org](http://www.hcsrnmeeting.org)

Selected Collaborative Projects
- Mental Health Research Network
- Cardiovascular Research Network
- Cancer Research Network
- AGING Initiative
- Addiction Treatment Network
- Sentinel Initiative
- Vaccine Safety Datalink

Selected Interest Groups
- Addiction
- Aging
- Genomics
- Health Equity/SDOH
- Natural Language Processing
- Patient Engagement
- Qualitative Methods
- Training
Our Annual Conference

- A venue to share research results, with ample opportunities for networking and collaborative meetings
- April 8-10, 2019, Portland Oregon
- Abstracts published in JPCRR
- Keynotes on Data Science, Care Design
- [www.hcsrnmeeting.org](http://www.hcsrnmeeting.org)
Opportunities at the Junctions of Health IT, Data, and Care

Informatics (Big Data)  

Team Science

Clinical & Scientific Expertise

- Rapid comparative effectiveness studies
- Policy-relevant research on cost, access, organization of care
- Predictive analytics/tools for point-of-care decision support
- Precision medicine
- Reducing health inequities
On the Horizon This Year

- 25th Anniversary & 25th Annual Scientific Conference
- Special Supplement to eGEMS (Journal for Electronic Health Data and Methods) highlighting our data and collaboration capabilities
- Newly created position, Director of Data Infrastructure, will deepen connectivity between science & “next generation” data resources
- Participation in major NIH and AHRQ Initiatives, including Alzheimer’s Collaboratory, HEAL
- Website Updates to facilitate finding collaborators
In summary, infrastructure & culture support research

- Culture of collaboration – we like working together!
- Infrastructure supports efficient multi-site research
- Attributes that support research efficiency include:
  - IRB – reciprocal reliance agreements
  - Data Use Agreement templates
  - Business Associate Agreement templates
  - Subcontract templates
  - Virtual Data Warehouse
- We’ve observed that with this infrastructure, each new condition-specific network has had a quicker start-up phase, as new networks can leverage assets and insights from antecedent collaborative projects
Looking Back, Looking Forward

- The HCSRN has built a substantial infrastructure since its founding in 1994, with the intent of bolstering scientific agility and overall visibility.

- The research environment is increasingly reliant on collaboration, and to the extent we can continue to find ways to facilitate collaboration and harmonize “back-end” research administration activities across our network members, we create a competitive advantage for our researchers.

- The HCSRN has been prescient in many undertakings, including creation of a common data model and IRB streamlining, we are actively looking ahead to the next frontiers in research and health care, and how we can leverage our assets to stay ahead of the curve.
And based on strong RELATIONSHIPS with our patients, clinicians, and health system leaders.

At the End of the Day, Our Goal for HCSRN Research

Rigorous
Uses highest quality data

Reliable
Results guide real-world decisions

Relevant
Addresses high priority issues

Responsive
Create efficiencies to shorten cycle

HCSRN Research
Thank You!

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