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Recognizing 30 Years of Accomplishments and Envisioning an Innovative Future - The 2024 Annual Conference of the Health Care Systems Research Network

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Abstract The Health Care Systems Research Network (HCSRN) kicked off the 2024 Annual Conference on April 9, 2024, in Milwaukee at the Hyatt Regency with nearly 275 participants from 19 HCSRN member institutions. This year, HCSRN attendees joined their colleagues to reconnect and network during the three-day conference featuring the theme, “Advancing High-Quality, Equitable Research in the Age of New Health Care Technologies.” (J Patient Cent Res Rev. 2024;11:112-117.)

Denise B. Angst, PhD, RN, Vice President, Academic Research & Strategic Partnerships at Advocate Aurora Research Institute, served as the informal host for the conference. She opened the meeting by reading a Land Acknowledgment recognizing that Milwaukee, Wisconsin, was on land that originally was, and continues to be, homeland to a number of Native American tribes. David M. Kent, MD, MS, provided the opening plenary address. Dr. Kent is the Founder and Director of the Tufts Predictive Analytics and Comparative Effectiveness (PACE) Center, at the Institute for Clinical Research and Health Policy Studies (ICRHPS), at Tufts University. During his presentation entitled, “An Overview of Bias and Fairness in Algorithmic Models,” he discussed the distinction between bias and fairness and reviewed different “fairness criteria,” citing the impossibility of simultaneously satisfying these. Audience members were introduced to the concept of “label bias” and the use of race in clinical prediction models. Importantly, Dr. Kent discussed the harms that may arise when race is omitted in some situations where the variable carries substantial prognostic information and the necessity of evaluating trade-offs in considering its use in clinical prediction. These insights prompted many discussions among attendees and will help inform the development of HCSRN’s and its member institutions’ Virtual Data Warehouse (VDW).

State of the Network
Governing Board Chair, Michael Horberg, MD, MAS, of Kaiser Permanente Mid-Atlantic States, provided the State of the Network address on Wednesday, April 10. Dr. Horberg noted the significance of coming together to facilitate stimulating collaborative research while...
disseminating research findings and promoting scientific rigor in health sciences and health services research. He pointed out that HCSRN is uniquely positioned to contribute to the national and international research agendas through a shared commitment to public domain research and by increasing the momentum of learning health systems, where research evidence informs practice and clinical practice informs research.

As HCSRN recognizes its 30th anniversary, a commemorative logo was designed for the occasion and utilized on specialty merchandise. In honor and special tribute to the insightful early leaders of the network, to whom HCSRN and its accomplishments are deeply indebted, a new annual award was announced, to be bestowed for the first time at the 2025 annual conference. Each year, the Founders Award will recognize an individual who has best exemplified the spirit of the early founders in their service and lasting contribution to the network, including the vision and confidence to create something new or unique in embedded health care research; the spirit of fostering collegiality and collaboration across partner organizations, which remains among the most important values of the network; and the persuasive expertise and determination to create a legacy of funded platforms or other valuable resources for conducting productive research in HCSRN. Videos of members sharing their HCSRN stories were collected, and the Welcome Reception featured a recap of HCSRN history.

Dr. Horberg noted the many accomplishments of the past year. HCSRN received its 501(c)3 designation from the IRS, affirming our non-profit status. There has been a focus on improving operational efficiencies through policy development, database implementation, enhanced communication, and engaged and committed leadership. The transition to SharePoint® and Teams®, which further fosters collaboration within the VDW was an important accomplishment during the year.

HCSRN created the Value Task Force with the explicit purpose of identifying and prioritizing ways to enhance the value of HCSRN membership for all constituencies. The task force spent part of the year gathering data through surveys, conversations with HCSRN investigators and staff, and a review of HCSRN Board reports and documents. In December, the task force issued their report to the Governing Board.

Dr. Horberg reviewed the task force recommendations noting that the emphasis in 2024 will be on the high-priority recommendations, including developing and implementing a mechanism for tracking collaboration across HCSRN institutions, creating a plan to increase HCSRN visibility internally within our member institutions and externally, and developing a long-term plan for HCSRN membership growth. The remaining recommendations will be reviewed and prioritized in 2025.

Dr. Horberg thanked the Value Task Force for their work. The group included Eric Wright, Geisinger Research; Teanie L. Davis, Kaiser Permanente Georgia; Denise Angst, Advocate Aurora Research Institute; Leslie Hinyard, Advanced HEAlth Data (AHEAD) Institute, St. Louis University; J.B. Jones, Sutter Health; Kathleen Mazor, University of Massachusetts Chan Medical School (retired); and support from the Central Office including Suzanne Simons, Mike Breslin, and Alex Grandin.

Dr. Horberg shared an overview of VDW^2 usage including the core tables. HCSRN's VDW utilizes the common data model, mapping clinical and claims data to a common format, which is designed to support multisite health system research. This approach creates efficiencies for data extraction, collection, and management. Appreciation was extended to Stacey Honda, MD, PhD, VOC Board Liaison; Mark Jurkovich, DDS, VDW Scientific Lead; Yonah Karp, VDW Technical Lead; Celeste Machen, VDW Coordinator; Jenny Staab, PhD, Quality Assurance; Rick Krajenta, Lab Consultant; and the workgroup leads for their dedicated work on behalf of the organization.

Dr. Horberg recognized Annual Conference Planning Committee Co-Chairs, Karen Coleman, PhD, and Denise B. Angst, PhD, RN, as well as the committee for their commitment and efforts in planning the event. Appreciation was also extended to volunteers for their role in the conference’s success. The 2025 conference will be held in Saint Louis, MO, April 8-10, 2025.

HCSRN welcomed sponsors who supported the meeting through financial contributions. Advocate Aurora Research Institute joined at the Platinum level. Genentech and the Patient-Centered Outcomes Research Institute (PCORI) participated at the Gold level, and AstraZeneca was a Bronze-level sponsor.

**Award Recipients**

HCSRN members celebrated their colleagues’ achievements with the award winners being announced. Lisa R. Miller-Matero, PhD, ABPP, of Henry Ford Health Systems, was recognized for Paper of the Year entitled, “Suicide Attempts After Bariatric Surgery: Comparison to a Nonsurgical Cohort of Individuals With Severe Obesity,” published in *Surgery for Obesity and Related Diseases* last year.1
Jordan Braciszewski, PhD, of Henry Ford Health Systems, was recognized as the Mentor of the Year. His colleagues from Henry Ford Health Systems, Kaiser Permanente, and HealthPartners Institute nominated him for this prestigious award, which acknowledges an individual who has provided guidance and motivation, as well as shares knowledge, expertise, and wisdom.

Jennifer M. Boggs, PhD, MSW, of Kaiser Permanente Colorado, received the Investigator of the Year Award for her abstract entitled, “Results from a Hybrid Effectiveness-Implementation Trial to Improve Uptake of a Secure Firearm Storage Program in Pediatric Primary Care.” Her abstract was reviewed on overall quality and specific criteria including research abstract quality, relevance and originality, quality of science, impact, generalizability, and scalability.

Two poster awards were presented. The Poster Session 1 winner was Jana Hirschtick, PhD, MPH, of Advocate Aurora Research Institute, for her abstract entitled, “Estimating Underdiagnosis Using the Electronic Health Record: A Long COVID Case Study.” The winner of Poster Session 2 was Amandeep Mann-Grewal, MPH, of Sutter Health Research Center for Health Systems Research, for her poster entitled, “Self-Reported Survey Results about Experience of Virtual Reality Headset on Reducing Anxiety in Pediatric Urgent Care Clinic.”

Workshops and Special Sessions

New this year was a pre-conference grant writing workshop bringing together experts throughout HCSRN to assist early investigators with NIH R-series applications. The goals of the workshop were to provide practical knowledge and feedback for writing NIH awards with a special emphasis on R grant mechanisms and to create a community of new investigators working towards NIH funding from which they can draw support. Topics included writing outstanding specific aims, understanding the sections of grants that are especially important for reviewers, creating a conceptual model, telling a “story,” formatting a grant for maximal visual impact, and choosing a funding announcement and institute. Workshop presenters included Karen J. Coleman, PhD, of Kaiser Permanente Southern California; Stephanie Hooker, PhD, MPH, of the HealthPartners Institute; and Kyle Christensen, PhD, of the HealthPartners Institute.

On Wednesday, April 10, HCSRN offered a special interest panel on “Public Health Research and Navigating the Media.” The panel explored how researchers interact with media and shared best practices. The panel featured researchers who have successfully navigated the science and media divide including Benjamin W. Weston, MD, MPH, FAEMS, of The HUB for Collaborative Medicine; Nick Buttrick, PhD, of the University of Wisconsin-Madison; and Devi Shastri, a public health reporter for The Associated Press.

The final plenary session entitled, “Funding Priorities and Funding Strategies: Insights and Information from National Funders,” convened a panel of established experts who provided an overview of each agency’s funding priorities, tips for navigating the grant application process, what to expect when one’s application is undergoing review, and the award process. The panel included Brent Sandmeyer, MPH, of the Agency for Healthcare Research and Quality; Steve Clauser, PhD, MPA, of PCORI; and Jamee Morris, PhD, MA, of the Robert Wood Johnson Foundation.

A special presentation by PCORI entitled, “Building Meaningful and Sustainable Engagement in Research: PCORI’s Foundational Expectations for Partnerships,” followed the Funder’s Panel. PCORI assembled a panel including Kimberly Haugstad, MBA, CEO, of UpEquity Corporation; a member of the PCORI Advisory Panel on Rare Disease, Karen E. Kippen, MSA, MT (ASCP), of Henry Ford Health Systems; Karen Margolis, MD, MPH, of HealthPartners Institute; Ellen Schultz, MS, of Ellen Schultz Consulting; and moderator Kristin L. Carman, MA, PhD, and Mabel Crescioni, DrPH, JD, both of PCORI. The session highlighted PCORI’s new “Foundational Expectations for Partnerships,” which updates the 2014 PCORI Engagement Rubric and provides expanded guidance for meaningful engagement to advance patient-centered outcomes research and health equity. Included was the exploration of the six new Foundational Expectations and the implications for principal investigators, study teams, and patient partners, as well as community perspectives on the impact and lessons learned from building meaningful engagement in research.

The VDW Implementation Group (VIG) Meeting was the final session of the conference. The half-day meeting brought together nearly 45 site data managers, coders, researchers, programmers, and other staff members. The agenda featured sessions on work groups including Enrollment and Demographics, Utilization, Patient Reported Outcomes (PRO), and Vital Signs and Social History. There was an open discussion surrounding SAS® (SAS Institute Inc). Specifically, discussion surrounded whether sites will be moving away from this analytics software and whether the rising cost is a consideration. Another topic focused on whether there have been organizational incentives for VDW programmers to learn new languages. The session also addressed how people are utilizing the new SharePoint/Teams environment,
which replaced Alfresco® last year. The VIG meeting is always a productive time bringing together members from different institutions to reconnect and engage in spirited dialogue, while advancing the work of one of HCSRN’s greatest assets.

**Concurrent, Poster, and Panel Presentations**

Looking at the conference by the numbers, there were 15 accepted abstracts and panel presentations, which resulted in 21 concurrent sessions and 7 panel presentations. During the two sessions, there were 51 peer-reviewed posters presented. Two ancillary meetings of scientific interest groups and research project teams were held to discuss their work. This was made possible due to the dedicated efforts of 14 Annual Conference Planning Committee members and 31 on-site volunteers who planned and ran the conference.

Social Determinants of Health, Mental Health, and Addiction; Stakeholder Engagement; Health Equity; Implementation/Health Delivery Science; Technology and Decision Support; and the Virtual Data Warehouse were some of the broad categories of the abstract submissions. Panel sessions covered a wide range of topics including:

- A Learning Health System Approach to Improving Racial and Ethnic Diversity in Clinical Trials Participation
- Advanced Analytics to Support Learning Health Systems: A Roadmap
- System-Based Strategies to Optimize Guideline-Directed Medical Therapy in Patients Living with Heart Failure
- Collaborative Cancer Research in HCSRN: The Past, Present, and Future
- Elevating the Patient’s Voice in Cancer Care
- Advances in Food and Nutrition Security in Healthcare: Progress from Kaiser Permanente’s Research and Human Centered Design
- The All of Us Research Program: Utilizing the Researcher Workbench

All the accepted scientific abstracts presented at the 2024 HCSRN Annual Conference can be found in this issue of the *Journal of Patient-Centered Research and Reviews.*

**HCSRN History**

As HCSRN looks forward to an innovative future, it is important to recognize its history and how it arrived at this pivotal time. In 1994, leaders of eight research groups housed within Health Maintenance Organizations (HMOs) established an informal consortium to foster collaborative health and health care research. Early objectives of the new partnership, which they concisely named the HMO Research Network, included providing a professional community for non-academic health researchers, exploring issues in the conduct of health research within the context of clinical practice, and raising their institutional and collective visibility to research sponsors.6 Fast forward to today, 30 years on from the founding, HCSRN retains those original objectives within its Mission, Vision, and Values.7 Indeed, it has enhanced itself along the way with membership growth and broadened organizational structures among participating health systems, demonstrating an impactful, ongoing history of funded research networks and multisite projects and establishing a well-regarded common data model.

Soon after its formation, the network held the first of what would become an annual conference in Portland, Oregon, in April 1995. The “First Annual Conference of HMO Research Centers” had over 100 registered attendees from founding member institutions, future member sites, and academic and sponsor partners. Plenary presentations at the inaugural meeting covered several timeless subjects in HCSRN, including research funding opportunities, navigating public domain research with industry partners, effective dissemination of study findings, and strategic directions for the network. Parallel research tracks for the conference covered a wide range of health and health care topics, including Mental Health, Substance Abuse, Cancer, Cardiovascular Disease, Genetics, Asthma, HIV, Diabetes, Immunizations, Prevention and Screening, Women’s Health, Behavioral Health, Long-Term Care, Practice Guidelines, and Shared Decision Making. Interestingly, the first conference 30 years ago was held in conjunction with the 30th anniversary of the local host organization, the Center for Health Research at Kaiser Permanente Northwest, and their own celebratory research symposium.6 Since then, with exception to the pandemic cancellation in 2020 and the virtual meeting in 2021, an in-person conference has been held in the spring of each year, organized by a multisite committee, with planning direction from a local/lead host organization and, more recently, from HCSRN’s central office.8 Other city venues for the annual network conference have included Minneapolis, MN; Boston and Cambridge, MA; Oakland, San Francisco, Long Beach, Pasadena, and San Diego, CA; Honolulu, HI; Atlanta, GA; Seattle, WA; Denver, CO; Detroit, MI; Santa Fe, NM; Danville, PA; Austin, TX; Phoenix, AZ; and Milwaukee, WI.

Early leaders of the network were inspired by the collaborative success demonstrated by the Centers for Disease Control and Prevention’s Vaccine Safety Datalink (VSD), which conducted efficient multisite
The VSD had formed in 1990, predating HCSRN, but with an organizational membership that included many HCSRN sites. Starting in the late 1990s, forward-looking HCSRN scientific leaders were able to make a compelling case to federal sponsors and peer-review panels regarding the promise of embedded health system research on a wider range of topics. These included the ability to assemble large patient populations with defined observation windows; direct links to, and familiar use of, a growing base of electronic medical record data; and the availability of researchers with close ties to clinical and system leaders to obtain guidance on relevant health care and health coverage questions, as well as on the feasibility of translational implementation plans. A succession of funded research (or public health surveillance) networks within HCSRN followed. A broad set of examples of these include the National Cancer Institute’s Cancer Research Network (CRN) in 1999;\(^9\) the National Institutes of Health Roadmap’s Coordinated Clinical Studies Network in 2004;\(^10\) the National Heart, Lung and Blood Institute’s Cardiovascular Research Network in 2007;\(^11\) the Food and Drug Administration’s Mini-Sentinel (later Sentinel) medical product safety surveillance initiative in 2009;\(^12\) the National Institute of Mental Health’s Mental Health Research Network in 2010;\(^13\) the National Institute on Aging’s HCSRN-OAICs Aging Initiative (in collaboration with the Claude D. Pepper Older Americans Independence Centers) in 2014;\(^14\) and the National Institute on Drug Abuse’s Health System Node in 2016.\(^15\)

The influence of funded research consortia within the history of HCSRN has been substantial and manifold. In addition to sponsoring specific impactful collaborative research projects, funded participation has resulted in the development of a critical multisite research infrastructure for HCSRN, including key contact directories, routine communications, approved contractual subaward and data use agreement templates, early mechanisms for Institutional Review Board deferral, a range of topical scientific interest groups, methodologic- or results-oriented webinars, pilot project funding, and investigator training. The CRN, for example, whose four cycles of funding from 1999 to 2019 included just 9 core projects, also conducted more than 400 supplemental, developmental, or separately funded ancillary projects leveraging CRN capacity and infrastructure.\(^16\) Several legacy CRN research projects are still underway today. A particularly successful initiative of the CRN was the CRN Scholars career development program, in which several dozen junior researchers from network sites and academic partner institutions received two years of mentored training to conduct successful embedded health system cancer research.\(^17\) Perhaps the most influential legacy of research network activity is the VDW mentioned above.\(^18\) First created by CRN leaders in 2002 to facilitate multisite research and preserve locally curated data in standardized form, the VDW allows participating sites to assemble provider-, patient-, and encounter-level data from claims and Electronic Health Records, in addition to mapped tumor registry data, within a common set of data standards. Each health system maintains VDW data in secure fashion behind its local firewall and directly controls its use. In addition to common data standards, the VDW incorporates code libraries, macros and applications, cohort definition tools, data quality assessment checks, and more. For over 20 years, the VDW has provided HCSRN research teams with an efficient approach to rapidly assemble standardized data for collaborative studies, and over time, it has served as a template for several other popular data models.

Currently HCSRN has grown to have 20 member organizations, including research departments within 19 US-based health systems and one based in Israel. Current member sites not among the eight founding institutions joined between 1995 and 2022. Over time, an additional handful of organizations joined and then later departed the network, either due to dissolution of their research institute or other realignment of their health system priorities. In 2015, an important symbolic adjustment was made, with a name change from HMO Research Network to Health Care Systems Research Network, purposefully reflecting the varied organizational structures among participating systems. With an eye for the future, with its new formalized non-profit status and association management team providing support, the network has strategically recommitted to efforts that will foster multisite collaboration of embedded health system researchers, raise network visibility, increase value at the individual and institutional level, and assure continued, efficient access to quality standardized health care data for research.

The 2024 HCSRN conference in Milwaukee celebrated the 30th anniversary of the network, and additional celebrative activities will continue throughout the year.

In summary, attendees of this year’s conference were exposed to leading-edge science, inspiring speakers, programming innovations, and time for networking and fostering an inclusive collaboration environment. Looking ahead, the 2025 Annual Conference will be held in Saint Louis, MO, April 8-10. We hope to see you there!

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References
2. Pardee R. (April 9, 2024). A brief history of (VDW) time – what a long, productive trip it’s been. Remarks presented at: 2024 Health Care Systems Research Network annual conference; April 9, 2024; Milwaukee, WI.

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