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Developing a Multi-source Surveillance System for Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure (SSFASD/PAE)

Report prepared for the Public Health Agency of Canada

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ISBN: 978-1-77114-441-4

Acknowledgements

This work was funded by the Public Health Agency of Canada.

The authors gratefully acknowledge the SSFASD/PAE Steering Committee for their project guidance and expert review of this report as well as programs and clinics for providing data to the SSFASD/PAE:

- Alan Bocking, University of Toronto
- Colleen Burns, Lakeland Centre for FASD
- Albert Chudley, University of Manitoba
- Jocelynn Cook, Canada FASD Research Network
- Audrey McFarlane, Canada FASD Research Network
- Elspeth Ross, FASD Group of Ottawa
- Valerie Temple, Surrey Place
- Kathy Unsworth, Canada FASD Research Network

The authors would like to acknowledge the following institutions and individuals who contributed to this project within the select provinces and territories:

- Calypse Agborsangaya, Government of Alberta Community and Social Services, Government of Alberta
- Shawn Brule, Statistics Canada
- Colleen Burns, Lakeland Centre for FASD
- Andrew Calzavara, ICES
- Albert Chudley, University of Manitoba
- Keith Covey, Alberta Parent-Child Assistance Program
- Claire de Oliveira, Centre for Addiction and Mental Health (CAMH)
- Lindsay Fitzsimmons, Surrey Place
- Victoria Glinsky, CAMH
- Anca Ialomiteanu, CAMH
- Robert Jagodzinski, Alberta Parent-Child Assistance Program
- Olaf Kraus de Camargo and his study team at Hamilton Health Sciences
- Nancy Lanphear, Sunny Hill Health Centre for Children, University of British Columbia
- Yona Lunsky, CAMH
- Audrey MacFarlane, Canada FASD Research Network
- Robert Mann, CAMH
- Vanessa Norris, Northwest Alberta FASD Network
- Graham O'Hanlon, CAMH
- Sonal Prasad, Surrey Place
- Catherine Riddell, Better Outcomes Registry & Network Ontario, Children's Hospital of Eastern Ontario
- Valerie Temple, Surrey Place
- Stacey Thurman, Government of Northwest Territories
- Caitlin Toews, Asante Centre
- Anna Vrban-McRae, Alberta Health Services
- Cathy Yang, Better Outcomes Registry & Network Ontario, Children's Hospital of Eastern Ontario

The authors would like to thank all participating clinics in REDCap surveys who contributed data pertaining to clinic diagnoses and diagnostic capacity. The authors would also like to thank all participants in the CAMH Monitor survey in the 2018 and 2019 cycles.

The authors acknowledge that the aggregate diagnoses in this report represent individuals with strengths, talents, and purposes as well as families and communities.

Any errors or omissions in this report are the sole responsibility of the authors.

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Abbreviations

A	AADAC: Alberta Alcohol and Drug Abuse Commission
	AB: Alberta
	ACA: active case ascertainment
	ACE: adverse childhood experience
	ADD: attention deficit disorder
	ADHD: attention-deficit/hyperactivity disorder
	AOR: adjusted odds ratio
	APHP: Alberta Perinatal Health Program
	ARBD: alcohol-related birth defects
	ARND: alcohol-related neurodevelopmental disorder
	ASD: autism spectrum disorder
	ASI: Addiction Severity Index
	AUD: alcohol use disorder
B	BC: British Columbia
	BCPDR: British Columbia Perinatal Data Registry
	BIS: BORN Information System
	BORN: Better Outcomes Registry & Network
C	CACS: CIHI Comprehensive Ambulatory Care Classification System
	CAMH: Centre for Addiction and Mental Health
	CanFASD: The Canada Fetal Alcohol Spectrum Disorder Research Network
	CCHICS: Canadian Children's Health in Context Study
	CCHS: Canadian Community Health Survey
	CCRS: Continuing Care Reporting System
	CCSA: Canadian Centre on Substance Use and Addiction
	CDBC: Complex Developmental Behavioural Conditions
	CEWH: Centre of Excellence for Women's Health (BC)
	CHEO: Children's Hospital of Eastern Ontario
	CI: confidence interval
	CIHI: Canadian Institute for Health Information
	CMDB: Canadian Management Information System Database
	CMG: Case Mix Groups
	COPD: chronic obstructive pulmonary disease
	CPS: child protective services
	CSC: Correctional Service Canada
	CSHS: cost of a standard hospital stay
	CVSD: Canadian Vital Statistics Death Database

D	DAD: Discharge Abstract Database
	DSM-5: The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (2013)
	DSM-IV: The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (1994)
E	ED: emergency department
	EDI: Early Development Instrument
F	FAS: fetal alcohol syndrome
	FASD: fetal alcohol spectrum disorder
	FASD-CMC: Fetal Alcohol Spectrum Disorder Cross-Ministry Committee
	FNHA: First Nations Health Authority
	FNIGC: First Nations Information Governance Centre
	FSCD: Family Support for Children with Disabilities
	FT: first trimester
	FY: fiscal year
G	GOA: Government of Alberta
H	HCD: Home Care Database
	HHS: Hamilton Health Sciences
I	ICD-9: International Statistical Classification of Diseases and Related Health Problems, 9th revision
	ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th revision
	ID: intellectual disability
	IPPV: intermittent positive pressure ventilation
	IQR: interquartile range
	IUGR: intrauterine growth restriction
L	LOS: length of stay
	LRDG: Low-Risk Drinking Guidelines
	LSD: lysergic acid diethylamide
M	MB: Manitoba
	MCHP: Manitoba Centre for Health Policy
	MHA: mental health and addictions
	MOHLTC: Ministry of Health and Long-Term Care
	MRD: most responsible diagnosis
N	NACRS: National Ambulatory Care Reporting System
	NAS: neonatal abstinence syndrome
	ND: neurodevelopmental disorder
	NICU: neonatal intensive care unit
	NLSCY: National Longitudinal Survey of Children and Youth
	NRS: National Rehabilitation Reporting System
	NT: Northwest Territories

O	OCAP: ownership, control, access, and possession
	OCD: obsessive-compulsive disorder
	ODSP: Ontario Disability Support Program
	OHIP: Ontario Health Insurance Plan
	OMHRS: Ontario Mental Health Reporting System
	ON: Ontario
	OR: odds ratio
	ORG: Office of the Registrar General
	ORS: Online Reporting System
P	PAE: prenatal alcohol exposure
	PCAP: Parent-Child Assistance Program
	PCOS: polycystic ovarian syndrome
	PEI: Prince Edward Island
	pFAS: partial fetal alcohol syndrome
	PHAC: Public Health Agency of Canada
	PHU: Public Health Unit
	PS: passive surveillance
	P/T: province(s)/territories
	PTSD: post-traumatic stress disorder
R	RCMP: Royal Canadian Mounted Police
	RHA: Regional Health Authority
	RHS: Regional Health Survey
	RIW: Resource Intensity Weights
	RJCHC: Ron Joyce Children's Health Centre
	RPDB: Registered Persons Database
	RSA: Research Society on Alcoholism
S	SAC: Statistical Area Classification
	SD: standard deviation
	SDS: Same Day Surgery Database
	SES: socio-economic status
	SFF: sentinel facial feature(s)
	SPME GC-MS: solid-phase micro-extraction coupled with gas chromatography-mass spectrometry
	SSFASD/PAE: multi-source surveillance system for FASD and PAE
	ST: second trimester
	SUD: substance use disorder
T	TT: third trimester
Y	YT: Yukon

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1.0 Executive Summary

The Centre for Addiction and Mental Health (CAMH) received funding from the Public Health Agency of Canada (PHAC) to conduct a comprehensive multi-source surveillance project on fetal alcohol spectrum disorder (FASD) and prenatal alcohol exposure (PAE) in four selected, populous provinces — Alberta (AB), British Columbia (BC), Manitoba (MB), and Ontario (ON) — and two territories, Northwest Territories (NT) and Yukon (YT). This project was conducted in collaboration with two national organizations: the Canada FASD Research Network (CanFASD) and the Canadian Centre on Substance Use and Addiction (CCSA).

The availability and feasibility of various data sources including national and regional information on FASD and PAE were explored. From April 2017 to June 2020, active and passive surveillance were conducted and FASD/PAE data were collected from all available, identified sources, including published epidemiological studies, population health surveys, administrative health care databases, and neurodevelopmental clinics capable of providing FASD diagnoses. Data from available sources were aggregated, anonymized, and analyzed to generate estimates of PAE and FASD prevalence in the general population and special subpopulations. To contextualize FASD diagnostic prevalence and clinic capacity, a cross-jurisdictional survey of diagnostic clinics was also conducted. When possible, data were stratified according to the following individual variables: age, socio-economic status, living arrangement, and geographic location. Maternal characteristics as well as characteristics of individuals diagnosed with FASD (e.g., demographics, mental and physical health comorbidities, and health and social service use) were analyzed, presented, and contextualized.

In order to expand FASD/PAE data collection within existing congenital anomaly surveillance systems, program managers responsible for pertinent perinatal surveillance systems were engaged throughout the project. This enhanced the sustainability of the multi-source surveillance system for FASD and PAE (SSFASD/PAE) initiative and increased capacity for the collection of FASD/PAE data.

The estimated prevalence rates of FASD/PAE emphasize the need to monitor trends over time, which can aid in the design and delivery of targeted prevention, diagnostic, and treatment resources. The tools used to improve case identification across provinces and territories are shared to facilitate improved, centralized, and coordinated data collection of PAE and FASD across Canada. Recommendations for surveillance based on the findings are provided to guide health human resource planning and policy creation, as well as improvements to the accuracy, timeliness, accessibility, and comparability of FASD/PAE surveillance information in Canada.

This pilot study represents a significant milestone in initializing the development of a nationally centralized FASD/PAE surveillance system in Canada. Currently, the provinces and territories all maintain different types of demographic and diagnostic data, which is stored in different formats; a great deal of work is needed to implement and coordinate appropriate surveillance methods for FASD/PAE on a national level. The data collection mechanisms and methodologies utilized in this project, however, demonstrate that there is a substantial foundation of regional and cross-jurisdictional PAE and FASD data that exists in Canada from which this endeavour can grow.

2.0 Background

Alcohol use during pregnancy is associated with spontaneous abortion, stillbirth, prematurity, low birthweight, and higher levels of insecure attachment (Henriksen et al., 2004; Lebel, Roussotte, & Sowell, 2011; Nykjaer et al., 2014; O'Connor, Kogan, & Findlay, 2002). Alcohol use during pregnancy can also cause fetal alcohol spectrum disorder, which is a leading cause of disability in developed countries including Canada (Chudley et al., 2005; Government of Canada, 2007).

FASD is a serious, chronic, systemic disease characterized by central nervous system damage and physical deficits caused by prenatal alcohol exposure, which subsequently lead to a wide range of permanent and lifelong health consequences. Thus, FASD is a chronic disorder with persistent impacts across the lifespan (PHAC, 2003; Legge, Roberts, & Butler, 2001). The complexity and chronicity of FASD impacts both the individual and their family and requires assistance from a wide range of services, such as health, community, remedial education, and many others. FASD has a huge economic and societal impact as individuals with FASD may experience a range of adverse outcomes and may require lifelong support (Popova et al., 2012; Popova et al., 2013a; Popova et al., 2013b; Popova et al., 2014a.; Popova et al., 2014b). The annual costs associated with FASD in Canada have been estimated at $1.8 billion (Popova et al., 2016a).

The burdens of illness and economic cost associated with FASD are significant and heightened by the fact that individuals exposed to alcohol before birth are at greater risk of having comorbid conditions (Popova et al., 2016b) and premature mortality as compared to individuals without PAE. The most common disabilities of people with FASD are those most closely related to the underlying central nervous system damage caused by prenatal exposure to alcohol; these include problems with adaptive behaviour, attention, cognition, executive functioning, and memory. Later in life, individuals with FASD often experience other adverse health and social outcomes such as mental health problems, disrupted school experience (suspension, expulsion, and/or drop-out), criminal justice system involvement, substance use issues, difficulty obtaining and maintaining employment, and difficulty with independent living (Streissguth et al., 2004). If FASD is diagnosed early, interventions may be able to lessen its impact; however, individuals with FASD will continue to face difficulties associated with this chronic condition across their lifespans. Early detection of FASD is extremely important given that it can lead to early participation in developmental and medical interventions, which can in turn improve the quality of life for children with FASD and reduce the social and economic burdens placed on society.

Currently, there is no centralized and coordinated national monitoring system on the incidence and prevalence of FASD/PAE in Canada. Estimates of the incidence and prevalence of FASD and PAE are vital for planning and implementing early detection, diagnosis, and intervention, as well as for informing policy-makers and politicians, families, and health care and other professionals of the impact of these conditions. Moreover, accurate estimates are necessary to generate policy and funding support for the numerous services required by those affected by FASD, thereby alleviating the economic burden of FASD on Canada. To prevent and manage the impact of FASD, there is a need for accurate and timely data to design and implement prevention programs. Baseline measures for risk factors and FASD/PAE prevalence are required to monitor progress toward health goals and objectives. Therefore, to better guide planning, policy creation, and decision-making, improvements are needed in accuracy, timeliness, accessibility, and comparability of FASD/PAE surveillance information in Canada.

2.1 Objectives of the SSFASD/PAE

In order to inform the development of a centralized and coordinated national monitoring system on the incidence and prevalence of FASD/PAE in Canada, the Public Health Agency of Canada (PHAC) provided funding to the Centre for Addiction and Mental Health (CAMH) to initiate cross-jurisdictional surveillance of FASD/PAE. The overall aim of this pilot project was to initiate and inform the development of a multi-source surveillance system for FASD and PAE, collecting data across four selected, populous provinces — Alberta, British Columbia, Manitoba, and Ontario — and two territories, the Northwest Territories and the Yukon. The specific objectives of the SSFASD/PAE were to:

1. strengthen the capacities of provinces and territories (P/Ts) to identify cases of FASD through ongoing capacity building and the development of tools, resources, and protocols that support the use of common FASD/PAE surveillance procedures across participating P/Ts;
2. compile data related to FASD and alcohol use during pregnancy from existing surveillance systems, epidemiological studies, and passive review of source records and novel sources; and
3. estimate the frequency of FASD cases and alcohol use during pregnancy.

3.0 Methodology

3.1 SSFASD/PAE Project Implementation

This study was approved by the CAMH Research Ethics Board.

STEERING COMMITTEE

The Steering Committee informed the project through expert review of data collection tools and methods employed to increase the use of existing data sources, and to develop new data sources, for FASD/PAE surveillance. The Steering Committee also approved surveillance case definitions for newborns, children, youth, and adults using recent advances in diagnosis, as well as knowledge mobilization activities. (See Appendix A for Steering Committee membership list.)

NATIONAL-LEVEL PARTNERS

Partnerships were established with national organizations CanFASD Research Network and the Canadian Centre on Substance Use and Addiction, capable of supporting the development of the SSFASD/PAE and disseminating findings both nationally and internationally.

REGIONAL RESEARCH PARTNERS

The selected P/Ts were chosen due to their expressed support for improving FASD/PAE surveillance and to allow the SSFASD/PAE to build upon numerous FASD and PAE data collection initiatives undertaken in these regions. The identification of these initiatives and the selection of co-investigators and research supervisors were informed by an environmental scan of existing Canadian systems and databases that capture data on FASD and PAE (Pulver & Popova, 2014).

Partnerships were established between CAMH and research partners in:

- Alberta (Lakeland Centre for FASD; research supervisor Audrey McFarlane);
- British Columbia (Vanessa Norris, research assistant);
- Manitoba (Manitoba FASD Centre, University of Manitoba Children's Hospital of Winnipeg; Dr. Ana Hanlon-Dearman);
- Northwest Territories (Government of the Northwest Territories; Stanton Territorial Hospital representatives);
- Ontario (Surrey Place; research supervisor Dr. Valerie Temple); and
- Yukon (Department of Health and Social Services).

3.2 Major Research Project Activities

1. Establish surveillance case definitions for newborns, children, youth, and adults. In order to gain consensus on common language to define and code FASD, the Steering Committee approved the use of the following diagnostic guidelines for case classifications:
   - 2016 diagnostic guideline for FASD across the lifespan, including the at-risk category (Cook et al., 2016);
   - 2005 FASD diagnostic guideline (Chudley et al., 2005);
   - relevant International Statistical Classification of Diseases and Related Health Problems 9th revision code (760.71, alcohol affecting fetus or newborn via placenta or breast milk) and 10th revision codes (O35.4, maternal care for [suspected] damage to fetus from alcohol; P04.3, fetus and newborn affected by maternal use of alcohol; Q86.0, fetal alcohol syndrome [dysmorphic]);
   - ICD-9 code 315.8 (other specified delays in development); and
   - FASD 4-Digit Diagnostic Code (Astley, 2004).
2. Collect data on the incidence and prevalence of FASD/PAE across the selected P/Ts and, when possible, other jurisdictions in Canada.
3. Measure the utilization of health care services and comorbidities among individuals with FASD.

3.3 Data Collection

The method used was a combination of passive review of source records and active case-finding procedures from existing epidemiological studies. Throughout years one and two of the project (2017–2018 and 2018–2019), the status of surveillance systems, registries, and academic publications with FASD and PAE data was identified to inform public health outreach activities. Perinatal health surveillance systems and other data sources were engaged with to determine their capacity and state of readiness to contribute data. Multi-sectoral partnerships across P/Ts were leveraged to collect data from FASD diagnostic and service programs, ceasing on the data submission cut-off date (May 31, 2020). This public health outreach resulted in data contributions to the SSFASD/PAE as well as in increased use of data collection tools by research partners.

DEFINITIONS USED

- **Passive surveillance (PS) systems:** existing record collections (e.g., medical records, administrative health data) are analyzed in select jurisdictions.
- **Congenital anomaly registries:** existing records are reviewed within a specific jurisdiction to regularly report on data pertaining to provincial/territorial cases of FASD.
- **Medical charts:** these contain record-level data pertaining to FASD diagnoses, comorbid medical conditions, and/or prenatal exposures.
- **Active case ascertainment (ACA) studies:** the most intensive level of case identification, ACA studies use a multi-disciplinary diagnostic team to actively seek, find, and recruit individuals in a population to screen for FASD in order to determine the prevalence within the study population.

- **FASD prevalence:** this indicates the number of total FASD diagnoses among all individuals within a specific source population at one specified time point.
- **FASD incidence:** this indicates the number of new FASD diagnoses in a specified time period within a specific source population.

DATA COLLECTION MECHANISMS

Data collection mechanisms, instruments, and protocols to guide implementation were developed in partnership with the SSFASD/PAE Steering Committee. Surveillance case definitions, data collection mechanisms, and tools to support jurisdictional-level data capture were implemented. These activities were foundational to establish the SSFASD/PAE and to derive the best possible estimates of the prevalence and incidence of FASD and PAE in the participating P/Ts in the years 2015–2020.

Existing Canadian surveillance systems and other data sources capable of capturing data on FASD and PAE were identified. These knowledge products informed data request submissions to national- and P/T-level governmental departments, perinatal programs, congenital anomaly surveillance systems/registries, and clinics with FASD diagnostic services to identify diagnoses of FASD and confirmed cases of PAE.

The data contained in the SSFASD/PAE were collected through primary and retrospective approaches used to study the prevalence, characteristics, and patterns of occurrence of PAE and FASD: surveillance and record review systems, clinic-based studies, and active case ascertainment studies. Population-level data were also collected to monitor FASD/PAE in different risk groups. In order to generate the best possible estimate of the number of FASD diagnoses and confirmed PAE in select P/Ts, ongoing monitoring of prospective data sources was completed by research analysts and research assistants proficient in FASD/PAE detection. The surveillance case definitions and the data collection mechanisms and tools supported jurisdictional-level data capture.

This monitoring identified gaps in clinic case review systems as well as a lack of data capture and analysis from existing surveillance systems. In order to address these gaps, active surveillance was conducted by the CAMH project team and regional research assistants to identify documented diagnoses of FASD from 2015 to 2020 across participating P/Ts.

EPIDEMIOLOGICAL STUDIES

A literature search with no restriction on publication year was conducted to identify published studies that reported prevalence of FASD/PAE in the general Canadian population and priority populations in select P/Ts.

Administrative Health and Clinical Patient Data

Once eligible data sources were identified, data requests were initialized in order to obtain relevant data from administrative health databases and main diagnostic centres for FASD in participating P/Ts. This involved an iterative process of review of appropriate data elements, creation of specific data request proposals, and initialization and formal processing of data-sharing agreements and ethics applications.

CLINIC-BASED SURVEYS

New mechanisms were required to conduct case reviews across all clinics capable of providing FASD diagnoses in participating P/Ts. Clinic surveys were co-developed as a data collection tool for FASD diagnoses, socio-demographic and medical information about individuals diagnosed with FASD, and FASD diagnostic capacity across the select P/Ts. Each survey collected data elements identified by the SSFASD/PAE Steering Committee in order to estimate the number of individuals diagnosed with FASD per year and the prevalence of PAE as well as to gauge FASD diagnostic capacity, identify risk factors, and promote the use of common standards and methods for FASD/PAE surveillance. Client information such as FASD diagnosis, age, socio-economic status, comorbidities, criminal justice system and child welfare system involvement, and geographic location (urban/rural) was not obtained through the second clinic survey due to lack of participation.

The diagnostic clinic surveys were disseminated to all clinics (including those that contribute data to the Universal Dataform project) in order to estimate the diagnostic capacity of clinics capable of providing FASD diagnoses. These surveys are a cross-jurisdictional data collection instrument that obtained estimates of diagnostic capacity (i.e., wait times, number assessed, number diagnosed) of pertinent clinics as well as individuals' diagnostic information recorded by clinics not currently participating in Dataform. These data collection instruments were tailored to clinics capable of providing FASD diagnoses, and were tested, refined, and disseminated to all pertinent clinics.

INCLUSION OF FASD/PAE INDICATORS TO EXISTING SURVEILLANCE SYSTEMS

In order to expand FASD/PAE data collection within existing congenital anomaly surveillance systems, surveillance program managers responsible for pertinent perinatal surveillance systems (see Appendix C) were engaged. This resulted in the inclusion of PAE-specific questions to the CAMH Monitor survey; subsequently, new PAE data were generated.

3.4 Surveillance System Proof of Concept

The multi-source surveillance proof of concept has been demonstrated through successful research partnerships, the use of the SSFASD/PAE surveillance case definitions, and the implementation of data collection mechanisms that enable FASD and PAE data capture across sites. This project has demonstrated that outreach to multi-sectoral partners enables a more accurate and comprehensive surveillance of FASD and PAE.

Partnerships with researchers, clinicians, treatment providers, and other experts in FASD, perinatal health, and epidemiology were leveraged to enhance population-based surveillance of FASD and PAE. Through partnership and capacity-building, CAMH and regional research assistants conducted surveillance across select P/Ts that resulted in ongoing data contributions to the SSFASD/PAE, increased use of data collection tools by research partners, and opportunities for co-developed knowledge products and dissemination strategies.

Early implementation of the SSFASD/PAE demonstrated the feasibility of collaborating with existing regional and national surveillance networks to collect standardized FASD/PAE-specific data. The use of agreed-upon methods for collecting and compiling data on select FASD/PAE-specific indicators improved the capacity of participating P/Ts to monitor FASD and PAE. It also established a foundation for a surveillance system that enhances Canada's capacity to develop prevalence estimates of FASD.

3.5 Data Validity

The number of cases in different population subgroups (e.g., adjusted age- and sex-specific prevalence rates) is likely an underestimate; however, complete data are not mandatory for estimating incidence rates, standardized incidence rates, or incidence rate ratios. The Steering Committee approved a data validation plan that required data from multiple sources to be analyzed separately in order to provide FASD/PAE estimates from different sources and for different populations. In order to avoid double counts, research analysts de-duplicated data to ensure that one diagnosis represents one unique individual, where possible. Preparation of data collected through REDCap surveys involved clinic staff ensuring the validity and completeness of the data submitted. An additional validation step was performed during the survey completion process, which involved automatic checks built into the online submission form. The final data validation step was a review by the CAMH senior scientist and research analysts.

Rather than aiming to register all cases, the SSFASD/PAE collects data from multiple sources to avoid small numbers of cases being captured by individual sources. Record-level data obtained from data requests were exported into statistical software (STATA, R, and SAS) in adherence to stipulations finalized in data-sharing agreements and ethics applications. Research assistants resolved data issues and clarified gaps in datasets. Data were stratified according to patient variables (e.g., diagnosis, age group, socio-economic status) and summarized to identify distribution of prevalence and associated socio-demographic factors.

3.6 Data Analysis and Interpretation

Active and passive surveillance of population-based data were conducted between April 2017 and June 2020. FASD diagnoses and cases of PAE across six P/Ts and from cross-jurisdictional data sources were captured using surveillance case definitions. Data were aggregated, anonymized, and analyzed. Data were stratified according to the following individual variables where possible: age, socio-economic status (SES), living arrangement, and geographic location.

Data amalgamation was conducted to aggregate obtained estimates from comparable sources of data on FASD/PAE: epidemiological studies, administrative health data, survey data, and clinic data. The diagnoses captured through the Universal Dataform Project and surveys administered to clinics capable of providing FASD diagnoses were aggregated with other applicable clinic data. These data were used to estimate the diagnostic prevalence of FASD across the participating P/Ts. Data from multiple sources were analyzed separately and used to estimate a range of incidence and prevalence rates. The numbers of cases in different subpopulations were analyzed to produce adjusted age- and sex-specific prevalence rates. Jurisdictional profiles present FASD surveillance information that advances understanding of P/T maternal and child health and that may inform strategies for FASD screening, diagnosis, prevention, and intervention.

These reported rates did not adjust for sources of error such as non-response and under-reporting. The use of predictive models would likely have obtained stronger prevalence estimates. For example, Land et al. (2012) reported higher estimates of prenatal cigarette smoking prevalence by using a predictive model that integrated socio-demographic correlates identified through predictors of smoking status under-reporting.

4.0 Results — Cross-jurisdictional Profile

Existing FASD/PAE surveillance infrastructure (e.g., longitudinal statistical surveys, epidemiological studies, administrative health databases) across participating P/Ts is the foundation for the SSFASD/PAE. All participating P/Ts collect FASD/PAE data on a regional level as well as through cross-jurisdictional statistical surveys (e.g., Canadian Community Health Survey). Data were collected from six P/Ts as well as from cross-jurisdictional data sources to show FASD/PAE data from 2015 to 2020. The data collected in project surveillance activities are summarized below.

4.1 Existing Surveillance — PAE

4.1.1 CANADIAN COMMUNITY HEALTH SURVEY

Introduction

The Canadian Community Health Survey (CCHS) collects information related to health status, health care utilization, and health determinants from a generalizable sample of the Canadian population. Data are collected through interviews with approximately 65,000 people aged 12 and older who live in households in all P/Ts (Statistics Canada, 2020a). Specific objectives of the study were to analyze secondary data from the most recent CCHS cycles (2015–2016 and 2017–2018) and to estimate the cross-Canada prevalence and patterns of alcohol use a) during pregnancy and b) while breastfeeding.

Methods

Sampling Frame

The CCHS collects information on cross-jurisdictional alcohol use during pregnancy since 2000–2001. From 2017–2018, 5,595 women and girls aged 15 to 55 who gave birth in the last five years (2012–2018) and 4,850 who reported breastfeeding their last baby were weighted to represent 1,672,300 and 1,457,500 Canadian women and girls; (retrospective breastfeeding and current breastfeeding) were examined. The following age categories were created: 15 to 24, 25 to 34, and 35 to 55.

Please note, as a result of the 2015 redesign, CCHS has a new collection strategy and a new sample design and it underwent major content revisions. (See Thomas & Tremblay, 2020, for further details.) Caution must therefore be taken when comparing data from previous cycles to data released from the 2015 cycle and onward.

Individuals excluded from the CCHS, and therefore the sample, include those living in institutions, children aged 15 to 17 in foster care, women experiencing homelessness, full-time members of the Canadian Armed Forces, those who live on reserve, and those who live in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. Combined, these individuals comprise an estimated 3% of the Canadian population. While the CCHS is nationally representative, language barriers or literacy levels may be a barrier to participation in the survey for some individuals.

Sample

Three nationally representative, non-independent subsamples of women and girls aged 15 to 55 who had a) given birth to at least one child in the past five years and/or b) breastfed their last baby from the past five years were used in the analysis:

1. women and girls who had given birth in the past five years at the time of completing the 2017–2018 survey and who responded to questions about alcohol use during the most recent pregnancy, which took place between 2012 and 2018;
2. women and girls who had breastfed or tried to breastfeed their last baby within the last five years and responded to questions about alcohol use while breastfeeding; and
3. women and girls who were currently pregnant while completing the survey and responded to questions regarding cigarette smoking and use of alcohol during the week preceding the interview.

Data Analysis

Self-reported alcohol use and cigarette smoking during pregnancy and while breastfeeding was examined by age, rurality, marital status, education, immigrant status, living/family arrangement, working status, total household income, household food security, perceived mental health, and perceived life satisfaction. The measures used to ascertain outcome and predictor variables are detailed in Appendix F.

Survey sampling weights were used in the subsamples so that results are representative of women from the communities included in the sample. SAS 9.3 was used with macros named BootVar to produce weighted estimates and calculate variance, using survey-defined bootstrap weights.

Results

Alcohol Use after Pregnancy Recognition, Canada, 2015–2016

Among women who were pregnant in 2015–2016 while completing the CCHS, 6.3% (n = 17,800E) reported past-week alcohol use, with an average of four drinks per week. Table 1 shows that these women reported being very satisfied with life less often than women who were pregnant and did not use alcohol during the last week (42.2%E vs 54.2%). They were also more likely to report most days as quite a bit or extremely stressful (28.8%E) as compared to women who did not use alcohol during the last week (18.5%).

The majority of women who were pregnant (72.6%) at the time of the survey and reported past-week alcohol use perceived their mental health as excellent or very good, which is similar to the rate reported by women who were pregnant and did not report alcohol use (72.1%) and higher than women who were not pregnant (65.8%).

Over one-third (35.5%E) of women who were pregnant and reported past-week alcohol use perceived their health to be excellent or very good, which is similar to the percentage of women who were pregnant and did not report alcohol use during the past week (37%) and higher than women who were not pregnant (26.8%). Among women who were pregnant and reported past-week alcohol use, 18.9%E perceived their health to be good, compared to 23.3% of women who were pregnant and did not report past-week alcohol use.(18.9%E), compared to 23.3% of women who were pregnant and did not report past-week alcohol use.

Alcohol use after Pregnancy Recognition in BC, ON and PEI (2017-2018)

During the 2017–2018 cycle, 9.5%E of women who were pregnant in Prince Edward Island (PEI), ON, and BC reported past-week alcohol use. Please note: data from PEI, ON, and BC collected during the 2017–2018 cycle include only past-week alcohol use.

Table 1. Wellness indicators during pregnancy, 2015–2016 (n = 114,800)*

Wellness indicator	Alcohol use past week		No alcohol use past week		Not pregnant	
	n (%)	Lower CI, upper CI	n (%)	Lower CI, upper CI	n (%)	Lower CI, upper CI
PERCEIVED LIFE STRESS						
Most days are not at all or not very stressful	F (40.7E)	20.3, 61	94,400 (35.6)	30.3, 40.9	2,547,200 (27.4)	26.6, 28.2
Most days are a bit stressful	5,400E (30.5E)	14.9, 46.2	122,000 (46)	40.8, 51.2	4,192,000 (45.1)	44.2, 46.1
Most days are quite a bit or extremely stressful	5,100E (28.8E)	13.8, 43.8	49,000 (18.5)	14.5, 22.5	2,547,700 (27.4)	26.6, 28.2
PERCEIVED MENTAL HEALTH						
Excellent or very good	12,900E (72.6E)	58.1, 87.1	191,800 (72.1)	67.4, 76.8	6,126,700 (65.8)	65, 66.7
Good	3,400E (18.9E)	6.4, 31.4	62,000 (23.3)	18.8, 27.8	2,443,000 (26.3)	25.4, 27.1
Fair or poor	F	F	123,000E (4.6E)	2.6, 6.6	735,900 (7.9)	7.4, 8.4
PERCEIVED HEALTH						
Excellent or very good	F (35.5E)	16.3, 54.7	98,600 (37)	31.8, 42.3	2,494,500 (26.8)	26, 27.7
Good	3,400E (18.9E)	6.4, 31.4	62,000 (23.3)	18.8, 27.8	2,443,000 (26.3)	25.4, 27.1
Fair or poor						
PERCEIVED HEALTH — ALL ANSWER CATEGORIES						
Very satisfied	7,500E (42.2E)	23.9, 60.4	143,200 (54.2)	49, 59.4	3,829,200 (41.3)	40.3, 42.2
Satisfied	9,400E (52.9E)	34.6, 71.2	108,200 (41)	35.9, 46.1	4,887,900 (52.7)	51.7, 53.6
DEPRESSION SCALE (EXCL. AB, BC, NT, QC, YT)						
No depression	F (62E)	38.4, 85.6	25,100E (20.6E)	14.4, 26.8	1,465,500 (31.2)	30, 32.5

Source: CCHS
Abbreviation: CI, confidence interval;
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%; F represents data too unreliable to be published
* Sample size is estimated using population weights

During the 2017–2018 cycle, 9.5%E of women who were pregnant in Prince Edward Island (PEI), ON, and BC reported past-week alcohol use. Please note: data from PEI, ON, and BC collected during the 2017–2018 cycle include only past-week alcohol use.

Alcohol Use before and during Last Pregnancy, Canada, 2012–2018

Half of Canadian women (51.0%) who gave birth to their last child between 2012 and 2018 did not drink alcohol three months before that pregnancy. The frequency of use among women who did drink alcohol during this time (n = 755,500) is identified in Table 2. Following pregnancy recognition, 5.1% (n = 72,500) of women reported alcohol use, 65% (n = 47,000) of whom reported alcohol use during the last trimester.

Table 2. Alcohol use before last pregnancy (N = 755,500), and alcohol use (N = 72,200E) and concurrent cigarette smoking (N = 3,800) during last pregnancy, 2012–2018

Frequency of alcohol use	n* (%)	Also smoked cigarettes, n* (%)
FREQUENCY OF ALCOHOL USE 3 MONTHS BEFORE LAST PREGNANCY	**755,500 (49)**	**N/A**
Less than once per month	171,500 (22.7)	N/A
Once per month	112,000 (14.8)	N/A
2 to 3 times per month	145,500 (19.2)	N/A
Once a week	157,500 (20.8)	N/A
2 to 3 times per week	133,000 (17.6)	N/A
4 to 6 times per week	15,000 (1.9)	N/A
Every day	20,500 (2.7)	N/A
Total	**755,500 (99.7)**	**N/A**
FREQUENCY OF ALCOHOL USE DURING PREGNANCY	**72,200E (5.1)**	3,800 (2.7E)
Less than once per month	45,900 (5.5E)	4,000 (2.8E)
Once per month or more	26,300 (4.3E)	7,800 (5.5E)
FREQUENCY OF ALCOHOL DURING LAST TRIMESTER[A]	**47,000 (65)**	**N/A**
Less than once per month	26,000 (55.3)	N/A
Once per month	7,500 (16)	N/A
2 to 3 times per month	9,000 (19)	N/A
Once a week	4,500 (9.6)	N/A
Total	**47,000 (99.9)**	**N/A**

Source: CCHS
N/A = Not available
* Sample size is estimated using population weights
[a] Among women who reported alcohol use following pregnancy recognition (N = 72,200)
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%

Alcohol Use before Pregnancy, Canada, 2016–2018

Among women who were pregnant while completing the 2017–2018 survey, the majority (71.9%) drank alcohol within the year preceding the survey. Over a quarter (26.2%) drank two to three times per month or once a week, 31.1% drank less than once per month or once a month, and 14.6% drank two to three times per week or more. Almost one-third of women who were pregnant during this CCHS cycle (28.1%) had four or more alcoholic drinks on one occasion in the past 12 months, usually once per month (30.0%) or less (29.9%). Less frequently, women reported two to three times per month or once a week (8.1%E), or two to three times per week or more (3.9%E). A higher proportion of these women had smoked cigarettes (75.4%) than cannabis (24.1%) in the year before becoming pregnant, as shown in Table 3.

Table 3. Past-year alcohol use, cigarette smoking, and cannabis use by pregnant participants in the 2017–2018 CCHS cycle (N = 755,500)

Frequency of alcoholic drink consumption during past 12 months (any amount)	Alcohol use, %	Smoked any cigarettes, %
Never in past 12 months (incl. never in lifetime)	28.1	24.6E
Less than once a month / once a month	31.1	41.0E
2 to 3 times a month / once a week	26.2	12.8E
2 to 3 times a week or more	14.6	N/A
Frequency of 4+ alcoholic drinks on one occasion (binge drinking)	**Alcohol use, %**	**Smoked any cigarettes, %**
Never in past 12 months (incl. never in lifetime)	28.1	24.6E
Less than once a month	29.9	41.0E
Once a month	30.0	36.1E
2 to 3 times a month / once a week	8.1E	12.8E
2 to 3 times a week or more	3.9E	N/A
Used cannabis in the past 12 months	**24.1**	**N/A**

Source: CCHS
Abbreviation: N/A, not applicable
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%

The majority of women who reported alcohol use following recognition of their last pregnancy (n = 63,900E) were older (aged 30 and over), had a household income of over $80,000 or more (n = 48,400, 66.9%), a post-secondary education (n = 62,500, 86%), were born in Canada (n = 56,700, 78.6%), and lived in food-secure households (n = 66,000). Most women who reported drinking alcohol during the third trimester of their pregnancies were 30 to 34 years old (n = 28,100E, 81%), had a post-secondary education (n = 42,700, 90%), lived with a household income of over $80,000 or more (n = 33,300E, 70%), and lived in food-secure households (n = 44,800, 94%). For further details, see Appendix G.

Similarly, most of these women who reported drinking alcohol during their last trimester were 30 to 34 years old (n = 28,100E, 81%), had a post-secondary education (n = 42,700, 90%), lived with a household income of over $80,000 or more (33,300E, 70%), and lived in food-secure households (n = 44,800, 94%). See Appendix H for further information.

Alcohol Use while Breastfeeding, Canada, 2015–2016

During the 2015–2016 CCHS cycle, 31.8% (n = 114,100) of women reported breastfeeding and alcohol use in the past week, with an average of less than one drink per day.

Alcohol Use while Breastfeeding in BC, ON and PEI (2012–2018)

Among women who reported breastfeeding their last baby during the 2017–2018 CCHS cycle, 27% (n = 368,500) also reported alcohol use while breastfeeding. The majority reported drinking alcohol less than once per month (41.9%), followed by once per month (17.5%), two to three times per month (11.7%), once a week (17.8%), two to three times per week (8.5%), four to six times per week (1.2%), and daily (1.4%) (see Table 4).

Table 4. Alcohol use while breastfeeding last baby among women in British Columbia, Ontario, and Prince Edward Island, 2017–2018 (N = 368,500)

Frequency of alcohol use while breastfeeding (last child born)	n* (%)
Less than once per month	154,500 (41.9)
Once per month	64,500 (17.5)
2 to 3 times per month	43,000 (11.7)
Once a week	65,500 (17.8)
2 to 3 times per week	31,500 (8.5)
4 to 6 times per week	4,500 (1.2)
Every day	5,000 (1.4)

Source: CCHS
* Sample size is estimated using population weights

The proportions of alcohol use while breastfeeding by socio-demographic characteristics are displayed in Appendix I. Almost half of women who reported alcohol use while breastfeeding were 30 to 34 years old (46.3%, n = 171,400) and the majority (84%) had a post-secondary education and lived with a household income of $80,000 or more.

Conclusions

The baseline rate (49%) of alcohol consumption prior to pregnancy recognition demonstrates the need for preconception prevention initiatives. The range of alcohol use occurring in 5.1% to 9.5%E of pregnancies identifies health promotion, preconception prevention initiatives, and substance use disorder treatment for pregnant women and their partners as public health priorities. Further, the high rate of women reporting alcohol use while breastfeeding their last baby (27%-31.8%) demonstrates the need for public education efforts to include the impacts on newborns of alcohol transmitted via breast milk.

4.1.2 FIRST NATIONS INFORMATION GOVERNANCE CENTRE'S REGIONAL HEALTH SURVEY

The First Nations Information Governance Centre (FNIGC), a non-profit organization with a mandate from the Assembly of First Nations Chiefs, conducts the Regional Health Survey (RHS), a national health survey of First Nations people living on reserve and in Northern communities. The RHS is compliant with OCAP (ownership, control, access, and possession), a set of fundamental ethical standards for conducting research with First Nations. RHS data fill an important information gap in population health, as First Nations individuals may not be included in national population health surveys (FNIGC, 2018). The RHS has been implemented in three phases: phase 1, 2002–2003; phase 2, 2008–2010; and phase 3, 2015–2016. Data from over 200 First Nations communities across Canada were collected in each of these phases from participating children, youth, and adults. These publicly available data are found in FNIGC reports summarizing the findings of each RHS phase.

RHS data on alcohol use and cigarette smoking during pregnancy and the number of people who have been told by a health professional that they have FASD were retrieved from FNIGC reports in three separate survey cycles (see Table 5). Phase 3 of the survey (conducted between March 2015 and December 2016) captured data from 253 First Nations communities. Findings from phase 3 indicate that 93.0% (95% CI: 91.9, 94.0) of women abstained from drinking alcohol while they were pregnant; no comparable data is available from previous survey cycles.

The prevalence of FASD among First Nations children (0 to 11 years) decreased to 0.5% (95% CI: 0.5, 0.8) in 2018 from 1.8% (95% CI: not available) in 2002–2003 (FNIGC, 2018). Of children with guardian-reported FASD diagnoses, 46.7% (95% CI: 28.4, 66.1) were receiving treatment for FASD, 75.2% (95% CI: 56.2, 87.8) were receiving treatment for autism spectrum disorder (ASD), and more than half (58.8%; 95% CI: 45.0, 71.3) were being treated for attention deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD).

The RHS phase 3 survey also found that the prevalence of smoking during pregnancy had decreased. Over one-third (37.5%) of female First Nations adults reported smoking at any point while pregnant, a decrease from 46.9% in 2008–2010 and similar to the rate of 36.6% reported in 2002–2003. Among women and girls who smoked at any point during their pregnancy, 58.8% (95% CI: 54.9, 62.6) smoked daily, an increase from 51.0% (95% CI: 47.6, 54.4) reported in 2008–2010, and 41.2% (95% CI: 37.4, 45.1) smoked occasionally, compared to 49.0% (95% CI: 45.5, 52.5) in 2008–2010. Overall, the proportions of tobacco smoking during pregnancy seem to be decreasing, even with the increase in the frequency of daily smoking during pregnancy.

Table 5. Alcohol abstinence and cigarette smoking during pregnancy and FASD diagnoses among First Nations people living on reserve and in Northern communities, 2002–2003, 2008–2010, 2015–2016

	RHS survey cycle		
RHS DATA ELEMENT	2002–2003, % (95% CI)	2008–2010, % (95% CI)	2015–2016, % (95% CI)
Abstained from drinking alcohol while pregnant	N/A	N/A	93.0 (91.9, 94.0)
FASD AMONG CHILDREN (0-11 YEARS) — GUARDIAN REPORT	1.8 (N/A)	0.9 (N/A)	0.5 (0.3, 0.8)
FASD AMONG YOUTH (12-17 YEARS) — SELF-REPORT	N/A	0.8 (0.5, 1.3)	0.5 (0.3, 0.8)
SMOKING AT ANY POINT WHILE PREGNANT	36.6 (N/A)	46.9 (44.5, 49.3)	37.5 (35.0, 40.1)
Daily*	N/A	51.0 (47.6, 54.4)	58.8 (54.9, 62.6)
Occasionally*	N/A	49.0 (45.5, 52.5)	41.2 (37.4, 45.1)

Source: RHS
Abbreviations: N/A, not applicable; CI, confidence interval
* Percentage derived from the women who reported smoking during pregnancy
Please note: due to low cell count or high sampling variability, the frequency of use was suppressed

4.1.3 PUBLISHED STUDIES — PAE

The prevalence of alcohol use during pregnancy in cross-jurisdictional settings in Canada (i.e., multiple P/Ts) has been investigated in several population-based surveys and cross-sectional studies, dating back to 1994. See Appendix D for a full list of identified peer-reviewed articles and reports with detailed findings.

No publications on cross-jurisdictional prevalence of alcohol use during pregnancy with study years 2015–2020 were identified. The most recent population-based estimate is from the CCHS in 2007–2008, which indicated a 5.8% prevalence of alcohol use during pregnancy (Thanh & Jonsson, 2010). Notably, this is lower than previous estimates from the CCHS, including 13.7% in 2002 (AADAC, 2004) and 10.5% in 2005 (PHAC, 2008). Prevalence estimates from the National Longitudinal Survey of Children and Youth (NLSCY) from earlier years also point to higher rates in previous years, including 17.4% in 1994–1995 (Health Canada, 2003) and 14.4% in 1998–1999 (Dell & Garabedian, 2003).

In more recent years (2008–2011), a cross-sectional study by Delano et al. (2019) compared prevalence estimates from meconium testing (1.2% to 2.4%) to that of maternal questionnaires pertaining to the same births, which indicated that 32% of mothers consumed less than two standard drinks per week. While meconium testing is the gold standard for measuring PAE, it does not capture alcohol exposure that occurred during the first trimester of pregnancy. It is important for measures of PAE to be thorough and to capture exposure during all time points of pregnancy, including prior to pregnancy recognition.

Special subpopulations in identified studies on alcohol use during pregnancy include women living in small, rural, and remote communities and women with high-risk pregnancies. Only one study was conducted in the years of interest (2015–2020), which found a prevalence of 7% among women participating in the Regional Health Survey in 2015–2016 (FNIGC, 2018). Among studies of women in these communities from previous years, the prevalence ranged from 4.8% (BC Provincial Health Officer, 2009) to 50.8% (Williams & Gloster, 1999), while one estimate (12.4%) was available for binge drinking (Godel et al., 1992).

The majority of women living in Métis Settlements and in First Nations communities in Inuit Nunangat do not drink alcohol while pregnant. Studies of alcohol use during pregnancy in Canada disproportionately focus on Indigenous women (Dell & Roberts, 2006), which may result in skewed prevalence data within Indigenous populations (Tait, 2003; Hunting & Browne, 2012). The pooled prevalence of alcohol use during pregnancy among women living in small, rural, and remote communities was estimated to be 36.5% (95% CI: 24.7, 49.1) for any use and 22.1% (95% CI: 0.0, 52.9) for binge drinking (Popova et al., 2017).

Among studies of women with high-risk pregnancies, the prevalence ranged from 2% to 30% (Goh et al., 2010), with the latter representing an estimate from meconium testing. Binge drinking in another sample of women with high-risk pregnancies was found to be 12.4% (Godel et al., 1992).

A systematic literature review and meta-analysis of original, quantitative studies published between November 1973 and December 2018 estimated the pooled prevalence of any alcohol use during pregnancy to be 10.0% (95% CI: 5.2, 16.2) and binge drinking to be 3.3% (95% CI: 2.6, 4.2) among women in the general population of Canada (Popova et al., 2017).

4.2 Existing Surveillance — FASD

4.2.1 CANADIAN NATIONAL FASD DATABASE (CANFASD UNIVERSAL DATAFORM PROJECT)

Introduction

The Canadian National FASD Database is an ongoing repository of diagnostic information regarding FASD assessments and diagnoses completed at 26 FASD diagnostic clinics in nine P/Ts across Canada. The project was designed to create a consistent set of data points that are input at the clinic level via a secure online portal and aggregated in a central location. The anonymized and de-identified information collected includes patient demographics, challenges, results of neurodevelopmental assessments, physical and mental health comorbidities, adverse outcomes being experienced, specific FASD diagnosis, and recommendations made following the assessment.

Objectives

The aims of this study were to examine in five select P/Ts (AB, MB, ON, NT, and YT) the following:

1. the prevalence of FASD diagnoses among individuals who completed an assessment;
2. the diagnostic categories among individuals diagnosed with FASD in this time frame, according to the 2016 Canadian criteria;
3. the demographic profile and social outcomes among individuals diagnosed with FASD;
4. the mental health comorbidities among individuals diagnosed with FASD; and
5. the recommendations for support services indicated by FASD diagnostic clinics for individuals diagnosed with FASD.

Methods

A cross-sectional analysis was performed by using record-level data collected from FASD diagnostic clinics in five select jurisdictions (AB, MB, ON, NT, and YT) from 2004 to 2019 by the CanFASD Universal Dataform project. Data cleaning steps involved the creation of three age variables, calculated based on information available for birth year and year of assessment. Diagnoses were adjusted for individuals diagnosed prior to 2016, so as to fit the 2016 Cook et al. diagnostic guidelines. Descriptive statistics were derived using STATA 16.

Results

Individuals Diagnosed with FASD (N = 1,185)

A total of 1,185 children and adults met criteria for diagnosis of FASD under the Canadian guidelines. Unless otherwise specified, the term FASD below refers to both FASD with sentinel facial features (FASD w/ SFF) and FASD without sentinel facial features (FASD w/o SFF). Data reported here was combined for all five P/Ts unless otherwise specified and reported as frequencies. In some cases, chi-square analyses were undertaken to compare groups.

Diagnostic Outcomes for FASD Assessments by Age Group

Under the current Canadian diagnostic criteria, individuals can be diagnosed as having FASD w/ SFF or FASD w/o SFF. Data below in Table 6 are presented by diagnosis and age group, with percentages being calculated for columns. Overall, 159 individuals (13.4%) received a diagnosis of FASD w/ SFF while 1,026 (86.6%) had FASD w/o SFF. Children 6 to 11 years were the age group most often diagnosed (34.5%), followed by ages 12 to 17 (30.5%).

Table 6. FASD diagnoses by age group in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,185)

Age group	FASD w/ SFF, n (%)	FASD w/o SFF, n (%)	Total, n (%)
Children 0-5 years	23 (14.5)	35 (3.4)	58 (4.9)
Children 6-11 years	45 (28.3)	337 (32.8)	382 (32.2)
Adolescents 12-17 years	22 (13.8)	316 (30.8)	338 (28.5)
Adults 18+ years	64 (40.2)	266 (25.9)	330 (27.8)
Age missing	5 (3.1)	72 (7.0)	77 (6.5)
Total	**159 (100)**	**1,026 (100)**	**1,185 (100)**

Source: CanFASD Universal Dataform project
Abbreviation: SFF, sentinel facial features

FASD Diagnoses for Children, Adolescents and Adults by P/T and by Sex

Data for those diagnosed with FASD by the five jurisdictions studied are presented in Table 7, which presents row percentages. The majority of those diagnosed across all P/Ts were children and adolescents (70.2%). In MB, only 18 (7%) of 259 individuals diagnosed were adults, compared to AB where 273 (48.8%) were adults. This is likely because the MB FASD clinics focus more on children and adolescents; however, it also highlights a potential need for greater diagnostic capacity in MB for adults.

Table 7. FASD diagnoses among children, adolescents and adults by P/T, 2004–2019 (N = 1,185)

P/T	Children and adolescents 0-17 years, n (%)	Adults 18+ years, n (%)	Total, n (%)
Alberta	286 (51.1)	273 (48.8)	559 (100)
Manitoba	241 (93)	18 (7)	259 (100)
Northwest Territories	11 (91.7)	<5 (S)	12 (100)
Ontario	239 (86.3)	38 (13.7)	277 (100)
Yukon	<5 (S)	<5 (S)	<5 (S)
Total	**778 (70.2)**	**330 (29.8)**	**1,108 (100)**

Source: CanFASD Universal Dataform project
Abbreviation: S, suppressed
Please note: age information is missing for 77 individuals diagnosed with FASD

Overall, 55.9% of individuals with FASD were male. Females comprise 44.1% and 43.9% of diagnosed children /adolescents and adults, respectively. See Table 8, which presents column percentages.

Table 8. Sex of individuals with FASD in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,185)

Sex	Children and adolescents 0-17 years, n (%)	Adults 18+ years, n (%)	Total, n (%)
Male	435 (55.9)	185 (56.1)	620 (100)
Female	343 (44.1)	145 (43.9)	488 (100)
Total	778 (100)	330 (100)	1,108 (100)

Source: CanFASD Universal Dataform project
Please note: age information is missing for 77 individuals diagnosed with FASD

Mental Health Comorbidities

Data in Table 9 are expressed in frequencies and row percentages for each mental health comorbidity by age group. For children and adolescents diagnosed with FASD, the most common comorbid mental health issue was ADHD/ADD (n = 520, 70.1%), followed by language disorder/impairment (n = 293, 40.8%). For adults, it was ADHD/ADD (n = 129, 47.8%), followed by mood disorder (n = 127, 49.6%). A high proportion of each age category was also reported to have an "other diagnosis" (29.0% of children and adolescents, 56.5% of adults), which indicates a diagnosis not specifically included in the survey.

The majority of children and adolescents (n = 691, 88.8%) and adults (n = 235, 71.2%) diagnosed with FASD were also assessed for intellectual disability (ID). Of these individuals, 283 (40.9%) children/adolescents and 143 (60.8%) adults were found to meet criteria for ID. This indicates that significantly more adults assessed for FASD have comorbid ID than children and adolescents [$X^2 = 27.94$, $p<.0000$].

Table 9. Mental health comorbidities with FASD diagnoses in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,185)

Comorbidities at time of assessment	Children and adolescents (0-17 years), n = 778			Total, n (%)	Adults (18+ years), n = 330			Total, n (%)
	Yes, n (%)	No, n (%)	Not assessed, n (%)		Yes, n (%)	No, n (%)	Not assessed, n (%)	
Congenital malformation	27 (4)	525 (78.5)	117 (17.5)	669 (100)	14 (5.9)	168 (70.3)	57 (23.8)	239 (100)
Intellectual disability	283 (39.1)	408 (56.4)	33 (4.6)	724 (100)	143 (57.9)	92 (37.3)	12 (4.9)	247 (100)
ADHD/ADD	520 (70.1)	169 (22.8)	53 (7.1)	742 (100)	129 (47.8)	112 (41.5)	29 (10.7)	270 (100)
Attachment disorder	52 (7.8)	378 (57)	233 (35.1)	663 (100)	19 (7.9)	145 (60.2)	77 (32)	241 (100)
Developmental coordination disorder	55 (8)	409 (59.2)	226 (32.8)	690 (100)	20 (8.4)	162 (68.1)	56 (23.5)	238 (100)
Language disorder/ impairment	293 (40.8)	344 (47.9)	81 (11.3)	718 (100)	55 (22.6)	155 (63.8)	33 (13.6)	243 (100)
Auditory deficit	42 (5.9)	515 (72.7)	151 (21.3)	708 (100)	14 (5.8)	175 (72.3)	53 (21.9)	242 (100)
Visual deficit	170 (23.9)	384 (54.0)	157 (22.1)	711 (100)	75 (29.4)	111 (43.5)	69 (27.1)	255 (100)
Tourette's disorder	<5 (S)	272 (41.2)	385 (58.3)	660 (100)	<5 (S)	77 (32.6)	158 (66.9)	236 (100)
Anxiety disorder	73 (10.3)	267 (37.7)	368 (52)	708 (100)	90 (35.7)	100 (39.7)	62 (24.6)	252 (100)
Autism spectrum disorder	14 (2.1)	189 (28)	471 (69.9)	674 (100)	<5 (S)	67 (28.4)	166 (70.3)	236 (100)
Bipolar disorder	<5 (S)	152 (22.8)	511 (76.6)	667 (100)	8 (3.3)	69 (28.9)	162 (67.8)	239 (100)
Conduct disorder	63 (9.4)	216 (32.1)	394 (58.5)	673 (100)	42 (17.5)	95 (39.6)	103 (42.9)	240 (100)
Mood disorder	106 (15.7)	186 (27.6)	383 (56.7)	675 (100)	127 (49.6)	76 (29.7)	53 (20.7)	256 (100)
Obsessive compulsive disorder	6 (0.9)	233 (34.9)	428 (64.2)	667 (100)	5 (2.1)	112 (47.5)	119 (50.4)	236 (100)
Personality disorder	<5 (S)	154 (23.1)	512 (76.7)	668 (100)	18 (7.6)	63 (26.5)	157 (66)	238 (100)
PTSD	26 (3.9)	142 (21.3)	499 (74.8)	667 (100)	32 (13.3)	56 (23.2)	153 (63.5)	241 (100)
Schizophrenia	<5 (S)	152 (22.8)	515 (77.2)	667 (100)	11 (4.6)	61 (25.7)	165 (69.6)	237 (100)
Suicide attempt(s)/ ideation	64 (9.5)	252 (37.5)	356 (53)	672 (100)	45 (18.7)	122 (50.8)	73 (30.4)	240 (100)
Other diagnosis	84 (29)	33 (11.4)	173 (59.7)	290 (100)	48 (56.5)	16 (18.8)	21 (24.7)	85 (100)

Source: CanFASD Universal Dataform project
Abbreviation: ADD, attention deficit disorder; ADHD, attention-deficit/hyperactivity disorder; PTSD, post-traumatic stress disorder; S, suppressed
Please note: age information is missing for 77 individuals diagnosed with FASD

Justice System Involvement and Substance Use

Previous research has suggested that individuals with FASD may become involved in the criminal justice system and can face challenges with substance use. Data for adolescents and adults with these challenges are presented in Table 10. Row percentages here are calculated based on the number of records available for each data element, among adolescents 10 to 17 years old (n = 464) and adults 18 years and over (n = 330). In the P/Ts studied, 4.4% of adolescents and 6.1% of adults were reported to be incarcerated at the time of their FASD assessment; 19.6% of adolescents and 28.5% of adults were noted to be involved with the criminal justice system as "offenders"; and 7.4% of adolescents and 37.0% of adults were reported to have a substance use disorder.

Table 10. Justice system involvement and substance use in individuals diagnosed with FASD in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,185)

Variables at time of assessment	Adolescents (10-17 years), n = 464			Total, n (%)	Adults (18+ years), n = 330			Total, n (%)
	Yes, n (%)	No, n (%)	Unknown, n (%)		Yes, n (%)	No, n (%)	Unknown, n (%)	
Legal problems: victim	9 (2.0)	427 (94.9)	14 (3.1)	450 (100)	6 (1.9)	307 (96.5)	5 (1.6)	318 (100)
Legal problems: offender	88 (19.6)	351 (78.0)	11 (2.4)	450 (100)	92 (28.5)	228 (70.6)	<5 (S)	323 (100)
Custody issues/ family court	7 (1.6)	420 (97.4)	<5 (S)	431 (100)	18 (5.7)	294 (93)	<5 (S)	316 (100)
Incarcerated	19 (4.4)	409 (95.1)	<5 (S)	430 (100)	19 (6.1)	290 (93.2)	<5 (S)	311 (100)
Special courts jail	<5 (S)	437 (97.1)	10 (2.2)	450 (100)	<5 (S)	310 (98.1)	5 (1.6)	316 (100)
Regular courts jail	<5 (S)	432 (97.3)	9 (2.0)	444 (100)	9 (2.8)	303 (95.6)	5 (1.6)	317 (100)
Substance use disorder	29 (7.4)	137 (35.0)	225 (57.5)	391 (100)	91 (37.0)	95 (38.6)	60 (24.4)	246 (100)

Source: CanFASD Universal Dataform project
Abbreviation: S, suppressed
Please note: age information is missing for 77 individuals diagnosed with FASD

Employment Problems and Assisted Housing among Adults Diagnosed with FASD

Past research suggests that adults with FASD have significant difficulty with employment and housing. Percentages reported in Table 11 are calculated based on the number of records available for each data element among adults (n = 330) diagnosed with FASD. Data for children were not included as employment and housing are predominantly adult issues. Overall, 68% of adults with FASD faced employment problems, 28.8% required assisted or sheltered housing, and 61.8% were reported to need help living independently.

Table 11. Employment and housing challenges at the time of FASD diagnosis in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019

Variables at time of assessment	Adults (18+ years), n = 330				
	Yes, n (%)	No, n (%)	Unknown, n (%)	To be followed up after clinic, n (%)	Total, n (%)
Employment problems	221 (68.0)	72 (22.1)	29 (8.9)	<5 (S)	325 (100)
Needs help living on own	199 (61.8)	71 (22.0)	47 (14.6)	5 (1.6)	322 (100)
Needs assisted or sheltered housing	93 (28.8)	177 (54.8)	49 (15.2)	<5 (S)	323 (100)

Source: CanFASD Universal Dataform project
Abbreviation: S, suppressed

Teaching Assistance Use and School Expulsion among Children Diagnosed with FASD

Children with FASD often face challenges both academically and behaviourally at school. Percentages reported in Table 12 are calculated based on the number of records available for each data element among children and adolescents aged 6 to 17 years (n = 720) diagnosed with FASD. Among this group, 52.4% reported using the services of a teaching assistant and 16.2% reported school expulsion at the time of their FASD assessment.

Table 12. Educational challenges at the time of FASD diagnosis in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019

Variables at time of assessment	Children and adolescents (6-17 years), n = 720				
	Yes, n (%)	No, n (%)	Unknown, n (%)	To be followed up after clinic, n (%)	Total, n (%)
Used teaching assistant service prior to diagnosis	355 (52.4)	270 (39.8)	48 (7.1)	5 (0.7)	678 (100)
Reported school expulsion/suspension	109 (16.2)	487 (72.3)	77 (11.4)	<5 (S)	674 (100)

Source: CanFASD Universal Dataform project
Abbreviation: S, suppressed

Support Services Recommended for Diagnosed Individuals

Children and adults diagnosed with FASD often require a range of support services to meet their individualized needs, which may be related to health and social outcomes, in addition to comorbidities. Data in Appendix J reflect clinic recommendations for support services for diagnosed individuals (N = 1,185) following the FASD assessment in all select P/Ts.

Among children, the most frequently recommended services were accommodations/adaptation in environment (n = 723, 95.3%); support, individual or group (n = 595, 81.4%); communication strategies (n = 561, 80.9%); and anticipatory guidance/prevention (n = 543, 75.9%). Among adults, the most frequently recommended services were support, individual or group (n = 250, 89.0%); income support (n = 276, 87.6%); accommodations/adaptation in environment (n = 254, 80.6%); and mental health support (n = 232, 77.3%).

Individuals Assessed for FASD Diagnosis (N = 1,975)

This section includes analyses representing all individuals (1,975) who were assessed for FASD diagnosis in FASD clinics from 2004 to 2019 in AB, MB, NT, ON, and YT. As noted above, diagnoses were undertaken using the 2016 Cook et al. guidelines. In this dataset, some of the individuals were diagnosed with FASD, some were designated "at risk for neurodevelopmental disorder (ND) and FASD," and some received no diagnosis. Please note that when totals do not add up to 1,975, this is due to missing data.

Diagnostic Outcomes Following Assessment

Across all years of data available, 28.8% of individuals assessed in AB, MB, NT, ON, and YT did not receive a diagnosis of FASD following assessment.

Table 13. Diagnostic outcomes following assessment in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,975)

Diagnostic category	Frequency	Percent
FASD w/ SFF	159	8.0
FASD w/o SFF	1,026	52.0
At risk for ND/FASD	222	11.2
No FASD diagnosis	568	28.8
Total	**1,975**	**100.0**

Source: CanFASD Universal Dataform project
Abbreviations: SFF, sentinel facial features; ND, neurodevelopmental disorder

Assessments for FASD Diagnosis by P/T and by Age Group

Based on the available data, the largest portion of FASD assessments done across the jurisdictions studied were of children between 6 and 11 years (38.9%) and adolescents between 12 and 17 years (29.1%). Notably, clinics have different service mandates and therefore see different age and client groups. Among individuals assessed for FASD in AB, 43.6% were 18 years of age or older, compared to MB where 4.9% of assessed individuals were in the adult category. The majority (94.4%) of individuals assessed in the YT were between zero and five years old at the time of assessment, likely because the only clinic in the territory contributing data is a children's clinic.

Table 14. Assessments for FASD diagnosis by P/T and age group, 2004–2019 (N = 1,975)

P/Ts	0-5 years, n (%)	6-11 years, n (%)	12-17 years, n (%)	18+ years, n (%)	Total, n (%)
Alberta	33 (4.1)	197 (24.5)	223 (27.8)	350 (43.6)	803 (100)
Manitoba	79 (16.1)	239 (48.8)	148 (30.2)	24 (4.9)	490 (100)
Northwest Territories	<5 (S)	9 (64.3)	<5 (S)	<5 (S)	14 (100)
Ontario	54 (9.1)	302 (50.7)	185 (31.0)	55 (9.2)	596 (100)
Yukon	17 (94.4)	<5 (S)	<5 (S)	<5 (S)	18 (100)
Total	**183 (9.5)**	**748 (38.9)**	**560 (29.1)**	**430 (22.4)**	**1,921 (100)**

Source: CanFASD Universal Dataform project
Abbreviation: S, suppressed

Diagnostic Outcomes by Age Group

Diagnostic outcomes following FASD assessment are presented in Table 15 in two age categories: children and adolescents, 0 to 17 years; and adults, 18 years and older. Children and adolescents represented the majority of individuals who were assessed but not diagnosed with FASD, and of individuals who were at risk of FASD (83.7% and 97.2%, respectively). The newly created at-risk category, which is not a diagnosis but a designation (Cook et al. 2016), was used in 11.5% of cases. The at-risk designation was created in 2016 to help identify individuals who do not yet qualify for a diagnosis of FASD but may in the future, in the hopes of aiding with follow-up at a later date.

Table 15. Outcomes following FASD assessment by age group in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,975)

Age Group	FASD w/ SFF, n (%)	FASD w/o SFF, n (%)	At risk*, n (%)	No FASD diagnosis, n (%)	Total, n (%)
0-17 years	90 (58.4)	688 (72.1)	211 (97.2)	472 (83.7)	1,461 (77.3)
18+ years	64 (41.6)	266 (27.9)	6 (2.8)	92 (16.3)	428 (22.7)
Total	154 (100)	954 (100)	217 (100)	564 (100)	1,889 (100)

Source: CanFASD Universal Dataform project
Abbreviation: SFF, sentinel facial features
* At risk for ND and FASD

Diagnostic Outcomes by P/T and Assessment Year

Please see respective P/T sections for diagnostic outcomes by year of assessment: AB (Section 5.3.2), MB (Section 7.3.2), NT (Section 8.3.1), ON (Section 9.3.2), and YT (Section 10.2.2).

The data available from the CanFASD Universal Dataform Project suggests that the number of assessments may have increased in recent years (2015–2019) in participating clinics located in AB, MB, and ON. Data from MB are sent from the same participating clinic, and this shows that across all assessment years available (2013, 2016–2019), 41.7% of assessed children were not diagnosed with FASD. Participating clinics in ON suggest that 53.5% of assessed individuals were not diagnosed with FASD. This proportion in ON is influenced by variations in participating clinics across the years, which also reflect variations in capacity, referral patterns, and age categories available for assessment.

Limitations

These data are cross-sectional in nature, and assumptions about development or prevalence of disorders across time (arising from data presented by age categories) should be viewed with caution. As well, these data are based on a patient population only, without a control group or general population rate to indicate prevalence of disorders in typically functioning individuals.

Data on diagnostic outcomes across assessment years in each P/T should also be interpreted with caution, as this is dependent on clinic participation in the project throughout this time frame. Although participation increased over time, only a few clinics submitted data in the first few years of data collection. Additionally, data available on assessment year and P/Ts are influenced by variations in timing of ethics approval and data entry. These data limit the potential to draw conclusions about trends in diagnostic capacity and number of assessments at the jurisdictional level.

Data on diagnostic outcomes do not represent all of the assessments provided in each of the P/Ts; instead, this data only reflects assessments from the clinics that contribute to the Canadian National FASD Database in each of the jurisdictions and those where a diagnosis of FASD was given.

4.2.2 DIAGNOSTIC CLINIC SURVEY

Objectives

1. To obtain the number of individuals assessed for and diagnosed with FASD per year (2015–2019) among clinics capable of providing diagnoses of FASD in each select P/T; and
2. to explore the diagnostic capacity of clinics capable of providing FASD diagnoses in each select P/T.

Methods

A list of neurodevelopmental clinics or other clinics that might capture diagnoses of FASD in AB, BC, MB, NT, and ON for the select project years was created.

A survey was designed to obtain information regarding diagnoses and diagnostic capacity in clinics, including:

- number of individuals assessed for FASD each year;
- number of individuals diagnosed with FASD each year;
- number of slots allotted to FASD diagnoses each year;
- number of people on the waitlist for FASD assessment each year; and
- clinic definitions of waitlists.

The survey was pilot-tested in August 2018. Data collection began in October 2018 and was ongoing until June 2020. Clinic coordinators were contacted and followed up with via email and phone to obtain their willingness to participate in the survey. Compensation of $20 was provided to clinics who contributed their data for years 2015 to 2020. Each clinic was assigned an alphanumeric identification, which was entered into the REDCap database and used to track completeness of data and compensation to clinics during the data collection process.

Descriptive statistics were generated separately for each participating jurisdiction, for FASD assessments, diagnoses, allotted diagnostic slots, and waitlist sizes among clinics that contributed data for each respective year. Free-text responses for the descriptions of waitlists provided were amalgamated and qualitatively analyzed for commonalities, including waitlist time, requirements for PAE confirmation, and referral processes.

Results

Results are presented in the following provincial/territorial profiles: AB (Section 5.3.3), BC (Section 6.3.3), MB (Section 7.3.3), NT (Section 8.3.4), and ON (Section 9.3.3).

4.2.3 PUBLISHED STUDIES — FASD

General Population

One study was found to estimate the prevalence of FASD based on a cross-jurisdictional Canadian sample. Pei et al. (2020) utilized data from the Canadian Children's Health in Context Study (CCHICS), a database used to monitor the development and health of children in Canada with health disorders. The CCHICS contains the Early Development Instrument (EDI), wherein teachers report on developmental diagnoses of their kindergarten students (aged four to six). Between 2010 and 2015, a total of 658 kindergarten students were identified to have FASD within the EDI, for a prevalence of 1.1 per 1,000 (0.11%). Of these children, 135 (20.5%) had comorbid conditions as well. This prevalence estimate did not include data from New Brunswick, Nunavut, or Prince Edward Island. No information was available for fetal alcohol syndrome (FAS). For a full list of studies identified to have prevalence estimates of FASD, please refer to Appendix E.

Special Subpopulations

A total of nine studies were found to indicate prevalence estimates of FASD in cross-jurisdictional samples of Canadian special subpopulations, with only one study (FNIGC, 2018) involving data collection in the years of interest (2015–2020). Previous literature is presented to contextualize these findings. Although FASD impacts all communities when individuals drink alcohol, epidemiological studies have reported higher prevalence among children in care (Fuchs et al., 2014), in individuals under criminal justice supervision (Fast, Conry, & Loock, 1999; Burd et al., 2003; Popova et al., 2019b; MacPherson & Chudley, 2011; McLachlan et al., 2019), and those in select small, rural or isolated communities (Popova et al., 2019b). For a full list of studies identified to have prevalence estimates of FASD, please refer to Appendix E.

In 2011, a study conducted by Correctional Service Canada (CSC) found that among a sample of newly admitted adult male offenders age 30 and under, 10% of participants met the criteria for FASD (MacPherson et al., 2011). A study on an exclusively female offender population in a Canadian federal institution found a 17.4% prevalence of FASD in a small sample of 23 (Forrester et al., 2015). In a systematic review and meta-analysis by Popova et al. (2019b), the pooled

prevalence of FASD among adults in the correctional system in Canada was estimated to be 146.7 per 1,000 (95% CI = 98.2, 204.9). Previous research shows that youth with FASD are overrepresented in the youth justice system, with 21% of youth with FASD in custody and 17% of youth who had ever been detained in a custody centre (Peled, Smith, & McCreary Centre Society, 2014). Children and youth in child welfare custody also have demonstrated higher rates of developmental disabilities, congenital anomalies, and mental health diagnoses compared to children and youth in the general population (Fuchs et al., 2008).

The FNIGC indicates a prevalence estimate of 0.5% for both guardian-reported child (0 to 11 years) diagnosis and self-reported youth (12 to 18 years) diagnosis, based on the results of the Regional Health Survey (FNIGC, 2018). Based on a few existing and outdated studies, the pooled prevalence of FAS and FASD among First Nations communities, including individuals with disabilities referred for assessment (Asante et al., 1985), was estimated to be 60.8 per 1,000 (95% CI = 42.1, 83.4) for FAS and 43.6 per 1,000 (95% CI = 37.9, 49.3) for FASD (Asante et al., 1985; Kowlessar, 1997; Robinson, Conry, & Conry, 1987; Popova et al., 2019b). The authors noted that these estimates were based on 20- to 30-year-old studies, which suffer from many methodological limitations that make them inapplicable for policy analysts and system planners.

Fuchs & Burnside (2014) indicated a cross-jurisdictional prevalence of 11.4% among children in care across three provinces in Canada. A systematic review by Popova et al. (2019b) found that the prevalence of FASD in children in care populations in Canada ranges from 32.6 per 1,000 (3.3%) to 241.4 per 1,000 (24.1%).

4.3 Healthcare Utilization

4.3.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Objectives

The objectives of this study were:

1. to examine health care utilization by individuals with FAS;
2. to estimate the associated direct cost of health care for individuals with FAS in select P/Ts; and
3. to estimate the mortality rate among individuals with FAS as captured by the health care system.

Methods

Data Sources

Health care utilization data of individuals with FAS were obtained from Canadian Institute for Health Information (CIHI). CIHI is a government-funded non-profit agency that collects, consolidates, and provides unbiased, credible, and comparable Canadian health care information. CIHI manages a large number of Canadian health databases and receives information/data from the Canadian government, as well as Canadian hospitals.

The record-level data (from 2014–2015 to 2017–2018) on health care service utilization where a diagnosis of FAS (see Variables of Interest section) was captured as either the most responsible diagnosis (MRD), secondary, or other diagnosis were searched for in the following databases:

- the Discharge Abstract Database (DAD);
- the National Ambulatory Care Reporting System (NACRS);
- the Ontario Mental Health Reporting System (OMHRS); and
- the National Rehabilitation Reporting System (NRS).

Definitions Used

- **Acute inpatient care**: The DAD contains the number of acute care hospitalizations and hospital days for all select provinces/territories.
- **Psychiatric care:** The DAD contains the number of psychiatric hospitalizations and hospital days for all select provinces/territories. Adult inpatient mental health services, as either acute or psychiatric care, for the province of ON is available from OMHRS.
- **Day surgery:** The DAD contains the number of day surgery hospitalizations and number of hours for select provinces/territories (BC, MB, NT, and YT). The NACRS contains day surgery data for AB and ON.
- **Emergency department:** The NACRS contains the number of emergency department (ED) visits and the number of hours spent in the ED.
- **Rehabilitation care**: NRS collects standardized information on rehabilitation hospitalizations, required by adults who experience debilitating illness or injury. The DAD also captures information on rehabilitation hospitalizations.
- **Diagnostic imaging:** NACRS collects information on diagnostic imaging.
- **Outpatient clinic:** NACRS collects information on outpatient clinics defined as: cardiac catheterization, renal dialysis, oncology clinic, mental health, and other (medical, surgical, cardiac, gynecology, neurology, obstetrics, pediatric, rehabilitation, rheumatology, ophthalmology, orthopedic, family practice, special day/night care, etc.).

Mortality within the Health Care System

Deaths of individuals with FAS were assessed if a death was indicated within the inpatient or outpatient health care system. The mortality rate was estimated using the death counts among patients with FAS captured by the health care system over the number of patients with FAS who used the health care system. The number of deaths was provided by DAD, NACRS, OMHRS, and NRS.

Cost of Health Care Utilization

The financial expenses generated by the individual records captured by DAD and NACRS were approximated by CIHI by taking into account the Case Mix Groups+ (CMG+) 2018 methodology, Resource Intensity Weights (RIW), and the cost of a standard hospital stay (CSHS) utilizing the Canadian Management Information System Database (CMDB). The financial expenses created by each day of inpatient psychiatric care, as captured by OMHRS, were calculated using the most conservative cost of inpatient psychiatric care, $414 per day (CIHI, 2019). Counts of the days of inpatient psychiatric care were combined with the relevant financial expense to approximate the financial burden.

Variables of Interest

The cohort contained individuals with the following diagnoses defined using diagnostic codes from the Canadian version of the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10-CA): Q86.0, fetal alcohol syndrome (dysmorphic); O35.4, maternal care for (suspected) damage to fetus from alcohol; and P04.3, fetus and newborn affected by maternal use of alcohol.

The cohort was stratified using several descriptive variables including age, gender, rurality, homelessness, fiscal year (2014–2015 to 2017–2018), and P/T. The reported P/T for each patient represents the location that provided their health card and not necessarily the health care service. To minimize the risk of identifying health care facilities or patients within the territories, some variables were recoded, amalgamated, or were not released by CIHI. The Statistical Area Classification (SAC) labelled the patients rural or urban (Ahmed, 2019). Homelessness was allocated by combining the markers of homelessness in the postal code and housing characteristic variables. Additionally, the number of health care encounters made by each patient with FAS was assessed within the study period.

Most Responsible Diagnosis

There can be up to 25 diagnoses recorded on a patient's medical chart in Canada. The most responsible diagnosis refers to the health-related problem that indicates the primary reason the individual was hospitalized or sought ambulatory services. In a case where multiple diagnoses may be classified as the MRD, coders are instructed to code the diagnosis responsible for the longest length of stay.

In the emergency care visits where the MRD was not indicated, the diagnosis reported at discharge was utilized instead. For psychiatric care hospitalizations (OMHRS), the final provided most important diagnostic code was utilized as the MRD. The MRDs were reported using the fourth and fifth editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV and DSM-5) and the ICD-10-CA chapters, blocks, and specific diagnostic codes. For the leading causes of death captured by the health care system, the MRD was utilized.

Due to the constraints created by the administrative databases or privacy concerns, details of individual-level ethnicity, employment, and language could not be used in the analysis. It should be noted that CIHI suppresses cells with fewer than five cases for hospitalizations, hospital days, and/or visits in order to ensure the confidentiality of the data.

Results

Demographic Characteristics

Within four fiscal years (from 2014–2015 to 2017–2018), 5,472 patients with FAS who used health care services in select P/Ts were identified. Over half of the patients were from the province of AB (n = 2,968) while less than 1% were from the NT and YT (see Table 16).

About 56% of the patients were male (n = 3,041). Almost half of the patients were between 15 and 29 years of age (n = 2,500, 45.7%), only 6.4% of patients were 45 years or older, and less than 1% of patients were aged 70 or older.

Table 16. Demographic characteristics of individuals with FAS at the time of the first health care encounter in select P/Ts, 2014–2017 (N = 5,399)

P/T	Frequency	Percent
Alberta	2,968	55.0
British Columbia	763	14.1
Manitoba	306	5.7
Northwest Territories	20	0.4
Ontario	1,334	24.7
Yukon	8	0.1
Total	5,399	100
GENDER		
Male	3,041	55.6
Total	5,472	100
AGE (YEARS)		
<1	310	5.7
1-3	67	1.2
4-7	279	5.1
8-11	590	10.8
12-14	550	10.1
15-29	2,500	45.7
30-44	828	15.1
45-59	265	4.8
60-69	52	1.0
70-79	17	0.3
≥80	14	0.3
Total	5,472	100
RURALITY		
Rural	1,396	26.7
Urban	3,828	73.3
Total	5,224	100
HOMELESSNESS STATUS		
Not homeless	5,151	96.3
Homeless	197	3.7
Total	5,348	100

Source: CIHI data holdings including DAD, NACRS, and OMHRS
Please note: 248 observations missing for rurality; 124 observations missing or not applicable for homelessness status; and 73 observations missing government health card

The majority of the individuals resided in urban areas (n = 3,828, 73.3%); see Table 16 and Table 17.

Table 17. Rurality of individuals with FAS by P/T at the time of the first health care encounter, 2014–2017 (N = 5,399)

P/T	Frequency	Percent
ALBERTA		
Rural	845	29.8
Urban	1,992	70.2
Total	2,837	100
BRITISH COLUMBIA		
Rural	130	18.4
Urban	577	81.6
Total	707	100
MANITOBA		
Rural	111	37.2
Urban	187	62.8
Total	298	100
NORTHWEST TERRITORIES		
Rural	7	38.9
Urban	11	61.1
Total	18	100
ONTARIO		
Rural	262	20.4
Urban	1,023	79.6
Total	1,285	100
YUKON		
Urban	6	75.0
Total	8	100

Source: CIHI data holdings including DAD, NACRS, and OMHRS
Please note: 319 observations missing government health card

Among individuals with FAS accessing health care in the select P/Ts, 3.7% (n = 197) of individuals with FAS were homeless (see Tables 16, 18, and 19).

Table 18. Homelessness status of individuals with FAS at the time of the first health care encounter by P/T, 2014–2017 (N = 5,399)

P/T	Frequency	Percent
ALBERTA		
Not homeless	2,878	97.0
Homeless	90	3.0
Total	2,968	100
BRITISH COLUMBIA		
Not homeless	714	94.1
Homeless	45	5.9
Total	759	100
MANITOBA		
Not homeless	299	97.7
Homeless	7	2.3
Total	306	100
NORTHWEST TERRITORIES		
Not homeless	20	100.0
Homeless	0	0.0
Total	20	10
ONTARIO		
Not homeless	1,228	96.0
Homeless	51	4.0
Total	1,279	100
YUKON		
Not homeless	8	100.0
Homeless	0	0.0
Total	8	100

Source: CIHI data holdings including DAD, NACRS, and OMHRS
Please note: 132 observations missing or not applicable government health card

Table 19. Homelessness status of individuals with FAS at the time of the first health care encounter in select P/Ts* by fiscal year, 2014–2017 (N = 5,399)

Status	Fiscal year								
	2014		2015		2016		2017		Total
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	
Not homeless	1,530	96.0	1,202	97.2	1,264	96.2	1,155	95.9	5,151
Homeless	63	4.0	35	2.8	50	3.8	49	4.1	197
Total	1,593	100	1,237	100	1,314	100	1,204	100	5,348

Source: CIHI data holdings including DAD, NACRS, and OMHRS
* Select P/Ts are AB, BC, MB, NT, ON, and YT
Please note: 124 observations missing or not applicable for homelessness status

Health Care Utilization

Between the 2014 and 2017 fiscal years, there were 100,169 hospitalizations and health care visits made by individuals with FAS in select P/Ts. Within each of those years, emergency department visits were the most common level of care received, while rehabilitation hospitalizations were the least common level of care received (see Table 20).

Table 20. Health care utilization of individuals with FAS in select P/Ts* by fiscal year, 2014–2017 (N = 5,399)

Level of care	Fiscal year				
	2014	2015	2016	2017	Total
Number of acute care hospitalizations	1,455	1,927	2,255	2,807	8,444
Number of psychiatric care hospitalizations	271	336	484	544	1,635
Number of rehabilitation hospitalizations	14	10	15	14	53
Number of clinical care visits	3,456	5,467	7,313	9,583	25,819
Number of emergency care visits	4,477	9,407	12,924	17,778	44,586
Number of day surgeries	105	255	311	400	1,071
Number of diagnostic images	93	233	341	497	1,164
Number of other**	2,166	4,026	4,942	6,263	17,397
Total	**12,037**	**21,661**	**28,585**	**37,886**	**100,169**

Ssource: CIHI data holdings including DAD, NACRS, NRS, and OMHRS
* Select P/Ts are AB, BC, MB, NT, ON, and YT
**Comprises chronic care, sub-acute care and uncategorized care

The highest number of hospitalizations and visits of individuals with FAS was recorded in AB (69,294), followed by ON (18,622) during 2014–2017 (see Appendix K). Within the 2014, 2015, and 2016 fiscal years, male patients with FAS had more hospitalizations and health care visits than females, while the reverse was observed in the 2017 fiscal year. Within the four fiscal years, both female and male patients with FAS most commonly accessed emergency care services (see Table 21).

Table 21. Health care utilization of individuals with FAS in select P/Ts* by gender and fiscal year, 2014–2017 (N = 5,399)

Gender / fiscal year	Level of care (n)								
	Acute care hospitalizations	Psychiatric care hospitalizations	Rehabilitation hospitalizations	Clinical care visits	Emergency care visits	Day surgeries	Diagnostic images	Other**	Total
FEMALE									
2014	679	96	7	1,072	2,131	55	42	782	4,864
2015	941	139	<5	2,475	4,647	146	127	1,606	10,084
2016	1,089	201	<5	3,134	6,561	171	173	2,500	13,832
2017	1,427	249	<5	4,443	9,383	221	259	3,041	19,025
Total	**4,136**	**685**	**15**	**11,124**	**22,722**	**593**	**601**	**7,929**	**47,805**
MALE									
2014	776	175	7	2,384	2,346	50	51	1,384	7,173
2015	986	197	7	2,992	4,758	109	106	2,420	11,575
2016	1,164	283	12	4,179	6,357	140	168	2,442	14,745
2017	1,376	295	12	5,139	8,374	179	238	3,222	18,835
Total	**4,302**	**950**	**38**	**14,694**	**21,835**	**478**	**563**	**9,468**	**52,328**
OTHER									
2014	0	0	0	0	0	0	0	0	0
2015	0	0	0	0	<5	0	0	0	<5
2016	<5	0	0	0	6	0	0	0	8
2017	<5	0	0	<5	21	0	0	0	26
Total	6	0	0	<5	29	0	0	0	36
OVERALL TOTAL	**8,444**	**1,635**	**53**	**25,819**	**44,586**	**1,071**	**1,164**	**17,397**	**100,169**

Source: CIHI data holdings including DAD, NACRS, NRS, and OMHRS
* Select P/Ts are AB, BC, MB, NT, ON, and YT
** Comprises chronic care, subacute care, and uncategorized care

The most common level of care utilized between the 2014 and 2017 fiscal years differed by age group. For the health care encounters made by the youngest patients with FAS, less than one year of age, acute care hospitalizations were most commonly required (n = 468), while the most commonly required health care encounters made by patients with FAS in the age category of 1 to 11 were in the category of other (n = 6,923). Additionally, clinical care was the most commonly utilized health care level for patients with FAS between 12 and 14 years (n = 2,912) and 70 to 79 years (n = 463). Patients in the remaining age groups utilized emergency care services most commonly (see Appendix L).

For patients with FAS who had health care encounters between the 2014 and 2017 fiscal years, most of the patients had between 6 and 14 health care encounters (n = 2,627, 23.5%), followed closely by 23.1% of the patients who only required one health care encounter (n = 2,575). Patients with FAS most commonly required only one health care encounter in the 2014 fiscal year; between 6 and 14 health care encounters were most commonly required in the following fiscal years (see Table 22).

Table 22. Health care encounters of individuals with FAS in select P/Ts* by fiscal year, 2014–2017 (N = 5,399)

Number of health care encounters	Fiscal year									
	2014		2015		2016		2017		Total	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%
1	451	28.9	544	22.9	726	22.5	854	21.4	2,575	23.1
2	270	17.3	320	13.5	456	14.1	543	13.6	1,589	14.2
3	165	10.6	275	11.6	333	10.3	403	10.1	1,176	10.5
4	121	7.7	202	8.5	286	8.8	308	7.7	917	8.2
5	86	5.5	148	6.2	212	6.6	272	6.8	718	6.4
6 to 14	304	19.4	549	23.2	784	24.3	990	24.8	2,627	23.5
≥15	166	10.6	333	14.0	435	13.5	625	15.6	1,559	14.0
Total	**1,563**	**100**	**2,371**	**100**	**3,232**	**100**	**3,995**	**100**	**11,161**	**100**

Source: CIHI data holdings including DAD, NACRS, NRS, and OMHRS
* Select P/Ts are AB, BC, MB, NT, ON and YT
Please note: 92 observations with a missing patient identification number were excluded

Most Responsible Diagnoses

The most common most responsible diagnoses fell within the ICD-10-CA categories "Mental and behavioural disorders" (F00–F99, n = 30,110, 31.6%), "Factors influencing health status and contact with health services" (Z00–Z99, n = 28,876, 30.3%), "Injury, poisoning, and certain other consequences of external causes" (S00–T98, n = 9,241, 9.7%), "Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified" (R00–R99, n = 9,067, 9.5%), and "Congenital malformations, deformations, and chromosomal abnormalities" (Q00–Q99, n = 3,236, 3.4%). See Table 23.

Table 23. Most responsible diagnoses, defined using ICD-10-CA chapters, of individuals with FAS in select P/Ts*, 2014–2017 (N = 5,399)

ICD-10-CA code range for each chapter	MRD defined using ICD-10-CA chapter	Frequency	Percent
F00–F99	5. Mental and behavioural disorders	30,110	31.6
Z00–Z99	21. Factors influencing health status and contact with health services	28,876	30.3
S00–T98	19. Injury, poisoning, and certain other consequences of external causes	9,241	9.7
R00–R99	18. Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified	9,067	9.5
Q00–Q99	17. Congenital malformations, deformations, and chromosomal abnormalities	3,236	3.4
J00–J99	10. Diseases of the respiratory system	2,482	2.6
K00–K93	11. Diseases of the digestive system	2,275	2.4
M00–M99	13. Diseases of the musculoskeletal system and connective tissue	1,413	1.5
E00–E90	4. Endocrine, nutritional, and metabolic diseases	1,227	1.3
N00–N99	14. Diseases of the genitourinary system	1,193	1.3
G00–G99	6. Diseases of the nervous system	1,185	1.2
L00–L99	12. Diseases of the skin and subcutaneous tissue	1,146	1.2
A00–B99	1. Certain infectious and parasitic diseases	1,092	1.1
O00–O99	15. Pregnancy, childbirth, and the puerperium	795	0.8
I00–I99	9. Diseases of the circulatory system	452	0.5

ICD-10-CA code range for each chapter	MRD defined using ICD-10-CA chapter	Frequency	Percent
H60–H95	8. Diseases of the ear and mastoid process	400	0.4
D50–D89	3. Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	376	0.4
H00–H59	7. Diseases of the eye and adnexa	330	0.3
P00–P96	16. Certain conditions originating in the perinatal period	324	0.3
C00–D48	2. Neoplasms	180	0.2
Total		95,400	100

Source: CIHI data holdings including DAD, NACRS, and NRS
Abbreviations: MRD, most responsible diagnosis
* Select P/Ts are AB, BC, MB, NT, ON, and YT
Please note: 3,782 missing observations excluded

Of MRDs defined by the ICD-10-CA blocks, the most commonly diagnosed were "Persons encountering health services for specific procedures and health care" (n = 13,655, 14.3%), "Persons encountering health services in other circumstances" (n = 7,582, 7.9%), "Mental and behavioural disorders due to psychoactive substance use" (n = 6,894, 7.2%), "Schizophrenia, schizotypal, and delusional disorders" (n = 4,998, 5.2%), and "Neurotic, stress-related and somatoform disorders" (n = 4,791, 5.0%). For a full list, please refer to Appendix M.

Between age groups, there was a lot of variation in MRDs when defined using ICD-10-CA chapters. The most common MRD was associated with chapter 21 "Factors influencing health status and contact with health services" for patients less than 1 year old (n = 533, 36.6%), 1 to 3 years (n = 1,013, 52.5%), 4 to 7 years (n = 2,122, 56.3%), and 8 to 11 years (n = 5,518, 53.9%). For the age categories between 12 and 44 years, the most common MRD was associated with chapter 5 "Mental and behavioural disorders": for patients 12 to 14 years (n = 2,921, 36.5%), 15 to 29 years (n = 17,140, 37.9%), and 30 to 44 years (n = 5,563, 30.6%). For the age categories between 45 and 79 years, the most common MRD was associated with chapter 21 "Factors influencing health status and contact with health services": for patients 45 to 59 years (n = 1,774, 34.2%), 60 to 69 years (n = 252, 36.2%), and 70 to 79 years (n = 471, 74.6%). For patients who were 80 and older, the most common MRD was associated with chapter 9 "Diseases of the circulatory system" (n = 19, 22.1%). For further detail, please see Appendix N.

Within the 2014 and 2015 fiscal years, "Schizophrenia, other psychotic disorders" and "Substance-related disorders" were the two most prevailing MRDs determined by the DSM-IV diagnostic codes for psychiatric hospitalizations, captured in OMHRS. See Table 24.

Table 24. Most responsible diagnoses, defined using DSM-IV diagnostic codes, in psychiatric care hospitalizations of individuals with FAS by fiscal year in select P/Ts*, 2014–2015

Most responsible diagnosis defined using DSM-IV	Fiscal years					
	2013–2014		2014–2015		Total	
	Frequency	%	Frequency	%	Frequency	%
Adjustment disorders	5	3.0	21	11.2	26	7.3
Anxiety disorders	<5	S	<5	S	7	2.0
Delirium, dementia, amnestic, other cognitive disorders	5	3.0	6	3.2	11	3.1
Disorders of childhood/adolescence	20	12.0	25	13.3	45	12.7
Factitious disorders	<5	S	0	0.0	<5	S
Impulse-control disorders	<5	S	<5	S	6	1.7
Mental disorders due to general medical conditions	<5	S	<5	S	<5	S
Mood disorders	14	8.4	27	14.4	41	11.6
Personality disorders	24	14.5	24	12.8	48	13.6
Schizophrenia, other psychotic disorders	55	33.1	43	22.9	98	27.7
Substance-related disorders	32	19.3	36	19.1	68	19.2
Total	**166**	**100**	**188**	**100**	**354**	**100**

Source: CIHI data holding OMHRS
Abbreviation: S, suppressed
* Select P/Ts are AB, BC, MB, NT, ON, and YT

Similarly, in the 2016 and 2017 fiscal years, "Schizophrenia spectrum and other psychotic disorders" and "Substance-related and addictive disorders" were the two highest prevailing MRDs, determined by the DSM-5 diagnostic codes for the psychiatric hospitalizations, captured in OMHRS and show in Table 25.

Table 25. Most responsible diagnosis, defined using DSM-5 diagnostic codes, in psychiatric care hospitalizations of individuals with FAS by fiscal year in select P/Ts*, 2016–2017

Most responsible diagnosis defined using DSM-5	Fiscal years					
	2015–2016		2016–2017		Total	
	Frequency	%	Frequency	%	Frequency	%
Anxiety disorders	<5	S	5	1.4	9	1.4
Bipolar and related disorders	17	6.0	21	6.0	38	6.0
Depressive disorders	31	10.9	43	12.3	74	11.7
Disruptive, impulse-control, and conduct disorders	9	3.2	9	2.6	18	2.8
Dissociative disorders	<5	S	0	0.0	<5	S
Neurocognitive disorders	5	1.8	<5	S	8	1.3
Neurodevelopmental disorders	38	13.4	34	9.7	72	11.4
Obsessive-compulsive disorders	<5	S	<5	S	5	0.8
Other mental disorders	<5	S	<5	S	6	0.9
Personality disorders	39	13.7	47	13.5	86	13.6
Schizophrenia spectrum and other psychotic disorders	69	24.3	89	25.5	158	25.0

Most responsible diagnosis defined using DSM-5	Fiscal years					
	2015–2016		2016–2017		Total	
	Frequency	%	Frequency	%	Frequency	%
Substance-related and addictive disorders	46	16.2	76	21.8	122	19.3
Trauma- and stressor-related disorders	15	5.3	19	5.4	34	5.4
Total	**284**	**100**	**349**	**100**	**633**	**100**

Source: CIHI data holding OMHRS
Abbreviation: S, suppressed
* Select P/Ts are AB, BC, MB, NT, ON and YT

Mortality within the Health Care System

In the 2014 to 2017 fiscal year period, there were 88 deaths among people with FAS captured by the health care system. This translates to the mortality rate of 1,608.2 deaths per 100,000 people with FAS who used the health care system during this period of time.

The leading causes of death, defined using the MRD ICD-10-CA diagnostic codes, were palliative care (11.4%); cardiac arrest, unspecified (8.0%); and anoxic brain damage, not elsewhere classified (5.7%). See Appendix O.

Cost of Health Care Utilization

It was estimated that the economic cost of health care utilized by individuals with FAS was $40 million per year. The largest cost drivers were acute care hospitalizations ($23 million per year), followed by psychiatric care hospitalizations ($10 million per year). See Table 26.

Table 26. Estimated cost of health care utilized by individuals with FAS in select P/Ts*, 2014–2017 (N = 5,399)

Level of care (data sources)	Total cost 2014–2017, $	Average cost per year, $
Acute care hospitalizations (DAD)	92,100,000	23,025,000
Psychiatric care hospitalizations (DAD, OMHRS)	41,166,636	10,291,659
Rehabilitation hospitalizations (DAD)	2,138,999	534,750
Clinical care visits (NACRS)	6,418,370	1,604,593
Emergency care visits (NACRS)	12,900,000	3,225,000
Day surgeries (DAD, NACRS)	1,471,549	367,887
Diagnostic images (NACRS)	438,606	109,652
Other** (DAD, NACRS)	4,417,332	1,104,333
Total	**161,051,492**	**40,262,873**

Source: CIHI data holdings including DAD, NACRS, OMHRS, CMDB
* Select P/Ts are AB, BC, MB, NT, ON and YT
** Comprises chronic care, subacute care, and uncategorized care

Conclusions

Between the 2014 and 2017 fiscal years, there were 100,169 hospitalizations and health care visits among the 5,472 patients with FAS within this cohort. Overall, emergency care visits were the most common level of care required by patients with FAS. This pattern was also observed by patients from BC, MB, NT, ON, and YT, while the health care encounters required by patients with a health card from AB were mainly clinical care visits.

Acute care hospitalizations accounted for a majority of the total economic costs per year associated with patients with FAS within this cohort. Additionally, the most commonly provided MRD was within the ICD-10-CA chapter 5 "Mental and behavioural disorders." More specifically, this ICD-10-CA chapter corresponded to diagnostic blocks such as "Mental and behavioural disorders due to psychoactive substance use," "Schizophrenia, schizotypal, and delusional disorders," and "Neurotic, stress-related, and somatoform disorders."

Furthermore, it was notable to see that such a small percentage of the patients were in the two oldest age categories, since in general older age groups require health services more frequently than younger age groups. The data show that only 6.4% of individuals with FAS aged 45 and over used health care services, which could suggest that the life expectancy of individuals with FAS is much shorter as compared to the general population, which is consistent with previous findings (see, for example, Thanh et al., 2016).

Limitations

The burden and cost associated with FAS found in this study are most likely underestimated. This is due to the following reasons:

1. FAS was the only diagnosis (out of three FASD entities) listed in the diagnostic formulations for episodes of health care. It is known that FAS represents only 10% to 20% of cases of FASD, with alcohol-related neurodevelopmental disorder (ARND) being the largest category of affected individuals. Therefore, the burden and health care cost would increase dramatically if all FASD-related diagnoses were included.
2. Individuals with FAS/FASD are known to have extremely high rates of comorbidities (Popova et al., 2016b); therefore, the rate of health care utilization is expected to be much higher as compared to the general population, which is not reflected in the obtained data.
3. The cohort of patients with FAS presented in this report may represent only a fraction of the population currently living with FAS and who utilized health care services, since individuals with FAS are often underdiagnosed or misdiagnosed (Denny, Coles, & Blitz, 2017). This again would result in an underestimate of the utilization and in turn the cost of health care.
4. CIHI does not present all health service utilization records collected within Canada; for example, NACRS captured approximately 65% of emergency room visits made by Canadians within the 2017 to 2018 fiscal year (CIHI, 2018).

4.3.2 CANADIAN VITAL STATISTICS DEATH DATABASE

Statistics Canada's Canadian Vital Statistics Death Database (CVSD) is an administrative survey which collects data from all P/T vital statistics registries on all deaths in the jurisdiction, noting demographic and medical information (Statistics Canada, 2020d). Data on cause of death are organized according to the ICD-10. Table 27 presents publicly available data on alcohol-related mortality in the perinatal period (code range P00–P96) and due to FAS (code Q86.0) for years 2015 to 2018.

Of approximately 1,000 deaths per year caused by conditions originating in the perinatal period, alcohol-attributable deaths represent less than 0.1% (Statistics Canada, 2020d). There were fewer than five FAS-attributable deaths within 2015 to 2018. However, many studies have reported that individuals with FASD have increased mortality rates as compared to the general population (see, for example, Burd et al., 2008). Thus, the mortality data due to FAS/PAE obtained from Statistics Canada may be under-reported and are likely invalid.

Table 27. Deaths attributed to perinatal alcohol exposure / FAS across Canada, 2015–2018

Cause of death (ICD-10)	2015	2016	2017	2018
Certain conditions originating in the perinatal period (P00–P96)	1,067	1,031	1,041	997
Fetus and newborn affected by noxious influences transmitted via placenta or breast milk (P04)	<5	<5	<5	<5
Fetus and newborn affected by maternal use of alcohol (P04.3)	<5	<5	0	0
Fetal alcohol syndrome, dysmorphic (Q86.0)	0	0	<5	N/A

Source: Statistics Canada, Table 13-10-0153-01 Deaths, by cause
Abbreviation: N/A, not applicable

5.0 Results — Alberta

5.1 Population Profile

5.1.1 OVERVIEW

The AB population was 4,428,247 as of April 1, 2020 (Alberta Government, 2020a), making it the fourth most populous province of Canada and the most populous province in the prairies (Kiprop, 2019). In 2018, there were 52,241 births (Alberta Government, 2020b).

AB is a founding province of the Canadian Northwest FASD Partnership (Alberta Government, 2008) and is regarded as a world leader in FASD research and service delivery (Coons-Harding et al., 2019). Awareness of FAS in AB grew in the 1990s through workforce development, and the cross-sectoral partnership on FAS was established in 1998 to maintain these efforts (Alberta Government, 2013). That partnership later became the government-led FASD Cross-Ministry Committee (FASD-CMC). By 2004, more than 70 programs were providing FASD prevention and support services (Evans, 2004).

The Alberta FASD 10-Year Strategic Plan (2007–2017) received implementation funding in 2008, and the plan guided awareness and prevention initiatives, assessment, diagnosis, and other supports for individuals with FASD using an evidence- and community-based approach (Alberta Government, 2017a; Alberta FASD-CMC, 2013). In 2009, the Alberta FASD Service Networks program increased to 12 networks responsible for delivering services for individuals of all ages (Alberta Government, 2013), thereby increasing community capacity to respond to the prevalence of FASD (FASD Alberta Networks, n.d.).

5.1.2 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO PAE

Alberta's overall poverty rate is one of the lowest in Canada at 12%. The overall incidence of poverty among children (aged zero to nine) in AB is 17%, with higher rates in single-parent families than in two-parent families (Alberta Government, 2013). A study in AB that examined adverse childhood experiences (ACEs), which occurred between ages 0 to 18, across the general population and their association to diagnosed health outcomes in adulthood found that almost half of respondents (44.2%) reported experiencing no ACEs, 35.8% experienced one to two ACEs, and 20% experienced three or more (McDonald & Tough, 2014).

Over a quarter (27.2%) of respondents experienced one form of abuse and almost half (49.1%) experienced one or more forms of household dysfunction (McDonald & Tough, 2014). The prevalence of experiencing physical abuse was 11% overall, and 20% among those living in a household with people who used substances or had a mental illness (McDonald & Tough, 2014). Similarly, the National Population Health Survey in Canada found that 19.4% of adults reported having a parent with a substance use disorder during childhood and 11.5% reported surviving physical abuse (Langlois & Garner, 2013).

After controlling for socio-demographic characteristics, the number of ACEs was significantly associated with a mental disorder, including substance use disorder and/or chronic pain. ACEs of women who were or had been pregnant were found to have an intergenerational impact through binge drinking during pregnancy. Overall, ACEs resulted in a two- to three-fold increase in the odds of at least one binge drinking episode during pregnancy (Currie, 2020).

A secondary analysis (N = 1,663) of the All Our Families Study prospective cohort study recruited 3,200 women who were at fewer than 25 weeks of gestation and undergoing prenatal care for a singleton pregnancy in Calgary, AB (Malta et al., 2012). Women recruited to the study were found to be socio-demographically similar to other women having children in large urban centres, with slightly higher than average incomes (All Our Families Study, n.d.). Data collected between 2008 and 2011 found that 1.5% of women had an alcohol dependency problem in their lifetime and that the majority drank alcohol within the year before becoming pregnant (82.6%), with almost half reporting binge drinking during this time (48.3%) (Currie, 2020). The majority (89%) reported adequate prenatal social support, 28% had survived abuse, 6% reported prenatal depression, and 15% reported anxiety (Malta et al., 2012). Significant independent predictors of alcohol use after pregnancy recognition included: smoking (OR 1.90, 95% CI: 1.43, 2.53) and binge drinking (OR 2.62, 95% CI: 2.16, 3.18) within 12 months of becoming pregnant, not trying to get pregnant (OR 1.91, 95% CI: 1.45, 2.52), and pre-pregnancy BMI <25.0 kg/m^2 (OR 1.41, 95% CI: 1.61, 1.72). Women with prenatal depression and prenatal anxiety were more likely to consume alcohol at low to moderate levels in pregnancy ($p < 0.05$) (Malta et al., 2012). Women who reported binge drinking in early pregnancy were more likely to be younger, receive lower incomes, have a high-school diploma or less education, not live with a partner, and be born in Canada ($p < 0.05$). This pattern of drinking was also associated with prenatal depression, prenatal anxiety, and low dispositional optimism ($p < 0.05$) (Malta et al., 2012).

5.1.3 FASD/PAE PREVENTION PROGRAMS

The Alberta Gaming and Liquor Commission has implemented extensive social responsibility campaigns targeting women who are pregnant through posters, pamphlets, print advertising, TV/radio advertisements, and online advertising (Vallance et al., 2014). Research has found that 89% of AB residents surveyed show a high level of awareness about the causes of FASD (Alberta Government, 2017b).

The FASD-CMC has adopted a Canadian FASD prevention model that provides a continuum of care and support for women (Poole, 2008). A client-focused network of care and services to prevent FASD is available through Alberta's FASD Prevention and Service Delivery Model, which includes the FASD-CMC, Alberta's 12 regional FASD Service Networks, family care clinics, outpatient addiction treatment services, and the Parent-Child Assistance Program (PCAP) (Alberta Government, 2017a).

Prevention support services are specialized, culturally safe, and accessible for women who currently use substances. Trauma-informed- and harm-reduction-oriented services are available to support women to reduce or stop alcohol and/or other drug use during pregnancy (Alberta Government, 2020c). Further, relational, trauma-informed, and community-centred FASD prevention programming was perceived to be suitable for use by Indigenous communities (Pei et al., 2019). PCAP is a three-year home visitation program for women who have used alcohol and/or other drugs, who are pregnant, and who may give birth to a child with FASD.

In 2012–2013, 446 women received network-funded PCAP services, 22% more women than in 2011–2012 and a 575% increase in people served since 2008–2009. Over the course of the three-year program, 65% of women enrolled one year or less and 81% of women completing their third year of the program did not drink alcohol during pregnancy. This prevented an estimated 31 individuals from being born with alcohol exposure before birth between 2008 and 2011, which led to a net cost savings of approximately $22 million in the cost of services (Thanh et al., 2015). The need for specialized residential addiction treatment facilities, increased diagnostic capacity and data collection as well as greater housing and respite supports is recognized, and plans were underway in 2017 to increase access to these supports and public health surveillance (Alberta Government, 2017b).

5.2 Existing Surveillance — PAE

5.2.1 NOTICE OF LIVE BIRTHS — GOVERNMENT OF ALBERTA

Introduction

The Alberta Notice of Live Birth or Stillbirth form (HS0001-130) is a multi-purpose communication form used for:

- Vital Statistics validation of birth — matched with Alberta Registries, Registration of Birth DVS3216 or Stillbirth DVS3218, Medical Certificate of Stillbirth DVS3219;
- transfer of care from facility or health care provider to public health for continuation of care to the mother and newborn baby;
- information on birth outcome to mother's and newborn's primary care provider; and
- Alberta Health Surveillance.

Live births are defined by a complete expulsion or extraction from the mother, irrespective of the duration of the pregnancy, of a fetus in which, after expulsion or extraction, there is breathing, beating of the heart, pulsation of the umbilical cord, or definite movement of a voluntary muscle.

Among women with live births, information on alcohol use is based on maternal self-report at the time of delivery via a questionnaire. The questionnaire measures alcohol intake, frequency of use of alcohol, and trimester of alcohol use. A "yes" to any of the questions is captured as valid use of alcohol.

Objectives

Data from 2006 to 2016 were examined in order to determine recorded prevalence of alcohol use in pregnancy among Albertan women delivering a live birth in 2003–2017.

Methods

Aggregate-level data were obtained from Alberta Vital Statistics reflecting entries in the Notice of Live Births form from 2006 to 2016.

Results

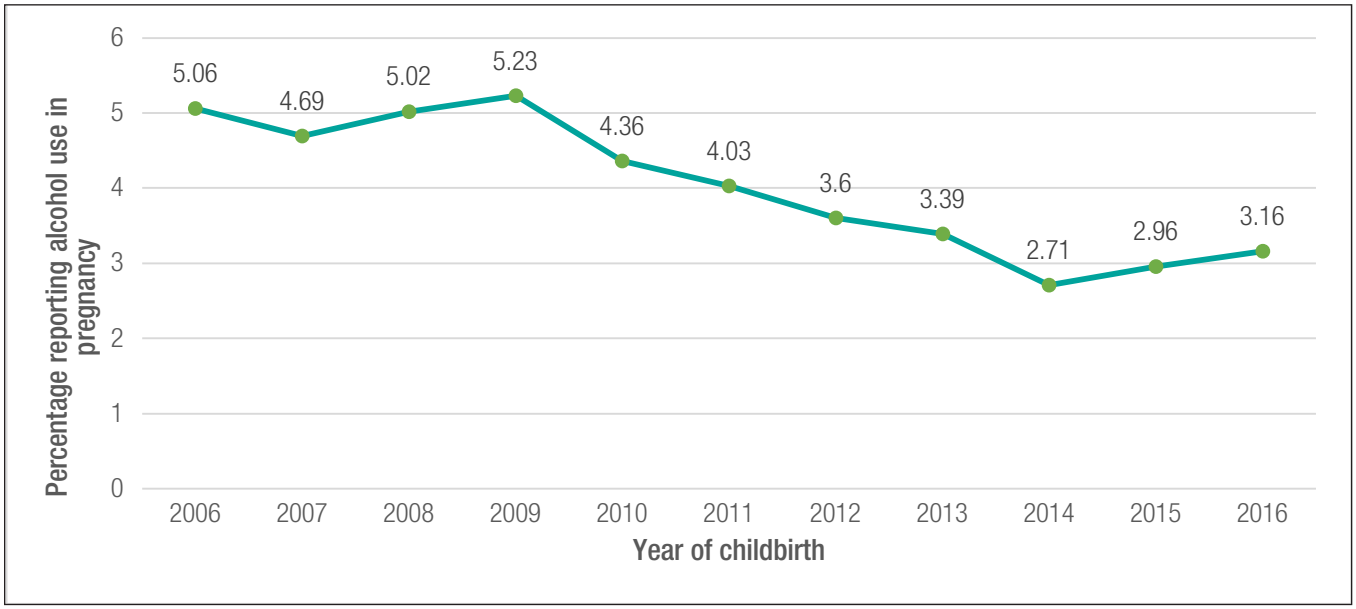
Table 28 presents the prevalence of reported alcohol use among women who delivered live births between 2006 and 2016, including missing entries.

Reported use of alcohol during pregnancy was ranged from 2.71% in 2014 (n = 1,193) to 5.06% in 2006 (n = 2,131). The data are relatively low in missingness, which ranges from 2.14% in 2016 (n = 928) to 7.04% in 2007 (n = 3,055), of records for which there was no data on alcohol use behaviour during pregnancy.

Table 28. Alcohol use among women during pregnancy in Alberta, 2006–2016 (N = 491,323)

Use of Alcohol	Description	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
NO ALCOHOL	Number (n)	38,375	38,307	43,088	39,934	39,211	43,785	42,751	41,329	41,391	43,858	40,997
	Percentage (%)	91.15	88.27	90.35	91.19	91.41	91.52	92.27	93.19	93.99	93.75	94.69
USED ALCOHOL	Number (n)	2,131	2,036	2,395	2,291	1,870	1,929	1,669	1,502	1,193	1,380	1,369
	Percentage (%)	5.06	4.69	5.02	5.23	4.36	4.03	3.60	3.39	2.71	2.96	3.16
MISSING DATA	No response (n)	1,596	3,055	2,208	1,568	1,815	2,129	1,914	1,518	1,455	1,543	928
	No response (%)	3.79	7.04	4.63	3.58	4.23	4.45	4.13	3.42	3.30	3.30	2.14
	Denominator (total # women)	**42,102**	**43,398**	**47,691**	**43,793**	**42,896**	**47,843**	**46,334**	**44,349**	**44,039**	**46,782**	**43,294**

Source: Government of Alberta, Vital Statistics



Source: Government of Alberta, Vital Statistics

Figure 1. Alcohol use in pregnancy among Albertan women with live births, by year of childbirth, 2006–2016

Figure 1 is based on the prevalence information from Table 28, based on years 2006–2016. This figure also indicates a downward trend on the population level of reported alcohol use during pregnancy.

Conclusions

From observing the trend over the years, it seems that PAE is declining. It was highest in 2009, which follows the recession in 2008. Economic stability may be a factor in this observed data point.

The questionnaire collecting information on alcohol use during pregnancy has changed several times in this time period. For example, a question on frequency of alcohol use was added to the questionnaire in 2008.

Possible influences on the downward trend seen in alcohol use behaviour during pregnancy (2009–2014) could include the availability of support services, PCAP program, and other harm-reduction services.

Changes over time in awareness of harms related to alcohol use during pregnancy may have also influenced social desirability bias over time, which could also explain the observed downward trend. The observed downward trend (2009–2014) coincides with the Alberta FASD Service Networks' implementation of awareness activities, which perhaps led women to be less forthcoming about alcohol use during pregnancy.

5.2.2 ALBERTA PERINATAL HEALTH PROGRAM

Introduction

The Alberta Perinatal Health Program (APHP) captures data from antenatal, intrapartum, and postpartum periods for all hospital births and from the registered midwives who attend out-of-hospital (home) births. APHP receives data from paper records, through secure electronic transfer, and through direct entry into the maternal chart within the facility the birth occurred. Data are collated in PeriLinkAB, a comprehensive perinatal repository that supports the APHP, Alberta Health Services, the Health Zones, and other stakeholders.

Data on maternal self-report of alcohol use during pregnancy are collected via a risk assessment form, which captures information from the prenatal chart and is self-identified by the respective patient. Information in the prenatal chart is recorded by the provider of antenatal care (e.g., obstetrician or midwife) throughout the pregnancy.

Objectives

1. Data from the APHP were obtained and utilized in order:
2. to estimate the prevalence of women who consumed one or more drinks per day during pregnancy in 2013–2019; and to estimate the prevalence of binge drinking (three or more drinks) among pregnant women in AB from 2013 to 2019.

Methods

Aggregate level data were received for years 2013 to 2019 for self-identified alcohol use in Albertan women delivering in this time period. These data are irrespective of birth outcome (live birth or stillbirth). Percentages presented in these data reflect exposed pregnancies (singleton and multiple) instead of exposed infants; therefore, percentages reflect the number of women who have self-identified each risk. There are two separate risk factors captured and reported on: 1) "three or more drinks on any one occasion during pregnancy," and 2) "one or more drinks per day throughout pregnancy." Where a pregnant woman was indicated to drink three or more drinks on one occasion during the pregnancy in addition to one or more drinks per drinking day, this was indicative of both risk factors.

Results

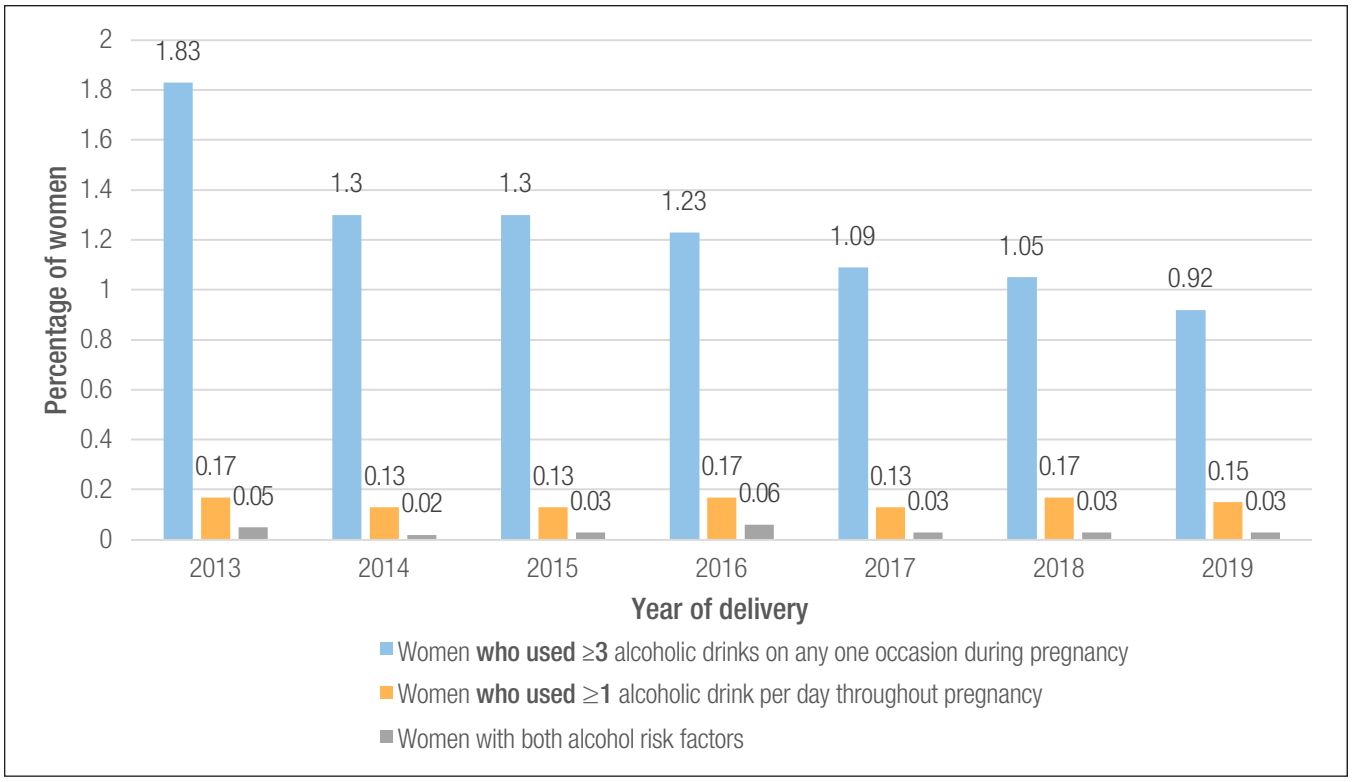
Data in Table 29 show that the prevalence of one or more occasion of women consuming three or more drinks during pregnancy steadily decreased from 1.83% in 2013 to 0.92% in 2019. The proportion of women consuming one or more alcoholic drinks per day ranges from 0.13% to 0.17%, while the proportion of women with both risk factors ranges from 0.02% to 0.06%.

Table 29. Alcohol use among women during pregnancy and at the time of delivery in Alberta, 2013–2019, (N = 379,617)

	2013		2014		2015		2016		2017		2018		2019	
Live births	54,233		56,779		57,888		56,833		54,639		53,322		52,524	
Women delivering	53,320		55,823		56,902		55,821		53,730		52,405		51,616	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Women who use ≥1 alcoholic drink(s) per day throughout pregnancy	93	0.17	70	0.13	72	0.13	94	0.17	68	0.13	87	0.17	78	0.15
Women who use ≥3 alcoholic drinks on any single occasion during pregnancy	974	1.83	727	1.3	742	1.3	685	1.23	586	1.09	549	1.05	474	0.92
Women with both risk factors: 1) use ≥1 alcoholic drink(s) per day throughout pregnancy; and 2) use ≥3 alcoholic drinks on any single occasion during pregnancy	27	0.05	11	0.02	18	0.03	32	0.06	18	0.03	16	0.03	16	0.03

Source: PeriLinkAB (APHP)

Figure 2 demonstrates the downward trend in the maternal self-report of consuming three or more drinks on any single occasion during pregnancy from 2013 to 2019. No obvious patterns are seen with respect to the proportion of women consuming one or more drink per drinking day and the number of women with both risk factors indicated on the delivery record.



Source: PeriLinkAB (APHP)

Figure 2. Alcohol risk factors among pregnant women delivering in Alberta, 2013–2019

Conclusions

These data demonstrate very low prevalence of alcohol use during pregnancy (less than 1%) as compared with population-based prevalence estimate in Canada (10%). These data show that binge drinking (three or more drinks on at least one occasion) during pregnancy appears to be decreasing among Albertan women from 2013 to 2019.

Limitations

Prevalence of alcohol use during pregnancy is dependent on the completeness of the data and thoroughness of screening in antenatal care. Social desirability bias may have influenced self-report of alcohol use behaviour. Fears of child apprehension may also contribute to under-reporting as the alcohol use behaviour is linked to the personal health information for each woman. It is not clear how pregnancy recognition influenced alcohol use screening, data collection, and derived prevalence estimates.

5.2.3 ALBERTA PARENT-CHILD ASSISTANCE PROGRAM

Introduction

The Alberta Parent-Child Assistance Program is a provincial program that aims to support women to reduce or abstain from alcohol and drug use during pregnancy, promoting healthy pregnancies and lives for women and their children. Alberta PCAP is a targeted, holistic, cost-effective (Thanh et al., 2015) harm-reduction initiative that operates to serve levels 3 and 4 of FASD prevention (Poole et al., 2016), using a three-year time span of home visitation and case management.

Objectives

Alberta PCAP data from fiscal years 2015–2016 to 2018–2019 were utilized to obtain the following estimates:

1. the prevalence of alcohol use and binge drinking (five or more drinks on one occasion) during the most recent pregnancy among women accessing the PCAP;
2. the prevalence of mothers with PAE accessing the PCAP; and
3. the prevalence of self-reported FASD diagnosis among mothers accessing the PCAP.

Methods

Cross-sectional (aggregate and record-level data) for fiscal years 2015–2016 to 2018–2019 on alcohol use during the current or most recent pregnancy, chronic medical conditions, and self-reported FASD diagnosis among mothers participating in the PCAP were obtained from intake assessment forms including: Provincial Intake Addiction Severity Index (ASI) — Part A Interview, Chronic Medical Conditions; and Provincial Intake Addiction Severity Index (ASI) — Part B Interview, Alcohol Use in Pregnancy.

Results

A total of 434 women accessed services provisioned by the Alberta PCAP in fiscal years 2015–2016 to 2018–2019. A total of 208 women accessing PCAP services provided information on their alcohol consumption during their most recent pregnancy. See Table 30.

Across all fiscal years, the proportion of women who reported use of alcohol during the first trimester (range: 52.0%-72.2%) was higher than in the second trimester of the respective pregnancy (maximum: 13.9%). While 64.9% (n = 135) reported using alcohol during the first trimester, only 10.1% reported using alcohol in the second and third trimesters. These data also indicate that alcohol was used more frequently overall in the first trimester, with 39 women (18.8%) indicating 1 to 4 days per week, while more than 31 women (over 14.9%) indicated daily or almost daily use. Across all years of data, 95 women (45.7%) reported binge drinking (consuming five or more drinks on one occasion) at least once during the first trimester, while only 16 women (7.7%) reported binge drinking in the second and third trimesters.

Table 30. Alcohol use during pregnancy of women participating in Alberta PCAP, 2015–2019 (N = 434)

Alcohol use during pregnancy	Fiscal years				
	2015/16 (n = 72)	2016/17 (n = 50)	2017/18 (n = 49)	2018/19 (n = 37)	All years combined (n = 208)
FIRST TRIMESTER					
Any alcohol use	**52 (72.2%)**	**26 (52.0%)**	**32 (65.3%)**	**25 (67.6%)**	**135 (64.9%)**
1 to 3 times per month	18 (25.0%)	7 (14.0%)	7 (14.3%)	7 (18.9%)	39 (18.8%)
1 to 4 days per week	15 (20.8%)	5 (10.0%)	10 (20.4%)	9 (24.3%)	39 (18.8%)
Daily or almost daily	17 (23.6%)	8 (16.0%)	6 (12.4%)	<5(S)	S
Any binge drinking*	**37 (51.4%)**	**17 (34.0%)**	**22 (44.9%)**	**19 (51.4%)**	**95 (45.7%)**
Less than once per month	<5 (S)	<5 (S)	6 (12.4%)	<5 (S)	10 (4.8%)
About once per month	<5 (S)	5 (10.0%)	<5 (S)	<5 (S)	11 (5.3%)
2 to 3 times per month	9 (12.5%)	<5 (S)	<5 (S)	6 (16.2%)	20 (9.6%)
1 to 4 days per week	11 (15.3%)	<5 (S)	7 (14.3%)	6 (16.2%)	S
Daily or almost daily	13 (18.1%)	7 (14.0%)	<5 (S)	<5 (S)	27 (13.0%)
SECOND AND THIRD TRIMESTERS					
Any alcohol use	**10 (13.9%)**	**<5 (S)**	**<5 (S)**	**<5 (S)**	**21 (10.1%)**
Any binge drinking*	**6 (8.3%)**	**5 (10.0%)**	**<5 (S)**	**<5 (5)**	**16 (7.7%)**

Source: Alberta PCAP
Please note: column percentages are in parentheses
* Binge drinking refers to the consumption of five or more drinks at a time
S – Suppressed

A total of 434 women were asked if their biological mother consumed alcohol while pregnant with them. Across fiscal years, 122 women (28.1%) self-reported as being prenatally alcohol-exposed, and 97 women (22.3%) indicated that they had been exposed to heavy alcohol consumption. About half of the sample (n = 212, 48.8%) indicated they were not prenatally alcohol-exposed, and 23% of women did not know this information. See Table 31.

Table 31. Women with prenatal alcohol exposure participating in Alberta PCAP, 2015–2019 (N = 434)

Prenatal alcohol exposure	Fiscal years				
	2015/16 (n = 128)	2016/17 (n = 124)	2017/18 (n = 93)	2018/19 (n = 89)	All years combined (N = 434)
No	55 (42.9%)	67 (54.0%)	46 (49.5%)	44 (49.4%)	212 (48.8%)
Yes (includes heavy and light drinkers)	42 (32.8%)	36 (29.0%)	18 (19.4%)	26 (29.2%)	122 (28.1%)
Don't know / no information	31 (24.2%)	21 (16.9%)	29 (31.2%)	19 (21.3%)	100 (23.0%)

Source: Alberta PCAP
Please note: column percentages are in parentheses

Of the 404 women who reported on chronic medical conditions across all fiscal years, 197 (48.8%) reported to have a chronic medical condition that continues to interfere with their daily lives. Of these women, 47 (23.8%) reported diagnoses of FAS or FASD, including suspected and confirmed cases. Overall, 11.6% (47 out of 404) of women in the total sample reported being diagnosed with FAS or FASD. See Table 32.

Table 32. Women who reported FASD as a chronic medical condition participating in Alberta PCAP, 2015–2019 (N = 434)

Fiscal years	Total number of women	Women who reported a chronic medical condition (including FASD)		Women who reported FASD as a chronic medical condition		Proportion of women reporting FASD among total sample
		Number	Percent	Number	Percent*	
2015–2016	83	48	57.8%	15	31.2%	18.1%
2016–2017	122	56	45.9%	23	41.1%	18.8%
2017–2018	102	48	47.1%	6	12.5%	5.9%
2018–2019	97	45	46.4%	S	S	S
All years combined	**404**	**197**	**48.8%**	**47**	**23.8%**	**11.6%**

Source: Alberta PCAP
Abbreviation: S, suppressed
Please note: reported FASD includes diagnosed and suspected cases
* Denominator is women who reported a chronic medical condition in the respective fiscal year(s)

Table 33 presents chronic medical conditions in ranked order of frequency in all fiscal years combined. Some women specified more than one condition; these conditions have been counted independently for ranking purposes.

Confirmed or suspected FAS or FASD diagnoses was the top ranked chronic medical condition in all fiscal years combined (47 out of 160 women; 29.4%).

Table 33. Ranked specified chronic medical conditions among women participating in Alberta PCAP, 2015–2019 (N = 434)

Chronic medical conditions	Number of women
FAS/FASD (incl. suspected)	**47**
Digestive (acid reflux, celiac, Crohn's disease, gallbladder, IBS, ulcers)	16
Brain (non-FASD) (damage, injury, migraines, PTSD, trauma)	13
Spinal/back/nerve (nerve pain, tendonitis, back pain, broken tailbone)	12
Asthma, COPD, lung condition	7
Anxiety	6
Hepatitis C and unspecified	6
Fibromyalgia	6
Arthritis (rheumatoid arthritis and osteoporosis)	5
Heart condition, hypertension, high BP	<5
Joint and/or mobility issues other than back/spine	<5
Epilepsy	<5
Low thyroid and low iron	<5
Diabetes	<5
Seizures	<5
ADHD	<5
Skin issues (eczema)	<5
Anemia	<5
Scoliosis	<5
Allergies	<5
Deformed ribs	<5

Chronic medical conditions	Number of women
Conversion disorder	<5
Spina bifida	<5
Nerve pain (nerve pain, tendonitis, back pain, broken tailbone)	<5
Thyroid (Graves' disease)	<5
Dental	<5
Cerebral palsy	<5
Polycystic ovary syndrome (PCOS)	<5
Hernia	<5
Interstitial cystitis	<5
Total	**160**

Source: Alberta PCAP
ADHD: Attention Deficit Hyperactivity Disorder; BP: blood pressure; COPD: Chronic obstructive pulmonary disease; PCOS: Polycystic ovary syndrome

Conclusions

The self-reported FASD diagnosis and PAE of mothers accessing the program, combined with a high proportion of reported alcohol use behaviour during the most recent pregnancy, suggests that PCAP may serve many families where there is risk for PAE and FASD familial recurrence.

In particular, the high prevalence of reported binge drinking during the most recent pregnancy suggests that children of respective mothers accessing PCAP are at higher risk of developing FASD.

5.2.4 PUBLISHED STUDIES — PAE

A total of ten studies were identified to present regional estimates of alcohol use during pregnancy in the general population of AB (see Appendix D). A number of data collection methods were utilized across these studies, including community-based surveys, population-based medical records, the T-ACE screener, as well as the CCHS.

None of the identified studies were found to present estimates of PAE within the years of interest (2015–2020). The most recent estimate was derived from a secondary analysis (N = 1,663) of the All Our Families prospective cohort study, which collected data between 2008 and 2011. This study by Currie et al. (2020) found a 10% prevalence of binge drinking during pregnancy, which was defined as five or more drinks, including alcohol use which occurred before pregnancy recognition.

Previously published studies on alcohol use during pregnancy among women in AB in the general population also obtained prevalence estimates from both pre- and post-pregnancy recognition. The earliest study was conducted by Wenman et al. (2002), which found that 17.5% of women in a hospital-based sample consumed alcohol during pregnancy in 1994–1995. In 2008, a community-based study found that up to 49% of women consumed alcohol (any amount) during pregnancy, prior to pregnancy recognition (McDonald et al., 2014). Alarmingly, 46% of women reported alcohol use following pregnancy recognition, mostly at low to moderate levels (McDonald et al., 2014). With respect to binge drinking, a study by Tough et al. (2006) found that up to 10.7% of women had engaged in binge drinking prior to pregnancy recognition, while 0% binge drank following pregnancy recognition. Data collected through the All Our Babies

(now All Our Families) Study between 2008 and 2011 found that almost half of women (49%) reported drinking some alcohol in pregnancy, including before they realized they were pregnant, and 13% reported binge drinking prior to pregnancy recognition (Currie et al., 2020).

One regional estimate was obtained on alcohol use during pregnancy among special subpopulations of women in AB, though it is outdated (study year: 1989). Dow-Clarke, MacCalder, & Hessel (1994) studied women in isolated communities in Northern Alberta and found that 69.8% and 48.8% of women consumed alcohol pre-pregnancy recognition and post-pregnancy recognition, respectively.

5.3 Existing Surveillance — FASD

5.3.1 FASD ONLINE REPORTING SYSTEM

Introduction

The FASD Online Reporting System (ORS), an initiative of the Alberta FASD Cross-Ministry Committee that is managed by the Ministry of Community and Social Services, was introduced in 2012. FASD-ORS collects data from clients served by the Alberta FASD Service Networks program, including client demographics, assessment and diagnosis results, presenting issues, and changes in the status of presenting issues. This reporting system captures assessment and diagnostic clinic data from FASD clinics in AB that receive provincial cross-ministry funding and have mandatory reporting requirements.

FASD diagnostic criteria (Cook et al., 2016) was utilized for assessment across all 19 clinics that receive funding through the Alberta FASD Service Networks program.

Objectives

FASD-ORS data from the 2017–2018 and 2018–2019 fiscal years were utilized to obtain the following:

1. an estimate of new FASD diagnoses during each year in AB; and
2. a demographic profile of individuals newly diagnosed in AB each year, including age, gender, racial origin, and geographic location.

Methods

Cross-sectional aggregate-level data were received from the Program Policy and Improvement Division within Community and Social Services, Government of Alberta (GOA) for two consecutive fiscal years (2017–2018 and 2018–2019). Provincial data was received from ORS on gender, age, ethnicity, location (rural/remote/urban), diagnostic category, and caregiver status (i.e., parents, in care, kinship).

Results

According to FASD-ORS, there were 363 new diagnoses (51% males) in 2017–2018 and 367 new diagnoses (51% males) in 2018–2019, including with and without sentinel facial features. In 2018–2019, according to FASD-ORS, an additional 71 unique individuals were diagnosed as "at risk for neurodevelopmental disorder and FASD associated with prenatal exposure."

The data presenting age breakdown (see Table 34) show a similar distribution in both fiscal years. In 2017–2018 and 2018–2019, more than half of individuals diagnosed were aged 18 and over (55.4% and 54%, respectively).

Table 34. Individuals diagnosed with FASD by age categories and fiscal year in Alberta (N = 730)

Age category (years)	2017–2018	2018–2019
0-5	1.9%	2.0%
6-12	28.1%	28.0%
13-17	14.6%	16.0%
18-24	17.9%	17.0%
24-65	37.5%	37.0%

Source: Alberta FASD-ORS

Table 35. Individuals diagnosed with FASD by location and fiscal year in Alberta (N = 730)

Location	2017–2018	2018–2019
On Métis Settlements	2.7%	2.7%
On reserve	18.3%	19.5%
Rural and remote	41.3%	42.4%
Urban	37.7%	35.4%

Source: Alberta FASD-ORS
Note: Individuals may report more than one location during the fiscal year

Conclusions

Data from FASD-ORS capture new diagnoses, which may indicate incidence in AB for 2017–2018 and 2018–2019 fiscal years. Most clinics in AB (19 of 23) are funded by the FASD Service Networks, and 18 out of 23 report into ORS.

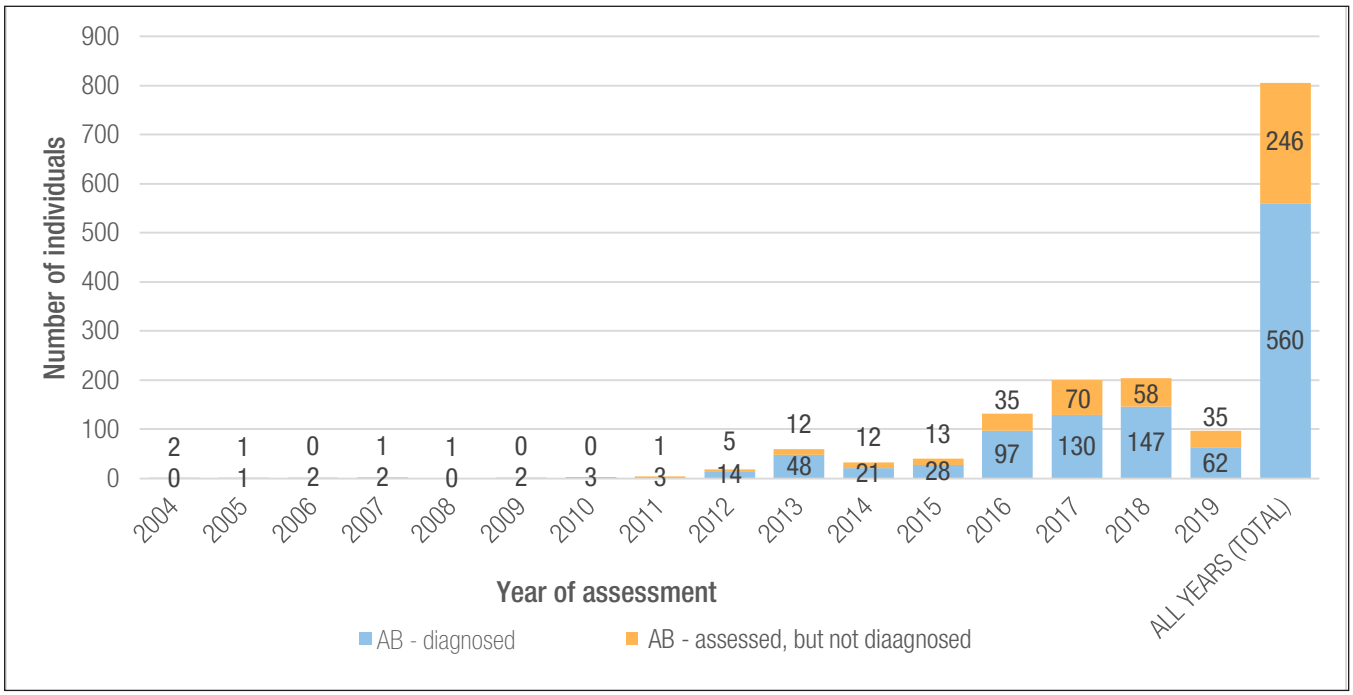
Data from the ORS has an overlap with data from the Family Supports for Children with Disabilities (FSCD) program; newly diagnosed children captured in the ORS may also be receiving services from the FSCD program.

In AB, the government supports (through the FASD Cross-Ministry Committee) FASD diagnostic services located on and off reserve communities. Access is available to all demographics. There are a few on reserve FASD clinics exclusively serving Indigenous people, but at least one of these does not report to ORS and is therefore not represented in these numbers.

5.3.2 CANADIAN NATIONAL FASD DATABASE

Please refer to the Canadian National FASD Database section of this report (Section 4.2.1) for a detailed analysis of these data.

Data in the figure below presents two categories of diagnostic outcomes: diagnosed, which includes individuals with FASD with or without sentinel facial features, and assessed but not diagnosed, which includes those in the at-risk category as well. Data are presented by year of assessment; where a year is missing, this indicates zero diagnoses and zero assessments in the respective year. Please note that only partial data were available for 2019. The data available from the database suggests that the number of assessments may have increased in recent years (2015–2019) in participating clinics located in AB.



Source: CanFASD Universal Dataform project

Figure 3. Individuals assessed for FASD diagnosis and individuals who received FASD diagnoses by year in Alberta, 2004–2019

5.3.3 DIAGNOSTIC CLINIC SURVEY

Methods

Please refer to the Diagnostic Clinic Survey section of this report (Section 4.2.2) for a detailed methodology.

Results

In Alberta, there were 23 clinics between 2015 and 2019 identified as having the capacity to conduct neurodevelopmental assessments for FASD among children and adults. Out of the 23 clinics, 14 participated in the survey (response rate 60.9%), contributing at least one year of clinic data. Among clinics that contributed data for diagnostic capacity, there were seven clinics in total that only accepted pediatric referrals for FASD (as of March 2020).

Table 36 represent all patient populations (children and adults) among clinics that have contributed data for the respective year. On average, 31 to 34 patients were assessed in each diagnostic clinic per year. Among them, roughly two-thirds were newly diagnosed with FASD, between 18 to 23 patients on average per year.

Diagnostic slots allotted to FASD diagnoses in this time frame ranged from 29 to 34 patients per year. The number of individuals on a waitlist ranged from 53 to 103 per clinic. This means that annual diagnostic capacity of clinics does not meet the demand for patients waiting to be assessed. Waiting time for FASD assessment ranges from one to three years.

Table 36. Diagnostic capacity of Albertan neurodevelopmental clinics that participated in the survey, 2015–2019 (N = 23)

	Year of assessment				
	2015	2016	2017	2018	2019
Number of clinics contributing data	7	9	9	12	10
INDIVIDUALS SEEN IN EACH CLINIC FOR FASD DIAGNOSES					
Mean (SD)	32 (10.0)	31 (14.3)	34 (10.6)	31 (17.2)	32 (9.7)
Range	13-45	12-49	14-45	6-71	21-47
INDIVIDUALS DIAGNOSED WITH FASD					
Mean (SD)	21 (7.0)	18 (10.8)	23 (8.0)	21 (14.7)	19 (6.5)
Range	8-29	7-39	11-34	2-48	11-32
DIAGNOSTIC SLOTS ALLOTTED TO FASD DIAGNOSES					
Mean (SD)	32 (15.1)	31 (16.8)	29 (14.9)	30 (20.2)	34 (14.7)
Range	2-48	2-48	2-48	2-72	2-50
INDIVIDUALS WAITING FOR FASD ASSESSMENT					
Mean (SD)	103 (17.5)	120 (0)	101 (26.3)	72 (54.4)	53 (39.8)
Range	85-120	120-120	65-140	0-185	1-110

Source: CAMH REDCap survey
Abbreviation: SD, standard deviation

Each participating clinic was also asked to describe their waitlist, and responses varied in the details provided. Among the 13 clinics that responded to this question, two were pilot clinics that did not have a waitlist defined or organized at the time of the survey. Four clinics indicated that PAE would need to be confirmed prior to the assessment, while three other clinics indicated that such confirmation is not always necessary, and that assessment would not be delayed if PAE information could not be found. One clinic indicated a three- to six-month assessment wait time for children and a minimum wait time of six months for adult patients. There was no information contributed with regards to possible referral sources (e.g., school or community agencies); it was simply noted that the completion of a referral package was necessary to be on the waitlist.

5.3.4 PUBLISHED STUDIES — FASD

Please refer to Appendix E for studies which reported on prevalence of FASD in AB based on PS. Regional data for AB from the Pei et al. (2020) study estimates that the prevalence of FASD among kindergarten students in the general population is 1.1 per 1,000, or 0.11%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database.

Thanh et al. (2014) used Albertan administrative health databases to examine the prevalence of FASD in AB using ICD-9 code 760.71 and ICD-10 codes Q86.0 and P04.3. In 2012, Thanh et al. (2014) found a prevalence of 11.7 per 1,000 (1.17%) of FASD among people of all ages in AB, for a total of 45,984 people living with FASD in AB from 2003 to 2012. This was estimated using the mid-year population size for AB in 2012. The prevalence of FASD was examined across age groups as well, the highest being among Albertans aged 0 to 9 years (3.27%) and the lowest among Albertans aged 40 to 49 years (0.39%).

It is estimated that 4.4% (44 per 1,000 births) of individuals in AB have FASD (Thanh et al., 2014). This equates to 739 to 1,884 people born annually with FASD and 46,000 people living with FASD (in March 2012), including 6,000 individuals with FAS and 40,000 individuals with FASD-related conditions. An estimate almost one-third higher than the previous estimate of 36,000 (Alberta Government, 2012). Sex-specific FASD prevalence is 12.9 (range 8.5 to 17.3) per 1,000 males in comparison to 10.4 (range 7.9 to 12.8) per 1,000 females. These differences are only found in individuals 29 years and younger, which may be reflective of men having higher rates of FASD and shorter life expectancy (Thanh et al., 2014).

Two publications were identified to have estimates for FASD for special subpopulations in AB. Among an Albertan population of children in care in 2010–2014, a prevalence estimate of 103.3 per 1,000 (10.3%) for FASD was obtained by the Tri-provincial FASD Project (Fuchs & Burnside, 2014). The 2006 Aboriginal Children's survey found the prevalence of FASD among children aged 0 to 5 who lived off reserve to be 13 per 1,000 (1.3%) (Werk, Cui, & Tough, 2013).

5.4 Health Care Utilization

5.4.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From the 2014 to 2017 fiscal years, a total of 69,294 hospitalizations and health care visits were made by patients with FAS in AB. These health care encounters were most often clinical care visits (n = 25,248). This pattern was consistent for each fiscal year (2014–2017). Among the patients with FAS with a health card from AB, 70.2% resided in urban areas and 3% of the patients with FAS were homeless.

5.4.2 ALBERTA AMBULATORY CARE CLASSIFICATION SYSTEM AND INPATIENT CARE DATABASES

Introduction

Data in the Alberta Ambulatory Care Classification System captures all ambulatory care encounters, including facility-based outpatient medical and/or surgical care that is provided in publicly funded clinics, day surgery, and emergency department visits. AB has submitted ambulatory care data to CIHI's National Ambulatory Care Reporting System since 2010 and utilizes CIHI's Comprehensive Ambulatory Care Classification System (CACS) grouping methodology.

Inpatient care data captures morbidity and separations in AB hospitals, including acute inpatient care, treatment, examination, and observations for hospital inpatients. This database, also known as part of the Discharge Abstract Database, contains records for hospitalizations and discharges for patients accessing care in free-standing rehabilitation and psychiatric hospitals in AB. These data are also reported to CIHI.

Since 1997, FASD is indicated with the use of the following ICD-10-CA codes for the respective health care encounters in these administrative health databases:

- Q86.0: fetal alcohol syndrome, dysmorphic
- P04.3: newborn affected by maternal use of alcohol

Objectives

1. To measure the frequency of use of ICD-10 codes Q86.0 and P04.3 in ambulatory and inpatient care encounters in AB (2006–2019);
2. to explore the use of ICD-10 codes Q86.0 and P04.3 in ambulatory and inpatient care encounters in AB (2006–2019) by patient sex/gender and age at time of encounter;
3. to measure the frequency of individuals with ambulatory and inpatient care encounters in AB wherein ICD-10 codes Q86.0 and P04.3 are first recorded (2006–2019); and
4. to explore the age and gender/sex breakdown by year (2006–2019) of individuals with ambulatory and inpatient care encounters in AB wherein ICD-10 codes Q86.0 and P04.3 are first recorded.

Methods

Data were extracted from the Alberta Ambulatory Care Classification System and inpatient (hospitalization) administrative data. Emergency department visits are derived from the Alberta Ambulatory Care Classification System file. Records from emergency departments and community urgent and advanced care centres are included. Frequencies and percentages in tables below are derived from both administrative health databases.

These data do not include members of the Canadian Armed Forces, Royal Canadian Mounted Police (RCMP), inmates in federal penitentiaries, or those who have opted out of the Alberta Health Care Insurance Plan. Observations with a missing value for sex, zone, or age are excluded in their respective tables. Transfers between facilities are included as multiple visits.

Results

Ambulatory and Inpatient Care in Alberta: Use of ICD-10 Codes Q86.0 and P04.3

Data in Table 37 represent health care encounters, not unique individuals. The use of the ICD-10 code Q86.0 does not equate to a diagnosis of FAS. Ambulatory and inpatient care data indicate that a total of 9,657 health care encounters include the use of diagnostic code Q86.0, and 453 encounters include the use of diagnostic code P04.3.

Table 37. Use of ICD-10 codes Q86.0 and P04.3 in ambulatory and inpatient care in Alberta, 2006–2019 (N=9,567)

Year of health care utilization	Frequency (n) of Q86.0 code use	Frequency (n) of P04.3 code use
2006	399	52
2007	470	48
2008	431	42
2009	504	61
2010	558	39
2011	577	33
2012	717	33
2013	733	19
2014	763	28
2015	812	24
2016	896	25
2017	1,040	17
2018	944	20
2019	813	12
Total	**9,657**	**453**

Source: Alberta Ambulatory Care Classification System and inpatient care data

An age breakdown of health care encounters utilizing both ICD-10 codes shows that the majority (98.5%) of encounters with P04.3 were those of neonates and young children (under five years). Encounters with Q86.0 are more distributed across age categories, indicating that individuals with FAS use ambulatory and inpatient care at all ages.

Table 38. Use of ICD-10 codes Q86.0 and P04.3 in ambulatory and inpatient care by age of patient at time of encounter in Alberta, 2006–2019

Age category (years)	Frequency of Q86.0 code use, n (%)	Frequency of P04.3 code use, n (%)
<5	384 (4.0)	446 (98.5)
5-12	1,040 (10.8)	<5 (S)
13-17	2,118 (21.8)	<5 (S)
18-24	2,979 (30.9)	0
25-64	3,118 (32.3)	<5 (S)
65+	**16 (0.2)**	**0**

Source: Alberta Ambulatory Care Classification System and inpatient care data
Abbreviation: S, suppressed

Data on sex/gender breakdown of patients with health care encounters indicating use of ICD-10 code Q86.0 show that male individuals with FAS use ambulatory and inpatient care more than female individuals with FAS in AB.

Table 39. Use of ICD-10 code Q86.0 in ambulatory and inpatient care encounters by year and patient sex/gender in Alberta, 2006–2019, (N = 3,884)

Year of health care utilization	Encounters of female patients with Q86.0, n (%)	Encounters of male patients with Q86.0, n (%)
2006	176 (44.1)	223 (55.9)
2007	192 (40.9)	278 (59.2)
2008	174 (40.4)	257 (59.6)
2009	227 (45.0)	277 (55.0)
2010	264 (47.3)	294 (52.7)
2011	236 (40.9)	341 (59.1)
2012	295 (41.1)	422 (58.9)
2013	323 (44.1)	410 (55.9)
2014	326 (42.7)	437 (57.3)
2015	351 (43.2)	461 (56.8)
2016	372 (41.5)	524 (58.5)
2017	465 (44.7)	575 (55.3)
2018	421 (44.6)	523 (55.4)
2019	350 (44.1)	463 (47.0)
Total	**4,172 (43.2)**	**5,485 (56.8)**

Source: Alberta Ambulatory Care Classification System and inpatient care data

The majority of encounters indicating ICD-10 code P04.3 are those pertaining to neonates and children (under five years), and among them, a slightly higher proportion of health care encounters are of male patients (52.5%).

Table 40. Use of ICD-10 code P04.3 in ambulatory and inpatient care encounters by patient sex/gender in Alberta, 2006–2019, (N = 3,868)

Patient sex/gender	Encounters of patients with P04.3, n (%)
Female	214 (47.2)
Male	238 (52.5)
Total	452 (100)

Source: Alberta Ambulatory Care Classification System and inpatient care data

Ambulatory and Inpatient Care in Alberta: First-Time Use of Q86.0

These data represent first-time entry of ICD-10 code Q86.0 (FAS, dysmorphic) in ambulatory and inpatient health care services in AB; however, this does not equate with an official new diagnosis of FAS. From 2006 to 2019, a total of 3,884 individuals had a health care encounter wherein Q86.0 was first reported in their health care record. Among them, 2,241 (57.7%) were male.

Table 41. First-time use of ICD-10 code Q86.0 for patients utilizing ambulatory and inpatient care in Alberta, 2006–2019 (n = 3,884)

Year of health care utilization	Number of patients with first-time reporting of Q86.0	Male patients with first-time reporting of Q86.0, n (%)
2006	305	169 (59.5)
2007	284	155 (59.6)
2008	260	166 (56.3)
2009	295	149 (56.0)
2010	266	161 (62.4)
2011	258	178 (60.1)
2012	296	159 (58.5)
2013	272	164 (57.5)
2014	285	155 (55.8)
2015	278	164 (59.9)
2016	273	180 (58.3)
2017	309	136 (52.1)
2018	261	136 (56.2)
2019	242	169 (59.5)
Total	**3,884**	**2,241 (57.7)**

Source: Alberta Ambulatory Care Classification System and inpatient care data

Among individuals with diagnostic code of Q86.0 indicated for the first time, the largest proportion (27.5%) was in the adult category (25 to 64 years) at the time of respective health care encounter.

Table 42. First-time use of ICD-10 code Q86.0 in ambulatory and inpatient care by age of patient at time of encounter in Alberta, 2006–2019 (n=3,868)

Age group (years)	Patients with first-time reporting of Q86.0 (n)	Percent of all first-time uses of Q86.0
<5	278	7.2
5-12	611	15.8
13-17	993	25.7
18-24	912	23.6
25-64	1065	27.5
65+	9	0.2
Total	**3,868**	**100**

Source: Alberta Ambulatory Care Classification System and inpatient care data

Conclusions

Data from frequency of ICD-10 code Q86.0 suggests that individuals with FAS access ambulatory and inpatient care services frequently. Among individuals represented in the data available, a significant proportion of encounters pertain to young adults (18 to 24 years), adults (25 to 64 years), and male individuals with recorded FAS. It may be the case, however, that this is simply due to FAS being coded more often for certain age groups and for male patients, and not actual trends in health care utilization.

ICD-10 code P04.3 is used less often in comparison, mostly for neonates and children (under five years). First-time data entry of code Q86.0 (FAS) in ambulatory and inpatient care data was more common with respect to young adults (18 to 24 years), adults (25 to 64 years), and male patients.

Limitations

These data may not correspond with actual rates of utilization of ambulatory and inpatient services among individuals with FAS in AB, as these statistics are solely based on encounters and individuals wherein FAS is recorded administratively. It is possible that FAS may not be recorded in some cases, or it is simply undiagnosed or misdiagnosed in some cases, and it is therefore not reflected in these data. These data also may not correspond with first-time FAS diagnosis by a multi-disciplinary FASD assessment team, among patients in this sample and time frame.

5.4.3 PHYSICIAN CLAIMS DATA — ALBERTA

Introduction

Practitioner claims in AB consist of processed claims for Albertan individuals who have lived in AB for at least three months, are registered with Alberta Health, and are covered by the Alberta Health Care Insurance Plan benefits. Data that are collected include patient, provider, and service information including up to three diagnostic codes, which are coded in ICD-9-CM/Schedule of Medical Benefits (modified Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures; CCP). The dataset consists of processed claims for eligible Albertans and medical reciprocal patients to pay medical doctors and other allied practitioners (optometrists, podiatrists, podiatric surgeons, and dentists) and to track shadow-billed claims. Claims data are collected for the purpose of paying providers fee-for-service payments or for tracking shadow-billed services.

In AB, information regarding the use of ICD-9 code 760.71 (alcohol affecting fetus or newborn via placenta or breast milk) is only used in physician claims data as a billing code. The use of this specific code began in 2013.

Objectives

1. To obtain the frequency of use of ICD-9 code 760.71 by patient age and sex in physician claims in 2013–2019; and
2. To obtain the frequency of individuals by patient age and sex newly diagnosed with FASD using ICD-9 code 760.71 in physician claims in 2013–2019.

Methods

Aggregate-level data were obtained from the Government of Alberta to represent use of ICD-9 code 760.71 among physician claims. As the use of this specific code began in 2013, frequencies for years 2013 and 2014 were under-reported and data for these years are suppressed; therefore, the total numbers do not match across the tables.

Results

Frequency of Use of ICD-9 Code 760.61

The data indicate that ICD-9 code 760.71 was used in 4,234 physician claims from 2015 to 2019. As this represents code use and not unique individuals, this may suggest that individuals who have been prenatally alcohol-exposed frequently seek physician care.

Table 43. Use of ICD-9 code 760.71 in physician claims in Alberta, 2015–2019 (N = 4,234)

Year of physician claim	Frequency of physician claims indicating use of 760.71	Percent of physician claims indicating use of 760.71
2015	752	17.8
2016	918	21.7
2017	799	18.9
2018	865	20.4
2019	900	21.3
Total	**4,234**	**100**

Source: Alberta physician claims data

Data on patient age breakdown among physician claims using ICD-9 code 760.71 cover years 2013 to 2019 (see Table 44). The majority of these claims pertain to patients 12 and under (53.9%). These data suggest that among Albertan individuals who have FASD recorded by their physician, those most likely to utilize physician services in these years are children (53.9%) and adults aged 25 to 64 years (20.0%).

Table 44. Use of ICD-9 code 760.71 in physician claims by age of patient in Alberta, 2013–2019 (N = 4,812)

Age category (years)	Frequency of physician claims indicating use of 760.71	Percent of physician claims indicating use of 760.71
<5	1,098	22.8
5-12	1,496	31.1
13-17	734	15.3
18-24	477	9.9
25-64	960	20.0
65+	47	1.0
Total	**4,812**	**100**

Source: Alberta physician claims data

Data on sex breakdown indicate that physician use of ICD-9 code 760.71 is more common in claims pertaining to male patients (2,506 claims) than those pertaining to female patients (1,728 claims).

Table 45. Use of ICD-9 code 760.71 in physician claims by patient sex in Alberta, 2015–2019 (N = 4,234)

Year of physician claim	Female, n (%)	Male, n (%)
2015	307 (17.8)	445 (17.8)
2016	358 (20.7)	560 (22.3)
2017	336 (19.4)	463 (18.5)
2018	342 (19.8)	523 (20.9)
2019	385 (22.3)	515 (20.6)
Total	**1,728 (100)**	**2,506 (100)**

Source: Alberta physician claims data

Frequency of New Diagnoses of FASD Using ICD-9 Code 760.71

Physician claims data indicate that code 760.71 was used for the first time with respect to 1,659 patients in AB (see Table 46). These data represent first-time entry of FASD diagnosis by physicians in the respective years.

Table 46. New diagnoses of FASD using ICD-9 code 760.71 in physician claims by year in Alberta, 2015–2019 (N = 1,659)

Year of physician claim	Frequency	Percent
2015	382	23.0
2016	405	24.4
2017	312	18.8
2018	279	16.8
2019	281	16.9
Total	**1,659**	**100**

Source: Alberta physician claims data

A total of 1,956 patients had FASD indicated for the first time with the recording of ICD-9 code 760.71 by physicians in the years 2013–2019. Among these patients, the majority are children and adolescents (58.7%). See Table 47.

Table 47. Age breakdown of individuals with FASD first indicated using ICD-9 code 760.61 in physician claims in Alberta, 2013–2019 (N = 1,956)

Age group (years)	Frequency	Percent
<5	374	19.2
5-12	502	25.7
13-17	269	13.8
18-24	238	12.2
25-64	540	27.6
65+	33	1.7
Total	**1,956**	**100**

Source: Alberta physician claims data

Among the 1,659 patients in AB newly diagnosed with FASD using code 760.71 in physician claims, 58.5% were male. See Table 48.

Table 48. Sex/gender breakdown of individuals with FASD first indicated using ICD-9 code 760.71 in physician claims in Alberta, 2015–2019 (N = 1,659)

Year of physician claim	Female, n (%)	Male, n (%)
2015	162 (23.5)	220 (22.7)
2016	162 (23.5)	243 (25.1)
2017	135 (19.6)	177 (18.2)
2018	107 (15.5)	172 (17.7)
2019	123 (17.9)	158 (16.3)
Total	**689 (100)**	**970 (100)**

Source: Alberta physician claims data

Conclusions

Data from physician claims suggest that individuals with FASD use physician care services frequently, especially children, adolescents, and/or male patients. These data also demonstrate that patients who had FASD indicated for the first time with the use of ICD-9 code 760.71 in physician claims were mostly 18 and under and/or male patients.

Limitations

These data may not correspond with actual rates of utilization of physician services among individuals with FASD in AB. The number of individuals newly diagnosed with FASD using ICD-9 code 760.61 in physician claims may not correspond with the number of FASD diagnoses established by multi-disciplinary FASD assessments in diagnostic clinics in AB.

5.4.4 FAMILY SUPPORT FOR CHILDREN WITH DISABILITIES

Introduction

In AB, families of individuals under the age of 18 with a diagnosed disability are able to apply for services available under the Family Support for Children with Disabilities program. The FSCD program provides services and supports to eligible families in AB, helping them plan, coordinate, and access services to raise a child with one or more disabilities. The child must be a permanent Canadian citizen living in AB with medical documentation of a diagnosed disability due to a developmental, physical, sensory, mental, or neurological condition or impairment. This may include FASD.

Alternatively, if the child does not have a diagnosed disability, they must have a health condition that impacts their daily living activities such as eating, grooming, walking, interacting with others, playing, and problem solving. This may also include FASD. Individualized services may be provided to families based on a needs assessment and may include counselling, coverage of medical appointment costs, temporary living arrangements for the child, support workers or respite services, specialized services, and general information resources.

Objectives

1. To determine the number of children (under 18 years old) with diagnosed FASD who are currently accessing services provided by the FSCD program in AB from 2018–2019; and
2. to explore demographics of children with diagnosed FASD with an open FSCD file in 2018–2019 by age groups in the respective years.

Methods

Children often have multiple diagnoses. The information system for FSCD will allow staff to enter up to three diagnoses; the primary diagnosis is the one with the most impact on the child's daily functioning. For this data request, information for FASD diagnoses was extracted from all three levels.

Annual cross-sectional data on the number of children with a diagnosis of FASD (primary, secondary, and/or tertiary diagnosis) who have an open file at the FSCD program were obtained for two consecutive years (2018, 2019) from the Disabilities, Inclusion, and Accessibility Division at the Ministry of Community and Social Services at the Government of Alberta.

Results

There were 464 and 471 children with a diagnosis of FASD that had an open FSCD file in 2018 (as of December 13, 2018) and 2019 (as of December 6, 2019), respectively.

As Table 49 demonstrates, the majority of children with an open file in 2018 and 2019 are 6 to 12 years (44%-47%) or 13 to 15 years (32%-35%). Demographic data in Table 49 show that the age distribution of children with open files does not vary significantly from 2018 to 2019. This indicates that many children with FASD are accessing both diagnostic and support services in AB quite early, though these data do not indicate when FASD diagnoses were first provisioned. Data from 2019 suggests a slight increase in the number of files (from 464 in 2018 to 471 in 2019), which is a 1.5% increase. The exact number of new individuals is unknown, as it is not clear from these data if some files were closed due to client age (i.e., reached 18 years) or other reasons (e.g., death, moved out of province).

Table 49. Children with diagnosed FASD and an open FSCD file by age category, 2018–2019 (N = 935)

Age group (years)	2018		2019	
	Number of children with FASD	Percent	Number of children with FASD	Percent
0-5	7	2.0	4	1
6-12	216	47.0	208	44
13-15	147	32.0	164	35
16-18	94	20.0	95	20
Total	**464**	**100**	**471**	**100**

Source: Alberta FSCD program

Conclusions

Data on age groups are based on individuals with active service utilization of the FSCD program only and therefore may not indicate prevalence or incidence of FASD among children and adolescents in AB.

These data do not show the duration of services received by children being served by the FSCD, and therefore the proportion of overlap between the data retrieved in the two different time points (December 13, 2018, and December 6, 2019) cannot be estimated.

5.4.5 PUBLISHED STUDIES — HEALTH CARE UTILIZATION

1. Diagnostic Capacity

AB has the highest number of FASD diagnostic services, with 12 FASD Service Networks and over 20 FASD assessment and diagnostic clinics available to AB residents across the lifespan (Coons-Harding et al., 2019). Assessments by multi-disciplinary teams conducted through the networks increased from 129 to 401 per year between 2008 and 2011 (Alberta Government, 2013).

The 2016 AB waitlist study found that the number of individuals awaiting assessment varied by clinic: 8 diagnostic clinics had no individuals awaiting an FASD assessment whereas 15 clinics had between 7 to 216 individuals awaiting an assessment. In total, 544 children and 589 adults were waiting for an assessment across AB (Burns, 2017);

however, there was variability in the way clinics had defined and identified their clients waiting for services. The number of responses from clinics may be influenced by clinic capacity (Coons-Harding et al., 2019), and findings may be limited by the definition of waitlist used. A 2018–2019 project, Managing FASD Clinic Wait Lists, focused on the development of a consistent definition of waitlist as well as recommendations to monitor and provide resources to individuals referred (PolicyWise, n.d.).

In 2012–2013, 315 individuals received referrals for diagnostic assessment, and 197 were on waitlists for diagnostic assessment in the beginning in 2014. Among the 212 individuals who received completed assessments, 76% were completed within three months, 15% within six months, and 9% within 15 months. Among the 332 who received completed assessments over 18 months, 86% were known to have been exposed to alcohol before birth and 77% received an FASD diagnosis. The 2,887 recommendations for support made for these individuals serve as a baseline for future longitudinal studies seeking to facilitate access to services that wish to link recommendations to received supports (Alberta Government, 2017b).

2. Service Utilization

Between 2005 and 2011, a longitudinal project identified 3,025 individuals with FASD in AB, aged 0 to 25, with individuals residing in the Northwest and North Central regions and a large portion living within the lowest socio-economic areas. Individuals with FASD accessed disability support services and health services more often than those without a diagnosis and had a higher rate of criminal offences (13% to 17% a year), compared to those without FASD (2% per year) (PolicyWise for Children and Families, 2017).

3. Comorbidities and Mortality

Thanh & Jonsson (2011) analyzed mortality data and clinic records from 2003 to 2012 and estimated that life expectancy at birth of individuals with FAS was 34 years (95% CI: 31, 37). The leading causes of death included “external causes” (44%), suicide (15%), accidents (14%), substance toxicity (7%), and other (7%). Other common causes of death were diseases of the nervous and respiratory systems (each 8%), diseases of the digestive system (7%), congenital malformations (7%), mental and behavioural disorders (4%), and diseases of the circulatory system (4%) (Thanh & Jonsson, 2016).

6.0 Results — British Columbia

6.1 Population Profile

6.1.1 OVERVIEW

BC is the third most populous province of Canada (Statistics Canada, 2020c), with 5,110,917 residents as of January 1, 2020 (Statistics Canada, 2020b). BC is a leader in improving FASD prevention, diagnosis, family support, and community development. The province joined the Canada Northwest FASD Partnership in 2001 and serves as the host agency for the Canada Northwest FASD Research Network (British Columbia, 2008).

In 2006, non-profit organizations were funded through the $10,000,000 FASD Action Fund to deliver women's health care, FASD education, and supports that improve the lives of people with FASD (George & Hardy, 2014). The cross-ministerial policy commitments were made in the document entitled FASD: Building on Strengths, A Provincial Plan for BC 2008–2018 (Ministry of Children and Family Development, 2008), which guided diagnostic and other services for children with FASD, teacher education, and FASD prevention programs and awareness campaigns (George & Hardy, 2014).

6.1.2 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO PAE

In 2015, 54.4% of residents in BC consumed alcohol, with 9.5% reporting patterns of use that are harmful (Krueger, Rasali, & Fong, 2018). Binge drinking among women of childbearing age (15 to 44 years) increased from 15.2% in 2003 to 22.3% in 2013–2014 (Statistics Canada, 2016). Supporting women's health before, during, and after pregnancy requires addressing the determinants of alcohol use as well as the diversity of social and health issues that limit women's ability to access and use support services. The British Columbia Centre of Excellence for Women's Health (CEWH) has identified the following factors in supporting women's health before, during, and after pregnancy: supportive housing, healing from experiences of intimate partner violence, trauma history, recognizing and treating mental health disorders, and eliminating women's fears of child apprehension (through specialized holistic services that use a non-judgmental, harm-reduction approach (Parkes et al., 2008).

The CEWH has identified that in many cases, women start using substances to cope with and manage emotions related to trauma (Parkes et al., 2008). Women in BC who have survived physical and/or sexual violence are more likely to report substance use disorders and other mental health disorders such as depression, post-traumatic stress disorder (PTSD), panic disorder, and eating disorders (Minister's Advisory Council on Women's Health, 1997; Janssen et al., 2003). Intergenerational trauma experiences perpetuated through residential school experiences, the '60s Scoop (Medley & Pierre, 2018), child apprehension, forced sterilization, and missing/murdered Indigenous women and girls are also determinants of women's substance use during pregnancy identified by the First Nations Health Authority (National Collaborating Centre on Aboriginal Health, 2012; FNHA, 2017; FNHA, 2019)..

The CEWH has identified that women who have birthed children with FAS have been survivors of violence and trauma, individuals with mental health disorders, and/or in difficult relationships with partners who often control their substance use and service access (Poole et al., 2003). Depressive symptoms during pregnancy are common among women in BC, with 10% to 12% of women having received a diagnosis of a major depressive episode and as many as 70% having reported depressive symptoms during the perinatal period (BC Reproductive Mental Health Program, 2006).

A survey of women who were pregnant/parenting and receiving care for substance use at Sheway in Vancouver, BC, found that many were living with experiences of child apprehension, poverty, inadequate nutrition, insecure access to safe shelter, intimate partner violence, sex work, and substance use with co-occurring mental health disorders (Poole et al., 2000). Among women receiving substance use treatment at Peardonville House in Abbotsford, BC, 85% were found to have survived intimate partner violence and about 95% survived sexual abuse (Ellis, 1995).

Intimate partner violence is a barrier for women who are pregnant and wish to change their substance use pattern. Among women surveyed in Vancouver, 70% reported continuity of intimate partner violence throughout their pregnancy (Janssen et al., 2003). An estimated 20,000 women in BC faced intimate partner violence annually between 1999 and 2004, 40% of whom reported their children were witnesses (BC Women's Hospital and Health Centre, 2020). The Maternity Experiences Survey found 11.3% of women from BC survived intimate partner violence, 40% of whom were pregnant. This compares to 10.9% of women across Canada, 31% of whom were pregnant (PHAC, 2009). A study found significant reductions in pregnant women's alcohol use and stress levels within three months of them living in a women's shelter, demonstrating that safety impacts opportunities for reduced alcohol use during pregnancy (Greaves et al., 2006).

6.2 Existing Surveillance — PAE

6.2.1 PERINATAL SERVICES BC

For the full methodology and description of analysis for findings, please refer to Popova et al., 2021a).

Objectives

Using linked maternal-neonatal record-level data from the British Columbia Perinatal Data Registry (BCPDR) for the fiscal years 2014–2015 to 2017–2018, the objectives of this study were the following:

1. to estimate the prevalence of alcohol use identified as a risk factor during pregnancy by antenatal care providers in a. each fiscal year; and b. all fiscal years combined;
2. to examine maternal risk factors associated with alcohol use identified as a risk factor; and
3. to examine the associations between alcohol use identified as a risk factor and a) pregnancy complications; and b) adverse neonatal outcomes.

Methods

Data Source

Perinatal Services BC provides, collects, and analyzes maternal and neonatal information through the British Columbia Perinatal Data Registry, a quality-controlled database containing clinical information on all births throughout the province of BC, from all service providers and obstetric facilities. The BCPDR collects standardized data on antenatal, intrapartum, postpartum, and neonatal data, including ICD-10 codes. Data from this registry are used to guide improvement of health care service delivery, to improve outcomes, and to conduct research to inform policy-makers and planners in maternal and child health.

Statistical Analysis

Estimates for the period and fiscal year prevalence were calculated. Chi-square tests were used to compare adverse neonatal outcomes and pregnancy complications by alcohol use during pregnancy. Logistic regression was used to examine the association between alcohol use during pregnancy and adverse neonatal outcomes and pregnancy complications.

Results

Study Population

The final study population included 142,545 maternal records linked to 144,779 neonatal records corresponding to live births that were discharged between January 1, 2015, and March 31, 2018 (Perinatal Services BC, 2020).

Prevalence of Alcohol Use during Pregnancy Identified as a Risk Factor

Data on alcohol use during pregnancy is based on maternal self-report during antenatal encounters and does not capture alcohol use that occurred prior to pregnancy recognition. There were 1,593 alcohol-exposed neonates during the study period and 144,779 birth records; the resulting period prevalence of alcohol-exposed pregnancies in BC was 1.1 cases per 100 live births between January 1, 2015, and March 31, 2018, or 1.1% overall.

Table 50. Alcohol use identified as a risk factor among live births by fiscal year in British Columbia, January 1, 2015–March 31, 2018

	2014–2015*	2015–2016	2016–2017	2017–2018	All years combined
Prevalence of alcohol identified as a risk factor	1.1%	1.1%	1.3%	0.9%	1.1%

Source: BCPDR, Perinatal Services BC
* Partial data obtained for this fiscal year, capturing three months in total

Maternal Risk Factors Associated with Alcohol Use

Among pregnancies in BC during the study period, it was found that being nulliparous compared to multiparous, having a greater number of living children, and having a maternal history of any mental illness were all significantly associated with greater odds of maternal alcohol use during pregnancy ($p < 0.001$). Older maternal age and a higher number of antenatal visits was associated with lesser odds of maternal alcohol use during pregnancy ($p < 0.001$). The characteristics of mothers for whom alcohol use during pregnancy was identified as a risk factor can be found in Appendix P.

Pregnancy Complications and Neonatal Outcomes

There were no statistically significant findings related to the risk of the following pregnancy complications with respect to indicated alcohol use: bleeding at fewer than 20 weeks gestation, antepartum hemorrhage at more than 20 weeks gestation, or intrauterine growth restriction (IUGR).

Table 51. Odds ratios of pregnancy complications associated with alcohol use during pregnancy identified as a risk factor among live births in British Columbia, discharged January 1, 2015–March 31, 2018 (N = 142,545)

Pregnancy complication	OR	Lower 95% CI	Upper 95% CI	p-value
Bleeding (<20 weeks)	1.14	0.79	1.61	0.40
Antepartum hemorrhage (>20 weeks)	0.58	0.30	1.02	0.06
Intrauterine growth restriction (IUGR)	1.11	0.79	1.51	0.51

Source: BCPDR, Perinatal Services BC
Abbreviations: OR, odds ratio; CI, confidence interva

On average, alcohol-exposed neonates were shorter at birth ($p = 0.003$) and had smaller head circumference ($p < 0.001$) than those who were alcohol non-exposed. There were also a greater proportion of alcohol-exposed neonates where drugs for resuscitation/stabilization ($p = 0.029$), oxygen for resuscitation ($p < 0.001$), and intermittent positive pressure ventilation (IPPV) mask given for resuscitation ($p < 0.001$) were reported. A lesser proportion of alcohol-exposed neonates had started breastfeeding within the first hour of life, and there was a greater proportion of alcohol-exposed neonates who were either not breastfed or died in the first two days, compared to those who were alcohol non-exposed ($p < 0.001$). The characteristics of newborns birthed to mothers with alcohol use during pregnancy identified as a risk factor are presented in Appendix Q.

Maternal risk factors that were deemed to be significant were adjusted for in logistic regression models, including maternal age, maternal smoking status, any maternal substance use, parity, prior neonatal deaths, prior stillbirth and low birthweight, maternal history of any mental illness, and the number of antenatal visits. Adjusted odds ratio (AORs) of adverse neonatal outcomes associated with alcohol use during pregnancy are presented in Appendix R.

Neonates with alcohol use indicated in the prenatal period had greater odds of being diagnosed with low birth weight (AOR = 1.25; 95% CI: 1.01, 1.53), other respiration distress of newborn (AOR = 2.57; 95% CI: 1.52, 4.07), neonatal difficulty in breastfeeding (AOR = 1.97; 95% CI: 1.27, 2.92), and unspecified feeding problems (AOR = 2.06; 95% CI: 1.31, 3.09). In the entire dataset from all fiscal years combined, only five newborns were diagnosed with FAS at birth, three of whom were from pregnancies wherein alcohol use was not identified as a risk factor.

Conclusions

There is no obvious trend that can be observed in this time frame with respect to alcohol use being identified as a risk factor among BC pregnancies. Low administrative prevalence may be due to under-reporting and social desirability bias. Additionally, alcohol use that occurred prior to pregnancy recognition is not included here, and there may be a discrepancy between reported alcohol use after pregnancy recognition and the identification of such use as being a risk factor by the antenatal care provider.

Conclusions about the incidence of FAS from PAE cannot be made as FAS is rarely diagnosed at birth. For three of the FAS cases, however, alcohol use was not identified as a risk factor during pregnancy, which emphasizes the need for care providers to conduct thorough, consistent screening of alcohol use among pregnant women, including that which occurred prior to pregnancy recognition. It may be especially important to screen women who are younger and nulliparous and who may have a history of mental health issues and/or substance use.

6.2.2 PUBLISHED STUDIES — PAE

A total of 22 regional prevalence estimates were identified for alcohol use in pregnancy among women in the general population of BC, from 10 peer-reviewed articles and reports.

With respect to the years of interest for this report (2015–2020), population-based estimates from the BCPDR (Perinatal Services BC) indicates that alcohol use was identified as a risk factor for 1.2% of BC pregnancies in 2014–2015, 1.1% of pregnancies in 2015–2016, and 1.3% of pregnancies in 2016–2017 fiscal years. This reflects all women who were pregnant and flagged for alcohol use by their antenatal care provider, and this was documented in their medical records. Prevalence of alcohol use identified as a risk factor varied across the years of data published: from 1.3% in 2000–2001 to 0.9% in 2007–2008. With these available data, no obvious trend can be observed with respect to alcohol use indicated in BC pregnancies. It has been recognized that a potential reason for the small proportion identified was the social acceptability of alcohol in general, which prohibited care providers from flagging use as problematic or caused them to informally discuss the importance of abstaining without documenting alcohol use on the record (BC Perinatal Health Program, 2008).

Regional estimates from medical record reviews are available from previous years, which indicate 0.6% in 2003–2008 (Stoll et al., 2014) and estimates of 7% for both 2004–2005 and 2006–2007 fiscal years (BC Stats, 2010). From population-based surveys, regional estimates for BC range from 15.9% in 1994–1995 to 9.2% in 1998–1999 from the NLSCY, while estimates from the CCHS range from 11.6% in 2002 (AADAC, 2004) to 7.2% in 2007–2008 (Thanh & Jonsson, 2010).

Among women who were pregnant while living in poverty, the Targeting High Risk Families study reported an average of 16% of infants were exposed to alcohol and other drugs before birth. In 1999, 5.5% to 6% of women who were pregnant and living in the the Greater Vancouver area required medical stabilization for substance use (Legare & Bodnar, 1999). A study of women living in Vancouver's Downtown Eastside reported that 46% used or were using alcohol and other drugs during pregnancy (Loock et al., 1993).

Using medical records in a birth registry to study pregnancies of women in small, rural, and remote communities, it was found that 4.8% of women living on reserve consumed alcohol during pregnancy, compared to 5.7% of women living off reserve (BC Provincial Health Officer, 2009).

Disclaimer: All inferences, opinions, and conclusions drawn in this publication are those of the authors and do not reflect the opinions or policies of Perinatal Services BC.

6.3 Existing Surveillance — FASD

6.3.1 SUNNY HILL HEALTH CENTRE FOR CHILDREN

Objectives

1. To explore demographic characteristics of children and youth with diagnosed FASD (2015–2018); and
2. to explore prenatal exposures and mental health and physical comorbidities of individuals with diagnosed FASD (2015–2018).

Methods

Data Source

BC created the Complex Developmental Behavioral Conditions (CDBC) program in 2006. CDBC is a provincial program distributed to the following regional health authorities: Interior Health, Island Health, and Northern Health. Vancouver Coastal and Fraser Health assessments are coordinated through Sunny Hill Health Centre, under BC Children's and the Provincial Health Services Authority.

This diagnostic program assesses children who have been exposed to substances in utero, including alcohol, and children suspected of having an intellectual disorder. Referrals are made by family doctors, physicians, and nurse practitioners in BC. The majority of children/youth referred are 4 to 19 years of age. They have often been assessed by community service providers including from the Infant Development Program (IDP), preschools, and schools. This information is used to determine eligibility and help streamline assessments. The program provides the needed multi-disciplinary assessments to answer the referral question. Data for this program is input into a provincial database that allows both referrals and document outcomes to be tracked.

Data Collection

The sample contains children and youth diagnosed with FASD between 2015 and 2018 who accessed the Sunny Hill Health Centre's CDBC program. Data were abstracted from patient charts relevant to the time of assessment, including demographic information — age, sex, year of diagnosis, FASD diagnosis, living arrangement, geographic location, languages spoken at home, adoption status, past personal/sibling involvement in child welfare system, past personal involvement in legal justice system — and medical information such as prenatal exposures and mental health and physical health comorbidities. The child welfare system involvement variable represents the Ministry of Children and Family Development involvement of the child or youth diagnosed with FASD or their siblings, as well as assistance given to the parents, denoted throughout the assessment. Prenatal exposures and maternal/neonatal conditions include confirmed and suspected exposures and were not mutually exclusive categories. The comorbidity categories are not mutually exclusive, and each child or youth may have more than one comorbidity from a unique category. The confirmed comorbidities were either indicated or newly detected within the assessment.

Statistical Analysis

Qualitative responses were converted to quantitative responses by listing all responses verbatim and amalgamating similar responses together. The comorbidity categories were amalgamated based on similarity, where applicable, and coding was completed in adherence to the new categories. A cross-sectional analysis was conducted based on the data

abstracted. Descriptive statistics were derived using Microsoft Excel 2017 and R version 3.6.3 using RStudio version 1.1.463. Cell counts with frequencies fewer than five were suppressed to protect patient privacy and confidentiality.

Results

Demographics of the Sample

The sample contains 1,187 children and youth diagnosed with FASD who accessed the Sunny Hill Health Centre's CDBC program. The sample had a higher proportion of males (n = 729, 61.4%) than females. Of the children and youth diagnosed between 2015 and 2018, 365 received a diagnosis in 2015 (30.7%), 273 in 2016 (23.0%), 301 in 2017 (25.4%), and 248 in 2018 (20.9%). For half of the sample, the age at diagnosis was from six to ten years (n = 628, 52.9%). Overall, the age at diagnosis ranged from 2 to 19 years, with an average age at diagnosis of 9.7 years (SD = 3.9 years). Of the children and youth diagnosed with FASD, 85% (n = 967, 81.5%) received one of the diagnoses without sentinel facial features.

The dominant language spoken at home was English only (n = 1,163, 98.0%). Over one-third of the children and youth resided with their biological parent(s) at the time of the assessment (n = 428, 36.1%). The living arrangements for the remainder of the sample included: foster care (n = 303, 25.5%), extended family (n = 218, 18.4%), and an adoptive home (n = 188, 15.8%). Further, 16.8% of the children and youth were adopted (n = 200). 76.1% (n = 903) of the children/youth lived in an urban area. Personal or sibling involvement in the child welfare system was identified for 12.7% of the sample (n = 151). There were 17 (1.4%) children and youth who were identified to have been involved in the justice system as a "perpetrator."

Of children and youth diagnosed with FASD, 161 (13.6%) had at least one sibling with FASD. In addition, 34 (2.9%) had sibling(s) with possible FASD/PAE. There were fewer than five individuals with sibling(s) not related maternally. Of the children and youth diagnosed with FASD, 174 (14.7%) had parent(s) with FASD/PAE. See Table 52.

Table 52. Demographics of children/youth diagnosed with FASD at Sunny Hill Health Centre, 2015–2018 (N = 1,187)

Characteristics at time of assessment	Frequency	Percent
SEX		
Male	729	61.4
Female	457	38.5
YEAR OF DIAGNOSIS		
2015	365	30.7
2016	273	23.0
2017	301	25.4
2018	248	20.9
AGE AT DIAGNOSIS		
2-5 years	137	11.5
6-10 years	628	52.9

Characteristics at time of assessment	Frequency	Percent
11-15 years	284	23.9
≥16 years	138	11.6
Range (years)	2-19	N/A
Mean (SD)	9.7 (3.9)	N/A
DIAGNOSIS		
FASD without sentinel facial features	698	58.8
FASD with sentinel facial features	129	10.9
FAS with confirmed exposure	S	S
FAS without confirmed exposure	<5	S
Partial FAS (with confirmed exposure)	79	6.7
Alcohol-related neurodevelopmental disorder (with confirmed exposure)	269	22.7
LANGUAGES SPOKEN AT HOME		
English only	1,163	98.0
English and one other language (not Indigenous)	14	1.2
English and an Indigenous language	6	0.5
Spanish, Portuguese, and English	<5	S
English, French, and an Indigenous language	<5	S
Arabic	<5	S
LIVING ARRANGEMENT		
With biological parent	428	36.1
Foster care	303	25.5
With extended family	218	18.4
Adoptive home	188	15.8
Group/resource home	13	1.1
With care provider	12	1.0
Independently	9	0.8
With guardian	6	0.5
Step-parent	<5	S
Significant other	<5	S
Unknown	6	0.5
ADOPTED		
Yes	200	16.8
N/A	987	83.2
GEOGRAPHIC LOCATION		
Urban	903	76.1
Rural	271	22.8
Unknown	13	1.1
SIBLINGS WITH FASD		
At least one sibling with FASD	161	13.6

Characteristics at time of assessment	Frequency	Percent
Sibling(s) with suspected FASD/PAE	34	2.9
Siblings with no maternal relation with FASD	<5	S
PARENT(S) WITH SUSPECTED/CONFIRMED FASD/PAE		
Yes	174	14.7
N/A	1,013	85.3
PERSONAL OR SIBLING INVOLVEMENT IN CHILD WELFARE SYSTEM		
Yes	151	12.7
N/A	1,036	87.3
PERSONAL INVOLVEMENT IN JUSTICE SYSTEM		
Involvement as perpetrator	17	1.4
Involvement as victim	<5	S
N/A	S	S

Source: Sunny Hill Health Centre
Abbreviations: N/A, not applicable; S, suppressed
Please note: data on languages spoken, justice system involvement, and child welfare system involvement are not consistently elicited or reported by clinicians in individual files

Maternal Substance Use

The most prevalent substances used by mothers while pregnant with the children and youth diagnosed with FASD were cigarette/tobacco/nicotine (n = 396, 50.9%), cocaine/crack (n = 321, 41.3%), and marijuana (n = 288, 37.0%). Also, there were 121 (15.6%) mothers who used opioids (excluding methadone maintenance treatment). Five (0.6%) mothers had methadone maintenance treatment, and six mothers (0.8%) had polysubstance use (explicitly stated) during their pregnancy. Also, fewer than five mothers had an admission to rehabilitation or a clinic due to substance use; timing of the admission with respect to the pregnancy is unknown. See Table 53.

Table 53. Prenatal exposure to substances of children/youth diagnosed with FASD at Sunny Hill Health Centre, 2015–2018 (N = 1,187)

Confirmed/suspected prenatal exposures*	Frequency	Percent
Cigarette/tobacco/nicotine	396	50.9
Cocaine/crack	321	41.3
Marijuana	288	37.0
Unspecified drug/substance (illegal and legal)	124	15.9
Opioid/opiate/heroin (excluding methadone maintenance treatment)	121	15.6
Stimulant drug	113	14.5
Other medication/supplement	89	11.4
Antidepressant	34	4.4
Benzodiazepine	26	3.3
Antipsychotic/antimanic medication	23	3.0
Hallucinogen	8	1.0
Polysubstance**	6	0.8

Confirmed/suspected prenatal exposures*	Frequency	Percent
Unspecified drug for mental illness / anxiety	6	0.8
Overdose	5	0.6
Methadone maintenance treatment	5	0.6
Rehab/clinic admission[a]	<5	S
Caffeine[a]	<5	S
Second-hand exposure to tobacco[a]	<5	S
Second-hand exposure to marijuana[a]	<5	S

Source: Sunny Hill Health Centre
Abbreviations: S, suppressed
* Categories are not mutually exclusive
** Included observations where polysubstance use was explicitly stated a Categories were not explicitly asked about by Sunny Hill Health Centre Please note: data on prenatal exposures was not available for 409 clients

Maternal Conditions

The three most prevalent maternal conditions respective to the prenatal period of the children and youth diagnosed with FASD were physical medical condition, procedure, injury, physical health issue, or undefined medical condition (n = 135, 17.4%); pregnancy complications (n = 112, 14.4%); and no/poor/limited/irregular/delayed prenatal care (n = 81, 10.4%). The presence of stress was indicated for 58 mothers (7.5%) during the respective pregnancy. There were 54 women (6.9%) for whom experiences of abuse as a victim or perpetrator were noted; however, fewer than five were classified as a perpetrator. Also, various mental disorders were reported or suspected for 40 women (5.1%) at the time of pregnancy. It should be noted that the mental disorder category includes mental health symptoms/factors impacting mental health but excludes women taking prescription drugs for mental health disorders without indication of the disorder. See Table 54.

Table 54. Maternal conditions during pregnancy of children/youth diagnosed with FASD at Sunny Hill Health Centre, 2015–2018 (N = 1,187)

Confirmed/suspected exposures at time of assessment	Frequency	Percent
Physical medical condition[a]	135	17.4
Pregnancy complication	112	14.4
No/poor/limited/irregular/delayed prenatal care	81	10.4
Stress	58	7.5
Abuse as victim/perpetrator	54	6.9
Mental disorder[b]	40	5.1
Intrauterine growth restriction	9	1.2
Poor nutrition	8	1.0
Homeless	6	0.8
Other/unspecified exposures	5	0.6
Eating disorder	<5	S
Justice system involvement	<5	S

Confirmed/suspected exposures at time of assessment	Frequency	Percent
High-risk/chaotic lifestyle	<5	S
Occupational/environmental exposure	<5	S

Source: Sunny Hill Health Centre
Abbreviation: S, suppressed
* Categories are not mutually exclusive
[a] Includes women with indication of the following: surgical procedure, injury, physical health issue, undefined medical condition
[b] Includes women with indication of symptoms/factors impacting mental health and excludes women taking prescription drugs for mental health disorders without indication of the disorder
Please note: data on prenatal exposures was not available for 409 clients. Data on medical conditions is not consistently elicited or reported in individual files. The above statistics likely underestimate maternal conditions during the respective pregnancies.

Physical Comorbidities

The five most prevalent physical comorbidities of the children and youth diagnosed with FASD were respiratory system problems (n = 120, 24.3%), nervous system problems (n = 112, 22.7%), genetic problems/congenital deformations/malformations (n = 107, 21.7%), eye problems (n = 87, 17.6%), and ear problems (n = 57, 11.5%). See Table 55. Categories are not mutually exclusive, meaning that a child or youth may have more than one comorbidity.

Table 55. Physical comorbidities of children/youth diagnosed with FASD at Sunny Hill Health Centre, 2015–2018 (N = 1,187)

Confirmed comorbidities	Frequency	Percent
Respiratory system problem	120	24.3
Nervous system problem	112	22.7
Genetic problem, congenital deformation/malformation[a]	107	21.7
Eye problem	87	17.6
Ear problem	57	11.5
Maternal substance use, undefined exposure impact	38	7.7
Cardiovascular system problem	33	6.7
Digestive system problem	32	6.5
Connective tissue and/or musculoskeletal problem	32	6.5
Nutrition, metabolism, and/or endocrine system problem	23	4.7
Blood and/or immune response problem	22	4.5
Physical/psychological developmental problem	21	4.3
Behavioural/emotional problem[b]	18	3.6
Injury, harmful exposure to lead, anaphylaxis	18	3.6
Genitourinary system problem	17	3.4
Infectious disease	14	2.8
Skin problem	13	2.6
Problem starting within the perinatal period[c]	11	2.2
Other factors impacting health	11	2.2
Mental/behavioural problem[d]	9	1.8
Neonatal abstinence syndrome	8	1.6
Procedure, brace, cast[e]	8	1.6
Overdose, intoxication, substance use	6	1.2
Hallucination	5	1.0

Confirmed comorbidities	Frequency	Percent
Tumour	<5	S
Self-injury and/or self-injury ideation	<5	S
Background of alcohol misuse within family	<5	S

Source: Sunny Hill Health Centre
Abbreviation: S, suppressed
Please note: Categories are not mutually exclusive; each child/youth may have more than one comorbidity from a unique category
[a] Also contains malformations/deformations suspected of being congenital
[b] Includes attention-deficit/hyperactivity disorder (ADHD), Tourette's disorder, tic disorder (motor, vocal, facial, neck), stuttering, sound outbursts, selective mutism, attachment injuries, emotional dysregulation, and stool incontinence related to emotional difficulties
[c] Includes neonatal stroke, congenital hypotonia, brachial plexus injury, birth palsy, cerebral ischemic or hypoxic ischemic injury, birth asphyxia (brain injury), bronchopulmonary dysplasia, amniotic band syndrome, prematurity, macrosomia, fetus and newborn affected by premature rupture of membranes
[d] Includes neurodevelopmental disorder, anxiety disorder (unspecified), intermittent panic attacks, restrictive eating disorder, gender identity issue, acute and transient psychotic disorder (unspecified), nightmares, and facial dysmorphia
[e] Observations where the comorbidity requiring the procedure/treatment was undefined
Please note: data on comorbidity was not available for 693 clients

The most common substances used by children and youth diagnosed with FASD were marijuana (n = 49, 4.1%), alcohol (n = 36, 3.0%), and stimulants (n =15, 1.3%). There were 5 individuals (0.4%) with indication of polysubstance use, fewer than 5 individuals with indication of overdose, and 12 individuals (1.0%) were treated for substance use. See Table 56.

Table 56. Current and past substance use and treatment of children/youth diagnosed with FASD at Sunny Hill Health Centre, 2015–2018, (N=1,187)

	Frequency	Percent
CONFIRMED/SUSPECTED SUBSTANCE USE*		
Marijuana	49	4.1
Alcohol	36	3.0
Stimulant drug	15	1.3
Cigarette/nicotine	14	1.2
Unspecified drug / substance	11	0.9
Cocaine/crack	9	0.8
Hallucinogen	7	0.6
Opioid/heroin	5	0.4
Other medication	5	0.4
Polysubstance[a]	5	0.4
Overdose	<5	S
Benzodiazepine	<5	S
Second-hand marijuana	<5	S
Antipsychotic medication	<5	S
SUBSTANCE USE TREATMENT		
Yes	12	1.0
No	<5	S

Source: Sunny Hill Health Centre
Abbreviation: S, suppressed
* Categories are not mutually exclusive; children/youth may have consumed more than one substance
[a] Polysubstance was explicitly stated

Conclusions

In addition to alcohol, prenatal exposure (mutually non-exclusive) to the following substances was common: tobacco (50.9%), cocaine/crack (41.3%), and cannabis (37%). It is important to thoroughly screen women for all substances, especially when combined with alcohol. Service providers implementing FASD prevention strategies may choose to incorporate these substances in the design and implementation of brief interventions provided to women at risk of alcohol-exposed pregnancies.

About 17% of children had at least one sibling with confirmed or suspected FASD and 14.7% had parent(s) with FASD/PAE, which highlights the importance of FASD reoccurrence prevention in these families.

Physical comorbidities are very common among children and youth diagnosed with FASD; the most prevalent (mutually non-exclusive) are respiratory, nervous system, and genetic/congenital problems (24.3%, 22.7%, and 21.7%, respectively). This may be associated with higher utilization of health care services among these children over time, incurring a high cost burden to service systems.

Use of substances among this sample is less than 5% for each substance, but this is significant as the mean age of the sample is younger than ten years. It is important to track these data over time to monitor children and youth who may be at risk of substance use or substance use disorders.

6.3.2 ASANTE CENTRE

For the full methodology and description of analysis for findings pertaining to this project component, please refer to Popova et al. (2021b).

Objectives

Using record-level client data from the Asante Centre (2015–2019), the objectives of this study were the following:

1. to describe the demographic characteristics, prenatal exposures, substance use, and other comorbidities among clients diagnosed with FASD (2015–2019);
2. to explore client variables when stratified by FASD diagnostic outcome and age; and
3. to explore associations between client variables and involvement in a) the child welfare system, and b) the criminal justice system.

Methods

Data Source

Asante Centre is a provincial organization that receives referrals for FASD assessment and diagnosis across BC. Referrals were received from a variety of sources, including the criminal justice system (adult and youth), the government (e.g., health services), and private referrals (e.g., self-referral, families, schools, community agencies). Individuals were referred to the centre if they were experiencing behavioural, learning, or developmental problems or if there was some evidence of PAE. The diagnosis was established by a multi-disciplinary team using Chudley et al. (2005) or Cook et al. (2016) FASD diagnostic guidelines.

Data Abstraction

A retrospective chart review of assessment reports was conducted on records of individuals diagnosed with FASD at the Asante Centre from January 2015 to July 2019. A pre-generated spreadsheet was used to abstract data from patients' charts. The following variables were included in chart abstraction: demographic (age, gender, living arrangement, living in an urban centre vs rural/remote community, FASD diagnosed in other family members); prenatal exposures; comorbidities; current and previous psychological and developmental diagnoses; current and previous substance use; current and previous mental health diagnoses; and current and previous involvement with the child welfare or criminal justice systems. Qualitative responses were converted to quantitative responses by listing all responses verbatim and amalgamating similar responses together, guided by the DSM-V and ICD-10-CA codes.

Statistical Analysis

A cross-sectional analysis of the data was conducted. Descriptive statistics were generated for the entire study population using means and frequencies. Categories with counts below five were suppressed in order to protect confidentiality, and the category was reported without the exact count. Results were also stratified by age group, sex, and involvement with the criminal justice and child welfare systems. When stratifying by involvement in the criminal justice system, individuals aged nine or younger were excluded as there were no instances of involvement. The Fisher exact test was used to evaluate differences between stratified populations, and the level of significance was set at 0.05 and was adjusted using Bonferroni correction. Variables with counts below five were excluded from the Fisher exact test to preserve statistical power. Logistic regression was conducted to investigate potential associations.

Results

Study Population

There were 162 records included in the chart review from January 2015 to July 2019, representing 162 unique individuals. One record contained a deferred diagnosis and was excluded from the analysis, resulting in a final sample size of 161.

Diagnostic Outcomes

The majority of individuals (124, 77.0%) were diagnosed using Cook et al. (2016) guidelines: 12.9% were diagnosed with FASD with sentinel facial features, 73.4% were diagnosed with FASD without sentinel facial features, and 13.7% were at risk for neurodevelopmental disorder/FASD where a full diagnosis could not be confirmed. Of those diagnosed using Chudley et al. (2005) guidelines (n = 37), 83.3% were diagnosed with ARND, 16.7% were diagnosed with partial fetal alcohol syndrome (pFAS), and 2.7% were diagnosed with FAS. See Appendix S.

Reasons for Referral

Individuals were referred to the clinic for a variety of reasons, and many individuals were referred for more than one reason. The five most common reasons for referral in this sample were learning and cognitive problems (52.2%), behavioural problems (39.1%), mental health problems (22.4%), social problems (19.3%), and lack of independence (11.8%). A large percentage of individuals were referred for "other" reasons (25.5%), which included referrals with no specific reason as well as referrals that were aimed at gaining an improved understanding of how better to support an individual. See Appendix S.

Demographics and Family History of FASD

At the time of diagnosis, the mean age of the individuals was 15.7 years (SD = 9.1) with a range of 3 to 52 years, and 86 were male (53.4%). One hundred twenty-seven individuals (78.9%) resided in urban settings and 34 (21.1%) in rural or remote communities. Thirty-two (19.9%) were adopted. The most common living arrangement at the time of assessment was foster family (17.4%), followed by birth family (14.3%) and extended family (12.4%). Roughly one in five individuals (21.1%) had a sibling who had been diagnosed with FASD, and roughly 1 in 15 individuals (6.8%) had a parent diagnosed with FASD. There were 121 individuals (75.2%) who reported previous or current involvement with the child welfare system and 48 individuals (29.8%) who reported previous or current involvement with the criminal justice system. See Appendix S.

Prenatal Exposures

The five most prevalent prenatal exposures reported, other than alcohol, were tobacco (37.9%); cannabis (37.9%); stimulants (37.3%); opioids (10.6%); other maternal risk behaviour, adversities, and/or stressful life events, including domestic violence and abuse (22.4%); and missing, poor, or lack of access to prenatal care (16.1%).

Table 57. Known and suspected prenatal exposures of individuals diagnosed with FASD, 2015–2019 (N = 161)

Known/suspected prenatal exposure*	n (%)
Tobacco	61 (37.9)
Cannabis	61 (37.9)
Stimulants	60 (37.3)
Other maternal risk behaviour, adversities, and/or stressful life events, during pregnancy	36 (22.4)
Missing, poor, or lack of access to prenatal care exposure	26 (16.1)
Opioids	17 (10.6)
Drug use unspecified (illicit and/or prescription)	11 (6.8)
Precarious situations	11 (6.8)
Prescription medications	6 (3.7)
Antidepressants	5 (3.1)
Adverse neonatal outcomes	<5 (S)
Anxiolytics	<5 (S)
Barbiturates	<5 (S)
Benzodiazepines	<5 (S)
Hallucinogens	<5 (S)
Incarceration	<5 (S)
Maternal age exposure (young or advanced maternal age)	<5 (S)
Maternal overdose	<5 (S)
Pain medication excluding opioids	<5 (S)
Polysubstance use including confirmed alcohol	<5 (S)
Polysubstance use not including confirmed alcohol	<5 (S)
Poor nutrition	<5 (S)
Pregnancy complications	<5 (S)
Prostitution/sex work	<5 (S)
None	9 (5.6%)

Source: Asante Centre
Abbreviation: S, suppressed
* These categories are not mutually exclusive

Comorbidities

Almost 78% of individuals with FASD reported current psychological/developmental diagnoses, and about 50% reported past psychological/developmental diagnoses. The five most commonly indicated current psychological/developmental diagnoses were learning disorders and cognitive issues (35.4%), ADHD (29.8%), neurodevelopmental disorders (24.2%), anxiety (14.3%), and brain damage due to PAE (12.4%). The five most common responses for past psychological/developmental diagnoses were ADHD (31.1%), anxiety (20.5%), mood disorders (14.3%), disruptive behaviour disorders (13.0%), and learning disorders and cognitive issues (10.6%). Overall, there were 84 (58.3%) individuals diagnosed with FASD who received either a current or previous diagnosis of ADHD. Thirty-eight percent of individuals with FASD reported physical comorbidities; the five most prevalent diagnoses were respiratory problems (13.7%), hearing problems (5.6%), congenital malformations and deformations (3.7%), infections (3.7%), and skin issues (3.7%). See Appendix T.

Substance Use and Substance Use Treatment

Half of the individuals with FASD were indicated to be current substance users. The most commonly reported substances were cannabis (16.1%) and alcohol (13.7%), followed by unspecified drug use (10.6%), tobacco (9.3%), and stimulants (5.0%). About half (47%) reported past substance use; the five most prevalent previously used substances were cannabis (15.5%), alcohol (12.4%), stimulants (12.4%), unspecified previous drug use (6.8%), and opioids (5.0%). There were seven (4.4%) individuals who reported current substance use treatment and seven (4.4%) who reported past substance use treatment. See Table 58.

Table 58. Substance use and substance use treatment among individuals diagnosed with FASD, 2015–2019 (N = 161)

Variables at time of assessment	n (%)
CURRENT SUBSTANCE USE	
Cannabis	26 (16.1)
Alcohol	22 (13.7)
Drug use, unspecified	17 (10.6)
Tobacco	15 (9.3)
Stimulants	8 (5.0)
Benzodiazepines	<5 (S)
4-hydroxybutanoate	<5 (S)
Hallucinogens	<5 (S)
Opioids	<5 (S)
Polysubstance drug use	<5 (S)
None	81 (50.3)
Unknown	31 (19.3)
PAST SUBSTANCE USE	
Cannabis	25 (15.5)
Alcohol	20 (12.4)
Stimulants	20 (12.4)
Drug use, unspecified	11 (6.8)
Opioids	8 (5.0)
Tobacco	6 (3.7)
Hallucinogen	5 (3.1)

Variables at time of assessment	n (%)
Benzodiazepines	<5 (S)
GHB	<5 (S)
Polysubstance drug use	<5 (S)
None	85 (52.8)
Unknown	25 (15.5)
CURRENT SUBSTANCE USE TREATMENT	
Yes	7 (4.3)
No	117 (72.7)
Unknown	37 (23.0)
PAST SUBSTANCE USE TREATMENT	
Yes	7 (4.3)
No	91 (56.5)
Unknown	63 (39.1)

Source: Asante Centre
S: suppressed

FASD Diagnostic Outcomes

Logistic regression revealed no evidence of an association between FASD diagnostic categories and any variables, including involvement in the child welfare system (relative to FASD with sentinel features; FASD without sentinel features $p = 0.25$; at risk for FASD $p = 0.28$) or involvement in the criminal justice system (relative to FASD with sentinel features; FASD without sentinel features $p = 0.88$; at risk for FASD $p = 0.62$). See Appendix U.

Client Age Category

When stratified by age categories (3 to 9, 10 to 19, and 20 years and above), there were statistically significant differences in terms of living arrangements (Appendix U). For example, a greater proportion of individuals aged 20 and above lived in group homes or independently (21.7%, 43.5%), compared to individuals aged 10 to 19 (13.0%, 8.7%) or under 10 (0%, 0%). A greater proportion of individuals aged under 10 lived in care (adoptive or foster) with some biological family members or with immediate birth and extended family (26.1%; 21.7%, respectively), compared to individuals aged 10 to 19 (6.5%, 6.5%) and 20 and above (0%, 4.3%). The greatest proportion of individuals aged 10 to 19 lived in foster care (20.7%), compared to individuals under 10 years old (17.4%) and 20 and above (4.3%).

There were also differences with respect to involvement in the criminal justice system by age category. There were no involved individuals aged under 10 years, 43 (46.7%) individuals aged 10 to 19 years, and 5 (21.7%) individuals aged 20 and above who were involved in the criminal justice system. There was also a greater proportion of individuals aged under 10 years with a current ADHD diagnosis (54.3%) at the time of assessment, compared to individuals aged 10 to 19 (18.5%) or 20 and above (26.1%). Similarly, there was a greater proportion of individuals aged under 10 years with a current learning disorder diagnosis (60.9%) at the time of assessment, compared to individuals aged 10 to 19 (4.3%) or 20 and above (0%).

Furthermore, there were also statistically significant differences (after correction) seen between age groups with respect to substance use. Individuals aged 20 and above reported the greatest proportion of past use of any substance (60.9%), past alcohol use (39.1%), and past stimulant use (30.4%), compared to individuals aged 10 to 19 (41.3%, 12.0%, 14.1%) and under 10 (0%, 0%, 0%). Individuals aged 10 to 19 reported the greatest proportion of past cannabis use (22.8%), followed by individuals aged 20 and above (21.7%) and under 10 (0%). The greatest proportion of no reported current drug use was seen in individuals aged 3 to 9 years (89.1%). The reported proportion of abstinence was lesser in older age groups (10-19: 37.0%; 20 and above: 26.1%). Similarly, with respect to no previous drug use reported, the greatest proportion was seen in individuals aged 3 to 9 years (97.8%) and abstinence was lesser in older age groups (10-19: 41.3%; 20 and above: 8.7%).

Substance Use

Stratified analysis revealed that individuals who were involved in the criminal justice system reported a greater proportion of current substance use (64.6% vs 28.4%) and past substance use (66.7% vs 29.9%), as well as current cannabis use (37.5% vs 13.4%) and past cannabis use (37.5% vs 11.9%), compared to those who were not involved in the criminal justice system. However, only past substance use remained significant after correction. There was also a greater proportion of individuals who were involved in the criminal justice system that were referred for behavioural reasons (50% vs 22.4%). Lastly, when comparing individuals involved in the child welfare system to those who had not been in this system, the only statistically significant difference (after correction) was found with respect to living arrangements at the time of the assessment. A greater proportion of individuals involved in the child welfare system were living in adoptive families (8.3%), foster families (23.1%), in care (adoptive/foster) with some biological family members (14.0%), or in group homes or community living (13.2%).

Mental Health

There was evidence of an association between involvement in the child welfare system and reported anxiety at the time of assessment. Individuals with FASD who were involved with the child welfare system had 4.11 times greater odds (95% CI = 1.25, 15.00; p = 0.024) of reporting anxiety at the time of assessment than individuals with FASD who were not involved with the child welfare system. The odds of reporting a mood disorder at the time of assessment were 71% lower (95% CI = 0.08, 0.91; p = 0.040) for individuals diagnosed with FASD who were involved in the child welfare system compared to those who were not involved.

Systems Involvement

Among individuals aged ten years or older in any FASD diagnostic categories, there was no evidence of a significant association between involvement with the child welfare system and involvement in the criminal justice system (OR = 2.03 [95% CI = 0.44, 10.16]; p = 0.368). Please see Appendix U for more information.

Conclusions

In addition to alcohol, prenatal exposure to the following substances was common: tobacco (38%), cannabis (38%), and stimulants (37%). As an FASD prevention strategy, women must be screened for alcohol use in pregnancy in addition to other substances, which can increase the risk of FASD in the child.

Psychological (78%) and physical (38%) comorbidities were very high among this sample of individuals diagnosed with FASD, comparable to findings of a systematic review on comorbidities associated with FASD (Popova et al., 2016b).

Over half of the sample were current substance users (alcohol: 14%), demonstrating the need for access to substance use treatment and interventions to prevent FASD familial recurrence. This is especially the case as 1 in 5 individuals had a sibling diagnosed with FASD and 1 in 15 had a parent with diagnosed FASD. Substance use interventions need to be informed by family contexts of substance use.

Systems involvement was high, with 30% being involved in the criminal justice system and 75% involved in the child welfare system. Psychological interventions should be tailored to the systems involvement of individuals with FASD, especially as they may affect substance use and anxiety disorder outcomes.

6.3.3 DIAGNOSTIC CLINIC SURVEY

Methods

Please refer to the Diagnostic Clinic Survey section of this report (Section 4.2.2) for a detailed methodology.

Results

There were two main clinics identified in BC that had the capacity to conduct neurodevelopmental assessments for FASD. Both clinics contributed data corresponding to years 2015 to 2019. Estimates have been combined for both clinics, as they represent the majority of FASD assessments and diagnoses in the province.

A total of 3,260 individuals were assessed for FASD in BC from 2015 to 2019, or an average of 652 per year (SD = 65.4). Among them, 1,765 individuals (54.1%) were diagnosed with FASD. An average of 353 individuals (SD = 50.5) were diagnosed each year within the two participating clinics.

FASD referrals were accepted as part of larger programs with referral streams. One clinic had noted that management of waitlists may change as clinic capacity and contract deliverables fluctuate from year to year. Wait times may vary based on complex needs and referral stream.

Table 59. Diagnostic capacity of neurodevelopmental clinics in British Columbia that participated in the survey, 2015–2019 (N = 2)

	Year of assessment					
	2015	2016	2017	2018	2019	All years combined
Individuals assessed	765	613	649	629	604	3,260
Individuals diagnosed	419	343	383	334	286	1,765
Slots assigned to FASD*	1,160	1,180	1,195	1,205	1,302	6,045
Individuals on the waitlist*	30	40	60	60	70	260

Source: CAMH REDCap survey
* Incomplete clinic data

6.3.4 PUBLISHED STUDIES — FASD

Regional estimates for FASD in the general population of BC were obtained from three publications (see Appendix E). In the most recent study (Pei et al., 2020), regional data for BC estimates that the prevalence of FASD among kindergarten students in the general population is 2.7 per 1,000, or 0.27%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database, and is the only study to report FASD in the general population in the years of interest (2015–2020).

One report published by Robinson et al. (2003) indicated a reported increase in the number of individuals receiving FASD diagnoses between 1995 and 2000 in the South Fraser Health Service Delivery Area in BC, based on Vital Statistics. This increase must be interpreted with caution, however, as a broadened definition of FASD and a focus on early diagnosis may have contributed to the increase.

Data on the prevalence of FAS are available in a study conducted by Marquis et al. (2018), where hospital-based data from Population Data BC was utilized to identify children with developmental disabilities using ICD-9 and ICD-10 codes. Based on these data and the algorithm used, the administrative prevalence of FAS steadily increased in this time period, from 0.12 per 1,000 BC children (0.01%) in 1986 to 1.75 per 1,000 BC children (0.18%) in 2013. This may not be indicative of actual increases in FAS, however, as these data are dependent on entry of FAS codes during encounters and on identification of FAS in the first place. Hospital-based data from Population Data BC (2018) reported that the almost half (45%) of children and youth (0 to 19 years) who had received a diagnosis of FAS between 1985 and 2014 were born into families living in the lowest income quintile (Marquis et al., 2018). Approximately one-third (33%) were born in the Northern Health Authority, while only approximately 6.3% of the provincial population lives in the region (Marquis et al., 2018).

A total of four publications were identified to have regional estimates for the prevalence of FASD in special subpopulations of BC, with none of the studies collecting data in the years of interest (2015–2020); see Appendix E. One study by Asante and Nelms-Maztke (1985) examined the rate of FASD among children with severe developmental disabilities in Northwestern BC, finding an FAS incidence rate of 10 per 1,000 children and an FASD incidence rate of 25 per 1,000 among children (16 years and younger) referred to as handicapped. In an isolated community in BC, a higher FASD prevalence rate of 190 per 1,000 live births was reported (Robinson, Conry, & Conry, 1987). According to the 2006 Aboriginal Children's Survey, 0.9% of children under six living in BC were diagnosed with FASD (Werk, Cui, & Tough, 2013). Among subpopulations in small, rural, and remote communities, the prevalence estimates ranged from 9.0 per 1,000 (0.9%) (Werk, Cui, & Tough, 2013) to 189.7 per 1,000 (19%) in a dated PS study by Robinson, Conry, & Conry (1987).

In 1995–1996, 23.3% of 287 youth remanded to inpatient psychiatric assessment in BC over a one-year period had an alcohol-related diagnosis, of which 1% had FAS and 22.3% had Fetal Alcohol Effects (FAE) (Fast, Conry, & Loock, 1999). An FASD screening study at Youth Forensic Psychiatric Services in Burnaby, BC, found that 23.3% of the youth remanded to inpatient psychiatric assessment who were screened had FASD, only 3 out of 67 of whom were diagnosed (Fast, Conry, & Loock, 1999). Among correctional populations in BC, the prevalence of FASD was found to be 108.7 per 1,000 (10.9%) from 1985 to 2004 by Rojas & Gretton (2007), and 116.8 per 1,000 (11.7%) by Murphy, Chittenden, & McCreary Centre Society (2005).

6.4 Health Care Utilization

6.4.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From the 2014 to 2017 fiscal years, a total of 8,898 hospitalizations and health care visits were made by patients with FAS with a health card from BC. These health care encounters were almost entirely emergency care visits (n = 6,279). This pattern was consistent for each fiscal year. Among the patients with FAS with a health card from BC, 81.6% resided in urban areas, and 5.9% of the patients were homeless.

6.4.2 COMORBIDITIES AND MORTALITY AMONG INDIVIDUALS DIAGNOSED WITH FASD

British Columbia Health Status Registry

Women who have alcohol or other drugs identified as risk factors were at a higher risk of emergency C-section and more likely to give birth to babies with congenital anomalies (4.3%) (BC Perinatal Database Registry, 2008). Among mothers identified as non-smokers, the preterm birth rate was 8.4%, compared to 19.5% among mothers who had alcohol use identified as a risk factor. A study of 62 adults (45% with FAS, 45% with FAE, and 10% with probable FAS) who participated in the FAS/E Support Network of BC were found to have a history of confinement in hospital or incarceration (Clark et al., 2004). Among these individuals, 87% had survived violence and 77% had survived physical and/or sexual abuse. The most common comorbidities were mental health disorders (92%) and a disruptive school experience (61%).

7.0 Results — Manitoba

7.1 Population Profile

7.1.1 OVERVIEW

During the 20 years since the initiation of Canada's FASD initiative (PHAC, 2019), individuals with FASD, women with substance use disorders, and other researchers, policy-makers, and service providers in MB have made unprecedented contributions to collecting FASD surveillance information. MB was the first jurisdiction in Canada to collect population-level data on alcohol use during pregnancy and generated the Population Health Research Data Repository, the most comprehensive collection of population-based administrative health and social databases in the world. The Manitoba Centre for Health Policy (MCHP) conducts research with these data to report on the scope of FASD and inform evidence-based prevention and treatment. This jurisdictional profile summarizes previously published epidemiological evidence including FASD/PAE prevalence data, recent prevention program evaluations, and indicators of FASD/PAE determinants.

Approximately half of the 1.3 million residents live in Winnipeg. Children and youth (0 to 19) represent a quarter of the population and 33% of new permanent residents. One in five children and youth (0 to 15) are from a visible minority group (Statistics Canada, 2016) and 29% of children and youth (0 to 19) are Indigenous (Healthy Child Manitoba, 2017). In 2018–2019, among females aged 15 to 49, there were 19,216 pregnancies, and in 2017–2018, there were 16,803 births, or 12.4 newborns per 1,000 population (Manitoba Health Seniors and Living, 2019).

7.1.2 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO FASD/PAE

Factors that increase the risk of alcohol and other substance use disorders in women and FASD in children include poverty, which reduces access to nutritious food and suitable housing; trauma; surviving physical and sexual abuse; and single parenthood (Healthy Child Manitoba, 2012, 2015; Singal et al., 2016; Chudley et al., 2005; Joya et al., 2014; Jones, 2011).

Research has shown that young women living in lower-income communities without a high school education are more likely to drink alcohol while pregnant (Healthy Child Manitoba, 2010, 2012; Heaman et al., 2012). Among women with children, the rate of high school completion increased from 78% in 2003 to 85% in 2015; however, the observed rate (47%) of Manitoban women with children who have completed post-secondary education in 2016 is below the national rate of 56% (Statistics Canada, 2016; Healthy Child Manitoba, 2017). In MB, the rate of individuals living with a low income fell to 9.4% in 2019 from 12% in 2015 (Manitoba Government, 2019). Since 2000, 24% of children in MB have lived in single-parent families, and 60% of children who live in female-led lone parent families in 2015 were found to live in poverty. In general, the rate of poverty among children under six years in 2015 in MB (31.2%) was 12.5% higher than the national rate, and a remarkable one in eight children lived with food insecurity (Healthy Child Manitoba, 2017; Campaign 2000 & Winnipeg Harvest Inc., 2017). Notably, subpopulations of children and youth (0 to 17) in MB live in poverty at a disproportionate rate (50% of children of Arab and Korean descent)

(Campaign 2000 & Winnipeg Harvest Inc., 2017), which affects other maternal well-being indicators as well. However, the overall poverty rate in MB in 2017 was 8.7%, a decrease of 7% from 2016. Additionally, the child low-income rate fell to 9.5%, a decrease of 20% from 2016 (Manitoba Government, 2019).

Surviving violence and trauma during pregnancy is associated with adverse pregnancy outcomes and poor maternal and infant health (Healthy Child Manitoba, 2012). From 2004 to 2011, the rate of mothers reporting relationship distress or violence declined from 7% to 6% (Healthy Child Manitoba, 2012). Notably, it was found that in 2014 10% of women in MB aged 15 to 24 (i.e., reproductive age) experienced physical/sexual violence, which was double the Canadian rate in the same year (Healthy Child Manitoba, 2017). From 2003 to 2011, mothers reporting a history of child abuse increased from 5% to 8%, respectively (Healthy Child Manitoba, 2012). In 2015, MB reported the second highest rate of all provinces for police-reported family violence, with 374 per 100,000 of children and youth (0 to 17 years) facing this type of violence. Girls experienced a higher rate of family violence than boys with 489 and 264, respectively, per 100,000 MB children and youth (Burczycka & Conroy, 2018; Healthy Child Manitoba, 2017).

Maternal mental health issues during and prior to pregnancy may impact outcomes and have also been found to increase the risk of mental health and development problems in their children (Healthy Child Manitoba, 2012, 2017). In 2005–2006, 6% of women (19 to 45 years) involved in addictions programs at Addictions Foundation of Manitoba were pregnant (Fuchs et al., 2007). In 2015, perinatal screening revealed that 18% of women were noted to have depression and anxiety during pregnancy, an increase from 13% in 2003 (Healthy Child Manitoba, 2017).

Children with FASD have an increased risk of developing comorbid depression, anxiety, and substance use, in addition to a higher likelihood of encountering criminal justice system involvement and premature death (Brownell et al., 2012). Protective factors supporting optimal outcomes include early FASD diagnosis, appropriate service access, higher levels of parent income and education, and a stable and nurturing home environment with a caregiver who understands FASD (Fuchs et al., 2010; Brownell et al., 2015; Streissguth et al., 2004; Burnside & Fuchs, 2013).

Tables 60 to 62 display the number of MB residents who accessed substance use treatment between 2012–2013 and 2018–2019.

Table 60. Number and percentage of individuals aged 10 years and older in Manitoba accessing treatment for substance use, 2012–2019

Years	N	%
2012–2013 to 2016–2017	56,962	4.7
2013–2014 to 2017–2018	55,520	4.5
2014–2015 to 2018–2019	54,522	4.4

Source: Manitoba Health, Seniors and Active Living, 2017; 2019

Table 61. Individuals aged 10 years and older accessing treatment for substance use in Manitoba by age category and sex, 2012–2017

Age (years)	Female (%)	Male (%)
10-14	1.44	0.9
15-19	3.57	3.49
20-24	4.78	5.21
25-29	5.17	6.21
30-34	5.57	6.80
35-39	5.27	7.05
40-44	5.29	6.98
45-49	5.45	6.63

Source: Manitoba government

Table 62. Individuals 10 years and older accessing treatment for substance use in Manitoba by age category and sex, 2014–2019

Age (years)	Female (%)	Male (%)
10-14	1.81	1.25
15-19	3.80	3.63
20-24	4.83	5.09
25-29	4.80	5.81
30-34	4.94	6.33
35-39	4.64	6.20
40-44	4.73	6.32
45-49	4.85	6.27

Source: Manitoba government

Mental Health Disorders in Children and Youth

In 2013–2014, 15% of girls and 4% of boys (aged 15 to 17) and 10% girls and 12% of boys (aged 18 to 19) reported major depressive episodes (Healthy Child Manitoba, 2017). In 2014–2015, rates of new cases of alcohol use disorder (AUD) were 2 per 1,000 males and approximately 1 per 1,000 females, compared to 4.4 per 1,000 males and approximately 2 per 1,000 females in 1990–1991 (Nickel et al., 2018).

7.1.3 FASD/PAE PREVENTION PROGRAMS

MB is a leader in FASD prevention program development (Shibler & Newton, 2006). Included among the FASD/PAE prevention programs in MB are Project CHOICES, the Insight Mentoring Program, Manito Ikwe Kagiikwe (the Mothering Project), and the STAR Program.

Project CHOICES is a Winnipeg-based PAE prevention program that provides four counselling sessions to women and girls who drink alcohol, are sexually active, and are not pregnant. Nurses use motivational interviewing strategies to encourage women to explore their use of alcohol and/or effective birth control. Women who completed the program reported a decrease in the average number of drinks per week from 43 to 19, as well as a 19% reduction in binge drinking and ineffective contraceptive use (Healthy Child Manitoba, n.d.).

The Insight Mentoring Program is a women-centred harm reduction program offered to pregnant women or women who gave birth within the past year and who use alcohol or other drugs. The three-year outreach program connects women to community resources and mentors that provide comprehensive case management and practical one-on-one support through a trauma-informed approach that is culturally safe. An evaluation of this program by the MCHP found that most women enrolled in the program reported an increase in healthy behaviours, such as a decrease in alcohol use before, during, and after pregnancy and increased contraceptive use (Ruth et al., 2015). The program also improved connections of women enrolled to social services such as social housing, food banks, and mental health services (Ruth et al., 2015).

Manito Ikwe Kagiikwe (the Mothering Project) offers advocacy, outreach services, prenatal care, support groups, access to traditional ceremony and teachings, and referrals to women who are pregnant and/or have a child under the age of three. An informal assessment of the program revealed that after 16 months, 47% had reduced their substance use and 36% were abstaining from using drugs or alcohol. At the beginning of the assessment, 56% of women were homeless or under-housed, and after 16 months, 63% of families were housed (Canadian Centre for Policy Alternatives, 2015).

The STAR Program aims to prevent alcohol use during pregnancy by using a harm reduction model to develop mentoring relationships with women of reproductive age. Women are offered support for three years in order to make positive changes in their lives. The program operates out of seven community-based and cluster sites to connect families to appropriate community resources.

MB's FASD strategy benefits from inter-sectoral government and community partnerships, guided by the Healthy Child Committee of Cabinet, the sole cross-departmental cabinet committee in Canada dedicated to child-centred public policy across government (Healthy Child Manitoba, 2012; Enns et al., 2020). In alignment with MB's FASD strategy, programs and services are available to support women with substance use disorders who experience violence, trauma, poverty, and mental health issues, as well as their partners. Community-based services are also available to support youth and adults with FASD (Healthy Child Manitoba, 2017). Resources have also been developed for educators and caregivers explaining how FASD affects the brain and provides strategies for child care (Healthy Child Manitoba, n.d.). A complete list of resources to support individuals living with FASD is available from the Healthy Child Manitoba (2019) website.

7.2 Existing Surveillance — PAE

7.2.1 PAE DATA SOURCES

MB was the first jurisdiction in Canada to collect population-level information on alcohol use during pregnancy. PAE and other biological, social, and demographic data for children and families have been collected since 2000 through the Families First screen (formally BabyFirst), a universal screening and home visiting program. The goal of the program is to direct families to resources and track risk factors to inform policy and planning. Public health nurses administer the screening questionnaire to families of newborns within one week of discharge from hospital. Coverage rates for the screening program were roughly 95% of all births from families with a postpartum referral (Healthy Child Manitoba, 2010a). First Nations families living on reserve and families who did not use the public health system were not included in the universal screening. (Strengthening Families is a parallel home visiting program that operates in First Nations communities.) It has been estimated that 83% of all births in MB were captured by the Families First screen (Healthy Child Manitoba, 2010a; Enns et al., 2019; Chartier et al., 2017). The MCHP stores Families First screening data from 2003 to 2017.

7.2.2 PUBLISHED STUDIES — PAE

The majority of Manitobans in the general population recognizes the impacts of PAE, including its ability to cause lifelong disabilities (Morrow, 2015). Between 2015 and 2016, 92% of youth respondents to the Regional Health Survey thought there was never a good time to drink alcohol safely during pregnancy (First Nations Health and Social Secretariat of Manitoba, 2018).

Population-level administrative health data on alcohol use during pregnancy are collected from the majority of mothers with newborns by public health nurses using the Families First screen, which are summarized in Appendix D (Healthy Child Manitoba, 2008, 2016, 2017). Alcohol use during pregnancy decreased from 13.3% in 2003 to 10% in 2015 (Healthy Child Manitoba, 2016, 2017). In 2007, mothers who reported alcohol use during pregnancy were asked follow-up questions pertaining to quantity, binge drinking patterns, and drinking patterns after pregnancy detection (Chartier, 2009). The rate of women who reported drinking alcohol after pregnancy recognition decreased from 19% to 8.8% between 2007 and 2013 (Healthy Child Manitoba, 2015, 2016).

Two studies have reported PAE prevalence among women in small, rural, and remote communities in Thompson, MB. High rates of alcohol consumption during pregnancy were reported in both studies, 26.3% (Williams, Odaibo, & McGee, 1999) and 50.8% (Williams & Gloster, 1999) of pregnant mothers interviewed. However, these figures should only be considered representative of the sample populations in Thompson and may not be generalizable to other small, rural, and remote communities in MB.

7.3 Existing Surveillance — FASD

7.3.1 FASD DATA SOURCES

Surveillance in MB is informed by the FASD Diagnostic Network which is overseen by a steering committee composed of representatives from Regional Health Authorities (RHAs), the Government of Manitoba, and the Manitoba FASD Centre. The network includes 11 FASD diagnostic coordinators in the five MB RHAs (Winnipeg, Southern Health, Prairie Mountain Health, Northern, Interlake-Eastern) and Norway House who are responsible for facilitating referrals and assessments for youth living in their region, aiding individuals with a FASD diagnosis in accessing community resources, and increasing knowledge and diagnostic capacities in rural and remote communities (Manitoba FASD Network, n.d.). The work of diagnostic coordinators supported a 60% increase in referrals between 2009 and 2014 (Manitoba Government, n.d.).

The Manitoba FASD Centre was established in 2009, replacing the Clinic for Alcohol and Drug Exposed Children, which had operated since 1999. The centre is a provincially centralized FASD assessment, diagnostic, education, training, and research clinic offering multi-disciplinary assessment and diagnosis to children and adolescents up to age 18 (with some young adults in exceptional situations) using the FASD Canadian National Guidelines for diagnoses. The centre plans to expand assessment services to adults. Cases are received on a referral basis, which can be made by physicians or health care professionals, Child and Family Services, schools, and other community organizations. Criteria for assessment include known PAE, legal guardian consent, and developmental or learning concerns (Manitoba FASD Centre, n.d.). FASD diagnostic prevalence data are collected by the Manitoba FASD Centre, which conducts clinical

and population health research. The Winnipeg RHA is the source agency for the Manitoba FASD Centre dataset, and de-identified individual level data from 1999 to 2016 are held at the MCHP. Information from assessments and diagnoses contained in this dataset includes the reason for referral, maternal and family history, growth parameters, developmental and genetics assessment, diagnoses, behavioral concerns, and who was present during the assessment (Health Data Research Network Canada, 2020).

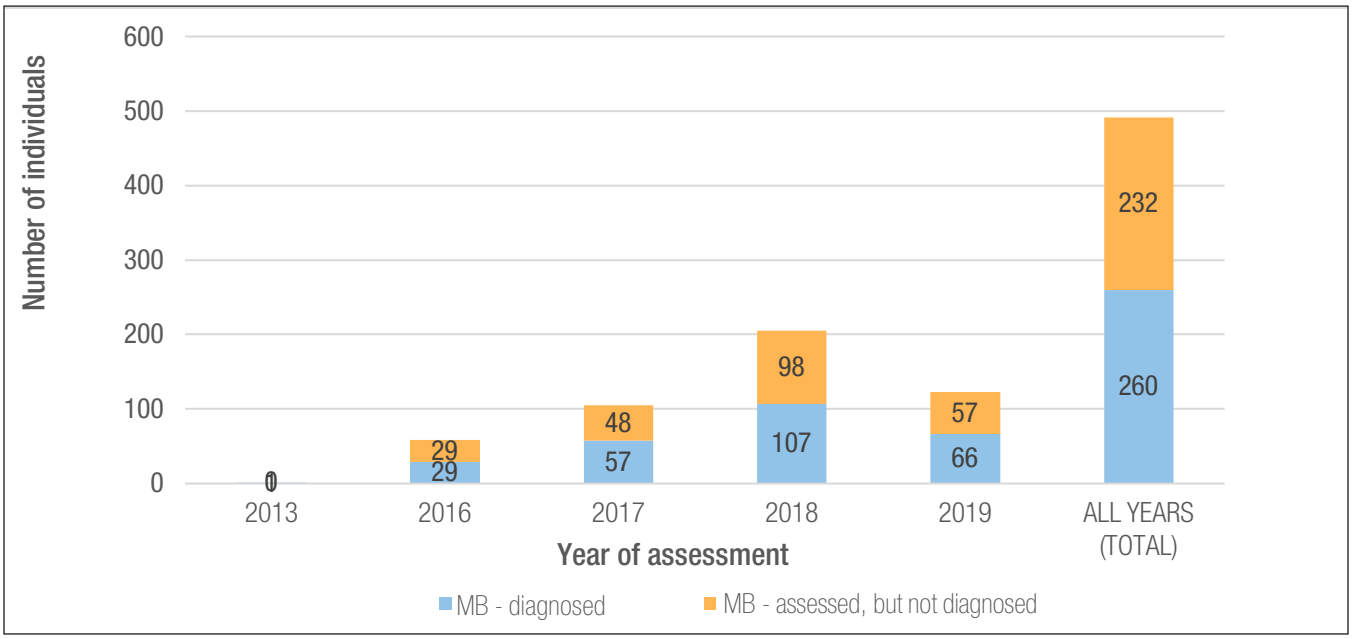
The centre increases knowledge and diagnostic capacity in rural and remote communities by providing diagnostic assessment through the Northern Consultation Clinic in Thompson and via telehealth in some communities (Ens et al., 2010). Utilizing telehealth services for FASD assessment, diagnosis, and follow-up expands the delivery of care, education, and support to families in rural and remote communities. An evaluation of diagnostic assessment as well as follow-up post-clinical assessment through telehealth found this technology to be effective. Recipients of the services supported the use of this technology, noting that it enabled them to remain in their home communities connected to their support systems (Hanlon-Dearman et al., 2014). The centre also operates the FASD Youth Justice Program from a satellite clinic at the Manitoba Youth Centre, the largest youth correctional centre in MB. The Youth Justice Program offers pre-sentencing, multi-disciplinary assessments for youth in Winnipeg with confirmed PAE and no prior diagnosis of FASD. Since implementation, 1,048 youth have been referred to the program, 332 were assessed, and 234 received a diagnosis of FASD (Longstaffe et al., 2018).

7.3.2 CANADIAN NATIONAL FASD DATABASE

Please refer to the Canadian National FASD Database section of this report (Section 4.2.1) for a detailed analysis of these data.

Data in the figures below present two categories of diagnostic outcomes: diagnosed, which includes individuals with FASD with or without sentinel facial features, and assessed but not diagnosed, which includes those in the at-risk category as well. Data are presented by year of assessment; where a year is missing, this indicates zero diagnoses and zero assessments in the respective year. Each figure represents diagnostic outcomes by year of assessment.

The data available from the database suggest that number of assessments may have increased in recent years (2015–2019) in participating clinics located in MB. Data from MB are sent from the same participating clinic, and this shows that across all assessment years available (2013, 2016–2019), 41.7% of assessed children were not diagnosed with FASD.



Source: CanFASD Universal Dataform project

Figure 4. Individuals assessed for FASD diagnosis and individuals who received FASD diagnoses by year in Manitoba, 2013–2019

7.3.3 DIAGNOSTIC CLINIC SURVEY

Methods

Please refer to the Diagnostic Clinic Survey section of this report (Section 4.2.2) for a detailed methodology.

Results

There was one clinic identified in MB that is capable of conducting neurodevelopmental assessments for FASD in children (under 18 years). This clinic provided data for assessment years 2015–2019. See Table 63.

There were between 239 and 275 children assessed each year, with an average of 259 assessments (SD = 15.8) per year. A total of 1,294 children were assessed for FASD in 2015–2019, and over half of them (n = 687, 53.1%) were diagnosed with FASD. Across all years, between 50% and 58% of assessments in each year resulted in diagnoses of FASD. In each year, there were between 120 and 150 children diagnosed with FASD, with an average of 137 children diagnosed per year (SD = 13.8).

The clinic allotted an average of 272 slots (SD = 62.2) per year to FASD diagnoses, or a total of 1,360 across all years. On average, there were 118 children on the waitlist (SD = 4.5) each year; based on these data, the estimated wait time for an FASD diagnosis is five months.

Children were eligible to be on the waitlist if screening criteria were met, which included legal guardian consent, confirmed PAE, and significant difficulties. In cases where there was a complicated referral (e.g., complex medical history), the clinic would have to determine if difficulties could be confidently attributed to PAE.

Table 63. Diagnostic capacity of the neurodevelopmental clinic in Manitoba that participated in the survey, 2015–2019 (N = 1)

	Year of assessment					
	2015	2016	2017	2018	2019	All years combined
Individuals assessed	275	273	260	247	239	1,294
Individuals diagnosed	142	147	152	126	120	687
Slots assigned to FASD	160	300	300	300	300	1,360
Individuals on the waitlist	110	120	120	120	120	590

Source: CAMH REDCap survey

7.3.4 PUBLISHED STUDIES — FASD

FASD Data Collection

Regional estimates for the prevalence of FASD in the general population of MB were obtained from three publications (see Appendix E). In the most recent study (Pei et al., 2020), regional data for MB estimates that the prevalence of FASD among kindergarten students in the general population is 3.0 per 1,000, or 0.30%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database.

From 1998 to 2003, a study using ICD-9 code 760 in administrative health databases to identify FAS estimated a prevalence of 0.2 per 1,000 (0.02%) of FAS in the general population of MB (Ouellette-Kuntz et al., 2009). More recently, a PS study by Brownell et al. (2012) found prevalence estimates of 2.0 per 1,000 (0.20%) in 1998–2003 and 2.2 per 1,000 (0.22%) in 2006–2010 for FAS in the general population of MB.

A total of five studies were identified to have prevalence estimates of FASD in special subpopulations of MB (see Appendix E). Among studies of small, rural, and remote communities in MB, the prevalence of FASD was found to be 101.1 per 1,000 (10.1%) (Kowlessar, 1997), while the prevalence of FAS ranged from 7.2 per 1,000 (0.7%) (Williams, Odaibo, & McGee, 1999) to 61.8 per 1,000 (6.2%) (Kowlessar, 1997). Among a Manitoban population of children in care in 2004–2005, a prevalence estimate of 113.0 per 1,000 (11.3%) was obtained by Fuchs et al. (2005). More recently, the Tri-provincial FASD Project (Fuchs & Burnside, 2014) obtained a regional prevalence estimate of 122.7 per 1,000 (12.3%) for FASD among children in this sub-population in MB. In a correctional population in MB (2005–2006), Murphy, Chittenden, & McCreary Centre Society (2005) found a prevalence of 98.9 per 1,000 (9.9%) for FASD among adults 19 to 30 years old.

7.4 Service Utilization

7.4.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From the 2014 to 2017 fiscal years, a total of 2,853 hospitalizations and health care visits were made among patients with FAS with a health card from MB. These health care encounters were mostly for emergency care visits (n = 2,098). This pattern was consistent for each fiscal year (2014–2017). Among the patients with FAS with a health card from MB, 62.8% resided in urban areas and 2.3% of the patients were homeless.

7.4.2 FASD IN SERVICE SYSTEMS IN MANITOBA

The leading Canadian source of data on characteristics, well-being, and prevalence of children with FASD in care was generated from a study in MB analyzing administrative data at the MCHP with clinical data from the Manitoba FASD Centre and conducting qualitative research with children with FASD in care (Fuchs et al., 2005, 2007, 2008, 2010, 2014). A series of research projects summarized below identified that FASD is a serious health and social justice issue, impacting families, the child welfare, health care, and education sectors in MB.

The FASD diagnostic capacity in MB, as in the rest of Canada, is lower than the number of referred patients (Chudley et al., 2005; Fuchs et al., 2009). The maximum number of diagnostic slots available for FASD diagnosis in MB was 198 in 2010 and 2011 (Clarren, Lutke, & Sherbuck, 2011). The diagnostic capacity survey was not completed in 2019 and therefore updated diagnostic capacity is not available.

The study by Fuchs et al. (2005) reported that the prevalence of FASD among children (0 to 20 years) in care was 11.3% (113 per 1,000). Of the 5,664 children in care, 1,869 had a disability, 34.2% of whom had a diagnosis of FASD. Of these children, 60% were male, and the mean age of the children was 10.5 years. One-third of these children had at least one disability, and 17% of children in care had diagnosed or suspected FASD. Among children with FASD, 89% were in permanent care, 46% had co-occurring mental health disorders, and 39% had comorbid ADHD. Later, between 2010 and 2015, researchers reported that 12.3% of children (0 to 21 years) in care had FASD (112.7 per 1,000) of a sample of 8,323 children (Fuchs et al., 2014). The prevalence of Indigenous children aged six and under living off reserve with FASD was measured using the 2006 Aboriginal Children's Survey conducted by Statistics Canada. The prevalence of FASD was 1.3% in MB, compared to the national prevalence of 0.7% (Werk, Cui, & Tough, 2013).

An analysis of pathways to care for children with FASD (Fuchs et al., 2007) found that children with FASD who became permanent wards or who were under a voluntary placement agreement received their first legal status at an earlier age than children with other disabilities and children with no disabilities. They also became permanent wards more quickly and at a younger age, with a mean of two years younger than children with no disabilities and three years younger than children with other disabilities. Children with FASD who were permanent wards were found to spend approximately three-quarters of their lives in care, 15% longer than other children who are permanent wards. In addition, fewer opportunities occurred for these children to be reunited with their families of origin (Fuchs et al., 2010).

Children in care with FASD had higher rates of mental health disorders and suicide completion at 17 years of age than other children in care, which signals the need for supportive transition planning (Shibler & Newton, 2006). Fuchs et al. (2007, 2008, & 2010) echoed the basic developmental need of children to be stabilized in consistent, nurturing, and permanent environments, which was demonstrated by children in care from a young age seeking bonding with their caregivers, yearning for genuine relationships, and requiring placement stability. It was determined that the process of transition planning for youth with FASD in care was well developed and that the uptake of transition process guidelines and protocol would result in effective transitions for youth with FASD to adult services. However, it was not possible to determine if guidelines for transition planning were being used (Fuchs et al., 2008). Youth with FASD transitioning from care identified the need for ongoing support and service access to adult services targeted to individuals with FASD. These youth experienced deficits in educational readiness, life skills, and social supports and identified that living with FASD was a barrier to acquiring needed education, life skills, and social networks (Burnside & Fuchs, 2013).

The use of data at the MCHP revealed the economic impact of this subpopulation on MB's child welfare system. A random sample of 400 children diagnosed with FASD that were permanent wards generated from MCHP data were allocated $65 per day on average (Fuchs et al., 2008). This included a basic maintenance rate of $22 allocated to all children and a $43 special rate, which was greater than the standard rate of $35 for all children in care at that time (Fuchs et al., 2008). In 2009, Fuchs et al. reported greater health care utilization among children with FASD who were permanent wards (Fuchs et al., 2009). It was found that the average cost for hospital visits, physician services, and prescription drugs for children diagnosed with FASD was 3.5 times greater than the general population. This translated into an average of $1,001 in additional health care costs each year for a child who was diagnosed with FASD and was a permanent ward.

A 2013 matched cohort study of 717 individuals with FASD matched to general population and asthma controls found a higher utilization of the child welfare system among individuals living with FASD (Brownell et al., 2013). Compared to matched controls without FASD, individuals with FASD were 10 times more likely to be in out-of-home care, 13 times more likely to have received protection or child welfare services, and 9 times more likely to be receiving special education funding (Brownell et al., 2013). The results of these studies all point toward an increased number of individuals impacted by FASD being involved with the child welfare system, which has been observed across Canada (Popova et al., 2014a).

Table 64. Studies on service utilization associated with FASD in Manitoba, 1999–2010

Study years	Sample size receiving services	FASD cases	Diagnostic guidelines / case definition	n (%) of male children	Age range (years)	Method and source
1999-2010	2,025 children in care of child welfare at least once	900	Chudley et al., 2005	2,127 (64.7)	1-25	Registry (Brownell et al., 2019)
2004	3,259 children in care receiving services	640 (631 FASD, 9 neurological behaviour disorder subsequent to substance use)	Physician assessment, FASD clinic assessment	N/A	0-20	Registry (Fuchs et al., 2005)
2005	400 children in care	400	Physician assessment, FASD clinic assessment	249 (62.3)	3-19	Fuchs et al., 2008
2006	6,324 children in care	722	Physician assessment, FASD clinic assessment	N/A	<18	Fuchs et al., 2009

N/A: Not available

7.4.3 HEALTH CARE UTILIZATION

In 2009, Fuchs et al. reported on the health care utilization in a sample of 6,324 children from MB (Fuchs et al., 2009). They reported that individuals living with FASD or children who have a parent with alcohol as a primary issue accounted for roughly 41% of hospital, physician, and pharmaceutical costs while accounting for roughly 22% of the study population (Fuchs et al., 2009). This amounted to an increase in hospital, physician, and pharmaceutical spending of $600 per individual living with FASD (Fuchs et al., 2009).

Individuals with FASD were also found to have greater health care utilization (i.e., hospitalizations, use of antidepressants and psychostimulants, and ADHD diagnoses) than those in the general population or individuals diagnosed with asthma (Brownell et al., 2013). Individuals living with FASD had a rate of hospitalizations 3.4 times greater than the general population and 2.9 times greater than the group of individuals with asthma (Brownell et al., 2013). Individuals with FASD has physician visits at a rate of 1.6 times greater than that of the general population (Brownell et al., 2013). Overall prescription drug use in individuals with FASD was also reported at a rate 1.4 times greater than that of the general population (Brownell et al., 2013).

7.4.4 EDUCATION

The average cost of education per child is greater in individuals living with FASD. In a study of 6,324 children, individuals living with FASD made up roughly 20% of the study population and 38% of total education costs (Fuchs et al., 2009). The average cost of education funding relative to the general population was 3.4 times greater for children diagnosed with FASD were permanent wards and 2.7 times greater for children diagnosed with FASD but not living in care (Fuchs et al., 2009). This represented $5,166 and $3,656 in additional spending per year compared to the general population, for children diagnosed with FASD living in and out of care, respectively (Fuchs et al., 2009).

Children living with FASD had lower average marks, lower high school graduation rates, and had a lower likelihood of being enrolled in school after the age of 15 (Fuchs et al., 2009). Further research on educational service utilization by individuals with FASD found that they were over three times more likely to repeat a grade than an age-, sex-, and income-matched general population or asthma control group. It was also reported that individuals with FASD were nine times more likely to receive funding for special education compared to the general population and six times more likely than those with asthma (Brownell et al., 2013; Gough & Fuchs, 2010).

7.4.5 CRIMINAL JUSTICE SYSTEM

The prevalence of FASD has also been previously reported to be higher in individuals involved with the criminal justice system (Fast, Conry, & Loock, 1999; Burd et al., 2003; Burd et al., 2004; Popova et al., 2019). The prevalence of FASD among males aged 19 to 30 entering incarceration at a federal facility (Stony Mountain Institution) for the first time was measured through a pilot of the FASD Brief Screen Checklist with a cohort of 91 males between March 2005 and September 2006. Data sources included the FASD Brief Screen Checklist, medical intake interview, FAS Facial Photographic Analysis Software, and neuropsychological assessments. The screening and diagnostic process found that 9.9% met the criteria for FASD, 15% met some diagnostic criteria but the information needed for diagnosis were missing, and 45% were found to have neuropsychological deficits unrelated to PAE (MacPherson et al., 2011). Among the 91 participants, there was one case of partial FAS, 8 cases of ARND, and 14 cases which lacked the information required to confirm or rule out a FASD diagnosis. Therefore, the prevalence of FASD during the study period was 10%, which was ten times greater than the Canadian general population estimate.

7.5 Comorbidities

7.5.1 COMORBIDITIES AMONG WOMEN WHO BIRTHED CHILDREN WITH FASD

The Manitoba Mothers and FASD Study examines life circumstances of women who have birthed a child diagnosed with FASD. Linked clinical and administrative data stored at the MCHP enables the generation of a population-based cohort of all women who birthed a child diagnosed with FASD in MB since 1999 (approximately 700 cases) and clinically relevant comparison groups. This cohort was generated to investigate risk factors that are associated with giving birth to a child who is diagnosed with FASD and to examine maternal physical and health outcomes and usage of health and social services (Singal et al., 2016).

The largest study in the world to investigate the rate of prenatal care among women who birthed a child with an FASD diagnosis found that 41% of 700 births from 1984 to 2012 received inadequate or no prenatal care, compared with 15% of women who birthed a child without FASD (Singal et al., 2019). Women who birthed a child with a FASD diagnosis were impacted by lower socio-economic status, a higher likelihood of mental disorders, single parenthood, and contact with child welfare services. Analysis of health system contact among a cohort of mothers of children with FASD diagnoses from 1979 to 2013 found higher rates of suicide attempts and suicide completion as compared to mothers of children without FASD diagnoses. Higher rates of poverty, single parenthood, alcohol use, and mental health disorders increased their risk of suicide (Singal et al., 2017b). Mothers who gave birth to a child diagnosed with FASD also had higher adjusted rates of substance use disorder, personality disorder, and mood and anxiety disorders in the three years before pregnancy, relative to mothers who did not give birth to a child diagnosed with FASD (Singal et al., 2017a). These women also had a higher rate of both prenatal and postpartum psychological distress and higher rates of prescribed antidepressants before, during, and after pregnancy (Singal et al., 2017a).

7.5.2 COMORBIDITIES AMONG INDIVIDUALS DIAGNOSED WITH FASD

Research conducted in MB has found comorbid depression, anxiety, substance use, ADHD, and suicide among individuals living with FASD (Fuchs et al., 2010; Fuchs et al., 2005; & Brownell et al., 2012). Chartier et al. (2016) found that among children (aged 6 to 12) diagnosed with FASD in MB from 2009 to 2013, 9.7% had externalizing disorders, 8.7% had ADHD, and 3.2% had developmental disorders. Among diagnosed adolescents (aged 13 to 19) from 2009 to 2013, 12% had mood and anxiety disorders, 7.5% had externalizing disorders, and 2.9% had developmental disorders (Chartier et al., 2016).

Fuchs et al. (2005) found that mental health disabilities occurred in 45.5% of children with a FASD diagnosis, 19.8% had a coincident medical condition, 16.7% had physical impairments, and 39.1% had an ADHD diagnosis. Individuals with FASD who were incarcerated at Stoney Mountain Institution were more likely than those without FASD to have diagnoses of ADD, ADHD, and other mental health disorders (MacPherson et al., 2011). High comorbid rates of ADHD and FASD warrant screening of patients for FASD when symptoms of ADHD present (Wittick & Hanlon-Dearmon, 2017). The Report of the Child Death Review found PAE was a direct cause of death for 10 children identified as dying of natural causes and that 13 babies who died in their sleep were born to mothers in active substance use (Shibler & Newton, 2006). These findings encourage proactive supports that assist women in reducing alcohol and other drug use (Shibler & Newton, 2006).

8.0 Results — Northwest Territories

8.1 Population Profile

8.1.1 OVERVIEW

As of July 2020, there were 45,161 residents of the Northwest Territories (NT Bureau of Statistics, 2020a), approximately half of whom live in Yellowknife (NT Bureau of Statistics, n.d.-a). The population consists of similar numbers of Indigenous and non-Indigenous residents (NT Bureau of Statistics, 2020b). In 2016, the NT had the second highest birth rate among the P/T in Canada (14.4 births per 1,000) with a total of 623 births in 2018 (NT Bureau of Statistics, 2019a).The NT has been part of the Canada Northwest FASD Research Network since 2004 and provides FASD diagnostic services to individuals of all ages.

8.1.2 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO FASD/PAE

The 2019 NT Community Survey found that nearly 80% of the working age population (25 to 64 years) had a high school diploma or higher level of education (NT Bureau of Statistics, 2019a). Almost half (42.7%) of the dwellings in the NT had at least one housing problem (i.e., affordability, adequacy, or a suitability issue) (NT Bureau of Statistics, 2019d). In 2018, 2,999 NT households (more than 20%) reported difficulties covering transportation, housing, food, clothing, and other necessary expenses. Of the 9,352 people living in these households, 24% were children under 15. Among these households, 61% reported often or sometimes being worried about having money for food, and 31% stated they experienced financial difficulties due to rent or mortgage increases and 12.5% of adults reported both food insecurity and general financial insecurity (NT Bureau of Statistics, 2020c).Youth with FASD are more likely to experience housing instability compared to youth without FASD. They are almost twice as likely than their peers to have moved in the past year, and over four times more likely to have run away in the last year (2020 4Y Program, 2020).

In 2016, the violent crime rate was 78.4 per 1,000 individuals, seven times higher than the national rate of 10.5. Similarly, the rate of property crime exceeded the national rate (206.6 vs 32.1 per 1,000). In 2015, the rate of police-reported physical and sexual assault from a family member was 1,709 per 100,000, an increase of 5% from 2014 (NT Bureau of Statistics, 2019b). In 2016, 21.7% of families in NT were led by a lone parent, compared to the national rate of 16.4%. During this same year, 48% of Indigenous women and 70% of non-Indigenous women rated their mental health as very good or excellent, compared to the national rate of 69% in women in the general population. Of the 614 births in 2017, 45 were teen births (NT Bureau of Statistics, n.d.-b).

In 2014, alcohol use during the previous 12 months was reported by 46.4% of women aged 14 to 24, 75% of women aged 25 to 44, and 68.5% of women aged 45 to 64. CCHS data also indicate that 38.8% of women reported drinking heavily (four or more drinks on one occasion during the last 12 months), and 29.8% were current cigarette smokers (NT Bureau of Statistics, n.d. -c) Compared to 18% of women across Canada, 26% of non-Indigenous and 34% of Indigenous women in the NT reported drinking heavily (consuming four or more drinks on one occasion at least once per month) (NT Bureau of Statistics, 2019b).

The results of the 2006–2007 Canadian Maternity Experiences Survey found that 46.6% (95% CI: 41.0, 52.3) of women smoked cigarettes prior to pregnancy or pregnancy recognition and one-quarter (24.9%; 95% CI: 19.8, 30.0) of women smoked cigarettes during pregnancy. Over one-third of women (35.5%; 95% CI: 30.1, 40.8) reported experiencing one or more abusive acts in the past two years and 8.2% (95% CI: 5.0, 11.4) reported that most days were very stressful (Chalmers et al., 2008).

The Photovoice project, "Brightening Our Home Fires" on woman's health and wellness was active in NT from 2010 to 2012. A participatory action research model was used to engage in dialogue on FASD prevention and identify what health and healing looks like in the context of women's communities in northern NT (Goose & Badry, 2013). There were 30 participants from Yellowknife, Lutselk'e, Behchokö, and Ulukhaktok which represented Dené and Inuit culture (Badry & Felske, 2013c). Themes important to women's health in the North were land and tradition, housing, poverty, food, family, health, mental health, trauma, and travel (Goose & Badry, 2013).

Three critical key factors that underlie FASD prevalence were trauma, alcohol use, and child welfare involvement (Badry & Felske, 2013b). Women who had insecure access to shelter spoke more often about addiction and child apprehension in comparison to women living in home communities (Goose & Badry, 2013). Participants also expressed fears about harms from past experiences (historical trauma and abuse), violence, lateral violence, poverty, remoteness, isolation, lack of support, and homelessness (Goose & Badry, 2013). Results found that FASD can be understood as a product of multiple factors that lead women to self-medicate with alcohol to cope with social and health problems (Badry & Felske, 2013b).

The Photovoice project identified health and healing as the foundation of FASD prevention. Healthy living was defined as social, emotional, and physical connectedness to people, culture and land (Goose & Badry, 2013). Women's voices captured through this project teach that preconception planning supports linked with community-based views of health that are mindful of tradition, culture, and the high value placed on family and community are needed within the context of broader health initiatives (Goose & Badry, 2013). Women who have insecure access to shelter require access to resources, such as local food and traditional activities. Experiences on the land and related to the land were identified as exceptionally important for women in the north. Programs and policies that support access to local foods (high-protein meat), low stress, and land- and culture-focused activities are important during pregnancy. This project speaks to the possibility of Photovoice in giving voice to unheard experiences in complex areas of health (Goose & Badry, 2013). The healing services and research in Canada are outstanding and indicate that lived experience and the existing health human workforce are capable of preventing FASD.

8.1.3 FASD/PAE PREVENTION PROGRAMS

In 2017, NT Health and Social Services was tasked with developing and delivering alcohol and tobacco education to women who are pregnant and/or recent mothers, as well as developing a referral form and triage process that prioritizes care for women who are pregnant (Government of NT, 2017a). Other initiatives that increase awareness of FASD include the Foster Family Coalition's posters which advertised the NT Help Line with supports for reducing alcohol use and supporting healthy pregnancies (CanFASD, 2019). Further, the NT and Yukon are the only P/Ts to require FASD warning labels on alcoholic beverages (Canadian Partnership Against Cancer, 2018).

Maternal and infant care is provided through community-based programs such as a Baby-Friendly Initiative–designated program in the Inuvik Regional Hospital and nursing programs at the Sahtú Got'iné Regional Health and Social Services Centre and Sahtú Dene Nechá Kǫ Long-Term Care Facility (NT Health and Social Services, 2018). The Healthy Family Program provides information on reducing alcohol use and on nutrition, as well as other supports to families from pregnancy through to age five (NT Health and Social Services Authority, n.d.). Similarly, the Centre for Northern Families provides an integrated continuum of services that support parents in meeting their children's developmental needs from pregnancy through to age six (Centre for Northern Families, 2018). It has also been shown that midwifery care supports reductions in alcohol use during pregnancy (DPRA Consultants, 2012).

8.2 Existing Surveillance — PAE

The revised 2017 NT prenatal record facilitates the assessment and documentation of women's health and pregnancy care. This tool outlines the components of evidence-based prenatal care, including screening for alcohol use at minimum every trimester, automatic referral for patients who have a positive alcohol screen, and prenatal vitamin recommendations for women who have used alcohol heavily (Government of NT, 2017).

8.2.1 PUBLISHED PREVALENCE STUDIES

CCHS modules are implemented every two years in NT, with two-three data points on maternal alcohol consumption within the addiction survey component. Literacy and language issues, however, complicate the accuracy of the CCHS data from respondents in the NT, as this results in low response rates and/or greatly underestimates PAE prevalence in the territory. (Government of NT, 2017a).

When compared to 2002 data, the 2006 NT Drug and Alcohol Survey results indicate that the frequency of alcohol consumption for those drinking during pregnancy did not decrease (Badry & Felske, 2013a). PAE data from the 2012 survey were suppressed due to a low number of respondents (NT Department of Health and Social Services, 2014).

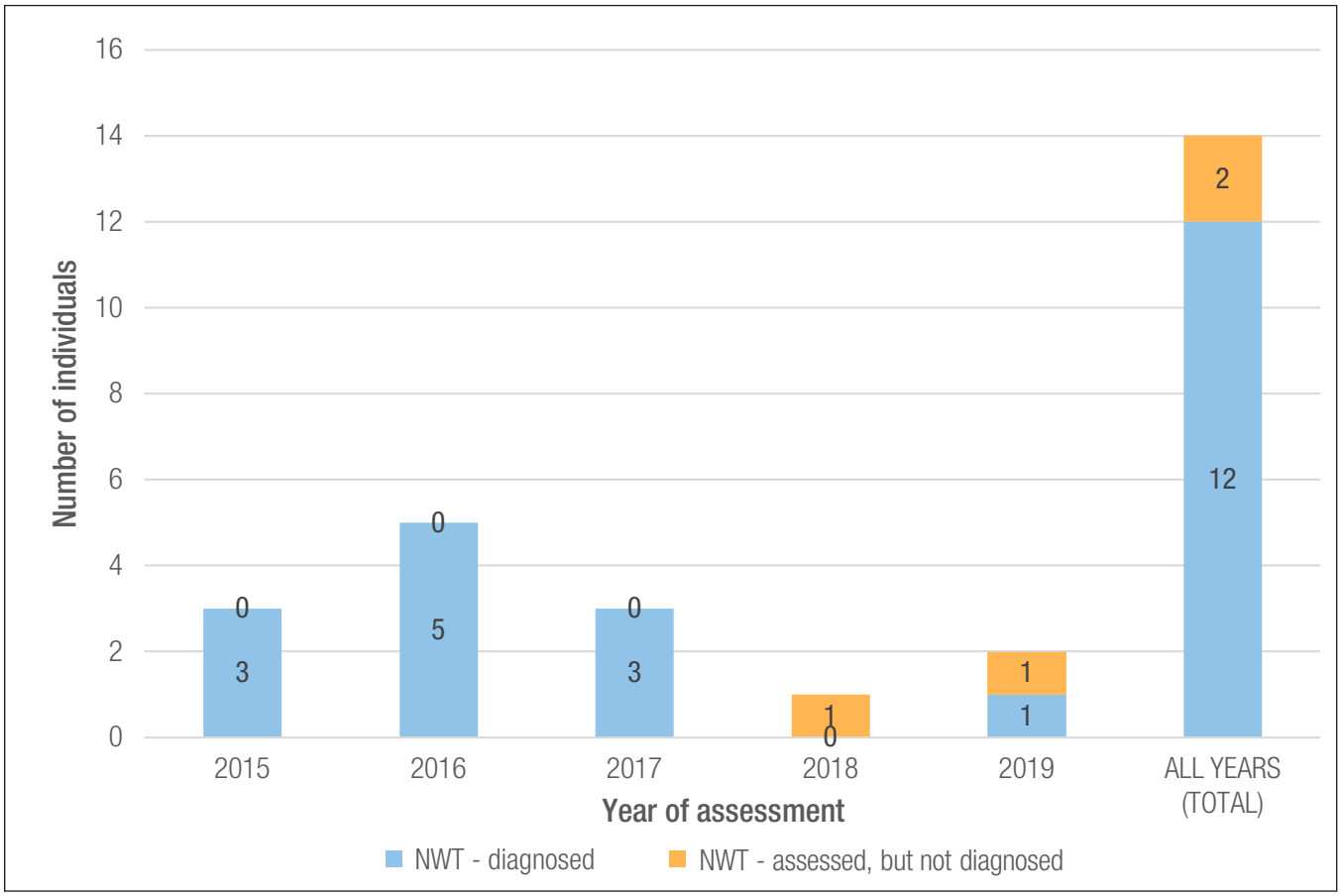
No published studies were identified to include regional estimates for PAE in the general population of NT. Among ten communities in the Inuvik Zone, the prevalence of alcohol use during pregnancy was estimated in two studies: 34.5% in 1987–1990 (Godel et al., 1992) and 24.3% in 2000 (Godel et al., 2000). See Appendix D. The former study found that alcohol use during pregnancy was more commonly reported by women who identified as "Caucasian" in comparison to women who were Indigenous.

8.3 Existing Surveillance — FASD

FASD diagnoses are provided by government-operated diagnostic clinics in the territory, with children and adults from NT receiving FASD diagnostic services in this jurisdiction as of February 2020. The NT Congenital Anomalies Registry, which dates back to 2011, covers approximately 680 births in NT per year, including live births and fetal deaths at more than 20 weeks, and collects data on individuals up to 19 years of age (Government of Canada, 2013).

8.3.1 CANADIAN NATIONAL FASD DATABASE

Please refer to the Canadian National FASD Database section of this report (Section 4.2.1) for a detailed analysis of these data. Data in the figure below present two categories of diagnostic outcomes: diagnosed, which includes individuals with FASD with or without sentinel facial features, and assessed but not diagnosed, which includes those in the at-risk category as well. Data are presented by year of assessment; where a year is missing, this indicates zero diagnoses and zero assessments in the respective year. Please note that only partial data were available for 2019. The Government of NT notes that these data only represent what was contributed to the Universal Dataform project in 2019 and do not represent the full number of FASD assessments and diagnoses that occurred during these years.



Source: CanFASD Universal Dataform project
Please note: partial data for 2019

Figure 5. Individuals assessed for FASD diagnosis and individuals who received FASD diagnoses by year in Northwest Territories, 2015–2019

Data collected from the Canadian National FASD Database show that there were 14 assessments and 12 individuals (85.7%) diagnosed with FASD. The majority (64.3%) of the assessed individuals were between 6 and 11 years old at the time of assessment. Almost all individuals diagnosed with FASD (n = 11, 91.7%) were 17 years or younger. It is important to note that the newly instituted Adult FASD Diagnostic Clinic did not contribute data to this study. Therefore, the age profile of individuals assessed and diagnosed is impacted by the Stanton Territorial Hospital Youth FASD Diagnostic Clinic and the FASD Family and Community Support Program solely contributing data to the study.

According to the most recent report received directly from the Government of NT (personal communication, October 29 2020), for the full years of 2015–2019, a total of 57 individuals were assessed for FASD, 44 of whom received an FASD diagnosis and 13 were deferred.

8.3.2 PUBLISHED PREVALENCE STUDIES

To date, one regional estimate has been identified for FASD in the general population of NT, derived from a recent study by Pei et al. (2020). See Appendix E. Regional data for NT estimates that the prevalence of FASD among kindergarten students in the general population is 1.2 per 1,000, or 0.12%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database. No studies have been identified to contain prevalence estimates of FASD in special subpopulations of NT.

The NT Health and Social Services Authority acknowledges the absence of statistics on the prevalence of FASD in the territory (Strong, 2020). A review of existing data sources will be conducted in 2019–2020 by the NT Health and Social Services Authority to determine the incidence of FASD (Government of NT, 2017a). The 2015 NT Congenital Anomalies Registry data captured 21 babies born in the NT with at least one congenital anomaly. This registry captured an average of 19 cases of congenital anomalies per year from 2011 to 2015, a prevalence rate of approximately 3% for individuals with a captured congenital anomaly in the jurisdiction (Government of NT, 2017b). Although this registry tracks FASD, it is unknown what proportion of these cases were individuals with FASD.

8.3.3 FASD DIAGNOSTIC CAPACITY

The NT Health and Social Services Authority provides adult FASD diagnostic services through the Adult FASD Diagnostic Clinic, which is located in Yellowknife. Individuals over the age of 18 can self-refer, and referrals can be made by Health and Social Services workers, government and non-government organizations, and family members. The goal of the clinic is to develop and implement appropriate intervention strategies for adults diagnosed with FASD and their support systems (Government of NT Health and Social Services, 2020). For the year following an individual's FASD diagnosis, the adult FASD program coordinator provides follow-up services (to individuals diagnosed and their supports) as recommended (NT Health and Social Services Authority, 2019). At the time of this report publication, 20 assessments are completed annually (personal communication, October 29, 2020).

Prior to the launch of the Adult FASD Diagnostic Clinic in 2020, adults travelled for diagnosis and therefore their cases were captured by clinics in different provinces (Clarren, Lutke, & Sherbuck, 2011). The number of suggested referrals prior to 2020 is assumed to be fewer than 20 per year (Salmon & Clarren, 2011). The Stanton Territorial Hospital Youth FASD Diagnostic Clinic and the FASD Family and Community Support Program in Yellowknife have served youth up to age 17 since 2010, with diagnostic clinics assessing children aged 7 to 17, and children between 0 and 7 years are supported by the youth FASD clinic.

8.3.4 DIAGNOSTIC CLINIC SURVEY

Methods

Please refer to the Diagnostic Clinic Survey section of this report (Section 4.2.2) for a detailed methodology.

Results

There were two clinics identified in NT, which are capable of conducting neurodevelopmental assessments for FASD. One of these clinics, which opened in 2020, focuses exclusively on adults (over 18). One clinic provided data for assessment years 2015–2017. In each year, ten individuals were assessed for FASD, and eight to nine were diagnosed with FASD. In all years combined (2015–2017), a total of 30 were assessed in the one clinic and 26 of them (86.7%) were diagnosed with FASD.

There were 10 spots allotted for FASD diagnoses and 45 individuals on the waitlist in each year. Based on these limited data, the estimated wait time to receive an FASD assessment is approximately 4.5 years. Individuals on this clinic's waitlist would be referred from health, social, or education services. Confirmation of PAE was not required to be on the waitlist, but it was required for the assessment to take place.

8.4 Health Care Utilization

8.4.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From the 2014 to 2017 fiscal years, a total of 81 hospitalizations and health care visits were made among patients with FAS with a health card from NT. These health care encounters were mostly for emergency care visits (n = 42). Among the patients with FAS with a health card from the NT, 61.1% resided in urban areas and none were homeless.

8.4.2 PUBLISHED STUDIES AND REPORTS ON SERVICE UTILIZATION

The average cost of special education per child in elementary and middle school in 2011–2012 was $7,976. An average of ten children and youth diagnosed with FASD were receiving special education in this time frame at a total cost of $79,564. Resources that support women's health in NT are more readily available in Yellowknife than in remote communities. The distance between communities is a barrier for some women who have survived trauma and/or domestic violence and live with substance use disorder (Badry & Wight Felske, 2013b). Limited academic literature on land-based healing treatment programs or cultural immersion camps for adults with substance use disorders exist (Laurie, 2013); however, there is large community support for these programs as holistic health solutions for community healing (NT Department of Health and Social Services, 2014).

The Foster Family Coalition of the NT developed the 4Y Program in order to address a gap in services for young people with FASD who are transitioning out of child welfare services (Kyle, 2019b) as well as for other individuals impacted by PAE. An active two-year (2019–2021) pilot of this trauma-informed program is designed to meet the needs of youth in Yellowknife who have a brain-based disability caused by PAE. Children and young adults (up to age 29) residing in NT

with or without an FASD diagnosis receive regular counselling and life-skills support during weekly one-to-one sessions and less frequent group sessions. Supports are also provided to family and support networks in order to strengthen individual and community resiliency. Program components including arts, music, culture, life skills, nutrition, and physical education are applied to encourage improved physical and mental health, self-confidence, and self-determination. Program participants who are Indigenous have access to culture-based activities. The goals of the program are to prevent mental health and social issues including housing insecurity, social isolation, and substance use disorder (Foster Family Coalition of the NT, 2019).

The Yellowknife Association for Community Living provides FASD supports and services in NT, including the FASD Peer Support Project and the Living and Learning with FASD project. Children and youth (aged 3 to 17) living in NT may access evidence-based mental health and well-being services at the Strongest Families Institute (Government of NT Health and Social Services, 2020). Targeted programing is delivered to support children and youth with ADHD, anxiety disorder, and oppositional defiant disorder (Strongest Families Institute, 2018).

9.0 Results — Ontario

9.1 Population Profile

ON is the most populous province in Canada, with 14.45 million residents, containing 38.3% of the country's population (Kiprop, 2019). The Ministry of Children and Youth Services in ON is leading the development of a cross-governmental approach to support individuals with FASD (Ontario Ministry of Children, Community and Social Services, 2016). The ON government responded to reported gaps in services for adults with FASD in ON (Anderson, 2015) with a $26-million investment (over four years) for FASD initiatives, including support services (Legislative Assembly of Ontario, 2017).

9.1.1 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO PAE

According to the 2014 Canadian Community Health Survey (CCHS), 10% of ON families experienced food insecurity in 2012 (Ontario Ministry of Children, Community and Social Services, 2016). Canadian Income Survey shows that the proportion of children and youth who live in low-income households remained fairly stable between 2009 and 2014: 14.6% in 2009, 13.8% in 2010, 13.6% in 2011, and 14% in 2014 (Ontario Ministry of Children, Community and Social Services, 2016). In 2016, 27.4% of census families with children were single-parent families, a rate which has remained stable since 2011 (Eastern Ontario Health Unit, 2019).

The proportion of ON students in grades 7–12 who reported past-month binge drinking (five or more drinks on one occasion) has steadily decreased in recent years: from 24.7% in 2009 to 17.6% in 2015 (Ontario Ministry of Children, Community and Social Services, 2016). In 2016, over one-third (36%) of women and 67% of men in Durham region drank alcohol in excess of Canada's Low-Risk Drinking Guidelines (CCHS, 2016), with 14% of women in this region reporting binge drinking once a month or more (Rapid Risk Factor Surveillance System, 2016). Overall, women's alcohol use in ON has increased from 1.9 drinks per week in 1996 to 3.6 drinks weekly in 2017 (Ialomiteanu et al., 2018). FASD awareness is high among the general population: 85% of survey respondents in the Region of Peel believed that drinking during pregnancy is harmful to a fetus (Kusi-Achampong, Gayle-Thompson, & Caprara, 2011) and 78.7% of residents in Middlesex-London reported an understanding that there is no safe level of alcohol use during pregnancy (Middlesex-London Health Unit, 2005).

From consultations led by the Ministry of Children and Youth Services to inform the development of an ON FASD strategy (Anderson, 2015), it was identified that FASD awareness strategies have typically not reached individuals at risk of having a child with FASD. This stakeholder feedback aligns with previous research showing that alcohol labels informing people of the teratogenic impacts of alcohol have not been found to be effective for individuals who have high risk alcohol use patterns (Thomas et al., 2014). This is anticipated to be due to messages primarily focusing on women's alcohol use without acknowledging contextual factors such as poverty, violence, addiction, mental health, and historical trauma (Choate et al., 2019).

These consultations also identified that Indigenous Peoples are healing from the intergenerational impacts of assimilationist policies and programs that apprehended children from their communities. These cultural factors have contributed to the development of mental health issues such as post-traumatic stress, substance use, and loss of traditional parenting practices (Anderson, 2015). An outdated study of family violence in ON found that eight out of ten Indigenous women survived family violence (Ontario Native Women's Association, 1989). Indigenous communities consistently support culturally appropriate responses that include data collection to measure the prevalence of FASD among Indigenous people in ON (Anderson, 2015).

Subpopulations identified as being high risk for FASD/PAE during these consultations were individuals who drink alcohol socially, individuals with mental health disorders (including substance use disorders), sexually active youth, and women over 30 who are working in professional settings (Anderson, 2015).

9.1.2 FASD/PAE PREVENTION PROGRAMS

The Breaking Cycles Program is a holistic early intervention program that supports women who are pregnant and use substances. Maternal wellness factors co-occurring among women who accessed the program included survival of sexual abuse (33%), physical abuse (81%), trauma (84%), and ongoing intimate partner violence (41%). The majority of these women had anxiety (88%), depression (76%), and sleeping/eating disorders (73%); approximately half had fears and phobias (46%), substance "misuse" (51%) (Pepler et al., 2002), and ongoing legal issues (41%) (Burns, 2015).

Effective programs in ON disseminating evidence-based educational resources on the impacts of alcohol use during pregnancy, as well as protective factors, include the Aboriginal FASD and Child Nutrition Program, which is delivered in over 180 communities, and Best Start, a program of Health Nexus. The Parent-Child Assistance Program is also available for women who are pregnant and use alcohol and/or other drugs. This program delivers a case-management model through home visitations. Early identification and intervention programs that support women who are pregnant with substance use disorders and those at risk include Mothercraft's Breaking the Cycle and Healthy Babies Healthy Children, which provides early screening and assessment, supports community service navigation, and has a specific program called Aboriginal Healthy Babies Healthy Children (Anderson, 2015).

9.2 Existing Surveillance — PAE

9.2.1 CAMH MONITOR

Introduction

The CAMH Monitor is the longest running anonymous health survey of adults in ON, first conducted in 1977. The survey monitors mental health and substance use among adults, as well as public opinion relating to drug issues and policies. The CAMH Monitor is an ongoing, repeated cross-sectional survey of ON adults and has been conducted continuously since 1996. Each year, the survey is conducted over the phone, utilizing random digit dialing to contact residents of ON aged 18 years and over. Each year, 3,000 to 5,000 ON adults are interviewed, with results utilized to identify areas of concern and emerging trends. All annual cycles of the survey share a common target population of non-institutionalized ON adults aged 18 or older and a sample derived from probability sampling. Response rates for the survey were 30% and 28% for 2018 and 2019, respectively. The cooperation rate was 37% for both years.

Objectives

The objectives of this study were as follows:

1. to estimate the prevalence of self-reported alcohol use (including amount and frequency) during the most recent pregnancy of parous women;
2. to estimate the prevalence of self-reported alcohol use (including amount and frequency) while breastfeeding last child for parous women;
3. to explore the demographic and health characteristics of parous women by alcohol use behaviour during the most recent pregnancy;
4. to estimate the prevalence of FAS and FASD among both men and women by asking if they have been told by others that they have FAS/FASD; and
5. to investigate the awareness of the negative consequences of alcohol use during pregnancy and FASD, among both men and women.

Methods

A cross-sectional analysis was performed on the record-level survey data from each survey cycle (2018 and 2019). Data cleaning steps involved the creation of an additional variable in each dataset to obtain age of the parous woman during the last pregnancy, based on information available on respondent age and year of last child born. Descriptive statistics were generated using STATA 16.1. Categories with counts below five were suppressed in the tables produced. Results were also stratified by reported alcohol use behaviour and respondent gender, where appropriate. The Fisher exact test was used to evaluate differences between stratified populations, and the level of significance was set at 0.05.

Results

Self-reported FAS and FASD, 2018–2019

Men and women in the 2018 and 2019 survey cycles were asked by the interviewer if they had ever been told by anyone, including a doctor, health professional, or a parent, that they (the respondent) have FAS or FASD.

Table 65. Prevalence of self-reported FAS/FASD, 2018–2019 (N = 3,154)

Respondent has been told they have FAS/FASD	2018 survey respondents (n = 1,334)	2019 survey respondents (n = 1,820)
Yes	<5 (S)	<5 (S)
No	1,325 (99.3%)	1,805 (99.2%)
Don't know	7 (0.52%)	11 (0.6%)

Source: CAMH Monitor survey
S: Suppressed

Data from 2018 and 2019 suggest a very low prevalence (0.1%-0.2%) of individuals who self-reported being told that they have FAS or FASD. It is unknown if this was an official diagnosis or suspected by the respondent.

Self-Reported Alcohol Use during Last Pregnancy, 2018–2019

A total of 1,025 women in 2018 and 1,051 in 2019 were asked if they had ever given birth to a child. In total, 743 (72.5%) in 2018 and 753 (71.7%) in 2019 women were parous; these women were subsequently asked about their alcohol use during pregnancy and while breastfeeding their last child (if applicable).

In total, among women, 92.2% (685 out of 743) in 2018 and 94.2% (710 out of 753) in 2019 had indicated they had ever used alcohol (lifetime) and went on to provide information on their alcohol use behaviour during their last pregnancy

Self-reported alcohol use during last pregnancy (any year) was slightly higher among parous women participating in the survey in 2019 (16.5%, compared to 13.0% in 2018). In 2019, 45.9% of the sample indicated using alcohol at least once a month (i.e., once a month, one to three times per week, or daily). Notably, in 2019, 2.0% reported using alcohol daily during their last pregnancy. No binge drinking was reported among parous women in either survey cycles. See Table 66.

Table 66. Alcohol use during most recent pregnancy among parous women, 2018–2019 (N = 1,395)

Self-reported alcohol use during most recent pregnancy	2018 respondents, n = 685	2019 respondents, n = 710
YES	89 (13.0%)	117 (16.5%)
Alcohol use frequency		
Less than once a month	10 (11.2%)	53 (54.1%)
Once a month	<5 (S)	17 (17.4%)
2 to 3 times a week	<5 (S)	14 (14.3%)
Once a week	<5 (S)	12 (12.2%)
Daily or almost daily	<5 (S)	<5 (S)
Don't know	79 (88.8%)	<5 (S)
Binge drinking (4 or more drinks on one occasion)		
No	10 (11.2%)	9 (8.9%)
Don't know	79 (88.8%)	92 (91.1%)
NO (ABSTINENT)	584 (85.3%)	593 (83.5%)
DON'T KNOW	12 (1.7%)	<5 (S)

Source: CAMH Monitor survey
Abbreviation: S, suppressed
Please note: percentages are derived using the number of women reporting alcohol use as a denominator

Self-Reported Alcohol Use while Breastfeeding Last Child, 2018–2019

In 2018, a total of 449 (65.6%) parous women reported that they had breastfed their last child and all of them reported on alcohol use behaviour during this period. In 2019, a total of 459 (63.9%) of parous women reported that they had breastfed their last child, and 444 (96.7%) of these women reported on alcohol use behaviour during this period.

Self-reported alcohol use while breastfeeding last child was roughly the same in both years (approximately 18%). In total, 56.8% of the sample in 2019 used alcohol once a month or more, with 5.4% reporting the use of alcohol daily while breastfeeding their last child. No binge drinking was reported among parous women in either survey cycles. See Table 67.

Table 67. Alcohol use while breastfeeding last child among parous women, 2018–2019 (N = 893)

Self-reported alcohol use while breastfeeding last child	2018 respondents, n = 449	2019 respondents, n = 444
YES	80 (17.8%)	80 (18.0%)
Alcohol use frequency		
Less than once a month	14 (17.5%)	28 (37.8%)
Once a month	<5 (S)	15 (20.3%)
2 to 3 times a month	<5 (S)	13 (17.6%)
Once a week	<5 (S)	6 (8.1%)
2 to 3 times a week	<5 (S)	8 (10.8%)
Daily or almost daily	<5 (S)	<5 (S)
Don't know	56 (70.0%)	<5 (S)
Binge drinking (4 or more drinks on one occasion)		
Yes	<5 (S)	<5 (S)
No	24 (30.0%)	71 (95.9%)
Don't know	56 (70.0%)	<5 (S)
NO (ABSTINENT)	361 (80.4%)	364 (82.0%)
DON'T KNOW	8 (1.8%)	<5 (S)

Source: CAMH Monitor survey
Abbreviation: S, suppressed
Please note: percentages are derived using the number of women reporting alcohol use as a denominator

Characteristics of Parous Women by Alcohol Use Status, 2018–2019

Data presented in Table 68 show that women who reported alcohol use in pregnancy were more likely to use alcohol while breastfeeding in both survey cycles ($p = 0.000$). Furthermore, women reporting alcohol use in pregnancy were less likely to be married/partnered ($p < 0.05$) and more likely to report their general health as "fair" or "poor" at the time of the survey ($p < 0.05$).

Women who reported alcohol use in pregnancy were more likely to report lifetime use of cocaine (2018: $p = 0.014$) or cannabis, marijuana and hashish (2018: $p = 0.041$); past 30-day ($p = 0.000$) and 12-month (2018: $p = 0.041$; 2019: $p = 0.006$) use of alcohol; and current/former tobacco use (2018: $p = 0.033$; 2019: $p = 0.000$).

Table 68. Characteristics of parous women by self-reported alcohol use status during last pregnancy, 2018–2019 (N = 1,395)

Characteristics at time of survey	2018		p-value	2019		p-value
	Alcohol use reported (n = 89)	No alcohol use reported (n = 584)		Alcohol use reported (n = 117)	No alcohol use reported (n = 593)	
AGE AT TIME OF SURVEY (YEARS)						
Mean (SD) Range	64.2 (14.0) 23-87	61.0 (14.8) 20-99	0.281	65.6 (13.4) 23-91	61.6 (15.7) 23-98	0.042*
CALCULATED AGE AT TIME OF MOST RECENT PREGNANCY (YEARS)						
Mean (SD) Range	29.8 (5.6) 17-40	30.0 (5.5) 16-45	0.000*	29.9 (4.8) 18-39	30.2 (5.3) 16-45	0.401
BREASTFED THEIR LAST CHILD	58 (65.2%)	385 (65.9%)	0.605	74 (63.2%)	380 (64.4%)	0.833
Used alcohol while breastfeeding last child	23 (39.7%)	56 (14.6%)	0.000*	26 (38.8%)	52 (13.9%)	0.000*
BORN OUTSIDE OF CANADA	15 (16.9%)	105 (18.0%)	0.965	25 (21.4%)	124 (20.9%)	0.902
IMMIGRATED TO CANADA IN LAST 20 YEARS	<5 (S)	12 (2.1%)	0.503	<5 (S)	19 (3.2%)	1.000
MARRIED/PARTNERED	58 (66.7%)	389 (66.9%)	0.404	60 (52.2%)	374 (63.5%)	0.028*
POST-SECONDARY EDUCATION (PARTIAL OR COMPLETED)	63 (72.4%)	394 (68.3%)	0.746	85 (72.6%)	395 (67.1%)	0.278
SELF-RATED GENERAL HEALTH AS "FAIR" OR "POOR"	18 (20.7%)	70 (12.0%)	0.042*	27 (23.3%)	81 (13.8%)	0.016*
SELF-RATED GENERAL MENTAL HEALTH AS "FAIR" OR "POOR"	9 (10.2%)	41 (7.0%)	0.433	13 (11.2%)	52 (8.8%)	0.384
LIFETIME USE OF COCAINE	11 (12.4%)	26 (4.5%)	0.014*	10 (8.6%)	32 (5.4%)	0.198
LIFETIME USE OF CANNABIS, MARIJUANA, OR HASHISH	48 (53.9%)	228 (39.0%)	0.006*	58 (49.6%)	240 (40.5%)	0.104
PAST 30-DAY USE OF ALCOHOL	77 (86.5%)	376 (64.6%)	0.000*	98 (83.8%)	370 (62.6%)	0.000*
PAST 12-MONTH USE OF ALCOHOL	81 (91.0%)	473 (81.0%)	0.041*	103 (88.0%)	455 (76.7%)	0.006*
CURRENT OR FORMER TOBACCO USE	57 (64.0%)	279 (48.1%)	0.033*	80 (69.0%)	278 (47.4%)	0.000*

Source: CAMH Monitor survey
Abbreviation: S, suppressed; SD, standard deviation
* p-value from Fisher exact test determined to be significant at the 0.05 alpha level
Please note: percentages are derived using the number of women reporting alcohol use while breastfeeding as a denominator. Age at pregnancy was missing for 14 parous women in 2018 and 14 parous women in 2019.

FASD Awareness among Survey Respondents, 2019

A total of 908 respondents (men and women) responded to questions intended to measure awareness of the detrimental consequences of alcohol use during pregnancy and FASD.

The majority of women conveyed personal opinions indicating that there is never a safe time (76.5%) or type of alcohol (71.2%) to be consumed during pregnancy. These proportions are smaller among men (70.9% and 64.6%, respectively), though these differences are not statistically significant. See Table 69.

In total, 112 (21.3%) of women and 96 (25.2%) of men believe that some alcohol consumption during pregnancy may be safe, including those who indicated "It depends." These respondents said that it may be safe to consume alcohol once a week (4.7% of women, 7.6% of men); one to three times a month (6.1% of women, 6.3% of men); and less than once a month (6.4% of women, 5.5% of men). More women (88.6%) as compared to men (80.2%) had heard about FAS or FASD prior to the survey (p = 0.001).

Table 69. Survey respondents' awareness of general risks of alcohol use during pregnancy and of FASD, 2019 (N = 908)

	Women	Men	p-value
"In your opinion, how often do you think a pregnant woman can drink alcohol without potentially harming the health of her unborn child?"			
Never	403 (76.5%)	270 (70.9%)	
Daily or almost daily	5 (0.9%)	<5 (S)	
2 to 3 times a week	9 (1.7%)	13 (3.4%)	
Once a week	25 (4.7%)	29 (7.6%)	
1 to 3 times a month	32 (6.1%)	24 (6.3%)	0.285
Less than once a month	34 (6.4%)	21 (5.5%)	
It depends	7 (1.3%)	6 (1.6%)	
Don't know	11 (2.1%)	14 (3.7%)	
Refused	<5 (S)	<5 (S)	
Total number of respondents	**527**	**381**	
"Only *some* types of alcoholic drinks, which are lower in alcohol content (such as beer or wine), can be considered safe to drink during pregnancy."			
Strongly agree	23 (4.4%)	20 (5.2%)	
Somewhat agree	48 (9.1%)	34 (8.9%)	
Somewhat disagree	52 (9.9%)	51 (13.4%)	0.264
Strongly disagree	375 (71.2%)	246 (64.6%)	
It depends	7 (1.3%)	9 (2.4%)	
Don't know	22 (4.2%)	21 (5.5%)	
Total number of respondents	**527**	**381**	
"Before today, had you ever heard about FAS or FASD?"			
Yes	467 (88.6%)	303 (80.2%)	
No	59 (11.2%)	74 (19.6%)	0.001*
Don't know	<5 (S)	<5 (S)	
Total number of respondents	**527**	**378**	

Source: CAMH Monitor survey
Abbreviation: S, suppressed
* p-value significant at the 0.05 level

Furthermore, these respondents who believe that some alcohol consumption during pregnancy may be safe said that it was safe during the last trimester (24.2% of women and 16.2% of men) or any time during the pregnancy (14.5% of women and 16.2% of men). The majority of men and women in this subsample also indicated that a small amount of alcohol (one or two standard drinks once or twice per month) may be safe during pregnancy (66.7% and 73.5%, respectively). Notably, only 60.0% of women and 51.8% of men indicated that abstinence from alcohol is the safest choice for a woman upon recognition of pregnancy. See Table 70.

Table 70. Survey respondents' views on safety of alcohol use during pregnancy, 2019 (n = 173)

	Women	Men	p-value
"In your opinion, at which time during pregnancy can it be considered safe for a woman to drink alcohol, without potentially harming the health of the unborn child?			
Beginning (first 3 months)	14 (11.3%)	17 (15.3%)	
Middle (4th to 6th months)	10 (8.1%)	9 (8.1%)	
End (last 3 months)	30 (24.2%)	18 (16.2%)	
Any time (during the pregnancy)	18 (14.5%)	18 (16.2%)	0.694
Never (during the pregnancy)	34 (27.4%)	28 (25.2%)	
It depends	<5 (S)	<5 (S)	
Don't know	16 (12.9%)	17 (15.3%)	
Total number of respondents*	**124**	**111**	
"One or two (standard) drinks once or twice per month can be considered safe to drink during pregnancy."			
Strongly agree	18 (20.0%)	28 (33.7%)	
Somewhat agree	42 (46.7%)	33 (39.8%)	
Somewhat disagree	14 (15.6%)	8 (9.6%)	0.279
Strongly disagree	6 (6.7%)	7 (8.4%)	
It depends	<5 (S)	<5 (S)	
Don't know	9 (10.0%)	5 (6.0%)	
Total number of respondents	**90**	**83**	
"In your opinion, once a woman who drinks learns she is pregnant, what would be the best or safest option for her during the rest of the pregnancy?"			
Drink alcohol as she would normally	<5 (S)	<5 (S)	
Cut back on alcohol	24 (26.7%)	32 (38.6%)	
Stop drinking alcohol	54 (60.0%)	43 (51.8%)	0.501
It depends	5 (5.6%)	<5 (S)	
Don't know	5 (5.6%)	<5 (S)	
Refused	<5 (S)	<5 (S)	
Total number of respondents	**90**	**83**	

Source: CAMH Monitor survey
Abbreviation: S, suppressed
* 62 respondents indicated they believed there was "never" a safe time to consume alcohol during the pregnancy in the first question. They were excluded from the overall denominator and skipped over the next two questions.

Conclusions

The derived prevalence estimates for alcohol use during pregnancy (13.0% in 2018 and 16.5% in 2019) are comparable with previous population-based estimates of 10% (Popova et al., 2017). The obtained prevalence estimates for alcohol use during breastfeeding (17.8% in 2018 and 18.0% in 2019) are comparable with previous population-based estimates of 20% (Popova et al., 2013c). Alcohol use during pregnancy may be associated with general lifetime substance use patterns of parous women.

Only about three-quarters of respondents (men and women) indicate there is no type, timing, or amount of alcohol that is safe during pregnancy. Higher proportions of men express that some alcohol intake frequency, type, and amount may be safe during pregnancy. This is important to address in FASD prevention education as partner and community attitudes often influence women's alcohol use behaviour during pregnancy.

Limitations

The obtained information on reported alcohol use during pregnancy does not take into account the alcohol type(s) consumed or the timing of the respective pregnancy recognition. Additionally, the information on reported alcohol use during breastfeeding does not take into account the timing or duration of breastfeeding or the alcohol type(s) consumed.

Two forms of bias may have affected the findings. The first is recall bias: parous women may not recall past substance use behaviour during pregnancy or breastfeeding accurately, as the last pregnancy was approximately 30 years ago in most cases. Secondly, social desirability bias may have influenced self-report of alcohol use behaviour or reported personal opinions regarding alcohol use in pregnancy.

9.2.2 BETTER OUTCOMES REGISTRY & NETWORK ONTARIO

Objectives

The objectives of analyzing the data from Better Outcomes Registry & Network (BORN) ON were:

1. to estimate the prevalence of self-reported alcohol use during pregnancy resulting in live births and stillbirths in ON (2012–2018); and
2. to explore demographics and maternal and neonatal characteristics pertaining to pregnancies with self-reported maternal alcohol use resulting in live births and stillbirths (2015–2018).

Methods

Data Sources

Funded by the Ministry of Health and Long-Term Care (MOHLTC), the Better Outcomes Registry & Network Ontario is administered by Children's Hospital of Eastern Ontario (CHEO). BORN Ontario has captured full information for all pregnancy, birth, and neonatal outcomes in ON since 2012. Information is collected from all prenatal, intrapartum, and postpartum encounters, including service utilization such as specialized antenatal screening and neonatal intensive care unit (NICU) stay. Fiscal year within maternal and neonatal records (ranging from April 1–March 31, inclusive) is defined by the infant date of birth.

Data on substance use during pregnancy is captured in the BORN Information System (BIS), including exposure to alcohol, marijuana, cocaine, opioids, hallucinogens, and gas/glue. Data on substance use during pregnancy is based on maternal self-report to antenatal care providers, and the information reflects reported substance use in one or more antenatal encounters during the respective pregnancy, including the birth event. Where the reported consumption of alcohol varied over the course of the pregnancy, the total sum is taken and averaged out the entire antenatal period for the alcohol use variable. In the BIS, data are also collected on confirmed and suspected congenital anomalies at birth, including FAS and other alcohol-related birth defects. Congenital anomalies, such as micrognathia and cleft palate, might indicate an alcohol-related birth defect (ARBD) (Chudley et al., 2005).

Two data sources were obtained from BORN Ontario:

1. aggregate-level data on self-reported alcohol use during pregnancy among live births and stillbirths born April 1, 2012, to March 31, 2018, in ON; and
2. record-level data for mothers and neonates pertaining to alcohol-exposed pregnancies resulting in live births and stillbirths born April 1, 2015, to March 31, 2018, in ON.

Data Analysis

Record-level data obtained from BORN Ontario were analyzed by the CAMH research team. Data cleaning steps involved the editing of values with respect to polysubstance use and multiple mental health concerns within the drug/substance use exposure and mental health concern variables, respectively. Descriptive statistics were generated using STATA 16.1 to reflect maternal and neonatal characteristics, and these were stratified by fiscal year. Records with missing values for fiscal year were excluded from the analysis of the cohort, with the exception of suspected and confirmed congenital anomalies. Categories with counts below six were suppressed in the tables produced in order to protect patient privacy.

Results

Prevalence of Self-Reported Alcohol Use during Pregnancy Resulting in Live Births and Stillbirths in Ontario, 2012–2018

The rate and number of records of all live births and stillbirths of women with self-reported alcohol consumption during pregnancy is presented over the total number of live births and stillbirths of ON residents in the BORN Information System (BIS) by fiscal year.

Table 71 shows that between April 1, 2012, and March 31, 2018, there were 18,043 live births and stillbirths in ON pertaining to women who reported alcohol use during pregnancy (any amount or frequency of alcohol use). This accounts for a total of 2.1% of all pregnancies in ON during this time period that resulted in a live birth or stillbirth.

Table 71. Live births and stillbirths of women with self-reported alcohol use during pregnancy in Ontario, 2012–2018 (N = 847,341)

Fiscal year	All live births and stillbirths of women with self-reported alcohol use during pregnancy		Live births and stillbirths of women with no self-reported alcohol use		Total number of live births and stillbirths	
	n	% (row)	n	% (row)	n	% (row)
2012–2013	2,438	1.7	139,889	98.3	142,327	Yes
2013–2014	2,099	1.5	138,519	98.5	140,618	100
2014–2015	3,198	2.3	137,447	97.7	140,645	100
2015–2016	3,419	2.4	137,470	97.6	140,889	100
2016–2017	3,506	2.5	137,784	97.5	141,290	100
2017–2018	3,383	2.4	138,189	97.6	141,572	100
All years combined	**18,043**	**2.1**	**829,298**	**97.9**	**847,341**	**100**

Source: BORN Information System

These prevalence rates indicate a slight upward trend in the self-report of alcohol use during pregnancy among parous women in ON who gave birth in this time period. This is likely influenced, however, by differences in data collection of alcohol use during pregnancy that were implemented in the BIS in 2014. That year, data enhancements were made to the BIS, and two new picklist values were added to the antenatal alcohol use data element: 1) episodic excessive drinking (binging), and 2) exposure prior to pregnancy confirmed, amount unknown. These picklist values may have been captured within the "missing" picklist value in previous years and would not be included in the calculated prevalence rates for the 2012–2013 to 2013–2014 fiscal years. Therefore, the prevalence of self-reported alcohol use in pregnancies in ON that resulted in a live birth or stillbirth may not be increasing; it may just be that the prevalence is captured more efficiently since 2014 in comparison to previous years.

Demographics and Maternal and Neonatal Characteristics of Pregnancies with Self-Reported Maternal Alcohol Use Resulting in Live Births and Stillbirths, 2015–2018

A record-level dataset with linked maternal and neonatal records was obtained for all the live births and stillbirths of women with self-reported alcohol use during pregnancy where the infant data of birth ranged from April 1, 2015, to March 31, 2018.

There was a total of 10,308 neonates in the cohort in this time period. Data on fiscal year were missing for 395 neonatal records, and descriptive statistics generated for neonatal characteristics were restricted to records wherein fiscal year was available: a total of 9,913 neonatal records. Using the pregnancy identification numbers to eliminate duplicates (n = 136) from the linked dataset, it was found that there were 10,172 pregnant women in the dataset (i.e., over 100 multiple births in the cohort). Data on fiscal year were missing for 386 of these maternal records and descriptive statistics generated for maternal characteristics were restricted to records wherein fiscal year was available: a total of 9,786 maternal records.

MATERNAL DEMOGRAPHICS

The majority (90.8%) of the mothers in this cohort were between the ages of 21 and 40 years. See Table 72. These women were mostly nulliparous (52.6%) or primiparous (27.7%) and had zero or one biological children living at the time of the pregnancy (52.6% and 27.8%, respectively). Linked census data on education quintiles of women in this cohort indicate that the distribution is comparable to that of the general population in ON (Statistics Canada, 2019).

MATERNAL SUBSTANCE USE, MENTAL HEALTH AND PREGNANCY CONDITIONS

Results show that 44.4% of mothers in the cohort reported consuming an unknown amount of alcohol prior to pregnancy confirmation (see Appendix V). One-third (32.9%) of women reported less than one drink per month during pregnancy and 2.7% of women reported episodic excessive drinking (bingeing).

At their first prenatal visit, 30.2% (n = 2,937) of mothers in the total cohort reported smoking. A total of 18.5% (n = 1,801) smoked less than 10 cigarettes per day and 7.8% (n = 759) smoked 10 to 20 cigarettes per day; 3,055 women (31.2%) reported living with a smoker at the time of the first prenatal visit, indicating a possible risk of exposure to second-hand smoke.

As all women in the cohort had reported consuming alcohol during the respective pregnancy, additional exposures would indicate polysubstance exposure. There were 1,591 mothers (16.5%) who reported drug and substance use during the respective pregnancy, which is defined as the use of street drugs or the inappropriate use of prescription or non-prescription drugs (see Appendix V). Notably, 928 mothers (9.7%) reported the use of marijuana, 133 mothers (1.4%) reported using cocaine, 265 (2.8%) reported using two drugs, and 82 (0.9%) reported using three or more drugs; these are all in addition to the self-reported use of alcohol during the respective pregnancy.

At the time of the pregnancy, 3,219 mothers (33.3%) had one or more pre-existing or current mental health problem, which were either self-reported or diagnosed (see Appendix V). Anxiety (8.3%) was the most commonly self-reported/diagnosed mental health concern, followed by depression (5.9%) and addiction (1.8%). Two mental health concerns (excluding addiction) were reported by 9.2% of mothers. The majority (73.9%) of women in the cohort did not experience any fetal, maternal, or placental pregnancy complications and 77.8% intended to exclusively breastfeed after childbirth.

NEONATAL OUTCOMES

Among neonates in the cohort with available data on fiscal year (n = 9,913), the majority were live births (99.6%); at birth, 66.7% were full term (between 39 and 41 weeks gestational age) and 24.4% were early term (37 to 38 weeks gestational age). See Table 73. Apgar scores were in the normal range on average, at the one-minute mark (mean score = 8.2) and the five-minute mark (mean score = 8.8). NICU admissions (level 3) were fairly prevalent (15.2% overall) in this cohort. Though data on level 3 NICU admissions are complete, BIS had received additional patient data from only half of the level 3 NICUs in ON during this time period, and information about neonates past NICU admission is insufficient. For a variety of reasons, it is noted that neonatal health conditions for these years are very under-reported, including neonatal abstinence syndrome (NAS). From the data available, however, it is indicated that 254 neonates (2.6%) in this cohort had a complication at birth, and notably, the most prevalent neonatal health condition (3.0% overall) was NAS, which is most commonly linked to prenatal exposure to opioids or stimulants.

Table 72. Demographic characteristics of women with alcohol-exposed pregnancies in Ontario, 2015–2018 (N = 9,786)

Maternal characteristics	2015–2016, n = 3,240	2016–2017, n = 3,332	2017–2018, n = 3,214	All years combined, N = 9,786
MATERNAL AGE (AT TIME OF BIRTH IN YEARS)				
≤20	264 (8.5%)	220 (6.9%)	199 (6.5%)	683 (7.3%)
21-30	1,434 (46.2%)	1,445 (45.1%)	1,373 (44.8%)	4,252 (45.4%)
31-40	1,350 (43.5%)	1,470 (45.9%)	1,431 (46.7%)	4,251 (45.4%)
≥41	57 (1.8%)	69 (2.2%)	62 (2.0%)	188 (2.0%)
PARITY				
0	1,667 (53.7%)	1,668 (52.2%)	1,586 (51.8%)	4,921 (52.6%)
1	837 (27.0%)	903 (28.2%)	853 (27.8%)	2,593 (27.7%)
2	370 (11.9%)	404 (12.6%)	374 (12.2%)	1,148 (12.3%)
3	122 (3.9%)	129 (4.0%)	128 (4.2%)	379 (4.1%)
4 or more	106 (3.4%)	94 (2.9%)	123 (4.0%)	323 (3.5%)
NUMBER OF LIVING CHILDREN AT THE TIME OF PREGNANCY				
0	1,664 (53.5%)	1,678 (52.3%)	1,600 (52.0%)	4,942 (52.6%)
1	842 (27.1%)	907 (28.3%)	865 (28.1%)	2,614 (27.8%)
2	378 (12.2%)	401 (12.5%)	361 (11.7%)	1,140 (12.1%)
3	123 (4.0%)	129 (4.0%)	134 (4.4%)	386 (4.1%)
4 or more	102 (3.3%)	91 (2.8%)	119 (3.9%)	312 (3.3%)
NUMBER OF PREVIOUS TERM BIRTHS				
0	1,732 (55.7%)	1,732 (54.1%)	1,657 (53.9%)	5,121 (54.6%)
1	814 (26.2%)	906 (28.3%)	847 (27.6%)	2,567 (27.4%)
2	367 (11.8%)	373 (11.7%)	349 (11.4%)	1,089 (11.6%)
3	107 (3.4%)	111 (3.5%)	123 (4.0%)	341 (3.6%)
4 or more	89 (2.9%)	79 (2.5%)	98 (3.2%)	266 (2.8%)
EDUCATION QUINTILE (FROM CENSUS DATA)				
1st quintile	654 (21.2%)	686 (21.6%)	650 (22.0%)	1,990 (21.6%)
2nd quintile	620 (20.1%)	606 (19.0%)	589 (19.9%)	1,815 (19.7%)
3rd quintile	598 (19.4%)	639 (20.1%)	611 (20.7%)	1,848 (20.0%)
4th quintile	620 (20.1%)	640 (20.1%)	548 (18.5%)	1,808 (19.6%)
5th quintile	592 (19.2%)	612 (19.2%)	558 (18.9%)	1,762 (19.1%)

Source: BORN Information System

Abbreviation: S, suppressed

* Please note: Percentages displayed in the table are column percentages. Variables with missing data excluded from percentage calculations (i.e., N of numerator / [N of denominator – N of missing]). Records with missing values for any variables required to calculate the numerator were included in the number of missing; the percentage was calculated by using N of missing / N of denominator.

* Please note the following:

1. The neighbourhood education level status is represented as the number of people in a neighbourhood who hold a diploma, expressed as a percentage of the total population aged 25 to 64 within that neighbourhood.
2. Lowest quintile values for neighbourhood education level represent the lower portion of the distribution by dissemination area of individuals who have completed a certificate, degree, or diploma in a neighbourhood relative to highest quintile values, which represent the upper portion of the distribution who have completed a certificate, degree, or diploma.
3. Neighbourhood education level values distributed by dissemination area were categorized by quintile. Each quintile represents approximately 20% of the total population for Ontario but does not necessarily represent 20% of the births in Ontario.

Table 73. Outcomes of prenatally alcohol-exposed live births and stillbirths in Ontario, 2015–2018 (N = 9,913)

Outcomes at birth	Fiscal years			
	2015–2016, n = 3,288	2016–2017, n = 3,378	2017–2018, n = 3,247	All years combined, N = 9,913
BIRTH OUTCOME				
Live birth	3,143 (99.7%)	3,230 (99.5%)	3,107 (99.6%)	9,840 (99.6%)
Stillbirth	10 (0.3%)	15 (0.5%)	14 (0.5%)	39 (0.4%)
NEONATAL DEATH	<6	10 (0.3%)	7 (0.2%)	S
GESTATIONAL AGE AT BIRTH (WEEKS)				
<25	9 (0.3%)	13 (0.4%)	13 (0.4%)	35 (0.4%)
Preterm: 25-33	55 (1.7%)	72 (2.2%)	68 (2.2%)	195 (2.1%)
Late preterm: 34-36	189 (5.6%)	188 (5.8%)	187 (6.0%)	564 (5.9%)
Early term: 37-38	791 (24.9%)	759 (23.5%)	771 (24.9%)	2,321 (24.4%)
Full term: 39-41	2,119 (66.7%)	2,178 (67.4%)	2,041 (65.9%)	6,338 (66.7%)
Post-term: ≥42	16 (0.5%)	21 (0.7%)	16 (0.5%)	53 (0.6%)
NEONATAL LEVEL OF CARE				
I	543 (17.6%)	530 (16.7%)	480 (15.8%)	1,553 (16.7%)
IIa	391 (12.7%)	433 (13.7%)	422 (13.9%)	1,246 (13.4%)
IIb	657 (21.3%)	675 (21.3%)	658 (21.7%)	1,990 (21.4%)
IIc	906 (29.3%)	856 (27.0%)	872 (28.7%)	2,634 (28.4%)
IIIa/IIIb	591 (19.1%)	672 (21.2%)	603 (19.9%)	1,866 (20.1%)
ADMITTED TO NEONATAL INTENSIVE CARE UNIT	493 (15.5%)	492 (15.1%)	462 (14.9%)	1,447 (15.2%)
APGAR SCORE (0-10): 1 MINUTE — MEAN (SD)	8.3 (1.6)	8.2 (1.6)	8.2 (1.7)	8.2 (1.6)
APGAR SCORE (0-10): 5 MINUTES — MEAN (SD)	8.8 (1.0)	8.8 (1.0)	8.8 (1.1)	8.8 (1.1)
NEONATAL HEALTH CONDITIONS*				
Hyperbilirubinemia	220 (7.6%)	210 (7.0%)	222 (7.1%)	652 (7.3%)
Neonatal abstinence syndrome	110 (3.4%)	92 (2.8%)	89 (2.9%)	291 (3.0%)
Confirmed congenital anomaly (any), 1 or more	56 (1.7%)	48 (1.4%)	53 (1.6%)	157 (1.6%)
Respiratory distress syndrome	31 (1.0%)	38 (1.2%)	50 (1.6%)	119 (1.2%)
Intrauterine growth restriction	32 (1.0%)	16 (0.5%)	30 (1.0%)	78 (0.8%)
Meconium aspiration syndrome	7 (0.2%)	6 (0.2%)	13 (0.4%)	26 (0.3%)
Confirmed seizures treated pharmacologically	<6	<6	<6	9 (0.1%)
Sepsis-positive blood culture	7 (0.2%)	<6	<6	14 (0.2%)
Other health conditions / hypertonia	<6	<6	<6	11 (0.1%)
No neonatal birth complication	3,193 (97.9%)	3,273 (97.7%)	3,112 (96.7%)	9,578 (97.4%)

Source: BORN Information System

Abbreviation: S, suppressed; SD, standard deviation

Percentages displayed in the table are column percentages. Variables with missing data excluded missing from percentage calculations (i.e., N of numerator / [N of denominator – N of missing]). Records with missing values for any variables required to calculate the numerator were included in the number of missing; the percentage was calculated by using N of missing / N of denominator.

* Neonatal health conditions are not mutually exclusive; neonates may have more than one of the listed health conditions

NEONATAL CONGENITAL ANOMALIES OF PRENATALLY ALCOHOL-EXPOSED NEONATES

When including neonatal records with missing values for fiscal year (n = 395) in the analysis, there were a total of 271 (2.6%) neonates with suspected or confirmed congenital anomalies at birth out of the 10,308 neonates in the cohort. Notably, 21.0% of the data for the 271 neonates with suspected or confirmed anomalies are missing (see Appendix W). A total of 175 neonates (1.7%) had one or more confirmed congenital anomalies at birth. The most prevalent confirmed congenital anomalies (among the 175 neonates) were cardiovascular: 20 neonates (7.4%) were diagnosed with an atrial septal defect, and 12 neonates (4.4%) were diagnosed with a ventricular septal defect. Notably, there were no confirmed cases of FAS. The full list of confirmed congenital anomalies with corresponding frequencies and percentage is available in Appendix W.

Conclusions

The obtained annual prevalence estimates for self-reported alcohol use during pregnancy (1.5%-2.5%) are considerably lower than previous population-based estimates of 10% (Popova et al., 2017). Among mothers of live births and stillbirths in ON who had reported alcohol use during pregnancy (2015–2018), approximately 44.4% reported only consuming alcohol prior to pregnancy confirmation. This demonstrates the need for prevention initiatives to emphasize the importance of abstaining from alcohol for women who are trying to become pregnant or think they might be pregnant. Additionally, this demonstrates that unplanned pregnancies may play a large role in the occurrence of alcohol use during pregnancy among live births and stillbirths in ON.

One-third (33.3%) of mothers of live births and stillbirths in ON reporting alcohol use during pregnancy (2015–2018) have one or more pre-existing or current mental health conditions, based on self-report and diagnostic data. Additionally, 16.5% of these women reported using one or more additional drugs during the same pregnancy. FASD prevention initiatives must focus on women with a range of mental health and substance use issues.

Limitations

Information on the frequency of reported alcohol use during pregnancy does not take into account the alcohol type(s) consumed or the timing of the respective pregnancy confirmation. Pregnancy confirmation may be affected by unplanned pregnancy or access to prenatal care; the timing of the first antenatal visit is also unknown in these data. Additionally, social desirability bias may have influenced the self-report of alcohol use behaviour.

Data on the prevalence of alcohol use during pregnancy in ON is dependent on the thoroughness of antenatal screening for alcohol use behaviour from antenatal care providers, which is also unknown in these data.

9.2.3 ICES COHORT 1 — ALCOHOL USE IN PREGNANCY

Introduction

ICES holds a variety of population health data sources and databases in ON, including demographic and health care–related data, population-based health surveys, anonymous patient records, and clinical and administrative databases. Data available at ICES include record-level and linkable datasets, which include information on most publicly funded health services available in the province. These datasets were linked using unique encoded identifiers and analyzed at ICES. Within the datasets available at ICES, researchers have the capacity to examine FAS and PAE through diagnostic codes recorded as part of hospital-based encounters.

Objectives: Cohorts 1 and 2

These overall objectives apply to this section and to the ICES Cohort 2 — FAS among Adults in ON section (9.3.1.) presented below:

1. to understand the incidence and prevalence of PAE and FAS in ON (2002–2019) as determined through hospital-based data; and
2. to understand the demographic profile, health care utilization, comorbidities, and mortality of individuals with PAE and FAS in ON.

Methods: Cohorts 1 and 2

Two cohorts were defined by the CAMH research team and derived by a research analyst at ICES. Descriptive statistics were generated for a) health care encounters associated with the specified PAE and FAS diagnoses (not limited to individuals in cohorts); and b) characteristics, diagnostic codes, and service utilization of unique individuals belonging to each cohort.

The following databases were used to achieve the overall objectives:

- MOM-BABY dataset (ICES-derived cohort)
- Discharge Abstract Database (DAD)
- Continuing Care Reporting System (CCRS)
- Home Care Database (HCD)
- National Ambulatory Care Reporting System (NACRS), including the ICES-derived Same Day Surgery Database (SDS) obtained from NACRS
- Ontario Mental Health Reporting System (OMHRS)
- Registered Persons Database (RPDB)
- Ontario Health Insurance Plan (OHIP) claims database
- Office of the Registrar General Death (ORG-D) database

Objectives: Cohort 1

Cohort 1 consists of mothers with alcohol-related diagnoses who used hospital-based health care services during pregnancy and their children/youth (2003–2017). The specific objectives for cohort 1 are:

1. to estimate the prevalence of pregnant women with alcohol-related diagnoses who utilized hospital-based care (e.g., acute care hospitalizations, emergency department (ED) visits, or hospitalizations for a delivery) in ON from 2003 to 2017;
2. to estimate the incidence of newborns affected by maternal use of alcohol (using ICD-10 code P04.3) among all birth (irrespective of maternal diagnoses) in ON from 2003 to 2017;

3. to estimate the prevalence of health care utilization (e.g., acute care hospitalizations and ED visits) associated with an FAS diagnosis (using ICD-10 code Q86.0) (irrespective of maternal diagnoses) among children and youth (0 to 17 years) in ON from 2003 to 2017; and
4. to estimate the number of children and youth diagnosed with FAS (using ICD-10 code Q86.0) or PAE (ICD-10 code P04.3) between 2003 and 2017 who were born to mothers with alcohol-related diagnoses in ON.

Methods: Cohort 1

For this cohort, the DAD and NACRS (including SDS) databases were used to identify pregnancies that were alcohol-exposed. The MOM-BABY database (derived by ICES from DAD) was used to link maternal and neonatal records and to study neonatal and child outcomes throughout the follow-up period.

This cohort used rolling retention to include women who used hospital-based health care services during pregnancy with alcohol-related diagnoses (please see Appendix X). It was used to study the outcomes of women's children who were followed up longitudinally from April 1, 2003 (earliest possible birth date) to December 31, 2016 (latest possible birth date). The maximum follow-up date was until December 31, 2017, or until death of child. Women with intentional termination of pregnancies were excluded from the study.

The NACRS and DAD databases were used to identify mothers with alcohol-related diagnoses indicated during an emergency department visit, an acute care hospitalization during pregnancy, or during the hospitalization for the birth event. ICD-10-CA codes were used exclusively.

The main codes in the maternal health care records, indicating PAE/fetal damage, were as follows:

- O35.401: Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition
- O35.403: Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication
- O35.409: Maternal care for (suspected) damage to fetus from alcohol, unspecified as to episode of care, or not applicable

Data were collected on diagnostic codes for neonates and children based on hospital-based encounters. These data refer to encounters wherein these codes were indicated as the most responsible diagnosis pertaining to the encounter, or as another diagnosis relevant to the encounter. The assignment of the code within the encounter cannot be distinguished within the data presented in this section.

The main codes in neonatal and/or child records, indicating PAE/fetal damage, were as follows:

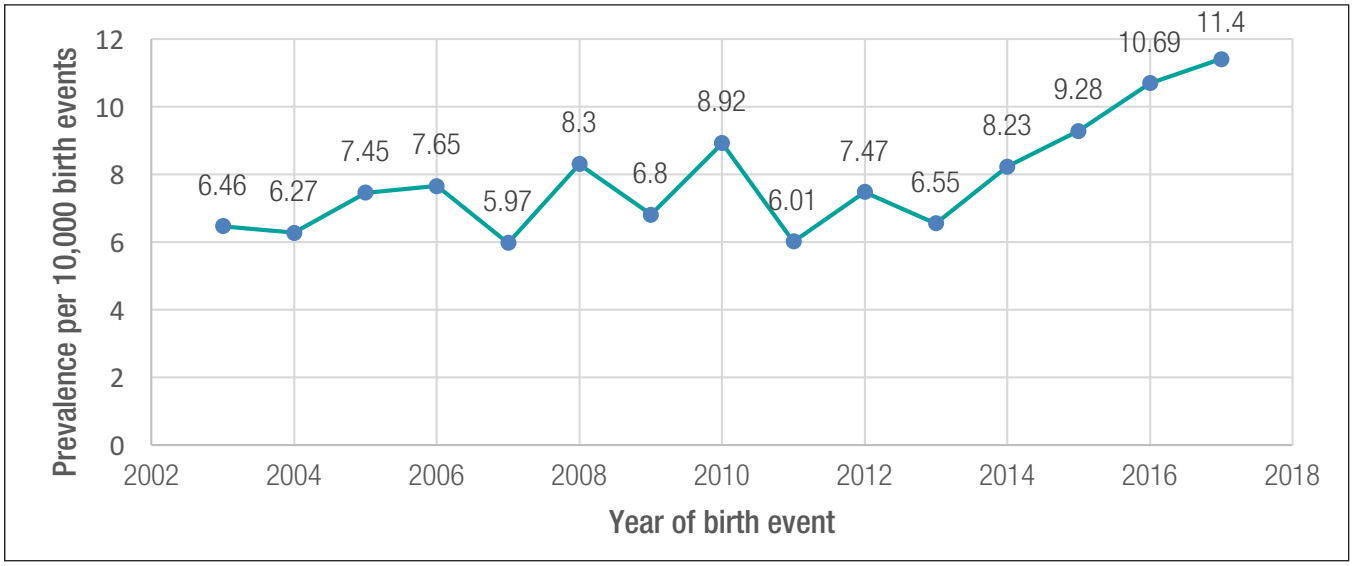
- P04.3: fetus and newborn affected by maternal use of alcohol
- Q86.0: fetal alcohol syndrome, dysmorphic

Results

Prevalence of Pregnant Women with Alcohol-Related Diagnoses Using Hospital-Based Health Care, 2003–2017

The table found in Appendix Y shows that the most common alcohol-related diagnosis in pregnant women who used hospital-based care services in ON from 2003 to 2017 was F10, mental and behavioural disorders due to the use of alcohol. All of these women were included in the cohort for analysis. Alcohol-related diagnostic codes during pregnancy or hospitalization for delivery are recorded during the respective encounters if they are the most responsible diagnosis or another diagnosis relevant to the encounter. The prevalence of the F10 code among women in this cohort suggests a mental health disorder relevant to current issues with alcohol addiction or misuse, during the respective pregnancy.

Figure 6 below presents the prevalence (as captured in the administrative health care data) of pregnant women in ON with any of the alcohol-related diagnoses (refer to Appendix X) who utilized hospital-based care (e.g., acute care hospitalizations, emergency department visits, or at delivery hospitalization). Data in Figure 6 are based on the information available in Appendix Y. The specified alcohol-related diagnostic codes captured within the administrative health data shows an increasing trend since 2013, with no clear pattern in earlier years.



Source: ICES data holdings, including DAD, SDS, NACRS, OHIP, and RPDB

Figure 6. Prevalence of pregnant women with alcohol-related diagnoses who utilized hospital-based care based on administrative health data in Ontario, 2003–2017

Incidence of Newborns Affected by Maternal Use of Alcohol among All Births in Ontario, 2003–2017

Table 74 presents the incidence of newborns diagnosed with ICD-10 P04.3 (newborn affected by maternal use of alcohol) among all births in ON from 2003 to 2017. (Please note: mothers of these newborns did not necessarily have alcohol-related diagnoses during pregnancy.) Based on the recording of the P04.3 diagnostic code, the incidence rates show an increasing trend since 2014, with no clear pattern in earlier years.

Table 74. Incidence of newborns affected by maternal use of alcohol among all births in Ontario, 2003–2017

Year	Number of newborns diagnosed with P04.3	Percent of newborns diagnosed with P04.3	Incidence of newborns diagnosed with P04.3 per 10,000	Number of live births
2003	22	0.02	1.68	130,919
2004	16	0.01	1.20	133,205
2005	12	0.01	0.89	134,238
2006	19	0.01	1.39	136,366
2007	15	0.01	1.07	139,539
2008	13	0.01	0.93	140,474
2009	10	0.01	0.71	139,951
2010	11	0.01	0.80	137,885
2011	13	0.01	0.94	137,699
2012	11	0.01	0.79	138,451
2013	11	0.01	0.81	135,794
2014	8	0.01	0.59	135,308
2015	10	0.01	0.74	134,671
2016	15	0.01	1.11	135,522
2017	17	0.01	1.26	135,083
Total	**203**	**0.01**	**0.99**	**2,045,105**

Source: ICES data holdings, including DAD, OHIP, and RPD

Prevalence of Health Care Utilization Associated with an FAS Diagnosis among Children/Youth in Ontario, 2003–2017

Data in Table 75 represent health care encounters (i.e., acute care hospitalizations and ED visits) pertaining to children (0 to 17 years) for whom a diagnosis of FAS (ICD-10 code Q86.0) was recorded. Individuals may have numerous health care encounters and therefore may be represented more than once in the table. These data are also irrespective of maternal diagnoses. Table 75 shows that the overall prevalence of inpatient discharges and ED visits associated with a diagnosis of FAS among children and youth with FAS have been steadily increasing since 2010 and 2009, respectively, with the highest value in prevalence recorded in 2017. Emergency department visits that did not result in admission are not included in the hospitalization counts; therefore, encounters are not being double-counted (e.g., in 2003, there were 60 unique encounters, including 51 admissions and 9 ED visits).

Table 75. Prevalence of health care utilization associated with an FAS diagnosis (ICD-10 code Q86.0) among children/youth in Ontario, 2003–2017

Year	Acute care hospitalizations*				ED visits**			
	Number of discharges with recorded FAS	Percent of discharges	Prevalence of discharges per 10,000	Total number of discharges	Number of ED visits with recorded FAS	Percent of ED visits	Prevalence of ED visits per 10,000	Total number of ED visits
2003	51	0.02	2.35	216,617	9	0.00	0.09	1,020,247
2004	68	0.03	3.12	218,069	48	0.00	0.49	981,193
2005	55	0.03	2.50	219,859	39	0.00	0.38	1,039,249
2006	80	0.04	3.71	215,634	45	0.00	0.44	1,027,835
2007	63	0.03	2.91	216,822	20	0.00	0.20	996,462
2008	81	0.04	3.75	216,280	54	0.01	0.55	989,477
2009	63	0.03	2.90	217,514	37	0.00	0.35	1,048,613
2010	58	0.03	2.70	214,907	59	0.01	0.59	991,969
2011	77	0.04	3.55	216,814	69	0.01	0.65	1,053,637
2012	95	0.04	4.37	217,211	96	0.01	0.90	1,068,923
2013	99	0.05	4.62	214,075	106	0.01	1.03	1,024,344
2014	134	0.06	6.22	215,465	130	0.01	1.23	1,060,862
2015	155	0.07	7.26	213,600	131	0.01	1.26	1,040,468
2016	187	0.09	8.59	217,775	130	0.01	1.19	1,090,679
2017	202	0.09	9.30	217,251	224	0.02	2.09	1,072,020
Total	1,468	0.05	4.52	3,247,893	1197	0.01	0.77	15,505,978

Source: ICES data holdings, including DAD and NACRS
* Data were derived from DAD
** Data were derived from NACRS

Number of children/youth diagnosed with FAS and PAE born to mothers with alcohol-related diagnoses in Ontario, 2003–2017

Table 76 displays neonatal records according to year of entry into cohort and presents the number of children/youth with diagnoses, indicating FAS (ICD-10 code Q86.0) and PAE (ICD-10 code P04.3) from 2003 to 2017. If maternal records indicated alcohol-related diagnoses listed in Appendix X (2003–2017), the neonatal record was included and followed until the child moved out of province, died, or until December 31, 2017.

The highest proportion of infants and children born to mothers with alcohol-related diagnoses who were diagnosed with FAS (1.2%-5.9%) and PAE (1.2%-5.9%) entered the cohort in years 2003 and 2004. These individuals would be 13 to 14 years old by the end of follow-up period in 2017 (see Table 76). This may be due to longer follow-up time for these individuals; the analysis does not take into account differential time of follow-up between the groups.

A total of 1,957 children were included in the cohort. All infants and children in the cohort were born to mothers with alcohol-related diagnoses. From visual inspection of the low cell counts (fewer than six cases) not published in this report, it is evident that P04.3 is always indicated within the first year of life, whereas FAS diagnosis may not be established until the age of six to eight. Therefore, due to the rolling cohort retention design in this cohort study and a delay in FAS diagnosis, these data may not capture the true prevalence of FAS among each subgroup in the cohort.

Table 76. FAS and PAE diagnoses in cohort of children/youth born to mothers with alcohol-related diagnoses, 2003–2017 (N = 1,957)

Outcomes in 2017	Year of entry into cohort (age in years in 2017)														
	2003 (13-14)	2004 (12-13)	2005 (11-12)	2006 (10-11)	2007 (9-10)	2008 (8-9)	2009 (7-8)	2010 (6-7)	2011 (5-6)	2012 (4-5)	2013 (3-4)	2014 (2-3)	2015 (1-2)	2016 (0-1)	2017 (0)
Total records	85	85	102	100	87	112	116	111	88	98	103	119	128	153	198
Total Q86.0[a] cases	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6
Percent Q86.0[a] cases	1.2-5.9	1.2-5.9	0.9-4.9	1.0-5.0	1.1-5.7	0.9-4.5	0.9-4.3	0.9-4.5	1.1-5.7	1.2-5.1	0.9-4.9	0.8-4.2	0.8-3.9	0.7-3.3	0.5-2.5
Total P04.3[b] cases	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6	<6
Percent P04.3[b] cases	1.2-5.9	1.2-5.9	0.9-4.9	1.0-5.0	1.1-5.7	0.9-4.5	0.9-4.3	0.9-4.5	1.1-5.7	1.2-5.1	0.9-4.9	0.8-4.2	0.8-3.9	0.7-3.3	0.5-2.5

Source: ICES data holdings, including MOM-BABY database, DAD, SDS, NACRS, OHIP, RPDB, and OMHRS
a Q86.0, fetal alcohol syndrome (dysmorphic)
b P04.3, fetus and newborn affected by maternal use of alcohol
Please note: the exact number of cases could not be reported due to low cell counts

Conclusions

The prevalence of women with alcohol-related conditions as recorded in the health care records of hospital-based care during pregnancy or at hospitalization for birth event ranged from 5.97 per 10,000 (2007) to 11.4 per 10,000 (2017). The recorded prevalence of women with alcohol-related conditions relevant to utilization of hospital-based care during pregnancy has been steadily increasing since 2013. In 2017, the prevalence (11.4 per 10,000) was the highest of all years studied (2003–2017). The most commonly recorded diagnosis among women with alcohol-related diagnoses who accessed hospital-based emergency or inpatient care during pregnancy, delivery or birth was alcohol-related disorders (ICD-10 code F10).

Based on all neonatal records in 2003–2017 (not limited to those in the cohort), the diagnostic code P04.3 (affected by maternal use of alcohol) was recorded (most responsible or other diagnosis) for a total of 203 newborns, or 0.99 per 10,000 live births. Recorded diagnoses (most responsible or other diagnosis) of code P04.3 (affected by maternal use of alcohol) ranged from 0.59 per 10,000 (2014) to 1.68 per 10,000 (2003). The data show a steady increase in incidence rates based on this recorded code from years 2014 to 2017.

From 2003 to 2017, there were a total of 1,468 acute care hospitalizations and 1,197 emergency department visits associated with a diagnosis (most responsible or other) of FAS (Q86.0) for children and youth (0 to 17 years). In this time frame, 4.52 per 10,000 inpatient discharges and 0.77 per 10,000 emergency department visits were associated with FAS for children and youth.

The number of cases of FAS/PAE (Tables 74 and 75) as determined by recorded diagnoses (most responsible or other) during health care encounters among neonates and children is higher in unlinked records as compared to neonatal records that are linked to maternal alcohol-related diagnoses, within the cohort (Table 76). This indicates that FASD and adverse effects from PAE is not limited to children of mothers who have pre-existing alcohol-related disorders, according to administrative health care data.

Limitations

Alcohol-related diagnoses recorded by physicians or obstetricians during routine antenatal screening were not captured by the databases included.

It is unlikely that alcohol-related diagnoses were the major reason (the MRD) for the hospitalization or ED visit among pregnant women in this cohort. In this cohort study, we did not examine the other comorbidities and physical health conditions of women with alcohol-related diagnostic codes indicated; it is therefore unknown if maternal comorbidities may have influenced the onset of FASD in light of alcohol use during pregnancy.

For general limitations applicable to both cohorts, see General Limitations in Section 9.3.1.

9.2.4 PUBLISHED STUDIES — PAE

A total of eight regional estimates of alcohol use in pregnancy in the general population of ON were obtained from six peer-reviewed articles and reports (see Appendix D). No data were published with study years of interest for this report (2015–2020). The most recent regional estimate is derived from the Better Outcomes Registry & Network (BORN Ontario, 2015), which reports a prevalence of 1.8% in 2012–2014, though this variable was found to have 26.7% missingness. Prior to that, the CCHS 2007–2008 survey indicated that 5.4% of women consumed alcohol during their last pregnancy (Thanh & Jonsson, 2010). Regional estimates for ON from previous years using the NLSCY data indicate 14.5% in the 1994–1995 survey cycle, 12.8% in the 1996–1997 survey cycle, and 13.6% in the 1998–1999 survey cycle. One study used meconium testing as a data collection measure, finding 2.5% prevalence of PAE in 2004–2005 (Gareri et al., 2008).

Three studies were identified to have prevalence estimates of alcohol use during pregnancy among special subpopulations in ON. Among women in a small community in ON in 2009–2010, a review of medical records found a prevalence of 25.3% for alcohol use during pregnancy (Kelly et al., 2011). Among studies of women with high-risk pregnancies, the prevalence estimates ranged from 2% to 30% for any alcohol use (Goh et al., 2010) and 3.1% for binge drinking during pregnancy (Gladstone et al., 1997).

9.3 Existing Surveillance — FASD

9.3.1 ICES COHORT 2 — FAS AMONG ADULTS IN ONTARIO

See Section 9.2.3 for objectives and methodology across ICES cohorts 1 and 2. The specific objectives for cohort 2 were:

1. to examine the prevalence of acute care hospitalizations and emergency department visits associated with a diagnosis of FAS (ICD-10 code Q86.0) for patients 18 and older (2014–2017);
2. to estimate the number of unique adult individuals with an FAS diagnosis recorded in ON on January 1, 2014, who had emergency department visits, hospitalizations, or same-day surgeries from April 1, 2002, to December 31, 2013;

3. to explore the demographics, mental health, and substance use of adults with FAS in the cohort based on diagnoses recorded during utilization of health care services (emergency department visits, acute hospitalizations, or same day surgery) in 2014–2017; and
4. to explore the utilization and characteristics of health care services (e.g., length of stay) used by adults with FAS in the cohort in 2014–2017.

Methods

Adults (aged 18 or over on January 1, 2014) with FAS were included in this cohort if the FAS code was documented as part of an individual's hospital discharge (DAD), emergency department visit (NACRS), or same-day surgery (SDS) from April 1, 2002, to December 31, 2013, and followed until December 31, 2017, or until death. OMHRS was not used as part of the algorithm to create the cohort of individuals since there is no DSM-IV code specific to FAS. This cohort is represented in data within objectives 2, 3, and 4 of this section.

Data on FAS are based on encounters wherein ICD-10 code Q86.0 was indicated as the most responsible diagnosis pertaining to the encounter or as another diagnosis relevant to the encounter. The assignment of the code within the encounter cannot be distinguished within the data presented in this section.

Results

Prevalence of Inpatient Discharges and ED Visits Associated with FAS among Adults, 2014–2017

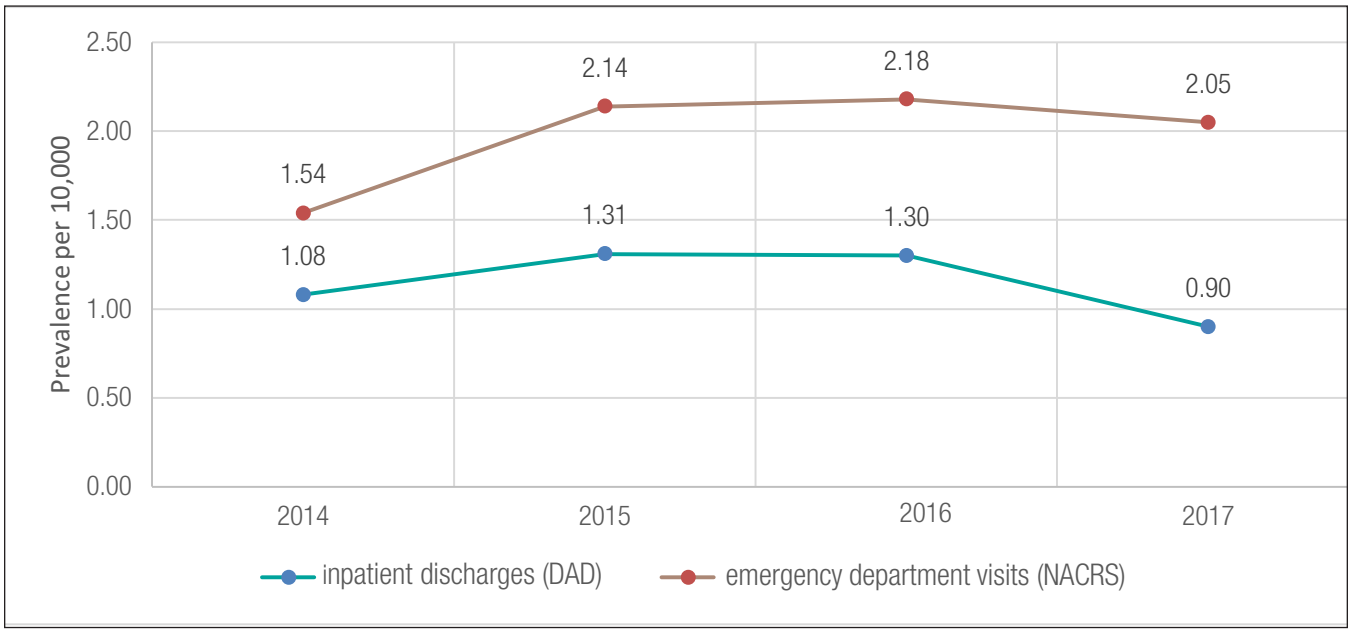
Health care encounters in DAD and NACRS associated with a diagnosis of FAS (most responsible or other) were examined in the years 2014 to 2017.

Data in Table 77 represent individual encounters and not unique individuals; therefore, this captures recorded diagnoses of FAS for health care encounters of adults, as opposed to prevalence of adults with FAS in these years. These entries may capture, but are not limited to, the health care encounters of the 565 unique individuals that were defined by the algorithm in this cohort (see Table 78).

Table 77. Acute care hospitalizations and emergency department visits associated with a diagnosis of FAS among adults in Ontario, 2014–2017

Year	Acute care hospitalizations*				Emergency department (ED) visits**			
	Number of hospitalizations	Percent	Prevalence per 10,000 discharges	Total discharges	Number of ED visits	Percent	Prevalence per 10,000 visits	Total ED visits
2014	98	0.01	1.08	910,239	615	0.02	1.54	4,000,322
2015	120	0.01	1.31	917,925	867	0.02	2.14	4,057,348
2016	121	0.01	1.30	931,046	915	0.02	2.18	4,187,919
2017	85	0.01	0.90	941,364	873	0.02	2.05	4,249,250

Source: ICES data holdings, including MOM-BABY database, DAD, and NACRS
* Data were derived from DAD
** Data were derived from NACRS



Source: ICES data holdings, including MOM-BABY database, DAD, and NACRS

Figure 7. Prevalence of inpatient discharges and emergency department visits associated with a diagnosis of FAS among adults in Ontario, 2014–2017

Figure 7 demonstrates health care encounters in 2014–2017 pertaining to adults who received an FAS diagnosis, wherein the FAS code (ICD-10 code Q86.0) was recorded. (See Table 77.) These prevalence estimates indicate that diagnoses of FAS were more frequently picked up within emergency department visits, as compared to inpatient discharges.

Number of Adults with FAS in Ontario on January 1, 2014, Who Had Health Care Encounters from April 1, 2002, to December 31, 2013

Table 78 captures adults (18 years and older) who received an FAS diagnosis (ICD-10 code: Q86.0) in a hospital discharge (DAD), emergency department visit (NACRS), or same-day surgery (SDS) from April 1, 2002, to December 31, 2013. The DAD and SDS databases were merged for this analysis. Individuals are included in a specific row based on the first time where Q86.0 was recorded for them in the specified health care encounter during this time period. There are no duplicates, and an individual is only represented once in this table.

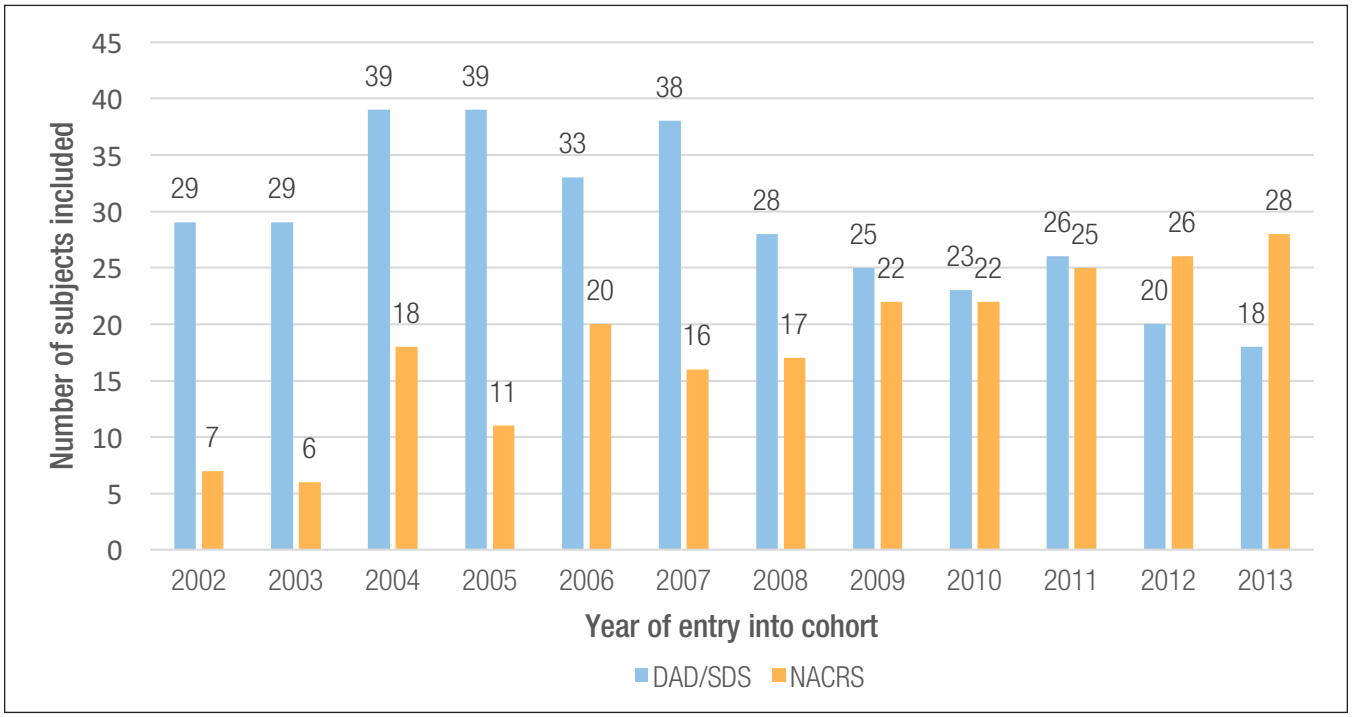
Table 78. Year of entry into cohort of adults with FAS who utilized health care services in Ontario (N = 565)

Data source	Entry year	Subjects alive at index	Percent	Cumulative count
DAD/SDS	2002	29	5.13	29
DAD/SDS	2003	29	5.13	58
DAD/SDS	2004	39	6.90	97
DAD/SDS	2005	39	6.90	136
DAD/SDS	2006	33	5.84	169
DAD/SDS	2007	38	6.73	207
DAD/SDS	2008	28	4.96	235
DAD/SDS	2009	25	4.42	260
DAD/SDS	2010	23	4.07	283

Data source	Entry year	Subjects alive at index	Percent	Cumulative count
DAD/SDS	2011	26	4.60	309
DAD/SDS	2012	20	3.54	329
DAD/SDS	2013	18	3.19	347
NACRS	2002	7	1.24	354
NACRS	2003	6	1.06	360
NACRS	2004	18	3.19	378
NACRS	2005	11	1.95	389
NACRS	2006	20	3.54	409
NACRS	2007	16	2.83	425
NACRS	2008	17	3.01	442
NACRS	2009	22	3.89	464
NACRS	2010	22	3.89	486
NACRS	2011	25	4.42	511
NACRS	2012	26	4.60	537
NACRS	2013	28	4.96	565

Source: ICES data holdings, including DAD, SDS, and NACRS

As of January 1, 2014, there were a total of 565 adults (unique individuals) with FAS who had emergency department visits, hospitalizations, or same-day surgeries in the time period between April 1, 2002, and December 31, 2013, where FAS was recorded. An additional 40 individuals had been identified based on the criteria but were excluded from the cohort because they died prior to January 1, 2014.



Source: ICES data holdings, including DAD, SDS, and NACRS

Figure 8. Number of adults with FAS diagnosis recorded as part of their emergency department visit, hospitalization, or same-day surgery by year of entry into cohort, 2002–2013

Figure 8 is based on the data in Table 78. Figure 8 shows that the NACRS identified more individuals with FAS from 2009 onward, while fewer adults with FAS were picked up via DAD/SDS in 2009–2013 than in previous years. These data reflect unique individuals as opposed to individual encounters, and therefore individuals are not repeated in this time frame.

Demographic Characteristics, Substance Use, and Mental Health Diagnoses of Adults with FAS Who Utilized Health Care Services, 2014–2017

Table 79 shows a demographic and mental health profile of adults with FAS as identified by the cohort study. The average age of adults with FAS in this cohort was 27.7 years and the proportion of males (55.0%) was slightly higher than that of females. Data are included for the top ten Public Health Units (PHUs; groups of urban/rural municipalities) among individuals in this cohort, though this information does not take into account the size and population density of each PHU. In this cohort, there were individuals from all 36 PHUs in ON.

Table 79. Demographics, substance use, and mental health diagnoses of adults with FAS who utilized health care services, 2014–2017 (N = 565)

Characteristics	Adults with FAS (N = 565)
AGE AT INDEX	
Mean (SD)	27.72 (9.8)
Median (IQR)	25 (21-31)
SEX	
Female	254 (45.0%)
Male	311 (55.0%)
TOP 10 PUBLIC HEALTH UNITS	
Toronto	66 (11.7%)
Northwestern	41 (7.3%)
Hamilton	33 (5.8%)
Ottawa	32 (5.7%)
Niagara	30 (5.3%)
Waterloo	29 (5.1%)
Simcoe-Muskoka	27 (4.8%)
Durham	23 (4.1%)
Thunder Bay	23 (4.1%)
Windsor-Essex	20 (3.5%)
DIAGNOSES PRESENT AT HOSPITAL ENCOUNTERS	
Substance use	
Alcohol use	89 (15.8%)
Multiple substance use	65 (11.5%)
Opioid use	34 (6.0%)
Stimulant use	33 (5.8%)
Cannabis use	22 (3.9%)
Cocaine use	21 (3.7%)
Hallucinogen use	7 (1.2%)

Characteristics	Adults with FAS (N = 565)
MENTAL HEALTH DIAGNOSES	
Anxiety/OCD/PTSD (F4)	178 (31.5%)
Mood disorder (F30-F34)	120 (21.2%)
Schizophrenia or psychosis (F2)	87 (15.4%)
Personality disorder (F6)	64 (11.3%)
Developmental disorder (F7-F8)	45 (8.0%)
Behavioural disorder (F5)	12 (2.1%)
HISTORY OF MENTAL HEALTH AND ADDICTIONS	
Personal history of MHA (Z86.5) / congenital (Z87.7)	29 (5.1%)
Family history of MHA (Z81.8)	0 (0%)

Source: ICES data holdings, including: DAD, SDS, NACRS, OHIP, RPDB
Please note: Mental health diagnoses based on ICD-10 codes
Abbreviations: SD, standard deviation; IQR, interquartile range; OCD, obsessive compulsive disorder; PTSD, post-traumatic stress disorder; MHA, mental health and addictions

These data show very high prevalence of substance use diagnoses (MRD or other) recorded during health care encounters (alcohol: 15.8%; opioids: 6.0%; stimulants: 5.8%), multiple substance use diagnoses (11.5%), and mental health disorders diagnoses (anxiety/OCD/PTSD: 31.5%; mood disorder: 21.2%; schizophrenia or psychosis: 15.4%) among adults with FAS during the follow-up period (2014–2017). These numbers are based on what information is entered at the hospital encounter, as part of *any* diagnosis, and is likely not the most responsible diagnosis (MRD) or reason for hospital encounter. These data are consistent with findings on high prevalence of mental health comorbidities in FASD (Popova et al., 2016b). These data, however, are based on hospital-based encounters during follow-up only and do not include OMHRS; therefore, mental health and substance use issues may be underestimated. Additionally, ICD-10 codes in the Z category are rarely used by health care providers; therefore, these data underestimate personal and family histories of mental health and substance use issues.

Given that recorded alcohol use diagnoses in health care encounters is fairly high (15.8%) and 45% of the sample is comprised of women of reproductive age, these data also suggest that there may be a high risk of alcohol-exposed pregnancies and familial recurrence of FASD. This risk is most relevant to individuals in the cohort who a) used hospital-based care during follow-up (2014–2017), and b) for whom alcohol use was recorded as a diagnosis (main or other) during the respective encounter, suggesting a current issue with alcohol misuse or dependence. Of note, pregnancy status and history were not examined among adults in this cohort.

Types of Health Care Services Used by Adults with FAS, 2014–2017

Table 80 shows that 46.7% of adults with FAS in this cohort visited an emergency department six or more times from 2014–2017. Women in this sample had a higher occurrence of urgent and elective inpatient admissions, and a higher proportion of women than men accessed the emergency department six or more times. Women in this cohort also had a higher incidence of same-day surgery, while men had a slightly higher number of inpatient admissions for psychiatric care.

Table 80. Utilization of health care services among adults with FAS, 2014–2017 (N = 565)

Type of health care service	Female n = 254	Male n = 311	Total N = 565
Inpatient admission — psychiatric	64 (25.2%)	88 (28.3%)	152 (26.9%)
Inpatient admission — urgent	77 (30.3%)	81 (26.0%)	158 (28.0%)
Inpatient admission — elective	54 (21.3%)	14 (4.5%)	68 (12.0%)
Emergency department visit (any)	216 (85.0%)	248 (79.7%)	464 (82.1%)
0 visits	38 (15.0%)	63 (20.3%)	101 (17.9%)
1-2 visits	46 (18.1%)	58 (18.6%)	104 (18.4%)
3-5 visits	36 (14.2%)	60 (19.3%)	96 (17.0%)
6-11 visits	49 (19.3%)	50 (16.1%)	99 (17.5%)
12+ visits	85 (33.5%)	80 (25.7%)	165 (29.2%)
Same-day surgery	75 (29.5%)	54 (17.4%)	129 (22.8%)
NACRS ambulatory clinic visit	15 (5.9%)	8 (2.6%)	23 (4.1%)
Complex continuing care	<6 (S)	<6 (S)	6 (1.1%)
Long-term care	<6 (S)	<6 (S)	9 (1.6%)
Home/community care — any	41 (16.1%)	54 (17.4%)	95 (16.8%)
Home/community care — case management	40 (15.7%)	51 (16.4%)	91 (16.1%)
Home/community care — nursing	25 (9.8%)	34 (10.9%)	59 (10.4%)
Home/community care — social work / mental health & addiction services	<6 (S)	<6 (S)	9 (1.6%)
Home/community care — occupational therapy	14 (5.5%)	17 (5.5%)	31 (5.5%)
Home/community care — speech and language therapy	<6 (S)	<6 (S)	<6 (S)
Home/community care — physiotherapy	10 (3.9%)	9 (2.9%)	19 (3.4%)
Home/community care — personal services / respite	10 (3.9%)	8 (2.6%)	18 (3.2%)

Source: ICES data holdings, including: DAD, SDS, NACRS, CCRS, HCD, and OHMRS
Abbreviation: S, suppressed

Table 81 shows that the average length of stay in inpatient psychiatric care for adults with FAS in this cohort was 15.2 days, 3.92 days in inpatient urgent admission, and 4.24 days for inpatient elective admissions from 2014 to 2017.

Table 81. Age and length of stay of adults with FAS during inpatient admission, 2014–2017 (N = 565)

Health care utilization type	
INPATIENT ADMISSION — PSYCHIATRIC	n = 152
Age at January 1, 2014	
Mean (SD)	27.64 (9.23)
Median (Q1-Q3)	26 (21-31)
Min-max	18-67
LOS (days)	
Mean (SD)	15.27 (24.62)
Median (Q1-Q3)	7 (3-14)
Min-max	1-181

Health care utilization type	
INPATIENT ADMISSION — URGENT	N = 158
Age at January 1, 2014	
Mean (SD)	30.47 (11.28)
Median (Q1-Q3)	27 (22-36)
Min-max	18-74
LOS (days)	
Mean (SD)	3.92 (4.93)
Median (Q1-Q3)	2 (1-4)
Min-max	1-32
INPATIENT ADMISSION — ELECTIVE	n = 68
Age at January 1, 2014	
Mean (SD)	25.91 (8.97)
Median (Q1-Q3)	24 (20-29)
Min-max	18-67
LOS (days)	
Mean (SD)	4.24 (6.55)
Median (Q1-Q3)	3 (1-4)
Min-max	1-40
ED VISIT	n = 464
Age at January 1, 2014	
Mean (SD)	27.98 (9.95)
Median (Q1-Q3)	25 (21-32)
Min-max	18-74
SAME-DAY SURGERY	n = 129
Age at January 1, 2014	
Mean (SD)	28.04 (9.40)
Median (Q1-Q3)	26 (21-33)
Min-max	18-66
NACRS AMBULATORY CLINIC VISIT	N = 23
AGE AT JANUARY 1, 2014	
Mean (SD)	27.87 (9.25)
Median (Q1-Q3)	26 (21-32)
Min-max	18-59
COMPLEX CONTINUING CARE	n = 6
Age at admission	
Mean (SD)	43.28 (22.10)
Median (Q1-Q3)	43 (22-63)
Missing data (%)	0.00
Min-max	19-70
LOS (days)	
Mean (SD)	65.25 (34.35)
Median (Q1-Q3)	74 (29-94)
Min-max	20-102

Health care utilization type	
LONG-TERM CARE	n = 9
Age at admission	
Mean (SD)	51.00 (15.22)
Median (Q1-Q3)	57 (41-63)
Min-max	23-70
HOME/COMMUNITY CARE — ANY	n = 95
Age at January 1, 2014	
Mean (SD)	31.56 (12.69)
Median (Q1-Q3)	27 (22-37)
Min-max	18-74

Source ICES data holdings, including DAD, SDS, NACRS, CCRS, HCD, and OHMRS
Abbreviations: LOS, length of stay; SD, standard deviation; Q, quartile

Table 82 presents mortality data, displaying the number of adults with FAS in this cohort who had died by the end of follow-up or by December 31, 2017. Among them, 14 individuals died with an average age of 38.7 years. These individuals were on average 11 years older as compared to those who were alive at the end of follow-up period. Additionally, 40 individuals were initially excluded from the cohort because they had died before the index date of Jan 1, 2014 and the ages and leading causes of death among these individuals were not examined.

Table 82. Mortality of adults with FAS in cohort, 2014–2017 (N = 565)

	Alive	Died
OUTCOME, N (%)	551 (97.5)	14 (2.5)
AGE AT INDEX (JANUARY 1, 2014)		
Mean ± SD	27.44 ± 9.36	38.71 ± 17.28
Median (IQR)	24 (21-31)	35 (26-53)

Source: ICES data holdings, including ORG Vital Statistics Agency and RPDB
Abbreviations: SD, standard deviation; IQR, interquartile range

Causes of death among individuals in this cohort who died by the end of follow-up (2017) included chronic conditions, communicable diseases, and intentional/unintentional injuries. In order to protect the privacy of these individuals, sex and causes of death were not reported.

Conclusions

Compared to the general adult population of ON (Canadian Mental Health Association, 2016), there is a high prevalence of mental health comorbidity among adults with FAS in this cohort based on hospital-based care. The prevalence of disorders as captured in the administrative health care data, such as anxiety, schizophrenia, and mood disorders, is very high (31.5%, 15.4%, 21.2%, respectively) compared to the general population of ON (Canadian Mental Health Association, 2016)

The 2014–2017 data show that a large proportion of adults (46.7%) with FAS in ON had six or more ED visits and just over one-quarter accessed psychiatric inpatient care (26.9%) and urgent inpatient care (28.0%). Use of hospital-based care is high among individuals in this cohort.

Limitations

The cohort (N = 565) only captured individuals with FAS if they were hospitalized or had an emergency department visit from April 1, 2002, to December 31, 2013, and had a diagnosis of FAS logged in the record of the health encounter. Therefore, the data available on demographic, mental health, and behavioural profile are likely not representative of all adults with FAS in ON, and this may overrepresent adults with FAS who are in poorer general health. The inclusion criteria are based on individuals' utilization of hospital-based care and the entry of specific diagnostic codes within those encounters in the specified time frame. Therefore, there could be many individuals with FAS who did not contact the health care system or who were not picked up in the database using the specific codes. The final sample size is not indicative of the true prevalence of FAS among adults in ON during this time period (2002–2013).

OHMRS was not used to identify individuals in the cohort as there is no DSM-4 code specific to FAS. Therefore, individuals with FAS who had psychiatric hospitalizations were not included in the cohort. Additionally, OMHRS was not used to examine the mental health and substance use of individuals in the cohort during the follow-up period.

Within these data, it is not possible to make conclusions about the life expectancy or mortality rate for individuals with FAS. Individuals may have left ON and died in another location not captured by ORG-D database. Additionally, follow-up of this cohort was only three years.

General Limitations (Both ICES Cohort Studies)

FAS is typically not identified at birth, with the exception of severe cases where there is significant prenatal exposure. Typically, FAS and FASD are diagnosed during outpatient care visits by physicians or pediatricians. Information on diagnoses made during outpatient care are captured within the OHIP claims database. However, this database does not include the specific five-digit codes used to record FAS or FASD. This means that although that diagnosis is made and recorded during outpatient care, the information cannot be gleaned from the OHIP database. Using administrative health care data to estimate prevalence of alcohol use during pregnancy relies on the codes entered in by physicians with respect to emergency department visits, inpatient hospitalizations, or birthing events only. In this case, data on PAE reflects only women who used health care services during pregnancy and for whom alcohol-related diagnoses were relevant to the encounter. Therefore, these data may not be representative of all cases of alcohol use during pregnancy.

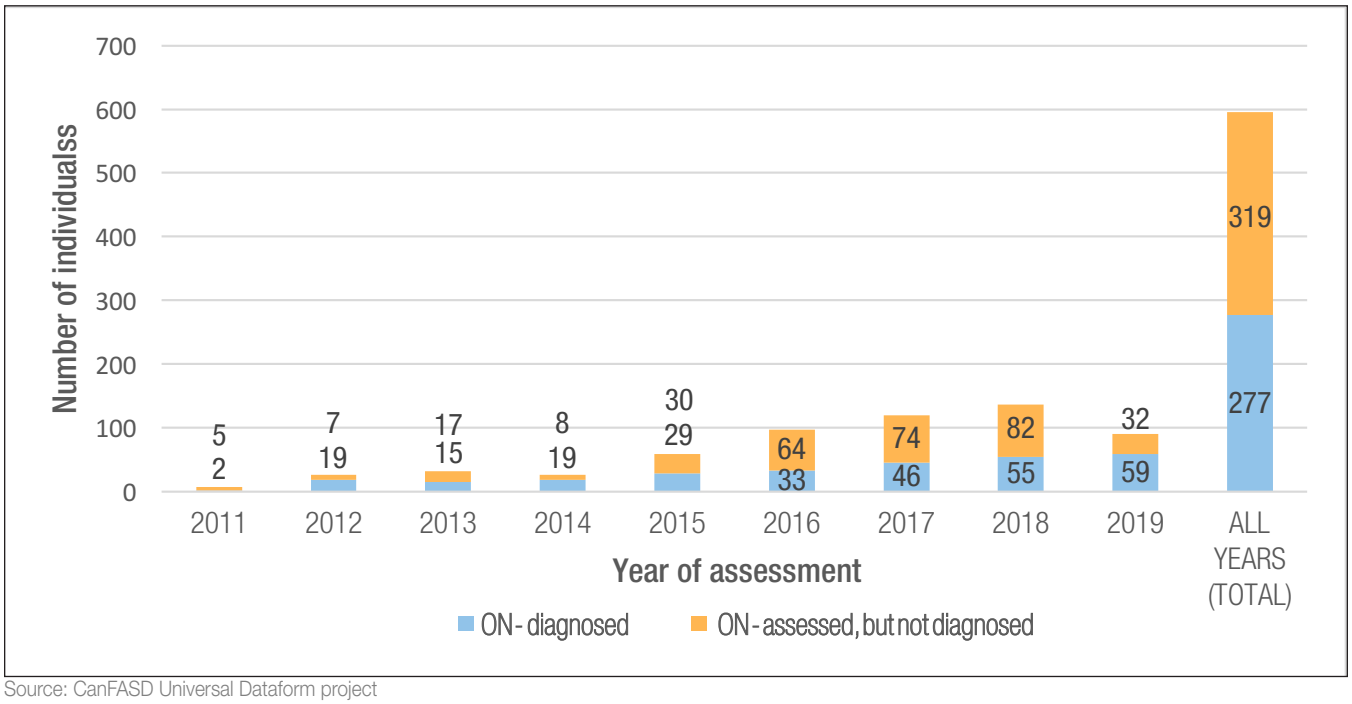
There are several challenges in using administrative health care data to identify individuals with FAS. Perhaps the single most limiting factor is the lack of an ICD-10 code for FASD; databases that utilize ICD-10 codes only have recorded diagnoses of FAS. A second challenge is that the ICD-10 code for FAS can only be reported in health care services which report ICD-10 codes. These include acute care hospitalizations (DAD) and emergency department visits and same day surgery (NACRS). These datasets not only allow for ICD-10 coding, but they also allow for multiple diagnoses to be recorded. Individuals with FAS are not captured in FAS data if a) they do not access hospital-based services, and b) if FAS is not recorded as a diagnosis within the hospital-based care encounter. FAS may not be recorded within the encounter if FAS is undiagnosed, misdiagnosed, or simply not seen as being relevant to the health care encounter.

Acknowledgement: This study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care. Parts of this material are based on data compiled and provided by CIHI or based on ORG information on deaths, the original source of which is Service Ontario. The opinions, results, and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by ICES, the Ontario MOHLTC, CIHI, or ORG is intended nor should it be inferred.

9.3.2 CANADIAN NATIONAL FASD DATABASE

Please refer to the Canadian National FASD Database section of this report (Section 4.2.1) for a detailed analysis of these data.

Data in the figure below present two categories of diagnostic outcomes: diagnosed, which includes individuals with FASD with or without sentinel facial features, and assessed but not diagnosed, which includes those in the at-risk category as well. Data are presented by year of assessment; where a year is missing, this indicates zero diagnoses and zero assessments in the respective year. Each figure represents diagnostic outcomes by year of assessment.



Source: CanFASD Universal Dataform project

Figure 9. Individuals assessed for FASD diagnosis and individuals who received FASD diagnoses by year in Ontario, 2011–2019

9.3.3 DIAGNOSTIC CLINIC SURVEY

Methods

Please refer to the Diagnostic Clinic Survey section of this report (Section 4.2.2) for a detailed methodology.

Results

A total of 30 clinics were initially identified in ON as capable of conducting neurodevelopmental assessments for FASD. Two of these clinics were closed prior to the start of data collection in October 2018. Of the remaining 28 ON clinics that were contacted, a total of 15 clinics contributed at least one year of data to the survey, resulting in a 53.6% response rate. See Table 83.

On average, 26 to 45 patients were assessed in each diagnostic clinic per year. A total of 1,368 patients were assessed in 2015–2020, and over half of them (n = 819, 60%) were diagnosed with FASD. This proportion varies across assessment years: diagnoses of FASD occurred in 68.3% of assessments in 2015, 53.6% in 2016, 55.4% in 2017, 62.4% in 2018, 54.3% in 2019, and 92.4% in 2020. The proportion in 2020 should be interpreted with caution, however, as only partial data were available, and few clinics (n = 3) contributed data as compared to previous years.

The average number of diagnostic slots allotted to FASD diagnoses in this time frame ranged from 22 to 32 patients per year (not including clinic year 2020). The average number of individuals on the waitlist ranged from 10 to 49 per year. Based on information from all clinics 2015–2019, the average number of slots is 26 and the average number of people waiting for an assessment is 32. Based on these data, the estimated wait time to get an assessment is approximately one month; however, the descriptions of individual clinics' waitlists varied in detail provided below.

Table 83. Diagnostic capacity of neurodevelopmental clinics in Ontario that participated in the survey, 2015–2020 (N = 28)

	Year of assessment					
	2015	2016	2017	2018	2019	2020*
NUMBER OF CLINICS CONTRIBUTING DATA	6	7	10	6	8	3
INDIVIDUALS SEEN IN EACH CLINIC FOR FASD DIAGNOSIS						
Mean (SD)	26 (11.2)	45 (22.7)	30 (26.6)	26 (23.4)	42 (32.7)	35 (38.9)
Range	7-44	9-78	6-96	8-63	6-106	5-90
Total (all clinics)	158	315	298	157	335	105
INDIVIDUALS DIAGNOSED WITH FASD						
Mean (SD)	18 (9.0)	24 (11.3)	17 (11.9)	16 (16.5)	23 (20.6)	32 (40.1)
Range	4-27	5-37	4-40	2-52	0-68	3-89
Total (all clinics)	108	169	165	98	182	97
DIAGNOSTIC SLOTS ALLOTTED TO FASD DIAGNOSES						
Mean (SD)	24 (18.7)	32 (25.7)	19 (19.3)	31 (32.2)	22 (20.7)	8 (5.7)
Range	0-54	0-75	0-60	0-100	0-60	0-12
INDIVIDUALS WAITING FOR FASD ASSESSMENT						
Mean (SD)	10 (19.8)	49 (52.0)	21 (35.3)	35 (50.3)	45 (41.3)	49 (53.9)
Range	0-50	0-120	0-100	0-140	0-96	6-125

Source: CAMH REDCap survey
Abbreviation: SD, standard deviation
* Data were available for part of this year

Two of the 15 participating clinics noted they did not have formal waiting lists and did not keep track of individuals waiting for assessment. Instead, there was an ongoing process based on client needs and referrals.

Four clinics indicated that individuals would be eligible to be on their waitlists following a screening process where either PAE or sentinel facial features are confirmed.

Five clinics served children and adolescents exclusively, two of whom specified the age criteria for the waitlist: individuals 21 and under, and individuals 0 to 6 years old. Two of these clinics organized assessments by school year, usually assessing only one child per school month (ten months of the year). Only one of these clinics noted waitlist duration, which was between one and two years, depending on a number of factors (e.g., whether a psychological assessment has already been completed).

Three clinics in total noted that referrals were organized based on complexity of client needs, age at time of referral, and/or assessment resources needed (e.g., if a whole team is required).

9.3.4 PUBLISHED STUDIES — FASD

Regional estimates for FASD in the general population of ON were obtained from two publications (see Appendix E), each focusing on child populations. In a study conducted by Pei et al. (2020) using passive surveillance, regional data for ON estimates that the prevalence of FASD among kindergarten students in the general population is 0.5 per 1,000, or 0.05%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database.

The first population-based FASD prevalence study using ACA in Canada was conducted in ON by the Centre for Addiction and Mental Health (Popova et al., 2019a). This study estimated that from 2% to 3% of children (aged 7 to 9 years) in the general population of Canada have FASD.

There were an estimated 116,480 individuals with FASD living in ON in 2007 (Hopkins et al., 2008) within a population of 12.8 million (Statistics Canada, 2007); this is a prevalence rate of 9.1 per 1,000 live births.

A total of three publications were identified to have regional prevalence estimates for FASD in special subpopulations of ON. The first Canadian estimate of FASD prevalence among children in care was reported in ON at 33 per 1,000 individuals, or 3.3% (Burge, 2007). Fuchs & Burnside (2014) found a prevalence of 105.1 per 1,000 (10.5%) in the ON sample of children in care. Additionally, in a 2017 study on a sample of individuals living in small, rural, and remote communities of ON, the prevalence of FASD was found to be 612.5 per 1,000 (61.3%) (Banerji & Shah, 2017).

9.4 Service Utilization

9.4.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From the 2014 to 2017 fiscal years, a total of 18,622 hospitalizations and health care visits were made among patients with FAS with a health card from ON. These health care encounters were mostly for emergency care visits (n = 14,609). These patterns were consistent for each fiscal year (2014–2017). Among the patients with FAS with a health card from ON, 79.6% resided in urban areas and 4.0% of the patients were homeless.

9.4.2 RON JOYCE CHILDREN'S HEALTH CENTRE, HAMILTON HEALTH SCIENCES

Objectives

The objectives of this study were:

1. to explore demographic characteristics of children with diagnosed or suspected FASD (2014–2020); and
2. to explore mental health and physical comorbidities of children with diagnosed or suspected FASD (2014–2020).

Methods

Data Source

The data were obtained from the Ron Joyce Children's Health Care Centre (RJCHC), which is a site in McMaster University in Hamilton, ON, and is part of Hamilton Health Sciences (HHS). A range of outpatient services are provided at RJCHC that focus on developmental health and child rehabilitation, such as autism services, school-based rehabilitation services, and specialized developmental and behavioural services.

Data Abstraction and Statistical Analysis

A list of record numbers for each patient diagnosed with FASD or undergoing assessment (2014–2020) was obtained in April 2020 and used to securely access the HHS database in order to abstract additional information from patients' charts, including patient demographics and comorbidities (suspected and confirmed). Data on comorbidities were derived from recorded ICD-10 codes recorded in patient charts as confirmed diagnoses. Categories were amalgamated based on similarity and code classification, where applicable, and coding was completed in adherence to these amalgamations. A cross-sectional analysis was conducted based on the data abstracted. Descriptive statistics were derived using STATA 16.1. Cell counts lower than five were suppressed to protect patient privacy.

Results

From 2014–2020, a total of 66 children were diagnosed or had suspected FASD (ICD-10 code Q86.0 was used) at RJCHC. See Table 84. The majority of these children (n = 59, 89.4%) were diagnosed with FASD and seven (10.6%) had suspected FASD. Of the children diagnosed with FASD (n = 59), fewer than five (<8.5%) were noted to have FAS. Some patients had previous diagnoses of FASD and other comorbid conditions, which were provisioned at other diagnostic centres. The average patient age at the time that FASD was first recorded in RJCHC was 9.9 years (SD: 3.6), and the youngest patient was 1 year old. A slightly higher proportion (51.5%) of all children with diagnosed or suspected FASD were male, and the majority (n = 61, 92.4%) lived in urban regions. A total of 59 children (89.4%) were in adoptive or foster care and/or had child protective services (CPS) involvement.

Among comorbid mental health conditions that were recorded in patients' charts, the most common were ADHD (60.6%), learning disability (37.9%), and developmental delay(s) (24.4%). Among recorded comorbid physical health conditions, the most common were nervous system / auditory issues (25.8%), and obesity / metabolic disorders (10.6%).

Table 84. Demographics and comorbidities of children with diagnosed/suspected FASD, 2014–2020 (N = 66)

Patient characteristics	Frequency (%)
SEX	
Male	34 (51.5)
Female	32 (48.5)
AGE (YEARS)	
Mean (SD)	12.0 (3.7)
Range	4-19
ADOPTED / IN FOSTER CARE / CPS INVOLVEMENT	59 (89.4)
GEOGRAPHIC LOCATION	
Urban	61 (92.4)
Rural/remote	5 (7.6)
AGE AT TIME FASD FIRST RECORDED (YEARS)	
Mean (SD)	9.9 (3.6)
Range	1-18
FASD DIAGNOSIS	
Diagnosed FASD	59 (89.4)
Diagnosed FAS	<5 (S)
Suspected FASD	7 (10.6)
YEAR FASD FIRST RECORDED	
2014	<5 (S)
2015	<5 (S)
2016	11 (16.7)
2017	13 (19.7)
2018	11 (16.7)
2019	18 (27.3)
2020	11 (16.7)
COMORBID MENTAL HEALTH CONDITIONS*	
Attention-deficit/hyperactivity disorder (F90.0)	40 (60.6)
Learning disability (F81.9, Z55.3, R27.8)	25 (37.9)
Developmental delay (F88, R62.8, F98.3, F80.1, R41.8, F82, F88, F81.8, R26.89)	16 (24.2)
Emotional, behaviour, and/or social problems (F94.2, F69, R46.88, F94.8)	12 (18.2)
Intellectual disability (F79.9, F70.9)	10 (15.1)
Oppositional defiant disorder (F91.3)	8 (12.1)
Anxiety disorder(s) (F41.1, F41.9)	7 (10.6)
Autism spectrum disorder (F84.0)	<5 (S)
Conduct disorder (F91.9)	<5 (S)
Depression (F32.9)	<5 (S)
Obsessive-compulsive disorder (OCD) (F42.9)	<5 (S)
Post-traumatic stress disorder (F43.1)	<5 (S)

Patient characteristics	Frequency (%)
Attachment, separation, bereavement issues (F94.1, F93.0. Z63.4, F94.1)	<5 (S)
COMORBID PHYSICAL HEALTH CONDITIONS*	
Nervous system / auditory issues/disorders (G25.8, F95.1, G40.10, Q07.0, G40.90, H91.9, R56.88, G43.9, G44.2, R27.8)	17 (25.8)
Obesity and/or metabolic disorders (E66.9, E78.0, E78.1)	7 (10.6)
Sleep disorders (G47.30, F51.2, G47.2, G47.9)	6 (9.1)
Digestive disorders (K59.0, E73.9, K21.9, R15, R74.8, Z93.1)	6 (9.1)
Cardiovascular problems (R03.0, I42.9)	<5 (S)
Chromosomal and congenital abnormalities (Q93.8, Q99.9)	<5 (S)
Endocrine disorders (E30.1, E03.9, E34.3)	<5 (S)
Eating disorder (F50.9)	<5 (S)
Underweight and/or unexpected weight loss (R63.4)	<5 (S)
Urinary incontinence (F98.0, R32)	<5 (S)
Feeding problems (F98.2, R63.3)	<5 (S)
Fetus and newborn affected by maternal exposure to environmental chemical substances (P04.6)	<5 (S)
Hemolytic anemias (D56.8, D50.9)	<5 (S)
Somatoform disorders (F44.9)	<5 (S)
Eye problems (H50.9, H53.0)	<5 (S)

Source: RJCHC
Please note: ICD-10 codes abstracted from medical charts
Abbreviations: S, suppressed; CPS, child protective services
* These categories are not mutually exclusive

Conclusions

Among children with diagnosed or suspected FASD, there is a high prevalence (84.9%) of involvement in the child welfare system. This is comparable to the high prevalence rates of FASD found in populations of children in care globally (Popova et al., 2019b).

Children in this sample were on average ten years old at the time FASD was first diagnosed, suggesting that the majority of FASD interventions would be accessed prior to adolescence. Early interventions are needed to reduce the risk of adverse health and social outcomes in children with PAE.

There is a high prevalence of comorbidities among children in this sample. The most common mental health conditions (e.g., ADHD, learning disability), in addition to the prevalent nervous system and auditory issues, suggest that children with FASD need access to a variety of FASD-informed services that meet learning and sensory needs. These must be delivered by service providers who have an understanding of FASD and who can tailor plans to individualized needs (e.g., individualized education plans in school).

9.4.3 SURREY PLACE

For the full methodology and description of analysis for findings pertaining to this project component, please refer to the following manuscript:

Temple VK, Prasad S, Popova S, Lindsay A. (2020). Long-term outcomes following fetal alcohol spectrum disorder (FASD) diagnosis in adulthood. *Journal of Intellectual & Developmental Disability* https://doi.org/10.3109/13668250.2020.1824612

Objectives

1. To explore health and social outcomes of adults with FASD; and
2. to measure the effect of receiving an FASD diagnosis in adulthood (after age 18) on subsequent health and social outcomes.

The overarching goal of the study was to better understand the needs of adults with FASD and to establish if they received benefit from their diagnosis through access to additional services, clinical recommendations, and/or better adaptation and understanding for themselves and those around them.

Methods

Data Source

At the time of writing, there are clinics in six of Canadian P/Ts that offer adult assessment for FASD (CanFASD, 2020), and one of these is the adult FASD diagnostic clinic in Surrey Place, Toronto, ON. This clinic offers full multi-disciplinary assessments, short-term interventions, and assistance with accessing community resources for individuals 18 and older.

Data Collection

This study contacted adults seen at the Surrey Place adult FASD clinic to gather information regarding their current situation and outcomes since receiving their diagnosis. Structured interviews were conducted with a research assistant to gather information about participants. Data gathered by the study included information about physical and mental health, access to and connections with supports and professionals (e.g., support workers, primary health care providers, psychiatrists, disability pensions), employment and residential placements, justice system involvement, and follow-up on recommendations made by the FASD diagnostic team. The information gathered was compared to information collected on individuals at the time of diagnosis of FASD (time 1) to see if any changes occurred in their situation since receiving an FASD diagnosis (time 2). The interval between time 1 and time 2 was at least one year and up to 11 years.

Data Analysis

Mixed methods were utilized in this study. Data that could be quantified (e.g., residence type, income sources, employment, medical / health care information, justice involvement, number and type of FASD team recommendations, sources of support) were collected from participant clinical records (time 1) and participant interviews (time 2) and then entered into an SPSS database. Simple frequencies and percentages for each variable were calculated for time 1 and time 2. For qualitative data analysis, all comments/statements made by participants for each open-ended question were transcribed into a word processing file and were then read and reviewed by the researchers. Based on this review, themes and groupings were developed and each statement was coded based on these themes. Example quotations are presented to better describe and explain the themes.

Results

In total, 128 adults were referred to the diagnostic clinic for FASD assessment during the period selected for this study. Thirty-two individuals either withdrew their request for assessment or were referred but did not follow-up with assessment appointments. Another 31 completed the assessment but did not receive an FASD diagnosis. This left 65 individuals who received an FASD diagnosis and were eligible for inclusion in the study. Of these, 2 were found at follow-up to be deceased, 2 were incarcerated, 36 individuals could not be contacted despite repeated attempts to contact them or their family members/support workers, and 5 individuals either refused to participate in the study or were deemed clinically inappropriate to contact. In total 20 individuals were contacted for the study and agreed to complete structured interviews. The mean age of the 20 participants was 30.9 years, with a range of 21 to 46 years. Eleven (55%) identified as female and 9 (45%) as male.

Table 85. Participant demographics at FASD diagnosis and at follow-up (N = 20)

Characteristics	At diagnosis	At follow-up
PLACE OF RESIDENCE		
Family	9 (45%)	5 (25%)
Independent living	7 (35%)	8 (40%)
Unstable housing	1 (5%)	2 (10%)
Supported living	3 (15%)	5 (25%)
EMPLOYED PART-TIME OR FULL-TIME	6 (30%)	3 (15%)
PRIMARY SOURCE OF INCOME		
Social assistance / welfare	6 (30%)	0
Disability support income	1 (5%)	19 (95%)
Children's services funding	4 (20%)	0
Family, employment, or no income	8 (40%)	1 (5%)
ELIGIBLE FOR DEVELOPMENTAL DISABILITIES SUPPORT SERVICES	3 (15%)	17 (85%)
HAS A PAID SUPPORT WORKER	12 (60%)	11 (55%)
HAS A PRIMARY CARE PROVIDER	17 (85%)	18 (90%)
OTHER PROFESSIONALS INVOLVED		
Psychiatrist	6 (30%)	5 (25%)
Counsellor	2 (10%)	5 (25%)
Other health care professionals	0	4 (20%)
Police/legal system contact	4 (20%)	3 (15%)

Source: Surrey Place

Housing and Health Care Utilization

At the time of diagnosis, the most common place of residence for participants was with a family member (45%). See Table 85. By the time of follow-up, however, it was most common for participants to live independently (40%) in their own apartment either alone or with a partner. The mean length of stay at their current residence was approximately 47 months, or 3.9 years (range: 2 months to 228 months), but a full 35% had been at their present residence for 12 months or less. Two individuals (10%) reported unstable housing at follow-up, which involved temporarily staying at the home of a friend or acquaintance due to being homeless.

Eighteen (90%) participants reported having a primary care provider at follow-up, but six (30%) indicated they still used walk-in clinics or hospital emergency departments for some or all of their health care needs. At diagnosis, eight (40%) saw other health professionals in addition to a primary care provider. By follow-up, 14 (70%) reported seeing other health care professionals for medical care. Most often, these providers were psychiatrists or counsellors involved in providing mental health support to the participants.

Participants were specifically asked at follow-up about five physical health concerns commonly found in adults with developmental disabilities (Sullivan et al., 2018): diabetes, heart problems, vision problems, hearing problems, and muscular/skeletal problems. Individuals were also asked about current substance use. Results are presented in Table 86.

Table 86. Reported medical issues and substance use at follow-up among participants (N = 20)

	At follow-up
MEDICAL ISSUES REPORTED	
Diabetes	2 (10%)
Heart issues	1 (5%)
Hearing problems	2 (10%)
Vision (incl. prescription glasses)	13 (65%)
Arthritis	2 (10%)
CURRENT SUBSTANCE USE (WEEKLY OR MORE)	
Alcohol	5 (25%)
Marijuana	4 (20%)
Other (illegal) drug use	5 (25%)

Source: Surrey Place

Participants were also asked if they have any mental health diagnoses during follow-up interviews. Overall, 11 (55%) individuals reported having one or more mental health diagnoses. Reported by six individuals (30%), the most common were anxiety disorders, which included diagnoses of obsessive-compulsive disorder, agoraphobia, and panic disorder. Also common were mood disorders, such as depression, reported in four (20%) cases and bipolar disorder, which was reported in two cases (10%). Borderline personality disorder was reported in three cases (15%). Autism, psychosis, and dyslexia were each reported in one case (5%).

Financial and Vocational

At diagnosis, eight individuals (40%) received either financial support from their family, had income from part-time/occasional employment, or had no regular income at all. Another six individuals (30%) received social assistance / welfare as their primary source of financial support. Only two individuals (10%) were receiving disability support income from Ontario Disability Support Program (ODSP). By follow-up, however, the number receiving disability support income had risen to 19 (95%), with no participants using welfare as a means of financial support. In all cases where individuals received ODSP, they were able to use documentation of their FASD diagnosis to demonstrate the presence of a significant and lifelong disability in order to receive the disability pension. Receiving ODSP, compared to welfare, is beneficial as it provides more financial support and serves as a permanent source of income for as long as required up to the age of 65. In addition to ODSP, eight individuals (40%) also received some financial support from other sources, such as their family and/or programs offered by other government agencies.

In terms of employment, three individuals reported having a job at follow-up. This places the unemployment rate at 85%. One individual worked full-time while the other two worked part-time. Of those who were unemployed at follow-up, 13 individuals reported having previous part-time employment and 3 individuals reported having previous full-time employment. A list of job titles held by participants is given in Table 87.

Table 87. Past and present part-time and full-time positions reported by participants (N = 20)

Amusement park worker	Daycare staff member
Assistant to painter	Dishwasher
Bartender	Elder coordinator
Bindery worker	Cleaning/maintenance worker
Car wash worker	Grocery stocker
Caregiver for family friend	Kitchen helper
Coffee shop staff	Security guard

Source: Surrey Place

Developmental Disability Services

At diagnosis and referral to the FASD clinic, only three individuals (15%) had been deemed eligible for developmental disability services. In ON, an individual must meet specific criteria to be accepted into these services, including having a documented intellectual deficit, significant challenges with daily living skills, and a disability that began during childhood. If accepted into developmental services, an individual is eligible for a broad range of specialized programs, such as supported housing (e.g., group homes, supported apartments), developmental disability case managers, and specialized allied health supports (e.g., counselling, employment and financial support) to assist with community integration. At follow-up, 17 individuals (85%) were deemed eligible for these services. Of those who were not, one lived out of province so was ineligible due to their location, and two did not have significant enough intellectual deficits to meet criteria, despite receiving a diagnosis of FASD.

Follow-Up on Recommendations Made by the Diagnostic Team

Participants were asked if they were able to follow up on recommendations made by the FASD diagnostic team. All recommendations given were individualized and therefore varied a great deal between participants. For the purposes of this research, only recommendations which involved measurable, actionable responses were evaluated. This included activities such as referral to other services, applying for various supports, enacting concrete changes, or attending programs and services. All participants (100%) enrolled in the study stated they were able to enact at least one recommendation, and 15 (75%) stated they were able to follow two or more recommendations.

Reactions and Thoughts about Receiving an FASD Diagnosis

Participants were asked the open-ended question: “How do you feel about your FASD diagnosis?” This was intended to elicit their views on FASD and what the experience of receiving a diagnosis was like for them. Results were reviewed and categorized by theme. Representative quotations are given below to illustrate each theme. The four most common themes are presented below.

IMPROVED UNDERSTANDING AND INSIGHT THROUGH DIAGNOSIS

Fifteen (75%) individuals stated that they felt getting an FASD diagnosis improved their understanding of themselves and led to personal insights. Some felt they were more able to ask for and accept support because of these insights, and others felt the understanding allowed them to develop personal strategies to use their strengths and work around weaknesses.

"Very excited about my diagnosis because everything made sense for once. I got a better idea of who I am."

"…an eye-opener…provided me with insight in terms of how to handle my life. It helped me learn more about myself."

IMPROVED ACCESS TO SUPPORTS

Six (30%) individuals spoke of how getting a diagnosis helped them to gain more support, both financial and practical, in their lives. Participants spoke of receiving financial support, as well as support from social workers, family members, employers, and other agencies.

"Got support and [was] less frustrated in general."

"Explaining it to my boss has made things easier at work. [My boss] explains things and does things in a way that accommodates me."

"Once I came in for the assessment and went through all the paperwork to get the FASD diagnosis, people interacted differently with me in a way that is [better] to my personal needs and struggles."

RELIEVED

Five (25%) individuals stated that they felt relief at knowing the reason for their challenges; knowing about their FASD diagnosis allowed them to feel less personal guilt. Participants stated that in the past they had experienced guilt and sometimes blamed themselves for the problems they experienced. Some noted that it was difficult to accept that they had a lifelong disability but that knowing they did had advantages.

"It was really hard at first, but it was a relief to understand."

"Good to learn about what I face and why…I didn't cause this situation."

"I'm not crazy or stupid for experiencing what I did. This helped me move forward and have a better life."

Receiving a diagnosis of FASD can be a fundamentally different experience for adults than for children because they are typically more self-aware. They may have faced failures in the past, during school or in vocational placements, which made them wonder why they were not able to accomplish tasks in the same way as other adults. Understanding the reasons for their struggles can lead to relief and greater self-acceptance.

Indifference or struggling

Four participants (20%) stated they were indifferent to getting the diagnosis or had not given it much thought. It did not affect them negatively, but they also did not feel strongly about it. Another two (10%) stated that they struggled with the idea of having FASD or had apprehensions about it.

> *"Not really sure how I feel."*
>
> *"I'm relieved to have my diagnosis but struggle to know what I'll achieve in life. Will I have a normal life? Get married? Have children?"*

When an adult receives a diagnosis of FASD, they are typically able to understand that it is a lifelong disability — not something that will disappear one day. In some cases, the individual and family may have believed that their challenges were "just a stage" that would pass with time. This realization of permanent disability can lead to fear, anger, sadness, and concern about the future. For this reason, many adults with FASD benefit from counselling and support after receiving their diagnosis.

Accomplishments Reported by Participants with FASD

Participants were asked a second open-ended question: "What are you most proud of?" This was intended to gather information about positive outcomes and accomplishments in addition to information about challenges. Previous research (Flannigan et al., 2018; Currie et al., 2016) has noted that individuals with FASD often have unique areas of strength and an open-ended question about positive accomplishments is a method that may capture many different types of strengths as well as what was viewed as important by the individual themselves.

Four (20%) participants stated they were proud to work, have a job, or attend school. (See Table 87 for a full list of jobs held, past or present, by participants.) Another two (10%) participants discussed their successes raising children and how this was a source of pride for them. Two (10%) different participants discussed being able to avoid drugs, alcohol, or dangerous situations in their lives. One of them stated they were proud to simply "be alive." Four (20%) participants said "I don't know" or could not answer.

Responses to "What are you most proud of?" included:

> *"Finishing my last semester and getting a passing grade, because last time I went to college I didn't get through one semester."*
>
> *"It may not sound like a lot, but I'm really happy to be back on my feet. I've been clean and off drugs for the past seven years. I volunteer at a rescue shelter."*
>
> *"I'm most proud of my son. I raised him alone which is hard to do with my condition. He's a great kid."*

Conclusions

One of the primary goals of any diagnosis is to allow individuals with a disorder or disability to be identified and gain access to appropriate supports and services. In this study, at the time of diagnosis, only 10% of individuals were receiving disability income support; by follow-up, it had risen to 90%. In many cases, individuals stated that they did not have access to disability income support prior to FASD diagnosis because, although they had significant challenges with day-to-day life, the reason for these challenges was not clear. In the absence of a medical explanation, challenges were sometimes attributed to "bad behaviour" (e.g., substance use, laziness) rather than disability — a common issue for those who were not diagnosed in childhood. Improved access to financial support is clearly much needed for adults with FASD, given that 85% of this sample were unemployed at the time of follow-up.

At diagnosis, only 15% of individuals were accessing developmental support services; by follow-up, it had risen to 85%. Like others with developmental disabilities, adults with FASD frequently benefit from ongoing and consistent structure, routine, and support in their lives to maintain well-being (Currie et al., 2016). This type of support service is available in the developmental disability sector much more readily than in other health sectors (e.g., rehabilitation, mental health) where it is often expected that an individual will improve and require less support over time. For this reason, developmental disability supports are a good fit for adults with FASD.

Adults with FASD reported that receiving a diagnosis was personally helpful and beneficial in a number of ways. It contributed to a sense of relief and self-understanding, and it improved their understanding of their own support needs. Participants reported following many of the recommendations made during their assessments and often found them helpful.

Much like other research in this area, this study found high rates of mental health problems, unstable housing, and unemployment. As well, although they reported having family doctors, many individuals also used walk-in clinics and emergency departments, possibly because of their difficulties with planning and organizing appointments. This suggests medical care for adults with FASD may be less consistent and lack appropriate follow-up.

Limitations

This sample may not be representative of the larger population of individuals diagnosed with FASD in adulthood, but the issues and themes found are consistent with other research in this area (Streissguth, et al., 2004). Given that this study relied on self-report from individuals with FASD, it likely suffers from many of the limitations found in other self-report studies, such as possible minimizing of problematic behaviours (e.g., alcohol and drug use, criminal justice system involvement). It is of note that two individuals were found to be incarcerated at the time of follow-up, suggesting that criminal justice system involvement rates would be higher if data could have been gathered from these individuals as well.

Another important limitation of the study is the inherent selection bias toward including those who are best supported and connected to services. Because the addresses and phone numbers on file for potential participants were often outdated, many individuals were contacted through their support workers or family. This means that individuals who were not in contact with a support worker or family member were less likely to be found and included in the study; these individuals may experience different and perhaps more negative outcomes than those contacted. It is therefore likely that the data reported here is a conservative estimate of the challenges faced by adults with FASD in general.

9.4.4 PUBLISHED STUDIES — DIAGNOSTIC CAPACITY

Difficulties with FASD diagnosis in ON have been found in previous research (Richards et al., 2019) and during community consultations (Anderson, 2015). For example, most clinics capable of providing an FASD diagnosis are for children, not adults (Anderson, 2015). Consultations revealed that families must remain on long waitlists prior to receiving an FASD assessment. Overall, ON has limited capacity to diagnose FASD (Clarren, Lutke, & Sherbuck, 2011), which may leave service systems without the critical information required for fair and appropriate responses, supports, and/or interventions.

FASD assessments have been found to be cost-effective, with an average cost of approximately $6,000. This is in contrast to the potential $94,000 to be spent on attempting to secure an assessment for a child with FASD (Legislative Assembly of Ontario, 2017). Limits on diagnostic capacity may impede accessibility of assessments. Consultations with experts identified that early screening for diagnosis and/or less stringent qualifying service criteria is needed for children in care (Anderson, 2015).

The Toronto Fetal Alcohol Spectrum Disorder (FASD) Network and the 2015 FASD Provincial Roundtable Report highlight concerns about limited FASD diagnostic services in Toronto and in ON as a whole (Richards, 2019; Ialomiteanu et al., 2018). Toronto currently has only two FASD diagnostic clinics: Surrey Place, which has a six-month to one-year waiting list, and Anishnawbe Health Toronto, which serves the city's Indigenous population. In 2020, there was not yet a formal FASD strategy released (Burns et al., 2020). It has been suggested that an FASD diagnosis code in the Ontario Health Insurance Plan could assist with the collection of FASD surveillance data.

10.0 Results — Yukon

10.1 Population Profile

YT has a population of 41,761 people, approximately 25% of whom are First Nations. The traditional territories of 14 YT First Nations cover almost all the land in YT. The majority of YT residents live in Whitehorse (Statistics Canada, 2019a; Yukon Bureau of Statistics, 2020).

10.1.1 OVERVIEW

Yukon Mental Wellness and Substance Use Service Branch (formerly Alcohol and Drug Services) has supported individuals with FASD and their families for decades. The first plan for the prevention of FAS/fetal alcohol effects released in 1997 (Government of Yukon, 2014). YT has been a member of the Canada Northwest FASD Partnership since 2001 (Government of Yukon, 2018; FASD Interagency Advisory Committee, 2019). The Yukon FASD Action Plan is focused on supporting individuals with FASD and providing maternal and prenatal supports (FASD Interagency Advisory Committee, 2019). PAE prevention initiatives are delivered to families and FASD assessment, diagnosis, and housing and education supports are provided to individuals with FASD by the YT government, First Nations governments, non-profit organizations, and the Public Health Agency of Canada (Government of Yukon, 2015; FASD Interagency Advisory Committee, 2019).

YT recently implemented the Health Information Privacy and Management Act. This new privacy legislation impacted the ability of governmental departments to contribute data to the SSFASD/PAE, as well as to the Universal Dataform project. A Privacy Impact Assessment has been created which would allow YT Public Health to contribute data relevant to FASD and PAE. The following jurisdictional profile summarizes previously published epidemiological evidence including FASD/PAE prevalence data.

10.1.2 MATERNAL AND CHILD WELL-BEING INDICATORS RELATED TO FASD/PAE

Alcohol use during pregnancy and FASD need to be understood in the context of socio-demographic factors. Experts from YT informed a virtual community of inquiry on improving treatment for women who use substances and are at risk of having a child with FASD. The inquiry identified experiences of early childhood abuse, sexual assault, intimate partner violence, and other forms of gender-based violence as the leading gendered pathway to substance use (Poole, Chansonneuve, & Hache, 2013). Surviving physical and sexual abuse, being unmarried (Wodinski, 2014), financial insecurity, a lack of shelter, cultural connectedness, and traumatic experiences are also known to impact substance use patterns during pregnancy. These FASD risk factors are compounded by limited access to health services, racism, and stigma (Badry & Felske, 2013a). Intergenerational trauma from residential schools also impacts substance use patterns experienced by YT First Nations people (Council of Yukon First Nations, 2010), and this should be examined within the historical and social context of colonization and discrimination against Indigenous Peoples in Canada.

In 2013–2014, 90% of YT residents reported being satisfied or very satisfied with life. The majority (65%) of residents reported very good or excellent mental health, compared to the national rate of 71%. Approximately 25% of residents reported experiencing quite a lot of life stress, with perceived life stress and life satisfaction similar to national levels. Over 10% reported mood or anxiety disorders, similar to the national rate (Yukon Health and Social Services, 2015). More recent estimates report 7,500 residents live with mental health issues, including substance use issues, and 31.5% report heavy drinking (five or more drinks on one occasion) each year (FASD Interagency Advisory Committee, 2019).

In 2010, 17.8% of women over the age of 12 reported binge drinking (five or more drinks on one occasion) at least once per month (Belik, 2012). According to the 2013–2014 CCHS, 14.8% of YT youth aged 12 to 19 reported daily or occasional smoking, compared to 8.3% nationally. The Health Behaviour in School-Aged Children survey found that 8.4% of students in grades 6 to 8 and 37.8% of students in grades 9 to 10 reported having been "really drunk" at some point (Yukon Health and Social Services, 2015). In 2014, 22.7% of women and girls (aged 12 and older) had reported heavy drinking (four or more drinks on one occasion) at least once a month in the previous year (Statistics Canada, 2015).

In 2013–2014, more than one-quarter of individuals aged 20 and over reported daily or occasional smoking, compared to about one-fifth of Canadians in that age group. In the previous 12 months, 18% of adults reported not drinking at all (Yukon Health and Social Services, 2015). First Nations adults reported a higher rate of abstaining, with 35% reporting not having alcohol in the 12 months prior to the 2008–2009 Regional Health Survey (Council of Yukon First Nations, 2013). Over one-quarter of women in YT reported monthly binge drinking (4 or more drinks on one occasion) through the Yukon FASD Interagency Advisory Committee compared to the national rate of 15% (Yukon Health and Social Services, 2015).

Only 37% of individuals 12 and older reported eating fruits and vegetables five or more times per day, which is comparable to 40% of all Canadians in this age group (Yukon Health and Social Services, 2015). Many residents ate food from locally harvested sources, including berry picking, hunting, and fishing: 34%, 33%, and 44% of residents in Whitehorse, and 52%, 58%, and 62% in rural areas, respectively (Yukon Bureau of Statistics, 2010).

The majority of individuals aged 25 to 64 earned a postsecondary education (68.3%), the highest proportion in Canada. The 2016 Census reported that 12.3% of households were lone parent families, 25.6% of which were male-led lone parent families. In total, 32.8% of children in YT lived with lone parents (Yukon Bureau of Statistics, 2017).

10.1.3 FASD/PAE PREVENTION PROGRAMS

Family support programs designed for women who may lack access to supports and services and are using alcohol or other drugs during and after pregnancy will be scaled up by the Yukon FASD Interagency Advisory Committee to reduce instances of PAE (FASD Interagency Advisory Committee, 2019). The FASD community-based prevention planning model involves ongoing public awareness campaigns and initiatives, including public service advertisements in recent years (Government of Yukon, 2002; Alsbury, 2014), FASD prevention literature (FASD Interagency Advisory Committee, 2019), and a population-level intervention with alcohol labelling that includes the Low-Risk Drinking Guidelines (LRDG) (Vallance et al., 2020).

In March 2015, the Fetal Alcohol Syndrome Society of Yukon placed pregnancy test dispensers and FASD awareness posters in bars and the Yukon College in Whitehorse in order to assess the best method to increase awareness of the effects of PAE. It was found that combining FASD education messaging with a pregnancy test dispenser in bars serving alcohol is an effective and inexpensive FASD prevention messaging strategy (Ray, 2017). There is a fairly high awareness of FASD among the general population (Government of Yukon, 2015).

FASD prevention education was provided for children and youth in junior and high school curricula as well as in college-level health programs and services in the 2014-2015 academic year (Government of Yukon, 2014). An FASD prevention prenatal education kit is available at community and First Nations health centres. Further, priority access to withdrawal services and outpatient/inpatient drug treatment is provided to women who are pregnant (Alsbury, 2014).

A Community Wellness Court is available for access to individuals with FASD; it offers support services and a therapeutic alternative for individuals who use substances and/or have mental health disorders that are related to the commission of their offence (Alsbury, 2014). The Community Wellness Court, however, may not be accessed by individuals with FASD if it does not have the capacity to meet their individual support needs. The Department of Justice also provides counselling services to adults with FASD through the Family Violence Prevention Unit and targeted services aimed at preventing PAE (Yukon Courts, 2008).

10.2 Existing Surveillance — PAE and FASD

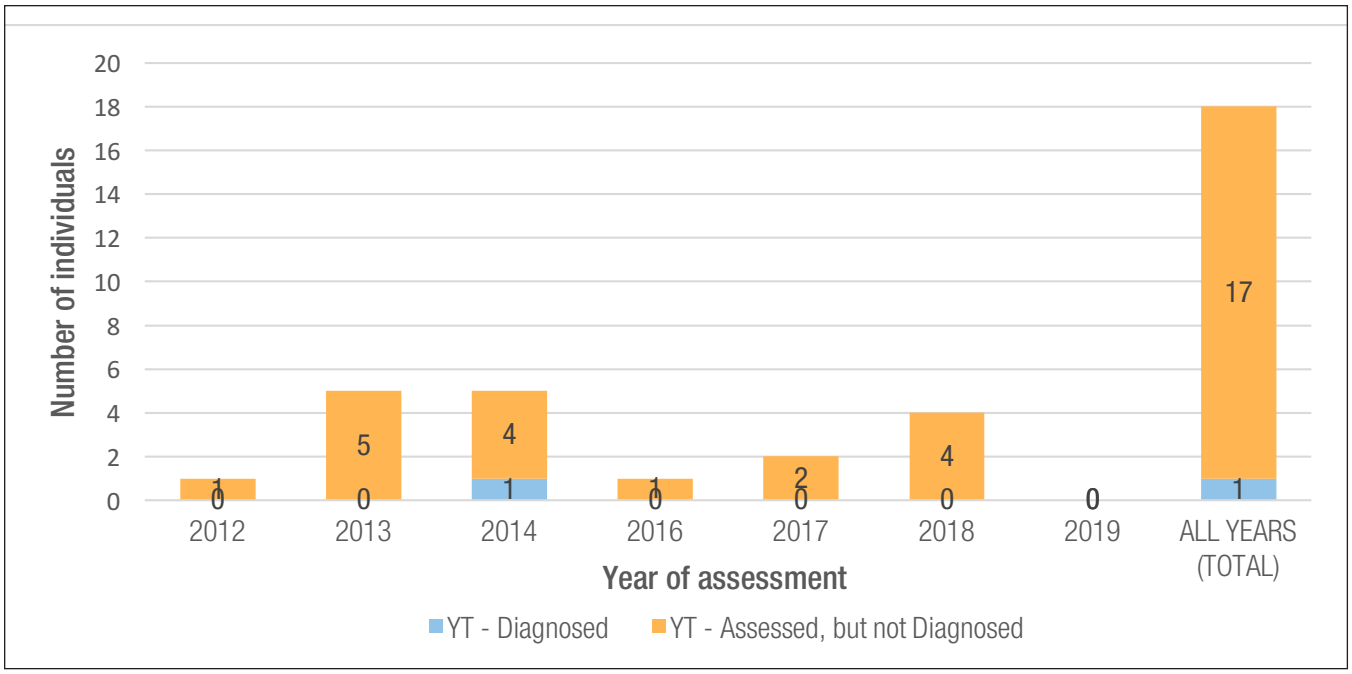
10.2.1 DATA COLLECTION MECHANISMS

Many organizations, agencies, and communities — including the Yukon Child Development Centre, Canada Prenatal Nutrition Program, Fetal Alcohol Syndrome Society Yukon, and medical and health centres — have engaged in various FASD prevention and support activities throughout YT. Any data on FASD/PAE incidence and prevalence published by these organizations are included below. No published studies were found to provide regional estimates of PAE in YT, in the general or subpopulations.

10.2.2 CANADIAN NATIONAL FASD DATABASE

Please refer to the Canadian National FASD Database section of this report (Section 4.2.1) for a detailed analysis of these data.

Data in the figure below present two categories of diagnostic outcomes: diagnosed, which includes individuals with FASD with or without sentinel facial features, and assessed but not diagnosed, which includes those in the at-risk category as well. Data are presented by year of assessment; where a year is missing, this indicates zero diagnoses and zero assessments in the respective year. Please note that only partial data were available for 2019.



Source: CanFASD Universal Dataform project

Figure 10. Individuals assessed for FASD diagnosis and individuals who received FASD diagnoses by year in Yukon, 2012–2019

In total, there were 17 assessments and one individual received an FASD diagnosis. The majority (94.4%) of the assessed individuals in YT were between zero and five years old at the time of assessment; this is due to the fact that only one clinic in YT contributes client data to the Universal Dataform project. At the time of writing, school and adult clinics are still signing onto the project in YT and in other jurisdictions

10.2.3 PUBLISHED STUDIES — FASD

The prevalence of FASD in YT has been identified as a significant issue facing many individuals, families, and communities, with high human and financial costs on the education, health, child welfare, and the criminal justice systems. It is recognized that many individuals with FASD may not be diagnosed; this is impacted by stigma, fear of child apprehension, and the inability to confirm PAE (FASD Interagency Advisory Committee, 2019).

To date, one regional estimate has been identified for FASD in the general population of YT, derived from a recent study by Pei et al. (2020). Regional data for YT estimates that the prevalence of FASD among kindergarten students in the general population is 2.0 per 1,000, or 0.2%. This was based on teacher-reported diagnoses of students in the EDI within a population-wide database; however, data for YT are based on an extremely low sample size (fewer than five children).

A study in 1985 found that 3.3% of children in YT and Northwestern BC had FASD, with a rate of 46 per 1,000 children in YT (Asante & Nelms-Maztke, 1985). However, this study was later appraised and found not to be representative of the general population, as the prevalence rate was derived from a small sample of children who were suspected of having chronic diseases and disabilities (Tait, 2003). YT's formal medical officer of health estimated that 24 of the 378 babies born in 2000 had FASD, representing 6% to 7% of the population (Timmermans, 2006).

Between May 2014 and September 2015, the prevalence of FASD among individuals in the YT criminal justice system was measured along with other neurocognitive deficits, mental health, and substance use–related difficulties using an active case ascertainment design in a study by McLachlan (2017). A total of 80 adults aged 18 to 40 were recruited from the Whitehorse Correctional Centre and Whitehorse Offender and Supervision Services. Results found that 17.5% met the criteria for FASD, 25% had confirmed PAE, and there were insufficient data to make a reliable clinical decision for 13.8%. The study was undertaken in parallel with the Yukon Health and Social Services' initiative to train and implement the adult FASD assessment and diagnostic team (Government of Yukon, 2015).

10.3 Service Utilization

10.3.1 CANADIAN INSTITUTE FOR HEALTH INFORMATION

Please refer to the CIHI section of this report (Section 4.3.1) for a detailed methodology. From 2014 to 2017 fiscal years, a total of 175 hospitalizations and health care visits were made by patients with FAS with a health card from the YT. These health care encounters were mostly for emergency department visits. These patterns were consistent for each fiscal year. None of these patients with FAS were homeless.

10.3.2 FASD DIAGNOSTIC CAPACITY

YT opened neurodevelopmental diagnostic clinics to develop the jurisdiction's capacity for FASD assessments, for preschool children in 2004 and for school-age children in 2006. The Child Development Centre in Whitehorse coordinates assessments for two teams, which assess approximately ten preschool and ten school-age children per year (Government of Yukon, 2015). The Child Development Centre received 18 new referrals to the preschool (12) and school-age (6) teams between June 1, 2018, and June 1, 2019. The preschool team completed ten full assessments, in addition to two additional assessments. Four children were diagnosed with FASD, eight with autism spectrum disorder, and one with complex behaviour. There were nine children waiting for assessments in 2019–2020 (Squair, 2019).

Adult diagnoses between 2004 and 2013 were conducted by assessment teams from AB that assessed approximately ten individuals in YT per year (Government of Yukon, 2015). It has been reported that an average of six adults were assessed for FASD per year between 2004 and 2013 (Joannou, 2015, 2016). In May 2015, the Adult Assessment Clinic initiated assessments in partnership with the Fetal Alcohol Syndrome Society of YT. Currently, adults with suspected FASD are assessed by Disability Services in the Department of Health and Social Services (FASD Interagency Advisory Committee, 2019). The two diagnostic centres are currently moving towards an integrated system where services are integrated.

An evaluation of FASD clinical diagnostic capacity showed that the maximum number of diagnostic slots available for FASD diagnosis in YT was 20 between 2010 and 2011. Using a formula for capacity calculation (slots available / jurisdictional population x 10,000) the clinical capacity in YT was 5.84 diagnostic slots (Clarren, Lutke, & Sherbuck, 2011). The diagnostic capacity survey was not completed in 2019 and therefore updated diagnostic capacity is not available.

10.3.3 PUBLISHED STUDIES — SERVICE UTILIZATION

The Yukon Department of Health and Social Services provides programs and services with a needs-based approach that uses care needs as the metric for access to care and for designing a framework to meet the identified needs. Resources are made available based on the needs of individuals regardless of whether they have an FASD diagnosis or are suspected of having FASD.

It has been documented that FASD imposes high direct costs to the health care, social services, education, and justice systems. Indirect costs, including the premature deaths of people with FASD, have also been acknowledged (Government of Yukon, 2018). Many individuals in the YT correctional system have been suspected of having FASD by service providers in the system, but were not diagnosed (The Four Worlds Centre for Development Learning, 2007). The cost of children and youth with FASD living in care in 2011 was estimated to cost between $162,183.69 to $555,356.26 (Popova et al., 2014a).

11.0 Summary and Conclusions

The SSFASD/PAE supports the PHAC FASD Initiative through enhanced data collection and analysis that inform programs and policies for individuals with FASD in Canada. As data sources were identified and data collection was initiated, this project consulted and collaborated with experts in FASD surveillance, diagnosis, and treatment to ensure rigorous and accurate methodologies were used. These collaborations supported data analysis and interpretation, identifying strengths and limitations of existing FASD/PAE data collection mechanisms and highlighting opportunities for further FASD surveillance.

Findings indicate that the foundational activities to support the development of a multi-source surveillance system promoted the use of consistent methods for reporting and analyzing FASD/PAE data. This project demonstrated that regional research capacity building supports the development of an SSFASD/PAE, which is needed to monitor trends and produce reliable and comparable data on an ongoing basis. Current epidemiological findings continue to demonstrate the need for increased FASD diagnostic capacity as well as prevention and treatment supports.

This project revealed that the selected P/Ts have a number of thorough data collection mechanisms to capture PAE and FASD in their respective jurisdictions. Birth registries and population health surveys collect data on alcohol use during pregnancy, including frequency and amount, which generate important population level estimates of PAE. Survey data tends to generate higher estimates, which illuminates potential areas for improvement in alcohol use screening in antenatal care. Data on individuals with FASD/PAE is captured in a variety of sources, including diagnostic clinic data, administrative health data, and epidemiological studies using PS or ACA.

The main findings of the data collected and analyzed for this project are presented below, organized by main outcome and data source classification.

PAE

CROSS-JURISDICTIONAL MEASURES OF PAE IN THE GENERAL POPULATION, 2015–2018

One cross-jurisdictional PAE data source was collected for the purpose of this report. Survey data from the CCHS showed that between 6.3% to 9.5% of women who had given birth between 2015 and 2018 reported use of alcohol during their respective pregnancy. While the CCHS is nationally representative, it is possible that some individuals may be restricted in participating due to language barriers or literacy levels. Additionally, an estimated 3% of the Canadian population is not represented in the CCHS sampling frame, including individuals living on reserves, women experiencing homelessness, women who are full-time members of the Canadian Armed Forces, and those living in two health regions in Quebec.

REGIONAL MEASURES OF PAE IN THE GENERAL POPULATION, 2015–2020

Based on identified epidemiological studies in the general population in 2015–2020, the prevalence of PAE was 10% in MB and ranged from 1.1% to 2.3% in BC (see Appendix D). Notably, these identified sources utilized information on alcohol use during pregnancy from provincial birth registries; however, the data were ascertained and recorded differently.

Data from provincial birth registries were collected to represent alcohol use during pregnancy in the respective regions. Data from AB show that approximately 3% of women reported alcohol use during pregnancy in this time period (see Notice of Live Births, Section 5.2.1), while a smaller proportion of women (0.13% to 1.3%) were indicated to have an alcohol use risk factor during pregnancy (see APHP, Section 5.2.2). In BC, data from the BCPDR show that between 0.9% and 1.3% of women were indicated to have alcohol use identified as a risk factor during pregnancy (see Perinatal Services BC, Section 6.2.1). Universal screening program data show a prevalence rate of 10% in MB (see Appendix D). In ON, data from BIS indicate that 2.1% of live births and stillbirths in ON in 2012–2018 fiscal years were born to women with self-reported alcohol use during pregnancy, with the yearly prevalence ranging from 1.5% to 2.5% (see BORN Ontario, Section 9.2.2). Though these estimates were obtained from the same data source type (i.e., birth registry), any appearance of provincial differences should be interpreted in light of differences in data collection. Across these regional birth registries, alcohol use data were ascertained and recorded differently, using different alcohol use definitions. Of course, these data depend on the thoroughness and consistency of alcohol use screening by antenatal care providers, and jurisdictional differences in that respect are unknown.

For the data collected for this report, one prevalence estimate of PAE was obtained from a population-based survey (see CAMH Monitor, Section 9.2.1), with survey questions created, data collected, and analyzed specifically for this project. CAMH Monitor data (2018–2019) revealed that between 13.0% and 16.5% of parous female respondents reported consuming alcohol during their last pregnancy. Of note, the respective pregnancies did not necessarily occur in 2015–2020, with some pregnancies dating as far as 30 years prior to the implementation of the survey.

There are great challenges with respect to identifying alcohol use in pregnancy in administrative health data outside of birth registry information. Generally, data are limited to the entry of alcohol-related diagnostic codes for women accessing hospital-based care during pregnancy or at birth, which may present an underestimate of PAE. Based on the pregnant women accessing hospital-based care during pregnancy or at the time of delivery in ON as captured by ICES (2015–2017), the prevalence of pregnant women with alcohol-related codes ranged from 0.09% to 0.11% (see Appendix Y). For the majority of women identified, the recorded alcohol use codes indicated the presence of mental and behavioural problems related to alcohol, which were relevant to the respective pregnancy. While this is not an adequate measure of the prevalence of alcohol use during pregnancy in ON, this finding from ICES data suggests that women with pre-existing alcohol use disorders may benefit from individualized alcohol use screening and counselling during pregnancy.

OVERALL PREVALENCE OF PAE IN THE GENERAL POPULATION, 2015–2020

Across all sources of data collected for this report with study years 2015–2020, alcohol use during pregnancy ranged from 0.9% to 16.5% in the general population. Based on all years of data in the available, identified sources, however, the prevalence of PAE ranged from 0.4% to 49% in the general population of Canada. The heterogeneity of data collection methods and alcohol use measures across identified sources inhibits meta-analysis.

MEASURES OF PAE IN SPECIAL SUBPOPULATIONS, 2015–2020

Based on identified epidemiological studies in special subpopulations in 2015–2020, the PAE prevalence among women in First Nations communities was 7% (FNIGC, 2018); no epidemiological studies measuring the prevalence of alcohol use among pregnant Inuit and Métis women were identified. This also pertains to data from FNIGC summarized in this report (see Section 4.1.2), which found that 93% of women abstained from alcohol during pregnancy, based on self-report in phase 3 of the Regional Health Survey. Data on alcohol use in pregnancy among Indigenous populations should always be interpreted in light of the intergenerational trauma and inequities that stem from the social and historical contexts of colonization and discrimination. Furthermore, data collected on pregnancy behaviours in Indigenous communities can follow the exemplary work done by FNIGC, which has implemented and collected data in full adherence with OCAP principles.

Data from AB PCAP (see Section 5.2.3) indicate the reported behaviour and conditions of pregnant women with substance use disorder (SUD) who have accessed this intervention service in years 2015–2019. Based on data collected on the women's behaviour during their own pregnancy while accessing the program, 64.9% consumed alcohol during their first trimester and 10.1% consumed alcohol in the second trimester. The timing of access to the program was not defined, though all alcohol use information was finalized at the end of each pregnancy. Additionally, 28.1% of women accessing this program had confirmed PAE, such that the alcohol use of their birth mother during pregnancy was previously recorded and reported to PCAP. These data highlight the importance of meeting the needs of women with AUD and SUD, as well as women who may have confirmed PAE or diagnosed FASD themselves, in FASD prevention activities.

OVERALL PREVALENCE OF PAE IN SPECIAL SUBPOPULATIONS, 2015–2020

Across all sources of data collected for this report with study years 2015–2020, alcohol use during pregnancy ranged from 7% to 64.9% in special subpopulations. Based on all years of data in the available, identified sources, however, the prevalence of alcohol use ranged from 2% to 69.8%. While the former range seems to be higher as compared to the general population, it is important to note that the prevalence for special subpopulations for years 2015–2020 is based only on two data sources and is dependent on self-report. These two sources of data are not eligible for comparison, as there is a substantial difference in sampling methodology and the two subpopulations have different social and cultural contexts. No prevalence estimates could be obtained for special subpopulations based on data available in regional birth registries, due to high missingness and data privacy concerns in using these data elements.

MATERNAL RISK FACTORS ASSOCIATED WITH PAE

Cross-sectional studies of parous women were conducted for this report, which have provided extensive maternal profiles, including demographic, mental health, and substance use variables, grouped by reported alcohol use during pregnancy (see CCHS, Section 4.1.1; Perinatal Services BC, Section 6.2.1; and CAMH Monitor, Section 9.2.1). Based on the available data where women were grouped, some findings indicated that women with reported alcohol use were more likely to report consistent, significant stress and more likely to rate their general health as "fair" or "poor." Women reporting alcohol use during their pregnancy were often nulliparous, had a history of mental illness, and had more antenatal care visits during the respective pregnancies. Additionally, women reporting alcohol use during pregnancy were more likely to have used substances other than alcohol during pregnancy as well as to use alcohol while breastfeeding.

Women's experiences and circumstances associated with alcohol use during pregnancy inform evidence-based decision-making, public health policy, and program development and implementation. These data identify opportunities to meet the identified health needs of women who are considered priority populations for FASD prevention efforts and to eventually monitor progress toward achieving federal and P/T health goals and objectives, including the prevention of alcohol use during pregnancy and new cases of FASD in Canada. Screening methods for alcohol use during pregnancy have also been criticized for inherent racial bias (Tait, 2003).

Women's alcohol use in Canada is understood to be contextualized by stress, trauma, isolation, general health, age, genetics, resilience, cultural discrimination, exposure to violence, abuse, access to prenatal care, grief and loss, social policy, and poverty (Tait, 2009) irrespective of ethnicity (Tait, 2003). Additional factors contributing to the alcohol-exposed pregnancies leading to FAS include partners who controlled women's substance use and access to services, serious mental health problems, and malnutrition (Poole, 2008).

FASD

CROSS-JURISDICTIONAL MEASURES OF FASD PREVALENCE IN THE GENERAL POPULATION, 2015–2020

Based on identified epidemiological studies in the general population of Canada in 2015–2020, one cross-jurisdictional FASD prevalence estimate obtained was 0.11% in a study by Pei and colleagues (2020). This study was conducted on a sample of over 600,000 children in Canada aged 4 to 6, and FASD data were based on diagnoses in student records, as reported by teachers. Notably, FASD may not be formally diagnosed until later in childhood, which may contribute to the production of an underestimate.

REGIONAL MEASURES OF FASD PREVALENCE IN THE GENERAL POPULATION, 2015–2020

Based on identified epidemiological studies in the general population in 2015–2020, regional FASD prevalence estimates obtained were 0.11% in AB, 0.27% in BC, 0.3% in MB, 0.12% in NT, between 0.05% and 2.93% in ON, and 0.2% in YT. For FAS, one regional estimate was obtained for this time period, with a prevalence of 0.12% found in ON.

For the data collected for this report, one prevalence estimate of FASD was obtained from a population-based survey (see CAMH Monitor, Section 9.2.1), with survey questions created, data collected, and analyzed specifically for this project. CAMH Monitor data (2018–2019) from ON revealed that 0.19% of adult survey respondents reported having been told by someone (e.g., a family member, friend, or physician) that they have FASD. The extent to which social desirability bias applies and the extent to which the population of adults with FASD in ON is represented in the survey are both unknown. This may not be indicative of the true prevalence of FASD among survey respondents, though the survey sample itself is representative of the general population in ON.

REGIONAL MEASURES OF THE ADMINISTRATIVE PREVALENCE OF FAS, 2014–2020

Data were also collected on the administrative prevalence of FAS, which is solely dependent upon the utilization of services by individuals with FAS, as well as the proper identification of FAS among these individuals. Numerous CIHI data holdings, including NACRS, DAD, OMHRS, and NRS, identified a total of 100,169 hospitalizations and health care visits among 5,472 patients with FAS in 2014–2017 in the selected P/Ts (see Section 4.3.1). Emergency visits were the most common level of care, while acute care hospitalizations were the largest contributors to the estimated cost burden of $40 million attributed to FAS, based on these data.

Data from ambulatory and inpatient care services in Alberta (see Section 5.4.2), which may overlap with data from CIHI, showed that ICD-10 code Q86.0 was recorded more often than ICD-10 code P04.3 in 2015–2020. A total of 1,363 first-time uses of the FAS code (Q86.0) were recorded in these years, mainly among adolescent and adult patient files, which shows the capacity of hospital-based services to identify FAS. This is comparable to the 1,659 first-time indications of ICD-9 code 760.71 for patients, as captured in Albertan physician claims in the same time frame (Section 5.4.3).

Administrative health data from ICES reveal that 0.74, 1.11, and 1.26 per 10,000 ON newborns in 2015, 2016, and 2017 (respectively) were diagnosed with the ICD-10 code P04.3, corresponding to approximately 0.01% of births with PAE in the general population (see Section 9.2.3). Among children and youth in Ontario (0 to 17 years), between 0.07% and 0.09% of acute care hospitalizations and 0.01% to 0.02% of emergency department visits in 2015–2017 were associated with the ICD-10 code for FASD (Q86.0). Among adults in ON (18 years and over), 0.01% of acute care hospitalization and 0.02% of emergency department visits in 2015–2017 were associated the ICD-10 code for FAS (Q86.0) (see Section 9.3.1). These estimates, however, are a gross underestimate of the true prevalence of FAS in ON and can be more accurately described as the identified burden of FAS in hospital-based care in ON, based on administrative health data.

OVERALL PREVALENCE OF FASD IN THE GENERAL POPULATION, 2015–2020

Across all sources of data collected for this report with study years 2015–2020, FASD prevalence in the general population of Canada ranged from 0.05% to 2.93%. Data based on all years (1985-2020) in the available, identified sources yields the same prevalence range. The heterogeneity of data collection methods across identified sources inhibits the potential of conducting a meta-analysis on these data.

MEASURES OF FASD PREVALENCE IN SPECIAL SUBPOPULATIONS, 2015–2020

Based on identified epidemiological studies in special subpopulations in 2015–2020, the obtained FASD prevalence estimates ranged from 0.5% to 61.25% (see Appendix E). This suggests that FASD in all special subpopulations across Canada is from 10 to 21 times higher as compared to the general population, based on the data in this report.

Data from FNIGC indicates that 0.5% of First Nations children and youth were identified to have FASD, based on self and guardian report in phase 3 of the Regional Health Survey (Section 4.1.2). This data presents the most recent measure of FASD among First Nations individuals, which was collected in complete accordance with OCAP principles. This obtained prevalence estimate is not generalizable to individuals living in Métis and Inuit communities.

Outdated previously published studies of isolated communities have found higher rates of FASD in Indigenous communities in comparison to primarily settler communities. These studies, however, are 20 to 30 years old and have methodological limitations that make them inapplicable for use by policy analysts and systems planners. Chudley et al. (2005) caution that these small, isolated studies should not be generalized to other First Nations communities or the Canadian population in general. Indeed, data collected for the purpose of this report do suggest the prevalence of FASD in First Nations communities is comparable, and perhaps even lower, than that in the general population of Canada. Overall, these variations in the available data emphasize the importance of Indigenous data sovereignty, especially with regard to PAE and FASD data.

Data on FASD from special subpopulations of women with alcohol and substance use disorders highlight the importance of examining alcohol use during pregnancy and FASD familial recurrence. Among women accessing PCAP in AB (Section 5.2.3), a harm-reduction initiative targeting alcohol use in pregnancy, 23.8% reported having a diagnosis of FASD as a chronic medical condition. As well, among pregnant women with alcohol-related diagnostic codes recorded during hospital-based care in pregnancy or at birth, 0.5% to 3.9% of the children from the respective pregnancies were noted to have FAS (ICD-10 code Q86.0) or PAE (ICD-10 code P04.3) during a longitudinal study using ICES data (see Section 9.2.4).

Available data on the prevalence of FASD in correctional populations is limited to estimates obtained from epidemiological studies, such as McLachlan (2017) which found a prevalence of 17.5% among individuals incarcerated in YT. This may correspond to research findings within clinical data in this report that show justice system involvement among individuals diagnosed with FASD. For example, data from the Canadian National FASD Database (see Section 4.2.1) show that up to 19.6% of adolescents (10 to 17 years) and 28.5% of adults (18 years and older) had legal problems wherein they were the “offender,” whereas 4.4% of adolescents and 6.1% of diagnosed adults had been incarcerated previously.

CLINICAL AND DIAGNOSTIC DATA ON FASD

Clinical data on the diagnostic outcomes of individuals assessed for FASD reveal that of individuals assessed in the respective P/Ts: 54.1% of individuals in BC were diagnosed with FASD, 53.1% in MB, 86.7% in NT, and 59.9% in ON (see Sections 6.3.3, 7.3.3, 8.3.4, and 9.3.3). Data from the Canadian National FASD Database show that approximately 60% of individuals assessed in the participating clinics in the select P/Ts were diagnosed with FASD, which does not include data from BC (see Section 4.2.1).

Cross-sectional and cohort studies on populations of individuals diagnosed with FASD were conducted for this report (see Sections 6.3.1, 6.3.2, and 9.3.1), which have provided rich patient profiles that illustrate common comorbidities, other prenatal exposures, adverse social outcomes, and support services needed. Within patient populations, ADHD, learning and cognitive disorders, and mood disorders were common comorbid mental health conditions, while respiratory and nervous system problems seemed to be the most common physical health conditions. Fairly common prenatal exposures (up to 50.9%) of diagnosed individuals, in addition to alcohol, were tobacco, cocaine/crack, and cannabis. Based on available data, child welfare involvement of diagnosed individuals was very high (up to 89.4%), criminal justice system involvement was fairly high (up to 28.5%), and substance use (including alcohol and tobacco) was fairly high, with up to 38.6% of adults reported to have a substance use disorder. These rates are comparable to the higher prevalence estimates of FASD in special subpopulations, such as children in care, correctional populations, and women

accessing PCAP services.

Commonly recommended support services for diagnosed children with FASD were accommodations/adaptation in environment, support, and communication strategies. Adults often needed the same support services, with the most commonly recommended services being general income and mental health support, as well as accommodations/adaptation in environment. Indeed, diagnoses of FASD can lead to improved health and social outcomes for children and adults, leading to access of required services and overall empowerment in adult life.

The data also revealed that diagnostic capacity of FASD clinics in participating P/Ts is low. Waiting time ranged from six months to four years across all P/Ts that participated in the survey. This range should be interpreted with caution, however, as P/Ts had varying proportions of diagnostic clinics contribute data to the CAMH REDCap survey across the implementation years. Previously identified epidemiological and economic considerations (Larcher & Brierley, 2014) continue to demonstrate the need for increased FASD diagnostic capacity as well as prevention and treatment supports.

12.0 Recommendations

The effects of exposure to alcohol before birth, including FASD, must be recognized globally as a substantial public health problem with a prevalence rate that exceeds that of Down syndrome, spina bifida, trisomy 18, and ASD (Popova et al., 2017; Popova et al., 2019a). Addressing the determinants of FASD, which are a complex interplay of factors including trauma and health inequity, is therefore a critical public health priority. Consistent universal screening and surveillance for FASD/PAE across Canada are needed along with expansion of intervention and substance use programs, diagnostic capacity, and education about the impacts of alcohol use during pregnancy. Research findings in this report can be used to promote the consistent implementation of the alcohol use screening guidelines (Graves et al., 2020) for physicians, nurses, and midwives providing antenatal care to pregnant women. The data presented in this report may be used to inform the establishment of a baseline against which to evaluate efforts to advance health equity, including preconception health. Benchmarks can be established to compare against when implementing and evaluating prevention of alcohol use during pregnancy, FASD intervention strategies, and other efforts to advance preconception health equity.

The following recommendations are offered based on results of the SSFASD/PAE project. These recommendations guide needs-based health human resources planning, policy creation, and evidence-based decision-making by identifying baseline measurements on FASD/PAE and their determinants.

1. Establish a Universal Screening Protocol and Surveillance System for Alcohol Use during Pregnancy in Canada

There is an urgent need to establish a universal screening protocol and surveillance system on alcohol use during pregnancy in order to monitor its prevalence across Canada. This will provide a basis for public health policy, health care planning, and resource allocation for FASD/PAE prevention initiatives. A universal screening protocol should be implemented by antenatal care providers and include validated screening tools which consistently ask pregnant women about their alcohol consumption. These tools should include specific definitions of standard drinks and questions regarding alcohol use prior to pregnancy confirmation.

Findings on alcohol use during pregnancy and while breastfeeding reveal that it is important to provide consistent and thorough screening for alcohol use during pregnancy, and it is especially important to collect data on alcohol use behaviour prior to pregnancy recognition. Universal screening for alcohol use during pregnancy by antenatal care providers using a standard protocol across Canada is recommended with all women of childbearing age, in combination with preconceptual health promotion and referral to treatment programs for individuals (including pregnant women and their partners) with an alcohol use disorder, as needed. This requires defining standard drinks and collecting information about alcohol use prior to pregnancy recognition. This screening has the potential to increase monitoring of child development, early diagnosis, and timely interventions, if required (Popova et al., 2016b). Standardized national guidelines for prenatal risk assessment may support this recommendation (Scime et al., 2019).

Health care providers are well positioned to disseminate preconception alcohol use during pregnancy prevention messages and to offer interventions to all patients (i.e., anyone who is planning on conceiving, anyone who is sexually active, those who have conceived a child) as part of their practice. Patients may also need support to reduce harm related to alcohol and other drug use while breastfeeding and information on the risks associated with post-natal exposure to alcohol and other drugs is also needed (Ordean, Wong, & Graves, 2017).

2. Expand Brief Interventions and Substance Use Programs for Women of Childbearing Age

Provision of brief interventions, where appropriate, to all pregnant women and women of childbearing age should be readily available across all jurisdictions. As well, enhanced access to substance use treatment programs for women of childbearing age and for mothers of children with FASD could provide important opportunities to prevent the occurrence and/or recurrence of FASD within families.

Identified alcohol use during pregnancy informs prevention and intervention programs as well as early diagnosis of FASD (Sarkar et al., 2009; Bryanton et al., 2014). In Canada, brief alcohol interventions and support are part of an integrated and comprehensive strategy to prevent FASD and to help women stop or reduce alcohol use during pregnancy (Poole, 2008). It is recommended that brief interventions are provided across Canada using a harm-reduction and gender-transformative approach that supports women who use substances and who have co-occurring influences on their health and recovery (Nathoo et al., 2018). Immediate access to substance use treatment programs for women of childbearing age and for mothers of children with FASD will provide important opportunities to prevent the occurrence and/or recurrence of FASD within families. A scale-up of this harm-reduction and gender-transformative approach to such interventions includes supportive and accessible resources that respond to trauma, alcohol use, and child welfare involvement (Badry & Felske, 2013b). It is also important to provide postpartum support, particularly to women who have children with FASD in order to prevent a recurrence of FASD within families (Popova, Dozet, & Burd, 2020).

Surveillance experts have identified health care providers' time capacity, stigma, and lack of knowledge about standard drink sizes as persistent barriers to collecting and recording alcohol use during pregnancy (Nathoo et al., 2018). This is problematic given that screening and brief interventions are useful in assisting pregnant women who consume low to moderate amounts of alcohol to reduce their use (Carson et al., 2017). It is important that these barriers be simultaneously addressed in order to enhance access to and increase the effectiveness of substance use treatment programs for women of childbearing age and for mothers of children with FASD.

3. Establish a Canada-Wide Surveillance System for FASD with Consistent Diagnostic Codes

This project demonstrated that regional research capacity building supports the development of an FASD surveillance system, which is needed to monitor trends and produce reliable and comparable data on an ongoing basis. The current surveillance project across the participating P/Ts can be implemented across remaining jurisdictions, thereby improving national FASD surveillance. Findings indicate that the foundational activities undertaken in this study to support the development of a multi-source surveillance system promoted the use of consistent methods for reporting and analyzing FASD/PAE data.

Harmonization of the ICD and DSM diagnostic criteria for FASD will address the absence of distinctive diagnostic codes, a persistent barrier to FASD surveillance (Popova, Dozet, and Burd, 2020). Practitioner billing codes specific to preconception and prenatal alcohol use screening and intervention are also recommended.

4. Expand Early Detection, Diagnosis, and Care for Individuals with FASD

FASD is typically detected through a broad spectrum of psychometric tests conducted by a multi-disciplinary team that includes specialist physicians, psychologists, occupational therapists, and speech pathologists. Inequitable access to this resource-intensive diagnostic process results in many individuals with FASD not receiving a diagnosis. However, a diagnostic FASD assessment has the ability to empower communities and policy-makers by identifying supportive and effective treatment services tailored to needs. Priority should be given to special populations (i.e., children in care, individuals who are incarcerated, and people living in remote areas) with higher prevalence rates of FASD as compared to general population.

Early detection of FASD increases the likelihood of individuals receiving developmental and medical interventions that improve their quality of life and reduce costs associated with hospitalization and institutionalization (Paintner, Williams, & Burd, 2012). Diagnosis and FASD-informed care are important for preventing adverse experiences. Substance use treatment programs for youth with FASD, for example, need to be holistic and address the wide range of factors that influence their substance use (Peled, Smith, & McCreary Centre Society, 2014).

The FASD prevalence rates in the general population and in special subpopulations indicate the urgent need for increased funding to expand diagnostic capacity and diagnostic services across many P/Ts. Clinics should provide assessments and diagnoses for patients of all ages, including adult and senior populations. In addition, timely medical and social interventions and support services to people with FASD and their families are needed. Special attention should be paid to children in care, prisoners, and people living in remote areas where the prevalence of FASD is much higher as compared to general population.

The health care utilization rates and comorbid diagnoses reported identify opportunities for detection, assessment, and intervention for individuals with undiagnosed FASD. Improved screening and diagnosis will increase the likelihood of individuals with FASD accessing interventions and resources that may reduce the occurrence of mental health conditions, including substance use, dangerous sexual behaviour, disrupted school experience, and contact with the criminal justice system (Streissguth et al., 1996). Given the high rate of comorbidity among individuals with FASD (Popova et al., 2016b), it is likely that health care providers encounter individuals with the condition who are yet to be formally diagnosed. It is recommended that alcohol use during pregnancy be assessed as a substantial clinical risk factor for comorbidity in patients with any number of the identified comorbid conditions (Popova et al., 2016b).

5. Continue and Expand Preconception Health Promotion and Education

No amount of alcohol use during the gestational period is deemed safe; therefore, alcohol use abstinence is recommended for individuals who are or may become pregnant (Walker et al., 2011; Carson et al., 2017; Williams & Smith, 2015; Chudley, 2008). Our findings also indicate the need to increase awareness of the effects of alcohol use during pregnancy, particularly low levels of alcohol consumption and consumption prior to pregnancy recognition.

Further efforts should be made to better educate women of childbearing age about the detrimental consequences of alcohol use during pregnancy and the importance of alcohol use abstinence during their entire pregnancy as well while attempting to become pregnant. Measures to reduce stigma associated with PAE and FASD in order to improve data collection and to provide adequate diagnostic and treatment services should also be undertaken.

Stigma directed at women who report alcohol use during pregnancy is strong (Canada FASD Research Network's Action Team on Prevention from a Women's Health Determinants Perspective, 2014) with serious impacts on women's health. Stigma creates a barrier to accurate reporting (Bryanton et al., 2014), resulting in under-reporting (Carson et al., 2017) and in health care provider hesitation to screen for alcohol use (Bryanton et al., 2014). In turn, this reduces access to appropriate diagnostic and support services and reduces the ability to report accurate prevalence rates. Anti-stigma strategies associated with alcohol use during pregnancy are needed with simultaneous dissemination of the public health message that there is no amount, type, or time to consume alcohol while pregnant or trying to become pregnant.

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Appendix A: Steering Committee Members

CHAIR, PRINCIPAL INVESTIGATOR

- Dr. Svetlana (Lana) Popova, Centre for Addiction and Mental Health

STEERING COMMITTEE MEMBERS

- Dr. Alan Bocking, CanFASD Research Network
- Colleen Burns, Lakeland Centre for FASD
- Dr. Albert Chudley, University of Manitoba
- Dr. Jocelynn Cook, CanFASD Research Network
- Vanessa Norris, Yukon Health and Social Services
- Elspeth Ross, FASD Group of Ottawa
- Shannon Ryan, Yukon Health and Social Services
- Dr. Valerie Temple, Surrey Place Centre
- Lori Twissell, Stanton Territorial Hospital, Government of Northwest Territories
- Kathy Unsworth, CanFASD Research Network

PHAC OBSERVERS

- Emily Hollink, Public Health Agency of Canada
- Claudia Lagace, Public Health Agency of Canada

Appendix B: SSFASD/PAE Data Sources Included in the Report

Data source	Focus
CROSS-JURISDICTIONAL	
Universal Dataform Project (neurodevelopmental clinics) · AB, MB, NT, ON, YT	FASD diagnosis PAE Mental health comorbidities Adverse social outcomes Support services
REDCap surveys · Neurodevelopmental clinics (some currently participating in Dataform) · Genetics clinics · Jurisdictions: AB, BC, MB, NT, ON	Diagnostic capacity of clinics Individuals diagnosed with FASD per year Clinic waitlist
Canadian Institute for Health Information Acute inpatient care, day surgery · Discharge Abstract Database Psychiatric care · Hospital Mental Health Database · Ontario Mental Health Reporting System · National Rehabilitation Reporting System Emergency department · National Ambulatory Care Reporting System Rehabilitation services · National Rehabilitation Reporting System (NRS) Cost of care · Canadian Management Information System Database (CMDB)	Health care utilization associated with FAS diagnosis Levels of care and cost associated with FAS Comorbidities of individuals with FAS Utilization trends by P/T, year, and rural and urban location
Canadian Community Health Survey · Alcohol use during maternal experience (MXA) survey	Alcohol use pre-pregnancy, during pregnancy, and while breastfeeding Demographic characteristics of women, by self-reported alcohol use group Mental health and substance use of women, by self-reported alcohol use group
First Nations Information Governance Centre · Regional Health Survey	Alcohol and tobacco use during pregnancy Guardian-reported FASD diagnosis of child (0-11 years) Self-reported FASD diagnosis of youth (12-17 years)
Canadian Vital Statistics Death Database	Leading cause of infant death caused by conditions in the perinatal period (P00–P96) and FAS (Q86.0)

Data source	Focus
Literature review: clinic-based and epidemiological studies For example: · Popova et al., 2019a · McLachlan et al., 2019 · MacPherson, Chudley, & Grant, 2011 · Fuchs & Burnside, 2014 · Williams, Odaibo, & McGee, 1999	FASD and PAE prevalence in general population FASD and PAE prevalence in special subpopulations (e.g., individuals who are incarcerated) Comorbidities of individuals with FASD Service utilization of individuals with FASD Cost burden associated with FASD
ALBERTA	
Family Supports for Children with Disabilities (FSCD)	Children with FASD accessing FSCD services, with an open file as of December 2019
Parent Child Assistance Program (PCAP) · Maternal Child Health (MCH) · Provincial Intake Addiction Severity Index	PAE of women accessing the program Alcohol use during pregnancy of women accessing the program: prevalence, severity Confirmed/suspected FASD: chronic medical conditions, comorbidities
Community and Social Services, Government of Alberta FASD Online Reporting System (ORS) · Assessment and diagnostic clinic data from FASD clinics that receive provincial cross-ministry funding and have mandatory reporting requirements	Individuals with FASD at risk for ARND and FASD associated with PAE in 2017–2019 Age and reported geographic location(s)
Government of Alberta — physician claims data	First-time use of PAE ICD-9 code 760.71 by physicians Demographic characteristics of patients wherein PAE code 760.71 was first recorded in a physician visit
Government of Alberta — Alberta Ambulatory Care Classification System and inpatient care databases	Hospital-based care associated with ICD-10 codes Q86.0 and P04.3 Demographic characteristics of patients wherein either code was first recorded in utilization of hospital-based care
Government of Alberta — Notice of Live Births	PAE: use of alcohol by year of childbirth
Alberta Perinatal Health Program	Prevalence of specific alcohol use risk factors
BRITISH COLUMBIA	
Asante Centre	Individuals diagnosed with FASD per year Demographic characteristics of patients Substance use Comorbidities Adverse social outcomes
Sunny Hill Health Centre for Children	Individuals diagnosed with FASD per year Demographic characteristics of patients Prenatal exposures Substance use Physical comorbidities

Data source	Focus
Perinatal Services BC	Alcohol use (including binge drinking) identified as a risk factor among all BC live births and stillbirths Substance use during pregnancy Mental health history and demographics by maternal alcohol use status Neonatal outcomes by maternal alcohol use status Pregnancy complications by maternal alcohol use status
ONTARIO	
Institute for Clinical Evaluative Sciences (ICES) · MOM-BABY dataset (ICES-derived cohort) · Discharge Abstract Database (DAD) · Continuing Care Reporting System (CCRS) · Home Care Database (HCD) · National Ambulatory Care Reporting System (NACRS) · Same Day Surgery (SDS) Database · Ontario Mental Health Reporting System (OMHRS) · Registered Persons Database (RPDB) · Ontario Health Insurance Plan (OHIP) · Office of the Registrar General (ORG) — Vital Statistics	Alcohol-related codes provisioned at time of utilization of hospital-based care during pregnancy or at hospitalization for birth event Health care utilization associated with FAS (P04.3) or prenatal alcohol exposure (P04.3) Health care utilization of adults with FAS Mental health comorbidities of adults with FAS
Better Outcomes Registry Network (BORN) Ontario	PAE prevalence; frequency of alcohol use in pregnancy Confirmed and suspected anomalies of children with PAE Maternal demographics Maternal substance use and mental health history
Ron Joyce Children's Health Centre, Hamilton Health Sciences (HHS)	Child patients diagnosed with FAS/FASD Demographic characteristics Comorbidities Adverse social outcomes
Surrey Place Centre	Effect of FASD diagnosis on health and social outcomes of adult patients
CAMH Monitor	Alcohol use during last pregnancy and while breastfeeding last child Awareness of FASD (men and women) Diagnoses of FAS (self-reported)

Appendix C: Explored SSFASD/PAE Data Sources

Data source	Data on FASD/PAE	Additional information
CROSS-JURISDICTIONAL		
Canadian Congenital Anomalies Surveillance System (pan-Canadian)	All infants diagnosed as having a congenital anomaly within the first year of life	Cannot capture data on FASD
Canadian Perinatal Surveillance System (pan-Canadian)	Determinants and outcomes of maternal, fetal, and infant health	National health surveillance system program
Canadian Maternity Experiences Survey	Experiences with pregnancy, childbirth and the postpartum period	Held once in 2006
National Longitudinal Survey of Children and Youth (pan-Canadian)	Long-term study of children & youth that follows their development and well-being from birth to early adulthood	Survey is inactive; data were not available for collection but some data are summarized in published studies
National Population Health Survey (pan-Canadian)	Prenatal alcohol exposure	Survey is inactive; data were not available for collection but some data are summarized in published studies
Canadian Survey on Disability (previously the Health and Activity Limitations Survey) (pan-Canadian)	Information about Canadians whose everyday activities may be limited because of a condition or health-related problem	Captures neurologic deficits such as deafness and blindness, not specific disabilities such as FASD
Correctional Service Canada (pan-Canadian)	Computerized mental health screening at intake which includes a cognitive impairment component (GAMA); individuals whose IQ score is 69 or below are then identified and flagged for mental health follow-up	CSC does not track cases of individuals living with FASD. On consent, federal inmates complete a computerized mental health screening at intake which includes a cognitive impairment component (GAMA). Data were not available for collection, but published data from CSC reports are summarized.
Canadian Mothercraft Society (pan-Canadian)	FASD	Partnering on a number of national FASD projects, including the Universal Dataform project. Data from the FASD diagnostic clinic ***Breaking the Cycle,*** an early intervention program part of the Society, are captured in the report in the Diagnostic Clinic Survey sections in the SSFASDPAE report, including new diagnoses and diagnostic capacity.
Aboriginal Peoples Survey	National survey on the social and economic conditions of First Nations people living off reserve, Métis people, and Inuit	This survey does not specify disability type and cannot capture FASD specifically
Canadian Primary Care Sentinel Surveillance Network	Multi-disease electronic medical record surveillance system	The project team contacted the epidemiologist to determine if inclusion in SSFASD/PAE is feasible; we offered to develop a case definition, but it was not pursued by the program
Canadian Paediatric Surveillance Program	National surveillance and research into childhood disorders that are high in disability, morbidity, and economic costs to society, despite their low frequency	Data on PAE is not captured. Diagnosed cases of FASD have been requested. Future collaborations and collection of FASD as a new data element will continue to be pursued by the project team.
National Autism Spectrum Disorder Surveillance System Working Group	Case-level information collected on individuals with ASD in Canada	The opportunity to incorporate FASD as a data element was explored during the first SSFASD/PAE Steering Committee meeting, at which point it was deemed not to be feasible

Data source	Data on FASD/PAE	Additional information
National Screening Tool Kit for Children and Youth Identified and Potentially Affected by FASD	Neurobehavioural screening tool Meconium testing for in utero exposure to alcohol Maternal drinking guide Medicine Wheel Student Index FASD Screening and Referral Tool for Youth Probation Officers	The feasibility of ordering data retrieved through the use of the tool kit was discussed with the Steering Committee
ALBERTA		
AB Community and Social Services Data Integration Project	Cross-ministry initiative to collect data and determine services accessed by persons with FASD	The project is in early stages; data collection has been initiated but was not available in time for the report
Alberta Congenital Anomalies Surveillance System	Ongoing collection of data for infants <1 year with congenital anomalies	No data collected on FASD
BRITISH COLUMBIA		
First Nations Health Authority	This health governance structure works in collaboration with B.C. First Nations to provide training on the PCAP model of service delivery to all funded sites	Individual community-based programs funded by FNHA collect data which was not accessible for the purpose of this report
Northern Health Authority	This system collects data on prenatal health interviews	FASD is not designated as a reportable congenital anomaly
MANITOBA		
Manitoba Centre for Health Policy Data Repository	FASD cases in general population and subpopulations	Published data is summarized in the report
NORTHWEST TERRITORIES		
Congenital Anomalies Registry	Prevalence of FAS (since 2011)	Data on FAS was not able to be extracted from the registry for the purpose of this report. Published findings are summarized in the NT chapter.
ONTARIO		
Aboriginal Legal Services	Service utilization of individuals with FASD	Unable to release individual-level or aggregated client information
Newborn Screening Ontario, Children's Hospital of Eastern Ontario	Screens newborn blood spot samples for 29 diseases	Does not screen for PAE/FASD; however, data on alcohol use in pregnancy were obtained from BORN Ontario
Prenatal Screening Ontario	Antenatal and birth outcomes: Down syndrome and trisomy 18	The Better Outcomes Registry & Network (BORN) Ontario and the Provincial Council for Maternal and Child Health (PCMCH), Ministry of Health and Long-Term Care (MOHLTC) announced a Prenatal Screening Program for Ontario in July 2017. The MOHLTC data request form was not required as the data were received through the BORN data request.
Healthiest Babies Possible	Confidential prenatal nutrition program; includes component on drinks to be avoided	HBP asks mothers at risk of poor birth outcomes about their substance use and nutrition during pregnancy. Data collection changes for PAE started in April 2019 and may enable future reporting to the SSFASD/PAE.
YUKON		
Congenital Anomalies Support Yukon	Evaluates rates/trends of congenital anomalies, teratogens, including alcohol	During the data collection period, a Privacy Impact Assessment governed by the Yukon FASD Interagency Committee was reviewing policy changes to allow for better data access for surveillance. This report does not include data collected from this source.

Appendix D: Epidemiological Studies on the Prevalence of Alcohol Use (Any Amount) and Binge Drinking during Pregnancy in Participating P/Ts, 1994–2018

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
General Population								
CROSS-JURISDICTIONAL								
1994–1995	Multi	Retrospective	N/A	Population-based	Survey (NPHS)	Any: 17%-25%	N/A	Dell & Roberts, 2006
						Throughout: 7%-9%		
1994–1995	Multi	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	17.4%	N/A	Health Canada, 2003
				<25 years		14.3%		
				25-29 years		14.1%		
				30-34 years		19.0%		
				≥35 years		24.7%		
1994–1997	Multi	Retrospective (4-5 years postpartum)	6,337	Population-based	Survey (NLSCY)	1,065 (16.8%)	N/A	Weeks et al., 2014
1996–1997	Multi	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	15.6%	N/A	Health Canada, 2003
				<25 years		10.4%		
				25-29 years		14.2%		
				30-34 years		14.6%		
				≥35 years		24.5%		
1998–1999	Multi	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	14.6%	N/A	Health Canada, 2003
				<25 years		14.1%		
				25-29 years		11.5%		
				30-34 years		13.6%		
				≥35 years		21.6%		
1998–1999	Multi	Retrospective	N/A	Population-based	Survey (NLSCY)	Any: 14.4%	N/A	Dell & Garabedian, 2003
						Throughout: 4.9%		
2000–2001	Multi	Retrospective	7,629	Population-based	Survey (CCHS)	12.2%	N/A	PHAC, 2008
2002	Multi	Retrospective	N/A	Population-based (18-44)	Survey (CCHS)	Any: 13.7%	N/A	AADAC, 2004
2003	Multi	Retrospective	7,399	Population-based	Survey (CCHS)	12.4%	N/A	PHAC, 2008

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
2003–2010	Multi	Retrospective (≤5 years postpartum)	18,612	Population-based	Survey (CCHS)	1,791 (9.6%)	N/A	Lange et al., 2015
2005	Multi	Retrospective	7,179	Population-based	Survey (CCHS)	10.5%	N/A	PHAC, 2008
2005–2006	Multi	Retrospective (5-9 months postpartum)	72,767	Population-based	Survey (MES)	Any: 7,799 (10.8%)	N/A	Walker et al., 2011
						Less than once per month: 5,488 (7.6%)		
						Once per month: 1,353 (1.9%)		
						2-3 times per month: 393 (0.5%)		
						Once a week: 474 (0.7%)		
						2-3 times per week: 91 (0.1%)		
						4-6 times per week: 0 (0.0%)		
						Daily: 0 (0.0%)		
2006	Multi	Retrospective (postpartum period)	6,421	Population-based	Survey (MES), phone interview	674 (10.5%)	N/A	Chalmers et al., 2008
2007–2008	Multi	Retrospective	767,479	Population-based (15-55)	Survey (CCHS)	5.8%	N/A	Thanh & Jonsson, 2010
2008–2011	Multi	Delivery	1,315	Community-based (18 and older)	Meconium testing: SPME GC-MS	21 (1.2%) – 32 (2.4%)	N/A	Delano et al., 2019
			N/A		Questionnaire	Less than 2 standard drinks per week: 32%		
						More than 2 standard drinks per week: 0.24%		
ALBERTA								
1994–1995	AB	During pregnancy (FT/ST)	1,991	Hospital-based	Questionnaire	Any: 348 (17.5%)	N/A	Wenman et al., 2002
						Weekly: 59 (3%)		
						Monthly: 122 (6.1%)		
						Less than once per month: 175 (8.8%)		
1994–1996	AB	Retrospective	106,306	Population-based	Medical charts/ records	7,970 (7.5%)	N/A	Tough et al., 2001

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
1995–1998	AB	Retrospective (time of delivery)	55,542	Population-based	Medical charts/ records	1,104 (2.0%)	N/A	Xiong et al., 2000
2001–2004	AB	During pregnancy (FT)	1,929	Hospital-based	T-ACE	430 (22.3%)	N/A	Hicks et al., 2014
		During pregnancy (ST)				74 (3.8%)	64 (3.3%)	
		During pregnancy (TT)				110 (5.7%)	N/A	
2001–2005	AB	Retrospective	191,686	Hospital-based	Medical charts/ records	3,768 (2.0%)	N/A	Burstyn, Kapur, & Cherry, 2010
2002	AB	Retrospective	N/A	Population-based (18-44)	Population-based survey (CCHS)	Any: 9.2%	N/A	AADAC, 2004
2002–2003	AB (urban)	Retrospective (3 months postpartum)	1,042	Population-based (primiparous only)	Telephone interviews, survey	Pre-pregnancy recognition: 520 (49.9%)	Pre-pregnancy recognition: 112 (10.7%)	Tough et al., 2006
						Post pregnancy recognition: 190 (18%)	Post-pregnancy recognition: 0 (0%)	

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
2008	AB	During pregnancy (34-36 weeks gestation)	All: 2,246	Community-based (all ages)	Questionnaires	Any amount prior to pregnancy recognition: 49%	Prior to pregnancy recognition: 13%; following recognition: 0 (0%)	McDonald et al., 2014
			127	Community-based: <25 years		0-1 drinks per occasion less than once a week or 2 drinks per occasion less than 3 times per week: 79 (68.1%)	Prior to pregnancy recognition: 35 (29.4%)	
			1,607	Community-based: 25-34 years		0-1 drinks per occasion less than once a week or 2 drinks per occasion less than 3 times per week: 820 (56.4%)	Prior to pregnancy recognition: 188 (12.4%)	
			512	Community-based: ≥35 years		0-1 drinks per occasion less than once a week or 2 drinks per occasion less than 3 times per week 269 (59.1%)	Prior to pregnancy recognition: 42 (8.9%)	
2008–2011	AB	Pregnancy (34-36 weeks)	1,663	Community-based	Surveys	N/A	166 (10.0%)	Currie et al., 2020
BRITISH COLUMBIA								
1994–1995	BC	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	15.9%	N/A	Health Canada, 2003
1996–1997	BC	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	12.7%	N/A	Health Canada, 2003
1998–1999	BC	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	9.2%	N/A	Health Canada, 2003
2000–2001	BC	Pregnancy	40,517 births in the fiscal year	Hospital-based: (all ages)	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.3%	N/A	BC Perinatal Health Program, 2008
2000–2001	BC: Vancouver Island Health Authority	Pregnancy	N/A	Hospital-based (all ages)	Medical records (BCPDR)	Alcohol use identified as a risk factor: 2.5%	N/A	BC Perinatal Health Program, 2008

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
2000–2001	BC: Vancouver Coastal Health Authority	Pregnancy	N/A	Hospital-based (all ages)	Medical records (BCPDR)	Alcohol use identified as a risk factor: 0.4%	N/A	BC Perinatal Health Program, 2008
2002	BC	Retrospective	N/A	Population-based (18-44)	Survey (CCHS)	11.6%	N/A	AADAC, 2004
2003–2008	BC	Retrospective	5,031	Hospital-based	Medical charts/ records	28 (0.6%)	N/A	Stoll et al., 2014
2004–2005	BC	Pregnancy	2,041	Population-based	Medical charts/ records	143 (7%)	Concern identified (binge drinking): 4%	BC Stats, 2010
2005–2006	BC (Western BC)	Retrospective (5-9 months postpartum)	704	Population-based	Questionnaire	55 (7.8%)	N/A	Walker et al., 2011
2006–2007	BC	Pregnancy	2,316	Population-based	Medical charts/ records	162 (7%)	Concern identified (binge drinking): 93 (4%)	BC Stats, 2010
2007–2008	BC	Pregnancy	44,196 births in the fiscal year	Hospital-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 0.9%	N/A	BC Perinatal Health Program, 2008
2007–2008	BC	Pregnancy	44,196 (total births)	<15	Medical records (alcohol use identified as a risk factor)	8.3%	N/A	BC Perinatal Health Program, 2008
				15-17		4.4%		
				18-19		3.2%		
				20-24		2.1%		
				25-29		0.8%		
				30-34		0.4%		
				35-39		0.6%		
				≥40		0.8%		
2007–2008	BC	Retrospective	N/A	Population-based (15-55)	Survey (CCHS)	7.2%	N/A	Thanh & Jonsson, 2010
2007–2008	BC	Retrospective	143,975	Population-based (20-49)	Survey (CCHS)	Any: 10,365 (7.2%)	N/A	Krueger & Associates, 2014
			16,483	20-24		Any: 1,446 (8.8%)		
			16,483	20-24		Daily: 810 (4.9%)		
			33,820	25-29		Any: 1,830 (5.4%)		
			41,170	30-34		Any: 2,150 (5.2%)		
			36,804	35-39		Any: 3,690 (10%)		
			12,335	40-44		Any: 428 (3.5%)		
			3,363	45-49		Any: 821 (24.4%)		
2008–2009	BC	Retrospective	N/A	Population-based	Survey (HCIP)	7%	N/A	BC Stats, 2010

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
2012	BC	During pregnancy	98	Population-based	AUDIT	11 (11.2%)	N/A	Caldeira & Woodin, 2012
2012–2013	BC	During pregnancy	43,853 total births	Population-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.2%	N/A	Perinatal Services BC, 2018
2013–2014	BC	During pregnancy	43,146 total births	Population-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.1%	N/A	Perinatal Services BC, 2018
2014–2015	BC	During pregnancy	43,805 total births	Population-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.2%	N/A	Perinatal Services BC, 2018
2015–2016	BC	During pregnancy	43,989 total births	Population-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.1%	N/A	Perinatal Services BC, 2018
2016–2017	BC	During pregnancy	44,591 total births	Population-based	Medical records (BCPDR)	Alcohol use identified as a risk factor: 1.3%	N/A	Perinatal Services BC, 2018
MANITOBA								
2003	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	13.3%	N/A	Healthy Child Manitoba Office, 2016
2004	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	12.3%	N/A	Healthy Child Manitoba Office, 2016
2005	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	13.1%	N/A	Healthy Child Manitoba Office, 2016
2006	MB	Retrospective (postpartum)	12,100	Population-based	Medical records: Families First screening form	12.7%	N/A	Healthy Child Manitoba, 2008; Healthy Child Manitoba Office, 2016
2007	MB	Retrospective (postpartum)	12,637	Population-based	Medical records: Families First screening form	16.1%	N/A	Healthy Child Manitoba 2009 Office; Healthy Child Manitoba Office, 2016
2008	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	13.7%	N/A	Healthy Child Manitoba Office, 2016
2009	MB	Retrospective (postpartum)	11,943	Population-based	Medical records: Families First screening form	13.0%	N/A	Healthy Child Manitoba, 2010 Office; Healthy Child Manitoba Office, 2016
2010	MB	Retrospective (postpartum)	12,920	Population-based	Medical records: Families First screening form	13.9%	N/A	Healthy Child Manitoba Office, 2016
2011	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	13.8%	N/A	Healthy Child Manitoba Office, 2016

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
2012	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	12.9%	N/A	Healthy Child Manitoba Office, 2016
2013	MB	Retrospective (postpartum)	N/A	Population-based	Medical records: Families First screening form	11.7%	N/A	Healthy Child Manitoba Office, 2016
2015	MB	Retrospective (postpartum)	15,000 (approx.)	Population-based	Medical records: Families First screening form	10%	N/A	Healthy Child Manitoba, 2017
ONTARIO								
1992–1993	ON	During pregnancy (ST & TT)	466	Hospital-based	Questionnaire	68 (14.6%)	N/A	Stewart & Streiner, 1994
1993–1994	ON	Pregnancy	19,991	Community-based: women who received counselling via hotline regarding various teratogenic, infectious and/or chemical prenatal exposures	Telephone interviews	N/A	153 (0.8%)	Gladstone et al., 1997
1994–1995	ON	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	14.5%	N/A	Health Canada, 2003
1996–1997	ON	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	12.8%	N/A	Health Canada, 2003
1998–1999	ON	Retrospective	N/A	Population-based: all ages	Survey (NLSCY)	13.6%	N/A	Health Canada, 2003
2004–2005	ON	Delivery	682	Hospital-based	Meconium testing	17 (2.5%)	N/A	Gareri et al., 2008
		Retrospective (postpartum)	1,019		Questionnaire (HBHC)	5 (0.5%)		
2007–2008	ON	Retrospective	N/A	Population-based (15-55)	Survey (CCHS)	5.4%	N/A	Thanh & Jonsson, 2010
2012–2014	ON	Pregnancy	N/A	Population-based	Medical records in birth registry	1.8%	N/A	BORN Ontario, 2015
Special subpopulations								
WOMEN LIVING IN SMALL, RURAL, AND REMOTE COMMUNITIES — CROSS-JURISDICTIONAL								
2015–2016	Multi	Retrospective	N/A	Population-based (on reserve)	Population-based survey (RHS)	7%	N/A	FNIGC, 2018

Study years	P/T	Timing of data collection	Sample size	Setting	Instrument used to obtain data	Prevalence of alcohol use, n (%)	Prevalence of binge drinking, n (%)	Source
WOMEN LIVING IN SMALL, RURAL, AND REMOTE COMMUNITIES — REGIONAL								
1989	AB	Retrospective	173	Community-based	Questionnaire	Before pregnancy confirmation: 120 (69.8%) After pregnancy confirmation: 84 (48.8%)	N/A	Dow-Clarke, MacCalder, & Hessel, 1994
1998–2004	BC	Pregnancy	All	Women living on reserve Women living off reserve	Medical records (BCPDR)	4.8% 5.7%	N/A	BC Provincial Health Officer, 2009
1994	MB	Retrospective	745	Hospital-based	Medical charts/ records	196 (26.3%)	N/A	Williams, Odaibo, & McGee, 1999
1994–1995	MB	Retrospective	242	Population-based	Questionnaire	123 (50.8%)	N/A	Williams & Gloster, 1999
1987–1990	NT	N/A	145	Hospital-based	Questionnaire	50 (34.5%)	18 (12.4%)	Godel et al., 1992
2000	NT	Retrospective (6-11 years postpartum)	70	School-based	Questionnaire	17 (24.3%)	N/A	Godel et al., 2000
2009–2010	ON	Retrospective	458	Hospital-based	Medical charts/ records	116 (25.3%)	N/A	Kelly et al., 2011
WOMEN WITH HIGH-RISK PREGNANCIES								
1985–1994	ON	Pregnancy	3,800	Community-based: women receiving in-person counselling regarding various teratogenic, infectious and/or chemical prenatal exposures	Medical records (outpatient)	N/A	119, (3.1%)	Gladstone et al., 1997
2006–2007	ON (Grey Bruce)	Retrospective: following delivery	50	Hospital-based: high-risk obstetrics unit	Meconium fatty acid ethyl esters analysis Questionnaire	15 (30%) 1 (2%)	N/A	Goh et al., 2010

Abbreviations: FT, first trimester; N/A, not available; ST, second trimester; TT, third trimester; SPME GC-MS, solid-phase micro-extraction coupled with gas chromatography-mass spectrometry; CCHS, Canadian Community Health Survey; NPHS, National Population Health Survey; NLSCY, National Longitudinal Survey of Children and Youth; HBHC, Healthy Babies Healthy Children; BCPDR, British Columbia Perinatal Data Registry; RHS, Regional Health Survey; HCIP: Healthy Choices in Pregnancy.

Appendix E: Epidemiological Studies on the Prevalence of FAS and FASD in Participating P/Ts, 1985–2020

Study years	P/T	Sample size	FAS cases	Prevalence of FAS, per 1,000 (%)	FASD cases	Prevalence of FASD, per 1,000 (%)	Diagnostic guidelines / case definition	Age range (years)	Sex (% male)	Method and source
General population										
CROSS-JURISDICTIONAL										
2010–2015	Multi	603,904	N/A	N/A	658	1.1 (0.11)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	65.65%	PS: Canadian Children's Health in Context Study (Pei et al., 2020)
ALBERTA										
2012	AB	N/A	N/A	N/A	45,984	11.7 (1.17)	FAS: ICD-9 code 760.71; ICD-10 codes Q86.0, P04.3; 21 FASD-related conditions with ICD-10 codes	All ages	N/A	PS: Prevalence estimates from provincial administrative health databases (Thanh et al., 2014)
	AB	N/A	N/A	N/A	16,666	32.7 (3.27)		0-9	N/A	
	AB	N/A	N/A	N/A	13,427	28.1 (2.81)		10-19	N/A	
	AB	N/A	N/A	N/A	5,296	8.8 (0.88)		20-29	N/A	
	AB	N/A	N/A	N/A	2,534	4.2 (0.42)		30-39	N/A	
	AB	N/A	N/A	N/A	2,207	3.9 (0.39)		40-49	N/A	
	AB	N/A	N/A	N/A	5,852	4.9 (0.49)		50+	N/A	
2010–2015	AB	N/A	N/A	N/A	81	1.1 (0.11)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study (Pei et al., 2020)
BRITISH COLUMBIA										
1995	BC (South Fraser Health Service Delivery Area)	N/A	N/A	N/A	12	N/A	ICD-9 and ICD-10 codes	N/A	N/A	PS: Estimates from BC Vital Statistics (Robinson et al., 2003)
1996		N/A	N/A	N/A	21	N/A		N/A	N/A	
1997		N/A	N/A	N/A	23	N/A		N/A	N/A	
1998		N/A	N/A	N/A	33	N/A		N/A	N/A	
1999		N/A	N/A	N/A	178	N/A		N/A	N/A	
2000		N/A	N/A	N/A	135	N/A		N/A	N/A	
1986	BC	823,031	104	0.12 (0.01)	N/A	N/A	Algorithm developed by Lin et al. (2013) to identify children with developmental disabilities. ICD-9 or ICD-10 codes in hospital separation data between 1985 and 2014.	0-19	(56.8%)	PS: Prevalence estimates using administrative health data from Population Data BC (Marquis et al., 2018)
1987	BC	828,773	132	0.16 (0.02)	N/A	N/A				
1988	BC	842,206	170	0.20 (0.02)	N/A	N/A				
1989	BC	858,240	225	0.26 (0.03)	N/A	N/A				
1990	BC	878,769	285	0.32 (0.03)	N/A	N/A				
1991	BC	892,328	345	0.39 (0.04)	N/A	N/A				
1992	BC	915,654	425	0.46 (0.05)	N/A	N/A				
1993	BC	938,321	502	0.53 (0.05)	N/A	N/A				
1994	BC	963,490	583	0.61 (0.06)	N/A	N/A				
1995	BC	984,505	685	0.70 (0.07)	N/A	N/A				

Study years	P/T	Sample size	FAS cases	Prevalence of FAS, per 1,000 (%)	FASD cases	Prevalence of FASD, per 1,000 (%)	Diagnostic guidelines / case definition	Age range (years)	Sex (% male)	Method and source
1996	BC	1,004,230	756	0.75 (0.08)	N/A	N/A				
1997	BC	1,016,272	829	0.82 (0.08)	N/A	N/A				
1998	BC	1,016,791	902	0.89 (0.09)	N/A	N/A				
1999	BC	1,012,793	965	0.95 (0.10)	N/A	N/A				
2000	BC	1,008,481	1,054	1.05 (0.11)	N/A	N/A				
2001	BC	1,005,216	1,161	1.15 (0.12)	N/A	N/A				
2002	BC	994,836	1,241	1.24 (0.12)	N/A	N/A				
2003	BC	984,133	1,314	1.34 (0.13)	N/A	N/A				
2004	BC	976,030	1,394	1.43 (0.14)	N/A	N/A				
2005	BC	971,449	1,475	1.52 (0.15)	N/A	N/A				
2006	BC	970,121	1,552	1.60 (0.16)	N/A	N/A				
2007	BC	968,341	1,608	1.66 (0.17)	N/A	N/A				
2008	BC	967,538	1,631	1.69 (0.17)	N/A	N/A				
2009	BC	966,920	1,662	1.72 (0.17)	N/A	N/A				
2010	BC	966,860	1,672	1.73 (0.17)	N/A	N/A				
2011	BC	966,255	1,669	1.73 (0.17)	N/A	N/A				
2012	BC	963,780	1,696	1.76 (0.18)	N/A	N/A				
2013	BC	960,083	1,684	1.75 (0.18)	N/A	N/A				
2010–2015	BC	N/A	N/A	N/A	242	2.7 (0.27)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study (Pei et al., 2020)
MANITOBA										
1998–2003	MB	1,152,281	279	0.2 (0.02)	N/A	N/A	ICD-9 code 760 (FAS)	0-34	N/A	PS: Prevalence estimates from administrative health databases (Ouellette-Kuntz et al., 2009)
2000–2005	MB	322,564 (2000)	N/A	2.0 (0.20)	N/A	N/A	Chudley et al., 2005 diagnostic guidelines	0-19	N/A	ACA: clinic-based study at FASD diagnostic centre (Brownell et al., 2012)
2006–2010	MB	322,447 (2009)	N/A	2.2 (0.22)	N/A	N/A			N/A	
2010–2015	MB	N/A	N/A	N/A	122	3.0 (0.30)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study, (Pei et al., 2020)
NORTHWEST TERRITORIES										
2010–2015	NT	N/A	N/A	N/A	3	1.2 (0.12)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study (Pei et al., 2020)

Study years	P/T	Sample size	FAS cases	Prevalence of FAS, per 1,000 (%)	FASD cases	Prevalence of FASD, per 1,000 (%)	Diagnostic guidelines / case definition	Age range (years)	Sex (% male)	Method and source
ONTARIO										
2010–2015	ON	N/A	N/A	N/A	127	0.5 (0.05)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study (Pei et al., 2020)
2014–2017	ON	2,555	3	1.2 (0.12)	18	18.1-29.3 (1.8-2.9)	Chudley et al., 2005 diagnostic guidelines	6.4-10.8	48.3%	ACA (Popova et al., 2019a)
YUKON										
2010–2015	YT	N/A	N/A	N/A	3	2.0 (0.2)	FASD diagnosis by a physician or psychologist, reported by teacher in EDI	4-6	N/A	PS: Canadian Children's Health in Context Study (Pei et al., 2020)
Special subpopulations										
Individuals living in small, rural, and remote communities — cross-jurisdictional										
1983–1984	Multi (BC & YT)	5,065	N/A	N/A	166	32.77 (3.28)	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980)	0-16	63.0%	ACA in children and youth with disabilities (Asante & Nelms-Matzke, 1985)
2002–2003	Multi	N/A	N/A	N/A	N/A	18 (1.8)	Guardian-reported diagnosis of child	0-11	N/A	PS: Survey (FNIGC Committee, 2005)
2006	Multi	11,868	N/A	N/A	83	7.0 (0.70)	Guardian-reported FASD diagnosis	0-5	N/A	PS: Survey (Werk, Cui, & Tough, 2013)
2008–2010	Multi	N/A	N/A	N/A	N/A	9.0 (0.9)	Guardian-reported FASD diagnosis	0-11	N/A	PS: Survey (FNIGC, 2012)
						8.0 (0.8)	Self-reported diagnosis (youth)	12-17		
2015–2016	Multi	N/A	N/A	N/A	N/A	5.0 (0.5)	Guardian-reported FASD diagnosis	0-11	N/A	PS: Survey (FNIGC, 2018)
						5.0 (0.5)	Self-reported diagnosis (youth)	12-17		
Individuals living in small, rural, and remote communities — regional										
ALBERTA										
2006	AB	N/A	N/A	N/A	N/A	13 (1.30)	Guardian-reported FASD diagnosis	0-5	N/A	PS: Survey (Werk, Cui, & Tough, 2013)
BRITISH COLUMBIA										
1984–1985	BC	116	14	120.69 (12.07)	22	189.66 (18.97)	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980)	3-18	49.6%	ACA (Robinson, Conry, & Conry, 1987)
2006	BC	N/A	N/A	N/A	N/A	9.0 (0.90)	Guardian-reported FASD diagnosis	0-5	N/A	PS: Survey (Werk, Cui, & Tough, 2013)

Study years	P/T	Sample size	FAS cases	Prevalence of FAS, per 1,000 (%)	FASD cases	Prevalence of FASD, per 1,000 (%)	Diagnostic guidelines / case definition	Age range (years)	Sex (% male)	Method and source
MANITOBA										
1981–1990	MB	178	11	61.80 (6.18)	19	101.12 (10.11)	IOM criteria (Stratton, Howe, & Battaglia, 1996)	5-15	N/A	ACA (Kowlessar, 1997)
1994–1996	MB	696	5	7.18 (0.72)	N/A	N/A	IOM criteria (Stratton, Howe, & Battaglia, 1996)	2	N/A	Mixed: ACA & PS (Williams, Odaibo, & McGee, 1999)
2006	MB	N/A	N/A	N/A	N/A	13 (1.30)	Guardian-reported FASD diagnosis	0-5	N/A	PS: Survey (Werk, Cui, & Tough, 2013)
ONTARIO										
2002–2012	ON (Toronto)	80	N/A	N/A	49	612.5 (61.25)	Chudley et al., 2005 diagnostic guidelines	<18	N/A	ACA: clinic-based study at diagnostic centre (Banerji & Shah, 2017)
Children in care — cross-jurisdictional										
2010–2014	Multi (AB, MB, ON)	15,623	N/A	N/A	1,776	113.7 (11.37)	Physician assessment, FASD clinic assessment (diagnosed & suspected)	0-21	51.3%	PS (Fuchs & Burnside, 2014)
	AB	6,767	N/A	N/A	699	103.29 (10.33)		0-21	52.3%	
	MB	8,323	N/A	N/A	1,021	122.67 (12.26)		0-21	50.1%	
	ON	533	N/A	N/A	56	105.07 (10.51)		0-21	57.8%	
Children in care — regional										
2004–2005	MB	5,664	N/A	N/A	640	113.0 (11.30)	N/A	0-21	N/A	PS (Fuchs et al., 2005)
2003	ON	429	N/A	N/A	14	32.6 (3.26)	N/A	0-18	56.9%	PS (Burge, 2007)
Individuals who are incarcerated — cross-jurisdictional										
1995–1996	Multi (BC, YT)	287	3	10.45 (1.05)	64	233.5 (23.35)	Inpatient assessment	12-18	N/A	Clinic-based (Fast, Conry, & Loock, 1999)
2001–2002	Multi	148,797	13	0.1 (0.01)	N/A	N/A	N/A	N/A	91.2%	PS: Survey (Burd et al., 2003)
2011–2012	Multi (federal institution)	23	N/A	N/A	4	174 (17.4)	Brief Screen Checklist for Women (BSC-W); Chudley et al., 2005 diagnostic guidelines	28 (mean age)	0 (all female)	ACA (Forrester et al., 2015)
Individuals who are incarcerated — regional										
1985–2004	BC	230	N/A	N/A	25	108.7 (10.87)	Case definition provided (based on Boland et al. 2000)	12-18	100%	PS (Rojas & Gretton, 2007)

Study years	P/T	Sample size	FAS cases	Prevalence of FAS, per 1,000 (%)	FASD cases	Prevalence of FASD, per 1,000 (%)	Diagnostic guidelines / case definition	Age range (years)	Sex (% male)	Method and source
2004	BC	137	N/A	N/A	16	116.8 (11.68)	Youth reported diagnosis	14-19	89.8%	PS (Murphy, Chittenden, & McCreary Centre Society, 2005)
2005–2006	MB	91	N/A	N/A	9	98.9 (9.89)	Chudley et al., 2005 diagnostic guidelines	19-30	100.0%	Mixed methods: ACA & PS-interview (MacPherson, Chudley, & Grant, 2011)
2014–2015	YT	80	0	0.0	14	175 (17.5)	Chudley et al., 2005 diagnostic guidelines	18-40	N/A	ACA (McLachlan et al., 2019)

Abbreviations: ACA, active case ascertainment; FAS, fetal alcohol syndrome; FASD, fetal alcohol spectrum disorder; MSP, medical services plan; N/A, not available; PS, passive surveillance; RSA, Research Society on Alcoholism

Appendix F: Measures and Definitions of Outcome and Predictor Variables in CCHS Data

CCHS variable	Ascertained by asking participants	Outcome measure for this study
Pregnancy status		
Pregnancy	Are you pregnant?	Women who were pregnant while completing the CCHS (2018)
Pregnancy (2012–2018)	Have you given birth in the past 5 years?	Women who were pregnant 2012–2018
Pregnancy (2009–2011)	What is your last child's date of birth? (minimum value 2010–2011)	Women who were pregnant 2009–2011
Pregnancy (2009–2018)	What is your last child's date of birth? (minimum value 2010–2018)	Women who were pregnant 2009–2018
Breastfeeding status		
Breastfeeding	Are you still breastfeeding or giving breast milk to [your last child]?	Women who were breastfeeding while completing the CCHS (2018)
Breastfeeding (2013–2018)	Have you given birth in the past 5 years? Was [your last child] breastfed or given breast milk even for a short time?	Women who were breastfeeding 2013–2018
Breastfeeding (2010–2018)	What is your last child's date of birth? (minimum value 2010–2018) Was [your last child] breastfed or given breast milk even for a short time?	Women who were breastfeeding 2010–2018
PAE		
PAE, pregnant while completing CCHS	Thinking back over the past week, that is, from last [day last week] to yesterday, did you have a drink of beer, wine, liquor, or any other alcoholic beverage?	PAE 2018
PAE frequency, pregnant while completing CCHS	During the last week, day 1-7, how many drinks did you have? (participants report amount of drinks per day)	PAE frequency 2018
PAE, last pregnancy	Did you drink any alcohol in the last 3 months of pregnancy?	PAE 2009–2018
PAE frequency, last pregnancy	Drank alcohol 3 months before last pregnancy or before pregnancy recognition: · Drank alcohol after finding out about pregnancy: · Drank alcohol last 3 months of pregnancy: How often did you drink? 1: Less than once per month 2: Once per month 3: 2 to 3 times per month 4: Once a week 5: 2 to 3 times per week 6: 4 to 6 times per week 7: Every day	PAE frequency 2009–2018
Postnatal alcohol exposure		
Alcohol use while breast-feeding, breastfeeding while completing CCHS	Thinking back over the past week, that is, from last [day last week] to yesterday, did you have a drink of beer, wine, liquor, or any other alcoholic beverage?	Postnatal alcohol exposure 2018
Alcohol use while breast-feeding frequency, breast-feeding while completing CCHS	During the last week, day 1-7, how many drinks did you have? (participants report amount of drinks per day)	Postnatal alcohol exposure frequency 2018

CCHS variable	Ascertained by asking participants	Outcome measure for this study
Alcohol use while breast-feeding, last baby	While you were breastfeeding [your last baby], did you drink any alcohol?	Postnatal alcohol exposure 2009–2018
Alcohol use while breastfeeding, last baby frequency	While you were breastfeeding [your last baby], how often did you drink? 1: Less than once per month 2: Once per month 3: 2 to 3 times per month 4: Once a week 5: 2 to 3 times per week 6: 4 to 6 times per week 7: Every day	Postnatal alcohol exposure frequency 2009–2018
Prenatal cigarette smoking exposure		
Smoking cigarettes during pregnancy, pregnant while completing the CCHS	In the past 30 days, did you smoke any cigarettes?	Prenatal cigarette smoking 2018
Postnatal cigarette smoking exposure		
Smoking cigarettes while breastfeeding, pregnant while completing the CCHS	At the present time, do you smoke cigarettes every day, occasionally or not at all?	Postnatal cigarette smoking exposure 2018
Smoking cigarettes while breastfeeding frequency, pregnant while completing the CCHS	During the past 30 days, did you smoke every day? How many cigarettes do you smoke each day now? On the days that you do smoke, how many cigarettes do you usually smoke?	Postnatal cigarette smoking exposure frequency 2018
Independent variables analyzed as potential risk and protective factors		
Socio-demographic factors	**Country of birth grouped** · Canada · Other — North America · South America, Central America, and Caribbean · Europe · Africa · Asia · Oceania · Antarctica and Adjacent Islands **Indigenous** · Aboriginal identity (First Nations, Métis, Inuit) · Non-Aboriginal identity **Top ten cultural/racial background specifications**	Cultural identity/ethnicity
	Immigrant flag · The respondent is a landed immigrant · The respondent is a non-immigrant (Canadian born) · The respondent is a non-permanent resident	Immigrant status
	Age (pertinent to women who were pregnant while completing the survey)	Age groups

CCHS variable	Ascertained by asking participants		Outcome measure for this study
	Marital status		Marital status, classified into the following categories: married or living as a couple; divorced, separated, or widowed; single; living with parents; living with others
Socio-economic factors	**Working status last week** · Worked at a job or business · Had a job but did not work (absent) · Did not have a job		Employment
	Highest level of education		Less than secondary school graduation Secondary school graduation, no post-secondary education Post-secondary certificate/diploma or university degree)
	Total household income before taxes No income or income loss Less than $5,000 $5,000 to $9,999 $10,000 to $14,999 $15,000 to $19,999 $20,000 to $29,999 $30,000 to $39,999 $40,000 to $49,999 $50,000 to $59,999 $60,000 to $69,999 $70,000 to $79,999 $80,000 to $89,999 $90,000 to $99,999 $100,000 to $149,999 $150,000 or more		Household income from the last 12 months was classified into four categories: <20,000, 20,000-59,999, 60,000-79,999, ≥80,000
	Food security: adult status **Food security: child status** **Household food security status**	· Food secure · Moderately food insecure · Severely food insecure	Food insecurity was grouped based on age and household
	· Rural area · Small population centre · Medium population centre · Large urban population centre		Population centre or rural area classification
	Household type: **Parental:** father/mother; birth father/mother; stepfather/mother; adoptive father/mother **Child:** son/daughter; birth child; step child; adopted child **Spouse:** husband/wife; common law; partner		Household type was classified into three categories: couples with children; female lone parent with children under 25; other household types

CCHS variable	Ascertained by asking participants	Outcome measure for this study
	Unattached, living alone. **Unattached individual living with others;** Selected respondent lives with others. They cannot have a marital/common-law or parental relationship with another household member but other relationships such as siblings are allowed. **Couple with children less than 25.** Married or C/L couple with at least one partner being the parent of at least one child less than 25 years old in the household. No other relationships in the household are permitted **Couple with children less than 25, others.** Married or C/L couple with at least one partner being the parent of at least one child less than 25 years old in the household. Other relationships in the household are permitted. **Couple with all children aged 25 or older.** Married or C/L couple with all children in the household aged 25 or older. No other relationships in the household are permitted **Couple with all children aged 25 or older, others.** Married or C/L couple with all children in the household aged 25 or older. Other relationships in the household are permitted The following four categories were compiled to "**lone parent**": 1. Female lone parent with children less than 25. At least one child in the household must be less than 25 years old. No other relationships in the household are permitted 2. Female lone parent with children less than 25, others. At least one child in the household must be less than 25 years old. Other relationships in the household are permitted 3. Female lone parent with all children aged 25 or older. All children in the household must be aged 25 or older. No other relationships in the household are permitted 4. Female lone parent with all children aged 25 or older, others. All children in the household must be aged 25 or older. Other relationships in the household are permitted (y/n)	
Mental health	**Life satisfaction** · Very satisfied · Satisfied · Neither satisfied nor dissatisfied · Dissatisfied · Very Dissatisfied	Self-perceived life satisfaction
	Self-perceived mental health In general, would you say your mental health is excellent, very good, good, fair, or poor?	
	Depression scale (t-score) Depression scale: severity of depression · No depression · Minimal depression · Mild depression · Moderate depression · Moderately severe depression · Severe depression	

CCHS variable	Ascertained by asking participants	Outcome measure for this study
	Drug use	
DRUG USE	**Alcohol, tobacco, marijuana and illicit drug use lifetime and past 12 months** Alcohol use: type of drinker, past 12 months · Regular drinker · Occasional drinker · Did not drink in the last 12 months Alcohol use during the past week · Weekly consumption · Has not had a drink in past week **Number of drinks consumed in past week** · Average daily alcohol consumption Binge drinking behaviour in the 12 months prior to the interview · 4 or more drinks per single occasion; used as a proxy to identify at-risk drinkers Increased long-term risk due to drinking · Increased long-term health risk due to drinking · No increased long-term health risk due to drinking Increased short-term risks due to drinking · Increased short-term health risks due to drinking · No increased short-term risk due to drinking	

Source: CCHS, Statistics Canada

Appendix G: Socio-demographic Characteristics of Women during Their Last Pregnancy (N = 72,500) by Self-Reported Alcohol Use after Pregnancy Recognition, 2012–2018

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Age at time of last child birth (years)								
15-24	F	F	N/A	N/A	91,400	98.2	96.8	99.6
25-29	6,700E	2.3E	1.2	3.5	283,700	97.7	96.5	98.8
30-34	29,900	5	3.7	6.3	566,600	95	93.7	96.3
35-55	34,000E	4.9E	3.3	6.5	660,600	95.1	93.5	96.7
Income ($)								
<20,000	4,200E	2.8E	1.3	4.3	145,600	97.2	95.7	98.7
20,000-59,999	12,100E	3.1E	1.7	4.5	378,900	96.9	95.5	98.3
60,000-79,999	7,600E	3.6E	1.5	5.7	203,100	96.4	94.3	98.5
≥80,000	48,400	5.2	4	6.5	874,500	94.8	93.5	96
Highest level of education								
Less than secondary school graduation	F	F	N/A	N/A	93,200	96.8	94.3	99.2
Secondary school graduation	6,300E	2.3E	0.9	3.6	269,700	97.7	96.4	99.1
Post-secondary certificate, diploma or university degree	62,500	4.8	3.8	5.9	1,229,200	95.2	94.1	96.2
Location of residence (population centre)								
Rural area	13,300E	4.9E	3.2	6.6	258,700	95.1	93.4	96.8
Small centre	6,600E	3.2E	1.8	4.7	196,300	96.8	95.3	98.2
Medium centre	6,100E	3.9E	1.9	5.9	151,300	96.1	94.1	98.1
Large centre	46,400	4.4	3.2	5.7	995,800	95.6	94.3	96.8
Household family type								
Couples with children	63,000	4.5	3.5	5.4	1,347,700	95.5	94.6	96.5
Female lone parent with children under 25	6,600E	3.3E	1.4	5.2	193,300	96.7	94.8	98.6
Other household types	F	F	F	N/A	61,200	95.6	91.2	100.1
Marital status								
Married/common-law	64,500	4.4	3.5	5.4	1,392,100	95.6	94.6	96.5
Other	7,900E	3.6E	1.6	5.6	209,500	96.4	94.4	98.4
Perceived health								
Fair or poor	F	F	N/A	N/A	102,800	99.5	98.9	100
Good	18,800E	4.5E	3	6	397,200	95.5	94	97
Very good or excellent	53,000	4.6	3.5	5.7	1,102,000	95.4	94.3	96.5
Employment — last week								
Worked at a job / business	40,400	4.8	3.6	6	801,400	95.2	94	96.4
Absent from work	17,600E	6.7E	3.9	9.6	244,300	93.3	90.4	96.1
Did not have a job	13,200E	2.4E	1.5	3.3	533,900	97.6	96.7	98.5

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Country/continent of birth								
Canada	56,700	5.2	4.1	6.2	N/A	N/A	N/A	N/A
Europe	6,200E	9E	3.8	14.3	N/A	N/A	N/A	N/A
Asia	F	F	N/A	N/A	N/A	N/A	N/A	N/A
Oceania or other	F	F	N/A	N/A	N/A	N/A	N/A	N/A
Indigenous identity								
Indigenous	F	F	N/A	N/A	88,100	97.8	95.6	100
Non-Indigenous	56,400	5.5	4.3	6.7	974,000	94.5	93.3	95.7
Minority visibility								
Visible minority	800E	1.7E	0.7	2.6	512,100	98.3	97.4	99.3
Non–visible minority	60,500	5.9	4.6	7.1	972,300	94.1	92.9	95.4
Immigrant status								
Immigrant or non-permanent resident	14,500E	2.7E	1.4	3.9	533,000	97.3	96.1	98.6
Non-immigrant (Canadian born)	56,700	5.2	4.1	6.2	1,044,100	94.8	93.8	95.9
Food security — household scale								
Food secure (includes marginal insecurity)	66,000	4.6	3.7	5.6	1,352,800	95.4	94.4	96.3
Moderately or severely food insecure	5,300E	2.5E	0.9	4	209,700	97.5	96	99.1

Source: CCHS
* Sample size is estimated using population weights
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%; F represents too unreliable to be published; N/A represents data not available

Appendix H: Socio-demographic Characteristics of Women in the Third Trimester of Their Last Pregnancy (N = 47,500) by Self-Reported Alcohol Use Status, 2012–2018

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Age at time of last child birth (years)								
15-24	F	F	N/A	N/A	180,300	99.6	99.1	100.1
25-29	6,800E	1.7E	0.8	2.5	399,200	98.3	97.5	99.2
30-34	28,100E	4.4E	3	5.7	615,800	95.6	94.3	97
35-55	10,500E	2.6E	1	4.2	389,400	97.4	95.8	99
Income ($)								
<20,000	2,100E	1.4E	0.5	2.4	147,700	98.6	97.6	99.5
20,000-59,999	7,400E	1.9E	0.7	3.1	383,600	98.1	96.9	99.3
60,000-79,999	4,400E	2.1E	0.8	3.4	206,400	97.9	96.6	99.2
≥80,000	33,300E	3.6E	2.5	4.8	889,300	96.4	95.2	97.5
Highest level of education								
Less than secondary school graduation	F	F	N/A	N/A	94,600	98.2	96.2	100.3
Secondary school graduation	F	F	N/A	N/A	273,500	99.1	98.1	100.1
Post-secondary certificate, diploma or university degree	42,700	3.3	2.4	4.2	1,248,700	96.7	95.8	97.6
Location of residence (population centre)								
Rural area	8,100E	3E	1.7	4.3	264,000	97	95.7	98.3
Small population centre	F	F	N/A	N/A	200,500	98.8	98	99.7
Medium population centre	F	F	N/A	N/A	153,800	97.6	95.9	99.4
Large population centre	33,100E	3.2E	2.1	4.2	1,008,800	96.8	95.8	97.9
Household family type								
Couples with children	41,900	3	2.2	3.8	1,368,600	97	96.2	97.8
Female lone parent with children under 25	F	F	N/A	N/A	196,300	98.2	96.6	99.8
Other household types	F	F	N/A	N/A	62,100	97.1	92.8	101.4
Marital status								
Married or common-law	43,500	3	2.2	3.8	1,412,900	97	96.2	97.8
Other	F	F	N/A	N/A	213,600	98.2	96.5	100
Perceived health								
Fair or poor	F	F	N/A	N/A	103,100	99.7	99.3	100.1
Good	12,000E	2.9E	1.6	4.2	404,100	97.1	95.8	98.4
Very good or excellent	35,000E	3E	2.1	4	1,119,600	97	96	97.9
Employment — last week								
Worked at a job	25,100E	3E	2	4	816,700	97	96	98
Absent	13,300E	5.1E	2.4	7.8	248,400	94.9	92.2	97.6
Did not have a job	8,900E	1.6E	0.9	2.4	538,300	98.4	97.6	99.1

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Country/ continent of birth								
Canada	37,700	3.4	2.5	4.3	N/A	N/A	N/A	N/A
Europe	5,100E	7.4E	2.5	12.2	N/A	N/A	N/A	N/A
Asia	F	F	N/A	N/A	N/A	N/A	N/A	N/A
Oceania or other	F	F	N/A	N/A	N/A	N/A	N/A	N/A
Indigenous identity								
Indigenous	F	F	N/A	N/A	88,600	98.4	96.3	100.5
Non-Indigenous	37,800	3.7	2.6	4.7	992,300	96.3	95.3	97.4
Minority visibility								
Visible minority	F	F	N/A	N/A	515,600	99	98.2	99.8
Non-visible minority	40,600	3.9	2.9	5	991,900	96.1	95	97.1
Immigrant status								
Immigrant or non-permanent resident	9,600E	1.8E	0.7	2.9	537,900	98.2	97.1	99.3
Non-immigrant (Canadian born)	37,700	3.4	2.5	4.3	1,062,900	96.6	95.7	97.5
Food security — household scale								
Moderately or severely food insecure	F	F	N/A	N/A	212,500	98.8	97.6	100
Food secure (includes marginal insecurity)	44,800	3.2	2.3	4	1,373,700	96.8	96	97.7

Source: CCHS
* Sample size is estimated using population weights
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%; F represents data too unreliable to be published; N/A represents data not available

Appendix I: Socio-demographic Characteristics of Women Who Breast-fed Their Last Baby (N = 370,500) by Self-Reported Alcohol Use Pattern, 2012–2018

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Age at time of birth								
15-24	25,700E	16.7	12	21.3	128,200	83.3	78.7	88
25-29	84,400	23.3	20.1	26.6	277,500	76.7	73.4	79.9
30-34	171,400	29.4	26.4	32.4	411,200	70.6	67.6	73.6
35-55	89,000	24.9	20.8	29	268,600	75.1	71	79.2
Income ($)								
<20,000	17,900E	13.9E	8.5	19.3	110,600	86.1	80.7	91.5
20,000-59,999	61,000	18.5	15	22	268,600	81.5	78	85
60,000-79,999	39,200	21.4	16.4	26.3	144,400	78.6	73.7	83.6
≥80,000	252,500	31	28.3	33.7	561,900	69	66.3	71.7
Highest level of education								
Less than secondary school	11,000E	14.5E	7.2	21.7	64,800	85.5	78.3	92.8
Secondary school	48,000	21.3	16.8	25.7	177,900	78.7	74.3	83.2
Post-secondary certificate, diploma or university degree	310,100	27.1	24.9	29.3	834,300	72.9	70.7	75.1
Location of residence (population centre)								
Rural area	59,200	25.6	22.2	29	172,200	74.4	71	77.8
Small population centre	52,300	29.7	25.6	33.9	123,600	70.3	66.1	74.4
Medium population centre	40,200	29	23.7	34.4	98,300	71	65.6	76.3
Large population centre	218,800	24	21.4	26.6	691,500	76	73.4	78.6
Household family type								
Couples with children	340,200	27.4	25.3	29.4	903,200	72.6	70.6	74.7
Female lone parent with children under 25	22,900E	14.3	10.3	18.3	136,800	85.7	81.7	89.7
Other household types	7,400E	14E	6.9	21.1	45,400	86	78.9	93.1
Marital status								
Married or common-law	346,000	26.9	24.9	28.9	940,000	73.1	71.1	75.1
Other	24,500E	14.4	10.4	18.5	145,100	85.6	81.5	89.6
Perceived health								
Fair or poor	13,500E	16.7E	9.4	24.1	67,000	83.3	75.9	90.6
Good	73,900	20.4	17	23.7	289,000	79.6	76.3	83
Very good or excellent	283,100	28	25.7	30.3	729,200	72	69.7	74.3
Satisfaction with life								
Satisfied of very satisfied	360,000	25.8	23.9	27.8	1,033,100	74.2	72.2	76.1

Characteristics at time of survey	Alcohol use, N*	%	Lower 95% CI	Upper 95% CI	No alcohol use, N*	%	Lower 95% CI	Upper 95% CI
Neither satisfied nor dissatisfied, or very dissatisfied	10,400E	17.6E	10.8	24.5	48,700	82.4	75.5	89.2
Employment — last week								
Worked at a job	200,800	27.6	25	30.2	526,400	72.4	69.8	75
Absent	81,000	33.8	28.6	39	158,700	66.2	61	71.4
Did not have a job	85,300	18.1	15.2	20.9	386,100	81.9	79.1	84.8
Food security — household scale								
Moderately or severely food insecure	21,900	12.2	9	15.3	157,800	87.8	84.7	91
Food secure (includes marginal insecurity)	344,700	27.6	25.5	29.7	902,200	72.4	70.3	74.5
Country/continent of birth								
Canada	315,500	32.9	30.6	35.3	643,000	67.1	64.7	69.4
Other North America, South or Central America, and Caribbean	20,900E	28.1E	17.2	38.9	53,500	71.9	61.1	82.8
Europe	15,600E	24.8E	14.7	35	47,200	75.2	65	85.3
Asia	F	F			77,800	96.7	93.1	100.3
Oceania or other	12,400E	4.7E	2.7	6.8	248,900	95.3	93.2	97.3
Indigenous identity								
Indigenous	16,200E	21.4E	14.3	28.5	59,500	78.6	71.5	85.7
Non-Indigenous	307,100	34	31.6	36.4	595,200	66	63.6	68.4
Minority visibility								
Visible minority	45,800E	10.1	7.3	12.8	409,500	89.9	87.2	92.7
Non-visible minority	304,500	33.7	31.3	36.1	599,300	66.3	63.9	68.7
Immigrant status								
Landed immigrant or non-permanent resident	51,500	10.8	8	13.6	426,400	89.2	86.4	92
Non-immigrant (Canadian born)	315,500	32.9	30.6	35.3	643,000	67.1	64.7	69.4

Source: CCHS
* Sample size is estimated using population weights
Please note: E represents data with a coefficient of variation (CV) from 15% to 35%; F represents data too unreliable to be published

Appendix J: Support Services Recommended to Individuals Diagnosed with FASD by Clinics in Alberta, Manitoba, Northwest Territories, Ontario, and Yukon, 2004–2019 (N = 1,185)

Recommendations following the assessment	Children (0-17 years), n = 778			Total	Adults (18+ years), n = 330			Total
	Yes	Yes, but service not available	No		Yes	Yes, but service not available	No	
Coaching	324 (45.8%)	<5	381 (53.8%)	708 (100%)	162 (63.5%)	<5	92 (36.1%)	255 (100%)
Support	595 (81.4%)	<5	135 (18.5%)	731 (100%)	250 (89.0%)	<5	31 (11.0%)	281 (100%)
Communication strategies	561 (80.9%)	<5	132 (19.0%)	693 (100%)	164 (65.9%)	<5	85 (34.1%)	249 (100%)
FASD assessment / early intervention	255 (35.6%)	6 (0.8%)	455 (63.6%)	716 (100%)	9 (3.6%)	<5	237 (96.0%)	247 (100%)
Counselling support group	97 (13.5%)	<5	618 (86.2%)	717 (100%)	25 (9.9%)	<5	227 (90.1%)	252 (100%)
Counselling or individual therapy	354 (47.4%)	5 (0.7%)	387 (51.9%)	746 (100%)	205 (67.7%)	<5	98 (32.3%)	303 (100%)
Couple/family counselling	118 (16.5%)	<5	594 (83.2%)	714 (100%)	50 (19.8%)	<5	203 (80.2%)	253 (100%)
Substance abuse counselling/ therapy	72 (10.4%)	<5	622 (89.5%)	695 (100%)	153 (52.0%)	<5	141 (48.0%)	294 (100%)
Respite	220 (31.4%)	<5	479 (68.3%)	701 (100%)	63 (25.6%)	<5	183 (74.4%)	246 (100%)
Child protection	8 (1.2%)	<5	674 (98.8%)	682 (100%)	N/A	N/A	N/A	N/A
Spousal abuse interventions	N/A	N/A	N/A	683	10 (3.9%)	<5	244 (96.1%)	254 (100%)
Mental health support	285 (40.3%)	<5	422 (59.6%)	708 (100%)	232 (77.3%)	<5	68 (22.7%)	300 (100%)
Income support	141 (20.0%)	<5	562 (79.7%)	705 (100%)	276 (87.6%)	<5	39 (12.4%)	315 (100%)
Food bank	<5	<5	680 (99.7%)	682 (100%)	29 (11.7%)	<5	220 (88.3%)	249 (100%)
Emergency housing/shelter	9 (1.3%)	<5	674 (98.7%)	683 (100%)	25 (10.0%)	<5	224 (90.0%)	249 (100%)
Daycare	9 (1.3%)	<5	676 (98.7%)	685 (100%)	9 (3.6%)	<5	239 (96.4%)	248 (100%)
Guardianship	80 (11.5%)	<5	613 (88.3%)	694 (100%)	118 (45.0%)	<5	144 (55.0%)	262 (100%)
Power of attorney	13 (1.9%)	<5	672 (98.1%)	685 (100%)	36 (14.5%)	<5	212 (85.5%)	248 (100%)
Personal directive	7 (1.0%)	<5	671 (99.0%)	678 (100%)	25 (10.0%)	<5	224 (89.6%)	250 (100%)
Legal aid	<5	<5	680 (99.4%)	684 (100%)	12 (4.8%)	<5	236 (95.1%)	248 (100%)
Speech and language pathologist	396 (54.9%)	<5	325 (45.1%)	721 (100%)	6 (2.4%)	<5	241 (97.6%)	247 (100%)
Behaviour therapy services	70 (10.0%)	<5	631 (90.0%)	701 (100%)	14 (5.7%)	<5	234 (94.3%)	248 (100%)
Medication/psychopharmacology	315 (45.6%)	<5	376 (54.4%)	691 (100%)	110 (41.5%)	<5	155 (58.5%)	265 (100%)

Recommendations following the assessment	Children (0-17 years), n = 778			Total	Adults (18+ years), n = 330			Total
	Yes	Yes, but service not available	No		Yes	Yes, but service not available	No	
Occupational therapy	359 (49.7%)	<5	364 (50.3%)	723 (100%)	14 (5.7%)	<5	232 (94.3%)	246 (100%)
Accommodations/ adaptation in environment	723 (95.3%)	<5	36 (4.7%)	759 (100%)	254 (80.6%)	<5	61 (19.4%)	315 (100%)
Anticipatory guidance/ prevention	543 (75.9%)	<5	172 (24.1%)	715 (100%)	215 (68.9%)	<5	97 (31.1%)	312 (100%)
Safety	323 (45.2%)	<5	391 (54.8%)	714 (100%)	173 (57.3%)	<5	129 (42.7%)	302 (100%)
Reassessment	109 (15.8%)	<5	581 (84.2%)	690 (100%)	20 (7.6%)	<5	244 (92.4%)	264 (100%)
Other substitute decision-making options	73 (10.6%)	<5	617 (89.4%)	690 (100%)	86 (33.2%)	<5	173 (66.8%)	259 (100%)
Other legal services	11 (1.6%)	<5	670 (98.4%)	681 (100%)	22 (8.9%)	<5	225 (90.7%)	248 (100%)
Other medical referral	298 (42.7%)	<5	399 (57.2%)	698 (100%)	175 (57.0%)	<5	132 (43.0%)	307 (100%)

Source: CanFASD Universal Dataform project
Abbreviation: N/A, not applicable

Appendix K: Number of Recorded Hospitalizations and Visits of Individuals with FAS by Select P/Ts and Fiscal Year, 2014–2017 (N = 5,399)

	Level of Care (n)								
P/T / fiscal year	Acute care hospitalizations	Psychiatric care hospitalizations	Rehabilitation hospitalizations	Clinical care visits	Emergency care visits	Day surgeries	Diagnostic images	Other*	Total
AB									
2014	516	80	7	3,334	2,125	43	91	2,131	8,327
2015	705	124	<5	5,273	4,412	89	231	3,991	14,827
2016	931	175	8	7,194	6,197	128	338	4,897	19,868
2017	1,113	168	9	9,447	8,636	199	495	6,205	26,272
Total	3,265	547	26	25,248	21,370	459	1,155	17,224	69,294
BC									
2014	433	9	<5	6	547	11	0	7	1,014
2015	538	9	<5	<5	1,349	31	0	<5	1,935
2016	603	13	<5	22	1,927	36	<5	<5	2,607
2017	825	14	0	<5	2,456	41	0	<5	3,342
Total	2,399	45	6	33	6,279	119	<5	16	8,898
MB									
2014	122	12	<5	0	279	9	0	<5	425
2015	152	14	0	0	468	13	0	10	657
2016	170	14	0	0	605	15	0	<5	805
2017	168	19	<5	0	746	32	0	0	966
Total	612	59	<5	0	2,098	69	0	13	2,853
NT									
2014	5	<5	0	0	<5	0	0	<5	12
2015	8	0	0	0	20	<5	0	<5	30
2016	<5	0	0	<5	8	<5	<5	8	22
2017	5	0	0	0	11	0	0	<5	17
Total	21	<5	0	<5	42	<5	<5	13	81
ON									
2014	356	169	5	116	1,502	42	<5	22	2,214
2015	490	188	5	190	3,125	120	<5	20	4,140
2016	492	278	5	89	4,130	129	<5	31	5,155
2017	614	337	<5	128	5,852	123	<5	53	7,113
Total	1,952	972	19	523	14,609	414	7	126	18,622
YT									
2014	<5	0	0	0	16	0	0	0	18
2015	<5	0	0	<5	30	0	0	<5	36
2016	<5	0	0	0	49	0	0	<5	52
2017	<5	0	0	0	68	0	0	0	69
Total	8	0	0	<5	163	0	0	<5	175
Total	**8,257**	**1,624**	**53**	**25,806**	**44,561**	**1,063**	**1,164**	**17,395**	**99,923**

Sources: CIHI data holdings including DAD, NACRS, OMHRS, and NRS
* Comprises of chronic care, subacute care, and uncategorized care
Please note: 246 observations were missing, not applicable, or with government health card

Appendix L: Number of Recorded Hospitalizations and Visits of Individuals with FAS in Select P/Ts* by Age Category and Fiscal Year, 2014–2017 (N = 5,399)

	Level of care (n)								
Age / fiscal year	Acute care hospitalizations	Psychiatric care hospitalizations	Rehabilitation hospitalizations	Clinical care visits	Emergency care visits	Day surgeries	Diagnostic images	Other**	Total
<1 year									
2014	109	0	0	25	76	<5	<5	26	239
2015	134	0	0	57	113	<5	<5	152	464
2016	110	0	0	56	135	<5	<5	53	359
2017	115	0	0	99	122	8	5	93	442
Total	**468**	**0**	**0**	**237**	**446**	**16**	**13**	**324**	**1,504**
1-3 years									
2014	26	0	0	49	39	7	<5	49	173
2015	21	0	0	148	104	7	11	127	418
2016	31	0	0	138	154	9	8	330	670
2017	39	0	0	153	221	19	8	276	716
Total	**117**	**0**	**0**	**488**	**518**	**42**	**30**	**782**	**1,977**
4-7 years									
2014	36	0	0	195	54	8	11	226	530
2015	39	0	0	349	86	10	<5	568	1,055
2016	28	0	<5	501	109	24	8	414	1,085
2017	43	0	0	404	128	11	9	534	1,129
Total	**146**	**0**	**<5**	**1,449**	**377**	**53**	**31**	**1,742**	**3,799**
8-11 years									
2014	73	<5	0	863	136	10	<5	872	1,958
2015	76	<5	0	825	235	14	21	1,083	2,255
2016	73	0	<5	1,380	293	24	19	1,287	3,080
2017	125	<5	<5	1,238	437	30	39	1,157	3,029
Total	**347**	**<5**	**6**	**4,306**	**1,101**	**78**	**81**	**4,399**	**10,322**
12-14 years									
2014	149	<5	<5	222	292	11	20	291	990
2015	188	<5	0	567	711	32	21	385	1,906
2016	165	<5	<5	626	612	18	26	457	1,908
2017	184	<5	<5	1,497	874	16	33	866	3,476
Total	**686**	**11**	**6**	**2,912**	**2,489**	**77**	**100**	**1,999**	**8,280**

	Level of care (n)								
Age / fiscal year	Acute care hospitalizations	Psychiatric care hospitalizations	Rehabilitation hospitalizations	Clinical care visits	Emergency care visits	Day surgeries	Diagnostic images	Other**	Total
15-29 years									
2014	735	206	6	1,516	2,764	36	30	538	5,831
2015	951	246	8	2,260	5,137	88	107	1,253	10,050
2016	1,199	343	6	3,268	7,053	130	165	1,724	13,888
2017	1,467	386	6	4,562	9,552	193	217	2,262	18,645
Total	**4,352**	**1,181**	**26**	**11,606**	**24,506**	**447**	**519**	**5,777**	**48,414**
30-44 years									
2014	220	43	0	288	835	27	18	119	1,550
2015	328	61	<5	665	2,178	76	45	333	3,687
2016	451	108	0	787	3,628	68	76	482	5,600
2017	600	121	<5	1,069	5,319	91	113	771	8,086
Total	**1,599**	**333**	**<5**	**2,809**	**11,960**	**262**	**252**	**1,705**	**18,923**
45-59 years									
2014	88	18	<5	161	240	<5	8	29	549
2015	145	24	0	364	755	11	21	95	1,415
2016	154	25	<5	419	860	26	31	151	1,669
2017	169	30	0	418	943	13	65	245	1,883
Total	**556**	**97**	**5**	**1,362**	**2,798**	**53**	**125**	**520**	**5,516**
60-69 years									
2014	10	0	<5	0	29	0	0	<5	42
2015	30	<5	0	7	74	7	0	<5	122
2016	26	<5	0	39	49	<5	<5	31	154
2017	51	<5	<5	139	135	9	<5	57	398
Total	**117**	**8**	**<5**	**185**	**287**	**20**	**<5**	**91**	**716**
70-79 years									
2014	<5	0	<5	137	6	<5	0	15	164
2015	13	0	0	225	11	5	0	28	282
2016	10	<5	0	99	19	<5	<5	13	150
2017	6	0	0	<5	21	<5	<5	<5	36
Total	**33**	**<5**	**<5**	**463**	**57**	**13**	**7**	**57**	**632**
≥80 years									
2014	5	0	0	0	6	0	0	0	11
2015	<5	0	<5	0	<5	<5	0	0	7
2016	8	0	0	0	12	<5	0	0	22
2017	8	0	0	<5	26	7	<5	<5	46
Total	**23**	**0**	**<5**	**<5**	**47**	**10**	**<5**	**<5**	**86**
TOTAL	**8,444**	**1,635**	**53**	**25,819**	**44,586**	**1,071**	**1,164**	**17,397**	**100,169**

Sources: CIHI data holdings including DAD, NACRS, OMHRS and NRS
* Select P/Ts are AB, BC, MB, NT, ON, and YT
** Comprises of chronic care, subacute care, and uncategorized care

Appendix M: Frequency and Percentage of the Most Responsible Diagnosis, Defined Using ICD-10-CA Blocks, among Individuals with FAS in Select P/Ts*, 2014–2017 (N = 5,399)

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Persons encountering health services for specific procedures and health care	13,655	14.3
Persons encountering health services in other circumstances	7,582	7.9
Mental and behavioural disorders due to psychoactive substance use	6,894	7.2
Schizophrenia, schizotypal, and delusional disorders	4,998	5.2
Neurotic, stress-related, and somatoform disorders	4,791	5.0
Unspecified mental disorder	4,062	4.3
Persons encountering health services for examination and investigation	4,020	4.2
Persons with potential health hazards related to socio-economic and psychosocial circumstances	3,027	3.2
Other congenital malformations	2,925	3.1
Symptoms and signs involving cognition, perception, emotional state, and behaviour	2,736	2.9
Symptoms and signs involving the digestive system and abdomen	2,729	2.9
Poisoning by drugs, medicaments, and biological substances	2,384	2.5
Behavioural and emotional disorders with onset usually occurring in childhood and adolescence	2,249	2.4
Mood (affective) disorders	2,212	2.3
Disorders of psychological development	2,023	2.1
General symptoms and signs	1,683	1.8
Symptoms and signs involving the circulatory and respiratory systems	1,402	1.5
Injuries to the head	1,337	1.4
Disorders of adult personality and behaviour	1,315	1.4
Injuries to the wrist and hand	1,030	1.1
Acute upper respiratory infections	913	1.0
Episodic and paroxysmal disorders	892	0.9
Diabetes mellitus	791	0.8
Infections of the skin and subcutaneous tissue	767	0.8
Mental retardation	766	0.8
Behavioural syndromes associated with physiological disturbances and physical factors	652	0.7
Other diseases of intestines	626	0.7
Injuries to the ankle and foot	577	0.6
Toxic effects of substances chiefly non-medicinal as to source	509	0.5
Chronic lower respiratory diseases	498	0.5
Persons encountering health services in circumstances related to reproduction	465	0.5
Effects of foreign body entering through natural orifice	462	0.5
Injuries to the knee and lower leg	455	0.5
Diseases of oral cavity, salivary glands, and jaws	453	0.5
Influenza and pneumonia	450	0.5
Intestinal infectious diseases	428	0.4
Injuries to the elbow and forearm	421	0.4

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Other diseases of urinary system	408	0.4
Other dorsopathies	401	0.4
Other soft tissue disorders	400	0.4
Other and unspecified effects of external causes	388	0.4
Other diseases of the digestive system	386	0.4
Complications of surgical and medical care, not elsewhere classified	312	0.3
Diseases of esophagus, stomach, and duodenum	303	0.3
Injuries to the shoulder and upper arm	258	0.3
Injuries to the abdomen, lower back, lumbar spine, and pelvis	249	0.3
Other joint disorders	240	0.3
Complications of labour and delivery	239	0.3
Disorders of other endocrine glands	225	0.2
Disorders of gallbladder, biliary tract, and pancreas	221	0.2
Symptoms and signs involving the skin and subcutaneous tissue	220	0.2
Diseases of middle ear and mastoid	214	0.2
Other acute lower respiratory infections	208	0.2
Injuries to the thorax	200	0.2
Non-inflammatory disorders of female genital tract	196	0.2
Other diseases of the respiratory system	182	0.2
Certain disorders involving the immune mechanism	178	0.2
Maternal care related to the fetus and amniotic cavity and possible delivery problems	171	0.2
Other forms of heart disease	171	0.2
Renal failure	162	0.2
Other disorders of the nervous system	160	0.2
Other maternal disorders predominantly related to pregnancy	158	0.2
Dermatitis and eczema	152	0.2
Organic, including symptomatic, mental disorders	148	0.2
Other diseases of upper respiratory tract	148	0.2
Injuries to the neck	146	0.2
Other viral diseases	145	0.2
Symptoms and signs involving the urinary system	145	0.2
Metabolic disorders	144	0.2
Other diseases of blood and blood-forming organs	135	0.1
Disorders related to length of gestation and fetal growth	134	0.1
Injuries to unspecified parts of trunk, limb, or body region	129	0.1
Other obstetric conditions, not elsewhere classified	129	0.1
Persons with potential health hazards related to communicable diseases	126	0.1
Injuries to the hip and thigh	118	0.1
Injuries involving multiple body regions	113	0.1
Other bacterial diseases	97	0.1
Diseases of male genital organs	96	0.1
Viral infections characterized by skin and mucous membrane lesions	95	0.1
Diseases of external ear	91	0.1

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Other disorders of the skin and subcutaneous tissue	88	0.1
Diseases of liver	88	0.1
Inflammatory diseases of female pelvic organs	87	0.1
Inflammatory polyarthropathies	87	0.1
Disorders of skin appendages	87	0.1
Cleft lip and cleft palate	87	0.1
Diseases of veins, lymphatic vessels, and lymph nodes, not elsewhere classified	86	0.1
Congenital malformations of the circulatory system	86	0.1
Hernia	83	0.1
Other disorders of ear	79	0.1
Mycoses	78	0.1
Fetus and newborn affected by maternal factors and by complications of pregnancy, labour, and delivery	75	0.1
Symptoms and signs involving the nervous and musculoskeletal systems	68	0.1
Other disorders of kidney and ureter	65	0.1
Infections with a predominantly sexual mode of transmission	64	0.1
Lung diseases due to external agents	63	0.1
Disorders of ocular muscles, binocular movement, accommodation, and refraction	60	0.1
Renal tubulo-interstitial diseases	60	0.1
Other disorders of eye and adnexa	57	0.1
Pregnancy with abortive outcome	54	0.1
Diseases of appendix	54	0.1
Abnormal findings on examination of blood, without diagnosis	54	0.1
Frostbite	53	0.1
Disorders of conjunctiva	50	0.1
Human immunodeficiency virus (HIV) disease	50	0.1
Burns and corrosions of external body surface, specified by site	49	0.1
Non-infective enteritis and colitis	49	0.1
Disorders of eyelid, lacrimal system, and orbit	47	0.0
Disorders of muscles	46	0.0
Respiratory and cardiovascular disorders specific to the perinatal period	44	0.0
Viral hepatitis	44	0.0
Extrapyramidal and movement disorders	44	0.0
Disorders of breast	44	0.0
Benign neoplasms	43	0.0
Other infectious diseases	43	0.0
Chondropathies	41	0.0
Urolithiasis	40	0.0
Cerebrovascular diseases	40	0.0
Other disorders originating in the perinatal period	39	0.0
Pediculosis, acariasis, and other infestations	37	0.0
Hypertensive diseases	37	0.0
Systemic connective tissue disorders	36	0.0
Ischemic heart diseases	36	0.0

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Visual disturbances and blindness	36	0.0
Congenital malformations and deformations of the musculoskeletal system	35	0.0
Congenital malformations of the nervous system	34	0.0
Pulmonary heart disease and diseases of pulmonary circulation	34	0.0
Glomerular diseases	31	0.0
Other osteopathies	30	0.0
Disorders of synovium and tendon	28	0.0
Complications predominantly related to the puerperium	27	0.0
Malignant neoplasms of digestive organs	27	0.0
Urticaria and erythema	27	0.0
Certain early complications of trauma	26	0.0
Chronic rheumatic heart diseases	25	0.0
Cerebral palsy and other paralytic syndromes	25	0.0
Coagulation defects, purpura, and other hemorrhagic conditions	23	0.0
Arthrosis	23	0.0
Neoplasms of uncertain or unknown behaviour	23	0.0
Deforming dorsopathies	23	0.0
Disorders of lens	22	0.0
Malignant neoplasms of lymphoid, hematopoietic, and related tissue	22	0.0
Aplastic and other anemias	22	0.0
Disorders of choroid and retina	21	0.0
Disorders of sclera, cornea, iris, and ciliary body	20	0.0
Infectious arthropathies	20	0.0
Obesity and other hyperalimentation	20	0.0
Hemorrhagic and hematological disorders of fetus and newborn	19	0.0
Chromosomal abnormalities, not elsewhere classified	18	0.0
Disorders of bone density and structure	18	0.0
Burns and corrosions of multiple and unspecified body regions	17	0.0
Spondylopathies	17	0.0
Oedema, proteinuria, and hypertensive disorders in pregnancy, childbirth, and the puerperium	17	0.0
Congenital malformations of genital organs	16	0.0
Nerve, nerve root, and plexus disorders	16	0.0
Other congenital malformations of the digestive system	16	0.0
Diseases of inner ear	16	0.0
Disorders of thyroid gland	16	0.0
Malnutrition	16	0.0
Papulosquamous disorders	15	0.0
Nutritional anemias	14	0.0
Polyneuropathies and other disorders of the peripheral nervous system	14	0.0
Abnormal findings on diagnostic imaging and in function studies, without diagnosis	13	0.0
Other disorders of glucose regulation and pancreatic internal secretion	13	0.0
Malignant neoplasms of thyroid and other endocrine glands	12	0.0
Other diseases of pleura	12	0.0

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Diseases of arteries, arterioles, and capillaries	12	0.0
Diseases of peritoneum	12	0.0
Inflammatory diseases of the central nervous system	11	0.0
Malignant neoplasms of ill-defined, secondary, and unspecified sites	11	0.0
Malignant neoplasms of respiratory and intrathoracic organs	10	0.0
Other and unspecified disorders of the circulatory system	10	0.0
Diseases of myoneural junction and muscle	10	0.0
Radiation-related disorders of the skin and subcutaneous tissue	10	0.0
Congenital malformations of eye, ear, face, and neck	9	0.0
Disorders of optic nerve and visual pathways	9	0.0
Abnormal findings on examination of other body fluids, substances, and tissues, without diagnosis	9	0.0
Burns and corrosions confined to eye and internal organs	8	0.0
Symptoms and signs involving speech and voice	8	0.0
Other degenerative diseases of the nervous system	6	0.0
Congenital malformations of the urinary system	6	0.0
Malignant neoplasm of breast	6	0.0
In situ neoplasms	6	0.0
Digestive system disorders of fetus and newborn	6	0.0
Malignant neoplasms of lip, oral cavity, and pharynx	5	0.0
Malignant neoplasms of eye, brain, and other parts of central nervous system	5	0.0
Transitory endocrine and metabolic disorders specific to fetus and newborn	5	0.0
Malignant neoplasms of male genital organs	<5	S
Hemolytic anemias	<5	S
Systemic atrophies primarily affecting the central nervous system	<5	S
Glaucoma	<5	S
Disorders of vitreous body and globe	<5	S
Other disorders of the genitourinary system	<5	S
Congenital malformations of the respiratory system	<5	S
Other respiratory diseases principally affecting the interstitium	<5	S
Tuberculosis	<5	S
Suppurative and necrotic conditions of lower respiratory tract	<5	S
Malignant neoplasms of urinary tract	<5	S
Demyelinating diseases of the central nervous system	<5	S
Other disorders of the musculoskeletal system and connective tissue	<5	S
Other diseases caused by chlamydiae	<5	S
Helminthiases	<5	S
Infections specific to the perinatal period	<5	S
Malignant neoplasms of mesothelial and soft tissue	<5	S
Other nutritional deficiencies	<5	S
Viral infections of the central nervous system	<5	S
Protozoal diseases	<5	S
Acute rheumatic fever	<5	S
Melanoma and other malignant neoplasms of skin	<5	S

Most responsible diagnosis defined using ICD-10-CA blocks	Frequency	Percent
Persons with potential health hazards related to family and personal history and certain conditions influencing health status	<5	S
Total	**95,400**	**100.0**

Sources: CIHI data holdings including DAD, NACRS, and NRS
Abbreviation: S, suppressed
* Select P/Ts are AB, BC, MB, NT, ON, and YT
Please note: 3,782 missing observations excluded

Appendix N: Frequency and Percentage of the Most Responsible Diagnosis, Defined Using ICD-10-CA Chapters, of Individuals with FAS in Select P/Ts* by Age Category, 2014–2017 (N = 5,399)

Age category (years)																						
Ch	<1		1-3		4-7		8-11		12-14		15-29		30-44		45-59		60-69		70-79		≥80	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%
1	58	4.0	65	3.4	21	0.6	54	0.5	44	0.6	472	1.0	289	1.6	81	1.6	7	1.0	<5	S	0	0.0
2	8	0.5	18	0.9	9	0.2	8	0.1	5	0.1	67	0.1	23	0.1	30	0.6	6	0.9	6	1.0	0	0.0
3	<5	S	13	0.7	6	0.2	10	0.1	7	0.1	114	0.3	210	1.2	11	0.2	<5	S	<5	S	0	0.0
4	6	0.4	6	0.3	8	0.2	34	0.3	87	1.1	750	1.7	168	0.9	138	2.7	18	2.6	7	1.1	5	5.8
5	12	0.8	40	2.1	593	15.7	2,701	26.4	2,921	36.5	17,140	37.9	5,563	30.6	1,026	19.8	100	14.4	8	1.3	6	7.0
6	20	1.4	48	2.5	60	1.6	104	1.0	56	0.7	537	1.2	261	1.4	86	1.7	12	1.7	<5	S	0	0.0
7	5	0.3	27	1.4	41	1.1	32	0.3	28	0.4	105	0.2	49	0.3	26	0.5	5	0.7	5	0.8	7	8.1
8	19	1.3	49	2.5	30	0.8	67	0.7	38	0.5	115	0.3	66	0.4	14	0.3	<5	S	0	0.0	0	0.0
9	<5	S	20	1.0	19	0.5	<5	S	25	0.3	144	0.3	93	0.5	95	1.8	10	1.4	20	3.2	19	22.1
10	177	12.1	268	13.9	133	3.5	156	1.5	165	2.1	978	2.2	421	2.3	157	3.0	22	3.2	<5	S	<5	S
11	34	2.3	50	2.6	99	2.6	159	1.6	114	1.4	983	2.2	612	3.4	164	3.2	51	7.3	6	1.0	<5	S
12	17	1.2	31	1.6	24	0.6	55	0.5	56	0.7	630	1.4	270	1.5	49	0.9	9	1.3	<5	S	<5	S
13	<5	S	<5	S	26	0.7	57	0.6	70	0.9	645	1.4	443	2.4	153	2.9	10	1.4	<5	S	<5	S
14	24	1.6	14	0.7	41	1.1	32	0.3	50	0.6	586	1.3	271	1.5	82	1.6	30	4.3	59	9.4	<5	S
15	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	678	1.5	117	0.6	0	0.0	0	0.0	0	0.0	0	0.0
16	285	19.6	14	0.7	23	0.6	0	0.0	0	0.0	<5	S	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
17	105	7.2	65	3.4	330	8.7	783	7.6	511	6.4	1,196	2.6	195	1.1	50	1.0	<5	S	0	0.0	0	0.0
18	101	6.9	107	5.5	110	2.9	229	2.2	568	7.1	4,404	9.7	2,638	14.5	784	15.1	101	14.5	12	1.9	13	15.1
19	44	3.0	80	4.1	77	2.0	243	2.4	531	6.6	5,155	11.4	2,542	14.0	471	9.1	59	8.5	27	4.3	12	14.0
21	533	36.6	1,013	52.5	2,122	56.3	5,518	53.9	2,722	34.0	10,492	23.2	3,970	21.8	1,774	34.2	252	36.2	471	74.6	9	10.5
Total	**1,457**	**100.0**	**1,930**	**100.0**	**3,772**	**100.0**	**10,245**	**100.0**	**7,998**	**100.0**	**45,193**	**100.0**	**18,201**	**100.0**	**5,191**	**100.0**	**696**	**100.0**	**631**	**100.0**	**86**	**100.0**

Sources: CIHI data holdings including DAD, NACRS, and NRS
Abbreviation: S, suppressed
* Select P/Ts are AB, BC, MB, NT, ON, and YT
Please note: 3,782 missing observations excluded
ICD-10-CA chapters: 1 Certain infectious and parasitic diseases (A00-B99), 2 Neoplasms (C00-D48), 3 Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89), 4 Endocrine, nutritional and metabolic diseases (E00-E90), 5 Mental and behavioural disorders (F00-F99), 6 Diseases of the nervous system (G00-G99), 7 Diseases of the eye and adnexa (H00-H59), 8 Diseases of the ear and mastoid process (H60-H95), 9 Diseases of the circulatory system (I00-I99), 10 Diseases of the respiratory system (J00-J99), 11 Diseases of the digestive system (K00-K93), 12 Diseases of the skin and subcutaneous tissue (L00-L99), 13 Diseases of the musculoskeletal system and connective tissue (M00-M99), 14 Diseases of the genitourinary system (N00-N99), 15 Pregnancy, childbirth, and the puerperium (O00-O99), 16 Certain conditions originating in the perinatal period (P00-P96), 17 Congenital malformations, deformations, and chromosomal abnormalities (Q00-Q99), 18 Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99), 19 Injury, poisoning, and certain other consequences of external causes (S00-T98), and 21 Factors influencing health status and contact with health services (Z00-Z99)

Appendix O: Leading Causes of Death Captured by the Health Care System, Defined Using the Most Responsible Diagnosis ICD-10-CA Code, in Descending Order among Individuals with FAS in Select P/Ts*, 2014–2017 (N = 5,399)

ICD-10-CA diagnostic code	Description of ICD-10-CA diagnostic code
Z515	Palliative care
I469	Cardiac arrest, unspecified
G931	Anoxic brain damage, not elsewhere classified
S065	Traumatic subdural hemorrhage
J690	Pneumonitis due to food and vomit
S0625	Diffuse brain injury without open intracranial wound
A410	Sepsis due to Staphylococcus aureus
J9691	Respiratory failure, unspecified, type II (hypercapnic)
K632	Fistula of intestine
A419	Sepsis, unspecified
K703	Alcoholic cirrhosis of liver
Z718	Other specified counseling
I500	Congestive heart failure
K704	Alcoholic hepatic failure
A4180	Sepsis due to Enterococcus
S352	Injury of coeliac or mesenteric artery
K631	Perforation of intestine (non-traumatic)
Q201	Double outlet right ventricle
R572	Septic shock
E1010	Type 1 diabetes mellitus with ketoacidosis
R33	Retention of urine
J151	Pneumonia due to Pseudomonas
A403	Sepsis due to Streptococcus pneumonia
I611	Intracerebral hemorrhage in hemisphere, cortical
G042	Bacterial meningoencephalitis and meningomyelitis, not elsewhere classified
I613	Intracerebral hemorrhage in brain stem
S066	Traumatic subarachnoid hemorrhage
I330	Acute and subacute infective endocarditis
B24	Human immunodeficiency virus (HIV) disease
B3780	Candidal esophagitis
J80	Adult respiratory distress syndrome
Z548	Convalescence following other treatment
J708	Respiratory conditions due to other specified external agents
T8453	Infection and inflammatory reaction due to hip prosthesis
S1410	Complete lesion of cervical spinal cord
S069	Intracranial injury, unspecified
C3490	Malignant neoplasm of right bronchus or lung unspecified
C189	Malignant neoplasm colon, unspecified
Q860	Fetal alcohol syndrome (dysmorphic)
I664	Occlusion and stenosis of multiple and bilateral cerebral arteries
J13	Pneumonia due to Streptococcus pneumonia
I270	Primary pulmonary hypertension
N185	Chronic kidney disease, stage 5
C837	Burkitt lymphoma
K550	Acute vascular disorders of intestine
I609	Subarachnoid hemorrhage, unspecified
R570	Cardiogenic shock
I612	Intracerebral hemorrhage in hemisphere, unspecified
J9600	Acute respiratory failure, type 1 (hypoxic)
C131	Malignant neoplasm aryepiglottic fold, hypopharyngeal aspect
K721	Chronic hepatic failure
Q433	Congenital malformations of intestinal fixation

Sources: CIHI data holdings including DAD, NACRS, OMHRS, and NRS
* Select P/Ts are AB, BC, MB, NT, ON, and YT
Please note: frequencies and percentages are not presented due to low cell counts

Appendix P: Characteristics of Mothers in BC by Alcohol Use during Pregnancy Identified as a Risk Factor, 2014–2015 to 2017–2018 (N = 142,545)

Variables	Alcohol use	No alcohol use	Overall	p-value
N (%)	1,569 (1.1)	140,976 (98.9)	142,545 (100.0)	N/A
Maternal age, mean (SD)	28.48 (5.7)	31.38 (5.2)	31.4 (5.2)	<0.001**
Maternal total length of stay (hours), mean (SD)	76.8 (156.9)	61.19 (77.6)	61.4 (79.0)	<0.001**
Number of living children, mean (SD)	0.83 (1.21)	0.80 (1.01)	0.80 (1.01)	0.28
Pregnancy history, n(%)				
Parity = nulliparous, n (%)	821 (52.3)	64,676 (45.9)	65,497 (45.9)	<0.001**
Prior neonatal death, n (%)	10 (0.6)	413 (0.3)	423 (0.3)	0.024*
Prior stillbirth, n (%)	14 (0.9)	998 (0.7)	1,012 (0.7)	0.475
Prior low birth weight baby (≤2,500g, n (%))	18 (1.1)	2,116 (1.5)	2,134 (1.5)	0.297
Major congenital anomalies (past pregnancy), n (%)	12 (0.8)	892 (0.6)	904 (0.6)	0.62
History of any mental illness, n (%)	699 (44.6)	30,169 (21.4)	30,868 (21.7)	<0.001**
Current pregnancy				
Number of antenatal visits, mean (SD)	9.02 (4.1)	9.44 (3.31)	9.44 (3.3)	<0.001**
Total antenatal hospital admissions (prior to delivery), mean (SD)	0.15 (0.6)	0.09 (0.4)	0.09 (0.4)	<0.001**
Bleeding (<20 weeks), n (%)	31 (2.0)	2,596 (1.8)	2,627 (1.8)	0.765
Antepartum hemorrhage >20 weeks, n (%)	11 (0.7)	1,804 (1.3)	1,815 (1.3)	0.055
Intrauterine growth restriction (IUGR)	40 (2.5)	3,040 (2.2)	3,080 (2.2)	0.328
Substance use, n (%)				
Any substance use	533 (34.0)	6,268 (4.4)	6,801 (4.8)	<0.001**
Marijuana	388 (24.7)	4,545 (3.2)	4,933 (3.5)	<0.001**
Cocaine	192 (12.2)	749 (0.5)	941 (0.7)	<0.001**
Other drug(s)a	104 (6.6)	629 (0.4)	733 (0.5)	<0.001**
Prescription drugs	26 (1.7)	681 (0.5)	707 (0.5)	<0.001**
Methadone	24 (1.5)	637 (0.5)	661 (0.5)	<0.001**
Heroin	44 (2.8)	594 (0.4)	638 (0.4)	<0.001**
Unspecified drug use	5 (0.3)	71 (0.1)	76 (0.1)	<0.001**
Solvents	0 (0.0)	13 (0.0)	13 (0.0)	1
ALCOHOL USE				
Alcohol during pregnancy identified as a risk	1,569 (100.0)	0 (0.0)	1,569 (1.1)	<0.001**
Number of drinks per week[b], mean (SD)	3.4 (9.6)	N/A	3.4 (9.6)	
Binge drinking[b], n (%)				<0.001**
Yes	369 (23.5)	0 (0.0)	N/A	
No	751 (47.9)	0 (0.0)	N/A	
Unknown	449 (28.6)	0 (0.0)	N/A	

Variables	Alcohol use	No alcohol use	Overall	p-value
N/A	0 (0.0)	140,976 (100.0)	140,976 (100.0)	
CIGARETTES				
Smoking during pregnancy, n (%)				<0.001**
Current	466 (29.7)	8,094 (5.7)	8,560 (6.0)	
Former	353 (22.5)	11,120 (7.9)	11,473 (8.0)	
Never (including unknown)	750 (47.8)	121,762 (86.4)	122,512 (85.9)	
Current number of cigarettes per day, mean (SD)	7.20 (47.8)	6.71 (5.1)	6.73 (5.2)	0.066
Exposure to second-hand smoke, n (%)	7.20 (6.0)	9,466 (6.7)	9,838 (6.9)	<0.001**

Source: BCPDR, Perinatal Services BC

Abbreviation: N/A, not applicable; SD, standard deviation

a Other non-prescription drugs including hallucinogens (lysergic acid diethylamide-LSD, magic mushrooms), stimulants (amphetamines, ephedrine, methamphetamine ice, crystal meth, methylenedioxyamphetamine [MDA]), methylphenidate (Ritalin), designer drugs (Ketamine-dissociative anesthetic, ecstasy-serotonergic effects, gamma-hydroxybutyrate [GHB]).

b Among those with alcohol use identified as a risk factor

* Difference between alcohol exposed and non-alcohol exposed p <0.05

** Difference between alcohol exposed and non-alcohol exposed p <0.001

Appendix Q: Characteristics of Newborns in BC by Alcohol Use during Pregnancy Identified as a Risk Factor, 2014–2015 to 2017–2018 (N = 144,779)

Variables	Alcohol exposed	Non-alcohol exposed	Overall	p-value
N (%)	1,593 (1.1)	143,186 (98.9)	144,779	N/A
Gestational age (weeks), mean (SD)	38.3 (2.2)	38.3 (2.2)	38.4 (2.0)	0.077
Sex, n (%)				0.616
Female	795 (49.9)	69,753 (48.7)	70,548 (48.7)	
Male	798 (50.1)	73,426 (51.3)	74,224 (51.3)	
Other	0 (0.0)	7 (0.0)	7 (0.0)	
Birth length (cm), mean (SD)	50.7 (3.4)	50.9 (3.0)	50.9 (3.0)	0.003*
Birth head circumference (cm), mean (SD)	34.5 (1.9)	34.7 (1.8)	34.7 (1.8)	<0.001**
IUGR, n (%)	42 (2.6)	3,418 (2.4)	3,460 (2.4)	0.51
NICU days (level 2), mean (SD)	7.80 (9.3)	8.41 (12.0)	8.40 (11.9)	0.541
NICU days (level 3), mean (SD)	8.79 (12.2)	15.98 (27.1)	15.89 (27.0)	0.195
Transfer NICU days (level 2), mean (SD)	3.52 (9.2)	3.10 (8.5)	3.10 (8.5)	0.604
Transfer NICU days (level 3), mean (SD)	3.37 (16.2)	1.60 (9.3)	1.62 (9.4)	0.051
Breastfeeding initiation, n (%)				<0.001**
≤1 hour	815 (51.2)	83,205 (58.1)	84,020 (58.0)	
>1 and ≤24 hours	499 (31.3)	42,984 (31.3)	43,483 (30.0)	
>24 hours	49 (3.1)	3,427 (2.4)	3,476 (2.4)	
N/A	156 (9.8)	4,756 (3.3)	4,912 (3.4)	
Unknown	74 (4.6)	8,814 (6.2)	8,888 (6.1)	
Newborn resuscitation/restabilization				
Drugs, n (%)				0.029*
Yes	19 (1.2)	932 (0.7)	951 (0.7)	
No	1,573 (98.7)	142,149 (99.3)	143,722 (99.3)	
Unknown	1 (0.1)	105 (0.1)	106 (0.1)	
Oxygen, n (%)	153 (9.6)	8,842 (6.2)	8,995 (6.2)	<0.001**
IPPV mask given, n (%)	170 (10.7)	9,441 (6.6)	9,611 (6.6)	<0.001**
Chest compressions given, n (%)	4 (0.3)	173 (0.1)	177 (0.1)	0.263

Source: BCPDR, Perinatal Services BC
Abbreviations: NICU, neonatal intensive care unit; IUGR, intrauterine growth restriction; IPPV, intermittent positive pressure ventilation; SD, standard deviation; N/A, not applicable
* Difference between alcohol exposed and non-alcohol exposed p <0.05
** Difference between alcohol exposed and non-alcohol exposed p <0.001

Appendix R: Adjusted Odds Ratio of Adverse Neonatal Outcomes Associated with Alcohol Indicated as a Risk Factor during Pregnancy in BC, 2014–15 to 2017–2018

ICD-10-CA code	Description	Odds ratio	Adjusted odds ratio[a]	Lower 95% CI	Upper 95% CI	p-value
P04.3	Fetus and newborn affected by maternal use of alcohol	135.84	55.93	21.11	158.32	<0.001**
P05.9	Slow fetal growth, unspecified&	1.40	1.07	0.79	1.41	0.648
P07.1	Other low birth weight (1,000-2,499g)	1.64	1.25	1.01	1.53	0.033*
P22.0	Respiratory distress syndrome	1.29	1.01	0.62	1.56	0.95
P24.0	Neonatal aspiration of meconium	0.76	0.72	0.22	1.71	0.52
P22.8	Other respiratory distress of newborns	2.72	2.57	1.52	4.07	<0.001**
P22.9	Respiratory distress of newborn, unspecified	1.22	0.98	0.64	1.42	0.90
P28.5	Respiratory failure of newborn	1.05	0.90	0.68	1.16	0.419
P28.9	Respiratory condition of newborn, unspecified	1.94	0.56	0.03	2.61	0.577
P29.9	Cardiovascular disorder originating in perinatal period, unspecified	0.00	0.00	N/A	N/A	0.97
P36	Bacterial sepsis of newborn	2.10	1.66	0.74	3.21	0.17
P90	Convulsion of newborn	2.69	1.58	0.47	3.92	0.385
P92.5	Neonatal difficulty in feed at breast	2.61	1.97	1.27	2.92	0.001*
P92.8	Other feeding problems of newborn	0.88	0.67	0.40	1.05	0.10
P92.9	Feeding problems, unspecified	2.53	2.06	1.31	3.09	<0.001**
P94.1	Congenital hypertonia	0.00	0.00	N/A	N/A	0.99
P96.1	Neonatal withdrawal symptoms from maternal use of drugs of addiction	3.90	0.37	0.21	0.60	<0.001**
P96.8	Other specified conditions originating in the perinatal period	3.07	2.02	0.70	4.58	0.13
Q05.9	Spina bifida, unspecified	0.00	0.00	N/A	N/A	1.00
Q24.9	Congenital malformations of heart, unspecified; includes anomaly or disease	2.19	5.34	0.30	25.58	0.100
Q35.9	Cleft palate, unspecified	1.58	1.42	0.08	7.08	0.74
Q36	Cleft lip without cleft palate	2.50	2.30	0.13	11.69	0.43
Q37	Cleft lip with cleft palate	1.21	1.02	0.06	4.87	0.98
Q86.0	Fetal alcohol syndrome (dysmorphic)	59.97	10.62	0.36	13.05	0.100
Q89.7	Multiple congenital malformations, not elsewhere classified	18.00	15.63	1.99	79.37	0.003*
Q89.9	Congenital malformation, unspecified	0.00	0.00	N/A	N/A	0.990
R25.1	Tremor, unspecified	2.64	1.46	0.08	7.38	0.718
R62.8	Other lack of expected normal physiological development, includes failure to gain weight, failure to thrive, infantilism NOS, lack of growth, & physical retardation	0.00	0.00	N/A	N/A	0.990
R68.1	Nonspecific symptoms peculiar to infancy, includes excessive crying of infant & irritable infant	0.00	0.00	N/A	6.78	0.975

Source: BCPDR, Perinatal Services BC
Abbreviations: CI, confidence interval; N/A, not applicable; NOS, not otherwise specified
a Adjusted for maternal age, maternal smoking status, any maternal substance use, parity, prior neonatal deaths, prior stillbirth and low birthweight, maternal history of any mental illness, and the number of antenatal visits
& Includes fetal growth restriction NOS, intrauterine fetal growth restriction, light for dates, light for gestational age (usually referred to weight below but length above 10th percentile), small and light for dates, small for dates, small for gestational (usually referred to weight and length below 10th percentile)
* Statistical significance of produced odds ratio has alpha = p <0.05
** Statistical significance of produced odds ratio has alpha = p <0.001

Appendix S: Demographic Characteristics, FASD Diagnosis, Reason for Referral, and Familial History of FASD of Individuals Diagnosed with FASD at the Asante Centre, 2015–2019 (N = 161)

Variables at time of assessment	
Total number of individuals	161
Year of diagnosis, n (%)	
2015	33 (54.1)
2016	13 (8.1)
2017	28 (17.4)
2018	79 (49.1)
2019	8 (5.0)
Diagnosis based on Chudley et al. 2005 guidelines, n (%)	
Alcohol-related neurodevelopmental disorder (ARND)	30 (83.3)
Partial fetal alcohol syndrome (pFAS)	6 (16.7)
Fetal alcohol syndrome (FAS)	<5
Alcohol-related birth defects (ARBD)	<5
Prenatally alcohol exposed	<5
Total	**37**
Diagnosis based on Cook et al. 2016 guidelines, n (%)	
FASD with sentinel facial features	16 (12.9)
FASD without sentinel facial features	91 (73.4)
At risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure — results of FASD assessment were not conclusive and FASD diagnosis cannot be confirmed	17 (13.7)
Total	**124**
Reasons for referral/assessment*, n (%)	
Learning and cognitive problems	84 (52.2)
Behavioural problems	63 (39.1)
Mental health problems	36 (22.4)
Social problems	31 (19.3)
Lack of independence	19 (11.8)
Substance use problems	16 (9.9)
Language problems	13 (8.1)
Suspected of ASD and/or ADHD	12 (7.5)
Physical health problems	7 (4.3)
Trauma/adversity	6 (3.7)
Self-referral	<5
Other referral	41 (25.5)
Age (years), n (%)	
3-9	46 (28.6)
10-19	92 (57.1)
20+	23 (14.3)
Mean (SD)	15.72 (9.1)

Variables at time of assessment	
Range	3-52
Sex (male), n (%)	86 (53.4)
Language spoken, n (%)	
English	158 (98.1)
English and Spanish	<5
English and Russian	<5
Living arrangement at the time of assessment, n (%)	
Foster family	28 (17.4)
Birth family	23 (14.3)
Extended family	20 (12.4)
In adoptive/foster care with some biological/extended family members	18 (11.2)
Living independently	18 (11.2)
Immediate birth and extended family	17 (10.6)
Group home and/or community living	17 (10.6)
Adoptive family	10 (6.2)
Detained at youth custody services centre	<5
Mental health and substance use treatment centre, youth treatment centre, or at a psychiatric inpatient centre	<5
Unknown	<5
Adoption status, n (%)	
Yes	32 (19.9)
No	129 (80.1)
Geographic location, n (%)	
Rural and/or remote community	34 (21.1)
Urban centre	127 (78.9)
Sibling with FASD, n (%)	
Yes	34 (21.1)
No	36 (22.4)
Unknown	83 (51.6)
No siblings (not applicable)	8 (5.0)
Parent with FASD, n (%)	
Yes	11 (6.8)
No	56 (34.8)
Unknown	94 (58.4)
Previous/current involvement with child welfare system, n (%)	
Yes	121 (75.2)
No	40 (24.8)
Previous/current involvement with criminal justice system, n (%)	
Yes	48 (29.8)
Ages 3-9	0
Ages 10-19	43
Ages 20+	5
No	113 (70.1)

Source: Asante Centre

Appendix T: Psychological/Developmental Diagnoses and Physical Co-morbidities among Individuals Diagnosed with FASD at the Asante Centre, 2015–2019 (N = 161)

Variables at time of assessment	n (%)
Current psychological/developmental diagnoses*	
Learning disorders and cognitive issues	57 (35.4)
ADHD	48 (29.8)
Neurodevelopmental disorders	39 (24.2)
Anxiety	23 (14.3)
Brain damage (due to prenatal alcohol exposure)	20 (12.4)
Mood disorders	15 (9.3)
Language and communication disorder	10 (6.2)
Trauma	8 (5.0)
Drug-related use issues/disorders	7 (4.3)
Aggressive behaviour/harm to others	<5
Attachment disorders	<5
Disruptive behaviour disorders	<5
Emotional problems	<5
Mental health concerns, unspecified	<5
Motor disorders	<5
Psychotic disorders	<5
Self-harm	<5
Suicidal behaviour	<5
None	11 (6.8)
Missing	25 (15.5)
Past psychological/developmental diagnoses	
ADHD	50 (31.1)
Anxiety	33 (20.5)
Mood disorders	23 (14.3)
Disruptive behaviour disorders	21(13.0)
Learning disorders and cognitive issues	17 (10.6)
Relational and attachment problems	15 (9.3)
Trauma and stress-related disorders	14 (8.7)
Drug-use related problems/disorders	13 (8.1)
Language and communication disorder	9 (5.6)
Neurodevelopmental disorders	7 (4.3)
Personality disorders	6 (3.7)
Psychosis	6 (3.7)
Motor disorders	5 (3.1)
Aggressive behaviour/harm to others	<5
Brain damage (due to prenatal alcohol exposure)	<5
Eating disorders	<5
Emotional problems	<5
Gender dysphoria	<5
Mental health concerns, not specified	<5
Physical condition	<5
Premenstrual syndrome	<5
Self-harm	<5
Seizure	<5
Suicidal behaviour	<5
None	23 (14.3)
Missing	58 (36.0)
Physical comorbidities	
Respiratory problems	22 (13.7)
Hearing problems	9 (5.6)
Congenital malformations and deformations	6 (3.7)
Infections	6 (3.7)
Skin issues	6 (3.7)
Chronic/acute pain	5 (3.1)
Urinary issues	5 (3.1)
Allergies	<5
Blood issues	<5
Drug use-related issues/disorders	<5
Gastrointestinal issues	<5
Genetic disorders	<5
Heart issues	<5
Kidney problems	<5
Low iron/anemia	<5
Neurological problems	<5
Seizure(s)	<5
Vision issues	<5
None	100 (62.1)
Missing	<5

Source: Asante Centre
Abbreviations: ASD, autism spectrum disorder; ADHD, attention-deficit/hyperactivity disorder
* These categories are not mutually exclusive

Appendix U: Stratified Analysis (Fisher Tests) by Sex, Age, Diagnosis, Criminal Justice System and Child Welfare Involvement for Individuals Diagnosed with FASD at the Asante Centre, 2015–2019 (N = 161)

Variable	Sex p-value	Age p-value	Diagnosis p-value	Criminal justice p-value	Child welfare p-value
Age	0.809	-	0.020	0.545	0.840
Year of diagnosis	0.256	0.051	0.361	0.009	0.813
Sex	-	0.596	0.782	0.277	0.252
Language spoken	0.558	0.847	0.154	0.482	0.603
Living arrangement at the time of assessment	0.077	<0.001*	0.253	0.182	<0.001*
Adoption status	0.814	0.414	0.533	0.110	0.013
Geographic location	0.798	0.025	0.028	0.792	0.002
Combined FASD diagnosis	0.782	<0.001	-	0.720	0.357
Previous/current involvement with child welfare system	0.252	0.306	0.357	1.000	-
Previous/current involvement with criminal justice system	0.521	<0.001*	0.056	-	0.865
Sibling with FASD	0.519	0.399	0.846	0.191	0.159
Parent with FASD	0.685	0.804	0.432	0.270	0.126
Prenatal exposures					
Tobacco	0.097	0.147	0.925	0.943	0.196
Opioids	0.244	0.152	0.375	0.942	0.134
Cannabis	0.211	0.071	0.922	0.030	0.291
Stimulants	0.238	0.014	0.953	0.943	0.013
Prescription medications	0.195	0.200	0.860	0.367	0.334
Antidepressants	0.276	0.205	0.028	0.643	0.150
Drug use unspecified (illicit and/or prescription)	0.103	0.164	0.809	0.888	0.119
Other maternal risk behaviour, adversities, and/or stressful life events during pregnancy	0.246	0.019	0.071	0.957	0.381
Missing, poor, lack of access to prenatal care exposure	0.288	0.204	0.790	0.966	0.006
Precarious situations	0.170	0.071	0.939	0.964	0.153
None	0.155	0.042	0.950	0.461	0.340
Reasons for referral/assessment					
Behavioural problems	0.637	0.031	0.965	0.007	0.498
Learning and cognitive problems	0.565	0.087	0.398	0.260	0.463
Language problems	0.562	0.062	0.868	0.412	0.746
Mental health problems	0.248	0.616	0.511	0.661	0.391
Physical problems	0.512	0.225	0.622	0.332	0.754
Social problems	0.245	0.120	0.453	0.051	0.841
Lack of independence	0.381	0.584	0.272	0.324	0.774
Trauma/adversity	0.305	0.001	0.725	0.543	0.620
Substance use problems	0.623	0.042	0.179	0.046	0.402
Suspected ADHD	0.601	0.005	0.819	0.227	0.018
Other referral	0.418	0.006	0.967	0.533	0.847

Variable	Sex p-value	Age p-value	Diagnosis p-value	Criminal justice p-value	Child welfare p-value
Current psychological/developmental disorders					
ADHD	0.264	<0.001*	0.103	0.953	0.264
Neurodevelopmental disorders	0.451	0.001	0.012	0.851	0.504
Learning disorders and cognitive issues	0.521	<0.001*	0.161	0.075	0.467
Language and communication disorders	0.557	0.001	0.364	0.920	0.755
Anxiety	0.438	0.004	0.104	0.927	0.738
Mood disorders	0.545	<0.001	0.551	0.820	0.331
Brain damage (due to prenatal alcohol exposure)	0.590	0.006	0.184	0.419	0.231
Trauma and stress-related disorders	0.538	0.003	0.603	0.665	0.557
Drug-use related problems/disorders	0.207	0.001	0.339	0.239	0.817
None	0.471	0.005	0.481	0.763	0.692
Past psychological/developmental disorders					
ADHD	0.536	0.093	0.063	0.142	0.015
Neurodevelopmental disorders	0.596	0.037	0.080	0.635	0.030
Learning disorders and cognitive issues	0.257	0.018	0.073	0.583	0.035
Language and communication disorders	0.083	0.043	0.125	0.332	0.019
Anxiety	0.273	0.084	0.084	0.339	0.036
Mood disorders	0.002	0.005	0.034	0.559	0.044
Trauma and stress-related disorders	0.620	0.096	0.074	0.306	0.023
Drug-use related problems/disorders	0.223	0.012	0.115	0.261	0.042
Disruptive behaviour disorders	0.753	0.055	0.086	0.662	0.040
Relational/attachment issues	0.358	0.089	0.095	0.463	0.025
Motor disorders	0.339	0.066	0.089	0.076	0.027
Personality disorders	0.170	0.059	0.080	0.635	0.024
Psychosis	0.170	0.059	0.075	0.343	0.024
None	0.473	0.073	0.092	0.265	0.040
Current substance use					
Any current substance use	0.163	<0.001*	0.056	<0.001	0.565
Tobacco	0.199	<0.001	0.232	0.556	0.675
Cannabis	0.092	<0.001	0.676	0.011	0.479
Alcohol	0.248	<0.001	0.942	0.379	0.271
Stimulants	0.205	0.012	0.995	0.415	0.792
Previous use, unspecified	0.265	0.002	0.403	0.033	0.745
None	0.163	<0.001*	0.056	<0.001	0.565
Past substance use					
Any previous substance use	0.592	<0.001*	0.110	<0.001*	0.716
Tobacco	0.179	0.007	0.194	0.889	0.752
Cannabis	0.191	<0.001*	0.191	0.003	0.810
Alcohol	0.277	<0.001*	0.440	0.660	0.782
Opioids	0.623	0.004	0.456	0.437	0.640
Hallucinogens	0.584	0.009	0.319	0.193	0.388
Stimulants	0.324	<0.001*	0.289	0.051	0.250
Previous use, unspecified	0.353	0.002	0.232	0.078	0.536

Variable	Sex p-value	Age p-value	Diagnosis p-value	Criminal justice p-value	Child welfare p-value
None	0.592	<0.001*	0.110	<0.001*	0.716
Physical comorbidities					
Hearing problems	0.192	0.146	0.709	0.462	0.416
Infections	0.634	0.102	0.287	0.479	0.532
Congenital malformations and deformations	0.462	0.554	0.287	0.154	0.207
Chronic/acute pain	0.641	0.410	0.697	0.372	0.114
Respiratory problems	0.475	0.065	0.857	0.158	0.588
Urinary issues	0.394	0.755	0.659	0.059	0.309
Skin issues	0.634	0.487	0.863	0.460	0.207
None	0.721	0.005	0.770	0.465	0.583

Source: Asante Centre
Abbreviations: ADHD, attention-deficit/hyperactivity disorder
* p-value remained significant after Bonferroni correction

Appendix V: Substance Use, Mental Health, and Pregnancy Conditions among Women with Alcohol-Exposed Pregnancies in Ontario, 2015–2016 to 2017–2018 (N = 9,786)

	2015–2016, n = 3,240	2016–2017, n = 3,332	2017–2018, n = 3,214	All years combined, n = 9,786
Alcohol use during pregnancy, n (%)				
Episodic excessive drinking (binging)	89 (2.8)	77 (2.3)	98 (3.1)	**264 (2.7)**
2-3 drinks per month	212 (6.5)	175 (5.3)	177 (5.5)	**564 (5.8)**
1 drink per week	115 (3.6)	147 (4.4)	105 (3.3)	**367 (3.8)**
>1 drink per month	114 (3.5)	96 (2.9)	108 (3.4)	**318 (3.3)**
1 drink per month	184 (5.7)	226 (6.8)	208 (6.5)	**618 (6.3)**
<1 drink per month	1,123 (34.7)	1,068 (32.1)	1,027 (32.0)	**3,218 (32.9)**
Exposure prior to pregnancy confirmation, amount unknown	1,391 (42.9)	1,507 (45.2)	1,450 (45.1)	**4,348 (44.4)**
Exposure, amount unknown	12 (0.4)	36 (1.1)	41 (1.3)	**89 (0.9)**
Smoking at first prenatal visit, n (%)				
>20 cigarettes per day	77 (2.4)	68 (2.1)	55 (1.7)	**200 (2.1)**
10-20 cigarettes per day	272 (8.5)	258 (7.8)	229 (7.2)	**759 (7.8)**
<10 cigarettes per day	602 (18.7)	598 (18.1)	601 (18.8)	**1,801 (18.5)**
Amount unknown	47 (1.5)	61 (1.8)	69 (2.2)	**177 (1.8)**
None	2,215 (68.9)	2,324 (70.2)	2,240 (70.1)	**6,779 (69.8)**
Mother resides with smoker at first prenatal visit, n (%)	1,008 (31.1)	1,052 (31.6)	995 (31.0)	**3,055 (31.2)**
Drug and substance exposure during pregnancy, n (%)				
Marijuana	304 (9.5)	321 (9.8)	303 (9.7)	**928 (9.7)**
Cocaine	40 (1.3)	46 (1.4)	47 (1.5)	**133 (1.4)**
Other	34 (1.1)	31 (1.0)	26 (0.8)	**91 (1.0)**
Opioids (misuse)	25 (0.8)	28 (0.9)	29 (0.9)	**82 (0.9)**
Gas/glue	<6	<6	<6	**6 (0.1)**
Hallucinogens	<6	<6	<6	**S**
2 drugs	79 (2.5)	93 (2.8)	93 (3.0)	**265 (2.8)**
3 or more drugs	28 (0.9)	22 (0.7)	32 (1.0)	**82 (0.9)**
None	2,688 (83.9)	2,728 (83.4)	2,609 (83.1)	**8,025 (83.5)**

	2015–2016, n = 3,240	2016–2017, n = 3,332	2017–2018, n = 3,214	All years combined, n = 9,786
Pre-existing or current mental health concern(s), n (%)				
Anxiety	260 (8.1)	265 (8.1)	276 (8.8)	**801 (8.3)**
Depression	183 (5.7)	218 (6.7)	168 (5.4)	**569 (5.9)**
Addiction	62 (1.9)	43 (1.3)	65 (2.1)	**170 (1.8)**
History of postpartum depression	52 (1.6)	63 (1.9)	50 (1.6)	**165 (1.7)**
Other	30 (0.9)	45 (1.4)	43 (1.4)	**118 (1.2)**
Bipolar	17 (0.5)	24 (0.7)	17 (0.5)	**58 (0.6)**
Schizophrenia	<6	<6	<6	**8 (0.1)**
2 mental health concerns (incl. addiction)	37 (1.2)	24 (0.7)	35 (1.1)	**96 (1.0)**
3 or more mental health concerns (incl. addiction)	48 (1.5)	53 (1.6)	48 (1.5)	**149 (1.6)**
2 mental health concerns (excl. addiction)	271 (8.4)	293 (9.0)	325 (10.3)	**889 (9.2)**
3 or more mental health concerns (excl. addiction)	64 (2.0)	63 (1.9)	69 (2.2)	**196 (2.0)**
None	2,192 (68.1)	2,178 (66.6)	2,042 (65.0)	**6,412 (66.6)**
Prenatal classes, n (%)	800 (24.7)	821 (24.6)	748 (23.3)	**2,369 (24.2)**
Intention to breastfeed, n (%)				
Yes, intends to exclusively breastfeed	2,430 (78.7)	2,508 (77.6)	2,379 (77.2)	**7,317 (77.8)**
Yes, intends to combination feed (breast milk / substitute)	320 (10.4)	310 (9.6)	339 (11.0)	**969 (10.3)**
No, does not intend to breastfeed	283 (9.2)	340 (10.5)	301 (9.8)	**924 (9.8)**
Mother unsure	55 (1.8)	73 (2.3)	62 (2.0)	**190 (2.0)**
Any fetal/maternal/placental pregnancy complication(s), n (%)	781 (24.4)	887 (26.9)	853 (26.9)	**2,521 (26.1)**
Hypertension disorder in pregnancy, n (%)				
Preeclampsia*	129 (4.0)	146 (4.4)	134 (4.2)	**409 (4.2)**
Gestational hypertension	53 (1.6)	57 (1.7)	41 (1.3)	**151 (1.5)**
Pre-existing hypertension**	8 (0.3)	8 (0.2)	13 (0.4)	**29 (0.3)**
None	3,046 (94.1)	3,119 (93.7)	3,020 (94.1)	**9,185 (94.0)**
Referred to specialized antenatal screening due to ultrasound abnormality, n (%)	43 (1.3)	35 (1.1)	25 (0.8)	**103 (1.1)**

Source: BORN Ontario

Please note: variables with missing data excluded missing from percentage calculations (i.e., N of numerator / [N of denominator - N of missing]). Records with missing values for any variables required to calculate the numerator were included in the number of missing, the percentage was calculated by using N of Missing / N of denominator. Percentages displayed in the table are column percentages. S, suppressed due to cell size <6

* Includes HELLP syndrome, eclampsia, preeclampsia, preeclampsia requiring magnesium sulfate, and pre-existing hypertension with superimposed preeclampsia

** Not including pre-existing hypertension with superimposed preeclampsia

Appendix W: Frequency and Percentage of Confirmed Congenital Anomalies among Prenatally Alcohol-Exposed Neonates Born in Ontario, April 1, 2015–March 31, 2018 (N = 10,308)

Confirmed congenital anomaly	Number	Percent
Missing data	57	21.0
None (anomaly was suspected by not confirmed)	39	14.4
Cardiovascular / atrial septal defect	20	7.4
Cardiovascular / ventricular septal defect (VSD)	12	4.4
Head — cranium & brain / other — malformations of the head & brain	10	3.7
Extremities — skeletal / hands, feet, club foot	9	3.3
Genitourinary tract / hypospadias	8	3.0
Cardiovascular, other heart abnormalities	7	2.6
Face/mouth — cleft lip & palate	7	2.6
Genitourinary tract / hydronephrosis (>10 mm)	7	2.6
Twins / dichorionic (DC) twins	6	2.2
Abdominal wall / gastroschisis	<6	S
Abdominal wall / omphalocele (exomphalos)	<6	S
Face/mouth — cleft palate	<6	S
Cardiovascular / arrhythmia	<6	S
Cardiovascular / tetralogy of Fallot (TOF)	<6	S
Chromosomes / trisomy 21 (Down syndrome)	<6	S
Extremities — skeletal / generalized/other — congenital malformations of spine & bony thorax	<6	S
Extremities — skeletal / hands/feet — polydactyly (feet)	<6	S
Genitourinary tract / renal agenesis	<6	S
Gastrointestinal / Other — malformations of the gastro-intestinal tract	<6	S
Head — cranium & brain / anencephaly	<6	S
Thorax / congenital diaphragmatic hernia (CDH)	<6	S
Thorax / other — congenital malformations of lung	<6	S
Abdominal wall / umbilical hernia	<6	S
Abdominal wall / other — congenital malformations of abdominal wall	<6	S
Cardiovascular / atrioventricular septal defect (AVSD) (endocardial cushion defect)	<6	S
Cardiovascular / premature closure of atrial septum	<6	S
Cardiovascular / pulmonary (valve) atresia	<6	S
Cardiovascular / supra ventricular tachycardia (SVT)	<6	S
Face / other — malformations of the face	<6	S
Genitourinary tract / other — malformations of urinary system	<6	S
Gastrointestinal / abnormal small bowel	<6	S
Gastrointestinal / duodenal atresia	<6	S
Head — cranium & brain / hydrocephalus	<6	S
Spine — back / other — malformations of the spine	<6	S
Structural — other / other — malformations not classified elsewhere	<6	S
Thorax / pulmonary hypoplasia	<6	S

Confirmed congenital anomaly	Number	Percent
Cardiovascular / ductus arteriosus — patent (PDA)	<6	S
Cardiovascular / other — cardiac malformations not classified elsewhere	<6	S
Extremities — skeletal / Generalized/other — hip dislocation — congenital	<6	S
Extremities — skeletal / generalized/other — skeletal dysplasia —other	<6	S
Extremities — skeletal / hands/feet — adactyly (absent fingers/ toes)	<6	S
Extremities — skeletal / hands/feet — clinodactyly (fifth finger)	<6	S
Extremities — skeletal / hands/feet — polydactyly (hands)	<6	S
Extremities — skeletal / hands/feet — syndactyly (feet)	<6	S
Extremities — skeletal / hands/feet — syndactyly (hands)	<6	S
Face / mouth — cleft lip	<6	S
Genitourinary tract / hydrocoele	<6	S
Genitourinary tract / renal cyst	<6	S
Genitourinary tract / undescended testicle(s)	<6	S
Genitourinary tract / other — malformations of male genitalia	<6	S
Gastrointestinal / abnormal esophagus	<6	S
Gastrointestinal / tracheo-esophageal fistula (TEF)	<6	S
Head — cranium & brain / Arnold Chiari malformation	<6	S
Spine — back / NTD (neural tube defect) with hydrocephalus	<6	S
Gastrointestinal / bowel obstruction small or large intestine	<6	S
Cardiovascular / aortic valve stenosis	<6	S
Cardiovascular / cardiomegaly	<6	S
Cardiovascular / coarctation of aorta	<6	S
Cardiovascular / double inlet ventricle (DIV)	<6	S
Cardiovascular / double outlet ventricle (DOV)	<6	S
Cardiovascular / aortic arch — hypoplastic	<6	S
Cardiovascular / hypoplastic left heart syndrome (HLHS)	<6	S
Cardiovascular / mitral valve dysplasia	<6	S
Cardiovascular / pericardial effusion	<6	S
Cardiovascular / pulmonary insufficiency	<6	S
Cardiovascular / single ventricle / univentricular connection	<6	S
Cardiovascular / transposition of great vessels (TGA)	<6	S
Chromosomes / trisomy 13	<6	S
Chromosomes / other	<6	S
Congenital infections / other — infections	<6	S
Extremities — skeletal / arms/legs — fracture(s) — long bones	<6	S
Extremities — skeletal / generalized/other — arthrogryposis multiplex congenital	<6	S
Extremities — skeletal / hands/feet	<6	S
Extremities — skeletal / hands/feet — ectrodactyly (lobster-claw / cleft hand)	<6	S
Extremities — skeletal / hands/feet — fused toes	<6	S
Extremities — skeletal / hands/feet — webbed toes	<6	S
Extremities — skeletal / muscle/connective tissue disorders — other — malformations of the musculoskeletal system	<6	S
Face / eyes	<6	S
Face / eyes — hypertelorism	<6	S
Face / mouth — retrognathia	<6	S

Confirmed congenital anomaly	Number	Percent
Genitourinary tract / bladder abnormalities	<6	S
Genitourinary tract / cystic kidney(s) — other	<6	S
Genitourinary tract / duplex kidney/collecting system	<6	S
Genitourinary tract / ectopic/pelvic kidney	<6	S
Genitourinary tract / multi-cystic kidney disease (MCKD)	<6	S
Gastrointestinal / atresia small or large intestine	<6	S
Gastrointestinal / Hirschsprung's disease	<6	S
Gastrointestinal / imperforate anus	<6	S
Gastrointestinal / esophageal atresia	<6	S
Gastrointestinal / pyloric stenosis	<6	S
Head — cranium & brain / acrania	<6	S
Head — cranium & brain / Dandy-Walker malformation / variant (DWM)	<6	S
Head — cranium & brain / holoprosencephaly	<6	S
Head — cranium & brain / macrocephaly	<6	S
Head — cranium & brain / megalencephaly	<6	S
Head — cranium & brain / ventriculomegaly — mild (10-15 mm)	<6	S
Neck / neck tumour — other	<6	S
Structural — other / amniotic bands	<6	S
Syndromes / syndrome not otherwise specified	<6	S
Syndromes / TAR (thrombocytopenia-absent radius) syndrome	<6	S
Thorax / lung cysts — other	<6	S
Thorax / pleural effusion(s) (hydrothorax)	<6	S
Structural — other / hydrops fetalis	<6	S
Total	271	100.0

Source: BORN Ontario
Please note: the table displays column percentages. S, suppressed due to cell size <6. Categories are not mutually exclusive and therefore the percentages do not sum up to 100.

Appendix X: List of Alcohol-Related ICD-10 and OHIP Diagnostic Codes Used to Identify Maternal Records in ICES Cohort 1, 2003–2017

Diagnostic codes (ICD-10-CA) from DAD, and NACRS	
ICD-10 diagnostic code	**Code description**
E24.4	Alcohol-induced pseudo–Cushing's syndrome
F10.1	Mental and behavioural disorders due to use of alcohol, harmful use
F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome
F10.3	Withdrawal state
F10.4	Withdrawal state with delirium
F10.5	Psychotic disorder
F10.6	Amnesic syndrome
F10.7	Residual and late-onset psychotic disorder
F10.8	Other mental and behavioural disorders
F10.9	Alcohol use, unspecified
G31.2	Degeneration of nervous system due to alcohol
G62.1	Alcoholic polyneuropathy
G72.1	Alcoholic myopathy
I42.6	Alcoholic cardiomyopathy
K29.2	Alcoholic gastritis
K70	Alcoholic liver disease
K85.2	Alcohol induced acute pancreatitis
K86.0	Alcohol-induced chronic pancreatitis
O35401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition
O35403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication
O35409	Maternal care for (suspected) damage to fetus from alcohol, unspecified as to episode of care, or not applicable
R78.0	Finding of alcohol in blood
T51	Toxic effect of alcohol
T51.0	Ethanol
T51.1	Methanol
T51.8	Other alcohols
T51.9	Alcohol unspecified
X45	Accidental poisoning by and exposure to alcohol
X65	Intentional self-poisoning by and exposure to alcohol
Y90	Evidence of alcohol involvement determined by blood alcohol level
Y90.0	Blood alcohol level of less than 20 mg/100 ml
Y90.1	Blood alcohol level of 20-39 mg/100 ml
Y90.2	Blood alcohol level of 40-59 mg/100 ml
Y90.3	Blood alcohol level of 60-79 mg/100 ml
Y90.4	Blood alcohol level of 80-99 mg/100 ml
Y90.5	Blood alcohol level of 100-119 mg/100 ml

Diagnostic codes (ICD-10-CA) from DAD, and NACRS	
ICD-10 diagnostic code	**Code description**
Y90.6	Blood alcohol level of 120-199 mg/100 ml
Y90.7	Blood alcohol level of 200-239 mg/100 ml
Y90.8	Blood alcohol level of 240 mg/100 ml or more
Y90.9	Presence of alcohol in blood, level not specified
OHIP diagnostic code*	**Code description**
291	Alcoholic psychosis, delirium tremens, Korsakov's psychosis
303	Alcoholism
571	Cirrhosis of the liver (e.g., alcoholic cirrhosis, biliary cirrhosis)

* Collected from any/all physician billings that occur on the date of admission and period of hospitalization

Appendix Y: Number, Percentage, and Administrative Prevalence of Pregnant Women with Alcohol-Related Diagnoses Who Utilized Hospital-Based Care (Acute Care Hospitalizations, Emergency Department Visits, or at Birth) in Ontario, 2003–2017

Year	ICD-10-CA code	Code description	Number of mothers	Percentage of mothers	Prevalence per 10,000 birth events	Total number of birth events
2003	F10	Mental and behavioural disorders due to use of alcohol	76	0.06	5.92	128,420
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	30	0.02	2.34	128,420
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	29	0.02	2.26	128,420
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	23	0.02	1.79	128,420
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	6	0.00	0.47	128,420
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	128,420
	With two or more alcohol-related diagnoses		77	0.06	6.00	128,420
	With any alcohol-related diagnosis		83	0.06	6.46	128,420
2004	F10	Mental and behavioural disorders due to use of alcohol	77	0.06	5.89	130,818
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	34	0.03	2.60	130,818
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	32	0.02	2.45	130,818
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	16	0.01	1.22	130,818
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	130,818
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	130,818
	With two or more alcohol-related diagnoses		77	0.06	5.89	130,818
	With any alcohol-related diagnosis		82	0.06	6.27	130,818
2005	F10	Mental and behavioural disorders due to use of alcohol	90	0.07	6.84	131,557
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	37	0.03	2.81	131,557
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	32	0.02	2.43	131,557
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	24	0.02	1.82	131,557
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	131,557
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	131,557
	With two or more alcohol-related diagnoses		93	0.07	7.07	131,557
	With any alcohol-related diagnosis		98	0.07	7.45	131,557
2006	F10	Mental and behavioural disorders due to use of alcohol	92	0.07	6.90	133,308
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	39	0.03	2.93	133,308
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	45	0.03	3.38	133,308

Year	ICD-10-CA code	Code description	Number of mothers	Percentage of mothers	Prevalence per 10,000 birth events	Total number of birth events
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	12	0.01	0.90	133,308
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	133,308
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	133,308
	With two or more alcohol-related diagnoses		96	0.07	7.20	133,308
	With any alcohol-related diagnosis		102	0.08	7.65	133,308
2007	F10	Mental and behavioural disorders due to use of alcohol	72	0.05	5.31	135,620
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	31	0.02	2.29	135,620
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	36	0.03	2.65	135,620
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	11	0.01	0.81	135,620
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	135,620
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	135,620
	With two or more alcohol-related diagnoses		74	0.05	5.46	135,620
	With any alcohol-related diagnosis		81	0.06	5.97	135,620
2008	F10	Mental and behavioural disorders due to use of alcohol	109	0.08	8.01	136,102
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	40	0.03	2.94	136,102
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	53	0.04	3.89	136,102
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	17	0.01	1.25	136,102
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	136,102
	With two or more alcohol-related diagnoses		110	0.08	8.08	136,102
	With any alcohol-related diagnosis		113	0.08	8.30	136,102
2009	F10	Mental and behavioural disorders due to use of alcohol	86	0.06	6.36	135,279
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	32	0.02	2.37	135,279
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	43	0.03	3.18	135,279
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	11	0.01	0.81	135,279
	F10.3	Mental and behavioural disorders due to use of alcohol, withdrawal state	6	0.00	0.44	135,279
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	135,279
	With two or more alcohol-related diagnoses		88	0.07	6.51	135,279
	With any alcohol-related diagnosis		92	0.07	6.80	135,279
2010	F10	Mental and behavioural disorders due to use of alcohol	110	0.08	8.25	133,384
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	43	0.03	3.22	133,384
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	48	0.04	3.60	133,384
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	19	0.01	1.42	133,384

Year	ICD-10-CA code	Code description	Number of mothers	Percentage of mothers	Prevalence per 10,000 birth events	Total number of birth events
	F10.3	Mental and behavioural disorders due to use of alcohol, withdrawal state	7	0.01	0.52	133,384
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	133,384
	With two or more alcohol-related diagnoses		112	0.08	8.40	133,384
	With any alcohol-related diagnosis		119	0.09	8.92	133,384
2011	F10	Mental and behavioural disorders due to use of alcohol	74	0.06	5.56	133,153
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	35	0.03	2.63	133,153
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	29	0.02	2.18	133,153
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	11	0.01	0.83	133,153
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	133,153
	With two or more alcohol-related diagnoses		75	0.06	5.63	133,153
	With any alcohol-related diagnosis		80	0.06	6.01	133,153
2012	F10	Mental and behavioural disorders due to use of alcohol	97	0.07	7.25	133,820
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	31	0.02	2.32	133,820
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	59	0.04	4.41	133,820
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	15	0.01	1.12	133,820
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	133,820
	With two or more alcohol-related diagnoses		98	0.07	7.32	133,820
	With any alcohol-related diagnosis		100	0.07	7.47	133,820
2013	F10	Mental and behavioural disorders due to use of alcohol	77	0.06	5.87	131,249
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	30	0.02	2.29	131,249
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	44	0.03	3.35	131,249
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	8	0.01	0.61	131,249
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	131,249
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	131,249
	With two or more alcohol-related diagnoses		81	0.06	6.17	131,249
	With any alcohol-related diagnosis		86	0.07	6.55	131,249
2014	F10	Mental and behavioural disorders due to use of alcohol	100	0.08	7.62	131,173
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	49	0.04	3.74	131,173
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	43	0.03	3.28	131,173
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	12	0.01	0.91	131,173
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	131,173
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	131,173

Year	ICD-10-CA code	Code description	Number of mothers	Percentage of mothers	Prevalence per 10,000 birth events	Total number of birth events
	With two or more alcohol-related diagnoses		102	0.08	7.78	131,173
	With any alcohol-related diagnosis		108	0.08	8.23	131,173
2015	F10	Mental and behavioural disorders due to use of alcohol	112	0.09	8.59	130,454
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	49	0.04	3.76	130,454
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	55	0.04	4.22	130,454
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	20	0.02	1.53	130,454
	F10.3	Mental and behavioural disorders due to use of alcohol, withdrawal state	7	0.01	0.54	130,454
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	130,454
	O35.403	Maternal care for (suspected) damage to fetus from alcohol, antepartum condition or complication	<6	S	S	130,454
	With two or more alcohol-related diagnoses		114	0.09	8.74	130,454
	With any alcohol-related diagnosis		121	0.09	9.28	130,454
2016	F10	Mental and behavioural disorders due to use of alcohol	129	0.10	9.85	130,960
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	42	0.03	3.21	130,960
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	69	0.05	5.27	130,960
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	22	0.02	1.68	130,960
	F10.3	Mental and behavioural disorders due to use of alcohol, withdrawal state	11	0.01	0.84	130,960
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	130,960
	With two or more alcohol-related diagnoses		131	0.10	10.00	130,960
	With any alcohol-related diagnosis		140	0.11	10.69	130,960
2017	F10	Mental and behavioural disorders due to use of alcohol	140	0.11	10.71	130,673
	F10.0	Mental and behavioural disorders due to use of alcohol, acute intoxication	48	0.04	3.67	130,673
	F10.1	Mental and behavioural disorders due to use of alcohol, harmful use	77	0.06	5.89	130,673
	F10.2	Mental and behavioural disorders due to use of alcohol, dependence syndrome	21	0.02	1.61	130,673
	F10.3	Mental and behavioural disorders due to use of alcohol, withdrawal state	13	0.01	0.99	130,673
	O35.401	Maternal care for (suspected) damage to fetus from alcohol, delivered, with or without mention of antepartum condition	<6	S	S	130,673
	With two or more alcohol-related diagnoses		143	0.11	10.94	130,673
	With any alcohol-related diagnosis		149	0.11	11.40	130,673

Sources: ICES data holdings including DAD, SDS, NACRS, OHIP, and RPDB
Abbreviation: S, suppressed
Please note: the following alcohol-related codes were not reported due to low cell counts (<6): F10.4, Withdrawal state with delirium; F10.9, Alcohol use, unspecified; K29.2, Alcoholic gastritis; K70, Alcoholic liver disease; K85.2, Alcohol-induced acute pancreatitis; K86.0, Alcohol-induced chronic pancreatitis; R78.0, Finding of alcohol in blood; T51, Toxic effect of alcohol; T51.0, Ethanol; T51.8, Other alcohols; X45, Accidental poisoning by and exposure to alcohol; X65, Intentional self-poisoning by and exposure to alcohol; and Y90, Evidence of alcohol involvement determined by blood alcohol level