

Physicians for Fetal Alcohol Spectrum Disorder Prevention

Project Report

October 2007

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1. Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) can be prevented. However, inconclusive evidence, insufficient data and conflicting opinions cause confusion and uncertainty among physicians and the general public. While physicians may appear to be in an ideal position to provide FASD screening and prevention services, this may not be the best approach.

The Physicians for FASD Prevention project, while not completed as originally planned, provided valuable insight into the disparities between research findings and recommendations for FASD screening and prevention, and the realities of primary care physicians providing those services in every day clinical practice. This project attempted to develop and implement supports for physicians to improve FASD screening and prevention services they deliver to all women of childbearing age. Despite being supported by existing research and recommendations, the supports that were developed were not well received by physicians. In this report, we attempt to understand why the disparities exist between FASD screening and prevention services recommended by research, and those that exist in physicians' every day practices.

Our observations suggest three reasons:

- More FASD research is required. Inconclusive evidence, particularly
 with regard to the amount and timing of alcohol consumption during
 pregnancy, causes uncertainty and confusion among physicians and the
 general public. There is also insufficient data concerning the incidence and
 prevalence of FASD, and the efficacy of FASD screening and prevention
 programs.
- FASD is not solely a medical issue. FASD does not occur in isolation and is not solely a medical issue. It impacts individuals and their families and many areas of society, including health care, education, the judicial system and the economy, in terms of lost productivity.
- Health crisis before health management. Lack of time and competing
 priorities are the most common, consistent reasons expressed by
 physicians for failure to provide FASD screening and prevention services.

It would be incorrect to attribute the lack of FASD screening and preventive services to all women of childbearing age to primary care physicians. However, the challenge of providing these services across all areas and strata of society remains. FASD must be viewed as an issue that impacts everyone and can happen to anyone, regardless of education, socio-economic status, or age. Surveillance and research must be stepped up to provide more conclusive evidence about the incidence and prevalence of FASD, and the amount and timing of alcohol consumption in pregnancy. Efforts to prevent FASD must be coordinated and collaborative. Without these changes, systematic improvements in alcohol screening and prevention of FASD will continue to be a challenge.

2. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of preventable birth defects and one of the leading causes of developmental delay in children in Canada. ^{1 2} It can be prevented by women abstaining from alcohol consumption during pregnancy. While there is inconclusive evidence regarding the amount and timing of alcohol consumption that causes FASD, Health Canada states "... the prudent choice for women who are or may become pregnant is to abstain from alcohol."

Fetal Alcohol Spectrum Disorder is an over-arching term describing a range of lifelong disabilities resulting from prenatal alcohol exposure.⁴ The impact of FASD on individuals and their families is significant, including physical, mental and behavioral impairments. Economically, FASD impacts health care, education, criminal justice and lost productivity. It has been estimated that the lifetime extra cost for an FASD-affected individual in Canada is \$1.4 million.⁵

It is essential to inform, educate and screen women of childbearing age, prior to conception, about the dangers of alcohol consumption during pregnancy, and for them to abstain from alcohol consumption during pregnancy.

The Alberta Clinical Practice Guidelines, Health Canada and other national and international bodies, such as the Center for Disease Control and Prevention (US) and the National Institute of Health (US) recommend that women completely abstain from alcohol when they are pregnant or considering pregnancy.^{6 7 8} Since FASD is considered to be preventable,^{9 10} ^{11 12} it is essential to inform, educate and screen women of childbearing age, prior to conception, about the dangers of alcohol consumption during pregnancy, and for them to abstain from alcohol consumption during pregnancy.

In a recent survey, 80% of urban Alberta women reported preconception alcohol consumption, and many who were planning a pregnancy did not

¹ Health Canada. Joint Statement-Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects in Canada. Health Canada 2006; Ottawa, ON.

² Ibid.

³ Ibid.

⁴ Masotti P, George MA, Szala-Meneok K, Morton AM, Loock C, Van Bibber M, Ranford J, Fleming M, MacLeod S. Preventing Fetal Alcohol Spectrum Disorder in Aboriginal Communities: A methods development project. PLoS 2006;Jan:3(1):1-15.

⁵ Clarke M, Tough SC, Cooke J. Fetal alcohol spectrum disorder: Knowledge and attitudes of health professionals about fetal alcohol syndrome: Results of a national survey. Health Canada 2004; Ottawa, ON

⁶ Health Canada. Joint Statement (2006).

⁷ Alberta Medical Association. Prevention of Fetal Alcohol Syndrome (FAS). Alberta Clinical Practice Guidelines. Alberta Medical Association. 2005 update.

⁸ Ibid.

⁹ Ibid

¹⁰ Tough SC, Tofflemire K, Clarke M, Newburn-Cooke C. Do women change their drinking behaviours while trying to conceive? An opportunity for preconception counseling. Clin Med & Res 2006;4(2):97-105.

¹¹ Health Canada. Joint Statement (2006).

¹² Basford DL, Thorpe K. State of the evidence: Fetal alcohol spectrum disorder (FASD) prevention. Alberta Center for Child, Family & Community Research 2005 Apr. University of Lethbridge, Lethbridge AB.

abstain from alcohol or reduce alcohol consumption patterns until pregnancy was recognized.¹³ Fifty percent the of respondents reported continuing alcohol consumption until they recognized that they were pregnant, at an average of five weeks gestation.¹⁴ Although the majority of women reduced or stopped alcohol consumption once they realized they were pregnant (well into the first trimester), the fetus would have been exposed to alcohol during early stages of embryonic development.¹⁵

Primary care physicians' practices have been identified in many studies as ideal settings in which to conduct FASD screening and prevention, ¹⁶ ¹⁷ ¹⁸ ¹⁹ and are the primary point of access to the health care system for most women. As the typical providers of primary medical care for women, primary care physicians play an important role in the prevention of FASD. ²⁰

¹³ Tough SC, Tofflemire K, Clarke M et al. (2006).

¹⁴ Ibid.

¹⁵ Ibid..

¹⁶ Clarke M, Tough SC, Cooke J. (2004).

¹⁷ Tough SC, Clarke M, Hicks M, Clarren S. Clinical practice characteristics and preconception counseling strategies of health care providers who recommend alcohol abstinence during pregnancy. Alcohol Clin Exp Res 2004 Nov;28(11):1724-31.

¹⁸ Saitz R, Horton NJ, Sullivan LM, Moskowitz MA, Samet JH. Addressing alcohol problems in primary care: A cluster randomized controlled trial of a systems intervention. Ann Intern Med 2003;138:372-82.

¹⁹ Burge SK, Schneider FD. Alcohol-related problems: Recognition and intervention. Am Fam Phys 1999 Jan;59(2):358-72.

²⁰ Alberta Medical Association (2005).

²¹ Diekman ST, Floyd RL, Decoufle P, Schulkin J, Ebrahim SH, Sokol RJ. A survey of obstetrician-gynecologists on their patient' alcohol use during pregnancy. Obs & Gyne 2000;95:756-763.

3. Background

The Fetal Alcohol Syndrome Survey, ²² funded by the Alberta Medical Association, was conducted in 1998 by Dr. Margaret Clarke. The purpose of the survey was to "explore the current levels of knowledge of FAS (Fetal Alcohol Syndrome) and FAE (Fetal Alcohol Effects) among Alberta physicians and to identify areas of knowledge gaps or practice gaps that could be remedied through educational strategies, clinical practice guidelines or policy changes."²³ A random sample of physicians from the Alberta Medical Association was surveyed, including family physicians, obstetricians, gynecologists and pediatricians.

In 1999, the Alberta Clinical Practice Guidelines for Fetal Alcohol Syndrome (FAS), now called Fetal Alcohol Spectrum Disorder (FASD), were developed by a working group of physicians and researchers. The guidelines are based on best clinical evidence and a province-wide survey of physicians. The goals of the guidelines are to assist in the recognition of disorders associated with fetal alcohol exposure, promote early and accurate diagnosis, prevent secondary disabilities and prevent future incidence of FASD-affected individuals by promoting abstinence for those who are pregnant or planning pregnancy. These guidelines are reviewed annually and were last updated in 2005.

In 2002, Drs. Margaret Clarke and Suzanne Tough conducted the Fetal Alcohol Syndrome Survey for Health Professionals, funded by Health Canada. A nation-wide random sample of pediatricians, psychiatrists, obstetricians, gynecologists, midwives and family physicians was surveyed. The purpose of the survey was to "determine current knowledge, attitudes and practice related to FAS and FAE across Canada."²⁴

The results of these two surveys were compared in an Alberta Health and Wellness report (2003).²⁵ Only the Alberta results from the national survey (2002) were included in the comparison. The information was compared to "provide insight into areas where educational initiatives could be directed and where health professionals require support in dealing with the complex issues and outcomes associated with alcohol use during pregnancy,"²⁶ and "to understand how attitudes and knowledge had changed over time and in light of intervening educational initiatives."²⁷

²² Clarke M. Fetal Alcohol Syndrome Survey: Final Report. Alberta Medical Association, 1998. Unpublished manuscript.

²³ Tough SC, Clarke M, Hicks M. A comparison of Alberta Physicians' responses on surveys in 1998 and 2002 regarding knowledge, attitudes and clinical practice related to fetal alcohol syndrome and maternal alcohol use during pregnancy. May 2003. Alberta Health and Wellness 2003 May.

²⁴ Ibid.

²⁵ Ibid.

²⁶ Ibid.

²⁷ Ibid.

The following differences in survey results were noted:

- In 2002, 94% of Alberta physicians recommended no alcohol use during pregnancy (up from 84% in 1998)
- In 2002, 97% of Alberta physicians asked obstetrical patients about frequency and quantity of alcohol intake (up from 81% in 1998)
- In 2002, 77% of Alberta physicians were using standardized tools (most commonly CAGE) to screen for alcohol use (up from 33% in 1998)
- In 2002, 58% of Alberta physicians were prepared to deal with or care for pregnant women in the area of alcohol abuse, and 67% were prepared to access resources for those women

The 2002 survey also noted that, despite the development of Alberta Clinical Practice Guidelines for the prevention and diagnosis of FASD in 1999:

- 47% of Alberta physicians discussed the risks of alcohol use during pregnancy with all women of childbearing age
- 66% of Alberta physicians obtained a detailed history of alcohol use with all women of childbearing age
- 23% of Alberta physicians provided written information on prenatal alcohol exposure to all women of childbearing age

Alberta Health and Wellness led the development of the "Framework for a Healthy Alberta"²⁸(2002), a 10-year plan targeting the health of Albertans. One of the targets identified was to reduce the proportion of women using alcohol during pregnancy from 4% to 0% by 2012. Proposed strategies to accomplish this objective included preventive education, provision of information, prevention and treatment services, and implementation of initiatives to prevent FASD.

The Alberta Fetal Alcohol Spectrum Disorder Cross-Ministry (FASD-CMC) Committee was formed in 2003, in response to the "Framework for a Healthy Alberta" target of reducing the proportion of women using alcohol during pregnancy. The FASD-CMC Committee, working at the provincial level to address FASD, comprises representatives from:

- Alberta Advanced Education and Technology
- Alberta Alcohol and Drug Abuse Commission (AADAC)
- Alberta Education
- Alberta Employment, Immigration and Industry
- Alberta Gaming and Liquor Commission
- Alberta Health and Wellness
- Alberta International, Intergovernmental and Aboriginal Relations
- Alberta Justice and Attorney General
- Alberta Seniors and Community Supports
- Alberta Solicitor General and Public Security

²⁸ Alberta Health and Wellness. Framework for a healthy Alberta. Alberta Health and Wellness 2002. Edmonton AB.

The committee developed a provincial strategic plan, approved in 2005, for the management of FASD. Priorities identified in the strategic plan include:

- Awareness and prevention
- Assessment and diagnosis
- Supports for individuals and caregivers
- Training and education
- Strategic planning
- Research and evaluation
- Stakeholder engagement

In parallel with the FASD-CMC Committee's work, funding for the Physicians for Fetal Alcohol Spectrum Disorder Prevention project was provided by Alberta Health and Wellness in 2005. The purpose of the project was to enhance Alberta physicians' contribution to the prevention of FASD.

4. Project Overview

The Physicians for FASD Prevention Project was initiated in December 2005 as a quality improvement initiative funded by Alberta Health and Wellness. The objective of the project was to enhance primary care physicians' contribution to the prevention of FASD. Since FASD can only be prevented by women abstaining from alcohol use during pregnancy, the project focused on improving the ability of Alberta physicians to help women to achieve this goal.

A Steering Committee was formed with membership including primary care physician representatives, and FASD experts and representatives from Health Canada, Alberta Alcohol and Drug Abuse Commission (AADAC), Alberta Perinatal Health Program (APHP) and Toward Optimized Practice (Appendix 1).

The Investigation Phase of the project focused on collecting information from physician focus groups and patient surveys. The data was analyzed to gain a better understanding of the current delivery of FASD prevention information by physicians to women of childbearing age in Alberta, and to design supports to assist physicians in the prevention of FASD.

In the Design Phase of the project, supports were drafted using data collected from the Investigation Phase, Steering Committee input and a literature search of current recommended methods of FASD prevention and screening. The supports that were designed were presented for physician feedback in focus groups in October 2006. In general, the supports were poorly received. Physician feedback showed low interest in the subject matter of FASD prevention, due to limited time and competing priorities.

The project sponsor extended the project timeline by one year, to allow for exploration of new approaches. Unfortunately, a viable solution within the project scope, budget and timelines was not found.

In May 2007, the project sponsor agreed to conclude the project without completing the Delivery or Evaluation Phases. This report documents details of the Investigation and Design Phases, as well as lessons learned, conclusions and recommendations.

4.1. Scope

The project was aimed at assisting Alberta physicians who provide general primary care to a diverse population. Physicians with focused practices specializing in prevention or management of prenatal substance abuse were excluded as participants in the project, although they were not excluded from contributing to the development of supports.

The project aimed to investigate, design and deliver supports to Alberta physicians to enhance their ability to support their patients to avoid alcohol during pregnancy. Target outcomes for the project were to enable physicians to:

- Evaluate the relative risk of undesirable alcohol use in all female patients of childbearing age
- Provide information and/or education appropriate to the relative risk and needs of those patients
- Do brief interventions with a select subset of patients with particular risks
- Refer a subset of patients to other services or specialist care for identified risks

Proposed supports were to be realistic given physicians' time and resources. Only brief interventions were to be included. Patients requiring extended interventions would be referred to appropriate resources and services.

4.2. Project Phases

The following project phases were planned:

- Investigation Phase Information from physician focus groups and surveys of women in prenatal care was collected and analyzed to design, develop and deliver tools to support physicians
- Design Phase Specific tools and supports were designed based on results of the investigation phase. The tools and supports were tested by conducting physician focus groups
- **Delivery Phase** The means of delivering the tools and supports was to be determined based on information developed in the investigation phase
- **Evaluation Phase** A formal independent evaluation was to be conducted to assess the delivery of the project and its impact on the target audience

5. Investigation Phase

The purpose of the Investigation Phase was to collect and analyze information regarding current screening and understanding regarding FASD prevention, in order to design, develop and plan delivery of support(s) to assist physicians in the prevention of FASD. The Investigation Phase was conducted by an independent consultant, Leah Lechelt of Lechelt Communications, in consultation with the project team (Appendix 2).

The Investigation Phase of the project was comprised of two components: physician focus groups and patient surveys of women of childbearing age.

The scope, approach and results of each component will be reviewed, followed by a general discussion of the Investigation Phase. The complete text of the Investigation Phase report is attached (Appendix 11).

5.1. Objectives

The objectives of the Investigation Phase were:

- To develop an understanding of current physician practices regarding pre-conception alcohol counseling and addressing the use of alcohol by pregnant women
- To establish the degree to which physician interventions were heard and understood by women of childbearing age

5.2. Physician Focus Groups

5.2.1. Scope

Twenty three physicians (eleven females and twelve males) from seven clinics participated in the physician focus groups. Seventeen physicians were from urban centers and six were from rural areas.

Seventy-eight percent of the physicians provided prenatal care and 22% did not. Within the physicians' practices, an average of 63% of the patients were female and 37% were male.

5.2.2. Approach

Physicians were contacted by a variety of methods including phone, fax, email and word of mouth. Physicians were asked to participate in focus groups to discuss 'the prevention, screening and intervention activities that physicians typically offer to female patients of child-bearing years.' The specific objective of gaining information for the Physicians for FASD Prevention project was not revealed until the end of the focus groups, in order to capture candid feedback regarding current practices and

priorities. Alberta Health and Wellness was identified as the project sponsor. Participants were aware that all information collected would be non-identifying. A meal was provided and participants were compensated for their time per Alberta Medical Association guidelines.

Focus groups were conducted in March 2006. The focus group sessions lasted from 60 to 120 minutes and were moderated by consultant Leah Lechelt. Discussion and feedback was recorded. Information collected included the topics discussed and the number of times topics were mentioned. Direct quotes were also recorded.

Physicians were asked to complete a questionnaire (Appendix 3) regarding their female patients of childbearing age, with the following information:

- Conditions and diseases for which they routinely screening female patients of childbearing age
- For each condition or disease, an indication of whether they screen all
 patients, only patients who offer a prompt or request, or symptomatic
 or at-risk patients only
- The physician's perception of the prevalence of the condition or disease and the likelihood of identifying a problem during screening, using a scale of 1 to 7
- The physician's perception of the disease or condition's impact on the patient's health in the event that a problem was identified, using a scale of 1 to 7
- Information regarding the demographic breakdown of their practices

The completed questionnaires were then used as a discussion tool. The moderator used a standardized script (Appendix 4) to guide the discussion for all the focus groups . Discussion topics included:

- Screening and prevention practices
- Preconception counseling and FASD prevention
- Barriers to screening and prevention
- Screening tools and interventions
- Managing patients who use alcohol
- Capacity to intervene with alcohol-using patients who are pregnant

In some instances, discussions were guided by the moderator (e.g. suggesting topics that were not initiated in the course of the discussion). At the conclusion of the focus group, physicians were told about the Physicians for FASD Prevention project and their responses to the project were recorded.

5.2.3. Results

All participating physicians were primary care physicians who provided care to women of childbearing age. The number of years in practice ranged from one to 30 years, with an average of 13 years. Seventy-eight percent of the physicians provided prenatal care, and 65% performed obstetrical care and deliveries. Physicians with specialized practices in either obstetrics or prenatal substance abuse were excluded from the focus groups.

5.2.3.1. General Prevention and Screening Practices

Participating physicians reported that they strive to conduct regular prevention and screening of all women of childbearing years. Annual physical examinations were identified as the best time to conduct screening and prevention measures. Lack of time and competing priorities were identified as significant factors impacting the regular provision of screening and prevention services.

Participants identified screening patterns and opportunities with four distinct clusters within the demographic of women of childbearing age:

- Young women aged 14-18 years difficult to screen routinely because they are uncomfortable with gynecological examinations and discussing their sexual health, and may not be accustomed to regular check-ups
- Women aged 19-25 years easier to screen routinely as they are more likely to be sexually active, so they tend to present regularly for contraceptive counseling and prescription refills
- Women aged 26-40 years perceived to have reduced screening needs because they are more likely to be in committed relationships and/or have young children
- Women aged 41+ years significantly increased screening requirements

A list of eighteen health issues was used as a discussion tool. Participating physicians ranked the issues in order of priority for which they are screened. The top four issues physicians identified they screened for were:

- Sexually transmitted diseases (STDs)
- Smoking/ tobacco use
- Cervical cancer
- Alcohol use

While 75% of the participating physicians reported routinely screening patients for alcohol-related issues, it was noted that many patients do not present regularly for health assessments. For these patients, screening occurs on an opportunistic basis.

Lack of time and competing priorities were identified as significant factors impacting the regular provision of screening and prevention services.

"Sure, we do a lot of the screening and we cover most of the current guidelines but it's getting them here to get it done that's the hardest thing."

"I can only do screening if the patients present themselves."

Physicians reported that, when screening for alcohol use, they were looking for consequences of alcohol use, such as problems with work or relationships, risky behaviors or mental health issues.

"Some patients just show in their appearance that they have alcohol problems: stress, emotional problems, depression, family history of alcohol abuse. A lot of these things go together."

While physicians identified certain populations (e.g. low socio-economic populations, substance-abusing women, Aboriginal women) as being at high risk for alcohol-affected pregnancies, only a few physicians identified other groups, which included women lacking social supports, educated professionals, middle-aged women with alcohol issues, and "bar flies in their twenties."

Some physicians say they do not routinely screen for alcohol use.

"If there are particular signs, then I will screen for alcohol, or maybe if I come across something during a complete. If they come in for STDs or they've been partying and taking other risks, then I would do more in-depth screening, but in general, I don't screen every patient."

5.2.3.2. Preconception Alcohol Counseling

A few physicians reported screening for alcohol use in relation to pregnancy.

"A huge issue is FASD if they're not practicing safe sex."

"I'm always looking for fetal alcohol issues. It's too late for prevention after the child is born."

Participating physicians were asked if they routinely discussed pregnancyrelated risks and prevention with alcohol-using patients. Most participants said they would not normally discuss pregnancy risks unless there was a prompt from the patient indicating a concern, or a desire to conceive.

"Do you mean me saying 'Do you realize that if you got pregnant, this could harm ..?' Is that what you mean? No, that's not something I would say unless the patient specifically raises it as a concern."

Patients who had consumed alcohol early in pregnancy were provided with a combination of assurance and cautionary advice. Physicians reported that they need clearer evidence regarding safe levels and timing of alcohol consumption in pregnancy.

"As physicians we want to adequately scare patients so they stop drinking from now on but not freak them out about their drinking up to this point."

"It would be very helpful to have more information about what is truly a safe level of alcohol. We always counsel patients not to drink, but for those who have, I would like to know at what point alcohol is likely to cause problems. There isn't any information about how much or when during the pregnancy."

Some physicians reported they felt their efforts should focus on contraception as a means of preventing alcohol-related complications of pregnancy.

"I think we have a bigger role to play in contraception management than we do in preventing alcoholism."

"Our goal really should be to optimize contraception. I wonder if this should be our focus rather than focusing on changing their alcohol use?"

Overall, the physicians' reports of alcohol users, and the physicians' role fell into four categories:

- Light, informed alcohol user:
 - Presents regularly for primary care
 - Plans her pregnancy
 - FASD awareness is well entrenched
 - FASD messages may have caused unrealistic fears

Physicians' perceived role: Screen, support and reassure.

- Week-end binge user:
 - Presents occasionally or annually for contraception
 - Is under 25 years, and will outgrow this stage
 - Binges may lead to unintended pregnancy
 - Is aware of FASD messages
 - Termination of pregnancy likely

Physicians' perceived role: Counsel regarding long-term alcohol use risks; refer if pregnant.

- Moderate to heavy alcohol user:
 - Presents occasionally for primary care
 - Unplanned pregnancy possible
 - Has some FASD awareness
 - Has other risk factors (e.g. addictions, social problems)
 - May present too late in pregnancy for intervention

Physicians' perceived role: Intervene if patient presents for care; refer if patient shows interest.

Some physicians reported they felt their efforts should focus on contraception as a means of preventing alcoholrelated complications of pregnancy.

- Chronic, complex alcohol abuser:
 - Never presents for primary care
 - Unplanned pregnancy and no prenatal care likely
 - May herself have FASD or other serious addictions or mental health or social issues
 - Socially isolated, marginalized, disadvantaged
 - Too complex for primary care intervention

Physicians' perceived role: No legitimate prevention role.

5.2.3.3. Screening Tools

Most physicians reported they did not use screening questionnaires to screen for alcohol use. They reported that keeping the discussion casual and non-threatening is more conducive to getting honest answers.

"I just screen for it in the broader context of lifestyle and social issues."

"I'll ask them about alcohol, drugs, tobacco, caffeine ... Then it seems like I'm just trying to get an accurate picture, not judging them."

Some physicians reported that they will use the CAGE standardized screening questionnaire if alcohol abuse is suspected.

"I'll only use CAGE if they're drinking way more than I expected or if they're being quite guarded and it's raising my level of suspicion."

"CAGE is really for secondary screening, not for primary."

5.2.3.4. Barriers

Some physicians reported that they generally do not view alcohol screening as a burden or onerous task while others reported that thorough alcohol screening was sensitive and time-consuming. Barriers to prevention and screening for alcohol use identified by participating physicians included limited time and competing priorities.

"You have to remember that if I'm going to probe (about alcohol use), I'm going to probe a whole long list of social questions ... I can probe that much more if I had time with every visit, but time is restricted."

"I really don't ask many screening questions because there's no time. If I ask, then I have to spend the time to do it properly. If you think they're being dishonest with you, it takes time to dig."

Most physicians reported they did not use screening questionnaires to screen for alcohol use.

Barriers to prevention and screening for alcohol use identified by participating physicians included limited time and competing priorities. Most of the physicians felt that another barrier was patient candor, which can vary considerably.

"It's really difficult to find the woman aged 25 to 40 who drinks too much – it's hard to get them to admit it."

Some physicians felt that they had sufficient knowledge and expertise to deal with alcohol-using women of child-bearing age. Others felt they didn't have enough time, resources or expertise and would often refer women to Alberta Alcohol and Drug Abuse Commission (AADAC).

"I don't think I do it very well. Time is part of the issue."

"I think there are better people to (help these patients) than me."

"Maybe we need a specific pregnancy-focused group within AADAC. The pregnant women could be together to talk specifically about their issues."

5.2.3.5. Response to Physicians for FASD Prevention Project

Many of the participants reported that they do not see many patients in their practices that are at high risk for alcohol and pregnancy-related concerns. Several physicians stated that they considered the high-risk patients to be primarily women who are marginalized, socially isolated, disadvantaged, mentally ill or otherwise living on the fringes of main-stream society.

"This is a group that we don't see. They're not coming to see us, so it's really hard to do anything if you don't see them. It's the drug-using population, those with a family history of alcoholism, those with psychiatric illnesses like schizophrenia."

"It's really an inner city issue."

"The population that's really at risk of an FASD baby isn't really part of our practices."

Several physicians were disappointed that the project was focused on FASD prevention.

"I'm disappointed this was just about FASD ... Basic screening is a far bigger issue."

"I think this whole FASD thing is blown out of proportion. Focusing on alcohol in pregnancy just isn't cost-effective."

"Why focus on FASD? ... I feel like obesity is a bigger issue than FASD."

"If I'd know this was going to be about FASD, I wouldn't have come."

5.2.3.6. Discussion of Physician Focus Group Results

To capture candid feedback regarding current practices and priorities, the specific objective of gaining information for the Physicians for FASD Prevention project was not revealed until the end of the focus group sessions. As such, while some of the physicians' comments regarding alcohol counseling and potential barriers were related specifically to FASD prevention, most were part of a more general discussion of routine screening and prevention measures for women of childbearing age.

FASD prevention is not viewed as a high priority. Other lifestyle issues and chronic conditions such as sexually transmitted diseases, smoking and tobacco use, cervical cancer, obesity, diabetes, hypertension and mental health issues are identified as being of more immediate concern.

Physician focus group results indicated that, while alcohol use is perceived to be a significant social and health issue, FASD prevention is not viewed as a high priority. Other lifestyle issues and chronic conditions, such as sexually transmitted diseases (STDs), smoking and tobacco use, cervical cancer, obesity, diabetes, hypertension and mental health issues are identified as being of more immediate concern. The most significant barriers to routine screening for alcohol use and preconception prevention among the physician participants appeared to be lack of time and competing priorities.

Most of the physicians indicated that patients at high risk for delivering FASD babies are not presenting for primary care, or are presenting too late for prevention or intervention strategies. The majority of the physicians perceived that these patients are a small, isolated patient population with complex social and medical conditions. If these patients present for medical care, issues of time and complexity of assessment and management were identified as barriers. Very few of the participants identified women with high incomes and high levels of education as being at risk, even though there is evidence that these women are among the highest risk for having alcohol-affected children.^{29 30}

5.3. Patient Surveys

5.3.1. Scope

Two hundred written surveys were distributed at five locations in Edmonton:

- Three diagnostic imaging centers
- A university health center
- An education and support program for pregnant teens

Thirty nine surveys were completed and returned, representing a 20% response rate.

²⁹ Alberta Medical Association (2005).

³⁰ Health Canada. Research update – Alcohol use and pregnancy: An important Canadian public health and social issue. Public Health Agency of Canada 2006. Ottawa ON.

5.3.2. Approach

Two written surveys were developed to determine patients' experiences, knowledge and intentions regarding FASD prevention and alcohol use during pregnancy, and when and what messages and/or support the women had received from physicians regarding the use of alcohol in pregnancy. One survey, the 'Prenatal Patient Survey' (Appendix 5) targeted pregnant women, and the other 'Patient Survey' (Appendix 6) targeted non-pregnant women of childbearing age.

Laboratories, diagnostic imaging centers that provided obstetrical ultrasounds, clinics and educational programs for pregnant women across the province were contacted to participate by distributing the surveys. The laboratories and diagnostic imaging facilities were asked to distribute the surveys to patients presenting for pregnancy tests or obstetrical ultrasounds. Most declined to participate, citing patient privacy concerns, limited time or staff workload concerns. The five facilities that agreed to participate were all located in Edmonton.

The surveys were distributed to women between the ages of 14 and 44. Participants filled out the survey and either left it in a sealed envelope in a box at the facility (which was picked up by project staff), or mailed it into the project office, using a pre-addressed, stamped envelope. Surveys were voluntary, and some involved a small incentive. Data collected was non-identifying and aggregate.

5.3.3. Results

All surveys returned were from pregnant women (Appendix 5). The ages of survey respondents ranged from 14 to 44 years. Eighty percent of the respondents were married or living common-law and educational levels ranged from junior high school to university graduates.

| Age | | Annual Family Income | | |
|--------------------|-----|----------------------|-----|--|
| Under 16 years | 13% | \$12,000 or less | 10% | |
| 17-25 years | 31% | \$12,001 - \$18,000 | 8% | |
| 26-35 years | 46% | \$18,001 - \$35,000 | 15% | |
| 36-45 years | 10% | \$35,001 - \$55,000 | 21% | |
| Marital Statu | ıs | \$55,001 - \$70,000 | 10% | |
| Married/common-law | 80% | > \$70,000 | 23% | |
| Single | 17% | No answer | 13% | |
| Divorced | 3% | | | |

Figure 1. Age, marital status and annual family income of survey respondents.

Respondents included full and part-time students, full and part-time working parents, stay-at-home parents and unemployed parents. All respondents were from Edmonton.

| Occupation | | Education | |
|-------------------------------|-----|------------------------------------|-----|
| Full-time student | 31% | University graduate | 31% |
| Part-time student | 5% | College diploma/certificate | 21% |
| Work full-time | 26% | Some college or technical training | 8% |
| Work part-time | 15% | High school graduate | 15% |
| Stay at home parent | 23% | Some high school | 21% |
| Not employed or not a student | 5% | Junior high school | 5% |

Figure 2. Occupational status and education of survey respondents.

Sixty-two percent of the pregnancies were planned and 28% were unplanned. The stage and number of pregnancies varied.

| # of Pregnar | ісу | Stage of Pregnancy | |
|---------------------|------|--------------------|-----|
| First | 49% | First trimester | 18% |
| Second | 41% | Second trimester | 44% |
| Third or more | 10% | Third trimester | 39% |
| Planned/Unpla | nned | | |
| Planned pregnancy | 62% | | |
| Unplanned pregnancy | 28% | | |

Figure 3. Number, stage and planned/unplanned status of pregnancy.

5.3.3.1. Preconception Counseling

Forty-one percent of the respondents said their physicians had discussed healthy pregnancy issues with them before they became pregnant. Of the survey respondents whose pregnancies were unplanned, only 23% said healthy pregnancy issues were discussed before pregnancy.

Thirty-one percent the respondents could recall their physicians discussing the risks of using alcohol during pregnancy before they were pregnant. Upon confirmation of pregnancy, 51% said their physicians discussed the risks of alcohol use with them once they were pregnant.

Nearly two-thirds (64%) of the respondents who discussed healthy pregnancy topics with their physicians said it was them (the patient), not the physician, who raised the issue. Survey respondents reported that physicians were more likely to discuss these issues after the patient was confirmed to be pregnant.

5.3.3.2. Messages about FASD

When asked where they had heard messages about FASD and its prevention, 77% of respondents reported hearing messages from 'TV/news.' Sixty-five percent reported hearing about it from 'family/ friends,' 61% from their physicians and 53% from other sources. Less than a third of respondents had heard that their physicians can help women to reduce or stop using alcohol.

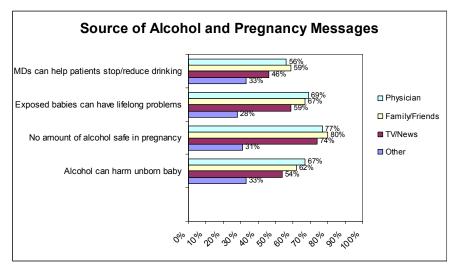


Figure 4. Sources of alcohol and pregnancy messages.

Twenty-three percent of respondents said their physicians provided them with information, pamphlets or other support/intervention material related to alcohol use and cessation during pregnancy.

5.3.3.3. Confidence in Physicians

Most of the women surveyed (80%) said they were comfortable discussing alcohol use with their primary care physician, while 88% were comfortable discussing it with family or friends. Ninety percent of the respondents said they trusted their primary care physicians to provide them with accurate information about alcohol use and risks.

Specific concerns that would prevent the respondents from discussing alcohol use with their physicians included:

- Embarrassment (5%)
- Being judged (10%)
- Being forced into alcohol treatment (5%)
- Being asked to give up their baby (8%)

Patient survey results are consistent with physician focus group results in tha physicians are not discussing healthy pregnancy issues prior to conception, and that discussion of these topics is more likely if the patien initiates the conversation or presents with a confirmed pregnancy.

5.3.4. Discussion of Patient Survey Results

Patient survey results are consistent with physician focus group results in that physicians are not discussing healthy pregnancy issues prior to conception, and that discussion of these topics is more likely if the patient initiates the conversation or presents with a confirmed pregnancy. Most patients trust their primary care physicians as an accurate source of information and felt comfortable discussing alcohol use with them.

6. Design Phase

Based on the results of the Investigation Phase, the Steering Committee determined the following criteria to be considered when designing supports:

- · Useful and easy to use
- Effective in encouraging physicians' screening practices
- Non-judgmental
- Consistent and focus broadly on routine care for all women
- Multi-faceted
- Relevant to physicians' practices
- Patient-friendly

A number of options were proposed, with a multi-faceted approach being preferred. The following options were investigated to determine feasibility within project scope, timelines and budget:

- Build on to existing tools or checklists (universal strategy)
- Motivational interviewing DVD training for physicians
- Updated information and education for physicians regarding FASD
- Marketing campaign approach
- "Tear-off" sheets with checklist
- Piggy-back interventions onto existing Continuing Medical Education (CMEs)
- Collaboration with industry
- Update or add to existing Alberta Clinical Practice Guidelines (CPG)
- Case studies (anecdotal) from everyday practice
- Incorporation of the T-ACE screening questionnaire
- Information package, including information on sexually transmitted diseases (STDs), contraception and alcohol use in pregnancy
- Education for family practice residents
- Develop partnerships with Primary Care Networks

The following options were investigated and found to be non-viable within the scope of the project:

- Collaboration with industry
- Education for family practice residents
- Incorporation of interventions into existing Continuing Medical Education (CMEs)
- Incentives (financial or other)

The Steering Committee recommended developing an information brochure and a screening tool, with a mass mail-out delivery to all Alberta primary care physicians after the tools were focus-group tested.

6.1. Supports Designed

An information brochure and screening checklist were developed by the project team. The information brochure (Appendix 7) included the following components:

- Definitions and general information on FASD and its prevention
- T-ACE standardized screening questionnaire
- Concepts of motivational interviewing
- Referral resources for alcohol counseling and support

The screening checklist, with accompanying introduction and practice points (Appendix 8) was designed to embed alcohol screening into a general lifestyle screening tool for women of childbearing age. Topics included on the checklist were:

- Diet and activity
- Tobacco use
- Caffeine intake
- Alcohol use (including the T-ACE screening questionnaire)
- Drug use (prescription and/or non-prescription)
- Intimate partner violence, mental and emotional health
- Sexual practices

The screening checklist was to accompany the information brochure.

A poster (Appendix 9) and a physician desktop reminder (Appendix 10) were also designed.

All options were reviewed and revised by the Steering Committee, and the final products were tested in physician focus groups.

6.2. Focus Group Testing

Physician focus group testing was scheduled for September 2006. Physicians were contacted by a variety of methods including phone, fax, email and word of mouth. Various locations and times of day were offered in order to accommodate physicians' schedules. A meal was offered and participants were compensated for their time per Alberta Medical Association guidelines.

Recruiting primary care physicians to participate in the 'Physicians for Fetal Alcohol Spectrum Disorder Prevention' project was a significant issue. Reasons given for not participating ranged from busy work schedules to lack of interest in the subject matter.

Five physicians from three clinics agreed to participate in the focus group testing. The focus groups were conducted in October 2006.

6.2.1. Summary of Focus Group Testing

Physician feedback suggested:

- Physicians' time with patients is limited and there are other issues that take priority over prevention and screening
- Physicians receive huge volumes of written materials, including standardized screening questionnaires, most of which is discarded unused
- Physicians conduct histories and physical examinations according to the way they were taught in medical school, and did not see a benefit to using a structured screening questionnaire
- CAGE is the screening tool that most physicians were taught in medical school, and most were not familiar with the T-ACE standardized screening questionnaire
- A screening questionnaire only for FASD is too specific FASD does not occur in isolation, and there are many other issues that need to be addressed
- Some of the information in the information brochure was perceived to be condescending and too basic for physicians ("more appropriate for medical students," or for "physicians trained in other countries or cultures")
- There is too much information in the information brochure
- Having local referral resources was a benefit
- Increasing public awareness through mass media public awareness campaigns seems to help patients internalize messages (e.g. smoking cessation)
- Patients at highest risk of having a child with FASD are alcoholdependent, don't think they have a problem and won't present for regular medical care
- One physician felt that specialists should not have been advising on this project, since the project was targeting primary care physicians.
- Physicians also felt that primary care physician' skills, knowledge and contributions were being under-estimated and under-valued

The focus group testing did not produce the anticipated outcomes. The interventions were poorly received by the participating physicians. It was clear that any further development or delivery of the interventions needed to be reconsidered.

6.3. Alternate Direction

The Steering Committee was presented with the physician focus group results in early December 2006. It was agreed that there would be no further development or mass delivery of the information brochure and screening tool.

A screening questionnair only for FASD is too specific – FASD does not occur in isolation, and there are many other issues that need to be addressed.

Following discussions, the project team was directed to explore the following options:

- Incorporating FASD education and screening into medical school or residency program curricula
- Influencing physician behavior by raising public awareness
- Targeting rural physicians with supportive education opportunities, in cooperation with existing programs such as Managing Obstetrical Risk Efficiently (MORE) program, a Society of Obstetricians and Gynecologists of Canada (SOGC) educational initiative, or Strategies for Teaching Obstetrics to Rural Caregivers (STORC), an Alberta Perinatal Health Program educational initiative
- Assisting physicians to deal with time limitations by providing process refinement support
- Creating an electronic self-reporting tool for patients
- Retaining the content of the supports designed, and making them available on-line at the Alberta Clinical Practice Guideline website

These options were investigated and the findings reported to the Steering Committee in February 2007. The following options were found to be non-viable for the following reasons:

- Medical school or residency program curricula any changes or additions to curricula require many stages of rigorous review, consultation and approval. This was determined to be beyond the scope and timelines of the project.
- Targeting rural physicians with supportive education opportunities, in cooperation with existing programs - the Managing Obstetrical Risk Efficiently (MORE) program targets healthcare providers in acute care facilities, and does not address preconception care, and the Strategies for Teaching Obstetrics to Rural Caregivers (STORC) program provides education for nurses, not physicians.
- Assisting physicians in dealing with time limitations by providing work process refinement support – this issue was determined to be too complex and beyond the scope of the project

The following options were deemed viable if <u>delivered collaboratively</u>:

• Increase public awareness through a public awareness campaign aimed at encouraging patients to discuss alcohol and pregnancy issues with their physicians - The goal of the public awareness campaign was to positively impact physicians' screening behavior by increasing patient demand for information about the risks of alcohol use in pregnancy. It was determined that there was no capacity for the project to launch its own public awareness campaign. It was therefore recommended that the project team work with an existing provincially funded FASD public awareness campaign by adding an "Ask your doctor" component." This option would be considered the 'cornerstone' element of the project initiative, upon which the other options would be developed.

- Modify the developed screening checklist into a 'self-reporting' checklist for patients, and explore the viability of having the checklist available in an electronic format It was felt that the modified 'self-reporting' checklist for patients would work in collaboration with the public campaign to provide additional information to patients. It could also be used as a physician aid in screening. The costs for the electronic formatting of a 'self-reporting' patient checklist were determined to far exceed the funds available for the project. The option of pursuing a paper-based format was accepted.
- Retain the content of the supports developed and make them available on-line through the Alberta Clinical Practice Guidelines website The information brochure developed for physicians would be modified so that it could be made available as a companion resource to the Clinical Practice Guidelines, to meet the demands generated by the public awareness campaign and 'self-reporting' tool.

All materials developed as part of the collaborative approach would be sent out to Alberta physicians in a mass mail-out. Materials would also be available on-line, on the Alberta Clinical Practice Guidelines website. It was proposed that the collaborative initiative could be introduced and supported by a series of articles or announcements in provincially circulated print media targeting physicians.

The project team was directed by the Steering Committee to proceed with further investigations into the collaborative options, and the project sponsor agreed to extend the project timelines by one year, until March 2008.

6.4. Public Awareness Campaign

The public awareness campaign option was the 'cornerstone' element,' upon which the other options would be developed, and therefore became the primary focus of the investigations. Campaigns focusing on the prevention of FASD or the importance of preconception abstinence from alcohol as a component of healthy pregnancy were preferred. Public awareness campaigns with which the project's "Ask your doctor" component could be linked were sought and investigated. Alberta Alcohol and Drug Abuse Commission (AADAC) and various provincial government ministries were contacted to identify ongoing or soon-to-be-released public awareness campaigns.

Development of the remaining options (self-reporting checklist for patients, and modification and linking supports to Alberta Clinical Practice Guidelines website) proceeded as the search for a public awareness campaign continued.

By the spring of 2007, the project team had been unable to identify any public awareness campaigns with which to collaborate by adding an "Ask

By the spring of 2007, the project team had been unable to identify any public awareness campaigns with which to collaborate by adding an "Ask you doctor" component.

your doctor" component. Without a viable public campaign, the other options (self-reporting checklist for patients, and modification and linking supports to Alberta Clinical Practice Guidelines website) were not deemed viable as 'stand alone' supports.

In June 2007, the project sponsor and the Steering Committee decided to close the project without completing the delivery and evaluation phases, and to concentrate on lessons learned in the process.

7. Discussion

There have been many studies that indicated that primary care physicians are the health care providers in the best position to provide screening and preconception FASD prevention services to women of childbearing age, 31 32 ³³ ³⁴ ³⁵ and that screening and prevention services should be incorporated into regular health examinations for women.³⁶ ³⁷ ³⁸ ³⁹ ⁴⁰ ⁴¹ However, although women report that their primary source of information is healthcare providers, 42 43 and the advice women get from their health care providers is an important factor in reducing or stopping alcohol consumption in pregnancy, 44 studies show that preconception risk factors such as alcohol consumption during pregnancy are not routinely discussed with women of childbearing age. 45 46 In fact, a 2006 national survey showed that less that 50% of healthcare providers discuss the risks of alcohol during pregnancy use with women of childbearing age. 47. These findings are consistent with the information collected in the investigation phase of the project, which indicated that many physicians do not discuss healthy pregnancy issues or alcohol use during pregnancy prior to conception, and that discussion of these topics is more likely to occur if the patient initiates the dialogue or presents with a confirmed pregnancy.

³¹ Tough SC, Clarke M, Hicks M. (2003).

³² Burge SK et al. (1999).

³³ Floyd RL, O'Connor MJ, Sokol RJ, Bertrand J, Cordero JF. Recognition and prevention of fetal alcohol syndrome. Obs & Gyne 2005 Nov; 106(5):1059-64.

³⁴ Clarke M, Tough SC, Cooke J. (2004).

³⁵ Saitz R et al. (2003).

³⁶ Canadian Task Force on Preventive Health Care. Effective dissemination and implementation of Canadian Task Force Guidelines on preventive health care: Literature review and model development. Health Canada 1999. Ottawa ON.

³⁷ Alberta Medical Association (2005).

³⁸ Tough SC, Clarke M, Hicks M, Clarren S. Attitudes and approaches of Canadian providers to preconception counseling and the prevention of fetal alcohol spectrum disorders. JFASI 2005;3:e3.

³⁹ Tough SC, Clarke M, Clarren S. (2005). Preventing fetal alcohol spectrum disorders. Preconception counseling and diagnosis help. Motherisk website 2005 Sep;

http://www.motherisk.org/prof/updatesDetail.jsp?content_id=737

 $^{40\} Tough\ SC,$ Clarke M, Hicks M, Cook J. Pre-conception practices among family physicians and obstetrician-Gynaecologists: Results from a national survey. J Obs Gyn Can 2006 Sep; 28; (9)L780-788.

⁴¹ Ockene JK, Wheeler EV, Adams A, Hurley TG, Hebert J. Provider training for patient-centered alcohol counseling in a primary care setting. Arch Int Med 1997Nov 10;157(20):2334-41.

⁴² Tough SC, Clarke M, Hicks M, Clarren S. (2004).

⁴³ Einarson A, Koren G. A survey of women's attitudes concerning healthy lifestyle changes prior to pregnancy. JFAS International 2006;4(2):1-6.

⁴⁴ Diekman ST et al. (2000).

⁴⁵ Tough SC, Clarke M, Hicks M, Clarren S. (2004).

⁴⁶ Tough SC, Tofflemire K, Clarke M, Newburn-Cooke C. (2006).

⁴⁷ Tough SC, Clarke M, Hicks M, Cook J. (2006).

Most research examining the best means of screening and prevention of FASD recommends preconception prevention and screening for FASD methods including:

- use of a structured screening questionnaire^{48 49 50 51 52 53 54 55}
- brief interventions, such as motivational interviewing^{56 57 58 59 60 61 62 63 64}
- referral to an appropriate resource^{66 67 68 69 70}

A 2001 position statement by the Canadian Medical Association states that "Physicians should use appropriate screening methods to identify alcohol use in their patients."⁷¹ There are a number of alcohol screening questionnaires, including T-ACE, TWEAK, CAGE, AUDIT and SMAST, that have been developed and validated for use in pregnant and non-pregnant women. They are easy to use and score, and are an objective and reliable way for healthcare providers to gather information related to alcohol

⁴⁸ Tough SC, Clarke M, Hicks M. (2003).

⁴⁹ Hicks M, Sauve RS, Lyon AW, Clarke M, Tough SC. Alcohol use and abuse in pregnancy: An evaluation of the merits of screening. Can Child Adol Psyc Rev 2003 Aug;3(12):78-80.

⁵⁰ Alberta Alcohol and Drug Abuse Commission. A review of addictions-related screening and assessment instruments – Measuring the measurements. AADAC 2004 Jan.

⁵¹ Sokol RJ, Delaney-Black V, Nordstrom B. Fetal Alcohol Spectrum Disorder. JAMA 2003 Dec 10;290(22):2996-9.

⁵² Burge et al. (1999).

⁵³ Floyd RL, O'Connor MJ et al. (2005).

 $^{54\} Gareri\ J,\ Chan\ D,\ Klein\ J,\ Koren\ G.$ Screening for Fetal Alcohol Spectrum Disorder. Can Fam Phys. 2005;51:33-34.

⁵⁵ Chang G, Wilkins-Haug L, Berman S, Goetz MA, Behr H, Hiley A. Alcohol use and pregnancy: Improving identification. Obs & Gyn 1998;91:892-98.

⁵⁶ Carroll KM, Ball SA, Nich C, Martino S, Frankforter TL, Farentinos C, Kunkel LE, Mikulich-Gilbertson SK, Morgenstern J, Obert JL, Polcin D, Snead N, Woody GE. Motivational interviewing to improve treatment engagement and outcome in individuals seeking treatment for substance abuse: A multi site effectiveness study. Drug and Alcohol Dependence. 2006;81:301-12.

⁵⁷ Chang G, McNamara, TK, Orav EJ, Koby D, Lavigne A, Ludman B, Vincitorio NA, Wilkins-Haug L. Brief Intervention for prenatal alcohol use: A randomized trial. Obs & Gyn 2005;105:991-98.

⁵⁸ Goh YI. Knowledge is the key to prevention: Reduction of alcohol-exposed pregnancies through motivational intervention. The Hospital for Sick Children. JFAS Int. Dec2003;1:e21.

⁵⁹ Hicks M et al. (2003).

⁶⁰ Burge SK et al. (1999).

⁶¹ Bien TH, Miller WR, Tonigan JS. Brief interventions for alcohol problems: A review. Addiction 1993;88:315-336.

⁶² Marlatt GA. Baer JS, Kivlahan DR, Dimeff LA, Larimer ME, Quigley LA, Somers LM, Williams E. Screening and brief intervention for high-risk college student drinkers: Results from a 2-year follow-up assessment. J Cons Clin Psych1998 Aug;66(4):604-15.

⁶³ Poirier MK, Clark MM, Ceryhan JH, Pruthi S, Geda YE, Dale LC. Teaching motivational interviewing to first-year medical students to improve counseling skills in health behavior change. Mayo Clinic Procedures, May Foundation for Medical Education and Research 2004;79:327-31. 64 Saitz R et al. (2003).

⁶⁵ Sheehy Handmaker N, Wilbourne P. Motivational interventions in prenatal clinics. Alc Res & Health. 2001;25(3):219-21.

⁶⁶ Burge et al. (1999).

⁶⁷ Floyd RL, O'Connor MJ et al. (2005).

⁶⁸ Chang G, Wilkins-Haug L et al. (1999).

⁶⁹ Sokol RJ et al. (2003).

⁷⁰ Saitz R et al. (2003).

⁷¹ Canadian Medical Association (2001). http://www.cma.ca/index.cfm/ci_id/3389/la_id/1.htm

consumption during pregnancy.72 73 74 75 T-ACE has been reported by a number of research studies as having the highest sensitivity and specificity when used to assess peri-conceptual heavy drinking.⁷⁶ ⁷⁷ ⁷⁸ ⁷⁹ ⁸⁰ Several studies have shown that using structured screening questionnaires, such as T-ACE, can significantly improve preventive service delivery and should be used. 81 82 Most of the physicians who participated in the focus groups stated they seldom or never used standardized screening questionnaires, and preferred unstructured, non-confrontational discussions with patients.

Some physician participants report that they are more likely to encourage the use of contraception in higher-risk patients than to utilize brief interventions. Research has shown that brief interventions, such as motivational interviewing, can reduce drinking and improve health when delivered to primary care patients with alcohol problems, 83 84 85 but that physicians infrequently use them.⁸⁶ One study showed that the amount of time physicians spend talking to patients after learning motivational interviewing did not differ from before using motivational interviewing.87 88 Most of the physicians who participated in the focus groups identified lack of time as a significant factor in their prevention practices.

Barriers to screening for alcohol use in women of childbearing age noted by physicians participating in the project are consistent with research findings. Studies have identified the following barriers to physicians providing preventive and screening:

Most of the physicians who participated in the focus groups stated they seldom or never used standardized screening questionnaires, and preferred unstructured, non-confrontational discussions with patients.

⁷² Clarke M, Tough SC, Cooke J.(2004).

⁷³ Hicks M et al. (2003).

⁷⁴ Tough SC, Clarke M, Hicks M, Clarren S.(2005).

⁷⁵ Floyd RL, O'Connor MJ et al. (2005).

⁷⁶ Alberta Medical Association (2005).

⁷⁷ Alberta Alcohol and Drug Abuse Commission. (2004).

⁷⁸ Hicks M et al. (2003).

⁷⁹ Floyd RL, O'Connor MJ et al. (2005).

⁸⁰ Chang G, Wilkins-Haug L et al. (1998).

⁸¹ Floyd RL, O'Connor MJ et al. (2005).

⁸² Health Canada. Joint Statement (2006).

⁸³ Hicks M et al. (2003).

⁸⁴ Marlatt GA et al. (1998).

⁸⁵ Bien TH et al. (1993).

⁸⁶ Saitz R et al. (2003).

⁸⁷ Sheehy Handmaker N, Hester RK, Delaney HD, (1999). Videotaped training in alcohol counseling for obstetric care practitioners: A randomized controlled trial. Obs & Gyn;93:213-18.

⁸⁸ Ibid.

- Lack of time 89 90 91 92 93 94 95 96
- Competing priorities (e.g. chronic conditions) ^{97 98 99 100 101}
- Shortage of providers¹⁰² 103
- Perceived lack of patient interest or readiness^{104 105 106}
- Lack of provider training 107 108 109 110 111 112 113 114 115 116
- Lack of reimbursement for preventive services 117 118 119
- Lack of referral resources¹²⁰ 121
- Lack of patient candor 122 123

⁸⁹ Tough SC, Clarke M, Hicks M, Clarren S. (2005).

⁹⁰ Alberta Perinatal Health Program. Preconception Health Framework. Alberta Perinatal Health Program 2007.

⁹¹ Clarke M, Tough SC, Cooke J. (2004).

⁹² Saitz R et al. (2003).

⁹³ Ockene JK et al. (1997).

⁹⁴ Diekman ST et al. (2000).

⁹⁵ Cranney M, Warren E, Barton S, Gardner K, Walley T. Why do GPs not implement evidence-based guidelines? A descriptive study. Fam Pract 2001;18(4):359-63.

⁹⁶ Canadian Task Force on Preventive Health Care. (1999).

⁹⁷ Beasley JW, Hankey TH, Erickson R, Stange KC, Mundt M, Elliott M, Wiesen P, Bobula J. How many problems do family physicians manage at each encounter? A WReN study. Ann of Fam Med 2004 Sep-Oct;2(5):405-10.

⁹⁸ Ockene JK et al. (1997).

⁹⁹ Saitz R et al. (2003).

¹⁰⁰ National Alcohol Strategy Working Group. Reducing alcohol-related harm in Canada: Toward a Culture of moderation. Health Canada 2007 Apr; Ottawa ON.

¹⁰¹ Heyes T, Long S and Mathers N. Preconception care. Practice and beliefs of primary care workers. Fam Prac $2004; 21\colon 22-27.$

¹⁰² Canadian Institute for Health Information. From perceived surplus to perceived shortage: What happened to Canada's physician workforce in the 1990's? Canadian Institute for Health Information 2002;Ottawa ON.

¹⁰³ Tough SC, Clarke M, Hicks M, Clarren S (2004).

¹⁰⁴ Ibid.

¹⁰⁵ Saitz R et al. (2003).

¹⁰⁶ Diekman ST et al. (2000).

¹⁰⁷ Tough SC, Clarke M, Hicks M, Clarren S. (2004).

¹⁰⁸ Clarke M, Tough SC, Hicks M, Clarren S. (2005).

¹⁰⁹ Nanson JL, Bolaria R, Snyder RE, Morse BA, Weiner L. Physician awareness of fetal alcohol syndrome: A survey of pediatricians and general practitioners. CMAJ 1995 May;152(7):1071-76.

¹¹⁰ Saitz R et al. (2003).

¹¹¹ Ockene JK et al. (1997).

¹¹² Millstein SG, Marcell AV. Screening and counseling for adolescent alcohol use among primary care physicians in the United States. Pediatrics 2003 Jan; 111(1):114-22.

¹¹³ Diekman ST et al. (2000).

¹¹⁴ Ibid.

¹¹⁵ National Alcohol Strategy Working Group. (2007).

¹¹⁶ Canadian Task Force on Preventive Health Care. (1999).

¹¹⁷ Tough SC, Clarke M, Hicks M, Clarren S. (2004).

¹¹⁸ Saitz R et al. (2003).

¹¹⁹ Ockene JK et al. (1997).

¹²⁰ Tough SC, Clarke M, Hicks M, Clarren S (2004).

¹²¹ Tough SC, Clarke M, Hicks M. (2003).

¹²² Hicks M et al. (2003).

¹²³ Basford DL et al.(2005).

Participating physicians expressed frustration about inconclusive evidence and conflicting expert opinion in areas of FASD. One key area identified by physicians is in the amount of alcohol that can safely be consumed during pregnancy. While all physicians participating in the project focus groups advised their patients to completely abstain from alcohol during pregnancy, some physicians felt they had to reassure patients that an occasional drink wouldn't cause FASD. One physician felt that there wasn't enough evidence to prove that all women are at risk of having an FASD-affected baby and that the statement could create unnecessary fear among women. Some physicians felt that preventive measures for other conditions, such as obesity or cardiovascular disease, took priority over FASD due to lack of evidence about the efficacy of FASD prevention programs.

While most experts agree that women who are or may become pregnant should err on the side of caution and completely abstain from alcohol consumption, 124 125 126 127 128 129 130 conflicting opinions state that low levels of alcohol consumption may be acceptable. The United Kingdom's Royal College of Obstetricians and Gynaecologists (2006) stated "there is considerable doubt as to whether infrequent and low levels of alcohol consumption during pregnancy convey any long-term harm, in particular after the first trimester of pregnancy." 131

Some physicians are not convinced that total abstinence from alcohol use is necessary for a pregnant woman, ¹³² and, in a 2004 national survey, 25% of the physician respondents said that the effects of alcohol on the fetus are unclear. ¹³³ In the same survey, almost 10% of Canadian physician respondents were still advising patients that a glass of beer or wine in moderation is acceptable during pregnancy. ¹³⁴

A meta-analysis reviewing studies between 1970 and 2005 on the effects of low to moderate levels of prenatal alcohol consumption concluded that "no convincing evidence of adverse effects of prenatal alcohol levels of exposure. However, weaknesses in the evidence preclude the conclusion that drinking at these levels during pregnancy is safe." Although the

Some physicians felt that preventive measures for other conditions, such as obesity or cardiovascular disease, took priority over FASD due to lack of evidence about the efficacy of FASD prevention programs.

Participating physicians expressed frustration about inconclusive evidence and conflicting expert opinion in areas of FASD.

¹²⁴ Alberta Medical Association (2005).

¹²⁵ Health Canada. Joint Statement. (2006).

¹²⁶ Tough SC, Clarke M, Hicks M, Clarren S. (2004).

¹²⁷ Hicks M et al. (2003).

¹²⁸ Floyd RL, O'Connor MJ et al. (2005).

¹²⁹ Mukherjee RAS, Hollins S, Turk J. Low level alcohol consumption and the fetus. BMJ 2005 Feb 19;330:375-376, doi:10.1136/bmj.330.7488.375a

¹³⁰ Koren G, Nulman I, Chudley AE, Loocke C. Fetal alcohol spectrum disorder. CMAJ 2003 Nov 25; 169(11):1181-90.

¹³¹ Royal College of Obstetricians and Gynaecologists. Alcohol consumption and the outcomes of pregnancy. RCOG Statement No. 5, Guidelines and Audit Committee of the RCOG. 2006.

¹³² Diekman ST et al. (2000).

¹³³ Clarke M, Tough SC, Cooke J. (2004).

¹³⁴ Ibid.

¹³⁵ Henderson J, Gray R, Brocklehurst P. Systematic review of effects of low-moderate prenatal alcohol exposure on pregnancy outcomes. BJOG 2007;114: 243-52.

The absence of conclusive evidence regarding the safety of low to moderate amounts of alcohol during pregnancy creates uncertainty, both with physicians and the genera public.

While health care professionals are sensitized to look for FASD in certain populations, no woman or population is exempt.

There has been minimal research into the effectiveness and impact of FASD prevention programs.

predominate message from most experts is that complete abstinence from alcohol is safest for all pregnant women or women contemplating pregnancy, and that heavy alcohol consumption is not safe, the absence of conclusive evidence regarding the safety of low to moderate amounts of alcohol during pregnancy creates uncertainty, both with physicians and the general public.

The incidence and prevalence of FASD is difficult to determine and study results have noted a wide range of estimates. Under-reporting of FASD is thought to be widespread and FASD surveillance criteria have been variable. The widespread and FASD surveillance criteria have been variable. The widespread and FASD surveillance criteria have been variable. The widespread are sensitized to look for FASD in certain populations, no woman or population is exempt. Some studies have shown that women at highest risk of not being identified as being at risk for an alcohol-affected pregnancy are women over 35 years with higher incomes, women with a college education students and smokers. Most of the physicians participating in Physicians for FASD Prevention project focus groups identified FASD with certain populations (e.g. Aboriginals, low socio-economic populations and substance abusing populations). A few identified that patients at risk of an alcohol-affected pregnancy could also be "educated professionals," bar flies in their twenties," and "middle-aged women who have alcohol issues."

There has been minimal research into the effectiveness and impact of FASD prevention programs. One study showed that while prevention programs increased awareness of FASD in high risk populations, behavioral changes were not observed. This study concluded that prevention programs probably have minimal or no impact in lowering the incidence of FASD.

The Physicians for FASD Prevention project provided a unique opportunity to observe and gain insight into disparities between research findings and recommendations, and everyday clinical practice in screening for and prevention of FASD. Significant project limitations were encountered and will be discussed. For the purpose of discussion, these observations have been grouped under the following headings:

- Screening and prevention
- Structured screening questionnaires
- Barriers
- Research and evidence
- Project participation

¹³⁶ Basford DL et al. (2005).

¹³⁷ Alberta Medical Association (2005).

¹³⁸ Ibid.

¹³⁹ Ibid.

¹⁴⁰ Health Canada. Research update (2006).

¹⁴¹ Clarke M, Tough SC, Cooke J.(2004).

¹⁴² Murphy-Brennan MG, Oei TPS. Is there evidence to show that Fetal Alcohol Syndrome can be prevented? J Drug Educ 1999;29(1);5-24.

7.1. Screening and Prevention

Physicians participating in the Physicians for FASD Prevention project focus groups report that they strive to conduct regular, routine preventive screening of women of child-bearing age but that barriers such as competing priorities and lack of time often preclude alcohol screening. This is consistent with studies that report that screening for and preconception prevention of FASD does not occur regularly in many physician practices. ¹⁴³ ¹⁴⁴ ¹⁴⁵ ¹⁴⁶ A Canadian Task Force on Preventive Health Care report ¹⁴⁷ states that physician reimbursement is not conducive to preventive practices. Focus group physicians reported that the most favorable time to conduct screening for alcohol use is usually during periodic health assessments because there is generally more time available than during opportunistic visits.

The Physicians for FASD Prevention project found that although 75% of the participating physicians reported that they routinely screen patients for alcohol-related issues, they also reported that many patients do not present regularly for health assessments. For these patients, alcohol screening only occurs on an opportunistic basis, and when time and circumstances permit.

Physician focus group participants were consistent with patient survey respondents in saying that physicians were not discussing healthy pregnancy issues prior to conception, and that discussing healthy pregnancy issues was more likely if the patient prompted the physician or presented with a confirmed pregnancy. Most of the survey respondents reported that they trust their primary care physicians as an accurate source of information, but less that a third realized that physicians could help patients stop or reduce alcohol consumption in pregnancy.

Physicians participating in the focus groups felt they did not have the time or resources to conduct brief interventions such as motivational interviewing with women at risk for having an FASD child, because of competing priorities. Other reasons participating physicians gave for not using brief interventions were lack of patient candor, patients not presenting for regular health assessments and pessimism about the efficacy of interventions. Most felt that they had the skills to address sensitive issues with patients.

Many of the participating physicians liked the list of local referral resources on the information brochure. They also said they would have liked to have required criteria for each referral resource on the brochure. One study A Canadian Task Force on Preventive Health Car report states that physician reimbursement is not conducive to preventive practices.

¹⁴³ Clarke M, Tough SC, Cooke J.(2004).

¹⁴⁴ Canadian Task Force on Preventive Health Care. (1999).

¹⁴⁵ Saitz R et al. (2003).

¹⁴⁶ Millstein SG et al. (2003).

¹⁴⁷ Canadian Task Force on Preventive Health Care. (1999).

showed that the availability of referral resources was associated with higher rates of screening and counseling. 148

Some of the participating physicians suggested that registered nurses or other healthcare providers in Primary Care Networks could provide preconception screening for FASD. A number of studies have recommended the use of multi-disciplinary teams or alternate care providers to provide preconception information and screening when patients present for birth control or periodic health assessments. 149 150 151

Focus group participants from this project and others¹⁵⁴ agreed that resource material for physicians needs to be clear, concise, simply presented, evidence-based and easy to access. 155 Physicians also stated that the source of the information should be clearly identified. Some of the physicians indicated that they would be more likely to look at resource material if it was from their own association, or if it was an Alberta Clinical Practice Guideline update.

7.2. Structured Screening Questionnaires

The Physicians for FASD Prevention screening questionnaire, along with the information brochure, was negatively received by most of the physicians participating in the design (testing) focus groups. Participants reported that they preferred routine clinical methods and nonconfrontational discussion with patients, rather than structured screening questionnaires. This is consistent with some studies that report that physicians appear to prefer routine clinical methods over structured screening questionnaires. 156

Most of the participating physicians reported that they seldom use standardized alcohol screening questionnaires, even though they are recommended by the Alberta Clinical Practice Guidelines¹⁵⁷ and a number of research studies. 158 159 160 161 Some studies report that physicians place

148 Millstein SG et al. (2003).

Physicians appear to

prefer routine clinical

methods over structured screening questionnaires.

¹⁴⁹ Health Canada. Health Human Resources: Balancing Supply and Demand. Health Canada 2004 ISSN 1499-3503

¹⁵⁰ Alberta Medical Association (2005).

¹⁵¹ Saitz R et al. (2003).

¹⁵² National Alcohol Strategy Working Group. (2007).

¹⁵³ Alberta Perinatal Health Program. (2007).

¹⁵⁴ Silzer J. Focus group final report. Consumer and provider perspectives: Informing preconception strategy development. Calgary, Quality Safety and Health Information, Survey and Evaluation 2007; Calgary Health Region.

¹⁵⁵ Ibid.

¹⁵⁶ Andreasson S, Jhalmarsson K, Rehnman C. Implementation and dissemination of methods for prevention of alcohol problems in primary health care: A feasibility study. Alcohol and Alcoholism. 2000;33(5):525-30.

¹⁵⁷ Alberta Medical Association (2005).

¹⁵⁸ Hicks M et al. (2003).

¹⁵⁹ Millstein SG et al. (2003).

little value on, and seldom use prevention materials and screening questionnaires, even when they are recommended by research studies. ¹⁶² All participating physicians were familiar the CAGE questionnaire, which is included in medical education curriculum. Most of the participating physicians were not familiar with T-ACE standardized screening questionnaire.

Physicians stated they are inundated with screening tools, information, posters and brochures on various diseases and conditions from many sources, including pharmaceutical companies and government agencies. They reported that almost all of this information is discarded unused. This is consistent with information gathered from other focus groups. Some physicians said that they would probably take time to look more closely at information identified with Alberta Clinical Practice Guidelines.

Physicians stated they are inundated with screening tools, information, poster. and brochures on various diseases and conditions from many sources, including pharmaceutical companies and government agencies.

7.3. Barriers

Participating physicians identified a number of barriers to providing preventive and screening services for FASD. The most frequently identified barriers were lack of time and competing priorities. Other barriers included lack of training, lack of referral resources and perceived lack of patient candor or readiness. These and other barriers are consistent with those identified in research studies.

Some physicians suggested that other providers (e.g. registered nurses) could provide FASD prevention services.

7.4. Evidence and Research

Participating physicians identified that inconclusive evidence and conflicting expert opinions have created uncertainty and confusion among physicians and patients, and do not offer clear guidance in many areas of FASD. There is also little evidence regarding the efficacy of FASD prevention activities, or the priority of FASD prevention versus other competing concerns, such as obesity or depression. While all participating physicians advised their patients not to consume any alcohol during pregnancy, some physicians felt that the evidence was insufficient to prove that all women are at risk of having an FASD-affected baby, and that the statement could create unnecessary fear among women. Some

Inconclusive evidence and conflicting expert opinion have created uncertainty and confusion among physicians and patients, and do not offer clear guidance in many areas of FASD.

¹⁶⁰ Nevin AC, Parshuram C, Nulman I, Koren G, Einarson A. A survey of physicians knowledge regarding awareness of maternal alcohol use and the diagnosis of FAS. BMC Fam Prac 2002;3:2. doi:10.1186/1471-2296-3-2.

¹⁶¹ Saitz R et al. (2003).

¹⁶² Health Canada. Research update (2006).

¹⁶³ Diekman ST et al. (2000).

¹⁶⁴ Saitz et al. (2003).

¹⁶⁵ Silzer J. (2007).

reported that they felt they had to reassure women that an occasional or isolated drink would not result in an FASD-affected child.

Most of the participating physicians identified FASD as a risk factor in specific populations (e.g. Aboriginals, low socio-economic populations, substance abusing populations, 'inner-city' populations and women aged 18 to 25 who are 'weekend binge drinkers'), and that high-risk women are less likely to seek regular medical care. Few of the participating physicians recognized that other groups could be at high risk.

7.5. Project Participation

The number of primary care physicians willing to participate in focus groups and other phases of the project was a significant limitation to the project overall. This was despite multiple recruitment approaches including phone, fax, email and word-of-mouth, flexibility in the timing and location of focus groups to work around physician schedules and locations, and incentives including a meal and financial compensation for time spent. Five physicians participated in the Design (testing) Phase, twenty-three participated in the Investigation Phase and there were two primary care physician representatives on the project Steering Committee (Appendix 9).

In the Investigation Phase focus groups, the subject matter was not revealed until the conclusion of the focus groups. Some participants said that they were disappointed that the focus groups were about FASD prevention. One physician said he would not have participated if he had known the project was about FASD.

When recruiting physicians for the Design (testing) Phase focus groups, the Physicians for FASD Prevention designed supports and the subject matter of the focus groups was revealed to the physicians as part of the recruitment. There was extremely low interest in the subject matter, and scheduling of the focus groups was delayed by over a month due to low enrollment. Five physicians from three clinics agreed to participate. One physician stated that there were too many subject matter experts and not enough primary care physicians on the 'Physicians for Fetal Alcohol Spectrum Disorder' Steering Committee.

Overall, competing priorities and low interes, in the subject matter were noted as barriers to primary care physician participation.

Overall, competing priorities and low interest in the subject matter were noted as barriers to primary care physician participation.

8. Conclusions and Recommendations

The Physicians for FASD Prevention project provided a unique opportunity to examine research-recommended strategies for FASD screening and prevention and the realities of implementing those strategies in primary care physicians' everyday practices. However, there appears to be a disparity between research-recommended FASD screening and prevention strategies and the realities of primary care practice in Alberta.

The Physicians for FASD Prevention project team has drawn three major conclusions based on the following:

- A literature review of FASD screening and prevention research, practices and recommendations
- Information collected from physician focus groups in the Investigation and Design Phases
- Analysis of the information collected during the project

In summary, the three major conclusions are:

- More FASD research is required
- FASD is a societal issue, not solely a medical issue
- Physician constraints need to be addressed

8.1. FASD Research

Although there has been much research regarding FASD, more study and clarification is needed, particularly in the area of defining safe levels of consumption during pregnancy and timing of consumption. Surveillance and incidence and prevalence data are limited in defining the true occurrence level and societal effects of FASD. Inconclusive evidence and conflicting expert opinions create uncertainty and confusion for physicians and the general public, and does not offer clear guidance in many areas of FASD.

- Inconclusive evidence has resulted in conflicting statements between some highly regarded clinical organizations regarding safe limits of alcohol consumption
- Given competing health screening priorities, physicians may not consistently implement FASD screening and prevention when there is no conclusive evidence about amount and timing of alcohol consumption in pregnancy and the incidence and prevalence of FASD, and limited evidence on the efficacy of prevention programs
- The value and use of FASD screening questionnaires has not been widely accepted by physicians
- FASD is often seen as afflicting only marginalized, disadvantaged populations
- The general public is confused by inconclusive evidence and conflicting expert opinions about alcohol consumption during pregnancy

There appears to be a disparity between research-recommended FASD screening and prevention strategies and the realities of primary care practice in Alberta.

More study and clarification is needed, particularly in the area of defining safe levels of consumption during pregnancy and timing of consumption.

Support funding of research and the development and implementation of surveillance systems to provide more definitive evidence regarding lowdose alcohol effects, highrisk populations, and incidence and prevalence of FASD.

Support allocated funding of FASD prevention strategies that are determined to be efficacious by research, rigorous testing and evaluation.

Recommendations:

- Support funding of research and the development and implementation of surveillance systems to provide more definitive evidence regarding low-dose alcohol effects, high-risk populations and incidence and prevalence of FASD
- Support research that examines the efficacy of FASD prevention programs
- Improve communication between research and health care providers regarding research findings
- Support research determining the most effective strategies for informing women about the risks of alcohol consumption during pregnancy and for reducing alcohol consumption among women at risk of becoming pregnant
- Support allocated funding of FASD prevention strategies that are determined to be efficacious by research, rigorous testing and evaluation
- Incorporate FASD research findings and screening and prevention measures into medical education curricula

8.2. FASD is a Societal Issue

FASD does not occur in isolation and is not only a medical issue. It impacts individuals and their families and many areas of society, including health care, education, the judicial system and the economy, in terms of lost productivity. FASD prevention must be addressed in a focused, consistent, collaborative and comprehensive manner.

- FASD screening and prevention is viewed by many researchers as the primary physicians' responsibility
- FASD prevention initiatives often occur independent of each other, and from many different sources
- FASD is often not viewed as a birth defect that can occur in any population
- Many people, including physicians, are not aware of the impact of FASD on society in general

Recommendations:

- Support the development, implementation and evaluation of a coordinated FASD prevention plan in partnership with government ministries, municipalities, school boards, regional health authorities, communities groups and provincial stakeholder organizations
- Align with other provincial initiatives and public awareness campaigns to support consistent, sustained messaging utilizing a broad range of vehicles, such as mass-media campaigns, internet, community-based programs and school-based education

- Include an evaluation component to initiatives and campaigns to determine their effectiveness
- Integrate FASD prevention and screening activities into existing programs and services, such as community health programs, school programs, parenting programs
- Raise the profile of, and advocate for people affected by FASD

8.3. Physician Constraints

Physician limitations and barriers to prevention and screening for FASD have been well documented in many studies. Despite recommendations that physicians should incorporate screening and prevention of FASD into their everyday practices, limitations and barriers persist.

- Physicians strive to conduct regular, routine alcohol screening but are limited by barriers and competing priorities
- Physicians may not see FASD prevention as a high priority, given other constraints, competing priorities and inconclusive evidence
- FASD screening and prevention takes a significant amount of time and resources
- Physicians may not provide patients with information on alcohol in pregnancy unless prompted by patients or the patient presents with a confirmed pregnancy
- Patient requests for preventive services are a powerful motivator for physicians¹⁶⁶

Recommendations:

- Align and collaborate with existing programs and services (e.g. Alberta Perinatal Health Program), to integrate FASD prevention and screening into preconception care
- Embed standard alcohol screening tools on all prenatal records
- Where possible, utilize alternate care providers (e.g. registered nurses, nurse practitioners or midwives) in Primary Care Networks (PCNs), Well Baby Clinics, and other community health programs and services, to provide preconception FASD prevention and screening when women present for contraception, perinatal or periodic health assessments
- Collaborate with professional associations and post-secondary institutions to develop and implement health provider education to address gaps in preconception FASD prevention and screening
- Support physician reimbursement to include preconception prevention care
- Address FASD prevention in the larger picture of preconception health

Integrate FASD prevention and screening activities into existing programs and services, such as community health programs, school programs, and parenting programs.

Align and collaborate wit existing programs and services (e.g. Alberta Perinatal Health Program) to integrate FASD prevention and screening into preconception care.

Where possible, utilize alternate care providers (e.g. registered nurses, nurse practitioners or midwives) in Primary Cal Networks (PCNs), Well Baby Clinics, and other community health programs and services, to provide preconception FASD prevention and screening when women present for contraception, perinatal or periodic health assessments.

Support physician reimbursement to include preconception prevention care.

¹⁶⁶ Canadian Task Force on Preventive Health Care. (1999).

Appendix 1. Physicians for FASD Prevention Project Steering Committee Membership

Physicians for FASD Prevention Project Steering Committee

Doug Stich (Chair)

Program Director, Toward Optimized Practice, Edmonton

Annette Lemire, Project Sponsor (January 2006 – December 2006) Population Health Strategies Branch Alberta Health and Wellness, Edmonton

Kesa Shikaze, Project Sponsor (January 2007 – present) Population Health Strategies Branch Alberta Health and Wellness, Edmonton

Dr. Gail Andrew

Developmental Pediatrician Glenrose Rehabilitation Hospital, Edmonton

Dr. Margaret Clarke

Professor, Pediatrics, University of Calgary Division Head, Developmental Pedicatrics Alberta Children's Hospital, Calgary

Dr. Carolyn Lane

General Practitioner, Calgary

Laureen McPeak

Alberta Perinatal Health Program Capital Health, Edmonton

Joann Nelson

Women's Framework and FASD Coordinator Health Partnerships AADAC, Edmonton

Mary Berube

Team Leader, Early Childhood Development, Alberta Region First Nations and Inuit Health Branch Health Canada, Edmonton

Dr. Johannes Botha

General Practitioner. Redwater

Dr. Suzanne Tough

Associate Professor Department of Community Health Sciences and Pediatrics Alberta Children's Hospital, Calgary

Appendix 2. Physicians for FASD Prevention Project Team

Physicians for FASD Prevention Project Team

June Austin, RN Co-Project Lead Toward Optimized Practice

Jane Renaud, RN Co-Project Lead Toward Optimized Practice

Joan Parsons, B. Comm.Project Team Member
Toward Optimized Practice

Appendix 3. Investigation Phase – Physician Screening Chart

Physician Screening Chart

| Routine/asymptomatic screening for: | Scr | eening patt | tern | Prevalence/ Likelihood of + result? | Potential impact on health if + or problematic? | | | | | |
|---|-----------------|--------------------|-----------------------|---|---|--|--|--|--|--|
| | All patients | If patient prompts | Signs/risk factors | 7=high/ 1=rare | 7=significant/ 1=minimal | | | | | |
| | | | | | | | | | | |
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| | | | | | | | | | | |
| Practice location: Large urban Regional Rural | | | | | | | | | | |
| Sex: N | Male | F | emale | | | | | | | |
| Years in practice (|)-5 _ | 6-10 | 11 - 1 | .516 - 2 | 0 | | | | | |
| 2 | 20 - 25 | | | | | | | | | |

Patient profile (%) ____ % Male ____ % Female

Prenatal care? ____Yes ____ No

Obstetrics/deliveries? ____ Yes___ No

Appendix 4. Physician Focus Group Script

Physician Focus Group Script

Routine screening patterns

- 1. First, how much opportunity do you have to conduct routine screening and prevention activities for females of child-bearing age say those between 13 and 45? Do you feel you have adequate opportunity to screen for the types of conditions you might expect to commonly see in these patients? Are there gaps between your professional intentions, the demands on your time, and the expectations of patients? How do you manage these gaps?
- 2. For annual visits & asymptomatic patients, what do you tend to screen for? Brainstorm list (contraception, cervical cancer/pap smear, depression, weight-related issues, alcohol use, ingestion of folic acid, etc.)
- 3. For each of these, would you say that you screen:
 - For all or most patients routinely?
 - Only when there's a prompt from the patient?
 - When you perceive there to be signs or risk factors present?
- 4. For each of these conditions, how would you rate them in terms of (1) prevalence, where 7 is extremely high and 1 is extremely rare (2) potential impact on health, where 7 is extremely significant and 1 is minimal.
- 5. Do you feel you are able to screen for all the things you'd like to screen for? Why? When setting priorities, which conditions drop off your list? Which ones remain as priorities? Why?

Screening for alcohol use - patterns, barriers, perceptions

- 6. (If alcohol use not mentioned so far):
 - I noticed screening for alcohol use isn't on our list so far. Why is that?
 - If we added alcohol to the list above, what would you say is your current screening pattern? How would you rate it in terms of incidence and potential impact on health?
- 7. Are there certain categories of patients you are more likely to screen for alcohol use in the absence of a clinical sign or prompt from the patient? Who are they, and why? (Probe re: knowledge and awareness of risk factors: First Nations, sexually active teenagers, college educated, single parent, unstable or abusive personal relationship, history of sexual abuse, history of STDs, history of prostitution).
- 8. What prevents you from conducting routine screening of all patients for alcohol use? (Probe re: perceived risk; time pressures; lack of opportunity; not part of routine thought process)

- 9. In your opinion, how much time & effort would it take to add alcohol screening to your list of routine screens? How practical and realistic is it for your particular practice environment?
- 10. Think of situations where you actually have screened patients for alcohol use. Do you use any screening tools or algorithms? Which ones?
- 11. When you screen for alcohol use, what exactly are you looking for? Anything else? (Probe re: binge drinking; alcohol dependency; relationship abuse; parenting issues; stress; etc.)

Obtaining alcohol consumption histories

- 12. When you have screened patients for alcohol use, what has been their reaction? What has been the outcome of these screenings that is, did you obtain information that you found helpful and useful in your clinical evaluation?
- 13. Do you feel patients respond honestly when you screen for alcohol use? How would you explain this? To what extent do you feel you are able to obtain a reliable alcohol-use history from patients?
- 14. Do you feel you play a role in influencing the degree of patients' honesty? In what way?

Managing patients who consume alcohol

- 15. If you do screen a patient for alcohol use and they are a light to non-user, what comes to mind in terms of next steps or ongoing management? Do you offer any information, resources, etc? Why?
- 16. What about a patient whose screening suggests they are a moderate to heavy user of alcohol what comes to mind in terms of next steps or ongoing management? Do you offer any information, resources, etc? Under what circumstances, or for which patients?

Perceived links between alcohol use and pregnancy risk

- 17. In moderate to heavy users of alcohol, does pre-pregnancy counseling come to mind for these patients as a potential flag for management or intervention? Would you normally discuss the potential for pregnancy, planned or unplanned? Why or why not?
- 18. When discussing alcohol use pre-conception, how important is it for you to receive a prompt from the patient regarding conception, pregnancy contemplation or family planning?
- 19. In the absence of a conception-related prompt from the patient, would you normally screen for alcohol use pre-conception? Why or why not?
- 20. Do you normally think of an alcohol-using patient as being at risk for an unintended pregnancy? Why? (probe re: alcohol use & binge drinking increasing chances of unprotected sexual activity, etc.)

Identifying and managing at-risk patients pre-pregnancy

- 21. In terms of offering advice, support or intervention to patients who are moderate to heavy users of alcohol, in your mind do you make a distinction between patients who have alcohol-related problems, and those who have BOTH alcohol-related problems and who are also at risk of pregnancy? In what way?
- 22. In general, are there patients you view as being more at risk of an alcohol-affected pregnancy? Who are these patients? Why do you believe they are at greater risk?
- 23. If you had a patient who was a moderate to heavy drinker, sexually active, and not using birth control reliably, would you perceive this patient to be at risk of an unintended pregnancy? How would you manage this?
- 24. Would you ever consider recommending that a patient in this situation use a method of contraception that is less dependent on patient compliance, such as an IUD or implantable hormones? Why or why not?
- 25. In your opinion, which patients are at the greatest risk of giving birth to a baby with fetal alcohol spectrum disorder? Do you see many of these patients in your practice?

Managing FASD risk during pregnancy

26. When a patient presents for a pregnancy test, do you discuss any of the following?

| | Neg. & happy | Neg. & unhappy | Positive |
|--|--------------|----------------|----------|
| Folic acid | | | |
| Other prenatal vitamins and supplements | | | |
| Smoking cessation or reduction | | | |
| Exercise in pregnancy | | | |
| Sexuality | | | |
| Drug use (prescription and non-prescription) | | | |
| Alcohol use | | | |

27. If a pregnant patient is believed to be a light user of alcohol, what do you discuss with the patient? (Probe re: reassuring concerned patients about alcohol consumption; recommendation cessation; etc.)

28. If a pregnant patient is believed to be a moderate to heavy user of alcohol, what do you discuss with her? (Probe re: cutting down or quitting; reassurance re: ability to manage; referral to treatment programs; discussion re: termination options; etc.)

Capacity to manage at-risk patients

- 29. Do you feel you have sufficient expertise and time to provide non-pregnant patients with the supports and intervention they need? How about pregnant patients?
- 30. Do you feel you have sufficient access to other resources outside your practice to give these non-pregnant patients the supports and intervention they need? Pregnant patients? Why?
- 31. What might enhance your ability and capacity to manage pregnancy patients who need help with alcohol consumption?

Appendix 5. Investigation Phase – Prenatal Patient Survey

Prenatal Patient Survey

This survey is about your experiences as a patient. All the information you provide will be kept confidential. Nobody will know how you answer these questions – not even your doctor.

| 1. How many weeks/months pregnant are you? | 6. Before becoming pregnant , did your family doctor, obstetrician/gynecologist or nurse/midwife talk to you | | | | |
|--|---|----------|-------------------|---------|--|
| ☐ 6 weeks or less | about any of the following | g? (Chec | k all that apply) | | |
| ☐ 6-1/2 weeks to 12 weeks | | Family | Obstetrician/ | Nurse/ | |
| □ 3 to 6 months | | doctor | gynecologist | midwife | |
| ☐ 6 to 9 months | | | | | |
| □ Not sure | Taking folic acid to | | | | |
| | prevent birth defects | | | | |
| 2. Would you consider this pregnancy to be: | | | | | |
| ☐ A planned pregnancy | _ | | | | |
| ☐ An unplanned pregnancy | Quitting or cutting down | | | | |
| ☐ I'm not sure | on cigarette smoking | | | | |
| | | | _ | | |
| 3. Is this your: | | | | | |
| ☐ First pregnancy? | Uning high control to | | | | |
| ☐ Second pregnancy? | Using birth control to | | | | |
| ☐ Third pregnancy? | prevent pregnancy | Ц | | | |
| ☐ Fourth or more pregnancy? | | | | | |
| 4. Who has been providing your prenatal care during this | Your own use of | _ | _ | | |
| pregnancy? (Check all that apply) | alcohol or drugs | | | | |
| ☐ Family doctor | | | | | |
| ☐ Obstetrician/gynecologist | | | | | |
| ☐ Pediatrician | Risks of using alcohol | | | | |
| □ Nurse practitioner | if you aren't using | | | | |
| ☐ Midwife | reliable birth control | | | | |
| ☐ Other: | | | | | |
| ☐ I have not received prenatal care. | _ | | | | |
| | Risks of using alcohol | | | | |
| 5. Before becoming pregnant , did you and your doctor | during pregnancy | |] [| | |
| talk about how to have a healthy pregnancy? | | | | | |
| ☐ Yes ☐ No ☐ Not sure | Using drugs during | | | | |
| V | pregnancy | | | | |
| If yes, who brought up the subject of pregnancy? <i>(Check one only)</i> | | _ | _ | | |
| ☐ My doctor brought it up without me | | | | | |
| asking. | | | | | |
| ☐ I brought it up on my own. | | | | | |
| ☐ We both brought it up together. | | | | | |
| ☐ I don't remember who brought it up. | | | | | |

| 7. After becoming pregnant , did your family doctor, obstetrician/gynecologist or nurse/midwife talk to you about any of the following? (Check all that apply) | | | 12. Have you heard any of the following things about using alcohol during pregnancy? Indicate whether you've heard these from your doctor, friends/family, tv/news or others. | | | | |
|--|--|----------|---|------------------|---------------------------|---------------------|--------------------|
| | Family Obstetrician doctor gynecologis | | (Check all that apply | <i>')</i> | Doctor Fam | - | Others |
| Taking folic acid to prevent birth defects □ | | | That alcohol can an unborn baby. | harm | | | |
| Taking prenatal vitamins or supplements □ | | | That no amount of alcohol is safe du pregnancy | | - | | |
| Quitting or cutting down on cigarette smoking | | | That babies export to alcohol during pregnancy may d problems that car their whole life. | evelop | - | | |
| Risks of using alcohol during pregnancy □ | | | That doctors can people stop drink | ing, or | | | |
| Risks of using drugs during pregnancy | | | drink less alcohol during pregnancy | | | | |
| Nutrition & healthy eating during pregnancy | | | 13. How comfor people about | alcoho Family | - | | Friends/ family |
| Exercising safely during pregnancy | | | Completely comfortable | | gynecologist | | |
| 8. Since you became pregnant, has your doctor asked you how much alcohol you normally drink? ☐ Yes ☐ No ☐ I don't know 9. Since you became pregnant, has your doctor asked you how often you normally drink alcohol? | | | Not really comfortable \subseteq \text{Not at all} | _ | | _ | _ |
| | | | | | | | |
| - | don't know | | I don't know | _ | _ | _ | _ |
| 10. Since you became pregnant, has your doctor asked you about your partner's alcohol use? ☐ Yes ☐ No ☐ I don't know | | | 14. How much do you trust these people to give you correct information about alcohol use? | | | | |
| 11. How would you descriamong your close family a | | ohol use | | Family doctor | Obstetrician gynecologist | / Nurse/ midwife | Friends/ family |
| (Check one only) | iid irielius? | | Trust completely | | | | |
| ☐ There is no alcohol use in my circle of friends and family. | | | Trust a little bit | | | | |
| ☐ Only a few people drink alcohol. ☐ Many people drink, but they drink lightly or | | | Don't trust very much | | | | |
| responsibly during social get-togethers | | | Don't trust at all | _ | _ | _ | _ |
| ☐ Most people drink alcohol regularly or daily. ☐ People regularly drink a large amount of alcohol or they usually drink to get drunk. | | | I don't know | | _ | | |
| or they usually drink to g ☐ None of the above, or I' | | | | | | | |

15. If you were to talk to your doctor about alcohol use, would you be concerned about the following? I would be concerned: A lot A little Not really Not at all Not sure Being embarrassed. Being judged by my doctor. Being forced into alcohol treatment. Being asked to give up my baby. 16. In what ways, if any, do you plan to change your pattern of drinking alcohol during this pregnancy? ☐ Nothing will change because I don't drink alcohol at all. ☐ I plan to stop drinking alcohol during this pregnancy. ☐ I plan to cut down on drinking alcohol. ☐ I will continue to drink the same amount as before. ☐ I don't know what I will do. 17. Does or your doctor think you might need to reduce your use of alcohol during pregnancy? ☐ I don't know, because we didn't talk about it. ☐ Yes, my doctor thinks I should use less alcohol during pregnancy. ☐ No, because I don't drink alcohol at all. ☐ No, because I've already decided not to drink alcohol during pregnancy. ☐ None of the above. 18. Has your doctor offered you any of the following? (Check all that apply) ☐ A pamphlet or other printed information about alcohol during pregnancy. ☐ Information about services from AADAC (Alberta Alcohol and Drug Abuse Commission) ☐ Information about support groups for women who want to stop drinking alcohol during pregnancy. ☐ Other (please specify): ☐ None of these were offered to me.

| 19. What year were you born? ☐ 1990 or later ☐ 1982 – 1989 ☐ 1971 – 1981 ☐ 1960 – 1970 ☐ Before 1960 |
|--|
| 20. What is your marital status? ☐ Married or common law ☐ Single ☐ Divorced ☐ Widowed |
| 21. What is the highest level of education you achieved? ☐ Elementary school ☐ Junior high school ☐ Some high school courses ☐ High school graduation ☐ Some college or technical training ☐ College diploma or technical certificate ☐ Some university courses ☐ University graduation |
| 22. What is your approximate family income? □ \$12,000 or less □ \$12,001 - \$18,000 □ \$18,001 - \$35,000 □ \$35,001 - \$55,000 □ \$55,001 - \$70,000 □ More than \$70,000 |
| 23. What is your current occupational status? □ Stay-at-home parent □ Part-time student □ Work part-time outside the home □ Full-time student □ Work full time outside the home □ Not employed or going to school |

Thank you. Please put your survey in the box provided.

Appendix 6. Investigation Phase – Patient Survey

Patient Survey

This survey is about your experiences as a patient. All the information you provide will be kept confidential. Nobody will know how you answer these questions – not even your doctor.

| Do you have a regular | r family do | ctor? | | | | | |
|--|---|---|-------------------|------------------------|----------------------|-----------------|---------------------|
| ☐ Yes ☐ No | | ☐ Not sure | | | | | |
| 2. Do you have a regular | | | t? | | | | |
| ☐ Yes ☐ No | | ☐ Not sure | | | | | |
| 3. Before thinking you i ☐ Yes ☐ No | | regnant, did y ☐ Not sure | ou and your | doctor talk ab | oout how to h | ave a healthy | pregnancy? |
| If yes, who brought (Check one only) ☐ My doctor brough ☐ I brought it up on ☐ We both brought ☐ I don't remember | up the subj ht it up with my own. it up togetl | ject of pregnar hout me asking her. | | | | | |
| 4. Before thinking you any of the following? | might be p | _ | your family | doctor, obstetr | rician/gyneco | logist or nurse | e talk to you about |
| | Family doctor | Obstetrician/ gynecologist | Nurse/ midwife | | | | |
| Taking folic acid to prevent birth defects | | | | | | | |
| Quitting or cutting down on cigarette smoking | | | | | | | |
| Using birth control to prevent pregnancy | | | | | | | |
| Your own use of alcohol or drugs | | | | | | | |
| Risks of using alcohol if you aren't using reliable birth control | | | | | | | |
| Risks of using alcohol during pregnancy | | | | | | | |
| Using drugs during pregnancy | | | | | | | |
| 5. Has your doctor recen ☐ Yes ☐ No ☐ | itly asked y I don't kno | | alcohol you | ı drink, or how | v often you n | ormally drink | alcohol? |
| 6. Has your doctor recen ☐ Yes ☐ No ☐ | itly ask you I don't kno | | artner's alc | ohol use? | | | |

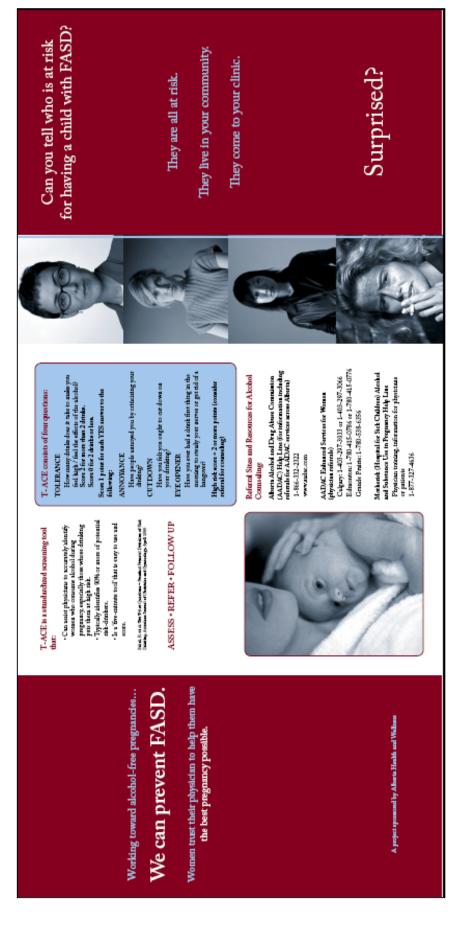
| 7. Would you consider th ☐ A planned pregnancy ☐ An unplanned pregna ☐ I'm not sure | | ancy to be: | | | | |
|---|------------------------------------|--------------------------------------|-------------|-----------|--|----|
| (Check one only) ☐ There is no alcohol us | - | | | se amon | g your close family and friends? | |
| and family. ☐ Only a few people dri ☐ Many people drink, bresponsibly during soo | ut they dr | ink lightly | or or | | | |
| ☐ Most people drink alc ☐ People regularly drink alcohol or they usually ☐ None of the above, or | ohol regu a large a drink to | larly or da mount of get drunk | · | | | |
| 9. How would you descr☐ I don't drink alcohol.☐ I drink alcohol once in | ribe your | typical pa | | alcohol | ise? (Check one only) | |
| social get-togethers. I drink alcohol a few to I have one or two drinks. | times per | week. | | | | |
| every day. ☐ At least once a week, drinks at a time. ☐ I drink alcohol until I | | ır or more | ; | | | |
| ☐ None of the above, or10. If it turns out that you | I'm not s | | hat way | s, if any | do you plan to change your pattern of drinking alcohol | |
| during this pregnancy? Nothing will change be alcohol at all. | | | | | | |
| □ I plan to stop drinking a pregnancy. □ I plan to cut down on d □ I will continue to drink of alcohol as before. □ I don't know what I wi | rinking al | cohol. | | | | |
| | of the fol | | | | alcohol during pregnancy? Indicate whether you've hea | rd |
| That alcohol can harm | Doctor | Family/ friends | TV/ news | Others | | |
| an unborn baby. | | | | | | |
| That no amount of alcohol is safe | | | | | | |
| during pregnancy | | | | | | |

| hose babies exp lcohol during pr nay develop prol nat can last their | egnancy blems | | | |
|---|------------------|-----------|-----------------------------------|--------------------|
| That doctors can people stop drink drink less alcohol during pregnancy | ing, or l, | | | . . |
| 12. How comfort | able do | you feel | talking to t | hese peopl |
| | Family doctor | Obstetric | ian/ Nurse/ ist midwife | Friends/ family |
| Completely | | | | |
| comfortable A little bit | | | | |
| comfortable Not really | | | | |
| comfortable | | | | |
| Not at all comfortable | | | | |
| I don't know | | | | |
| 13. How much do | o you tri | ust these | people to g | ive you co |
| | Family doctor | Obstetric | ian/ Nurse/ ist midwife | Friends/ family |
| Trust completely | | | _ | |
| Trust a little bit | | _ | | _ |
| Don't trust very | | | | |
| much | | | | |
| Don't trust at all | | | | |
| I don't know | | | | |
| 14. If you were to | talk to | your doc | ctor about a | lcohol use |
| | A lot | | d be concerned of really Not a | |
| Being embarrasse | d. 🗖 | | | |
| Being judged by my doctor. | | | | |
| Being forced into alcohol treatment. | | | - | |
| Being asked to giv up my baby. | ve | | | |

| 15. What year were you born? ☐ 1990 or later ☐ 1982 – 1989 ☐ 1971 – 1981 ☐ 1960 – 1970 ☐ Before 1960 |
|---|
| 16. What is your marital status? ☐ Married or common law ☐ Single ☐ Divorced ☐ Widowed |
| 17. What is the highest level of education you achieved? (Check one only) ☐ Elementary school ☐ Junior high school ☐ Some high school completed ☐ High school graduation ☐ Some college or technical training ☐ College diploma or technical certificate ☐ Some university ☐ University graduation |
| 18. What is your approximate family income? □ \$12,000 or less □ \$12,001 - \$18,000 □ \$18,001 - \$35,000 □ \$35,001 - \$55,000 □ \$55,001 - \$70,000 □ more than \$70,000 |
| 19. What is your current occupational status? ☐ Stay-at-home parent ☐ Part-time student ☐ Work part-time outside the home ☐ Full-time student ☐ Work full time outside the home ☐ Not employed or going to school |

Appendix 7. Physicians for FASD Prevention Project Information Brochure (Draft)

Patient Information Brochure (Draft)



Women considered at-55th for hering a child with EASD come from all walks of this.

· According others, weeking or

Bary may be:

· Married or semanded In their sudy or later diddlessing year

What is Fetal Alcohol Spectrum Disorder (FASD)?

Feel Alcabel Specimen Disorder (FAEO) is normalised summand in document of a reage of officer dans can estable as a habital who was personally reproduced including with impact reducer for land ansura, impactor, and retaing in pregrammy of the alcohologoroum, along with impacts reduce for land conservations, and are the factor of conservations of the anomaly of the alcohologoroum, along with impacts reduce for land conservations. The account of the factor of the servation of the factor of conservations of the account of the design of the servation of the factor of secondarion of the factor of the account of the account of the servation of the factor of the servation of the factor of the servation of the factor of the factor of the servation of the servation with due distributions require conservations when the factor of the process recording distribution with due distributions.

Old wou know?

FAXD is most of the top them cause of mental regulation to the Western world (doing with Down) syndrome and gains history.

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provider was genulately interested in their policies. Teed today, 8.3% felt the provider was genuinely interested in their encorated well bring and 7.2.4% felt the provider was interested to the reverse successed with proposary. where felt their primary beath care to me Alberta souty 923 % of



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Whatara come of the concessor associated with FASD?

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Use needs ands as the women's bloomisk questioners are passibled with this felt, or other chart chart strategies or connecting mosts, to prompt

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- Include any referes knowing and to the confidence in any relation in any setting and date from our

To easter of and are community referred measures. Deck feel yes must proceed commaking and recently health support on your Make a retired and schoolskie follow spines: to appared the patient's progress.

Will asking the questions mally maken

What is mathematical interviewing?

Studios indicatos facts e supposible connecting and be a connecting program and reads in 18 to 1879 of program women relating four ideals treads before the dead or concerned if in 1878 energing beary desirang.

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"No cond only rate the feet req. But we extended you can rate year patent.
To far retained.

What if there really is a problem?

construction for the grant serious and the grant serious of the grant of the grant

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What can you do to previous EASD?

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Of other former high

• Зеведове се поп-наодия e Bron expirity of outress

backgrounds

Stad gpålig donne their alocked une

· Far losing their bady or other children

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 Ark open-order questions
 Provide angustivets: orderessors these

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> Епосия соперопеской спостопи nders per passes tipedes mades.

Spherototo

We need need and attended the appears of alcohol they donk. They may:

· Sear traing judged

Patient Information Brochure Text

Front Flap:

Working toward alcohol-free pregnancies we can prevent FASD.

Women trust their physician to help them have the best pregnancy possible

(Small print at bottom) A project sponsored by Alberta Health and Wellness

Inside Flap:

Can you tell who is at risk for having a child with FASD?

They are all at risk. They live in your community. They come to your clinic. Surprised?

Women considered at-risk for having a child with FASD come from all walks of life. They may be:

- Attending school, working or not working
- Married or unmarried
- In their early or later childbearing years
- Uneducated or have college degrees
- Of either low or high socioeconomic status
- Smokers or non-smokers
- From a variety of cultural backgrounds
- Socially, emotionally and mentally healthy, or suffering from a history of trauma, violence or mental health issues

Women may under-report the amount of alcohol they drink. They may:

- Feel guilty about their alcohol use
- Fear being judged
- Fear losing their baby or other children

First Inside Page:

What is Fetal Alcohol Spectrum Disorder (FASD)?

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of effects that can occur in an individual who was prenatally exposed to alcohol, with the impact influenced by the amount, frequency, and timing in pregnancy of the alcohol exposure, along with multiple other fetal and maternal factors. This can result in damage to the developing fetal brain most often at the level of neuronal function. The expression of this damage can be physical, mental, learning and behavioral disabilities that have lifelong implications in terms of not being able to function in daily life. Individuals with this disability will require external supports across their life span and to prevent secondary disabilities.

Did you know?

- FASD is one of the top three causes of mental retardation in the Western world (along with Down's syndrome and spina bifida).
- In an Alberta survey 50% of women reported drinking alcohol during the pre-pregnancy recognition period. In the same survey 80% of women reported consuming alcohol 6 months prior to pregnancy.
- In a national sample 25% of women reported drinking during pregnancy.
- In one Alberta study 92.3 % of women felt their primary health care provider was genuinely interested in their physical well being , 82% felt the provider was genuinely interested in their emotional well being and 72.4 % felt the provider was interested in the stresses associated with pregnancy

Who pays the cost and bears the burden of FASD?

We all do, especially the individuals affected and their families. The economic burden of FAS is substantial with some studies estimating lifetime costs of \$844,066 to \$1.5 million dollars. These costs include additional educational, social service and healthcare costs, and in some cases disability payments per individual with FASD. However, other estimates, some of which include judicial and incarceration costs are as high as \$3.0 million per individual per lifetime. One study shows conservative costs of FASD in Canada to be an estimated \$344.2 million annually.

What are some of the consequences associated with FASD?

- · Mental health problems
- Disruptive school experience
- Trouble with the law
- Inappropriate sexual behavior
- Drug/alcohol problems

What can you do to prevent FASD?

- Routinely ask all female patients of child-bearing years about alcohol use.
- **Advise** all women who are pregnant or considering pregnancy **to abstain** from alcohol. There is **no known safe level of alcohol** consumption during pregnancy.
- Advise pregnant women and their partners about the benefits of stopping or reducing alcohol use at any time during pregnancy.
- **Educate** all female patients and their partners **about FASD** and the adverse effects of alcohol on the fetus.

Will asking the questions really make a difference?

• Studies indicate that a supportive counseling and/or case management program can result in 60 to 80% of pregnant women reducing their alcohol intake before the third trimester and 35 to 50% stopping heavy drinking.

Do you have the time and skills to ask questions about alcohol use?

- You may feel that asking women about alcohol use is a challenging task and will take extra time. In
 fact, studies show that physicians using motivational interviewing techniques were more effective but
 spent less time talking to patients about drinking than physicians who didn't use the technique.
- The discussion does not have to be lengthy. If you identify a possible problem, refer the patient to appropriate counseling and resources and arrange for medical follow-up.

How can this be done effectively?

- Combine your discussions relating to alcohol use with other routine screening, contraception counseling and screening for STDs, to "normalize" the topic. Include these as a part of routine care.
- Use tools such as the women's lifestyle questionnaire provided with this kit, or other chart reminders or screening tools, to prompt and assist you to ask about alcohol use.
- **Use** the **T-ACE** screening tool.
- Use brief intervention techniques (e.g. motivational interviewing) to create a safe and supportive context for discussion.
- Refer to the Women's Lifestyle Questionnaire and desktop reminder provided with this kit for more information and links to referral sites.

What if there really is a problem?

- You need only take the first step. There are other professionals you can refer your patients to for assistance.
- Be aware of and use **community referral resources**. Don't feel you must provide counseling and mental health support on your own.
- Make a referral and schedule a follow up visit to monitor the patient's progress.

What is motivational interviewing?

- An interviewing technique that has been traditionally utilized in mental health and counseling settings.
- Includes empathetic listening, and is non-confrontational, non-judgmental and clientfocused.

Essential components of motivational interviewing:

- Express empathy, warmth and acceptance
- Point out the contrast between the patient's desire for a healthy pregnancy and the fact that she is drinking
- Avoid confrontation and minimize defensiveness
- **Support** the patient's belief in her ability to change
- Ask open-ended questions
- Provide empathetic reflection on her responses
- Ask for a drinking reduction goal
- Schedule a short-term follow-up appointment to monitor progress.

For more information on Motivational Interviewing techniques please refer to "The SMART Guide – Motivational Approaches Within the Stages of Change for Pregnant Women Who Use Alcohol – A Training Manual for Service Providers" - order at aware@kos.net

Back Page:

T-ACE is a standardized screening tool that:

- Can assist physicians to accurately identify women who consume alcohol during pregnancy.
- Typically identifies 90% or more of potential risk-drinkers.
- Is a 'five-minute tool' that is easy to use and score.

Sokol, R. et al. The T-Ace Questions – Practical Prenatal Detection of Risk Drinking American Journal of Obstetrics and Gynecology April 1989

T- ACE consists of four questions:

TOLERANCE – How many drinks does it take to make you feel high/feel the effect of alcohol?
 Score 2 points for more than 2 drinks. Score 0 points for 2 drinks or less.

Score 1 point for each YES answer to the following:

- **ANNOYANCE** Have people annoyed you by criticizing your drinking?
- **CUT DOWN** Have you felt you ought to cut down on your drinking?
- **EYE OPENER** Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?

High risk score = 2 or more points (consider referral for counseling)

ASSESS - REFER - FOLLOW UP

Referral Sites and Resources for Alcohol Counseling

 Alberta Alcohol and Drug Abuse Commission (AADAC) Help Line (for information including referrals for AADAC services across Alberta 1-866-332-2322 www.aadac.com

AADAC Enhanced Services for Women (physician referrals)

Calgary – 1-403-297-3033 or 1-403-297-3066 Edmonton – 1-780-415-0786 or 1-780-415-0776 Grande Prairie – 1-780-538-6356

 Motherisk (Hospital for Sick Children) – Alcohol and Substance Use in Pregnancy Help Line (physician training, information for physicians or patients) 1-877-327-4636

Appendix 8. Physicians for FASD Prevention Project Screening Checklist (Draft)

Adult Women's Lifestyle Screening Checklist (Draft)

Introduction to Women's Lifestyle Questionnaire



Why should you use this questionnaire?

Asking women about alcohol use can be a sensitive undertaking. However, the benefits both to the patient and her developing child during pregnancy are immeasurable. Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of preventable birth defects and one of the top three known causes of mental retardation in the western world. Prevention – abstinence from alcohol during pregnancy – may appear simple. However, the reality of achieving it is far more complex.

As a primary care physician you may wonder whether you have the time, training or comfort level to ask the necessary questions. You may also perceive that this is not a particular problem among your patient population. Many recent studies reveal that alcohol abuse among women cannot be confined to specific socioeconomic, educational or racial groups.

Creating a safe and supportive environment can help ease the discomfort associated with asking sensitive questions pertaining to alcohol consumption. Normalizing these questions by including them with other lifestyle topics will help you to explore a range of issues women may be facing. As such, the attached lifestyle questionnaire presents the question of alcohol use within a series of questions that may be perceived as routine health topics.

When and how should you use the questionnaire?

When using the lifestyle questionnaire, let your patients know you ask these questions of all your female patients on a regular/annual basis, so they don't feel they are being singled out or confronted. For example, wording such as "I want to ask you a series of questions today about your lifestyle. I ask all my female patients these questions because it helps me to get a better understanding of what your day-to-day life is like in terms of diet, exercise and other lifestyle issues. It will help me to know you, and that will help me to provide better care."

As a physician, you may wonder what to do if you determine drinking is a problem for a particular patient, or whether you have the time, training and resources to follow through. You no doubt also recognize that there are many social issues attached to alcohol abuse, and that, as a primary care physician, it is difficult if not impossible to address all the issues related to alcohol abuse.

What should you do if there is a problem?

Once a problem is identified, it is important for you to work with your patient to assess her readiness to cut back on her drinking. If she needs and wants help, there are numerous alcohol treatment and counseling programs designed specifically to assist women. Contact information is provided with the lifestyle questionnaire for your use to refer patients as appropriate. The questionnaire also includes information on resources and further training for physicians, if this is something of interest to you.

How will this help your patients?

Addressing the issue of alcohol consumption using the lifestyle questionnaire and related techniques and resources will allow you to handle physiological issues associated with your patient's alcohol use, and follow up on her progress. This process will facilitate open discussion regarding healthy pregnancy, thereby ensuring you have done everything you can to assist your patient to deliver a healthy child.

Adult Women's Lifestyle Questionnaire

| | Date | Comment / Action Plan |
|--|------|-----------------------|
| Diet / Activity | | |
| What dairy or calcium rich foods do you include in your diet? How often do you include these? | | |
| What green leafy vegetables, nuts, and whole grains do you include in your diet? What do you do for regular exercise? | | |
| Smoking | | |
| Do you smoke cigarettes? (If yes proceed with next questions) How many cigarettes do you smoke in a day? Have you ever considered quitting or cutting back? | | |
| Caffeine Intake | | |
| How many cups of coffee or other caffeinated beverages (e.g., soft drinks) do you consume on an average day? | | |
| Alcohol | | |
| Do you use alcohol? (If no consider to be low risk. If yes proceed with next questions). | | |
| In a typical week, on how many days do you drink? On those days, how many drinks are usual? Administer standard screening test (T-ACE) | | |
| T-ACE | | |
| TOLERANCE – How many drinks does it take to make you feel high / feel the effect of alcohol? Score 2 for more than 2 drinks. Score 0 for 2 drinks or less Score 1 for each YES answer to the following: ANNOYANCE – Have people annoyed you by criticizing your drinking? CUT DOWN – Have you felt you ought to cut down on you drinking? EYE OPENER – Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover? | | |
| High risk score = 2 or more points (consider referral for counseling) | | |
| Drug Use Other Than Alcohol or Tobacco | | |
| What drugs other than alcohol or tobacco (including non-prescribed over-the-counter or prescription drugs) do you use? How much and how often do you take these? | | |
| Intimate Partner Violence (IPV) Mental / Emotional Health | | |
| Over the past year have you felt down, depressed or hopeless? Can you describe these feelings? | | |
| Over the past year have you felt little interest or pleasure in doing things? Have you been hit, kicked, punched or otherwise hurt by someone in the past year? If so by whom? Do you feel safe in your current relationship? | | |
| • Is there a partner from a previous relationship who is making you feel unsafe now? | | |
| Sexual Practices | | |
| Are you currently sexually active? How many sexual partners have you had in the last twelve months? What do you use to protect you and your partner from STDs? What type of birth control do you use? Do you always use birth control/protection? Is there a possibility you are pregnant right now? Are you currently planning to become pregnant? | | |

Explanations for the Adult Women's Lifestyle Questionnaire

Diet / Activity

- To prevent osteoporosis, the Osteoporosis Society of Canada's recommended calcium intake for adults is 1000 1500 mg of elemental calcium per day. Calcium supplementation should be recommended if diet does not satisfy requirements.
- To prevent neural tube defects, the recommended intake of folic acid for all women of childbearing years capable of becoming pregnant is 0.4 – 0.8 mg per day.
- To prevent cardiovascular disease, hypertension, obesity, Type II diabetes mellitus, and osteoporosis, moderate physical activity has been shown to be effective.
 - » Examples of moderate physical activity include normal walking, golfing without the use of a power cart, slow biking, raking leaves, cleaning windows, slow dancing and light restaurant work.
 - » Should be performed consistently to a level of 30 minutes or more on most days of the week.
- To prevent coronary artery disease and colon cancer, general dietary advice to decrease fat intake and increase fiber intake is recommended.
- For general information on healthy nutrition refer to Canada's Food Guide to Healthy Eating.
- Refer those at increased risk to a clinical nutritionist for nutritional counseling in greater detail.

Smoking

- To prevent tobacco-caused disease, smoking cessation counseling is recommended for patients who smoke. Referral by a physician to a validated smoking cessation program improves participation.
- Nicotine replacement therapy increases cessation rates and can be offered as an adjunct to smoking cessation.
- Eating an average of seven portions of fruit or green leafy vegetables per week may lower the risk of lung cancer in smokers.

Caffeine Intake

- To prevent osteoporosis, the Osteoporosis Society of Canada recommends total intake of less than 4 cups of coffee, tea, colas and energy drinks per day.
- For a guide to caffeine content in common beverages please refer to www. mayoclinic.com/health/caffeine/AN01211

Alcohol

- Alcohol consumption in females of child-bearing age crosses all educational, cultural and socioeconomic borders.
- The prevalence of alcohol consumption in women aged 18 to 34 ranges from 60% to 75%, with 4% considered to be alcohol abusers or alcohol dependent.
- · In a national sample, 25% of women reported drinking during pregnancy.
- FASD can be attributed to prenatal exposure to alcohol and can be entirely
 prevented by abstinence of alcohol during pregnancy. A prudent choice for
 women who are pregnant or who are considering pregnancy is to abstain
 from alcohol.
- FASD is the leading cause of preventable birth defects and one of the top three known causes of mental disability in the western world.
- Abnormalities range along a continuum of severity from miscarriage and still birth at the most severe end to secondary disabilities such as mental health problems, difficulty in school, trouble with the law, inappropriate sexual behavior and drug and alcohol problems at the other end.
- There is no cure for FASD and as such the repercussions both to the individual and society are lifelong with significant economic and societal costs.
- Studies indicate that a supportive counseling and/or case management program can result in 60 – 80% of pregnant women reducing their alcohol intake before the third trimester, and 35 – 50% stopping heavy drinking.
- It is recommended that all women be asked about their use of alcohol using T-ACE, which has a higher sensitivity and specificity when used to assess periconceptual heavy drinking.
- If necessary refer to community resources for counseling and treatment.

Drug Use Other Than Alcohol or Tobacco

- To prevent possible deleterious side-effects to the developing fetus, use of recreational drugs (i.e., cannabis, cocaine, etc.) is contraindicated during pregnancy and for those contemplating pregnancy.
- Over-the-counter and prescribed medications may pose a risk if taken for "off-label" purposes without consultation with a physician.
- · Assess relative risk and refer for counseling and treatment if necessary.
- Refer to http://corp.aadac.com/other%5Fdrugs/ for information on illicit drugs
- Refer to www.motherisk.org for more information on drug use as related to pregnancy.

Intimate Partner Violence (IPV) Mental / Emotional Health

- A past or present history of IPV, mental / emotional illness or histories of having been secondary witnesses of family violence or mental illness are strong stressors to possible alcohol and drug use.
- Assessment in this area is complex and women may not recognize that they are being abused.
- Sample questions have been provided from validated sources however, while there has been much research in this area, to date there are no defined evidence based interventions documented for IPV.
- Recognition of the signs of physical evidence of abuse is important. i.e.

 abusers will often target areas of the body such as behind the ears, genital area, under the hairline not readily visualized on general assessment. Abuse can take many forms including: verbal, physical, sexual, psychological, emotional, spiritual, economic, and the violation of rights.
- To facilitate disclosure of IPV how questions are asked and the environment is important to consider. It is advised to assess when the patient is alone (away from abuser) and in a safe, supportive environment. Provide empathy and support. Be aware that before asking the questions having the time to hear the answers fully is important. Patients need to feel that they have permission to talk.
- Patients may not disclose during the initial interview but once the "seed has been planted" they may present in the future to disclose.
- Assess relative risk for further abuse and if she has a safety plan in place.
 Refer to ______ (HealthLink?) if necessary.
- A safety plan may include: how to leave safely, where to go to be safe, where to keep important documents and papers, which neighbors to tell about violence so they can call police is necessary, teaching children how to call police, how to protect self and children in dangerous situations, local emergency numbers, practicing and reviewing safety plans with children, possible home safety measures, establishing a code word with children to be picked up by other adults or to call police or to leave house quickly, inform employer and co-workers of risk.
- Assure your patient of confidentiality. Only if a patient wishes to report
 the abuse are police services contacted. There is no mandatory reporting for adults. Mandatory reporting to police applies only when children
 present in the home are being abused or being impacted by abuse. When
 reporting errs on the side of safety of potential victims those individuals
 who report are not held legally culpable. Whether a disclosure and / or
 request to report have been given or not let your patient know that your
 documentation is your legal testimony for her.

Sexual Practices

- Abstinence is most effective in prevention of transmission of sexually transmitted diseases (STDs) but there is fair evidence in use of condoms.
- Counseling and provision of educational materials has been seen to result in no increase in compliance with medications or willingness to inform sexual contacts, but an increase in patient compliance with follow-up has been noted.
- Provide counseling regarding effective forms of birth control in order to prevent unwanted, unplanned pregnancies.
- Provide counseling regarding adequate intake of folic acid and abstinence from alcohol for those patients planning to become pregnant.

Appendix 9. Physicians for FASD Prevention Project Poster (Draft)

Poster (Draft)



Appendix 10. Physicians for FASD Prevention Project Desktop Reminder (Draft)

Desktop Reminder (Draft)

Women, Pregnancy and Alcohol Use

There is no proven safe level of alcohol use during pregnancy. ASK ALL WOMEN ABOUT ALCOHOL USE.

Do you use alcohol?

USES ALCOHOL

ASK: In a typical week, on how many days do you drink? On those days how many drinks are usual?

Administer T-ACE screening test.

TOLERANCE

How many drinks does it take to make you feel high?

Score 2 for more than 2 drinks.

Score 0 for 2 drinks or less.

Score 1 point for each YES answer to the following:

ANNOYANCE

Have people annoyed you by criticizing your drinking?

CUT DOWN

Have you felt you ought to cut down on your drinking?

EYE OPENER

Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?

Total Score of 2 or more - consider possible HIGH RISK:

- · Assess readiness to stop drinking.
- · Consider referral for counseling.
- Arrange for follow up.

DOES NOT USE ALCOHOL

Consider Low Risk.

ADVISE: That abstinence is the best choice when pregnant or considering pregnancy.

Alberta Alcohol and Drug Abuse Commission (AADAC) Help Line (for information including referrals for AADAC services across Alberta)

1-866-332-2322

www.aadac.com

AADAC Enhanced Services for Women (physician referrals)

Calgary: 1-403-297-3033 or 1-403-297-3066

Edmonton: 1-780-415-0786 or 1-780-415-0776

Grande Prairie: 1-780-538-6356

Motherisk (Hospital for Sick Children) Alcohol and Substance Use in Pregnancy Help Line

Physician training, information for physicians or patients

1-877-327-4636

Appendix 11. Physicians for FASD Prevention Project Investigation Phase Report

Physicians for FASD Prevention Project

Results of the Investigation Phase

Prepared by Lechelt Communications

For the Toward Optimized Practice Program

Final draft: April 13, 2006

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Physicians for FASD Prevention Project

Results of the Investigation Phase

Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is a serious health issue in Alberta, and physicians are in an ideal position to offer both routine and targeted screening, prevention and intervention activities aimed at women and teens of child-bearing age. However, some studies suggest that physicians may not always offer the range or depth of intervention strategies available to them.

The Physicians for FASD Prevention Project was initiated to better understand the context for physician practices and to enhance physicians' contribution to the prevention of FASD. The project specifically seeks to support Alberta physicians who provide general primary or obstetrical care to a diverse population.

This project is sponsored by Alberta Health and Wellness and administered by the Alberta Medical Association. The Toward Optimized Practice (TOP) Leadership Committee provides the TOP program infrastructure under which the project operates. Project direction is provided by a Steering Committee comprised of physicians and representatives from Alberta Health and Wellness, AADAC, Alberta Perinatal Health Program, TOP Leadership Committee, and Health Canada.

The investigation phase of the project involved focus group interviews with 23 Alberta physicians, revealing that alcohol use is a significant social and health issue among teens and women of child-bearing age, ranking fourth in a list of routine screening and prevention activities that physicians reportedly undertake. As a health issue, participating physicians suggest that alcohol-related issues are surpassed only by sexually transmitted diseases, smoking and cervical cancer in terms of prevalence and impact on health.

About three-quarters of physicians report that they routinely screen female patients for alcohol use. However, physicians note that patients who present for complete/annual physicals are more likely to be screened, and others may only be screened on an opportunistic basis or when they present with an acute condition that may have a connection to alcohol.

Participants suggest that patients vary considerably in the extent to which they answer questions truthfully about their alcohol use, and that it demands a certain level of expertise and time for a physician to fully assess and obtain accurate information and context. Physicians also note that social norms around alcohol use are changing.

Physicians say they commonly screen patients for the potential social and functional consequences of alcohol use and/or for associated mental health, isolation or abuse issues. While physicians overwhelmingly acknowledge that alcohol-using patients are more at risk for an unintended pregnancy, few physicians say they probe these patients specifically for pregnancy-related risks.

A majority of physicians report that they are unlikely to discuss pregnancy and contraception issues with alcohol-using patients unless the patient either raises it as an issue preconception or the patient presents with a pregnancy that may be alcohol-affected. In general, participating physicians feel that patients are getting the message about alcohol use during pregnancy, and some suggest the messages have gone too far.

Physicians generally feel they have sufficient expertise and resources to manage patients who are at risk of an alcohol-affect pregnancy; however, most participants feel they see very few patients who fall into this category. Those most at risk are perceived to be patients who rarely, if ever, seek primary care from mainstream physicians' offices.

Sexually active women under the age of 25 who are frequent users of alcohol or binge drinkers are seen as a high risk for an unintended pregnancy due to the impaired judgment and impulsiveness that often accompanies binge drinking. Yet most physicians do not view this demographic as a target for FASD prevention. Some physicians believe this sector is using contraception reliably, and that those who become pregnant unintentionally may opt to terminate their pregnancy anyway, particularly if heavy alcohol use was involved. Physicians do acknowledge that access to safe, reliable contraception is important for this sector.

A written survey administered to female patients corroborates many of the physicians' reported screening and intervention activities. Patients report that they are unlikely to have discussed "healthy pregnancy" topics (including alcohol use and FASD prevention) with their physician prior to actually conceiving, and that their likelihood of discussing alcohol use increases considerably upon confirmation of the pregnancy.

In general, patients report that they trust their physicians for information about alcohol use, and that they are comfortable discussing the issue with physicians. Few report being reluctant to speak with their doctors about alcohol, and most say they have heard a number of FASD-related messages from both their physicians and other public/media sources.

While participating physicians believe FASD prevention is an important issue, many feel they are not in a position to significantly influence outcomes because the patients most at risk of delivering babies with FASD are not presenting for primary care and prevention services. Many physicians feel that while alcohol use is a significant health and social issue within their practices, FASD prevention is not as relevant an issue given their practice demographics.

Overview

Background

Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of non-genetic mental retardation in the Western world, and it is 100% preventable by complete abstinence from alcohol during pregnancy. Physicians are considered a trusted source of information and influence to women of child-bearing age and, as a result, may be in an ideal position to conduct routine screening and interventions aimed at preventing FASD.

Indeed, a 2001-02 survey of physicians conducted by Clark, Tough, Hicks and Clarren¹ suggests that physicians are, in fact, intervening to prevent FASD, with 94% of Alberta physicians reporting that they recommend no alcohol use during pregnancy, up from 84% in 1998.

However, while physicians may routinely advise against alcohol use in women who are already pregnant or contemplating pregnancy, questions remain in a number of areas:

- To what extent do physicians conduct screening and/or interventions with women who are neither pregnant nor contemplating pregnancy? Are there barriers that prevent or discourage physicians from conducting brief interventions and/or prevention activities with female patients of child-bearing age? The Clark, et. al. study suggests that only 46% of Canadian family physicians discuss the risk of alcohol during pregnancy with all women of childbearing age.
- To what extent do physicians have the knowledge, expertise, tools and resources
 to appropriately manage pregnant women who have alcohol problems? The
 Clark, et. al. study indicates that 58% of Alberta physicians are prepared to deal
 with or care for pregnant women in the area of alcohol abuse, and 67% are
 prepared to access resources for those women.

To better understand ways to enhance physicians' contributions to FASD prevention, the Physicians for FASD Prevention Project commissioned Lechelt Communications to conduct physician focus groups and patient surveys to further understand the role of Alberta physicians who provide medical care to female patients of child-bearing age (14 - 40). The focus groups addressed the following questions:

 Are there barriers that prevent or discourage physicians from conducting FASD prevention or intervention activities? Are physician interventions in FASD prevention practical? Feasible? Realistic?

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¹ Suzanne C Tough, Margaret Clarke, Matt Hicks, Sterling Clarren, "Attitudes and Approaches of Canadian Providers to Preconception Counselling and the Prevention of Fetal Alcohol Spectrum Disorders", <u>Journal of FAS International 2005</u>; Volume 3:e3 – Jan. 2005.

- While FASD has serious and life-long health implications, do physicians consider it to be a priority from a primary prevention standpoint? Why or why not?
- Do physicians routinely raise of the issue of conception and pregnancy in the absence of a prompt from the patient? Do physicians feel there is a realistic and appropriate opportunity to discuss alcohol consumption pre-conception? Why or why not?
- Given that some pregnancies are unplanned, are there issues or barriers
 preventing physicians from discussing alcohol use pre-conception with these
 patients? Do physicians perceive that there are opportunities to discuss FASD
 prevention within the broader contexts of sexuality and contraceptive counseling
 with females of child-bearing age?
- Do physicians feel they are able to obtain honest and accurate information from patients about their alcohol consumption?
- To what extent do physicians feel their advice will be heeded by the patient? Do physicians feel they have adequate influence?
- What do physicians understand and believe about FASD risks, prevalence, interventions, screening opportunities, etc?
- Do physicians feel they have the time, expertise, tools and resources to provide screening and intervention supports to patients?

Lechelt Communications was also commissioned to conduct a brief, anonymous written survey of female patients to determine their experiences, knowledge and intentions regarding FASD prevention and alcohol use during pregnancy. The survey set out to answer these questions:

- Do patients recall receiving advice, information or intervention from various primary care providers (family physicians, midwives, etc.) regarding FASD prevention and education?
- How does alcohol-avoidance rank among the range of healthy-pregnancy practices physicians may recommend to patients (e.g., folic acid intake; prenatal vitamins and supplements; smoking cessation or reduction; etc.)?
- Are there barriers that may prevent or discourage patients from disclosing their alcohol-related questions or usage patterns to their physician or other primary care provider?

Methodology

Physician focus groups

Using a variety of recruitment approaches (direct contact by phone, fax and email; wordof-mouth referrals), Lechelt Communications recruited 23 practising physicians from across Alberta to participate in focus group sessions.

Participants were asked to participate in a focus group regarding "the prevention, screening and intervention activities that physicians typically offer to female patients of child-bearing years." Physicians were not advised that the focus group was specifically about the prevention of Fetal Alcohol Spectrum Disorder. Alberta Health and Wellness was identified as the sponsor of the study, and participants were compensated for their time as per Alberta Medical Association guidelines. Physicians with a specialized practice in either obstetrics or prenatal substance abuse were excluded from the focus groups.

Physician focus groups were conducted between March 2.-.31, 2006 and lasted between 60 and 120 minutes, depending on the size of the group. Sessions were held primarily outside of normal clinic hours and were held either in, or in close proximity to, participating physicians' offices. All sessions were moderated by Leah Lechelt and recorded by various clerical staff. A copy of the interview script is contained in Appendix One.

Participants reflect a cross-section of current Alberta physicians and can be described as follows:

12 males and 11 females

75% urban and 25% rural as follows:

52% from large urban centres (Edmonton & Calgary)

22% from regional (small urban) centres

25% from rural areas

Participants range from 1 – 30+ years in practice. The median is 11 – 15 years in practice.

Practice profile: on average, 63% of participants' patients are female and 37% are male

78% provide prenatal care and 22% do not provide prenatal care

65% perform obstetrics/deliveries and 35% do not.

Limitations of the project investigation include the very small sample size (representing less than one per cent of family practitioners in the province) and the voluntary nature of recruitment. Because the interviews were conducted over a one-month period, the study excludes physicians who were unavailable during this time.

Focus group research is by its very nature exploratory, often providing rich insights into the opinions and intentions of participants. However, it is important to note that although this report accurately represents the themes and issues discussed during the interviews, as well as the opinions articulated by participating physicians, the findings cannot be generalized to the larger physician population. Readers are cautioned against drawing conclusions or attributing results beyond those who participated in the focus groups.

Patient survey

Two written surveys (see Appendix II) were developed, targeting both pregnant and nonpregnant female patients. Investigators approached laboratory and diagnostic imaging facilities across Alberta, asking them to administer the surveys to patients who present for obstetrical ultrasounds or pregnancy tests.

All but one of the laboratories and diagnostic imaging owners/managers approached by TOP declined to participate in the study due to concerns about patient privacy, time, and the extra workload required to administer the survey.

Survey participants included one diagnostic imaging facility comprised of three sites; a university health centre; and an education/support program for pregnant teens. All participating organizations experienced some difficulties implementing the survey (i.e., inconsistent approaches with patients; staff not following protocols; etc.). In total, of the 200 surveys distributed to the various sites, 39 were completed, representing a 20% response rate. Patients who completed the survey did so on a voluntary basis, and some were offered a small incentive. Of the two survey versions, all the responses were from the "Prenatal Care Survey" (aimed at patients who are already confirmed to be pregnant).

While this report accurately reflects the findings from the completed surveys, investigators can not make any broader conclusions or draw any statistical inferences from the survey due to the exploratory nature of the survey, the very small sample size, and the sampling bias inherent with voluntary recruitment.

General screening and prevention activities

Screening opportunities and challenges

Physicians who participated in these focus groups generally report that they strive to conduct regular, routine preventive screening of female patients of child bearing years. Physicians² find the most opportune time to screen patients is during annual physical exams (periodic health assessments) because physicians feel they have more time to conduct complete screening during this visit.

"A full exam is the opportunity to do a lot of preventive things and to review things like cholesterol and home issues, and screen for diabetes and do those preventive things."

Patients who don't present on their own initiative or book annual physicals are more difficult to screen on a regular or reliable basis. For these patients, physicians suggest they are selective and targeted about the screening activities they undertake. Many say they screen on an opportunistic basis based on the patient's risk factors, lifestyle, etc.

"Sure, we do a lot of the screening and we cover most of the current guidelines, but it's getting them here to get it done that's the hardest thing."

"I can only do screening if the patients present themselves."

Physicians report that acute/episodic visits present a less optimal time to conduct routine screening.

"During an acute visit, (the patient and I) both have a job to do. I have an agenda and the patient has an agenda, and we have to deal with both."

Participants note that there are particular screening patterns and opportunities associated with three distinct clusters within this patient demographic:

 Patients aged 14 – 18 are viewed as more difficult to screen routinely because they are typically not yet accustomed to regular, annual check-ups, and many are uncomfortable with their sexual health, gynecological exams, etc.

> "It is hard to get younger teens to come in to the clinic because the implications of a screening process are not fully understood by this age group."

² Throughout this document, any references to the beliefs or opinions of physicians or patients refer only to the expressed opinions of those who participated in this study, and are not intended to refer to the opinions of the physician or patient population in general.

"Most of the younger teenage girls would rather go the Birth Control Clinic, where they know they won't run into their neighbors or the guys from school."

"If they're not on birth control or not sexually active, then you have a lot less opportunity (to conduct screening)."

 Patients aged 19 – 25, on average, are often easier to screen because are more likely to be sexually active and tend to present regularly for contraceptive counseling and prescription refills.

"You actually have more opportunity (with this age group) than with the males, and it's tied to birth control and coming in for refills."

 Patients aged 26 – 40 are more likely to have committed relationships and/or be involved with children of their own, so while they still need regular screening for cervical cancer and other issues, they are perceived to potentially have reduced screening needs (e.g., STDs) until they reach age 40, at which time their screening requirements increase significantly (cholesterol, diabetes, bone density, etc.)

Finally, several physicians note that time is a critical determinant of their screening activities:

"I'm probably doing less screening on mental health issues than I feel I should, and that's probably reflective of the time . . . I don't necessarily have the time to get deeply into it."

Prevalence and impact of conditions and diseases for which physicians routinely screen

Physicians were asked to complete a table (see Appendix III) with the following information:

- A list of the conditions and diseases for which they routinely screen female patients aged 14 - 40.
- For each of the conditions/diseases listed, an indication of whether they typically screen (a) all patients, (b) only patients who offer a prompt or request, or (c) only symptomatic or at-risk patients.
- A score to reflect their <u>perceived prevalence</u> of the condition/disease in this demographic group and/or the likelihood of obtaining a positive result or identifying a problem during screening, where:

- o 7 = high prevalence
- 1 = low prevalence
- A score to reflect their perception of the condition's/disease's impact on the patient's health in the event of a positive result, where:
 - o 7 = significant impact
 - o 1 = minimal impact

The intent of the table was three-fold:

- To determine the extent to which <u>alcohol use</u> emerges as a top-of-mind screening activity among physicians.
- To determine the relative ranking of alcohol use/problems compared to other health conditions in terms of <u>perceived prevalence</u>.
- To determine the relative ranking of alcohol use/problems compared to other health conditions in terms of <u>perceived impact on health.</u>

Table A: Prevalence and impact scores of various conditions/diseases

Perceived Perceived Total score prevalence/ Number of Percentage (Prevalence Impact on likelihood participant Condition/disease/screen health if a + impact) x participant of + result mentions + result no. mentions or problem (Max = 23)mentions (Max = 7)(Max = 322)(Max = 7)STDs 22 96% 3.7 205 5.6 74% 189 Smoking/tobacco use 17 5.0 6.1 Pap/cervical CA/dysplasia 20 87% 3.4 5.9 186 Alcohol use 4 17 74% 5.8 167 14 61% 3.5 5.9 132 Recreational drugs Cardiovascular 5.4 128 16 70% 26 health/BP/hypertension 13 57% 22 6.3 111 Breast cancer/exam Situational stress/anxiety/ 10 43% 4.6 5.6 102 depression/mood disorders Diet/weight/BMI/obesity/body 10 43% 4.1 5.4 95 image/eating disorders Family history 82 8 35% 4.1 4.1 Diabetes/FBS 8 35% 2.8 6.6 75 Contraception, sexual health 7 30 5.3 5.1 73 7 30 4.4 5.4 69 Exercise/activity level Anemia/iron/menstrual 8 35% 3.8 4.6 67 disorders Thyroid/metabolic disorders 8 35% 2.9 5.0 63 Family violence/abuse 6 26% 3.3 5.8 55 6 26% 3.5 5.0 51 Cholesterol/lipids 22% Calcium intake/bone health 5 4.6 5.2 49

Table A discussion

According to Table A data, the top five conditions/diseases for which physicians screen are STDs, cervical cancer, tobacco use, alcohol use, and cardiovascular health (including hypertension).

Physicians report that five conditions are the most prevalent in this demographic and/or most likely to be identified as a problem during screening. These are: contraception counseling and sexual health issues; tobacco use; stress/anxiety/depression; bone density or bone health; and exercise/activity level. Virtually all of the conditions are

viewed as having a significant impact on health, with the top five being diabetes, breast cancer, tobacco use, cervical cancer and recreational drugs.

Relative ranking among Table A items

In order to gauge the relative ranking of each disease/condition based on prevalence, impact and frequency of mention, the following formula was used to determine the **total score** for each item:

(Perceived prevalence + Perceived impact on health) x Number of mentions where the maximum score is 322 and the minimum score is 46.

Based on this formula, the following conditions/diseases emerged as the most significant in terms of prevalence, impact and number of mentions:

- STDS (total score of 205 out of a possible 322)
- Smoking/tobacco use (score of 189)
- Cervical cancer (score of 186)
- Alcohol use (score of 167)
- Recreational drugs (score of 132)

Alcohol use emerged as the fourth most significant issue in women of child-bearing age, suggesting that physicians view it as an important health and social issue within Alberta. Among conditions for which focus group participants say they screen, problems with alcohol are reportedly more common in this patient group than problems with weight/BMI, anxiety/depression/mood disorders, diabetes, exercise and cholesterol.

It is important to note that the table simply asked physicians to identify, *unaided*, the conditions and diseases for which they routinely screen women aged 14 - 40. The table was used primarily as a discussion tool and not as a true measure of physicians' actual screening practices.

Alcohol screening activities

Routine screening for alcohol use

According to Table A, three-quarters of participating physicians say they routinely screen patients for alcohol-related issues. In the discussion about alcohol screening that followed, many physicians offered the following observations.

"I ask everyone about drug and alcohol use. It's just part of the screening process I go through."

"I screen for alcohol use, not alcohol abuse. If there's an event that could have been related to alcohol, or if I suspect something, then I will go into greater detail."

"I always ask about alcohol at the annual medical. And if it's someone with anxiety or depression, or someone with elevated liver enzymes, then I'll probe a little deeper."

Physicians generally report that screening for alcohol use is not a burden or onerous task. Some, however, say time is a barrier and alcohol screening doesn't always make it onto their priority list. Many emphasize that thorough screening is a sensitive and time-consuming undertaking.

"I really don't ask many screening questions because there's no time. If I ask, then I have to spend the time to do it properly. If you think they're being dishonest with you, it takes time to dig."

"A lot of times I think (patients) aren't honest, and depending how I'm feeling that day, that determines how much further I will go (to probe)."

"You have to remember that if I'm going to probe (on alcohol), I'm going to probe a whole long list of social questions — have you ever had an impaired, did you ever get into a fight — I can probe that much more if I had time with every visit, but time is restricted."

Some physicians say they do not routinely screen for alcohol use.

"If there are particular signs, then I will screen for alcohol, or maybe if I come across something during a complete. If they come in for STDS or they've been partying and taking other risks, then I would do more in-depth screening, but in general, I don't screen every patient."

When asked whether they use any particular screening tools or algorithms, physicians report that they generally use a simple probing question. Keeping the discussion casual and non-threatening is seen as being most conducive to getting honest answers.

"I just screen for it within the broader context of lifestyle and social issues. I ask if they drink milk, coffee, alcohol, and how much. I approach the whole thing casually and it's not a big deal."

"I'll ask them about alcohol, drugs, tobacco, caffeine . . . I'll even go into detail, like how large a coffee do you usually drink? Then it seems like I'm just trying to get an accurate picture, not judging them."

"How far I probe is based on 'gestalt' – if I think there are other issues behind the scenes, like mental health issues or abuse – I will probe a little deeper."

If alcohol abuse or alcoholism is suspected, some physicians say they will use CAGE, but they do not find CAGE applicable in most cases.

"I only use CAGE if they're drinking way more than I expected, or if they're being quite guarded and it's raising my level of suspicion."

"I think CAGE is more for alcohol-dependent patients who are having trouble holding down a job or maintaining relationships."

"CAGE is really for secondary screening, not for primary."

Patient candor about alcohol use

When asked whether they feel they get reliable information from patients regarding alcohol use, reaction is mixed, with a majority feeling patient candor can vary considerably.

"It's mixed in with lots of other screening questions, so it doesn't stick out that you're trying to pin them on this one. But still, I think I miss a lot in my screening, especially the binge drinkers."

"I just ask the question casually, in the context of how much milk and caffeine they drink, and how much exercise they get. If you make it less stigmatizing, then you get much better information."

"It's really difficult to find the woman aged 25-40 who drinks too much – it's very hard to get them to admit it."

Several physicians report that patients often don't know how much alcohol is a safe or acceptable amount, so they may not see their alcohol use as a problem.

"There's a lot of individual interpretation as to what is too much alcohol. Some will admit to drinking three drinks a night and they don't see anything wrong with it."

"I know statistically about one in 10 will have a problem, but we just don't know who they are. We know who the falling-down-drunks are, but the others, they're very hard to detect."

Physicians' screening intentions and priorities

When asked to identify what they are looking for when they screen for alcohol, physicians report that they are looking for consequences of alcohol use, such as problems with work, relationships, risky behaviours, impaired driving, co-dependencies, mental health issues, etc.

"Some patients just show in their appearance that they have alcohol problems: stress, emotional problems, depression, family history of alcohol abuse. A lot of these things go together."

"I'm just looking for the impact on their life in terms of personal life, family, work, risk to society and risk to their health. Like, have you had problems getting to work? Have you been caught driving drunk?"

"I want to find out if they drink every day, what they drink, how much they're drinking. With people who are chronic drinkers, you'll pick it up along with family dynamics, abuse, violence."

A few physicians say they also look for pregnancy-related issues and risks.

"I'm really looking for bigger things related to alcohol, like alcoholism and pregnancy."

"I'm always looking for fetal alcohol issues. It's too late for prevention after the child is born."

"A huge issue is FASD if they're not practising safe sex."

When asked whether there are certain patients or demographic sectors that physicians are more likely to target for routine alcohol screening, participants report that patients with high-risk lifestyles are a natural focus, as are those who present with addictive behaviours, mental health issues, unstable family/social environments, and unusual traumas or accidents.

"Anything dealing with trauma – falling down, cutting yourself – any of these may point to substance abuse."

"People with mental health issues obviously have more of an addiction risk."

Several physicians report that binge drinking is a concern in younger women, particularly those between 18 and 25.

"The peak alcohol years are really the 18-20-year olds – they're doing lots of partying and it's part of that whole risk-taking age."

"I think I'm seeing a generational change in attitudes. The older generation, say over 30, if you ask them how much they drink, there is still a bit of guilt involved and they'll underestimate or lie to you about it. But I find the younger people now don't see anything wrong with telling you they drink until they pass out, and some of them are under 18. They don't see anything wrong with it, and the liquor companies have done a good job marketing this concept."

"Most people drink heavily on the weekends, and there is no concept of longterm damage. It's probably the norm in high school or college or university . . . the weekend drinking and passing out is the norm. It's just accepted, whereas a 70-year-old feels bad drinking 2 –3 times a week."

Managing patients in general who use alcohol

Light users of alcohol

When asked how they would normally manage a patient whose routine alcohol screen suggests they are a light user of alcohol – that is, what steps or interventions come to mind for this patient – physicians generally report that no particular management strategies come to mind. Some say they would simply record the patient's response and ask the patient periodically in the future.

"In a lot of respects, it's healthy, so I wouldn't do anything at that point."

"I think there's an element of how much nagging do you do to one patient. Often I feel we're sort of criticizing patients if they smoke, they're overweight, they've got to exercise, they drink too much – at some point it becomes counterproductive. So if they're drinking within acceptable limits, then I'm not going to go there."

"If you've got an 18-year-old girl who has been sexually active for four years and you finally got her to come in for a physical exam and a Pap, and she says, 'Yeah, I drink a few drinks a week,' I don't think you're going to say, 'Be careful how much you drink' because you want her to come back."

A few physicians raised pregnancy risk as a potential flag among light alcohol users.

"I'd intervene only with respect to pregnancy. That's the only thing that jumps out at me."

"I'd go into how much of an impact this is having on your life: are you driving drunk? Are you at risk of becoming pregnant?"

Several physicians make the point that the distinctions between light, moderate or heavy are somewhat arbitrary and may even give a false sense of security to lighter users of alcohol.

"Sometimes people don't realize the impact (of alcohol use) on their life. Maybe they just drink socially, maybe three times a year – that doesn't sound big. But if it's three times a year and you were falling over one time and got in a bad relationship, or had an argument or ended up getting into a fight, then we as physicians might have something more to say on the issue."

Moderate to heavy users of alcohol

If a patient screens as a moderate to heavy user, a majority of physicians report that they would discuss the issue with the patient to determine readiness or desire for treatment.

"Sometimes all we do is just let them know we think it's a problem. Getting them to realize it's a problem is a bit of a barrier, but often I find they're very receptive when they hear it from a health professional."

"You may probe their interest in maybe curtailing their drinking a little bit and see if there is interest. If there is absolutely no interest, you're not going to get very far harassing them."

Several say they would do blood work or check liver enzymes to show tangible consequences of the alcohol use.

"If I can do some blood work to show some numbers, it can definitely have a big impact. You're not going to have an impact unless they see it as a problem."

More physicians raise the issue of pregnancy risk in a patient who is a moderate to heavy user of alcohol.

"Early pregnancy definitely comes to mind. I'd be concerned about fetal alcohol syndrome and I'll advise the patient to stop drinking."

"If they are planning or open to being pregnant, then I tell them to have zero alcohol because we don't know what a safe level of consumption is during pregnancy."

Association between alcohol use and pregnancy

At this stage in the interviews, the topic of pregnancy risk associated with alcohol use was not yet raised by the moderator. The aim was to determine whether participants would initiate, unaided, the subject of pregnancy risk within the context of alcohol-related discussions. In fact, the link was raised spontaneously by about one-quarter of participants.

"If they are fairly good at coming in regularly, I would continue to ask about their drinking habits. Are they planning to get pregnant? The vast majority of people are aware of the repercussions of alcohol and pregnancy, but some aren't. We do pre-pregnancy discussions with them in terms of drinking."

The moderator then directed participants specifically to the issue of pregnancy, asking physicians whether they consider alcohol-using patients to be at a greater risk of an unintended pregnancy. Participants overwhelmingly believe that to be the case.

"Yes, absolutely. It's the impaired judgment of alcohol, and perhaps other risktaking behaviours that put them at risk."

"The risk of an unintended pregnancy is an alcohol-related issue."

"People who are most at risk of an unintended pregnancy that is affected by alcohol are often just in party mode. This would be an idea time to make mention of the risk, but in truth I'm just not doing it."

Participating physicians believe that the patients who are more at risk of an alcoholaffected pregnancy are those with accompanying mental illness, those who are marginalized, and those who have highly unstable social/family dynamics. Comments include:

"People lacking social supports are most at risk."

"The bar flies in their twenties – they're most at risk."

"Bright, educated professionals – they can be at risk."

"The middle-aged woman who has alcohol issues."

Preconception counseling and prevention regarding FASD

Physicians report that many responsible and motivated patients plan their pregnancy, and either initiate their own preconception strategies or book a preconception visit with their family physician.

"Patients who present for pre-conception counseling are typically worried about everything. They are the type of person who has been successful in their careers and their life, and they expect a successful pregnancy, too. They have stopped using alcohol, they're taking folate, and they're eating organic foods."

"In patients who are considering pregnancy, alcohol is just about the first thing we talk to them about. It's the most easily preventable thing, and everyone knows this."

Chronic alcohol users, binge drinkers, and women who become pregnant unintentionally are considerably less likely to have stopped using alcohol during the early stages of pregnancy – particularly if they're unaware they are pregnant. In this context, physicians were asked to what extent they would initiate FASD prevention strategies within these high-risk groups. Specifically, participants were asked, in the absence of a prompt from the patient indicating a concern or a desire to conceive, whether physicians would routinely discuss pregnancy-related risks and prevention with an alcohol-using patient. A couple of physicians report that they would raise the issue of pregnancy with patients.

"Contraception is part of a routine exam. If they're using alcohol, I ask, 'Is there any chance you're pregnant?""

"You might as well tell them about the risks of FAS – give them a handout so they are at least aware of it."

A majority of physicians say they would not normally discuss pregnancy risks unless there was a prompt from the patient.

"Do you mean me saying, 'Do you realize that if you got pregnant, this could harm . . .' Is that what you mean? No, that's not something I would say unless the patient specifically raises it as a concern."

"On a few occasions I have talked to people in that age group, that if you're drinking that much, you might be at risk, but it's usually more about date rape drugs. People who are drinking that much have a lot of things to be worrying about, not just pregnancy."

"I don't always talk about it, no. Despite people having the information, I don't know if there is always an impact."

When asked how they might manage a high-risk patient who is a moderate to heavy user of alcohol, sexually active, and not using reliable contraception, many physicians report that they would be more persistent in encouraging her to use birth control.

"I would probably mention that you need to be on contraception. We have lots of handouts available on the various methods of contraception, so I will talk to the patient and give them 10 or 15 handouts."

"I would have a serious discussion about their contraception, and maybe talk about using a form that's not so dependent on them remembering to take it, like an IUD or Depo-Provera."

"I would encourage them to accept responsibility for their life. But sometimes these patients actually want to get pregnant – in some way, they think it will bring some structure and some control to their lives -- so they're taking the risks with intent."

Some physicians say that while they can try to influence patients' behaviour, in the end they can't make patients comply.

"You can't force them to do something, but you can present the information."

"At our facility, every examining room has a box full of condoms, right in the examining room where no one can see them – the patients can just help themselves, like it's a candy dish. Short of putting it on for them, I don't think we can do much more."

Perceptions of at-risk patients within the practice

In spite of physicians' suggestions about how they would manage high-risk patients, most say they simply don't see many patients in their practices that they perceive to fit the high-risk profile. Several physicians consider the high-risk group to be comprised primarily of patients who are marginalized, socially isolated, disadvantaged, mentally ill, or otherwise living on the fringes of mainstream society, and they perceive that these patients are not often seen in mainstream primary care.

"This is a group that we don't see. They're not coming to see us, so it's really hard to do anything if you don't see them. It's the drug-using population, those with a family history of alcoholism, those with psychiatric illnesses like schizophrenia."

"We're just not seeing patients who fit that category."

While a majority of physicians say they view binge-drinking, under-25, "party mode" women as being at particular risk for an unintended pregnancy, only a couple of participants suggest targeting this group specifically for FASD prevention/intervention.

"Maybe we can target alcohol discussions and contraception to our 18-20 yearolds. This seems like a good place to take action."

"Our goal really should be to optimize contraception. I wonder if this should be our focus rather than focusing on changing their alcohol use?"

While physicians acknowledge the impairment and impulsiveness surrounding alcohol use and binge drinking may affect the reliability of contraception, most physicians don't feel a need to offer interventions to these patients unless an intended pregnancy does occur. One clinic suggests this age group presents more commonly for pregnancy terminations, which may be another way of managing the risk.

"We do have a lot of presentations for terminations. And we have the ones who come in for the morning-after pill because they've been partying and they were drunk and can't remember what they did last night."

Preconception vs prenatal activities

Physicians were offered a list seven potential issues they may discuss with patients either prior to conception or upon confirmation of a pregnancy:

- Folic acid intake
- Other prenatal vitamins and supplements
- Smoking cessation or reduction
- Exercise during pregnancy
- Contraception and sexual health
- Drug use, including prescription, recreational and over-the-counter.
- Alcohol use

For each item, physicians were asked to indicate whether they would discuss the subject with each of three hypothetical patients who present for a pregnancy test:

- Negative and happy: this patient tests negative and was not intending to conceive.
- Negative and unhappy: this patient tests negative and was hoping to conceive.
- Positive: this patient tests positive and is proceeding with the pregnancy.

A summary of physician responses is shown the table below.

Table B: Physicians' intended screening/prevention activities according to pregnancy test outcome (N = 23)

| | Positive result | | Negative result & patient unhappy | | Negative result & patient happy | |
|---------------------------------|-----------------|-----|-----------------------------------|-----|---------------------------------|------|
| | Yes | No | Yes | No | Yes | No |
| Folic acid | 100% | 0% | 100% | 0% | 9% | 91% |
| Prenatal vitamins & supplements | 100% | 0% | 52% | 48% | 0% | 100% |
| Smoking cessation/ reduction | 100% | 0% | 91% | 9% | 22% | 78% |
| Exercise | 61% | 39% | 17% | 83% | 0% | 100% |
| Contraception & sexual health | 30% | 70% | 13% | 87% | 100% | 0% |
| Drug use | 100% | 0% | 74% | 26% | 22% | 78% |
| Alcohol use | 100% | 0% | 83% | 17% | 9% | 91% |

Physicians say they will typically discuss a full range of healthy-pregnancy topics with patients who test positive for pregnancy. Physicians discuss the same topics with patients who test negative but who are wanting to become pregnant – presumably in anticipation of a positive result in the near future.

Relating to alcohol use specifically:

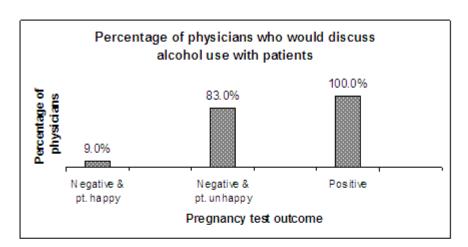
- 100% of participants³ say they will discuss alcohol use with a positive-result patient.
- 83% will discuss alcohol use with a negative-result patient who still hopes to become pregnant in the future.

However, in patients who present for an unplanned, accidental pregnancy (i.e., they are relieved the results are negative), physicians generally focus on contraception issues. Physicians say they view this as a prime opportunity to discuss potential changes and patient compliance with birth control, with all participating physicians saying they will typically discuss contraception and sexual health with patients in this group. Nine

Note that these discussions occur near the end of the focus group sessions, following a lengthy and detailed discussion about alcohol use during pregnancy, so these figures should not be considered an unbiased account of physicians' intended or actual practices.

percent of the physicians say they would raise the issue of alcohol use during pregnancy at this visit.

Figure 1



Managing pregnant patients who use alcohol

Motivated and light users of alcohol

Participating physicians suggest that public education and awareness about FASD prevention is well disseminated among motivated patients who are light users of alcohol. Several physicians suggest that FASD messages directed at this population may have even gone too far.

"It's great that the province is taking FASD seriously with all the posters and the pamphlets and the awareness. They've done a good job scaring people, and the biggest social change has occurred among the motivated light user. Maybe we have even scared them too much."

"I appreciate the attention that has been given to FASD prevention, but it causes a lot of anxiety in patients who had a couple of glasses of wine before they knew they were pregnant. They freak out – and about 50% of women have consumed alcohol before they knew they were pregnant."

For patients who have consumed alcohol early in pregnancy, physicians use a combination of assurance and cautionary advice. Some physicians feel they must reassure patients that an isolated drink won't cause FASD.

"As physicians we want to adequately scare patients so they stop drinking from now on, but not freak them out about their drinking up to this point."

"If I hear about binges they had before they knew they were pregnant, I try to figure out when the binges were. And I tell them, from this point on, reduce your drinking how ever you can."

"I tell them, don't beat yourself up if you have a celebration and you had a glass of wine."

"It would be very helpful to have more information about what is truly a safe level of alcohol. We always counsel patients to not drink, but for those who have, I would like to know at what point alcohol is likely to cause problems. There isn't any information about how much or when during the pregnancy."

"We really only see two ends of the spectrum: on one end is patients who have consumed some alcohol early on, and as physicians we need to reassure them. The other extreme is the serious or heavy user of alcohol, and we haven't done a good job reaching out to them."

Heavy or chronic users of alcohol

Some physicians say they feel powerless to intervene for the minority who don't heed the messages about alcohol use during pregnancy.

"I will always say that we don't know much alcohol is safe – that no amount is safe – so they need to stop drinking entirely."

"I emphasize that they do need to quit, because these are not the people who are only having one glass of wine on their birthday."

"If they are a heavy drinker, I will bring up the issue of terminating the pregnancy."

"You feel like you have to intervene very early to be of any effect. You know, probably by the time you've figure it out, the damage is already done. You may be helping for the next pregnancy but not necessarily this one."

"Patients who are heavier drinkers are usually surprised at being pregnant, and often they don't come in until they're 20 weeks. So the concept of catching these women before they get pregnant, or early in their pregnancy, just isn't realistic."

A number of physicians feel patients who consume alcohol during pregnancy are almost impossible to reach or change.

"With all the information out there, they know alcohol is bad and they still went ahead with (becoming pregnant)."

"I will tell them about having a fetal alcohol baby and the responsibilities that come with that, because chances are, their baby will have it."

"A lot of times it's FASD adults having FASD babies. It's really hard to counsel them."

"The 10 or 20% of women who don't present until 20 or 30 weeks into their pregnancy have so many other issues to deal with that we are just trying to help them get through their life in general, deal with STDS and things, get the pregnancy dated, and cram in all the tests we can. So alcohol consumption isn't something we're focused on at that time."

Others feel their only course of action is to focus on contraception for these patients.

"I think we have a bigger role to play in contraception management than we do in preventing alcoholism."

One physician believes alcohol use within Aboriginal populations is a critical challenge.

"There is a significant cultural barrier with Aboriginal patients – huge cultural differences. We need to get honest with this before we can really address the problem. Our entire (health) system is set up around organized visits, but that's not the way their life works. We're not on the same clock. Our North American solutions don't begin to deal with their different view of pregnancy, the young age of their pregnancies, the level of sexual abuse, etc."

Most physicians conclude that they simply don't see many maternity patients with alcohol problems.

"The alcoholics don't present to us. They present in emergency because they've had too much alcohol."

"It's really an inner-city issue. They are the patients who have mental disorders and they're out of the public education system, or they have significant social issues. These people are not coming into our offices because they don't make appointments, or keep them."

"The reality is, I just don't see much FASD here."

"If I had a patient in this category, it's hard to say what I'd do. You really need a multi-factoral approach – the GP alone can't manage it."

"The population that's really at risk of an FASD baby isn't really part of our practices. And for everyone else, the general knowledge about not using alcohol or drugs during pregnancy is already out there."

Capacity to intervene regarding FASD

While some physicians feel they have sufficient information and expertise to deal with alcohol-using patients, others don't feel well equipped to manage alcohol-using maternity patients, and typically refer patients to AADAC. Others have social workers within their area who can provide support and intervention.

"For a heavy drinker, I will send them to AADAC because I don't have the time. If they are pregnant, the social worker has time for them."

"I think there are better people to (help these patients) than me."

"I don't think I do it very well. Time is part of the issue."

A few physicians suggest that pregnant patients would benefit from maternity-specific AADAC support groups, or different programming locations, or even different admission criteria.

"There should be someplace besides a downtown AADAC, which has a lot of stigma around it."

"Maybe we need a specific pregnancy-focused group within AADAC, so they don't have to get sent to Al Anon where there's a perception they'll be sitting in a room with a bunch of 50-year-old alcoholic men. The pregnant women could be together to talk specifically about their issues."

"A lot of times you have to be sober for a week before you can (get admitted), and that's difficult if you're an alcoholic – if you could do that, you wouldn't be here, right?"

"There isn't anywhere close, and especially for women if they have children, there are no supports to look after the family and children, so they're reluctant to attend these things."

Physician response to FASD project in general

Several physicians were disappointed that the focus groups – purportedly about prevention and screening activities for women of child-bearing age – were focused solely on FASD.

"If I'd known this was going to be about FASD, I wouldn't have come."

"I'm disappointed this was just about FASD. It's not the biggest issue I deal with in my practice. Basic screening is a far bigger issue – patients who don't feel they have good access or sufficient choices."

"I think the whole FASD thing is blown out of proportion. Focusing on alcohol in pregnancy just isn't cost-effective."

"Why the focus on FASD? People who are overweight and hypertensive will produce troubled babies, too. I feel like obesity is a bigger issue than alcohol."

"There are far more male alcoholics than women. It's just not a huge issue."

"It kind of bugs me that they're focusing so much on alcohol and not doing anything about smoking."

Patient survey results

The survey that was administered to female patients (in Edmonton only) offers some insights into the experiences of patients. Despite the small sample size and limited number of responses, the results correlate with many findings of the physician focus groups.

It is important to note that the patient survey simply asks respondents to indicate whether they recall discussing certain topics with their physician or other provider. Patients may or may not accurately recall the discussions they've had with physicians, and no attempt was made to identify whether these various discussion opportunities ever presented themselves.

Preconception care and healthy pregnancy strategies

Of the 39 survey respondents, 41% say their doctor (obstetrician, family physician, or both) discussed "how to have a healthy pregnancy" prior to the patient becoming pregnant. Eighteen percent of patients under 25 (those born in 1981 or later) and 23% of patients whose pregnancies were unplanned say their physician discussed healthy pregnancy prior to conception. When prompted with specific "healthy pregnancy" topics (Table C), patients remain consistent in reporting that these topics were not discussed with them prior to pregnancy.

Table C. Did your family doctor, obstetrician/gynecologist, or nurse/midwife talk to you about any of the following?

| | % of patients saying "yes" | | |
|--|----------------------------|--------------------------|--|
| Healthy pregnancy topic | Before pregnancy | Upon/during pregnancy | |
| Taking folic acid to prevent birth defects | 38% | 77% | |
| Quitting or cutting down on cigarette smoking | 38% | 59% | |
| Taking prenatal vitamins or supplements | N/A | 93% | |
| Using birth control to prevent pregnancy | 38% | N/A | |
| Your own use of alcohol or drugs | 23% | N/A | |
| Risks of using alcohol if you aren't using reliable birth control. | 20% | N/A | |
| Risks of using alcohol during pregnancy | 31% | 51% | |
| Using drugs during pregnancy | 28% | 49% | |
| Nutrition and healthy eating during pregnancy | N/A | 67% | |
| Exercising safely during pregnancy | N/A | 56% | |

Nearly two-thirds (64%) of the respondents who discussed healthy pregnancy topics with their physician say it was the patient, not the physician, who raised this issue. Patients report that physicians were more likely to discuss the issues *after* the patient was confirmed to be pregnant.

Patient survey results are consistent with physician focus results about not discussing healthy pregnancy issues prior to conception, and being more likely to discuss these topics when the patient initiates the discussion or the patient presents with a confirmed pregnancy.

Alcohol use during pregnancy

Patient recollection about alcohol-specific counseling <u>preconception</u> versus <u>post-conception</u> is relatively consistent with the physician focus groups. Both physicians and patients report that physicians are more like to discuss general or potential alcohol-related risks upon confirmation of the pregnancy rather than prior to conception.

According to patient survey responses:

- 77% of patients report that their alcohol use in general was not discussed prior to conception;
- 80% report that their physician did not discuss the risks of using alcohol if the patient is not using reliable birth control;
- 31% can recall their physician or other provider discussing, prior to conception, the risks of using alcohol during pregnancy prior to conception. Upon confirmation of pregnancy, this number increases to 51%.

Detailed assessment of alcohol use during pregnancy

Patients recall being asked more detailed questions by their physician after becoming pregnant (Table D) than they were asked prior to conception. This is consistent with physicians' reports that they are more persistent and detailed about assessing patients' alcohol use once a pregnancy is confirmed.

Table D. Since you became pregnant, has your doctor asked you about the following?

| | Yes | No | Not sure/ no answer |
|---------------------------------------|-----|-----|------------------------|
| How much alcohol you normally drink? | 49% | 49% | 2% |
| How often you normally drink alcohol? | 51% | 41% | 8% |
| Your partner's alcohol use? | 10% | 85% | 5% |

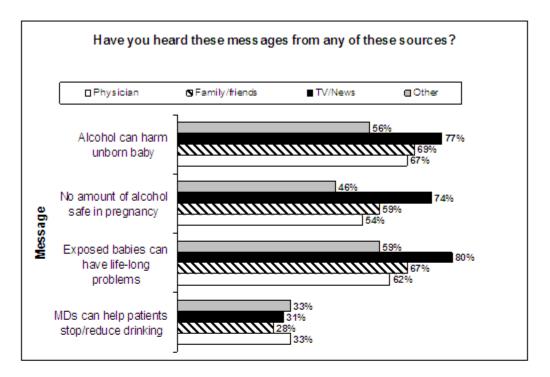
Social context, knowledge and use of alcohol

When asked to describe the social context for alcohol use among their friends and family:

- 21% of respondents say there is no alcohol use in their circle of family and friends
- 41% say only a few people drink alcohol
- 33% say many people drink alcohol, but they drink lightly or responsibly during social get-togethers
- 3% say people regularly drink large amounts of alcohol or they usually drink to get drunk.

When asked whether they have heard information or educational messages about alcohol use during pregnancy, between half and two-thirds of patients report hearing various FASD-prevention messages from their physician. "Physicians" and "family/friends" are closely ranked as sources of information, and "TV/news" ranks slightly higher. Of note is patients' limited recollection, from all sources, of the message that physicians can help patients stop or reduce their use of alcohol during pregnancy. Details are summarized in Figure 2 below:

Figure 2



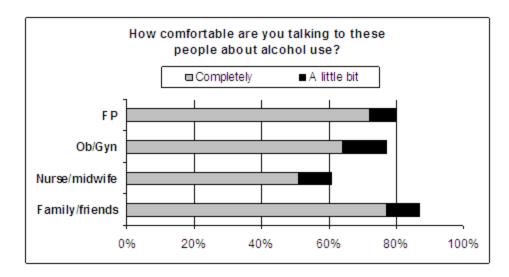
When asked about their own alcohol-consumption plans during their pregnancy, a majority (80%) of patients say they have already decided not to use alcohol during their pregnancy. Another 18% say they plan to stop or reduce their use of alcohol during the pregnancy.

Patients whose pregnancies are unplanned, or whose social circles include people who drink regularly, or who possess high school graduation as their highest level of education, are more likely to indicate that they <u>plan</u> to stop or reduce their use of alcohol during the pregnancy. Some respondents (23%) say their physician has provided them with information, a pamphlet or other support/intervention material related to alcohol use/cessation during pregnancy.

Comfort level and trust discussing alcohol use with physicians and others

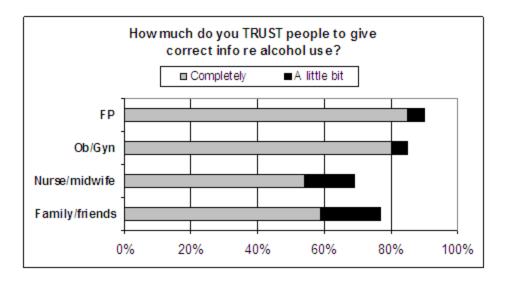
Patients report a high degree of comfort discussing alcohol use with both their physician and their friends/family, and to a slightly lesser degree with nurses or midwives, as shown in Figure 3.

Figure 3



Percentages are comparable when patients are asked about their degree of <u>trust</u> in various providers to offer correct information about alcohol use, as shown in Figure 4.

Figure 4



Barriers to discussing alcohol use during pregnancy with physicians

When patients were asked about specific concerns that may prevent them from discussing alcohol use with their doctor, the following responses were received:

- 5% say they would feel embarrassed a lot or a little
- 10% would worry about being judged by their physician
- . 5% would worry about being forced into alcohol treatment
- 8% would worry about being asked to give up their baby.

Patients with the least education (some high school courses or less) are most likely to feel these concerns exist.

Survey respondent profile

Survey respondents reflect a range of demographic and socioeconomic sectors as follows:

| Marital status | | | Family income | | |
|--------------------|-------|-----|---------------------|-----|--|
| Married/common law | 80% | | \$12,000 or less | 10% | |
| Single | 18% | | \$12,001 - \$18,000 | 8% | |
| Divorced | 3% | | \$18,001 - \$35,000 | 15% | |
| Year of b | oirth | | \$35,001 - \$55,000 | 21% | |
| 1990 or later | | 13% | \$55,001 - \$70,000 | 10% | |
| 1981 – 1989 | | 31% | More than \$70,000 | 23% | |
| 1971 – 1980 | | 46% | No answer | 13% | |
| 1961 – 1970 | | 10% | | | |

| Occupation | | Education | | |
|-----------------------------|-----|------------------------------------|-----|--|
| Full-time student | 31% | University graduate | 31% | |
| Work full-time outside home | 26% | College diploma or certificate | 21% | |
| Stay-at-home parent | 23% | Some college or technical training | 8% | |
| Work part-time | 15% | High school graduate | 15% | |
| Part-time student | 5% | Some high school courses | 21% | |
| Not employed or a student | 5% | Junior high school | 5% | |

| Stage of pregn | ancy | Pregnancy number | | Planned/unplanned status | |
|------------------|------|------------------|-----|--------------------------|-----|
| 12 weeks or less | 18% | First | 49% | Planned | 62% |
| 3 – 6 months | 44% | Second | 41% | Unplanned | 28% |
| 6 - 9 months | 39% | Third or more | 10% | | |

Conclusions

In conclusion, results from the focus groups indicate that while participating physicians perceive alcohol use to be a significant social and health issue within their practices, FASD per se is not viewed as a high priority issue. Patients who routinely seek primary care are perceived as already cognizant of FASD prevention activities, and patients at the highest risk of delivering babies with FASD are viewed as those who generally don't seek primary care.

Physicians who specifically target alcohol use among their female patients often do so for reasons other than FASD prevention -- i.e., to manage the social and medical conditions that may accompany heavy alcohol consumption. Many physicians feel that so long as these patients are using reliable contraception, FASD is not a significant issue.

Based on the findings from this investigation, several themes have emerged. These include:

- Relevance may be a barrier to physician education/intervention strategies
 because many physicians believe patients most at risk of delivering babies with
 FASD are not presenting for primary care, or they are presenting too late to
 initiate prevention/intervention strategies. There is some doubt as to whether
 this population is even reachable through mainstream primary care.
- Priority may be an issue as physicians feel other lifestyle issues and chronic conditions (STDs, obesity, diabetes, hypertension, mental health issues) are of more immediate concern. There was some question as to whether physicians should be focusing their efforts on a small population that requires require multidisciplinary and resource-intensive management.
- Prevalence may be an issue as physicians perceive patients most at risk of delivering babies with FASD are a very small and isolated patient population with multiple, complex social and medical conditions.
- Efficacy may be a challenge as physicians perceive that patients who are most at risk of an alcohol-affected pregnancy can be hard to reach, and that it is very difficult to affect the outcomes in this complex, high-needs population.

Appendix I: Physician Focus Group Script

Routine screening patterns

- 1. First, how much opportunity do you have to conduct routine screening and prevention activities for females of child-bearing age say those between 13 and 45? Do you feel you have adequate opportunity to screen for the types of conditions you might expect to commonly see in these patients? Are there gaps between your professional intentions, the demands on your time, and the expectations of patients? How do you manage these gaps?
- For annual visits & asymptomatic patients, what do you tend to screen for?
 Brainstorm list (contraception, cervical cancer/pap smear, depression, weight-related issues, alcohol use, ingestion of folic acid, etc.)
- For each of these, would you say that you screen:
 - For all or most patients routinely?
 - Only when there's a prompt from the patient?
 - When you perceive there to be signs or risk factors present?
- 4. For each of these conditions, how would you rate them in terms of (1) prevalence, where 7 is extremely high and 1 is extremely rare; and (2) potential impact on health, where 7 is extremely significant and 1 is minimal.
- 5. Do you feel you are able to screen for all the things you'd like to screen for? Why? When setting priorities, which conditions drop off your list? Which ones remain as priorities? Why?

Screening for alcohol use - patterns, barriers, perceptions

- (If alcohol use not mentioned so far):
 - I noticed screening for alcohol use isn't on our list so far. Why is that?
 - If we added alcohol to the list above, what would you say is your current screening pattern? How would you rate it in terms of incidence and potential impact on health?
- 7. Are there certain categories of patients you are more likely to screen for alcohol use in the absence of a clinical sign or prompt from the patient? Who are they, and why? (Probe re: knowledge & awareness of risk factors: First nations; sexually active

- teenagers; college educated; single parent; unstable or abusive personal relationships; history of sexual abuse; history of STDs; history of prostitution).
- What prevents you from conducting routine screening of all patients for alcohol use? (Probe re: perceived risk; time pressures; lack of opportunity; not part of routine thought process)
- 9. In your opinion, how much time & effort would it take to add alcohol screening to your list of routine screens? How practical and realistic is it for your particular practice environment?
- 10. Think of situations where you actually have screened patients for alcohol use. Do you use any screening tools or algorithms? Which ones?
- When you screen for alcohol use, what exactly are you looking for? Anything else? (Probe re: binge drinking; alcohol dependency; relationship abuse; parenting issues; stress; etc.)

Obtaining alcohol consumption histories

- 12. When you have screened patients for alcohol use, what has been their reaction? What has been the outcome of these screenings – that is, did you obtain information that you found helpful and useful in your clinical evaluation?
- 13. Do you feel patients respond honestly when you screen for alcohol use? How would you explain this? To what extent do you feel you are able to obtain a reliable alcohol-use history from patients?
- 14. Do you feel you play a role in influencing the degree of patients' honesty? In what way?

Managing patients who consume alcohol

- 15. If you do screen a patient for alcohol use and they are a light to non-user, what comes to mind in terms of next steps or ongoing management? Do you offer any information, resources, etc? Why?
- 16. What about a patient whose screening suggests they are a moderate to heavy user of alcohol -- what comes to mind in terms of next steps or ongoing management? Do you offer any information, resources, etc? Under what circumstances, or for which patients?

Perceived links between alcohol use and pregnancy risk

- 17. In moderate to heavy users of alcohol, does pre-pregnancy counseling come to mind for these patients as a potential flag for management or intervention? Would you normally discuss the potential for pregnancy, planned or unplanned? Why or why not?
- 18. When discussing alcohol use pre-conception, how important is it for you to receive a prompt from the patient regarding conception, pregnancy contemplation or family planning?
- 19. In the absence of a conception-related prompt from the patient, would you normally screen for alcohol use pre-conception? Why or why not?
- Do you normally think of an alcohol-using patient as being at risk for an unintended pregnancy? Why? (probe re: alcohol use & binge drinking increasing chances of unprotected sexual activity, etc.)

Identifying and managing at-risk patients pre-pregnancy

- 21. In terms of offering advice, support or intervention to patients who are moderate to heavy users of alcohol, in your mind do you make a distinction between patients who have alcohol-related problems, and those who have BOTH alcohol-related problems and who are also at risk of pregnancy? In what way?
- 22. In general, are there patients you view as being more at risk of an alcohol-affected pregnancy? Who are these patients? Why do you believe they are at greater risk?
- 23. If you had a patient who was a moderate to heavy drinker, sexually active, and not using birth control reliably, would you perceive this patient to be at risk of an unintended pregnancy? How would you manage this?
- 24. Would you ever consider recommending that a patient in this situation use a method of contraception that is less dependent on patient compliance, such as an IUD or implantable hormones? Why or why not?
- 25. In your opinion, which patients are at the greatest risk of giving birth to a baby with fetal alcohol spectrum disorder? Do you see many of these patients in your practice?

Managing FASD risk during pregnancy

26. When a patient presents for a pregnancy test, do you discuss any of the following?

Neg. & happy Neg. & unhappy Positive

- Folic acid
- Other prenatal vitamins and supplements
- · Smoking cessation or reduction
- Exercise in pregnancy
- Sexuality
- Drug use (prescription and non-prescription)
- Alcohol use
- 27. If a pregnant patient is believed to be a light user of alcohol, what do you discuss with the patient? (Probe re: reassuring concerned patients about alcohol consumption; recommendation cessation; etc.)
- 28. If a pregnant patient is believed to be a moderate to heavy user of alcohol, what do you discuss with her? (Probe re: cutting down or quitting; reassurance re: ability to manage; referral to treatment programs; discussion re: termination options; etc.)

Capacity to manage at-risk patients

- 29. Do you feel you have sufficient expertise and time to provide non-pregnant patients with the supports and intervention they need? How about pregnant patients?
- 30. Do you feel you have sufficient access to other resources outside your practice to give these non-pregnant patients the supports and intervention they need? Pregnant patients? Why?
- 31. What might enhance your ability and capacity to manage pregnancy patients who need help with alcohol consumption?

Appendix II: Prenatal Patient Survey

See separate pdf attachment on legal size paper.

Appendix III: Physician screening chart

| Routine/asymptomatic screening for: | Screening pattern | | | Prevalence/ Likelihood of + result? | Potential impact on health if + or problematic |
|-------------------------------------|-------------------|-----------------|-----------------------|---|---|
| | All pts | If pt prompt | Signs/risk factors | 7=high/ 1=rare | 7=significant |
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| Practice location: | Large un | ban | Regional | Rura | al |
| | Male | | | | |
| | | | | 11 – 15 | 16 - 20 |
| - | 20 - 25 | 25 - 3 | 0>30 | | |
| Patient profile (%) | % Male | % Fer | male | | |
| Prenatal care? | Yes | | _ No | | |
| Obstetrics/deliveries? | Yes | No | | | |

Appendix 12: References

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