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# ▶ Fetal alcohol spectrum disorder: a systematic review of the cost of and savings from prevention in the United States and Canada.

Greenmyer J.R., Popova S., Klug M.G. et al.

Addiction: 2019, 115, p. 409-417.

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Study set in Canada and the United States finds more than enough financial justification for expanding prevention of foetal alcohol spectrum disorders. But what does 'expansion' mean – universal prevention, or focusing resources on those most at risk?

**SUMMARY** Foetal alcohol spectrum disorders are lifelong physical, behavioural, and cognitive disabilities caused by foetal exposure to alcohol. Despite the significant cost to society, only 0.19% of the total cost of foetal alcohol spectrum disorders is used to fund research and prevention in the United States (a 526-fold difference), and only 0.4% of the total cost of foetal alcohol spectrum disorders is spent in Canada (a 250-fold difference).

Prevention programmes have been successful in reducing maternal drinking during pregnancy and the prevalence of foetal alcohol spectrum disorders (1 2 3). The Parent–Child Assistance Program (P-CAP) is an example of a well-established and effective prevention programme for alcohol- and drug-exposed pregnancies, which incorporates case management, home visitation, and harm reduction. P-CAP was launched by the University of Washington in the United States, and has been replicated at 40 sites in Canada. It enrols women who are pregnant or up to six-months postpartum and currently drinking alcohol or using drugs.

The featured paper sought to understand if increasing funding for prevention programmes in the United States and Canada could reduce overall spending, taking into account the cost of care for an individual with foetal alcohol spectrum disorder.

The review used the following data:

- the cost of prevention per case for foetal alcohol spectrum disorders:
- the annual cost for all individuals with foetal alcohol spectrum disorders:
- the estimated lifetime cost of care for an individual with foetal alcohol spectrum disorder.

All values were updated to 2017 currency.

## Key points From summary and commentary

Foetal alcohol spectrum disorder is a preventable condition with a significant cost to society. Yet, in the United States and Canada only a very small proportion of the total costs of foetal alcohol spectrum disorders is used to fund research and prevention.

The featured review found that increasing spending on prevention programmes to just 1% of the estimated costs of care for people with foetal alcohol spectrum disorders would be economically worthwhile.

Prevention strategies with the greatest potential cost-savings prioritise women at high risk of having a child with foetal alcohol spectrum disorder, especially women who have already had a child with foetal alcohol spectrum disorder, and women of low socioeconomic status who are heavy drinkers and smokers, and have poor diets.

### Main findings

### Cost of prevention

In the US, estimates of the cost to prevent foetal alcohol spectrum disorders vary dramatically based on the risk factors of the woman participating. The estimated cost per prevented case of foetal alcohol spectrum disorders was \$134,810,000 among women who drink compared to \$20,200 for the highest-risk population, women who have had a previous child with foetal alcohol syndrome. Another high-risk population was women who were heavy drinkers and smokers with a low income, costing \$316,800 to prevent one case.

Under the P-CAP model in Washington State (United States), the cost to prevent one case of foetal alcohol spectrum disorder was \$47,615 when the programme focused on treating women who have had a previous child with foetal alcohol spectrum disorder. In Alberta (Canada), the cost of preventing one case of foetal alcohol spectrum disorder averaged \$99,400 (\$76,390-\$162,329 range), focusing on women with heavy alcohol consumption.

### Savings from prevention

Estimates of the annual cost of care for foetal alcohol spectrum disorders in the United States range from \$1.29–10.1 billion (1 2). If prevention services received 1% of the estimated cost of care, funding would be in the region of \$12,900,000-\$101,000,000.

Targeting the highest-risk women, the cost to prevent one case of foetal alcohol spectrum disorder was estimated at \$47,615. Using low and high estimates of the cost of care, funding at 1% of this could prevent between 270 and 2,121 cases through the P-CAP model in Washington State.

The lifetime cost of care for one case of foetal alcohol spectrum disorders in the United States is \$1.24 million which means that, for every case prevented, society saves \$1.24 million in spending. Therefore, the net savings of funding a similar prevention programme to P-CAP in Washington State at the level of 1% the national cost of care is predicted to be between \$326,220,000 and \$2,562,976,000.

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In North Dakota (United States), it costs approximately \$316,800 to prevent one case of foetal alcohol spectrum disorders among women with low income who are simultaneously heavy drinkers and smokers. Using the high and low values of 1% theoretical funding, this equates to between 40 and 318 prevented cases and net savings of \$37,340,000 to \$298,408,000. By further classifying maternal risk factors and focusing on women with a previous child with foetal alcohol spectrum disorders, between 638 and 5,000 cases would be prevented. This would save the United States between \$788,428,000 and \$6,179,000,000.

Annual costs of care for foetal alcohol spectrum disorders in Canada are estimated at \$1.9–10.5 billion (1 2 3). Funding the equivalent of 1% of the annual national cost of care would be \$19,000,000 to \$105,000,000. The cost to prevent one case of foetal alcohol spectrum disorders among women with heavy alcohol consumption in the P-CAP programme is \$102,914. Using the high and low estimates for 1% funding predicts between 184 and 1,020 prevented cases. The lifetime cost of care for one case of foetal alcohol spectrum disorders in Canada is \$849,000. Based on the cost of prevention estimates for Alberta (Canada), P-CAP funding equivalent to 1% the annual cost of care would provide net savings of \$137,216,000 to \$761,208,679.

#### **Additional savings**

Experts in the field were also consulted to identify studies and data not found by the review of papers. This highlighted that economic benefits of the P-CAP model are not limited to prevention of foetal alcohol spectrum disorders. Other sources of significant cost–savings would include decreasing the time taken for birth parents to be reunified with their children if they have been taken into foster care, reducing dependence on public assistance, increasing employment, and increasing levels of education.

### The authors' conclusions

There have been relatively few attempts to calculate the cost-savings of prevention for foetal alcohol spectrum disorders, though what studies there are demonstrate the large return on investment that established prevention models in Canada and the United States are able to provide. In addition to the economic incentives, the intangible costs (suffering) that could be alleviated should encourage policymakers to invest in prevention of foetal alcohol spectrum disorders.

Prevention strategies with the greatest potential cost-savings are those that prioritise women at high risk of having a child with foetal alcohol spectrum disorder, including: (1) women who have already had a child with foetal alcohol spectrum disorder; and (2) women of low socioeconomic status who are heavy drinkers and smokers, and have poor diets.

Studies of costs and savings are based on prevention programmes which have the infrastructure already in place. If more funding was to be funnelled towards prevention, the cost of prevention may transiently rise as there would be an increased cost associated with training healthcare professionals.

**FINDINGS COMMENTARY** The featured review compiled data on the costs and savings of foetal alcohol spectrum disorder prevention programmes in the United States and Canada, concluding that there is more than enough financial justification for further investment in prevention, and the optimal place to start would be with women at high risk of having a child with a foetal alcohol spectrum disorder. Due to the study analysing data and prevention programmes specific to the North American context, its findings are not directly applicable to the UK. However, the study is nonetheless an important addition to the evidence base and discourse about how to tackle alcohol-related harm during pregnancy in Britain, where there is currently no nationwide strategy for, or clinical guideline on, the prevention, diagnosis, and treatment of foetal alcohol spectrum disorders.

Some of the studies used to inform the estimates of costs and savings specified 'foetal alcohol syndrome' as opposed to 'foetal alcohol spectrum disorder' – the former referring to a condition indicated by abnormalities of the central nervous system and a specific pattern of facial abnormalities and growth impairment, and the latter referring to the broader category or continuum of birth defects caused by maternal drinking, of which foetal alcohol syndrome is one type. As the British Medical Association says:

"While [foetal alcohol syndrome] is widely accepted as a clearly diagnosable disorder, the clinical features of other forms of [foetal alcohol spectrum disorder] ... are less well defined and subject to considerable debate."

"In the UK, data on the incidences of [foetal alcohol spectrum disorder] are extremely limited, and are restricted to [foetal alcohol syndrome]."

What this probably means is that the full extent of harm caused by drinking during pregnancy was not accounted for, and therefore the study may have underestimated the costs and limited the savings to people at the higher end of the spectrum of harm.

The highest-risk group identified in the featured study was women who have already had a child with foetal alcohol spectrum disorder. Implementing an intervention which successfully reaches this group hinges on foetal alcohol spectrum disorder being diagnosed in the first place. This is a particular pinch point in the UK, where there is a lack of data on the prevalence of foetal alcohol spectrum disorders, and what little there is suggests an unrealistically low occurrence stemming from under-diagnosis. Based on clinical experience and published evidence, reasons for this are said to include:

- failure to consider prenatal alcohol exposure as a possible cause of neurodevelopmental delay and/or behavioural difficulties;
- lack of a standardised diagnostic approach and training in its use, lack of expertise and/or confidence in making a diagnosis, lack of referral in order for children to be appropriately assessed, and reluctance to make a diagnosis where it is perceived to be unhelpful or more damaging than not making a diagnosis;
- additional substance use problems in mothers overshadowing the potential for prenatal alcohol exposure and features of foetal alcohol spectrum disorders.

Knowing the prevalence of foetal alcohol spectrum disorders is essential for informing treatment and prevention. Attempting to compensate for the gap in formal diagnoses, a 2018 study applied three novel methods of estimating the prevalence, putting the proportion of the population with foetal alcohol spectrum disorders somewhere between 6% and 17%. These figures are high, but are also in line with other European estimates and explain why foetal alcohol spectrum disorders are understood to be "the most common non-

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genetic cause of learning disability in the UK".

In 2018, Deputy Chief Medical Officer Professor Gina Radford co-hosted two stakeholder events with the National Organisation for Foetal Alcohol Syndrome (NOFAS) to discuss the evidence base about foetal alcohol spectrum disorders, facilitate the sharing of good practice, identify problem areas, and consider options for the development of future policy. Key messages from the events were that: there is no central data on foetal alcohol spectrum disorders; not enough is happening on prevention, women still think they can safely consume alcohol when pregnant; education and awareness about foetal alcohol spectrum disorders is poor among staff in the healthcare system; foetal alcohol spectrum disorders are not just health and social care problems, they impact education, employment, the benefit system and justice; and the diagnosis and treatment pathway is often too lengthy and poor. Responding to these points, and influenced by "pioneering work" in Scotland (see point 2 below), the Department of Health and Social Care asked the National Institute for Health and Care Excellence to develop a quality standard to help improve diagnosis and care of those affected. This work commenced in 2019.

In the meantime, two important documents are for UK stakeholders are:

- Report from the British Medical Association, first published in 2007 and then updated in 2016.
  This summarises international evidence on the effects and consequences of alcohol when a
  child is exposed to it before birth, and provides recommendations on how to tackle the harms
  caused by foetal alcohol spectrum disorders including diagnosis, treatment, research and
  education.
- 2. National clinical guideline for Scotland produced by Healthcare Improvement Scotland, which supports the healthcare priorities of the Scottish Government. This document provides recommendations based on the best available evidence and/or medical consensus on the assessment and diagnosis of children and young people affected by prenatal alcohol exposure. This includes the identification of children at risk of foetal alcohol spectrum disorder, criteria for diagnosis, medical assessments and physical examinations (including of facial features and neurodevelopment), and the management and follow-up of children and young people affected by prenatal alcohol exposure.

# From prevention targeting 'at risk' groups to screening and brief intervention across the whole population

Interventions designed to minimise or prevent harms have tended to focus on cessation of substance use during pregnancy. The models of prevention considered in the featured study were different, focusing instead on the period before conception, and aiming to prevent an alcohol-exposed pregnancy from occurring in the first place by working concurrently on issues such as risky drinking and ineffective (or non-use of) contraception.

In the United States and Canada, one particular model of prevention has been widely tested: the Parent-Child Assistance Program (P-CAP). In the featured review, P-CAP was discussed in the context of preventing foetal alcohol spectrum disorders, but as its webpage at the University of Washington shows, it has a broader remit to "help mothers build healthy families and prevent future births of children exposed prenatally to alcohol and drugs". This was found to be an effective model of prevention over time and across different sites based on outcomes including completion of substance use treatment, abstinence from drugs/alcohol, subsequent birth of a child not exposed to drugs/alcohol, and regular use of contraception. P-CAP also inspired the First Steps programme, which has demonstrated promising outcomes for women at risk of giving birth to a child with foetal alcohol spectrum disorder.

Another example of prevention also analysed in the Effectiveness Bank is CHOICES Plus, which provides a bundle of services in primary care settings to address drinking, smoking and ineffective contraception among women in low-income populations. Compared to women assigned to brief advice, women assigned to the CHOICES Plus intervention had a significantly lower risk of alcoholand tobacco-exposed pregnancies.

Interventions that can prevent alcohol- and tobacco-exposed pregnancies from occurring (or at least reduce their likelihood) have clear benefits over interventions that seek to mitigate the harms among women already pregnant. However, less clear is what criteria should be used to capture the pool of women at risk. The featured study based its recommendations on programmes which targeted women who have already had a child with foetal alcohol spectrum disorder, and women of low socioeconomic status who are heavy drinkers and smokers, and have poor diets. In the CHOICES Plus trial, of the 11,470 women screened, only 5% were considered eligible. This group of women were all aged 18–44 years, had no known fertility problems preventing pregnancy, were not pregnant or planning to become pregnant in the next nine months, had vaginal intercourse with a man with no known fertility problems during the previous three months without using effective contraception, and drank at risky levels (more than three drinks per day or more than seven drinks per week, on average) in the previous three months.

A different approach favoured in the UK is screening and brief intervention, the aim of which is to reduce alcohol-related harm across a whole population including those unaware of or unconcerned about their risky drinking. Estimates suggest that 41% of women in the UK consume alcohol at some point during pregnancy, putting the UK rate among the highest in the World Health Organization European region. Identifying women who drink during pregnancy, and providing information and effective support, is therefore of great public health importance.

There are two studies in the Effectiveness Bank about brief interventions before and during pregnancy:

• Study one spotlighted antenatal care in Scotland – one of three priority settings in a national programme to deliver screening and brief interventions. Implementation leaders discussed midwives' roles in facilitating disclosures about drinking in pregnancy, and what happens when their professional opinions deviate from guidance. It found that in several health boards where reported maternal alcohol use was lower than expected, implementation leaders discussed midwives' roles in facilitating disclosures, for example through having positive conversations, exploring pre-pregnancy drinking habits, and building a trusting relationship. In contrast with current antenatal alcohol

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screening recommendations, a more flexible, conversational approach was advocated to enhance the accuracy and honesty of reporting.

• Study two asked how infertility specialists can integrate screening, brief intervention, and referral to treatment into their everyday practice. Given that, by definition, pregnancies conceived with infertility treatments are planned, pre-conception counselling was proposed to include universal screening for substance use. Describing effective brief interventions, the paper said they should consist of: providing feedback about personal responsibility (eg, "As your doctor, I recommend you stop smoking cigarettes for your health and to improve your chances of getting pregnant, but it's your decision on what you want to do"); listening to and understanding a patient's motivation for using one or more substances (eg, "I hear that you use pills to deal with the pain of your pregnancy losses"); and exploring other options to address patient's motivation for substance use (eg, "Are there other ways you deal with stress in a more healthy way?"). For women who fell into the higher-risk category, a referral to treatment for substance use disorders was recommended before initiating infertility treatment – the same as for other mental health or medical conditions.

#### Communicating risk (to the extent that it is known and understood)

In the UK, targeted prevention is one of several areas that the British Medical Association have advised needs further research and development, along with diagnosis and management of foetal alcohol spectrum disorders, screening and brief interventions in antenatal care, and dissemination of "consistent and clear" guidance on alcohol consumption in pregnancy.

Foetal alcohol spectrum disorders are in theory entirely preventable as long as women do not drink during pregnancy. However, this does not easily translate into policy and practice. There are many reasons why women may continue to drink during pregnancy, including not knowing they are pregnant, not being aware of the risks of drinking during pregnancy, and having pre-existing problems with drinking. They may also, in the absence of evidence that light drinking can cause serious lasting effects, want to continue to have 'a glass every now and again' for the same reasons why people who are not pregnant enjoy doing the same.

There is a lack of evidence about "exactly how much alcohol is linked to increased risk" (ie, the level at which drinking becomes significant). Weighing this against the severe problems that children can develop when exposed to alcohol before birth, official guidelines have opted to advise that the safest option is for women who are pregnant or could get pregnant to not drink at all.

The British Medical Association's recommendation for women who are pregnant, or considering a pregnancy, is that "the safest option is not to consume any alcohol".

The Royal College of Obstetricians and Gynaecologists advises that "The safest approach is not to drink alcohol at all if you are pregnant, if you think you could become pregnant or if you are breastfeeding".

Guidelines from the Chief Medical Officer state that "If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum". However, "The risk of harm to the baby is likely to be low if a woman has drunk only small amounts of alcohol before she knew she was pregnant or during pregnancy".

However, key stakeholder groups including policymakers, health service practitioners, antenatal educators, and parents have expressed concern about this precautionary principle underpinning advice about drinking before/during pregnancy, arguing that it is inconsistent with "the informed-choice approach that underpins alcohol advice for the general population". According to a report commissioned by Alcohol Concern (which merged with Alcohol Research UK in 2017, and launched as the new charity Alcohol Change UK in 2018), the dominant advice was felt to be "an example of over-reach, legitimising social surveillance of pregnant women" and "congruent with a normalised directive approach to communicating with women in pregnancy". Some stakeholders concluded for themselves (ie, it was not explicit in the guidelines) that guidance was intended to "protect more vulnerable and less educated women who lack the capacity to interpret the evidence wisely" and to "provide an extra layer of protection to the foetus".

Emphasising the importance of removing the stigma from women who drink during pregnancy, or who enter pregnancy with existing drinking problems, the British Medical Association have advised that:

- Healthcare professionals should reassure pregnant patients that, while there is no definitive evidence, the risks associated with drinking small quantities of alcohol are likely to be low.
- Healthcare professionals should be given sufficient time and resources to ensure that any woman who is pregnant, or who is planning a pregnancy, and who is identified as drinking at low-to-moderate levels, is offered brief intervention counselling. This should occur at the earliest possible stage and be considered part of routine antenatal care.
- Where high levels of consumption are identified, and with this a high-risk of prenatal alcohol exposure, pregnant women should be offered referral to specialist alcohol services for appropriate treatment.
- Healthcare professionals should avoid blame, and create an environment where patients can disclose their drinking without feeling threatened or judged.
- There should be a deeper understanding of the many reasons why women may drink during pregnancy, and a deeper appreciation for the fact that "alcohol consumption during pregnancy does not occur in isolation [and...] must be viewed in the context of society's

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### relationship with alcohol".

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