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Fetal Alcohol Spectrum Disorder

Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome: Results of a National Survey

Canada

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Acknowledgements

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Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and/or learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

FASD is the leading non-genetic cause of mental retardation in the Western world, affecting approximately 1% of Canadians. It has been estimated that the lifetime extra costs for affected individuals in Canada are $1.4 million. Perhaps most important are the significant social and health impacts for people with FASD, their families and society.

This study collected information from Canadian health care professionals (a random sample of 5,361 paediatricians, psychiatrists, obstetricians and gynaecologists, midwives and family physicians) to determine their current levels of knowledge and attitudes towards Fetal Alcohol Syndrome (FAS) and alcohol use during pregnancy. The response rate to the survey was 41.3%, with rates ranging from a low of 31.1% among family physicians to a high of 63.5% among midwives.

The objective of this study was to determine, on a national level and across selected health care professional groups, knowledge and attitudes regarding alcohol use and Fetal Alcohol Syndrome.

The results provide insight into areas where educational initiatives for health care professionals could be directed, as well as areas where they require support in dealing with the complex issues and outcomes associated with alcohol use during pregnancy. The survey findings provide baseline information that could be used in assessing the effectiveness of educational initiatives and policy in the area of health care professional practice.

The study methodology and questionnaire were developed after consultation with stakeholder groups and clinical experts, including the Health Canada National Advisory Committee on FASD and representatives from the Canadian Paediatric Society, the Canadian Psychiatric Association, the Society of Obstetricians and Gynaecologists of Canada, the College of Family Physicians of Canada and the National Association of Midwives, as well as international experts. The study was approved by the Child Health Scientific Review Committee of the Calgary Health Region and received ethical approval from the Conjoint Health Research Ethics Board of the University of Calgary.

Key Findings and Recommendations

In general, the survey results suggest that Canadian health care providers, while aware of some aspects of FASD, require more education and training to support their work of caring for both individuals at risk for having a child with FASD, and for those with FASD and their families. The findings also call for supports to help health care providers make accurate diagnoses and referrals.

A closer look at the survey findings points to the need for specific action to improve the ability of health care professionals to support people with FASD, and their families and caregivers. The results point to the need for a number of changes and improvements on several fronts:

Concerning Professional Education and Practice . . .

- ***Improvements in the use and implementation of standard screening tools for alcohol use among pregnant women.*** While almost all health care professionals (94%) ask pregnant women about alcohol use, only 62% report using a standardized screening tool. Those most likely to miss being identified include women over 35 years of age, social drinkers, those who are highly educated, those with a history of sexual or emotional abuse, and those of high socioeconomic status. Provincial government action to embed standard screening tools on alcohol use on all prenatal records and support accurate completion of the screening tool would help to improve screening rates and effectiveness.
- ***Better implementation of the existing clinical practice guidelines recommending that no alcohol be consumed during pregnancy.*** Survey results suggest that only 88% of health care professionals provide advice according to these guidelines. Moreover, significant regional variation exists, with 75% of health care professionals in Québec providing this advice, compared to over 90% in the Prairies.
- ***Improvements in information exchange between health care professional and patient on some key health issues*** — particularly related to the definition of "moderate alcohol consumption" among non-pregnant women, and the use of alcohol and drugs in the prenatal period and during pregnancy. Less than half of the professionals surveyed said they frequently discuss these issues with all women of childbearing age.
- ***Better training on the diagnostic features of FAS.*** Only 60% of those surveyed recognize that the most accurate information about a diagnosis of FAS is a combination of growth, brain and facial abnormalities. Moreover, over one half of health care professionals indicate that the absence of specific training on FAS limits their ability to diagnose.
- ***Improved professional understanding of the long-term secondary disabilities associated with FAS.*** Although 70% of providers surveyed are aware that FAS is associated with long-term emotional disorders, only 35% are aware of the association between FAS and inappropriate sexual behaviour.
- ***Clarifying and effectively communicating the terminology related to Fetal Alcohol Effects (FAE),*** for the benefit of clients, care providers and systems responsible for the care of people with FAE and their families.
- ***Improved professional preparedness to care for alcohol dependent/abusing pregnant women and individuals with FAS.*** Survey results show that fewer than 60% of health care professionals surveyed feel prepared to care for these clients. However, a greater proportion (70%) is prepared to access resources for these clients. Results also indicate that professionals are generally not interested in receiving training in addiction counselling, preferring instead to use a registry of consultation specialists, clinical practice guidelines for diagnosis of FAS, referral resources for women with alcohol problems and/or materials or training on FAS.

Concerning Policy . . .

- ***Development of consensus among health professional associations concerning guidelines for moderate alcohol consumption for non-pregnant women, as well as guidelines for alcohol use among women at risk for unplanned pregnancy.*** Eighty-five percent of health care providers routinely address the issue of birth control with their clients/patients; counselling about alcohol use and FAS would ideally be addressed at the same time.
- ***Development of guidelines for the advice and treatment of pregnant women discovered to be drinking during pregnancy.*** This approach would reduce reported inconsistencies in practice. For example, approximately 65% of physicians report always discussing the adverse effects of alcohol when a pregnant woman reports moderate alcohol use, which implies that 30% do

not. Furthermore, 85% of physicians always discuss the adverse effects of alcohol or advise women to abstain from alcohol when they report binge or heavy drinking during pregnancy, and 53% refer binge or heavy drinkers to treatment.

- ***Development of resources related to alcohol consumption during pregnancy and the effects of prenatal alcohol exposure*** — for use as reference information by health care providers and for distribution to their clients.

Concerning Research . . .

- Determining the most effective strategies for ***providing women with information about the risks of alcohol during pregnancy*** and for ***reducing alcohol consumption among women at risk of conception.*** Research should be carried out to determine the relative effectiveness of different intermediaries for information dissemination and behaviour change (i.e., community leaders, opinion leaders, and non-physician health care professionals such as pharmacists and nurses, birth mothers and teachers).
- Improved understanding of the ***prevalence of alcohol consumption during pregnancy and identification of the characteristics of women who consume alcohol while not using birth control*** — information essential for the development of appropriate and targeted interventions.
- Determining the ***prevalence of FAS.*** Since prevalence in the general population is largely unknown, and because of the lack of tools and guidelines for diagnosis, it is likely that FAS is frequently misdiagnosed or underdiagnosed.
- Developing and implementing ***surveillance systems to improve the understanding of the distribution and prevalence of FAS diagnosis*** — aimed at identifying communities at risk and at improving treatment and outcomes for individuals and families.
- ***Monitoring of health care professionals' knowledge through periodic surveys, and evaluation of education and support programs*** — to determine changes in the awareness and knowledge of health care professionals.

While survey results indicate that many health care professionals have a basic understanding of the issues related to both alcohol consumption during pregnancy and FAS, there are clear regional and professional differences in knowledge and attitudes toward both. At the same time, the data clearly call for standardized training programs to meet the specific needs of each health care professional group.

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1 Introduction and Methodology

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This report presents the results of a national survey of physicians and midwifes — specifically, their attitudes, knowledge and behaviours related to Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) and alcohol use during pregnancy.

Purpose, Objectives and Research Questions

Conducted between March 2001 and October 2002, the study was undertaken to obtain information from physicians and midwives across Canada regarding current levels of knowledge and attitudes about Fetal Alcohol Syndrome (FAS). The resulting data provide baseline information that can be used in the assessment of policy effectiveness and in designing educational initiatives in this area of health care professional practice.

More specifically, the objectives of the study were to:

- conduct a national survey of the knowledge levels, beliefs and attitudes of Canadian physicians and midwives about FAS and related conditions
- develop recommendations based on survey findings that can be used to direct policy development and educational initiatives for physicians and midwives
- propose a strategy for using the survey instrument and results to monitor outcomes of policy and educational initiatives

The researchers also addressed a number of underlying research questions in the design and implementation of the survey, and in the analysis of results:

- What are the current knowledge levels, beliefs and attitudes of Canadian physicians and midwives with respect to FAS and related conditions?
- What are the current knowledge-based practices of Canadian physicians and midwives with respect to alcohol consumption during pregnancy?
- How might this information inform the development of national policies and educational initiatives for clinical practice with respect to FAS and related conditions?

Methodology

The research team consulted Health Canada's National Advisory Committee (NAC) for Fetal Alcohol Syndrome/ Fetal Alcohol Effects (FAS/FAE) and professional health organizations* during the project development phase to ensure that stakeholder needs were addressed. Consultations also helped determine the feasibility of responding to survey results with improvements to and/or changes in approaches to training, clinical practice guidelines and policy.

About the questionnaire

The survey questionnaire employed in this survey was modified from a previous questionnaire used in an Alberta study.[1] Modifications (based on consultations with Health Canada's NAC and professional groups) were made to the original questionnaire to expand its scope and modify its format. The final questionnaire package was assembled, translated into French and formatted into the Teleform data management program for electronic entry of data returned in paper format. A web-based version was programmed in HTML for secure completion and data collection through an independently created web page on the University of Calgary website. The questionnaire consists of four parts:

- General Knowledge (Part A, 10 questions)
- Prevention Issues (Part B, 13 questions)
- Diagnostic Issues (Part C, 15 questions)
- Background Information (Part D, 10 questions)

All but two questions are a forced-choice format with response options varying and depending on question content (e.g., yes/no, Likert-type scales, select all that apply). The questionnaire is included as Appendix C to this report.

Sampling, recruitment and response rate

A random sample of 5,361 health care professionals was selected from membership lists obtained from the Canadian Paediatric Society (N = 1,396), the Canadian Psychiatric Association (N = 851), the National Association of Midwives (N = 197), the

*The professional organizations consulted were: the Canadian Medical Association, the Society of Obstetricians and Gynaecologists of Canada, the Canadian Paediatric Society, the College of Family Physicians of Canada, the Canadian Psychiatric Association and the Canadian Association of Midwives. Additional consults included Dr. Sterling Clarren and Dr. Sandra Clarren of the Fetal Alcohol Syndrome Diagnostic and Prevention Network at Washington State University.

College of Family Physicians of Canada (N = 2,378), and the Society for Obstetricians and Gynaecologists of Canada (N = 539).

For midwives, paediatricians and psychiatrists, 60% of each organization's membership was randomly selected for inclusion in the survey. For family physicians (given their large numbers) and obstetricians (whose numbers are generally underestimated) — random sampling was based on the number of active members in each province — 20% were sampled from provincial populations of greater than 500, 25% from provincial populations of 101 to 500, and 50% from provincial populations of less than 100 each of family physicians and obstetricians.

The sample was adjusted by eliminating the names of those health care professionals who either could not be located or who were found during follow-up to have maintained professional organization membership but who were no longer practising.

Due to the small number of potential participants in some areas of the country, provinces and territories were clustered into geographic regions in order to ensure the anonymity of respondents from these areas and the ability to compare data statistically.

Participation packages were mailed to all randomly selected participants. Each package contained a cover letter (printed on the recipient's professional organization letterhead*) describing the relevance of the study and requesting participation. Also included were instructions for completing either a paper or a web-based version of the questionnaire and the survey questionnaire itself, as well as a notice of eligibility for a random draw for a prize (a Palm Pilot).

Return of the completed questionnaire was interpreted as consent to participate. Responses from participants choosing to complete the questionnaire online at the University of Calgary website were retrieved securely and stored in a password-protected file.

Follow-up was targeted at maximizing response rates across all regions and professional groups (i.e., more follow-up was conducted for regions and professional groups with lower interim response rates). A reminder postcard was sent to non-respondents approximately three weeks after the initial mailing. For those who still did not respond, a reminder letter and second copy of the survey were mailed three weeks later. Approximately three weeks after that, a second reminder postcard was sent to non-respondents, with the instruction to contact the study team if they had actively chosen not to participate. Finally, a follow-up telephone call was made to the remaining non-respondents inviting their participation. At this stage, they were offered the opportunity to participate in the survey through a telephone interview, by completing it online, or having the paper version re-mailed or faxed to them.

Given the large sample size, participation packages were distributed in two waves to allow adequate time for rigorous follow-up. The professional groups included in each distribution wave were determined by access to professional association mailing lists and approval of the study for endorsement by the professional association. Professional groups included in the first distribution (Wave 1; $n = 2{,}493$) were paediatricians, midwives and psychiatrists. After follow-up postcards, participation packages and telephone calls, the total number of non-respondents from Wave 1 was 977. Professional groups included in the second distribution (Wave 2; $n = 2{,}984$) were family physicians and obstetricians. After follow-up postcards, participation packages and telephone calls, the total number of non-respondents from Wave 2 was 1,895.

The overall participation rate was 41.3%, resulting in a sample of 2,216 health care professionals. Response rates ranged from a high of 63.5% among midwives to a low of 31.1% among family physicians. Of note, web-based responses to the survey were obtained from 3.0% of paediatricians, 3.5% of psychiatrists, 6.4% of midwives, 7.5% of family physicians and 2.3% of obstetricians. Tables A1 and A2, Appendix A, offer more detailed information on response rates.

Ethics and confidentiality

The Calgary Health Region Child Health Scientific Review Committee approved the study for scientific and administrative merit. The Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions granted ethical approval. Data were pooled for analysis and individual responses are not identifiable. All data stored for analysis were identified only by study identification number.

Data analysis

Possible independent variables considered in the analysis of results included: specialty; age; years in practice; academic appointment; practice location (urban, rural); and region (western Canada, including British Columbia and Alberta; the Prairies, including Saskatchewan and Manitoba; Ontario; Québec; and

*Each cover letter was hand signed by a co-investigator and copy signed by the president of the relevant professional organization. The exception was family physicians who received the package on University of Calgary letterhead, with the letters handsigned by each of the co-principal investigators.

eastern Canada, including New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador). Dependent variables included questions on prevention and diagnosis of FAS with respect to awareness of and attitudes about FAS, knowledge about FAS and related conditions, and common practices related to the care of pregnant women and women of childbearing age, as well as infants and children.

Data were analyzed using Statistical Package for the Social Sciences (SPSS)/PC Version 10.0. Descriptive analysis and bivariate comparisons were considered to better understand health care professionals' attitudes, knowledge and practices towards FAS. In addition, specific analyses were completed to address clinical questions about the use of standard tools for assessment of alcohol use, the impact of provider definition of moderate alcohol consumption on recommendations during pregnancy and preparedness to care for women in the areas of alcohol abuse and addiction.

Generalizing from the survey results

The survey results indicate that the participant profile reflects the distribution of health care providers across Canada and gives some measure of support to the extent to which the sample is representative of the full population of professionals surveyed.

The gender distribution across professional groups was compared to national data and, in general, was found to be comparable. A slightly larger number of female obstetricians participated in the survey than would be expected based on the distribution of obstetricians in Canada — for this reason, obstetrician responses may be more reflective of female health care professionals. Gender distribution of the sample is illustrated in Table A3, Appendix A.

The sample of paediatricians closely reflects provincial distribution of paediatricians. In general, the prairie region is slightly over-represented and Québec is slightly under-represented among obstetricians, psychiatrists and family physicians. Thus, the results may reflect more of those professionals in western Canada compared to eastern Canada.

Generally speaking, regional response rates reflect the distribution of providers across the regions. As well, the distribution of responses reveals that approximately 20% of respondents provide health care in rural settings, reflecting the concentration of health care services in urban settings in Canada.

2
Background — FASD

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Fetal Alcohol Syndrome (FAS) refers to a group of symptoms including facial features, growth deficiency and central nervous system dysfunction in children whose mothers consumed alcohol during pregnancy. The connection between maternal alcohol consumption and abnormalities in children was first described in the literature by Lemoine,[2] but the term Fetal Alcohol Syndrome was first used by Jones and Smith in an article in* The Lancet *in 1973.[3] This article brought worldwide attention to this condition as a preventable birth defect. FAS has been called the most common and preventable cause of mental disability in the western world.[4]

Prevalence and Costs of FASD

The adverse effects of gestational alcohol exposure exist along a continuum with full expression of FAS, "partial FAS," "alcohol-related birth defects" (ARBD) and "alcohol-related neurodevelopmental disorder" (ARND) — all diagnostic terms to describe conditions along this spectrum. FAS, partial FAS and ARND are all associated with significant neurobehavioral deficits.[4] Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe all of the above related conditions — it is not a diagnostic term.

The incidence of FASD has been reported at 9.1/1,000 live births in the United States,[5] but may be higher in some populations. A summary of incidence/prevalence information is illustrated in Table 1.

Economic costs of FASD are high

The economic burden of FASD is substantial. Lifetime direct tangible costs per diagnosed individual related to health care, education and social services in Canada is estimated to be $1.4 million.[6] A recent Canadian study suggests that costs of $855,000 are associated with FASD up to age 21 years (excluding justice-associated costs).[7] It has been estimated that, in the United States, the cost of providing effective pre-pregnancy prevention programs for a mother who has already given birth to an FAS child would be 30 times less than the cost of raising another child with FAS.[8]

Health Care Professionals and FASD

In the past decade, a number of health and social policy initiatives in the United States and Canada have focused on public awareness, prevention and improved detection of FAS and maternal alcohol consumption. (Of note is the work by the U.S. Centers of Disease Control, the Prairie Northern Pacific Partnership and the Federal FAS/FAE Initiative.) A key component of these initiatives has been the development of strategies to improve health care provider awareness of issues related to the detrimental effects of alcohol on pregnancy outcomes and early detection of FAS.[9-11]

Table 1: **Estimated Prevalence of FAS and FASD, by Selected Jurisdictions and Years**

Location	FAS Prevalence (% of live births)	FASD Prevalence (% of live births)
Alaska[12]	0.02† 0.30‡	
Aberdeen[13]	0.39‡	
Institute of Medicine Report[4]	0.06–0.30† 2–8.50‡	
Seattle[5]	0.28	0.9*
Cleveland[5]	0.46	
Roubaix[5]	0.13–0.48	
South Africa (Wellington)[14]	4.80	
South Africa (Western Cape)[15]		
1997	4.64	
1999	7.47	
2002	10.00	
South Africa (Gauteng, four areas)[15]		
2000	0–3.70	
South Africa (Northern Cape, two areas)[15]		
2001–2002	5.30–10.30	

†Non-American Indian/American Native.
‡ American Indian/American Native.
* Includes FAS and FAE.

Health care professionals have an important role

Typically, physicians are the primary providers of medical care for pregnant women and they play an important role in the prevention and diagnosis of FAS.[16-19] Efforts around the world are aimed at improving health care professional awareness and education regarding FASD. The American Academy of Paediatrics has recommended that paediatricians and other health care professionals become better informed and assume a leadership role in public education regarding *in utero* alcohol exposure.[19] In the United States, a national goal has been set to increase the proportion of pregnant women who abstain from alcohol from 86% found in 1996–1997 to a level of 94% by 2010.[20] In Britain, obstetricians, paediatricians and other health care professionals are encouraged to increase their awareness, education and knowledge about FAS and related conditions and to work in a coordinated manner to prevent service provisions from being discontinued.[21] At the same time, there may be considerable disparity among physicians in terms of knowledge, attitude, practices and educational needs regarding this condition.[9,22,23]

The Canadian Paediatric Society has made several recommendations concerning FAS diagnosis and prevention that relate to clinical practice.[24] The Society suggests that all women — pregnant or not — be asked about their drinking habits in a respectful, sympathetic and supportive manner, when a routine history is taken. The extent to which a woman drinks should be categorized and at-risk drinkers (pregnant or non-pregnant) should be advised to cut down and abstain from drinking. The Society also suggests that problem drinkers be advised to abstain and that they be referred for specialized treatment. The Society supports the goal for all pregnant women of complete abstinence. It also stresses the importance of early diagnosis of the child, since early diagnosis has been shown to improve the opportunity for effective management, guidance and support, and allows for development of planning for the child's education and social needs. Moreover, the Society suggests that, with early diagnosis, secondary disabilities often associated with FASD (such as criminal behaviour) can be minimized.[24]

Earlier research points to disparities in health care professional knowledge

Prevention of FAS/FASD depends, in part, upon knowledge about risks associated with prenatal alcohol exposure among health care professionals and their patients (the public). Previous surveys indicate disparity in the knowledge, attitudes, practices and educational needs of physicians regarding FAS, resulting in inconsistency in diagnosis, treatment and management of children and their families.[9,22,23]

Provincial surveys in Saskatchewan[9] and in Alberta[22] have provided some Canadian information on physician understanding of alcohol use during pregnancy and have guided the content of public awareness and physician training initiatives.[10,25] Selected results of these two surveys are illustrated in Table 2.

Table 2: **Comparison of Selected Knowledge/Beliefs Reported by Health Care Professionals in Two Surveys — Saskatchewan, 1991, and Alberta, 1998**

Selected Knowledge/Beliefs	Saskatchewan[9]	Alberta[22]
	% of survey respondents who agree	% of survey respondents who agree
FAS is an identifiable syndrome	97%	<3%
FAS occurs primarily in minority families	27%	66%
Discussion of alcohol use would deter clients from treatment	16%	90%
(I feel) prepared to deal with patients/parents with alcohol abuse	80%	56%

Current survey builds on earlier work

While this two-province research clearly demonstrated the need for standardized and effective training on FASD for health care professionals, variability between provincial results does not allow them to be generalized to a national level. Health Canada determined that national or pan-Canadian data on a broad range of health care provider attitudes and beliefs was a prerequisite for developing a national strategy for the design and development of professional training initiatives. The current survey is intended to provide such data. Given the range of health care professionals who come into contact with women of childbearing age, pregnant women, and infants and children, Health Canada also determined that data needed to be collected for each health care professional category — particularly if the results were to be used to shape education, training and policy geared toward primary prevention of FAS and management of FAS cases.

Results of a 1999 national survey[25] indicate that Canadian public awareness of the effects of alcohol use

during pregnancy was high at that time — in fact, 98% of those surveyed believed that the more alcohol a pregnant woman drinks, the more likely that the baby will be harmed, and 89% believed that alcohol use during pregnancy can lead to a lifelong disability. Seven out of ten respondents said that it is not safe for a pregnant woman to have one drink of alcohol per day during pregnancy or three to four alcoholic drinks each weekend. In the same survey, a doctor/doctor's office was identified by the largest proportion of respondents (47%) as the best source of information about the effects of alcohol use during pregnancy.

These results indicate public interest in receiving information about alcohol consumption during pregnancy from physicians. At the same time, results from the current survey provide evidence of variability in physician practices related to discussion of alcohol consumption and/or addictions. So, while addiction centres will generally see pregnant women with alcohol dependency as soon as possible after referral,[26] if physicians are unwilling to approach the subject with their patients this resource may be underutilized. Moreover, additional resources are likely required for the treatment of pregnant women with alcohol dependencies.[27] For example, evidence suggests that counselling reduces alcohol consumption and morbidity in the offspring of these women,[28] and this type of information should be made available to physicians and other health care professionals.

3

Identification and Prevention of FASD

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Prevention of FAS depends upon prevention of maternal alcohol consumption during pregnancy. Identification of who is drinking and determination of the most effective strategies to reduce consumption in the women most at-risk are key issues in the prevention of FASD.

FASD is preventable, but the factors associated with alcohol use and abuse are both complicated and resistant to change.[8] One American study estimated that, if effective, the cost of referral and prevention services for a woman with an FAS child would be 30 times less than raising a child with FAS. Yet, FAS and its related disabilities may remain underdiagnosed if physicians fail to perceive that an accurate diagnosis would benefit the child, the birth mother, the family and society.[8]

Importance and Role of Prevention

Pregnancy and alcohol consumption — Canadian data

Although there is a dearth of Canadian data on alcohol consumption during pregnancy, empirical evidence shows that some women consume alcohol while pregnant. Identifying at-risk women is a necessary step in preventing the deleterious effects of alcohol on the developing fetus. Treating these women with effective forms of intervention adaptable to their needs is essential.

The 1994–1995 *National Population Health Survey* (NPHS)[29] and the 1994–1995 *National Longitudinal Survey of Children and Youth* (NLSCY)[30] suggested that between 17% and 25% of Canadian women consume alcohol at some point during their pregnancy. Seven to nine percent reported drinking throughout their pregnancy. However, according to the 1998–1999 NLSCY data,[31] only 14.4% of women reported drinking at some point during their pregnancy and 4.9% drank throughout. Three percent of women in that survey reported binge drinking during pregnancy, a pattern that has been shown to be particularly harmful to fetal growth and development.

An Alberta study surveyed women who were pregnant in the years 1994 to 1996 — 7.5% of these mothers said they drank alcohol during pregnancy.[32] The majority reported occasional or infrequent consumption. Other studies conducted between 1982 and 1993 and in 1999 report prevalence of moderate alcohol consumption among pregnant women ranging from 5.0% to 20.0%.[17,33] Indeed, data from the 2003 *Canadian Perinatal Health Report* indicate that 14.6% of children under the age of two years have mothers who reported alcohol use during pregnancy.[34] Together, these data suggest the likelihood that substantially more fetuses are exposed to moderate amounts of alcohol (one to three drinks per day) than to heavy doses.

In 1996, Gladstone and colleagues[35] reported that of 3,800 women seen in Toronto's Motherisk clinic, 3.1% reported binge drinking. Of the 19,991 who were counselled over the telephone, 0.8% reported binge drinking during pregnancy. The mean number of drinks per binge was 7.2 and the majority binged in excess of 10 times — and more often in the first trimester.[35] It is known that women who binge drink are also far more likely to use cigarettes, marijuana, cocaine and other illicit drugs,[32] putting their fetus at even greater risk.

There appear to be regional/demographic differences in the amount and pattern of alcohol consumption during pregnancy. For example, it has been reported that the incidence of alcohol consumption among young, unmarried women may be greater among higher risk populations, including Aboriginal women[36,37] and those who have suffered prior sexual and physical abuse.[38,39] Canadian data also suggest that older mothers are more likely to report prenatal alcohol consumption — 11.7% of children whose mothers were under age 25 compared with 22.6% of those whose mothers were aged 35 or older had prenatal alcohol exposure.[34] Data from Alberta reveal varying rates of alcohol consumption by region, consumption being more common in the far northern region of the province where most of the population reside in rural areas. The study found that, in general, pregnant women in the less-populated regions were younger, more likely to smoke and consume alcohol, and less likely to attend prenatal classes or to have four or more prenatal visits to a health care professional.[32]

Consumption findings from other countries

Results of studies conducted in other countries also suggest that women who drink while pregnant are more

likely to be white, better educated, of a higher income level, be married and smoke.[40] However, those who drink *frequently* during pregnancy (six or more drinks per week) are more likely to be older (over 35 years), non-white and of a lower income level. Other studies suggest that women who drink heavily during pregnancy are more likely to be single, divorced or separated, living alone or with a boyfriend, out of the work force, and with a higher education level than pregnant light drinkers.[41]

A significant relationship has been observed between pre-pregnancy drinking and both depression and attitude toward pregnancy.[42] Among 18,594 women who drank prior to pregnancy, those who were depressed or had a negative attitude towards pregnancy were shown to make smaller decreases in their drinking after finding out they were pregnant.

Prevention Activities in Canada

Prevention activities, as defined by Roberts and Nanson,[10] are activities undertaken with healthy populations to maintain or enhance physical and emotional health. Prevention can focus on changing behaviour, systems and/or the environment. Prevention of FAS is the result of prevention of maternal drinking during pregnancy. Activities include alcohol control measures, public awareness, health promotion, outreach, screening, referral and intervention programs.

Prevention strategies may also address issues related to decreasing harm to the fetus and reducing the likelihood of another alcohol-exposed pregnancy, often using strategies of education and support.[10] Thus, prevention of maternal drinking, and subsequently FAS, can take place during prenatal care, postnatal follow-up, substance abuse treatment and/or management of withdrawal. Indeed, data suggest that a number of programs developed to assist women with alcohol misuse and dependency appear to have met with some success in reducing alcohol consumption during pregnancy.[43-45] As noted in the *Alberta Clinical Practice Guidelines*,[46] brief motivational intervention strategies are successful in reducing both moderate and heavy alcohol consumption.

Best practices examples . . .

In Canada, there are several examples of home visitation models of enhanced case management to work with at-risk women who are pregnant and using alcohol and drugs or who have previously had an alcohol-affected child, based on the Seattle Birth to Three Program developed by Streissguth and Grant.[47] There are programs in both Alberta and Manitoba based upon this model. Preliminary results from both Seattle and the Canadian sites show significant reductions in the use of drugs and alcohol among the women in the study, and improved access to resources and programs, employment opportunities, use of contraception and access to primary medical care for their children. Sheway in Vancouver and Breaking the Cycle in Toronto are two additional examples of best practice programs for women who are pregnant and using substances.

Screening for alcohol consumption during pregnancy . . .

In order to provide prevention and intervention programs and strategies, maternal alcohol consumption must be identified. Asking questions about alcohol use during pregnancy (screening) is key to gathering the accurate and reliable information necessary to refer the mother to appropriate treatment/intervention programs for help, as well as to later receiving an accurate diagnosis for individuals affected by prenatal alcohol exposure.

The situational analysis document produced by Legge and colleagues for Health Canada[48] identified the importance of routine screening of women at risk of having an alcohol-affected baby through the use of standardized screening tools such as the T-ACE. Standardized questionnaires* have been developed to overcome the biases inherent in self-reporting. These "five-minute tools" are easy to use and score. Each of the scales has been validated in different populations and has varying sensitivity and specificity.[49] Use of a standardized screening tool is an objective and reliable way for physicians and midwives to gather information related to alcohol consumption during pregnancy.

Survey Results

The previous section in this chapter highlighted the prevalence of alcohol consumption during pregnancy and the importance of prevention. Past research shows that the application of prevention measures by Canadian health care professionals varies as well. The current study investigates this issue further.

A number of survey questions sought to learn more about the prevention-related attitudes and activities of physicians and midwives. Respondents were asked to identify, for example, their perception of the effects of alcohol on the fetus, the scope and nature of questions about alcohol that they pose to women of childbearing years and pregnant women, and whether they use screening tools. The survey also asked about barriers to discussing alcohol use during pregnancy — including those faced by the health care provider and those possibly faced by their women patients.

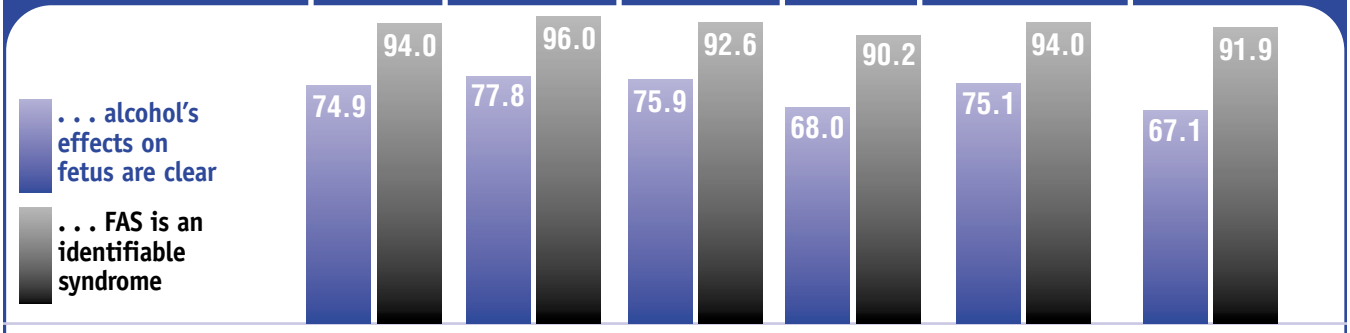
*Including CAGE, AUDIT, TWEAK, SMAST and T-ACE.

Results show that, generally speaking, most physicians and midwives are aware that prenatal alcohol exposure is a serious health risk, although fewer say they feel prepared to deal with the issue of drinking during pregnancy. In spite of a high level of knowledge and awareness, and while many physicians and midwives use a standard screening tool for alcohol use with pregnant women, fewer than one in five provide patients with written information about the dangers of alcohol use during pregnancy, despite the fact that such information is readily available. Moreover, only slightly more than one half say they feel adequately prepared to care for pregnant women or birth mothers in this area. Physicians report that lack of time is the biggest barrier to discussing alcohol use with pregnant patients; at the same time, however, both physician and midwife respondents say they would welcome a registry of specialists and referral resources as a support to their clinical practice. Among the many reasons why pregnant women do not seek treatment for alcohol, respondents identify co-dependence, fear of public shame and blame, fear of losing their children and family violence as the top concerns of women.

Health care providers agree — prenatal alcohol consumption is a risk for brain damage

Almost all (93%) of physicians and midwives surveyed agree that prenatal alcohol exposure is a risk for brain damage, and most (95%) agree that FAS occurs in all strata of society. Nevertheless, 25% do not agree that the

Table 3: **Selected Beliefs about Alcohol and FAS, by Health Care Professional Group**



Agree/Strongly Agree . . .	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
. . . FAS occurs in all strata of society	95.4	95.8	94.1	98.4	95.1	96.0
. . . prenatal alcohol exposure is a risk for permanent brain damage	93.3	94.8	92.1	90.3	93.5	91.5
. . . with telling patients to drink in moderation	60.7	62.3	67.8	51.3	57.9	57.6

Table 4: **Agreement with Selected Statements about Alcohol and FAS, by Region**

Agree . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . alcohol's effects on the fetus are clear	74.9	72.2	76.8	74.4	75.8	75.8
. . . FAS is an identifiable syndrome	94.0	94.0	96.3	94.2	90.4	93.9
. . . FAS occurs in all strata of society	95.4	97.2	93.7	95.8	94.2	97.0
. . . prenatal alcohol exposure is a risk for permanent brain damage	93.3	92.5	95.9	92.3	91.9	95.5
. . . with telling patients to drink in moderation	60.7	60.2	49.4	62.1	71.6	62.8

Table 5: **Health Care Professional Definition of Moderate Drinking, by Region**

Agree that Moderate Drinking for Non-Pregnant Women is Defined as . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . ≤ two drinks per occasion	91.0	93.6	91.0	91.2	88.1	91.2
. . . drinking ≤ three occasions per week	74.3	74.8	75.2	71.4	79.7	75.0

Table 6: **Physician Role in and Preparedness to Deal With Alcohol Use during Pregnancy, by Region**

Agree that . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . the physician's role is to manage alcohol use problems	76.1	75.1	76.5	80.3	65.2	77.6
. . . (I feel) prepared to care for pregnant women with alcohol use problems*	54.2	62.9	58.9	51.8	45.8	49.7
. . . (I feel) prepared to care for birth mothers with alcohol use problems*	55.6	62.9	60.3	52.0	49.2	56.6
. . . (I feel) prepared to access alcohol-related resources for pregnant women*	70.9	80.8	72.2	68.8	65.3	69.0
. . . (I feel) prepared to access alcohol-related resources for birth mothers*	70.9	77.6	72.8	69.1	64.7	72.0

*Among those who care for pregnant women.

effects of alcohol on the fetus are clear. Paediatricians have the highest level of agreement (78%) that the effects of alcohol on the fetus are clear and that prenatal alcohol exposure is a risk for permanent brain damage (95%) (see Table 3).

Over 60% of respondents agree with the practice of advising patients in the general population to drink in moderation. Those in the Prairies (49%) are least likely to agree with this practice, while those in Québec (72%) are most likely to agree (see Table 4).

Widespread agreement on moderate drinking

Results also suggest that there is widespread agreement among physicians and midwives on the definition of moderate drinking for non-pregnant women — 91% define moderation as two or fewer drinks per occasion, and 74% agree that moderation means consuming alcohol on three or fewer occasions per week (see Table 5).

Many health care providers are not prepared

At the same time, responses suggest that physicians and midwives are not, overall, adequately prepared to care for either pregnant women or birth mothers in the area of alcohol abuse/dependency, with only 56% saying they feel prepared to do so. There are significant regional variations in levels of preparedness. In general, more practitioners in the West and in the Prairies say they feel prepared to deal with pregnant women and birth mothers in the area of alcohol use or dependency than those in Québec or the East (see Table 6). Obstetricians (65%), followed by psychiatrists (58%), report the highest levels of preparedness. Midwives report feeling the most prepared to help pregnant women access resources in the area of alcohol abuse (86%), followed by psychiatrists (81%) and obstetricians (74%) (see Table 7).

A greater proportion (71%) of physicians and midwives say they are prepared to access resources for pregnant women and birth mothers, with the same regional trends as noted for preparedness to care for pregnant women and birth mothers — i.e., higher in the West and the Prairies, lower in Québec and the East (see Table 7).

Table 7: **Physician Role in and Preparedness to Deal With Alcohol Use during Pregnancy, by Health Care Professional Group**

Agree/Strongly Agree that . . .	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
. . . the physician's role is to manage alcohol use problems	76.1	74.8	73.8	61.0	83.6	67.7
. . . (I feel) prepared to care for birth mothers with alcohol use problems*	55.6	50.4	58.3	50.4	56.6	61.2
. . . (I feel) prepared to access alcohol-related resources for birth mothers*	70.9	61.1	81.8	84.2	69.8	70.5
. . . (I feel) prepared to access alcohol-related resources for pregnant women*	70.9	55.3	80.9	85.8	70.8	74.3
. . . (I feel) prepared to care for pregnant women with alcohol use problems*	54.2	40.5	58.1	54.7	55.2	65.2

*Among those who care for pregnant women.

Half of health care providers collect detailed relevant history . . .

A number of questions related to professional practice were put to family physicians, midwives and obstetricians, with the goal of developing a picture of practices that aim to prevent FAS and optimize birth outcomes (Appendix C).

The most common prevention issue discussed by family physicians, obstetricians and midwives with all women of childbearing age is birth control (86%) (see Tables B3 and B4, Appendix B). In general, fewer than half of providers report *frequently* counselling women prior to pregnancy about folic acid (50%), smoking (49%), alcohol (40%) and drug use (39%) in pregnancy. Moreover, few providers say they *frequently* obtain a detailed history of sexual abuse (14%) and emotional abuse (14%) (see Table 8).

A greater proportion of providers say they obtain a detailed history of alcohol use (58%) and addictions (46%) from women of childbearing age, although such practice is significantly less common in the East (40% and 33%, respectively). Of note, 62% of providers report using a standard tool for screening prenatal patients for alcohol use — use of standard tools is most common in Québec (85%) and least common in the East (52%) (see Table 9).

Family physicians report the highest rate of using a standard screening tool use — 74% report routine use for prenatal patients, compared to 20% of midwives and 45% of obstetricians. Only 17% of respondents say they frequently provide written material on the dangers of alcohol use in pregnancy, despite the fact that much material is available (see Table 8).

Physicians and midwives seek information about alcohol use

Almost all physicians and midwives surveyed say they routinely collect information regarding quantity and frequency of alcohol intake during pregnancy (97%) (see Table 10) and explore pre-pregnancy alcohol intake (86%) (see Tables B5 and B6, Appendix B). These health care professionals tend to ask more specific questions as well — 73% say they routinely ask about binge drinking and 64% routinely ask about history of addictions treatment. Most of those surveyed (88%) report recommending to women that they consume no alcohol during pregnancy, with significant regional variations, as shown in Table 10 — 75% of those in Québec say they make this recommendation, compared to over 90% of those in the Prairies. At the same time, few respondents say they enquire about evidence of alcohol-related birth defects in a woman's other children (40%), history of sexual abuse (34%) and whether the woman's partner has a history of alcohol abuse (21%).

Table 8: **Selected Prevention Practices Employed by Health Care Professionals, by Health Care Professional Group**

Frequently Discuss, Provide, Obtain or Use with Women of Childbearing Age . . .	Overall (%)	Midwife (%)	Family Physician (%)	Obstetricians (%)
. . . folic acid in decreasing neural tube defects (discuss)	50.1	70.4	47.2	57.8
. . . risks of smoking during pregnancy (discuss)	49.2	82.2	46.9	56.0
. . . risks of alcohol during pregnancy (discuss)	40.1	75.0	37.9	43.0
. . . risks of drug use during pregnancy (discuss)	38.9	67.9	35.9	45.8
. . . birth control (discuss)	85.9	81.5	85.2	89.1
. . . detailed history of sexual abuse (obtain)	13.5	50.0	10.8	18.2
. . . detailed history of emotional abuse (obtain)	13.5	57.7	11.4	15.1
. . . detailed history of alcohol use among (obtain)	57.5	65.4	59.8	47.9
. . . detailed history of addictions (obtain)	45.6	50.0	46.2	42.7
. . . detailed family history of addictions (obtain)	23.9	38.5	25.5	16.1
. . . written information on prenatal alcohol exposure (provide)	16.8	37.9	14.6	21.2
. . . standard tool (i.e., T-ACE, CAGE) to screen all prenatal patients for alcohol use (use)	62.3	19.8	73.6	44.7

Table 9: **Selected Prevention Practices Employed by Health Care Professionals, by Region**

Frequently Discuss, Provide, Obtain or Use with Women of Childbearing Age . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . folic acid in decreasing neural tube defects (discuss)	50.1	42.0	48.5	52.9	54.2	52.2
. . . risks of smoking during pregnancy (discuss)	49.2	45.6	52.2	48.2	49.5	51.1
. . . risks of alcohol during pregnancy (discuss)	40.1	42.0	47.2	38.6	30.8	35.5
. . . risks of drug use during pregnancy (discuss)	38.9	42.0	41.5	38.1	35.5	34.4
. . . birth control (discuss)	85.9	88.6	85.6	88.1	80.2	83.9
. . . detailed history of sexual abuse (obtain)	13.5	19.3	12.6	14.4	9.4	7.6
. . . detailed history of emotional abuse (obtain)	13.5	19.3	13.9	13.8	9.4	6.6
. . . detailed history of alcohol use among (obtain)	57.5	53.7	66.1	59.9	51.9	39.6
. . . detailed history of addictions (obtain)	45.6	47.3	49.6	42.5	55.7	32.6
. . . detailed family history of addictions (obtain)	23.9	29.5	27.9	21.7	24.5	12.1
. . . written information on prenatal alcohol exposure (provide)	16.8	15.3	22.7	12.4	11.2	26.9
. . . standard tool (i.e., T-ACE, CAGE) to screen all prenatal patients for alcohol use (use)	62.3	72.6	67.7	53.6	84.5	52.0

Table 10: **Selected Topics Related to Alcohol Use Routinely Included in Interviews with Pregnant Patients, by Region**

Topics/Questions Routinely Included . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . currently drinking alcohol	93.6	94.0	95.6	94.1	93.0	87.0
. . . drinking history of partner	21.4	27.8	19.4	19.2	24.8	19.2
. . . personal history of sexual abuse	33.8	39.7	27.7	35.2	35.2	31.3
. . . history of addictions treatment	64.0	72.0	66.4	57.3	76.0	55.6
. . . quantity/frequency of drinking during pregnancy	97.4	98.9	97.2	97.5	95.3	97.0
. . . personal history of binge drinking	73.0	72.8	77.6	70.8	72.1	71.7
. . . evidence of alcohol-related birth defects in other children	39.8	43.8	48.8	35.8	29.4	39.8
. . . recommend patient consume no alcohol during pregnancy	87.5	89.8	92.3	87.7	74.8	86.0

Table 11: **Selected Topics Related to Alcohol Use Routinely Included in Interviews with Pregnant Patients, by Health Care Professional Group**

Topics/Questions Routinely Included . . .	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
. . . personal history of sexual abuse	33.8	73.7	25.3	40.5
. . . recommend patient consume no alcohol during pregnancy	87.5	79.2	89.7	83.9
. . . currently drinking alcohol	93.6	99.2	92.3	95.0
. . . drinking history of partner	21.4	39.3	19.1	19.4
. . . family history of alcohol abuse or dependency	52.7	56.7	55.4	41.5
. . . quantity/frequency of drinking during pregnancy	97.4	96.7	97.7	96.8
. . . personal history of binge drinking	73.0	59.3	74.2	76.4
. . . evidence of alcohol-related birth defects in other children	39.8	42.2	37.8	45.5

Overall, family physicians (90%) are the most likely to recommend that no alcohol be consumed during pregnancy, followed by obstetricians (84%) and midwives (79%) (see Table 11). Routinely asking pregnant women their history of binge drinking is included in patient interviews by obstetricians (76%) more than by other groups surveyed, while family history of alcohol abuse or dependency is routinely discussed more often by midwives (57%) and family physicians (55%) than by obstetricians (42%) (see Table 11). Only 25% of family physicians say they ask about a personal history of sexual abuse, compared to 74% of midwives and 41% of obstetricians. Midwives (39%) are more likely to ask about the drinking history of the pregnant patient's partner than are family physicians (19%) or obstetricians (19%).

Health care professionals advise moderate and binge drinkers to abstain

When asked about the prevention approaches they use with their pregnant patients, less than half of health care providers (48%) say they frequently discuss what drinking "in moderation" means to their patients (see Table 12). Among providers who see women with a reported moderate drinking profile,* 65% say they always discuss adverse effects and 70% say they always counsel to abstain. However, this practice was reported most frequently in the Prairies (79%) and the East (77%) and least often in Québec (58%). Among those who identify binge or heavy drinkers,** a higher proportion report always discussing adverse effects (88%) and almost as high a proportion counsel to abstain (85%). Just over one half of these respondents (53%) say they always refer women with binge or heavy drinking to treatment.

Results indicate that family physicians are the most likely of all professional groups surveyed to discuss with the patient what "in moderation" means (51%) and to always counsel women to abstain from further alcohol use, including those who report consuming alcohol in moderation (70%) and those who say they binge (85%) (see Table 13). In general, there were strong consistencies across professional groups with regard to prevention practices used for women who report moderate or heavy/binge alcohol consumption during pregnancy (see Tables B7 and B8, Appendix B).

*757 survey respondents reported that their practice includes women who report moderate drinking.

**559 survey respondents reported that their practice includes women who report heavy/binge drinking.

Table 12: **Use of Selected Prevention Approaches with Women Who Reported Moderate or Heavy/Binge Drinking, by Region**

Approach to Prevention Always Used*	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . discuss what patient thinks "in moderation" means (frequently used)	48.2	41.0	45.6	49.1	54.8	55.6
With women who report moderate* alcohol use during pregnancy . . .**						
. . . discuss adverse effects of alcohol use among pregnant women	64.9	61.1	67.9	67.4	57.0	64.1
. . . advise to abstain from alcohol use	70.0	70.7	79.4	65.7	57.6	76.6
With women who report heavy/binge alcohol use during pregnancy . . .**						
. . . discuss adverse effects of alcohol use among pregnant women	88.2	92.2	89.0	88.8	82.9	83.0
. . . advise to abstain from alcohol use	85.0	92.1	87.7	84.9	71.4	82.7
. . . refer to treatment	52.9	57.4	60.0	50.0	37.1	55.8

Agreement defined as "agree" and "strongly agree."

*"Moderate" as defined by respondent: one to two occasions of alcohol consumption per week (56%); three occasions (18%); one drink per occasion (37%); two drinks per occasion (54%).

**Among those who care for these patient populations.

Table 13: **Use of Selected Prevention Approaches with Women Who Reported Moderate or Heavy/Binge Drinking, by Health Care Professional Group**

Approach to Prevention Always Used*	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
. . . discuss what patient thinks "in moderation" means (frequently used)	48.2	37.0	51.4	43.7
With women who report moderate* alcohol use during pregnancy . . .**				
. . . discuss adverse effects of alcohol use among pregnant women	64.9	82.9	64.2	58.9
. . . advise to abstain from alcohol use	70.0	55.3	72.4	69.3
With women who report heavy/binge alcohol use during pregnancy . . .**				
. . . discuss adverse effects of alcohol use among pregnant women	88.2	87.8	88.5	87.5
. . . advise to abstain from alcohol use	85.0	80.5	87.6	79.7
. . . refer to treatment	52.9	63.4	49.3	59.0

Agreement defined as "agree" and "strongly agree."

*"Moderate" as defined by respondent: one to two occasions of alcohol consumption per week (56%); three occasions (18%); one drink per occasion (37%); two drinks per occasion (54%).

**Among those who care for these patient populations.

Table 14: **Selected Resources and Supports Identified by Respondents as Helpful, by Health Care Professional Group**

Selected Resources and Supports	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Materials/Training on FAS/FAE	51.7	54.2	47.3	72.7	50.1	44.7
Assistance with diagnosis of FAS/FAE through telemedicine	24.1	26.5	21.1	42.0	21.7	19.3
Internet resources	35.8	37.8	33.4	54.2	34.3	28.6
Registry of specialists available for consultation about FAS/FAE	61.8	53.9	53.9	85.1	66.9	62.1
Referral resources for women of childbearing age with alcohol problems	62.6	47.5	58.7	82.0	73.0	72.1
Clinical practice guidelines for diagnosis of FAS	60.8	66.7	55.7	69.7	59.8	48.9

A registry of experts would be helpful to providers

Survey participants were provided with a list of potential resources and supports, and were asked to select which ones they would find helpful in their work. Some of these resources are clearly seen to be more helpful than others — in particular, a registry of specialists available for consultation about FAS/FAE was identified as helpful by 62% of respondents and was selected most often by midwives (85%) and family physicians (67%). Results show that many (63%) would welcome referral resources, as well as clinical practice guidelines for diagnosis of FAS (61%). Neither the use of telemedicine to assist with diagnosis of FAS/FAE (24%) nor Internet resources (36%) were identified as helpful supports by many respondents (see Table 14).

There are barriers to discussing alcohol use during pregnancy

Both obstetricians (61%) and family physicians (59%) report that time is a barrier to the discussion of alcohol use during pregnancy — on the other hand, only a small proportion of midwives (7%) identify this barrier. Midwives are much more likely (72%) to identify the fact that many clients already have a good understanding of alcohol use as a barrier to discussing alcohol use compared to all respondents (43%). Almost half of all respondents (49%) report that information is not in a useful format for clients to use (see Table 15).

Midwives identify barriers to clients seeking treatment for alcohol use during pregnancy

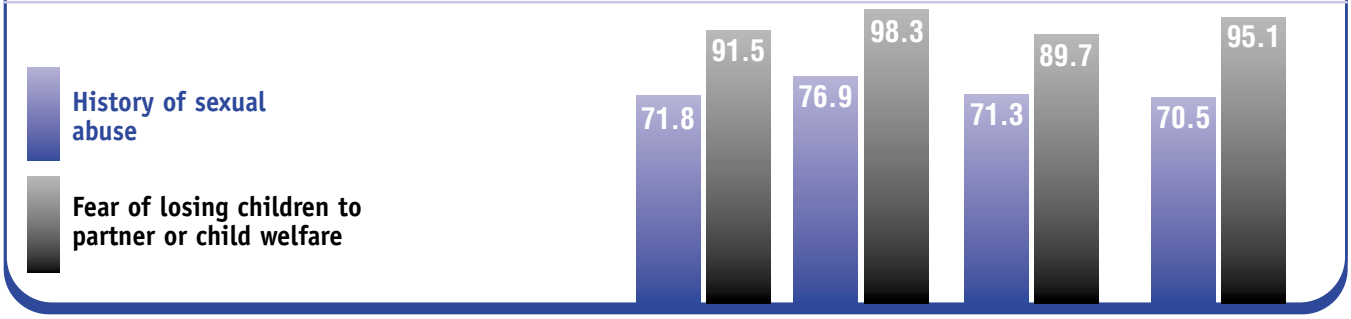
Survey respondents agreed that many of the suggested barriers to women seeking care for alcohol use during pregnancy are, in fact, real barriers. Midwives are much more likely than family physicians and obstetricians to identify systemic prejudice (89%), language (83%), fear of losing children (98%), lack of addiction treatment services (83%) and lack of gender specific services (85%) as barriers than the other two groups (see Table 16). More information about barriers is included in Table B11, Appendix B.

Table 15: **Agreement with Selected Barriers to Discussing Alcohol Use during Pregnancy, by Health Care Professional Group**

Selected Barriers	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
There is not enough time to talk to women about alcohol before they are pregnant	58.0	6.7	59.4	60.9
Many clients already have good knowledge about alcohol use	42.8	72.4	41.3	43.7
Information is not in a useful format for clients to use	48.8	37.0	48.0	53.4

Table 16: **Selected Barriers to Women Seeking Treatment for Alcohol Use during Pregnancy, by Health Care Professional Group**

Selected Barriers	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
History of domestic abuse	82.6	86.3	82.7	80.4
Co-dependence (partner/peer/parental substance abuse)	91.9	92.4	92.0	91.4
Current violence in the home	87.9	93.2	87.7	85.9
Fear of public shame, blame	91.1	97.4	90.7	88.9
Systemic prejudice based on social/economic class	62.9	88.9	59.3	61.0
Communication/language barriers	64.2	82.9	69.3	63.8
Lack of addiction treatment services	67.9	82.8	66.7	64.1
Lack of gender specific addiction treatment services	65.4	84.5	63.2	62.6



Discussion of Findings

The findings of this study suggest that health care professionals' awareness of and knowledge about FAS have improved substantially in Alberta when compared to results of the Alberta study conducted in 1998.[22] For example, the current study reports a much higher level of awareness of FAS as an identifiable syndrome — 94% of physicians surveyed agree that FAS is an identifiable syndrome, compared to only 3% in the Alberta survey conducted five years earlier.[22] However, Saskatchewan health care professionals showed a higher level (97%) of awareness in 1991.[9]

Attitudes and prevention practices are improving

Moreover, results of the current study demonstrate that attitudes and prevention practices related to FAS have improved as well. Health care professionals portray increased awareness of and agreement on the role of alcohol as a physical and neurobehavioural teratogen. At the same time, while the majority of professionals agree that prenatal alcohol exposure is a significant risk factor for brain damage, one quarter (25%) of respondents still say that the effects of alcohol on the fetus are unclear. This issue needs to be addressed, given the clear evidence of the impact of alcohol on the fetus. Further investigation is called for to understand why health care providers are not receiving this evidence, and, if they are, why they are not using it in their prevention practices.

The misconception found in earlier studies[9,22] that FASD only occurs in certain populations seems to have been dispelled — the current study suggests that the vast majority of Canadian physicians believe that FAS occurs in all strata of society.

Providers need help to feel more prepared

A significant proportion of health care providers are not well prepared to care for pregnant women or birth mothers in the area of alcohol abuse or pregnancy. It is clear that, in spite of the improvement in professional awareness of and knowledge about FASD, effort is still required to help providers feel more prepared to care for pregnant and post-partum women in the area of alcohol abuse. Given the important role that health care professionals play in the prevention of FASD and alcohol consumption during pregnancy, education and training programs need to be developed and implemented to better equip them.

The survey findings provide valuable information to inform the design, development and implementation of training and education initatives for health care professionals.

Survey results suggest that many physicians and midwives (over 75% of those surveyed) believe it is the physician's role to manage problems in the area of alcohol use. In fact, most Canadian health care professionals say that discussing alcohol use during pregnancy would not deter women from continuing or seeking treatment — almost all (94% of those surveyed) report routinely asking all women who are pregnant if they are currently drinking alcohol. Of interest, in an ongoing community-based, randomized clinical trial of 1,500 women regarding prenatal care, preliminary results suggest that, on average, 54% of prenatal patients attending one of three low risk maternity clinics recalled a discussion about the impact of alcohol use during pregnancy.[50] While not directly comparable to those of the current study, these data help inform the issue.

It is clear that the majority of health care professionals are appropriately counselling women that it is best not to consume any alcohol during pregnancy. However, almost 10% of professionals are still advising that a glass of beer or wine in moderation is acceptable during pregnancy. It is imperative that these professionals be educated on the importance of advising that no level of alcohol is safe during pregnancy and that they advise patients accordingly in their practice. This group warrants a closer look.

Providers who advise moderate drinking during pregnancy need better education

Professionals who report advising consumption of beer and wine in moderation differ significantly from their colleagues who advise "no alcohol" in several ways. Those advising moderate drinking are:

- less likely to get information from medical journals and books
- more likely to report there is not enough solid information available about alcohol use
- more likely to report that their clients are not interested in discussing alcohol use
- more likely to report that information about alcohol use is not available in a form that was useful to their clients

In essence, these providers do not appear to be as knowledgeable about FASD as their counterparts who promote abstinence from alcohol during pregnancy, nor do they appear to be as prepared to access information

and resources for their patients or for themselves. Again, this group should be a target for specific education initiatives.

Similarly, while a large proportion of health care professionals reports always discussing the adverse effects of alcohol with pregnant patients who are moderate drinkers and binge drinkers, a significant proportion does not. Moreover, only slightly more than one half refer patients for treatment who are self-reported binge or heavy drinkers. Again, further research and education are required to address this shortcoming in health care professionals' practices.

It is important to note that the majority of providers say they define moderate consumption in non-pregnant women to be two or fewer drinks per occasion and fewer than three occasions per week. There are no differences between providers who advised drinking in moderation versus abstinence in their definition of moderation in terms of drinks per occasion; however, providers who defined moderate drinking as drinking on three or more occasions per week were more likely to advise these patients not to drink any alcohol during pregnancy (see Tables B7 and B8, Appendix B). This definition of moderate drinking is lower than that recommended by the Centre for Addiction and Mental Health in Toronto, which specifies low risk drinking to be two or fewer drinks daily and no more than nine drinks per week.[51]

Use of screening tools needs a closer look

Although survey results reveal relatively consistent practice patterns of advising pregnant women not to consume alcohol when pregnant and of asking the question of alcohol use to all pregnant women, the use of standard screening tools requires further investigation. Over 60% of health care professionals surveyed report using a standard tool to screen prenatal patients for alcohol use — however, it is very likely that standardized tools are primarily used if a professional suspects alcohol use. If that is the case, there are many missed opportunities for identification of women at risk.

Although almost 70% of physicians reported always discussing adverse effects of alcohol when pregnant women report moderate alcohol use, this implies that 30% do not do so. Again, this lends support to the development of education and training programs targeted to the specific needs of health care providers, emphasizing the importance their professional role plays in prevention. Given the effectiveness of the Internet as a vehicle for professional education, a closer look at the reasons why health care professionals do not embrace this as a means of receiving information on FASD should be examined more closely, and use of the Internet as an effective tool should be promoted to this audience, as should strategies that encourage the discussion of adverse effects of alcohol consumption during pregnancy with pregnant women who report moderate alcohol use.

The midwives, family physicians and obstetricians who report feeling prepared to deal with pregnant women in the area of alcohol use and dependency differ significantly in some respects from their colleagues who report feeling unprepared. Those who were prepared are more likely to:

- be over the age of 40 years
- hold university appointments
- gain knowledge regarding FAS from patients, colleagues, Continuing Medical Education or medical journals
- routinely obtain detailed family and personal histories regarding abuse and addictions
- include, in their routine primary care of women of childbearing age, discussion of folic acid, the risks of smoking, alcohol and drug use during pregnancy, as well as nutrition and partner use of drugs and alcohol

It is notable that even among those who report feeling prepared to deal with alcohol abuse, less than 20% of physicians routinely screen for sexual or emotional abuse, although these are two important determinants of risk related to drinking during pregnancy. Barriers more frequently reported by those who feel unprepared included:

- lack of time
- not enough solid information regarding alcohol abuse
- belief that their clients already had good knowledge
- belief that information regarding alcohol use was not available in a useful form

Clearly, appropriate resources must be developed and made available to this group. Moreover, such systemic barriers as lack of time call for more fundamental changes to the operating environment of health care providers.

It is important to consider and address alcohol prevention strategies within the broader prevention and promotion framework advocated by Canadian health care providers. As a point of comparison, 86% of health care professionals surveyed say they discuss birth control with all women of childbearing age — at the same time, fewer than half frequently discuss

the role of folic acid (50%), smoking (49%), alcohol (40%), drug use (39%) or addictions history (46%). This is an opportunity lost.

Few providers capture important sexual/emotional abuse history

Less than 15% of professionals frequently obtain a detailed history of sexual and emotional abuse, an important determinant of alcohol use in general. In addition, less than 40% of professionals routinely investigate evidence of alcohol-related birth defects in previous pregnancies. The importance of gathering these types of information must be communicated to health care professionals, and professionals must be provided with strategies to help them collect such information.

Some of the perceived barriers to discussion of alcohol use noted in this study must also be addressed through further research and action, including perceived lack of time, belief that information available is not in a form useful for clients/patients, and the perception that clients already have a good knowledge about alcohol abuse.

4 Diagnosing FASD

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Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and/or learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis. Prenatal exposure to alcohol can cause many physical and behavioural effects[24] — the detrimental effects of alcohol on fetal growth and development are thought to be dose-dependent.[52]

The Value of Diagnosis

Excessive drinking during pregnancy has been associated with prenatal and/or postnatal growth deficiency, characteristic facial features and central nervous system damage. The extent of impairment is believed to result from differences in the amount of alcohol consumed, the pattern and timing of drinking, and/or the mother's genetic ability to metabolize alcohol.[24] FASD is the leading non-genetic cause of mental retardation in the Western world.[8]

The aims of diagnosing disabilities related to prenatal exposure to alcohol include:

- assisting professionals to recognize the disorders associated with *in utero* alcohol exposure
- early accurate diagnosis
- prevention of secondary disabilities
- prevention of siblings from being affected by FAS

The terms "alcohol-related neurodevelopmental disorder" (ARND), "alcohol-related birth defects" (ARBD) and "partial FAS" (pFAS) are used to describe the large number of children affected by prenatal alcohol exposure who do not display all of the characteristics for a diagnosis of FAS.[4] The term "fetal alcohol effects" (FAE) is frequently used when a child displays few FAS traits,[53] similar to ARND, ARBD and pFAS. No two individuals with FAS/ARND/ARBD/pFAS present with the same anomalies and disabilities — rather, all vary along a continuum.[24]

The newest terminology uses FASD as an umbrella term to describe the spectrum of disabilities/diagnoses (ARND, ARBD, pFAS, FAS) associated with prenatal alcohol exposure. Many people believe that individuals with FAS are the most affected, but those with one of the other diagnoses can be just as impaired. For example, between 10% and 40% of individuals born to alcohol-abusing women have the combination of growth, craniofacial and neurobehavioural dysfunction, and are diagnosed with FAS, while those who do not exhibit the physical characteristics suffer from psychosocial impairment and may have neurobehavioural effects that are just as impairing.[54,55] In fact, they may even be more impaired than those with an FAS diagnosis, possibly because they do not have access to the same services or interventions.

Common characteristics of individuals with the diagnosis of FASD are summarized in Table 17.

In recent years, FASD-related research has focused on the long-term effects of prenatal alcohol exposure. In one 12-year follow-up study it was found that the longer the exposure to alcohol during pregnancy, the worse the academic, psychosocial and social outcomes, regardless of severity of initial diagnosis in infancy.[56] Spohr and colleagues[57] studied 44 children with FAE or mild, moderate and severe FAS over a 10-year period. At follow-up, one third were living in institutions, one third were living with biological parents, foster parents or had been adopted, and one third had either moved or no information was available.

Streissguth's data[58] strongly suggest that diagnosis of FAS and its related disabilities mitigates the onset of secondary disabilities (i.e., substance abuse, trouble with the law, inappropriate sexual behaviour, disrupted school experience, mental health problems). Other experts in the field agree that diagnosis ultimately improves outcomes for affected individuals and their families. Diagnosis may provide access to supports and services that are appropriate; early diagnosis is best.

Members of Health Canada's National Advisory Committee (NAC) on FASD who are experts in diagnosis, in consultation with other international experts in the field and relevant stakeholders, have developed Canadian guidelines for the diagonosis of FASD.[59] They state, for example, that diagnosis should *only* be made by a team of trained professionals. It is hoped that these guidelines will improve the objectivity of the diagnostic and referral procedures, and will result in more reliable and accurate referrals and diagnoses.

Table 17: **Overview of Common Characteristics of People Diagnosed with FASD**

At birth, characteristics include . . .	Most newborns (80%) have: • abnormally small head[19] and underdeveloped brain • growth deficiencies after birth • low muscle tone • less fatty tissue • identifiable facial features[60] One half (50%) have: • major organ malformation[61] • vision problems[62,63] • hearing problems[61,62,64] • repeated middle ear and respiratory infections[61] • visible brain damage as seen with an MRI[64]
Cognitive characteristics include . . .	Most people (80%) have mild to moderate mental retardation.[65] One half (50%) have: • speech and language disorders, and/or expressive language delays[22,60,66] • mathematical deficiency, difficulty with abstraction, problems generalizing one situation to another, poor attention, poor concentration skills, memory deficits, impaired judgment and impaired comprehension and abstract reasoning[67] • seizure disorder[64]
Motor characteristics include . . .	Most people (80%) have motor delays.[61] One half (50%) have: • poor coordination • fine motor impairment • clumsiness • subtle delays in motor performance[22]
Behavioural characteristics include . . .	Most people (80%) have: • behavioural problems[19] and infantile irritability, severe tremors and withdrawal symptoms[62] One half (50%) have: • attention deficit disorder with hyperactivity,[60] hyperactivity, impulsivity, lying, stealing, stubbornness and oppositional behaviour[67]
Psychosocial characteristics include . . .	Most people (80%): • have not achieved age-appropriate socialization or communication skills; fail to consider consequences of their actions; lack response to appropriate social cues; lack reciprocal friendship; are affected by social withdrawal, sullenness, mood liability; have teasing or bullying behaviour; periods of high anxiety; and/or excessive unhappiness[67] • have mental illness[68]
Secondary disabilities include . . .	A wide range: • mental health problems; chemical dependency; failure to develop appropriate sexual behaviour; and consequent legal problems;[67] lying; stealing; impulsivity; lack of response to appropriate social cues; low self-esteem; depression; school failure; criminality[69]

Survey Results

Seventy-five percent of paediatricians, family physicians and midwives surveyed say that making a diagnosis of FAS was within their scope of practice — 91% say they believe that diagnosis changes outcomes for the child. At the same time, a much smaller proportion says that reporting FAS (31%) or FAE (24%) should be mandatory. Québec respondents are the least likely to say that reporting should be mandatory (see Table 18).

Results by professional group (including paediatricians, psychiatrists, family physicians and midwives) presented in Table 19 are similar, but some differences between groups are evident. While all groups say that children benefit from diagnosis (91%), paediatricians (94%) are more likely than the other groups to say so. Only 32% of midwives say that making a diagnosis is within their scope of practice, compared to over 65% or more of the remaining professional groups. A smaller proportion of psychiatrists say that reporting should be mandatory — 20% are in favour of mandatory reporting for FAS, and 15% of FAE.

Lack of specific training, more than lack of time, is a barrier to diagnosis

When asked to identify barriers that keep doctors from diagnosing FAS, more health care professionals across all regions and all professional groups identified lack of specific training more than any other barrier — overall, 56% say that lack of training is a barrier (see Tables 20 and 21). Respondents in the East (61%) are most likely to say that lack of training is problematic. Their counterparts in Québec are least likely (12%) to say that lack of time is a barrier, compared to 29% of Prairie respondents and 20% of all respondents. While lack of training is seen as a barrier by all health care professional groups to some extent, family physicians (69%) and paediatricians (68%) are much more likely to identify it as a barrier than are midwives (20%).

Table 18: **Agreement with Selected Statements about Diagnosis and Reporting of FAS and FAE, by Region***

Statement	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Diagnosis changes things for a child	90.9	91.5	92.7	91.0	88.5	88.9
Reporting of FAS should be mandatory	30.6	27.1	29.4	31.7	16.8	29.9
Reporting of FAE should be mandatory	23.9	22.0	25.3	25.9	17.3	26.0
Making a diagnosis of FAS is within the scope of (my) practice	75.0	78.1	78.6	71.9	72.6	80.2

*Among paediatricians, psychiatrists, family physicians and midwives.

Table 19: **Agreement with Selected Statements about Diagnosis and Reporting of FAS and FAE, by Health Care Professional Group***

Statement	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)
Diagnosis changes things for a child	90.9	94.4	88.5	88.8	90.0
Reporting of FAS should be mandatory	30.6	36.1	20.1	36.9	29.6
Reporting of FAE should be mandatory	23.9	28.0	15.1	30.3	23.3
Making a diagnosis of FAS is within the scope of (my) practice	75.0	84.9	65.7	32.0	77.0

*Among health care professionals who make a diagnosis of FAS.

Table 20: **Selected Barriers to Diagnosis, by Region***

Barrier *Many doctors do not make a diagnosis of FAS due to . . .*	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
. . . lack of time	20.0	23.7	29.3	16.8	11.7	21.2
. . . lack of specific training	56.4	54.3	55.6	56.4	57.0	60.6
. . . the belief that making the diagnosis will not make a difference to the individual	12.2	13.6	15.9	11.6	7.3	12.1

*Among health care professionals who make a diagnosis of FAS.

Table 21: **Selected Barriers to Diagnosis, by Health Care Professional Group***

Barrier *Many doctors do not make a diagnosis of FAS due to . . .*	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)
. . . lack of time	20.0	23.9	13.2	6.8	27.9
. . . lack of specific training	56.4	68.2	52.9	20.5	69.4
. . . the belief that making the diagnosis will not make a difference to the individual	12.2	15.7	18.4	3.4	10.8

*Among health care professionals who make a diagnosis of FAS.

Providers get FAS information through medical journals, books and training

Virtually all health care professionals say they had heard of FAS prior to 1997 (99%) and almost all (94%) agreed it was an identifiable syndrome. A smaller proportion of respondents (56%) say they had heard of FAE prior to 1997 — of note, a higher proportion of paediatricians (68%) say that they had heard of FAE before 1997. The majority report that they gained knowledge of FAS or FAE from medical journals and books (76%) or through formal medical training (64%). One half (50%) say they have gained knowledge through CME seminars or rounds, while a much smaller proportion of respondents (24%) say they learn from parents or patients. Paediatricians are most likely to acquire knowledge of FAS from academic sources. More information about health care professional awareness is included in Table B12, Appendix B.

Diagnostic knowledge about FAS and FAE is patchy

Seventy percent of health care professionals surveyed recognize that FAE is a partial expression of FAS. At the same time, regional differences are evident, with respondents in Québec (58%) and Ontario (66%) less likely to recognize this fact than their counterparts in the Prairie region (80%) and in the West (79%). Overall, less than 60% of respondents correctly identified that FAE is not used in selected circumstances: when birth defects diminish over time (59%); when there are no IQ deficits (52%); when maternal alcohol use is unclear (53%); and when a child is too young for a diagnosis to be made (48%). Only a small proportion (14%) correctly identified that FAE is not a less severe form of FAS (see Table 22).

Paediatricians, psychiatrists, midwives and family physicians were asked about facial and neurological characteristics that define FAS — overall, between 64% and 74% recognize the facial features of flat philtrum, thin upper lip and short palpebral fissures as characteristics of FAS. A larger proportion (between 80% and 88%) say they are aware that prenatal growth deficiency and central nervous system dysfunction are indicators of FAS. Less than 60% of respondents (correctly) identified that the most accurate information about a diagnosis of FAS is a combination of growth, brain and facial abnormalities (see Table 23).

All health care professionals were asked about diagnosis of FAS and results show some significant differences across professional groups (see Table 24). In general, paediatricians are more aware of the facial and cognitive issues related to FAS — for example, flat philtrum was selected as a characteristic by 89% of paediatricians (compared to 58% of psychiatrists). Of particular

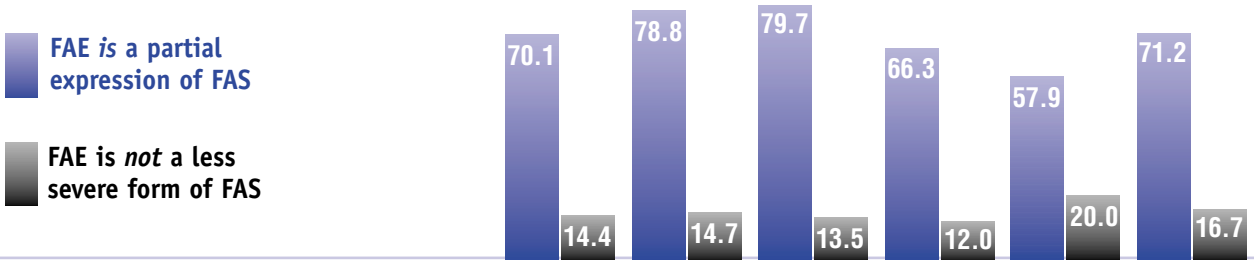
importance is that only 60% of respondents correctly recognized that a combination of growth, brain and facial abnormalities provides the most accurate diagnosis of FAS.

Long-term outcomes associated with FAS are not well understood

Paediatricians, psychiatrists, midwives and family physicians were asked about long-term outcomes associated with FAS. Survey results show considerable variation by both region (see Table 25) and across professional groups (see Table 26). It is particularly striking that only 35% of all respondents correctly identified inappropriate sexual behaviour as being associated with FAS. A greater proportion correctly identified other long-term outcomes, including long-term emotional disorders (71%), disrupted school experience (67%) and addictions (62%). In general, Québec respondents were less likely to identify the long-term outcomes, while those in the West were more likely to do so (see Table 25).

Some differences across health care professional groups is also evident — for example, paediatricians were less likely than their counterparts in other groups to identify disrupted school experience (63%) and addictions (54%) as long-term outcomes of FAS (see Table 26).

Table 22: **Diagnostic Knowledge about Selected Characteristics of FAE, by Region**



Selected Knowledge (agree with the following statements)	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
FAE is *not used* as diagnosis when birth defects diminish over time	59.2	67.1	70.5	53.0	54.4	54.7
FAE is *not used* as diagnosis when there are no IQ deficits	52.3	55.4	64.6	46.9	47.1	51.1
FAE is *not used* as diagnosis when a child has birth defects but maternal alcohol use is unclear	53.4	54.2	62.1	49.4	49.6	55.5
FAE is *not used* as diagnosis when a child is too young to make a diagnosis of FAS	48.2	54.3	60.7	43.1	39.8	46.1
Using the term FAE *does not* result in better long-term social outcome than using the term FAS	39.9	42.8	49.5	34.9	35.7	42.4

Table 23: **Diagnostic Knowledge about Selected Characteristics of FAS, by Region***

Selected Characteristics of FAS Recognized . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Flat philtrum	74.3	84.9	82.6	71.2	62.5	73.9
Thin upper lip	69.4	77.4	77.6	66.9	61.2	64.9
Short palpebral fissures	64.1	71.3	72.0	59.3	61.9	61.8
Central nervous system dysfunction	87.7	90.8	90.8	87.1	82.8	87.3
Prenatal growth deficiency	80.4	82.3	78.3	80.6	81.2	79.6
Combination of growth, brain and facial abnormalities provide the most accurate info. about diagnosis of FAS	59.7	61.8	61.7	59.8	55.3	59.3

*Among paediatricians, psychiatrists, midwives and family physicians.

Table 24: **Diagnostic Knowledge about Selected Characteristics of FAS, by Health Care Professional Group***

Selected Characteristics of FAS Recognized . . .	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)
Flat philtrum	74.3	88.8	58.2	73.7	68.2
Thin upper lip	69.4	90.7	48.8	70.8	58.3
Short palpebral fissures	64.1	81.8	52.5	47.7	55.0
Central nervous system dysfunction	87.7	93.6	82.3	80.9	85.8
Prenatal growth deficiency	80.4	89.6	68.8	81.9	76.8
Combination of growth, brain and facial abnormalities provide the most accurate info about diagnosis of FAS	59.7	61.4	61.4	49.1	58.8

*Among paediatricians, psychiatrists, midwives and family physicians.

Table 25: **Identification by Health Care Professionals* of Long-Term Outcomes Associated with FAS, by Region**

Selected Characteristics of FAS Recognized . . .	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Long-term emotional disorders	70.8	76.2	71.9	74.4	53.0	74.4
Inappropriate sexual behaviour	34.8	54.7	49.1	29.4	15.3	31.2
Disrupted school experience	67.3	71.3	67.1	70.5	53.2	72.7
Addictions	61.7	74.0	69.0	58.8	48.5	62.1
Legal problems	68.2	78.9	81.7	67.6	48.7	69.6

*Paediatricians, psychiatrists, midwives and family physicians.

Table 26: **Identification of Long-Term Outcomes Associated with FAS, by Health Care Professional Group**

Selected Characteristics of FAS Recognized . . .	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)
Long-term emotional disorders	70.8	69.7	70.5	70.4	72.0
Disrupted school experience	67.3	63.1	69.0	73.1	69.7
Addictions	61.7	53.5	62.0	70.8	68.0
Legal problems	68.2	66.8	67.4	63.0	73.6
Inappropriate sexual behaviour	34.8	35.3	36.8	39.2	32.6

Discussion of Findings

Experts agree that diagnosis can improve the outcome of individuals affected by FAS/FAE and their families in several ways — diagnosis can generate access to supports and services, it can lead to the development of a treatment plan, and it can enhance the likelihood that those diagnosed and their families will receive follow-up care. In order for diagnosis to be accurate and beneficial, it must be performed by a multidisciplinary team of health care providers.

Health care professionals surveyed agree with two important points: making a diagnosis of FAS is within the scope of their practice; and making a diagnosis improves outcomes for children. A closer look at why all health professionals are not diagnosing indicates that the primary reason (consistent across all regions and all professional groups, with the exception of midwives) is the lack of specific training. Nevertheless, time is also clearly identified as a barrier — one that training cannot address.

Some critical gaps in knowledge exist

There is a very high awareness (90%) among health care providers that a diagnosis of FAS makes a difference in patient outcomes. At the same time, there appears to be confusion about FAE. A full 85% of professionals surveyed continue to be of the opinion that FAE is a less severe form of FAS, and 60% incorrectly say they believe that a child diagnosed with FAE has better social outcomes. Together, these results suggest that health care professionals require information and education on FAE.

Survey results also point to the fact that health care professionals' knowledge of FAS is greater than their knowledge of FAE. This may be due to the fact that researchers and professionals speak and publish on issues related to the end of the spectrum of FASD with the most obvious defects and disabilities, rarely focusing on other alcohol-related disabilities. While almost 100% of health care professionals surveyed say that they had heard of FAS by 1997, less than 60% had heard of FAE by the same year. The majority gained knowledge from academic sources, including medical journals, medical school, residency and fellowship. About 70% of professionals correctly recognized the facial features associated with FAS, and over 80% identified central nervous system damage and prenatal growth deficiency as distinguishing features of FAS. At the same time, less than 60% identified that a combination of growth, facial and brain abnormalities provides the most accurate information regarding diagnosis — a finding that reinforces the need for specialized training of health care professionals.

The key secondary disabilities of FAS, including emotional disorders, disrupted school experience, addictions and legal problems, were identified as associated with FAS by over 60% of respondents. A much smaller proportion (35%) recognized inappropriate sexual behaviour as a secondary disability of FAS. There were considerable regional variations regarding recognition of inappropriate sexual behaviour as associated with FAS.

What health care professionals want

The health care professionals surveyed are most interested in accessing the following supports: a registry of specialists available for consultation; referral resources for women; and clinical practice guidelines for diagnosis. Results show they are less interested in training for addictions counselling and assistance with diagnosis or access to information via tele-medicine. These findings suggest that health care professionals are more interested in referring at-risk women to specialized addiction treatment centres and to having access to guidelines for diagnosis.

Of interest is the fact that only a small proportion (35%) of respondents identified tele-medicine as a helpful support, as the tele-diagnosis model has been used successfully in rural and remote areas that do not have access to diagnostic centres or team members necessary for a comprehensive assessment.[70] The current results point to the need for further investigation of the reasons why health care providers do not embrace the tele-medicine approach, as well the need to increase their awareness of the potential of tele-medicine and tele-diagnosis for both diagnostic and referral purposes.

Education and training are needed to fill knowledge gaps

Survey findings suggest that Canadian health care professionals are aware of some aspects of FASD. At the same time, they clearly require more education and training to support their role in caring for women at risk of having a child with FASD, and for people with FASD and their families and caregivers. Similarly, training and education are needed to support health care providers to make accurate diagnoses and referrals.

While many approaches to education are possible, it is worthwhile considering those identified by survey respondents as being helpful resources and supports. For example, the development of clinical practice guidelines were identified by six in ten survey respondents as a helpful resource in their practice. Ideally, guidelines

would be standardized on a national scale to ensure that diagnoses and referrals are as accurate and objective as possible. Development of national guidelines for diagnosis and prevention of FASD should take into account the gaps in knowledge made evident by the current survey results.

Other considerations that should be taken into account as guidelines are developed and disseminated include:

- integrating national clinical practice guidelines and supporting documents into a broader education program for physicians and other health care professionals
- addressing primary, secondary and tertiary prevention of FASD through tailored recommendations in the clinical practice guidelines
- clearly explaining diagnostic guidelines to assist physicians in recognizing disorders associated with fetal alcohol exposure, in promoting early and accurate diagnosis and in offering interventions designed to prevent future FAS children in affected families

Clinical practice guidelines are an excellent tool

In fact, health care professional guidelines are a well-established method of disseminating information to physicians and are commonly used to disseminate new information with the intent of improved patient care.[71] Successful dissemination and implementation should lessen inappropriate variation in practice and hasten the application of effective medical advances in daily practice.[72] At the same time, guidelines have had limited effect on changing physician behaviour,[73] possibly due to lack of awareness, agreement with the guidelines, self-efficacy, outcome expectancy, and ability to overcome the inertia of previous practice, among other reasons.[74,75] Reduced physician autonomy, oversimplification of medicine, lack of an evidence base, increase in litigation, and a belief that clinical practice guidelines are meant to lower health care costs rather than improve patient care are also identified as barriers to guideline implementation.[76]

Successful dissemination and implementation could include varied approaches, such as timely Internet-based publication of guidelines and the use of clinical champions — both to support widespread use of guidelines and to train peers in their use — as well as the involvement of specialty societies to promote and disseminate the guidelines, and the development of guideline-based tools, such as decision support systems and computerized decision-making tools.[77] Numerous other strategies have been developed to encourage inclusion of new information into practice patterns, such as provision of credit for attending educational events, training courses and conferences.

5 Recommendations

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Responses by five health care professional groups have provided a wealth of information about the views, opinions and practices of these care providers. Results shed light on areas of knowledge and practice that reflect improvements in how people with FASD are diagnosed and how prevention of FASD is put into action through these health care professionals.

At the same time, the findings point to some major weaknesses that need to be addressed in the areas of professional education and practice, policy and research, and suggest a number of recommendations in each of these areas:

Concerning Professional Education and Practice . . .

- ***Expanded use and implementation of standard screening tools for alcohol use.*** While most professionals ask pregnant women about their alcohol use, far fewer use a standardized screening tool. It is most likely that the tool is used when alcohol use is suspected — women most likely to be missed because of this practice include those over age 35 years, social drinkers, those who are highly educated, those with a history of sexual or emotional abuse, and those of high socioeconomic status. Provincial government action to embed standard screening tools on alcohol use on all prenatal records and support accurate completion of the screen would help to improve screening rates and effectiveness.
- ***Better implementation of existing clinical practice guidelines recommending that no alcohol be consumed during pregnancy.*** Results from the survey indicate that more than one in ten health care professionals do not make this recommendation to patients, with regional variation that could be reduced with effort to ensure guidelines are implemented consistently across the country.
- ***Improved information exchange between health care professional and patient on some key health issues.*** Survey results indicate that issues related to alcohol use during pregnancy are not widely discussed between health care provider and patient. For example, not even one half of health care professionals discuss with their patients in the childbearing years such issues as the risks of using alcohol during pregnancy and the definition of "moderate alcohol consumption."
- ***Better training on the diagnostic features of FAS.*** The most accurate information on which to make a diagnosis of FAS is a combination of growth, brain and facial abnormalities, although fewer than two in three health care providers is aware of this fact. Moreover, more than one half of professionals say that the absence of specific training on FAS limits their ability to diagnose.
- ***Improved understanding among health care professionals of the long-term secondary disabilities associated with FAS.*** Although seven in ten health care providers surveyed are aware that FAS is associated with long-term emotional disorders, only three in ten are aware of the association between FAS and inappropriate sexual behaviour. Better awareness would provide a basis for referrals designed to improve long-term outcomes for people with FAS.
- ***Clear and effective communication of the terminology related to Fetal Alcohol Spectrum Disorder.*** Survey results indicate that FAE is much less well understood by health care professionals than FAS. Clear and consistent use of terminology by health care and other service providers would benefit clients/patients, health care providers and systems responsible for the care of people with FAE and their families.
- ***Improved professional preparedness to care for alcohol dependent/abusing pregnant women and individuals with FAS.*** Survey results show that fewer than two in three health care professionals surveyed feel prepared to care for these clients, although more are prepared to access resources for them. Professionals are most interested in some specific types of support, including a registry of consultation specialists, clinical practice guidelines for diagnosis of FAS, referral resources for women with alcohol problems, and/or materials or training on FAS. They are much less interested in some other supports, including training in addiction, Internet resources and tele-medicine. Better understanding of the reasons behind these preferences would help guide initiatives to improve health care professional preparedness over the longer term.

Concerning Policy . . .

- ***Consensus among professional associations on guidelines for both moderate alcohol consumption for non-pregnant women and alcohol use among women at risk for unplanned pregnancy.*** Such consensus would allow health care professionals to discuss alcohol issues with women during an annual physical examination and at the same time such issues as birth control are discussed. In fact, most health care providers (8.5 in 10) routinely address birth control with their clients/patients of childbearing years — counselling about alcohol use and FAS would ideally be addressed at the same time.
- ***Development of guidelines for the advice and treatment of pregnant women found to be drinking during pregnancy.*** Inconsistencies in health care professional practice with respect to advice and treatment are evident. For example, not all health care professionals always discuss the adverse effects of alcohol when a pregnant woman reports moderate alcohol use. While most providers always discuss the adverse effects of alcohol with pregnant patients who are binge/heavy drinkers, or advise them to abstain from alcohol, far fewer refer them to treatment. Guidelines would help to ensure that more women receive consistent and correct advice and appropriate treatment.
- ***Development of resources related to alcohol consumption during pregnancy and prenatal effects of alcohol exposure.*** More and better reference materials for health care providers and information materials for clients/patients are called for. Even though information currently exists, survey results indicate that it is not always accessible to clients/patients. New materials developed should be fact-based, easy for all women to read and understand, culturally appropriate, and present a clear and consistent message.

Concerning Identification of Research . . .

- ***Identification of the most effective strategies for informing women about the risks of alcohol during pregnancy and for reducing alcohol consumption among women at risk of conception***. Research should specifically address determining the relative effectiveness of different intermediaries for information dissemination and behaviour change (i.e., community leaders, opinion leaders, and non-physician health care professionals such as pharmacists, nurses, birth mothers and teachers).
- ***Improved understanding of the prevalence of drinking during pregnancy and identifying the characteristics of women who drink while not using birth control*** — information essential for the development of appropriate and targeted interventions.
- ***Determining the prevalence of FAS.*** Since prevalence in the general population is largely unknown, and because of the lack of tools and guidelines for diagnosis, it is likely that FAS is frequently misdiagnosed.
- ***Development and implementation of surveillance systems to improve the understanding of the distribution and prevalence of FAS diagnosis*** — aimed at identifying communities at risk and at improving treatment and outcomes for individuals and families.
- ***Monitoring of health care professionals' knowledge through periodic surveys, and evaluation of education and support programs for health care professionals*** — to determine changes in the awareness, knowledge and behaviour of health care professionals.

Although survey results indicate that, while many health care professionals have a basic understanding of the issues related to both alcohol consumption during pregnancy and FAS, there are clear regional and professional differences in knowledge and attitudes toward both. At the same time, the data clearly call for standardized training programs to meet the specific needs of each health care professional group.

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Appendix A

Participation Rates, Response Rates and Sample Description

Table A1: **Participation Rate by Region**

Region	Provinces/Territories Included	Participation Rate (%)
West	British Columbia, NWT, Yukon, Nunavut	45.0%
Prairies	Alberta, Saskatchewan, Manitoba	46.0%
Ontario	Ontario	41.0%
Québec	Québec	39.0%
East	New Brunswick, Nova Scotia, PEI, Newfoundland and Labrador	36.0%

Table A2: **Response Rate by Professional Group**

Professional Group	Total Membership	Random Sample	Response Rate
Canadian Paediatric Society	2,374	735/1,396	52.7
College of Family Physicians (Canadian)	11,258	740/2,378	31.1
Canadian Psychiatric Association	1,439	391/851	45.9
Society of Obstetrics and Gynaecology	1,728	225/539	41.7
Midwives	344	125/197	63.5

Table A3: **Sample Description**

	Overall N (%)	Paediatrician N (%)	Psychiatrist N (%)	Midwife N (%)	Family Physician N (%)	Obstetrician N (%)
Age Group						
<40	672 (30.8)	182 (24.8)	47 (12.2)	37 (29.8)	341 (46.4)	65 (29.1)
40+	738 (33.8)	223 (31.1)	133 (34.6)	51 (41.1)	252 (34.3)	79 (35.4)
50+	541 (24.8)	202 (28.2)	134 (34.9)	31 (25.0)	125 (34.3)	49 (22.0)
60+	232 (10.6)	110 (15.3)	70 (18.2)	5 (4.0)	17 (2.3)	30 (13.5)
Total	2,183 (100.0)	717 (100.0)	384 (100.0)	124 (100.0)	735 (100.0)	223 (100.0)
Mean age (SD)	45.7 (10.3)	47.8 (10.8)	50.4 (9.0)	43.8 (9.3)	41.3 (8.8)	46.3 (10.0)
Year of Graduation						
<1959	50 (2.4)	32 (4.4)	15 (3.9)	1 (1.9)	173 (23.6)	3 (1.4)
<1979	810 (39.4)	348 (47.7)	206 (53.6)	19 (35.2)	224 (0.6)	83 (39.3)
<1989	633 (30.8)	209 (28.6)	126 (32.8)	21 (38.9)	336 (45.8)	74 (35.1)
1990+	565 (27.5)	141 (19.3)	37 (9.6)	13 (24.1)	733 (100.0)	51 (24.2)
Total	2,058 (100.0)	730 (100.0)	384 (100.0)	54 (100.0)	1,466 (100.0)	211 (100.0)

	Overall N (%)	Paediatrician N (%)	Psychiatrist N (%)	Midwife N (%)	Family Physician N (%)	Obstetrician N (%)
University Appointment						
Yes	1,143 (53.4)	503 (71.1)	244 (65.2)	23 (19.0)	251 (34.8)	122 (55.7)
No	998 (46.6)	204 (28.9)	129 (34.5)	98 (81.0)	470 (65.2)	97 (44.3)
Gender						
Male	1,125 (51.0)	399 (54.6)	251 (64.9)	—	367 (49.7)	108 (48.2)
Female	1,079 (49.0)	332 (45.4)	136 (35.1)	124 (100.0)	371 (50.3)	116 (51.8)
Location of Practice						
Urban	1,677 (78.5)	686 (90.0)	324 (87.1)	79 (64.8)	486 (67.4)	152 (70.7)
Rural	424 (19.8)	62 (8.8)	41 (11.0)	30 (24.6)	230 (31.9)	61 (28.4)
Both	36 (1.7)	9 (1.3)	7 (1.9)	13 (10.7)	5 (0.7)	2 (0.9)
Region						
West	319 (14.4)	80 (10.9)	53 (13.6)	25 (20.0)	110 (14.9)	51 (22.7)
Prairies	466 (21.0)	133 (18.1)	79 (20.2)	14 (11.2)	183 (24.7)	57 (25.3)
Central ON	884 (39.9)	287 (39.0)	181 (46.3)	68 (54.4)	288 (38.9)	60 (26.7)
Central QC	348 (15.7)	170 (23.1)	47 (12.0)	15 (12.4)	82 (11.1)	34 (15.1)
East	199 (9.0)	65 (100.0)	31 (7.9)	3 (2.4)	77 (10.4)	23 (10.2)

Table A4: **Survey Population by Selected Practice Characteristics and Health Care Professional Group**

Practice Characteristics	Overall N (%)	Paediatrician N (%)	Psychiatrist N (%)	Midwife N (%)	Family Physician N (%)	Obstetrician N (%)
Aboriginal Clients						
<25%	1,247 (89.0)	488 (90.2)	296 (96.7)	37 (84.1)	316 (83.4)	110 (79.7)
26–50%	84 (6.0)	32 (5.9)	6 (2.0)	2 (4.5)	31 (8.2)	13 (9.4)
51–100%	87 (6.0)	21 (3.8)	4 (1.3)	5 (11.3)	32 (8.5)	15 (10.8)
Women Aged 16 or Greater						
<25%	520 (29.0)	401 (89.9)	57 (16.4)	10 (9.3)	45 (6.4)	7 (3.3)
26–50%	368 (20.0)	22 (4.9)	52 (14.9)	1 (0.9)	277 (39.3)	16 (7.7)
51–100%	928 (51.0)	13 (5.1)	182 (52.3)	97 (89.9)	383 (54.3)	186 (89.0)
Children Aged 16 or Less						
<25%	881 (46.0)	13 (2.0)	249 (78.3)	35 (50.7)	437 (62.9)	147 (82.1)
26–50%	291 (15.0)	9 (1.4)	9 (2.8)	—	245 (35.3)	28 (15.6)
51–100%	750 (39.0)	639 (96.7)	60 (18.9)	34 (49.3)	13 (1.9)	4 (2.2)

Table A5: **Survey Population by Gender and Selected Health Care Professional Group**

	Paediatrician (%)	Psychiatrist (%)	Family Physician (%)	Obstetrician (%)
National sample males	56.7%	66.3%	55.4%	65.8%
Survey sample male	54.6%	64.9%	49.7%	48.2%

Appendix B

Data Tables

Table B1: **FAS Awareness and Attitudes about Prevention, by Region**

	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Agree alcohol's effects on fetus are clear	74.9	72.2	76.8	74.4	75.8	75.8
FAS is an identifiable syndrome	94.0	94.0	96.3	94.2	90.4	93.9
Agree physician's role to manage in area of alcohol use	76.1	75.1	76.5	80.3	65.2	77.6
Agree FAS occurs in all strata of society	95.4	97.2	93.7	95.8	94.2	97.0
Agree prenatal alcohol exposure is a risk for permanent brain damage	93.3	92.5	95.9	92.3	91.9	95.5
Moderate number of drinks per occasion among non-pregnant women is ≤2	91.0	93.6	91.0	91.2	88.1	91.2
Moderate number of occasions per week among non-pregnant women is ≤3	74.3	74.8	75.2	71.4	79.7	75.0
Agree with telling patients to drink in moderation	60.7	60.2	49.4	62.1	71.6	62.8
Prepared to care for pregnant women in area of alcohol abuse or dependency*	54.2	62.9	58.9	51.8	45.8	49.7
Prepared to care for birth mothers in area of alcohol abuse or dependency*	55.6	62.9	60.3	52.0	49.2	56.6
Prepared to access resources for pregnant women in area of alcohol abuse or dependency*	70.9	80.8	72.2	68.8	65.3	69.0
Prepared to access resources for birth mothers in area of alcohol abuse or dependency*	70.9	77.6	72.8	69.1	64.7	72.0

*Among those who care for pregnant women.

Table B2: **FAS Awareness and Attitudes about Prevention, by Health Care Professional Group**

	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Agree alcohol's effects on fetus are clear	74.9	77.8	75.9	68.0	75.1	67.1
Agree FAS is an identifiable syndrome	94.0	96.0	92.6	90.2	94.0	91.9
Agree FAS occurs in all strata of society	95.4	95.8	94.1	98.4	95.1	96.0
Agree discussing alcohol use *will not* deter from treatment	86.1	82.3	90.5	85.1	87.0	88.4
Agree discussing alcohol use *will not* frighten/anger patients	93.6	91.9	95.7	91.1	94.8	92.9
Agree physician's role to manage problems in area of alcohol use	76.1	74.8	73.8	61.0	83.6	67.7
Agree prenatal alcohol exposure is a risk for permanent brain damage	93.3	94.8	92.1	90.3	93.5	91.5
Moderate number of drinks per occasion among non-pregnant women is ≤2	91.0	93.0	93.4	93.7	88.6	87.2
Moderate number of occasions per week among non-pregnant women is ≤3	74.3	82.6	74.8	84.4	63.2	80.1
Agree with telling patients to drink in moderation	60.7	62.3	67.8	51.3	57.9	57.6
Prepared to care for pregnant women in area of alcohol abuse or dependency*	54.2	40.5	58.1	54.7	55.2	65.2
Prepared to care for birth mothers in area of alcohol abuse or dependency*	55.6	50.4	58.3	50.4	56.6	61.2
Prepared to access resources for pregnant women in area of alcohol abuse or dependency*	70.9	55.3	80.9	85.8	70.8	74.3
Prepared to access resources for birth mothers in area of alcohol abuse or dependency*	70.9	61.1	81.8	84.2	69.8	70.5

Agreement defined as "agree" and "strongly agree."
*Among those who care for these patient populations.

Table B3: **Prevention Issues Related to General Practices,* by Region**

	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Quebec (%)	East (%)
Frequently discuss folic acid in decreasing neural tube defects among all women of childbearing age	50.1	42.0	48.5	52.9	54.2	52.2
Frequently discuss risks of smoking during pregnancy among all women of childbearing age	49.2	45.6	52.2	48.2	49.5	51.1
Frequently discuss risks of alcohol during pregnancy among all women of childbearing age	40.1	42.0	47.2	38.6	30.8	35.5
Frequently discuss risks of drug use during pregnancy among all women of childbearing age	38.9	42.0	41.5	38.1	35.5	34.4
Frequently discuss birth control among all women of childbearing age	85.9	88.6	85.6	88.1	80.2	83.9
Frequently obtain a detailed history of sexual abuse among all women of childbearing age	13.5	19.3	12.6	14.4	9.4	7.6
Frequently obtain a detailed history of emotional abuse among all women of childbearing age	13.5	19.3	13.9	13.8	9.4	6.6
Frequently obtain a detailed history of alcohol use among all women of childbearing age	57.5	53.7	66.1	59.9	51.9	39.6
Frequently obtain a detailed history of addictions among all women of childbearing age	45.6	47.3	49.6	42.5	55.7	32.6
Frequently obtain a detailed history of family history of addictions among all women of childbearing age	23.9	29.5	27.9	21.7	24.5	12.1
Frequently/sometimes provide all women of childbearing age with written information on prenatal alcohol exposure	16.8	15.3	22.7	12.4	11.2	26.9
Use a standard tool (i.e., T-ACE, CAGE) to screen prenatal patients for alcohol use	62.3	72.6	67.7	53.6	84.5	52.0

*Among family physicians, midwives and obstetricians.

Table B4: **Prevention Issues Related to General Practices, by Selected Health Care Professional Group**

	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Frequently discuss folic acid in decreasing neural tube defects among all women of childbearing age	50.1	70.4	47.2	57.8
Frequently discuss risks of smoking during pregnancy among all women of childbearing age	49.2	82.2	46.9	56.0
Frequently discuss risks of alcohol during pregnancy among all women of childbearing age	40.1	75.0	37.9	43.0
Frequently discuss risks of drug use during pregnancy among all women of childbearing age	38.9	67.9	35.9	45.8
Frequently discuss birth control among all women of childbearing age	85.9	81.5	85.2	89.1
Frequently obtain a detailed history of sexual abuse among all women of childbearing age	13.5	50.0	10.8	18.2
Frequently obtain a detailed history of emotional abuse among all women of childbearing age	13.5	57.7	11.4	15.1
Frequently obtain a detailed history of alcohol use among all women of childbearing age	57.5	65.4	59.8	47.9
Frequently obtain a detailed history of addictions among all women of childbearing age	45.6	50.0	46.2	42.7
Frequently obtain a detailed history of family history of addictions among all women of childbearing age	23.9	38.5	25.5	16.1
Frequently or sometimes provide all women of childbearing age with written information on prenatal alcohol exposure	16.8	37.9	14.6	21.2
Use a standard tool to screen all prenatal patients for alcohol use	62.3	19.8	73.6	44.7

Table B5: **Routinely Included in Patients' Interviews Regarding Alcohol Use during Pregnancy,* by Region**

	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Ask all pregnant women if they are currently drinking alcohol	93.6	94.0	95.6	94.1	93.0	87.0
Drinking history of partner	21.4	27.8	19.4	19.2	24.8	19.2
Family history of alcohol abuse or dependency	52.7	80.4	50.0	45.3	52.7	39.4
Personal history of sexual abuse	33.8	39.7	27.7	35.2	35.2	31.3
History of addictions treatment	64.0	72.0	66.4	57.3	76.0	55.6
Quantity of alcohol intake (during pregnancy)	97.4	98.9	97.2	97.5	95.3	97.0
Frequency of alcohol intake (during pregnancy)	97.4	98.9	97.2	97.5	95.3	97.0
Personal history of binge drinking	73.0	72.8	77.6	70.8	72.1	71.7
Type of alcohol consumed	76.9	72.2	72.4	77.0	85.2	85.9
History of drinking prior to knowing about pregnancy	86.2	91.1	87.2	83.0	86.0	87.9
Evidence of alcohol-related birth defects in other children	39.8	43.8	48.8	35.8	29.4	39.8
Recommend no alcohol during pregnancy	87.5	89.8	92.3	87.7	74.8	86.0

*Among all health care professional groups.

Table B6: **Routinely Included in Patient Interviews Regarding Alcohol Use during Pregnancy, by Selected Health Care Professional Group**

	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Ask all women who are pregnant if they are currently drinking alcohol	93.6	99.2	92.3	95.0
Drinking history of partner	21.4	39.3	19.1	19.4
Family History of alcohol abuse or dependency	52.7	56.7	55.4	41.5
Personal history of sexual abuse	33.8	73.7	25.3	40.5
History of addictions treatment	64.0	64.7	61.9	70.8
Quantity of alcohol intake	97.4	96.7	97.7	96.8
Frequency of alcohol intake	97.4	96.6	97.6	96.8
Personal history of binge drinking	73.0	59.3	74.2	76.4
Type of alcohol consumed	76.9	66.4	79.7	73.3
History of drinking prior to knowing about pregnancy	86.2	85.7	86.5	85.3
Evidence of alcohol-related birth defects in other children	39.8	42.2	37.8	45.5
Recommend no alcohol during pregnancy	87.5	79.2	89.7	83.9

Table B7: **Prevention Approaches Related to Moderate Drinking, by Region**

	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Frequently discuss what patient thinks "in moderation" means	48.2	41.0	45.6	49.1	54.8	55.6
Always discuss adverse effects of alcohol use among pregnant women who report moderate alcohol use*	64.9	61.1	67.9	67.4	57.0	64.1
Always advise to abstain from alcohol when a pregnant woman reports moderate alcohol use*	70.0	70.7	79.4	65.7	57.6	76.6
Always discuss adverse effects of alcohol use among pregnant women who report binge drinking**	88.2	92.2	89.0	88.8	82.9	83.0
Always advise to abstain from alcohol when a woman reports binge drinking during pregnancy**	85.0	92.1	87.7	84.9	71.4	82.7
Always advise to reduce consumption when a woman reports binge drinking during pregnancy**	73.7	80.2	68.3	73.1	82.6	66.0
Always refer to treatment women who report binge drinking during pregnancy**	52.9	57.4	60.0	50.0	37.1	55.8

Denominator varies according to number of completed responses (range 757–1,050).
*Among 757 who reported moderate alcohol use in their practice.
**Among 559 who reported binge drinking or heavy alcohol use in their practice.

Table B8: **Prevention Approaches Related to Moderate Drinking, by Selected Health Care Professional Group**

	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Frequently discuss what patient thinks "in moderation" means	48.2	37.0	51.4	43.7
Always discuss adverse effects of alcohol use among pregnant women who report moderate alcohol use	64.9	82.9	64.2	58.9
Always advise to abstain from alcohol when a pregnant woman reports moderate alcohol use	70.0	55.3	72.4	69.3
Always discuss adverse effects of alcohol use among pregnant women who report binge drinking	88.2	87.8	88.5	87.5
Always advise to abstain from alcohol when a woman reports binge drinking during pregnancy	85.0	80.5	87.6	79.7
Always advise to reduce consumption when a woman reports binge drinking during pregnancy	73.7	75.0	71.7	78.3
Always refer to treatment women who report binge drinking during pregnancy	52.9	63.4	49.3	59.0

Table B9: **Supports Perceived as Helpful, by Health Care Professional Group**

	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Literature on the impact of alcohol use during pregnancy	50.0	44.7	49.5	75.4	49.3	56.8
Pregnancy history checklists including terms on alcohol use	39.4	34.0	35.8	57.0	42.7	41.8
Materials or training on FAS/FAE	51.7	54.2	47.3	72.7	50.1	44.7
Training on addiction counselling	25.9	17.0	26.1	32.5	34.3	23.0
Registry of specialists available for consultation about FAS/FAE	61.8	53.9	53.9	85.1	66.9	62.1
Referral resources for women of childbearing age with alcohol problems	62.6	47.5	58.7	82.0	73.0	72.1
Clinical practice guidelines for diagnosis of FAS	60.8	66.7	55.7	69.7	59.8	48.9
Assistance with diagnosis of FAS/FAE through tele-medicine	24.1	26.5	21.1	42.0	21.7	19.3
Access to information about FAS/FAE through tele-medicine	25.8	28.3	22.6	45.0	22.9	22.1
Internet resources	35.8	37.8	33.4	54.2	34.3	28.6

Table B10: **Barriers to Providers Discussing Alcohol Use during Pregnancy, by Selected Health Care Professional Group**

	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
There is not enough time to talk to women about alcohol before they are pregnant (agree)	58.0	6.7	59.4	60.9
There are other sources of information on alcohol use to which I refer women (agree)	26.7	37.0	24.9	31.6
There is not enough solid information available about alcohol use (agree)	10.9	7.1	11.0	11.1
Many clients are not interested in discussing alcohol use	31.1	20.7	30.2	36.4
Many clients already have good knowledge about alcohol use (agree)	42.8	72.4	41.3	43.7
Information is not in a useful format for clients	48.8	37.0	48.0	53.4

Table B11: **Provider-Identified Barriers to Women Seeking Treatment for Alcohol Use during Pregnancy, by Selected Health Care Professional Group**

	Overall (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Dual diagnosis (i.e., depression, bipolar disorder)	78.7	77.8	79.9	75.3
History of sexual abuse	71.8	76.9	71.3	70.5
History of domestic abuse	82.6	86.3	82.7	80.4
Co-dependence (partner/peer/parental substance abuse)	91.9	92.4	92.0	91.4
Current violence in the home	87.9	93.2	87.7	85.9
Extrinsic barriers: child care, housing, poverty	85.0	91.5	83.5	86.8
Fear of public shame, blame	91.1	97.4	90.7	88.9
Misinformation about the safety of alcohol use during pregnancy	69.4	76.1	69.2	66.7
Fear of losing children to partner or child welfare	91.5	98.3	89.7	95.1
Systemic racism	49.1	82.9	45.7	42.1
Systemic prejudice based on social/ economic class	62.9	88.9	59.3	61.0
Communication/language barriers	64.2	82.9	69.3	63.8
Lack of addiction treatment services	67.9	82.8	66.7	64.1
Lack of gender specific addiction treatment services	65.4	84.5	63.2	62.6

Table B12: **Provider Awareness of Sources of Information on FAS,* by Region**

	Overall (%)	West (%)	Prairies (%)	Ontario (%)	Québec (%)	East (%)
Had heard of FAS prior to 1997	98.8	99.4	98.9	98.5	98.0	100.0
Had heard of FAE prior to 1997	55.7	63.0	58.3	48.5	64.9	53.5
FAS is an identifiable syndrome (agree)	94.0	94.0	96.3	94.2	90.4	93.6
Gained knowledge of FAS from medical journals and books	76.4	78.4	79.0	78.7	64.9	77.4
Gained knowledge of FAS from medical school, residency or fellowship	63.6	59.9	66.1	62.3	64.4	68.3
Gained knowledge of FAS from CME** seminars or rounds	50.9	61.4	64.4	47.1	32.5	51.8
Gained knowledge of FAS from parents or patients	24.1	40.4	35.8	20.0	8.3	16.6
Gained knowledge of FAE from medical journals and books	61.2	63.3	65.9	59.8	55.5	62.8
Gained knowledge of FAE from medical school, residency or fellowship	34.0	29.8	36.3	29.8	44.3	36.7
Gained knowledge of FAE from CME** seminars or rounds	43.0	49.8	57.9	39.1	29.0	38.7
Gained knowledge of FAE from parents or patients	14.4	24.5	24.5	10.9	4.3	8.5

*Among all health care professional groups.
**Continuing Medical Education.

Table B13: **Provider Awareness of Sources of Information on FAS, by Health Care Professional Group**

	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Had heard of FAS prior to 1997	98.8	99.2	97.7	99.2	98.8	99.1
Had heard of FAE prior to 1997	55.7	68.1	52.5	58.4	43.7	58.7
FAS is an identifiable syndrome (agree)	94.0	96.0	92.6	90.2	94.0	91.9
Gained knowledge of FAS from medical journals and books	76.4	82.2	78.3	84.0	68.5	76.4
Gained knowledge of FAS from medical school, residency or fellowship	63.6	69.1	52.4	15.2	70.5	69.3
Gained knowledge of FAS from CME* seminars or rounds	50.9	60.8	39.9	27.2	48.9	57.3
Gained knowledge of FAS from parents or patients	24.1	26.1	26.9	24.8	22.8	16.9
Gained knowledge of FAE from medical journals and books	61.2	72.0	58.6	74.4	49.5	61.8
Gained knowledge of FAE from medical school, residency or fellowship	34.0	42.3	31.7	12.8	29.7	36.9
Gained knowledge of FAE from CME* seminars or rounds	43.0	56.7	34.5	21.6	34.9	51.6
Gained knowledge of FAE from parents or patients	14.4	15.4	18.7	16.0	12.4	9.8

*Continuing Medical Education.

Table B14: **Diagnostic Knowledge about FAE, by Health Care Professional Group**

	Overall (%)	Paediatrician (%)	Psychiatrist (%)	Midwife (%)	Family Physician (%)	Obstetrician (%)
Recognized FAE *is* a partial expression of FAS (agree)	70.1	77.7	65.3	68.6	65.4	69.6
Recognized that FAE is *not used* when birth defects diminish over time	59.2	74.3	50.9	56.5	48.5	60.4
Recognized that FAE is *not used* when there are no IQ deficits	52.3	70.2	49.3	38.5	40.3	45.2
Recognized that FAE is *not used* when a child has birth defects but maternal alcohol use is unclear	53.4	63.6	51.2	43.9	46.2	52.1
Recognized that FAE is *not used* when a child is too young to make a diagnosis of FAS	48.2	63.1	47.6	43.4	37.0	39.7
Recognized that FAE is *not* a less severe form of FAS	14.4	21.7	11.9	13.8	10.2	8.4
Recognized that using the term FAE does *not* result in better long-term social outcome than using the term FAS	39.9	54.4	40.2	26.4	29.4	34.0

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Fetal Alcohol Syndrome Survey for Health Professionals

Part A
(General knowledge and attitudes)

In recent years there has been increased investigation about the effects of alcohol consumption during pregnancy and the potential for subsequent morbidity and mortality among offspring. Experimental findings have been the main focus. Clinical aspects have received less attention. It would be helpful to know what information has reached you, whether it has been useful, and how it could be improved.

Fetal Alcohol Syndrome (FAS)

1.1 When did you first hear of FAS? (Please select one answer only.)

- In the last year or two ○
- Three to four years ago ○
- More than four years ago ○
- Never ○

1.2 From what sources have you gained knowledge about FAS? (Please select all that apply.)

- Mass Media ○
- Parents/patients ○
- Colleagues ○
- CME seminars, rounds ○
- Medical journals, books ○
- Medical school, residency, fellowship ○
- Other (please specify) ○

_____

2. In your opinion, is the incidence of FAS in Canada higher, equivalent, or lower than the incidence of each of the following?

	Higher	Equivalent	Lower	Don't know
2.1 Down's Syndrome	○	○	○	○
2.2 Spina Bifida	○	○	○	○
2.3 Asthma	○	○	○	○
2.4 Ceberal Palsy	○	○	○	○
2.5 Juvenile Diabetes	○	○	○	○

3. Please indicate your opinion on the following statements:

	Strongly agree	Agree	Disagree	Strongly disagree	Undecided
3.1 FAS is an identifiable syndrome.	○	○	○	○	○
3.2 Alcohol's effect on fetal development remains unclear.	○	○	○	○	○
3.3 It is the physician's role to manage problems in the area of alcohol use.	○	○	○	○	○
3.4 It is the Midwife's role to manage problems in the area of alcohol use.	○	○	○	○	○
3.5 FAS occurs in all strata of society.	○	○	○	○	○
3.6 FAS occurs at similar rates among all cultures and ethnic groups.	○	○	○	○	○
3.7 The drinking patterns of pregnant women are substantially influenced by the drinking patterns of their male partners.	○	○	○	○	○
3.8 Discussing alcohol use during pregnancy will frighten or anger patients.	○	○	○	○	○
3.9 Discussing the use of alcohol during pregnancy will deter women from continuing and/or seeking treatment.	○	○	○	○	○
3.10 Making a diagnosis of FAS does not change anything for the child.	○	○	○	○	○
3.11 Prenatal alcohol exposure is a significant risk factor for permanent brain damage.	○	○	○	○	○

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Fetal Alcohol Effects (FAE) or Alcohol-Related Neurodevelopmental Defects (ARND)

4.1 When did you first hear of FAE or ARND? (Please select **one** answer only.)

- In the last year or two ○
- Three to four years ago ○
- More than four years ago ○
- Never ○

4.2 From what sources have you gained knowledge about FAE or ARND? (Please select **all** that apply.)

- Mass Media ○
- Parents/patients ○
- Colleagues ○
- CME seminars, rounds ○
- Medical journals, books ○
- Medical school, residency, fellowship ○
- Other (please specify) ○

_____

5. Please indicate your opinion on the following statements. **The term FAE** …

		Agree	Disagree	Don't know
5.1	is used if the child is too young to make a firm diagnosis of FAS.	○	○	○
5.2	is used when birth defects from prenatal alcohol exposure diminish over time.	○	○	○
5.3	is used to denote a less severe form of FAS.	○	○	○
5.4	is used if there is no obvious facial dysmorphology.	○	○	○
5.5	is used if the child shows only partial expression of FAS.	○	○	○
5.6	is used if there are no IQ deficits.	○	○	○
5.7	is used if the child has birth defects but maternal alcohol use history is unclear.	○	○	○
5.8	is used if the child demonstrates only behavioural components of syndrome.	○	○	○
5.9	results in better long term social outcomes than if the term FAS is used.	○	○	○

Prenatal Alcohol Exposure

6. Do you consider the following types of problems to be outcomes of prenatal alcohol exposure?

		Yes	No	Don't know
6.1	Infantile withdrawal symptoms	○	○	○
6.2	Delayed development	○	○	○
6.3	Birth defects/malformations	○	○	○
6.4	Mental disorders	○	○	○
6.5	Learning disabilities	○	○	○
6.6	Lowered IQ/retardation	○	○	○
6.7	Craniofacial deformities	○	○	○
6.8	Behavioural problems	○	○	○
6.9	Low birth weight	○	○	○
6.10	Growth retardation, small for gestational age	○	○	○
6.11	Premature birth (<37 weeks)	○	○	○
6.12	Above average birth weight (>4000 grams)	○	○	○
6.13	Seizures	○	○	○
6.14	Vision problems	○	○	○
6.15	Structural brain damage	○	○	○
6.16	Spontaneous abortion	○	○	○

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7. **In your opinion, are the following specific conditions now considered to be under the spectrum of disorders associated with prenatal alcohol exposure?**

		Yes	No	Don't know
7.1	Fetal Alcohol Syndrome (FAS)	○	○	○
7.2	Sentinel Birth Defect	○	○	○
7.3	Asthma	○	○	○
7.4	Neurological Impairment, Organic Brain Damage	○	○	○
7.5	Fetal Alcohol Effects (FAE)	○	○	○
7.6	Alcohol Related Neurodevelopment Defects (ARND)	○	○	○
7.7	Diabetes	○	○	○
7.8	Alcohol Related Birth Defects (ARBD)	○	○	○
7.9	Hyperactivity disorder	○	○	○
7.10	Failure to thrive	○	○	○
7.11	Bronchopulmonary dysplasia	○	○	○
7.12	Necrotizing Enterocolitis	○	○	○

Alcohol Use

8. **Patients, both men and women, are often told to drink only "in moderation."**

8.1 Do you agree with this practice? ○ Yes ○ No

8.2 What is your definition of a moderate level of alcohol consumption for **non-pregnant women**?

8.2a Average number of drinks per occasion: ☐

8.2b Average number of drinking occasions per week: ☐

9.1 **How prepared do you feel to care for the following groups of clients in the area of alcohol abuse or dependency?**

		Very prepared	Prepared	Unprepared	Very unprepared	Do not care for
9.1.1	Pregnant women	○	○	○	○	○
9.1.2	Birth mothers	○	○	○	○	○
9.1.3	Foster parents	○	○	○	○	○
9.1.4	Affected individuals	○	○	○	○	○

9.2 **How prepared do you feel to access resources for the following groups of clients in the area of alcohol abuse or dependency?**

		Very prepared	Prepared	Unprepared	Very unprepared	Do not care for
9.2.1	Pregnant women	○	○	○	○	○
9.2.2	Birth mothers	○	○	○	○	○
9.2.3	Foster parents	○	○	○	○	○
9.2.4	Affected individuals	○	○	○	○	○

10. **Please rate how helpful the following kinds of materials or supports would be to you in your clinical practice.**

		Very helpful	Somewhat helpful	Not very helpful	Not at all helpful
10.1	Literature on the impact of alcohol use during pregnancy	○	○	○	○
10.2	Pregnancy history checklists including terms on alcohol use	○	○	○	○
10.3	Materials or training on FAS/FAE	○	○	○	○
10.4	Training in addiction counselling	○	○	○	○
10.5	Registry of specialists available for consultation about FAS/FAE	○	○	○	○
10.6	Referral resources for women of childbearing age with alcohol problems	○	○	○	○
10.7	Clinical Practice Guidelines for diagnosis of FAS	○	○	○	○
10.8	Assistance with the diagnosis of FAS/FAE through Telemedicine	○	○	○	○
10.9	Access to information about FAS/FAE through Telemedicine	○	○	○	○
10.10	Internet resources	○	○	○	○
10.11	Other (please specify)	○	○	○	○

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Part B
(Prevention issues)

Women receive different types of information about how to achieve and maintain a healthy pregnancy. Please consider your own practice when answering the following questions.

Non-Pregnant Women

11.1 Do you treat non-pregnant women of childbearing age? ○ Yes ○ No

If "No," please proceed to Question 15.

11.2 How often do you discuss the following with...	...all women of childbearing age?				...those in a likely position to conceive?			
	Frequently	*Sometimes*	*Rarely*	*Never*	*Frequently*	*Sometimes*	*Rarely*	*Never*
11.2.1 role of folic acid in decreasing NTD	○	○	○	○	○	○	○	○
11.2.2 risks of smoking during pregnancy	○	○	○	○	○	○	○	○
11.2.3 risks of alcohol during pregnancy	○	○	○	○	○	○	○	○
11.2.4 risks of drug use during pregnancy	○	○	○	○	○	○	○	○
11.2.5 nutrition	○	○	○	○	○	○	○	○
11.2.6 workplace stress	○	○	○	○	○	○	○	○
11.2.7 mental health	○	○	○	○	○	○	○	○
11.2.8 weight management	○	○	○	○	○	○	○	○
11.2.9 partner's use of drugs and alcohol	○	○	○	○	○	○	○	○
11.2.10 depression	○	○	○	○	○	○	○	○
11.2.11 birth control	○	○	○	○	○	○	○	○
11.2.12 Pap testing	○	○	○	○	○	○	○	○
11.2.13 sexual history	○	○	○	○	○	○	○	○

12. How routinely do you **obtain a detailed history** about the following from...	...all women of childbearing age?				...those in a likely position to conceive?			
	Frequently	*Sometimes*	*Rarely*	*Never*	*Frequently*	*Sometimes*	*Rarely*	*Never*
12.1 sexual abuse	○	○	○	○	○	○	○	○
12.2 emotional abuse	○	○	○	○	○	○	○	○
12.3 alcohol use	○	○	○	○	○	○	○	○
12.4 personal history of addictions	○	○	○	○	○	○	○	○
12.5 family history of alcohol misuse	○	○	○	○	○	○	○	○

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13. How routinely do you **provide written information** about prenatal alcohol exposure to...

13.1 ...all women of childbearing age?

○ Frequently ○ Sometimes ○ Rarely ○ Never

13.2 ...those in a likely position to conceive?

○ Frequently ○ Sometimes ○ Rarely ○ Never

14. There are many reasons why health professionals may not be talking to women about alcohol use before they become pregnant.

Indicate whether the following apply to you.

		Yes	No
14.1	There is not enough time in an office visit to talk to women about these topics.	○	○
14.2	There are other sources of information on alcohol use to which you refer women.	○	○
14.3	There is not enough solid information available about alcohol use.	○	○
14.4	Many of your clients are not interested in discussing alcohol use.	○	○
14.5	Many of your clients already have a good knowledge about alcohol use.	○	○
14.6	Information about alcohol use is not available in a form that is useful for your clients.	○	○

Pregnant Women

15. Would you consider the following to be **barriers to women seeking care for alcohol use during pregnancy**?

		Yes	No
15.1	dual diagnoses (e.g., depression, bipolar disorder, panic attacks)	○	○
15.2	history of sexual abuse	○	○
15.3	history of domestic abuse	○	○
15.4	co-dependence (partner/peer/parental substance abuse)	○	○
15.5	current violence in the home	○	○
15.6	extrinsic barriers (e.g., childcare, housing, transportation, poverty)	○	○
15.7	fear of public shame, blame, etc.	○	○
15.8	misinformation about the safety of alcohol use during pregnancy	○	○
15.9	fear of losing children to partner or child welfare	○	○
15.10	systemic racism	○	○
15.11	systemic prejudice based on social/economic class	○	○
15.12	communication/language barriers	○	○
15.13	paucity/absence of addiction treatment services	○	○
15.14	paucity/absence of gender-specific addiction treatment services	○	○

16. Do you ask all women who are pregnant if they are currently drinking alcohol? ○ Yes ○ No

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17. Please indicate if you are currently using any of the alcohol screening tools or tests listed below in screening prenatal patients for alcohol use. (Please check all that apply.)

T-ACE: Tolerance, Annoy, Cut-down, Eye-opener
TWEAK: Tolerance, Worry, Eye-opener, Amnesia, (C)Kut down
CAGE: Cut-down, Annoy, Guilty, Eye-opener
MAST: Michigan Alcoholism Screening Test
AUDIT: Alcohol Use Disorders Identification Test

- None ○
- T-ACE ○
- TWEAK ○
- CAGE ○
- MAST ○
- AUDIT ○
- Urine or blood test ○
- Other (please specify) ○

_____

_____

18. How do you asses the risk of alcohol misuse by patients who report drinking during pregnancy? (Please check all that apply.)

- Standardized screening tool (name) _____ ○
- Informal methods (describe) _____ ○
- None at all ○

19. Do you routinely include the following in your interview with patients regarding alcohol use during pregnancy?

		Yes	No
19.1	drinking pattern of partner	○	○
19.2	family history of alcohol abuse or dependency	○	○
19.3	personal history of sexual abuse	○	○
19.4	history of addictions treatment	○	○
19.5	quanitity of intake (alcohol)	○	○
19.6	frequency of intake (alcohol)	○	○
19.7	personal history of binge drinking	○	○
19.8	type of alcohol consumed	○	○
19.9	history of drinking prior to knowing about pregnancy	○	○
19.10	evidence of alcohol related birth defects in other children	○	○

20. Which of the following best describes the advice you currently give pregnant women regarding alcohol use during pregnancy?

- No alcohol is recommended. ○
- Alcohol is only dangerous during the first trimester. ○
- A glass of beer or wine in moderation is OK. ○
- No specific recommendations are given. ○
- Other (please specify) ○

_____

_____

21. How often do you discuss what the patient thinks "in moderation" means?

○ Frequently ○ Sometimes ○ Rarely ○ Never

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22. Please indicate the frequency with which you take each of the following actions when a pregnant woman reports **moderate** alcohol use (e.g., 3-13 drinks per week):

If this is never reported in your practice, please check box and skip to question 23. ☐

		Always	Usually	Sometimes	Never
22.1	Advise that this level is not harmful	○	○	○	○
22.2	Discuss adverse effects	○	○	○	○
22.3	Advise to abstain	○	○	○	○
22.4	Advise to reduce consumption	○	○	○	○
22.5	Refer for treatment	○	○	○	○
22.6	Refer to social services	○	○	○	○
22.7	Order a toxicology screen	○	○	○	○
22.8	Take no action	○	○	○	○

23. Please indicate the frequency with which you take each of the following actions when a pregnant woman reports **heavy** alcohol use (e.g., 14 or more drinks per week) or **binge drinking** (5 or more drinks on any one occasion):

If this is never reported in your practice, please check box and skip to the next section. ☐

		Always	Usually	Sometimes	Never
23.1	Advise that this level is not harmful	○	○	○	○
23.2	Discuss adverse effects	○	○	○	○
23.3	Advise to abstain	○	○	○	○
23.4	Advise to reduce consumption	○	○	○	○
23.5	Refer for treatment	○	○	○	○
23.6	Refer to social services	○	○	○	○
23.7	Order a toxicology screen	○	○	○	○
23.8	Take no action	○	○	○	○

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Part C

(Mainly related diagnostic issues)

Please consider your own practice over the **past 5 years** when answering the following questions.

24. In your practice, have you:

	Yes	No	If "Yes," how many?
24.1 diagnosed any patient as having FAS?	O	O	
24.2 cared for FAS affected patients?	O	O	
24.3 suspected (but did not diagnose) FAS?	O	O	
24.4 referred patients to confirm a diagnosis of FAS?	O	O	

25. Have you ever reported an FAS diagnosis? O Yes O No

26. Have you ever reported an FAE diagnosis? O Yes O No

27. If you answered "Yes" to reporting either FAS or FAE, with whom did you share the information? (Please check **all** that apply.)

- Education O
- Social Services O
- Other (please specify) O

_____

28. Do you think there should be mandatory reporting of:

28.1 FAS?	O Yes	O No	O Don't know
28.2 FAE?	O Yes	O No	O Don't know

29. Are these reportable conditions in your province or territory?

29.1 FAS	O Yes	O No	O Don't know
29.2 FAE	O Yes	O No	O Don't know

30.1 Do you make use of a diagnostic schema in your practice? O Yes O No

30.2 If "Yes," which one of the following do you use?

- Seattle 4 digit diagnostic criteria O
- U.S. Birth Defects Surveillance criteria O
- American Association of Pediatrics criteria O
- Institute of Medicine criteria O
- Other (please specify) O

_____

31. Do you make use of standardised terminology for diagnosis? O Yes O No

32. In your opinion, do the following characteristics define FAS?

	Yes	No	Don't know
32.1 prominent forehead	O	O	O
32.2 flat philtrum	O	O	O
32.3 thin upper lip	O	O	O
32.4 thick upper lip	O	O	O
32.5 short palpebral fissures	O	O	O
32.6 upslanting palpebral fissures	O	O	O
32.7 downslanting palpebral fissures	O	O	O
32.8 CNS dysfunction	O	O	O
32.9 prenatal growth deficiency	O	O	O
32.10 postnatal growth deficiency	O	O	O

33. Which of the following items would give you the most accurate information regarding the diagnosis of FAS? (Please select **one** only.)

- Mother has history of alcohol abuse or dependency O
- Small at birth O
- Behaviour problems O
- Cognitive problems O
- Special facial characteristics O
- Combination of growth, brain, and facial abnormalities O

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34. Please indicate whether the following, in your opinion, are associated with or are directly caused by FAS:

	Associated with FAS	Directly caused by FAS	Neither	Don't know
34.1 Long term emotional disorders	○	○	○	○
34.2 Disrupted school experience	○	○	○	○
34.3 Addictions	○	○	○	○
34.4 Legal problems	○	○	○	○
34.5 Diabetes	○	○	○	○
34.6 Cleft palate	○	○	○	○
34.7 Hearing problems	○	○	○	○
34.8 Alzheimer's	○	○	○	○
34.9 Attention Deficit Disorder	○	○	○	○
34.10 Low IQ	○	○	○	○
34.11 Average IQ	○	○	○	○
34.12 High IQ	○	○	○	○
34.13 Albinism	○	○	○	○
34.14 Inappropriate sexual behaviour	○	○	○	○

35. Where would you refer suspected patients with FAS?

_____

_____

_____

36. Many doctors do not make the diagnosis of FAS in their practice. Please indicate which of the following factors may contribute to this situation. (Please select **all** that apply.)

If making the diagnosis would be beyond your scope of practice, please check this box and skip to Question 38. ☐

- Lack of time needed to make diagnosis ○
- Lack of specific training to make the diagnosis ○
- Belief that making the diagnosis will not make a difference to the individual ○
- Other (please specify) ○

_____

_____

37. Please rate the helpfulness of the following in making an FAS diagnosis, or indicate that they are not available in your community.

	Very helpful	Somewhat helpful	Not very helpful	Not at all helpful	Not available in my community
37.1 Access to a psychologist	○	○	○	○	○
37.2 Access to educational information	○	○	○	○	○
37.3 Access to a multidisciplinary team	○	○	○	○	○
37.4 Outreach clinic with an expert diagnostic team	○	○	○	○	○
37.5 CME training	○	○	○	○	○
37.6 Use of Telehealth for diagnosis by an expert diagnostic team	○	○	○	○	○

38. What do you think are the most commonly held misconceptions about FAS?

_____

_____

_____

_____

_____

_____

39. Where would you seek more information on FAS?

_____

_____

_____

_____

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Part D
(Background information)

The following information will be used to help us understand more about health care practitioners, their experience, and their work environment.

40. What is your gender? ○ Male ○ Female

41. What is your age? [ ][ ]

42. Marital status:
- Single ○
- Married ○
- Living with a partner ○
- Divorced ○
- Separated ○
- Widowed ○

43. Number of children: [ ][ ]

44. **Physicians only:** Year of graduation from medical school: [ ][ ][ ][ ]

45. **Midwives only:**

45.1 Are you a graduate of a Canadian Midwifery Education Programme?
○ Yes ○ No If "Yes," year of graduation: [ ][ ][ ][ ]

45.2 Are you a Michener Pre-Registration graduate?
○ Yes ○ No If "Yes," year of graduation: [ ][ ][ ][ ]

45.3 Are you a Prior Learning and Assessment (PLEA) registrant?
○ Yes ○ No If "Yes," year of graduation: [ ][ ][ ][ ]

45.4 Do you have a degree or diploma in Midwifery from another jurisdiction?
○ Yes ○ No If "Yes," name of jurisdiction: _____
Year of graduation: [ ][ ][ ][ ]

46. What is your primary mode of practice: (Please select only **one**.)
- Solo practice ○
- Group practice ○
- Other (please specify) ○

_____

47. Do you have a university appointment of any type? ○ Yes ○ No

48. Do you consider your practice to be:
○ Urban ○ Rural

49. What proportion of your practice is:
(**Note**: categories are not mutually exclusive.)

49.1 Aboriginal _____
49.2 Women (aged 16 years or older) _____
49.3 Children (birth to 16 years of age) _____

THANK YOU FOR YOUR ASSISTANCE

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