

# Analysing Data With Members of a Stigmatised Community: Experiences, Reflections and Recommendations for Best Practice From the Finding the Formula Community Analysis Group

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## Abstract

Participatory research approaches hold potential to better understand society through valuing lived experience. Formula feeding babies is routinely stigmatised in the UK, despite inadequate support to facilitate breastfeeding. Our community science project investigated the safety of powdered infant formula preparation in the home through the completion of an at-home experiment and a research diary with closed and open questions ( $n = 151$ ). To add validity to the interpretation of open text data in research diaries, a community analysis group of five formula-feeding mothers was established. The community analysts undertook inductive thematic analysis through a series of analysis group meetings focused around data extracts, contributed to the study's empirical outputs and this methodological output, meeting 23 times over a nine-month period. Detailed notes were taken during meetings and the methodological elements of these were thematically analysed with the community analysts to produce this article, with extracts from the academic researchers' field notes added where relevant. The overarching themes, presenting both positive experiences and areas for improvement, focused on: (i) clarity of expectations and the impact this had on community analysts' confidence, (ii) the stigmatising topic area and how this was managed by the facilitators, and (iii) feeling valued, in relation to honoraria, inclusion in outputs and community analysts coming to recognise their own expertise. Furthermore, the community analysts co-produced recommendations for including community analysts in future research. It provides guidance on how this can be appropriately costed for and supported by funding bodies and research teams, as well as providing guidance on recruitment and chairing meetings. We hope that this article can provide valuable input into how to involve the community more inclusively as research partners in qualitative analysis related to stigmatised topics.

## Keywords

action research, participatory action research, community science, citizen science, qualitative, qualitative analysis, infant feeding, formula feeding

## Introduction: Infant Feeding as a Moral Maze

Participatory research approaches, including Participatory Action Research (Cornwall & Jewkes, 1995), Community Based Participatory Research (Israel et al., 1998) and Citizen Science (European Citizen Science Association, 2015), emphasise that research should be done *with* communities, rather than *on* them. In doing so, they hold potential to better understand society through valuing lived experience, which is

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increasingly recognised as valuable by research funders. Such participatory approaches have long been understood to be valuable (Brown & Tandon, 1983), particularly when researchers do not have experience of the phenomenon, (Telford & Faulkner, 2004) or when the behaviour under investigation is stigmatised (Quinn & Knifton, 2012). Our community science project investigated the safety of powdered infant formula preparation in the home through the completion of an at-home experiment and a research diary with closed and open questions ( $n = 151$ , Grant et al., 2024b). To add validity to the thematic analysis of open text data in participants' research diaries and to contextualise this, a community analysis group of five formula-feeding mothers was established. This paper reports on our – the community analysts and academic researchers – reflections on this process. It is important to note that we do not believe that these reflections would be universally applicable in research using lay community partners in analysis relating to stigmatised topics, but we hope that they – alongside a co-developed list of recommendations – provide some useful grounding for other researchers using participatory methods.

To recognize the importance of this article, it is imperative to understand the moral context around infant feeding. At the population level, breastfeeding is established as having health benefits for mother and baby, when compared to infant formula (Victora et al., 2016), including significantly fewer gastrointestinal infections (Renfrew et al., 2012). It is recommended that babies are breastfed exclusively until they are six months old and that they continue to receive breastmilk alongside solid food until they are at least two years old (World Health Organization, 2017). Infant formula is a breastmilk substitute used when mothers are unable or do not want to breastfeed or use donor human milk. Although breastfeeding is recommended by health professionals, the UK has some of the lowest breastfeeding rates in Europe (Victora et al., 2016) with four in five women initiating breastfeeding, but only one third still giving any breastmilk at six months of age (Health and Social Care Information Centre et al., 2012). Mothers in the UK report inadequate breastfeeding support, broader challenges around loneliness and a lack of parenting support (Brown, 2021), and they exist in a patriarchal society where breasts are sexualised (Grant, 2016). Many mothers in the UK report that they stopped breastfeeding before they wanted to (Health and Social Care Information Centre et al., 2012). This can lead to significant guilt and trauma (Brown, 2019). It is within this context that many parents begin formula feeding. Transitions to formula feeding can therefore feel stressful as they are often unexpected and sometimes contextualised by breast pain or their baby losing weight and sometimes returning to hospital for increased monitoring (Fallon et al., 2016). Additionally, a lack of sufficient information and support around formula feeding is often reported (Grant et al., 2024b), and some mothers report feeling stigmatised when formula feeding (Grant et al., 2022; Grant et al., 2018b). Somewhat ironically,

low breastfeeding rates can lead to women who breastfeed feeling isolated, unusual and ashamed, showing that there is no morally safe infant feeding method for mothers in the UK (Thomson et al., 2015).

## Community Involvement in Infant Feeding Research

To date, Action Research approaches have been used in the UK in relation to breastfeeding (Condon & Ingram, 2011), and a significant proportion of UK breastfeeding support is provided by unpaid and highly motivated volunteers, often known as breastfeeding peer supporters (Grant et al., 2018a). As well as providing support to individuals, breastfeeding peer supporters have also attempted to change public perceptions of breastfeeding, for example by developing community exhibitions (Condon et al., 2010), responding to criticism of breastfeeding in public on social media (Marcon et al., 2019) and using nurse-ins as a form of protest (Grant, 2015). Most infant feeding research has focused on mothers who breastfeed, or their reasons for stopping breastfeeding, with fewer studies focused on mothers' formula feeding experiences and support needs. We are not aware of any Action Research focused on formula feeding, although an Action Research project focused on improving family support in neonatal intensive care included infant feeding (Skene et al., 2019).

Over the past decade there has been a new framing of Action Research type approaches to community engagement in research originating from the natural and physical sciences. This movement is referred to as *citizen science* which has been defined as: “the involvement of the public in scientific research – whether community-driven research or global investigations” (CitizenScience.org, 2022). This approach has primarily been used with populations undertaking traditionally middle class pursuits as unpaid volunteers, such as members of a regional botanical society (Oswald, 2020). However, it has also been successfully used with parents of young children who actively co-designed research projects through the Parenting Science Gang, including undertaking research on breastfeeding experiences (Collins et al., 2020) and the bacterial composition of human milk (Shenker et al., 2020). In 2021, UK Research and Innovation and the Food Standards Agency announced a call for research projects that used a citizen science methodology and funded our study. Our team had not used a citizen science approach previously but had aimed to work with communities of parents in our research. Citizen science most commonly follows a set of 10 principles (see Box 1; European Citizen Science Association, 2015), which shares some similarity to Action Research approaches, but in our opinion focuses more explicitly on achieving scientific outcomes, than community improvement and capacitation (Holkup et al., 2004). Due to the potential of the word “citizen” to have negative and racialised connotations, we chose to use the term “community science” in our own research practice and the rest of this article.

### Box 1: European Citizen Science Association Ten Principles of Citizen Science (Emphasis Original)

1. Citizen science projects actively involve citizens in scientific endeavour that generates new knowledge or understanding. Citizens may act as contributors, collaborators, or as project leader and have a meaningful role in the project.
2. Citizen science projects have a genuine science outcome. For example, answering a research question or informing conservation action, management decisions or environmental policy.
3. Both the professional scientists and the citizen scientists benefit from taking part. Benefits may include the publication of research outputs, learning opportunities, personal enjoyment, social benefits, satisfaction through contributing to scientific evidence e.g., to address local, national, and international issues, and through that, the potential to influence policy.
4. Citizen scientists may, if they wish, participate in multiple stages of the scientific process. This may include developing the research question, designing the method, gathering and analysing data, and communicating the results.
5. Citizen scientists receive feedback from the project. For example, how their data are being used and what the research, policy or societal outcomes are.
6. Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for. However unlike traditional research approaches, citizen science provides opportunity for greater public engagement and democratisation of science.
7. Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format. Data sharing may occur during or after the project, unless there are security or privacy concerns that prevent this.
8. Citizen scientists are acknowledged in project results and publications.
9. Citizen science programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact.

10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities.

### Literature Review: Existing Approaches to Community Involvement in Analysis

We reviewed existing approaches to understand what good practice could look like for *meaningfully* involving the community as analysts of qualitative data. Due to the potential for formula feeding to be stigmatised, we proactively searched for literature on the co-analysis experience of groups that may have felt stigmatised. This included a range of topic areas, for example involving patients in the analysis of mental health data (Jennings et al., 2018), involving Autistic people in the development and evaluation of health interventions (Nicolaidis et al., 2019) and collaboratively analysing qualitative data with women experiencing long-term homelessness (Clover, 2011; Vaccaro, 2020).

Within the literature, ethical and practical issues in how to conduct co-analysis were described, highlighting that collaborating with lay researchers is not always easy or quick (Oswald, 2020). This is in part due to the varied realities and expectations between academic and lay researchers, particularly when the topic under study is not shared between the two groups (Clover, 2011). However, the recruitment of co-analysts can be viewed as a promise from academics to community researchers to share power with communities that must be upheld (Eleta et al., 2019). Accordingly, clear discussions around expectations, roles and how community scientists will inform study outputs provide reassurance (Jennings et al., 2018), and are motivating (Eleta et al., 2019), for community scientists. Furthermore, where community analysts will be involved in collecting or producing data, as well as taking part in research oversight, existing ethical guidelines may prove to be inadequate (Resnik, 2019), so the research team must carefully consider these ethical aspects throughout. This includes ensuring that recognition for contribution occurs, including in the form of scientific credit, financial compensation and benefits for the individual and broader community (Smith et al., 2019).

When considering *how* to involve the community as analysts, Jennings et al. (2018) described four levels ranging from only influencing interpretation, to lay community analysts being provided with extensive data analysis training and undertaking analysis as the academic researchers would (Jennings et al., 2018). By contrast, Vaccaro (2020) described

their approach, where an academic partner analysed the data using NVivo, and significant themes were presented back to the community analysts who used arts-based approaches to consider these themes. There was no single agreed protocol for involving the public as community analysts, however the European Citizen Science Association Ten Principles of Citizen Science (European Citizen Science Association, 2015) formed a set of guiding principles in our study (Box 1). This was to ensure that we provided benefit for community analysts, and that the research had a clear scientific outcome, with the exception of sharing our data with the public due to the potential for this to undermine breastfeeding (World Health Organization, 1981).

### The Finding the Formula Study

The Finding the Formula study was a community science project designed to understand the barriers and facilitators to safely preparing powdered infant formula in the home, and to assess the feasibility of collecting a wide range of data using a community science approach. Our empirical results have been published separately (Grant et al., 2024b). The study's academic team came from a range of disciplines, including social sciences, psychology, nursing, and biosciences. We utilised a constructionist lens, with post-positivist leanings in our 'at home experiment' where participants used a thermometer to test the temperature of water used to reconstitute powdered infant formula. In using constructionist epistemology, we acknowledge that the knowledge generated by this study – in both our primary analysis and this methodological paper – was socially situated and constructed by researchers and participants, and that if others were to conduct this study or analyse the data, they may have framed the findings differently (Alvesson & Sköldbberg, 2009).

The study's objectives were to:

1. Develop an online community of parents, who would co-design the study and take part in data analysis;
2. Investigate the feasibility of using community science methods to collect formula feeding safety data;
3. Generate data on the temperature of water used to prepare bottles of infant formula and barriers to following safer infant formula preparation guidance.

The community science comprised three major elements (see Figure 1). First, a Facebook group was established where parents or carers ( $n = 78$ ) of formula-fed babies contributed to designing data collection tools. Second, parents or carers were sent resources to test the temperature of the water that they used to prepare a bottle of infant formula. They also completed a research diary, containing questions about each element of the NHS guidance for safely preparing powdered infant formula (NHS, 2019). Participants were given the opportunity to describe barriers and facilitators to each element of infant formula safe preparation, as well as their experiences of taking part in the at-home experiment through a series of open questions. Third, the open text data from research diaries was thematically analysed (Braun & Clarke, 2022) with five community researchers. The co-analysis is the focus of this article. All elements of the study received ethical approval from Swansea University School of Health and Social Care Research Ethics Committee.

### Data and Analysis

This paper is informed by the analysis of relevant documents (Grant, 2019) including: plans for community analysis group meetings ( $n = 23$ ), detailed notes taken in analysis meetings ( $n = 23$ ), and Facebook messenger conversations between Aimee and the community analysts. Additional data included

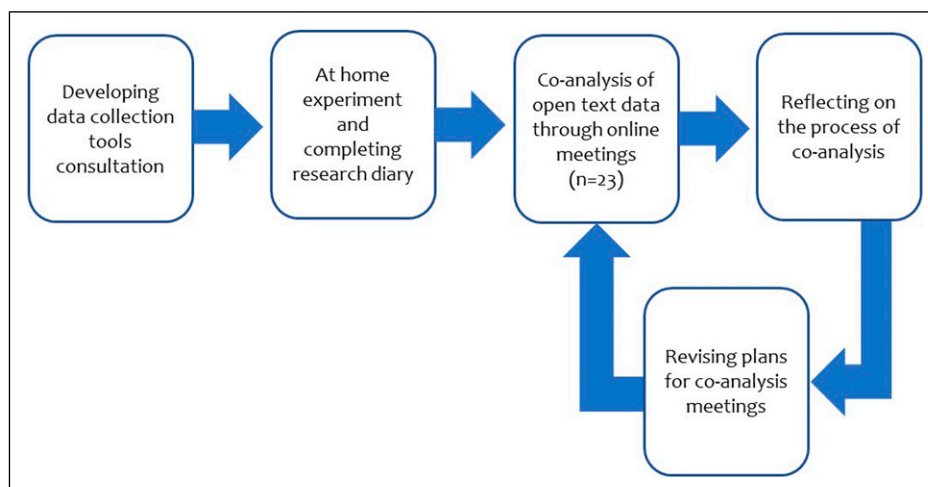


Figure 1. Overview of the finding the formula study community science elements.

verbatim transcripts from two meetings on the community analysts' experiences of being part of the project, undertaken in meetings 12 and 13, and field notes from Aimee and Rebecca who facilitated meetings. Unlike the detailed low-inference notes that were taken as part of the meeting, including direct quotations and summaries of what each person had said in relation to each thing, these field notes focused on methodological insights. Field notes were produced in free form, without reference to particular prompts; Aimee hand-wrote her fieldnotes, whilst Rebecca typed theirs allowing for whichever strategy best suited each researcher. They were usually produced on the same day as the meetings.

Our analysis approach was shaped by reflexive thematic analysis, containing six phases (Braun & Clarke, 2022), with slight variation to allow for accessibility by lay co-researchers. Modifying thematic analysis to involve lay people in analysis has been reported elsewhere, including in Moyse's (2021) research where Autistic teenagers thematically analysed their own interview content. To undertake our analysis, first, Aimee familiarised herself with the data (phase 1). She then developed initial codes on paper copies of the data (phase 2). She presented this to community analysts who felt that it would be most useful and accessible to focus the next stage of analysis on (i) positive experiences and (ii) things that could have been improved, a deviation from reflexive thematic analysis. The data sources were input into NVivo R1 by Aimee, who coded them around the two major deductive themes pre-agreed with community analysts, with inductive thematic coding created within these categories (a variation of phase 3). The initial coding was presented in written form for reflection from the community analysts (phase 4) who attended four further analysis meetings to discuss the coding, including removing the initial deductive framework focused on positive and negative aspects, to refine themes until consensus was reached (phase 5). During this phase we also developed practical recommendations (see Box 2), which were separately added to by the wider members of the academic team. Finally, the report was produced (phase 6). Below we consider our positionality, prior to reporting on the way in which community analysts were involved in the study and how this impacted community analysts' experiences of researching a stigmatised topic.

### Positionality

**Aimee: Principal Investigator and Primary Facilitator.** Aimee is a white British gender ambivalent Autistic and Disabled woman. She has a background in social policy and has researched experiences of pregnancy and infant feeding for the past decade, within the UK NHS as well as in university settings. Her infant feeding research has focused on the experiences of marginalised groups, including those on low incomes, living in stigmatised areas and those who are Disabled and Autistic (see for example: Grant et al., 2024a). Aimee has

also considered the importance of the environment on infant feeding experiences, aiming to emphasise the lack of 'choice' in infant feeding decisions (Grant et al., 2019). She has experienced multiple pregnancy losses and is childless not by choice. Prior to this study, Aimee had worked with patient representatives on projects, although the input of the public was relatively small.

**Jonie: Community Analyst.** Jonie is a white British cis-woman aged 33 living in Suffolk, England. She is married to a man and has two children - Elsie aged three years, and Ronnie, aged 11 months; both infants were born prematurely and spent time in PICU. Jonie tried to breastfeed both of her children and expressed for around 6 weeks before formula feeding both children. Jonie has a BA in Design Crafts and an MA in Fashion Knitwear. She currently works as a cooking and nutrition secondary school teacher to students aged 11 to 16 in a short stay education provision. Prior to being involved in the study, Jonie studied research methods in her degree, focused on textile artists and concepts of design. Jonie had not been involved in research as a participant or community scientist prior to this study.

**Abbie: Community Analyst.** Abbie is a white British woman aged 32 living in Wigan, England. She is married to a man and has three children: Sakura, aged seven; Órla, aged five; and Sidney, who is 9 months old. Abbie experienced a lack of support for breastfeeding with all three babies, despite requesting help multiple times. All three babies were put on to formula early on due to this. Prior to her pregnancies, Abbie worked in the veterinary pharmaceutical sector, qualified as a hypnobirthing teacher and, since having her family, Abbie has been a housewife. She has shared her experiences of pregnancy and birth with student midwives at two local universities. Abbie had not been involved in research at all prior to this study.

**Susan: Community Analyst.** Susan is a white woman with dual nationality; born in New Zealand, she has British Citizenship. She is 43, married to a man and has two children, Mila (5 years old) and Luka (19 months). Susan had a difficult birth and lack of support with breastfeeding with Mila. With Luka, Susan experienced some breastfeeding difficulties and received some assistance from health professionals. She was able to breastfeed for five months, but not exclusively. Susan has a BA in Criminology and Sociology and has worked in the banking industry for the past twenty years. She has some limited research experience from her degree, including writing psychology papers and training in research methods. Susan had been a participant in research studies, but had not previously been involved as a community scientist.

**Tara: Community Analyst.** Tara is a 31-year-old white British woman who lives in west Sussex. She is married to a man and has a one-year-old child, Phoenix, who was born by emergency caesarean. Tara attended maternity courses antenatally,

giving her the impression that breastfeeding would happen easily and naturally. However, breastfeeding was difficult and the support provided was limited. In the absence of sufficient breastfeeding support, Tara felt she had no choice but to introduce formula. Tara's undergraduate degree was in Social Sciences, and she has a PGDip in Applied Psychology. She has been involved in research as part of her undergraduate and postgraduate degree, including taking part in studies and carrying out her own research projects.

**Rebecca: Facilitator.** Rebecca is a white, British, Autistic early career researcher. Prior to her PhD, she gained an MA in Person-Centred Counselling and Psychotherapy. Her PhD in Human and Health Sciences focused on improving care pathways for Autistic children and young people. Alongside this, she has worked as a Research Assistant using qualitative and realist methods to understand health (see for example: [Ellis et al., 2023](#)). She does not have children.

**Carol: Support Worker to Aimee.** Carol is a British white woman who lived in Johannesburg from age 7 to 32. She is a qualified Executive Assistant and has obtained a Distinction in Business Management, and a Level 2 in Counselling. Carol aims to be non-judgemental, empathetic, and patient. She has experienced pregnancy loss and been told she would never carry a child to full term but was never given a medical explanation as to why.

**Sara: Study Manager.** Sara is a white British woman, academic, and health professional. She has been a qualified nurse since 2009 and a health visitor since 2014. Her research centres on childhood obesity, infant feeding, and parenthood (see for example: [Jones et al., 2020](#)); she has also volunteered with an NGO as an infant feeding expert in migrant and displaced communities. She is a stepparent to two children and would like to have children in the future. Sara has worked with patient representatives on the dissemination of research findings including public engagement events.

**Amy: Mentor to Aimee.** Amy is a professor of maternal and child health and is white British. She has a background in psychology and has spent the past 17 years exploring psychological, social, and cultural influences on infant feeding experiences ([Brown, 2021](#)). Her research (alongside her own experience as a mother and peer) has highlighted that parents often feel that they have insufficient support and information around infant feeding regardless of feeding method, leaving mothers feeling frustrated, angry, and let down ([Brown et al., 2023](#)). The ultimate goal of Amy's work is to improve infant feeding environments so that families have more genuine choice in how they feed their baby. Amy works closely with parents and professionals in developing and disseminating research and has a large and active social media presence. However, this is her first project working with parents as community scientists.

## Views and Experiences of the Community Analysis Approach

Below, the views and experiences of the community analysts are reported in relation to: clarity of expectations, research on a stigmatising topic, and feeling valued. In the reporting of our findings, we do not identify individual community analysts to protect their privacy.

### Clarity of Expectations

**Recruitment.** We recruited five mothers from our study's Facebook group in May 2022, having made a single post asking for people who were interested in helping to analyse the data, noting that they would receive an honorarium of £20 per hour as a voucher, or that they could receive remuneration as cash. In addition to Susan, who was already involved in this project, requests from five eligible parents were made. One of the community analysts decided not to take part after receiving further information; the four others who enquired joined the group. Four of the five community analysts were participants in the at-home experiment, contributing data to the study. All confirmed that they did not, and had not previously, worked for an infant formula company. This safeguard was to ensure that recognised unethical marketing and influencing strategies used by some formula industry representatives did not influence the study design or outcomes ([Hastings et al., 2020](#)).

Aimee had conversations with each interested community analyst via Facebook Messenger. Preferences for how to be involved focused on whether the individual wanted to take part in group activities or if they would prefer one-to-one activities, and if they would prefer for contact to occur synchronously via online meetings held on Zoom, or asynchronously through a closed Facebook group. Contact was always planned to be held online due to: the geographical spread of analysts alongside parental responsibilities, Aimee being Disabled and permanently working from home, and the limited budget available for the study. All community analysts were happy to take part in group analysis activities. They initially preferred to have one online meeting, via Zoom, followed by asynchronous chat in a closed Facebook group, to fit around busy family life more easily. However, following the first meeting, the community analysts preferred to continue meeting online, which is explored further below. The timing of meetings was designed to fit around community analysts' schedules, including work, school pickup and drop-off confines, and babies' nap and feeding times.

The initial plan centred on ensuring that participants had access to enough data that they could meaningfully contribute to the analysis, whilst ensuring that the community researchers were not overwhelmed by large datasets ([Jennings et al., 2018](#)) nor expected to participate for longer than the hours we had available to remunerate them for their input ([Smith et al., 2019](#)). We also aimed to make participation easy for those who may have a baby to care for whilst contributing ([Collins et al.,](#)

2020). Otherwise, we planned to recruit community analysts and develop a way of working that was accessible to those involved. A tentative plan was put in place to hold up to five community analysis workshops. This was due to two factors: uncertainty about the extent of community enthusiasm to discuss a stigmatised topic and the end of our nine-month research project occurring in three months' time, including one month of the UK school summer holidays. This initial lack of certainty felt uncomfortable to Aimee, who had read widely about best practice for community science and did not feel that they were able to achieve this within these confines, as described in their field notes:

“Planning the first group feels stressful. I want to get this right, but I’m aware that we might not get the extension (to our funding). I think I’ll need to get them started by looking at actual data, rather than having a more general welcome session or training to ensure we can achieve something with the time available. The funding (for community analysts time) is so limited, so I don’t feel like I can ask for much participation between meetings.” (pre meeting 1).

**Initial Meetings.** In the first community analysis meeting brief introductions were made by all attendees, and then Aimee established ground rules with the group, stating that confidentiality was essential, and that the group could add any other rules they wanted. The group decided that being kind, supportive and non-judgemental to each other was the only other rule to add. Aimee then provided a verbal overview of the community analysts’ first task, which was to interpret what was meant by participants in their research diaries in relation to elements of formula feeding guidance. The five community analysts were shown ten short data extracts relating to barriers to washing hands ahead of preparing infant formula and were split into two Zoom meeting rooms (without a facilitator) to discuss what they thought was meant by the individual participants. All community analysts then returned to the group to discuss their thoughts. Upon reflection some months later, the community analysts noted that the design of this first session resulted in a missed opportunity for bonding among community analysts, which was particularly impactful due to the online nature of the groups’ meetings:

“Maybe, you know the first meeting we had, it was sort of like a meet and greet, wasn’t it? Maybe add a bit where you ask people to say...a bit of background about each person.”

Following this meeting, community analysts decided that meeting together via Zoom would be the best model to continue, with the Facebook discussion group and email both valued as a way of sharing the data before the meeting. Sharing the data and a meeting agenda was particularly valued by those who were caring for their babies during meetings, as it allowed them time to think and reflect on the data before the meeting: “It was easier (being able to look at the data in

advance) when (baby) was busy during meetings.” Sharing data in the Facebook group also served as a back-up option for if the community analysts could not attend a meeting. This approach was appreciated by community analysts throughout the project, including when they had returned to work from maternity leave and: “When I had childcare issues, I could think about it and still contribute.”

In meeting 2, community analysts chose to skip the step of discussing the data in small groups without a facilitator, and this pattern of working together to examine data or to reflect on their experiences of being part of the study continued throughout. However, later when discussing their experiences of being part of the group, it became clear that insufficient clarity about the role had been provided at the outset which led to community analysts having reduced confidence in their ability to participate in earlier meetings:

In the beginning...I sometimes struggled to know exactly what sort of feedback was expected of us or when we did the analysing going through all of the (data), I sometimes found it hard coming back to the responses. But I don’t necessarily know if it was because it was unclear or if it was because I was new to this and sleep deprived (laughs)...The idea that it could have been a bit more simplified in terms of our contribution and what kind of constructive feedback and input was expected from us.

Some community analysts also noted that providing additional research methods teaching in the early meetings, such as modelling more clearly *how* to do qualitative analysis would have been valuable. Furthermore, community analysts’ role in theme development was not clearly communicated in the beginning, so some did not initially understand what they were bringing to the team compared to the academic researchers: “I looked at it like you’re a bunch of academics and I didn’t think I would have much of a contribution.”

Much of the existing literature on the co-analysis of data is based on interview transcripts, and the less-rich open text data from participants’ research diaries may have made the task of theme development more challenging. The analysts noted that they “wanted more” context around the data, so in meeting 5, an entire research diary was presented in an anonymised narrative format. However, they were still left “wanting more information”, perhaps due to the relatively brief responses to open text questions. Another area where additional clarity was requested related to the tasks being undertaken and where these fit into the outputs being prepared by the study team, leading to the development of a visual timetable (see [Figure 2](#)), which was appreciated. The timetable was updated and re-shared on two occasions where new items were added or timelines shifted.

**Confidence Grew Over Time.** When the community analysts met to discuss the contents of this paper, it was clear that their understanding of the value of community involvement in analysis had grown over time: “(it’s a) Great idea! It allows the

Month	June	July	August	Sept	October	November	December	January	February	March	End of funding
<b>Discussions in meeting</b>											
Analysing research diaries											
Reflecting on being part of the study											
<b>Reviewing study reports</b>											
1. Food Standards Agency report											
2. Experiences of being part of study paper (detailed analysis group)											
3. Experiences of being part of the study paper 2 (full study)											
4. Food safety paper											
<b>Creating/ reviewing other content</b>											
Video for Health and Care Research Wales awards											
Video for UKRI community science seminar											
Input into infographic for parents to go with report											
May be opportunities to speak with the media											

**Figure 2.** Overview of community analysis meeting tasks.

main researcher to gain valuable insights that they may not have gained individually.” One explanation is that the community analysts’ understanding of their role and how this fed into the study’s outputs became clearer following discussions about how to improve the facilitation of the group. This confidence was also clear to see as community analysts undertook independent experiments and investigations into infant feeding policy which they reported back to Aimee via messenger and sometimes to the community analysis meetings. This growth in confidence could also be seen in the four (of the original five) community analysts who remained part of the group for over six months and expressed a strong interest in taking part in additional research projects in the future, as was found in the Parenting Science Gang (Collins et al., 2020):

“Absolutely (yes) to a follow on project, I would like to take part in a follow on project, to get as much experience as I can gain. I like the idea of being involved in research on parenting matters as I feel I have a lot I can contribute more than anything else. So definitely if there are any others that relate to childcare, infant feeding or anything like this I’d 100% like to be involved.”

### Research on a Stigmatising Topic

**Formula Feeding and Social Stigma.** Reflections during the analysis group were often framed around a hostile societal context for formula feeding, including all four members describing either negative responses to them formula feeding, a subtler stigmatising culture that they were aware of (even though it was rarely spoken about), or both:

“You’ll get people saying, ‘Oh, well, why would you want to do that (formula feed)?’ Or ‘have you not thought about breastfeeding?’ and they don’t think about the reasons why you might be using formula.”

For some, this impacted on their maternal self-identity in a context of pro-breastfeeding public health advice, but very limited breastfeeding support. For example, one community analyst noted: “I feel less guilt now about formula feeding.” Discussions in the group were considered to provide a valuable counter-narrative to this stigmatisation of formula feeding mothers and to result in something positive coming out of a difficult experience, for example:

“we’re all just trying to do the best we can to try and feed our baby...For me the positives are if I hadn’t been part of this group I think I would have been thinking I’d failed. Because I wanted to breastfeed and that didn’t go to plan, and it’s made me feel I’ve failed. But I’ve not failed and I’m providing my experience, for us to come up with simpler guidelines to help future mums.”

Furthermore, in response to community analysts sharing negative experiences, Aimee, who is not a qualified health professional, regularly shared her own viewpoint that the societal factors that made breastfeeding difficult meant that it absolutely was not the “fault” of the community analysts not being able to breastfeed for as long as they wanted to:

“None of you should have any guilt to start with and it makes me really angry that our society is so crap at supporting breastfeeding. And it doesn’t matter how you feed your baby (breast or formula); everyone always seems to have some negative opinion on it.”

On one occasion, however, this stigma was inadvertently introduced to the group by Aimee, who had taken the community analysts’ questions about safer formula preparation methods back to health professionals on the study team and forwarded the health professionals’ responses verbatim. This highlighted areas where the health professionals recommended parents be *more* cautious than current guidance (NHS,



2019). This response recommended sterilising the scoops used to portion powdered infant formula (Cho et al., 2019), and that parents *both* shake off cold water sterilising solution *and* rinse equipment in cooled boiled water, rather than just doing one of these. This resulted in significant tension between Aimee and several community analysts for the first time, with two community analysts messaging her with concerns. Additionally, a person unknown to Aimee contacted them to say that the email, which had been sent using BCC to the five community analysts, had been shared in a “mums’ WhatsApp group” and caused “distress”. This is the only known confidentiality breach to have occurred, showing the damage done by this insensitive email. Aimee and the community analysts reflected on how Aimee had responded to this, several months after the event:

Aimee: “I just thought with this one email, where I hadn’t checked what the health professionals had said was right (ie: matched the NHS advice), I’d messed up this lovely group, I’d spent months building trust with.”

Community analyst 1: “I felt really worried about going to the meeting afterwards. I’d sent you screen shots by (Facebook) messenger (showing what they said was not part of the NHS advice), but I was worried about what it was going to be like (in the meetings), because I had strong opinions, I didn’t know if I’d be able to stay in the group. And then you started the meeting by saying “I’m so, so sorry, I really shouldn’t have sent you on the email like that, I should have put myself in your shoes and thought you are parents first and then researchers” and I just went “Phew! It’s going to be alright.”

Aimee: “I think if that had happened earlier (i.e., after fewer community analysis meetings), you might not have come back to the group.”

Community analyst 2: “I agree with that”.

This discussion led to Aimee reflecting further on the differentiation between the low-judgement facilitation that they were able to provide as standard, and what Sara, the study manager, would have been *obliged* to say as a registered Health Visitor:

“In facilitating the community analysis group, I’m able to “be on the side” (Becker, 1966) of the community analysts, but Sara would have to have pointed out instances where practice wasn’t in line with NHS guidance. This would have made it almost impossible for community analysts to be open about the everyday challenges they face and would have likely added to the stigma already felt.”

The benefit of impartial facilitation was also reported by the community analysts:

“I’m pleased it was you, and not (a health professional), because it meant we could be really honest. (Otherwise), I’d think, are they

going to be trying to contact me outside of the group (to tell me how I should be preparing formula)?”

Within the context of stigmatised behaviour being considered, it is particularly important to ensure that analysis meetings are facilitated in a supportive way. This was achieved in relation to ensuring stigma was not introduced by the facilitator during meetings. Whilst we held specific sessions for participants to provide feedback on the methods used within meetings, with hindsight it would have been beneficial to request feedback at the end of each session, as has been recommended in best practice for involving Autistic co-researchers (Nicolaidis et al., 2019), to improve clarity and ensure the meetings were not stigmatising.

*Stigma and Working With Peers.* Being part of the community analysis group was viewed as “cathartic” and “solidarity” was formed among the group, as all the community analysts were chosen specifically *because* they formula fed their babies. Furthermore, the way in which meetings were facilitated was considered to provide a “no judgement zone” and “a supportive environment” which was valued and seen as “lovely”:

“There’s no judgement, we’re all in the same boat. We’ve all had a negative experience with going from breastfeeding to formula and we’ve all got different ways of making formula. We’re all in the same position.”

Over time, community analysts felt surer of what was expected and felt confident to share experiences that they would not routinely share with their peers:

“I was quite shy at first, I think it helps we have similar ideas we can bounce off each other.”

This sharing was viewed as bonding the group over time: “So it actually helped us to come together as a group and as we’ve come along each week together, we’re more like friends who can have a chat now.” This included disclosing a broad range of personal experiences beyond feeding babies. One mother returned to work after maternity leave, and was unable to attend six regular meetings, instead having one-to-one meetings with Aimee. They noted that although they appreciated being able to continue contributing via one-to-one meetings, it felt different and “it was nice to be back with the group.”

On one occasion, one community analyst reported that they felt they may have broken the group’s non-judgemental norms and said that they followed up afterwards to apologise:

“At one point, I said something to (a community analyst) and I felt worried after that I might have said something a bit (judgemental) So I sent (the community analyst) a private apology by Facebook messenger.”

However, the experience of being part of the group could not eliminate societal stigma, and all five community analysts noted that they had initially planned to breastfeed. When discussing the contents of this article, they reflected that they had unconsciously justified their transition from breastfeeding to formula feeding during meetings, through identifying breastfeeding challenges and their attempts to mitigate them, such as attending courses and requesting breastfeeding support. This included the use of statements like: “I gave (breastfeeding) my all”. This transition and the challenges that accompanied it were reasons for the community analysts wanting to be involved in the project. Additionally, it led to the shared feeling that “we’re in the same boat”, and that involving those who had always planned to formula feed could have been stigmatising for those parents or led them to not disclose their antenatal feeding intention. Despite this, the analysts supported each other when disclosures of guilt were made:

Community analyst 1: “It’s been a year and I still feel a bit bad because I wasn’t able to (breastfeed).”

Community analyst 2: “It’s still with me too and he’s almost one.”

Community analyst 3: “Me too. It’s still with me; you just learn to live with it.”

### Feeling Valued

Although community analysts noted that the lack of clarity about their role and how their work was being used initially reduced their feeling of being valued until corrected after meeting four (Jennings et al., 2018), several areas of good practice were also noted. These included providing honorariums, having a consistent facilitator and admin support, Carol, who was warm and friendly, as well as them coming to increasingly recognise their own expertise.

**Payment.** We budgeted funding to provide honoraria of £20 per hour, to avoid exploitation of community analysts and to acknowledge their valuable contribution (NIHR, 2023). In our pre-application consultation, it was noted that paying people with vouchers, as opposed to money, reduces their options with where to utilise payment, making it less valuable, and that this was not expected of the salaried research team members. However, a significant challenge in realising this aim was the disparity between wanting to pay community researchers promptly and in a format that was easily accessible and meaningful to them, and university finance rules and procedures. Additionally, elements that were designed to ensure payments were the most accessible, ethical, and rewarding to researchers within the university finance rules, such as offering a choice of supermarket vouchers rather than a fixed single option, created significant additional workload and delays, particularly when problems arose, such as being provided with vouchers that did not work when community analysts redeemed them.

Receipt of honorariums was rarely discussed in the group, due to the sensitivity of discussing money in UK society, however the honorariums were valued: “I saved mine up and it paid for the Christmas shop!” In addition, having an individual person attend meetings to take notes and be the named contact for sending vouchers was viewed positively, particularly as sometimes the contents of meetings were sensitive. In addition to consistently being one particular person, Carol was viewed as being friendly and approachable, which reinforced the feeling of being valued by the study team:

Community analyst 1: Carol has been lovely. She always gets in touch if the voucher is going to be late. She always says things like “have a nice weekend”.

Community analyst 2: “I’ll second that with Carol. She’s lovely and warm. She’s helped very quickly with issues, and you get a personal email with the voucher.”

**Recognising Expertise.** Community analysts also noted that being part of the group helped them to understand the expertise that they possessed and were using everyday as a parent (Collins et al., 2020), which routinely went unacknowledged and unappreciated by society:

“It’s nice just speaking to other mums and talking about your experiences and then looking at all of the answers thinking about how difficult and how complex it is and how many things there are to remember as a parent.”

This expertise was viewed as in contrast to needing a formal education or background in research or science:

“We have a unique point of view as most parents have the experience in feeding but potentially not the science education (in my case anyway!).”

It may well have been influenced by Aimee not being a parent or a health professional, so that she was often genuinely learning during discussions. For example:

“Discussing self sterilising bottles today. Although they were on the list in our survey (because a health professional added it), I’d never seen one. It was so valuable to have a parent physically show me how they worked.” (Aimee’s field notes)

When considering how this feeling of value arose, the way in which community analysts were enabled to provide insights was noted as important (Nicolaidis et al., 2019), as one analyst describes in how they would encourage other to take part in similar community analysis ventures:

“Don’t worry about your knowledge level/ standard of English etc. My responses and opinion has felt so valued at every point. It has also shown me that I do have something worth saying!”

In addition to undertaking the initial analysis activities, meetings were also dedicated to ensuring that the community analysts met the Committee on Publication Ethics criteria to be an author on all study outputs (COPE, 2019). Being acknowledged as a research partner through being named on the study's report, was unexpected but appreciated:

“Having my name on the report was a real surprise. I was like, maybe I've undervalued my contribution. I like the idea that we're named, that we're being acknowledged as being instrumental. Any friends I've told about it, they seem to be quite impressed by it. It's a nice feeling, you feel like you're doing something worthwhile.”

## Recommendations for Practice

Within the Finding the Formula study, the most in-depth community science activities occurred through the co-analysis workshops. For both the facilitators and the community analysts, this was a new way of working, and as in other community science research on parenting, there “was a learning curve for everyone involved” (Collins et al., 2020). Aimee coded all community analysis meeting materials to identify recommendations, which were discussed with the community analysts and refined, and are presented in Box 2.

We wish to emphasise some points with relation to the existing literature. Within the context of stigmatised behaviour, it is particularly important to ensure that analysis meetings are facilitated in a supportive way. In the main this was achieved in ensuring stigma was not introduced by the facilitator. It may have been relevant that the primary facilitator had very limited experience of formula feeding and was not a parent. Furthermore, neither facilitator was a health professional. The community scientists noted that this allowed for a feeling of safety, but also allowed them to be the experts on infant feeding practice in the group. Within the area of child public health, however, it did feel important to the facilitator to have the support of health professionals on the team who could answer questions about safely preparing infant formula. However, this led to an instance where stigma was introduced to the group leading to the only known breach of confidentiality when a screenshot of an email was shared with somebody outside of the group, despite the confidentiality agreement. When designing future studies, it is important to carefully consider who will lead these groups, as the status of the facilitator may impact on the reflections community scientists feel comfortable sharing. The bounds of confidentiality should also be clearly discussed and reinforced to prevent intentional data breaches. Furthermore, researchers should carefully consider what materials are shared with community analysts, when they will mainly not be using the secure Information Technology systems that Universities typically use, which could lead to non-intentional data breaches.

Whilst we held specific sessions for participants to provide feedback on the methods used within meetings, with hindsight

it would have been beneficial to request feedback at the end of each session, as has been recommended in best practice for involving Autistic co-researchers (Nicolaidis et al., 2019). It has also been suggested that researchers need to allow adequate time for all tasks (Jennings et al., 2018); and we wish to reinforce this point and suggest that researchers should allow twice the amount of time – and budget for honorariums – that they think they will need. This should allow time for community analysis tasks, providing initial sessions as ‘ice breakers’, providing training on research methods, as well as payment for pre-meeting reviewing of documents. In doing so, it is likely that community analysts will feel more confident about their role and contribution and be more engaged in the project. The number of community analysts to be involved is also important (Jennings et al., 2018). Our group mostly contributed through one-hour meetings, and within this context a group of four to five community analysts had the space to provide their thoughts; if we had involved a bigger group, meetings would have needed to be longer, with correspondingly larger honorariums, to allow all community analysts to take part.

Due to the small budget available from the funder for this project, we did not adequately cost staff time to facilitate the community analysis element. As such, Aimee was funded for 2 hours per week for nine months to oversee the entire project as Principal Investigator and to prepare for and conduct these meetings. In practice, Aimee spent around four to 7 hours per meeting on facilitating the community analysis, including promptly responding to messages from community analysts outside of working hours. Facilitators of community analysis groups, particularly those that run over a long period, may wish to use separate accounts for work-related communication to facilitate work-life balance. An additional under-anticipated issue was the amount of time it would take to navigate University procurement processes to secure supermarket vouchers for honoraria via an online university requisition system. Accordingly, we would recommend that researchers planning to use co-analysts discuss processes for payment with their university's finance team at the application stage, to ensure sufficient time is available.

### Box 2: Recommendations for Community Analysis Groups

#### Funders

- Should ensure that they provide suitable budgets for community science research to be conducted in a meaningful way

#### Resources

- Ensure sufficient researcher time to:

- Prepare pre-meeting agendas and circulate documents in advance
- Attend and chair meetings
- Write fieldnotes following meetings
- Circulate summary of notes to community analysts after meetings
- Maintain contact with community analysts between meetings
- Ensure sufficient administrative support
  - Take detailed notes during meetings or to transcribe recorded meetings
  - Ensure prompt delivery of honorariums
  - Provide a prompt, warm, and supportive response to questions regarding issues with honorariums and other administrative queries
- Community analysts should be recognised for their input
  - The UK National Institute for Health Research (NIHR) recommended rate is currently £25 per hour
  - Pre-meeting preparation time should be included as an expense to be paid for
  - Time should be budgeted to enable community analysts to meet the COPE publication standards and then be included as authors
  - In reports it should be clear where community analysts have lead on workstreams/contributed
  - Researchers should keep community analysts updated on the status of all outputs, so they can see what they've achieved
  - Researchers should provide training in research/outputs processes
  - Researchers should offer to provide references for all community analysts

#### Recruitment

- Diversity
  - Recruit in multiple places or ways if possible
  - Provide multiple modes of communication for potential community analysts to ask questions or refer themselves into the project
  - Discuss access needs, including Disability-related needs, with community analysts and provide necessary accommodations, including breaks and support for technology issues
  - Be aware of costs of taking part

- Clarity
  - Be clear about the aims of the project, the tasks to be undertaken, the duration of the role and other core elements

#### Chairing meetings

- Empathy
  - Be aware of societal stigma, and foster a supportive atmosphere
  - Consider any professional obligation that potential facilitators may have and how this could reinforce stigma
- Clarity
  - Provide an outline of the aims for the project - a visual model may be useful – and update this where necessary
  - Provide agendas and documents prior to meetings, to allow time for reflection
  - Provide a 'summary' and a 'full detail' version of agendas and documents, so that busy community analysts can engage with the high-level information
- Fostering a community
  - Provide space to allow community analysts to get to know each other, particularly in early meetings
  - Be aware of potential tensions and stigma that could arise between community analysts with different experiences or perspectives
  - Establish group rules and chairing meetings in a way to foster a supportive environment regardless of differences
  - Establish and reinforce the importance of confidentiality
- Modes of participation
  - Consider the mode of participation, eg: online or face-to-face and the synchronicity with community analysts
  - Allow participation outside of meetings if needed
- Ask community analysts for feedback on how meetings have been chaired
  - Ask analysts for feedback regularly
  - Be open to receiving feedback outside of meeting environments

## Conclusion

The Finding the Formula study community analysis group was successful in meeting its initial aim of undertaking community-facilitated thematic analysis of data. However, analysts noted areas that could have been improved including increased: induction, research methods training, team building activities, and clarity regarding both roles and the extent of involvement. Improvements were introduced in an iterative cycle as issues were raised by community analysts. These issues were caused in part by awaiting confirmation of a no-cost extension from the funder for this low-budget study, which was initially only funded for nine months, but was extended to 17 months. Following an initial programme of five meetings, four of the five community analysts stayed involved in the writing up of empirical outputs and this methodological paper. Gentle, non-judgemental facilitation, and warm and friendly admin-support for the study were valued and seen as particularly important due to the stigmatised nature of formula feeding. This was achieved in the main, although one poorly worded email sharing health professional advice was a significantly destabilising event, which could have had major impacts had it occurred earlier in the project. The community analysts have provided recommendations which we hope will help researchers who wish to involve community analysts with lived experience in the co-analysis of data on stigmatising topics.

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