THE SASKATCHEWAN PERINATAL DATABASE PROJECT

1st STRATEGIC PLANNING MEETING, Nov 28th, 2024

Summary Report

Perinatal Database Planning Committee Meeting, University of Saskatchewan and SHA
Dr. Tim Bradley, Associate Professor, Pediatric Cardiology, University of Saskatchewan
Dr. Sarah Smith, Assistant Professor, Obstetrics & Gynecology, University of Saskatchewan
Leah Thorp, Director, Education and Research, Maternal and Children's Provincial Program, SHA
Jessica Bailey, Provincial Midwifery Manager, SHA
Tova Dybvig, Research Facilitator, Department of Pediatrics, University of Saskatchewan

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Table of Contents

Meeting Overview

Executive Summary

On November 28th, 2024, maternal and child health stakeholders from across the province met to discuss the creation of the first Saskatchewan Perinatal Database. This event was an opportunity to explore next steps in designing and implementing a Saskatchewan database that meets the needs of all stakeholders. This was funded by University of Saskatchewan College of Medicine Conference fund and Saskatchewan Health Research Foundation Align Grant. The meeting was hosted by the Perinatal Database Planning Committee Meeting. The meeting was available virtual and in person on Treaty 6 territory, traditional Homeland of the Metis in Saskatoon, SK at the University of Saskatchewan.

Attendees:

Sarah Smith, RGH Obstetrician
Ernesto Figueiro, RGH Obstetrician/MFM
Kat Nikel, JPCH Obstetrician/MFM*
Joanne Siverston, HOD ObGyn
Mark Milne, Research Facilitator, ObGyn
Adrielle Souza Lira, Obs. RN/Research Trainee
Seirin Goldade, JPCH Obstetrician

Tim Bradley, JPCH Pediatric/Fetal Cardiology
Darryl Adamko, JPCH Respirology/Research
Asma Nosherwan, JPCH Neonatology*
Terry Klassen, HOD Pediatrics
Tova Dybvig, Research Facilitator, Pediatrics
Lorynn Labbie, Med Student/Research Trainee

Jessica Bailey, Provincial Midwifery Manager
Debbie Vey, Midwifery Lead, Fort Qu'Appelle
Shanna Fenton, Co-ADL Family Medicine*
Michelle James, Family Medicine/Prince Albert*

Paul Lawrence, Director, EHealth-SK
Janell Senft, Director, Digital Health-Urban & Tertiary, SHA

Carrie Dornstauder, Executive Director, Maternal and Children's Programs, SHA
Leah Thorp, Education & Research Maternal and Children's Provincial Program, SHA

Veronica McKinney, Indigenous Health Research/Family Medicine/Rural & Remote
JoLee Sasakamoose, Indigenous Health Research/Public Health Research/Health Psychology
Megan Clark, Research and Evaluation Specialist, Saskatchewan Prevention Institute

*Virtual attendee

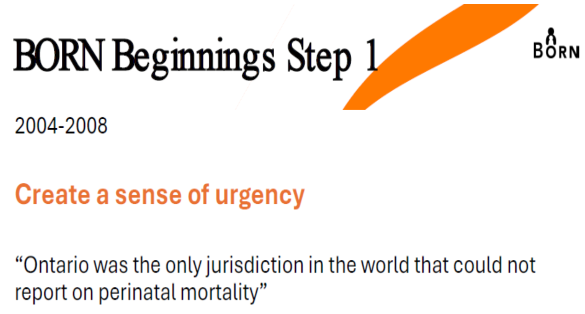
The objective of this meeting was to engage a robust interdisciplinary team of researchers, heath care providers, knowledge users, administrators, and digital health specialists to collaborate on the design and implementation of the Saskatchewan Perinatal Database. The meeting began with a keynote session highlighting the Ontario perinatal registry called, Better Outcomes Registry & Network (BORN). This was followed by a presentation by medical student, Lorynn Labbie who shared a summary of key findings from Canadian and International studies that demonstrate the geographic and socioeconomic determinants of perinatal care and congenital anomalies. Dr. Sarah Smith then provided an overview and update on the development of the Maternal Database for Saskatchewan (MAT-SK) and Dr. Bradley did the same for the Congenital Anomalies Database of Saskatchewan (CASK). A roundtable discussion followed where stakeholders provided feedback from their perspective background.

This report provides a summary of the discussions that occurred at this meeting and is intended to stimulate further conversation that can be utilized for the development of the Saskatchewan Perinatal Database. A major consensus from this 1st Strategic Planning Meeting was that we should first focus on developing a standardized electronic clinical perinatal dataset with Digital Health and eHealth. Universal access to this dataset is essential for optimizing individual patient care and facilitating province-wide quality assurance and quality improvement projects. Prospective collection of this standardized dataset will then be an invaluable resource for future research initiatives and resource planning.

Keynote Presentation: Improving Care & Outcomes with a Provincial Perinatal Registry: Celebrating the Successes and Overcoming the Barriers, Better Outcomes Registry & Network (BORN) Ontario.

Presenters: Dr. Eyal Cohen, Dr. Nan Okun, Dr. Mark Walker, and Ms. Alicia St. Hill

Dr. Mark Walker, MFM Specialist at The Ottawa Hospital, Senior Scientist at the Ottawa Hospital Research Institute, and Professor in the Faculty of Medicine and School of Epidemiology and Public Health at the University of Ottawa, kicked off the keynote presentations by discussing the steps required to design and implement a perinatal registry. This included creating a sense of urgency by highlighting the loss of perinatal mortality reporting in Ontario. Step 2 was ensuring that the right team was as the table including database owners, government and healthcare leadership. Next step was to develop a strategic plan including a vision and mission statement. Finally the registry needs to be designed for all stakeholders and have a long-term sustainability plan to continually improve and innovate.



BORN Beginnings Step 1

2004-2008

Create a sense of urgency

"Ontario was the only jurisdiction in the world that could not report on perinatal mortality"

BORN Beginnings Step 2

Form a powerful coalition

- Existing database owners
  - Niday, Fetal Alert, Newborn Screening
- Ministry of Health
- BORN leaders

BORN Beginnings Step 3

Create a Vision

Vision: To promote the best possible pregnancy outcome for women and children in the province of Ontario

Mission: To perform health services research to provide the most cost effect, evidenced based care for pregnant women and newborns in Ontario.

BORN Beginnings Step 4

Create Value for all Groups involved

Dr. Nan Okun, a MFM Specialist at Sunnybrook Hospital in Toronto, Professor at the University of Toronto, Department of Obstetrics and Gynecology and Co-Medical Director of the

Prenatal Screening Program with BORN Ontario, then provided some clinical context on how the BORN registry has impacted prenatal screening in Ontario.

Dr. Cohen, Professor of Paediatrics and Health Policy, Management and Evaluation at the University of Toronto, and Scientist with the CanChild Centre for Childhood Disability Research at McMaster University, then highlighted how the BORN registry has informed development of resources for clinical follow-up of abnormal newborn screening tests and provide real time data on impact of province-wide disease intervention strategies.

Ms. Alicia St. Hill, Executive Director of Ontario's Better Outcomes Registry & Network (BORN), including the Prenatal Screening Ontario (PSO) program, rounded out the presentation by discussing lessons learned from the Ontario model and how to take advantage of current innovation. This included EMR integration, optimization through existing data standards and quality and finally early acceptance of artificial intelligence. She emphasized the importance of data vigilance, including Indigenous data governance and applying an equity lens.

Registry is more than digital paper

Saskatchewan has a good start by focusing on use cases.

EMR integration
- Avoiding pitfalls & exploiting opportunities

Data Standards + Quality

Artificial Intelligence
- Early acceptable use cases?

Opening Remarks:

Ms. Carrie Dornstauder (Executive Director, Maternal and Children's Programs, SHA), Dr. Joanne Sivertson (Provincial Department Head of ObGyn, and Dr. Terry Klassen (Provincial Department Head of Pediatrics) offered their support from their respective leadership oversight.

ED Mat Child Strategic Goals
ELT Sponsor John Ask and Dr. Mark Fenton

- Optimize clinical care services to improve health outcomes

Year End Deliverables

Perinatal Pathway & Registry Design

SK Interactive perinatal clinical pathway is scoped to support effective transition of maternal newborn

Patient and capture health data for the HRDP. The pathway establishes a strong foundation for incremental growth of clinical pathway and data capture along the mother child journey from conception thru the first 2 years of life

Carrie shared a high level overview of how the First 1000 Day visioning event from 2023 identified a perinatal database as a provincial priority. This has been added to the SHA roadmap for 2024. Carrie discussed the multi-stage approach and longer-term vision between clinical pathway development and the data markers. Dr. Joanne Sivertson: discussed the importance of a perinatal database and standardized perinatal forms. Dr. Terry Klassen shared his enthusiasm about the opportunity to create a perinatal database in Saskatchewan. He offered support to advocate for this on behalf of the Department of Pediatrics.

Presentation: Geographical and Socioeconomic Determinants of Perinatal Care and Congenital Anomalies

Presenter: Lorryn Labbie (Medical Student / Research Trainee)

Lorryn presented studies highlighting the geographical and socioeconomic determinants of prenatal care utilization in both Canada and internationally. The studies show that inadequate prenatal care is a major risk factor for adverse pregnancy outcomes and despite universal healthcare within Canada, that many women still receive inadequate care. Her presentation set the stage for the importance of today's meeting and establishing the Saskatchewan Perinatal Database.

Summary of Determinants of Perinatal Care and Congenital Anomalies

Geographical Factors

Rural or remote residence; low income, low employment and lower educated neighbourhoods, proportion of immigrants and minorities in neighbourhood, population density, accessibility of care.

Socioeconomic Factors

Young maternal age, race, ethnic minority, single parent, low income, low employment, lower education, social isolation, late recognition of pregnancy, high parity, short inter-pregnancy interval, unplanned place of delivery.

Problem in Saskatchewan is we have no data.

Presentation: Maternal and Perinatal Database of Saskatchewan MatSK Introduction and Update

Presenter: Dr. Sarah Smith, RGH Obstetrician

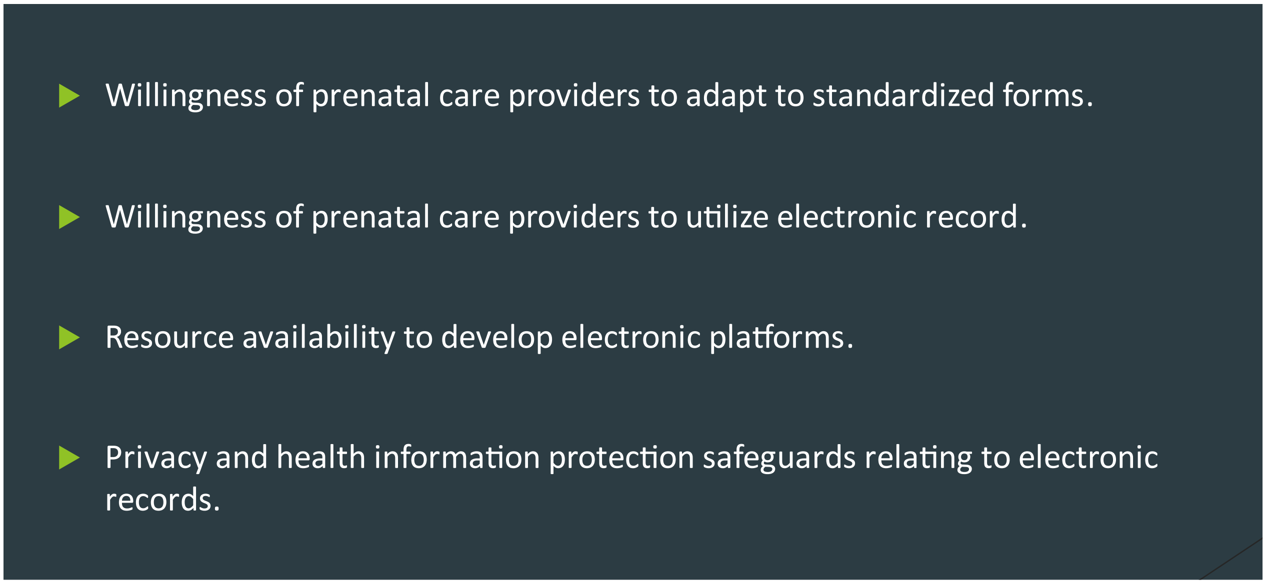
Dr. Smith presented a vision for a Maternal and Perinatal database in Saskatchewan. She highlighted three goals:

1. Create standard prenatal record, delivery summary, maternal discharge summary, and infant discharge summary.
2. Create a provincial prenatal electronic health record
3. Establish an electronic perinatal database.

Dr. Smith discussed the benefits of a perinatal database including:

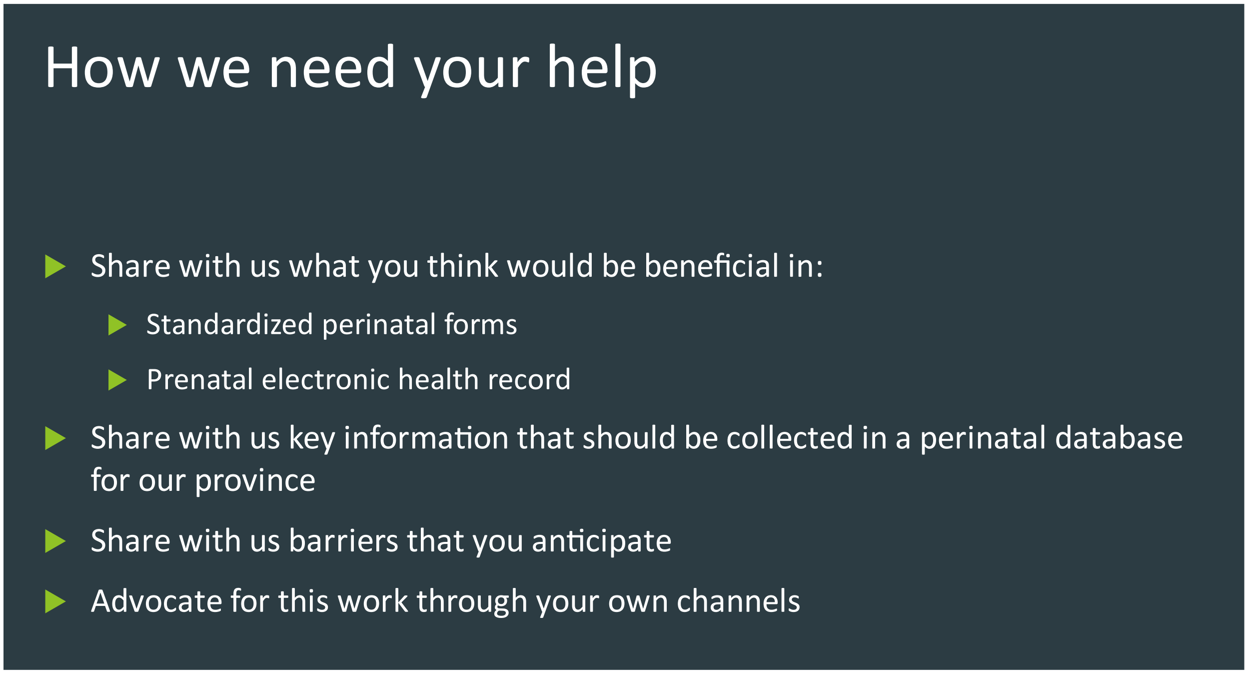
- Improved communication between patients and prenatal care providers through prenatal electronic health record.
- Investment in health care infrastructure for reliable, safe, efficient, and effective delivery of health care services and programs for pregnant people and their families.
- Increased accuracy in perinatal health outcome data improving health care policy decision making.
- Increased perinatal health research in Saskatchewan due to increased accessibility and breadth of data available.

Dr. Smith also highlighted the potential barriers:



- Willingness of prenatal care providers to adapt to standardized forms.
- Willingness of prenatal care providers to utilize electronic record.
- Resource availability to develop electronic platforms.
- Privacy and health information protection safeguards relating to electronic records.

Dr. Smith requested support from the audience:



How we need your help

- Share with us what you think would be beneficial in:
    - Standardized perinatal forms
    - Prenatal electronic health record
- Share with us key information that should be collected in a perinatal database for our province
- Share with us barriers that you anticipate
- Advocate for this work through your own channels

Presentation: Congenital Anomalies Database of Saskatchewan CASK Introduction and Update

Presenter: Dr. Tim Bradley, JPCH Pediatric/Fetal Cardiology

Dr. Bradley discussed how they plan to establish a comprehensive provincial congenital anomalies database and participate in the Canadian Congenital Anomalies Surveillance System.

This included the following goals:

1. Create a standardized Saskatchewan - Congenital Anomalies Reporting Form (SK-CARF)
2. Establish an electronic Congenital Anomalies Database of Saskatchewan (CASK)
3. Report our data to the Public Health Agency of Canada Canadian Congenital Anomalies Surveillance System (CCASS) and strengthening existing platforms created in the community.

Dr. Bradley highlighted how Saskatchewan is the **only** province in Canada not participating in the Canadian Congenital Anomalies Surveillance System. Therefore, we have no data on the incidence, prevalence, outcomes of congenital anomalies in Saskatchewan and the impact of geographical and socioeconomic factors on access to maternal, fetal, and pediatric care.

Dr. Bradley shared our current progress with the **A**ssessment **B**ased on **A**vailable data for **C**ongenital Anomalies **U**ploaded already in datasets in **S**askatchewan (ABACUS) study. The study team is utilizing Health Research Data Platform–Saskatchewan (HRDP-SK) which is the province's first fully integrated multi-agency data access platform for health research.

Where are we at?

ABACUS

Study design: Retrospective observational cohort study.

Study methods: Using HRDP-SK we will extract data from the MOH datasets (1APR2016 -31Dec2023)

- Discharge Abstract Database (**DAD**) – 'Hospital Discharge Database'
- Medical Services Branch (**MSB**) – 'Physician Billing Database'
- National Ambulatory Care Reporting System (**NACRS**) – 'Emergency Department Visit Database'
- Person Health Registration System (**PHRS**) – 'Health Card Database'

to create the Maternal Cohort and Pediatric Cohort are as follows.

Study populations:

Maternal Cohort: ~140,000 pregnant mothers

~111,050 live births, ~950 stillbirths, ~14,000 terminations (10%), ~14,000 spontaneous abortions (10%)

Pediatric Cohort: ~ 111,050 live births

SCPOR Saskatchewan Centre for Patient-Oriented Research

Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

SASK KIDS PEDIATRICS

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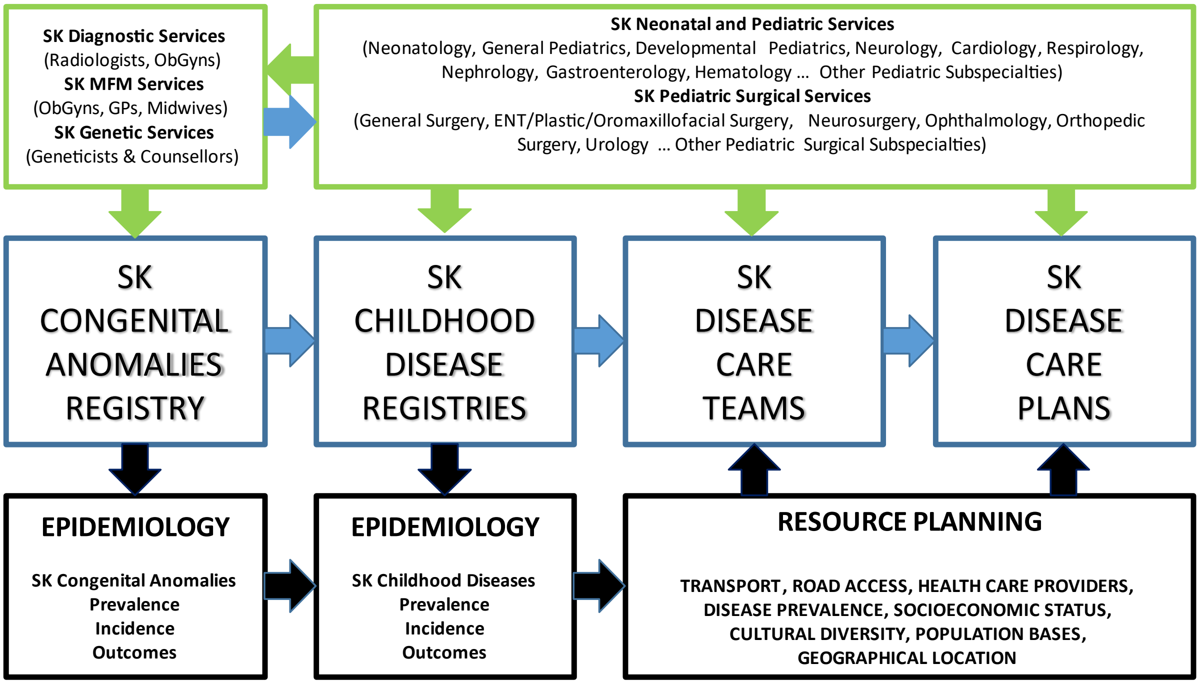
Finally, Dr. Bradley discussed where we want to go next:



Breakout Session 1: Engaging Stakeholders and Defining Roles

Moderator: Leah Thorp, Director Education & Research Maternal and Children's Provincial Program, SHA

Leah Thorp facilitated the conversation with attendees to collect valuable feedback and suggestions. The discussion was concentrated on the importance of patient and family care, information at care transitions, and accessibility of patient health history to inform care planning. The information was captured on the SK Prenatal EMR/Perinatal Database MURAL.

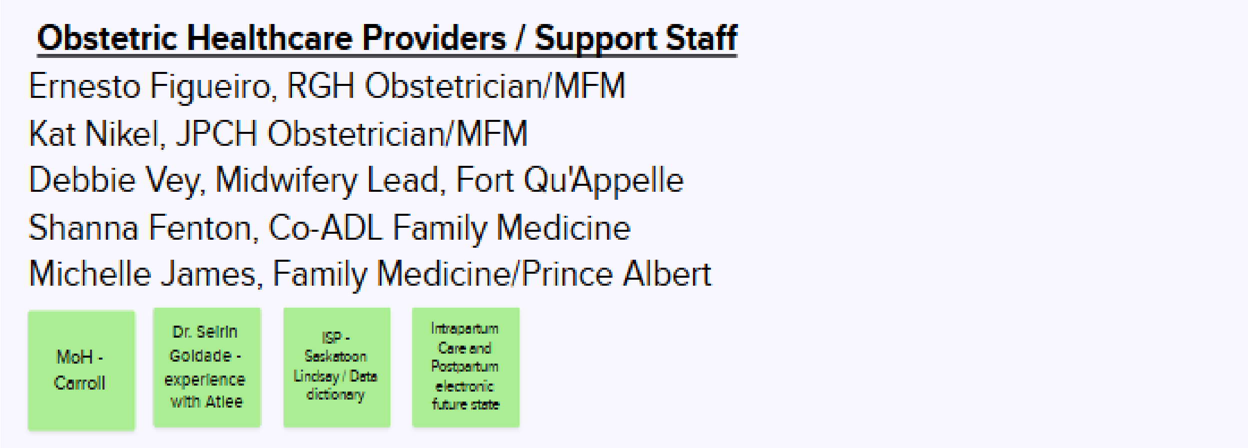
Administrative / Departmental Support

Carrie Dornstauder, Executive Director, Maternal and Children's Programs, SHA
Joanne Siverston, HOD ObGyn
Terry Klassen, HOD Pediatrics

- Melissa Kimens - MoH
- Chris Rheinlander MoH
- Dr. S development and engagement of the prenatal record Sponsor and guide
- Dr. Delivery record - physician engagement and buy in
- Wendy and Dr. Khan - ISC
- Primary Services Branch
- ED Sponsor and facilitate relationships - as a strat initiate
- Carrie - specific asks and engagement
- Primary Care - Clinics and expectation in network Jacquie Holzman
- Dr. Klassen sponsor and relationships/ engagement

Pediatric Healthcare Providers / Support Staff

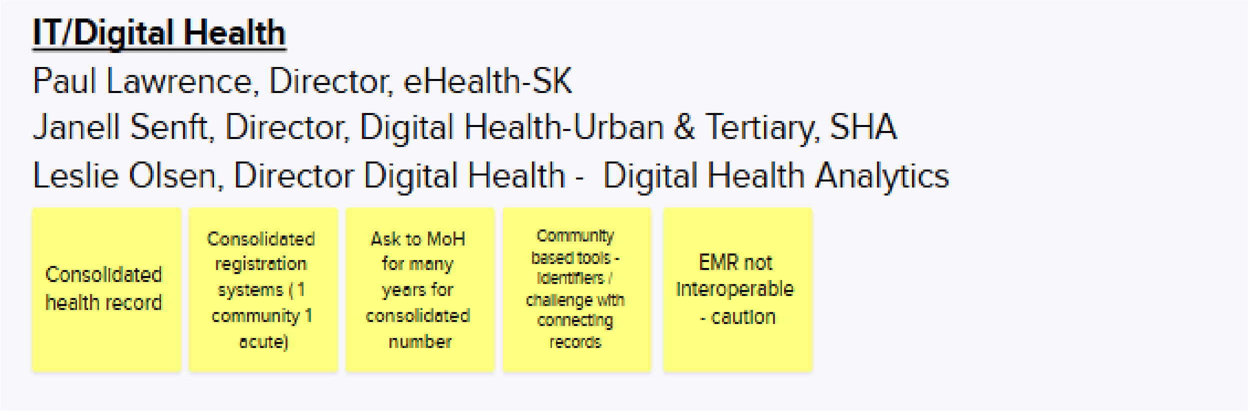
Darryl Adamko, JPCH Respirology/Research
Asma Nosherwan, JPCH Neonatology



Obstetric Healthcare Providers / Support Staff

Ernesto Figueiro, RGH Obstetrician/MFM
Kat Nikel, JPCH Obstetrician/MFM
Debbie Vey, Midwifery Lead, Fort Qu'Appelle
Shanna Fenton, Co-ADL Family Medicine
Michelle James, Family Medicine/Prince Albert

- MoH - Carroll
- Dr. Selrin Goldade - experience with Atlee
- ISP - Saskatoon Lindsay / Data dictionary
- Intrapartum Care and Postpartum electronic future state



IT/Digital Health

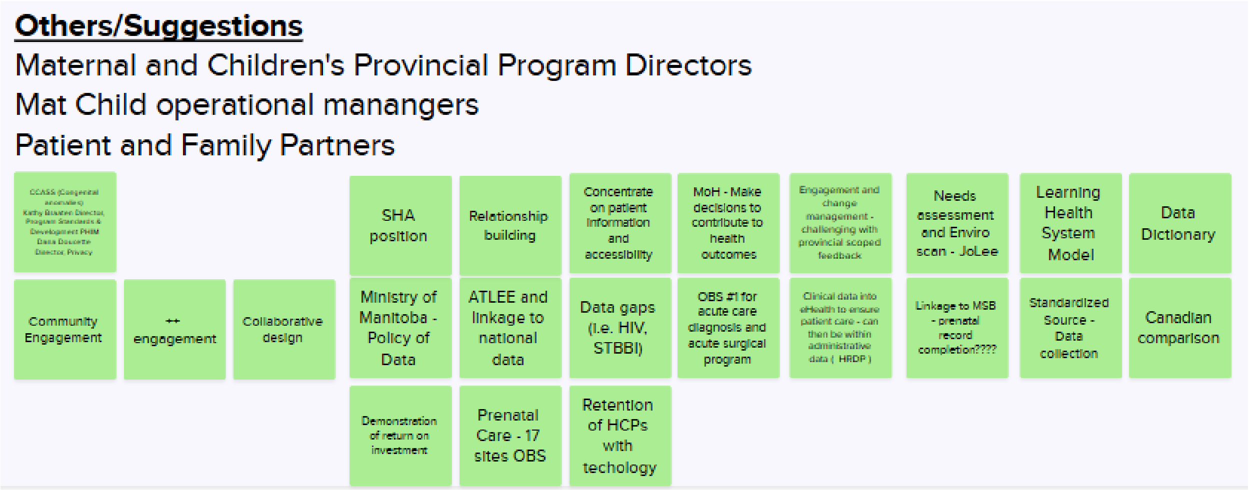
Paul Lawrence, Director, eHealth-SK
Janell Senft, Director, Digital Health-Urban & Tertiary, SHA
Leslie Olsen, Director Digital Health - Digital Health Analytics

- Consolidated health record
- Consolidated registration systems (1 community 1 acute)
- Ask to MoH for many years for consolidated number
- Community based tools - identifiers / challenge with connecting records
- EMR not interoperable - caution

Indigenous Health / Preventative Health

Veronica McKinney, Indigenous Health Research/Family Medicine/Rural & Remote
JoLee Sasakamoose, Indigenous Health Research/Public Health Research/Health Psychology
Megan Clark, Research and Evaluation Specialist, Saskatchewan Prevention Institute

- Engagement with Indigenous First Nations/Metis and systems they have in place currently
- FSIN - STAG Team 74 first nations
- Tribal councils
- KPI Health Indicators
  - Mental Health and Addictions
  - ?next possible Maternal Health
- Co-creation
- Relevant
- Accessible
- How to engage properly
- Specific need for sensitivity with small population and potential health outcomes of specific population
- Potential for Grant specific for First Nations / Indigenous populations
- Formation of trust
- ISC - Dr. Khan



Others/Suggestions

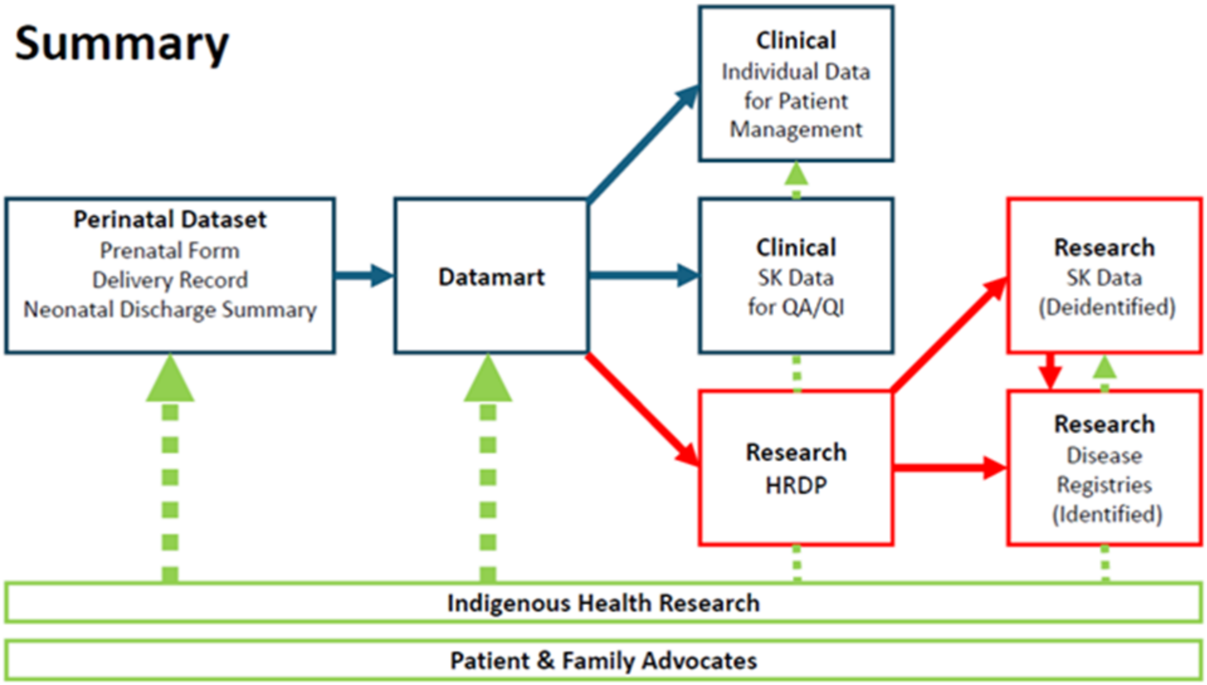
Maternal and Children's Provincial Program Directors
Mat Child operational manangers
Patient and Family Partners

- CCASS (Congenital anomalies) Kathy [illegible] Director, Program Standards & Development PHIM Dana Doucette Director, Privacy
- Community Engagement
- ↔ engagement
- Collaborative design
- SHA position
- Ministry of Manitoba - Policy of Data
- Demonstration of return on investment
- Relationship building
- ATLEE and linkage to national data
- Prenatal Care - 17 sites OBS
- Concentrate on patient information and accessibility
- Data gaps (i.e. HIV, STBBI)
- Retention of HCPs with techology
- MoH - Make decisions to contribute to health outcomes
- OBS #1 for acute care diagnosis and acute surgical program
- Engagement and change management - challenging with provincial scoped feedback
- Clinical data into eHealth to ensure patient care - can then be within administrative data (HRDP)
- Needs assessment and Enviro scan - JoLee
- Linkage to MSB - prenatal record completion????
- Learning Health System Model
- Standardized Source - Data collection
- Data Dictionary
- Canadian comparison

Breakout Session 2: Next Steps

General discussion followed amongst all the attending stakeholders, with the following consensus on our next steps:

1. We should first focus on developing a standardized electronic clinical perinatal dataset with Digital Health and eHealth.
2. Universal access to this dataset is essential for optimizing individual patient care and facilitating province-wide quality assurance and quality improvement projects.
3. Prospective collection of this standardized dataset will then be an invaluable resource for future research initiatives and resource planning.



Meeting Conclusions

Our 1st Strategic Planning Meeting offered an opportunity for stakeholder engagement and to familiarize everyone with the current state of the development of the Saskatchewan Perinatal Database. The major take-home messages were:

- Defining where this clinical data will be housed and processed – Datamart
- Understanding that the first focus is to develop the standardized electronic clinical perinatal records (Prenatal Record, Delivery Record, Neonatal Discharge Record) with SHA Digital Health
- Implementing these standardized electronic clinical perinatal records as Saskatchewan's clinical standard of care is essential for optimizing individual patient care and facilitating province-wide quality assurance and quality improvement projects.
- Future research projects may also be able to be extracted retrospectively from the SHA Datamart using the HDRP, like we are currently doing from the MOH datasets for ABACUS.
- Finally, it is essential that we co-develop in parallel in these early stages, an Indigenous Health stream and a Patient-Oriented stream with our current and further representative stakeholders.