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**Practice case study**

# Reflections of experts by experience and research team members on research and development about a sensitive issue that attracts stigma

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## Abstract

To reduce the number of alcohol-exposed pregnancies in antenatal care in the UK, the CHAMPION study objective was to design appropriate training and resources to develop the midwifery skills and confidence required to have an effective conversation about alcohol with pregnant women. Women with lived experience of drinking during pregnancy and 'birth mums' of a child with fetal alcohol spectrum disorders (FASD) were central to the co-creation process of the CHAMPION study. Some remarkable unintended positive outcomes resulted from this collaboration process for the women involved. They include increased confidence levels from newfound friendships with other mothers of children with FASD, and an acceptance that societal influences had a significant role to play in their

personal situations. Reflecting on this authentic co-creation process has elicited important learning outcomes to inform future research design. The significance of excellent communication channels, robust support networks and genuinely valuing and respecting experts by experience as equal partners should not be underestimated.

**Keywords:** alcohol; pregnancy; FASD; co-production; stigma

### Key messages

- Authentic co-creation about stigmatising conditions takes courage and personal resilience for those sharing their experience, and hearing their stories is highly emotive for all team members.
- The provision of a sensitive and nurturing safe space facilitated peer support, and made it possible to share painful experiences that can attract stigma and feelings of guilt.
- Involving a skilled participant advocate was pivotal to support those involved, and to ensure their psychological and emotional well-being; it was at first time-consuming, and then a privilege to see experts by experience develop confidence and a sense of achievement.

## Background to the CHAMPION study

If a woman drinks alcohol during pregnancy, it can harm her baby. Sometimes this can lead to fetal alcohol spectrum disorders (FASD). These problems are lifelong and can affect a child's growth and development, including their physical and mental health, their behaviour and their ability to learn. Midwives play a key role in the prevention of FASD by discussing alcohol consumption with women during routine antenatal appointments, and by supporting them if they need help to stop drinking. But not all midwives have this conversation. We identified some of the main reasons for this (Howlett et al., 2019; Schölin et al., 2019), and developed the CHAMPION (alCOhol HARm PreventiOn iN pregnancy) research study to address the issues. We used co-creation strategies to design pertinent training and resources, aiming to develop the midwifery skills and confidence required to have the conversation about alcohol with women. The voices of midwives, women who use maternity services and importantly, women with lived experience of drinking during pregnancy and 'birth mums' of a child with FASD were central to the co-creation process of CHAMPION.

## Voices of women with lived experience

The focus of this reflection is on the perspectives of three birth mums who worked with us as research partners on CHAMPION. The women were three of six 'lay' women who were current or previous maternity service users taking part in our research involving the co-creation of training materials for midwives, and they were filmed describing their personal experiences. These three women all share a strong personal motivation to help others, which is expressed through their support of the FASD Network. Each has a child with lifelong FASD, associated learning disabilities and health problems. The challenges they encounter on a daily basis make them experts by experience and passionate advocates for helping others avoid alcohol-related harms. There is significant stigma associated with alcohol consumption during pregnancy, especially when this leads to having a child with FASD. Making the decision to collaborate on the CHAMPION study presented a personal risk to these birth mums. It took courage to share their experiences and perspectives with researchers, midwives and other women, as they are very vulnerable to societal judgement and censure. The perspectives of the birth mums have been central to CHAMPION, and they have yielded some unintended positive consequences that we aim to capture in this article, which describes their reflections on the impact that participating in the CHAMPION study had on them.

The involvement of women with lived experience of giving birth to a child with FASD would not have been possible without the support of the FASD Network UK. Founded by Maria Catterick, this began as a support group for families who were raising children with FASD in the Durham and Tees Valley area. The network now works across the whole of the North East and Yorkshire. Maria Catterick acted as the lead for public involvement in the CHAMPION study, and she recruited three birth mums to join the research team. The three birth mums demonstrated emotional resilience and a willingness to engage with this research. Of different ages, backgrounds and geographic locations, all had a child diagnosed with FASD, were passionate about raising awareness of alcohol-related harm and FASD, and were already part of the FASD Network UK. Also taken into consideration was the length of time being a parent to a child with FASD, whether the woman was alcohol-dependent during pregnancy or accidental exposure was the cause and crucially, their availability to participate in this study. As a result, this cohort offered a broad range of variables. Consequently, Maria knew these women well enough to determine whether they could cope with the self-disclosure and introspection involved in the research process. Supporting emotional needs of women during the study, and acting as a bridge between the women and the researchers, was an essential part of Maria's role. In the larger study sample, mothers were included who did not have children affected with FASD, to capture a diverse service user voice. Diversity and inclusivity was an early objective to recruitment in this study. However, the Black, Asian and minority ethnic community was not well represented in this relatively small regional network, and this is reflected in our sample of women.

## Their role

Over a period of six to eight weeks, three co-creation workshops were held with users of maternity services, including the three birth mums, a group of midwives and the research team. Due to the restrictions related to Covid-19 in place at the time, the workshops took place online via Zoom, and they lasted up to three hours each. We reviewed different techniques to support midwives in their practice, and co-developed effective strategies to help them address alcohol consumption with women during routine antenatal appointments. Strategies included how to communicate and deliver training to midwives – using information leaflets, videos or a mobile phone app, for example. Discussions included how best to implement the chosen strategies. The intention was for all participants to attend all three workshops, but family and work commitments meant that this was not always possible in the midwifery cohort of participants and for some of the mothers who did not have children affected with FASD. All sessions were recorded, and field notes were taken to capture the suggestions and recommendations made by participants. A further day was arranged to undertake filming of a simulated conversation between a midwife and woman at a routine antenatal appointment. All three birth mums attended this session, and they were filmed sharing their personal stories.

The co-creation process enabled the development of training materials for midwives, including videos of various scenarios and conversations between midwives and pregnant women. The lived experiences of the maternity service users, including the birth mums, were essential in ensuring that these training materials were authentic and likely to change the thinking and behaviour of midwives.

## Their views on the research process

None of the birth mums had university-level qualifications or previous research experience as equal co-producers. This induced in them a level of excitement, as well as anxiety. The research process, its language and methods were alien concepts, and it took courage for them to gain the confidence to engage with the researchers. One mum had never publicly shared her story before, and therefore self-disclosure during this research project was a considerable step for her.

Alcohol use in pregnancy can be a sensitive subject, and this underpins one of the premises of this research – that some midwives are reluctant to ask the question of pregnant women. The emotional

impact of hearing that midwives may be reticent to broach the subject was hard for one birth mum. As she put it, 'Stop pussyfooting around, just ask the question.'

## The benefits for them

The birth mums did not meet in person until the day of filming because they were located across the North East and Yorkshire region. This meant that the day was a special one for them. Two of the women arranged to car share, and travelling to the venue together enabled them to share their stories. One is 15 years further along in her personal journey than the other, so sharing her experiences was cathartic for her and nurturing for the other. They felt it was a blessing to meet like-minded mums, and new friendships have been forged, building new support networks for the women and turning their negative experiences into positive outcomes.

The birth mums have gained a new confidence, pride and sense of achievement through their involvement with this research project. They found the research interesting, and they were excited to be involved, especially on the day of filming. They all shared pictures taken on the day on social media, and they received a lot of positive feedback from family and friends. One mum expressed the pride she felt about helping to change the future for other families, regardless of her educational or social background. They all described the satisfaction of having the opportunity to give back and make a difference to others. Feeling that their family and friends were proud of them was also important to them.

## What worked for them

The research team initially set up a private WhatsApp group as a simple and easily accessible way of communicating with the birth mums, and is supported by any smartphone. However, a second WhatsApp group was also set up which would only be accessed by the birth mums and Maria as their personal advocate. This group provided a safe and invaluable support mechanism, and a means of open dialogue that worked on several levels.

- Some of the language and processes involved in research were not necessarily familiar or easy to understand to the participants, so they could liaise with the research team to check their understanding and provide clarification.
- When participants were feeling stressed or anxious, they felt they had others to share their concerns with. This gave them more confidence than if they were isolated individual participants disconnected from the researchers.
- The participants could see all dialogue with open and equitable transparency for the duration of the research process, promoting inclusivity and engagement.
- The women could reflect together after each session, as they digested new information and processed any episodes of self-discovery. This reflection provided opportunity to re-evaluate their personal emotional responses.
- The group formed and bonded much better through the ease of contact, which facilitated regular informal conversations. This contributed to a sense of community and belonging for the participants in a predominantly online research experience.

## Reflections of the patient and public involvement (PPI) coordinator

Maria Catterick acted as the lead for public involvement in the CHAMPION study, and she recruited three birth mums to join the research team. She says:

At the outset, I felt that my particular role in the research was mostly centred on the need to locate mums I knew who might be able to participate in the research. During the process,

I found that while all the women we selected were very able to do that task, I underestimated the value they would place in my availability and reassurance. They liked having someone they already knew in the process who understood their perspectives and the subject and would be there for them throughout. I was able to remind them about the meetings, check they had the resources, coordinate the trip to Hull [for the filming day], be a listening ear, stand with them as they made themselves vulnerable, and be there when they needed to debrief or celebrate. I had to allocate a lot of extra time before and after meetings to allow for that; not that it was a burden in any way, it was a privilege to be there and witness their involvement and their humour and sense of fun, and how they have moved forward in confidence as individuals and as a group of women with things in common.

## The challenges and frustrations for them

Maria also says:

The technical jargon was potentially confusing and alienating to participants, so the research team were cognisant of this and endeavoured to ensure clarity and understanding at every stage. Likewise, the bureaucratic world of academia combined with rigid research processes were at times perceived by participants with incredulity that such barriers had to be tolerated and navigated.

It took a lot of organising and personal resources to get to the face-to-face meeting. Due to the geographical distance, one mum had to get up at 5.30 a.m. to arrive on time. All had to arrange childcare and work commitments to attend.

The process was very emotional and we saw tears on the day, with one rehearsal of the filming of actors sending a mum to tears as she recognised her story in the scenario, and saw a warm and caring approach by the acting midwife. Nerves, stress and anxiety were all mentioned, especially at the beginning, but after the first workshop they completely relaxed and felt comfortable with everyone.

One mum got in front of the very formal camera set-up and panicked and needed reassurance when the reality of sharing her story for the first time hit her. She took a break, clarified what it would take for her to tell her story, and was proud of herself for achieving this.

Most meetings were online due to the pandemic. This was convenient regarding transport and childcare logistics, but from a social perspective, it did not facilitate teambuilding and bonding.

## Unintended consequences and changing the future

Maria and the wider research team say:

The birth mums shared ideas about how to improve support to other mothers, and they are now looking at practical ways to move this work forward. They want to continue to champion for FASD and alcohol-dependence awareness, and they have all now become proactive agents of change.

One birth mum described the three of them as 'soul sisters' in the closed chat that they share. She was really nurturing of another, as a woman further along the journey with similar life experiences. They plan to meet virtually in a few weeks to discuss how they can better support other birth mums and create some written resources designed for mums by mums.

As a direct consequence of research involvement, one birth mum realised that she truly needed to forgive herself for what had happened, as she was not solely to blame. She had not received any advice to abstain from alcohol in pregnancy. It was also the lack of information and society's relationship with alcohol combined with a lack of support that had contributed to what happened to her and her child.

Another mum now has the confidence to begin volunteering with an alcohol organisation, and she has spoken about going back into education to gain qualifications to advance her skills as a direct result of her involvement with this research initiative.

## Conclusions and reflections

To our knowledge, this article is the first in the UK exploring how to effectively include experts by experience in the authentic co-creation of research on the prevention of FASD, where there has been a historic tendency for shame and stigma to prevail. The closest comparable study found was the Canadian Co-Creating Evidence (CCE) project, which employed conventional qualitative research methods to gain the perspectives of pregnant and parenting women with substance use and multiple vulnerabilities to inform the development of a multi-service prevention programme (Rutman et al., 2020). While this cohort of women were authentically part of the co-production process, they were not specifically members of the research team. Also, the Canadian cohort were contemporary recipients of the service, whereas our UK cohort were reflecting on their retrospective experiences of antenatal care. The benefit of hindsight provided our women with valuable insight and the motivation to prevent others suffering the consequences of alcohol-exposed pregnancies and a lifetime of parenting a child with FASD. It could also be argued that our group of women had a greater capacity, maturity and resilience to actively participate as members of the research team, as they were in a more stable state of well-being than the Canadian women. Due to the small sample size, this reflection does not claim to represent all birth mothers of children with FASD, but it does provide new insight into the important considerations and strategies required to successfully facilitate this process.

Communication has been fundamental to the success of this collaboration. We recommend the establishment and maintenance of effective communication strategies for the duration of any research project. The ice-breaking opportunity for participants prior to the first research meeting provided the chance to clarify expectations, ground rules, confidentiality and logistical arrangements. This facilitated the commencement of research activity in the first workshop, and improved the efficiency of working to time and target.

The role of a participant advocate was crucial, as Maria supported the emotional well-being of the women throughout the process through regular debriefing. She had good relationships with the women, and she knew them well enough to monitor how they were coping and to pre-empt and respond to issues with potential for an emotional impact. Maria has a professional background as a social worker, and as a champion and advocate of FASD families. As such, she had the necessary skills and experience to competently manage this situation. Supporting the psychological and emotional well-being of the women was essential.

Time is an important consideration during the planning and funding of research. Patient advocates need sufficient time factored in to attend research planning and implementation meetings, plus relevant workshops and any relevant research activity tasks. Maria undertook the preliminary study discussions to recruit the women to the study, then engaged in regular correspondence to ensure their well-being and understanding, and to answer any questions. On the intervention days, Maria connected with the women for at least thirty minutes before the session to check that they had everything they needed, understood everything, and were organised with childcare and so on. Afterwards, Maria provided a debriefing session

of up to one hour. During the meetings, the women would message Maria if they were struggling with IT issues or were confused about anything. Maria also travelled with the women to the University of Hull on the day of filming to support and debrief.

The women were always regarded as equal partners to the research team, were genuinely valued members of the team, and were respected as experts by experience. The adoption of technologies such as WhatsApp proved very effective for creating a safe space where the women could speak candidly and share their ideas in a constructive manner. The financial resources to underpin the co-creation were vitally important, as the budget allowed reasonable reimbursement of participants for their time and expenses. In this study, this represented around 3–4 per cent of the total budget. It is vitally important for similar research projects to plan generous time and support for authentic co-creation, particularly when dealing with sensitive issues.

In conclusion, the process of participating in this research has had a positive impact on these women. The entire team has enjoyed this research experience, and the sense of achievement felt by everyone by working on this important issue is widely evidenced. To sum up the project, Maria, and then the women themselves, have the final comments:

I believe their involvement has shaped them as individuals, helped them see that they have a powerful contribution to make, and has validated and challenged them as individuals, all while the study has progressed.

It was life-changing for me, as I finally made peace with myself.

I know it will eventually become part of history as all the research and a bunch of eager people coming together can make a difference to our future.

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## Declarations and conflicts of interest

### Research ethics statement

The authors declare that research ethics approval for this article was provided by the Faculty of Health Sciences Research Ethics Committee, University of Hull (REF FHS323).

### Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

### Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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