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Early health. Lifelong health.
Début en santé. Longue vie en santé.

BORN Ontario:
Use of Data for Improving Care, Quality Improvement, Reporting and Research

BORN Ontario Briefing

June 2011

Ann Sprague RN, PhD

Objectives

- Review BORN purposes
- To learn about the 5 W's of BORN data
  - ***who*** is using BORN data,
  - ***what*** are they using it for,
  - ***where*** they access it,
  - ***when*** it is appropriate to use aggregate vs record level data,
  - ***why*** BORN data is undergoing changes in the new build

BORN Purposes

1. Identify ***individuals or settings*** where appropriate care has not been received and facilitate access to care and treatment for mothers, infants and children.
2. Facilitate ***continuous improvement of healthcare delivery tools*** to minimize adverse outcomes.
3. Determine where maternal and/or newborn ***outcomes are clinically or statistically discrepant*** with accepted norms and raise alerts where necessary.
4. Enable health care providers to improve care by providing information & tools to ***compare their outcomes and performance with peers*** and/or benchmarks.
5. Identify ***areas where best practice evidence needs implementation*** (knowledge translation strategies) to improve the quality and efficiency of care for mothers, infants and children.
6. ***Create reports*** that can be used to provide the Ministry of Health and Long-Term Care, Local Health Integration Networks and Public Heath Units with comprehensive and timely information for mothers, babies and children

Secondary Use: Research

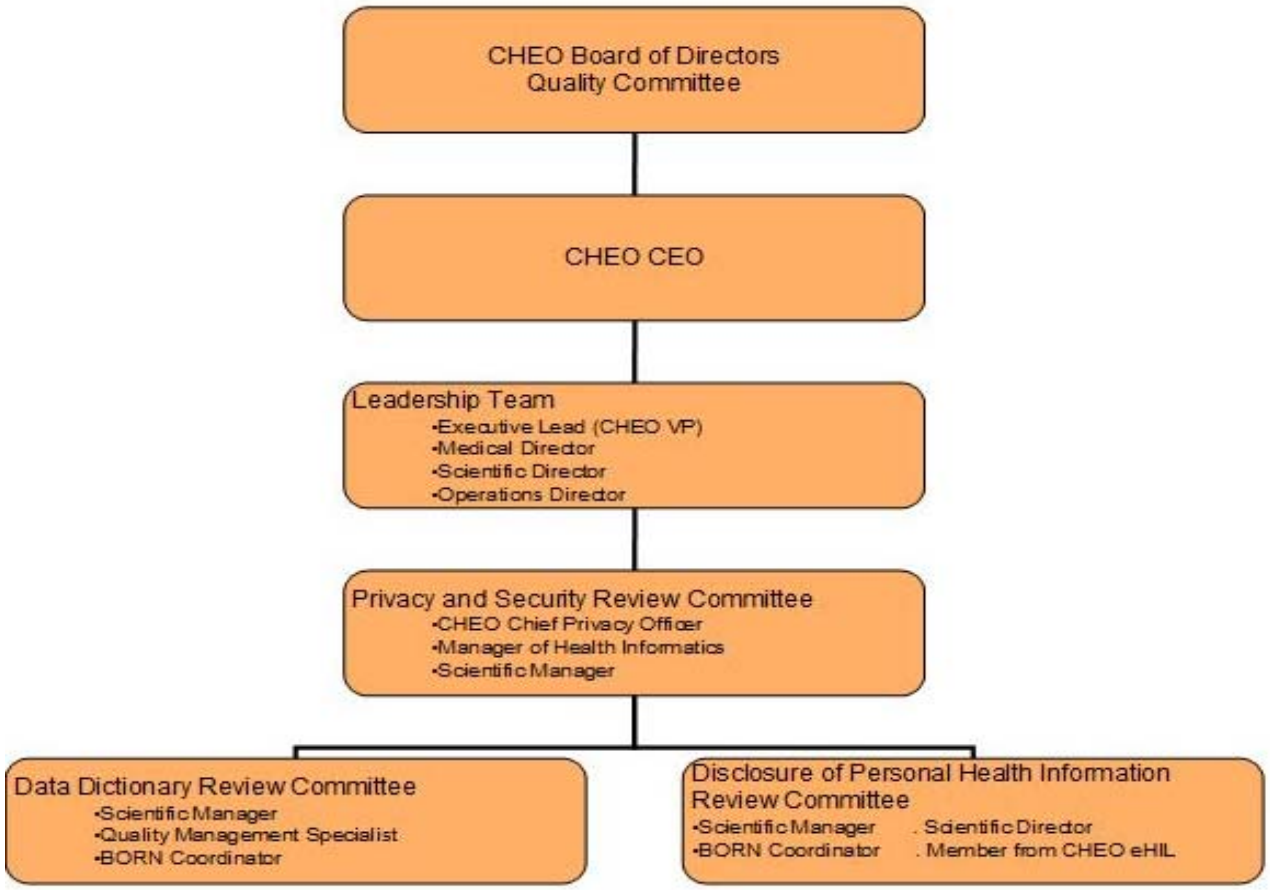
- Data collected within the Registry can be used for research, if:
  - the research plan is submitted and BORN has data to inform
  - there is REB approval
  - the researcher can meet the requirements for security of the data

BORN is a PHIPA Registry

- BORN (as OPSS) was granted registry Status under the *Personal Health Information Privacy Act* (PHIPA) in Nov 2009 – name formally changed to BORN in June 2010
- Registry status affords BORN authority to collect, use and disclose personal health information **without consent** "for the purpose of "**facilitating or improving the provision of health care**".

This special authority requires BORN to develop and adhere to ***rigorous*** privacy policies – and have them reviewed and approved by the Ontario Information and Privacy Commissioner

BORN Privacy Structure



Privacy Landscape – PHIPA 2004

Health Information Custodian (HICs)	Share information with implied consent within the circle of care	•Physicians •Nurses •Allied health
Other HICs	Require information for planning & facilitation but don't have direct patient access	•Public Health Units •MoHLTC •LHINs
Prescribed Entity	HICs are permitted to disclose PHI to an entity for the purposes related to planning and management of the healthcare system	•CCO •CIHI •ICES •POGO
Prescribed Registry	HICs are permitted to disclose PHI to a registry for the purpose of improving the provision of healthcare	•Cardiac Care Network •Canadian Stroke Registry •Joint Replacement Registry •BORN

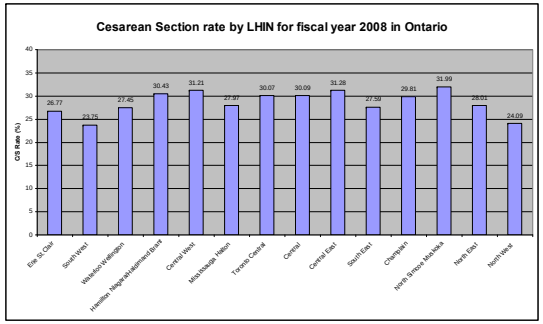
BORN – Data In

BORN Data In

- Current State
  - 5 datasets that support different clinical programs
  - No communication between these databases – any linking of mothers to babies is done by probabilistic matching
- Future State
  - One database that will allow a longitudinal view of pregnancy, birth, early newborn period OR an encounter view
  - Automatic linking and matching – ability to link interventions and tests to mothers; mothers to babies and siblings

BORN – Data Out

At BORN Central



Point of Care

Can retrieve and use:

- what they put in

-aggregated data for comparison to others

-have participation agreement with BORN that outlines best practice principles for protection of data

Can retrieve, use, and disclose:

-must aggregate and remove PHI to use or disclose (reporting, dashboards, guiding policy)

-only disclosure of PHI is to HICs for directly improving or facilitating care to ***an individual***

-can disclose PHI for research but best practice is to de-identify to best extent possible (lots of research on re-identification!)

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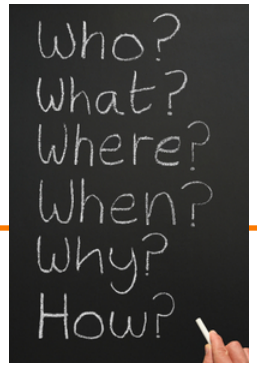
Disclosures (NOT for Research)

- PHIPA allows for disclosure of PHI for a number of reasons
  - Section 49(1)(a) – improve and facilitate care to individuals
    - Missed Screen
    - Gestational diabetes follow-up
  - Section 47
    - Data sharing with ICES
- Approval process followed prior to disclosure

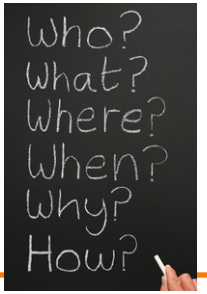
Data from BORN



Who is using BORN Data?

- Hospitals & care providers
- Gov't & policy developers (MOHLTC strategy, MCYS, HQO, ECHO, PCMCH, PHAC)
- Professional associations and special interest groups (SOGC, CPPC, AOM, maternal child regional programs)
- Health units
- Researchers
- BORN Central

BORN Data



What are they doing with BORN Data?

1. Aggregated Data

- Developing health or social policy or background for funding decisions
- Examining health services issues
- Performance measurement
- Trending over time
- Supporting data for proposals
- CQI projects
- To support public health programming
- Generating research questions
- Producing reports (issue specific, group specific)

Policy Decisions- ROP

The number of infants with a birth weight of less than 1500 g or gestational age of 30 weeks or less in Ontario, fiscal year 2008/09
By mother LHIN of residence

	Total number of birth		Infant with a birth weight <1500 g or GA ≤30		Missing data	
	N	%	N	%	N	%
Erie St.Clair	6660	4.9	124	1.9	11	0.2
South West	9912	7.3	132	1.3	9	0.1
Waterloo Wellington	7623	5.6	109	1.4	12	0.2
Hamilton Niagara/Haldimand Brant	12789	9.4	187	1.5	32	0.3
Central West	11331	8.3	214	1.9	30	0.3
Mississauga Halton	12417	9.1	172	1.4	10	0.1
Toronto Central	13178	9.7	184	1.4	47	0.4
Central	18181	13.4	255	1.4	33	0.2
Central East	16019	11.8	253	1.6	27	0.2
South East	4412	3.2	81	1.8	3	0.1
Champlain	12545	9.2	179	1.4	34	0.3
North Simcoe Muskoka	3724	2.7	45	1.2	7	0.2
North East	4795	3.5	55	1.2	4	0.1
North West	2440	1.8	24	1.0	7	0.3
Total	**136026**		**2014**	**1.5**	**266**	**0.2**

Health Services

Birthplace for babies needing Level 3 neonatal care in GTA LHINS, *Ontario, fiscal years 2008 - 2009*

Indicator	Fiscal Year	Total number of birth	Hospital Level							
			Level 1		Level 2		Level 2+		Level 3	
			N	%	N	%	N	%	N	%
Gestational age < 30 Wks	Fiscal year 2008	586	23	3.92	126	21.50	111	18.94	326	55.63
	Fiscal year 2009	562	23	4.09	124	22.06	66	11.74	349	62.10
	Total	1148	46	4.01	250	21.78	177	15.42	675	58.80
Gestational age < 32 Wks	Fiscal year 2008	882	27	3.06	219	24.83	167	18.93	469	53.17
	Fiscal year 2009	890	29	3.26	204	22.92	117	13.15	540	60.67
	Total	1772	56	3.16	423	23.87	284	16.03	1009	56.94
Birth weight < 1000g	Fiscal year 2008	375	11	2.93	83	22.13	71	18.93	210	56.00
	Fiscal year 2009	379	17	4.49	87	22.96	46	12.14	229	60.42
	Total	754	28	3.71	170	22.55	117	15.52	439	58.22

Note:

1. Data Source: BORN ONTARIO (Niday Perinatal Database).
2. Time Period: Fiscal years 2008 - 2009 .
3. This analysis includes hospital live births.
4. GTA region includes LHIN 5 - 9. LHIN is based on hospital site.

HEALTH SERVICES

Number of women living in Strathroy Hospital catchment area – where do they give birth?

Other Hospitals	2008-2009		2009-2010	
	n	%	n	%
Windsor Regional Hospital	69	3.3	89	4.3
Leamington District Memorial Hospital	44	2.1	56	2.7
Chatham-Kent Health Alliance - Public General Hospital	386	18.5	358	17.3
Bluewater Health - Sarnia General Site	331	15.9	334	16.1
South Bruce Grey Health Centre - Walkerton Site	<6		<6	
London Health Sciences Centre - Victoria Hospital	315	15.1	311	15.0
St. Joseph's Health Care London	629	30.2	612	30.0
Woodstock General Hospital	9	0.4	8	0.4
Huron Perth Healthcare Alliance - Clinton Site	37	1.8	37	1.8
Huron Perth Heathcare Alliance - Stratford Site	154	7.4	156	7.5
Alexandra Marine and General Hospital Goderich	16	0.8	16	0.8
Listowel Wingham Health Alliance - Listowel Site	<6		<6	
St. Thomas Elgin General Hospital	79	3.8	89	4.3
Brant Community Healthcare System - Brantford General Hospital	<6		0	
Niagara Health System - St. Catharine's General Hospital	<6		<6	
Norfolk General Hospital	<6		<6	
Grand River Hospital	<6		0	
Halton Healthcare Services - Oakville	<6		0	
William Osler Health Centre - Brampton Civic Hospital	<6		0	
Credit Valley Hospital	0		<6	
Royal Victoria Hospital	0		<6	
Mount Sinai Hospital	<6		0	
St. Michael's Hospital	<6		0	
Kingston General Hospital	<6		0	
The Ottawa Hospital - General Campus	<6		0	

*Proportions generated using a denominator of 2085 for 2008-2009 and 2074 for 2009-2010 and rounded up to 1 decimal place

Comparison with Others or CQI

Elective repeat c-s in low risk women not in labour prior to 39 weeks

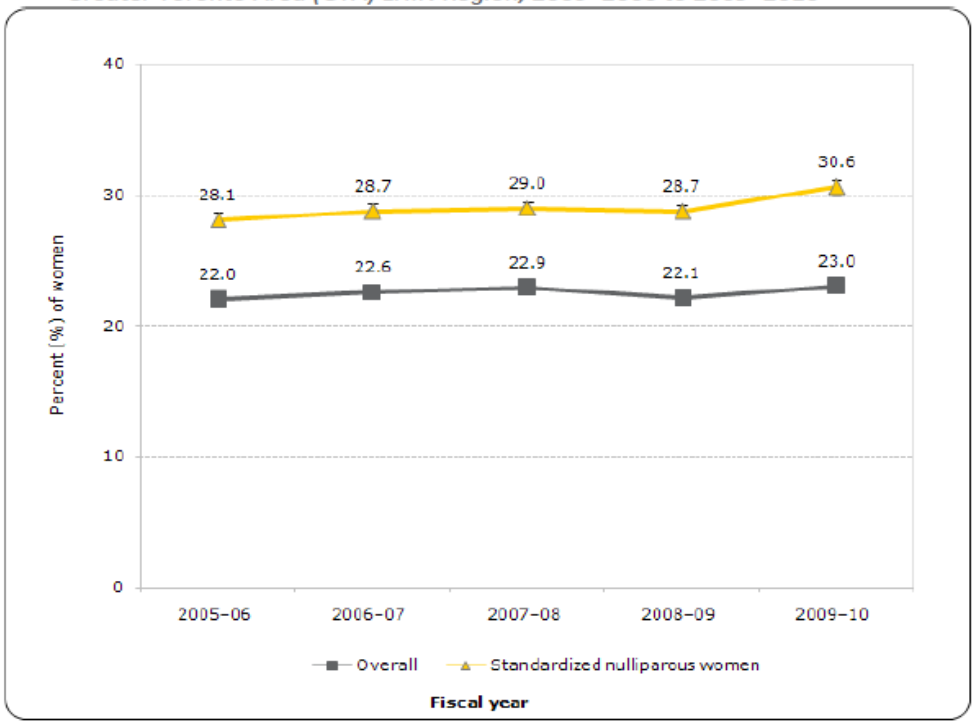
	Fiscal year 2009-10						
	Total #	37 weeks		38 weeks		39~40 weeks	
LHIN Name		#	%	#	%	#	%
Erie St. Clair	294	<6		118	40.14	171	58.16
South West	218	6	2.75	90	41.28	119	54.59
Waterloo Wellington	371	14	3.77	144	38.81	205	55.26
Hamilton Niagara Haldimand Brant	636	24	3.77	302	47.48	296	46.54
Central West	510	34	6.67	295	57.84	175	34.31
Mississauga Halton	770	19	2.47	409	53.12	333	43.25
Toronto Central	586	44	7.51	343	58.53	183	31.23
Central	1430	85	5.94	864	60.42	459	32.10
Central East	871	77	8.84	448	51.44	327	37.54
South East	248	9	3.63	131	52.82	100	40.32
Champlain	464	20	4.31	209	45.04	221	47.63
North Simcoe Muskoka	228	<6		100	43.86	123	53.95
North East	275	22	8.00	138	50.18	109	39.64
North West	76	<6		38	50.00	32	42.11
Total	6977	366	5.25	3629	52.01	2853	40.89

Note:

1. Low risk is defined as those women who do not have health problems prior to pregnancy, have no obstetrical complications during pregnancy and are carrying a single baby at 36~42 weeks gestational age (term).
2. Total #: the number of elective repeat cesarean sections done among low risk women who are not in labour and had any previous C-section by each LHIN.
3. LHIN based on birth hospital and not include midwifery group.

Trending Over Time

Figure 4.5 **Rate of labour induction, by fiscal year**
Greater Toronto Area (GTA) LHIN Region, 2005–2006 to 2009–2010



Data source *BORN Ontario (Niday Perinatal Database), 2005–2006 to 2009–2010*
Local Health Integration Network (LHIN) based on hospital of birth

Definition of indicator *The number of women who had labour induction, expressed as a percentage of the total number of women who had a live birth or stillbirth (in a given place and time). For this analysis, both the overall rate of labour induction and the rate among standardized nulliparous women are presented. **Standardized nulliparous women** were defined as nulliparous women (i.e., parity = 0) with a singleton live birth in cephalic presentation at term gestation (≥37 weeks).*

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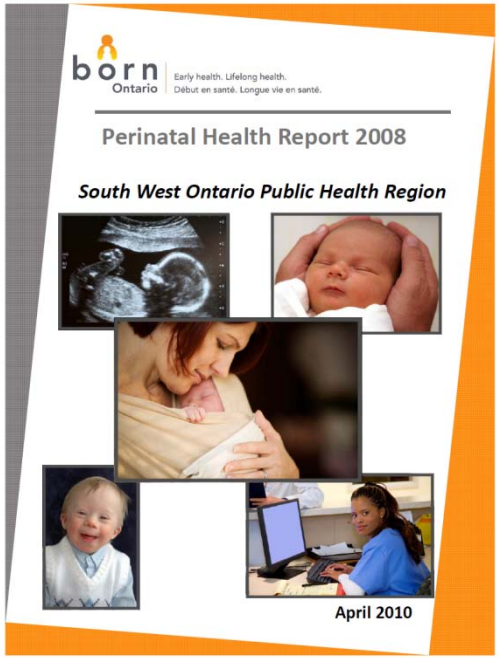
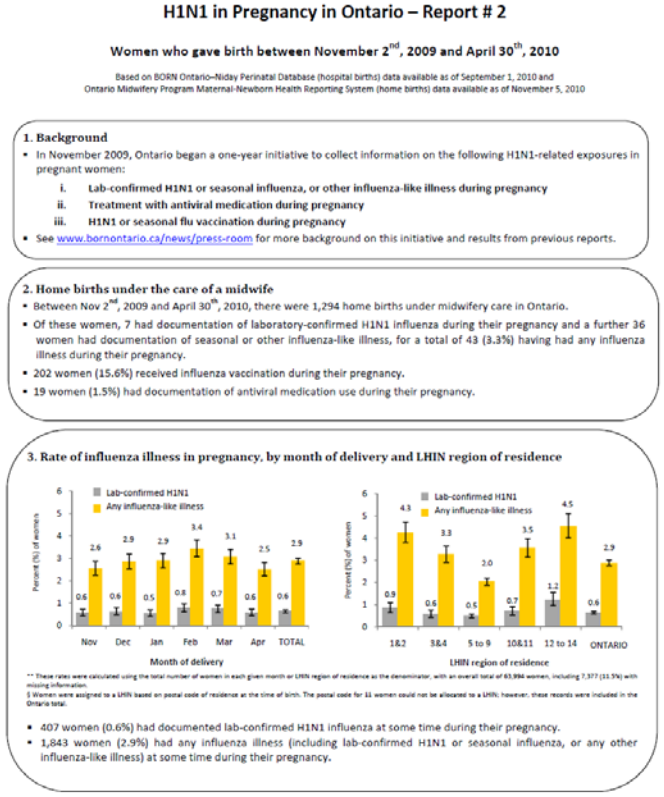
Data to support proposals – Hospitals Collecting BMI data

Table 1: The number and percentage of entering maternal BMI data by each hospitals for each fiscal year in the province

		Maternal BMI				
		Enter BMI		Not enter BMI		Total
Site name	Fiscal	N	%	N	%	N
Hospital 1	2007	0	0	863	100	863
	2008	0	0	995	100	995
	2009	0	0	1013	100	1013
Hospital 2	2007	397	30.35	911	69.65	1308
	2008	237	17.49	1118	82.51	1355
	2009	333	23.82	1065	76.18	1398
Hospital 3	2007	0	0	371	100	371
	2008	0	0	385	100	385
	2009	0	0	388	100	388
Hospital 4	2007	0	0	33	100	33
	2008	0	0	49	100	49
	2009	2	3.39	57	96.61	59
Hospital 5	2007	812	55.24	658	44.76	1470
	2008	1096	74.66	372	25.34	1468
	2009	1016	67.73	484	32.27	1500

Producing Reports





H1N1 in Pregnancy in Ontario – Report # 2

Women who gave birth between November 2nd, 2009 and April 30th, 2010

Based on BORN Ontario–Niday Perinatal Database (hospital births) data available as of September 1, 2010 and Ontario Midwifery Program Maternal-Newborn Health Reporting System (home births) data available as of November 5, 2010

1. Background

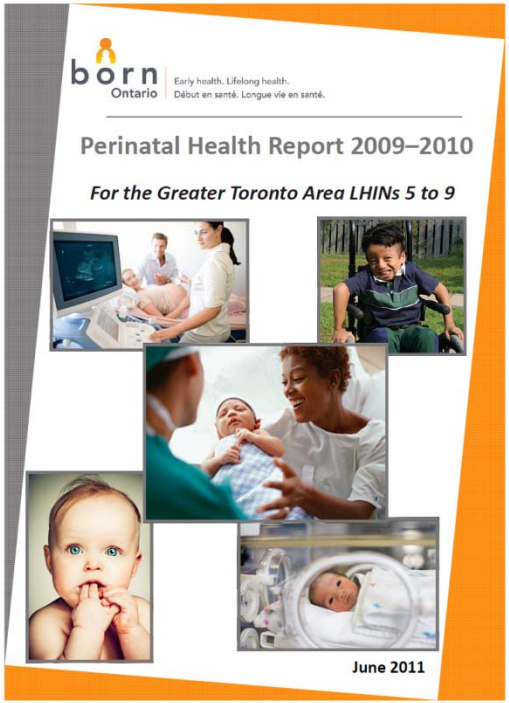
- In November 2009, Ontario began a one-year initiative to collect information on the following H1N1-related exposures in pregnant women:
  - i. **Lab-confirmed H1N1 or seasonal influenza, or other influenza-like illness during pregnancy**
  - ii. **Treatment with antiviral medication during pregnancy**
  - iii. **H1N1 or seasonal flu vaccination during pregnancy**
- See www.bornontario.ca/news/press-room for more background on this initiative and results from previous reports.

2. Home births under the care of a midwife

- Between Nov 2nd, 2009 and April 30th, 2010, there were 1,294 home births under midwifery care in Ontario.
- Of these women, 7 had documentation of laboratory-confirmed H1N1 influenza during their pregnancy and a further 36 women had documentation of seasonal or other influenza-like illness, for a total of 43 (3.3%) having had any influenza illness during their pregnancy.
- 202 women (15.6%) received influenza vaccination during their pregnancy.
- 19 women (1.5%) had documentation of antiviral medication use during their pregnancy.

3. Rate of influenza illness in pregnancy, by month of delivery and LHIN region of residence

- 407 women (0.6%) had documented lab-confirmed H1N1 influenza at some time during their pregnancy.
- 1,843 women (2.9%) had any influenza illness (including lab-confirmed H1N1 or seasonal influenza, or any other influenza-like illness) at some time during their pregnancy.



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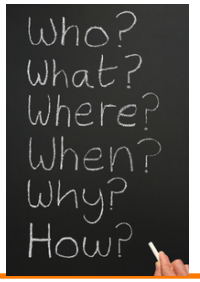
BORN Data Requests 09-10

- ~80 requests of varying complexity for aggregate data
- 6 request from researchers for record-level data sets.
  - Of these, a number of researchers requested that BORN analysts actually do their analysis and provide them with aggregated data tables
- Expecting increases with enhanced data

BORN Data

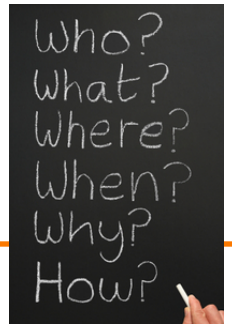


What are they doing with BORN Data?

2. Record-level data

- GIS mapping of adverse perinatal outcomes - hot spots?
- Relationship between air pollution levels and adverse perinatal outcomes
- Maternal and neonatal outcomes associated with BMI classification
- Secular trends in induction of labour in ON
- Adolescent pregnancy outcomes
- Subsequent birth outcomes for women with perineal tears
- Impact of diabetes and obesity on breastfeeding rates

Data from BORN



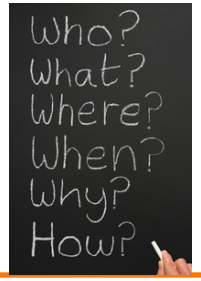
Where they access BORN Data?

- People who input data into the system can access 'their own data' in their site with approval of site lead. Have some ability to compare among sites/levels
- Some people/groups request aggregated data from BORN
- Some people/groups request data from other clinical programs (until they become BORN)
- Data request forms on website

Costs for BORN Data

- Cost-recovery model for:
  - Researchers: estimates prepared to go in with grant submissions
  - Agencies/depts: depends on the extent of the data request

Data from BORN

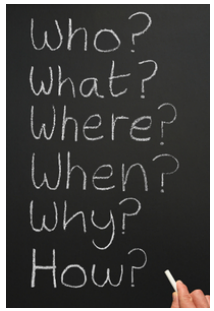


When to use aggregate vs record level data BORN Data?

- Depends on the question
- BORN will always try and aggregate PHI, even for those requesting record-level data (i.e. maternal age at time of birth in intervals instead of maternal DOB)

Data from BORN

- ***Why*** BORN data is undergoing changes in the new build
  - Up-to-date terminology and consistent terminology among stakeholders
  - New data elements that are critical to outcomes (BMI)
  - Data consolidation
  - Deleting data elements with poor quality
  - Trying to reduce keystrokes for users



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Data in BORN

- Still to come:
  - User acceptance testing
  - Education/training on new BORN data elements and data entry screens
  - Data element review/request change cycle
  - New data request forms that mirror new data dictionary

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Take Home Message

- All measurement and decisions hinge on timely, accurate documentation and data entry
- BORN Ontario and BORN regional coordinators will work with you to achieve this goal
- BORN system is an excellent tool for helping hospitals/labs/programs meet the requirements under “Excellent Care for All” Act – Maternal Child can be ahead of the curve in measuring and promoting quality care!

Questions?

www.BORNOntario.ca
science@BORNOntario.ca