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Evolution of clinical Health Information Exchanges to population health resources: a case study of the Indiana network for patient care

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Abstract

Background Motivated by the Triple Aim, US health care policy is expanding its focus from individual patient care to include population health management. Health Information Exchanges are positioned to play an important role in that expansion.

Objective The objective is to describe the evolution of the Indiana Network for Patient Care (INPC) and discuss examples of its innovations that support both population health and clinical applications.

Methods A descriptive analytical approach was used to gather information on the INPC. This included a literature review of recent systematic and scoping reviews, collection of research that used INPC data as a resource, and data abstracted by Regenstrief Data Services to understand the breadth of uses for the INPC as a data resource.

Results Although INPC data are primarily gathered from and used in healthcare settings, their use for population health management and research has increased. By December 2023, the INPC contained nearly 25 million patients, a significant growth from 3.5 million in 2004. This growth was a result of the use of INPC data for population health surveillance, clinical applications for data, disease registries, Patient-Centered Data Homes, non-clinical population health advancements, and accountable care organization connections with Health Information Exchanges.

Conclusion By structuring services on the fundamental building blocks, expanding the focus to population health, and ensuring value in the services provided to the stakeholders, Health Information Exchanges are uniquely positioned to support both population health and clinical applications.

Keywords COVID-19 pandemic, SARS-CoV-2 virus, Public health surveillance, Communicable disease control, Infectious disease transmission

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Background

United States healthcare policy continues to expand its focus on the care of individual patients to include the management of population health. Motivated by the Triple Aim of improved individual experience of care, improved health of populations, and reduced cost [1], this expansion requires the collection and analysis of population health data to support both public health policy and improved clinical care. Health Information Exchanges (HIEs) can play an important role in this process by expanding their focus on decision-making during individual patient encounters to include understanding population health and using population health data to guide clinical care.

Traditionally, an HIE facilitates exchange of comprehensive health care information across multiple providers to help avoid readmissions and medication errors, improve diagnoses, and decrease duplicate testing [2]. Community-based HIE organizations serve states or regions by enabling sharing information across providers and care settings. They may be called “public exchanges” because they are usually supported with public funds [3, 4]. Studies have found that HIEs make patient information more available and accessible across organizations and have reduced duplicate testing and imaging and diagnostic discrepancies, lowered costs, and improved patient safety [5–8].

In addition to supporting individual patient care, HIEs have the potential to gather health information for entire populations, presenting opportunities for improving health at a broader level [6, 9]. For example, comprehensive data about individuals in a community provides a more complete picture of population health to support public health activities such as surveillance and prevention programs. Also, hospitals’ predictive analytics and risk-stratification tools are currently limited for use with a small slice of data in the form of “sick care” information from the hospital’s electronic medical record (EMR) system. In contrast, the more comprehensive information collected by HIEs can help care become more health focused. Community HIEs have a particular role in this process since positive effects on cost savings and care decisions have been associated with the community HIEs [10].

Introduction

Over the past 20 years, the Indiana Network for Patient Care (INPC), a clinical and claims data repository that is operated by Indiana’s Health Information Exchange (IHIE), has evolved to support the goals of population health in addition to patient care [11, 12], thus serving as a laboratory for change and innovation in parallel with evolving health policy. As one of the most mature and largest HIEs in the United States, the INPC’s experience

helps illuminate the process and benefits of this evolution for both its patients and population health [13]. Although there are several manuscripts that describe services and individual research studies supported by the INPC, there is no comprehensive synthesis on the capabilities of the INPC. Moreover, there is no recent review of the population health services developed and implemented by the INPC over the past two decades.

This viewpoint paper describes the INPC’s evolution and discusses examples of its innovations that support both population health and clinical applications. These innovations range from disease registries and COVID-19 data commons to integrating HIE data for use by emergency clinicians and accountable care organizations. The example of the INPC can increase understanding of the benefits of these new directions and serve as a model for other HIEs making similar transitions.

Methods

This case study used a descriptive analytical approach to gather information on the INPC and its evolution towards a population health data resource. First, a limited review of the extant HIE literature using recent systematic and scoping reviews was employed. Two authors (SR, BED) were co-authors on recent reviews. The literature informed a working theoretical lens through which to view the INPC case study. Second, to gain insights into the evolution of the Indiana Network for Patient Care (INPC), both published studies and working documents from the Regenrief Institute were collected. Data from the INPC are routinely used for research, and each article briefly describes the INPC as a resource. These reports and data abstractions by Regenrief Data Services [14] were used to understand its incremental growth in terms of population size and scope. Reports were used to understand the breadth of uses for the INPC as a data resource.

Using available publications and reports, the authors iteratively developed a narrative of the evolution of the INPC from a clinical HIE to a population health data resource. Working documents were shared with leadership of the HIE for validation, and edits were made based on feedback following further discussion and consensus among the authors. This study was deemed non-human subjects research; therefore ethics approval and informed consent were deemed unnecessary, not applicable, and waived according to national regulations by Indiana University’s Institutional Review Board. This study also adhered to the guidelines of the Declaration of Helsinki.

Theoretical framework

As described in the book *Health Information Exchange* [15], a number of fundamental building blocks comprise core HIE services. For example, a facility registry enables

HIE networks to uniquely identify all clinics, hospitals, and other facilities that exist in its health ecosystem. Similarly, uniquely identifying patients is a fundamental service that links EHR records from all of the locations where the patient has received care. These core building blocks enable HIE networks to perform various services, such as displaying a longitudinal view of a patient's health record.

These building blocks create layers of HIE within a network. Core services can be developed over time to enable new services that sit atop each layer (Fig. 1). For example, many HIE networks begin with a foundational layer that allows basic clinical messages to flow between facilities. Laboratory results, for example, can be delivered from the laboratory to the EHR or Internet-based portal for clinician view using a clinical messaging service. Over time, networks deploy terminology standardization processes and record-linkage algorithms that enable more complex services such as trending laboratory results for a patient.

Evolution of the Indiana network for patient care

The INPC was originally designed to support patient care by making it easier to access information from multiple healthcare organizations for a specific patient [19]. The HIE focused on services to address the information needs of clinicians during a clinical encounter. For example, IHIE supports a web-based application (INPC CareWeb) to view integrated medical records from providers across the state. IHIE further offers a 17-year-old clinical messaging service (Docs4Docs) that delivers laboratory and

imaging results to primary care providers and specialists. These applications provided business value to health systems, enabling the HIE to receive financial support from providers to develop and maintain its infrastructure. Beyond these essential HIE services, data from the INPC can be leveraged for academic research (see Appendix), and the network developed specialized clinical applications. This was facilitated by grants and contracts from the federal government. In more recent years, the INPC evolved to develop applications that focus on population health and well-being, incorporating non-clinical data into its infrastructure. This growth was facilitated by federally-funded agreements as well as financial support from insurance companies who invested in infrastructure to improve the quality of care and enable new payment models.

Prior publications have described the variety of HIE services developed to support individual patient care [1, 19, 20]. The following sections describe innovative HIE services that illustrate how the INPC has evolved from routine care applications to creative uses of HIE data for population-level clinical applications and research. These innovations include several applications supporting public health, which became of high importance in the recent past during the COVID-19 pandemic.

Results

Growth of the Indiana network for patient care

Founded in 2004, the Indiana Health Information Exchange (IHIE) [11] manages the INPC to capture and exchange data with now more than 123 hospitals,

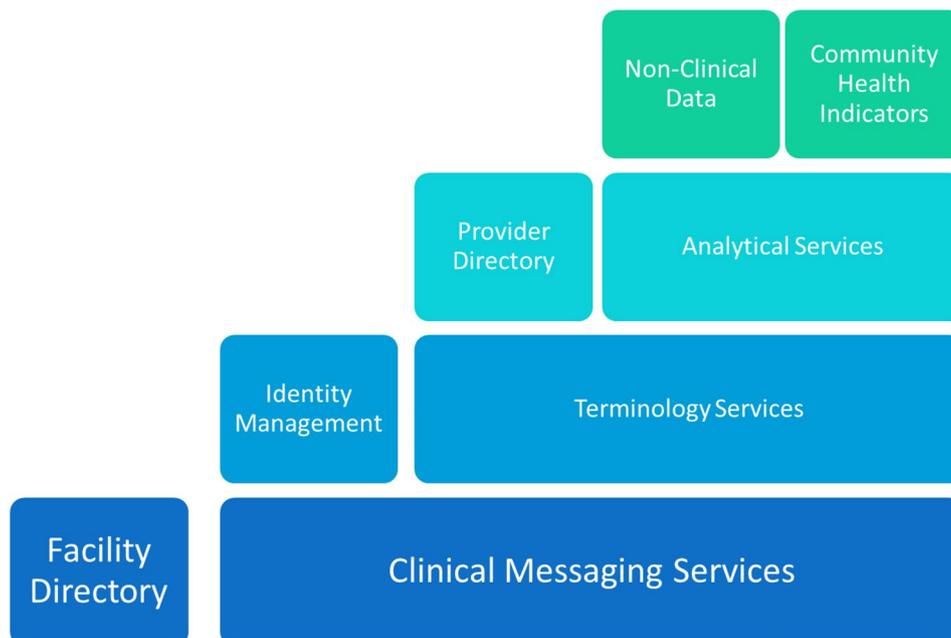


Fig. 1 Building blocks of HIE networks and core services

Table 1 Comparison of data in the INPC in 2004 and 2023

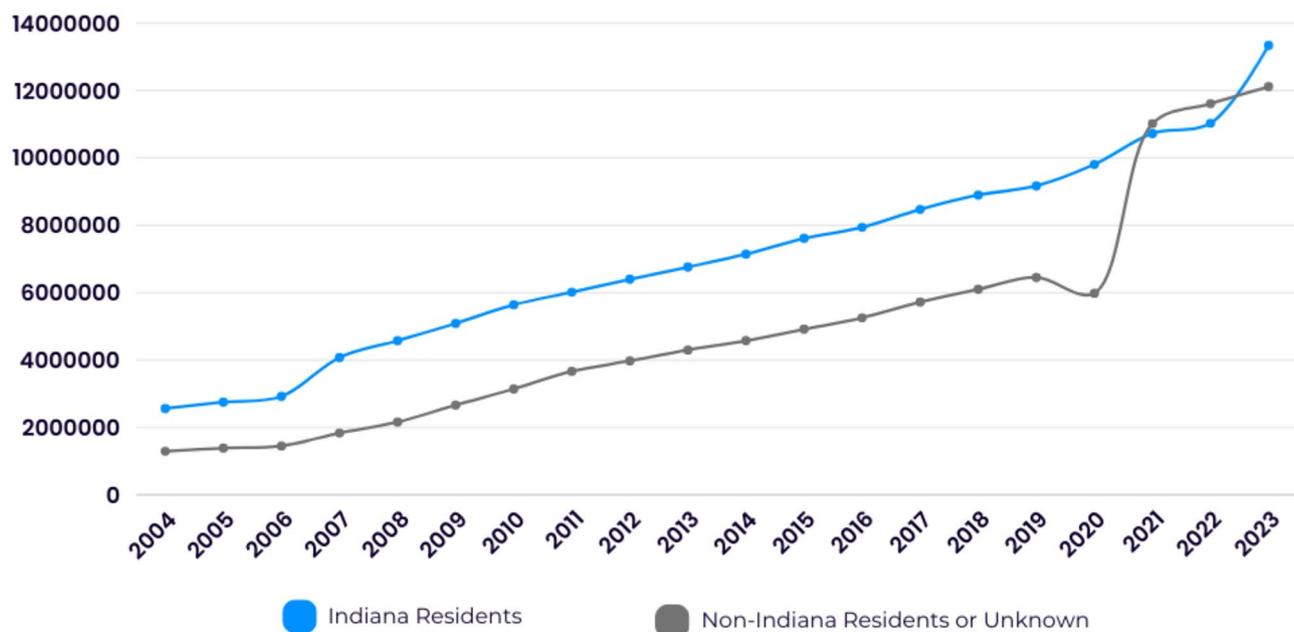
INPC Data Element	2004 [16, 17]	2023 [12]
Indiana counties	9	92
Total patients	3,554,480	25,449,906
Total Indiana patients in INPC	2,562,836	13,336,671
Clinical data elements	~53,055,000	16,000,000,000
Mineable text reports	~14,500,000	339,627,290
Encounter records available	~50,000,000	1,723,368,077
Patient records	~1,300,000	25,456,708
Orders	~24,000,000	50,418,515
Coded results	~660,000	6,908,843,049
Dictated reports	~12,000,000	247,715,536
Radiology reports	~8,800,000	91,911,754
Prescriptions	~25,000,000	42,396,184
EKG tracings	~480,000	7,951,355

19,000 practices, and 54,500 providers across Indiana and beyond [12, 13]. IHIE recently merged with two additional regional HIEs, expanding INPC coverage to Indiana and portions of southern Michigan. The information in the INPC comprises over 16 billion clinical data elements, such as encounters, lab tests, microbiology, pathology, radiology, cardiology, EKG, pharmacy data, and text reports. INPC data are aggregated from providers, payers, and public health agencies in real-time, which was a recommended practice in Dixon et al.'s systematic review [16], enabling online functions such as clinical alerts that can influence patient care decisions at the point of care. Table 1 indicates the aggregated total

of types of data points available in the INPC. INPC data are primarily gathered from and used in healthcare settings, but their use for population health management and research is increasing [11, 17]. With this growth from multiple sources, Regenstrief Data Services (RDS) handles discrepancy data by employing a multi-layered approach that includes data cleaning, validation processes, and expert review, where inconsistencies are flagged, investigated, and often resolved through manual review, particularly when dealing with sensitive patient health information from multiple sources within their electronic medical record (EMR) data warehouses; they also leverage data standardization techniques to minimize discrepancies arising from different data entry practices across institutions [14].

In 2004, the network included data for three and a half million patients [18]. By the end of December 2023, the network had grown to contain information on nearly 25 million patients, with over half being Indiana residents both living and deceased, as well as people who visited from other states, such as Illinois, Ohio, Kentucky, and Michigan [14]. Table 1 compares the INPC's data volume for 2004 and 2023. By the end of 2023, the INPC contained at least one patient encounter for nearly two-thirds of the population in Indiana's 92 counties. Figure 2 shows consistent growth of the total number of patients from approximately 3.6 million in 2004 to over 25 million in 2023.

Indiana and Non-Indiana Patients in INPC by Year

**Fig. 2** Indiana and non-Indiana patients in the INPC from 2004 to 2023

Applications for population health surveillance

Nearly from its inception, the INPC supported applications that deliver data and information to public health agencies. One of the first applications was electronic laboratory reporting (ELR), which reports notifiable diseases (e.g., HIV, measles) from laboratories to public health agencies. Individual patient records are sent to public health agencies, notifying them that someone in the community has been infected with a communicable disease. This enables public health workers to initiate contact tracing protocols and contact the treating provider for more information about the case. Shortly after Effler et al. [21] demonstrated the value of ELR, the INPC began implementing methods for sending ELR messages. Additional studies from Regenstrief investigators showed that ELR improves the completeness and timeliness of reporting in support of public health surveillance [22, 23]. Moreover, ELR provides a robust foundation upon which HIEs can offer electronic case reporting (eCR) [24]. eCR involves providers sending clinical treatment and other details proactively to public health authorities, usually required by law in most U.S. states and a component of the updated Promoting Interoperability program from CMS [25].

Beyond notifiable diseases, the INPC developed several innovative applications in support of population health surveillance. Building upon its Docs4Docs service, the INPC provides population-level messages from public health departments to clinicians during localized outbreak events [26, 27]. Moreover, the INPC electronically notified infection preventionists in hospitals about a patient's prior infection with a multi-drug resistant organism [28], enabling rapid identification and isolation of patients who may carry "super-bugs." HIE services for infection preventionists are often overlooked but constitute an important component of supporting population health in a community [29].

Clinical apps for efficient data retrieval

Community HIEs typically do not integrate work and data flows directly with electronic health records (EHRs) in health care practices and other organizations. This lack of integration forces clinicians to access HIE data using a system separate from their EHR, resulting in workflow inefficiencies, increased information retrieval effort, and cognitive friction [30]. Since 2016, there has been work on integrating INPC data directly with the Cerner EHR using an app that retrieves high-value information about specific clinical conditions. The app, called *Health Dart* [31], leverages Fast Healthcare Interoperability Resources (FHIR), a recently developed standard for accessing information in health IT systems that works across all major EHR platforms [26, 32]. The app allows clinicians to retrieve relevant data more efficiently and effectively

than the traditional, Web-based viewer for patient data in the INPC (called *CareWeb*). It is being developed by a partnership of the Regenstrief Institute, IHIE, and Indiana University Health.

The app was implemented in January 2018 in the main IU Health Emergency Department (ED) for a single chief complaint, chest pain [32]. Today, the app allows the clinician to choose one of seven chief complaints depending on the patient's presentation (Fig. 3) chest pain, abdominal pain, weakness/dizziness/headache, back/flank pain, pregnancy, arrhythmia, and dyspnea. The app displays INPC data elements relevant to the chosen chief complaint. For example, in the case of chest pain, the application retrieves the patient's last EKG, cardiology notes, discharge summary, cardiac catheterization report, and echo, stress, and nuclear medicine tests.

During the pilot project phase from September 2017 through March 2018, 111 clinicians at IU Health Methodist ED had access to the app. The study found that clinicians at the intervention ED site used HIE significantly more (10.55%) than at other EDs (3.2%) during the study period ($p < 0.001$) [30, 32]. The App was associated with increased odds of HIE usage (OR: 1.15; CI: 1.02, 1.30; $p = 0.026$) in a difference-in-difference analysis [32]. In qualitative interviews, clinicians rated the usefulness of the application as very high but identified several opportunities for improvement. A laboratory experiment showed that the app reduced the number of clicks from 50 to 6 and search time from 3 min to 10 s, compared to existing methods for accessing the same information. Consequently, the app has now been deployed at all 15 EDs in the IU Health system. The app successfully demonstrated that integrating HIE data directly with the EHR is feasible and has several benefits.

Disease registries

Clinical registries—an essential tool for population health—contain curated collections of health records, typically focused on a specific disease, for clinical, epidemiological, and health services research. HIE infrastructures are ideal for developing registries because they typically curate many records for multiple populations drawn from varied sources across health systems, attenuating the common problem of data fragmentation plaguing retrospective database studies [33, 34].

The INPC has significantly augmented state registries. For example, in 2015, researchers linked INPC patients to the Indiana State Cancer Registry using probabilistic matching to determine the completeness of the registry [35]. Approximately 89% of the patients with longitudinal records in the registry were matched, and additional cancer patients present in the INPC but not in the registry were identified. Higher completion rates were reported to the Indiana State Cancer Registry because of the

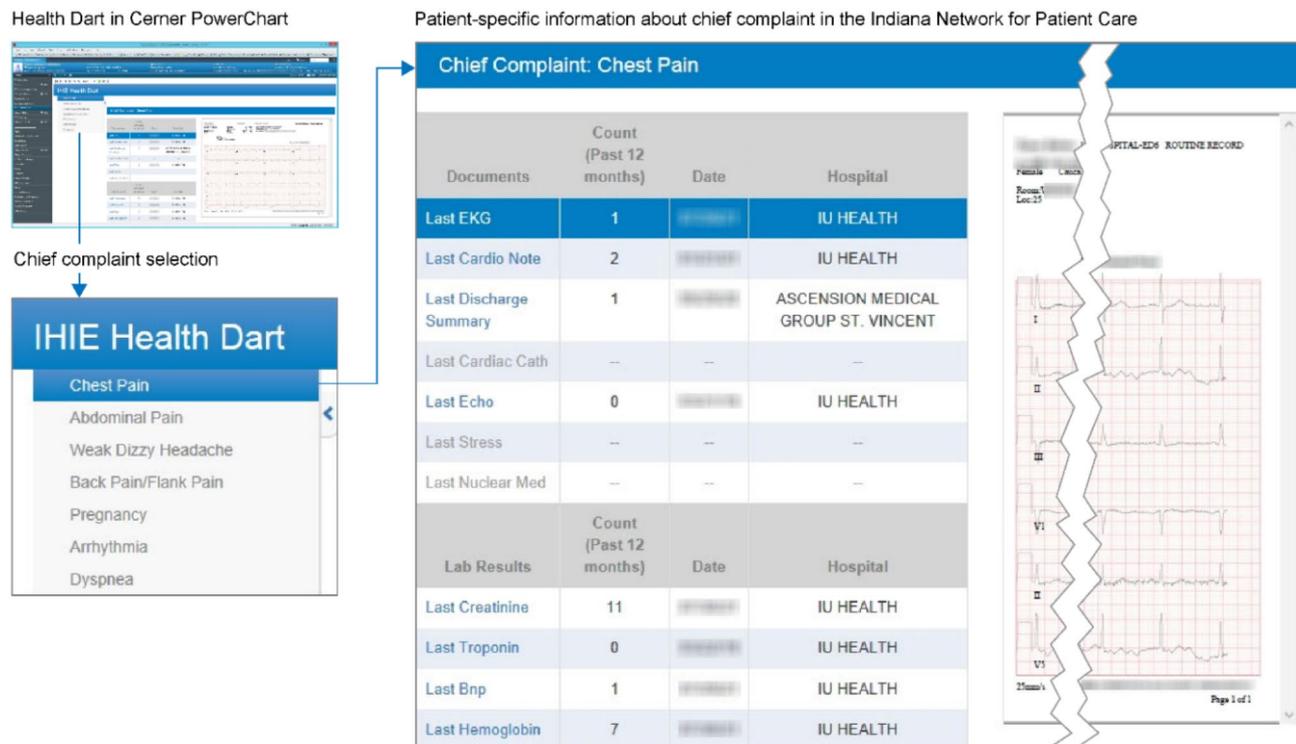


Fig. 3 Screenshot of *Health Dart*, a FHIR app in the Cerner EHR, showing HIE information relevant to chest pain

newly identified cases. Based on this research, RDS also gained access to the Indiana State Cancer Registry [14]. As a result, analysts at Regenstrief matched records from INPC to the existing registry and at the beginning of June 2020 had identified an additional 746,311 patients [14].

Similarly, when the Indiana State Department of Health sought to enhance its surveillance of sickle cell disease patients, which relies on a registry maintained by a large care provider in the state, the agency contacted RDS. The additional records strengthened the registry and enabled the state health department to secure additional funding for sickle cell disease surveillance, which significantly impacts the African American population living in Indiana.

In other instances, registries were created to support epidemiological and health services research. For example, IHIE, through the INPC, and like other HIEs supports broad data types as well as longitudinal records to track disease progression, treatment, and outcomes, reducing data fragmentation that is common in retrospective data-based studies as mentioned above [33–35]. An example of this is the traumatic brain injury, spinal cord injury, and stroke registry developed using the INPC [36]. This registry has been used to examine the risk of stroke [37] and the utilization of health services following traumatic brain injury [38]. Similarly, a registry was created for individuals tested for sexually transmitted infection [39]. This registry enables examination of

provider adherence to testing guidelines and health services for those tested or treated for a sexually transmitted infection [40–[42].

Further, the INPC supports various diabetes research and development projects using a registry of over one million Type 2 diabetics and 1.7 million controls. For example, a partnership among Roche Diabetes Care GmbH, IBM, Eli Lilly and Company, the Regenstrief Institute, and the Indiana Biosciences Research Institute developed a predictive algorithm identifying patients at risk for chronic kidney disease [43]. A second project seeks to refine a pharmacotherapy selection algorithm for Type 2 diabetes patients in collaboration with Hitachi Corp [44, 45]. The latter two projects illustrate how community HIEs can support partnerships among clinical, industry, and research organizations.

U.S.-Wide patient-centered data home [46]

To increase their utility and impact, HIEs must extend their reach beyond regions and states [8]. Leveraging the regional positioning of HIEs, the Strategic Health Information Exchange Collaborative (SHIEC), now CIVITAS Networks for Health [47], initiated the Patient-Centered Data Home (PCDH) to share data among HIEs across the United States. The PCDH process allows comprehensive medical histories to follow patients wherever they seek care.

In September 2016, SHIEC piloted the PCDH initiative in the Central, Western, and Heartland regions. The Heartland Region included seven HIEs in five states: East Tennessee Health Information Network in Knoxville, Tennessee; Great Lakes Health Connect in Grand Rapids, Michigan; HealthLINC in Bloomington, Indiana (now part of IHIE); Indiana Health Information Exchange in Indianapolis, Indiana; Kentucky Health Information Exchange in Frankfort, Kentucky; Michiana Health Information Network in South Bend, Indiana (now part of IHIE); and The Health Collaborative in Cincinnati, Ohio. Over the pilot year, nearly 8,500,000 admission, discharge, and transfer (ADT) messages were exchanged among HIEs in the Heartland Region. Through this bottom-up approach, the PCDH offers a pragmatic grassroots approach to national interoperability.

Integration of nonclinical data for population health

The INPC has also supported pioneering work developing and using research data commons, which collocate data, storage, and computing infrastructure with commonly used tools for analyzing and sharing data to create an interoperable resource for the research community [48]. For example, in the Indiana Addiction Data Commons (IADC), patient health information and demographics were aggregated with other data such as criminal justice, socioeconomic status, and environmental factors to help manage substance use disorder (SUD). Through the IADC, stakeholders across the state have partnered to lower barriers to access clinical and non-clinical data elements to enable research, interventions, and health and healthcare improvement. In addition, this partnership supports data sharing and standardization to ensure the appropriate data are available and used to address SUD in Indiana.

While the INPC has traditionally collected clinical information, facilitating many productive public health use cases, health departments and research entities seek to access information beyond health data. By using a data commons to gather extensive health and non-health data (e.g., Social Determinants of Health) pertaining to patients, the scope of data collection has the potential to be expanded beyond illness and encompass factors related to overall health. This includes incorporating behavioral and environmental information about the population, thereby broadening the focus beyond mere sickness. Based on the INPC, Regenstrief partnered with Indiana-based public health and community organizations to develop the Indiana Network for Population Health (INPH). The INPH seeks to combine clinical data from the INPC with non-clinical information from local and state public health organizations, emergency medical services, and governmental data sources. For example, an epidemiologist may be interested in potential

relationships between education levels and vaccination rates in young children across the region. In contrast to the tight correlation between the INPC and IADC, which focuses on SUD, the INPH is a broader initiative providing needed data in one easily accessible location. Although the INPH is still in its early stages, it will expand as the infrastructure and experience in capturing, analyzing, and sharing varied information about populations grow.

A more recent instance of a data commons is the COVID-19 Research Data Commons (CoRDaCo) [49]. The goal of CoRDaCo is to integrate the various sources of clinical and social determinants data about COVID-19 patients into one central repository that can then be leveraged for many uses, including public health surveillance and health services research. In addition, creating a curated collection of standardized COVID-19-related data elements allows Regenstrief's data analysts to create study-specific data sets more rapidly than previously feasible.

When COVID-19 first appeared in Indiana, Regenstrief and its partners (IHIE and public health agencies) quickly developed a community-level dashboard to monitor hospitalizations, comorbidities, health disparities in testing, and fatalities (Fig. 4). In March 2020, there were concerns among health system partners and public health agencies that a surge in COVID-19 patients might overburden the health system, as seen in China and New York City [50, 51]. The dashboard aided public health agencies in monitoring population-level hospitalization rates as well as critical care utilization. It further supported community-level discussions about resource sharing and disparities and identified major differences in hospitalization rates among non-white populations in specific counties and zip codes. The pre-existing data commons infrastructure enabled rapid development of the dashboard. New data streams were also added to enhance a visualization tool that provides quick value in an emergency health scenario.

Work to create CoRDaCo has been underway since early April 2020 and by February 2023 contained data for 1,858,220 patients infected with COVID-19. Using published papers and the clinical expertise available at Regenstrief, data elements for inclusion in the registry were selected. While the focus of the dashboard was limited to tracking the inpatient clinical progress of COVID-19 patients, it quickly expanded to capture a broad range of variables associated with COVID-19 patients across all care settings. These variables include demographics, healthcare utilization, treatments, laboratory and testing data, comorbidities, and the overall clinical course of the patients.

An essential function necessary to establish CoRDaCo is the automated identification of

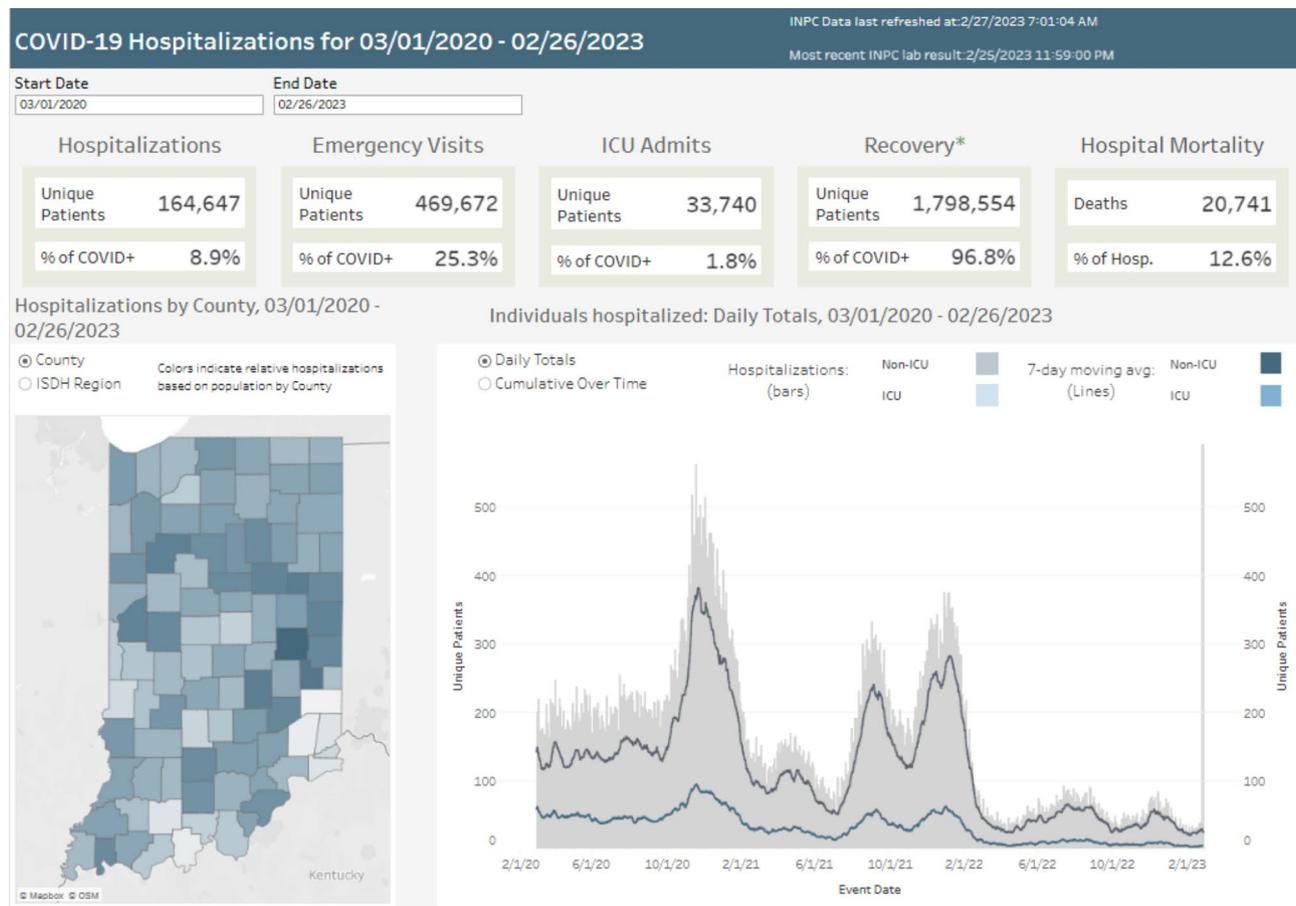


Fig. 4 Screenshot of Regenstrief's COVID-19 dashboard for the state of Indiana, which is updated daily

COVID-19-positive patients. Positive test results from various sources, including the Indiana State Department of Health, are matched with the INPC database, enabling identification of any COVID-19 positive patient and their health history regardless of the provenance of the test result. In addition, granular patient data was retrieved, such as ventilator status and details related to critical care, directly from clinical data warehouses of health system partners. Manual chart review of unstructured data, such as clinical notes and radiology reports, is used to retrieve as much granular data as possible from the other health systems in Indiana. Important secondary uses of CoRDaCo include easier participation in national collaborations, such as the NCATS N3C initiative [49, 52, 53, 54], which will greatly expand the pool of individuals who can directly access this data.

Accountable care organizations and HIEs

Accountable Care Organizations (ACOs) align physicians, hospitals, and other healthcare providers to provide coordinated, high-quality care to their patients. Participation in ACOs has also been found to expand HIE breadth due to electronic data sharing with more

partner types [55]. Coordinated care can help ensure that patients receive the right care at the right time while avoiding unnecessary duplication of services and preventing medical errors [56]. The INPC supports participating in ACOs by providing more complete and comprehensive clinical data than an individual ACO can typically obtain on its own. This information includes healthcare encounters and specific data such as medications, laboratory test results and procedures.

For ACOs in Indiana, INPC information supports coordinating care, reducing the duplication of services, and calculating quality metrics. For instance, by reviewing which healthcare services other organizations provide, a care manager can monitor care events to deliver proper care. In addition, duplication (and costs) may be reduced when relevant information, such as the results of a recent CT scan, is made available to care managers and clinicians [57]. In addition, HIE information can help calculate quality measures more accurately than previously possible. For instance, the HIE may have information on the patient's last colonoscopy, which is needed to calculate CMS Quality Measure Prev-6 (Colorectal Cancer Screening). Since a colonoscopy typically occurs every

five to ten years, an HIE is the most likely place to contain that information due to its longitudinal nature.

INPC data provided to ACOs vary depending on the organization and its needs as well as its capabilities. For larger organizations, completely automated information transfers are common, such as ADT alerts or CCD transmissions. The receiving organizations typically ingest this information into their health IT infrastructure, such as electronic data warehouses. The ACOs then route information directly to individuals who need it or process it further, such as through population health management and analytics systems. Smaller organizations with less sophisticated health IT infrastructures often receive information from the INPC in spreadsheets and similar formats. The IHIE also provides reports and dashboards for population health management directly.

In these ways, HIEs can be a valuable asset for ACOs by providing a more comprehensive record of patients. More complete and comprehensive information allows ACOs to achieve the Triple Aim objectives of delivering the right care at the right time, reducing unnecessary duplication, and preventing medical errors more efficiently and effectively than previously possible.

Discussion

This case study described the INPC's evolution and discussed examples of its innovations that support both population health and clinical applications. These innovations range from disease registries and a COVID-19 data commons to integrating HIE data for use by emergency departments and accountable care organizations. The example of the INPC can increase understanding of the benefits of these new directions and serve as a model for other HIEs evolving along similar trajectories. In order for HIEs to evolve, there has to be a dedication to building the fundamental services, expanding beyond the clinical care only focus, and investing in the services that are valuable to its stakeholders.

Using the fundamental building blocks, HIE services can become more complex and valuable over time. First HIEs create core services that are the base for new services that can be built on for the next layer of services. This prepares HIEs for scalability with the foundational support for technology and services that are yet to come. Additionally, the evolution involves the expansion of HIE focus from individual patient care towards population health given where the US health policies and systems are generally moving. Policy in the US is moving towards national HIE with strong subnational units, such as states and districts, while INPC is advanced it is trending in the same direction as policy [58]. Finally, evolution requires investment and development of services that have value to stakeholders. HIEs are unable to evolve if they do not exist.

Implications and recommendations

The INPC sheds light on the numerous ways that HIEs can and should evolve in support of population health and well-being. Major areas in which HIEs can provide value to population health include the following:

- Policy in US is moving towards the national HIE with strong subnational units (e.g., states, districts); INPC is advanced and is trending in the same direction as policy.
- Creating and sustaining HIE remains a challenge. In the US, policies encourage the use of standards and interoperability, yet many implementations continue to rely on proprietary terminologies with limited translation to international standards. Moreover, implementation of messaging standards is often suboptimal, where real-world messages fail to adhere to standards even though vendor products pass certification tests. In addition, many health systems continue to see data as an asset that needs to be protected rather than an important shared resource that is needed by all of the organizations taking care of the patient. Technical, policy, and social issues must be overcome to achieve HIE everywhere.
- Many places lack HIEs with population health capabilities like the INPC. More investment will be needed by the US and other nations to develop and sustain HIE for population health. By using non-clinical, community data, the broad coverage of populations could expand HIEs from a primary focus on sick care towards supporting health and well-being. Comprehensive data about populations can facilitate prevention and health promotion at a much larger scale than is common today. This would support the broad sustainable development goals of the World Health Organization in the U.S. and other nations [59].
- Future research can refine and explore new services and core building blocks that will be necessary for analytics, AI, environmental data, and other innovations that are ideas now and need time to mature. Many types of clinical applications can benefit from the more complete and comprehensive coverage of HIEs. This is especially important as increasingly sophisticated clinical algorithms (e.g., machine learning and AI) are developed. Sparse data often limit algorithm performance, and more complete data can help improve analytical accuracy [34, 45, 60]. Additionally, algorithms developed within a single hospital or health system may potentially be overfitted to that population or biased towards unique characteristics of the patient population seeking care in that health system. HIE offers a more diverse set of patients and can help

support less biased algorithms. More representative population data can also help avoid or mitigate biases common in algorithms built on less inclusive data sets. HIEs can also support sophisticated clinical decision support interventions that may be difficult or impossible to implement in traditional EHR frameworks.

- HIEs have a model that allows for non-standardized health information exchange compared with that of the standard-based health information exchange of vendors. The vendor-based models leave out latency due to standards and have a non-population focus. HIEs have the advantage of being agnostic to the type of data they include and the organizations providing the data. Thus, HIEs can combine health-related with non-health-related data, for instance, to connect patient populations with their sociodemographic or environmental context. The relative independence from corporate or proprietary interests can facilitate data aggregation in a patient- rather than organization-centered fashion. Moreover, HIEs in a community are more in tune with that community's health priorities and needs. While vendor-based and proprietary HIEs have the potential to advance the use of non-clinical data [4], their capabilities to address local community priorities are likely to be limited.
- With strong, collaborative organizations such as CIVITAS Networks for Health, and initiatives such as The Trusted Exchange Framework and Common Agreement (TEFCA) [61] that support health data sharing by connecting health information networks nationwide, there is now longitudinal, supportive data for the return of investment and benefits of HIEs. Collectively within organizations like CIVITAS, more than 95% of the US population is represented within an HIE [47].

As the Patient-Centered Data Home initiative has demonstrated, a network of community HIEs could make the vision of transparent and accessible patient information throughout the country (and, potentially, worldwide) a reality. The ability to aggregate various data across organizational boundaries, enable disease prevention and health promotion, support novel clinical applications, and make the vision of worldwide patient record connectivity a reality makes a strong case for the development and evolution of community HIEs. Maintaining and advancing HIE infrastructure and engagement, and aligning policy with those efforts, remains necessary for expanding the reach and impact of community HIEs [4, 7, 8, 46]. Given the continued pressure of the regulatory environment on healthcare providers, community HIEs can be excellent partners for healthcare delivery

systems to advance health and healthcare, which ultimately advances population health. By connecting with these partners, community HIEs also have an opportunity to be a driver for national interoperability of health information.

Conclusion

Health Information Exchanges are essential components for national health data exchange and must continue to evolve to remain relevant and sustainable. Specific evolution of the INPC has been described through examples of its innovations that support both population health and clinical applications. HIEs must continue to build upon existing capabilities, expand the focus to population health, and ensure value in the services provided to the stakeholders. To take full advantage of their potential, HIEs must continue to innovate and evolve.

Abbreviations

HIE	Health Information Exchange
INPC	Indiana Network for Patient Care
IHIE	Indiana Health Information Exchange
RDS	Regenstrief Data Services
IADC	Indiana Addiction Data Commons
INPH	Indiana Network for Population Health
CoRDaCo	COVID-19 Research Data Commons
EHR	Electronic Health Record
FHIR	Fast Healthcare Interoperability Resources
SUD	Substance Use Disorder
SHIEC	Strategic Health Information Exchange Collaborative
PCDH	Patient-Centered Data Homes
ACO	Accountable Care Organizations

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12911-025-02933-9>.

Supplementary Material 1

Acknowledgements

We would like to acknowledge and thank Anna Roberts and Zachary Carr of Regenstrief Data Services, Drew Richardson, Jennifer Williams, Laura Orcutt, and John Kansky of Indiana Health Information Exchange, and Dan Robertson and Rong Qi of Indiana Biosciences Research Institute. This work was supported, in part, by the Indiana Spinal Cord & Brain Injury Research Fund from the Indiana State Department of Health. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Indiana State Department of Health.

Author contributions

All authors conceived and designed the study. KSW and SR wrote the initial draft of the manuscript. TKS and BED assisted in drafting the methods section and supported the creation of figures. KSW and SR coordinated with RDS for data collection. The following authors reviewed, commented, and participated in revisions of the manuscript: SR, SJG, TKS, and BED. KSW synthesized feedback and finalized the manuscript as well as the figures. All authors read and approved the final manuscript.

Funding

Karmen S. Williams was supported by a training grant (Award Number T15LM012502) from the National Library of Medicine of the National Institutes of Health, and Brian E. Dixon and Saurabh Rahrkar are supported by grant number R21HS025502 from the Agency for Healthcare Research and Quality

(AHRQ). Part of this publication was made possible by the Lilly Endowment, Inc. Physician Scientist Initiative and the Indiana Clinical and Translational Sciences Institute (funded in part by grant ULI TR002529) from the Clinical and Translational Science Award of the NIH's National Center for Advancing Translational Sciences.

Data availability

Data sharing to support the findings in this study are not publicly available but can be available upon reasonable request and permission through Regenstrief Data Services (<https://www.regenstrief.org/rds/>).

Declarations

Ethics approval and consent to participate

This study was deemed non-human subjects research; therefore ethics approval and informed consent were deemed unnecessary, not applicable, and waived according to national regulations by Indiana University's Institutional Review Board. This study also adhered to the guidelines of the Declaration of Helsinki.

Consent for publication

Not applicable.

Competing interests

The authors are involved with research at Regenstrief Institute and receive funds related to work on Health Information Exchanges. Dr. Dixon reports a grant from IU Health which funded the analysis. Dr. Dixon report a grant from CDC to study COVID-19 vaccine effectiveness and grants from the Indiana State Department of Health to study COVID-19 infection rates and surveillance. The authors are involved with research at Regenstrief Institute and receive funds related to work on Health Information Exchanges. No other potential conflicts of interest were disclosed.

Received: 22 July 2024 / Accepted: 11 February 2025

Published online: 24 February 2025

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