

Reset Ethics Study



Public focus groups

4th July 2021

Final Report for Participants

*With grateful thanks to
everyone who took part
in our focus groups*

What we did

We held 5 focus groups during May and June 2021. These were all held online, via Zoom. We had 26 participants, 24 female and 2 male, who either had experience of using maternity and paediatric services during the COVID-19 ‘reset’ phase, when NHS services were returning to ‘normal’ following initial lockdown, or who were involved in patient groups with their local NHS Trust.



Focus groups lasted around 90 minutes. The questions asked included how involved participants felt in local NHS Trust decision-making and how local Trusts could seek to involve more local people, how Trusts had communicated during the ‘rest’ phase, how participants felt Trusts had made decisions during this phase, and how these decisions affected the care that they received during this time.

What did we find?

Results

Involvement in local Trust decision-making

Participants reported varying levels of involvement in local Trust decision-making; for example, some were members of the Trust (Trustees), some were members of patient involvement groups such as local Applied Research Collaborations (ARCs) or

Maternity Voices Partnerships (MVPs), some had given feedback to local NHS providers through surveys, while some were not involved at all.

Participants were overwhelmingly in favour of public involvement in local NHS decision-making, with only one participant voicing some concerns about involving the public during the initial stages of the pandemic *‘they had to tackle it in a way that was immediate. And talking to us about that would have been really, really hard for them to do there are circumstances like this last year that it would have probably been dangerous for them to do it.’* (participant, focus group1).

When asked about how Trusts could encourage more involvement of local people, participants were keen that they should include under-represented voices, both in terms of diversity and seeking those who would not usually volunteer for this kind of activity. There was a feeling that sometimes it is the same faces who are always involved in ‘official’ patient involvement groups. For example, a participant in focus group 3 said, *‘it often attracts, whether it attracts or the messaging gets to, a particular type or member of the public’* and some participants felt that there should be more done to attract a more diverse membership: *‘we use a phrase ‘seldom heard voices’ but you know, areas of the community, which maybe don't have a say, and whether that's young people, whether that's older people, whether that's people from different ethnic backgrounds and cultures...’* (participant, focus group 2).

Some participants expressed an interest in being involved in the future, and suggested ways of getting more people involved. These included having more *‘focus groups like these, which is amazing to be able to do at home with my cup of tea’* (participant, focus group 1) or enlisting people at the first contact with the service, for example, *‘for maternity services, if possible to, you know, have an opt in almost at the beginning of your pregnancy journey’* (participant, focus group 1).

Current use of online platforms to hold meetings was seen as both an advantage: *‘everything going to Zoom was a big help for me to be involved in some of those conversations and decisions’* (participant, focus group 2) and perhaps a disadvantage: *‘what about their data usage? You know, what about actual equipment to be able to access and, and that kind of thing?’* (participant, focus group 3). A participant in focus group 5 presented a clear plan for increasing involvement, emphasising the importance of key individuals: *‘I think the project managers need to take resources out to say, we are going to invest in people, we are going to train people, you know, these people can become peers, and help the system and, like I said before, champions..... (B)ut I think they need to understand it takes time to build those relationships and to trust.’*



Communication with Trusts

Participants realised that communication was taking place in times that were far from normal. For example, referring to a local Trust's use of social media, a participant in focus group 2 remarked that it worked well in 'normal' times, *'when they didn't have people hanging on every single post they put on there. And commenting 73 times asking them if they could have partners at scans and so on.'*

Use of remote consultations was welcomed by a participant in focus group 3, *'having video conference appointments, where it wasn't necessary to have bloods done or any other kinds of investigations was brilliant. It was so much better.'* However, they did not work for everyone: *'I mean, the online appointments that we have were a waste of time really. But at least the contact is there.'* (Participant, focus group 4).

Personal contact with members of the healthcare team was appreciated, *'And the member of staff, the nurse that was based in the hospital, rather than the community specialist, she gave us her number after pre op appointments to follow up and just double check with us for the couple of weeks prior to him going in for his surgeries, just keeping us up to date saying everything's still on track.'* (participant, focus group 1).

Some participants reported occasions where communication within Trusts was poor. For example, different messages would appear on different media, *'They changed the guidance on the scans on the Facebook page before they changed it on the website'* (participant, focus group 2). Another source of frustration was inconsistency between Trusts. As one participant from focus group 4 highlighted, *'...it didn't feel like there were consistent decisions made like across the country and across services. And that's still an issue. That's still something that I've seen out there the amount of visiting that people are allowed after they've had the baby.'*

Trust decision-making

Many participants were able to appreciate how Trusts had made decisions during the ‘reset’ phase, and acknowledged how difficult it was for them, for example, ‘*They were concerned about safety, definitely. And as I said it was a really tricky situation. And nobody had kind of been in that situation before. So decisions had to be made, and perhaps weren't made with enough time or thought ...*’ (participant, focus group 5).

Decisions impacted on service users in many ways, from a total ban on visitors, ‘*then we were [in hospital] in July last year, again, for the three weeks. Again, the country was opening back up, so you could go to pubs. And you could go inside, yet, the Trust decided to continue not having any visitors. So I was in for three weeks with no visitors.*’ (participant, focus group 4), to only allowing limited visitors, ‘*they reduced down to one, one visitor at <<hospital>> as well, which is, which is really hard, especially when you've got really, really poorly children and the parents kind of crossover in the car park.*’ (participant, focus group 3).

Trust decisions also impacted on service users’ decisions, such as a decision to be induced: ‘*I declined induction, when they wanted me to have an induction because I was like, more than two weeks past my due date and things. And part of that was about the fact that my partner wouldn't be allowed to be there for the induction.*’ (participant, focus group 4)

Reflecting on care

Participants shared their experiences of care during the ‘reset’ phase in maternity and paediatric services. For example, even something as routine as being discharged from hospital was not straightforward. A participant in focus group 2 shared her story: ‘*I got told at 9am I'd be discharged, wasn't actually discharged until 7pm. For no clinical reason, just the fact there were no doctors available to fill out the paperwork, was never actually spoken to by a doctor because there was only this one poor reg[istrar]. She was lovely. It was just her on for everybody on a really busy day.*’

Meanwhile, in hospital, facilities that would normally have been available were not. ‘*...parents are normally provided with, like a room where you can breastfeed for special care babies, because obviously, a lot of them can't latch on and feed themselves. So you have to express and if you want to do that now, because of COVID, that facility wasn't available. So if I wanted to breastfeed, and for <<name>>, I had to sit, you know, back by his bed with the curtain pulled round.*’ (participant, focus group 3).

Participants also commented on the fact that no health visitors seemed to be involved in post-natal care ‘*...they didn't get a health visitor at all. And they was wondering when was that person going to come? And to be honest, with myself, my midwives were carrying that role, because they were told that the health visitors were not coming out.*’ (participant, focus group 5).

Key findings

1. Clarity of communication from local Trusts to service users is important, and should be consistent across the various methods used
2. Disparity between Trusts is confusing, while disparity between healthcare and other areas of everyday life is irritating
3. Participants recognize the tension between keeping NHS staff safe, and allowing support from family members, but wonder if the balance is right.
4. Some of the changes that have been instigated during the pandemic would be useful to continue post-pandemic (e.g., video or phone consultations in certain circumstances, less crowding in waiting rooms)
5. Service users do not feel involved in NHS Trust decision-making, although targeted patient involvement groups, such as Maternity Voice Partnerships, seem to work well



Next steps



The team is now writing several papers to be published in academic journals, where the findings from interviews with healthcare professionals and senior managers in NHS Trusts will be supplemented with the findings from these public focus groups. You can keep an eye on what's happening with the project by visiting the website news page <https://www.liverpool.ac.uk/law/research/research-projects/reset-ethics/news/> or following us on Twitter [@resetethics1](https://twitter.com/resetethics1)

Reset Ethics study team

c/o School of Law and Social Justice
University of Liverpool
Email reseteth@liverpool.ac.uk