



health care systems
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Health Care Systems Research Network

NEWSLETTER

2024 Volume 2

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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The Health Care Systems Research Network (HCSRN) Annual Conference has a long-held reputation of serving as a venue to facilitate new collaborations, disseminate scientific findings, and share the challenges and triumphs of conducting research in a real-world care delivery setting. Bringing together a diverse group of members and non-members, study managers and researchers, health systems leaders, funding agency representatives, clinicians, and patient partners, this meeting is eagerly anticipated every year. Attendees appreciate the ample opportunities to network and exchange the latest scientific findings. The conference objectives for this year were to highlight scientific findings from HCSRN research projects and to spur collaboration on research initiatives that improve health and health care for individuals and populations.

Deeply committed to supporting public-domain collaborative research that benefits patients, communities, and the broader population, HCSRN is an integral part of the US and international research and science. Through its established partnerships with other major research organizations, federal funders, and universities—and through leadership in important national initiatives— HCSRN is a leader in population health research.

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).

[Click here to read the full article.](#)

This article originally appeared in the Journal of Patient Centered Research and Reviews Volume 11, Issue 2 , Summer 2024.

Abstracts From the 2024 Health Care Systems Research Network (HCSRN) Annual Conference, Milwaukee, Wisconsin

The Health Care Systems Research Network (HCSRN) comprises 20 learning health systems with integrated care delivery and embedded research units. The network's annual conference serves as a forum for research teams from member institutions to disseminate project findings, explore scientific collaborations, and share insights about population-based research practices that can measurably improve health and health care for all. The theme of this year's conference was "Advancing high-quality, equitable research in the age of new health care technologies." Abstracts presented at HCSRN 2024 are published in this issue supplement of the Journal of Patient-Centered Research and Reviews, the journal of record for HCSRN's annual conference proceedings.

[Click here to read the abstracts from the conference.](#)

Journal of Patient Centered Research and Reviews Open Call for Papers

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VIG Work Group Updates

PRO

Patient Reported Outcomes (PRO) data are collected from patient self-administered questionnaires, interview-based questionnaires completed by health care team members, or questionnaires completed by patients via web portal. The PRO workgroup has included a standardized list of questions and answers as part of the VDW Data Dictionary (Appendix J). Through the cooperation of HCSRN sites, the PRO data for the Patient Health Questionnaire (PHQ), Generalized Anxiety Disorder (GAD), and Columbia-Suicide Severity Rating Scale (C-

SSRS) is available for multisite reporting. Although already available across the Kaiser Permanente sites, we are prioritizing the implementation of the Brief Pain Index (BPI), Alcohol Use Disorders Identification Test (AUDIT), and Edinburgh Postnatal Depression Scale (EPDS) into the data model. Please contact Mark Gray (Mark.T.Gray@kp.org) or Dan Vaughn (Daniel.R.Vaughn@kp.org) if you would like to learn more.

Tumor

Tumor Workgroup is committed to ensuring that VDW Tumor data table contains the up-to-date and accurate tumor related data available for the users. The tumor data is in the North American Association of Central Cancer Registries (NAACCR) format (<https://www.naacr.org/interactive-data-on-line/>) which is adopted by both North America and International Associations of Cancer Registries. Tumor data table consists of two tables, TumorMain which provides a snapshot of tumor characteristics including group stage, grade and type of treatments given, and TumorSupp which provides further detailed tumor related data items such as individual AJCC staging items, tumor markers, collaborative staging item and site-specific diagnostic indicator items. Tumor Workgroup is currently working on updating tumor data table with NAACCR version 24 data items. If you or your organization would like additional information or have questions related to the tumor tables, please contact the Tumor Workgroup leads, Aung Oakkar (Aung.Oakkar@kp.org) or Jenny Staab (Jenny.Staab@kpchr.org).

Vital Signs/Social History

The Vital Signs/Social History workgroup has completed QAs for both content domains in the last year and sent out an exploratory program to examine possible new sources or variables for Social History data. Due to the extensive amount of data discovered, the work group will be sending out a survey to users to help assess how and whether to integrate new data into the table.

Enrollment/Demographics

The Enrollment/Demographics group is formulating a spec change to accommodate race/ethnicity information that complies with the Office of Management and Budget's [newly-revised directive](#) on collecting and reporting this information. You can see [the draft proposal here](#), and send comments to the workgroup at: chr_vdw_enroll_demo@kpchr.org. The workgroup is especially interested in whether it would be useful to include granular ethnicity information in the VDW.

Utilization

The Utilization Workgroup has committed to a hard deadline to move away from the old Provider table process and support only the new Provider and Provider_Taxonomies table processes as of June 30, 2024. Sites who have implemented these tables have reported easier use for their end-users and have managed to reconcile provider IDs across disparate systems, resulting in cleaner and more accurate data. The workgroup is currently working on compiling the multi-site results for the Diagnosis QA for review at the July workgroup meeting. The workgroup's next large undertaking will be the review of Encounter

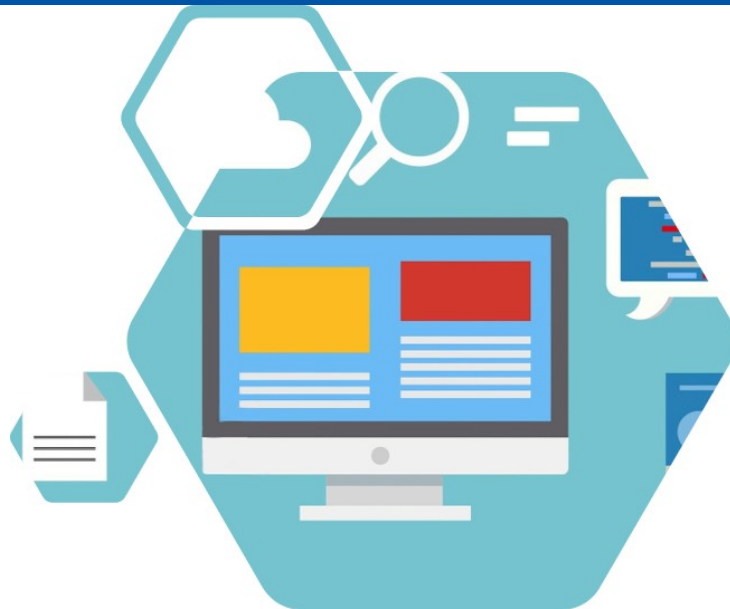
Encotypes and Subtypes. We are looking for scientific input as we review the meaning of these variables and how they could be better defined to support research initiatives. The commitment would be 10 hours or so over a span of a few months, advising the workgroup leads on how these variables could better be defined and any issues you have experienced in your multisite work. We have volunteers so far from KPNW and KPCO and would love to get a more representative group across the network (experience with claims, those in sites doing inpatient research with owned hospitals, etc.). Please contact Heather Tavel (Heather.M.Tavel@Kp.org) if you or someone in your organization would like to be part of this initiative.

Lab

The Lab Workgroup is currently reviewing all Test_Type definitions. This work will continue into 2025, after which a new process to review and add new LOINC's will be put into place.

In late summer or early fall the Lab QA program will be sent out to sites. Please plan the time to allow for data maintenance and improvement. Having qualitative value standardization work and quantitative result unit standardization work completed before running the QA program will make comparisons across the HCSRN sites easier to understand and increase the usefulness of the QA multi-site reports. Documentation to support this effort can be found here [VDW_Qualitative_Laboratory_Test_Standardizations.xlsx](#) and here [Result Unit Standardization](#). Questions can be directed to Gwyn.Saylor@kpchr.org and sbole1@hfhs.org.

**Join Us for the Scientific Data Resources Forum
on August 13 from 4:00 – 5:00 PM ET**



**Results from a Hybrid Effectiveness-Implementation Trial
to Improve Uptake of a Secure Firearm Storage
Program in Pediatric Primary Care**

Jennifer M. Boggs, PhD, MSW



Investigator
Institute for Health Research
Kaiser Permanente Colorado

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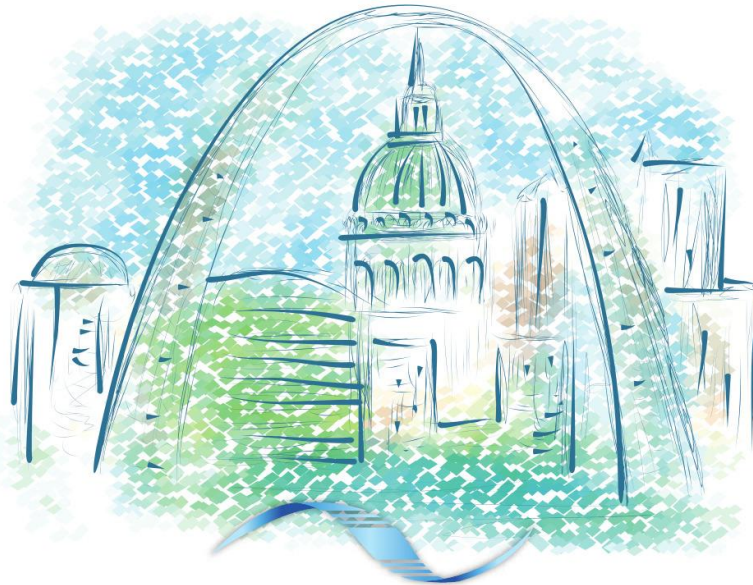
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2025

FOR THE 2025 ANNUAL CONFERENCE



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Keeping the HCSRN communication list current is an ongoing task. We don't always know when new people join our member institutions and others leave. Please share this [link](#) with people in your organization who should know about the latest HCSRN happenings. Whether it's conference updates, information about the next SDRF presentation, Governing Board news or job postings, the best way to stay up to date,

is by completing the link above.



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