White Paper

2023: State of US Healthcare's National Network Data Exchanges





This white paper discusses:

- → What Health Information Networks are.
- → Quantitative comparisons of the data currently exchanged on Health Information Networks.
- → What healthcare organizations and digital platforms can do with Health Information Network data.
- → How networks will evolve over the next several years due to TEFCA.

Table of Contents

Introduction	04
Glossary	05
What Are The Major Health Information Networks (HINs)?	06
Health Information Networks 101	06
The Three Big Networks and Frameworks	07
Technical Differences Between National Networks	09
HIN Data Recency (It's Fresh)	12
How Long Does It Take for HINs To Search for and Return Data?	13
Current HIN Constraints	14
Purpose of Use	14
Reciprocity or Bidirectionality	16
Network Questionnaires and Approval	17
Query Frequency Limitations	17
Directory Management	17
Upcoming HIN Improvements	18
Purposes of Use Expansion	18
Event Notification Services	18
Native FHIR Support	19
Closing Data Coverage Gaps	19
Health Information Network Coverage Data	21
HIN Coverage by State	21
Carequality Endpoint Density	
CommonWell Endpoint Density	
eHealth Exchange Endpoint Metrics	
Query Success Rate by State	
How Many Files Does the Average Patient Have on HINs?	
What Clinical Information Is Available on HINs?	
Why Do Solutions Like Particle Health Exist?	
Consolidating Network Access	
Faster Implementation	
Value-Add Services	
C-CDA to Flattened Data (FLAT)	
C-CDA to FHIR Transformation	
Medical Specialty Searches	
Data Curation	
Streamlined Network Complexities	
Current Data Use Cases for Healthcare Information Network Participants	
Who's Plugged in to the Networks, and Why?	37
A Kidney Care Data Use Example	
What's in Store for the Future of Health Information Networks?	41
TEFCA and QHINs	41
Increasing Transactional Volume	44
How Particle Health Complements HINs	
We Are Not Trying to Be a Network (or Compete With Other Networks)	
Our Mission: Add Value on Top of All Health Information Networks	
Conclusions	47

Introduction

It's highly likely that your most recent medical records were indexed by a national Health Information Network (HIN). The overall amount of networked clinical records is becoming truly remarkable with tens of millions of transactions occurring daily across the major networks. Today, clinicians can access these networks through APIs like Particle. Thanks to new regulations and policies, patients and other stakeholders will soon be able to get relevant records through networks as well.

The scope of these networks in consolidation has surpassed what most would likely agree is the beginnings of true interoperability. Network participants can submit basic demographic information into an API and receive full, longitudinal medical records. Records come in a parsed, standardized format, on demand, with a success rate above 90%.

There is still much work to do to spread the true value of HINs across all stakeholders in the healthcare ecosystem. We will explore the current and future status of HINs in this **2023 State of U.S.** Healthcare's National Network Data Exchanges.



Glossary

- → ADT (admission, discharge, transfer messages) ADT messages are a common type of HL7 notification that can be sent to providers when their patient experiences a care transition at a facility.
- → API (application programming interface) APIs are a standardized set of commands that allow different applications to connect and securely exchange data. Some APIs have minimal functionality, while others are gateways to complex platforms.
- → C-CDA (Consolidated Clinical Document Architecture) C-CDA is an HL7 patient data standard that's also the default format for HIN data exchange. Some of the challenges in using C-CDA for advanced applications are that it's generally readonly, and that there's no way to selectively intake data without converting to a different format.
- → Endpoint A server, URL, or device that serves as the point of connection between a network and another computing device. Endpoints can be queried by other programs.
- → FHIR (Fast Healthcare Interoperability Resources) A modern HL7 data format which permits flexible data sharing instead of rigid read-only formatting. Most healthcare organizations are moving towards FHIR adoption.
- → Health Information Networks (HINs) Nearly all Americans have medical records which have been connected to these networks, which are described in detail in this paper.
- → HL7 (Health Level 7) An international standards body that shapes technical standards for healthcare data exchange.
- → Individual Access This legal right, not always realized, entitles patients to query HINs for their own clinical data and underlies the information blocking rules.
- → Information Blocking Rules Providers, HINs, and other health IT entities must comply with this 2022 regulation, also called the Anti-Information Blocking Rule, against interference around the access, exchange, or use of electronic health information (that is, it allows patients to use the same technical method as clinicians or platforms).
- → Interoperability In healthcare, this broadly describes the free flow of patient records, on a technical and policy level, to facilitate care coordination.
- → Purpose of Use (PoU) Queries to a Health Information Network must be accompanied by a Purpose of Use, like Treatment or Operations, to indicate compliance with patient privacy laws.
- → QHIN (Qualified Health Information Network) Entities which sign TEFCA's Common Agreement, agreeing to abide by TEFCA's Trusted Exchange Framework, can become a QHINs. These specialized and regulated HINs will connect to each other, serving as core infrastructure for healthcare data exchange.
- \rightarrow Query A request for information from one computer to another.
- → RLS (Record Locator Service) A type of algorithm, some of which are more accurate or complete than others, that tell HINs and APIs which endpoints to query for patient records.
- → TEFCA (Trusted Exchange Framework and Common Agreement) a legallymandated government initiative that's leading to nationwide baseline standards for clinical data sharing.

What Are The Major Health Information Networks (HINs)?

Health Information Networks 101

There are around one hundred Health Information Networks in the US.¹ Most of these are small regional organizations which are centered around a specific purpose, like networking different healthcare providers in a single state or coordinating around a certain disease.

All HINs (regional ones are generally called Health Information Exchanges, or HIEs) have some characteristics in common.

- → They are driven by incentive to have access to information, and accept regulation.
- ightarrow They don't sell data, and carefully support HIPAA-defined use cases.
- ightarrow Their individual participants must agree to reciprocally share data.
- → Participating organizations must maintain an endpoint, or a server that other organizations can query for clinical data, since networks don't store clinical records in a central database.
- → Presently, most network participants exchange data in the C-CDA format by default. Many networks are piloting next-generation data formats (particularly FHIR), and C-CDA data is frequently transformed into a different format at its destination.



The Three Big Networks and Frameworks



There are three large national networks (or frameworks) which together have access to healthcare records from well over 90% of the population:

CommonWell

The CommonWell Health Alliance was the first major nonprofit interoperability network, founded in 2013 by a number of health IT vendors which wanted to advance information sharing.²

In 2022, Particle received millions of files from CommonWell. CommonWell has a number of unique and highly-engaged participants, however, giving these records outsized importance. CommonWell lists over 29,000 sites on its network and claims to have records for over 153 million unique individuals.^{3 4} CommonWell processes over 100,000,000 documents per month.⁵

CommonWell is a tech-centric Health Information Network, with technology infrastructure provided by Change Healthcare. Change's solution allows for a centralized Record Locator Service and Master Patient Index, making it relatively easy for organizations to connect on their own. The drawback to this is organizations that connect cannot create new or innovative tools for things like searching for records, as Change controls this for every participant.



- → 29,000 sites
- → 153 million individuals

carequality

- → 55,000 sites
- → 300,000,000 document exchanges per month

eHealth Exchange

- → 75,000 sites
- → 120 million individuals

Carequality

Carequality (pronounced "care-e-quality") was founded in 2015. Epic, the largest EHR vendor, played a major role in Carequality's creation.⁶

Carequality operates as a contractual and operational framework that members can use to share information in a common way - in other words, allowing two participants to exchange data with each other directly.⁷

In 2022, Particle received over a hundred million files, a majority of our records, from Carequality. The high number of natively-compatible Epic EHR instances account for some of this volume. Additionally, we had used Carequality to get records from a network (eHealth Exchange) with which Particle now has a direct connection.

Carequality provides health information exchange in a decentralized manner. Within Carequality, each entity connected with the network is responsible for its own patient matching and record location.

It is important to note that Carequality does not maintain any technology or product offering. Carequality's framework is a set of rules and policies that dictate how participants can essentially build their own network within its constraints. While a relatively limited description, we often think of Carequality as a program that allows for organizations to build networks.

This makes Carequality difficult to connect to. While the lift to begin is higher, it allows organizations like Particle to build solutions that are distinct from other vendors. This competitive pressure pushes companies to focus on best-in-class KPIs like hit rate, number of records found per search, and latency.

One of Carequality's strengths is its native integration with Epic, the most commonly-used EHR vendor. Epic's Care Everywhere interoperability tool natively connects Epic EHR instances to Carequality. Accordingly, KLAS Research found that "Epic customers' longtime use of Care Everywhere has given them an advantage in data sharing; they are the only customer base comfortable with outside data flowing directly into the patient chart without prior human screening."⁸

Over 300,000,000 documents per month are processed through Carequality, which states that over 55,000 organizations are connected to its framework.⁹

eHealth Exchange

eHealth Exchange is a government-founded HIN, with roots dating to 2006, that's intended to connect federal agencies to the wider healthcare ecosystem. The Department of Veterans Affairs and Indian Health Service share data through eHealth Exchange, as do 85% of dialysis centers and 77% of state and regional HIEs.¹⁰

Over one billion requests per month are processed through eHealth Exchange.¹¹ It claims to have records for 120 million patients and over 75,000 organizations. Particle established a direct connection to eHealth Exchange at the end of 2022, and it will account for a greater proportion of our records in 2023.

Technical Differences Between National Networks

At a high level, each of the three major national networks creates their own implementation guides for generic Query-Based Document Exchange (QBDE) processes established by IHE, a nonprofit which coordinates messaging standards.

Actual queries to networks are formed in different ways, but all messages are comprised of XML requests using both SOAP and SAML protocols. These are relatively uncommon areas of expertise for enterprise networking (for comparison, Particle's API allows users to initiate queries in the more common JSON format, automatically handling XML on the backend). Messages commonly facilitate the exchange of text, PDFs, or images.

Each network's different communities that hold the same patient's data must respond to the same set of unique patient demographics or identifiers in a similar fashion. They must make their data available to queries from other participating organizations via an endpoint server that is exposed to other network participants. They must run their own patient matching algorithms (mapping their data to an internal Master Patient Index), and deal with thousands or millions of differently-formed requests each day.

Arguably the most significant difference between national networks is whether they employ a centralized or federated architecture. This affects the design of their Record Locator Service (RLS), or how they look for patient records.

Their architecture also affects Cross-Community Patient Discovery, or XCPD, which is the process for asking network endpoints whether or not they have data on the patient being queried.

Carequality and eHealth Exchange are federated networks. They manage XCPD by having requesters determine, on their own, which

endpoints in their network need to be called to request patient documents. Particle's solution for this is to continuously maintain an up-to-date list of endpoints and connection protocols on its RLS for each network. It's the only practical way to use the networks at scale, and has resulted in an industry-leading Query Success Rate.

Carequality organizes their endpoints in a hierarchical fashion, with top-level directories and smaller networks within them. A Carequality endpoint will tell query initiators the full address (including latitude and longitude) of each associated care site.

eHealth Exchange has different messaging standards and a flat hierarchy, requiring different parsing for each request. This network has relatively few endpoints, some of which service multiple states. Instead of revealing each endpoint's associated sites, their endpoints will list all the states in which any sites are serviced by the particular endpoint.

CommonWell operates in a more centralized manner, requiring each participant to maintain their own patient index - storing a list of updateable identifiers and demographics for each patient - which can then be queried by CommonWell's central server which is managed by Change Healthcare. Their endpoints are organized in a web interface.

When the HINs do make changes to their protocols, their participants have to change as well, incurring a constant maintenance cost. For example, Carequality is preparing to implement a more modern endpoint directory, requiring engineering work from each of its participants to ensure their endpoints respond correctly.

Sharing Data Between National Networks

Connections between the three major networks do exist. Carequality and CommonWell established a connectivity protocol in 2018,¹² and eHealth Exchange reached an agreement to participate in Carequality in 2022.¹³

While participants can theoretically query data across these three networks, the "bridges" that connect HINs together are not perfect. Complications make these connections less than reliable, and result in lower success rates than connecting directly with each network.

Carequality, for example, doesn't have a Record Locator Service. CommonWell is registered as a Carequality connection, but acts as a single node on Carequality's endpoint directory. Additionally, a number of eHealth Exchange's most prominent federal endpoints remain exclusive to its network.

Individual members of each organization must take steps to comply with the other organization's bylaws before sharing records. Information sharing is delayed when compared to a direct connection, or results in highly duplicated data. The most consistent way to get patient data is to be independently connected to each HIN.

Later we will discuss how TEFCA and QHINs generate new requirements for the networks to be interoperable with each other. However, it is not very clear what they will do differently to solve some of the technical problems we see with network-to-network data sharing today.

HIN Data Standards

Patient records are exchanged in the C-CDA format, an old standard which is the most common one used in healthcare today. C-CDA is an inflexible XML export of a patient's full healthcare information.

FHIR, a type of healthcare data format with modern features, is generally accepted as the way forward for HINs and the rest of the healthcare system. This flexible JSON-based standard, which has been put into law as the successor to C-CDA, could theoretically allow for tailored sharing of patient data points like specific vital signs.

Switching from C-CDA to FHIR exports will take a great deal of time, as most network participants are not used to the FHIR standard. Different protocols, new versions of the standard, and the classic chicken-andegg network problem are affecting its momentum. FHIR only reached normative status in 2019, and is slowly seeing industry uptake. Since it isn't the easiest standard to learn, many developers, product teams and key decision makers are attempting to balance the cost-benefit of when to invest into commiting to FHIR.

CommonWell¹⁴, Carequality¹⁵ and eHealth Exchange¹⁶ have each made efforts to support FHIR on their networks, and some participants have implemented FHIR in a limited fashion. Full-scale HIN-side FHIR participation is not yet in sight.

HIN Data Recency (It's Fresh)

Most of the data found on national networks is relatively recent. From a representative sample of 250 kidney care patients in 2022, Particle found:¹⁷



Recent data is particularly important for providing care. Providers can use it to determine whether a patients' chronic conditions are trending in the right direction. Cumulatively, years of data helps providers understand where their patients were, and importantly, where they are now.

The vast majority of data found on HINs was generated within the past decade (we'll discuss what this data includes in the next section). The health system prior to 2012 had minimal digitization, little interoperability, and poor EMR data collection, leading to a relative paucity of earlier data. As the health system continues to adopt digital tools, the number of recent files will increase.

Network participants don't necessarily upload new data every day, but once there is data available on a patient on any of the major networks, then getting that data is an achievable task.

The near-universal sentiment from HIN participants is that the current volume of data is sufficient and comprehensive. In fact, their challenge is parsing and making sense of the large amount of data that Particle finds across the US.

How Long Does It Take for HINs To Search for and Return Data?

Particle Health is adept at querying HINs. In 2022, we saw on average:

- \rightarrow A query completion time of 1 minute
- → 134 files returned per patient
- → 2.3 matching endpoints per patient query¹⁸
- → 51.3 files returned per successful endpoint match

Searching for a record is accomplished by a Record Locator Service (RLS). No two RLS algorithms are the same. Good ones find more records - or more importantly, the one record that really matters.

There is a careful balance in not branching queries too far out, which creates problematic network traffic issues, while putting out enough queries to find the completely longitudinal set of records a patient has out there.

Most organizations will use a radius search around an individual's home zip code. While this method works well the majority of the time, Particle's team has harnessed additional logic that can reduce the number of endpoints being searched, while increasing the number of high probability endpoints. Endpoints which receive patient demographics from an RLS will then determine if a patient exists in their system, and determine which documents to return.

With every query, the search itself is run fresh across the network to find the most up-to-date information possible. Sometimes, particularly with sick patients, Particle finds thousands of files. This can increase the query time as downloading these records and processing them into parsed FHIR R4 can take compute time.

Current HIN Constraints

Purpose of Use (PoU) Requirements

Any query to a Health Information Network must be accompanied by a Purpose of Use, or PoU.

PoUs fall under a Treatment, Payment, or Healthcare Operations (TPO) subcategory. Public health needs are also a permitted PoU.¹⁹ PoUs expand as regulation or the private sector decides collectively they should be adopted.

PoUs have roots in the Health Insurance Portability and Accountability Act (HIPAA) as the "core health care activities" in which providers can share information with other covered entities. They have been expanded upon by regulation to include individual-directed information requests as well.²⁰

Treatment - the Most Common Purpose of Use

Most requests to health information networks to date have been submitted with a Treatment PoU. To fulfill the Treatment PoU, information must be requested by an organization that uses it under the strict criteria of HIPAA's Privacy Rule, which defines Treatment as:

"The provision, coordination, or management of health care and related services among health care providers or by a health care provider with a third party, consultation between health care providers regarding a patient, or the referral of a patient from one health care provider to another."²¹

Essentially, the Treatment PoU occurs when a medical professional is requesting information to care directly for their patient.

Non-Treatment PoUs

Definitions for other use cases have also been expanded upon in greater detail. These Non-treatment PoUs can be thought of as the "PO" of TPO.

In practice, the industry found that in the digital world, subjects like "Operations" are simply too broad to stand as a PoU term on their own. An EMR or other provider receiving an electronic request for data needs to know exactly what kind of request is being queried for. This allows endpoints to respond differently depending on what's being asked, giving the network participants the ability to follow rules like HIPAA's Minimum Necessary standard for disclosure of protected health information.

Payment and Operations (TPO Purposes of Use)

As core health care activities that are thoroughly defined under HIPAA, these PoUs don't necessarily require patient consent and ID verification, but they do entail additional HIPAA safeguards.

There are multiple subtypes of these PoU queries. For instance, Care Coordination, or sharing information among patient stakeholders like social services organizations, is a relatively common Operations PoU. Quality Assessment, which covers outcomes evaluation and development of clinical guidelines, is another. These must be part of a direct patient-provider relationship, but can be treatment-adjacent instead of primarily for the purpose of treatment.

The best way to think of Operations vs. Treatment is: will querying for this patient's record be used to *decide* if the patient needs treatment (Operations) or is the patient already coming to an appointment or consult (Treatment)?

Non-TPO Purposes of Use

Non-TPO Purposes of Use require additional policy discussion between network representatives to establish the acceptable parameters of data exchange.

Individual Access, or records requests initiated by patients themselves, is a highly anticipated PoU. This will power a wave of consumer-directed digital health tools that will easily outstrip the total query volume on HINs today.

While providers and HINs are legally required to comply with this PoU due to TEFCA and the information blocking rules, networks are racing to make sure that their policy infrastructure (such as identity verification and mandatory query responses) supports consistent delivery of Individual Access requests.

Notably, the technical HIN infrastructure to provide Individual Access is already in place. However, stakeholders are struggling to figure out operationally how to handle these requests.

Public Health, involving case reporting, is another non-TPO Purpose of Use that shows the enormous potential of HINs. Carequality temporarily allowed public health agencies to initiate these queries and empowered participants to respond during the start of the COVID-19 pandemic.²² This powered COVID-19 data for statewide public health agencies, which tapped into existing databases to understand the prevalence and typical progression of the pandemic.

Limited Purpose of Use Uptake

Stakeholder	Mandated Today?	PoU
Providers	Yes	Treatment
Payors	No	Operations, Payment
Pharma	No	Individual Access
Patients	No	Individual Access
App Developers	No	Individual Access
Life Insurance	No	Individual Access
Disability Insurance	No	Individual Access
Law Firms	No	Individual Access

It's important to note the distinction between permitted purposes of use, and Treatment, the PoU that is actually being utilized today. The networks support but do not currently enforce PoUs like Operations, Payment, Public Health or Individual Access (the ability for patients to request their own records). Almost all network participants have not yet adopted these PoUs.

Thanks to the information blocking rules and TEFCA, there is considerable pressure for HINs and providers to begin mandating that their participants comply with new PoUs. Most efforts today are focused around support for Care Coordination (a subcategory of Operations) and Individual Access.

Reciprocity or Bidirectionality Requirements

Networks are built on the idea of reciprocity, or the idea that each participant must give and take data in full measure. Participants must make their patient data available, and their network connection is expected to result in "net new data". If they are found to make little data available or refuse requests, they can be kicked off the network. There are certain exceptions to this rule in limited circumstances.

To make data available, organizations must operate their own servers, or endpoints, which other participants can query. Some organizations include hundreds of sites in a single endpoint. Other organizations may maintain endpoints for each individual care site.

Particle's bi-directional API takes care of endpoint maintenance, making it easy for participants to share data back with all three large national networks. Few other API vendors have simple ways to fulfill this requirement.

Network Questionnaires and Approval

Joining a network is not automatic. Participants are screened by networks to ensure that they meet the requirements for a valid Treatment Purpose of Use. Generally they'll need to be associated with an NPI number, be a HIPAA Covered Entity, or have a BAA with one. They'll need to assert a real provider-patient relationship and illustrate the data will be used for the active treatment of these patients.

Query Frequency Limitations

A healthcare data platform can't query every endpoint in the country every 5 minutes. EHRs and other vendors can't handle that volume, and HINs don't appreciate it either!

Query initiators have to limit the number of endpoints they look across, depending on the PoU they are running. Meanwhile, record holders must be prepared to handle high query volumes.

Record Locator Services are the solution to query frequency limitations. These tools limit the query broadcast to the endpoints in which a patient is likely to be found.

Directory Management

Getting endpoints indexed, and keeping them online, is a challenging task. It's more than just server maintenance - every member of Health Information Networks must maintain directory hygiene.

Directory hygiene encompasses things like deactivations for canceled and closed accounts while still maintaining historical records. Accurate hierarchy listings of organizations, sites, and providers are also critical so as to tell network participants which organization, and which of their provider end users, is initiating a query.

What's more, providers and query initiators can't actively participate in networks using multiple vendors (i.e. two APIs at once, or an API and a direct connection) so as not to create a duplicate data "echo" that would gum up the works.

Good endpoint management is critical. Doing this across multiple HINs is no easy feat.

Upcoming HIN Improvements

Purpose of Use Expansion

2016's 21st Century Cures Act makes clear that healthcare organizations are required to respond to requests from individuals in technically-feasible ways - a policy called *Anti-Information Blocking*. If a doctor can get records from a Health Information Network, then patients should be able to access records in that same manner as well.²³ Regulators have promised to start issuing penalties for information blocking rule violations in 2022. It's a long-promised change with big implications for the healthcare system, allowing new apps like a "Mint of healthcare" to finally become a reality.

While enforcement officially started in October 2022, the networks and frameworks are playing a bit of catch up with the rule. They're sorting through complicated multi-stakeholder policy, security and technical nuance. Progress is slow but getting close to a day, hopefully in early 2023, where individuals will have the ability to access their own records.

HINs are aware of the new rule, and are incentivizing a collective effort among large healthcare organizations to share patient records directly back with patients.

Non-provider participants may be the rule on Health Information Networks, not the exception, once more PoUs are widely supported.

Event Notification Services (ENS)

Carequality,²⁴ CommonWell,²⁵ and eHealth Exchange²⁶ are offering or developing their own "Event Notification Service" or ENS. Similar to a facility's Admission, Discharge, Transfer (ADT) feed, these services will send push notifications to a patient's providers if their patient has had a care transition at an acute care facility.

Researchers found that event notifications were linked to subsequent query-based HIN usage, especially for older patients, suggesting that the service is incredibly valuable for organizations managing risk.²⁷

While there is growing adoption, network participation in ENS is in early stages. HINs that are offering these services have seen very slow uptake. We believe that fewer than 10% of endpoints support ENS through HINs, as it is not yet mandatory for endpoints to implement this feature.

Native FHIR Support

Each major HIN is actively exploring how to share patient data in the FHIR format and exchange modality through working groups and roadmaps. Regulations in various stages of completeness will require a FHIR backbone for more than just clinical records – payer data exchange,²⁸ provider directories,²⁹ and price transparency³⁰ to name a few use cases – so robust FHIR support will make HINs more compatible with the many new developments in digital health.

However, no HIN appears close to incentivizing adoption at critical mass. C-CDA is the ingrained standard and will likely be so through 2023. Entities that want to generate FHIR data from national networks will need to use Particle's data transformation feature, or create their own solution.

Closing Data Coverage Gaps

Today, HINs have widespread coverage from doctors and medical centers. Financial incentives have pushed most healthcare providers to adopt electronic health records and nominally participate in data sharing, even if they don't make use of data they receive.

Not having access to clinical data puts the remaining HIN holdouts at a disadvantage. Accordingly, healthcare entities that provide services other than treatment are now considering joining the networks.

HINs are working to increase support for greater numbers of these participants:

- → Clinical trial companies the pharmaceutical industry is generally unconnected to HINs due to current lack of support for PoUs other than treatment. Once new Purposes of Use - from Individual Access to support for clinical trials - receive network support, we expect to see patient records used to match into trials, monitor patients for adverse events during trials and perform cost effective post-market surveillance after a new drug or device makes it to market. Today, this use case is not supported by the networks.
- → Pharmacists pharmacists have lacked incentives to join HINs, and also lack the opportunities to generate net new clinical data that's a requirement of HIN participation. As value-based care organizations continue to integrate pharmacists into care teams - and other HIN opportunities open up commercial possibilities - pharmacists will connect in greater numbers. Pharmacies are currently served by HINlike medication management services (also offered by vendors like Particle Health) which may be incorporated directly into HINs in the future.
- → "On-behalf-of" companies On-behalf-of companies typically use data to help providers offer care; they could be an EMR add-on app or similar tool. However, these are initiator-only organizations. They

can't generate new, non-duplicative clinical data nor respond to data requests from networks. While providers and patients would benefit from HIN queries to support patient care, HINs require bi-directional data sharing of original data resulting in a large number of providerfacing tools unable to pull data from the networks, even for the Treatment Purpose of Use.

→ Regional HIEs – some nonprofit regional HIEs with a relatively narrow purpose are isolated from national networks. Cajoling these networks to participate in national HINs is an ongoing effort, where many state HIEs have joined through groups like eHealth Exchange.

Health Information Network Coverage Data

Exchanging data for the Treatment Purpose of Use has been a resounding success for Health Information Networks. All participants are on board with this PoU and have been able to consistently support it.

Since Particle Health is connected to all three national networks, our data scientists have an unparalleled view of how they perform. With this PoU that networks do support, what records do they find?

HIN Coverage by State

We've mapped out each network endpoint in the United States, and ranked states by their endpoints per capita.

At a high level, this shows the density of endpoints by state. Fewer persons per endpoint indicates better coverage.

This also shows whether or not anyone - including Particle Health, the API with incredibly widespread endpoint connectivity 😌 - has robust coverage in a particular area.



Carequality Endpoint Density



Persons per Endpoint



22

Total U.S. Endpoints	43,800+
Maximum Endpoints per State	4,385
Minimum Endpoints per State	70
Median Endpoints per State	580
Average Endpoints per State	860
Most Persons per Endpoint	12,191
Fewest Persons per Endpoint	4,730
Average Persons per Endpoint per State	7,993

State	Persons per Endpoint	State	Persons per Endpoint	State	Persons per Endpoint
North Carolina	4,730	Georgia	6,801	Nebraska	8,998
ldaho	4,827	Rhode Island	6,945	New Jersey	9,143
Oregon	5,117	Illinois	6,967	lowa	9,168
South Carolina	5,244	Michigan	6,984	DC	9,194
Delaware	5,294	Arizona	7,137	Hawaii	9,574
Kentucky	5,611	Connecticut	7,314	New York	9,778
Colorado	5,655	Alabama	7,378	Wisconsin	10,162
Alaska	5,730	Arkansas	7,381	Maine	10,480
Massachusetts	5,767	Montana	7,635	Washington	10,498
Wyoming	5,769	Virginia	7,659	New Mexico	10,749
Oklahoma	6,129	West Virginia	8,044	California	10,759
Maryland	6,303	Pennsylvania	8,086	South Dakota	11,083
Mississippi	6,341	Ohio	8,200	North Dakota	11,130
Tennessee	6,465	Vermont	8,574	Utah	11,243
Florida	6,519	Indiana	8,600	Minnesota	11,345
Texas	6,647	Nevada	8,947	Missouri	11,679
Louisiana	6,721	Kansas	8,957	New Hampshire	12,191

Qualifications:

While we believe this to be an accurate count of endpoints, each endpoint may represent anything from a smaller HIE controlling thousands of locations to a single department at a health system's hospital, depending on the organization.

These results were calculated by taking state populations from the 2020 U.S. Census, then dividing them by the number of endpoints we found in each of the 50 U.S. states and the District of Columbia in December 2022.

CommonWell Endpoint Density



Persons per Endpoint 7,720 39,031

Average Persons per Endpoint per State	16,018
Fewest Persons per Endpoint	7,720
Most Persons per Endpoint	39,031
Average Endpoints per State	429
Median Endpoints per State	272
Minimum Endpoints per State	28
Maximum Endpoints per State	2,436
Total U.S. Endpoints	21,800+

State	Persons per Endpoint	State	Persons per Endpoint	State	Persons per Endpoint
Alaska	7,720	Oklahoma	12,855	Illinois	16,511
Wyoming	9,614	Idaho	12,951	Kentucky	16,566
Florida	9,667	Montana	13,385	South Carolina	17,118
Arizona	10,364	New Jersey	13,721	New York	17,460
Districbio Colum-	10,608	Nebraska	13,813	North Carolina	17,876
Vermont	10,718	Hawaii	13,860	Ohio	18,849
Maryland	10,743	Alabama	13,879	lowa	20,583
Delaware	10,999	New Mexico	14,117	Pennsylvania	20,639
Georgia	11,518	Kansas	14,124	New Hampshire	20,872
Tennessee	11,615	Michigan	14,417	Missouri	21,371
Rhode Island	11,674	Virginia	14,629	Indiana	21,541
Texas	11,964	Nevada	14,855	Washington	22,205
Arkansas	12,242	Connecticut	14,901	North Dakota	23,609
Massachusetts	12,531	Colorado	15,036	California	24,681
Louisiana	12,657	West Virginia	15,598	South Dakota	31,667
Oregon	12,686	Utah	15,959	Minnesota	31,703
Mississippi	12,819	Maine	16,414	Wisconsin	39,031

Qualifications:

While we believe this to be an accurate count of endpoints, each endpoint may represent anything from a smaller HIE controlling thousands of locations to a single department at a health system's hospital, depending on the organization.

These results were calculated by taking state populations from the 2020 U.S. Census, then dividing them by the number of endpoints we found in each of the 50 U.S. states and the District of Columbia in March 2022, the most recent data available.

eHealth Exchange Endpoint Metrics

Total U.S. Endpoints	643
Maximum Endpoints per State	49
Minimum Endpoints per State	3
Median Endpoints per State	11
Average Endpoints per State	13

Compared to CommonWell and Carequality, it may seem like eHealth Exchange has a small number of connected participants based on endpoint count. However, endpoint locations don't tell the full story for this Health Information Network.

eHealth Exchange endpoints service hundreds or thousands of sites, from different organizations, even across different states. That means these endpoints are pulling double duty (and a lot more).

eHealth Exchange has minimal variation among endpoints on a state-bystate basis, making it difficult to display the locations of its endpoints in an appropriately de-identified manner. Nevertheless, eHealth Exchange has robust coverage throughout the country.

Qualifications:

This counts the endpoints in the 50 U.S. states and the District of Columbia which we obtained from eHealth Exchange's participant listing in December 2022.

While we believe this to be an accurate count of endpoints, each endpoint may represent anything from a smaller HIE controlling thousands of locations to a single department at a health system's hospital, depending on the organization.

Query Success Rate by State

The best available method to quantify patient record availability is the Query Success Rate (QSR) metric.

If any files are found for a patient during a query, on any of our HINs, then we record this as a success. Finding no files for a patient would count against the Query Success Rate.

The Query Success Rate allows Particle to track our ability to find a patient's record nationwide. Particle's volume of data, and our constant maintenance of our Record Locator Service, allows us to deliver the highest QSR of any service that we know of. This gives us an excellent view of the current ceiling for patients who have queryable records.

Interestingly, there is major query success variation between different states. States with the most endpoints don't necessarily return the most records.

Factors that would lower a state's Query Success Rate include: requiring patients to opt-in to data sharing, being spread out and affecting radiusbased records searches, or having fewer networked providers. States with a high proportion of residents served by the VA may have artificially lower QSRs, as our QSR does not account for Military Health System and Veterans Affairs records on eHealth Exchange today.

Factors that would increase a state's Query Success Rate include: having multiple regional HIEs and a corresponding legislative focus on data exchange, or adopting opt-out only data sharing policies.

Lastly, while global QSRs across Particle's base of partners gives us an indication of the actual state of QSR, these numbers are not a truly accurate representation of each state's response rates. For example, if only 1 of Particle's partners queries for 5 patients in Alaska, and we get 1 response, then we would report a 20% response rate when in reality Alaska's true QSR might be closer to the rest of the US. As Particle's customer base and nationwide query volume grow, we will be able to determine QSR with increasing statistical significance.

Query Success Rates by State



Maximum	94.99% (Michigan)
Median	76.51% (Maryland)
Mean	73.91%
Minimum	37.90% (Montana)
Average Cross-network QSR	85.98% *

*As more queries take place in higher QSR states, this is above the mean.

State	Query Success %	State	Query Success %	State	Query Success %
Michigan	94.99	Indiana	81.52	Georgia	70.04
Virginia	93.96	Florida	81.12	Texas	69.96
Alabama	93.55	Ohio	80.25	Arizona	69.36
Oregon	92.52	Illinois	79.39	California	68.79
Washington	91.55	Louisiana	79.36	Massachusetts	67.73
Kanasa	91.39	South Carolina	78.69	lowa	66.67
Connecticut	91.28	Arkansas	77.54	Wyoming	63.93
Colorado	91.00	New Jersey	77.48	West Virginia	59.38
Tennessee	90.13	Maryland	76.51	Wisconsin	57.40
Missouri	89.86	Maine	74.17	Nevada	53.20
Rhode Island	89.68	Utah	74.02	Minnesota	52.79
Mississippi	89.15	Idaho	73.17	South Dakota	50.77
Alaska	87.50	Kentucky	72.84	Vermont	50.39
Delaware	84.13	District of Columbia	71.79	Hawaii	43.18
Oklahoma	82.87	New York	70.87	New Hampshire	41.04
New Mexico	82.40	North Carolina	70.36	North Dakota	39.44
Pennsylvania	82.39	Nebraska	70.09	Montana	37.90

Qualifications:

The QSR was measured across Carequality and CommonWell (but excluding eHealth Exchange) during a 30-day period from November to December 2022.

How Many Files Does the Average Patient Have on HINs?

On average, each queried patient returned dozens of Office Visit Summary C-CDA documents (around 26 per patient) and Hospital Encounter Summary C-CDAs (around 24 per patient), among other document types.

The most common documents that Particle finds when querying Health Information Networks are:

- → Continuity of Care Documents e.g. high-level summaries of recent vitals, known medications, diagnoses, care plans, and other details about a patient's history with a specific institution.
- → Office Visit Summaries e.g. details from a small primary care provider or a radiology appointment
- → Hospital encounter summaries e.g. visited the emergency room, had surgery, or admitted as an inpatient
- → Administrative records e.g. telephone summaries, transfer summaries, script refill notes

HINs will share these documents in the C-CDA format, but Particle can convert them to FHIR R4. In both cases, their data elements will map to the widely-used USCDI government standard for healthcare data.

While the "average" patient results in the above numbers, sicker patients often have skewed statistics.

On a sample of 250 kidney care patients in 2022,³¹ Particle found an average of 222 files per patient, with a 95% query success rate.^A The patient with the most data had 1,991 different files.

A Query Success Rate measures whether or not Particle found records associated with the patient queried. A QSR of 95% indicates that data was available for 19 out of 20 patients.

What Clinical Information Is Available on HINs?

Within the hundreds of C-CDA documents per patient that are connected to HINs, you can expect to find a wealth of data elements. Notes, medications and vital signs are only just the start.

More than 95% of patients which Particle finds data on have these clinical data elements available:

- \rightarrow Known problem lists and conditions
- → Medication lists, dosages, and patient instructions
- Encounter information & associated provider and location types, including:
 - → PCPs, consulting providers, specialists, case managers, home care specialists
 - → Provider NPI, location, facility type, address, and contact information
- → Procedure history e.g. surgeries, exams, therapies
- ightarrow Laboratory results, social history, and vital signs
- → Radiology reports e.g. a radiologist's notes from reviewing a CT scan or MRI
- → Allergy information e.g. newly diagnosed, recorded during patient onboarding/intake, patient dictated
- → Immunization records
- → Related provider notes e.g. history and physical, patient discharge instructions, hospital course, ED notes, assessments surgery notes, progress notes, and more

As a rule, patients with relatively sparse medical history (like younger and healthier populations) will typically have less data recorded than those with chronic conditions.

Organizations that convert these documents into FHIR R4 format - on their own or through a vendor like Particle - get additional control over what information to use and how to use it. For example, using FHIR, you could parse out medications prescribed within the last two years instead of sorting through a full medical record. FHIR is made up of resources (the "R" in FHIR), or discrete building blocks, whereas C-CDA is more difficult to parse.

Why Do Solutions Like Particle Health Exist?

Direct integration with a Health Information Network is prohibitively difficult for most organizations. Many entities that could be good candidates for direct integration face the additional challenge of deriving value from their participation.

Vendors like Particle exist to make a wide array of diverse network data accessible and actionable for the many stakeholders and organizations that would benefit from network participation.

In addition to simply facilitating network access for digital health companies, vendors will add both essential services (like record location) and optional services (like data transformation) that greatly increase the value of network participation. The amount of specialized work needed to maximize the value of HIN connectivity makes these services a preferable option for most participants.





Consolidating Network Access

Any one of the major Health Information Networks is a huge source of exchangeable data, but as discussed previously, records may not make it from one network to another. To replicate what Particle does, one would have to create separate processes for each network and then combine the results.

Particle consolidates each network within a single API implementation, making it manageable to use multiple HINs covering over 270 million patient lives. This developer-friendly approach is unique in the industry, as other vendors require separate APIs to access each network.



Care Facilities: Surgical, ambulatory, & urgent care facilities, hospitals, clinics, GPs & specialists

Particle's API connects to the three major Health Information Networks, and helps participants use them effectively.

Faster Implementation

Joining a network may require approval from the network administrators, which itself requires knowledge to facilitate.

Healthcare API companies like Particle are experienced with vetting candidate companies and quickly moving into a standardized implementation process. As an added bonus, Particle generally integrates partners into multiple HINs at once with the same information, turning three separate HIN processes into one.

Bottom line - network implementation with an API partner can be completed in a few months or sprints, in line with a typical B2B integration (organizations that are highly prepared may be able to work even faster). Network implementation on your own requires an extraordinary time investment and opportunity cost.

How long does it really take to implement one network? Getting on to one of these networks for the first time, without an API partner, will take between 6-12 months to implement and productionize the data into something useful for a typical healthcare business. It involves operations, engineering, and clinical expertise at different stages throughout the process. Layer on additional network connections and you're looking at years of development.

Before doing the technical work, an organization must navigate policy requirements that are not at all open or straightforward.

Part of this involves satisfying bidirectionality. In other words, an organization must have a way to send new patient data back to the network. This requires maintaining an MPI (Master Patient Index), or a patient record and document store with near-constant uptime that's synchronized to whatever original source of data that an organization maintains.

Bidirectional data sharing is not a small thing - endpoints can typically get a million queries per day. Unlike initiating a query for data, responding to a query for data entails knowledge of different message formats that all must be properly serviced. Technical procedures to validate that the query initiator is a trusted party, with clearance to access sensitive clinical documents, must also be in place.

If approved, an organization must be properly listed in each network directory before testing begins. Only then can endpoint testing take place. This includes appropriately formatting message responses, which will have to pass validation steps in tooling. Properly writing SAML headers, which

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identify an organization with content and timestamps signed separately in a dated XML standard, is particularly confusing.

Once messages work, organizations must build or contract for a Record Locator Service and identity verification services, which will take additional development time. An effective record locator function will have to parse each network directory to choose endpoints in a sensible manner. It also has to handle implementation differences (IHE standards are open to interpretation) on different endpoints so as not to miss data.

Finally, organizations will need to learn how to implement data in your workflow. There's no shortcut to removing duplicate information and parsing out useful data from records. Ongoing maintenance is also required.

Value-Add Services

These services on top of a healthcare API integration can (literally) turn data into something more.

C-CDA to Flattened Data (FLAT)

Although Health Information Networks exchange clinical records in the C-CDA format, most organizations prefer to use their existing architecture when implementing networked clinical data. Getting started with C-CDA documents for the first time, or even having experts integrate C-CDAs into an existing platform, is a time-consuming process.

Healthcare APIs can turn the C-CDA data that comes from HINs into formats that are more realistic for businesses to work with, like a common JSON file. This removes the need for healthcare organizations to specialize in either C-CDA or FHIR R4.

Particle's FLAT feature, for example, curates HIN data into a flattened JSON output grouped by human-concept datasets (like medications, encounters, and lab results) that highlights the key data values leveraged by a majority of organizations. This potentially will allow for included terminology to be normalized at the source under medical classification standards like the Unified Medical Language System in the future.

Well-formatted data from an API helps health tech organizations get actionable insights into the hands of clinicians months ahead of older approaches. An easily ingestible JSON format gives digital health companies maximum speed and flexibility when implementing HIN data. Formats like a flattened JSON file are designed for persistence, helping companies sustain their use of networked data over time.



An API with advanced data curation capabilities can turn blocks of code into immediately usable information.

C-CDA to FHIR Transformation

C-CDA documents can be transformed into the FHIR data format today, even though HINs don't have this capability. Healthcare API connections can convert rigid C-CDA exports into discrete FHIR resources.

The effectiveness of this depends on each API provider's solution. Particle will make a full C-CDA to FHIR conversion, while some companies will "wrap" their C-CDA data within FHIR. FHIR transformation allows organizations to adopt this next-generation format while still leveraging HIN benefits.



Medical Specialty Searches

Record location algorithms can be enhanced by targeted or bespoke search capabilities. For example, Particle offers a condition-specific records search that queries the most prominent Centers of Excellence for chronic illnesses nationwide.

For conditions in which patients get second opinions, frequently traveling far and wide during their care journey, such information is invaluable. This is effectively what certain specialists need when they think of "interoperability".

Data Curation

The nodes across each network will format data in different ways, even if they both deliver it in the C-CDA format. Some will include a field in one place; others will have it in a different location. They may list vital statistics differently. Duplicate information abounds.

We recognize that providers and other key decision makers don't want 135 different C-CDA documents. Instead, they want clinically relevant data organized and delivered in the most helpful way possible.

Particle's API will transform this data so that the entire patient record is filtered, sorted and organized in a way that allows for fast and informative decision making. For example, several partners use Particle to pull A1c values from each C-CDA found for a patient. Then, Particle organizes the A1c values in a timeline view to illustrate the trends associated with a patient's diabetes progression as well as flag 'out-of-range' values or go so far as to find potential gaps of care in the patient's history.

Many organizations require the same core data no matter what workflow they use. A healthcare API vendor can bring similar expert advice to your team's HIN data implementation, using lessons learned from helping to set up other workflows.

Streamlined Network Complexities

You could build separate Record Locator Services, directory management schemes, webhooks, search features and more for each network connection. Or, a healthcare API could provide them all in a consolidated instance.

Connecting to networks without the help of an API is difficult, requiring membership fees, security reviews, and months of engineers working with multiple arcane messaging formats for each network.

For example: to query Carequality using Particle, one would need to pass our Purpose of Use review, connect to our API, confirm receipt of FHIR or C-CDA data, and fine-tune their integration. This generally takes three sprints, on average. For comparison, connecting to Carequality alone can take several years, as explained above.

Current Data Use Cases for Healthcare Information Network Participants

Make no mistake - healthcare information networks are already in heavy use by prominent digital health organizations in the know. And although most providers have yet to use the networks to their full extent, EHR participation incentives mean that most providers are sharing patient data.

Value-based care organizations in particular have cut through the hype and adopted HIN-mediated patient data because of the help it provides. These providers can use HINs to generate a first-ever copy of a patient's longitudinal health record. With this data, they can predict, monitor, and capture key information (including previously unknown conditions).

Patient data has an immediate impact at healthcare companies. Once clinician workflows are set up to incorporate this new data on a routine basis, HINs achieve their fullest potential.



While every part of the healthcare industry has a presence on HINs, entities will participate for different reasons. These are some of the heavier adopters:

Who's Plugged in to the Networks,

- → Skilled Nursing Facilities and Assisted Living Centers HIN data is vital for improving SNF care transitions. Their admitted patients are generally unable to communicate clinical details. Meanwhile, even the best hospital transfers can be slow and incomplete, especially with regard to pre-admission data. Connecting to HINs lets SNFs get data by the time a patient reaches their doors during the highest-risk period of their stay. This can be the difference between successful rehabilitation or hospital readmission in a number of cases. If part of a larger health system, SNFs and ALFs can use this data to provide better longitudinal care.
- → Specialist Providers Fields like gastroenterology, pulmonology and musculoskeletal rehabilitation must halt the progress of chronic conditions. These illnesses generate a great deal of data over time, but records are scattered across different care providers. HINs allow specialists to get the precise data that makes a difference. Particle's unique Specialty Search feature also queries national Centers of Excellence to target their records specifically, helping specialists improve and accelerate better outcomes.

This word cloud illustrates the 100 most common words used to identify organizations that participate in the Carequality or CommonWell Health Information Networks. We scanned the titles of each named endpoint in our database to determine this data.

- → Hospitals Virtually all EHR instances connect to HINs. Acute care facilities have seen the benefits of this as they shift into value-based care models and target healthier operating margins. The highest utilizers of care will tend to have the most data, which can in turn be used to reduce utilization.
- → Nephrology Kidney care generates a relatively large amount of actionable data, which can be used to identify and prevent patients at risk of deteriorating. New legislation continues to affect reimbursement models for these providers, but data lets them respond to policy changes in a flexible way.
- → Home Health Personalized attention to patients is a strength for home healthcare providers, but this is typically balanced out by a deficit in high-quality data. Truly effective home health providers need a robust mobile platform they can count on whether they're preparing on the road or visiting a patient.
- → Virtual Care These services are relieved to get data that would be prohibitively difficult to get from paperwork or forms on tiny screens. HINs help them speed up accurate onboarding, assist with transcription, and deliver the level of personalized care that patients are accustomed to from an in-person visit.
- → Analytics Providers Clinical data can help these entities provide decision support in ways that maximize efficiency and improve outcomes. These organizations use HIN data to perform risk stratification and population analysis for health systems. When they direct specific programs to a subset of high-risk patients, they frequently rely on medical records obtained from national networks. Evaluating an individual patient's medical history for a clinician can be done with HIN data as well.

A Kidney Care Data Use Example

The value of HINs is most clear when highly valuable clinical data information that is key to informing patient care - makes its way to a treating physician. Since clinical data from HINs comes in a standardized format, an API like Particle can filter it into a readable, well-sorted format by the time it reaches a treating provider.

This means that important data points can be highlighted and analyzed before a patient arrives and during future encounters. Numbers can be turned into visualizations, and text can be surfaced within existing workflows.

Kidney care is an instructive example of clinical data from HINs that's already in active use with Particle customers.

Providers treating chronic kidney disease can tap into an EHR add-on to see the most important clinical information at a glance.

These HIN-powered tools immediately surface ongoing graphs of GFR and creatinine levels, which are standard measurements for CKD care.



A sample patient's kidney function history, as collected by different providers over time and visualized on a health tech platform. This data would have been made available to Health Information Networks, aggregated by an API, and delivered to a healthcare platform in a usable and replicable format. Data can easily be plotted over time to indicate trends, which helps clinicians understand how their patient is progressing.

A doctor can tap into this important clinical information at any point in their workflow - whether or not the data was initially generated in their office - while sharing it with other providers.

Critical biomarkers are only a starting point. With that information front and center, HIN-powered apps can also track other labs, like potassium levels and BMI measurements, and automatically prompt clinicians when their patient starts to drift out of a safe range.

Determining this information without an API-based HIN connection involves searching for and reading dozens of documents. It's frequently skipped on account of it being so impractical to do.

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Providers can surface relevant treatment data in their own platforms by using API-delivered data from Health Information Networks.

What's in Store for the Future of Health Information Networks?

For their first decade, Health Information Networks made foundational steps in governance and infrastructure development. Now, HINs are adding new capabilities and increasing their capacity.

TEFCA and QHINs

The Trusted Exchange Framework and Common Agreement (TEFCA) will reorder the landscape for HINs. TEFCA consists of a technical Trusted Exchange Framework (TEF) and policy-oriented Common Agreement (CA), which together establish standards for clinical data clearinghouses in the US.

Some HINs will want to become one of these clinical data clearinghouses which facilitate data exchange through TEFCA. If approved by TEFCA's coordinating body, they will be called QHINs, or Qualified Health Information Networks.

QHINs can connect to each other and will serve as the core entities for nationwide data exchange. However, the actions they can take are regulated. HINs and similar organizations can apply to become a QHIN.

TEFCA was required by the bipartisan 21st Century Cures Act, signed in 2016. After seven years of development, the first QHINs are scheduled to connect with each other in 2023.

Only Certain HINs Will Become QHINs

Carequality has decided not to become a QHIN. It already supports an interoperability framework common to EHRs, but lacks many of the technical features that would enable a transition to QHIN status.

However, CommonWell intends to become one of the first operating QHINs.³² It already has more robust data broker-type services that would



help it qualify for QHIN status through its technology service provider Change Healthcare.

Other healthcare organizations with technical expertise can also apply to become or operate QHINs. Epic, the EHR vendor, has announced its intention to become a QHIN. So did NextGen Healthcare, an IT vendor.³³ Each will have to follow rules and submit to ongoing oversight from TEFCA's coordinating body, but will have an easier time connecting providers to data.

QHINs are technically made up of their participants, and may be created to serve the interest of certain stakeholders. The government envisions that different QHINs may serve payers, HINs, or data analytics companies.³⁴

QHINs Must Support More Than What HINs Support Today

Today, HINs do little more with other HINs than respond to requests for Treatment - an important but limited function. QHINs, however, will form the backbone of all types of healthcare consumerism by supporting both new technical functions and new query purposes.

QHINs, and their flow-down participants, will be required to respond to valid requests for:

- → Treatment (immediately)
- \rightarrow Individual access (within 6 months of rules being published)

Over time, QHIN networks will also have to support:

- → Healthcare operations
- → Public health
- → Payment
- → Government benefits determination

Other response requirements are also in the planning stages for after these are complete.

What does this mean? Individual Access - the term for a voluntary request from a patient to electronically share their records - will open up a world of new possibilities with data. With patient consent, life and health insurers will be able to use existing records to inform risk adjustment, and are already greatly interested. Clinical trial solutions can use patient records to accurately identify prospective study participants, leading to a wave of new research. Social determinants of health data, which have been carefully collected in obscure EHR instances, can be used to power the already accelerating trend of health equity.

QHINs will have multiple technical capabilities beyond exchanging records.

QHINs must also support push notification delivery from one network to another. This will enable event notification-like functionality currently under development by HINs. It will lead to more proactive updates of health information in general as information is updated across networks instead of siloed until a pull request is made.

QHINs will have to submit to oversight by the government's coordinating technical body, providing regular uptime statistics and increased transparency over their functions.

Anti-Information Blocking, Individual Access, and QHINs

The information blocking rules - like TEFCA, another long-awaited consequence of the 21st Century Cures Act - took effect in October 2022. On paper, this rule bars healthcare providers from refusing to provide records to their patients via technically-feasible means. In other words, if doctors can request records via a QHIN, then Individual Access patient requests must be facilitated as well.

While it's long been an established right for patients to have access to their own records, this generally comes from portals or (worse yet) printouts. Individual Access is exciting because it will likely lead to patient records being easily shared on smartphones, browsers, and apps. Patients will be able to share this information with the apps of their choice, without requesting permission from a doctor.

With Individual Access in place, healthcare experts can rapidly build services outside of the traditional healthcare system which nonetheless improve patient lives using the patient's own data.

Increasing Transactional Volume

Health Information Networks are already processing as much data as they can, which is far less than what will be required for full nationwide interoperability. To support robustly networked interoperable treatment nationwide, TEFCA coordinators anticipate that networks will need to process over 50 million transactions per day.³⁵

Network Reliability

Networks today can get overloaded with traffic during high-volume periods. As these networks make more connections to other networks – and their growing number of participants – requests can pile up and eventually lead to significant slowdowns. Individual endpoints, often maintained by participants without much IT knowledge, can also fail on high demand. Even small endpoints can be overwhelmed if they're in high-query areas, like a major city.

Every interoperability network will need to develop improved technical capabilities to cope with the much higher volume of query requests resulting from the increasing growth of clinical data exchange.

Frequency Limitations

Since networks are already pushing their computational and connective limits, some potential capabilities are currently limited. For instance, participants can't query the same patient frequently so as to limit the stress on the network.

A patient receiving a high-risk treatment could benefit from frequent queries, for example. When other use cases are supported, like Care Coordination, this could also lead to frequent queries from different participants.

QHINs are aiming to facilitate more robust endpoints and relax their query frequency restrictions.

Networks generally don't support cross-network push notifications for care transitions or data updates either. Since this was not the primary use case for HINs, little attempt was made to put this in their initial technical infrastructure. Networks are starting to think about this more, since push notifications (including ADT messages) have a real impact for value-based care when deployed. Additionally, push notifications would remove the need for participants to query the same patient frequently if they could simply rely on a notification instead.

QHINs have a roadmap to implement push messages,³⁶ and push messages are a natural capability for all HINs to include. This is impactful but will be a technical leap for HINs to make, benefiting both treatment and public health needs.

How Particle Health Complements HINs

Particle Health is effectively a network-of-networks, giving us a unique viewpoint of the interoperability space as a whole. Our team is steeped in the latest HIN developments, with experience in the space under our one specialized organization.

Particle Health has built the easiest way to get patient data from national networks. Unencumbered by slow-moving planning cycles or a focus on one specific network, we've built what is by far the most effective Record Locator Service in the country. It spans multiple HINs and is regularly maintained to deliver a >90% query success rate, with over 135 documents found per query and proprietary enhancements that are making it even more effective.

We Are *Not* Trying to Be a Network (or Compete With Other Networks)

Particle's API plays nicely with CommonWell, Carequality, and eHealth Exchange. We're a valued member of each network. A handful of other companies have similar connectivity, but they're trying to become networks themselves, leading to a different focus and direction.

We use and can compare different HINs, and our interest is in the development of a value-add layer across all networks and data sources - not becoming another network entirely.



Our Mission: Add Value on Top of All Health Information Networks

Particle's birds-eye view of different HINs gives us the ability to build tools and services that greatly enhance their value for digital health companies.

Since day one, we've maintained a focus on making HINs accessible. That entails not only easing access, but making it easier to use data too.

Particle's one-contract, one-connection API consolidates:

- Direct connections to many networks. Both potential QHINs and networks which will not become QHINs - into one, making it easy to connect.
- → Pricing for different networks. What would be a complex legal and accounting task is an affordable, comprehensible, and predictable payment managed by Particle's API.
- → Data outputs from our organizations. Complying with network bidirectionality requirements so as to remain a network participant in good standing can be a difficult engineering lift. Particle's platform takes care of this cumbersome task, enabling digital health companies to focus on the service they provide instead of their tech backbone.
- → Data standards from different participants. The naming standards and format of data within C-CDA files is inconsistent from endpoint to endpoint, leading to manual munging that precludes the data's usefulness. Particle's API can sort patient data out, in your format of choice, before it reaches you.

Conclusions

Health Information Networks are in the early stages of what is promising to be a paradigm shift in what is possible across U.S. healthcare. While several stakeholders continue to push back, progress is moving along albeit slowly.

It is entirely disappointing that individuals still do not have the ability to access their own records through Health Information Networks, as is their right. Organizations that have followed the legal and policy push for many years have seen implementation deadlines come and go like a wet noodle in the wind. Still, there is good reason to believe we're closer than ever to the day our government decides to empower its citizens with equal access to their data.

Our survey of Health Information Networks does show that their functionality has far surpassed the public perception of interoperability. Sufficient data for transformative change across the healthcare ecosystem is already being collected and uploaded at scale.

The three networks in the U.S. have proven something that has yet to be accomplished; we can have true interoperability. It's complex, raw and immature, but for one class of stakeholders (treating physicians) there is a patchwork of integrations that together create real outcomes.

Fortunately, we're now in a position to make more use of Health Information Networks, rather than building them up for the first time. Their existing technical infrastructure is mature enough to power many more exciting applications of clinical data than are in use today.



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2023: State of US Healthcare's National Network Data Exchanges White Paper January 2023

About Particle Health

Particle is shaping the new standard for healthcare data exchange with a user-friendly API platform. We create intuitive experiences for developers, build scalable infrastructure that product teams love, and collaborate with innovative leaders launching data-driven healthcare solutions. Particle's API helps healthcare providers access data from over 70,000 health systems through a single integration — and FHIR-enabled medical records for over 270 million patients via a single query.

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