Building community, infrastructure and insights for perinatal and reproductive health research in OHDSI

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Background

Despite childbirth being the number one reason for hospitalizations worldwide, pregnancy is understudied. Pregnant people are systematically excluded from most trials and studies, despite often being in greatest need of effective therapies. More than 90% of pregnant patients use at least one medication (1), yet studies of medication safety and effectiveness during pregnancy using traditional approaches such as randomized clinical trials (RCTs) are limited due to concerns for fetal safety (2–4). Observational health data, and specifically data collected during the course of routine care and captured in electronic health records (EHRs), are crucial to filling this evidence gap.

OHDSI has a successful track record of leveraging observational health data from international sources to study medication safety and effectiveness for a variety of diseases and therapies e.g. (5) – it is time to bring these data and methods to perinatal and reproductive health research. We will describe our preliminary work towards this long-term goal, including the founding of a dedicated OHDSI work group, building on prior work to develop infrastructure at multiple sites to represent pregnancy and birth specific data, and early insights derived from this research.

Methods

We founded the Perinatal and Reproductive Health Work Group (PRHeG) in December 2022. Our work group comprises multi-disciplinary investigators with complementary expertise in informatics, data science, maternal-fetal medicine, and perinatal pharmacoepidemiology. In our six monthly group meetings to date, we have presented and discussed research being done internationally within the group to incorporate EHR, claims and registry data specific to pregnancies and deliveries into the OMOP CDM; to identify and link maternal and infant records using USA insurance claims data; and to characterize pregnancies and births in Spain, Norway, Scotland and the USA. We have also initiated collaborations with members of the OMOP CDM and patient-level prediction (PLP) work groups to identify best practices for representing pregnancy and birth specific data in the CDM, and to develop prediction models for pregnancy outcomes.

Results

The Perinatal and Reproductive Health Work Group consists of more than 40 investigators across approximately 20 institutions (Figure 1). PRHeG’s purpose is to develop tools and standards for pregnancy and reproductive health data to foster collaborative studies within the OHDSI network and advance research in the field. Our objectives are to: 1) improve capture and representation of pregnancy and reproductive health data in the OMOP CDM, 2) create an OHDSI data network of partners interested in pregnancy and reproductive health research and 3) launch at least one network study in our first year.
Toward these objectives, PRHeG members at Stanford University have developed ProgressDB, a database of ~100,000 pregnancies and ~30,000 live births (6) from 2016-2022 using Stanford Medicine’s OMOP CDM instance (STARR OMOP; Figure 2), using validated methods to extract pregnancy- and birth-specific information including gravidity, parity, gestational age, plurality, and fetal presentation at birth from a combination of notes, flowsheets and coded data. They have also completed preliminary work to incorporate additional records about pregnancies and deliveries from the Epic Stork module. These data have been used as part of a pilot study of antihypertensive medication usage during pregnancy at 3 OHDSI sites - Stanford University, Columbia University and MaineHealth. PRHeG members at Janssen Research and Development have developed and evaluated an algorithm for linking mothers and infants in two USA commercial healthcare claims databases for pharmacoepidemiology research (7). PRHeG members at IDIAPJGol in Spain, the University of Oslo in Norway, the University of Oxford in England, and the University of Dundee in Scotland, funded by the European Health Data & Evidence Network (EHDEN), have developed a perinatal expansion for the OMOP CDM, have implemented it at two OHDSI sites in Europe, and are using this unique resource to study COVID-19 vaccine uptake and effectiveness in pregnancy.

These ongoing studies and infrastructure efforts have been presented and discussed at our PRHeG monthly meetings, towards the shared goal of a common approach for representing pregnancy and birth specific data across OHDSI sites and identifying opportunities for future network studies. Similarly, our guest presentations by members of the OMOP CDM and PLP work groups have identified best practices for representing perinatal health data in the OMOP CDM that have been implemented at Stanford and
are planned for implementation and evaluation at other OHDSI sites. These discussions have also identified potential collaborations to develop predictive models for pregnancy-related events including hypertension in pregnancy and stillbirth.

**Conclusion**

In its first 6 months, the Perinatal and Reproductive Health Work Group has brought together more than 40 international investigators to improve capture and representation of pregnancy and reproductive health data in the OMOP CDM and create an OHDSI data network of partners interested in pregnancy and reproductive health research. Much of this progress is the result of work by long-standing and new members of the OHDSI community who have come together through PRHeG. With PRHeG, we aim to provide a platform as well as a growing body of infrastructure, tools and data for future studies towards improving health care for pregnant people around the world.

**References**


