Issue Brief

A Home for Patient Data:
Data follows the patients in a new model of health information exchange

Would you like to take a look at your *complete* medical record? You probably can't. And, probably, neither can your provider. If you're like most people, you've probably moved from one community to another several times. Or changed doctors. Or seen more than one doctor. Or become sick on vacation. If so, then your health records are like most people's—they reside in the separate data silos across different health care provider organizations. Health events don't always happen close to home. When you get care in a new place, it's like Dorothy leaving Kansas. You might as well be in Oz. The doctor there won't have access to your Kansas records and, if you ever get back, your Kansas doctor won't have a record of the care you received in Oz.

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The solution: Let the data follow the patient.

That's the concept behind the Patient Centered Data Home™ (PCDH), which is currently being rolled out by members of the Strategic Health Information Exchange Collaborative (SHIEC), a nonprofit national trade association of state, regional and community health information exchanges. SHIEC, working with Colorado's Quality Health Network (QHN) and other member health information exchanges, is testing this new way to share data among its 47 members. They gather and exchange patient data for nearly 200 million patients throughout the U.S.

The PCDH automatically alerts providers when a patient seeks care away from home. It represents a significant improvement in nationwide data exchange, says Dick Thompson, Quality Health Network CEO and executive director of SHIEC. "It's game changing."

The system enables providers to close the loop: They are automatically notified when one of their patients receives care outside their normal "home," and they can initiate a simple targeted query across state or other geopolitical lines to access real-time information.

The concept—the brainchild of MyHealth Access CEO David Kendrick, MD—originated at a national SHIEC conference. It has been piloted among HIEs that share common borders or patients. The first PDCH test site involved QHN, the Arizona Health-e

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Connection and the Utah Health Information Network. Thompson and Kendrick both emphasize that SHIEC does not "own" the idea; any HIE is welcome—even encouraged—to participate.

Defying boundaries

"Doctors and hospitals care for patients from across state and even national boundaries all the time, and this is increasing as we become a more mobile society," Kendrick says. "MyHealth Access Network, an HIE in Oklahoma, has patient data on people who live in more than 60 percent of U.S. zip codes—meaning that all of these people have received care in Oklahoma at some point over the last six years." He acknowledges they comprise a small fraction of the patient base. But it matters because many of those records are the first documentation of a critical event, and nearly all involve changes in diagnosis or treatment.

Once fully deployed, the PCDH allows providers access to real-time data—which may include imaging studies—anywhere a patient may present for care. "It gives us the ability to understand a patient has been somewhere, to know what happened, and how to get more information about it. It all starts there," says Marc Lassaux, QHN's chief technology officer.

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Here are the basics: A "triggering-episode alert" notifies providers a care event has occurred outside of the patient's "home" HIE. The alert-sending HIE includes the location, the HIE's unique patient identifier, and institution's medical record information. Return acknowledgements confirm the availability and the specific location of the clinical data. Thus, providers can initiate a simple targeted query to access real-time information across the care continuum. *All* the clinical data becomes part of the patient's comprehensive longitudinal record in his or her "home" HIE, called—naturally—the Patient Centered Data Home. (For a more detailed explanation, see "How it works" on page 3.)

"Pilots are ongoing, and we've put in grant applications for funding to expand, but we're not waiting," says Kendrick. Some SHIEC members have already received ONC grants to accelerate deployment and adoption of the model.

It's moving quickly beyond the test phase, says Thompson. "Don't call it a pilot anymore," he adds. "It's reality."
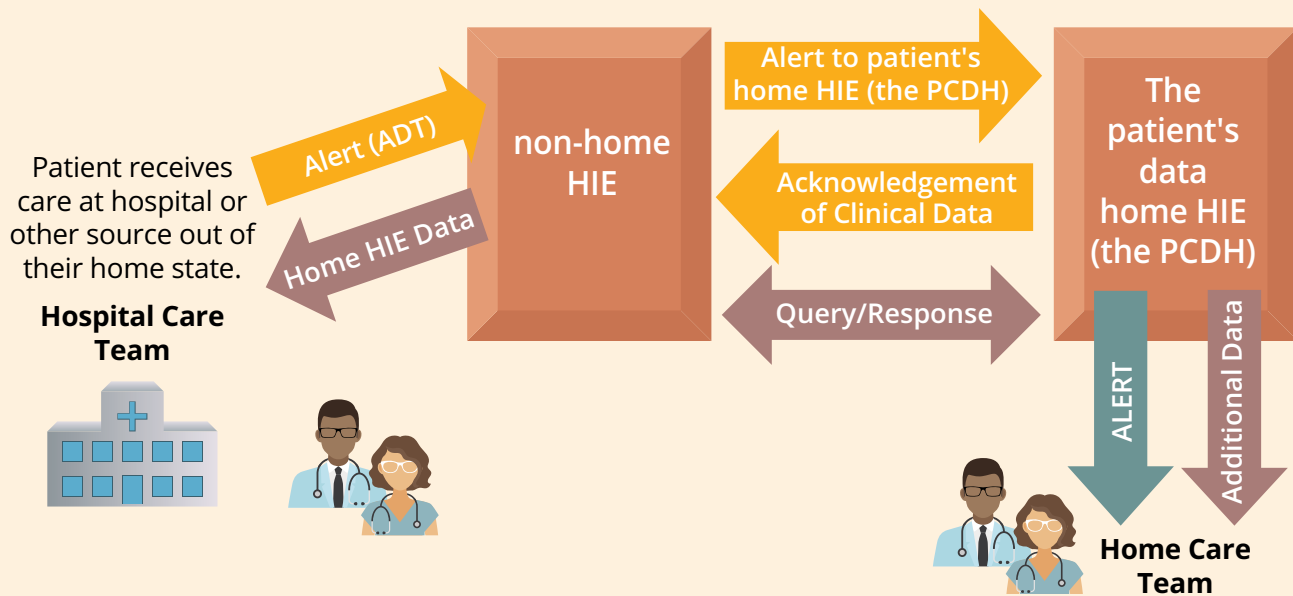
Thompson expects all 47 SHIEC members to be participating in the next 24 months, covering more than half the U.S. population. Ultimately, they can all be linked. SHIEC will establish a common architecture and develop consistent measures of success for reporting purposes.

How PCDH is different

Kendrick, Lassaux and Thompson identified the ways in which this approach is different from the status quo and/or other approaches to HIE data sharing.

- **Community autonomy:** The PCDH honors each HIE's unique structure—its governance, identity management, data use, privacy, patient consent models, etc. For example, in the Colorado/Utah/Arizona pilot, Arizona manages consent the way *its* stakeholders want to manage it.

- **Central consent management:** Ultimately the PCDH will create the opportunity for each patient to manage consent in one central place—from his or her own HIE. To use the Arizona example again, if a patient opts out of the Arizona Health-e Connection, no data will be shared with any HIE."

- **Vendor agnostic:** HIEs connect data from all EHR vendors. By being vendor agnostic, and by establishing and enforcing the rules of local

How it works[1]

Patient receives care at hospital or other source out of their home state.

Hospital Care Team

Alert (ADT)

Home HIE Data

non-home HIE

Alert to patient's home HIE (the PCDH)

Acknowledgement of Clinical Data

Query/Response

The patient's data home HIE (the PCDH)

ALERT

Additional Data

Home Care Team

The triggering event: A patient encounter outside the patient's "home" area will trigger a message to the local HIE. The local HIE then consults the coverage areas to determine which PCDH the patient belongs to, based on their home address.

Automated notification to home HIE: An automated notification is then sent to the patient's home HIE to determine if there is information available for sharing and—depending on the policies of the patient's PCDH HIE, and the patient's consent status—the patient's regular doctor may be alerted.

Acknowledgement and confirmation: If clinical data is available, an acknowledgment message confirms the data's availability and location. The automated notification confirms for providers—from both HIEs—that a simple query will allow them to access that information. So, for instance, an ED physician at St. Mary's Medical Center can query and pull patient records from the patient's home HIE in Arizona.

Two-way exchange: Providers from both HIEs can query and pull information. In addition, the clinicians' phone numbers are included in the responses, so "if you don't get everything you need, you can pick up the phone," says Thompson.

Data comes home: And just as important, the patient's home HIE can query and pull information on that out-of-state encounter, making it part of the patient's longitudinal record.

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[1] Much of the technical description draws on information from SHIEC's PCDH http://strategichie.com/patient-centered-data-home-pcdh and a May 2016 QHN presentation, "Patient-Centered Data Home," a version of which is here: https://qualityhealthnetwork.org/PDFs/HIE%20to%20HIE%20Data%20Exchange.pdf

governance, the HIEs ensure protection of the patient's right to have their comprehensive medical record available wherever and whenever they want it, says Kendrick. "These rights should not be subject to which particular EHR vendor their doctor or hospital chooses to use."

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>
> **— David Kendrick, MD, MPH**
> **CEO of MyHealth Access Network**

- **Patient ownership of, and access to, records:** Ultimately, patients and their providers will be able to access all their information in one place. Just as they have a patient-centered medical home, if they are participating in an HIE, they will have a data home. Today "Many patients need to log into several patient portals to get a full picture of their health records," Kendrick says. "The PCDH enables each region to offer a single patient portal, or to partner with existing portals, to supply the data securely and according to the patient's consent."

- **Targeted information:** Not only does the PCDH make data available, says Thompson, "It tells the provider where the data lives. It tells them exactly where to look and that there's something there." He compares it to fishing. "If you want to catch fish, you do not put your boat to sea and crisscross the Atlantic Ocean. You go where you know the fish are."

- **Quality improvement support**: With access to complete information, more robust research and quality improvement data is available. This allows for a more complete picture that supports—rather than working against—what's needed for value-based payment models. Having the complete longitudinal record in place permits more complete and comprehensive reporting, care gap analysis—"the types of things that improve care and patient health over time," Kendrick says. Making decisions with complete information is critical to a *learning health system.* (See sidebar on page 5)

- **Attention to social determinants:** Health is more than just health care. "It's well known that much of the cost and poor health outcomes in America are attributable to events and activities outside of the health care delivery system," Kendrick explains. These "social determinants" have been identified as critically important drivers as well, most recently by CMS which has announced its Accountable Health Communities programs. Thought it may seem obvious now, health care providers have long focused on the health care data alone, wondering why their patients weren't getting better while ignoring critical facts: the patient lacks enough food to eat or transportation to get to the doctor, or is exposed to violence at home. The PCDH and the HIEs that support it are uniquely positioned to link the food banks, shelters and other social services agencies that are critical to achieving a healthier population.

The future of patient care

In a sense, says Thompson, it's wrapping the data around the patient, "trying to make the data go with the patient, wherever they go." It could be a center of excellence for cancer care, or it could be an ER in a city where they are vacationing. It can also be used to get information to loved ones after an accident or serious health event. "This is about making the patient data available. There is 'no wrong door.'"

And that, all three agree, is what interoperability is all about.

"The goal of health IT is not about making records electronic or making sure every doctor has an EHR, but having *interoperability*—so patients are comfortable that when they get care, their providers have the current data," Kendrick says. "In essence, every

patient has the right to have their complete longitudinal health record available wherever and whenever it is needed for decisions about their care."

It's hard to imagine just what the full implications are, he acknowledges. "In the days before the telephone, we didn't have a concept of what was possible. Now that we know what is possible, think of all the ways the telephone has changed how we interact with each other. That's what's happening now with the Patient Centered Data Home."

A learning health system

When the HITECH portion of the 2009 Stimulus legislation passed, it became clear that ONC and the other federal agencies hoped those funds would achieve the health care equivalent of the interstate highway system connecting all of America. "Unfortunately we missed the mark," Kendrick explains "Every doctor and hospital now has an EHR product, but they don't really 'interoperate' very well, so interoperability was not achieved." It's still aspirational.

In 2015, ONC acknowledged this and released a 10-year roadmap for the nation to achieve interoperability. "The most interesting part of that roadmap, to me, is the fact that its objective is to position the nation to have a learning health system," reports Kendrick.

The learning health system was described in the 1990s and embraced by the Institute of Medicine. In a learning health system, the health care decisions made today generate data and outcomes that can be used to inform and improve tomorrow's. According to the 10-year roadmap, in such a system, electronic health data can be securely and efficiently shared as needed to support patient-centered care, enhance health care quality and efficiency, and advance research and population health.[2] "This requires not only interoperability but advanced governance and capabilities such as analytics and alerting that are enabled by the Patient Centered Data Home," Kendrick says.

Here's how a learning health system was described in the Interoperability Roadmap:

> "[I]ndividuals are at the center of their care; providers have a seamless ability to securely access and use health information from different sources; an individual's health information is not limited to what is stored in electronic health records (EHRs), but includes information from many different sources and portrays a longitudinal picture of their health, not just episodes of care; and where public health agencies and researchers can rapidly learn, develop, and deliver cutting edge treatments." [3]

Kendrick puts it more succinctly: "A learning health system enables data from today's care activities and decisions to become tomorrow's clinical decision support, population management and clinical research findings."

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[2] ONC report to Congress: Report on Health Information Blocking, April 2015
[3] A Shared Nationwide Interoperability Roadmap version 1.0. https://www.healthit.gov/policy-researchers-implementers/interoperability

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DAVID KENDRICK chairs the Department of Medical Informatics at the University of Oklahoma's School of Community Medicine, and serves the OU Health Sciences Center as the assistant provost for strategic planning. Kendrick is the principal investigator and CEO of MyHealth Access Network, Oklahoma's non-profit health information exchange network. MyHealth Access was one of the original Beacon Communities selected by the ONC, and has served as both the convener and data aggregator for the CMMI Comprehensive Primary Care initiative, which has saved Medicare and Oklahoma payers more than $100 million over the last four years. Kendrick is a member of the board of directors of NCQA and the Strategic Health Information Exchange Collaborative.

DICK THOMPSON is executive director and CEO of Quality Health Network. As one of the first HIEs in the nation, QHN has been fully operational for almost 10 years and is continually expanding its services and footprint throughout the 40,000 square miles of Western Colorado. QHN's significant progress has been noted by industry publications including *Healthcare Informatics, Health Leaders Magazine, Most Wired, Managed Healthcare Executive* and many others. Thompson is a charter board member of Colorado's Center for Improving Value in Healthcare organization and serves on numerous state and national boards and committees that advance health IT. His extensive business background includes three decades of management experience in software technology and support organizations with special success in startups.

MARC LASSAUX
Chief Technical Officer, QHN

MARC LASSAUX'S responsibilities include managing technology architecture and deployment, providing technology vision, enabling innovation and understanding the health information technology solutions that create business value. He currently serves on the Colorado eHealth Commission appointed by Governor Hickenlooper, as a Colorado SIM HIT Workgroup co-chair, and was previously a co-chair for the Beacon Community of Practice for HIT and Meaningful Use under the ONC for HIT. Prior to QHN he was in consulting and managing relational database systems and applications. In 2006, he joined QHN and later directed QHN's role in the Colorado Beacon Consortium.

About Rocky Mountain Health Plans

Founded in Grand Junction, Colo. in 1974, as a locally owned, not-for-profit organization, Rocky Mountain Health Plans provides access to affordable, quality health care enabling its more than 229,000 members across the Western Slope to live longer, healthier lives.

About the Community

Western Colorado is creating an accountable community that uses health IT in a meaningful way, adopts value-based payment models, coordinates care and empowers patients to take charge of their health.

We aspire to ensure the following:

- High-quality health care is affordable and accessible to all.
- Those who purchase health care are assured that care is effective, safe and appropriate.
- Patient care is a team effort, with roles that are well-defined, connected and collaborative.
- Patients have access to the support and information they need to take charge of their health and make their own decisions.
- Payment reform will foster reimbursement models that support accountability for population health and resource use.

- Information technology supports population health, helping providers predict outcomes, prioritize interventions and prevent disease.
- Health data is a community resource used in a secure way to support coordinated care at the population, practice and personal levels.
- Investments in information technology and health system transformation will improve quality of life and economic well-being across the state.
- Health is a community resource that requires leadership, stewardship, individual responsibility, community support and ongoing maintenance.

For more information:

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