

WORCESTER POLYTECHNIC INSTITUTE

National FASD: Social Media Reimagined

Supplemental Materials



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National Organization for FASD



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About the Sponsor

Information, Location, and Mission

The National Organization for Fetal Alcohol Spectrum Disorder (FASD) is a non-profit charity based in Lambeth, England on Black Prince Road. The registered charity number that can be found on their website is 1101935. The National Organization for FASD, founded in 2003, is dedicated to providing support to people directly affected by FASD, their families, and local communities by campaigning to raise public awareness and promoting relevant policies and practices. Their founder, Susan Fleisher, is an adoptive mother to a child with FASD and has made it her mission to increase public education on the causes and serious long-term effects of these disorders. By collaborating with many other partners and organizations who are also dedicated to aiding those affected by FASD, the National Organization for FASD can reach members of their targeted communities all over Europe and the United States.

Programs and Initiatives

The National Organization for FASD has many programs and initiatives to promote wellbeing for people with FASD and their families. They provide general practitioners, midwives, and teachers with the materials they need to create resources and experiences with people who have FASD. Recently, they have begun expanding their programs and introduced some exciting new programs. They started a three year national creative media prevention campaign that is specifically aimed at people under the age of 25. They created a new series of classes for people to take online and learn about FASD and the prevention of it. The Department of Health funded a project they developed in a partnership with Seashell Trust to work with people who have FASD and their families to develop a “Me and My FASD” toolkit. With this program, they will also decide and model the most successful practices for FASD training. This organization has been working for years to raise awareness for FASD and created programs and initiatives to help people affected by FASD.

Position/Role within the Community

The National Organization for FASD plays a big role in their community and has a relationship with many collaborating partners. They work closely with stakeholders and people who have experienced this first hand. They are a part of the 'FASD UK Alliance', which is a coalition of groups and people all over the UK who strive for a positive social change for people who are affected by FASD. Being a part of this alliance also helps them partner with other groups. They are also a part of the 'Alcohol Health Alliance' which works to reduce the harm caused by alcohol. They partner with the 'Embracing Complexity Coalition' to improve the lives of people who have neurodevelopmental issues, the 'EU FASD Alliance' to help European professionals and non-governmental organizations that are concerned with FASD to get together and share their ideas, and the 'Council for Disabled Children' to work with different professionals, policy-makers, and practitioners. They participate in 'Neurodiversity Celebration Week' and stay connected with the birth mothers they met through their partnership with the 'European Birth Mother Support Network', even though this is no longer an active connection. They are a part of the 'NOFAS Affiliates (USA)' which unites organizations to prevent FASD and help people living with FASD. This organization is the largest and longest standing group of international FASD organizations. They also work closely with the National FASD Clinic, the Center for FASD, the 'Alcohol Exposed Pregnancy Programme of Greater Manchester ('Drymester')', and other leading clinicians and practitioners. The National FASD relies on their relationships with educational, medical, and scientific experts all over the UK and looks for input on their available resources, including from anyone affected by FASD.

Unique Organization Qualities

One of the unique qualities of the National Organization for FASD is that they are currently working with Gen Z and trying to get further input from the younger generation. They have launched campaigns aimed towards people under 25 as well as created online courses to direct people into becoming educated about Fetal Alcohol Spectrum Disorder. Another unique quality is that the National Organization for FASD is also a UK-based charity for people of all ages that seems to be the center of a network, meaning that they act as a segway between all the

various organizations and the public. They work with organizations within the UK and also in the United States as well. This particular organization has created a media initiative to encourage people to become involved within spreading information about this disease. They are currently launching a National competition called, WhyRiskIT, to help raise awareness for the prevention of FASD as well as working on creating more social media pages.

Notable Achievements and Awards

- Received one of first government grants - 2020
- The Seashell Trust-National FASD partnership with the Department of Health
- September 9th is International FASD Awareness Day
- The award-winning film, RISK, was provided by Frogspawn Film to be used on National Organization for FASD's PreventFASD.info site
- Approached to host an event discussing future policies regarding FASD (2018)

Human Resources

The organization is made up of varying staff who all work together to keep it running smoothly. They have their main executives, such as Joanna Buckard who is the specialist projects coordinator and Sandy Butcher who is the chief executive, as well as Susan Fleisher, the honorary lifetime President and Founder. They also have volunteers who work on their helpline, such as Elizabeth Mitchell, and various staff members that run the website, organize events, or hold Trustee positions. Lastly, the National Organization for FASD has an Experts Committee made up of doctors, teachers, and other important members in the community which help to advise them, particularly on projects funded by the Department of Health.

Additional Background

Personal Connections to FASD

It is important to look at the relationship dynamics between people with FASD and their supporting communities, who are also directly affected by these disorders. Along with affecting the lives of those diagnosed, these disorders also greatly impacts the lives of the caregivers and family members of those with FASD. We want to research the characteristics of people with FASD, their families and their caretakers, and how their relationship with FASD affects their lives.

We begin by looking at people directly affected by FASD—those who were diagnosed with it. Earlier in this paper, we described the characteristics of people with FASD, but it is impossible to understand exactly what they experience everyday. Through previous research we know that many people with FASD have other medical issues as well. These issues can affect their neurodevelopment, specifically, their motor skills, brain structure and size, IQ, language skills, academics, memory, attention, functioning skills, regulation, communication, and their behavior (Mohamed et al., 2020). Socially speaking, children with FASD are also more likely to have disrupted schooling, inappropriate sexual behavior, issues with law enforcement, and an increased risk of developing drug and alcohol problems (Mohamed et al., 2020). Overall, FASD has been connected to over 400 different conditions (Mohamed et al., 2020). With low rates of awareness in the UK, it is assumed that there are not as many diagnoses as there are cases of FASD. Because of this, it is important to discuss the limitations of the research conducted in this country. The children involved in many of the studies surrounding FASD in the UK are on the more severe end of the spectrum and often have very challenging functional difficulties (Mohamed et al., 2020). Ideally in the future, research will include a group of subjects that have a varied level of severity in their diagnosis. Using a sample of people with different levels of severity and abilities will give more insight into the many people that have FASD.

Although it's important to understand the characteristics of people with FASD, their families also experience many of the side effects that result from the disorder. In general, Autism Spectrum Disorders (ASD) are known to be one of the most stressful disabilities for parents. A study about parents of children with ASD and FASD used an index to measure the amount of stress they are regularly experiencing. On the PSI-SF (Parenting Stress Index - Short Form) scale

of stress, parents of children with FASD had reported experiencing significantly more stress than parents of children with ASD (Bobbitt, 2016). Through this study, the researchers found 4 main themes that contribute to the parent's stress. These include the need for a formal diagnosis quickly to find beneficial services, the process of getting a diagnosis, dealing with the behavioral issues the child presents, and the need to advocate for the best services for their child (Bobbitt, 2016). The parents and families of people with FASD have to handle the behavioral and social issues that having these disorders can present, along with going through the difficult diagnosis process and finding specialists and services for their child.

Another important group of people to look at is the caregivers of people with FASD. Caregivers can also experience high levels of stress. As such, we must consider the caregiver's needs in order for them to successfully support the people with FASD that they are responsible for. Through a study conducted in 2016, researchers have found that 89% of caregivers admitted they would like more help: specifically, 86% of caregivers want networks, organizations, and agencies to represent the people they take care of to enact policies, 92% require emotional support, and 80% require financial support (Bobbitt, 2016). Caregivers expressed that they would benefit from having the opportunity to meet other caregivers and share knowledge, resources, and experiences with them (Bobbitt, 2016). Caregivers experience a lot of stress which affects their ability to support the children with FASD they are in charge of. Therefore, they would benefit from more information and resources to help them.

Additional Methodology

Project Deliverables

Universally, the data we collected was used in our final project centered on creating an effective marketing campaign designed to increase the overall public awareness of FASD. However, each data set was used in a different manner. The qualitative data that we collected from focus groups was used in illustrating the specific approach and generalizing the perspective that we will take when creating our campaign. To further the use of these data sets, we could potentially use direct quotes and/or personal testimonials with the consent of each participant when designing the actual social media content. On the other hand, we used the quantitative data collected from both our broadened surveys and current social media analysis to define which platforms are the most effective amongst our target audience, which falls within the boundaries of people in the UK between the ages of 16-25 years old. All in all, we were able to make suggestions on how to expand the National Organization for FASD's current digital footprint furthermore increasing their overall social media impact.

Potential Obstacles

There are many obstacles we may face in gathering our data and creating our final project deliverables. There are first the cultural differences that we will need to take into consideration. The drinking culture in the UK is something that we must know about in order to better understand and analyze the responses we may obtain in conducting surveys and polls. Additionally, the current feminist movement may make women reluctant to listen to our messaging because of the mindset that it is a woman's right to choose what happens to her body—including her ability to consume alcohol while pregnant. Some who oppose the messaging of the National Organization for FASD may do so because they do not wish to be told what to do. This resistance to messaging is an obstacle that we must navigate around in order to have an effective campaign.

The nature of our project itself poses a challenge. There are many paths we could follow to go about creating a campaign, making suggestions, and gathering our information. Based on the meetings with our sponsors, we have learned that this will be an evolving project with no

rigid plans set in place. This could prove challenging but also gives us the freedom to explore many different solutions to the problem that we have been tasked with addressing.

One of the possible ways to approach these concerns would be to frame this campaign by placing emphasis on the correlation between female empowerment and contraceptives. If our sponsors put too much emphasis on the detrimental consequences that drinking in pregnancy can cause, they run the risk of alienating their audience. If not handled correctly, some may interpret that the National Organization for FASD is trying to promote the removal of their autonomy and freedom to choose what they please with their own bodies. Therefore, it is essential that the core framework of this campaign must involve a conscious effort to eliminate these concerns. The solution to preventing life-long consequences through the use of contraceptives should be presented as an empowering autonomous choice that supersedes the alternative. Another framework that may redirect the audience's concern over self-autonomy is by using comparisons to draw parallels between the use of contraceptives as a preventative measure for FASD and the use of helmets as a preventative measure for sporting activities. By drawing these comparisons, it may help our sponsor's audience apply the logic of one scenario into the logic of a similar scenario in order to erase potential points of sensitivity.

Ethical Considerations and IRB

IRB considerations included sensitive issues and ethical concerns. Our project focused on preventing FASD, a disorder with implications for families in ways that are complex and have emotional, mental and physical dimensions. In order to learn more about the effects that FASD has on people's lives, we conducted focus groups with people who have been diagnosed with FASD and their caretakers. This called some sensitive issues into light such as needing to be very cautious and respectful in asking our questions and also ensure that sensitive personal information is properly protected. Additionally, we needed to be considerate of the presence of ideological, philosophical, and personal biases, because this is a sensitive topic for many given the amount of passion that often comes with it. As such, we had to word our questions carefully to be sensitive to these issues.

In regards to ethical concerns, there was the issue of consent. Considering that our original target audience was 16-25 year olds, there were many concerns surrounding the ability

of the younger portion of this audience being able to give consent. We dealt with this concern by making sure a parent or legal guardian signed any consent forms which explained the purpose and methods of our focus groups prior to any participation. We also reduced the potential for minors engaging in the focus group by narrowing our audience to 18-25 year-olds for our closed Facebook group which was used to foster discussion based conversations in the event that Zoom was no longer an option.

National Poll Materials

Proposed Questions

Demographic

1. What is your age? (one response)
 - a. 18
 - b. 19
 - c. 20
 - d. 21
 - e. 22
 - f. 23
 - g. 24
 - h. 25
2. What gender do you most identify with? (one response)
 - a. Male
 - b. Female
 - c. Other:
3. What is your ethnicity? (one response)
 - a. Asian or Pacific Islander
 - b. Hispanic or Latino
 - c. White or Caucasian
 - d. Black or of African Descent
 - e. Native American or Alaskan Native
 - f. Multiracial or Biracial
 - g. Other:
4. What levels of education have you completed? (choose all that apply)
 - a. Elementary School
 - b. High School
 - c. Some college, no degree
 - d. Completed college, with degree
 - e. Other
5. Did you complete any personal social health education (PSHE or other health classes) during your education?
 - a. If so, what classes and at what level?

Social Media

1. What platforms of social media do you use regularly? (choose all that apply)
 - a. Facebook
 - b. Instagram
 - c. Twitter
 - d. Snapchat

- e. TikTok
 - f. Other:
2. Out of the options chosen above, what type of social media do you use the most? (one response)
 - a. Facebook
 - b. Instagram
 - c. Twitter
 - d. Snapchat
 - e. TikTok
 - f. Other:
 3. Have you ever used social media to repost information? (one response)
 - a. Yes
 - b. No
 - i. If no, how likely are you to start using social media to repost information? (one response)
 1. Extremely likely
 2. Somewhat likely
 3. Not likely
 4. Never
 - ii. If yes, how often do you use social media to repost information? (one response)
 1. Always
 2. Often
 3. Sometimes
 4. Never
 4. What type of content are you most likely to repost? (choose all that apply)
 - a. Songs/Music
 - b. Funny content
 - c. Videos
 - d. Photos
 - e. Serious content (education, politics, news, etc.)
 - f. Other:
 5. Based on your previous answer, what method of sharing would you use to repost this information on social media? (choose all that apply)
 - a. 24 hour Story/Highlight
 - b. Retweet/Repost/Share
 - c. Create your own permanent post
 - d. Direct message to another user
 - e. Other:

Access to Knowledge/Help

1. Where are you most likely to go to learn health information? (choose all that apply)
 - a. Sexual Health Clinic (GUM)
 - b. General Practitioner

- c. Other Searches
 - d. Family/friends
 - e. Education
 - f. Other:
2. How much do you trust the accuracy of the health information that you receive about sex and alcohol? (one response)
 - a. Very much
 - b. Somewhat
 - c. Not really
 - d. Not at all
 3. How comfortable do you feel sharing your personal experiences about sex and alcohol with these health care individuals? (one response)
 - a. Very much
 - b. Somewhat
 - c. Not really
 - d. Not at all

Lifestyle

1. Are you participating in any sexual activity that could result in pregnancy? (one response)
 - a. Yes
 - b. No
2. Do you use contraception (condoms, the pill, LARCs, etc.)? (one response)
 - a. Always
 - b. Sometimes
 - c. Never
3. On average, how many units of alcohol do you consume per week? (one response)



- a. None
- b. 1-2
- c. 3-6
- d. 7-10
- e. 11-13

- f. 14+
4. How likely are you to use contraception while under the influence of alcohol?
 - a. Extremely Likely
 - b. Somewhat Likely
 - c. Not Likely
 - d. Extremely Unlikely
 - e. N/A
 5. In what setting are you most likely to consume alcohol? (choose all that apply)
 - a. Socially in a public setting
 - b. Socially in a private setting
 - c. Accompanying a meal
 - d. To celebrate (a birthday, holiday, etc.)
 - e. Other:

Current Knowledge

1. Do you personally know someone who has or currently consumes alcohol while pregnant?
 - a. Yes
 - b. No
 - c. Not that I am aware of
 - d. Other:
2. Is there a time in pregnancy that is considered safe to consume alcohol during? (choose all that apply)
 - a. First Trimester
 - b. Second Trimester
 - c. Third Trimester
 - d. None of the Above
3. How much alcohol would you expect a pregnant woman to consume during pregnancy?
 - a. More than usual
 - b. As much as usual
 - c. Less than usual
 - d. None at all
4. How uncomfortable would it make you to see someone consuming alcohol while you know they are pregnant?
 - a. Extremely uncomfortable
 - b. Very uncomfortable
 - c. Mildly uncomfortable
 - d. Not at all uncomfortable
5. Have you heard of FASD?
 - a. Yes
 - b. No
 - c. Other:
6. What do you think the acronym FASD stands for?
 - a. Foundation for Autistic Spectrum Disorders

- b. Foetal Alcohol Spectrum Disorder
 - c. Friends and Advocates Supporting Dementia
 - d. Fight Against Schizophrenia Disorder
 - e. Female Anxiety Spectrum Disorder
 - f. I don't know
7. If yes, where did you hear of FASD?
- a. In school
 - b. The news
 - c. Social Media
 - d. Family/Friends
 - e. Other:

Finalized Questions

To poll adults aged 16-25

Screener questions:

16-17 year olds via parents:

Which of the following best describes you? (choose which applies)

Single + no children

Single + I have children

In a relationship + no children

In a relationship + I have children

Cohabiting + no children

Cohabiting + I have children

Married + no children

Married + I have children

Divorced + no children

Divorced + I have children

Widowed + no children

Widowed + I have children

Which of the following age ranges does your child / do your children fall into?

- a. 0-4
- b. 5-9
- c. 10-12
- d. 13-15
- e. **16-17**
- f. 18-20
- g. 21+

This is a survey designed for children aged 16-17. It contains questions on how comfortable they are/would be talking to you or another parent about sex, sex education at school,

where they get information on topics such as sex, contraception and alcohol, and their knowledge about pregnancy, and particularly drinking alcohol during pregnancy. If you are happy for one of your children within this age range to complete this survey, and they are able to complete it on this device now, please click the ‘Continue’ option below and ask your child to answer the rest of the questions.

Continue – one of my children aged 16-17 will complete this survey now
Exit survey

18-25 year olds:

How old are you? (choose which applies)

18-25

26-35

36-45

46-55

56+

The following survey will contain questions about talking to other people about sex, such as your parents or a healthcare professional, where you receive information about sex, contraception and alcohol from, and your knowledge surrounding pregnancy and particularly drinking alcohol during pregnancy. All responses are entirely confidential and you can withdraw from the survey at any point. If you do not wish to continue, please select exit to return to the OnePoll homepage. If you are happy to answer questions on this topic, please select continue to enter the survey

Exit
Continue

1. To what extent do you agree or disagree with the following statement: ‘I prefer to talk to my parents about topics such as to sex, drugs and alcohol’
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
 - f. Prefer not to say

2. Why might you not talk to your parents about things to do with topics such as sex, drugs and alcohol?
 - a. I don’t want them to worry
 - b. I don’t want them to know what I am doing
 - c. They are not very open about things like that
 - d. We don’t talk about sex in our family
 - e. They don’t believe in sex before marriage
 - f. I’m pretty sure they wouldn’t have the answers

- g. I am not comfortable talking about sex
 - h. Worried about getting into trouble
 - i. I had regrets about something I had done
 - j. Feeling ashamed
 - k. They expect better of me
 - l. Other reasons
 - m. N/A – not sure / wouldn't have a problem with this
 - n. Prefer not to say
3. To what extent do you agree or disagree with the following statement: 'I would happily chat to a friend about a good or bad time I've had in bed with someone, or to chat about a fun binge drinking session or night out'
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
 - f. Prefer not to say / N/A

4. Which of the following people would you feel comfortable seeking advice about each of the below topics?

(Check all that apply)	Mum	Dad	Siblings	Friends	Doctor	Other medical professional	Prefer not to say / Nobody
Sex in general	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contraception	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexuality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. During COVID have you experienced any of the following:
- a. It's harder to get access to contraception
 - b. I am drinking more
 - c. I am having sex more
 - d. My anxiety about sex and alcohol has increased
 - e. I or my partner have become pregnant [If yes, have you had medical advice re alcohol in pregnancy?]
6. Which of the following topics do you rely on the internet for all/most of your information on?
- a. Sex in general
 - b. Sex education
 - c. Contraception
 - d. Pregnancy
 - e. Drinking alcohol

- f. Drinking alcohol in pregnancy
 - g. Drugs
 - h. Sexuality
 - i. Alcohol in pregnancy
 - j. None of the above
 - k. Prefer not to say
7. Which of the following topics do you think the information you read/see online can be confusing about?
- a. Sex in general
 - b. Sex education
 - c. Contraception
 - d. Pregnancy
 - e. Drinking alcohol
 - f. Drugs
 - g. Sexuality
 - h. Alcohol in pregnancy
 - i. None of the above
 - j. Prefer not to say
8. To what extent do you agree or disagree with the following statement: ‘In general, I find talking about topics such as sex, drinking during pregnancy, and sexuality embarrassing.’
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree [won't answer Q8 \[WHY? These are the people we need to know what they are thinking about family planning/alcohol\]](#)
 - d. Somewhat disagree [won't answer Q8](#)
 - e. Strongly disagree [won't answer Q8](#)
 - f. Prefer not to say [won't answer Q8](#)
9. Why do you find talk of things like sex, drinking during pregnancy, and sexuality embarrassing?
- a. It makes me feel guilty
 - b. I feel like I should know everything already
 - c. I don't want people thinking I am naïve
 - d. It's a private matter
 - e. It makes me feel dirty
 - f. Other reasons
 - g. Prefer not to say
10. To what extent do you agree or disagree with the following statement: ‘I'm unsure what I need to do to prepare for a healthy pregnancy for me or my partner when we are ready to start a family/have children.’
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree

- d. Somewhat disagree
 - e. Strongly disagree
 - f. Prefer not to say
 - g. N/A – I already have started a family / have children
11. According to UK government medical advice, do you think women have to give up drinking alcohol altogether when pregnant?
- a. Yes
 - b. No
 - c. I'm not sure
12. To what extent do you agree or disagree with the following statement: 'I don't think I have learned nearly enough at school about topics such as sex education, pregnancy and alcohol, drugs, contraception or sexuality'
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
13. Do you know of anyone who has been / is pregnant, and continues to drink a bit of alcohol every now and again?
- a. Yes
 - b. No
 - c. Prefer not to say
14. Which of the following count as one UK unit of alcohol? (tick all that apply)
- Half a pint of cider
 - Half a pint of beer
 - A single (25ml) measure of spirit such as whisky or gin or vodka
 - 125ml glass of wine
 - One alcopop
 - None of the above / I don't know
15. To what extent do you agree or disagree with the following statement: 'I think it is okay to have one or two alcoholic drinks every now and then when pregnant'
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree [won't answer Q16, 17 \[WHY not?\]](#)
 - d. Somewhat disagree [won't answer Q16, 17](#)
 - e. Strongly disagree [won't answer Q16, 17](#)
16. Considering 6 units of alcohol is a binge drinking session (for example, 3 pints of cider or beer, or 4 small glasses of wine, or 4 shots of spirit). How often do you drink more than 6 units in one go?
- a. Daily

- b. Weekly
 - c. Fortnightly
 - d. Monthly
 - e. Every other month
 - f. Rarely
 - g. Never
17. Which of the following do you think it would be okay to have the occasional drink of while pregnant?
- a. Cider
 - b. Beer
 - c. Wine
 - d. Vodka
 - e. Gin
 - f. Whisky
 - g. Alcopop
 - h. None of the above
18. Which of the following would you be most comfortable talking to someone else about? (tick all that apply)
- The act of having sex
 - Foreplay
 - Binge drinking
 - Alcohol in pregnancy
 - How to get pregnant
 - Pregnancy and what you and can't do
 - Contraception
 - Changes in your body
 - Hangovers
 - None of the above
19. Which of the following did you learn about at school / from a teacher? (tick all that apply)
- The act of having sex
 - Foreplay
 - Binge drinking
 - Alcohol in pregnancy
 - How to get pregnant
 - Pregnancy and what you and can't do
 - Contraception
 - Changes in your body
 - Hangovers
 - None of the above

20. **Only ask those aged 18+** Which of the following have you ever done? (tick all that apply)

- Forgotten to take contraception when having sex that could lead to pregnancy with a partner, due to having drunk too much alcohol
- Had sex during a night of drinking alcohol
- Had sex, and not remembered the following day whether you used contraception or not due to having drunk alcohol
- Found out you (or your partner) were pregnant after drinking alcohol
- You or your partner drank alcohol, while pregnant
- None of the above
- N/A – I do not drink alcohol **won't answer Q20**

21. If you had alcohol and found out you were pregnant immediately after, would you seek advice from any of the following?

- a. Parents
- b. Health professional
- c. Friends
- d. Parenting forum
- e. Internet
- f. No one/It wouldn't occur to ask me about this specifically

22.

Alcohol and pregnancy can lead to Fetal Alcohol Spectrum Disorder (FASD). Which of these do all people with FASD have:

- a. Certain facial features
- b. Brain damage
- c. Heart defects
- d. Kidney and liver damage
- e. Addiction problems
- f. Mental health problems
- g. I don't know
- h. None of the above

Should be informed at the end of the survey after all questions asked that the UK Chief Medical Officers' guidance is that "it's safest to avoid alcohol during pregnancy to keep the risks to a minimum." And that drinking alcohol in pregnancy risks FASD, which means lifelong organic brain damage and other effects.

ENDS

Poll Results

The poll results are broken down into 3 different categories. First is the standard results which is the general results of the poll questions for the 1200 people who responded. Next is the results broken down based on gender. Lastly are the results broken down based on age brackets.

The poll results summary can be accessed [here](#).

Focus Groups

Initial Survey for Facebook Group

[Consent Form Agreement](#)

What is your age?

- 24
- 24
- 22
- 21
- 20

What is your gender?

- Female
- Female
- Female
- Female
- Female

What levels of education have you completed?

- Undergraduate degree
- Bachelors of science
- BTEC (college)
- A-levels
- Some college

Did you complete any personal social health education (PSHE or other health classes) during your education? If so, what classes and at what level?

- Yes, High School
- No
- No
- Yes, High School
- No

Which of the following count as one UK unit of alcohol?

- A single (25mL) measure of spirit such as whisky or gin or vodka
- 125 mL glass of wine
- None of the above / I don't know
- None of the above / I don't know
- Half a pint of cider

In what setting are you most likely to consume alcohol?

- Socially in a public setting, Socially in a private setting, Accompanying a meal, To celebrate (a birthday, holiday, etc.)

- Socially in a public setting, Accompanying a meal, To celebrate (a birthday, holiday, etc.), Other: During work when customers buy us shots/drinks
- Socially in a public setting, Socially in a private setting, Accompanying a meal, To celebrate (a birthday, holiday, etc.)
- Socially in a public setting, Socially in a private setting, To celebrate (a birthday, holiday, etc.)
- Socially in a private setting

What social media platforms do you use regularly?

- Facebook, Instagram, Reddit, TikTok, Twitter
- Facebook, Instagram, Reddit, Snapchat, Twitter
- Facebook, Instagram, Reddit, TikTok, Twitter
- Facebook, Instagram, Reddit, Twitter, Other platforms
- Instagram

What type of content are you most likely to repost on social media?

- Funny content, Photos, Videos
- Funny content, Photos, Serious content (education, politics, news, etc.)
- Funny content, Photos, Serious content (education, politics, news, etc.)
- Serious content (education, politics, news, etc.)
- Funny content

Based on your previous answer, what method of sharing would you use to repost this information on social media? (choose all that apply)

- Direct message to another user
- 24 hour Story/Highlight
- Retweet/Repost/Share
- Retweet/Repost/Share
- 24 hour Story/Highlight

Thank you for your participation in this survey!

Look to the Facebook group for further instruction.

We look forward to hearing your feedback on our posts.

Questions for Facebook Group and Answers

Rachelle Wailes

Admin · March 4 at 11:23 AM · 🗨️

Please take a look at these questions and respond with your opinions and personal perspectives. Feel free to engage with other members of the group!

- Does it make you uncomfortable to see a pregnant woman smoking? Why or why not?
- Does it make you uncomfortable to see a pregnant woman drinking? Why or why not?
- If your reaction differs between seeing a pregnant woman smoking vs. a pregnant woman drinking, why do you think that is?



2 Comments Seen by 7

Like

Comment

It makes me equally uncomfortable to see a pregnant woman drinking or smoking (in theory at least... I'm not sure I've actually seen this in real life). This is because I know how harmful both smoking and drinking can be to an unborn baby. I would assume that the person had a really extreme addiction if they couldn't not have a cigarette/drink while pregnant - 9 months really isn't a long time in the grand scheme of things

Like · Reply · 1w

I'd be uncomfortable with both as I'd take it as a sign that she doesn't care about her baby. I probably wouldn't say anything however if I was at work (bartender), I'd probably refuse her service or suggest non alcoholic versions of beer or spirits to her as a replacement.

I don't see either Rolf them as better or worse as I don't know if one is more harmful to unborn babies than the other.

Like · Reply · 1w

Laura Staugler

Admin · March 2 at 3:09 PM · 🌐

Thank you to everyone who filled out our survey! We would now love to get your opinions on a couple images we are linking below. All three are related to the no smoking in pregnancy campaign. If possible, please try to answer a couple of the questions in the comments to let us know what you think! Feel free to interact with other group members.

- Which picture generates the most shock value?
- Which picture draws your eye the most?
- Which picture are you more likely to reshare? Why?
- Which picture are you more likely to remember? Why?
- Which picture is most likely to inspire you to take action? (ie. not smoke during pregnancy)

EVERY CIGARETTE HARMS YOUR BABY

Cigarettes restrict the essential oxygen supply to your baby. So their tiny heart has to beat harder every time you smoke. Quit for you and your baby with the free NHS support services explained on our DVD.

Breck SMOKING WHILE PREGNANT

Tobacco use: Approximately 20% of women who become pregnant smoke.

Early signs: Poor weight gain in the first two months of the pregnancy, usually a marker of low placental flow.

Low birth weight: Growing and then ending birth by 1000g, the maximum weight for babies.

Childhood obesity: 1 in 10 babies born to 17 year olds are overweight or obese at 5 years old.

Don't breathe.

2 3 Comments Seen by 8

Like Comment

Version A draws my eye the most and I would probably be most likely to reshare. Version C generates the most shock value/gets the message across in a striking way too but I would be less likely to share as I think the picture of the unborn child could be upsetting for some and perhaps actually detract from the message that is trying to get across. Although version B contains more stats and information I personally am not a fan of its cartoonish style and it's the sort of thing I would scroll by instead of reading in full if I'm honest. Overall I would say it's a tie between A and C in terms of which one would encourage me to act the most - they both show a clear warning message in a very visual way

Like · Reply · 2w

Version C generates the most shock value but I think it may be a bit too distressing and distasteful to share. Version A draws my eye the most as it gets the point across and is quite dark themed, it gets the scary message across without showing anything that's actually distressing. I'd also be more likely to share version A. Version B has too much information that I'd probably be too lazy to read and the image looks like it's for kids.

Like · Reply · 1w

I'd say c is most shocking as well and it also draws my eyes the most, I'm most likely to reshare B and it is most likely to inspire me to take action as well but I'd likely remember a most

Like · Reply · 1w

Introductions: How they got involved in the competition

- I really enjoy poetry and am hoping to do something medical in the future
 - I heard about it through Instagram
- I like writing and I want to pursue medicine in university
 - I thought I was up to date on things like this, but I didn't know about it so I had the opportunity to learn a lot
- I really like to do poetry and draw
 - Also came across it on Insta
 - Liked spreading awareness about something important
- I have FASD and am passionate about spreading awareness
 - Found out about it on TikTok someone commented on one of my videos
- I found it on Instagram and it was something to do during quarantine and I'm glad I did because it was interesting to learn about

1. What was the extent of your knowledge on FASD/alcohol in pregnancy prior to this competition?
 - Learned about it in GCSE biology and that it was bad to drink.
 - Had PSHE for only about half an hour a week and talked about how to put on a condom and it brought up what you can't have in pregnancy. Mainly smoking was brought up but also alcohol was brought up that caused problems. (From people in the education field)
 - I had the background that my mum drank in pregnancy. Mom and aunt found out in courses and her CAMs doctor didn't know what it was. Knew about it a bit before and got my diagnosis on my 16th birthday.
 - Didn't know anything about it. Had a lesson that talked about the dangers of drinking and smoking but not the effects. Went on the website and learned something new and spread the word about it.
 - Watched a video on YouTube about a family that had FASD. Didn't really understand it until the Competition.
2. How much research did you do on FASD prior to creating your content?
 - This question was not asked due to its being answered without need for prompting.
3. Where did you find your information for the content you created?
 - Didn't get to go back to the teacher that they originally learned it. Went on the NHS website because they wanted to incorporate that into their poem.
 - Found it on the FASD website - the one for preventing, and the NHS
 - Through her personal experience of it and what happened and how I feel about it. More about how I feel about what happened to me.

- Started off on the FASD Prevent website, then went to look into medical documents. Got invested in how it affects people in their lives.
4. How easy was it to find information for the content you created?
- It's easy if you know what you're looking for
 - Most people have a hard time finding information because they don't know about it
 - I never knew about it but once I searched it, a lot of stuff came up so I'm surprised it's not spoken about more
5. How much do you trust the information you find on social media?
- I don't often trust it because they use things to just try and catch your attention. The idea that the more people having ice cream at a beach causes more shark attacks is because there are more people swimming in the oceans. I don't trust headlines so I don't quite trust the media because they twist things.
 - If it was the FASD or World Health organization, I would trust it more over other accounts.
 - I didn't really trust the national FASD account at first so I had to look into it first to be able to trust them.
 - On TikTok you can find a lot of people who talk about FASD on there and I get a lot of questions which I answer honestly. I do trust TikTok quite a lot.
6. Did you trust the information you were getting from your sources?
- First thing I was looking into was symptoms so I went to the NHS. Then when I read other stuff, I compared it to stuff I had already heard about. I don't always trust new information.
 - Yes because most were quite similar. They talked about how relevant it was and how even drinking one cup of wine could affect two babies differently.
 - If the site was medical and well referenced, I would believe it. I was shocked that it was more harmful than heroin.
7. What are some of the struggles you had finding information for the content you created?
- Trying to form the post or poem in away that wouldn't offend someone
 - Didn't want to be judgemental but still wanted to get the point across
8. Were you surprised by any of the information you found about FASD during your research?
- One cup could change somebody's life. You wouldn't think of it like one cup of water but just that one cup can affect someone forever.
 - It's more common that autism quite struck me because autism is common. The symptoms are common as well so kids with autism could also have FASD. The diagnosis process is so difficult I think that's why it's not as known about.
 - After I entered the competition, I asked a few of my friends who had a different class for PSHE and they didn't know about it. We all were 16 year olds but most

of them didn't know. It's kind of scary because you've got these things and you could really harm someone.

- Only 17% know that alcohol has more effect than smoking because smoking is talked about more in school with pregnancy than alcohol
 - That it's more common than autism. They kept trying to diagnose me with autism or ADHD and didn't want to properly diagnose me. That they can tell you no you don't have it when you do.
9. Did anything you found about FASD/alcohol in pregnancy contradict information you knew/thought you knew?
- I had the idea that it had to be a large amount to have an effect. Just knowing it had to be quite small was quite shocking.
 - Initially we were told that smoking was the worst one, that smoking was more damaging. So that was contradicting now knowing that alcohol can cause more harm.
 - Just noticing how big the effect is just with one drink. I didn't know one cup could do so much damage.
10. Did you have a particular audience in mind when you began to create your content?
- Slightly older girls who may be sexually active. To reach them before it's too late
 - With poetry, I guess you could twist it into social media posts which should be quite useful
 - Teenagers and going up. Wasn't trying to use big words in a way that everyone in that age would understand.
 - Aim it more at girls who were thinking about getting pregnant or wanting to have children in the future. Use my experiences to reach more people and get a crowd
 - Writing to people who were pregnant at the time. Mine was more about probabilities (maybe I should go for it, maybe I shouldn't) so that was what mine was about.
11. What effect do you think your content would have on people viewing it? (Were you looking for/expecting a certain response when creating your content?)
- Social change. One of the things of social change to make it work is the majority of people have to know it. I was hoping that there would be people thinking about it and then looking into it themselves.
 - My poem is written from the baby's perspective. It was supposed to give kind of a shocked reaction and spread awareness.
 - Mine was about thinking twice about drinking and what could happen if you don't.
12. Did you really want to evoke emotion or raise awareness?
- I think if you are moved by something, you'll learn something and it will stick with you. So I went for emotion.
 - Emotional response

- Both. I wanted to show people what it was like from my perspective and then also that it is not heard enough, so spreading awareness of it. Then also this is what it did to me.
13. What social media platform would you picture your content on? Why?
- My content was quite short, so it would fit in a screenshot. I pictured it going in an Instagram post so they couldn't have to scroll and read it. They could just read it without going into it to read the rest of it. A lot of people may just skim it.
 - Artistic content does well on all social media, but especially Instagram or TikTok. Couplets are quite short and get people's attention
 - My poem could be seen on TikTok or should be played while you are waiting to have your baby's scan. Then even though you are pregnant, it could prevent you from drinking more or getting help if you have drunk. And you can share with your other pregnant friends.
 - Snapchat. They have health stories that I watch often. Then you could have spoken word and art going along with it as well.
14. Which social media platforms do you think would have more of an impact in influencing the public?
- TikTok could be a good place for creating videos.
 - Instagram reels or TikTok. Poems could do good on Twitter posts as well.
 - TikTok and Twitter. YouTube can be very impactful and allows people to talk about it in the comments.
15. Do you think there are certain platforms that should be used in conjunction with each other?
- TikTok and Instagram and Twitter link together very well. And they are quite popular too.
 - I get a lot of Facebook, TikToks on WhatsApp. Things that could also go on TikTok and Facebook to reach a larger community.

Content Creation:

16. What are your thoughts on this example content? (Cosette's Instagram Series on information about FASD)
- I would swipe through all the slides
 - I would wonder if it was fake news - maybe include a references page
 - Maybe have a linktree with multiple options
 - The FASD website but also help lines
17. What are your thoughts on this example content? (Cosette's Instagram Series on steps to follow if you've been drinking during pregnancy)
- It would be helpful to have the helpline in the post in case people need urgent help
 - Have it in both - caption of the post but also in the linktree
18. Which do you think would be perceived better?

- I think with the facts, it's harder to believe they aren't just clickbait
- Like having the image in the two facts one
- Like the image in the first one - it really draws you in
- May be drawn to believe the fact on eis fake news without references. The helpline one seems less fake.
- Try putting the picture in scenario one.
- Likes the fact one better

19. What are your thoughts on this example content? (Laura's Infographic on steps to follow if you've been drinking during pregnancy)

- Having it in a campus as well, not just a nurses office
- Even put it on a pub door, throw them all over the floor
- Eye catching, would still read it
- It is not an information overload so it doesn't scare you off
- Tells them then and there what to do
- Likes the color
- Likes the footprint colors
- Try and tackle not just the people who are pregnant, but also posts of if you know someone is pregnant, here's what you can do to help. It may affect someone they know. There was a study done about social support and how to stop with pregnant women smoking. It was found that those that had the older buddy that stopped smoking with them were more likely to stop smoking without the buddy after the program ended.

20. Any final thoughts?

- Maybe getting just "signs that you are pregnant" put more in bars. Not everyone knows they are pregnant so they could be doing damage. Really raising awareness for pregnancy and not drinking could really help.
- In the UK, we are going to be ending social distancing on June 21st and how everyone is going to get wasted during that time. I think it is important to get it out now so people are informed sooner than later.

Questions for Cohort B Focus Group and Answers

1. Have you heard of FASD before?
 - Yes, my dad's partner adopted 3 kids with FASD
2. Do you know what effect drinking alcohol in pregnancy has on a fetus?
 - Do you know of anyone who has been / is pregnant, and continues to drink a bit of alcohol every now and again?
 - No
 - Does it make you uncomfortable to see a pregnant woman drinking? Why or Why not?
 - 100% yes it makes me uncomfortable after seeing the impact it has had on my dad's partner's kids
3. Do you trust the information you get from online sources? Would you trust information you found on social media? (in general, from a specific account, which platforms, etc.)
 - Yes as long as it's a credible source, but less so on social media
 - The people I follow have a similar mindset to me so I trust them more

Debrief: FASD (fetal alcohol spectrum disorder) is a term describing a spectrum of disorders which result from the consumption of alcohol during pregnancy. It is a neurodevelopmental disorder which can co-occur with over 400 conditions and can cause behavioral, cognitive, and emotional challenges that a child will face for their lifetime. FASD is 100% preventable if no alcohol is consumed during a pregnancy.

4. Were you surprised by any of the information we talked about related to FASD?
 - No because I know quite a bit about it from my family
5. Did anything we talked about related to FASD/alcohol in pregnancy contradict information you knew/thought you knew?
 - No
6. Do you ever repost content?
 - No, I more so just watch. I don't repost unless i was really passionate about it
7. Do you have a particular audience in mind when you repost content? (public vs private account)
 - I'm private on everything so it's more so for my family and friends. I post privately but i would try to educate as many people as i could if i felt it was important
8. What effect do you think your reposted content would have on people viewing it? (Do you look for/expect a certain response when reposting content on social media?)
 - It would be to educate themselves or to spread awareness. I would hope that it wouldn't just stop with me
9. What social media platform would you picture seeing FASD content on? Why?

- Facebook, I see a lot on facebook. Twitter is a good platform for it too
10. Which social media platforms do you think would have more of an impact in influencing the public?
- Places like instagram is a hard place to spread awareness because it's just one picture
 - Facebook and twitter both use more words. Twitter can trend really easily and Facebook is good for a local community, family and friends

Questions from the smoking campaign:

11. Which picture generates the most shock value?
- Bottom left because it shows realistic photos - creates the most impact
 - First one doesn't seem as realistic so i wouldn't take it as seriously
12. Which picture draws your eye the most?
- The color on the bottom right is the most eye catching
 - The graphic draws attention
 - The real woman on the bottom left grabs my attention though because she's real
13. Which picture are you more likely to reshare? Why?
- The one on the left looks like it would be on a bus stop
 - The bottom right is good for sharing on social media
14. Which picture are you more likely to remember? Why?
- The top one because it's so graphic
 - Like the drawings on cigarette boxes
15. Which picture is most likely to inspire you to take action?
- Bottom left because its from the NHS
 - Top one doesn't even have a source on it
16. Now that you have seen these images from the smoking campaign, does it make you uncomfortable to see a pregnant woman smoking? Why or why not?
- Yes
17. If your reaction differs between seeing a pregnant woman smoking vs. a pregnant woman drinking, why do you think that is?
- Similar reactions to both
18. Why different reaction
- In the UK there's more complaints about smoking - lots of adverts on the tv
 - Not as many about drinking
 - Lack of education
19. If you were to see information about the risks of drinking during pregnancy, do you think your views would change? (If you are given knowledge about the risks of drinking during pregnancy, how likely are you to take any precautions to prevent the consequences?)
- I think their views would change

- If they advertise it the same way they do for smoking i think they'd get similar reactions

Content Feedback:

20. What are your thoughts on this example content? (Cosette's Instagram Series on information about FASD)
- Shock value post, info about FASD, resource at the end
 - I hadn't thought about series before and I think that would work well
 - Maybe too many words
 - I think having the hotline on there would be good - that's a big part of spreading awareness
 - Maybe more pictures? To draw attention
 - Would having the National FASD logo would give the same effect bc it wouldn't be as well known
 - Part of me thinks they won't know what it is
21. What are your thoughts on this example content? (Cosette's Instagram Series on steps to follow if drinking during pregnancy)
- Steps for people to follow
 - From my experience, there's a lot of blame culture
 - Maybe putting the blame too much on them and it will stop them from getting help
 - But also raising awareness that it's serious
22. What are your thoughts on this example content? (Laura's Infographic on steps to follow if drinking during pregnancy)
- I really like that
 - Like the colors, graphics, drawings
 - Eye catching
 - In GP Office

Blueprint Questions:

23. Opinions on using the terms Fetus vs baby in content?
- Fetus because if you talk about it scientifically you should use scientific terms
 - You then get into religious beliefs about when a baby becomes a baby
 - You could discredit yourself by not using the scientific terms
24. Do you think framing content more as stating facts or creating scenarios that the audience might relate to would be more effective?
- Facts and statistics are what people are looking for
 - Give them it then tell them where to get help
 - Scenarios could cause more guilt
25. Should links be kept in the bio or linked in posts? Both?

- Both - you can have link trees would be effective but also have it in the post because what's the point of not putting it there
26. Should helplines be kept in the bio or put directly in posts? Both?
- Same, have it available wherever you can
27. Any final thoughts?
- Why the UK?
 - IQP! Our sponsors and their local community
 - Hard to not have first hand experiences
 - Give National FASD a blueprint for their social media campaign

IRB Materials

Competition Participant Consent Form

Informed Consent Agreement for Participation in a Research Study: "Initial Survey for Focus Group on British Drinking Culture"

Investigators and contact information:

- National FASD Student Researchers (gr-FASD-IQP@wpi.edu)
- Dr. Bethel Eddy (bleddy@wpi.edu)
- Dr. Sarah Stanlick (sstanlick@wpi.edu)

Purpose: This study will involve answering questions about alcohol volumes, drinking habits, and other related topics in a discussion based format.

Procedures to be followed: After signing this consent form you will be asked questions related to the topics mentioned above.

Record keeping and confidentiality: By signing this form, you are consenting to helping us learn about this experience and its impact on our students. You should feel free to answer to any level to which you wish to disclose. Again, your identity can not and will not be disclosed in that sharing of information. This is not a mandatory assignment and your consent is given freely of your own choice.

This call may be recorded for the purposes of transcription but will be deleted upon the completion of the study.

Records of your participation in this study will be held confidential so far as permitted by law. However, the study investigators, the sponsor or it's designee and, under certain circumstances, the Worcester Polytechnic Institute Institutional Review Board (WPI IRB) will be able to inspect and have access to confidential data. Any publication or presentation of the data will not identify you.

For more information about this research or about the rights of research participants, or in case of research-related injury, contact the investigators (email addresses are at the top of this document. You can also contact the IRB Manager (Ruth McKeogh, Tel. 508-831-6699, Email: irb@wpi.edu) and the Human Protection Administrator (Gabriel Johnson, Tel. 508-831-4989, Email: gjohnson@wpi.edu).

Cost/Payment: After the zoom call is over all participants will be entered in a raffle with a grand prize of a £50 gift card to Amazon.com. The winner will be contacted by the team through Sharon.

Your participation in this research is voluntary. Your refusal to participate will not result in any penalty to you or any loss of benefits to which you may otherwise be entitled. You may decide to stop participating in the research at any time without penalty or loss of other benefits. The project investigators retain the right to cancel or postpone the experimental procedures at any time they see fit.

By typing your name in the box below, you acknowledge that you have been informed about the study and wish to consent to participate.

If you are under 18 years-old, a parent or legal guardian must sign on your behalf.

Informed Consent Agreement for Participation in a Research Study: "Initial Survey for Focus Group on British Drinking Culture"

Investigators and contact information:

- National FASD Student Researchers (gr-FASD-IQP@wpi.edu)
- Dr. Bethel Eddy (bleddy@wpi.edu)
- Dr. Sarah Stanlick (sstanlick@wpi.edu)

Purpose: The purpose of this study is to understand British drinking culture and norms in order to fulfill a specific purpose directly related to but not limited to increasing public awareness. This study will involve answering questions about alcohol volumes, drinking habits, and other related topics in a discussion based format.

Procedures to be followed: Upon completing this consent form, you will fill out a survey with your demographics and personal perspective on common topics related to British drinking culture, as mentioned in the purpose. Following this survey, you will be asked to interact with posts made in the Facebook group in the form of comments to provide feedback and more information for the researchers.

Record keeping and confidentiality: By clicking "next", you are consenting to helping us learn about this experience and its impact on our students. You should feel free to answer to any level to which you wish to disclose. Your reflections will come to us as anonymous entries. We will have a sense on who completed it, but cannot tie the data back to particular participants. We will also be sharing this information back with the advisors for evaluation purposes anonymously. Again, your identity can not and will not be disclosed in that sharing of information. This is not a mandatory assignment and your consent is given freely of your own choice.

Records of your participation in this study will be held confidential so far as permitted by law. However, the study investigators, the sponsor or it's designee and, under certain circumstances, the Worcester Polytechnic Institute Institutional Review Board (WPI IRB) will be able to inspect and have access to confidential data. Any publication or presentation of the data will not identify you.

For more information about this research or about the rights of research participants, or in case of research-related injury, contact the investigators (email addresses are at the top of this document). You can also contact the IRB Manager (Ruth McKeogh, Tel. 508-831-6699, Email: irb@wpi.edu) and the Human Protection Administrator (Gabriel Johnson, Tel. 508-831-4989, Email: gjohnson@wpi.edu)

Cost/Payment: Upon the completion of this survey as well as participation in the Facebook group (in the form of comments), all participants will be entered in a raffle with a grand prize of a £50 gift card to Amazon.com. The winner will be contacted through the closed Facebook group and will be asked to provide an email through which they will claim their prize. If the winner does not respond to the Facebook message within the first 72 hours, they will be considered ineligible to receive the prize and the raffle will be redrawn from the pool of remaining participants.

Your participation in this research is voluntary. Your refusal to participate will not result in any penalty to you or any loss of benefits to which you may otherwise be entitled. You may decide to stop participating in the research at any time without penalty or loss of other benefits. The project investigators retain the right to cancel or postpone the experimental procedures at any time they see fit.

By clicking "next" below, you acknowledge that you have been informed about the study and wish to consent to participate. You will be asked again after completing the survey for your consent as a matter of respect for your right to change your mind.

Focus Group on British Drinking Culture Debriefing Statement

Thank you for participating in this focus group. Now that it is completed we would like to provide background on why we were interested in doing focus groups.

The purpose of this study:

The purpose of this study is to see what level of information 18-25 year olds in the United Kingdom (UK) have regarding the consumption of alcohol and the effect it has during pregnancy. Through the focus groups we are hoping to learn three critical points: where 18-25 year olds are learning information and if it is from a reliable source providing accurate information, what type of social media is popular in the UK and how to best target content towards this age group, and how the campaign to raise awareness for FASD compares to other well-known campaigns. The information gained in the sessions will help us to achieve our goal of learning how the National Organisation for FASD can spread accurate information about alcohol and its effects on pregnancy in a more effective way. These focus groups will allow us to gain insight on what information needs to be accessible, how to make it accessible to the target audience, and how their spread of awareness compares to the spread of other campaigns.

How we studied this topic:

We had two different ‘cohorts’ per which participants were randomly assigned. The first sessions each had a different purpose. The first group referred to as “*Cohort A*” was formed with the intention of trying to best represent the general population of the UK and therefore any and all discussion directly related to FASD was avoided and instead had a singular heavy focus on discussions related to alcohol, drinking habits, defining binge drinking, and other related topics. The second group referred to as “*Cohort B*” participated in a first session that included discussions directly about FASD in relation but not limited to alcohol and drinking culture in the UK. The second session of both groups had the same purpose of conducting a social media content analysis of materials and topics directly about raising awareness of FASD. The figures, images, and words created for this content analysis were altered slightly depending on the discussions and answers from the first sessions.

Why is this important to study?

Having two separate cohorts to our focus groups allowed us to gain more perspective on what is the most effective way to provide information to the National Organisation for FASD’s target audience that will reach the widest range of people. The responses that *Cohort A* provided helped us gain insight on how people who do not have prior knowledge of FASD will respond to content providing information and awareness on this topic. The responses of Cohort B conversely provided insight on how people who are informed about the topic of FASD prior to

being exposed to content spreading FASD knowledge will respond. The nuance in information allowed for more perspectives to be heard on the matter, which in turn serves as a better representation of the variations in opinions and multiple perspectives and backgrounds in the general British population of young adults between ages 18-25. Both groups were given the chance to respond to the same content coming from different levels of background knowledge, which will further allow us to extrapolate and examine what changes will be needed to be implemented in order for our goal of building an effective awareness campaign blueprint for our sponsors to be achieved.

Restatement of confidentiality:

We will not be keeping any identifiers of any participants. All data collected will remain anonymous. Your refusal to participate will not result in any penalty to you or any loss of benefits to which you may otherwise be entitled. You may decide to stop participating in the research at any time without penalty or loss of other benefits. The project investigators retain the right to cancel or postpone the experimental procedures at any time they see fit. If selected as the winner of the raffle, you will be contacted through the Facebook group to claim your prize.

Suggested Reading Material:

For further resources and materials concerning the topic of FASD, please visit the National Organisation for FASD's website at <https://preventfasd.info/> or nationalfasd.org.uk/about-fasd/.

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Thank you for your participation!

Project Deliverables: Blueprint

[Link to Blueprint with Example Content](#)

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