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A statewide system for maternal-infant linked longitudinal surveillance: Indiana's model for improving maternal and child health

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Abstract

Indiana, located in the Midwest region of the United States, faces significant challenges with respect to health, especially maternal and child health (MCH). These challenges include high rates of stillbirth, neonatal abstinence syndrome (NAS) and congenital syphilis (CS). Not only are these often-fatal conditions underreported, but it can also be difficult to track them longitudinally, as mothers and infants are not routinely linked through electronic health records (EHRs). This paper describes the process, structure and planned outcomes of a partnership between Indiana University, Regenstrief Institute and public health partners in support of the U.S. Centers for Disease Control and Prevention's Pregnant People-Infant Linked Longitudinal Surveillance (PILLARS) program. Together, academic, clinical and public health organisations are collaboratively developing an infrastructure and deploying novel methods to surveil stillbirth, CS and NAS longitudinally. The infrastructure includes: (a) deploying deterministic and probabilistic algorithms to link mothers and their infants using multiple, linked data sources; (b) creating and maintaining a registry of maternal-infant dyads; (c) using the registry to perform longitudinal surveillance in collaboration with Indiana public health authorities on stillbirth, NAS and CS and (d) translating information from surveillance activities into action by collaborating with public health and community-based organisations to improve and implement prevention activities in vulnerable Indiana communities. Our long-term goal is to improve outcomes for these conditions and other priority MCH outcomes by expanding our work to additional MCH use cases.

Keywords
data linkage; maternal health; child health; Health Information Exchange

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Introduction

Indiana, located in the Midwest region of the United States, faces significant health challenges, especially related to maternal and child health (MCH). The state ranks 35th of 50 states in overall health and has the 10th highest rate of infant mortality in the country, with 6.5 infants dying for every 1,000 live births [1]. Not included in these statistics are stillbirths, or foetal deaths after 20 weeks of gestation, for which Indiana ranks second. Overall, Indiana experiences about 500 stillbirths, or 6.09 foetal deaths/1,000 births, every year. Prior work has demonstrated that stillbirths are often underreported in Indiana; this applies especially to early stillbirths, or foetal deaths before 27 weeks gestational age [2].

After birth, infants in Indiana are likely to have other life-altering diagnoses. They are more likely to be born with congenital conditions, such as congenital syphilis (CS), than infants in other states. Babies infected with CS suffer in the immediate postpartum; they can have spleen and liver damage, jaundice and meningitis. When left untreated during pregnancy, 40% of these babies are either stillborn or die shortly after birth. Perinatal testing is critical for prevention, yet studies show that perinatal syphilis testing in Indiana does not consistently meet U.S. Centers for Disease Control and Prevention (CDC) guidelines [2, 3]. Despite this lack of testing, CS cases in Indiana more than doubled from 2020 to 2021, suggesting an even greater problem than is evident in the data.

Another common postnatal diagnosis for infants born in Indiana is Neonatal Abstinence Syndrome (NAS). High rates of NAS in Indiana result from a statewide acute substance use problem; NAS occurs when infants are born substance-exposed to opioids, benzodiazepines and barbiturates. NAS can result in low birthweight, seizures, skin conditions, jaundice, breathing problems and issues with infant feeding. Our prior work shows that seven out of every 1,000 babies born in Indiana are diagnosed as substance-exposed or with NAS, ranking 22nd out of 50 states for NAS diagnoses at birth [4].

To improve longitudinal surveillance of mothers and infants with these conditions, a team from the Indiana University Fairbanks School of Public Health and the Regenstrief Institute in Indianapolis are in the first year of a four-year cooperative agreement with the CDC's Pregnant People-Infant Linked Longitudinal Surveillance (PILLARS) program. Participation in this program will allow Indiana to strengthen its public health information infrastructure to impact MCH in the long-term [5]. Specifically, participation will enhance and expand statewide surveillance efforts to capture infant exposures and outcomes and translate maternal and infant data into action with community partners who work with vulnerable mothers and their infants.

This paper describes the process, structure and planned outcomes for the partnership between Indiana University/ Regenstrief Institute and the CDC's PIILLARS program. By sharing information about this collaboration, we hope to provide a model for other jurisdictions interested in longitudinally surveilling mothers and their infants.

Context for mothers-infant linked surveillance

In the United States, interoperability of electronic health record (EHR) systems varies from state to state, and often from region to region within a state [6]. Despite its dismal health statistics, Indiana has one of the most connected health systems in the U.S., with a statewide health information exchange (HIE) that includes data sharing among clinics, hospitals and public health [7, 8]. To date, MCH surveillance has not been conducted systematically in Indiana, nor has the state utilised its robust information infrastructure to its fullest extent. Instead, maternal-infant surveillance is siloed across state and local initiatives. Until now, the state has not used the HIE specifically to support systematic MCH surveillance or prevention. Participation in the PILLARS program gives the State the opportunity to increase capacity, surveillance and overall health of Indiana mothers and babies.

Infrastructure and approach to maternal and child health surveillance

Aims

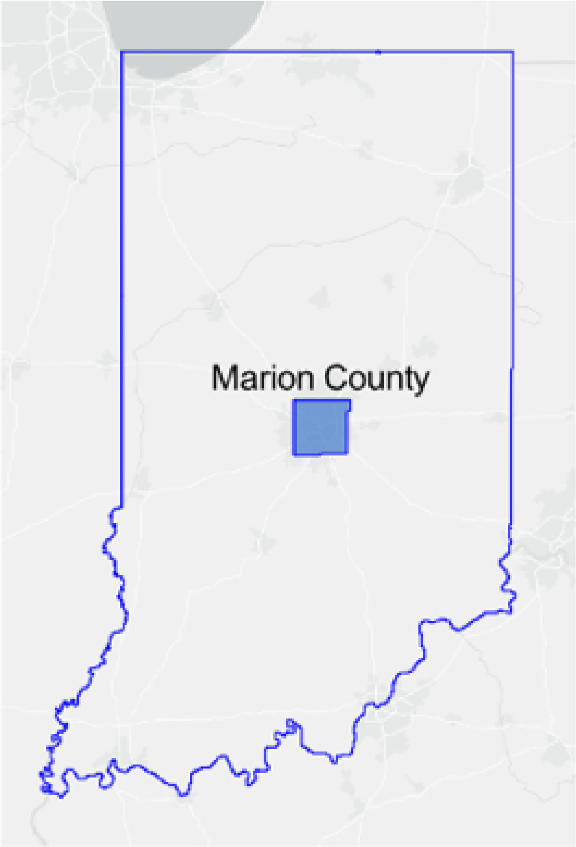
Through this surveillance project, we aim to do the following: (1) Implement and improve an algorithm to link mothers and their infants across multiple, linked data sources; (2) Create and expand a registry of mother-infant dyads that includes pre-, perinatal and infant health records; (3) Use the integrated registry to perform longitudinal surveillance on stillbirth, NAS and CS and (4) Collaborate with public health and community-based organisations to implement prevention activities in vulnerable Indiana communities.

Target populations

The primary target population for this surveillance project is all mothers who gave birth in Indiana hospitals from 1st January 2020 to 31st December 2026. Our initial surveillance efforts focus on Marion County, Indiana, as it is the largest county and registers the most births (∼14,000/year) [9]. Marion County also has some of the highest rates of stillbirth, NAS and congenital syphilis cases in Indiana and the nation (see Figure 1). Marion County is also diverse. For example, Black populations account for 29.6% of city-county residents compared to 10% in the state. Marion County also has growing populations of Hispanic, Burmese, Haitian and other diasporic populations. As the project moves forward, we intend to expand our efforts statewide. This will become possible as new data sources are integrated and as public health agencies make progress with data modernisation efforts supported by the CDC.

Because certain exposures exacerbate some MCH conditions, we will use our registry to examine equity for specific populations known to be at increased risk in Indiana. For example, non-Hispanic Black babies in Indiana are more than twice as likely to die by age one than their White counterparts, and Black mothers suffer stillbirth at twice the rate of White mothers [10]. For late-term stillbirths, Black

Figure 1: Map of Indiana with Marion County highlighted



race, low education, unmarried status and rurality carry the highest risk. Black babies are more likely to be diagnosed with NAS as Black mothers are less likely to be treated for Opioid Use Disorder (OUD) during pregnancy [11]. And throughout the state, rural populations are disproportionately affected by opioid use and addiction, with urban populations experiencing the lowest rates of injection drug use compared to rural and mixed rural/urban areas [12]. Black mothers in Indiana are also significantly less likely to be tested for CS during pregnancy.

Partners

Linking the EHRs of mothers and their babies requires participation from multiple institutional, state and local entities. This section describes key players in our surveillance efforts (see Figure 2). Two institutions serve as host sites. The first is Fairbanks School of Public Health (FSPH) at Indiana University Indianapolis (IU). The second institution is the Regenstrief Institute (RI), a research organisation closely affiliated with Indiana University. Project management staff and data analysts for this project are based at RI and many of the study investigators have joint appointments at RI in addition to IU.

Three primary organisations build this project's informatics operations. The non-profit Indiana Health Information Exchange (IHIE) operates Indiana's robust and extensive HIE. IHIE's purpose is to improve the accessibility and efficiency of healthcare information for the entire State of Indiana. Next, Regenstrief Data Services (RDS) is a service that the Regenstrief Institute provides to researchers in building datasets. Analysts at RDS serve as the honest data brokers for the Indiana Network for Patient Care (INPC), the data repository that powers the IHIE. INPC houses EHR data of over 25 million patients from over 100 separate Indiana healthcare entities [6]. IHIE manages INPC and RDS is the custodian of its data when used for research.

PILLARS in Indiana would not be possible without data and support from government agencies. At the state level, the Indiana Department of Health (IDOH) is an accredited state public health department and provides data such as newborn screening and vital records [13]. MCH is a key component of its strategic plan with focus on reduction of maternal and infant mortality. Locally, the Marion County Public Health Department (MCPHD) contributes data and support as a goal of the PILLARS project is to focus on vulnerable populations. MCPHD is the largest local health department in Indiana, serving Indianapolis and associated municipalities and has a rich history of engagement in MCH-related programs. Both public health partners will be integral in helping to translate registry data results into prevention and treatment programs for mothers and their babies.

Data sources

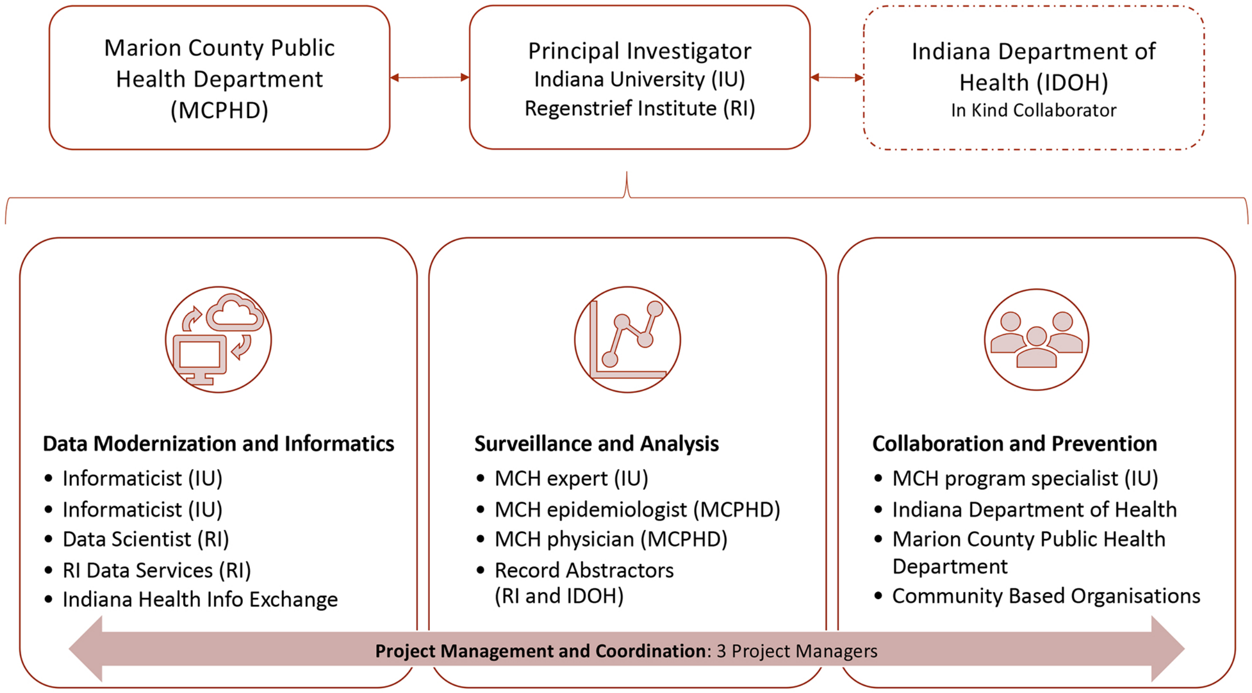
Although RDS has access to extensive EHR data of many mothers and babies through the INPC, it does not cover the entire state and can be incomplete. We must supplement EHR records with state and other administrative data. Similarly, administrative data is also often incomplete and does not guarantee a direct path to the person who gave birth, nor does it paint the full picture of the mother's health status and prenatal health care utilisation. Our registry necessitates additional types of data. IDOH contributes birth certificate data as well as newborn screening (NBS) data to the INPC. These data are routinely captured by birth registrars and hospital systems across Indiana. IDOH also contributes data from the Indiana Birth Defects and Problems Registry (IBDPR). State law requires healthcare providers to notify the IBDPR when a child is born with a birth defect so this data may contain information about key exposures.

Finally, our project uses Medicaid data to augment information from the INPC. As the U.S. does not have universal health insurance, Medicaid is government health insurance for adults and children with low incomes. Integrating this data will bring dyads into the registry that may have been excluded for not seeking care at one of the INPC health systems. Many of these dyads will be rural, at some distance from Indianapolis, and include dyads commonly at risk for health inequities.

Case definitions

Our case definitions for stillbirth, NAS and CS cases correlate with those used by the CDC and other states/participants in this cooperative agreement. We use the definition from the United States National Center for Health Statistics (NCHS) to identify stillbirth [14]. In short, a case involves foetal death at 20 weeks of gestation or greater if the dates are known, and if not, at 350 grams of weight or greater. Foetal death must be verified from foetal death certificates and at least one other source such as medical records.

Figure 2: Organisational chart detailing partner organisations and collaborators



We identify cases of NAS using standardised criteria from the United States Council of State and Territorial Epidemiologists (CSTE) [15]. In brief, cases are categorised hierarchically as Tier 1 or Tier 2 cases. Tier 1 cases are those identified from clinical records and are the preferred way to identify cases as they use higher standards of sensitivity and specificity. This includes a need for laboratory evidence of circulating drug metabolites in the neonate. Tier 2 cases are those identified from administrative databases. Tier 2 cases contain greater variability in the quality of criteria used; this includes *explicit* mention of an NAS diagnosis or *implicit* description of clinical symptoms of withdrawal.

Finally, we identify CS using standardised maternal and/or congenital criteria from the CSTE [16, 17]. These criteria are flexible given the variable nature of testing protocols and clinical manifestations of syphilis. Broadly speaking, an infant case should have laboratory evidence of treponemal infection and/or consistent physical findings such as an ulcerative lesion or inflammation of the long bones. A maternal case should also involve a combination of laboratory findings and/or physical findings during pregnancy.

Capacity Building

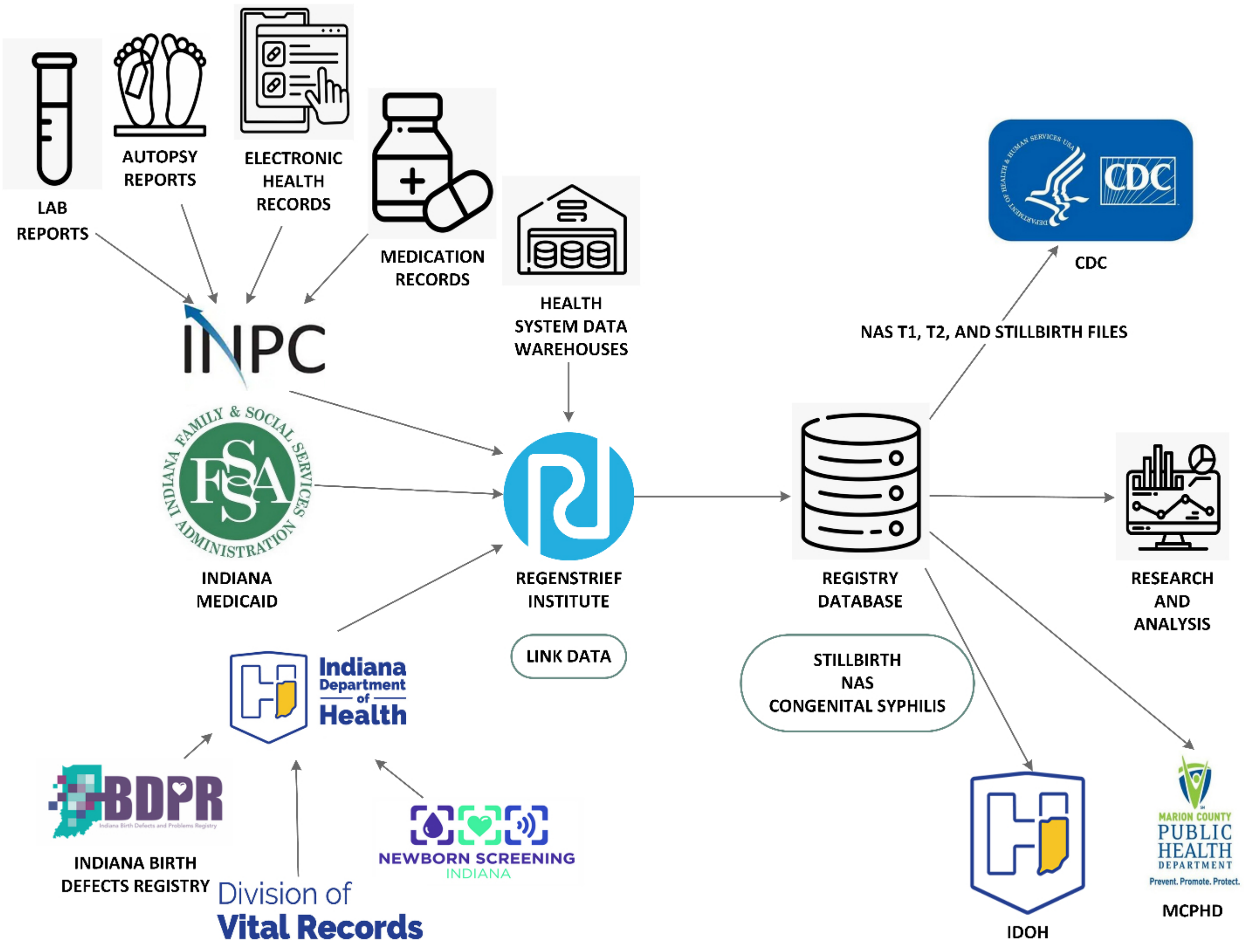
The data architecture for the registry is depicted in Figure 3. Regenstrief Institute aggregates and links the following data: (a) Indiana Network for Patient Care (INPC) data, including lab reports, autopsy reports, EHRs and medication records; (b) Indiana Medicaid data and (c) Indiana Department of Health data from the birth defects registry, newborn screening and vital records. These linked data of mothers (in the case of stillbirth), mothers (when able to be linked to children), and the children themselves are de-identified by removing personally identifiable information (PII) like name, address, phone number and medical facility name and loaded into a registry (database) and stored in a secure computing environment, with outputs delivered to CDC, MCPHD, IDOH and Regenstrief researchers.

To link mothers with infants/children accurately, we will employ advanced informatics methods. IU and Regenstrief currently lead the Maternal and Pediatric PRecisioN In Therapeutics (MPRINT) Hub, a national resource funded by the National Institutes of Health (NIH), for expertise in maternal and paediatric therapeutics [18]. This team has developed initial, deterministic algorithms for linking mothers to infants. Regenstrief has deployed these algorithms within its infrastructure and, in parallel, is continuing work to develop probabilistic algorithms for use in the future. While many variables will be able to be directly drawn from existing structured data elements in the INPC, some will need to be obtained through extracting unstructured data via natural language processing methods or manual abstraction (e.g. pathology reports, social factors, physical exam findings, developmental screenings, etc.). This is work that will be enhanced by the PILLARS project.

The current, deterministic algorithm has created an initial set of more than 800,000 dyads for use by the registry. A probabilistic linkage algorithm remains under development with a preliminary F-measure (calculated based on precision and recall) of 0.77 (where 1.0 is perfect) for mothers linked to infants [19]. Working with the Regenstrief team, we plan to refine the probabilistic algorithms to improve performance and deploy for use by the registry in the future. Specifically, we aim to increase the F-measure to $>$0.90 using available data and efforts from our technical team to enhance the weighting of specific data fields. The enhanced algorithm will then be deployed in future years to improve accuracy, enabling expanded surveillance of dyads.

Once linked, RDS data analysts extract data from the mother's EHR and other information for inclusion in the

Figure 3: Data flow chart for construction of registry



registry. We capture data on prenatal care, perinatal physical health diagnoses (preeclampsia, gestational diabetes) and perinatal mental health diagnoses (substance abuse disorder, depression and anxiety). Data from NBS and IBDPR as well as clinical diagnoses enable comprehensive capture of conditions such as hemoglobinopathies (e.g. sickle cell anaemia), endocrine disorders, amino acid disorders and other conditions (e.g. cystic fibrosis, congenital heart defects). Analysts will capture data on the mother and child up to age six. In quarterly updates to the registry, these data will be appended into the registry for established dyads. Over time, our team plans to expand access to prenatal, OB/GYN and postpartum data for patients whose records are not covered in the INPC through future partnerships with those outside providers, many of whom are rural. As these partnerships are formed and new data are integrated, we will strengthen not only MCH linkage but also surveillance capacity for current and future MCH exposures and outcomes.

Ongoing surveillance and data quality

We are conducting ongoing data quality assessments, including regular chart reviews to confirm diagnosis, especially with respect to commonly misdiagnosed stillbirth and NAS. Stillbirth is often not documented between 20-27 weeks gestation, and providers often do not use ICD-10 codes for NAS diagnosis [20, 21]. IDOH and MCPHD support these chart reviews as they currently perform case reviews for these conditions. Chart reviews for CS will be performed using a sampling approach based on criteria established by IDOH and MCPHD. Chart reviews will allow us to see trends in misdiagnosis and refine data ascertainment with help from partners.

We evaluate data quality, including missingness, timeliness, accuracy and consistency at three points in the data management process. The first point is data ingestion, when IHIE first receives the data. Transactions are checked for common errors and conformance to semantic and syntactic standards and evaluated for missing values. Non-standardised codes and values are mapped to standard vocabulary. The second point is in data extraction procedures. As we extract the desired cohort from the IHIE repository and transform it to the required common data model, we apply additional conformance tests related to specific codes. Finally, we perform a series of data quality checks to detect unusual trends or outliers. Quality measures are reported regularly, enabling the team to improve completeness, timeliness and accuracy after each update of the registry.

Planned outcomes

Our activities and strategies will achieve myriad outcomes. In the short term, we will see improved surveillance data collection between clinical and public health partners. By linking multiple sources, we can quickly and significantly increase ascertainment of pregnancies, and infant and maternal outcomes of interest. As an output of producing this data, we will increase access and availability of EHR and MCH public health data for both mothers and babies, leading to better understanding of the pre- and perinatal conditions that may influence proximal and distal child health. To broaden the practical implications of our work, we will collaborate with our partners to publish reports on public health authority websites, distribute information on social media platforms, deliver scientific presentations and publish possible dashboards on the Regenstrief Institute website [22]. Regenstrief currently hosts dashboards for COVID-19 and addiction-related data, and has developed advanced dashboard designs [23, 24]. A maternal child health dashboard could present key visuals for researchers, public health professionals, community-based organisations and the public to understand MCH trends in Indiana. Through our data transfers to the CDC, reporting of key exposures and outcomes that impact mothers and their infants will be vastly improved, leading to increased awareness by CDC of the data and how data are shared and processed.

In future years, our work with the CDC and other states/organisations within the collaborative agreement will yield an expanded and strengthened collaborative network to address public health issues that have an impact during pregnancy and to infants. Within the State of Indiana, data infrastructure will improve and along with increased interoperability. The result will be an improved state and national surveillance system that can be leveraged during emerging threats to mothers and their infants. This includes increased data availability to internal and external partners.

Finally, long-term outcomes will include the availability of timely, high-quality, modern and efficient surveillance data related to reporting of key exposures and outcomes that impact mothers, infants and children. This vastly improved surveillance data will yield practical impacts on public health, including new public health strategies for addressing MCH, innovative clinical recommendations and novel research findings. Ultimately, implementation of prevention activities and dissemination of findings will be overall more efficient.

Translating information into action

As data and information are produced from surveillance activities, we will share findings with our collaborators, including the CDC. We will engage community-based organisations in discussing the findings and applying the information to prevention efforts in communities across Indiana with a focus on increasing health equity for disadvantaged populations. Meetings with our partners will be reciprocal in that we will both disseminate findings and ask for community input on how to apply the data in prevention activities. There are several existing prevention programs that will benefit from our data. These include the Indiana Chapter of March of Dimes, faith-based maternal and child health initiatives, Women, Infants, and Children (WIC), the Indiana Primary Healthcare Association (IPHCA) and the Indiana Pregnancy Promise Program.

Discussion

Indiana's PILLARS initiative is currently developing a statewide mother-infant linked surveillance system to monitor stillbirth, neonatal abstinence syndrome and congenital syphilis. By including pre-, perinatal and child health records, the system will enable ongoing, systematic clinical and public health awareness as well as decision-making with respect to long-term MCH outcomes and interventions. Participation in PILLARS presents Indiana's public health, academic and community-based partners with the unique opportunity to strengthen an already-robust statewide health information infrastructure, expanding it in support of MCH.

Our work contributes to the understanding of mother-infant linked longitudinal surveillance topically in terms of the specific exposures to be examined and methodologically with respect to data integration and translation to interventions. Several prior studies use similar methods for creating registries of linked longitudinal maternal and child health data and examining specific conditions, including childhood obesity, child maltreatment and Downs Syndrome [25, 26, 27]. Although a limited number of prior studies, such as Salemi *et al*. [28], use longitudinal surveillance to track infant and early childhood deaths, none specifically create an ongoing, continually updated registry to link maternal and child medical records and longitudinally surveil stillbirth, NAS and CS in a jurisdiction. A Brazilian study [29] linked national birth records with national infectious disease surveillance data to track congenital syphilis, methods consistent with CDC's SET-NET program [5]. Ongoing maternal-infant linked longitudinal surveillance systems are starting to emerge in the United States in response to the CDC's call for ongoing integrated surveillance of NAS [30], which is unsurprising given that, in the U.S., 1-in-7 adults report experiencing a substance use disorder [11].

Many prior studies in the United States link data for specific, one-time analysis of disease trends, exposure prevalence, or death rates. Prior studies also link disparate data sources for child health, but do not link child and maternal medical, administrative and public health data. To this point, multiple studies exist outside of the U.S., such as ECHILD-MB in England, that offer ongoing maternal-child linked surveillance [31]. Administrative data sets, such as birth defects registries and birth certificates, have also been linked with survey and/or EHR data in prior studies [26, 32, 33]. Our work will go beyond linkage and a single study to analyse exposures and outcomes and regularly translate findings into practice. In other words, we seek to operationalise our surveillance system for routine public health work by local and state epidemiologists in addition to the teams at IU and Regenstrief.

Key members of our team are community-based researchers with ties to organisations that perform outreach to at-risk maternal populations in Marion County. Analyses from the registry will be used to inform development and evaluation of interventions. For example, if we find that many of the mothers have not received prenatal care, we will work with our program partners to devise interventions targeted at communicating the importance of prenatal care and connecting mothers to services. Our goal is to influence population-level decision-making that will improve MCH in Indiana.

Importantly, we intend to use our operational surveillance system to examine or improve maternal health. Our work is positioned so that maternal health will not only be seen as a predictor of infant and/or child outcomes, but as longitudinally and inextricably linked to the health of the child. Moreover, we intend to leverage the surveillance system to examine maternal health trends and outcomes, enabling the development and evaluation of interventions that protect and support the health of mothers. This includes maternal health during preconception, prenatal, postpartum and interconception time periods.

Our work further aligns strongly with the CDC's data modernisation initiative (DMI), including bolstering the U.S. early warning systems and integrating nationwide standards for data access and exchange [34]. With data sharing across clinical and public health organisations at the heart of DMI, our participation in the PILLARS project advances data sharing both within the State of Indiana and through the nationwide network of PILLARS and SET-NET participants [35]. Specifically, this project will implement methods for routinely extracting critical MCH data from EHR systems and integrating these data with public health data systems, such as vital records and birth defects registries. The project will further enable surveillance on an ongoing basis using these linked datasets. As we develop our infrastructure, we hope to demonstrate the vision set forth in CDC's DMI.

Conclusion

Participation in the U.S. CDC PILLARS program presents an opportunity for the State of Indiana to improve both its public health information infrastructure and maternal-child health. In developing an infrastructure and novel methods for ongoing, systematic surveillance of stillbirth, congenital syphilis and neonatal abstinence syndrome prenatally to age 6, our long-term goal is to improve outcomes for these conditions and other priority maternal-child health outcomes. Participation in PILLARS will facilitate enhancing and expanding statewide surveillance efforts to capture infant exposures and outcomes and translate the resultant data into action with community partners who reach vulnerable mothers and their infants.

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Statement of conflicts of interest

The authors declare that they have no conflicts of interest.

Ethics statement

This study did not require ethical approval as it is not human subjects research.

Data availability statement

No new data was created or used in this research.

References

1. Infant mortality in the United States, 2021: Data from the period linked birth/infant death file [Internet]. National Center for Health Statistics (U.S.); 2023 Sep [cited 2024 Feb 27]. Available from: https://stacks.cdc.gov/view/cdc/131356

2. Ho YA, Allen K, Tao G, Patel CG, Arno JN, Broyles AA, et al. Provider adherence to syphilis testing guidelines among stillbirth cases. Sex Transm Dis. 2020 Oct;47(10):686–90. https://doi.org/10.1097/OLQ.0000000000001230

3. Ojo OC, Arno JN, Tao G, Patel CG, Dixon BE. Syphilis testing adherence among women with livebirth deliveries: Indianapolis 2014-2016. BMC Pregnancy Childbirth. 2021 Oct 30;21(1):739. https://doi.org/10.1186/s12884-021-04211-8

4. Regenstrief Institute. Indiana Addiction Data Commons Dashboards [Internet]. [cited 2023 Apr 4]. Available from: https://www.regenstrief.org/iadc-dashboards/.

5. Tong VT, Woodworth KR, Blau E, Shinde N, Akosa A, Gilboa SM, et al. Population-based linked longitudinal surveillance of mothers and their infants: A critical resource for emerging, re-emerging, and persistent threats. J Womens Health (Larchmt). 2023 Jan;32(1):1–9. https://doi.org/10.1089/jwh.2022.0419

6. Rahurkar S, Jonnalagadda P, Tutt JK, Dixon BE, Menachemi N. Chapter 3 - Policies and incentives for adoption: toward broader use. In: Dixon BE, editor. Health Information Exchange (Second Edition): Academic Press; 2023. p. 57-86.

7. Overhage JM, Kansky JP. Chapter 22 - The Indiana Health Information Exchange. In: Dixon BE, editor. Health Information Exchange (Second Edition): Academic Press; 2023. p. 471–87.

8. McDonald CJ, Overhage JM, Barnes M, Schadow G, Blevins L, Dexter PR, et al. The Indiana network for patient care: A working local health information infrastructure. An example of a working infrastructure collaboration that links data from five health systems and hundreds of millions of entries. Health Aff (Millwood). 2005;24(5):1214–20. https://doi.org/10.1377/hlthaff.24.5.1214

9. County highlights: Hoosiers by the numbers [Internet]. [cited 2024 Feb 27]. Available from:

https://www.hoosierdata.in.gov/highlights/profile.asp?geo_val=S18;C097&page_id=1

10. Ananth CV, Fields JC, Brandt JS, Graham HL, Keyes KM, Zeitlin J. Evolving stillbirth rates among Black and White women in the United States, 1980–2020: A population-based study. Lancet Reg Health Am. 2022 Oct 28; https://doi.org/16:100380

11. Stigma reduction [Internet]. [cited 2024 Feb 27]. Available from: https://www.cdc.gov/stopoverdose/stigma/index.html.

12. Kooreman HE, Greene MS. Substance abuse in Indiana - An urban-rural perspective.pdf [Internet]. IUPUI Center for Health Policy; 2017 Jun [cited 2024 Feb 27] p. 1–20. Available from: https://fsph.iupui.edu/doc/research-centers/Substance%20Abuse%20in%20Indiana%20-%20An%20Urban-Rural%20Perspective.pdf

13. Perrault EK, Inderstrodt-Stephens J, Hintz EA. Tracking success: Outputs versus outcomes—A comparison of accredited and non-accredited public health agencies' Community Health Improvement Plan objectives. J Community Health. 2018 Jun;43(3):570–7. https://doi.org/10.1007/s10900-017-0454-0

14. Gregory EC, Barfield WD. US stillbirth surveillance: The National Fetal Death File and other data sources. In Seminars in Perinatology 2023 Dec 19 (p. 151873). WB Saunders. https://www-clinicalkey-com.proxy.ulib.uits.iu.edu/#!/content/playContent/1-s2.0-S0146000523001763?returnurl=null&referrer=null.

15. Elmore AL, Tanner JP, Lowry J, Lake-Burger H, Kirby RS, Hudak ML, et al. Diagnosis codes and case definitions for neonatal abstinence syndrome. Pediatrics. 2020 Sep 1;146(3):e20200567.

16. Sosa L. Update to public health reporting and national notification for syphilis: position statement 17-ID-11 Atlanta. GA Retrieved from https://cdn.ymaws.com/www.cste.org/resource/resmgr/2017PS/2017PSFinal/17-ID-11.pdf. 2017.

17. Sosa L. Update to public health reporting and national notification for congenital syphilis: Position statement 14-ID-03 Atlanta. GA Retrieved from https://cdn.ymaws.com/www.cste.org/resource/resmgr/2014PS/14_ID_03upd.pdf. 2014.

18. MPRINT Hub: Indiana University [Internet]. [cited 2023 Apr 6]. Available from: https://mprint.org/index.html.

19. Morgan TP, Barboi C, Grannis SJ, Schleyer TKL. Development and initial validation of an algorithm to infer family relationships in a large health information exchange database. *Paper submitted to the 2023 Annual Meeting of the American Medical Informatics Association*; 2023.

20. Frøen JF, Gordijn SJ, Abdel-Aleem H, Bergsjø P, Betran A, Duke CW, et al. Making stillbirths count, making numbers talk - Issues in data collection for stillbirths. BMC Pregnancy and Childbirth. 2009 Dec 17;9(1):58. https://doi.org/10.1186/1471-2393-9-58

21. Goyal S, Saunders KC, Moore CS, Fillo KT, Ko JY, Manning SE, et al. Identification of substance-exposed newborns and Neonatal Abstinence Syndrome using ICD-10-CM — 15 Hospitals, Massachusetts, 2017. MMWR Morb Mortal Wkly Rep. 2020 Jul 24;69(29):951–5. https://doi.org/ 10.15585/mmwr.mm6929a2

22. Regenstrief Institute. Indiana Addiction Data Commons dashboards [Internet]. [cited 2023 Apr 4]. Available from: https://www.regenstrief.org/iadc-dashboards/.

23. Dixon BE, Dearth S, Duszynski TJ, Grannis SJ. Dashboards Are trendy, visible components of data management in public health: Sustaining their use after the pandemic requires a broader view. Am J Public Health. 2022 Jun;112(6):900–903. https://doi.org/10.2105/AJPH.2022.306849

24. Qaurooni D, Herr BW, Zappone SR, Wojciechowska K, Börner K, Schleyer T. Visual analytics for data-driven understanding of the substance use disorder epidemic. Inquiry. 2024 Jan 28;61, https://doi.org/00469580241227020

25. Hawkins SS, Gillman MW, Rifas-Shiman SL, Kleinman KP, Mariotti M, Taveras EM. The Linked CENTURY Study: Linking three decades of clinical and public health data to examine disparities in childhood obesity. BMC Pediatr. 2016 Mar 9;16:32. https://doi.org/ 10.1186/s12887-016-0567-0

26. Newby-Kew A, Marshall LM, Zane S, Putz JW, Parrish JW. Replication and validation of a statewide linkage method to estimate incidence proportion of child maltreatment. Ann Epidemiol. 2023 Aug;84:1–7. https://doi.org/ 10.1016/j.annepidem.2023.04.020

27. Doidge J, Morris J, Harron K, Stevens S, Gilbert R. Prevalence of Down's Syndrome in England, 1998–2013: Comparison of linked surveillance data and electronic health records. Int J Popul Data Sci. 5(1):1157. https://doi.org/ 10.23889/ijpds.v5i1.1157

28. Salemi JL, Tanner JP, Bailey M, Mbah AK, Salihu HM. Creation and evaluation of a multi-layered maternal and child health database for comparative effectiveness research. J Registry Manag. 2013;40(1):14–28. PMID: 23778693

29. Paixao ES, Ferreira AJF, Pescarini JM, Wong KLM, Goes E, Fiaccone R, et al. Maternal and congenital syphilis attributable to ethnoracial inequalities: a national record-linkage longitudinal study of 15 million births in Brazil. The Lancet Global Health. 2023 Nov 1;11(11):e1734–42. https://doi.org/10.1016/S2214-109X(23)00405-9

30. Frey MT, Meaney-Delman D, Bowen V, Yazdy MM, Watkins SM, Thorpe PG, et al. Surveillance for emerging threats to pregnant women and infants. Journal of Women's Health. 2019 Aug;28(8):1031–6. https://doi.org/10.1089/jwh.2019.7943

31. Feng Q, Ireland G, Gilbert R, Harron K. Data Resource Profile: A national linked mother-baby cohort of health, education and social care data in England (ECHILD-MB). International Journal of Epidemiology. 2024 Apr 11;53(3). https://doi.org/0.1093/ije/dyae065

32. Chapman DA, Ford N, Tlusty S, Bodurtha JN. Evolution of an Integrated Public Health Surveillance System. J Registry Manag. 2011;38(1):15–23. PMC4870589

33. Danielsen BH, Carmichael SL, Gould JB, Lee HC. Linked birth cohort files for perinatal health research: California as a model for methodology and implementation. Annals of Epidemiology. 2023 Mar 1;79:10–8. https://doi.org/10.1016/j.annepidem.2022.12.014

34. Carney TJ, Wiltz JL, Davis K, Briss PA, Hacker K. Advancing chronic disease practice through the CDC Data Modernization Initiative. Prev Chronic Dis 2023;20:230120. https://doi.org/10.5888/pcd20.230120

35. What is the Data Modernization Initiative? | DMI Basics | CDC [Internet]. 2023 [cited 2024 Feb 27]. Available from: https://www.cdc.gov/surveillance/data-modernization/basics/what-is-dmi.html

Abbreviations

CDC:	Centers For Disease Control and Prevention
CS:	Congenital syphilis
CSTE:	Council of State and Territorial Epidemiologists
DMI:	Data modernization initiative
EHR:	Electronic Health Record
FSPH:	Fairbanks School of Public Health
HIE:	Health information exchange
IDOH:	Indiana Department of Health
IHIE:	Indiana Health Information Exchange
INPC:	Indiana Network for Patient Care
MCPHD:	Marion County Public Health Department
MCH:	Maternal-child health
NAS:	Neonatal Abstinence Syndrome
NBS:	Newborn screening
RDS:	Regenstrief Data Services
RI:	Regenstrief Institute