

# Stigmatisation, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder

John Aspler, Natalie Zizzo, Emily Bell, Nina Di Pietro and Eric Racine

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## Article abstract

Background: Fetal alcohol spectrum disorder (FASD), a complex diagnosis that includes a wide range of neurodevelopmental disabilities, results from exposure to alcohol in the womb. FASD remains poorly understood by Canadians, which could contribute to reported stigma faced by both people with FASD and women who drink alcohol while pregnant. Methods: To better understand how information about FASD is presented in the public sphere, we conducted content analysis of 286 articles from ten major English-language Canadian newspapers (2002-2015). We used inductive coding to derive a coding guide from the data, and then iteratively applied identified codes back onto the sample, checking inter-coder reliability. Results: We identified six major themes related to clinical and scientific media content: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy. Discussion: Across these six themes, we discuss three instances of ethically consequential exaggeration and misrepresentation: 1) exaggeration about FASD rates in Indigenous communities; 2) contradiction between articles about the effects of prenatal alcohol exposure; and 3) scientifically accurate information that neglects the social context of alcohol use and abuse by women. Respectively, these representations could lead to harmful stereotyped beliefs about Indigenous peoples, might generate confusion about healthy choices during pregnancy, and may unhelpfully inflame debates about sensitive issues surrounding women's choices.



ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

# Stigmatisation, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder

John Aspler<sup>1,2</sup>, Natalie Zizzo<sup>1,3</sup>, Emily Bell<sup>1,4</sup>, Nina Di Pietro<sup>5</sup>, Eric Racine<sup>1,6,7</sup>

## Résumé

**Contexte :** L'ensemble des troubles causés par l'alcoolisation fœtale (ETCAF), un diagnostic complexe qui comprend une vaste gamme de troubles neurodéveloppementaux, résulte de l'exposition à l'alcool dans l'utérus. L'ETCAF demeure mal compris par les Canadiens, ce qui pourrait contribuer à la stigmatisation dont souffrent les personnes atteintes d'ETCAF et les femmes qui consomment de l'alcool pendant leur grossesse.

**Méthodes :** Pour mieux comprendre comment l'information sur l'ETCAF est présentée dans la sphère publique, nous avons analysé le contenu de 286 articles tirés de dix grands journaux canadiens de langue anglaise (2002-2015). Nous avons utilisé le codage inductif pour établir une grille de codage à partir des données, puis nous avons appliqué de façon itérative des codes identifiés sur l'échantillon, en vérifiant la fiabilité intercodeurs.

**Résultats :** Nous avons identifié six grands thèmes liés au contenu cliniques et scientifiques des médias : 1) prévalence de l'ETCAF et de la consommation d'alcool chez les femmes ; 2) recherche en lien avec l'ETCAF ; 3) diagnostic d'ETCAF ; 4) traitement de l'ETCAF et de l'abus de substances par les mères ; 5) incapacités primaires associés à l'ETCAF ; et 6) effets de l'alcool pendant la grossesse.

**Discussion :** Dans le cadre de ces six thèmes, nous examinons trois types d'exagération et de fausse représentation qui ont des conséquences sur le plan éthique : 1) l'exagération des taux d'ETCAF dans les communautés autochtones ; 2) la contradiction entre les articles sur les effets de l'exposition prénatale à l'alcool ; et 3) l'information scientifiquement exacte qui néglige le contexte social de la consommation et de l'abus d'alcool par les femmes. Respectivement, ces représentations pourraient mener à des croyances stéréotypées préjudiciables au sujet des peuples autochtones, pourraient créer de la confusion quant aux choix sains pendant la grossesse et risqueraient d'enflammer inutilement les débats sur des questions délicates concernant les choix des femmes.

## Mots-clés

ensemble des troubles causés par l'alcoolisation fœtale, ETCAF, stigmatisation, alcool et grossesse, incapacité, communication scientifique, Autochtones, Canada

## Abstract

**Background:** Fetal alcohol spectrum disorder (FASD), a complex diagnosis that includes a wide range of neurodevelopmental disabilities, results from exposure to alcohol in the womb. FASD remains poorly understood by Canadians, which could contribute to reported stigma faced by both people with FASD and women who drink alcohol while pregnant.

**Methods:** To better understand how information about FASD is presented in the public sphere, we conducted content analysis of 286 articles from ten major English-language Canadian newspapers (2002-2015). We used inductive coding to derive a coding guide from the data, and then iteratively applied identified codes back onto the sample, checking inter-coder reliability.

**Results:** We identified six major themes related to clinical and scientific media content: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy.

**Discussion:** Across these six themes, we discuss three instances of ethically consequential exaggeration and misrepresentation: 1) exaggeration about FASD rates in Indigenous communities; 2) contradiction between articles about the effects of prenatal alcohol exposure; and 3) scientifically accurate information that neglects the social context of alcohol use and abuse by women. Respectively, these representations could lead to harmful stereotyped beliefs about Indigenous peoples, might generate confusion about healthy choices during pregnancy, and may unhelpfully inflame debates about sensitive issues surrounding women's choices.

## Keywords

fetal alcohol spectrum disorder, FASD, stigma, alcohol and pregnancy, disability, science communication, Indigenous, Canada

## Introduction

Fetal alcohol spectrum disorder (FASD), a complex diagnosis that spans a wide range of neurodevelopmental disabilities affecting roughly 1 in 100 Canadians [1], results from alcohol exposure in the womb. A heterogeneous and difficult-to-diagnose disorder, FASD presents in myriad ways, including with characteristic facial features (e.g., thin upper lip, no philtrum), and with disabilities in executive function (e.g., hyperactivity, impulse control), cognition (e.g., low IQ, learning difficulties), and other brain domains (e.g., motor function, language, mood regulation) [2,3]. Previous diagnostic guidelines included diagnoses like fetal alcohol syndrome (FAS), partial FAS, and alcohol-related neurodevelopmental disability [2], but more recent guidelines have simplified the diagnosis into the following categories: 1) FASD with sentinel facial features; 2) FASD without sentinel facial features; and 3) an at-risk category [3].

Although more recent studies indicate that the prevalence of FASD could prove higher than 1 in 100 (i.e., as high as 2-5 in 100 in the US and some European countries) [4], it remains a largely "invisible disability": only about 10% of people diagnosed with FASD present with identifiable physical features [5]. Compounding the issue, survey data indicate that while most Canadians know that FASD exists (86%) and that drinking alcohol when pregnant can harm a fetus (76%), they provide less accurate descriptions of its signs and symptoms [6-8]. This lack of public knowledge could indicate that sources other than exposure or personal experience, such as the news media, could be important for the public's understanding of FASD. They could also be sources of stigmatisation for people with FASD and women who drink while pregnant.

Stigmatisation, a process of negative stereotyping causing discrimination [9], remains a tremendous social challenge and a barrier to the wellbeing of marginalized groups. Link and Phelan [9] describe this process as one where certain identified differences between groups become fodder for stereotyping, othering, and discrimination – in a context where various forms of power align against the group in question. As an example, some people with FASD report experiencing problems ranging from social exclusion to employment discrimination [10,11]. In addition, since FASD results from alcohol exposure in the womb, some women who drink alcohol during pregnancy can also face stigmatisation [12]. This stigma might be exacerbated by judgmental public discourse and health messaging that emphasize individual blame and responsibility [13], and which stereotype women who drink while pregnant as unfit – or even criminally negligent – mothers [14].<sup>1</sup>

Public discourse could be one potential factor contributing to the stigmatisation of people with FASD and women who drink while pregnant – especially given the media’s long history of misrepresenting and stereotyping people with disabilities (e.g., as victims, as villains, as superhuman) [17]. Broadly speaking, since the mass media are thought to both reflect and impact public attitudes and opinions [18], this could include how the public perceives and constructs identities around issues such as health and disability. As we will discuss later in this paper, these perceptions can also include Indigenous identities and stereotypes surrounding alcohol use.

Previous media studies exploring discourse related to FASD in the US, the UK, and Australia indicated a larger media focus on the implications of alcohol use during pregnancy than on stories about the lives of people with FASD [14,19,20]. This was sometimes by design [21]; however, even when FASD itself was the primary focus of a study, pregnant women and issues of alcohol consumption usually came to the fore – including in study discussion sections. Ultimately, these articles identified common narratives framing women who drink while pregnant as dangerous, blameworthy, and irresponsible, as well as discussions about how women should behave when pregnant [14]. In contrast, FASD was framed as a crisis [21], with occasional stories about people with FASD who were “blameless victims” of their mothers’ drinking [19,20], or occasionally as themselves victimizing others [14]. To the best of our knowledge, no research has characterized media coverage about FASD in Canada. Accordingly, to gain deeper insight into the kind of information the public receives about FASD, which could inform public attitudes toward individuals with the disorder as well as women who drink while pregnant, we conducted an analysis of the FASD-related content found in Canadian media.

## Methods

In this study, we employed a qualitative media content analysis approach [22], similar to several previous media studies [23-25]. We reported these methods in full in an article about the social dimensions of discourse identified during the same content analysis, some of which is reprinted here or else is specific to this manuscript [26].

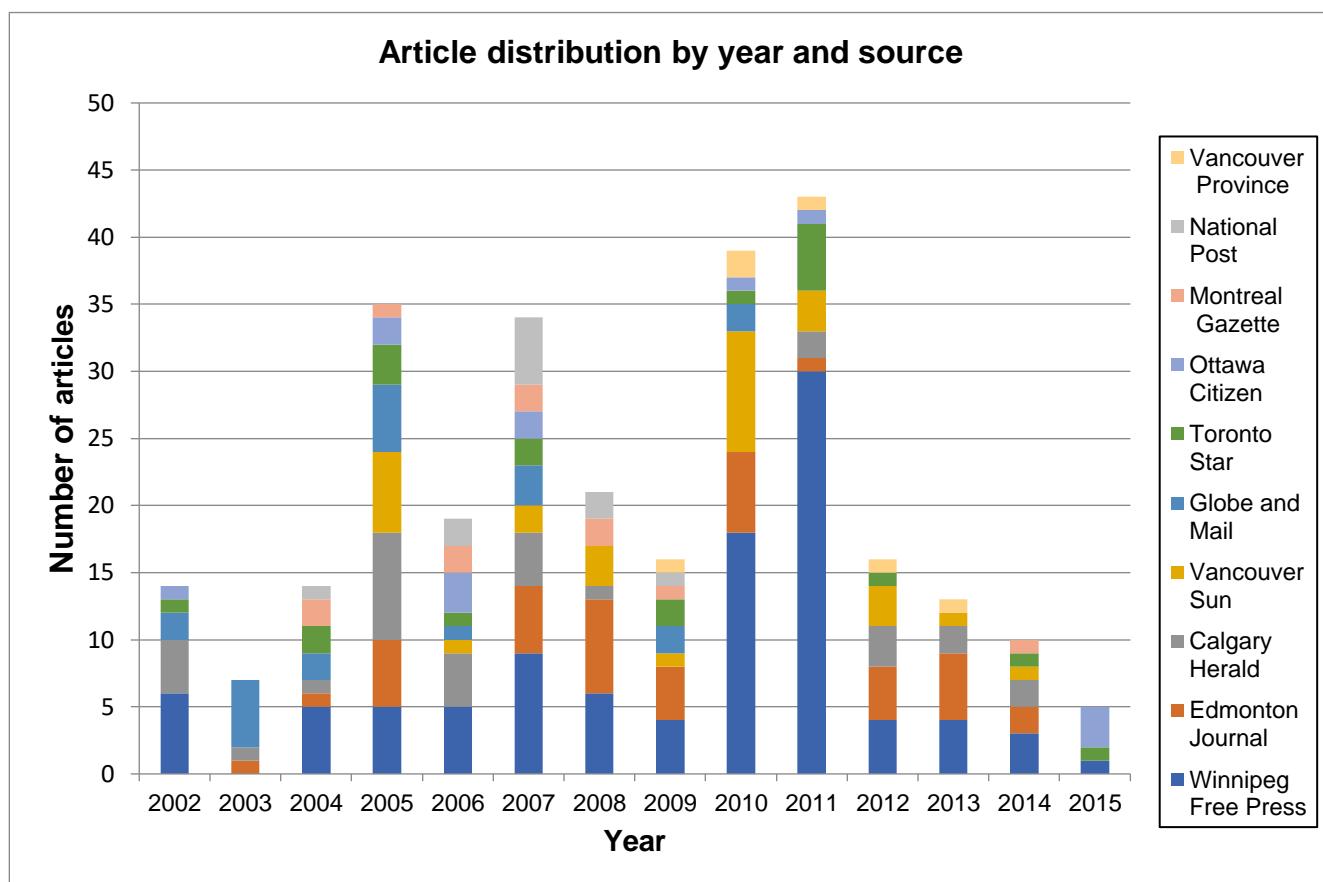
## Sample

Using the Factiva news database, we searched for English and French print news articles published in Canada between January 1<sup>st</sup> 2002 and October 31<sup>st</sup> 2015. We searched for the following keywords in headlines and lead paragraphs: “fetal alcohol spectrum disorder” OR “FASD” OR “fetal alcohol syndrome” OR (“alcohol” AND “pregnancy”) OR “ensemble des troubles causés par l’alcoolisation foetale” OR “ETCAF” OR “syndrome d’alcoolisation foetale” OR (“grossesse” AND “alcohol”).

We restricted our search to 10 of the most-distributed Canadian print news sources [27], all of which are available electronically: *The Toronto Star* (n=20), *The Globe and Mail* (n=22), *The Montreal Gazette* (n=11), *The Vancouver Sun* (n=30), *The Vancouver Province* (n=6), *The National Post* (n=11), *The Winnipeg Free Press* (n=100), *The Calgary Herald* (n=32), *The Ottawa Citizen* (n=13), and *The Edmonton Journal* (n=41). Note that more than one third of this sample (100/286 articles) came from *The Winnipeg Free Press*, which won a 2010 Canadian Institutes of Health Research (CIHR) grant to specifically cover FASD and its “causes, social costs, treatments, and prevention” [28].<sup>2</sup> Of the rest of the articles, more than a third came from the other Western provinces (British Columbia and Alberta – no newspaper from Saskatchewan was included). In total, almost three quarters of the sample came from these three Western provinces, with only 27% (77/286 articles) coming from Ontario, English Quebec news, or national papers like *The Globe & Mail*. We had to exclude *Le Journal de Montréal*, *La Presse*, *Le Journal de Québec*, and *The Toronto Sun* because Factiva only began archiving these sources in 2011. See Figure 1 for more information about the distribution of the sample by year and by source.

<sup>1</sup> In some jurisdictions in the US, the use or abuse of certain substances during pregnancy, including alcohol, can be used as evidence of crimes that include child abuse and neglect [15]. These approaches have not yet materialized in the Canadian context [16].

<sup>2</sup> The article cited here was included in the sample. In addition, given these funds, the coverage was typically more nuanced and in depth than other coverage, despite the somewhat sensational series title “Wounded in the Womb”.



**Figure 1:** Stacked bar graph indicating the distribution of articles across the sample, sorted by year and by source. The colour legend for sources and the stacked bars themselves are organized in ascending order, from the Winnipeg Free Press at the bottom ( $n=100$ ) to the Vancouver Province on the top ( $n=6$ ). Figure reprinted with permission from [26].

## Coding Process

Three coders used a random sample of 25 articles to develop a coding guide inductively, capturing key areas of content present in the sample. The coding guide was then systematically applied to the remainder of the sample. This process was repeated through several sample updates and coding guide refinements. We assessed intercoder reliability for each code through each iteration, discarding six codes and five sub-codes with a percent agreement below 0.75.

## Coding Guide

We coded 286 articles for coverage of three broad categories: 1) scientific content; 2) clinical content; and 3) social content. This article reports on the six codes (and fifteen sub-codes) in the scientific (See Table 1) and clinical (See Table 2) categories. Scientific content reflects scientific knowledge about FASD as reported by the media (e.g., research related to FASD). Clinical content reflects clinical care for people with FASD (e.g., diagnosis of FASD) and mothers (e.g., treatment of maternal substance abuse), as well as descriptions of what FASD entails symptomatically (i.e., primary disabilities associated with FASD). The 'Effects of alcohol exposure during pregnancy' code, categorized in clinical content, has also been further broken down into four categories beyond the parameters defined in the coding guide to gain deeper insight into this particularly complex area of discourse. Another article reported on the findings of the social content code since there are too much data to report in a single article, and the data in that content category provides opportunities to engage with different literatures [26].

## Results

We identified six major themes, or content areas corresponding to our codes, broken down across fifteen sub-themes (sub-codes), with the most frequent being descriptions of the primary disabilities associated with FASD (48%,  $n=136$ ), and prevalence of FASD and of women's alcohol consumption (46%,  $n=131$ ). Tables 1 and 2 describe the coding structure in detail, and explain the scope of each code and sub-code (with pertinent examples). After each table, we elaborate on some of the more complex and multidimensional codes, which require more space for elaboration than the table can provide (i.e., a richer unpacking of the content found in the 'diagnostic challenges' sub-code than seen in Table 2), with illustrative in-text examples provided to exemplify important nuances of the content. When providing quotes, both in text and in the tables, we reference each article by newspaper and year, to avoid singling out any given journalist, while maintaining transparency on data sources. We do not include these sources in the References section, as they are data.

## Scientific content

**Table 1: Scientific Content Results: Coding Structure and Examples**

Code	Sub-code	Scope	% of sample & total number of articles	Examples
Prevalence of FASD and of women's alcohol consumption		Article reports on FASD prevalence, or on alcohol consumption rates in different groups of women.	46% (n=131)	
	General population	Article reports on FASD prevalence across all ages around the world, but mainly in Canada's Western provinces.	35% (n=99)	"It's estimated that there are more than 36,000 Albertans with FASD" (Edmonton Journal 2014).
	Uncertainty	Article reports a lack or insufficiency of current FASD prevalence estimates.	14% (n=39)	"There are no clear numbers to determine how many people are living with FASD in Manitoba" (Winnipeg Free Press 2006) and "A relatively new paper... says all the best estimates are lowballed" (Winnipeg Free Press 2011).
	Criminal justice system	Article reports on FASD prevalence in the criminal justice system. Includes proportion of offenders with FASD, and proportion of people with FASD behaving criminally.	11% (n=32)	"A study of 91 inmates... found 10 per cent have some form of fetal alcohol spectrum disorder – 10 times the incidence in the general population" (Calgary Herald 2007).
	Indigenous populations	Articles reports on FASD prevalence in Indigenous populations in Canada.	8% (n=24)	"Among aboriginal people, the prevalence of FAS is much higher than the national average—as high as 10 per cent in some communities where alcohol abuse is widespread" (The Globe and Mail 2005).
	Child welfare system	Articles reports on FASD prevalence in the child welfare system. Includes proportion of kids in the system with FASD, and proportion of kids with FASD in the system.	5% (n=14)	"Another study indicated that 80 per cent of FASD-affected individuals are [raised] by adoptive parents or through foster care" (Ottawa Citizen 2006).
	Women's alcohol consumption	Article reports on the prevalence of pregnant women's alcohol intake. Also includes discussions about drinking in relation to unplanned pregnancies, or rates of women who consume alcohol in general.	5% (n=14)	"In 2003, about 12 per cent of women in Winnipeg admitted to consuming alcohol while expecting. In 2008, that number inched up to 14 per cent" (Winnipeg Free Press 2011).
Research related to FASD		Article reports research into any dimension of FASD. Excludes examples with no research findings.	26% (n=73)	
	Diagnosis & screening	Article reports research on novel diagnostic or screening tool/methods. Includes screens in subgroups (e.g., criminal justice system).	9% (n=26)	"... a simple test that tracks eye movements may offer a new tool to accurately diagnose fetal alcohol syndrome" (Edmonton Journal 2005).
	Treatment & prevention	Article reports research into novel treatments for FASD itself, or novel prevention methods ('treating fetuses').	6% (n=18)	"... aboriginal researchers had to consider a number of questions when designing programs to prevent FASD, including: How would you approach a woman in the community?" (Vancouver Sun 2006)
	Levels of prenatal alcohol exposure	Article reports research findings connecting levels of prenatal alcohol exposure to FASD outcomes (see text).	5% (n=15)	"The University of Pittsburgh recently released findings from a study following 565 mothers and children since 1982, when the women were all four months pregnant. Even children whose mothers drank less than 1.5 drinks a week during pregnancy were a few pounds smaller as adolescents" (The Globe and Mail 2003).
	Primary disabilities	Article reports on research into specific disabilities and symptoms that may appear in cases of – or help identify – FASD.	2% (n=5)	"Writing in the journal Alcoholism: Clinical and Experimental Research, researchers say their findings indicate that deficits in so-called eye-blink conditioning, or EBC, can identify children with probable fetal alcohol syndrome." (Vancouver Sun 2008)

### ***Prevalence of FASD in the general population – Societal burden and public health concerns***

Prevalence was sometimes used to frame FASD as a burden on society, e.g., "...it's estimated that at least one child is born with fetal alcohol syndrome each day in Canada, with the lifetime costs of caring for such children estimated at \$1.4 million" (Edmonton Journal 2007). In addition, a focus on the need to decrease FASD prevalence was associated with public health concerns, e.g., "Brain damage from alcohol exposure in the womb is the leading preventable cause of mental retardation in the Western world" (Globe and Mail 2010). Notably, FAS prevalence was sometimes conflated with FASD prevalence – e.g., "...[FAS], a developmental disorder that affects about one in every 100 Canadian children" (Vancouver Sun 2005), "about one in 100 people have FASD" (Winnipeg Free Press 2010) – with only a few articles making the distinction, e.g., "Health

Canada estimates nine in every 1000 babies born here have FASD; one to three of those babies will have full [FAS]" (Calgary Herald 2005).

### **Research related to FASD: Levels of prenatal alcohol exposure – Inconsistent definitions, findings, and variables across the sample**

Many articles used the amount of alcohol consumed while pregnant as a stand-in for prenatal alcohol exposure. Definitions of these amounts differed across the sample, as in the case of 'light drinking', e.g., "... light drinkers had a mean consumption of a drink a week" (Winnipeg Free Press 2002), "light drinking during pregnancy says one study... found detectable 'deficits'... at exposure levels of less than one drink a day" (Edmonton Journal 2007); however, a few articles explicitly commented on this confusion, e.g., "...people tend to vary in what is considered light drinking" (Winnipeg Free Press 2010). In addition, the definition of a standard drink differed between reports, e.g., "355 mL of beer or 118 mL of wine" (Calgary Herald 2006), "175 [mL] of wine... or just under a pint of beer" (Vancouver Sun 2009). Articles also presented inconsistent findings across the sample, suggesting that light drinking 1) caused harm, e.g., "[children] whose mothers drank even lightly were shorter, lighter and had smaller head circumferences" (The Globe and Mail 2003); 2) caused no harm, e.g., "light drinking is fine" (Vancouver Province 2013); or 3) was potentially beneficial, e.g., "... [babies of mothers who drank lightly] were markedly less likely to demonstrate behavioural problems" (Winnipeg Free Press 2010). The articles that reported potential benefits of alcohol all pointed to a British study first published online in 2010 [29]. Finally, the variables measured to indicate harm varied between studies, and included anything from physical features – e.g., "detectable 'deficits' in height..." (Edmonton Journal 2007) – to behavioural features, e.g., "3.2 times more likely to have behaviour and aggression problems" (Montreal Gazette 2007).

## **Clinical content**

**Table 2 – Clinical Content Results: Coding Structure and Examples**

<b>Code</b>	<b>Sub-code</b>	<b>Scope</b>	<b>% of sample &amp; total number of articles</b>	<b>Examples</b>
Diagnosis of FASD		Article reports on FASD diagnosis. Includes examples from Research related to FASD sub-code on diagnosis and screening.	20% (n=58)	
	Diagnostic challenges	Article reports on real-world challenges in diagnosing FASD. Includes discussions about misdiagnosis (see text).	19% (n=55)	"But it's often an invisible brain injury, difficult to diagnose and masked by articulate speech and regular appearance" (Ottawa Citizen 2015).
	Diagnostic process	Article reports on different elements of the FASD diagnostic process. Includes both medical and logistical processes.	8% (n=24)	"Everyone from defence lawyers to judges to probation officers can refer a youth to the program, where a team of co-ordinators does an initial screen... even tracking down biological mothers to ask if they drank..." (Edmonton Journal 2010).
	Diagnostic criteria	Article reports explicit and clear features of FAS (not FASD) that may lead to diagnosis.	2% (n=6)	"Physicians make the diagnosis of FAS in children who exhibit a small head, characteristic features of the face and cognitive and neurological abnormalities" (Winnipeg Free Press 2002).
Treatment of FASD and maternal substance abuse		Article reports on treatments for elements of FASD, or, in a minority of cases, alcohol addiction for pregnant women. The latter case does not necessarily reflect a causal connection between addiction and FASD, but rather, one target for treatment in the context of our sample (which included the term "alcohol and pregnancy", independent of FASD). Includes interventions for features of FASD. Includes examples from Research related to FASD sub-code on treatment and prevention.	28% (n=80)	"The Ministry of Education is trying to change attitudes and help students with FASD succeed in school through the Provincial Outreach Program for FASD..." (Vancouver Sun 2010).

Primary disabilities associated with FASD		Article reports on features, symptoms, or disabilities associated with FASD. Includes examples from Research related to FASD sub-code on primary disabilities. Excludes social concerns sometimes described as secondary disabilities (e.g., homelessness).	48% (n=136)	
	Cognitive and behavioural features of FASD	Article reports examples of primary social, behavioural, cognitive, & emotional features of FASD. Includes broad range of features, categorized differently across articles.	42% (n=121)	"The consequence of these physical changes can be profound... impairment of fine motor skills, hearing loss, ability to coordinate gait and hand-eye functions. From these deficits cascade a host of others... Subsequent learning difficulties involve poor capacity for abstract thought, which limits development of mathematical and language skills, all compounded by problems with memory, attention span and poor judgment" (The Vancouver Sun 2005).
	Physical features of FASD	Article reports examples of primary physical features of FASD. Includes facial features, and growth, organ, and sensorimotor issues.	28% (n=80)	"...a very thin upper lip and no groove between the upper lip and nose" (Calgary Herald 2012), "Other defects include malformation of such organs as the heart, liver, and kidneys. Vision and hearing problems..." (Montreal Gazette 2008)
Effects of alcohol exposure during pregnancy		Article reports on concerns about the impact of different variables related to alcohol consumption on FASD outcomes (see text). Includes examples from Research related to FASD sub-code on levels of prenatal alcohol exposure. Note that in text, four further subdivisions are reported that were not assessed for inter-coder reliability.	19% (n=55)	"I have patients who think a couple of beers a day is not an issue. And the question is, is it an issue? That's what we're going to look at,'... She said one doctor may tell a pregnant woman, or one trying to get pregnant, 'don't drink at all,' while another may say 'moderate drinking' is OK." (Edmonton Journal 2009).

### ***Diagnosis of FASD: Diagnostic challenges – Medical, healthcare systems, and social barriers***

A main challenge identified in the articles was the issue of delaying or missing diagnosis, and its consequences, e.g., "Being misdiagnosed can have serious lifelong effects because children miss out on specialized therapy" (Vancouver Sun 2005). Otherwise, three broad kinds of challenges were reported: 1) medical barriers; 2) healthcare system barriers; and 3) social barriers. *Medical barriers* included issues like difficulty identifying and defining features across a wide spectrum of disabilities, e.g., "Because it's a spectrum disorder, effects can range from very subtle to full-blown and intense. You don't know what you're dealing with" (Calgary Herald 2005), or a lack of appropriate tests. *Healthcare system barriers* included issues like lengthy waitlists, difficulty accessing diagnostic services based on location (e.g., "...and many kids in rural and remote communities never get diagnosed" (Winnipeg Free Press 2010)) or age (e.g., "...only children can get a diagnosis.... Adults are out of luck." (Winnipeg Free Press 2013)), or limited resources (e.g., "If resources were available, justice staff say they could send five times that many kids with suspected FASD to the clinic" (Edmonton Journal 2010)). *Social barriers* included issues like possible racial biases (e.g., "FASD is also seen as an aboriginal disease, so it goes under-reported among non-aboriginals" (Winnipeg Free Press 2011)), or a reluctance to report drinking while pregnant (e.g., "Researchers say the number is an underestimate because... mothers [...] fear the stigma from admitting they drank alcohol while pregnant" (Ottawa Citizen 2015)).

### ***Treatment of FASD – Early social interventions for people with FASD and at-risk women***

For the treatment of people with FASD, an emphasis was placed on early interventions, e.g., "The sooner a baby is properly diagnosed, the faster special social and education services can be provided" (Montreal Gazette 2006). Most discussed interventions had social goals, like stopping criminal behaviour, e.g., "The... FASD program is designed to aid youths with the disorder before their troubles either land them in jail or in harm's way" (Winnipeg Free Press 2006). Very few articles mentioned biomedical treatments. The few options mentioned were speculative or novel, e.g., "...vitamin A could act almost like an antidote to the effects of alcohol on very early embryos..." (Edmonton Journal 2011). While most articles discussing the treatment of at-risk women focused on treating alcoholism, a few editorials suggested extreme measures that included criminalization and forced interventions, e.g., "These doped-up druggies should be sterilized after the second child..." (Calgary Herald 2005).

### ***Effects of alcohol exposure during pregnancy***

#### ***Alcohol consumption – Abstention advice and uncertainty***

Many articles mentioned that a) women should not drink alcohol when pregnant (e.g., "The best advice is to abstain from alcohol while expecting a baby" (Calgary Herald 2006)) or that b) alcohol is never safe for pregnant women (e.g., "But [the doctor] stressed modern evidence shows no amount is safe" (Toronto Star 2015)). Additionally, several articles mentioned uncertainty about the link between alcohol consumption and FASD outcomes, with a few framing uncertainty as the reason for advising abstinence, e.g., "[She] is correct that no one knows what amount of alcohol during pregnancy is safe. That's why [many organizations] recommend that the most prudent choice for women who are pregnant is to abstain from alcohol" (Ottawa Citizen 2002).

### **Alcohol consumption – Cross-border debates about harmful amounts**

Many articles mentioned how much drinking can harm a fetus, e.g., “A number of studies have linked heavy drinking on a regular basis during pregnancy to stunted growth, birth defects and brain development problems” (National Post 2007). These articles described harm as caused by: 1) heavy drinking, 2) single or occasional binges, 3) drinking in moderation or moderate amounts, 4) light drinking, and 5) a single drink. In contrast, several of these articles discussed British research and policy contradicting advice that any amount of alcohol is harmful: “...it’s safe to drink a little bit of alcohol during pregnancy... experts have concluded ‘no consistent evidence’ exists that low-to-moderate alcohol consumption during pregnancy – less than one drink per day – is harmful to the fetus after the first three months of pregnancy, though they can’t rule out risk completely” (Vancouver Sun 2007). Suggestions that some alcohol is acceptable were based on: 1) reports of new British guidelines, based on inconsistent evidence; 2) parenting books suggesting inconsistent evidence; 3) research suggesting a lack of evidence connecting light drinking or occasional binge drinking to harm; and 4) a study suggesting that a little alcohol when pregnant may prove beneficial. Various amounts were described as relatively safe, including: 1) low-to-moderate amounts; 2) light amounts; and 3) even occasional binge drinking. Several articles outlined how Canadian experts found the British approach surprising, e.g., “[The doctor]... called the British move ‘scary.’ ‘It’s quite shocking for us to see it. It neglects, or just ignores, a huge body of evidence that does show mild drinking does cause issues’” (Edmonton Journal 2007). Of the articles suggesting the possibility of no harm after light or moderate drinking, only a few did not cite these British sources.

### **Drinking advice about risk factors for FASD development**

Drinking advice focused on the safety of 1) different amounts of alcohol; 2) alcohol at different times; or 3) different kinds of alcohol. Fewer articles mentioned other factors besides alcohol involved in assessing risk. A few of these articles specified that not only alcoholics have children with FASD, e.g., “The first myth is that FASD only occurs in alcohol-dependent women. All women are at risk.” (Ottawa Citizen 2015).

### **Concerns about publicly communicating information about alcohol and pregnancy**

Several articles outlined concerns about communication and public understanding of the risks of alcohol consumption during pregnancy. These included concerns about mixed messages leading to confusion (e.g., “Even her own doctor advised her to drink one or two gins to settle her stomach as a cure for morning sickness” (Vancouver Sun 2010)), and tension about what or how to tell women (e.g., “[The adoptive mother]... thinks it is ‘mind-boggling irresponsible’ for anyone to produce pregnancy materials that even hint at the possibility that drinking during pregnancy might be acceptable” (Toronto Star 2011)).

## **Discussion**

Stigma surrounding FASD has been identified as an important issue for both individuals who are affected by FASD as well as women who give birth to children with FASD [12]. The implications of this stigma include negatively-affected life trajectories for individuals with FASD and fear of blame [30] and criminalization for women who drink while pregnant [31,32]. Our analysis of scientific and clinical print media content about FASD provides an overview of key science and health-oriented FASD themes to which the Canadian public could be exposed, and which could, in part, contribute to stereotyped understandings of FASD. We identified six themes related to scientific and clinical content (see Tables 1 and 2 respectively). Across these themes, we now explore three ethical concerns about this discourse that could perpetuate or produce stigma: 1) exaggeration about FASD rates in Indigenous communities, which could lead to harmful stereotyped beliefs about Indigenous peoples; 2) contradiction between articles about the effects of prenatal alcohol exposure, which might cause confusion about healthy choices during pregnancy; and 3) scientifically accurate information that neglects social context, which might unhelpfully inflame debates about sensitive issues (e.g., whether pregnant women should be punished for drinking alcohol). To discuss these issues, we take a two-pronged approach: 1) we compare information reported in the media with scientific literature, and 2) we discuss why we think each problem could perpetuate stigma about FASD.

### **Exaggeration: A potential source of harmful stereotypes about Indigenous peoples in Canada**

Exaggeration beyond a given set of research findings can raise serious ethical concerns. For example, if hyperbolic and misleading claims are granted the veneer of scientific legitimacy by experts, previously untenable positions become more easily (if wrongly) defensible.<sup>3</sup> And while the goal of much research is to create generalizable knowledge, there exists a fine line between appropriately generalized claims and inappropriate exaggeration. When those claims begin to impact the social world, and beliefs about particular groups of people, there exists a danger of endorsing positions that turn generalizations into stereotypes. In this section, we explore current FASD prevalence data in Canada, and then discuss some of the reasons why Indigenous communities might have or be seen as having higher rates of FASD.

<sup>3</sup> We want to emphasize that possible sources of exaggeration in media also include academic institutions and researchers, not only journalists and news editors. For example, a 2014 study by Sumner [33] concluded that “exaggeration in news is strongly associated with exaggeration in [institutional] press releases”. Additionally, a 2015 study by Vinkers et al [34] found an increase in the use of superlatives (e.g., novel, innovative), and negative terms to a lesser extent, in scientific abstracts published from 1974-2014, concluding frankly that “scientists may assume that results and their implications have to be exaggerated and overstated in order to get published”. Hype and exaggeration should be explored more thoroughly both within academic contexts as well as outside of them.



### ***FASD prevalence in the general population: A case of limited data and extrapolation***

Most conservative estimates suggest that FASD affects roughly 9 in 1000 Canadians [35]. However, given a lack of Canadian prevalence studies, this estimate has relied on American and European data from the 1980s and 1990s [1,2]. This means that we do not know what proportion of the Canadian population has FASD [1]. When journalists, the experts interviewed, or editorial writers reported rates of roughly 1 in 100, and then translated that into “330,000 Canadians” or “11,000 Manitobans”, they extrapolated based on external estimates combined with Canadian demographic data; these numbers do not necessarily represent diagnosed cases. That was rarely done transparently – although, as reported, a fair number of articles qualified these estimates with uncertainty, indicating a general acknowledgement of the limitations of current knowledge. Ultimately, readers could have assumed that these estimates were based on studies of the general population of Canada, when none exist.

### ***Exaggerated FASD prevalence reported in Indigenous communities***

The epidemiological studies that do exist in Canada have been done with subpopulations often deemed vulnerable, such as Indigenous peoples and criminal offenders [36], and sometimes at the intersection of these populations. Most of this work has been conducted in western Canadian provinces (i.e., Saskatchewan, Manitoba, and British Columbia), which aligns with our observation that most Canadian news coverage about FASD has emerged from those provinces. Despite variations in prevalence across studies, most of these subpopulation studies found rates far higher than the expected 1 in 100 (e.g., 1 in 10). In the case of Indigenous populations, these studies were conducted on specific, often remote reserves, with results that likely cannot be generalized to all Indigenous communities or groups; however, several news articles did not specify the region of study, simply reporting higher rates for Indigenous people overall – an exaggeration beyond existing findings. The results of these prior prevalence studies should not be taken as suggesting that all Indigenous groups are at higher risk for FASD, or that all Indigenous communities actually have higher rates.

### ***What factors might contribute to exaggeration of FASD prevalence in Indigenous communities?***

Concern about an exaggerated focus on Indigenous peoples reaches beyond the media. A disproportionate focus on FASD research in Indigenous groups in Canada – and a corresponding lack of research in the general population – may also contribute to exaggerated beliefs and assumptions about which groups are most affected by FASD. For example, one recent study noted that 51 of 52 reports on neurodevelopmental disabilities in Indigenous communities in Canada since 1981 focused exclusively on FASD (rather than other neurodevelopmental disabilities, like autism or cerebral palsy) [37]. Such biases in research could be fueled in part by common stereotypes attributed to Indigenous individuals (e.g., irresponsible drinking) [38], which may themselves be perpetuated in the kind of discourse we have analyzed here. This kind of reporting could lead to misconceptions about FASD as an Indigenous-only problem [37], which could lead to over-diagnosis or misdiagnosis of FASD in Indigenous peoples (see work by Tait for a more detailed exploration of this topic [39]). Beyond the FASD context, the needs of Indigenous peoples in Canada do not always match the goals of Canadian health research [40].

Articles addressing prevalence among Indigenous communities sometimes sought to mitigate the harm of problematic racial stereotypes; however, they did not analyze the situation in depth. Only one article in the sample featured an explanation for why some Indigenous people have FASD: “The grandmother is a survivor of the Indian residential school system who had her share of trouble with alcohol, a rough crowd and an abusive relationship as a young mother. ‘That’s how my children saw me... I passed it on’” (Winnipeg Free Press 2011). It is important to keep in mind that Canada’s racist residential school system kidnapped Indigenous children from their families, forcing them to assimilate – stripping them of their languages and cultural practices (sometimes referred to as ‘cultural genocide’) [41]. Many suffered from abuse, and many other children died. Residential schools are only one recent example of forced assimilation in Canada, the effects of which are still felt today in some Indigenous communities where high suicide rates, increased alcohol consumption, disproportionate prison representation, and poor health outcomes can be prevalent [42].

Only a few articles implied a connection between a history of colonialism, any potential alcoholism, and FASD, presenting the information in a list of facts that allowed readers to draw their own conclusions: “98% of adults are alcoholics. That includes 99% of the community’s residential school survivors” (National Post 2007). Readers here are given little context as to why some Indigenous groups might drink more. The public could therefore interpret this in a way that conforms to pernicious, racist stereotypes about Indigenous peoples. This situation stands in stark contrast to the recent Calls to Action of the Truth and Reconciliation Commission of Canada regarding “media and reconciliation”, calling for more comprehensive coverage of Indigenous populations with a specific focus on and careful attention to the history and legacy of residential schools in Canada (Call to Action 84, point iii) [41].<sup>4</sup>

### **Contradictions between articles about the effects of prenatal alcohol exposure: A potential source of confusion**

Identifying causal links between different amounts of alcohol, prenatal alcohol exposure, and developmental outcomes remains difficult given a number of confounding variables (e.g., genetics, metabolism, socioeconomic status). This complexity can pose a major challenge to communicating clear public health information. Consequently, many health

<sup>4</sup> We should note that Calls to Action 33 and 34 explicitly address the issue of FASD in Indigenous communities [41]. Action 33 calls for FASD prevention programs developed collaboratively and “delivered in a culturally appropriate manner”. Action 34 calls for criminal justice reforms for offenders with FASD. The latter Call to Action reflects concerns seen in our data in discussions about Indigenous communities, FASD, and criminal behaviour. Please see our other manuscript based on this dataset for further discussion of the connection between crime and FASD [26].

organizations, including the Public Health Agency of Canada [43], favour the message that no amount of alcohol is safe to drink at any time during a pregnancy. When this topic was raised in our media sample, the ‘no alcohol’ message was dominant; however, contradictions between articles appeared as we analyzed the whole sample. For example, as reported, light drinking was presented as harming, not harming, and even helping child development – with different definitions of light drinking presented. These contradictions could lead to public confusion about whether or not drinking small amounts of alcohol is harmful when pregnant, despite attempts at clear public health messaging.

### ***Contradiction about how much alcohol can harm a fetus in the academic literature***

High levels of prenatal alcohol exposure, linked to heavy regular drinking or bingeing, can have a negative impact on neurodevelopment [44]. This amount of alcohol does not have an impact in each and every case, but increased prenatal alcohol exposure is generally associated with increased risk of FASD [45]. In contrast, debate continues over the effects of light – and to a lesser extent moderate – prenatal alcohol exposure [46]. Depending on the outcomes measured (e.g., IQ, head size), the definition of light drinking, the variables controlled for, or the population studied, light drinking has been found to be both harmful [47] and not harmful [48]. The overall evidence seems to be weighted toward ‘not harmful’, but uncertainties that persist in the academic literature appear to extend into the public sphere, potentially contributing to conflicting medical advice about alcohol use – i.e., some evidence suggests that medical professionals may not broach the topic of alcohol with their pregnant patients beyond routine screening, or else might provide unspecific advice about medical risks, partly to ease patient anxieties [49].

### ***When can clear and certain messaging backfire – and what messages might work better?***

Although clear messaging and discourse that fosters negative public attitudes toward drinking while pregnant can be useful from a public health perspective (i.e., discouraging unhealthy behaviour at the population level), it could also unhelpfully stigmatise individual women who do drink [12,50]. The clarity and certainty of abstinence messaging could, in some cases, have an effect opposite to the one intended, rigidifying public opinion against women most in need of support, and driving those women ‘underground’ [31]. Concerns about drinking have even begun to expand beyond the category of pregnancy, as medical advice shifts toward the implication that fertile women live in a constant state of pre-pregnancy. For example, recent CDC advice to doctors suggested they should “recommend birth control to women who are having sex (if appropriate), not planning to get pregnant, and drinking alcohol” [51]. In this way, responsibility and blame for FASD largely lands on women alone [32,52]. This concern is highlighted by the fact that barely any of the articles in our sample mentioned the contribution of family, partners, or social circles to an alcohol-free pregnancy. If both alcohol use and parenthood were understood in more community-oriented terms, rather than as the individual actions and responsibilities of solitary women, prevention methods and messages could shift toward social support, rather than blame and shame.<sup>5</sup>

However, even with less judgmental and more community-oriented approaches, the problem of uncertainty remains. A clear tension exists between 1) public health and medical guidelines requiring clear and actionable messages; 2) ensuring that marginalized women feel supported throughout their pregnancies; and 3) the importance of communicating the truth about research findings – even if that truth involves complexities. If media were to communicate only the clear but rigid message of abstinence in all cases, then the previously outlined issues of stigmatisation could arise, along with questions about paternalistic approaches to women’s healthcare [53]; however, if contradictions are reported without care, some worry that this could provide women with a “license to drink” [50]. In our sample, contradiction more often appeared without comment between, rather than within, articles. To that end, a kind of compromise could be reached, whereby news articles could try to place such claims in the context of the literature – emphasizing both the public health messages and the current state of research together.

### **Accurate science and health information, without context: A source of stigma?**

Even if science and health communication were completely accurate, the social context of the research in question may nevertheless be considerably important. Presenting only the ‘facts of the matter’ without an understanding of this context could unnecessarily inflame tensions, and further stigmatise affected groups. For example, presenting Indigenous prevalence data without qualification could exacerbate racial tensions in Canada, which, again, goes against the spirit of the Truth and Reconciliation Commission’s Calls to Action [41]. In this section, we examine the importance of social context for better understanding different dimensions of FASD.

### ***Social context and women who drink while pregnant***

While it is technically true that “FASD... is 100 per cent preventable” (Calgary Herald, 2005) – in the sense that if all pregnant women abstained from alcohol, no child would ever be born with FASD – women typically have reasons for drinking that are not so easily addressed. For example, some struggle with addiction, or use alcohol as a coping mechanism, while others are entirely unaware of their pregnancy [54]. Explaining the social context of alcohol use is therefore both constitutive of a truly scientific understanding of FASD and necessary so as to avoid simplistic public narratives about alcohol and pregnancy. Failing to critically attend to reasons for drinking ultimately feeds into narratives that emphasize maternal blame and shame, which could have the unintended effect of making it more difficult for women to reach out for help [31], or can lead to punitive rather than rehabilitative or supportive interventions. In our sample, although a few articles

<sup>5</sup> For a more detailed discussion of gendered concerns around how and why women can sometimes be framed as the sole actor responsible for the wellbeing of their children – and where blame and shame can become criminalization and forced intervention – see [26].

explored how women might need a non-judgmental environment in which to seek assistance, most described FASD as “the leading cause of” preventable disability, some even going so far as to describe FASD as “easily” or “highly” preventable. Calls for public acknowledgement of more critical and nuanced messaging were few; most media discourse concluded that abstinence-only messaging remains both necessary and appropriate. Concerns about stigmatisation could be a strong reason to re-examine current prevention messaging and awareness campaigns, to better understand unwanted or unintended side-effects of FASD discourse. If FASD is seen as easily preventable, then women who fail in the task of prevention can be more easily marginalized.

### ***Social context and people with FASD***

In the case of people with FASD, discourse was often negative, even hopeless – e.g., as reported, people with FASD were sometimes described as a financial burden on society. People with FASD were commonly described as victims (e.g., of ‘irresponsible mothers’, of crime) [26], and long lists of symptoms categorized, organized, and explained differently in each case served as unqualified examples of their suffering. And while we should never dismiss the self-reported struggles and pain of people with FASD, focusing so strongly on weaknesses and challenges, rather than on any strengths and successes, painted their lives rather bleakly. Ultimately, framing FASD as hopeless and desirably preventable might also stigmatise people currently living with the diagnosis. Hopelessness could contribute to the sense that nothing can be done (leading to limited or poor interventions and support), while prevention framing raises concerns similar to the ‘expressivist objection’: that “prenatal diagnosis expresses a discriminatory or negative attitude towards people with disability” [55]. Managing the tension between respecting individuals who have already been born with FASD, and the desire to prevent individuals from being born with it in the future, should be carefully considered. Within prevention efforts, how scientists, healthcare professionals, journalists, and members of the public choose to talk about FASD as unwanted could have a major impact on the lives of people with FASD. The framing of health and science information matters; it is important to acknowledge the social context in which research and medicine are embedded.

### **Limitations**

This study has several limitations, which we have reported in full elsewhere, some of which is reprinted here or specific to this text [26]. First, we only searched for keywords in article headlines and lead paragraphs to ensure that they were central to the story being told. Second, our sample focused on stories from the most-distributed newspapers in Canada, which meant only those in Canada’s larger cities and provinces. Third, there were several limitations tied to the availability of sources. For example, Factiva only included major French newspapers in Canada as of 2011. While we do not know if these sources discussed FASD before 2011, no articles were found from 2011-2015. This could be due to differences in knowledge across Canada [6-8], differences in attitudes about drinking [56], or our choice of keywords. Three sources also have minor gaps in database coverage (i.e., the *Toronto Star*, the *Edmonton Journal*, and the *Vancouver Province*). In addition, as of 2010, six of ten newspapers were owned by a single corporation (Postmedia), which might have had an influence on the kind of coverage we analyzed. Fourth, most of the discarded codes that failed the reliability test related to key issues in the study of and care for people with FASD – specifically, prevention and FASD’s cause. In part, the theme of prevention overlaps with our analysis of the theme of treatment, since care for at-risk or alcoholic mothers often serves as FASD prevention. In the case of FASD’s cause, while we lack a detailed analysis, several other codes clarified relevant variables connected to risks for having a child with FASD, so the missing analysis has been partly addressed elsewhere. Finally, we did not undertake separate analyses on the impact of events that could have led to increased or decreased media coverage (e.g., the CIHR award for *Winnipeg Free Press* coverage of FASD).

### **Conclusion**

Our analysis of science and health content in Canadian newspaper articles discussing FASD identified six key themes: 1) prevalence of FASD and of women’s alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy. These results were discussed in light of three major concerns: 1) exaggeration about FASD rates in Indigenous communities, which could perpetuate harmful stereotypes and myths about Indigenous peoples (e.g., ‘the drunk Indian’); 2) contradiction between articles about the effects of prenatal alcohol exposure, which could create public confusion; and 3) scientifically accurate (but incomplete) information that neglects the social context of alcohol use/abuse by women, which could unnecessarily inflame social tensions and attitudes toward marginalized group (e.g., leading to calls for pregnant women who drink to be ‘locked up’). Looking forward, ethical considerations surrounding communication about FASD, alcohol, and pregnancy in the public sphere should be further explored, to better understand, recommend, and test more appropriate messaging, especially in the context of stigmatisation, scientific uncertainty, and stereotyping about Indigenous peoples, women who consume alcohol during pregnancy, and people with disabilities. We hope that such work and coverage would help improve public attitudes, social accommodations, and opportunities or programs for support.

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## Conflits d'intérêts

Aucun à déclarer

## Responsabilités des évaluateurs externes

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateurs n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la [Revue canadienne de bioéthique](#) assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

**Édition/Editors:** Lise Levesque, Emmanuelle Batisse & Aliya Afhdal

**Évaluation/Peer-Review:** Chris Hackler & Michelle Stewart

## Affiliations

<sup>1</sup> Neuroethics Research Unit, Institut de recherches cliniques de Montréal, Montreal, Canada

<sup>2</sup> Integrated Program in Neuroscience, McGill University, Montreal, Canada

<sup>3</sup> Biomedical Ethics Unit, Experimental Medicine, McGill University, Montreal, Canada

<sup>4</sup> Department of Neurology and Neurosurgery, McGill University, Montreal, Canada

<sup>5</sup> Department of Psychology, Faculty of Social Sciences and Humanities, Douglas College, New Westminster, Canada

<sup>6</sup> Department of Medicine and Department of Social and Preventive Medicine, Université de Montréal, Montréal, Canada

<sup>7</sup> Department of Neurology and Neurosurgery, Experimental Medicine, McGill University, Montreal, Canada

**Correspondance / Correspondence:** Eric Racine, [eric.racine@ircm.qc.ca](mailto:eric.racine@ircm.qc.ca)

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None to declare

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