CITIZEN SCIENCE:
THEORY AND PRACTICE

The Feasibility and Acceptability of a Community Science Approach to Explore Infant Formula Preparation Safety in the Home

METHOD

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ABSTRACT

Parents often seek out information about health and parenting topics, but despite this, there have been few attempts to actively engage them in the research process. We aimed to assess the feasibility and acceptability of using community science (CS) in a pilot study to explore infant formula preparation safety in the home in the United Kingdom.

Parents were involved at each research stage, including (i) pre-funding consultation (n = 17), (ii) research design (n = 19), (iii) data generation (n = 151), (iv) research education (n = 8), (v) data analysis (n = 5), (vi) reflections on participation in CS (n = 151) and participation in the data analysis group (n = 5), and (vii) the development of research outputs (n = 5).

Parents proposed that a closed Facebook group would be a feasible platform for CS. This had limited effectiveness in engaging parents in research design but was more successful in recruitment to the data generation stage. Many parents reported enjoyment in taking part and feeling valued for their knowledge, although for a minority, increased awareness of the risks of preparing infant formula caused distress. Research education engagement on social media was limited. The small data analysis group allowed for more in-depth contributions; however, facilitation was resource intensive so was necessarily limited.

Participant fatigue is a risk in CS. Solutions to ongoing engagement, especially (in our case) with research education, are needed. Researchers must also mitigate harm to community scientists arising from their involvement in investigating sensitive topics. Existing research contexts created barriers, so in practice, more funding is needed to facilitate CS.

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INTRODUCTION

Community (and citizen) science (CS) have evolved to consider a wide range of topics including health and biomedical research (Wiggins and Wilbanks 2019). We note here that we prefer the term community science to citizen science, as the latter can appear exclusionary (Cooper et al. 2021). However, health research is still considered to be underrepresented in CS (ECSA 2020). Pregnancy and new parenthood are life-changing experiences, and people are often highly motivated to find out more about health and parenting topics at this time (Olander, Smith, and Darwin 2018). Despite this, parents are often merely passive recipients of research, rather than taking an active role in the research process.

To our knowledge, there has been only one documented example of CS with parents—The Parenting Science Gang (Collins et al. 2020), who crowd-sourced parents' questions via a Facebook group and subsequently developed several CS projects. These included an exploration of the temperature of babies being carried in slings (Filingeri et al. 2020), child eating behaviour (Dovey et al. 2019), and the biological composition of breast milk from longer-term breastfeeding mothers (Shenker et al. 2020). Parents who participated in the Parenting Science Gang said that they enjoyed being part of a like-minded community, perceived increases in their science skills and confidence, and felt satisfaction from creating new knowledge. Academic researchers reported benefits in finding research gaps in an under-researched field. Limitations were related to academics' discomfort with the uncertainty inherent in community scientist–led research, and with managing community scientists' expectations (Collins et al. 2020). Lack of diversity in the sample was also reported, though this is a commonly identified problem in CS research (Pateman, Dyke, and West 2021).

While some of the Parenting Science Gang's projects related to breastfeeding, no CS research had explored parents' formula feeding experiences. Infant feeding is extremely personal, emotive, and often highly judged. resulting in infant feeding behaviour being termed a "hidden reality" (Dattilo et al. 2020). Research with formula-feeding parents has found that feelings of guilt and stigma are prevalent (Fallon et al. 2017), especially if formula was introduced after stopping breastfeeding earlier than planned (Brown 2019). CS methods could be an excellent opportunity to engage parents in infant feeding research and may allow a wider and deeper exploration of this often-stigmatized topic. The aim of our pilot study was to assess the feasibility of engaging community scientists to explore infant formula preparation safety in the home. The empirical findings of this research have been published separately (Grant et al. 2024a); however, this paper will focus on the feasibility of the CS method for this type of investigation.

THE CONTEXT OF OUR STUDY

Despite the widespread use of infant formula in the UK (McAndrew et al. 2012), parents and carers report feeling under confident about preparing it (Brown, Jones, and Evans 2020). The proper preparation of infant formula is important because formula-fed babies are at greater risk of gastrointestinal infections than breastfed babies (Renfrew et al. 2012). Powdered infant formula (PIF) is not sterile and can contain harmful bacteria (Crawley, Westland, and Sibson 2020). In addition, bottles, teats, and scoops are vulnerable to contamination during preparation (Cho et al. 2019). To minimise the risk of infection, PIF must be carefully prepared, by mixing powder with water 70° Celsius (°C) or greater to kill any harmful bacteria that may be present (WHO 2007). The UK National Health Service (NHS) provides a process that parents should follow to achieve this (NHS 2023). Therefore, our research explored parents' formula preparation practices, comparing them with the NHS guidelines, including the measurement of water temperatures used to make formula.

METHODS

Our CS design incorporated parent involvement within 7 stages of the research process: (i) pre-funding consultation (n = 17), (ii) research design (n = 19), (iii) data generation (n = 151), (iv) research education (n = 8), (v) data analysis (n = 5), (vi) reflections on participation in CS (n = 151) and participation in the data analysis group (n = 5), and (vii) the development of outputs (n = 5), including this paper. How parents contributed to each stage is outlined in Table 1.

COMMUNITY SCIENTIST ENGAGEMENT THROUGHOUT THE STUDY

We reviewed the literature to inform good practice for involving stigmatised communities in research (Jennings et al. 2018; Nicolaidis et al. 2019; Vaccaro 2020). We recognised the varied realities and relationships that exist between academic and lay researchers, and how our positionality as public health researchers or health professionals might influence community engagement and trust (Clover 2011). We also had to consider the influence of our own ethnic backgrounds as white western women, and the influence of historical power imbalances in biomedical research (Topp et al. 2021). That said, our team consisted of members who are neurodivergent, disabled, and from varying socioeconomic backgrounds, which we

RESEARCH STAGE	COMMUNITY SCIENTIST CONTRIBUTIONS
Pre-funding consultation	Parents were asked in Facebook posts about their preferences for being involved in a study of this kind, including what would be feasible and their preferred methods of engagement and remuneration. Parents commented on posts.
Research design	Parents critically reviewed study instruction sheets and data collection tools (research diary questions). These were posted in the Facebook group, and parents commented on them. More detail on these posts can be seen in Table 2.
Data generation	Parents actively contributed to data collection by detailing their infant formula–making process in a research diary and undertaking an at-home experiment by measuring the water temperature used to make up powdered infant formula.
Research education	Parents were invited to contribute and engage with research education and scientific awareness via regular posts in the private Facebook group. More detail on research education posts can be found in Table 4. Likes, views, and comments indicated the level of engagement with this stage of the process.
Data analysis	Parents were invited to join a data-analysis sub-group to analyse qualitative data arising from the research diaries. This data analysis sub-group contributed in part asynchronously via email and through comments in another separate closed Facebook group (for the analysis sub-group only), and some contributed via a series of live online video conferencing meetings (23 meetings over 8 months).
Reflections on participating in CS	The research diary contained questions that addressed participation in the research: for example, "How did you feel about doing this experiment?" and "Would you take part in a similar experiment again?". Conversations also took place in the analysis sub-group about this, and notes were kept by the academic researcher.
Development of research outputs	Parents in the analysis sub-group offered critical reviews of the research outputs (academic papers and conference presentations) via email.

Table 1 Community scientist contributions to each stage of the research process.

felt enhanced our empathy for stigmatised groups. Some of the team are parents with their own infant feeding experiences, and some are not. Therefore, we were aware of our ethical responsibility to respect the contribution of lay researchers and to share power with them throughout the process (Eleta et al. 2019).

There is no single agreed-upon protocol for involving community analysts in research; however, the European Citizen Science Association (ESCA) Ten Principles of Citizen Science (ECSA 2015) served as our guidance to ensure the work had a clear benefit for the community scientists. We explored our experiences of analysing data with stigmatised groups in this study in more depth in a published paper (Grant et al. 2024b). Here, we aim to provide a broader overview of our CS approach with parents through the whole process.

The following section outlines the degree and nature of community scientist engagement at each stage of the research process.

PRE-FUNDING CONSULTATION

Seventeen parents, recruited via social media posts on Facebook and Twitter (now known as "X"), contributed to our pre-funding consultation. We presented some of our initial ideas for generating data on infant formula preparation in the home via open conversations and 1:1 conversations through Facebook messenger and email. One initial idea that was not supported was having parents video record themselves preparing a bottle of formula. There was a consensus that measuring the temperature of the water used to make a bottle of formula was feasible and acceptable. Many parents said that they would not need a financial incentive to take part in the study, but that it would show that parents were valued partners.

In addition, we asked about how parents wanted to be involved in developing the research design and data generation tools. Of the 17 parents in our pre-application consultation, 15 thought that an online community hosted on Facebook was an accessible way of taking part in the study, considering the lifestyle of parents of young babies. When asked about incentives, most parents said that payment would not be needed, although some parents noted that it could encourage people to complete the experiment. The need to make the research quick and easy for participants was stated clearly, including the need to supply thermometers and not expect too much time from participants. This included not asking parents to take temperatures too frequently as it was perceived that this could deter parents from taking part or result in incomplete data.

Parents involved in the consultation also clearly expressed their concerns that stigma directed towards formula-feeding parents could come across through this study if it was not approached with sensitivity. One participant wrote, "Can I just ask it's not to put a negative impression on formula fed babies??".

RESEARCH DESIGN

A closed Facebook group was established and publicised on the researchers', one of the funder's (the UK Food Standards Agency), and Swansea University's social media platforms. We advertised the group on Twitter and Instagram, as well as Facebook. Participants had to agree to group rules (pertaining to courteous conduct) and

eligibility criteria before joining, and group joining requests required approval from the academic team. To be eligible, a prospective member had to be over 18; be a parent or caregiver who uses powdered infant formula to feed a baby who is under 12 months old; and live in the UK, regardless of immigration status. The group membership totalled 78 community scientists at its largest.

Parents in the Facebook group were asked to provide feedback on aspects of research design and tools for the at-home data generation task, which we called "the at-home experiment" (see Table 2).

Nineteen unique community scientists commented on research design posts. We asked parents to comment on the instruction sheets for the at-home experiment and asked parents a series of questions about the contents of the online research diary, where results would be recorded. We received recommendations around different milk types to include donor human milk, specialist infant formula (which is prescribed), and to allow parents to tick yes to more than one option to allow for combination- (breast and formula) fed babies. Community scientists also highlighted other equipment that was commonly used, which we had not included, such as brushes to clean bottles, scoops to measure powdered infant formula, formula powder storage pots, flasks for storing hot water, bottle warmers, and devices and ice packs to cool prepared infant formula quickly.

DATA GENERATION

Two-hundred parents and carers were recruited to the study via social media. At first, we advertised within the closed Facebook group and then made the recruitment post shareable so that members could disseminate it among their own online networks. Recruitment was initially slow, and in order to achieve our desired sample size of 200, the academic teams' social media networks, which include Facebook, Instagram, and Twitter (X), needed to be exploited. One of our team members has a large following of around 110 K across platforms, which may have helped us to reach our sample size within 8 weeks. We sent out 200 research packs containing thermometers and instruction sheets in the post over a period of four months (March–June 2022). The slow posting of packs was partly due to a delay in receiving thermometers from the supplier and partly because of study manager Jones' limited working hours and leave.

Two key pieces of data were collected during this phase. First, the research diary comprised a one-off online survey that aimed to collect data on participants' usual formula preparation practices. Questions were designed to assess compliance with each step of the NHS guidelines for safe formula preparation. Second, participants completed the at-home experiment following the detailed instructions provided, in which they were asked to measure the temperature of the water they used to make a bottle of infant formula, and the method they used to heat the water – kettle, formula preparation machine, or other methods such as hot water taps or baby kettles. All participants were provided with new food thermometers of the same brand and quality.

Of the 200 people who received a research pack, 151 (75.5%) returned completed online research diaries and the at-home experiment and were sent a £5 shopping voucher

POST	VIEWS	TOTAL NUMBER OF LIKES (NUMBER OF LIKES FROM COMMUNITY SCIENTISTS)	TOTAL NUMBER OF COMMENTS (NUMBER OF COMMENTS FROM COMMUNITY SCIENTISTS)	NUMBER OF INDIVIDUAL COMMUNITY SCIENTISTS COMMENTING
Request for feedback on first draft of instruction sheet	43	5 (4)	15 (7)	3
Request for suggestion on questions to ask in the research diary	65	6 (4)	19 (12)	9
Request for information on types of milk used	50	1 (0)	10 (7)	5
Request for information on what equipment is used to prepare bottles of formula	62	1 (0)	18 (10)	7
Request for information on types of infant formula preparation machines used	62	0	4 (2)	2
Asking for feedback on second draft of instruction sheet	68	1 (1)	6 (3)	3
Participant-initiated post about the rationale for the use of two bottles in the at-home water temperature testing	63	2 (1)	3 (2)	2
Sharing drawings to go on instruction sheet	59	7 (6)	0	0

Table 2 Research design posts in the Facebook group and community scientist interaction.

for completing the study. Demographic information was collected as part of the research diaries, which gave insights into the participant characteristics (see Table 3).

The vast majority identified as Welsh/English/Scottish or Northern Irish (90.1%); unfortunately, it was not possible to discern the ethnicity of these respondents owing to an error in the ethnicity question wording. All community scientists completed or mostly completed their research diaries in relation to their usual formula preparation practices, and 143 (94.7%) reported usable data relating to the temperature of the water used to prepare infant formula.

Crucially, parents were not given information by the research team reminding of the NHS guidance on formula preparation *before* completing their research diaries, as the aim was to capture parents' real-world practices. However, in the research diary, parents were asked to rate how knowledgeable they felt regarding the NHS guidelines, and this allowed us to assess prior knowledge. On a 5-point Likert scale (Very knowledgeable to Not knowledgeable at all) only 48 (31.8%) regarded themselves as very knowledgeable, indicating a need for improved public health messaging on this topic. To ensure the wellbeing of babies and as part of the ethical requirements of the study, parents' responses on Facebook and the research diaries were screened by a health professional, who was part of the research team. Parents who reported water temperatures that were lower than the recommended 70°C were contacted by email and provided links to reputable sources of further information on how to safely prepare infant formula. One parent replied to the email stating that they felt upset about receiving this information, as they had recently had to move from breastfeeding to formula feeding and had found this decision difficult.

RESEARCH EDUCATION

Our study aimed to provide community education to enhance understanding of research among parents. The schedule of education posts was developed by the study public engagement lead (Yhnell) and study lead (Grant), with the purpose of understanding group members' baseline knowledge about research and to elicit discussion of what group members would like us to provide.

Within our closed Facebook group, we sought engagement in some research education. First, we asked parents "What does the word 'research' mean to you?" Four people commented, using terms such as "gathering

Gender	Mother	*n* = 143, 94.7%
	Father	*n* = 8, 5.3%
Age		*M* = 32.87 years, *SD* = 4.46, range: 21–43 years
Nationality	Welsh/English/Scottish/Northern Irish	*n* = 142, 90.1%
	Other white background	*n* = 1, 0.7%
	White and Black Caribbean	*n* = 1, 0.7%
	White and Black African	*n* = 1, 0.7%
	Chinese	*n* = 1, 0.7%
	Any other Asian background	*n* = 1, 0.7%
	Caribbean	*n* = 1, 0.7%
	Prefer not to say	*n* = 3, 2%
Age of youngest baby		*M* = 7.05 months, *SD* = 2.74, range: 1–12 months
Parity	1st-time parent	*n* = 88, 58.3%
	Have more than one child	*n* = 63, 41.7%
Disability status	I consider myself to be disabled	*n* = 4, 2.6%
	I do not consider myself to be disabled	*n* = 147, 97.4%
Education	Postgraduate qualification or equivalent	*n* = 75, 49.7%
	Bachelor's degree or equivalent	*n* = 47, 31.1%
	A-level or equivalent (age 18 school leaver qualification in the UK)	*n* = 24, 15.9%
	GCSE or equivalent (age 16 school leaver qualification in the UK)	*n* = 3, 2.0%
	Prefer not to say	*n* = 2, 1.3%

Table 3 Participant demographics, data generation phase. *n*: number in subsample, *M*: mean, *SD*: standard deviation.

information," "peer-reviewed studies," "empirical," "controlled," and "scientific". However, when we asked community scientists what their understanding of "community science" was, four people noted that they had "not heard that term before." Table 4 shows the topics of discussion on the Facebook group that relate to research education and the engagement with those posts.

There were eight unique community scientists who commented on the research education posts. However, as Table 4 shows, engagement with the research education element of our CS approach was low and declined over time. We had planned to develop research education webinars; however, we decided that due to lack of interest from the group, these should not go ahead.

DATA ANALYSIS

Statistical data from the research diaries and temperature measurements were analysed using descriptive and inferential statistics and are described in more detail in our empirical findings paper (Grant et al. 2024a). Open text data from the research diaries were analysed using reflexive thematic analysis (Braun and Clarke 2022). Ellis, supported by Grant, undertook the initial coding and development of themes. This was then shared with five community scientists who contributed to reviewing and developing the themes as well as writing up the results. All of these were mothers of white ethnicity, who were recruited via our Facebook group. Initially, all five community scientists stated that they would prefer to take part in the analysis activities asynchronously online via email or in a separate closed Facebook group, due to the time challenges associated with looking after a young baby and returning to work. However, following the first two meetings, community scientists decided that online meetings where the community scientists could contribute together would be more valuable. Anyone who could not attend a meeting had the option to contribute via posting comments to the Facebook group or by contacting the facilitator.

At the outset, it was not clear how many analysis meetings could occur because the study had a limited funding period and there was a lack of certainty about how long community scientists would like to be involved. Ultimately, 23 meetings occurred over a period of 8 months. This allowed for five community scientists to be involved in two of the six stages of reflexive thematic analysis (Braun and Clarke 2022) of open text data—reviewing and refining themes—and for four (of the five) to continue to be involved in writing up the study outputs (the final stage of reflexive thematic analysis) and contributing to the development of other outputs, including infographics and a press release. All community scientists involved in the analysis group received a £20 voucher per hour of participation.

First, Grant familiarised themselves with the data, developed initial codes, and then presented these to the community analysts who discussed and reflected on them. The community analysts felt that experiences could be divided into two categories: "positive" experiences and "negative" experiences which included considerations for how advice for formula-feeding parents could be improved, deviating from the usual reflexive thematic analysis approach. With these two categories in mind, Grant undertook further stages of thematic coding, reviewing and

POST	VIEWS	TOTAL NUMBER OF LIKES (NUMBER OF LIKES FROM COMMUNITY SCIENTISTS)	TOTAL NUMBER OF COMMENTS (NUMBER OF COMMENTS FROM COMMUNITY SCIENTISTS)	NUMBER OF INDIVIDUAL COMMUNITY SCIENTISTS COMMENTING
What does the word "research" mean to you?	56	2 (0)	7 (6)	4
What does the term "community science" (sometimes also known as citizen science) mean to you?	51	1 (0)	5 (4)	4
Shared a video of a presentation about the research study (7 minutes, no subtitles)	42	4 (3)	0	0
Have you noticed the phrase "evidence-based policy" being used in the news recently?	48	0	2 (0)	0
What would you like to know about research?	47	0	0	0
Did you know these facts about infant formula from First Steps Nutrition Trust? (with infographic)	57	3 (3)	3 (2)	2
Should I give water to my baby? Guidance and recommendations from First Steps Nutrition Trust (during a heatwave)	53	2 (2)	2 (1)	1
Link to blog post: "Formula feeding will NOT make your baby Autistic" (Autistic UK)	29	2 (2)	0	0

Table 4 Research education posts in the Facebook group and community scientist interaction (in chronological order).

developing themes as well as writing up the results, which were presented to and agreed on by the group at each stage. We, including the community scientists, produced a separate in-depth reflective account of the process of undertaking the reflexive thematic qualitative analysis in our study (Grant et al. 2024b).

REFLECTIONS ON PARTICIPATING IN COMMUNITY SCIENCE

Closed questions in the research diaries identified that the most people were either very positive (n = 105, 70.9%) or quite positive (n = 30, 20.5%) about taking part in the research. In open-text responses, twenty-one people (13.9%) reported positive experiences such as finding the project interesting, enjoyable, or empowering. Conversely, seventeen community scientists noted that the study had been a challenging experience, and this was illuminated by answers in the open-text box that accompanied the question. While parents had gained a more accurate understanding of the risks involved in preparing infant formula through taking part, a common theme among respondents (n = 10) was that this meant they were more worried about it as a result, and some felt that participation had reduced their confidence. One participant wrote, "It made me question whether I was doing the right thing for my baby again." Three parents explicitly noted that taking part in the study had made them revise their PIF preparation practices to make them safer. This data was collected as part of the research diary, so it was not possible to discern how many others had also changed their practices as a result of receiving the debrief information.

One hundred and thirty-seven people (92.6%) said that they would take part in a similar study again over a longer period with several temperature measurements; however, 21 people (13.9%) highlighted the additional inconvenience as a potential barrier and that further incentives may be needed. One suggested, "the thank you payment would need to be worth it." This sentiment was echoed by community scientists in the analysis sub-group.

All five community scientists involved in the data analysis activities provided feedback after four meetings to the facilitator. Following this, some improvements were made to the way in which the analysis group functioned, including sharing data extracts earlier and making more explicit links between the analysis activities being undertaken and the creation of the study's scientific outputs. Further reflection was provided through a series of meetings with four of these community scientists to develop a detailed paper on being part of the community analysis group (Grant et al. 2024b).

The community scientists noted that being involved in the analysis group was something that they initially felt some anxiety about, but that they valued being part of a "supportive" community where "there's no judgement" and analysis meetings could feel "cathartic." The community scientists highlighted the importance of a facilitator who was non-judgemental and approachable, and reflected that the facilitator's relative lack of familiarity with formula feeding and status as a non-mother and an academic (rather than health professional) contributed to this feeling of ease. However, at one point, the community scientists' formula preparation safety questions were taken to health professionals, who were part of the wider study team. The facilitator shared the health professionals' advice verbatim, and this resulted in significant tension in the group, particularly when it was identified by a community scientist that the advice went beyond existing NHS guidance, including a recommendation that scoops used to portion powdered formula should always be sterilised (recent research supports this view (Cho et al. 2019), but it is not yet included in the guidance for the public). Though community scientists were aware that members of the team were health professionals, upon reflection, community scientists felt that if an event such as this had happened at an earlier stage in the study it could have led to disengagement.

Analysis group members appreciated the oral format of meetings ("I process things better by talking about it"), and that online meetings "fit around family life," although they felt that this reduced opportunities for group bonding compared with the face-to-face parenting groups with which some had been previously involved. In addition, several members appreciated being able to contact the facilitator separately if they were unable to attend, were unsure of instructions, or had concerns. Over the course of their involvement, the community scientists reported increased knowledge and confidence when it came to research, including seeking information such as peer-reviewed literature and policy documents, and conducting their own experiments relating to the safety of preparing infant formula.

DEVELOPMENT OF OUTPUTS

Four community scientists in the analysis sub-group contributed critical edits to academic outputs. In addition, they were involved in the development of social media infographics aimed at parents to disseminate the research findings.

DISCUSSION

The following discussion outlines our reflections on doing CS with parents of young babies, with particular reference to social media as a platform for doing CS, to the engagement with research education, and to the issues we faced when doing CS on a sensitive topic such as infant feeding. Finally, we discuss the barriers to doing CS within existing research frameworks.

SOCIAL MEDIA IN COMMUNITY SCIENCE PARENTING RESEARCH

Social media was a useful platform to involve community scientists in the study; however, community scientist engagement within the Facebook group was relatively superficial. We posted 31 times over the span of a year; 8 were dedicated to research design, 8 to education and the rest to recruitment to the main study or to prompt engagement. Posting daily, on average, is thought to be optimal, so our approach, which was much less often than this, may have led to low engagement (Oliveira et al. 2021).

Social media was much more effective for advertising the study and for recruitment to the data generation phase (the research diaries and at-home experiment), and we have found this to be the case in our previous survey research with parents (Brown, Jones, and Evans 2020). However, recruitment was initially slow, potentially as a result of our small incentive relative to the task and lack of paid advertising, or because of the single platform (Facebook) chosen over other possible or multiple platforms. We had to rely on the large social media following of one member of our team (Brown) to achieve the required sample size. This was an advantage as well as a limitation, as it may have restricted engagement to people associated with the research team. Despite this, we expected that a degree of snowballing via onward sharing would occur, likely widening the study advert's reach. Engagement with the data generation itself was extremely successful, with a high rate of return of the diaries and experiment data (75.5%), suggesting that if reached, parents can be excellent contributors to CS outside of social media.

In comparison, the Parenting Science Gang achieved more successful recruitment of parents to social media–led CS, with more than 2,500 community scientists involved across eight Facebook groups (Collins et al. 2020). However, unlike our study, which was time-limited to nine months and focused on a pre-determined question, the Parenting Science Gang ran for two years with parental input into the research questions to be investigated. The relatively short timeframe of our research undoubtably affected the ability for the project's online presence to grow organically.

The choice of social media platform may also be impactful; while Facebook is the most popular social media platform among 25–34-year-olds, it is noteworthy that social media engagement trends differ among generations and can also change rapidly, with younger people preferring to engage with Instagram or TikTok (Zote 2024). This perhaps explains why the average age of parents participating in our research is slightly older at 32. Future research using social media as a recruitment and participation method for younger parents may wish to consider broadening their scope to include other platforms.

We were aware of the sensitivity of the topic and recognised **[British spelling]** the risk of bullying and othering behaviour, which could be increased by the anonymity of social media (Harmer and Lumsden 2019), and the possible existence of grief and trauma among parents for whom formula feeding was not their first choice (Brown 2019). Therefore, we decided to form a closed Facebook group, with rules and strict eligibility criteria to promote a safe space for discussions. However, the closed nature of the group may have further limited our opportunities for community scientist recruitment and engagement. We found much more in-depth engagement with community scientists was possible in the smaller analysis sub-group, but this was resource intensive, in terms of researcher time and honorariums, and required significant flexibility to fit around parents' child-caring commitments.

RESEARCH EDUCATION IN COMMUNITY SCIENCE

In our short project with limited resources, we found that community scientists were happy to take part in research but were less interested in our educational content on research methods. We loosely measured research education engagement by observing likes and comments on relevant Facebook group posts and reflecting on conversations within the smaller analysis sub-group. However, existing knowledge of research methods and the degree of change was not explicitly measured, and we found engagement with the research education posts in the Facebook group to be low. It may have been that the research design content was more interesting to the community scientists because they were able to contribute their personal expertise rather than simply being passive recipients of knowledge. That said, the tailing off of engagement may also be explained by participant fatigue as the education posts came later in the project. Participant fatigue may be more likely to occur where there are extraneous requests for engagement (Zettler et al. 2017), where the impact of community scientists' efforts is not made clear or tangible (Nelms et al. 2022), or if social media posting frequency is either excessive or too sporadic (Oliveira et al. 2021).

We observed that interest in understanding the research process was more evident in the analysis sub-group than the broader Facebook group. The community scientists in the sub-group reported that they found the experience to be empowering, that it increased their confidence in accessing research, and that it inspired them to undertake small research projects and exploration of policy documents on their own. This may be because this particular group of parents were more motivated (evidenced by their commitment to being in the analysis group), but also may be a reflection of the relationships built between the community scientists and the facilitator

during these smaller online meetings. Engagement may also have been maintained due to community scientists receiving an additional incentive.

Research and science education are seen as desired outcomes in CS projects (ECSA 2020). However, many CS projects fail to measure research education engagement, limiting researchers' ability to evaluate success in this aspect (Bonney et al. 2016; Phillips et al. 2018). Phillips et al. (2018) suggest that having common CS learning outcomes and consistent measurement metrics across projects could improve how education in CS is implemented and evaluated. Our study had the broad educational aim of enhancing understanding of research among parents, but upon reflection, the project would have benefitted from having more specific learning outcomes and plans to measure these. This has been an important learning point from this pilot study, which the team recognised needs closer consideration for future projects.

CS educational learning outcomes need not always be research process–based and can be tied to content or community health (Phillips et al. 2018). Motivations for participating in CS vary generally within populations and/or may be population specific. For many CS participants, interest in the topic rather than in research itself is key a motivating factor (Kragh 2016). However, most CS has previously been undertaken in environmental science, and there is little research exploring the motivating factors for parents of young babies to participate in CS or in research more broadly. One now-dated study explored this, and found that the most important factors were a desire to help other parents and to improve their own knowledge about their baby and safe child-care practices (Hayman et al. 2001). Creating topic-based, rather than research-based CS education may therefore also improve uptake. More research exploring parents' motivations to participate in research and CS is needed.

DOING COMMUNITY SCIENCE ON SENSITIVE TOPICS

From the study's outset, our pre-consultation phase identified that there were risks inherent in undertaking CS on formula feeding. Sensitivity to participants' wellbeing was carefully considered through the research design, and research questions were screened by community scientists to ensure that they would not appear to be judgemental. However, a minority of community scientists in the data generation phase of the study reported that taking part in the research increased their anxiety about preparing infant formula. A standard email was sent to participants with advice on safe water temperatures to prepare infant formula and signposts to NHS guidance; however, this caused upset for one community scientist in the data generation phase, and three members of the analysis group were negatively impacted by advice provided by health professionals in the group that went beyond the scope of existing NHS guidance. Guilt, grief, stigma, and trauma are common emotional responses among women who have either decided to formula feed or who have had to stop breastfeeding and move to formula feeding before they were ready (Fallon et al. 2017; Brown 2019). Furthermore, parents may have had negative experiences with health professionals leading to dissatisfaction and mistrust (Collins et al. 2020).

We found that developing a supportive environment, particularly within the analysis sub-group was crucial to enable the community scientists to be open and honest about their experiences, with sensitivity and empathy for the other group members. The analysis sub-group also highlighted the importance of non-judgementalism and appreciated that the sub-group's facilitator was not a health professional and had limited lived experience preparing infant formula, somewhat levelling the power dynamic (although we recognise that a dynamic still exists between professional academic and lay researchers). For example, discussions of infant formula preparation practice, which did not fully meet the NHS (2023) recommendations was relatively normalised in the community science analysis group. The group facilitator, as a non–health professional, was perhaps able to explore this more freely with the community scientists and understand the barriers to following the recommended process.

To ensure community scientists are not re-traumatised by their involvement in research, CS researchers exploring sensitive topics may wish to explore trauma-informed approaches (Office for Health Improvement and Disparities 2022), and undertake training in facilitating CS projects.

DOING COMMUNITY SCIENCE WITHIN EXISTING RESEARCH CONTEXTS

We encountered several challenges to doing CS within existing research structures. The study ended up taking longer than the funding allowed: Community scientists continued to be willing to be involved in the analysis group, and the research team believed that extra analysis contributions would be a major strength, which resulted in many additional hours of academic researchers' time. The impact of this can be further contextualised by the increasing workloads and precarity within UK academia, and periods of industrial action undertaken during the study's life (Universities and Colleges Union 2023). For example, Jones, who had previously been on insecure short-term contracts, which are common in UK academia, had to reduce her time on the project because she obtained a longer-term academic contract. However, she was not

able to be easily replaced due to her professional and research expertise in the area, which were important for the study's safety netting. This led to Ellis being employed for 16 days on the study to analyse open-text data from research diaries, which was then passed to Grant to review with the community scientists. This division of tasks was unavoidable but was not ideal in relation to maintaining oversight of all elements of the study.

Further constraints relate to the current research funding landscape in the UK. Although we held a pre-application consultation, funding was unavailable to pay community scientists for their time at this stage, which resulted in relatively superficial, but impactful, involvement. Ideally, providing funding of £25 per hour should have been available for pre-application consultation, in line with UK research guidance on involving the public in research (National Institute for Health and Care Research 2024). We advise researchers using CS to become familiar with organisations in their countries that offer similar funding for the development of research projects. The status as a pilot project meant that the study's budget was limited, impacting the incentives and remuneration we could offer community scientists and the time the study team were able to put into the project.

CONCLUSION

We found that social media was a useful platform for doing CS with parents, but mainly for recruitment to the data generation part of the study, and this relied on one of our team's large social media following. Furthermore, volunteer fatigue is a risk for longer-term projects. Creative solutions for ongoing community scientist engagement, especially with the educational aspect, are needed, as is an understanding of what motivates parents to participate in CS. CS education should be clearly planned and specific desired learning outcomes measured. Researchers must mitigate harm arising from community scientist involvement in investigating sensitive or stigmatizing topics, by implementing trauma-informed practice. Existing research contexts created barriers to doing CS, and more funding is needed to facilitate the method in practice.

DATA ACCESSIBILITY STATEMENT

The data from this project have not been made available, as the research was hosted at LIFT (the centre for Lactation, Infant Feeding and Translational research) at Swansea University, which strongly adheres to the World Health Organization (1981) code on the marketing of breastmilk substitutes, which exists to protect and promote breastfeeding and prohibits the marketing of infant formula or related products to parents of babies under 6 months.

ETHICS AND CONSENT

Participants in the data generation aspect of the study provided informed consent. Parents at the pre-application and research design stage did not provide written consent but consent was implied by their involvement. Similarly, community scientists in the analysis sub-group did not give additional written consent, but all had consented as part of the data generation stage and were further reminded that their involvement was entirely voluntary. All community scientists were free to leave the project at any time without judgement. Ethical approval was provided by the Swansea University School of Health and Social Care Research Ethics Committee.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Jones was the study manager and contributed to study design, quantitative data analysis, and draft writing of this paper. Cooper, Dolling, McNamara and Dvorak were community scientists who took part in research design, data generation, and analysis and contributed to critical edits of this paper. Sibson, Brown, Yhnell, Buchanan and Breward contributed their professional expertise and critical edits to all aspects of study design and research outputs. Ellis analysed the qualitative data and contributed

to critical edits of research outputs. Grant was the study's principal investigator and oversaw study design, data analysis, facilitating community scientist analysis sessions, draft writing, and critical edits.

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