

Public Engagement Case Study

Consultation and co-design of a qualitative longitudinal cohort study with disadvantaged parents in partnership with a community centre

Project lead:

Georgia Chisnall, PhD Candidate

Local collaborator:

Healthy Me Healthy Communities (Sally Devine)



Overview and context

Lower-income parents are significantly more likely to experience barriers to accessing childhood vaccination services resulting in delayed (or even missed) vaccinations. To better understand these barriers and inform inclusive practice Georgia Chisnall is conducting a qualitative longitudinal study with lower-income parents from the birth of their child to age 1. A two-part (face-to-face) workshop series was held with disadvantaged parents to consult and co-design elements of the study. These workshops were funded by a successful application to the LSHTM Participatory Seed Fund 22/23, which is in turn funded by Research England, a subsidiary of UK Research and Innovation.

The basics

Who: Disadvantaged parents

What: To consult with disadvantaged parents on the design of a study exploring lower income parents' experiences of accessing childhood vaccination services

When:

- Workshop 1: 17th January 2023
- Workshop 2: 7th February 2023

Where: Gorton Community Centre, Manchester

How: Two-part (face-to-face) workshop series

Funder: LSHTM Participatory Seed Fund 22/23

By the numbers

Development time: 2 months (starting 18th November 2022)

Project duration: 3 months (ending 23th February 2023 – including write-up)

No. of participants: 10

LSHTM staff involved: 1

No. of volunteers: 0

Project spend: £3095.07

- Participant compensation: £1600
- Community centre collaboration fees (1 & 2): £500
- Researcher travel costs: £295.08
- Infographic design (1 & 2): £220
- Refreshment costs: £111.64
- Sessional worker fee: £110
- Childcare costs: £109.50
- Venue hire: £90
- Workshop materials: £50.95

Project aims

1. To get feedback on key study materials and processes (i.e., recruitment flyer, diary keeping guidance, engagement plan) and host a general discussion on the study topic (i.e., accessibility of childhood immunisation services).

2. To plan the participatory activities which will take place throughout the project.

The audience

10 disadvantaged parents (8 mums, 2 dads) with children under 5 took part in the workshops taking place on 17th January 2023 and 7th February 2023. Parents self-identified as white British (n=2), Asian (n=2), Black African (n=1), Eritrean (n=1) and Arab (n=1); some preferred not to say (n=3). Parents ranged in age, number of children, educational attainment, and co-habiting status.

This audience was chosen to reflect the target participant group for the primary research study. We hoped through consulting and co-designing elements of the study with the target group that we could: 1) optimise recruitment, data collection, data analysis and reduce sample attrition; and 2) ensure that participatory activities were those desired by the community thereby increasing reach and impact.

Parents were recruited by the collaborating community centre (Healthy Me Healthy Communities) during food aid sessions. To support their recruitment activities, we provided the centre with a *recruitment flyer* and an *information sheet*.

The project

All participants were required to sign a consent form at the start of each workshop after being reminded of key involvement principles outlined in the information sheet (e.g., right to withdraw). Participants had the opportunity to ask questions prior to signing the consent form. Giving permission for anonymous photographs was optional and did not preclude workshop involvement.

Workshop 1 (4 hours)

To start the workshop series there was an icebreaker in the form of an interactive demo on low-budget, healthy cooking. This activity introduced sensitive topics on economic hardship, food insecurity, and competing priorities as a disadvantaged parent.



Following the icebreaker activity, participants were asked to draw a 'life map' outlining the factors which shaped their experiences to date of accessing/using vaccination services for their children. Parents were guided to share their experiences in an open discussion and to reflect on items of particular significance/importance.



Interview guides

The 'life map'/discussion exercise provided critical insight into the factors shaping lower income parents' ability to access vaccination services and their experience of service use. This information was used as a validation tool for the pre-existing interview guide and several edits were made. These included more explicitly asking about child specific needs, vaccine attitudes, appointment reminders/errors/changes, late attendance, access to pain relief, appointment duration, baby vaccination records, and waiting times.

Flyer design

Participants found the volume of information presented in the study flyer overwhelming. Furthermore, they found the flyer language unwelcoming/technical. Based on the designs created by workshop participants an infographic designer produced a new study flyer.

Before

PARTICIPANTS NEEDED!
CHILD HEALTH STUDY FOR SOON TO BE PARENTS

Up to £150 available in compensation for participation.

Researchers from the London School of Hygiene and Tropical Medicine are looking for people to participate in a study about lower-income parents' experiences of accessing childhood vaccination services.




Who do we need?

- Parent(s) 7+ months (28+ weeks) pregnant
- Consider themselves to live in a 'lower-income' household:
 - Co-habiting parents, 1 child: household income less than £571 per week
 - Co-habiting parents, 2 children: household income less than £666 per week
 - Co-habiting parents, 3 children: household income less than £762 per week
 - Single-parent, 1 child: household income less than £414 per week
 - Single-parent, 2 children: household income less than £509 per week
 - Single-parent, 3 children: household income less than £604 per week
- Older than 18
- Able to speak English (you can still take part if you cannot read or write)
- Not have a baby that is expected to be admitted to the neonatal unit after birth

What is involved?

- Dates and times for participating are flexible and involve 3 interviews over the period of 1 year.
- You will also be asked to keep a brief diary about your thoughts/experiences of childhood vaccination services.

Contact for more information:
Georgia Chisnall
Email: georgia.chisnall@lshtm.ac.uk
Phone/WhatsApp: +44(0)7800529416



After

ARE YOU A LOW-INCOME PARENT TO BE?

UP TO £150 COULD BE YOURS IF YOU CHOOSE TO PARTICIPATE IN A STUDY ABOUT YOUR EXPERIENCES OF CHILDHOOD VACCINATION SERVICES.



SEE IF YOU QUALIFY!

- 7+ months pregnant
- 18+ years old
- Can speak English (don't need to be able to read/write)
- Baby not expected to be admitted to neonatal unit after birth

WHAT IS INVOLVED?

- 3 interviews over the period of 1 year
- Keeping a brief diary (text/audio)

INTERESTED? CONTACT US!
Georgia Chisnall
Email: georgia.chisnall@lshtm.ac.uk
Phone/WhatsApp: +44(0)7800529416



Diary keeping guidance

Participants found it difficult to review the diary keeping guidance document. They said that it was too complicated to understand and that there was too much information presented. Instead, they suggested a simple statement on the diary keeping process accompanied with a checklist to prompt diary entries combined with reminders from the study team. The diary keeping guidance document was remade as a result in line with participant feedback.

Before

The Vaccine Access Study

How to complete your diary

Keep up with diary entries and receive up to £60!

What
We are interested in hearing about your experiences of having your child vaccinated as and when it happens, in real time. Please include the following topics:

- 1) Any information or communication (face-to-face/remote) you receive about vaccinating your child (e.g., health visitor, letter from GP).
- 2) How you made the appointment to have your child vaccinated (state appointment date) and what options were available.
- 3) Whether you were able to attend the appointment:
 - o Any factors which helped you attend or made it difficult.
 - o How much it cost you to attend the appointment (e.g., travel costs, car parking, loss of earnings).
- 4) Any thoughts you had on the facilities/appointment itself.
- 5) Any changes in your personal circumstances (occupation, employment, education, relationship status, number of people in your home, moving home, finances, or any major life events).


How

- **As soon as possible** after any of the items above occur (preferably on the same day), make a diary entry.
- **Either text, voice note, or send pictures to 07800529416 via WhatsApp.** Alternatively, diary entries can be made via email to georgia.chisnall@lshtm.ac.uk. If your access to WhatsApp/email is limited, contact Georgia to discuss a paper-based diary keeping option. Similarly, if you struggle with reading/writing let Georgia know and she can discuss alternative diary keeping options with you (e.g., via phone call).
 - o Any picture should also be sent with a descriptive text (e.g., waiting at bus stop on way to appointment; appointment reminder letter).
 - o Entries will be adapted to protect your identity (e.g., faces/names will be blurred in pictures; audio entries will be turned into text; in text, names/places will be replaced with fake names)

Payment

- If you have kept up with diary entries, you will receive a bonus after each interview (there are three interviews).
- At each interview you will be paid up to £20.
 - o A complete diary (4+ topics covered) will receive £20.
 - o A mostly complete diary (3 topics covered) will receive £15.
 - o A partially complete diary (2 topics covered) will receive £10.
 - o A limited diary (1 topic covered) will receive £5.
 - o A diary with no entries will not receive a bonus.

Contact Georgia Chisnall if you have any questions (georgia.chisnall@lshtm.ac.uk)



After

How to complete your diary

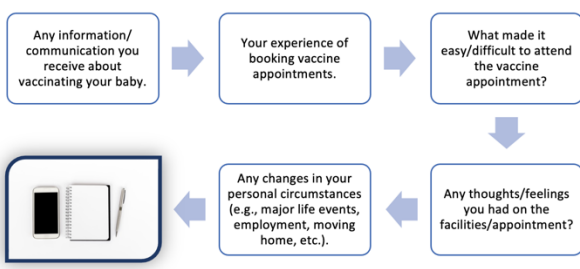
Keep up with diary entries and receive up to £60!

1. How to make diary entries

Either text, voice-note, or send pictures to 07800529416 via WhatsApp

If you prefer, diary entries can be made via email to georgia.chisnall@lshtm.ac.uk

2. Checklist of diary entry topics
After any of the items below occur (preferably on the same day), make a diary entry!



3. Payment

If you have kept up with diary entries, you will receive a bonus after each interview (there are three interviews).

At each interview you will be paid up to £20.

- A complete diary (4+ topics covered) will receive £20.
- A mostly complete diary (3 topics covered) will receive £15.
- A partially complete diary (2 topics covered) will receive £10.
- A limited diary (1 topic covered) will receive £5.
- A diary with no entries will not receive a bonus.

Contact Georgia Chisnall if you have any questions or to discuss a paper-based/verbal-based diary keeping option (georgia.chisnall@lshtm.ac.uk)

Engagement plan

Workshop participants generated a list of ideas (e.g., birthday cards) in relation to keeping study participants engaged with the study and reducing drop-out. These suggestions have been integrated into the main study protocol, but caveats those referencing small gifts as subject to funding.

Dissemination strategy

Participants provided invaluable insight into their engagement preferences and have resulted in a different strategy to that originally devised. Originally, the plan was to have a gallery and a lay blog, however the effort required to attend a gallery and the text-based nature of a blog/creative piece did not appeal. Instead, participants voted for and designed ideas for an animation and a leaflet.

What worked?

- **Detailed project preparation:** In conjunction with this project an appropriate workshop protocol was developed, which included a workshop flyer, information sheets, consent forms, risk assessment, workshop presentation slides, and feedback forms.
- **The use of an ice-breaker activity:** The icebreaker, an interactive demo on low-budget cooking, successfully introduced sensitive topics on economic hardship, food insecurity, and competing priorities as a disadvantaged parent.
- **Creative/engaging activities:** 'life-map' drawing, group design activities, constructive peer-review of ideas, individual feedback opportunities, and sticker-based voting exercises were all well received by workshop participants.
- **Collaborating with a local community centre:** The collaborating community centre played a vital role in accessing the target community group and providing a trusted space to host the workshop. Furthermore, the logistical support provided in relation to recruitment, obtaining the sessional worker, and refreshment provision was incredibly helpful.

- *Sharing updates from the first workshop:* At the start of the second workshop parents were updated on the edits made based on their feedback from the previous workshop. This was really appreciated by workshop participants who greatly enjoyed seeing their thoughts/ideas put into action.

What did not work?

- *Childcare:* Some participants raised challenges with childcare during recruitment. As a result, we sought additional funds to cover childcare costs and as a last resort invited parents to bring their children with them to the workshop. While a limited number of participants used the childcare support, a number of parents brought their children with them to the workshop; it is not known whether this is because they could not arrange childcare at short notice, or whether this was their preference. While overall these participants were highly engaged, at times they struggled to take part in group activities and were somewhat separate to the main group. While they were invited to sit at the workshop tables with their children, they felt more comfortable sitting at the back of the workshop room where they could more easily tend to their children.
- *English literacy:* At times, English literacy was an issue for a minority of participants in relation to their ability to fully understand/engage with the workshop activities.
- *Activity duration:* In the first workshop some activities overran, and this put pressure on refreshment breaks and subsequent activities.
- *Research literacy:* Running the second workshop was slightly more challenging than the first due to the somewhat 'abstract' nature of event/material planning. In the first workshop where I was able to physically provide study documents and ask for opinions there was greater structure/guidance to the activity. Once I re-iterated that they were helping co-design a funding application for a public engagement grant and that the idea was that they had complete freedom to form their own ideas rather than simply reviewing pre-existing ones this made more sense to them.

Feedback from participants and collaborating community centre

In anonymous feedback participants shared that they valued:

- Group discussion/sharing of experiences
- The opportunity to input ideas
- Meeting others in similar circumstances/socialising
- Receiving useful information/learning something

100% of participants:

- Were satisfied with the workshop outputs
- Felt they were given opportunity to express their views
- Would be willing to take part in future engagement activities

All but one participant wanted to receive updates on the (1) the impacts/outputs of the workshop and (2) receive updates on the main study.

The collaborating community centre reported value/impact which benefited their centre and would be willing to collaborate again in the future.

This is a snapshot of the key evaluation findings. The full evaluation findings can be found in the 'Outcome Report' which is available upon request.

Future potential or plans

Beyond the legacy of the amendments made to the upcoming qualitative longitudinal cohort study, we will be applying for further funds to implement the co-designed dissemination activities (i.e.,

animation/leaflet). We hope that this would involve re-visiting the same group of parents and involving them in the design of these outputs. As mentioned, we will also be keeping in contact with parents from the workshop who wanted to be updated on the impact of the final workshop and the progress of the main study.

In addition, we have several activities planned which seek to promote ongoing sharing of learning in relation to the design of public engagement activities beyond the production of this case study. This includes presentations, blogs, an academic publication (in collaboration with the community centre), and dissemination of the infographic which summarises the project.

Advice for other researchers

- Appropriately prepare for engagement activities (protocol, flyers, information sheets, consent forms, risk assessments, presentation slides, feedback forms, insurance, workshop materials, participant compensation, etc.). Note, this takes time and organisation!
- Try to collaborate with pre-existing community 'hubs' to gain access to communities through a trusted third-party. Note, budget to not only appropriately compensate workshop participants but also collaborators.
- Carefully consider group specific needs (e.g., childcare) and put effort into coming up with creative/exciting engagement activities for your group.
- Provide explanation/structure/training for more abstract topics of engagement (i.e., co-design).
- Take (with the appropriate consent) anonymous pictures! They really capture the vibrance of engagement activities and what it is all about – the inclusion of people!

Further information

You can find out more about the project or request to see project documents by contacting georgia.chisnall@lshtm.ac.uk.